

# **Anorexia Boy Recovery**

**A mother's blog about her teenage son's recovery from anorexia**

**Part I – 2011**

**BEV MATTOCKS**

**(aka 'Batty Matty' – the nickname I used to write my blog back at the start)**

© Bev Mattocks 2017

## **IMPORTANT NOTE**

The content for this book is taken from my Blog. As a result, it is written like a diary. Accurate English grammar and correct sentence construction were not at the forefront of my mind; I simply wanted to get my thoughts and experiences down “on paper”. Therefore, in places, it might not flow perfectly. I also dart around from one topic to another, some days looking back and others writing about whatever was going on in our lives at that present moment. There is also some repetition; I may describe the same event a number of times to remind my readers of a key event that occurred earlier on my son's journey to recovery.

As you would expect from a blog, there are days when I'm angry, days when I'm frustrated, days when I'm reflective and days when I offer advice based on our own experiences of what worked and what didn't. It's important, therefore, to judge these posts as being “of the moment”, chronicling my current point of view and feelings. What you see here is also my own personal recollection of events. Other people's opinions and recollections of the same events might differ.

Most importantly, this book should never be treated as a substitute for advice or treatment from a professional medical clinician. Also what may work for one family may not work for another. Therefore I strongly recommend taking professional advice if you are at all concerned that your child may be developing an eating disorder.

## CONTENTS - LINKED TO THE INDIVIDUAL POSTS

A SUMMARY OF OUR STORY IN THE LEAD UP TO TREATMENT .....	11
ANOREXIA NERVOSA HITS TEENAGE BOYS AS WELL AS GIRLS.....	15
BREAKTHROUGHS - THE EATING DISORDER IS LOSING THE FIGHT... ..	21
ANOREXIA NERVOSA - THE NEED TO PUT ON WEIGHT... ..	23
ANOREXIA AND SCHOOL - A TYPICAL SCHOOL DAY 12 MONTHS AGO .....	24
ANOREXIA - LITTLE CHALLENGES WIN BIG BATTLES .....	27
ANOREXIA BRINGS IN REINFORCEMENTS .....	27
ANOREXIA - MORE COMPARISONS WITH A YEAR AGO.....	29
THE ANOREXIA GETS WEAKER... ..	31
ANOREXIA - GETTING SUPPORT FROM THE SCHOOL .....	32
ANOREXIA FROM A PARENT'S PERSPECTIVE - WHAT HELPED MOST?.....	33
EXERCISE AND HONESTY WITH ANOREXIA.....	36
ANOREXIA - BEING HONEST AND KEEPING TALKING.....	39
ANOREXIA PARENTS, IMPORTANCE OF GOOD FRIENDS.....	40
WALKING AND TALKING ABOUT THE ANOREXIA... ..	42
FATTY SAUSAGES AND CHEESE - TWO FINGERS UP AT THE ANOREXIA!.....	43
PREDISPOSED TOWARDS ANOREXIA? .....	44
ANOREXIA - PROOF OF WHAT WE'RE UP AGAINST... ..	45
HELP FROM OTHER PARENTS OF TEENAGERS WITH EATING DISORDERS .....	48
JUGGLING WORK, PLAY AND ANOREXIA .....	48
ANOREXIA ECHOES? ONLY KIDDING! .....	50

SURPRISE WEIGHT LOSS! .....	50
100 EXTRA CALORIES A DAY ON THE EATING PLAN... ..	52
WHAT A DIFFERENCE SIX MONTHS MAKES.....	52
THE ROAD GETS ROCKY .....	53
WE'RE STILL BEATING THE ANOREXIA.....	54
I THINK I HEAR DEMONIC LAUGHTER.....	55
THE BATTLE FOR CAKE MOUNTAIN. WHO WON? .....	56
WHAT IF ANOREXIA HADN'T STOLEN 20 MONTHS FROM HIS LIFE...? .....	58
A WHOLE DAY AWAY FROM MAMA'S EAGLE EYE.....	59
WHAT SHOULD YOU DO IF YOUR CHILD IS BEHAVING LIKE BEN WAS AT THE START? .....	60
UPDATE FOLLOWING WEIGH-IN ON FRIDAY.....	61
CALORIE CRISIS - IS THIS ANOTHER TURNING POINT, I WONDER..?.....	62
WHAT ABOUT YOUR TEENAGER'S FRIENDS? WHAT SHOULD THEY DO? .....	63
WE SEEM TO HAVE REACHED A (TEMPORARY?) PLATEAU.....	64
TO BOOK A HOLIDAY OR NOT TO BOOK A HOLIDAY.....	65
LOOKING BACK AT MY ATDT POST FROM AUGUST 2010.....	68
A NICE WALK IN THE WOODS .....	70
AND I THOUGHT IT WOULD ONLY TAKE SIX MONTHS OR SO – MAX.....	71
ANOREXIA IS NO FUN... LITERALLY.....	72
IDENTIFYING ALL THE STUFF THAT FUELS THE INSOMNIA AND BREAKING FREE .....	74
IT'S PANCAKE DAY - GET OUT THE FRYING PAN! .....	75
CASUALTIES OF "ED RAGE" .....	76
WATERSHED WEEKEND... PHEW.....	80

ONE STEP AT A TIME.....	83
SOME VERY DIFFICULT JUGGLING TO DO THIS WEEK... ..	83
MELTDOWN IN MANCHESTER... ..	85
BIG PLANS ARE UNDERWAY.....	86
TRYING OUT A RECOVERY CONTRACT... ..	87
ONE WEIGHT GAIN CONTRACT DRAWN UP! .....	89
DAY FOUR OF THE CONTRACT.....	90
UNIVERSITY WAS NEVER THIS TOUGH.....	91
0.9KG WEIGHT GAIN .....	92
MOTHERS’ DAY LOOMS... ..	93
PIZZA... WINE... OLIVES... FUDGE ICE CREAM PUDDING... ..	94
CAMHS DAY TODAY.....	95
OUR SECOND FORTNIGHTLY WEIGH-IN... ..	96
SOMETHING IS UP.....	97
A BLIP, THANKFULLY... FINGERS CROSSED... ..	98
BIT OF A GAP SINCE LAST ENTRY .....	99
OKAY, SO “PLAN B” (AND NOW “C”) FOR THE WEEKEND IS.....	101
CAMHS CAN OF WORMS? .....	102
CRAZY IN-LAWS FAMILY HERE WE COME... ..	104
OKAY, SO WHERE SHALL I BEGIN...? .....	105
WHAT A WEEK! .....	106
EXAM WEEK - AND WHAT A CHANGE FROM LAST YEAR!!!!!!.....	108
UP 1.8KG ON FRIDAY!.....	109

WHY IS THE FEAR OF WEIGHT GAIN STILL SUCH AN ISSUE? .....	110
BIT OF FURNITURE THROWING AT CAMHS.....	111
NO, IT'S NOT OKAY FOR BEN TO REACH A WEIGHT HE "FEELS HAPPY WITH" AND STICK THERE...112	
KENTUCKY FRIED CHICKEN AD MAKES ME THINK BACK... ..	112
EARLY WARNING SIGNS IN BOYS - WHAT TO LOOK OUT FOR... ..	114
A BIT OF "ME TIME" URGENTLY REQUIRED, I THINK... ..	117
SOME PEOPLE ARE AMAZING... POSITIVELY SAINTLY! .....	120
DELEGATING AND TALKING... ..	122
A BIT OF BRIBERY (HOPEFULLY) GOES A LONG WAY.....	123
1.2KG WEIGHT GAIN SINCE OUR LAST SCALES SESSION... ..	124
THE MORE I THINK ABOUT IT, THE MORE I'M ANGRY ABOUT FRI'S CAMHS SESSION.....	127
DR SARAH RAVIN SPEAKS SENSE.....	127
KEEPING THE BUGS AT BAY.....	129
IMPRESSED WITH BEN'S PERSEVERANCE .....	129
AGAIN, MIXED FEELINGS BUT GENERALLY HAPPY WITH THE RESULT.....	130
A NORMAL SCHOOL DAY? .....	132
TOP 20 BIGGEST CHANGES AS A MOM IN THE LAST NINE MONTHS.....	133
POINTS BEING AWARDED THICK AND FAST.....	135
SPOOKILY SIMILAR "WR" PROBLEM 14 MONTHS AGO.....	136
CLEARED THINGS UP WITH CAMHS RE WEIGHT NORMALISATION.....	139
UPDATING THE CONTRACT TO ACHIEVE NEW GOALS.....	139
FINDING WORKABLE SOLUTIONS TO "IMPOSSIBLE" PROBLEMS .....	140
FRUSTRATED BUT NOT IN THE LEAST BIT SURPRISED.....	143

TESTING THE WATER NEXT MONTH WITH A SHORT HOLIDAY...	145
SCHOOL AND DABBING FAT OFF CHORIZO...	145
“WHAT MATTERS?” ASKED THE CHURCH WEBSITE. THIS MATTERS!!!!	148
MOST DEFINITELY NOT YOUR TYPICAL “MAMA MATERIAL” ...	148
HOPING TO STAY IN SCHOOL LONG ENOUGH FOR THE INTER-HOUSE TALENT CONTEST...	150
LIKE LAST SUMMER, SOMETHING HAD TO GIVE BEFORE MY BRAIN IMPOLODED...	151
OKAY, SO HOW DID THE TALENT CONTEST AND THE FULL SCHOOL DAY GO?	154
JUST WHEN I THOUGHT IT WAS SAFE TO GO BACK INTO THE WATER...	155
PIZZA EXPRESS INCIDENT WAS DUE TO ED-INDUCED CONFUSION.....	157
16 MONTHS OF TREATMENT AND HOW EFFECTIVE HAS IT BEEN?	158
FINDING OUT WHAT BEN THINKS ABOUT IT ALL...	160
OLD BLOG FROM MAY 2009 WHICH SHOWS THE STORM CLOUDS WERE GATHERING...	162
LOOKING BACK ON A YEAR AGO HAS BEEN “VERY USEFUL” ...	164
MORE ON ONE YEAR AGO TODAY, HERE’S THE NOTE I SENT TO THE PSYCH.....	166
YAY, SUCCESSFUL FULL DAY AT SCHOOL YESTERDAY!.....	168
TWINGE OF THE GREEN-EYED MONSTER? .....	169
MORE ABOUT THE SURREAL WORLD OF BEING A PARENT OF A TEENAGER WITH ANOREXIA .....	170
ANYTHING FOR A SIMPLE LIFE... ..	172
LEMON MERINGUE PIE, SPICY MEXICAN PORK AND CHICKEN TIKKA.....	174
CHATTING TO THE SAME PERSON ON THE SAME GRASSY BANK, TWO YEARS ON... ..	174
WORRIED ABOUT THE SUMMER HOLS AGAIN... ..	176
TRYING TO PICK UP WHERE YOU LEFT OFF BEFORE YOU TOOK OFF FOR PLANET ED... ..	177
“EXPERIMENTS”, “CHOICES” AND “MISTAKES” ... AAARRRGGGHH! .....	179

TRUE SOUL FOOD ON THE ATDT PARENTS' FORUM.....	181
SHEFFIELD UNIVERSITY CHALLENGE.....	182
BEN, ME, THE CONTRACT, KITCHEN SCALES AND PLENTY OF FOOD, BUT NOT ED.....	184
IT'S RAINING, IT'S POURING... BUT SO FAR SO GOOD ON VACATION AS REGARDS ED.....	185
SO FAR, SO RELAXED... SO MUCH BETTER THAN LAST YEAR.....	186
A VIRTUALLY ED-FREE HOLIDAY, ALL IN ALL, AND 1KG HEAVIER.....	188
BACK TO REALITY AND SORTING OUT ALL THOSE OUTSTANDING ED BITS AND PIECES.....	189
ONE OF THE MOST SUCCESSFUL ASPECTS OF OUR RECOVERY CONTRACT .....	190
IT'S (NOT) FUNNY HOW CERTAIN SITUATIONS CAN CAUSE FLASHBACKS.....	191
ROCK-HARD ABS, YET WITHOUT WORKING OUT 24/7/365 TO ACHIEVE IT.....	193
IT'S OKAY TO LISTEN TO CHILLED SUMMER MUSIC AGAIN! .....	194
WHIZZING AROUND WAITROSE AT A RATE OF KNOTS! .....	195
SEASIDE, HERE I COME - THIS TIME WITH BEN IN TOW... ..	195
OKAY, SO WHAT IS THE PURPOSE OF THIS BLOG? .....	196
I DO WISH THEY WOULDN'T DO THAT.....	198
UPS AND DOWNS IN THE SOUTH WEST .....	199
ED SURFACES IN BATH AND LUNCH IS A WASHOUT.....	199
AND NOW FOR THE GOOD NEWS... ..	200
SCHOOL IS JUST TWO WEEKS AWAY... BUT WHICH SCHOOL? .....	201
EXAM RESULTS SEASON MADE ME THINK... ..	202
ODD EXPERIENCE - BEN STRIDES THROUGH THE "FAT CAMP" .....	204
THE EATING DISORDER GOES BACK FIVE YEARS AT LEAST... ..	205
FIGHTING THE EXERCISE COMPULSIONS .....	211

A TRICKY WEEK IN DERBYSHIRE.....	213
STAYING ON AT THE SAME SCHOOL .....	214
ONWARDS AND UPWARDS.....	216
UNSETTLING GLIMPSE INTO MY PAST LIFE AS A “NORMAL” PERSON.....	216
SO SMALL, SO CUTE, SO MANY HOPES AND DREAMS FOR THEIR FUTURE.....	218
PUTTING ON MY “NORMAL” HAT AGAIN, IF ONLY FOR ONE NIGHT.....	219
NEW PARENTS’ EVENING .....	220
TOUCHING BASE ON HOW THINGS HAVE BEEN THIS WEEK .....	222
MEMORY IS A FUNNY THING.....	223
SOMETHING ISN’T RIGHT WITH SCHOOL.....	225
PROBING TO FIND OUT WHAT’S WRONG.....	226
LIVING A DOUBLE LIFE .....	228
“LONG TIME, NO SEE” THEY WILL THINK THIS EVENING.....	232
BEN’S LONG-STANDING RELATIONSHIP WITH FOOD... ..	234
“IS IT SOMETHING WE’VE DONE? IS IT SOMETHING I’VE DONE?” .....	237
WHY DID IT TAKE 22 WEEKS FROM THE FIRST GP VISIT TO OUR FIRST CAMHS APPOINTMENT?	239
WHY DIDN’T I TAKE ACTION SOONER, YOU MAY ASK... ..	241
THE HARDEST BIT OF CRAMMING I EVER DID.....	243
YE HAR! THE RECOVERY CONTRACT IS SIX MONTHS OLD THIS WEEK! .....	246
SCHOOL IS STILL PROVING DIFFICULT AND THE INSOMNIA IS BACK.....	247
I’VE BEEN READING HARRIET BROWN’S “BRAVE GIRL EATING” .....	249
THREE HOURS OF BRAIN STORMING ABOUT SCHOOL.....	251
BEAUTIFUL HEALTHY HANDS.....	252

THESE DAYS A “SIX PACK” ISN’T SO IMPORTANT .....	253
AROUND THE DINNER TABLE... LITERALLY! .....	255
DOES YOUR OWN INTERNAL VOICE CHIP IN WITH THIS KIND OF THING ON “BAD” DAYS? .....	256
TRICKY FEW DAYS... .....	257
WHY I’M NOT PUTTING ALL THIS BEHIND ME... YET. ....	258
IT’S 12 MONTHS SINCE BEN TURNED A CORNER... .....	260
MAKING AN INROAD INTO MY BOOK .....	262
UPPER SIXTH FORM PARENTS’ EVENING LAST NIGHT .....	263
CONTRACT STILL VALID? .....	264
ADJUSTING TO “PEACETIME” AFTER TWO-PLUS YEARS OF WAR .....	264
STILL ADJUSTING TO “PEACE TIME” ... .....	265
WHY RECOVERY IS LIKE RENOVATING A HOUSE .....	266
AS FAR AS THE EAST IS FROM THE WEST... .....	267
THAT OLD WATER STAIN ON THE CEILING IS SHOWING THROUGH THE NEW PAINT.....	269
MY APOLOGIES - I’VE BEEN AWOL FOR A COUPLE OF WEEKS!.....	270
IMPROVED SCHOOL SOCIAL SITUATION - AN IMPOSSIBLE ASK?.....	271
ED CHANGES PEOPLE .....	273
THE 12 DAYS OF (ED) CHRISTMAS ... .....	274
ON THE FIRST DAY OF CHRISTMAS, THE ED GAVE TO ME... “THE NIGHTMARE ON CHRISTMAS FAIR EVE” ... .....	274
ON THE SECOND DAY OF CHRISTMAS, THE ED GAVE TO ME... “TWO DOZEN CHRISTMAS TREE COOKIES” ... .....	277
ON THE THIRD DAY OF CHRISTMAS, THE ED GAVE TO ME... “THE THREE OF US... OUR STRONG FAMILY UNIT” .....	278
ON THE FOURTH DAY OF CHRISTMAS, THE ED GAVE TO ME... “FOUR MONTHS ‘TIL TREATMENT” ...	280

ON THE FIFTH DAY OF CHRISTMAS, THE ED GAVE TO ME... “FIVE ‘SAFE’ RECIPES” ... ..	282
ON THE SIXTH DAY OF CHRISTMAS, THE ED GAVE TO ME... “SIX FRIENDS A-STAYING X 2” ... ..	283
ON THE SEVENTH DAY OF CHRISTMAS, THE ED GAVE TO ME... “SEVEN TREATMENT SESSIONS?? OR EIGHT?? NINE??” .....	286
ON THE EIGHTH DAY OF CHRISTMAS, THE ED GAVE TO ME... “EIGHT BILLION SNOWFLAKES FALLING” ... ..	287
ON THE NINTH DAY OF CHRISTMAS, THE ED GAVE TO ME... “NINE LESSONS AND CAROLS” ... ..	288
ON THE TENTH DAY OF CHRISTMAS, THE ED GAVE TO ME... “TEN SWANS NOT SWIMMING” ....	289
THAT’S ENOUGH OF THE 12 DAYS OF ED CHRISTMAS.....	290
WE ARE ASSUMING BEN WILL GO AWAY TO UNI... ..	291
FIVE RESITS IN JANUARY... ..	293
DETECTIVE MAMA MAKES A DISCOVERY .....	296
FUNNY HOW OUR RELATIONSHIP WITH CAMHS HAS CHANGED SO MUCH... ..	297
FOUR NIGHTS IN EDINBURGH .....	298
MY “LITTLE BOY” IS 18 TOMORROW!! .....	299
“I’M ALRIGHT, JACK”.....	299
SUCH A BIG TOPIC I HARDLY KNOW WHERE TO START ... ..	300
AND SO A WHOLE YEAR OF BLOG POSTS DRAWS TO AN END ... ..	301

JANUARY 2011

### **A summary of our story in the lead up to treatment**

*In case you're new to this blog and are unfamiliar with our story, here is a summary which should give you a rough idea of how my teenage son, Ben, found himself on the road to anorexia (and eventually, thankfully, on the road to recovery).*

BACK AT THE START I HAD no idea that boys got eating disorders. Like many people, I thought anorexia was something exclusive to girls. I assumed it was a “diet gone wrong”, that all they needed was a good talking to and they'd snap out of it.

But of course eating disorders aren't like that. Not one bit.

At primary school, my (only child) Ben was overweight. He was quiet, well-behaved and most definitely not “sporty”. Then, at the age of 11, he won an academic scholarship to a fabulous independent secondary school with a reputation for sport – especially rugby.

Surprisingly for a sports-shy boy, Ben took to rugby like a duck to water. He has a natural talent for the game and was immediately given the position of Number 3 in the team, a position given to the biggest, toughest boys. Soon, Ben was playing rugby virtually every day of the week, including local club rugby on Sundays.

Before long the puppy fat disappeared to be replaced with an awesome athletic physique. Being good at sport at a “sporty school” also carried a distinct kudos. Soon Ben was one of the most popular boys in his peer group and he revelled in the change. He was good at other sports, too. In the summer of 2008 – one year before the eating disorder began to manifest itself – he and his dad did the Coast2Coast cycle ride across Northern England, up and down some of the most challenging terrain in the country. Ben was a star on the athletics field and in the cross country running team. In fact I think the only sport he wasn't good at was cricket.

But, before long, Ben began to tire of all this sport and exercise. He felt

increasingly lazy. Yet he was worried that if he didn't keep it up he might lose the athletic physique and the kudos he'd earned as a rising star in the rugby team. Worse, he might get fat again. And, being a growing teenage boy, Ben loved his food! During the spring of 2009, as the rugby season came to a close, Ben gradually discovered that, by eating diet foods, he could consume the same quantities and do less exercise, without putting on any weight. Great, he thought to himself, I've discovered the magic bullet...

Unfortunately things didn't work out like that. In the event Ben began to exercise more, not less. But diet foods and generally cutting down on intake meant he was consuming less calories and fats. It wasn't a great mix for a growing teenage boy.

For us, as parents, the alarm bells began to tinkle during the summer of 2009. It began with our summer holiday in France where Ben was swimming 100 metres of the villa pool every day and going for gruelling runs in the heat. He was also reading all those "Men's Health" magazines packed with diets and exercises to develop bodies like the impossibly toned models in the photographs.

Getting a "six pack" became Ben's Number One goal. Back in the UK he joined a gym and went seven days a week supplemented by yet more gruelling runs plus hundreds of daily sit-ups, press-ups and crunches. Meanwhile he devised even more low calorie, low fat meals. Cooking became a passion. But at the same time, eating was getting more ritualistic, for example chopping fruit into tiny pieces before carefully arranging on a plate. He was also avoiding certain foods – more foods than he was actually eating.

We noticed that he was getting increasingly depressed and withdrawn. He'd have sudden and distressing outbursts, sometimes violent, which became more and more frequent. And, over that summer, he completely cut himself off from his friends.

Worryingly, Ben was losing weight, very, very quickly. During that summer of 2009 Ben lost one quarter of his body weight. Something was seriously wrong.

It wasn't until late September that I was prompted to take him to the doctor. I

simply didn't know what we were dealing with. Was it just a teenage phase or was it something more sinister? Worse – because sometimes Ben would eat and behave normally – was it simply my imagination?

I don't think the GP was too sure, either. The problem was that, to anyone that hadn't seen Ben as a rugby forward, he didn't look like the stereotypical anorexic i.e. skin and bones. He was skinny by this stage, yes, but then that isn't that unusual in some teenage boys. Neither is fussy eating.

I took him to the GP a few times but each time Ben was simply instructed to “eat sensibly and come back in a couple of weeks' time”. In the end it was the school nurse that suggested I get Ben referred for treatment. The staff were becoming increasingly concerned, especially Ben's rugby coaches. Already he had been invalidated out of the team after having been moved to less aggressive positions. I used to worry that if Ben played rugby at this stage, he'd snap in half.

It took a while for the penny to drop – that Ben was developing an eating disorder. My husband and I were horrified. We didn't know what to do or where to turn. In the end it was the school nurse who told me about CAMHS (the NHS Child and Adolescent Mental Health Services). So we went back to the GP and insisted Ben was referred right away.

We assumed we'd get an instant appointment but were horrified to find we might have to wait five or six months just for an initial assessment. Meanwhile Ben was disappearing in front of my eyes. He was doing strange things – because anorexia doesn't just affect your weight, it affects your mood and your behaviours. He was becoming out of control at school, his personality was changing into someone we didn't recognise... basically everything was imploding.

Then, in January 2010, while still on the waiting list for treatment, Ben was admitted to hospital with a dangerously low pulse rate of 29. Thankfully this meant we were able to get him fast-tracked into treatment and he spent the next two years being treated for anorexia.

It took a long time. It's difficult for people with eating disorders to acknowledge they have a problem and even if they do, they are often powerless to do anything about it. This is not an illness you can just snap out of. It is all-consuming and debilitating. Left unchecked it can destroy lives. Indeed eating disorders have the highest mortality rate of any mental illness.

Through my blog – and now my books - I want to do everything in my power to “fast track” other parents through this massive learning curve and point them towards good, solid, evidence-based support in a world where there is still precious little awareness about eating disorders, especially in boys.

Of course I'm not a clinician or an expert; I am just an ordinary mum writing about the day to day experiences of living with a teenage boy recovering from anorexia. But when you suddenly find yourself on this devastating journey, it can be so reassuring to know that others have been along this road too. To know what they went through, to know what signs to watch out for and to know what worked. And, importantly, during those many false summits and disappointments, to know how they found the strength to continue fighting as they helped to guide their child towards recovery. This is why I write my blog.

But the problem with my blog is that, by the end of 2012, it was getting extremely long. There are now 418 posts in total which makes it difficult for other families to plough through everything. Blogs aren't like books. You can't just read through them from start to finish and you can't easily refer back to something you found particularly helpful or relevant. You're clicking here, there and everywhere. Worse, much of the earlier information – for example from 2011 - risks getting overlooked altogether. And there's some important stuff in there! I know, because I've had so much positive and encouraging feedback from my blog followers.

I hope this PDF proves useful to you.

**Wednesday, 5 January 2011**

## **Anorexia nervosa hits teenage boys as well as girls...**

Only last night there was a programme on the TV reporting on the pressures of young girls to look stick-thin. But it's not just girls that develop eating disorders. For the past 18 months, my 17 year old teenage son (who I'll call "Ben" here) has been battling with anorexia nervosa and this new blog will be about our progress.

By coincidence, this morning Ben and I were comparing this January with where we were a year ago. The progress has been painfully slow; in fact I'd say things were on a serious downward spiral for the first six months of last year and, as anyone who's lived with anorexia will know, eating disorders are jam-packed full of "false summits" which can raise your hopes only to be dashed back down again.

But, after months of hell, I firmly believe we turned a corner three months ago in October 2010. Not a corner in terms of weight gain unfortunately, but a definite corner in terms of attitude change. But I'm not wearing rose coloured spectacles. I know there will be trouble ahead (as the song goes...). But in 2011, both of us are better equipped to deal with the anorexia than we were 12 months ago. Hopefully this blog may help other parents of anorexia or eating disorder sufferers who are where we were 12-18 months ago.

### ***But first a quick summary...***

It's difficult to pin-point when Ben's anorexia started. Ever since he moved to secondary school, he'd been an active and athletic boy. Before the anorexia kicked in he'd been a star player in the school rugby team. He also played for his local team. Pre-anorexia, he enjoyed squash, swimming, walking, cycling, cross-country and athletics. Being part of the sporty crowd gave Ben a kind of kudos. He already had his own close circle of friends, but being "the guy in the rugby team" earned him respect and admiration across the year group.

Anorexia crept in virtually unnoticed at some point during the summer of 2009 (although, looking back, the warning signs were there even earlier). By October 2009,

we realised with horror that anorexia had entered our lives. By Christmas, Ben was locked into the illness; it held him like a vice.

In contrast, at primary school, Ben carried quite a bit of “puppy fat”. He was quieter and was bullied by another boy. But once at secondary school and away from the bully, Ben threw himself into lessons, sporting activities and his new circle of friends. He was very happy at school and at home. The puppy fat disappeared, but in a healthy, normal kind of way.

Then in summer 2009 everything changed... Anorexia tempted Ben with promises of looking physically perfect. His role models became the Adonis-style men you get in men’s fitness magazines in the same way that girls might aim to look like the airbrushed, size zero celebrities or models you get in women’s magazines.

The only problem was that, in practice, it didn’t work out like this. Anorexia robbed Ben of his self-confidence, his self-esteem, his social skills and his sense of fun. He even lost his much sought-after “six pack” as the anorexia began to eat away at the muscles in his body.

Although the green shoots of Ben’s anorexia had been germinating for months, it wasn’t until late September 2009 that the alarm bells began to ring in our heads. Ben was exercising more than ever and carefully watching what he ate.

He became increasingly interested in cookery. Crucially, he also started paying a lot of attention to what went into a recipe: calories, fat, etc and the word “healthy” crept into his conversation about food over and over again...

On holiday in France in July 2009 Ben was swimming 100 lengths a day of the holiday villa pool (mind you, he’d done that the previous year so we weren’t unduly concerned). But he was also going for a run every day, turning down all offers of ice cream, refusing to put butter on his toast, making his own pack lunches and increasing his intake of fruit and dried fruit.

When we got home he joined the local gym, went on lengthy and very gruelling runs, and started to see his friends less. This concerned us because up to then

sleepovers, meals out, cinema visits and hanging out with his mates around town had been a regular part of his life. Ben also seemed quite subdued. He seemed to have lost his usual zest for life and his sense of fun.

Then in September my in-laws came to stay and Ben's grandma immediately commented on how much weight Ben had lost. I guess when you see your child every day it's not so obvious. She hadn't seen him for six months.

The first time we took Ben to the GP he just said, "Eat more and come back in two weeks' time," followed by three similar appointments. In the end we insisted that Ben was referred to the specialist anorexia team at the (UK NHS) CAMHS unit (Child and Adolescent Mental Health Services). But then, to our horror, we were faced with a months-long wait for treatment. A quick calculation told me it could be *Easter* before we got help. I wanted to scream!!!

Over the next few months our family life underwent a complete shift from being a normal family to being a family coping with anorexia nervosa.

Anorexia had taken over Ben. Anorexia had taken over our family. And anorexia isn't just about eating; it's about a stack of other symptoms - like depression, panic, zero self-esteem, etc. I don't just mean feeling a bit "down" now and again, I mean deep, dark depression and self-hatred. I mean banging your head against the wall, or thumping your fists against your skull, throwing things around and animal screaming kind of depression.

In the end we managed to find a private CBT therapist (Cognitive Behavioural Therapy) who provided a bit of "stop gap" treatment, but it wasn't ideal.

But still the CAMHS waiting list loomed ahead. What state would Ben be in by the time our place came up at Easter? And how many assessments would we have to go through before the actual treatment started and, more crucially, began to take effect?

With anorexia it's as if someone else moves into your head. Someone that taunts you all the time, telling you you're fat and unattractive and that you'll never be

popular until you get thin.

Many anorexics give this “someone” a name. Anorexia is often named Ana, Anna, Rex or ED (Eating Disorder). One parent described anorexia as being like having a goblin on his daughter’s shoulder all the time. Some people even think of anorexia as a kind of “demon”. That’s how we came to think of it.

Anorexia has you pinching the skin on your skinny stomach, taunting you that it’s rolls of fat. Anorexia makes you exercise like mad and examine yourself in the mirror critically. Anorexia makes you hate what you see. Anorexia lies to you that it can make you ultra-handsome, ultra-slim and ultra-confident.

Anorexia lies that it can put you in control of your life. And part of this control is to control exactly what goes into your stomach, how much of it and when. The minute you deviate from this rigid eating pattern, anorexia lies to you that you’re out of control. Just one serving of dinner that’s not the “right size” and anorexia can have the sufferer banging their head on the fridge and screaming. I know, because that’s what Ben was doing by February 2010.

Looking at family photographs was a painful, instant reminder of what Ben used to look like and should look like, but didn’t anymore. We had a thin waif for a son who looked like a concentration camp victim and whose mood was so volatile I was terrified every time I picked him up from school for fear of how his day had been.

For any parent, watching your child suffer with anorexia is one of the most excruciating and painful things you’ll ever face. I just wished there was a magic pill you could take and - hey presto! - the old Ben would be back. I can tell you, we were been keeping the *Kleenex* manufacturers in business!

Unlike a physical illness, you can’t take any medication for anorexia (apart from anti-depressants). You can’t have an operation and it goes away. Worse, the wonderful, level-headed, intelligent child you’ve spent 16 years rearing has undergone a total transformation into a volatile stranger whose very sanity seems to have gone AWOL.

You feel angry. (“Can’t he see what he’s doing to himself / us?!”) You feel frightened. (“How long is the anorexia going to last? Will we ever get our boy back?”) You feel frantic. (“What damage is anorexia doing to his body? Could something tip the balance and lead to the ‘S’ word we never mention and daren’t even think about?”)

You feel preoccupied. (You can’t think of anything but anorexia and the situation.) You feel jealous. (“Why is everyone else’s child okay when mine isn’t?”) You feel guilty. (“Is it something we’ve done as parents? Should we have picked up on it earlier?”)

Anorexia also makes you feel very isolated. Okay, there are anorexia help lines you can call and a fabulous forum called *Around the Dinner Table* which was a massive help to us. But it’s difficult to talk to a “lay person” about it; to the outside world it’s such a little-known, much misunderstood and even taboo condition. I knew virtually nothing about anorexia until Ben contracted it - now I’m an anorexia expert!

But living with anorexia is like living in a surreal world while the rest of the world goes on around you as normal. Around July 2010 – five or six months after Ben began treatment – his anorexia took a turn for the worse. It started with our summer holiday in France which was a nightmare with Ben resisting food intake and in a terrible, depressed mood. The rest of the summer holidays were a nightmare with regular threats of suicide. Ben even tried to climb out of the loft *Velux* window on one occasion.

The depression got worse, as did the resistance, and it was a real uphill battle to keep things afloat. Meanwhile Ben continued to lose weight; something which continued for the next few months as he headed to his lowest ever weight (but not low enough to warrant hospital admission).

Considering Ben had been absent from school since February or March, I was really nervous about him starting back in the lower sixth form in September. I was worried about the social problems (the previous spring and summer he’d found it virtually

impossible to handle something as straightforward as walking across the playground or even sit his GCSE exams with his peers). I was worried about school dinners and the fact he'd be eating next to nothing. How would we manage them? I didn't live locally so I couldn't go into school to monitor them.

The first few weeks in the lower sixth form weren't good. Ben avoided his peers like the plague and spent all his time including breaks, lunchtimes and free periods in the library, swotting. Meanwhile he began a brand new phase of not sleeping due to anxiety - and I mean *really* not sleeping; at the most a couple of hours a night. School lunches were predictably disastrous which resulted in me sending him in with packed lunches which also proved pretty disastrous as he was still resisting food unless actively encouraged by me being there physically.

It also didn't help that some younger kids were making fun of him eating his packed lunches (no-one else at his school eats packed lunches). After a few crises, we - with the fantastic support of the school and at the suggestion of CAMHS - made a decision. Ben would go into school mornings only and come home for lunch. School would send home work for the afternoons and friends would lend him their notes.

On days when Ben didn't sleep, he often missed school altogether. However his sheer determination to keep up with his peers, the fact he's pretty bright and the incredible support of the school has meant that he's not doing too badly at all. His grades are a bit lower than usual, but - frankly - who cares? The most important thing to me isn't whether he gets straight A's and gets into university; it's that he eventually recovers - fully.

Things have improved on the social front - no more escaping to the library! In fact if it wasn't for the sleeping problems and the school lunch issues, he would probably be able to be in school full time, without any of the nightmarish issues we experienced last year. His weight is still low, but in October he turned a corner, attitude-wise, prompted - I believe - by a second visit to the hospital when he passed out at school and his pulse dropped again.

That hospital visit was a nightmare, mainly due to Ben's behaviour when hospital security had to be called to restrain him as he tried to discharge himself, violently.

Following all this, CAMHS "read the riot act" explaining that if he didn't put on weight, he might need to be hospitalised sooner rather than later. I believe Ben was sufficiently frightened to make the decision to turn a corner.

More about our progress in the battle against anorexia nervosa next time...

**Thursday, 6 January 2011**

### **Breakthroughs - the eating disorder is losing the fight...**

What do smoked mackerel, *After Eight* mints, low fat spread and jam on toast, five varieties of biscuit and carrot cake have in common? They are all things that, 12 months ago, Ben would have avoided like the plague but which he's eaten this week without any problem. And this Christmas, he had a chocolate advent calendar.

Okay it's not an ideal situation in that he is still counting calories and finds it virtually impossible to go over his current daily total by more than, say, 20 or 30 calories. But the other difference is that he's not resisting eating food that adds up to the calorie total. And unlike a year ago with the anorexia, he isn't cheating, fibbing, cutting down or secretly throwing food away.

A negative is that he still freaks out if he puts on weight on a weekly basis. The NICE (National Institute for Clinical Excellence) guidelines recommend a gain of 0.5kg per week for anorexia outpatients. After several months of *losing* weight consistently, Ben's weight has been pretty much static for the past couple of months. It's gone up by up to 0.5kg, but it's also gone down by that amount too. And again. And again. And again... So, in effect, he isn't gaining yet.

But the big difference is a definite attitude shift which began back in October. After months and months of fighting us – CAMHS and his family - and resisting recovery, he finally embraced the need to kick the anorexia into touch.

With anorexia, recovery is very slow and a snail-like step at a time. We all believe

that with this attitude shift will come gradual weight gain. And, unlike the quick weight gain he experienced at the start of the CAMHS treatment back in the spring of 2010 (which he promptly lost over the summer and early autumn), he won't be fighting it. Well not most of the time, at any rate.

I said to Ben that when he recovers from the anorexia he will make us prouder than any academic or sporting achievement could. He will have conquered one of the hardest things that teenagers ever have to conquer - a serious eating disorder. It is very, very hard for him to fight the anorexia.

Newcomers to the horrible illness can't understand why the anorexia sufferer can't just "snap out" of the anorexic thinking. I was no different. I thought I could logically persuade Ben to recover. But anorexia doesn't work on logic; the thinking is totally irrational. I even thought it would only take a few months of professional treatment and - hey presto! - he'd be better. I was wrong. Very wrong.

But right now, as I write, Ben is baking a carrot cake complete with cream cheese icing. Just before Christmas he baked another carrot cake for his birthday. 12 months ago, no way would he have baked a second cake so close to the first. Well he might have done, but he wouldn't have touched it. He would have offered it to us, like an indulgent grandma spoiling the grandchildren, while depriving himself.

Also, 12 months ago, any baking would have been completely free of fats or oils. With Ben, anorexia has meant a horror of all fats. It's taken a long time to change his mind-set over fats and he will now happily eat all the "good" fats (sunflower oil, olive oil, rapeseed oil, *Flora*, nuts, oily fish, etc); it's just saturated fats that he has an issue with. He still examines the nutritional guidelines on food packaging...

But that, in itself, brings me round to another breakthrough in the anorexia.

12 months ago, supermarket shopping was a nightmare with Ben picking up items, examining the nutritional content, and then putting them down again. He'd return items from my trolley to the shelves in horror. He would also spend *ages* choosing groceries, moving from one shelf to another, picking things up, then putting them

down... It was horrible and I'd hate watching "normal" people shop, buying everyday items without batting an eyelid. Our situation was surreal...

Now we just go shopping, like normal people. Well, almost normal. As I said, he still examines packaging and will reject one high calorific item for something lower. But the difference between now and then is acute. I can now go supermarket shopping without dreading the experience or feeling terrified of picking up something that will freak him out - and hating buying low fat or low calorie stuff when I could see him disappearing physically in front of my eyes.

Imagine an anorexia sufferer tucking into steamed pudding and custard!

As well as the carrot cake, we have a steamed ginger pudding in the fridge and I'll be making some more custard to go with it this evening. If I'd been able to look into the future 12 months ago, I would have been amazed.

And ecstatic.

But, as always with this illness, I need to be vigilant. There can be a "blip" at any time and it's not plain sailing by any means whatsoever.

18-plus months on in the fight against anorexia, I can be quietly and patiently confident. But not overly confident...

**Friday, 7 January 2011**

**Anorexia Nervosa - the need to put on weight...**

Following our weekly CAMHS meeting today, Ben's weight continues to hover around the same level. He is delighted with this weight, but we all know it needs to be a few kilos higher to be considered as "healthy".

Now that he has turned a corner as regards attitude and determination to recover, the next step will be the (no doubt slow) process of changing his mind-set about what does and does not equal a healthy weight for his age and height - and for him to feel relaxed about steadily increasing his weight at the recommended 0.5kg a week.

It will happen, but it might not happen for a while...

Meanwhile he's frustrated that he still isn't allowed to do cardio exercise (ever since his pulse rate dropped very low, thought to be generated or influenced by the low weight level caused by the anorexia).

Having said all this, one year ago I would have been astonished if I could have seen him tucking into steamed ginger pudding and lashings of custard like he did last night.

The fact his weight has maintained after all his "challenges", eating-wise this week, has once again proved to him that eating normally is okay. Week upon week of "proof" seems to be one of the main motivators for Ben, enabling him to "stick two fingers up", so to speak, at the "anorexia voice" which tries to tell him the reverse.

**Tuesday, 11 January 2011**

### **Anorexia and school - a typical school day 12 months ago**

12 months ago when the anorexia was at its height a typical school day might have looked like this...

Lots of shouting to get him ready for the school bus with Ben in a rock bottom "black mood" due to the way the anorexia was making changes in his brain. We'd drive to the school bus stop in silence, then he might slam the car door as he got out and then stand apart from the other kids at the bus stop.

Often I'd be in tears by the time I got home.

I'd be on tenterhooks all morning wondering when the first distressing text would come in, fuelled by the anorexia. Or maybe it'd be a voice text on the landline which would be even more sinister and frightening with the robotic woman's voice relaying Ben's latest anorexia-fuelled message.

Meanwhile, at school, Ben might be locked in the toilets, keeping away from people - or hiding away somewhere in the school. He might not turn up for a lesson -

or he might walk out. With anorexia comes the need for compulsive exercise and he'd ask to be excused to visit the toilet only to snatch the opportunity to run round the grounds a couple of times. A typical school dinner with his anorexia would comprise a bit of salad and some fruit, maybe a small bowl of soup, but not always.

I'd be in regular contact with the school nurse who was well aware of Ben's anorexia and hugely supportive. Often she'd have to rescue Ben from the toilets or act as "agony aunt" when Ben used the school medical centre as a bolt hole. And she or Ben would call me, asking me to pick him up on days when the anorexia meant that school got too much for him.

Once Ben bolted out of the school dining room, unable to cope with the pressure. A member of staff ran after him as Ben headed across the school field towards the river, thankfully catching up with him and bringing him back to school.

Another time Ben stormed noisily out of class and had to be restrained by staff. He ended up in the Deputy Head's office and I had to come to school to collect him.

This was totally uncharacteristic of Ben who, before the anorexia, had been a well-respected, conscientious and immaculately behaved boy - a star pupil, academically and on the sporting front.

On days when he managed to stay until 4pm, my anxiety levels would be sky high as I drove to school or to the school bus to pick him up. I never knew what kind of mood he would be in, but I'd have a pretty good idea...

Separate from all the normal looking, chatting and joking school kids would come Ben - getting thinner and paler by the day with black rings round his eyes. His mood would be rock bottom and he'd either remain in total silence or have frightening outbursts on the way home - a known side-effect of anorexia.

Teatime would be a nightmare as the anorexia meant that Ben ate next to nothing. Dessert would always comprise dried fruit which he would ritualistically chop up into tiny pieces, taking ages over the process.

My anxiety levels would be primed for the regular disturbance at mealtimes.

Something, perhaps the fact the food wasn't piping hot - or there was a food that freaked him out on the plate - or, more often than not, the portion size was too large or too small (because the anorexia made it impossible for Ben to gauge what a normal portion size looked like). This would result in him slamming down his knife and fork and storming out of the room. Outside the room the anorexia would make him stamp and crash around, thumping things and bashing his head against the wall while screaming in agony like an animal in pain. Or he might break crockery.

It was absolutely terrifying for me to watch this or know how to cope. All the anorexia advice says that you should remain calm and supportive, but it's virtually impossible to do that when your child is behaving like this.

As things gradually improved over time (a small bit) he might come back into the dining room and resume eating, always acting as if nothing had happened, but in an ultra-stressed and silent way that made me terrified to say anything in case the anorexia behaviour kicked off again.

The rest of the evening would be a mix of violent tears and hysterics; the transformation which anorexia had on my son was astonishing. He was a completely different boy - deeply depressed and howling like an animal in pain. I'd try to talk things through with him, sometimes reasonably successfully and other times not, but always knowing that whatever was said or agreed would be forgotten by the next day.

It wasn't that he didn't want to keep his promises and resolutions; the anorexia had made it so he couldn't. The anorexia was in total control. So I'd go to bed dreading what anorexia would bring me the next day - and we went from day to day, week to week, month to month like this until March 2010 when the stress got too much for me and I started smashing crockery and breaking things myself (in private). And I decided to take Ben out of school for the time being.

**Wednesday, 12 January 2011**

## **Anorexia - little challenges win big battles**

This afternoon I had a walk in the park with Ben which is always a great opportunity for a chat about how his recovery is progressing. I pointed out how different our conversations are these days compared with a year ago when I felt I was banging my head against a brick wall, trying to reason with the warped, irrational thinking caused by anorexia. Nowadays Ben can see it as exactly that - the fact that, back then, the anorexia was convincing him that black was definitely white or whatever.

He was telling me about the little challenges he's been creating for himself in his battle against the anorexia. Like putting *Nutella* on his toast, eating small amounts of chocolate and so on - all challenges that would have freaked him out only a few months ago, thanks to the anorexia.

At that time, he was convinced that certain foods (mainly those containing fats) would put on weight massively faster and in greater quantity than other foods with the same calorie content. These days, his thinking is much more rational as he succeeds in reducing the impact of the anorexia thinking on his everyday life and eating.

He told me how yesterday, as a "two fingers up at anorexia" challenge which he set for himself, he put a whole walnut in the cake he'd made as a surprise treat when he came to that slice. That, he said, would have freaked him out in the days of high-anorexia. The anorexia wouldn't have let him do it "let alone put *Nutella* on the slice as well!" he laughed "or the two puddings I had for lunch".

Ha ha, anorexia, you're losing the battle!

## **Wednesday, 12 January 2011**

### **Anorexia brings in reinforcements**

The analogy that anorexia is like a battle is a pretty obvious one to make. But as an enemy, anorexia is extremely cunning. It's as if the anorexia realises that it is losing

on the main fronts so it brings in reinforcements - a new anorexia battalion that we didn't know existed. You can almost see the anorexia jumping up and down with devilish glee...

In our case the anorexia reinforcements arrived with a vengeance when Ben started back at school in September of last year (2010) after having been away from school since March (except for GCSE exams which the school allowed him to sit in private).

I was naturally worried about how the anorexia would affect the return to school. How would the socialising go? Would the school phobia still be present? Would the distressing "I can't go on..." anorexia fuelled texts start again? How would the anorexia affect school dinners?

But what I hadn't planned for was the insomnia.

At the heart of Ben's anorexia lies extreme anxiety. And within a couple of days of starting back at school (a "two fingers up at the anorexia" victory) - pow! - the anorexia brought in reinforcements in the form of insomnia.

Strangely, ever since then, it's really only the lack of sleep and the school dinners issue that have affected school. After an initial rocky start on the social front, the other issues have been mainly resolved.

Thanks to the anorexia "reinforcements", Ben finds it impossible to sleep. Occasionally he will sleep for five hours, but it's very rare, and never more than that. Usually, the "anorexia demon" (as we call it) wakes him up at 1 or 2 am and keeps him awake. Often it sends his thoughts racing, worrying about what he's going to eat for breakfast and throughout the day - and host of other things.

Because of this, Ben is off school far more often than he should be at this stage in the anorexia recovery. Thankfully, the school is sympathetic and emails work home, and gets other pupils to pass on notes from missed lessons.

But today Ben is sitting two AS level exams and this morning, thanks to the demon keeping him awake all night, he was like the walking dead.

No doubt the demon is thrilled at this victory, jeopardising his chances in the exams when he would otherwise have done very well. And the exam boards just don't understand - they really don't make allowances these days, and like many people they simply don't understand anorexia and other eating disorders.

I think with the GCSE exams a few per cent extra could be awarded as a special case, thanks to a letter from our psychiatrist, but that was all. Thankfully back in June when Ben sat the GCSEs he was sleeping. Now, the anorexia could seriously undermine his chances of getting AS and A-level qualifications.

But, as I always tell him, exams can be re-sat.

It's just so frustrating that, just when you seem to be making headway, the anorexia brings in a brand new battalion that's been hiding round the corner, taking you completely by surprise.

And, so far, no-one seems to be able to do anything about the insomnia. Not the GP, CAMHS nor anyone.

**Thursday, 13 January 2011**

**Anorexia - more comparisons with a year ago...**

Telling Ben about this blog, he said: "Why don't you write about last night's evening meal?" which he cooked as a "surprise" for me.

Eating disorder experts recommend that you keep the sufferer out of the kitchen and away from food preparation and planning. One year ago, had anorexic Ben been permitted to cook dinner, he would have done it to micro-manage exactly what went into the meal, removing all traces of fat, oils and other "enemies".

We would have ended up with something very low calorie and dry. One of his anorexia-fuelled party pieces before he was banned from the kitchen was to see how much he could de-calorise recipes to come up with something ultra-low calorie and fat-free, and usually pretty tasteless, but which he, fuelled by the anorexia, would label as "healthy".

Strictly, while he is still recovering from anorexia, Ben is banned from meal preparation, but is permitted to bake cakes, breads, biscuits, etc now that he is reasonably okay about cooking with oils and fats. But last night's meal was cooked "as a surprise" for me. I smelled bacon cooking and realised something was up!

Now that the anorexia is reducing, Ben says he enjoys cooking in a way he would never have done a year ago. Also, he was relaxed enough to ensure the calorie total came to 600 (the benchmark we use for evening meals), even including two tablespoons of oil and some bacon. Then, as he usually does these days, he ate the meal without any problems.

Continuing the comparison with a year ago when the anorexia was at its height, I asked him about when he used to "down tools" at mealtimes, ranting and raving if things weren't micro-perfect.

He said: "When the anorexia was strong, because I was taking in calories at meal times, those calories had to be absolutely perfect in every way. If they weren't 'perfect', no matter how small the issue, the anorexia would make me freak out. The outburst wasn't because the meal was 'imperfect'; it was me being annoyed with myself for being affected by the fact that things weren't 'perfect'. I was angry with the anorexia. Now that the anorexia thoughts are quieter I am much more relaxed about eating and actually enjoy it for all the right reasons, like a normal person. I don't even mind if things aren't 'perfect', for example the carrot cake I baked the other day was a bit soggy. A few months ago this would have freaked me out [and resulted in him banging and crashing around, maybe smashing something]. This is because the anorexia would 'tell me' that I'd taken in 'fatty' food that wasn't absolutely 'perfect'. In the high-anorexia days I couldn't handle that. But now I'm much more relaxed about it."

**Thursday, 13 January 2011**

## **The anorexia gets weaker...**

When the anorexia was at its height (and before he was banned from the kitchen) Ben would spend *ages* preparing food. He would ritualistically chop dried and fresh fruit into tiny pieces and eat a diet which scarcely changed from one day to the next - behaviour that is common with anorexia sufferers.

Over the next year he felt compelled to eat his meals at certain times and eat the food in a certain order. Even when we were “re-feeding” to regain the weight lost by the anorexia his meals were still pretty regimented and he would take *ages* over their preparation. He would insist on making his own breakfast and lunch because if I made either of these, my “version” wouldn’t be as “perfect” and “precise” as his and he would freak out. And if his own meals fell short of the “perfect” mark in any way, he would also go mad.

Also, when the anorexia was at its height, Ben couldn’t bear any interruptions to mealtimes, for example if visitors came round or if I wasn’t sitting with him. The slightest problem would cause him to go crazy.

Because he had a fats phobia, his meals were huge while re-feeding, imbalanced with far too many carbs. This meant that he had to get up at the crack of dawn to prepare his breakfast in time to catch the school bus.

As time progressed, the anorexia “voice” got weaker and Ben’s fats phobia diminished, his meals got smaller with the extra calories made up in fats, oils, nuts, etc. Plus, he wouldn’t mind when he ate his meals; lunch didn’t have to be “on the dot” of 12.30...

And as he started to recover from the anorexia, his food rituals ceased. Instead of taking ages over food preparation, he’d whiz up his breakfast in moments - and eat it quickly, too, without needing the “perfect setting” and sufficient time to eat his “perfect” meal. A quick bowl of (high calorie) porridge and a couple of (thick) slices of toast with jam or *Nutella* and he was ready to catch the bus. And he would happily vary it, something the anorexia wouldn’t have permitted him to do in the “old days”.

Also, unlike the “bad old days” of high anorexia, he no longer spent ages agonising over his body image or hair in front of the mirror. A swift blast with the hairdryer after the shower, on with the clothes and out the door.

Wow, who would have thought it?!

**Friday, 14 January 2011**

### **Anorexia - getting support from the school**

Back in November 2009 after Ben started behaving very strangely at school, I decided it was time to “come clean” and tell school about the anorexia...

I got in touch with the Head of Year 11 and explained that we believed that Ben was developing an eating disorder and to be aware that he may start to behave unusually.

Mr H said that the PE staff had mentioned that Ben had lost an awful lot of weight recently. From that moment on, the school was incredibly supportive and, well over one year on, they still are.

What’s more, our CAMHS team actually went into school back in November to talk to a group of 25 or so of Ben’s friends. They explained all about eating disorders, how it had affected Ben and answered questions.

It was an extremely useful session. Ben’s friendship group has always been superb, but this session was a watershed in Ben’s “rehabilitation” into the school social scene.

I took Ben out of school in March 2010, mainly because he was spending more time at home than at school (due to extreme school phobia) and we needed to get some kind of structure in place. Ben is very academic and eager to learn, so it was important for him to continue with his studies, especially with GCSEs looming in June.

Between then and the exams, we developed a workable routine whereby we picked up work once a week and dropped other work off for marking. Other work was emailed home - and now and again we’d have a “catch up” with staff to check

that Ben was still on track.

The school allowed him to sit his GCSEs in private, separate from everyone else, mainly because we didn't want to risk (a) Ben freaking out and ruining his own chances in the exam, and (b) freaking out his peers and ruining theirs!

Amazingly, Ben got excellent GCSE results.

School has continued to be flexible and supportive this year as Ben started back at school in the lower sixth form.

When he started to find full days difficult, he tried attending mornings only, coming back home for lunch (which was much more manageable than crossing our fingers and hoping he'd eat enough calories at school) and reverting back to the email-work-home routine.

He also picked a couple of friends from each subject group who would be happy to photocopy their notes for him in his absence.

Some days Ben doesn't make it into school, because of the insomnia. On these occasions, I email the fantastic Head of Sixth Form who arranges for staff to send work home, so Ben doesn't get behind. And he's managed to keep up brilliantly.

The point I'm making is that it's vital to let school know what's going on, very early in the diagnosis - and also to "educate" them on eating disorders as much as you can, because - as you'll probably know from experience - precious little is known about these much misunderstood conditions.

**Friday, 14 January 2011**

### **Anorexia from a parent's perspective - what helped most?**

When anorexia first became obvious in our lives, I knew *nothing* about this horrible mental illness. So, back in autumn 2009, I began the biggest learning curve of my life. But if you're a parent of a son or daughter who's arrived at this stage, where do you start?

Below I list the four steps which, looking back, I believe could have "fast-tracked"

our own learning curve and even accelerated our own family-based support for Ben at this early stage. But first, here's how it was for us...

We started (in early October 2009) with a visit to our GP, however he seemed to have little experience or knowledge of anorexia. Also, because Ben's BMI wasn't particularly low at the time, the GP didn't seem to think it was much of a problem. Although the alarm bells were ringing loud and clear in my head, they weren't in our GP's head. They should have been.

After fobbing us off on a number of occasions, I had to put my foot down and get our GP to refer us to CAMHS. Note: the only reason I discovered that CAMHS existed was because the school nurse told me about it, not the GP!

Naively I assumed we'd get an appointment with CAMHS virtually straight away. In practice, we had to go through various administrative stages (letters to and from... signing this and that...) before we were offered our first appointment... on some unspecified date which could be as early as... Easter 2010!!!

Horror! Panic! What on earth were we to do between now and then? Ben was deteriorating at a rate of knots, physically and mentally, and we had *zero* support, practically no knowledge of anorexia and no immediate treatment planned out.

This period of the anorexia is particularly murky as we spent our money on private "stop-gap" treatment (psychiatric assessment followed by some CBT sessions). Looking back, none of these sessions were any use and the private psychiatrist was positively scary!

Naively I assumed it might only take a finite series of, say, 12 appointments and - hey presto! - Ben would be cured. Just like taking medication for a physical illness.

Meanwhile I was in a state of complete and utter panic. Worse, nothing I said or did seemed to make any difference to Ben's thought processes, weight loss or his behaviour around food. I couldn't understand why he seemed unable to "get it" - that he didn't need to lose weight to be popular and that the fact that he was getting more and more reclusive and depressed certainly wasn't going to work in his favour

in the peer popularity stakes. I almost expected Ben to suddenly “get it” and say: “Okay, I’ll start eating again” and everything would be fine.

But unfortunately anorexia doesn’t work like that. You need proper treatment from professionals highly skilled in the latest thinking on anorexia and other eating disorders.

The bad news is that if you live in the UK there is little you can do about the NHS / CAMHS waiting list. But what you can do is keep reminding them you are there and things are getting increasingly urgent. *Don’t do nothing.*

As I said above, our personal experience of private treatment wasn’t that helpful, but I do know parents who have found it very useful, even swapping free CAMHS treatment for private treatment in some cases. I also know parents that have gone it alone with the support of a very understanding, supportive and knowledgeable GP.

But, even so, where do you start if anorexia and eating disorders are about as alien to you as life on Mars? Is there a way to fast-track yourself through the learning curve? (Sorry, but as a parent you have no choice but to go through this learning curve...)

Okay, here’s my advice...

- ★ First see your GP and don’t let them fob you off with weeks of “Go away, eat more and come back next week”. If your gut feeling tells you that your son or daughter is spiralling into anorexia or another eating disorder then trust your instinct. If in doubt and you need good, sound, speedy advice on what to do next, post up a message on the excellent ATDT forum mentioned below [and at the back of this book].
  
- ★ Next, get hold of two very good books and read them from cover to cover - then read them again. *Skills-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method* is by Janet Treasure (et al) - one of

the most respected eating disorder experts in the UK. *Help Your Teenager Beat an Eating Disorder* is by James Lock and Daniel Le Grange, two leading US experts on anorexia and other eating disorders. As a starting point, these are probably the only books you will need and are recommended by many parents of teenagers with anorexia and other eating disorders.

- ★ Join *FEAST* and their online forum *Around The Dinner Table* (ATDT). Both of these have been lifelines in our family's battle with anorexia. Through the forum I have met some incredibly supportive parents, across the world. We even keep in touch on *Facebook* and I've met up with a number of the UK-based parents. Just talking to someone else who is going through the same or similar experience as you is incredibly empowering. Many of these parents' teenagers have now recovered or nearly recovered which makes it even more helpful.
  
- ★ Read blogs like this one. Also, Laura (Collins) Lyster-Mensch of *FEAST* (above) has a brilliant blog which includes a list of other parent-related anorexia / eating disorder blogs which she recommends. Another good blog is *EdBites* written by a recovered anorexic. [See back of book.]

**Friday, 14 January 2011**

### **Exercise and honesty with anorexia**

Oh boy, two issues here: compulsive exercise and honesty in anorexia / eating disorders. Both came to light during today's meeting with CAMHS.

First, the Good News. Ben was (brutally) honest about his exercising habits (or, more correctly, compulsions). As any parent of an anorexic will know, anorexia sufferers don't always tell the truth. The truth about hiding food, avoiding food,

exercising and so on. The Good News is that, over the past few months, Ben has been very honest, if challenged about an anorexia behaviour by CAMHS or, indeed, by me. This, in itself, is progress.

And now the Bad News. Ben described his seven-days-a-week exercise regime. Because of a low pulse rate and low body weight, he isn't permitted to do PE at school for the time being. We are all aware that he has a problem with compulsive exercising to compensate for this, and also to ensure he doesn't "put on enormous amounts of weight" (as he puts it) from week to week. It's a kind of purge, almost like a sufferer of bulimia might vomit to control their weight.

The extent of Ben's compulsive exercising is *huge* - much bigger than any of us imagined. Just when we thought he'd listed all his "100 crunches, 100 sit-ups and 100 press-ups" for any one day he'd interrupt with "I haven't finished yet!" not just once, but several times... And he listed exactly how many of which exercise he did when during any day, school days and home days. Ben exercises from morning to night (but, thankfully, not during the night).

Before he catches the school bus in the morning he's already done hundreds of crunches, sit-ups, etc - during the 60 minutes we rush to get up, showered, breakfasted and leave the house. I was stunned...

At school, he still runs around the building from lesson to lesson, deliberately making himself late so he has an excuse for all the running.

In the days when the anorexia was at its height I was aware that he used to excuse himself from lessons to run round the block. When sitting his GCSE Art exam separately from the others, he even did crunches, sit-ups, etc when the invigilator was out of the room. (Probably why he got a low grade in Art, one of his strongest subjects...) But, these days thank goodness, he doesn't exercise to that extent. So that's "progress" of sorts, as well.

One reason he does mornings only at school at the moment is because he can't handle the thought of "doing nothing", as he puts it, for the afternoon as well. When

he gets home, he does another few sets of the crunches, etc and repeats these throughout the afternoon and before and after the evening meal.

Most days he likes to keep even more active still, hating to “just sit around”. He’s much happier if we go walking, for example. If he stays at home he gets edgy and starts to suffer from withdrawal symptoms. In addition he does a couple of aerobic free-weight sessions every week (which I already knew about).

Unfortunately our psychiatrist wasn’t there today and we saw the psychiatric nurse (the other half of the CAMHS team). She was pretty shocked and so was I.

The next stage in the treatment is to try and break this cycle, presumably just as you might try to break an alcohol or drug addiction, whilst at the same time continuing to bring him round to the idea that it’s okay to put on weight rather than just maintain it.

That’s the thing with anorexia and other eating disorders... Just when you’ve ironed out one issue, there’s often something else lurking in the background about to rear its ugly head and you have to be on the ball all the time. If only it was as simple as “just being about food”. But it isn’t. Far from it.

But as I said above, the Good News is that Ben was brutally honest about his exercise regime (and how much he hates doing it).

Knowing exactly how much he hates it brings home just how much of his life the anorexia has stolen. All this planning and carrying out of exercise, and feeling ill at ease or depressed when he’s not doing it... all this is time that he could be spending with his friends, living his life like a “normal” teenager.

That’s the other thing about anorexia. It steals a huge chunk of a young person’s life away. It also hammers home just how much work there is still to do on the recovery front.

This is why full recovery from anorexia can take *ages*.

I long for the day when “normal” thoughts take over his mind rather than these unhealthy obsessions dominating every waking moment.

It will happen, but the progress is *so slow* (but no-one ever said it would be quick!)

**Saturday, 15 January 2011**

### **Anorexia - being honest and keeping talking**

"I found yesterday really hard," said Ben out of the blue when frying the onion in oil (yes, oil!).

"In what way?" I asked. "Loads of ways," he said, "Starting with the girls on the school bus who wouldn't stop talking about diets, then P and L were talking about their latest diet in Psychology, then at break N offered me some crisps and a chocolate muffin. It was really hard..."

"To an anorexia sufferer, things like that are a bit like ultra violet light when people are wearing white," I replied. "The white things show up really bright whereas in normal light they'd look the same as everything else. To a recovering anorexic, things like that are really difficult to handle."

But the good news is that Ben is still being very open about things. "In town today I chose the higher calorie sandwich," he said, "and a packet of curly crispy things. It was hard, but I made myself do it."

And I know for a fact that last night's evening meal was difficult for him. We'd run out of tuna in brine for our pasta, so I had to opt for tuna in oil (two tins of it!). In the past he would have freaked out and refused to eat it.

Last night he ate the meal without any hesitation or problem. I'd also thrown in a tonne of anti-pasti loaded with olive oil. In the past he'd have dug it out and dabbed it clean with a piece of kitchen paper, but he didn't last night.

So today I gave him a hug and said: "Well done, I'm really proud of you. And also thank you for being so open about the exercising yesterday at CAMHS. You know this is something we need to work on, don't you?"

And he does.

**Wednesday, 19 January 2011**

### **Anorexia parents, importance of good friends**

The trouble with anorexia and other eating disorders is that many people just don't "get it". As a parent of an anorexia sufferer the learning curve is bad enough - I never studied as hard as this on my university degree! As a result you can feel terribly alone, as if you're living in a parallel world to everyone else.

Anorexia has meant that Ben and I have discovered who our real friends are - those wonderful, selfless, loving and supportive people who don't just care about what's happening, but who are willing to go through a massive learning curve in an attempt to understand it.

Along the line, other friends have moved off the radar. Maybe they can't understand it or simply don't want to understand it.

Or perhaps they have their own problems to deal with - or just don't want any negativity or hassle in their lives.

Also, I've found myself avoiding many people, mainly because anorexia has become such a huge part of my life that I find it difficult to talk about much else during bad times - and I don't want to "inflict" myself on people.

Our social life has suffered because, initially, we couldn't make any plans. We never knew from one day to the next where Ben's mood would take us (usually to hell and back...) And during those hellish months when things were spiralling downwards I was in floods of tears most days. Not exactly the best frame of mind to spend a night on the town with girlfriends!

We still have problems accepting dinner party invitations or going out for meals. Any social event that features food is going to be a problem if Ben is invited too.

Last summer, we were invited to an Indian birthday celebration where the most mouth-watering curries in the universe were served up. Ben miserably watched us eat while I miserably tucked in. Our hosts had no idea what was going on or why we left early.

But some people are more than willing to be “in” on our ‘secret’...

11 months ago I met Sue, one of the most amazing and selfless women I have ever met. Sue “got it” it practically straight away and what she didn’t understand, she was eager to learn.

The thing with Sue is that she has her own problems. Millions of them. She’s had a double mastectomy and suffers from secondary breast cancer which means that her lungs, liver, spine and various other parts of her body are plagued by tumours. Right now, she’s on her umpteenth course of chemo and waiting for her hair to fall out (again).

Yet Sue has been my “rock”, week in, week out. Throughout our most frightening period with anorexia, Sue was there to offer a willing shoulder to cry on. She understands anorexia more than anyone else I know who isn’t directly involved with this horrible illness. I hope I can do the same for her when she needs it.

Other “rocks” have been the group of mums on the ATDT forum. Despite dealing with eating disorders in their own families, they haven’t hesitated to pick up the phone and call me if they felt I needed a bit of support. Or email, or answer my posts on the forum.

Another “rock” has been the school nurse who has gone over and beyond the call of duty to offer support, a sympathetic ear and a comforting mug of coffee in the cosy little medical centre.

In a similar way, anorexia has resulted in Ben sorting out the “wheat from the chaff” in his own friendship group. New friends have come onto the scene, many of them girls because the boys seem to find it harder to deal with.

Anorexia is strange in that it’s a horrendous experience for parents and teenagers to go through (understatement!) yet out of it comes a lot of good.

It’s made both of us stronger and better people - and it’s enabled us to meet strong, supportive and fantastic people too.

And that’s something I don’t want to lose, long after the anorexia has well and

truly gone.

**Friday, 21 January 2011**

### **Walking and talking about the anorexia...**

Over the past 18 months Ben and I have got to know the beautiful local countryside very well indeed. We've walked and talked... walked and talked again... and again... and again... across all four seasons... in the hot sun, the crunchy leaves of autumn and the deep snow.

On Tuesday, as the sun set behind the lake and we squelched through yet another muddy field, Ben said how much he has appreciated our "little chats" (as he calls them) finding them "incredibly therapeutic".

I talked about how, for ages, I felt that I was banging my head against a brick wall. We'd talk about recovery on these walks and Ben would promise to do X, Y or Z, but he'd rarely keep his word. Not because he didn't *want* to, but because the anorexia meant that he just *couldn't*.

As I watched Ben get thinner and thinner, and more embedded in the anorexia, these walks and talks broke my heart, especially on days when things seemed totally without hope.

But lately, things have been very different. We're going over similar stuff, but the difference is that, since the autumn, Ben has been actively committed to his recovery. We have turned a corner. These days, he follows up suggestions or discussions and we make significant progress. Far from banging my head against a brick wall, I actually feel I am doing good.

Watching the wildfowl silhouetted against the setting sun over the lake, we talked about exercising (how he's making a real effort to cut it back, and managing to do this reasonably successfully)... about easing back into school full time (and examining the problems that are making it hard for him - and working out ways to overcome them)... about socialising (the importance of the fantastic friendships he's developing

with his supportive friends)... about eating (What has he found difficult this week? What challenges has he made himself? Were they successful?)

Plus, contrasting how different eating is now compared with several months ago... about what life will look like without the anorexia (why he really looks forward to having kids when he's older - and also why life without anorexia seems real now, whereas only a few months ago it seemed unobtainable)... and so on. Phew, we covered a lot of ground - talking and walking!!

And, having walked and talked our way around virtually all the local countryside pathways, I've just sent off for a map of the adjacent area so we'll have a stack more countryside paths to walk and talk across soon!

**Friday, 21 January 2011**

### **Fatty sausages and cheese - two fingers up at the anorexia!**

Two massive challenges in one meal: fatty sausages and cheesy mashed potato. Both are things which would have sent Ben into a frenzy a few months ago. But yesterday he ate both, without any problem at all. In fact, for the first time for *ages*, he actually saw the sausages cooking, surrounded by oozing fat and it didn't faze him at all.

Another thing we talked about on our walk was how he is now relaxed about "condensing" his calories, as he describes it. The days of elaborately prepared meals comprising loads of low calorie stuff that took ages to eat are over. Now he's able to include higher calorie foods, including fats, which make preparation and eating easier, quicker and much more "normal".

Also, he said, "On Saturday I bought and ate a high calorie sandwich... *and* I ate it in dad's car... *and* I ate it at 2pm... *and* I came home and had a snack in the middle of the afternoon knowing that our evening meal wasn't far away". In the old anorexia past, he would have had to eat in a certain place (at a table, for example) and at a specific meal "time" (i.e. 12.30pm). Plus, he couldn't rush it. In the Bad Old Anorexia Days, every single meal had to be "perfect", or else...

And, despite the fact that recovering anorexics are really supposed to have mid-morning and afternoon snacks, Ben has never been able to do this. So an afternoon snack, entirely of his own choosing, is massive progress.

**Tuesday, 25 January 2011**

### **Predisposed towards anorexia?**

In a recent report, Child Psychologist *Dr Sarah Ravin* explores the belief that certain people are predisposed towards developing the particular brain disorder known as “anorexia nervosa”. In short, she (and many other experts) believes that, while two different teenagers might embark on a weight-loss diet or significantly increase sports activities “without appropriate caloric compensation” (to give two examples only), one teenager might go on to develop anorexia nervosa whereas the other won’t. The reason being that one teenager’s brain chemistry is predisposed to react in a certain way to food restriction whereas the other teenager’s brain is not. And anorexia is always “precipitated by a period of low nutrition”.

She goes on to say why, with this kind of genetic makeup, it is essential that “eating a complete, well-balanced diet and maintaining ideal body weight are of utmost importance in recovery from AN and preventing relapse”.

Like many people, I came into the world of anorexia believing it was primarily about “dieting gone wrong”; teenagers who were unable to stop dieting once they started and who viewed themselves as fat when they were very obviously emaciated. To me, it seemed a simple case of “just get them to eat”. If they ate properly, they’d put on weight and be fine again. Simple as that.

The longer you live with anorexia in the family, the more you realise that this is not the case. Far from it. Ah, if only it was that simple! It’s not that sufferers don’t want to eat; they *can’t*. Worse, they gain comfort from the “calming and mood-elevating effects of food restriction” which seems to happen in people predisposed towards anorexia.

The more I thought about it, the more it made sense that anorexia is due to genetic makeup and the sufferer's "particular brain chemistry". On both sides of our family we have mental health issues, some diagnosed, others undiagnosed. Add the two sets of genes together and - ker pow! - you (maybe) get whatever has been going on in Ben's brain chemistry over the past months.

This makes complete sense to me.

(However I am not necessarily implying that families with a history of mental health conditions could go on to develop anorexia; I am theorising that anorexia sufferers have something that's "hard-wired" into their genetic makeup. In other words, it's a biologically-based illness.)

And it seems to explain why anorexia can return. Something (e.g. stress) triggers the food restriction which in turn triggers the brain chemistry and the anorexia rears its ugly head again. Just as it might if a recovered alcoholic had another drink. So I am guessing that people who have "recovered" from anorexia need to be enormously vigilant throughout their lives, able to cope with any "triggers" before they kick off another bout of anorexia.

This is my theory, anyway, and the concept that anorexia can return seems to be backed up by Dr Sarah Ravin when she says: "Sustained full nutrition and weight restoration are essential for mental and physical recovery. Continued good nutrition and maintenance of a healthy body weight for life protect patients against relapse."

**Wednesday, 26 January 2011**

**Anorexia - proof of what we're up against...**

With anorexia, bulimia and other eating disorders, there is a light at the end of the (often very long and gruelling) tunnel for many teenagers. However the heart-breaking fact is that not everyone makes it. Statistics show that over the last ten years, the number of children hospitalised in UK NHS hospitals with eating disorders has risen by one third. A recent press release reported that there were 800

emergency admissions for eating disorders in 2009. Statistics also show that eating disorders have the highest mortality rate of any psychiatric illness – and only 35 per cent of sufferers ever fully recover while 18.5 per cent die and the remainder semi-recover.

I'm not saying this to scaremonger, but to be realistic.

As a mother of a teenager with anorexia, the worry that this condition could steal my child from me has been foremost in my mind from the very first day we realised there was a problem. That terrible, cold, clanging feeling inside when you start to research the illness and discover the statistics. There's no point in burying your head in the sand.

Saving my child's life is the primary driver in everything I do and have done for the past year or so. Sure, I am fortunate that Ben's weight has never been low enough to warrant admission to a specialist eating disorder inpatient unit; he has always been treated on an outpatient basis at CAMHS. But I do know what it's like to sit in abject terror in the hospital while my son is wired up to umpteen machines, his heart doing dangerous things...

And then to go through the same procedure again, several months later.

I also know what it's like to have an anorexic child that is so clinically depressed they feel that suicide is the only way out. I know what it's like to grasp my child in my arms, trying to get across to an eating-disorder-numbed mind that he is the most important thing in our lives so please, please, please don't think like this.

And to feel that you're getting nowhere as his depression hits rock bottom.

At a particularly low point last summer I caught him trying to climb out of the attic window onto the roof, not caring what happened to him...

Following this, my fantastic friends and family told me I could call them, day or night, if I needed back-up because, often, my son was too physically strong for me. Once he packed his bags and climbed out of the conservatory window - physically I wasn't strong enough to stop him (I went through a phase of hiding all the house

door keys, but had stupidly left the window unlocked). I thought he had left home for good. Thankfully he came back later.

We also prepared ourselves to ring 999 if I ever found myself in a situation where I believed my son's life could be in danger.

Thankfully, this was last summer and we have come a massive, massive way since then, especially since he started on a course of antidepressants. His mood lifted enormously and his numbed mind started to feel love, happiness and pleasure for the first time in months. Rather than thinking of suicide, he developed a passion for life and a future without anorexia.

With this came the huge change in attitude I've talked about so much in this blog. Okay, we still have many "blips" but the general direction, I am thankful to say, is forward.

But there is always one child that doesn't make it. And this week I learned of another teenager whose body gave up the fight against anorexia nervosa. Her internal organs simply shut down; her body had been so ravaged by this devastating condition.

My heart goes out to her mother. Although I've been to hell and back over the past 18 months, I am so eternally thankful that I never went where this caring, loving, hurting mother is now. To lose your child to an illness like anorexia is hell in its truest sense. It is something that no parent should ever have to go through. But the awful fact is that, with the number of diagnosed eating disorders increasing year on, year out, the chances are that more of our beautiful children will lose the fight against anorexia.

This is one of the reasons why I write this blog: to do my small bit to hopefully help another parent in their fight against teenage anorexia. And Ben is right behind me in doing this. These days he recognises anorexia for what it is: an evil fiend that is no friend to our children, even though it pretends to be. The fight goes on...

**Wednesday, 26 January 2011**

### **Help from other parents of teenagers with eating disorders**

The absolutely brilliant eating disorders website FEAST has just set up a *Hall of Fame* page comprising what its forum contributors believe to be the most helpful posts over the past few years.

Members of FEAST's ATDT forum come from all over the world. What we all have in common is that we are parents of teenagers with anorexia, bulimia or other eating disorders. We're all at different stages of recovery and the truly supportive aspect of this forum is that many parents of recovered eating disorder sufferers return time and time again to offer advice and talk about the drivers that helped their child recover from anorexia, bulimia, etc.

So please check out the *Hall of Fame*. You might just find the answer to your current problem. For example, I found a link to an old post about boys with anorexia which is incredibly relevant to my own experience / situation. Because it's an old post, I might not have found it otherwise.

Brilliant. Keep up the excellent work, FEAST!

**Thursday, 27 January 2011**

### **Juggling work, play and anorexia**

Once upon a time I had a brilliant career as a freelance copywriter, working from home for businesses up and down the country, writing websites, sales letters, brochures... in short, everything to do with sales and marketing. Then anorexia invaded our home and gradually I had to cut back on work to spend more time focusing on helping my son to recover.

By summer 2010, I was having to turn down work left, right and centre, trimming my business back to a couple of hours a week... if I was lucky. Okay, we had to make huge financial sacrifices, but with anorexia on the scene I didn't feel much like

treating myself to shopping trips or holidays, anyway. But I always said, “We’ll be okay as long as my husband doesn’t lose his job”. I think you can guess what’s coming next...

Working in the construction industry in a recession is never going to be good news - and this week my engineer husband received the news that the company he works for is going out of business. By today, he could have no job and - as a result - no income. And he won’t get any redundancy. He might not even get his pay packet at the end of the month.

Talk about extra stress when you don’t need it! Of course it’ll mean I have to crank up my freelancing business again and juggle work with caring for my son. But at least with Ben back in school most mornings, I can work then. And thank God it’s not like it was a year ago when I’d be on red alert every single morning ready for the latest “I can’t go on” text from his phone.

Plus, I am so so so so fortunate that I work for myself, from home. I have become an expert at “flexible working” as I switch from eating disorders to goodness only knows what the latest sales letter or website is about - in a split second.

The bad news is that we’ll have to trim our household expenses still further, at a time when we’d already cut back massively. But hopefully I’ll be able to juggle morning work with caring for my son in the afternoons while my husband looks for another job. And hopefully I’ll be able to make sufficient money for us to stay afloat in the meantime. Because, when you have a recovering anorexic in the house, it’s vital to keep calm, positive and stress-free.

I know other eating disorder parents that juggle work and caring - and I admire those that manage to hold down what I call a “proper” 9 to 5 job enormously. In an ideal world, we’d all stop work and care for our anorexic children full-time, regardless of the financial sacrifice. But unfortunately, it’s also vital to keep a roof over your child’s head, and for that you need an income. And, for now, that income will have to come from me.

FEBRUARY 2011

**Tuesday, 1 February 2011**

**Anorexia echoes? Only kidding!**

Phewee.... Ben decides to do some baking in the kitchen downstairs. Then I hear this banging and crashing following by a loud shriek-like noise... then a repeat... My heart stops. I recognise those sounds. Something has gone wrong with the baking and Ben is crashing around the kitchen, throwing stuff and making “animal noises” just like the anorexia used to make him do... So I brace myself and go downstairs, taking a deep breath before walking into the kitchen (armed with clean laundry so he’d think I was entering by coincidence...) LOL, there he is, enthusiastically kneading dough, banging it on the surface, loudly singing along to *Wizard’s* 1970s hit *See my baby jive...!!*

Pheweee...

It’s a bit like after I was mugged (back in the 1980s in London). It was ages before I could walk down a street without freezing in terror if I heard someone running behind me.

It was the same this afternoon.

I still can’t hear banging and crashing in this house without having flash-backs to the Dark Days of Anorexia...

Maybe one day I’ll be able to relax...

**Saturday, 5 February 2011**

**Surprise weight loss!**

Yesterday we had our weekly CAMHS weigh-in session and everyone was stunned to

find Ben had *lost* over a kilo in the past seven days. So the decision was made to add an extra 100 calories a day to his intake with immediate effect. In the past, such a decision would have freaked him out big-style, but yesterday he accepted the need for extra nutrition without batting an eyelid - together with the psychiatrist's explanation that it could be due to his metabolism speeding up now his body is successfully healing itself from within.

Okay, we all know you can't take a week's weight gain or loss in isolation, but we've been carefully monitoring Ben's weight for the last few weeks to check if his current calorie intake is sufficient. This has also enabled Ben to check his exercising against any weight gain / loss. Significantly, last week he reduced his exercising to a minimum while occasionally going "over calories" on some days. So the kg weight loss was an extra surprise to him.

Anorexia is notoriously irrational, insisting that "black is white". So in the past, "proof" like this eating / exercise combo would have gone in one ear and out the other. Maybe he would have readily agreed to increase his calorie intake at the CAMHS meeting, but in practice he wouldn't have been able to do it. The anorexia wouldn't have let him.

Now, several months after Ben turned a corner, his reaction is completely different and I hope the extra calories will now become the norm. Also, he knows that if he continues to lose weight on this extra intake, he may need to increase his calories still further.

A sticking point, though, is when I suggested today that we buy "ordinary" cheese instead of "reduced fat" cheese. He recoiled at the idea; it was a step too far. Maybe I'll try again in a month or so. He was also going on about the fat content in something or other so I simply said: "Fats are what have helped to heal your brain so they are here to stay." And he seemed to accept that. Or at least, he didn't object.

**Sunday, 6 February 2011**

## **100 extra calories a day on the eating plan...**

This week we are trialling 100 additional calories every day to see if Ben will put back the weight he lost last week, and also to gauge the optimum intake he needs for the recommended 0.5kg a week weight gain. I believed the previous level was too low and was eventually proved right. So how will he adjust to having to eat more?

We shall see, but I'm monitoring his intake discreetly but diligently. For example today I found he'd omitted to include the extra 100. I am hoping it was just an error and not deliberate...

## **Sunday, 6 February 2011**

### **What a difference six months makes...**

Get this... In September we went out for a meal and Ben refused to eat a single morsel. Instead he just sat there, in floods of noisy tears, while we miserably ate our meals. It was a busy and very popular country inn and everyone was staring. After all, it's not often you see a 16 year old boy in tears in public! Also the worried waitress kept coming over to see if the food was okay and to ask what was wrong - of course she'd never be able to understand why our son was in tears, refusing to eat what was, to all intents and purposes, a perfectly delicious meal...

Last night we returned to the same inn for the first time since the above incident. Our son consumed a large plate of battered cod, chips and mushy peas without any stress or hesitation whatsoever. Also, there was none of the old stress where he used to take *ages* choosing something, changing his mind backwards and forwards... and then going for the option containing the least fat / calories... And there was none of the old after-meal blues when the anorexia would beat him up about being a "greedy pig".

Another victory against anorexia... Hopefully it will help to put back some of the weight he lost last week...

**Monday, 7 February 2011**

### **The road gets rocky**

Mood-wise, today is “one of those days” as Ben miserably slouches around the house as the demon tries to muscle its way back in. I can always tell because some of the old, familiar comments return like: “I feel as if I’m just living to eat, existing from one meal to the next” and “I feel useless” and so on.

All afternoon I’ve felt my own old anxiety levels rising while trying to appear calm, positive and in control. At least he’s responding when I give him a cuddle; often in the past he’d just stand cold and emotionless, arms by his side. He also wants to “help me cook tea” which, in the old days, meant “checking and freaking out at the fat content going into the meal”, so I’ll be keeping a very watchful eye. And I need to query the list he’s made of the food he’s consumed today because I’m not entirely convinced the calories add up... (Yesterday they did, by the way.)

It could just be me being paranoid, but it’s definitely a “rocky road” day. It would be unrealistic to assume that, on the journey to recovery, there aren’t “glitches” along the way. The trick is to keep your eye firmly on the ball, all the time.

Funny how I recognise when it’s the anorexia speaking and not the new confident, positive Ben. But I am always on the alert for the demon trying to muscle its way back in as it’s prone to do. The demon doesn’t give up easily.

One trigger could be that Ben has set himself a week of challenges. Every single meal is a challenge, starting with the fish and chips supper on Saturday through to the creamy chicken stew with potato dauphinoise yesterday - and the sardine pasta today. Then tomorrow it’s shepherd’s pie with the dreaded “horribly high in fat” lamb mince. And of course, this week he’s having to eat 100 extra calories every single day...

Typically all this has come on a day when I’m up to my eyeballs in work and when my husband has finally received his redundancy notice.

Ah well, no-one ever said it would be an easy road... But you have to plough on regardless; as the parent of an anorexia sufferer you can never give up. And each day is a new day - one more day towards recovery.

### **Wednesday, 9 February 2011**

#### **We're still beating the anorexia...**

Thankfully, Monday's mood was a "one off" and Ben did eat all his calories without issue, including the extra 100 per day he needs to consume now. Yesterday he was back to his normal recovering self. Ditto today (except for the insomnia which was improving slightly after his psychiatrist prescribed some *Melatonin* tablets, but which came back with a vengeance last night). So it will be interesting to see what his weight does on Friday when we go to our weekly CAMHS session...

Yesterday I asked him if he'd been finding it hard to eat the extra 100 calories. "No," he said, "because it's not like in the days when I'd do anything *not* to put on weight; now I know I need to and I don't mind. I don't actually like where I am now, physically, and want to put some of the weight back on".

He did find the lamb shepherd's pie a bit of a challenge (because "fatty" lamb has always been a problem for the anorexia), but he managed to eat it in a normal, relaxed way and followed it up with a custard-laden pudding.

So today he's been doing school work and I've been earning a crust, working hard at my PC. Unlike Monday, I wasn't ultra-anxious which meant it was soooo much easier to work!

I am constantly astonished at how I managed to work during Ben's decline into anorexia last winter and spring, although I had to stop over the summer because working and threats of suicide / leaving home don't go together very well...

### **Friday, 11 February 2011**

## **I think I hear demonic laughter...**

The demon is falling about on his back laughing till he cries. "Brilliant!" I imagine him chortling, "All I had to do at the end of a week where Ben seriously challenged himself almost every day *in addition to* eating an extra 100 calories a day *and* munching his way through fish and chips on Saturday... All I had to do to mess it all up was to make sure Ben put on a tonne of weight by the end of the week. Bingo! Chortle, chortle, chortle..." etc...

Today was our weekly CAMHS appointment and it all started very well. In fact, apart from Gloomy Monday, this week has felt like a really successful week with the light at the end of the tunnel getting stronger and brighter every day. Ben went into the weighing room in a light-hearted, chatty mood. But he emerged from it with a face like thunder.

Of course the team tried to point out to him over and over again that if he looked at it over the long term i.e. over the past four weeks he would see that his weight has averaged out at 0.25kg gain per week. Really, you should be looking at an average weight gain of 0.5kg i.e. *double* this.

"Don't listen to them!" shouted the demon inside Ben's head. "All those challenge foods have made you F-A-T and this is the undisputed proof. Look at what the scales are saying... you put on 1.9kg this week, you fat greedy pig! Everyone was W-R-O-N-G, see? I was right all along!!!"

And the demon is really great at making Ben totally deaf to the team's response of "But you lost 1.2kg last week and over all you're only looking at an average weekly weight gain of 0.25kg per week".

So CAMHS said: "If you were being treated at the inpatient unit you would be fed on a very rigid diet every day. They just put the food in front of you and you have to eat it. And if you refuse, you just stay sitting there until you do. Then, at the end of the week, if you'd put on a similar amount of weight to the 1.9kg you put on today, they would expect you to continue the same rigid diet, without any tweaks or

changes to it. So in an ideal world we should be asking the same of you, as an outpatient...”

But, sorry, the demon had made Ben totally deaf to that fact, too. And when we got home, out came the weights for a punishing exercise session, for the second time today...

Ker-ping! I feel as if we've been catapulted back six months or so.

But with this horrible illness it's all too easy to suddenly panic, hold up your hands and think it's all a total waste of time so why bother.

But it's probably better to take a bit of time out, then pick myself up, dust myself down, keep calm and carry on...

Watch this space...

**Sunday, 13 February 2011**

### **The battle for Cake Mountain. Who won?**

Okay, so General Anorexia took our side by surprise on Friday afternoon by dropping a 1.9kg bombshell on us which sent everyone running for cover. However, on closer examination (and after sending in our undercover spies to keep tabs on what's happening in the kitchen and at the dining table), things aren't as serious as we first thought. Yes, there is some damage which will take a little time to repair and, yes, it has thrown us off course a bit, but it's nothing that we can't solve. Hopefully...

So Captain Mum spent Friday afternoon keeping a close eye on things without alerting The Enemy in any way. And General Anorexia must have been caught off guard when Ben decided that, yes, he was going to go out with his friends on Friday night, despite The Enemy telling him he might as well cancel his entire social life...

And he had a good time, came back totally chilled and happy to be with his friends. Then he ate tea and pudding as normal, followed by a good night's sleep followed by breakfast as normal. So far so good...

But, of course, we veterans never take our eye off the ball for one instant. And half

way round *Tesco's* on Saturday morning, General Anorexia sent in reinforcements with a vengeance. The result was Battle for Cake Mountain which had distinct echoes of the kind of thing we used to experience at the supermarket in the past.

For a while now, Ben has happily eaten slices of *McVities* slab cakes (e.g. *Jamaican Ginger* and *Golden Syrup*) and it was Buy One, Get One Free. So he put two cakes into the trolley. But then The Enemy prompted him to put them back on the shelf and dither around putting other cakes into the trolley, taking them out, putting more cakes in, taking them out again... etc... etc...

This went on for 20 minutes before he, predictably, decided he wasn't going to have any of them. But I wasn't going to let The Enemy get off lightly so I insisted Ben picked some cakes, refusing to give into the anorexia.

We won and took *Battenburg* and *Date'n'Walnut Slices*.

In the afternoon, Ben went to the cinema with E. Another social success. However by late evening General Anorexia had returned with reinforcements forcing Ben to think about food all the time followed by a sleepless night with nightmares about food.

But, generally, I think we'll pull through, even though Ben is finding it Very Hard at the moment.

The trick is to keep reminding him of what Life Without Anorexia looks like. He's already experienced it to a certain extent and it would be a crying shame to let the anorexia drag him back into the darkness.

I reminded him that all the anorexia wants is to destroy. It will lie and fib, convincing the sufferer that it is the safe, secure, easy option. But all it wants to do is act like a Boa Constrictor and squeeze the life out of the sufferer. I won't let it do that.

**Tuesday, 15 February 2011**

## **What if anorexia hadn't stolen 20 months from his life...?**

I went through a lengthy phase last year where I could scarcely bear to look at other teenagers, especially those that looked ultra-fit, happy and healthy. The stark contrast between them and my son was strongest when he used to slouch across the school car park at the end of the day looking emaciated, gaunt, tired and miserable, with dark rings round his eyes and his clothes hanging off him.

Suddenly it seemed as if everyone else was leaping and bounding across the car park, blossoming with health and full of the joys of spring. And I'd think back to the days when I would almost weep with pride at my handsome, muscular, healthy-looking son and the way girls would blush when they looked at him.

Ben still is incredibly good looking. But he's also incredibly thin. Thankfully the dark rings have gone from around the eyes as his nutrition has improved over the past months and he doesn't look as gaunt. But these days I find it simply isn't helpful to compare him with his peers. Nor is it helpful to wonder what might have happened in Ben's life if he hadn't been enslaved by the anorexia for the last 20 months or so.

It's similar to anyone who has a child with an illness. As time goes by you simply have to accept that, for a time, they won't be like everyone else and there's no point wishing they were. But some good things have come out of this... The way Ben and I are closer than we ever might have been if the anorexia hadn't arrived on the scene. He's also much more sensitive to other people's feelings and gets on brilliantly with the girls because girls can talk deeply in a way that many teenage boys can't, and Ben likes doing that.

He is recovering and he will come out of this. One day he will get his weight back and look like the big strapping lad he should be. But while we're still on the road to that destination, it's pointless comparing him with other teenagers who have more muscle and flesh than him.

At least, these days, when he walks across the school car park he's usually waving goodbye enthusiastically to someone in the sixth form common room, smile on his

face...

Most times, anyway...

**Wednesday, 16 February 2011**

**A whole day away from Mama's Eagle Eye...**

Today Ben went on a school politics trip to London to visit Parliament and trying to put together a "suggested menu" for him entirely comprising *Starbucks* and *Marks & Spencer's* food was far from easy, especially as Ben will be in charge of buying his own food...

Of course I'm nervous about whether he managed it all or not. At this stage in his recovery, I believe he will be honest with me (which wasn't the case in the past). But whether or not he ate anything that comes close to his required daily calories, I won't know until he returns at 9pm.

Yesterday we visited *M&S* to buy a load of stuff for his packed lunch. Like the Battle for Cake Mountain on Saturday, we went through the "pick it up / put it back / pick it up again" scenario with me adding up the calorie total, then taking away what was put back, then adding on what was picked up, taking away what was put back - to ensure he didn't underdo it. By the time we eventually reached the checkout, I was exhausted.

Will he repeat this lengthy process in London? If so, he'll probably miss the train. If not, then he might just end up with nothing to eat which may result in significant weight loss when he gets weighed at CAMHS on Friday.

He's just called to say he's on the train and I resisted the strong temptation to ask if he'd bought some food, instead just asking him if he'd had a good time. Sounds like he had a wonderful time, thankfully. But watch this space about the food...

(Update next day...)

PS. He had a fab time and I do believe he ate all but a few of his calories. Anyway, we shall see what the scales say at CAMHS on Friday...

**Saturday, 19 February 2011**

**What should you do if your child is behaving like Ben was at the start?**

The thing is, as I said earlier, you don't expect boys to get anorexia or other eating disorders. So, as a parent, you might notice that something isn't "quite right" but aren't sure whether you should seek professional help.

Also, there's a misconception that, to be suffering from anorexia, you have to be stick thin.

Obviously, during the early period, they might still be within a "healthy weight range". So if you visit your GP with your teenager in tow, you might not be taken seriously if their BMI is still within a "safe" range.

As a parent, you have a gut feeling when something just isn't right - and if your teenager is demonstrating behaviour similar to that described elsewhere in this blog, take them to the GP and explain your concerns. If the GP fobs you off, keep pestering them.

With us, the alarm bells were ringing loud and clear but the GP wasn't taking me seriously. The GP never explained what professional help was available; it took the school nurse to tell me about CAMHS. Then I had to twist our GP's arm to get Ben referred. After that we had to wait *months* before we got our first appointment. This "limbo" time can be really scary as you watch your child plummet into the eating disorder. You feel helpless and frightened, knowing your original gut instinct was right.

The first thing you should do during this limbo is to get yourself clued up on the facts and get some good peer support. Buy the books I referred to earlier, visit the FEAST website and join the ATDT forum. Introduce yourself - dozens of other mums will quickly come to your aid, offering help, advice and a shoulder to cry on.

**Sunday, 20 February 2011**

## **Update following weigh-in on Friday...**

As you may have gathered, last week was a tricky week following the 1.9kg weight gain the week before. Ben had found it difficult to come to terms with this and it sparked off all manner of anxiety-related issues throughout the week. However the Good News was that, despite this, he continued to cooperate and eat in the way he should. He admits the “anorexia voice” was telling him to cut back most of the time, but he refused to listen to it, insisting on ploughing on. I am so proud of him...

He was really tetchy by Friday, worrying that the scales would show a similar “massive” weight gain. However he’d actually lost weight, despite the week’s eating. Almost immediately he relaxed and his mood improved.

In the past this would have been because he was relieved at *losing* weight rather than gaining it.

Now, the relief was because he’d proved to himself that he *could* eat, as required, without putting on a “massive amount” of weight in one go.

Also, that the 1.9kg gain could just be an anomaly which, hopefully, he can live with.

This week we have agreed to increase intake slightly to see what happens on Friday. So far, he seems to be managing this and is already challenging himself to eat things that would have freaked him out in the past. But it remains to be seen what his weight will be at the end of the week. The aim is to maintain a gradual weight increase of the recommended 0.5kg average per week. At the moment, he’s only managing an average of half of this and that includes the 1.9kg increase the other week.

So we’re at the tricky stage of winning him over to the idea that increasing “massively” some weeks and less on others (or not at all) can average out at *less* than the recommended / desired average. At the moment he is finding it hard to see the bigger picture, although he is trying and I believe, given time, he will see it. It is a slow process but we are moving in the right direction.

Is this the same for all recovering anorexia sufferers? Not necessarily. What works for some people may not work for others. Ben is the kind of person who needs to “prove things” to himself before he believes them - like seeing the results of a scientific experiment, and this is the kind of approach which seems to work for him and may, indeed, work for others.

Before the anorexia, our logic would have seemed obvious and he wouldn't have needed “proof” that we are right. But anorexia is a notoriously irrational condition when the sufferer loses much of the logic they had when they were “normal” and it's as if the brain has to be reprogrammed to get it back to a normal way of thinking.

**Monday, 21 February 2011**

**Calorie crisis - is this another turning point, I wonder..?**

Not everyone advocates calorie counting as a means for the anorexia sufferer to gain weight. But, for Ben, calorie counting was the only way to get him to eat enough food - especially as he prepares his own breakfasts and lunches these days.

However calorie counting definitely plays into the anorexia's hands in that it's a very “controlling” thing and puts the person in a completely artificial environment. So yesterday Ben announced out of the blue that he'd had enough of counting calories.

At first, alarm bells went off as I worried it might result in him eating *less* and as a result losing weight which he can't afford to do. Also, I wasn't entirely sure he was at the “right stage” to do this yet. But, on the other hand, it could prove to be another positive turning point. So after some discussion we decided to give it a try until Thursday when he goes for his next CAMHS weighing session.

I think he just feels so imprisoned by the anorexia and is longing to break free. As he said last night: “I just want a *holiday* from it all and the last time I had a real holiday was in spring 2009, before all this kicked in.”

**Monday, 21 February 2011**

## **What about your teenager's friends? What should they do?**

My very dear friends and fellow ATDT forum members, *C&M Productions*, have produced a fabulous little video about how to explain the eating disorder to the sufferer's friends and suggesting ways they can provide helpful support.

What I especially like about this video clip is that it features two teenage boys discussing "Mike", a friend who's developed an eating disorder, rather than the familiar angle of talking about anorexia as a girls' illness.

Friends find it particularly hard to know how to deal with a peer who has developed an eating disorder. After all, their friend has undergone a kind of scary Jekyll-and-Hyde type transformation.

What's happened to them? What caused it? How can we help? What about social invitations that involve food - or school dinners? Will we ever get our old friend back? And, in the meantime, how should we handle it?

These are just some of the questions they might be asking themselves. Close friends in particular can get quite concerned and may even worry they were to blame in some way.

C & M's excellent little video is a great starting point for any teenager wanting information, guidance and advice on the illness that has transformed their friend, how they can offer helpful support plus what they should and should not do.

Anorexia is a very lonely illness. It steals teenagers away from their friends and isolates them. Meanwhile friends simply don't understand. Ben, for example, used to be incredibly popular and had a marvellous circle of friends.

But, once the anorexia had taken hold, he withdrew from his social group altogether - so much so that for a number of months he was completely isolated and couldn't even go to school.

One or two core friends tried to stay in touch - but Ben's uncharacteristic and unpredictable behaviour upset and almost certainly scared them. And of course, their best friend... the boy who'd always loved sport, who was a star *forward* in the rugby

team and who, at the end of the summer term, had won the 1500 metres title for his *house*... was disappearing before their eyes.

The best thing we did to rectify the situation was to ask the CAMHS team to visit school to talk to a select group of Ben's friends (approx 20 girls and boys) which took place in November 2010.

The talk was along the lines of the info you'll find on C&M's little video. Ben's friends embraced this session enthusiastically and asked the CAMHS team dozens of thoughtful questions afterwards.

Before the visit, even though Ben had been back in school for a couple of months, Ben's friends still tended to keep their distance, worried of saying or doing the wrong thing. Ben, too, didn't know what he should say to them and kept himself at arm's length. Since the visit, Ben's relationships with his friends have gone from strength to strength, especially with the girls who seem to find it easier to talk about things on a deeper level.

### **Saturday, 26 February 2011**

#### **We seem to have reached a (temporary?) plateau...**

After four months of forging forward, Ben has reached a plateau and seems to be going neither forwards nor (thankfully) backwards in his fight to recover from anorexia. He is still gradually putting on weight but he's reached the stage where he thinks his current weight is okay and he can't see any reason why he needs to put on any more. This, despite the psychiatrist telling him yesterday that he has another 5kg to go before he reaches the minimum healthy weight for his height. His mood has dipped, too. So we're trialling an increased dose of the *Prozac* to see if (a) that lightens his mood a bit, (b) gives him the "leg up" he needs to move onto the next stage and (c) sleep better.

The problem at the moment is that he's lost his motivation. After *months* of being chained to anorexia, it's taken so much effort to get where he is that, when he looks

ahead and sees how far he *still* has to go, I think it seems an impossible task.

We reminded him how far he has come. This week it's been evident in the kind of food he's been happily eating; stuff which would have freaked him out only 10 months or so ago. Back then he would buzz around the kitchen closely watching what went into a meal and freaking out if any fear foods reared their ugly heads. Thankfully he no longer does this and I have added "fear foods" to the cooking right in front of his eyes. Up until only a few months ago, I couldn't have done that.

This week we've had cheese (two nights running!), fatty sausages, tuna in oil, chocolate, pretzels, a *Starbucks* muffin and biscotti, *Battenberg* cake, *Golden Grahams* and a few other things he wouldn't have touched with a bargepole in the "bad old days". But we're back to counting calories. I think it was too soon for him to try without and he found he was still adding them up in his head, so he figured that he might as well write them down on paper. And this way I can be sure he's getting enough. Today, though, he's at his friend's house and has had lunch there which I hope went well... Meanwhile I think it's time to put a post on the ATDT forum to see if anyone has any bright ideas on how to move him on from this plateau...

**Sunday, 27 February 2011**

**To book a holiday or not to book a holiday...**

After last year I'm in two minds as to whether or not we should book a holiday. So far we haven't booked anything and I'm tempted to leave it until nearer the time to see what happens... Before, we always used to book well in advance to be sure of getting the pick of (reasonably cheap but luxurious) French villas in nice locations, so last year we'd booked well before we noticed that anorexia had muscled its way into our lives.

I think it was about this time last year that I emailed the villa owners to say we might need to cancel and, if so, would they be able to find replacement guests... But, by Easter, I had to make a definite decision which was really difficult as my instinct

said it might be a disaster, yet I *so wanted to go on holiday!!!!*

At the time I really thought that by telling Ben he'd need to get a move on with recovery or we wouldn't go to France, he'd somehow swing into action and head towards recovery at a rate of knots. But now, older and wiser, I know that could never have happened.

Going on holiday to France was really weird. To all intents and purposes we were a normal family going on a fantastic holiday. Before the anorexia, as a treat, I'd booked us into a first-class *Commodore Cabin* on the ferry and booked a night at a swish hotel on the way back plus another in Southampton. Also, the weather was lovely and we'd always had such fabulous holidays as a family.

But right from the start, things went wrong. On the drive to Portsmouth we stopped off for lunch at a dear little olde worlde pub with a fantastic menu. It took Ben *ages* to order by which time we were predictably tense. When the food arrived, he immediately insisted on swapping his and his dad's meal, as his fishcakes had obviously been deep fried and he couldn't handle it. So the tension mounted almost before we'd left home and his behaviour was predictably strange, should any nosy fellow diners cast a look our way...

This was followed by the familiar "pick up / put down / pick up again / put down again" routine at *Tesco's* in Portsmouth as we attempted to buy a snack meal to eat on the ferry. The predictable mega low calorie option was eventually chosen... And, once on the ferry, Ben's mood deteriorated. We sat as miserable as sin in our luxury cabin and, later, in the bar (Ben ended up skulking off to bed early, refusing to have a drink with us at the bar).

By the time we arrived at our lovely villa with pool, sun shining, weather wonderfully warm and villa owners friendly and inviting, Ben was in a foul mood. Even before we'd unpacked he'd descended into an "ED rage" and we had a hellish screaming match which I'm sure our hosts could hear... ED the anorexia demon at its worst... Ben ended up barricading himself in his bedroom, me in tears and his dad

sobbing on a garden seat outside, threatening to go home the next day... (Ha ha ha! How many times did we threaten to do that throughout the holiday...)

Then our hosts came round to formally welcome us - you could have cut the atmosphere with a knife!

So that was the start of our wonderful French holiday last summer... and, no, in general, things didn't improve as time went on and, yes, Ben did return having lost some weight...

**Low points:** on the beach when Ben's mood tended to drop to rock-bottom. In one direction was the sea - and I was seriously worried that he would get so depressed and helpless that he might "walk out to sea", not caring what happened; one day I had to swim like an Olympic swimmer to drag him back towards the shore as the anorexia "forced him" to do the crawl up and down... up and down... without caring how far out to sea he drifted. I was *terrified!!!* In the other direction were sand dunes with a forest behind leading to God knows where and once he paced off up there, not caring where he went, and didn't come back for *ages*... So beaches were *bad news*... What was weird was that, all around us, life was going on as normal yet we were in this hellish kind of "capsule" of high tension, mega low moods (by now Ben was descending into what was eventually diagnosed as clinical depression) and unpredictable behaviour. (Or, rather, predictable in that you could predict it would be *hellish*.)

**High points:** Er, er, er.... we did some nice cycle rides. But, of course, the demon loved cycle rides, especially up very steep hills... And some nice walks, which the demon liked, too, though not as much as the strenuous cycle rides and daily 100 lengths up and down the villa pool...

As a result, we haven't made a holiday booking for this year. It's our first year without a holiday and we used to love our family holidays so much...

**Monday, 28 February 2011**

## Looking back at my ATDT post from August 2010...

Horrible though it was to recall, it's amazing how far we've come since that summer holiday in France. For example that hellish tension - I remember being on red alert virtually *all* the time in those days, primed for whatever the demon would throw at me next. Anorexia behaviour is often referred to as "unpredictable behaviour", but it's actually highly predictable in that you can *predict* it will happen one way or the other, sometimes several times a day. My nerves were red raw and I'd wake up every morning dreading what that day would bring and long for Ben's dad to come home at weekends to take the strain off me a bit (in those days he worked away during the week, so I had to deal with everything alone).

In those days, I didn't always see eye to eye with the treatment team. I was concerned about them insisting that the vacation should be an opportunity for Ben to "take a holiday from the eating plan". The thinking was that it would enable us all to relax and we'd have a lovely happy family holiday, just like we used to - because that's what Ben (and all of us) so dearly wanted to have.

In practice it meant that Ben cut down on his food quite drastically. I'd been made to promise everyone that I wouldn't make comments or "nag" if I noticed anything like this, the thinking being that Ben could relax if I kept quiet. But it wrenched my heart to see Ben instantly going for all the "diet options" in the supermarket after we'd worked so hard to steer him away from them. And breakfast immediately transformed from a hefty two-course affair into a quick couple of slices of toast.

He'd have the minimum for lunch, too, and at teatime I had to be characteristically careful with what I cooked (we were self-catering which, in a way, was better than a hotel). In those days meal times were particularly tense as you never knew how Ben would react to a meal. Sometimes he'd violently "down tools", walk out, cry out like an animal in pain and bang his fists and head against the wall. At least he never got to the stage where he threw our furniture around like some anorexia sufferers do, but he did break or damage quite a few things, thankfully nothing in the holiday villa...

Of course Ben didn't eat between meals in France or have any ice creams and so on. So I didn't either. I couldn't sit there enjoying an ice cream knowing that the anorexia wasn't permitting him to do likewise.

I guess that being on red alert didn't make things easy for anyone, least of all Ben. If you're in this situation now, you'll know exactly what I mean. In an ideal world, you'd be Janet Treasure's "dolphin" (relaxed, calm and encouraging) [see back of book for resources] but in practice it's more like an explosive volcano about to erupt.

Naturally we avoided all restaurants, except when we couldn't help it, like when we were staying in a hotel on the way back home. In a pub near Southampton we deliberately chose to sit upstairs in an empty room to avoid spoiling the evening for other diners should the demon decide to kick off. Ben took almost an hour to decide what to eat, debating what he could ask to be removed from the dish. Usually it was asking for something without cheese, without a sauce or whatever.

But, hang on a mo... this post is supposed to be looking at how far we've come since then...

Rewind to a couple of weeks ago to when we were sitting in a country pub with Ben merrily tucking into a large plate of battered fish, chips and mushy peas. Or my birthday when Ben and I went to *Pizza Express* and he had a normal pizza (not the low calorie option!), a glass of wine and a dessert! And this, after having a slap up lunch care of *Marks & Spencer* food department.

In the back of my mind there is still a slight bit of tension when eating out. Will something happen and we'll have a repeat of that other time in the same pub when he asked for a stir-fry and when he got it, refused to eat it, ending up in noisy tears with half the pub staring at us no doubt wondering why a 16 year old boy was behaving like the "terrible twos" and the waitress coming over, time and time again, to ask what was wrong...

Back then I'd say I was on one hundred per cent red alert virtually all the time. These days, it's about two per cent and really it just translates itself as me being

quietly vigilant to make sure things are moving along smoothly.

Yesterday Ben had cheesy nachos for lunch. Imagine that back in the “bad old days” of last summer!

MARCH 2011

**Tuesday, 1 March 2011**

### **A nice walk in the woods**

Ah, sunshine, warmth and spring flowers at last - which was a great excuse for a walk in the woods this afternoon to gather some dead wood for the fire (if you remember, Ben is still doing mornings only at school, although he didn't make it in today due to another night's insomnia...) And, also as you may remember, these days walks are great opportunities for nice, positive heart-to-heart chats as Ben opens up about his anorexia. Back in the “bad old days” we'd do umpteen walks, especially when he was off school last spring / summer, and I'd be so frustrated at the lack of progress - or promises to improve this, that and the other which I knew the anorexia wouldn't let him keep.

Autumn would turn into winter... it would snow, then spring would come followed by summer and the negative slide downhill would continue. It was incredibly disheartening and worrying; I just didn't seem to be able to get through to him. This spring feels altogether different and I know this summer will, too. Like the description of the beach on holiday in France, last summer had a surreal feel to it. To all intents and purposes, life was going on as normal all around us and we should have been full of the joys of spring with gorgeous weather and beautiful countryside. But, really, it might as well have been darkest, deepest winter for how we all felt inside...

I love it when Ben talks about his anorexia in the past tense and looks forward to an anorexia-free future. We've also been talking about possible last-minute bookings for a holiday this summer, probably somewhere in England. Both of us know that he'll probably be absolutely fine this time round. Well, ninety per cent fine; we may still have a few glitches such as getting sufficient food into him when he's in a different environment to the home environment he's used to. Or not. Who knows. What I do know is that things have changed and the warmer, brighter, happier days are on the way.

"And look at my body!" he exclaimed this lunchtime, pulling up his tee-shirt to show me a torso while, still thin, wasn't so stick-thin you could see his ribs which used to be the case. And his hip bones don't stick out like they used to do. Plus, his face looks more fleshy and he lost the dark rings-around-the-eyes waif look ages ago, I'm thankful to say.

"I'm so proud of you!" I said and gave him a great big hug as he reached for the *Flora* margarine to spread on his fruit tea loaf. (For ages, any butter-type spread was a fear food, but no longer.)

He's also talking about trialling full days at school (sorry, but I couldn't help mentioning school dinners which has always been my main concern...) He doesn't like to talk about that because the anorexic thoughts still stress him out in the way they make him feel he has to plan things meticulously and he'd rather not think about it right now.

**Saturday, 5 March 2011**

**And I thought it would only take six months or so – max...**

Funny how at the start you look at the anorexia as if it was a physical illness in that you can ask the doctor how long it will take to cure and they tell you "Six months max" or whatever. I even found stuff on the internet which reckoned teenagers have undergone a full recovery, from diagnosis to discharge from treatment, in just

months. Then it gradually dawns on you that, sorry, but you're in for the long haul and no-one can tell you how long it will last...

I'd love to sit here and write that recovery is a quick, straightforward process because I know that's what I longed to hear at the start. Unfortunately it isn't. And the deeper you get into this, the more you realise that anorexia will be part of your family life for some time, possibly years, to come.

Even after official "full recovery", they say it can take up to a year for the brain to fully heal. Also, our CAMHS treatment team have said they will continue to monitor Ben for 12 months after he is officially "discharged". And I know that relapses can be common especially in new stressful circumstances like going away to university.

It's not nice and it isn't what I would have chosen for Ben's teenage years. But that's the way it is and the way it will be for some time to come - and I've kind of got used to it by now, in a bizarre way.

**Saturday, 5 March 2011**

### **Anorexia is no fun... literally...**

Back in the pre-anorexia days, Ben loved nothing better than to go out with his friends and have a giggle. Yes, he was serious at times but on the whole, he was funny and enjoyed life.

Then along came the anorexia and gradually seeped all the heart, life and soul out of him. It sucked him dry of all his humour, enjoyment and good emotions - and at the worst point it was if he had no emotions at all. He'd just stand there like a zombie, staring into space, completely unable to *feel* anything. He was totally numb.

And he wouldn't respond if you tried to hug him or tell him you loved him. He'd watch TV comedy shows without moving a face muscle and would be as miserable as sin whenever we were out anywhere. It was horrible...

When he went out with his friends, he simply went through the motions. He pretended to have fun, but inside he was completely dead. Christmas was heart-

breaking because he felt completely numb emotionally. When he found he'd got excellent GCSE results in the summer, it meant absolutely nothing to him. Ditto holidays, lovely weather, nice walks, presents, etc.

Yes I know that, since September, he's been on *Prozac* (albeit a low dose), but over the past six months it's as if he's gradually thawed out. It really is like a freezing cold, icy, snow-covered wilderness that has thawed out. The warmth has started to return and the flowers are in bloom. A bit like *The Lion, the Witch and the Wardrobe* when all the snow disappears.

Gradually as Ben recovers, it's as if new life is being breathed into him and he can laugh again. I hear him singing at the top of his voice in the shower or in the kitchen and I know all is well with the world. Okay, he isn't fully recovered; he has a long way to go and *does* get down in the dumps every so often, sometimes very much so. But it's not like before when he was totally empty of any joy or fun, like an empty shell.

And these days he can go out with his friends without his mind being one hundred per cent on food. He still finds it hard to eat with his friends, but these days he manages it. Like last Saturday when he was at E's house and tucked into a huge pizza. No longer does he return miserably saying things like: "All I thought about was food..." or feeling guilty because he ate something he "shouldn't" have eaten.

I'd say to him: "When you're old and grey and look back on your life, what will be the most valuable memory? The fact you sacrificed a day's fun with your friends to worry about how much exercise you should do to work off the pizza you'd shared - or the fact that you had a fun day with friends, watching movies, playing games and having a laugh - and you all shared a pizza together which was great fun?"

**Saturday, 5 March 2011**

### **Identifying all the stuff that fuels the insomnia and breaking free**

It's been a difficult week which is why I haven't been blogging much. The main issue this week (apart from the usual insomnia) has been to make a list of all the other things that the anorexia still controls with a view to working on them one by one to move Ben up to the next stage of recovery (and hopefully help to address the insomnia in the process). Many of these are things that keep him awake at night - worrying about stuff, planning stuff, etc. Basically, the psychiatrist asked him to picture his life as it will be without the anorexia and list all those things that won't feature in it, which are currently driven or controlled by the anorexia.

Many of them belong to the same category as compulsive exercise (although he is managing this reasonably successfully). The main issue with that is that he finds it very hard if not impossible to "do nothing" as he puts it - and, still, if he treats himself to extra food, he feels he needs to do activity to compensate for it. "Doing nothing" isn't necessarily what you or I might perceive as "doing nothing". Spending the entire afternoon walking up and down a shopping mall would be classed as "doing nothing" whereas you or I would see it as quite tiring exercise! "Doing nothing" is being at school all day which is the main reason (apart from lack of sleep) why Ben still does mornings only. We hope that as we start to address all these extra anorexia "nasties" it may help his sleeping by reducing the anxiety.

This week Ben's weight remained the same although he was convinced he'd "put on loads" of weight. It's yet more proof that his perceptions are not always accurate and hopefully this coming week, he will feel able to eat more.

The good points this week were a huge impromptu frozen yoghurt snack at the shopping mall the other afternoon (no way would he have done something like that in the past). He also made some scones (and ate them, too). Plus we've had "challenge foods" in evening meals, for example lamb mince.

But, all in all, he still feels as if he's on a kind of plateau. Yes, his life is jam-packed

full of improvements and we have come on a heck of a long way in the past six months and more, but he is very aware that many of the so-called positive things are still very much controlled by the anorexia, “control” being the watch-word...

Basically he wants to do these things, but free from the rules and regs imposed by the anorexia. Rather than having to plan stuff in advance (which he often finds himself doing in the early hours of the morning), he longs to be more impulsive and not to feel guilty or that he needs to “earn” the right to do / eat something.

**Tuesday, 8 March 2011**

**It's Pancake Day - get out the frying pan!**

And Ben has made a stack of amazing pancakes with various combos: lemon and sugar, *Nutella*, yoghurt and fresh fruit, and maple syrup - all fried up in oil. I ate one and he ate the rest, followed by a large iced coffee. Then, last weekend, he made a batch of enormous and very delicious fruit scones which we all had with jam and butter. Today he was the first to make claim to our new ice-cream maker to whip up some frozen fruit yoghurt.

Ben has always loved cooking and in the Bad Old Days of High Anorexia, he was an absolute whiz at de-calorising recipes to come up with some horrible, bland, fat-free concoctions. He wouldn't even add a tablespoon of oil to bread dough. These days, his cookery and baking is pretty close to normal, the only glitch being that he often uses low fat margarine instead of the full fat version. But you still won't catch him baking a chocolate fudge cake or anything like that. Or, if you did, he wouldn't have a slice.

One day he will...

I hope...

**Thursday, 10 March 2011**

### **Casualties of "Ed Rage"...**

Every morning I drive Ben to the bus stop to catch the bus to school. And this morning when he chucked his school bags into the back of the car, I reminded him to put them in the car boot instead. Why? Because driving Ben to the bus stop in the Bad Old Days of High Anorexia used to be an altogether different experience...

12 months ago Ben dreaded going to school. He dreaded everything to do with school including being amongst his peers. Virtually every morning was a battle to get him to the bus. And virtually every morning he'd explode into a massive ED Rage which meant verbal abuse en route to the bus stop, usually lots of tears and finally the violent slamming of the rear passenger door as the incredibly distressed 16 year old skulked off down the hill to the bus stop. My car door has never recovered...

Getting teenagers ready for school is a nightmare at the best of times. But getting an anorexia teenager ready for school is a million times worse. Every single morning was a battle. Not your usual teenage battle, but something altogether worse and much, much darker. Even before we left the house we'd have screaming matches and I'd invariably drive back home in tears, unable to cope with the morning ahead - and definitely unable to work.

Within an hour or so I'd get the first text. Sometimes it would be on my mobile; other times it would be one of those sinister robotic voices you get when voice texts come through on the land line. I used to dread the phone ringing and the voice robotically saying: "You have received a voice text from 077XXX XXXXXX. Voice text received on the Blah, Blah date..." by which time my levels of dread were rising rapidly... followed by the robotic text along the lines of "I can't go on like this" or similar...

Here's what happened on Monday 8th March 2010 (almost one year ago to the day!!!):

The following is from my journal...

*Crisis day - last day at school and the day I crashed the dinner plates on the kitchen floor, the tension was so much after getting 22 distressing texts and 2 phone calls from Ben at school, being faced with the pack lunch I'd given him (we'd given up on school dinners after he'd walked out of the dining hall, unable to make the choice of what to eat) - followed by the prospect of a burger for the evening meal (too many carbs!!)*

*I also discovered that although Ben had told me that he'd PUT ON WEIGHT at the last CAMHS weigh-in, he'd actually put on NO weight...*

***Ben text:*** *I can't eat the bagel and have a burger tonight.*

***My reply:*** *Eat it. CAMHS told me today you put on no weight last week.*

***Ben text:*** *I can't do it!*

***My reply:*** *Eat it.*

***Ben text:*** *No! There's way too much and the chicken's really fatty.*

***My reply:*** *Then I'll call dad!*

***Ben text:*** *It's too much!*

***My reply:*** *It's what you asked for. Eat it.*

***Ben text:*** *It's simple. If you want me to eat lunch don't give me something that*

*stresses me out!*

***My reply:*** *Eat it!*

***Ben text:*** *Too big and too late now!*

***My reply:*** *(No reply)*

***Ben text:*** *I can't stand this!!!*

***My reply:*** *Go to medical. Ask if I can get you. [Medical was an agreed bolt hole for Ben to escape to, although he often texted me from the boys' toilets rather than brave the Medical Centre.]*

***Ben text:*** *I'm in medical.*

***My reply:*** *Ask if I can get you.*

***Ben text:*** *What am I gonna do? I've had my Quorn things and pud yet I haven't had quite enough yet it's too late to have anything and yet I'm having a big tea tonight so really I have had enough.*

***My reply:*** *Eat bagel. You said you'd put on weight on Friday and you hadn't.*

***Ben text:*** *Bagel's too much and like I said it's too late.*

***My reply:*** *(No reply)*

**Ben text:** *And I've had the Quorn and pud.*

**My reply:** *(No reply)*

**Ben text:** *I hate this feeling!!!*

**My reply:** *Talk to the medical staff. See if I can come and get you.*

**Ben text:** *What's happening then?*

**My reply:** *Talk to the medical staff.*

**Ben text:** *Have*

**My reply:** *Did she say you could go home? Need her ok for you to go home. And I don't want you to go to yoga [after school] if you stay. Get bus if she says no.*

**Ben text:** *Nothing's been said. And that friggin' bagel's ruined my day more than it was already.*

**My reply:** *(No reply)*

**Ben text:** *F\*\*\* it! I can't stand this! Too confusing! Have I had enough? Have I done enough? Should I go home? Am I doing enough for it? Is tea too big? Was my lunch too big? Why am I doing nothing? Is it too late to eat? Was what I had for lunch actually the right amount? Should I eat more? Why do people distance me? Will I ever be normal?*

**My reply:** *(No reply - stress gets too much and I deliberately smash a dinner plate on the kitchen floor and end up in floods of tears.)*

**Ben text:** *If you're not coming, I'm going to yoga.*

**My reply:** *OK, but only if you promise to be nice to me.*

**Ben text:** *[towards the end of school day] To be honest I don't know or care what's right or wrong any more.*

**My reply:** *I'm coming now. Be in car park at 4.15.*

**Ben text:** *No!!!*

Plus two phone calls along similar lines. This was followed by an evening of ultra-distress as he fell apart when faced with the ciabatta he was supposed to have with his burger. Eventually he calmed down and I decided to take him out of school for the time being.

How things have changed since then!!!! He's like a different boy!

Well, he *is* a different boy.

The car door is never slammed - and (touch wood!) the only texts and phone calls I get are really nice ones!

**Sunday, 13 March 2011**

**Watershed weekend... phew...**

It's been one of those watershed type weekends where you all end up being forcibly moved onto the next level of recovery. Having been in *Limboland* for a few weeks, I knew we needed to get over the next hurdle but, like many things with anorexia, it

doesn't always happen when or how you planned it. To cut a long story short, we're making changes this week with a view to addressing those nasty niggly problems that are still well and truly embedded in the eating disorder. Basically, if we don't, then they will stay and Ben will stay in *Limboland* for as long as we put off working on them...

Another thing that has left us in *Limboland* for a while is that I'm not totally convinced our CAMHS team know what to do next. We've spent the last four or five sessions not really achieving anything and with no clear focus. So it's time to make a private appointment with our psychiatrist to ascertain where we are, where we go from here and what we need to do to get there - without compromise.

By "without compromise" I mean far less of this "We'll only do it if Ben finds it helpful" approach which, in retrospect, sometimes has the effect of doing what the eating disorder "finds helpful" i.e. staying put and keeping a firm hold on the OCD-like problems that are still controlling Ben's behaviour and preventing him from moving on.

One of these is the obsession with being weighed every week. Yes, his parents and the professionals need to keep a firm eye on his weight at this stage while he is still teetering on the brink of a "healthy weight range", but we believe it's only feeding the eating disorder by letting Ben know what this weight is – and by weighing him so frequently. So we would like to try drip-feeding the concept of "blind" weighing. But Ben recoiled at the idea when it was explored in our session on Friday. And, because it wasn't thought "to be helpful to Ben" to take the decision out of his hands and say, tough, we're going to blind-weigh you anyway, CAMHS have decided to put it on hold.

However we are still going ahead with fortnightly weighing. To put his mind at rest, Ben will have the "safety net" of knowing that we have promised him that we won't let his weekly average weight gain spiral over and above the recommended 0.5kg weekly maximum (and of course we will monitor it the other way, too, for our own

peace of mind). So far, having talked this calmly and sensibly through with Ben this morning, he seems quite open to this idea. I believe he can see how the obsession with numbers is fuelling the obsessive side of the eating disorder. Also, if his weight goes *up*, it's tended to mean that the CAMHS session is completely wasted as all we do is try to allay his fears that his weight is about to spiral out of control.

An example is Friday. When you look at it over the long-term i.e. the past four weeks, Ben has actually only gained 0.6kg *over the entire period* which is well, well below the recommended 0.5kg per week. Ben gained 0.5kg on Friday and immediately hell broke loose as, last week, he'd been eating more *and* exercising more (another sticking point), yet had gained 0.5kg. So the eating disorder was screaming at him that this "proved" that he needed to eat far less (and exercise more). The entire CAMHS session was spent trying to get into his head the fact that the body doesn't work like this and you need to look at it over the long term, etc etc. But by then Ben was in a bit of a state - and the meeting simply went pear-shaped.

So blind-weighing will enable the precious CAMHS sessions to be put to more profitable use. It will also mean Ben gets to see what his weight is over the long term, not the short term. And it will hopefully mean he gradually loses the obsession with figures.

My dear ATDT friends say that when they introduced blind-weighing at this (what I call third) stage of recovery, positive things started to happen very quickly afterwards.

So that's the plan.

This is just one of the *many* things that have come out of this brain-pulverising weekend and I will talk more during the week.

Phew!

**Tuesday, 15 March 2011**

**One step at a time...**

My very good friend W on the ATDT forum has advised (re. escaping from *Limboland*) that when she “broke this process down into manageable steps, it was less exhausting and anxiety provoking”. She recommends “One step at a time - don’t worry about the future... Stick to the task that needs to be tackled now” and “When that’s solid, move on to the next step”.

Excellent advice, W, because it’s so easy to see *everything* that needs tackling at this next stage of recovery as massively daunting. A bit like when you realise the whole house is a total tip (like mine is) and you don’t know which room to begin with - and, even then, cleaning the individual rooms is daunting because there’s so much to do!!! So this week I am focusing on (what has ended up as being) three things:

1. Phasing in blind-weighting (mentioned above).
2. Keeping an eye on the compulsive exercise.
3. The school plan (mentioned in the next entry).

On Friday the nurse mentioned that some people choose to stay at a low BMI (to which I couldn’t help thinking: “Rewrite: ‘Some people choose to stay sick, so we let them’.”) Of course this led Ben to believe that his current BMI is absolutely fine and there isn’t much work to do. He feels that his body is okay now; it’s just his mind that needs working on...

**Tuesday, 15 March 2011**

**Some very difficult juggling to do this week...**

So, as you’ll have gathered, I am keen for us to move onto the next stage of recovery from the anorexia. This, in itself, is going to take some careful juggling while still being supportive / loving / helpful while introducing a bit of a “tough love” / no

compromise element. If I don't, then he risks staying in a comfort zone rut. It's far easier for the eating disorder to keep him away from school and friends at comfortable "safe" home. It's also far easier for the eating disorder to continue to be very selfish, looking inside instead of outside. So I am carefully nudging him out of both of these comfort zones...

Since the autumn, Ben has been going to school in the mornings only. Two or three mornings he doesn't make it at all due to the insomnia problem, yet increasingly he is "recovering" by mid-morning and definitely by the afternoon. School is much easier for him these days (note, I didn't say *easy*, I just said *easier*...)

I have agreed with Ben and school that he will go in *every* day if possible. By this I mean mornings only for the time being, but on days when he doesn't sleep, I'll take him in later for half the morning - or the afternoon. What's more, I'll take him in *before* lessons i.e. at break time to allow him to socialise. From this we will build up to some trial full days.

I have also agreed with school that Ben's friends will be a little more vigilant in keeping him with them at break times and in free periods to avoid the temptation to "go for a walk round the grounds" (read "go for a run / exercise") like he did yesterday.

In a normal world, this plan would be reasonably simple to put into action, but in the world of the eating disorder, it's jam-packed with hurdles and potholes...

First, there's the insomnia which still needs addressing...

Then there's Ben's mood which has been below par for a few weeks as a result of knowing he's in a rut and feeling unable to move on...

Then there's the Big Issue of compulsive exercise which is still well and truly a problem. It is the primary reason why Ben can't do full days at school - because he sees school as "sitting around doing nothing" and still can't handle this. He feels compelled to move around and simply can't sit still and concentrate for long.

And there's the other Big Issue of the 24/7 thoughts buzzing round his head all the

time - thoughts about food. He can't stop thinking about food.

Plus, advising him on how to handle peers who talk about food all the time. (If he was a girl, it would probably be about how to handle peers who talk about dieting all the time or whatever...) He finds this particularly difficult.

So the juggling is not as straightforward as it might seem and is a massive challenge for all of us.

But, like last time round when I instinctively knew we had to move on and out of a rut (at the end of last summer), I have to find a way to do it. Basically, we don't have a choice. It's "do" or stay ill. (Last summer it was more of a case of "do or die"... or at least it felt like that, with Ben's threats of suicide...)

Oh, and my husband has just found out that the temporary job he got when he was made redundant from his main job a few weeks ago is finishing at the end of the week.

So he really will be out of work.

Which means my juggling has just got a little bit more complicated...  
Aaaaaaggggghhhh!

**Wednesday, 16 March 2011**

**Meltdown in Manchester...**

So I picked up the phone and it was the Deputy Head from school saying Ben had gone AWOL in central Manchester while on the school trip today... For an hour, staff searched the area trying to find him to no avail. Eventually, one hour later, Ben answered his phone, saying he was making his way back to base. Deputy Head phoned me to say he'd met up with the teacher and continued on the school trip.

Ben innocently says he "went shopping" and raved on about how amazing Manchester's *Arndale Centre* is; bought himself a shirt from *NEXT* and had a coffee in a studenty café. Meanwhile staff were tearing their hair out, calling school 60 miles away, Deputy Head calling me, Ben not answering his phone, etc etc... for one hour...

Personally I think it was ED, the Eating Disorder, that did it. Faced with the prospect of “sitting around all day doing nothing in history lectures”, he couldn’t handle it. So when everyone else went to *Café Nero* to kill time when they got to Manchester early, he went AWOL for an hour. But, so far, Ben’s not talking about it...

**Sunday, 20 March 2011**

**Big Plans are underway...**

So I went into CAMHS on Friday where we were seeing the nurse (psych is on holiday for two weeks), armed with a load of paperwork and a Plan for the next few months.

I went through it, point by point, and on the whole the nurse thought it was all a good idea. Also it follows on from their suggestion last week to start blind-weighing or weighing less frequently.

I asked the nurse to look back over the past six months and especially over the last two months to see what the weight gain pattern has been. Unfortunately it showed a weight maintenance more than anything else, so I said that, although we have experienced massive improvements on many fronts (which we indeed have!!!), the weight gain plan is clearly not working.

I also insisted we examine *exactly* what a boy of his age and height should be weighing - min / mid / max, mentioning the WHO (*World Health Organisation*) BMI guidelines. The nurse had a chart on her which showed that he should be weighing 64-68kg minimum (BMI 20-25-ish), but is currently around 54.5kg / 18.4BMI and has hovered around this level since September. I said this isn’t okay for a 17 year old boy and former rugby player.

I insisted we move to fortnightly / blind-weighing from now onwards. This way all of us gets a wider picture of what is going on, preferably starting to analyse weight gain over a month - and aim at an average of 0.5kg a week, as per the NICE guidelines. If we are not achieving this very shortly, then adjustments will be made to food intake.

Anyway, the Good News is that Ben agreed to all these changes.

The only idea he refuses point blank to entertain is the concept of being over 59kg. At this stage there is no point arguing the case because of the ED thinking, so I've just left it for the time being, hoping that weight gain will reduce the ED effect on the logic / brain and he will naturally come round to the idea. So I've left this on a back-burner for the time being...

Re. exercise... this is being rigidly monitored and reduced. Obviously if you're going to do things like nice walks in the countryside / park, etc then you can't stop all exercise; it's impossible. Ben has agreed to this, too, and I am monitoring this very carefully to make sure he does.

Hopefully the above will achieve some progress, get us out of *Limboland* and also enable the CAMHS sessions to be put to better use because the team won't spend most of the session allaying his fears about the "huge amount of weight" he's just gained.

Now I need to wait for the psych to get back from her hols and have a private meeting with her to reinforce this and set up a Plan for the next few months.

**Sunday, 20 March 2011**

### **Trying out a Recovery Contract...**

I've just been incredibly inspired by a thread on the ATDT forum about *Recovery Contracts*. Why has no-one in our treatment team suggested something like this, I wonder? They sound like a really workable idea at this stage in Ben's recovery! It is so *important* that, having been in *Limboland* for a few weeks, we move forwards in a purposeful way.

I already laid the cards on the table, so to speak, at CAMHS on Friday re. my Plan for the next few months. As a way of implementing my Plan, setting up a Contract seems like a great idea - and Ben thinks so, too. (Thus far...)

Basically the idea is that, at various stages of recovery, you draw up a written

“contract” which you stick to until the time comes to review / revise it.

Certain parameters and goals are set out which need to be achieved within agreed time frames. When the eating disorder sufferer sticks to elements of the contract they earn “rewards” e.g. in the form of “points” which add up to a worthwhile reward (not food and preferably not cash).

As the thread suggests, it could be a sleepover at a friend’s house, a trip out or whatever it is that “floats your teenager’s boat”. When they don’t stick to the Contract, you agree a list of consequences (removal of *iPod*, no sleepover or whatever it is that your child would hate to be without!)

Obviously the aim is to drive forward with continuous momentum towards an end goal and prevent what I call “pussyfooting around” with an unclear, vague or non-existent plan. Having it all typed out on paper, too, is so much better than verbal agreements which can be quickly forgotten (or denied!).

Also, particularly in our situation, a written Contract is a good talking point so I can regularly review progress with Ben. We do this anyway, but having the Contract will be a useful reference tool.

My ultimate aim is to get Ben to consistently increase his weight, within the recommended guidelines, and avoid relapses or slips. Also, to curb any compulsive exercise.

Looking back over the past six months, we have had *enormous* improvements in virtually every aspect of the recovery process *except* weight gain (and the exercise issue).

I *refuse* to do the same for another six months - the time has come for Ben to put on some serious weight. Slowly but most definitely surely otherwise I will take a tougher stance...

I have yet to draw up our own Contract, but obviously the idea is that you personalise it to your situation and where you are on the recovery ladder. Watch this space...

**Monday, 21 March 2011**

### **One Weight Gain Contract drawn up!**

Okay, so it may or may not work, but I have high hopes for it at this stage in the recovery process.

Today I drew up a Contract aimed at steady Weight Gain over the next few months with a view to hopefully getting Ben ready to go to University in September 2012 (that's another topic altogether...)

Most importantly, it's about turning round the stagnation we've been experiencing since the summer on the weight gain front (constantly swinging up and down so in reality he's virtually maintained, despite huge improvements on most other fronts) - so he gains some serious weight.

#### **Aim**

1. To keep the momentum going and avoid going round in circles
2. To see sustained weight gain and marked improvement
3. To ideally get Weight Restored by 31st August (23rd December latest)
4. To maintain weight once WR
5. To eliminate calorie counting and all "numbers" by Christmas
6. To maintain weight at WR for six months from Christmas to qualify for 2012 Uni entry (subject to being sufficiently ready for University by August 2012)
7. To agree to a *University Transition Contract* (similar to the one on the FEAST website) prior to leaving for Uni to hopefully avoid relapses
8. I've drawn up a draft Contract and been through it with Ben, making it clear that this is a two-way thing. It covers Eating, Exercise, School and Weight Gain with points that can be earned for all the key things with penalties for dishonesty, failing to keep to key elements of the plan or doing too much exercise.

Before I go into more detail here, it's best if we trial it for a few weeks to see how it goes. Hopefully by having a definite aim and rewards rather than something vague with vague promises of "We'll buy you X when you're better," it will have a better chance of working.

But obviously what I want to avoid is for Ben to be able to claim rewards without achieving sustained weight gain. In other words, staying pretty much where we are. So whatever reward(s) the points buy mustn't be achievable without moving significantly forward. And hopefully with the weight gain will come additional improvements on other fronts - notably the exercising, school and social life. Also, the plan is to review the Contract whenever necessary.

**Thursday, 24 March 2011**

**Day four of the Contract...**

It's early days, but the Contract seems to be working. More importantly, Ben has taken it on board enthusiastically ("Points win prizes!" he says, thinking of the *X-Box* thing he'll "buy" with however many points I eventually decide it's worth...)

One thing that is working well is the exercise element of the Contract. As you know Ben's exercising was a bit out of control and what the Contract has done is sign, seal and deliver what is "allowed" and what isn't. Having it all down in writing means it's far easier for him to stick to the limits. And in case you're wondering, we're only permitting "healthy exercise" that's enjoyable to do. No aerobics, frantic gym sessions or anything like that.

"What about exercise at school?" I asked, referring to the way he's tended to dash between lessons as a way of cramming even more exercise into his day.

"Oh I dealt with that ages ago," he replied confidently. And he hasn't been doing sport or PE for months.

Everything on the Contract is "subject to revision" as time goes on. If we have problems with the exercise, then Ben knows it will stop - and exercise will become a

kind of “reward” in itself maybe.

But for the time being, everything seems to be working okay and Ben feels more confident. And I haven’t noticed any anxiety about the fact he won’t be getting weighed tomorrow. Remember at CAMHS last week we agreed to start fortnightly weighing sessions rather than weekly. I must admit I’m a bit nervous that he may have lost weight (whereas no doubt he thinks the reverse).

But at the end of the day he knows that weight gain is the only option.

Just as important as the X-Box “bribe”, he knows that if he doesn’t cooperate and make progress, then he won’t be going to University in September 2012. Basically, if he’s not ready for University then he won’t go. Well not for another year at any rate.

**Monday, 28 March 2011**

**University was never this tough...**

Since my last entry I’ve been “cramming” like mad, collating links to research, scientific papers and other stuff about the latest evidence-based eating disorder treatment. Yet again, the fellow moms at the ATDT forum have been awesome in helping me get information together.

To say that, over the last 19 months or so, the learning curve has been *massive* would be an understatement. These days I know so much about eating disorders that I could sit an exam in it. And many of the other “experienced” moms at ATDT could do a Doctorate in it with their eyes closed... I am constantly *in awe* at how much stuff they know.

I don’t know about you, but when I found myself press-ganged into this hellish journey I knew nothing. Zilch. Zero. Nothing. Eating disorders were something that happened to girls, not boys. Sure, I’d heard about girls with anorexia, but like many people I just assumed it was “dieting gone mad” and, if someone gave them a hard enough kick up the you-know-what, they’d eat. Or at least they darn well should. I’d heard of Karen Carpenter. And there was a skeletal girl at the gym who everyone

used to whisper about, saying “They shouldn’t let her into the gym” as she punished herself on the treadmill.

19 months on since we first became aware our son had anorexia, I am a different person. They say “be careful what you wish for” and I remember that spring / early summer of 2009, before the anorexia became apparent, I felt especially restless. I remember praying: “God, please find me a direction in life other than being just a mom, wife and freelance copywriter.”

Later that summer I got the answer to my prayers as the worst episode in our family life kicked off and anorexia took up residence in our home. Sure enough, I got my direction in life - and it was in the fast lane. Not only was I faced with a mad panic to try and get my son recovered from a condition I knew nothing about, I was faced with a *massive* learning curve - and the worst thing was the sheer amount of *conflicting* information, especially on the internet.

By November I had accidentally landed upon the FEAST website and its ATDT forum which has proved an invaluable source of information and support over the past 17 months or so - and it looks as if I’ll be with them for some time...

So if you’re new to this and faced with a horrendous and scary learning curve, please, please pay a visit to “my mums” at ATDT. Meanwhile, I’ll write soon about what it is I’ve been cramming up on over the last few days...

APRIL 2011

**Saturday, 2 April 2011**

**0.9kg weight gain**

Good news; we are on target (or just about) with a 0.9kg gain over the past fortnight - and it’s the first time we haven’t been weighed every week. (Funny how I keep

referring to it as “we” but that’s just the way it’s become...)

CAMHS thought Ben would get stressed and unable to cope with 14 days of not standing on the scales, but he was fine. Also, the Contract is still working splendidly and I am convinced that it is responsible for the progress we have made over the past two weeks. “Points win Prizes!” is Ben’s mantra...

Of course some might say it isn’t ideal to “bribe” someone into recovering. But, from experience, I believe that if he didn’t want to recover and was unable to stick to the recovery plan, then no amount of “bribing” would work. I know, I tried it right at the start when I thought getting Ben “back to normal” was as simple as dangling a large carrot in front of his face. It didn’t work. This time, so far, things are different. But it is still early days.

Likewise the strict “eating plan” we introduced at the start of the CAMHS treatment didn’t work for us. It might work for a younger teenager, but Ben is virtually an adult and has always been incredibly independent. So we are having to tailor the recovery to suit the way he is. This doesn’t mean compromising; it means carefully formulating plans in a way that Ben can embrace for long-term gains on all fronts.

This is markedly different from “waiting until Ben is ready to recover”. Instead, it involves working *with* Ben very slowly towards recovery, gently encouraging him and refusing to let him stand still or go backwards.

But of course, it’s never straightforward with an eating disorder and we must be prepared for rocky times ahead. No rose-coloured spectacles in the world of ED recovery!

**Saturday, 2 April 2011**

**Mothers’ Day looms...**

Last year I spent a large part of Mothers’ Day sitting alone in my car on top of the Moors “drowning my sorrows” in a box of Belgian chocolates which Ben had given

me earlier in the day, armed with a box of tissues to wipe my tears.

Although it isn't Mothers' Day until tomorrow, tonight we're all going to *Pizza Express* and I have no qualms whatsoever about it. Even five months ago on my birthday we managed *Pizza Express* without any stress - in stark contrast to a visit to the restaurant 11 months before when Ben had made a noisy and embarrassing scene, eventually storming out, threatening to throw himself in front of a car and physically fighting his dad and me on the way home. He almost pushed me to the ground with the violence.

This is why so many people describe it as an "anorexia demon" because it really is as if the sufferer is possessed...

I will be extremely surprised if this Mothers' Day and the *Pizza Express* meal don't go one hundred per cent smoothly. I am absolutely confident it will be completely without stress and that Ben will be able to choose from the menu in minutes rather than spend almost an hour chopping and changing his mind interspersed with visits to the gents' toilet to exercise... And he's planning to have one of the larger pizzas...

How far we have come since then...

Thousands and thousands of miles....

**Tuesday, 5 April 2011**

**Pizza... wine... olives... fudge ice cream pudding...**

I forgot to say that Mothers' Day went brilliantly - a zillion years away from what happened last year. Ben wrote me the sweetest poem; the kind that brings tears to your eyes, and hand-painted a lovely card.

The previous night's meal at *Pizza Express* was about as happy and relaxed as you can get - not a hint of the evil ED as Ben tucked into a huge seafood pizza plus a side of plump olives accompanied by a large glass of white wine and followed by an ice cream pud with fudge bits in it.

And then he came home and took a large bite out of some chocolate peanut brownies which he'd baked that afternoon. Result? Mama Matty grinning like a Cheshire cat all the way back home. A triumph!

**Friday, 8 April 2011**

**CAMHS day today...**

It's Friday which means it's CAMHS day, but no weigh-in as we're doing fortnightly weighing sessions now. The psych has been away for three weeks, so it will be interesting to see where we go from here...

The Contract is still going strong and Ben "spent" some of the points last weekend on some *Warhammer* models which he paints - so points really do "win prizes"! But do they get results?

I believe it's working. Since we started the Contract, Ben's made an effort to get into school more, even when he hasn't slept (and this week has been particularly bad on that level...) He is challenging himself more by eating extra calories, facing "fear" foods not just once, but again and again (e.g. chocolate). And he is still sticking to the exercise part of the Contract which is making his life a lot easier.

Now that he's broken up from school for the Easter holidays, I suggested we come up with something else that earns points to replace the points he gets for going into school (1 point for a part morning, 2 points for a full morning - which will rise to 3 points for a full day plus another point for successful school dinners, probably) - so he doesn't lose out now he's on a three week break.

I reminded him that this is a two-way thing. It's not me imposing my will on him; it's a joint effort where we both agree what goes into the Contract. He suggested points for revising for exams, but I reminded him that we're talking about things that aid his recovery from anorexia, so although revising is extremely commendable, we can't include it in the Contract. He was fine about that.

Ben studies A-level Psychology and, coincidentally, they've been looking at

Contracts as a means of aiding recovery from various mental illnesses - so that has reinforced our Contract in his mind as something that has been proven to work.

I wonder why our CAMHS team never suggested it? In fact the nurse had never heard of a Contract like this.

Yet another example of why I believe the USA is ahead of the UK in the successful treatment of and research into eating disorders...

**Saturday, 16 April 2011**

### **Our second fortnightly weigh-in...**

As you know, we've changed the weekly weigh-ins to fortnightly so Ben doesn't become so obsessed with numbers. Interestingly, the last two weeks have been a virtual carbon copy of the previous two weeks, food-wise. If anything, Ben has eaten many more challenge foods like cake, chocolate, ice cream, chocolate brownies, etc. Last time he put on 0.9kg but yesterday his weight was stable, with no change. So that equals 0.9kg across the whole month, around half the weight gain recommended by NICE, but never mind. As a result we've made some little adjustments to the Contract.

This weigh-in, of course, Ben didn't earn the monster points I award him for weight gain. But what we have done is adjusted the Contract so he gets an extra point if he goes over his daily calories by 100 and 2 if he goes over by 200.

Also, the result taught Ben quite a few lessons in that it's okay to eat all these challenge foods without ballooning out into a huge monster; in fact on some days he's eaten two challenge puddings one after the other.

He seems keen to try to "up" his calorie intake slightly to see what happens at the next weigh-in, which is now *three* weeks away, not two. And I shall be strongly but gently encouraging this by careful use of the Contract which has now been running for four successful weeks.

Must go to cook roasted Mediterranean vegetables in olive oil with feta cheese

served with large chicken breasts wrapped in pancetta, served with French bread and wine.

**Wednesday, 20 April 2011**

**Something is up...**

I get the impression he's resisting calories again after agreeing to increase them at CAHMS (because he'd maintained over the last fortnight we agreed he'd go *over* the required calories as many times as possible).

He went over calories on Saturday by 200 but hasn't done so on any other day since then, despite coaxing from me... And over the last 48 hours he's been very "tetchy".

Today he flew off the handle a couple of times and ended up in tears after shouting out a bit like he used to do... the kind of shouting that makes me jump out of my skin...

He seems to be avoiding his friends; he's thinking of cancelling the outing with them tomorrow; says he'd only "bore them"...

Something is up, and he won't talk about it.

I can always tell when he's not cooperating and something is wrong because he closes up... the blinds go down and we're not permitted in...

At times like this (thankfully few, these days) it takes me back to darker times one year ago.

It's half way through the school Easter holidays at the moment. He's avoiding his friends, yet he's getting stir crazy, trying to get us to go out and do things when, unfortunately, we have to work. Husband is still officially out of work, but is doing some freelancing which he has to do to get money. Me, I'm having to work, too, to keep the wolf from the door, hence the reason why I haven't written any of my blog this week...

Echoes of last summer holidays... I start to dread this summer because if he's like

this after one and a half weeks, what the heck is he going to be like after eight weeks of school holidays if he avoids his friends and doesn't take up all the other suggestions I'm always putting forward so he socialises with people his own age and doesn't get bored.

Most important of all... so he doesn't slip back into the hellish suicidal mood he was in for the whole of last summer...

Hopefully this is just a blip but at times like this when the "Evil ED" is speaking loudly in his ear it makes me feel so uneasy and worried we're undoing much of the good we've done.

But it's hopefully just a blip...

**Friday, 22 April 2011**

**A blip, thankfully... fingers crossed...**

Thankfully it was only a "blip" the other day and Ben is now back to his usual, on-the-road-to-recovery self after deciding to talk about it in depth to me yesterday, which was good. And he managed to go over calories by an extra 200 yesterday. But I'd like to get him weighed when we go to CAMHS on Wednesday afternoon to see how things are panning out.

At the last CAMHS session he agreed to regularly go over calories but, in practice, has only gone over three times since last Friday which may mean his weight has maintained - in which case I will *insist* we formally increase the calories on the Contract. I'm not going to let CAMHS settle for "vague promises" from Ben which they are prone to do and which he finds hard to keep.

I think this is why we haven't come as far as I believe we should have come. For *months* we relied on Ben promising he'd do such-and-such, when in practice all the good intentions went straight out of the window the moment he left CAMHS resulting in 12 months where he weighed *less* at the end than he did at the *start*.

Okay, he'd come on emotionally, but modern eating disorder research shows that

weight gain must take a priority rather than being placed on a “back burner” until the patient “feels ready to eat more”. This kind of thinking went out with the Ark...

I’m not being negative; believe me there has been a *massive, enormous* improvement over the past 12 months, but I believe the focus should have been placed equally as strongly on weight gain - and it wasn’t, otherwise Ben’s weight would be far higher than it is, 13 months into CAMHS treatment.

This is why I’d rather CAMHS didn’t go down the “Ben will do it when he’s ready” route any longer...

MAY 2011

**Monday, 2 May 2011**

**Bit of a gap since last entry**

Bit of a busy week what with all the Easter bank holidays, then the *Royal Wedding* and bank holidays. During this time I’ve managed to injure my hip somehow.

Been busy with work, too, which isn’t easy when you have a short week due to bank hols and are in agony. Then, over the Easter weekend, husband’s granddad passed away so we’re all off to London next weekend for the funeral and meanwhile the family fights over what they should have at the funeral, etc. Me, I keep well out of it.

Thankfully, everything is still going fine with Ben’s recovery and he’s back at school after the Easter break. *And* I insisted on a permanent increase in daily calories at CAMHS on Wednesday when it was found that Ben had *lost weight* by almost the same amount he’d put on last month. Thus far he has kept to this increase. But there may be a spanner in the works when we go to London at the weekend...

Unfortunately my H’s family are totally disorganised when it comes to doing things

which includes mealtimes - a potential disaster area for someone with anorexia. H has taken Ben to visit his parents twice since the onset of the illness and both times it's been a total disaster. They rarely have standard mealtimes as such, eating as and when they eventually get around to it and often deciding to eat out instead or get a take-out which resulted in some particularly stressful occasions last summer. I strongly believe there is the potential for Ben to lose more weight over this coming weekend. At least I will be there this time, armed with my calculator to check he's as close to target as possible. Not easy, though, when there are no planned meals as such and I'm really not sure how to handle that...

... especially with all the emotions and potential fighting over the funeral... I wish Ben and I could stay at home; I was really praying he'd have some exams or something that would prevent us going, but unfortunately not...

The next CAMHS session is on Friday, but the next time they weigh Ben will be next Friday. I may blind-weigh Ben here before we go to London and on our return just to check there's been no damage caused over the weekend. Even though Ben continues to recover in his mind, he is still at an unhealthily low weight and cannot afford to lose any more. He cannot afford for his BMI to go under 18.

I need to come up with a "Plan B" for if it becomes obvious that Ben is not eating sufficient over this weekend (three days away from home) and I need to talk this through with him so we know exactly what we are doing. Last summer a "Plan B" of this nature wouldn't have worked as Ben would have actively resisted, but this time there is a chance it might work...

I've got a very busy week work-wise with the added stress of having to get ready to go to London and sort out "Plan B", etc not to mention the hip pain... woe... woe... woe...

**Tuesday, 3 May 2011**

**Okay, so “Plan B” (and now “C”) for the weekend is...**

I’ve been mulling over the problem of H’s family’s haphazard attitude to mealtimes coupled with the problem of not being at home with our usual eating regime this weekend and this is the Plan I propose to put forward to Ben:

That we take the breakfast and pudding ingredients with us (cereal, bread, jam, cake, biscuits, etc). This way we know approx how much he should be having for lunch and evening meal. If it’s lunchtime and no move is made by the family to eat, we will head to the supermarket and pick up a sandwich or similar. In the evening Ben will eat the equivalent of our usual evening meal (which will hopefully take place!!) (+ the porta-pud).

On the journey there we will stop off for lunch at a service station *M&S* so Ben gets his calories; ditto on the return journey.

Hopefully this should solve the problem of Ben reducing his intake over the weekend and losing weight.

And, in the event that he does lose weight, we have agreed that “remedial measures” will be taken in terms of adding calories to the Contract.

Sorted.

Providing Ben agrees...

**Post script:** He won’t play ball...

So Plan C (agreed with Ben) is to weigh him before we go and when we return. If he’s lost weight during this time then we will increase the calories in the run up to the CAMHS weigh-in session on the Friday.

Balls. That’s the trouble with this illness - what seems like a logical solution to a problem actually isn’t, in practice. Sometimes “thinking creatively” helps, but other times it doesn’t.

You might wonder why I don’t just put my foot down and enforce this. But I know from experience that this doesn’t work with Ben; it can actually have the reverse

effect - and ED angst is the last thing we want in a household charged with negative emotion this weekend.

Boy, people who claim to be “excellent problem solvers” on job application forms have nothing on the experience of a parent of an anorexic teenager. You become an expert at finding practical, workable solutions for the most complex and unsolvable problems only to find they don’t work in practice due to the illogical nature of eating disorder thinking... So you think again... And again...

Ben has promised to ensure he has sufficient to eat in any one day. As this is quite vague, I will be ultra-vigilant and meanwhile will try to think of other solutions. Suggestions welcome...

To “normal” people I might sound as if I’m making a massive mountain range out of a tiny molehill, but, from experience, I know how quickly an anorexic can lose weight, how potentially dangerous this can be and how many calories they need to have to prevent this from happening - and, believe me, it’s *a lot*.

**Friday, 6 May 2011**

### **CAMHS can of worms?**

Sometimes I wonder if our CAMHS visits are just opening up a can of worms that is better left on the shelf... What I mean is... Ben and I are a pretty close-knit team.

These days he’s happy to talk to me about pretty much anything to do with his eating disorder and anything else, basically because he knows I “get it”.

We’re also very similar people. I know the current issues as regards his recovery and everything is going reasonably well, despite the odd blip which is only normal in what is bound to be a bumpy ride to a certain extent. Basically, I believe I know pretty much what is going on inside his head these days...

At this stage we go along to our CAMHS meetings wondering what needs discussing. In fact I asked Ben if we’d be better off reducing the number of sessions to, say, fortnightly rather than weekly as I often feel I’m more helpful to Ben than

they are, especially since we started the Contract.

Then we get to CAMHS and they get out the can opener and out come the worms i.e. we start discussing something in-depth that I'm not at all sure is helpful. Yes it's stuff that's still there, there's quite a bit still there, but sometimes analysing stuff can be less helpful than dealing with it as you go along. Or talking about it when you feel like it, not when it's forced out of you.

In other words I sometimes feel that CAMHS delve deep into Ben's soul and bring up stuff just for the sake of it, rubbing salt into a wound that would be better left to heal itself in the fresh air.

I can always tell when this is happening because Ben starts to get flushed patches on his face and gets quite annoyed, with what can only be described as a "What the hell are we talking about *this* for?" expression on his face...

Difficult to explain what I mean, but as a mum you have a certain gut instinct about these things...

What definitely isn't helpful is when CAMHS start discussing target weight. It's usually fine when there's just the psychiatrist present, but for some reason her colleague (who sometimes sits in on our session) goes all over the place with regards to Ben's weight, throwing spanner after spanner into the works.

One week she's saying he's under the healthy weight for his age and height (which he is) and then the next she's implying he's okay as he is - and could, in effect, choose to stay that weight if he so desires... (Music to an anorexia sufferer's ears, hey...)

One moment she's calculating his BMI as under 18.3 and then, without his core weight actually having changed at all, stating he's over 21 BMI...

These mixed messages are *not okay*. They confuse Ben and they result in him looking "daggers" at me, accusing me of "forcing" him to "get fat" because I insist that he needs to put on more weight.

Looking at the *World Health Organisation* BMI chart-for-age for boys, Ben is way underweight. So I'm not picking out a weight from the ether...

Also the psychiatrist regularly agrees that Ben is *under* the healthy weight for his age, sex and height. Then her colleague chips in and spanners go flying into the works...

Result = the kind of triangulation undercurrents so loved by ED, the anorexia demon, who never misses anything like that. (Says she from bitter experience...)

As you and I know all too well, everyone involved (treatment team and parents) has to be on the *same page* when it comes to recovery otherwise ED zooms in and takes advantage of the discord...

The Good News was that at the end of the session they actually suggested that we reduce our sessions which is not a Bad Thing, hey... And I may suggest we only need to see the psychiatrist from now onwards...

**Friday, 6 May 2011**

**Crazy in-laws family here we come...**

So tomorrow we're off to London to my H's crazy family for the funeral - and a weekend of haphazard eating and goodness-only-knows-what-else awaits.

One thing is certain, it's not going to be a smooth ride as there's always some kind of Extreme Trauma going on with someone in the family which results in the whole family talking about nothing else all weekend.

This is a family of High Drama - from the wayward uncle who ran away with the gypsies when he was a boy to various mental health problems (the genes associated with which, I often wonder, may be the cause of our own problems over the last 20 months or so...) - not to mention a host of other dramas which I'd really rather not go into here... Plus all the heightened emotions that a family funeral brings...

And meanwhile I have Ben and his eating disorder to worry about... No-one could accuse us of leading a boring, uneventful life... but I sometimes wish we did...

**Tuesday, 10 May 2011**

**Okay, so where shall I begin...?**

Probably at the end and work backwards... Starting with my 84 year old mum who's just called to say my elderly dad is "playing up" again and she wants to come round to let off steam (he had a seizure in November resulting in delirium; to all intents and purposes he seemed to have made a reasonable recovery but now he's snapped back into old behaviours and is making things impossible for her...)

Preceded by my back agony which has been hellish all weekend...

Preceded by the fact my M-in-Law wouldn't even look at me, let alone talk to me by the funeral yesterday.

Why?

Because I'd deliberately kept a low profile all weekend, much of the time keeping Ben (and as a result H) away from the chaotic emotional hot-house that was my sister-in-law's home where everyone else was staying. We kept our distance because the whole situation was having an horrendous "trigger" effect on Ben's eating disorder behaviours and risked messing up the entire weekend for everyone - yet I think my in-laws probably took this as me being rude and keeping Ben and H at arm's length on what was a very important family weekend. A textbook case of not being able to please all of the people all of the time and ending up pleasing none of the people all of the time...

Then there was the eating (hotel meals, restaurant meals, family meals, breakfast, lunch, dinner, you name it...) ... then there was the "fight / flight" potential kicking off from Ben with me taking him on walks to talk things through and calm him down... then there were the endless trips to the supermarket...

The only saving grace was having a pub/restaurant opposite the hotel that served a rather nice large glass of *Chilean Merlot* wine with the evening meal...

More on the above later when I've got my thoughts together...

**Friday, 13 May 2011**

### **What a week!**

What a week's it been what with the weekend (already alluded to) and my dad deteriorating daily until he was hospitalised yesterday (and still continues to deteriorate...) Meanwhile Ben has cooked three evening meals *very successfully* because I've been too busy sorting out my parents. We've had sausage, butter bean and veg casserole; chorizo and chicken jambalaya with pitta breads; and creamy home-baked ham with leek and mushroom spaghetti - all without "slimming them down" in any way. And today Ben has put on 1.5kg in weight at his fortnightly weighing session...

Initially that didn't go down too well, but when we looked at it over the past month it averages out at an eighth of a kg a week which is well below the NICE guidelines. I have made sure he's well aware of this rather than seeing it as a "huge weight gain" over a short period, to avoid a knee-jerk reaction.

But I was relieved to know that the funeral weekend was successful, food-wise, gaining rather than losing weight. Yes we had some pretty extreme angst at the weekend, but in general Ben persevered and put on weight, thank goodness.

Which brings me back to the weekend...

From the start it was jam-packed with potential stressors. Firstly, we were eating outside "the comfort zone" of home cooking and calorie counting. Secondly, we arrived to find the family had made zero plans for meals which immediately made Ben anxious with vague suggestions of a BBQ or take-out fish and chips at some unspecified time of night.

My sister-in-law suggested that she "rustle up a quick salad for Ben" while we eat the other stuff. Hmn...

So I collared Ben and we went for a walk to formulate a workable plan. I knew this plan wouldn't please everyone, but my Number One priority is Ben and his recovery, so as long as that was successful (or at least as successful as possible given the

circumstances) I had done my job.

H's decision to stay at a local hotel was a Good Decision because we could eat proper breakfasts and could sleep in beds as opposed to on the floor. Ben and I decided that the only workable plan for evening meals was for us to eat at the hotel, too, which we did - reasonably successfully - both nights.

With no plans whatsoever for family lunches either, we picnicked on the Sunday and went to the post-funeral meal on the Monday before driving 300 miles home for our evening meal. Unfortunately each one of these decisions combined to make my mother-in-law furious with me and by the funeral she wouldn't even look at me, let alone speak to me. I had to virtually force myself on her when we said goodbye.

Unfortunately she saw it all very differently from me (confirmed by H when he spoke to her later). Me making the decision to stay at the hotel (actually it was H's decision). Me taking Ben and H away for other meals, too (well I had no choice if I wanted to keep the peace - they know what happened last time Ben stayed with them and was faced with haphazard or non-existent meal plans... basically the anorexia can't cope with it and he flips. I didn't want a "flip" at a weekend that was already high in emotion...)

Also, most importantly, I wanted to be sure Ben ate sufficient so he didn't lose any more weight.

It's sad that, almost two years into the eating disorder, my in-laws still don't seem to "get it".

It was also hard for me to see Ben's teenage cousins tucking into a massive three-course post-funeral meal as if they'd been on starvation rations for a couple of years and meanwhile Ben ate a piece of griddled fish, half a red pepper and a plain jacket potato (no butter) followed by an apple. Okay the first two items were doused in olive oil, but still...

Anyway, I didn't have time to feel sorry for myself for long because virtually the moment we got home, my mum phoned to say my dad was ill...

**Sunday, 15 May 2011**

**Exam week - and what a change from last year!!!!!!**

This time last year Ben sat his GCSEs. He'd been away from school since March, unable to face it at all. The school arranged for him to sit his exams in a separate room away from the main examination hall. And before each exam he registered in the school medical centre rather than the form-room. In other words, everything was carefully managed so Ben didn't have to meet any of his peers at what was an extremely stressful time for all of them.

Being with his peers would have stressed out Ben and could easily have resulted in him walking out and going AWOL - or just freaking out during the exam which, in turn, would have upset everyone else. I'd drive Ben to school because ED-fuelled social anxieties prevented him from getting the school bus and we'd deliberately arrive at school after the other pupils had gone to their classrooms. That's how bad things were...

On the one day we had to arrive when everyone else arrived (art exam), it took Ben *ages* to pluck up the courage to walk from the car park to the art block; in the end he just fled with his head down... And I later found out he'd been doing sit-ups in his private exam room whenever the invigilator went out (which they did occasionally because it was a full day exam).

This week Ben's AS level exams start - and what a difference!

He'll be getting the school bus as normal and sitting the exams with everyone else, as normal; no question of needing special treatment of any sort. And, although he is still unable to do full days at school, he's been doing full mornings, every morning, virtually since the start of the Contract - mainly because he is sleeping much better. I just hope he sleeps okay before the exams...

There's only one day when there's an exam in the morning and afternoon which will mean a full day in school, but so far he seems cool with that.

**Sunday, 15 May 2011**

**Up 1.8kg on Friday!**

Funny how for me it was a cause of celebration whereas for him it was a cause of shock... Thankfully he began to accept it as *okay* after a while as I reminded him that we're looking at gradual weight gain over the *long term* and when we pan out and look at the past month the weight gain is actually very manageable.

Mind you, I know it's going to be difficult if he puts on a similar amount next time he's weighed. I don't believe he would be able to handle that at this stage unfortunately... *unless* we pan out to the long term again and the rational side of his mind accepts that as being *okay*. As any parent of an eating disorder teenager will know, rational thinking goes totally AWOL for quite a few months as the condition gets worse.

But the Good News is that it gradually comes back. This is why I am keeping a chart to show the *gradual* increase over the long term to avoid potential knee-jerk reactions.

We're into our ninth week of the Contract and it's still working. This weekend Ben had £30-worth of points to spend, having gained a load of points for Friday's weight gain! And after eight full weeks of the Contract I am delighted to say we haven't had to deduct any points at all for resistance, over-exercising, etc.

Ben is also sleeping much, much better. I believe that this may be due to a reduction in anxiety because all the control is set out in the Contract so he doesn't have to worry. Plus there's a general feeling that, yes, we are moving forward after our period of limbo over some of the winter months.

**Thursday, 19 May 2011**

### **Why is the fear of weight gain still such an issue?**

I get so frustrated that, at this advanced stage in recovery, Ben still stresses about putting on weight.

Today I asked him if we could work on doing full days at school once the AS level exams are over and he starts A2 course work towards the end of this term. "Not if I find I've put on loads of weight next Friday," he said.

So I reminded him (again) that we have to look at weight gain over the long term to avoid knee-jerk reactions to every scales session which result in maintaining or losing weight over the long term.

Next Friday we will be eight weeks into the Contract and I've been making notes of how much his weight has gone up and down during this time. At the moment he's averaging 0.33kg gain per week over six weeks.

I pointed out to him that he'd have to increase by a massive 2kg next Friday for it to average out at the 0.5kg gain recommended by the NICE guidelines. So, in theory, that shouldn't stress him out now that he is much, much more rational in his thinking.

So I guess it's a case of reinforcing this concept over the next week and also the fact that he is not yet weight restored.

But it frustrates me that he still worries that he will suddenly "balloon out" into some kind of blubber monster - and even at just a couple of kg heavier he feels he wouldn't be attractive to the opposite sex.

The Good News is that I've heard so many mums say that one of the most amazing things about full weight restoration and recovery is that gradually weight and appearance become less important, sometimes disappearing altogether...

But we're not weight restored yet...

And they also say the last few kg are the hardest...

**Saturday, 21 May 2011**

**Bit of furniture throwing at CAMHS...**

A few months ago it was the table; yesterday it was the heavy arm chair which Ben picked up and threw across the room at our CAMHS session before punching the wall and walking out. Thankfully he eventually returned and we were able to resume our session.

Then, to rub salt into the wound, we returned to my car to find it had been "keyed" all the way along the side. So not a good afternoon, all in all...

The trigger? Ben was brimming with nervous energy - the kind that's set to explode at any minute. He desperately wanted to be weighed, but the scales session isn't until next Friday and CAMHS weren't going to give in (all credit to them).

Yet again it was the old familiar story of being sure he's put on "loads of weight" during the week.

"If you came back next week and found you hadn't put on loads of weight, how would you feel?" asked the psych.

"Happy, relaxed and able to continue with eating extra calories and challenge foods," he said - something we have heard umpteen times over the last year or so... And then it would be pretty much the same story the following week, etc etc etc.

He was convinced he'd had a "binge" on Sunday night, a result of "greed". The psych asked for a breakdown of exactly what he'd had. Much of it, if not all of it, was within the calorie allowance plus the 100-200 we challenge him to go over when he feels that he can. Things like bread and jam, a handful of healthy cereal, a few pieces of dried fruit and nuts and a couple of *Hob Nob* biscuits...

"So not really what most boys of your age would consider a 'binge'," said the psych...

Hopefully this was just one of the odd "blips" we get in the recovery process...

**Saturday, 21 May 2011**

**No, it's NOT OKAY for Ben to reach a weight he "feels happy with" and stick there...**

For some time now, our psych's assistant has been throwing spanners into the works in a way that makes me want to scream in frustration. Several times she's implied that it's *okay* for Ben to reach a "weight he feels happy with" and stick there rather than push further forwards and out of his current comfort zone. It's as if Ben gets to choose when he feels happy with a particular weight and remain there if he'd rather not go any higher.

*To me this is like giving him permission to remain ill.*

I am not alone in believing that full brain healing only comes with full and proper weight restoration. Anything below this is just asking for relapse. And, of course, it takes work to maintain your weight at an artificially low level when your body is screaming out to level out at something a tad higher (or even a great deal higher). So Ben would be forever counting calories and remaining obsessed with scales, never allowing himself to comfortably eat with friends or anything like that - all the usual things that a normal teenage boy would do without batting an eyelid, let alone reaching for the kitchen scales and calorie chart...

Sorry, CAMHS, but I'm not going to allow you to let Ben choose his final weight.

**Sunday, 22 May 2011**

**Kentucky Fried Chicken ad makes me think back...**

Watching a *Kentucky Fried Chicken* ad on the telly yesterday reminded me of one of the very early indicators that all was not right with our son, back in the summer of 2009. It was early August and H, Ben, Ben's friend and me had gone down to London for my sister-in-law's birthday party - a lively drinks and buffet party at her home. I was vaguely aware that Ben wasn't eating much - just picking at the buffet now and again, and being very selective with what he ate.

On the return journey we stopped off at a motorway service station for something to eat. While we three tucked into some (not very nice) *Kentucky Fried Chicken*, Ben went off to see what else he could find to eat. Ages later he came back with a sandwich and I was acutely aware that here we were, H, me and Ben's friend, eating our meal yet Ben had gone AWOL to locate something "more healthy" to eat. These were just two occurrences that indicated that something odd was happening. Meanwhile, the previous month we'd been on holiday to France where Ben was swimming 100 (short) lengths of the villa pool and going for a run every single day. He was also avoiding snacks like ice creams...

Thinking about this really brought it home that, had Ben been a girl, some alarm bells might have started ringing in my head at this early stage. As a parent of a girl I might have been more tuned in to what were the early stages of an eating disorder manifesting itself. But as a parent of a boy, it never entered my head. Eating disorders didn't even feature on our radar. I had an inkling that something wasn't right, but I didn't know what.

This continued throughout the summer holidays as Ben swapped socialising for punishing daily trips to the local gym followed by runs or cycling. He became obsessed with "healthy eating" and marvelled at the way he could "slim down" recipes. He became a keen cook.

His mood started to change, too, as he began to withdraw into himself. But it took until late September before I was prompted to take him along to the GP...

The point is... I'm not sure how many parents of teenage boys are aware that their son could succumb to an eating disorder, just like a girl can. I can't be unique in that all the warning signs were there but I failed to "put two and two together" and take early action. From the first signs in July 2009 to our first CAMHS appointment we waited eight months. It was a further eight months (October 2010) before we noticed any positive changes and Ben finally began to turn a corner. Then it was a further five months or so before he eventually began to put on weight.

Would he be further ahead in the recovery process if I had been more clued up about eating disorders in boys? Or does it take as long for the penny to drop with parents of girls, too?

I guess no parent expects their child might develop an eating disorder, boy or girl...

**Monday, 23 May 2011**

### **Early warning signs in boys - what to look out for...**

Today I was thinking back nostalgically to our family holidays before the anorexia muscled its way into our lives. Anorexia wasn't even on our radar; it was something that happened to girls, not boys.

Not in a million years of my wildest nightmares could I have dreamed that my wonderful teenage son was developing anorexia nervosa.

Maybe if he'd have been a girl, I'd have been alerted sooner. But I thought it might help other worried parents of boys if I listed the warning signs that should have set the alarm bells ringing that all was not right with our son...

**Body obsession.** I guess every teenager gets obsessed with their appearance at some time or other, especially girls. But, increasingly during the early part of 2009, Ben became completely obsessed with his looks. He'd take *ages* to get ready, preening himself with hair gels and straighteners. He loved shopping for clothes and spent a great deal of time examining himself in the mirror, inside and outside the home.

**Puppy fat.** Ben had been an overweight child. Not obese, but overweight. He was also very shy and introverted, preferring one or two close, equally introverted friends to a group of boisterous boys. However by Year 9 Ben had lost all the puppy fat and looked fantastic! But he himself was extremely self-critical.

**Exercise.** At primary school, Ben had hated sport although he did play rugby on Sunday mornings with the local club. He wasn't wild about it and felt he was pushed

to do it by his dad. However he was rather good at it - and at senior school he was a regular in the *first team* in his year. But he was always the one who kept away from the boisterous boys. Although he was turning into quite a sportsman, he was still very quiet, shy and academic. In July 2009 when the eating disorder was about to start manifesting itself, he won the 1500 metre race for his *house* at school sports day, beating his constant rival, K. Ben also did cross country running twice a week.

Also, he started to buy *Men's Health* magazine and enthusiastically follow the exercise routines in order to try and get a "six pack" like the men in the pictures...

On holiday in France in July 2009 Ben was swimming 100 lengths of the villa pool every day and also going for a run. Back in the UK, he was getting so enthusiastic about how fit and healthy his body was getting that his dad signed him up for the local gym. (Ironically his dad thought he was doing Ben a favour...) Ben went to the gym every single day over the summer holidays and also went for runs and cycle rides. I started to notice that it was becoming almost like an addiction - and he wasn't actually enjoying the exercise that much...

**Friends.** Ben had blossomed at senior school and built up a lovely circle of friends. He was a regular at parties, sleepovers, cinema trips, meals, etc - and his own birthday weekend in December was always a massive affair with half his friends sleeping over on the Friday night and the other half on the Saturday. He had so many friends he couldn't fit them all into his room at once! And the *massive* breakfasts I used to cook for them on the Saturday and Sunday mornings were legendary.

During the summer holidays of 2009 I was acutely aware that Ben had traded in sleepovers and cinema trips for the gym and running. He rarely saw his friends over the summer.

**Eating.** The teenage Ben had always been interested in healthy eating; however over the summer of 2009 it became more and more extreme. He started to cut out certain "unhealthy" foods. He also developed a passion for cooking and recipes - and especially for "slimming down" so-called "fatty" recipes. He also policed what we, his

parents, purchased and ate. At first I found this kind of endearing, but after a while I realised something wasn't quite right...

By the end of the summer his eating had become very rigid. He began to insist on set meal times and was also pretty rigid with what he ate. He started meticulously preparing all kinds of weird and wonderful concoctions for snacks and puddings. Most noticeable was his chopping up of dried fruit; he'd cut the fruit into tiny pieces. And all this food preparation would take *ages*; sometimes an hour just to make a pudding (comprising nothing but fruit). He also developed a passion for fresh fruit and for visiting the supermarket with me to buy the darned stuff, along with dried fruit. He also raved about low calorie foods; the lower in calories the better - and he became an expert at the nutritional content of just about everything; not just calories but the all-important (to Ben) fat content, too (especially the demon "sat fats" ...)

On holiday he avoided snacks like ice creams. When eating out, he'd deliberately choose the lowest calorie item and sometimes this meant moving cafés or restaurants until we found somewhere "suitable".

**Mood.** Ben was becoming more and more introvert. His mood was also quite depressed and he'd get snappy and bossy. Gradually he seemed to be losing his usual zest for life, his confidence, his optimism and his sense of humour. Also, once he started back at school, he started to develop an awful lot of illnesses (which he now claims were faked).

**Weight.** Ben was losing weight rapidly because he was eating less and exercising more. I was also acutely aware that his diet wasn't balanced. There he was rambling on about "healthy eating" yet he'd cut out important components from his diet, notably all fats, even "good" fats. By late September he had lost around one third of his body weight and was looking skinny rather than the handsome "strapping lad" he'd been before.

If I think of any more early warning signs, I'll update this entry.

**Wednesday, 25 May 2011**

## **A bit of “me time” urgently required, I think...**

You know when you pour something into a jar and you can't get the lid on because there's just too much in it? Well, that's my brain at the moment and I appear to have reached yet another “burn-out”. However, as we parents know, it's not like a stressful job where you can just walk out and never come back; we're in this for the long-haul, whether we like it or not and whether we can handle it or not. Basically we have no choice. There are six things going on at the moment which are causing a serious power surge in my brain –

1. **Managing Ben and his recovery** (despite being much better than he used to be, I have to keep my eye on the ball round the clock because ED likes nothing better than to sneak in when your defences are down. Also, Ben is still at the stage where he relies on his parents for “entertainment”. Unlike other kids his age, he isn't becoming independent and still rarely sees his friends, although it's much better than the days when he had no social life at all. So there's the constant pressure of knowing that Ben is hanging around, lonely and unhappy, often nagging at us to “down tools” and go out, which only makes me more tired like it did yesterday afternoon... I am also acutely aware of when “all is not well” with Ben. It only takes the slightest action or facial expression and I know ED is at work in his head... like last night...)
2. **My dad** (who is still very much in hospital and has reached a stage in his illness where the prognosis isn't brilliant - for example he'll never be able to eat properly again; now he needs to be fed through a tube directly into his stomach. Meanwhile there's the worry about my elderly mum and having to support her through it all, not to mention the worry about what the heck will happen when he eventually gets discharged - if, indeed, he does. Oh, and I'm visiting him every day, too, and sorting out his paperwork).

3. **My job** (thankfully I work for myself, from home, but I'm finding it very difficult to work. Back in the summer I had no option but to give up work for three months because I simply couldn't juggle Ben at his worst with my work. But with everything that's going on at the moment, it's very difficult to concentrate for more than a couple of minutes at a time. I need the cash because H has been out of work for a couple of months. He started a new job this week, but the pay is pretty cr\*p, so we still need my earnings).
4. **My house** (which is disappearing in dust and filth, with laundry scattered everywhere un-ironed or sorted; it's starting to look like one of those pigsties on TV's *How clean is your house?* or whatever it's called. I used to have a weekly cleaner who was brilliant, especially during the worst period with Ben. But when H lost his job, she had to go).
5. **Meals** (with anorexic meals are vital, as is food shopping. Working out suitable menus, cooking food and ensuring Ben has sufficient for all his other meals so he doesn't "skimp" on stuff is a nightmare. He himself has cooked a few meals on evenings when I've had to visit my dad, but I'd rather I was in charge, obviously...)
6. **School PTA** (well that's had to go. After six years of being *Deputy Chair*, I've made the decision to resign. Mind you, this past year or so I've had to put things on a back burner; however I was always the person in charge of the massive, monster Xmas Fair. In 2009, it was an absolute nightmare as Ben spiralled downwards and we had an ultra-anorexia meltdown the day before it took place. In 2010, Ben was better but my dad was in hospital again. Goodness only knows how I did it on both occasions, but - sorry - this year I

can't - so I've resigned).

And I'm acutely aware that I'm neglecting my friends, especially Sue who has cancer and needs friendship / support...

Last summer I was so stressed that my GP put me on *Prozac* after I got to the stage where my physical body just "locked" and I couldn't move!!! And when I wasn't like that, I was curled up in a corner somewhere like the kitchen or hallway or bed, in floods of tears, often chucking things around like the day I smashed the second-best dinner service, plate by plate, on the kitchen floor.

So the *Prozac* deadens the stress and panic to a certain extent. But I've been so anxious this week I can't concentrate and I am feeling totally and utterly exhausted. It came to a head last night when Ben reached out for help because he was battling with a strong urge to binge and it all ended up in a massive row with Ben kicking furniture and chucking stuff around, then storming off. So much for being the model "Dolphin" parent; I bet ED loved that!!!!

So something needs to give and I'm not sure what. Or what can.

A bit of "me time" is needed, yes. But the trouble is, as I found last summer when I took myself off to the seaside for a few days, you can distance yourself physically from the ED but, unfortunately, you can't mentally. It goes with you - and I ended up having to come home early. It just wasn't having the desired effect.

Oh, and then there are the physical symptoms - like a skin condition which has reared its ugly head again.

But, hey, life goes on...

**Wednesday, 25 May 2011**

**Some people are AMAZING... positively SAINTLY!**

My friend, Sue, has secondary breast cancer which has spread to her lungs, spine and liver. She is currently having horrible intravenous chemo which makes her feel pretty naff most of the time and all her lovely hair has fallen out. Yet Sue has a cunning way of getting you to come clean with what's bugging you - and also of phoning you when you could really use a good chat with a friend. She is a saint.

I felt bad because, with all the stuff that's going on at the moment, I'd been neglecting her. She can't go out much and she was forced to give up work ages ago. When she does go out it's usually to have needles stuck into her at the local hospital - or to be "wired" up to a machine while they pump nasty chemicals into her body. Not surprisingly being such a lovely person, Sue has loads of friends who come round to see her - yet I was acutely aware I'd been neglecting her, and she's the main non-eating-disorder-related-person who has helped me get through the last 15 months.

Sometimes I get really cross with her because she has a habit of turning the conversation around to me and my problems when she has so many problems of her own. She's always chirpy and smiling, and offers emotional and practical support to other people who aren't handling their cancer as well as she appears to be. Before this round of chemo she used to lobby for better patient understanding; she was even invited to talk to a conference in Munich about how professionals can better understand the patients they are treating.

So she called me today and said she'd put the kettle on. So I "downed tools" and took a break. Part of me feels really selfish for unburdening all my problems on her while - each time I tried to ask her about herself - she deflected the conversation back to me. But that's typical of Sue who is one of the most selfless people I have ever met.

I first met Sue 15 months ago when, during the lowest months with the eating disorder, I was desperate for emotional support. An obvious place to find it seemed

like the local church. So one Sunday I sat down in the local church. Everyone ignored me or just gave me polite smiles - and all my instincts cried out for me to walk out and leave. Then this tiny smiling woman rushed over and invited me to sit with her. After the service we just talked and talked... It was as if we'd known each other for years!

Although we both had very different issues - Sue with her cancer and me with Ben's anorexia - our experiences kept hitting common ground. We really seemed to understand each other. I stopped going to the church after a while (apart from Sue I never did get the emotional support; everyone else kept a bit of a distance) but Sue and I have met up for coffee every week since.

Sometimes I provide (hopefully helpful) emotional support for her - and sometimes (well, most times) she provides it for me, as she did this afternoon. But whichever way round it is, time flies by and the whole morning or afternoon is gone before you know it. The same with telephone calls. Thank goodness we get our local calls free!

I am very aware, however, that my problem does, hopefully, have a light at the end of the tunnel at some point in the future. And, on the whole, things are getting a lot better. I'm not sure what the prognosis is for Sue, though. I'm not sure whether remission is on the cards or not. I do know that current chemo seems to be working, though, which is good news.

Sue has certainly opened my eyes to what living with cancer is about; I didn't realise how ignorant I was about the condition or its treatment. Likewise she's now an expert on eating disorders. I don't know anyone else outside the wonderful eating disorder parents' circle that is, with the exception of my dear supportive sister. Most people just don't want to know or only want to know a bit - like politely asking how things are with us and then moving on.

So Sue's taken the edge off my stress today. I should have spent this afternoon working, but what the heck!!

**Thursday, 26 May 2011**

### **Delegating and talking...**

Thanks for the lovely feedback re. my “cry for help” the other day! Ben offered to clean the house yesterday afternoon in exchange for some new shoes he wanted, so that’s sorted for a while. My sis has been visiting my dad and is going again tonight, so I won’t need to go until tomorrow. As you’ll see from my other entry, my wonderful friend Sue has been brilliant; her cups of tea are positively soothing. And I had a word with Ben about his behaviour the other night...

I explained that, whereas we all know that anorexia can be an incredibly self-centred and selfish illness in that the behaviour often doesn’t give a monkeys about how it’s affecting other people, I believed Ben had arrived at a stage in recovery where he needed to be less self-centred and work at sometimes taking the focus off himself and his illness and onto other people who may also be experiencing issues. I explained that, although I am usually delighted to talk through any issues that are bothering him, sometimes it’s difficult for me to be on top form. After all, I am only human.

I suggested we spend a bit of time over the weekend going through the Contract and updating it to be more helpful to whatever is bothering Ben at the moment. I suggested that maybe this week hadn’t been as positive as other weeks and, at this stage in recovery, it’s vital to address stumbling blocks to avoid landing back in the dreaded *Limboland*.

I know for a fact that he’s extremely anxious about getting weighed tomorrow at CAMHS. As you know, he wanted to be weighed last Friday, but the psych rightfully refused because we now only weigh every fortnight rather than every week (to avoid Ben getting obsessed with “numbers” which was causing knee-jerk reactions to the weekly weight and resulting in weight maintenance rather than gain).

Of course he’s convinced he’s put on a “hell of a lot of weight”. Looking at him I

know for a fact this isn't the case and yet again I reminded him that he'd have to put on a total of 2kg this Friday in order to average out at the NICE guidelines' 0.5kg per week weight gain. Having been monitoring it and doing the Contract for eight weeks now I reminded him that this is an excellent long term period to look at - we *must* look at weight gain over the long term because that gives us a far more accurate picture of what's going on. So I will be there with my figures and my calculator so I can dive in with facts the moment he starts to freak out because he's put on "loads of" weight.

And if he hasn't, he has (reluctantly) agreed to increase the calories by 100 a day for the next fortnight.

A lot of research - and other people's experiences - suggest strong evidence for the belief that, with true weight restoration comes mind healing. Many of the eating disorder behaviours evaporate away. Not immediately, but they do. With a bit of patience. Some say it can take up to a year – or even longer. But it's vital that an individual reaches their true natural weight with room on either side for weight fluctuation.

I am very frustrated that, after *so long* of living with the eating disorder, Ben should still have such a powerful aversion to weight gain. He longs to recover, but he finds it extremely hard (impossible at times) to envisage that recovery in terms of being a higher, healthier, more natural weight because he is convinced he is okay as he is.

Oh, and tomorrow at CAMHS we're seeing the psych's assistant (psych is away), and I'll go crazy if she says anything whatsoever along the lines of "If you feel happy with your weight, Ben, you might find it easier to stick at that weight" kind of thing...

**Friday, 27 May 2011**

**A bit of bribery (hopefully) goes a long way...**

The prices of Ben's favourite *Warhammer* models go up tomorrow, so yesterday he

wanted to do a bulk buy online.

He didn't have enough cash so he asked for an advance on the Contract points money.

So I said "Okay, yes, in principle, but it would have to be a 'conditional' loan"...

It would be subject to him working on the rational, non-ED side of his mind when we go to CAMHS this afternoon to be weighed. If he's put on weight, then he must look at it in the context of the last eight weeks i.e. as a weekly average.

If it comes close to the 0.5kg a week recommended by the NICE guidelines, then the rational side of his mind must accept this as being *okay* and plough on with our arrangement.

If he's lost or maintained weight then he must agree to increase his daily calories by a further 100 and stick to this until he's weighed next time when we will take a look over the long term again.

I also said we must revisit the Contract this weekend at some point and update it so it's relevant to what's going on in his recovery at the moment and addresses any new or difficult issues.

I said that if he "defaulted" on what is an "interest free" loan (i.e. if he doesn't keep his word about the reaction to being weighed), then I would work out some kind of "interest charge" on it which would result in less points over a specified period.

Or something along those lines...

He agreed. So we shall see what happens this afternoon...

## **Saturday, 28 May 2011**

### **1.2kg weight gain since our last scales session...**

Mixed messages at our CAMHS session yesterday with the psych's assistant. Some of it was absolutely fine, but my gut instinct wasn't too sure about other bits - unless it was a clever way of making Ben react in a positive way to yet more weight gain... It

might be... so the jury, as they say, is out on that... But the Very Good News is that, 10 weeks into the Contract, and over the past eight weeks, Ben has averaged out at a weekly weight gain of 0.4kg which is almost what the NICE guidelines recommend. Considering that for *months*, he'd lost and then maintained (after an initial fast gain right at the start of our CAMHS treatment last spring), I think that's well worth celebrating!

Initially at our CAMHS session yesterday a fly on the wall might have thought Ben was reacting extremely badly to this news. But, as often happens, I think it's just Ben's way of coming to terms with it. By the time we arrived home, he was fine and readily agreeing to continue on his current daily calories rather than being tempted to cut back. We also agreed to update the Contract so it's addressing whatever areas we need to address now.

What niggled me, however, was how the assistant seemed to imply that Ben is now "Weight Restored" - something that Ben picked up on immediately - as if that was it, finished. Sorted. Job Done. She said that CAMHS would be quite happy to discharge Ben on the basis of his current BMI if that's what he wanted (but she did add that it might help to do some work on his relationship with food which isn't good...).

"So what if he started to spiral downwards again?" I asked, playing devil's advocate and voicing my natural concern as a mum who's spent almost two years battling with Ben's eating disorder.

"You'd have to go back through the GP route," she said.

"So we'd have to wait months to see someone at CAMHS?" I asked horrified, "Just like we did at the start?"

She didn't answer.

Yet again, it all seemed to be about Ben "choosing" to stay at a certain weight - to pick a weight out of the ether "he feels comfortable with" and stick with it. If this isn't recovery level, then maybe he will never recover fully, but that's what happens

with some patients. It is his choice, especially at his age. Or, at least, that's the impression I was getting...

So my hackles began to rise. And then Ben started spitting venom at me in his "Big Bad Mum" hatred voice when he refers to me as "*she*". ("*She* insists...") So it felt as if mum was the "baddie" and Ben and the assistant were the "goodies". Nice triangulation, that. And we all know the ED loves triangulation...

Yes I admit that Ben has done splendidly over the past couple of months, sticking to the Contract like glue with great results. Yes I admit he is now what experts consider to be a healthy BMI and could possibly have arrived at his natural weight. But he is definitely still entrenched in the eating disorder as regards his relationship with food and certain other aspects - although he has improved immeasurably on those counts, too.

However I know for a fact that, before Ben started to lose weight, he was a much fitter, healthier looking, muscular, "strapping lad". Perfect physically, really, and so handsome! The kind of boy that girls would stare at admiringly while I swelled with maternal pride.

He hasn't got back to that stage yet and is still much thinner. Also, in those days, he naturally did a great deal of sport. If he did the same amount of sport now, I believe his weight would plummet very quickly.

So, as Ben's mum, my instinct says that, no, Ben is not "Weight Restored". He isn't a million miles off it, but he's not there yet. And, in my opinion, the assistant shouldn't have implied Ben is - because ED latches onto that kind of thing immediately; it's the perfect ammo for ED in the war against Big Bad Mum and Dad...

However, as I said above, it may be an extremely clever way to get Ben to feel *okay* about his weight and be happy to hover around that level... So the jury is out on this, as they say...

But I'm not happy with it. I'm happy with Ben for having done so well, but I'm not happy with the way CAMHS are handling these last few kg and all the ED-related

thinking that is still entrenched in Ben's head.

They shouldn't be jumping in so quickly and readily with conclusions about being Weight Restored, because Ben – or rather the ED – latches onto that kind of thing immediately.

**Sunday, 29 May 2011**

**The more I think about it, the more I'm angry about Fri's CAMHS session...**

Seeing Ben and H go off cycling today spoke volumes about where Ben is in the weight recovery stakes. He may be within the first six per cent centile of boys of his age, height, etc, but in my very strong opinion he is *not* Weight Restored...

In summer 2008 Ben and H did the *Coast2Coast* cycle ride across Northern England. Today Ben was wearing the same cycling gear he wore back then and the contrast was pretty acute.

Never forget, Ben was a strapping rugby player who also won the 1500 metre run in his school sports day in 2009. He is also a keen hiker. Yes, he is looking healthy and eats an extremely healthy and balanced diet which is *brilliant* progress, but he is still too thin. Unfortunately, to him, CAMHS have implied that he is now *okay*; to all intents and purposes he is Weight Restored. And, of course, ED loved this. Triumph! "See I told you so, Big Bad Mom was wrong all along, hey!" chuckles ED.

So where to go from here... How to undo this? How do I get Ben back on board and working towards his natural weight rather than have him fighting against me to stay where he is? I need to set up a meeting with the psych.

**Tuesday, 31 May 2011**

**Dr Sarah Ravin speaks sense....**

I've just been reading *Dr Sarah Ravin's* latest article. (Dr Ravin is a really clued-up US expert on eating disorders.) The content is particularly relevant to us at the moment.

The number of times I've heard how Ben's treatment won't work until and / or unless "Ben chooses to get better" and, lately, why it's important to "let Ben choose a final weight he feels comfortable with" rather than enforcing a higher and almost certainly more realistic and relapse-resisting goal! (Or at least that's what I believe CAMHS have been saying.)

Ultimately we are told that the choices are "Ben's choices", not ours. We can't inflict our own will on him - he has to "want to get better".

However I was interested to see that Dr Ravin points out that "The problem with emphasizing insight and motivation early in treatment is the presumption that the patient must 'choose' to get well and that, if she does not make that 'choice,' no one else can make it for her. Precious weeks, months, even years are wasted trying to form an alliance, cultivate motivation, and develop insight".

I understand from our treatment team that we are also about to embark on a few sessions exploring the reasons "why" Ben might have developed the eating disorder... looking back at his early life, etc. But Dr Ravin says: "In reality, childhood experiences are generally irrelevant to the patient's eating disorder... there is no evidence that an ill patient can overcome her eating disorder by 'exploring' or 'processing' such experiences."

I am still frustrated at how Ben came away believing on Friday that his current weight is fine and that he is, to all intents and purposes, Weight Restored. We've had a weekend of "Xxxxxxx says I'm Weight Restored and she's a professional; you are not, so what do you know?" shouted at us by Ben (or, rather, ED...)

I know that we shouldn't look religiously at "numbers" but no way is 17 year old Ben Weight Restored. He needs at least another half stone on top... at least... This is a former "strapping" rugby player, cyclist and athlete we are talking about, not a *Mr Puniverse* weakling... He can't be allowed to "choose" to stay where he is or he may never recover.

Sorry, but I won't settle for anything below what is obviously Ben's natural weight.

JUNE 2011

**Thursday, 2 June 2011**

**Keeping the bugs at bay...**

It's just what we could do without in our household... Paul has got a tummy bug and I'm dreading Ben catching it. This is one of the reasons why it's *so not okay* for Ben to remain at his current weight without going any higher. I know, from having talked to other ED parents, that all it can take is just one sickness and diarrhoea bug and - ping! - their child is back in the land of the unhealthy weight range or even lower.

It just goes to show that "weight recovery" at this too-low level is so very fragile and it's vital that we reach somewhere that's far more solid, with sufficient leeway either side.

So whatever happens, be it a sickness bug, a sporty week, a holiday, school dinners, a weekend with friends, fending for themselves, going to university... whatever... it's vital that our children are sufficiently weight restored and metabolically back on track to be able to cope with blips and dips.

And I don't want Ben to have to relapse before our treatment team accept that, yes, weight normalisation for Ben *is* higher than they originally pitched it.

As *Dr Sarah Ravin* says: "Out of immediate medical danger does not translate to optimal physical and mental health."

**Friday, 3 June 2011**

**Impressed with Ben's perseverance**

Despite feeling grotty and losing his appetite, I have been incredibly impressed by the

way Ben is ploughing on with the usual eating regime. So much so that I gave him extra points on our Contract yesterday. So far he hasn't been sick, etc so what's going into his body is staying there. Fingers crossed things won't get worse...

I don't know about you but, in the "good old days" before anorexia reared its ugly head, the first thing that came into my mind when Ben fell sick was: "Oh poor thing; what can I do to make it better?" etc etc.

With an eating disorder, the first thing that comes into your mind is: "How am I going to keep my child eating through the duration? What will we do if they lose weight and catapult back into the Land of ED?"

Feeling sorry for them comes second...!

In an hour we'll be with the psych. I did suggest to Ben that because he doesn't feel too well, he stays at home, but he's keen to go.

In the "bad old days" of High Anorexia, I'd have got him to CAMHS come hell or high water, but these days it's not so important.

Hopefully the psych read the letter I left with the receptionist and I wonder what her reaction will be. I am crossing my fingers and toes that she will back me on the evidence-based treatment information I am relaying to Ben.

Whichever way, she does tend to be very skilled at keeping a good balance between what messages are being said so any "triangulation" is eliminated or kept to a minimum. And we all know how much ED loves "triangulation" between treatment team and carers...

Watch this space...

**Saturday, 4 June 2011**

**Again, mixed feelings but generally happy with the result**

We had a meeting with the psych yesterday. She is incredibly skilled at being diplomatic and subtle - and also digging us out of a hole without actually appearing to be doing so.

She carefully explained her methods in more detail and suggested that we should be aiming for a workable solution which Ben can handle without freaking out.

Yes, she said, Ben had arrived within the healthy weight range, but it was right at the bottom of that range. Ideally and professionally we would all like him to weigh more.

Ben believes he looks the same as he did before the eating disorder kicked in, but that's just not true - he is still thin. She asked him how he felt about himself during that pre-eating disorder period and he said he felt healthy, fit and reasonably happy - and he said they'd calculated BMI in biology lessons and his came out at 20 at the time.

The psych explained that, although a BMI of 20 was middle ground for a boy of 15 years old, now he's nearly 18 we'd really be looking for a higher BMI. For full grown men, a reasonable BMI is between 21 and 25 (implying that ultimately he will need to aim for that).

She also explained that his current BMI was still quite a way below 20. So, in effect, the "recovered" Ben *would* need to weigh more. Especially if he wanted to resume his previous sporty activities and allow a buffer zone for any other blips and dips.

Over the next few weeks the psych will work on the perceptions that are still distorted so he is better able to handle any weight gain and, ultimately, be as care-free about weight, eating, etc as any other boy.

But meanwhile it's not a disaster if he remains where he is for a while, weight-wise. However he is not permitted to go *below* this weight and should view it as a *minimum* not a middle range (i.e. not Weight Restored).

Also we would all use this next year to really iron out all the little glitches that could, at worst, result in a relapse when Ben goes away to University in September 2012.

My thoughts on this? As one of my ATDT forum friends put it last night, we seem to have achieved "a good balance between FBT [Family Based Therapy] and the non-

coercive British approach of treating the patient with respect and allowing them the right to choose their own treatment”.

I think we can work with that. I could have done without the “being allowed to remain where he is weight-wise for a while” stuff, though, when modern evidence-based treatment focuses on full nutrition first and foremost, followed by everything else e.g. the “talking treatment”.

Having said that, the general outcome was to get Ben to understand that - yes, he’s arrived within the healthy zone, but he’s at the bottom end and must never go any lower. Higher isn’t a problem and ultimately we’re aiming for a middle ground which allows for fluctuations in either direction.

**Tuesday, 7 June 2011**

### **A normal school day?**

As you know, Ben has been doing mornings-only at school since October. Today is the last AS level exam day and he has two exams, one in the morning and the other in the afternoon which will mean him having to be in school all day.

Not only will this mean quite a bit of free time between the end of the a.m. and beginning of the p.m. exam (having to socialise), but it will also mean returning to *school dinners* because, at Ben’s school, pupils don’t take pack lunches.

Ben’s had a tummy bug for the past week, although he’s ploughed on with his eating regime admirably. Maybe it was a mix of anxiety about today and the bug, but he didn’t sleep well last night and said he felt “ill” this morning.

But it felt hugely different from a similar morning with the eating disorder. Apart from his tummy ache and lack of sleep, he seemed like “normal Ben” who I’ve been treating in exactly the same way as I used to - without any special treatment to allow for / cope with anorexia behaviours, many of which have completely disappeared (fingers crossed...).

Yesterday he went into school for a revision session and said he wasn’t going to go

if his gut was playing up.

But I insisted that gut ache wasn't a good enough reason not to go to something so important, so off he went. ED, the eating disorder, simply wasn't there; it was just like a normal parent talking to a normal teenager.

Sitting here I feel echoes of the old anxiety creeping in from the days when Ben would be in a heck of a mood and make my life hell on his return from school and throughout the evening. Stress levels were off the scale...

I also feel echoes of the worry that Ben will cut back at school dinners. In the Bad Old Days he'd make a beeline for the salad bar or soup, followed by fruit.

On one occasion he got that he couldn't handle being in the dining hall at all and freaked out, sprinting out of the hall, out of the school, across the playing fields and (worryingly) towards the river. Thankfully he was intercepted by a member of staff who brought him back to the building...

And on many occasions he'd hide in the boys' toilets or somewhere in the grounds, texting me with frantic messages of the kind that makes your heart thud to a stop when your phone goes. Much worse was when he texted the landline and it would "call me" with a robotic woman's voice relaying the gruelling text message.

It will be interesting to see how he handles today. But we haven't talked about it that much, or the dinners issue, as I know it's something he needs to do by himself.

If, in the hopefully very unlikely event, he calls or texts me today, then I will firmly refuse to pick him up or pacify ED, the eating disorder.

But (says she tempting fate...) I don't think he will.

**Tuesday, 7 June 2011**

### **Top 20 Biggest Changes as a Mom in the last nine months**

Get set for the *Top 20 Biggest Changes* in my life over the past nine months as the mom of a teenager successfully recovering from anorexia (in no particular order, as they're all wonderful!):

1. No more heart-stopping dread-filled heart thuds as Ben makes a noise of some kind in the house
2. No more stress at mealtimes and no need to distract Ben by talking about non-food topics
3. No more curling up in a weeping ball somewhere in the house because I can't take any more
4. No more cancelling my freelancing work because of ED
5. No more dreading it as I pick up Ben from school or the school bus
6. No more hiding house keys so he can't go AWOL or watching him storm off, not knowing when or even if he will come back
7. No more worries that he might harm himself - or worse...
8. No more worries about constantly "treading on eggshells" in case he flies off the handle or threatens to leave home
9. No more heart-break as I see a pale, rings-round-eyes skeleton in place of my "strapping" sporty teenage son
- 10.No more having to eat with Ben or having to check he's had sufficient food
- 11.No more suspicions about why Ben's taking over-long in the kitchen with his plate, then checking in the trash bin to see what he's thrown away...
- 12.No more eliminating the majority of food recipes from our repertoire because they contain "fear foods"
- 13.No more wondering where the "real Ben" has gone when faced with what appears to be and sounds like some kind of demon from a horror movie like the *Exorcist*
- 14.No more watching out for those almost imperceptible body movements or facial expressions that mean ED is on its way to disrupt the evening / morning / meal / outing / etc / etc
- 15.No more wishing we could see the CAMHS team every single day and finding it

virtually impossible to wait until our next appointment, then clock-watching through the session to get as much out of it as possible

- 16.No more horrible texts or phone calls from Ben at school of the “I can’t go on / handle it any more” variety
- 17.No more having to phone teachers, school nurse, etc to talk through Ben’s latest mishap - and no more dreading it when “school” comes up on caller display on my phone (My thought: “What the heck has he done this time...?”)
- 18.No more worrying that his pulse is dangerously low and this thing could actually kill him
- 19.No more stressing out over family holidays
- 20.No more stressing out while I cook a meal in case Ben comes into the kitchen and sees me put that slug of oil in the pan - and no more worries about the kind of recipes I choose

And I am sure there are many, many more... such as *No more* having to cancel outings with friends at the 11th hour... *No more* feeling I can’t leave Ben in the house alone... *No more* trying to get into Ben’s room but can’t because he’s forcing the door shut... *No more* worries about violence... etc etc...

### **Wednesday, 8 June 2011**

#### **Points being awarded thick and fast**

We’re into Week 12 of the Recovery Contract and it’s still doing its job - and yesterday saw a massive 7 points awarded including the first Full Day at School (3 points) (yes I know he had to be there because he had two exams, but he still managed it perfectly okay).

You see, one of the main issues about being in school for a full day is that ED, the eating disorder, taunts him for “sitting around doing nothing all day” when he “could be exercising”.

Until very recently this was a major problem. But since we devised an exercise contract as part of the overall Contract, it's been much, much more successful.

Also, the Contract has enabled us to examine how everything falls into place over the Long Term, thus avoiding knee-jerk reactions to weighing sessions which, in the past, resulted in us staying in *Limboland* for ages.

Overcoming challenges has been key, too, with points awarded for certain challenges. Then, when challenges are no longer a challenge and part of "normal life", they stop earning points - and we regularly discuss where he's at as regards particular challenges and whether or not he still sees them as challenges.

Yesterday's challenges, for example, included eating a normal lunch at school, in the dining hall with his friends - and eating a large evening meal made from ("fatty") lamb complete with extras like onion bhajis and samosas despite having been "sitting around all day doing nothing" at school.

It is getting to a tricky phase, however... those last few kg... This is often the hardest part for anyone recovering from anorexia and Ben said today that he feels he's about to "tip over the edge". So it's going to take some careful juggling on our part to ensure the transition between here and where he should be. Unfortunately he still feels he's "absolutely fine" at his present weight...

**Wednesday, 8 June 2011**

**Spookily similar "WR" problem 14 months ago...**

Interesting looking back at my ATDT threads from 14 months ago (end of May 2010) when, it appears from the chart I made back then, Ben's weight had increased to 59.3kg after the rapid initial weight gain (which was to go pear-shaped from the end of May onwards as Ben's weight plummeted off the bottom of my chart).

At his last scales session on 27th May 2011 Ben weighed 57kg which is around 2kg less than he weighed then. Here's an edit of what I wrote back then which, from what CAMHS were saying about the weight, rings some spookily topical bells...

*My S has sneaked through into the “healthy BMI” range and for the first time for MONTHS actually looks pretty normal (if still quite thin).*

*The trouble is... his mind-set is way, way off “healthy”... which means we’re faced with a new “demon” as all the previous “you must eat to put on weight” stuff becomes obsolete and he panics that he’s about to spiral out of control and become a complete blob.*

*It also makes it masses harder to make him eat anything with fat in it. (“I’ve put on weight WITHOUT eating fats so why should I eat fats now?” blah blah blah...)*

*It also means we have more “pokey / proddy” / mirror sessions than ever as he develops “rolls of fat” on his belly almost by the minute, not to mention umpteen “double chins” etc etc etc as he becomes convinced we are dead set on transforming him into Michelin Man like some kind of warped child abuse...*

*I’d appreciate advice on how to cope with this “eggshells” stage in ED when the body is reasonably okay but the mind-set hasn’t really moved on at all...*

*Already the dietician at CAMHS has become the “goodie” and mum’s become the enemy because “she says I’ve reached my ideal weight”... unfortunately the psych implied that, too. (“Congratulations!” says the psych, all smiles, “Your weight is healthy again!”)*

*How can mum’s instinct be right when “the professionals” imply he’s virtually there... hey...?*

*Every pound gained results in mum’s life being made hell on the drive back home.*

*But to our dietician's credit, she did talk about the "set weight" where your weight kind of settles naturally. I don't believe we are there yet, but she obviously thinks we're much closer than I do. Conflict isn't good - and S is sure to take her side, not mine.*

Followed by:

*So there were, coming along swimmingly when - pow! - ED decides to fight back in a bid to get control of S again.*

*The problem being that he's now within the "healthy" BMI range (albeit at the bottom end of it) and is putting on weight at what is really a "maintenance" level i.e. ounces, not even pounds.*

*Ever since we saw the psych on Friday (who was brilliant, actually...) S has started to rebel, refusing to stick to the eating plan any longer, body checking, refusing to eat any fats of any sort, constantly arguing with us (the old irrational arguments that don't get you anywhere) and being in a generally depressed state of mind. (Because he feels he's gaining weight at a fantastic rate and is getting flabby. He wants to take charge of his own meals (no way!!!!) He also feels very tired, though psych said this is because his body is still going through umpteen physiological changes as it tries to heal itself on the inside. She says this is totally normal, but he won't hear of it.)*

*We feel as if everything we've achieved has been given a real kicking as ED tries to get control again and drag S back down to where he was.*

*It feels as if we're on an elastic lead and have plodded along the road almost at our*

*destination when - ping! - the elastic pulls us right back to where we were a few months ago...*

*Help!!!!!!!*

Thankfully the *big difference* between now and then are the cognitive changes.

This is why I believe it will work this time round, if I'm given half the chance to get him to his "set weight" level rather than settling for a sub-optimal weight level.

**Friday, 10 June 2011**

### **Cleared things up with CAMHS re weight normalisation**

It was just the psych at CAMHS today and I was able to clear things up about the weight restoration / normalisation levels.

Contrary to what the assistant implied the other week, yes Ben does need to be a higher weight and BMI and, at this stage in the anorexia treatment, we'll be working on carefully juggling both the weight gain and cognitive stuff. So that's good news. The bad news is that...

Ben has lost weight. Mind you, I wasn't surprised. Remember he's had that tummy bug. He's gone down to 55.5kg which is 1.5kg down on the previous fortnight.

So the pressure is on to get back to what has now been agreed as the "bare minimum" weight - and if he doesn't manage it by the next scales session, action will need to be taken (presumably in the form of increased calories).

So, apart from the weight loss, I am happy with that.

**Saturday, 11 June 2011**

### **Updating the Contract to achieve new goals**

The great thing about the Contract is that it can be updated whenever you need to

focus on a particular problem area.

I always ensure this is seen as a mutual thing and never seen as me, the parent, inflicting “my will” on Ben. This is how we’ve agreed to update the Contract - and why...

Yesterday at CAMHS Ben had lost 1.5kg over a fortnight. Okay, he’s had a tummy bug, so that could be the reason.

However it is vital that he gets back to the agreed minimum permitted weight level - and then continue to work on increasing.

This week he also plans to go back to school full-time - his first full days and, hopefully, full week since spring 2009 (apart from some tricky full days back in September 2009). This will also mean school dinners - and there’s always the danger with school dinners that Ben will cut back. In the Bad Old High-Anorexia Days he’d go for salad and fruit, nothing else. So we need to achieve three things: significant weight gain, maintaining full days at school and managing school dinners. Therefore, for the short term, we have agreed the following update to the Contract:

Re. the exercise part of the Contract: No “abnormal” exercise is permitted in school (e.g. running round the grounds, running from lesson to lesson, exercising in the toilets, etc). We’ve doubled the points Ben gets for exceeding his daily calories by 100 or 200. Also, Ben gets one extra point for a satisfactory school dinner. We also plan to update it over the summer holidays so we don’t have similar problems to last year when Ben was avoiding social contact.

**Sunday, 12 June 2011**

### **Finding workable solutions to “impossible” problems**

One thing you quickly learn as the parent of a teenager with anorexia or another eating disorder is that the most obvious and logical solutions to problems aren’t workable.

For one thing, at what I call the High Anorexia stages, anorexia changes the mind-

set from normal logical to totally illogical and irrational. Anorexics will swear that black is white - and believe it. Logic tells you this is not true and never will be - so what do you do? That's just one of the "impossible" problems you regularly get with anorexia...

An example of this might be the *#1 Problem* which is: child is losing weight fast... they need to eat more to put the weight back on... so the logical solution would be to ensure they eat more food. Sorted, right?

Pah. We've been finding "creative ways" around this problem for *months* and some solutions have proved more successful than others. Also, the *way* you approach things is key.

I've found a very subtle and discreet approach often works better than an enforced approach and over the months I've developed a range of little "tricks" that I bring into play whenever I need to.

One of the most obvious "tricks" has been the Recovery Contract. The idea is that Ben and I agree this together rather than it be seen as me "imposing my will" on him. But, of course, it was me that instigated the Contract; I wanted to test it out no matter what. Thankfully he thought it was a Good Idea first time round. No need for "Plan B", "C", "D" or whatever.

Another major problem you'll come across is of the "as a parent I can't stand this any longer... I can't handle this... let him / her get stick-thin and end up in hospital for all I care..." variety. With me, this kind of thinking was usually accompanied by me in floods of tears, curling up in bed or in some corner - usually following an almighty scene with Ben or just when the stress got to me.

Now, we all know that, unfortunately, caring for an anorexic teenager isn't something you can opt out of. You have to go on. You have no choice. No matter how impossible or hard it may seem, basically you have no choice. So you have to think of yet another "creative" solution to an "impossible" problem with various Plan Bs, Cs, Ds, etc just in case.

I always smile when I think of the standard question in job interviews i.e. "Do you see yourself as a problem solver?" Ha ha ha ha ha - they should try solving *our* problems as parents of anorexic teenagers!

Now, that's what I call a *real* "problem solver".

So which solution worked in the case of Ben not being able to go into school?

We decided that Ben would go into school when he felt able to - and when he had had a reasonable night's sleep. This would be either a full morning or a part morning. Because of the school dinners problem (food, social and "inactivity" for the full day) I'd pick him up at lunchtime every day. Some days he didn't go at all.

I set up a system with school staff whereby Ben took work or lesson notes home. I would also email staff on problem days and they'd email work to me for him to do.

Meanwhile, to overcome the potential problem of Ben not completing the year or "flunking" it, we applied to the local state school sixth form to re-do the year, starting September 2011. We got a place and the school has agreed to keep our application open until Ben gets his AS level exam results in August. Hopefully we won't need to take them up on this offer, but it's there just in case.

Throughout the term, I constantly tested the water to see if Ben was ready to do full days. Then, after Christmas, when Ben ended up in a bit of a rut and didn't seem to be making any progress on any front, I introduced the Contract.

It's achieved several things including making Ben more relaxed because everything is agreed and written down, including food and exercise, so he's not worrying about it in the middle of the night. So he started sleeping much better (before this he was a total insomniac).

Because he gets points for being in school part or full mornings, it's encouraged him to be in school more - so much so that by the start of this term he was doing full mornings every day.

By adjusting the Contract yesterday to encourage full days and adequate school dinners, we're hoping that Ben will start full days at school.

But, as we parents know, with anorexia it's often a case of "the best laid plans"... so I accept that he may not succeed right away.

However, at this stage in the recovery, I'm less inclined to make it "easy" for Ben to opt out of school, so I will need to be a little stricter - a case of being a teeny weeny bit "cruel to be kind". But I'll cross that bridge if or when I come to it.

Another thing with anorexia is that you can't rush recovery. Solutions take a long time to yield results or show you need to bring an alternative solution into play.

Unfortunately that's just the way it is, but there you go.

**Monday, 13 June 2011**

**Frustrated but not in the least bit surprised...**

...That I got a phone call from Ben at break time saying: "Can you come and pick me up at lunchtime?" So much for doing full school days from today onwards, but there you go... I knew he'd had a sleepless night but I wanted to check if there was anything else that was holding him back from doing a whole day - so when I picked him up, I asked him.

"It's a number of things," he said. "Today has been a really hard day. For a start I had a bit of a lonely morning. Then I saw the lunch menu and there was nothing on it I could really have."

"Why, what was on it?"

"Spaghetti carbonara and chicken kiev's," he said. "And I couldn't handle the girls in history lesson talking about slimming down for their summer hols. All I heard was constant talk about cutting back on meals, bikinis, flab, stuff like that, and it was too much for me."

"So how will you come to terms with listening to girls talking about things like that? After all, I guess most girls talk about that kind of thing at this time of year, so you will have to get used to it."

He's mentioned that kind of thing before and it's another roadblock we need to

overcome.

Undeterred, I stuck my oar out and added: "Do you feel able to go over calories today?" (because we agreed he would try to go over as much as possible in order to get back the lost weight).

"No," he said, which is exactly what he said yesterday and the day before too. "There are just too many pressures going on at the moment. All the above stuff plus loads of challenge foods and every meal this week is a challenge meal."

So I risked upsetting ED by pushing out the oar again and saying: "But you know you not only need to gain the 1.5kg you've lost but also get back on target. So, in a way, you need to gain more than 1.5kg over the next fortnight."

"I only lost the 1.5kg because I was ill; no other reason," he insisted.

B\*gger, I thought.

Of course I wanted to scream: "You're bl\*\*dy skinny! You could eat fish and chips five times a day every day for a week and you still wouldn't put on much weight, let alone blob out into Billy Bunter! Why can't you blooming well see this? We've been with this bl\*\*dy thing now for so long you'd think you'd at least be able to realise that, yes, you can eat what the heck you like and, indeed, you *do* need to eat what the heck you like or we'll be at this skin-and-bones weight forever!!!!"

But of course I kept silent.

Which is why, this afternoon, I was in one of my "jittery" frames of mind when I can't focus on anything and feel anger and frustration bubbling up inside me - anger at the anorexia for continuing to steal my son's life when he's been ill for nearly two years. Frustration at CAMHS for letting him stay at this low weight - now a lower weight than he was at the start of the CAMHS treatment back in February 2010. Yet, from what he's picked up from them, Ben believes he is "Weight Restored" which, of course, ED latched onto immediately, possibly taking it as a cue to put on the brakes.

ED, CAMHS or whatever; I just wanted to vent my anger / frustration at something today for showing that there are still so many issues we need to overcome before

Ben recovers.

Oh well, tomorrow is another day... another bash at trying to stay in school for a full day...

## **Monday, 13 June 2011**

### **Testing the water next month with a short holiday...**

Last summer, ED the anorexia demon, stowed away on our holiday and ruined it. So this year, so far, we hadn't booked anything. Yesterday I tested the water by booking a week in a cottage in the Peak District in July on condition that, this time, we stick to the eating plan / calories. Last year, CAMHS encouraged us to "take a holiday" from calorie-counting and "just eat / act normally".

Not surprisingly, Ben had lost quite a bit of weight by the time we returned - and continued to lose weight before stabilizing at a sub-optimal weight in the autumn, increasing in spring 2011 before returning to a sub-optimal weight on Friday.

On top of this there was *nothing* "normal" about our summer holiday. It was sheer hell!

But this year I've decided to push out the boat and test a week away. Being in the UK and in a self-catering cottage makes it easier to "police" and I have high hopes that it will be a success.

So, in addition to the usual holiday lists, there are meals to plan: breakfast, lunch and evening meals - because, this time, ED will be kicked out the door the moment he tries to ruin our holiday and make our son lose more weight!

## **Tuesday, 14 June 2011**

### **School and dabbing fat off chorizo...**

"Unless you hear otherwise, pick me up at lunchtime," he said this morning.

"Any reason why?" I asked. "We don't have any lessons in the afternoon today."

“Really?”

“Well only RS and then we have two frees.”

“But you know,” I responded, “It’s not just about lessons; it’s about all the other things that add up to being in school: social stuff, etc...” Anyway, we’ll see what happens.

As I said yesterday, there are a number of reasons why he is still finding school difficult. One year ago he found school impossible, so we must be thankful for (not so) small mercies. And I know we can’t rush these things. But I also know that it’s not always a Good Thing to be a permanent “safety net” he can run to whenever he needs to. Not at this stage, at any rate. Back in the Bad Old High Anorexia Days when the alternative might have been for him to flee across the school field and jump into the river or just go AWOL, maybe... But not these days.

So it’s difficult to know the best and most helpful thing to do.

The best thing is probably to be there if he really needs me, but make it clear that I “might be out” or “working” or whatever, so it would “help me enormously if you could do a full day” kind of thing... Or just to treat every new day as if it was going to be a full day at school rather than, as before, taking it for granted that I would pick him up at lunch. Play it by ear and gut instinct... this usually works...

Yesterday afternoon I drove past the local secondary school at home time and watched a bundle of sixth form boys the same age as Ben laughing and joking as they walked down the road, each of them looking just like a 17 year old boy should look like, not stick-thin and pale like Ben.

But comparisons like this aren’t helpful, really, in the same way they’re not helpful to any parent of a child who is different from its peers through illness, disability or whatever. Or worse.

I know he’s finding it particularly hard at the moment; I can always tell.

He was pretty down in the dumps and silent last night, and we had an argument when I was preparing tea. He was hovering around watching me cook (echoes of the

Bad Old High Anorexia Days), telling me how I should cook the chorizo in the paella (“Cook it first, then remove it from the pan and dab off the fat”), me ignoring him completely except to say “I will cook as I always cook,” then him zooming in with some kitchen paper to dab the “masses of fat” off before the tin of tomatoes went in and it was too late...

When I challenged him, he gave me a lecture on healthy eating. (Yep, we parents are all familiar with these “lectures” about saturated fats, blocking the arteries, heart attacks, blah blah blah blah...)

Well you know that yesterday I was frustrated and angry with things so I was spoiling for a bit of a fight.

But the Good News is that it wasn't like in the Bad High Anorexia Days. Well, not quite. Sorry, but I couldn't help saying, “I can never get my head around why anorexics are so obsessed with ‘healthy eating’ while on the other hand they are busy damaging their bodies, sometimes quite seriously...”

A red rag to a bull, I know, but I'm only human. I'm not perfect. And when he said, “You know mum, that kind of comment isn't helpful to me *at all*”, I responded with: “Well all of this isn't exactly helpful to *me*, either. I'm a person, just like you, you know...”

It wasn't a Bad Row. In the past, it would have spiralled out of control and Ben would probably have walked out of the house or started thumping things / throwing things around. But he didn't do this last night and I kind of knew he wouldn't.

So, despite everything, I can still see massive improvements and positive things.

The Very Good News is that I can now speak my mind without worrying like heck that I'm treading on eggshells and about to detonate a lethal explosion.

In other words, I'm feeling positive... strange as it may sound!

**Tuesday, 14 June 2011**

**“What matters?” asked the church website. This matters!!!!**

Someone from the church I used to attend sent me an invite to upload a photo onto their new website in answer to the question: “What matters?”

I have a photo I would like to upload, but probably won't as it's far too personal and the “uninitiated”, as they say, just wouldn't “get it” - because, as another boy who has anorexia who messaged me today said, people find it hard to “get” anorexia in boys. Why this photo sums up “What matters?” to me is...

... because it (taken when Ben did the *Coast2Coast* cycle ride with his dad back in the summer of 2008) says: “Yay, I've done it!!!!”

And he will... I know he will...

**Wednesday, 15 June 2011**

**Most definitely NOT your typical “mama material”...**

Until my mid 30s I vowed never to marry and definitely never to have kids. I was an independent “career woman”.

If that sounds impressive, it wasn't. I had a pretty chequered past with hideous teenage years where I messed up my school exams, ended up on a dead-end college course, changed friends, boyfriends, apartments and jobs in almost indecent quick succession and went through a particularly “wild phase” in my twenties.

By the time I was 30 I was a decade behind my more “sensible” peers on every single front: maturity, career, relationships and kids. Then at 34 I got married and by 35 I was expecting Ben...

I was never cut out to be a mother. I remember being in floods of tears at six months pregnant because I was petrified I'd be a bad parent.

I'd always avoided babies and kids like the plague and I hated “talking nappies” with other mums-to-be. Basically Batty Matty wasn't “mama material” and never would be.

Ben's birth was a nightmare experience to say the least with just about every intervention known to womankind, but when he was born I was surprised at the overwhelming bonding that took place. I felt this powerful emotion that I would protect Ben no matter what.

I always loathed Mother and Toddler Groups, play groups and stuff like that. So did Ben because he was always the child that screamed blue murder all the time while the other kids played nicely. As a result, the other mums avoided me like the plague, but I didn't care.

I was always the one that rebelled against the "norm". When all the other babies were decked in pale pink and blue, Ben was wearing clashing primary colours, wearing weird and wonderful hand-knits and had a home-made *Coca Cola* logo'd pram parasol made from a boot-fair bargain and some cheap fabric I acquired at the local market.

Despite the fact I loved Ben and – in the event – turned out to be a reasonably good mother I guess, I was never your "typical mama". I was always the rebel.

Yet it's funny how the eating disorder has meant that my primary job these days *is* being a mother - the very thing that once seemed so alien to me.

But I think one of the things that's helped me manage this the most *is* my chequered past, especially my experiences as a teenager which aren't a million miles away from what Ben has gone through (but without a marked eating disorder, but I definitely had "disordered eating", if you like...).

Ben is also spookily similar to me in so many ways.

I think this is why I seem to "get it" and also why I spend so much time thinking about eating disorders and moving in these circles.

It's not because I want everyone to think "What a saintly mother; she manages her son's eating disorder awesomely!" or anything like that - because I don't.

I don't work as much as I used to, and when I do work I work from home, so I have far more time to devote to the eating disorder than many parents.

I have an awesome support network - the other mums on the ATDT forum plus some amazing former anorexia sufferers who have provided invaluable help.

I have the best friend in all the world – Sue - who is always there to lend a shoulder for me to cry on and offer wise, practical advice.

In addition, the support I get from Ben's school is incredible with teachers – and especially the school nurse - going over and beyond the call of duty to help Ben.

And this blog acts as a kind of catharsis in the same way my teenage diary did during the 1970s (ha, that's another story!!).

Oh, and I probably spend far too much time on this blog: time I should spend earning some money and, more importantly, spending quality time with Ben which is why my guilt feelings have prompted me to promise to go to the park with him in a minute.

**Thursday, 16 June 2011**

### **Hoping to stay in school long enough for the inter-house talent contest...**

Ben is a fantastic singer and the last couple of years he's taken part in the school *inter-house* talent contest in aid of charity.

In 2009 he came first and last year he came second which was amazing considering he hadn't been officially in school since the spring and found it really hard, if not impossible, to be amongst his peers.

But there he was, standing up in front of the audience, singing away...

And today, if he can manage to stay in school long enough, it's the 2011 contest and I'm taking my mum along to watch.

Last year I was probably the only parent in the audience who had completely different stuff going on in their head when I sat down in the school theatre.

Firstly, I was worried sick that Ben would get up on stage and then freak out and / or flee, in front of everyone. I didn't care what anyone else thought, but I did care about how it affected Ben...

But he went ahead. And he was fine. In fact he came across so incredibly confident, relaxed and poised you'd never have guessed there was a problem except that he was very thin.

But what did break my heart was the fact that none of his friendship group or peers bothered to turn up to support him.

Unlike the other acts which received whooping and cheering from the other kids, the audience simply clapped politely when Ben finished and when he eventually won second prize. Apart from me, of course, who desperately tried to make up for it...

That really cut me to the core.

It really did.

Let's hope, if he manages to do it today, that some of his friends turn up to support him this time.

**Friday, 17 June 2011**

**Like last summer, something had to give before my brain imploded...**

I have no idea how I managed to carry on "business as usual" with my freelance copywriting during Ben's rapid descent into anorexia, but I did... in a way... until something just had to give, and it did... and I think it has again...

First, let me just say that I am in total, absolute and complete awe of any parent of a child with an eating disorder who manages to carry on working for someone else, outside the home. I simply couldn't have done it, not with having to be on constant red alert for emergency phone calls from school: from Ben, from the medical centre and from staff. Not to mention all the tears.

Every day it felt as if I was having to "down tools" at a moment's notice and rush into school to face some kind of disaster, followed by a terrible afternoon and evening back here when I brought Ben home - not to mention the sleepless nights, etc etc etc... you know where I'm coming from...

I was incredibly lucky in that I worked for myself, from home. So, to a certain

extent, I could work around the problems. It meant having to drastically reduce my hours because I had to allow so much “buffer time” for any longer, more distressing issues. But somehow I still managed and I have no idea how. I’m not saying this to boast or sound like “super woman”. I’m saying it to show that (a) I was lucky having this flexibility so my clients never knew anything was going on (so I didn’t lose clients and I continued to earn money), and (b) that even this wasn’t sustainable and something had to give.

As well as juggling the Ben issues, I was constantly moving projects around in my diary, saying no to new clients or anything too mentally demanding, cancelling stuff, making excuses, constantly pretending to be “rushing out to urgent meetings” and so on. Boy, my clients must have thought I was incredibly successful, lol...!!

I managed work better after we’d made the decision to remove Ben from school. Also, because he was revising for his GCSEs, I worked while he was studying. Then we’d both take a break and spend time together, walking, shopping or whatever. When he did his exams, I worked on my laptop in the school car park. So, thankfully, I was able to pay my share of the household bills. However when the summer holidays came, things changed drastically in every way.

Not only did Ben’s mood and weight deteriorate rapidly but he embarked on a suicidal phase which was a total nightmare for everyone. I tried to forge ahead with my work, already cutting it down to the absolute essential stuff - loyal and long-standing clients who I simply didn’t want to lose and who I love working with.

Then during the summer I got to a stage where I realised something had to give before my brain imploded. I was an emotional and nervous wreck.

It was as if something “pinged” in my brain and shut off. I just stopped. I knew I had to take a break from work and had no choice. So much so that I had to explain the situation to most of my regular clients and pass work onto another copywriter.

Apart from the odd five-minute job, I stopped work altogether to concentrate on Ben and on me. I wasn’t going to be in the slightest bit useful to Ben as a carer if I

was a total and utter emotional wreck!

My GP put me on a low dose of *Prozac* which calmed me down once it started to work and enabled me to be a better mum to Ben. The psychiatrist put Ben on the same stuff, which helped him, too.

By being frugal we pretty much lived on my H's income until he lost his job earlier this year when I had no choice but to crank it all up again and start earning some money!

Thankfully this coincided with Ben's improvement, so it couldn't have been a better time, really, and I was able to do it. And I *enjoyed* doing it. I managed to work around Ben's schooling; the days of being on constant red alert for phone calls and texts had well and truly gone! Also, despite a couple of casualties who obviously went elsewhere, I managed to keep my regular clients who were happy to wait until things improved.

But lately I've been aware of things building up again. Yes, H has started a new job thankfully and, yes, Ben has improved, but we've had additional problems /stressors – like having to sort out the damage caused by Ben believing he was Weight Restored when he most definitely was not. It's had a marked and very negative impact on how he's responded to my encouragement and the Recovery Contract and on his morale in general. It's as if ED has gleefully leaped in and taken the advantage.

I feel that so much of the good, positive stuff we have achieved over the spring was destroyed and I'm having to re-build from the ashes.

Oh and my dad is still in hospital and I've been visiting him every day as well as looking after my elderly mum who is on her own.

I think it was a mixture of lack of sleep, anxiety, juggling too many balls at once, anger at the damage caused by the CAMHS / Weight Restored incident, other issues with Ben, dashing around here there and everywhere, not eating properly, not to mention all the cooking and food shopping / planning you have to do with and anorexic teenager in the house... that drove me to make a silly mistake yesterday

when I pulled out of my road into another car. My first accident in 20 years of driving!! And the most stupid, elementary mistake in the universe. A learner driver wouldn't have done that. It wasn't even busy traffic; it was lunchtime!

By the end of the day (having continued to juggle balls, report the accident and all the other stuff that goes with it) I felt as if my brain and being were about to implode.

So that's where I am at the moment. Probably not a bad idea to visit my GP again, and also take a break from work for a while...

Just like I did back in late August of last year, I need to work out what I can drop from my life; what's not important and can be put onto a back burner.

So it's time for a bit of a "life laundry", I think...

## **Friday, 17 June 2011**

### **Okay, so how did the talent contest and the full school day go?**

Well, he managed to do it all and he had his first school lunch for ages. However he chose to sit alone and went for Mediterranean veg "oozing with oil so I left some of it", pitta bread and fruit. Hmn.

"I also had a problem sitting around all day doing nothing," he said. "And my performance at the contest wasn't my best to say the least." Actually I thought it was good and Ben seemed ultra-relaxed, but then he always does when he's up on stage singing.

My heart sank when the teacher said there were 17 acts to get through. "Looks like we're going to be here for a while..." I said to my mum who I'd brought along and we watched a mixed bag of performers before finally getting to Ben.

Unlike last year, quite a few of his friends were there and he got loads of applause, etc. But I could tell something was up and he was very quiet by we got home. He took himself off to bed at 9 o'clock in a bit of a low mood...

**Sunday, 19 June 2011**

**Just when I thought it was safe to go back into the water...**

After eight-plus months of relatively problem-free eating out, who should come along to our Father's Day Eve meal at *Pizza Express* last night but ED... and it wasn't unlike the time when it made a similar unwanted and distressing appearance at a country pub back in the winter and at *Pizza Express* the previous winter. And I have yet to work out how to deal with it...

It all started out reasonably well until Ben decided to put together his own choice of pizza toppings. When the pizza arrived, he took one look at it and the volcano started to erupt... The reason? There weren't enough of the ordinary toppings, but far too much cheese. H insists he heard him exclaim under his breath: "I can't eat all those calories!"

Ben demanded we send it back and started to get stropky in a loud and embarrassing way which included tears. Meanwhile baffled staff including the manager rushed to our table to see what was wrong - and in the end Ben fled from the restaurant.

Of course this totally ruined the evening for H, but, hey, we're "old hands" at this kind of disruption...

Somehow (probably due to the wine) I managed to keep things extremely calm and calm down H who was muttering stuff like: "We are *never* coming here again... he is no longer my son... he's had the best education in the world and look how he repays us, the selfish little g\*t... I want *nothing* more to do with him... for all I care he can go off and top himself," etc etc etc...

This time I insisted we carry on as if nothing had happened, not letting ED upset us or ruin the evening more than it had done already and ignoring the untouched pizza rapidly going cold on the table beside us. To be honest, I didn't care where Ben had gone. Nor did I give a damn about what our fellow diners were thinking about the very public display. I still felt extremely "zombie-fied" from last week, unable for

some reason to feel extreme emotions. It was as if my brain and emotions were totally numb.

We finished our meal and asked for the bill which (cringe) the manager brought personally. He (cringe) said he wouldn't charge us for the uneaten pizza. We insisted we pay for it - but he wouldn't let us (cringe again), believing the restaurant was at fault. Never in a million years could he have known that there was nothing wrong with the pizza and everything wrong with Ben... It was surreal. So I left a large tip covering the cost of the untouched pizza which I will deduct from Ben's points along with the points I deduct for "unacceptable behaviour" which I've only had to do once before.

Then Ben returned and apologised. I insisted he drink his glass of wine which was also standing on the table untouched. And I asked him what he was planning to do to make up for all the lost calories. When we got home he cooked himself a curry and managed to make up the lost calories.

But that wasn't the point.

It was almost a carbon copy of other experiences we had during the Bad Old Days of High Anorexia.

Why had ED returned in such a stark and disturbing way?

I wouldn't be surprised if Ben is still losing weight after last Friday's significant weight loss. He has actively been resisting extra calories over and above the agreed daily total and he hasn't been looking very healthy.

It might be just me looking for a scapegoat, but I can't help thinking that this recent decline coincided with the Assistant's remarks about Ben being Weight Restored.

And this Friday, the psychiatrist made a comment that made me seethe. But that's for another blog entry...

Meanwhile there I was at 1.30am this morning, unable to sleep, just like in the High Anorexia days... making a hot drink in the kitchen and stuffing my face with

“comfort” biscuits... then trying to get back to sleep telling myself that it was neither the time nor the place to start working out a Plan to patch up any damage and get back on course.

I am just about to embark on a conversation with Ben as he’s said *nothing* about last night...

**Sunday, 19 June 2011**

### **Pizza Express incident was due to ED-induced confusion**

“Okay, so let’s do yesterday’s points, Ben. First, I’m deducting four points for unacceptable behaviour last night. Also, I paid £10 for a pizza you didn’t eat so I’m afraid that will have to come out of your points, too, because - as you know - the contract points are about moving us forwards and I believe last night was a step backwards.”

“No, it was nothing to do with anorexia,” insisted Ben. “I genuinely thought there wasn’t enough topping: four prawns, a few mushrooms, a couple of pieces of pepper... if it was the anorexia I’d have complained there was *too much*! Then the manager came over and it all started getting out of hand. On one hand there was me saying I didn’t have *enough* toppings and on the other, there was the manager insisting I’d been given the ‘correct portion’ for each topping. Result, total confusion. Were the toppings too mean or was I being greedy wanting more? I was confused. I couldn’t handle it so I walked out.”

“Aha, so it *was* about the eating disorder, then,” I responded, to which he protested that we hadn’t backed him up in complaining to the restaurant manager and surely we “could have seen the toppings were on the mean side?”

“The point is,” I said, “that we were there to celebrate Fathers’ Day and to give dad an enjoyable and relaxed evening. The reverse happened. The way you behaved simply wasn’t the way a mature 17 year old should have behaved, especially on Fathers’ Day. Most people would have bitten the bullet and pretended everything

was fine, even if, in your opinion, the pizza wasn't ideal. Basically it was selfish and unacceptable behaviour, do you not agree? The *good* side of it all was that you *did* go on to have all your calories once you were back home."

"And 100 over," he interrupted.

Anyway, I'd made my point.

The incident was caused by ED-induced confusion. And people with eating disorders get confused about stuff that other people don't. But eating disorders are notoriously self-focused and remove the ability to see the bigger picture. You have the double whammy of teenagers being inherently selfish coupled with the extreme self-centeredness of the eating disorder.

Hmn.

**Tuesday, 21 June 2011**

### **16 months of treatment and how effective has it been?**

As you know Ben has come on leaps and bounds on the behaviours / mood front over the past eight months. He is also managing lots of "fear foods" which used to freak him out. But I can't help thinking that the treatment has been a bit odd... In fact it's difficult to pinpoint exactly what form the treatment takes.

Yes, our two-person treatment team is brilliant at listening and asking questions. They're also great "fire-fighters" in a crisis and very nice people, too. Very nice indeed.

The psychiatrist's assistant in particular is also very good at taking notes. At first I thought the purpose of this copious note taking was so they could go away, have a meeting and formulate a strategic plan of action. But 16 months on she's still taking notes. We've had loads of promises about the need to focus on this, that and the other, but - unless these things are like some kind of hidden agenda working away in the background - I still haven't a clue what the Big Plan is...

At first, back in February 2010, the team didn't take us very seriously. Or at least

that's the impression I got. Yes Ben was underweight for his age and height, but not disastrously so. (Let's forget the fact they hadn't known him when he was a strapping athlete and rugby player...)

I was kind of treated like a paranoid mother and felt as if I was making a load of fuss over something that really wasn't too bad at all.

Because his weight wasn't dangerously low, there was minimum focus on the need for weight gain. Instead the focus was on the cognitive side of things i.e. talking about the past, talking about our issues as parents, talking about Ben's problems with socialising, being in school, anxiety, etc. But just talking about it, really...

Oh and emphasising that Ben had to "want to recover" before he could.

But, importantly, I felt strongly at the time that I wasn't being supported in my powerful gut instinct that the primary focus should be on getting the weight back onto Ben - and that we shouldn't stop until he was well and truly Weight Restored.

It was always a case of suggesting it might be "easier for Ben to handle" if we arrived at a weight "he could cope with", even if that was well below his previous weight. Ben was (and is) asked what kind of weight he'd "be happy to settle at".

The assistant even once said that "some people just choose to settle at a lower level and stay there, so they do. After all, it's their choice; no-one can force them. By this stage they are adults making their own choices".

Aaarrggghh! How I hate the word "choices"!

But in those first few months of treatment I had no idea that this kind of approach might not get us anywhere. Indeed the weight issue has proved a definite "spanner in the works", especially recently. Ref the assistant leading Ben to believe he'd "arrived" at an acceptable weight the other week and ref this week when Ben was told that "medically you *do* need to weigh more than you do now. Probably not as much as your mum would like you to weigh but somewhere in-between".

This has been bugging me ever since and has led me to ask exactly how we are benefiting from the professional treatment. If all it does is make Ben depressed and

undermine my efforts to gently push him towards a proper weight level, is the treatment actually of any use?

I am tugged in so many directions and am very, very confused.

My own experience has shown that Ben flourished once I put my foot down, challenged the treatment team and started to follow my gut instincts on the eating / weight gain front.

I first put my foot down back in September and we gradually experienced a turning point in the recovery process which started around October and continued.

I put my foot down again earlier this year when I realised that we'd reached a plateau / *Limboland*. So I formulated our Recovery Contract which saw Ben gain weight at an acceptable weekly level over a number of weeks.

It can't be a coincidence that his current resistance to weight gain started at exactly the same time as the team challenged my concept of weight restoration and then made that other unhelpful comment last week.

Eating disorders love triangulation between parents and professionals - and, obviously, the eating disorder is going to take the side that implies they can "finally settle" at a weight they are "happy with". In other words, don't listen to mum who's insisting you need to weigh even more.

Translated into ED-think read: "Don't listen to mum who is trying to make you fat."

More on this subject later no doubt...

**Tuesday, 21 June 2011**

**Finding out what Ben thinks about it all...**

I wanted to know what messages Ben has been taking home from our recent treatment sessions as regards weight gain / weight restoration.

With this came lots of positive stuff about the other ways the team has been supporting us over the past 16 months which, I agree, they have.

This is reassuring because I wasn't entirely convinced our sessions were doing him

any good as he always seems depressed, before, during and afterwards. Unfortunately, however, he does believe the team is happy for him to settle at a final weight which is “massively lower than what you and dad would like me to weigh”.

It’s really hard at this final stage (I say “final”, but I still believe we have quite a few kg to go...) to know if the treatment team has “overstayed its welcome”, so to speak. They’ve done their job on a number of counts and helped us fire-fight crises; the only thing they’ve never really pushed for is proper and continuous weight gain.

After all, he weighs less now than he did at our first session 16 months ago and this can’t be right when we’re talking about a former rugby player / athlete / cyclist who is 5ft 7ins tall and is almost 18 years old.

The only thing that has resulted in regular and consistent weight gain recently is the Contract I introduced a couple of months ago.

But the more the Contract works on this front, the more we (me, son and team) end up disputing what constitutes a sensible and acceptable weight range.

And of course the eating disorder sides with the person who insists on the lower range, distorting what we parents are pushing for into “wanting to make me fat”.

Some might say I’m getting obsessed with numbers again. But at the end of the day I know my son will never recover until he reaches his natural weight level otherwise known as “full nutrition”.

Treatment methods like the *Maudsley* would have focused on weight gain first and not second. To be at a lower weight than he was when he started treatment 16 months ago and for this to be perceived as “almost there” is just wrong.

Yet, on the other hand, the team acts as a kind of anchor. I guess it’s a bit like having parents that irritate or embarrass you but you’d miss them like hell if they weren’t there!

**Tuesday, 21 June 2011**

## **Old blog from May 2009 which shows the storm clouds were gathering...**

Accidentally clicking onto a blog I used to write for a regional newspaper I found this entry following our spring half term vacation in Somerset. Read it and realise that, yes, the storm clouds were seriously gathering... and no-one realised!!! (The eating disorder began to manifest itself more clearly a couple of months later...) Just look what I've written near the end re. "anorexic"! Aaarrrrggghhh!!!

### ***Meltdown at the Marine Lake***

*In case you missed it, there was a serious emergency going on by the Marine Lake at Half Term. 15 year old Ben wasn't just having a Bad Hair Day; he was having a Total Image Meltdown...*

*So there was NO WAY he was getting out of the car when we arrived in Weston from home.*

*His hair was all wrong. Just as tragic, he'd left his rock star sunglasses at home. His (positively concave) abs were "fat" and the face wash he'd pinched off me had given him spots.*

*"You look wonderful," I sighed for the umpteenth time as he carefully positioned each expensive 'putty' covered hair into place.*

*"I beg to differ," he said in a condescending way, pouting his lips in the car mirror and scrutinising his face from each side.*

*Honestly, it's worse than having a daughter. He spends more time getting ready in the morning than I ever did. And in my day we didn't have hair straighteners, ionic*

*hairdryers and half the goo, wax, putty, gunk and gel you can get these days.*

*It was so much easier when Ben was little. Back then he was content with a quick short back and sides at the barbers. A quick rub with the towel, a free lollipop and he was as happy as Larry. Or, if funds were tight, a swift once-over with his dad's electric clippers.*

*Now he's taken a liking to the rather pricey hair salon I use. Even the "graduate stylist" costs a sharp-intake-of-breath-inducing £26... Add on the tub of hair goo and you don't get much change from £35.*

*The only consolation is that hubby's hair costs absolutely nothing to maintain. He's as bald as a coot.*

*Anyway walking towards the Marine Lake, Ben was taking a critical sideways glance into every window.*

*He was pinching bits of "fat" on his stomach and checking if his (skinny) bum looked "too big"... "Do you think I'm good looking?" he asked doubtfully.*

*"I think you look wonderful!" I replied brightly, worrying he may be bordering on the anorexic. But then remembering how he enthusiastically cleared his plate the evening before and feeling reassured it was "just a phase".*

*"I'm going to dye my hair black," he said. "Oh, and I'm planning to become a Buddhist."*

*"You're WHAT?!"*

*But he wasn't listening; he was busy texting his mates. "They've gone into town shopping," he said, hating being stuck with us in Weston-super-Mare on a Bad Image Day and scowling as hubby took a photo of him and me on the beach as we walk towards the Pier.*

Crucially that day, I remember trying to find some lunch that suited all three of us. H went for fish and chips while Ben went for nothing in particular (I can't even remember him eating) while I went for a sandwich in a café later on.

**Thursday, 23 June 2011**

**Looking back on a year ago has been "very useful"...**

I've been looking back on my ATDT posts to see where we were 12 months ago. Truly, I feel the anger I felt in June 2010 when...

...Just because Ben's BMI wasn't rock bottom, my concerns weren't taken seriously, despite the fact that rugby-playing Ben had lost one quarter of his total body weight over the past 12 months.

Initially the treatment team did permit me to administer a 3 x meals / 3 x snacks Eating Plan and he started to regain some lost weight.

But when the Eating Disorder threw a tantrum three months on and refused to continue, the team decided to "hand back the control to Ben" because it was felt this would be "more helpful to him".

When, as a result, his weight started to go down they weren't "unduly concerned" because, at that stage, he was "nowhere near what he was when the treatment started" which was a "good sign because he's done so well".

The team decided it was "time to focus less on the eating side of things and more on working together as a family to see what is helpful to Ben and what isn't".

With our family vacation coming up and the long summer break from school it was

decided that “we should take things a bit easier all round” and use our vacation “as a holiday from food pressures and calorie counting”.

I was banned from mentioning food, eating and calories whilst on vacation. The vacation was a nightmare and Ben lost some weight. Over the next few months, Ben’s weight continued to go down and, with this, his moods and behaviours deteriorated, including suicide threats plus some increasingly dangerous and distressing behaviours.

At the treatment sessions he was in a Good Mood when he’d lost or maintained weight - and was hell to live with if he’d gained. As a result the weight continued to zigzag downwards.

Meanwhile Ben was still in complete control of his eating and food preparation (except evening meals). The thinking was that by “experimenting to see what does and doesn’t work” and “making mistakes” he’d learn from them and this would help him change. “It’s all a bit of an experiment,” they insisted.

By September / October 2010 we were still “experimenting” and getting nowhere. But then in October 2010 we experienced a breakthrough.

*What triggered this breakthrough?*

For the first time ever, the treatment team came down on Ben like a tonne of bricks following his second heart scare in six months when his pulse went down to 29 and I rushed him to hospital again. He fought tooth and nail to be discharged, kicking furniture and having to be restrained by security staff and eventually the police.

Suddenly at our next treatment session the atmosphere was different with direct, straight-talking of the “we insist you have to do X or there is a real chance you could end up in hospital. With the heart scare we don’t have to wait until your BMI is dangerously low; we could hospitalise you now” kind of thing. The word “sectioning” was used...

I believe that something “clicked” inside Ben. By now he completely trusted the treatment team because they were working with him in the way he (the ED?) wanted

them to, and here they were laying down the law, so they must be right!

Also the *Prozac* he'd been prescribed back in August started to have some positive effects on his mood.

Maybe it was a combination of the two, but Ben's motivation, moods and behaviours did a U-turn for the better. However he didn't gain any weight. Six months on he'd simply maintained and fell into a motivationless *Limboland* because he felt he wasn't achieving anything.

Also, the positive action and drive I'd seen from the treatment team following the heart scare kind of melted away and we were back to "experimenting".

After a few months of genuinely feeling that the treatment team and me were "on the same page", moving forward and achieving things, everything ground to a halt.

This is when I introduced the Recovery Contract which worked a treat in every single respect (weight gain, motivation, etc) until a couple of unhelpful comments from the team (see recent entries) stopped Ben in his tracks and appeared to undo the good that had been done.

So I feel the anger I felt 12 months ago almost to the day.

And this anger hasn't changed that much really...

**Thursday, 23 June 2011**

**More on one year ago today, here's the note I sent to the psych...**

I've just found a copy of a note I sent to the psychiatrist one year ago following Ben's "melt-down"...

*Last night Ben had another serious breakdown similar to the "roof" incident a couple of weeks ago. Yet again he went into that "manic" state of mind where he has "no emotions" and starts to talk in a deeper, slower, almost drugged kind of way, saying there's no reason to go on, his life is a total waste of time, etc.*

*Ben started the descent at teatime (in response to being gently encouraged to eat more than the 2,000 calories per day he's been eating and which is probably responsible for his recent weight loss).*

*Initially I was alerted by his friend's mum who called to say she was very concerned because Ben had sent her son an email saying: "Give me three good reasons why I should live." I immediately confronted Ben about it and things spiralled downwards after that – seriously downwards.*

*My husband is working away this week so it was just me on my own and none of my friends was available to come round.*

*Ben refused to go to A&E and the Emergency Doctor didn't sound as if he was going to be much use. It didn't warrant a 999 call, thankfully...*

*But it was very serious and Ben said he's always thinking about suicide only he doesn't have the courage to do it. Or, as I said last time, it will happen as a result of some action taken simply because he's lost all his emotions and doesn't give a damn about what happens.*

*I worry that one day he WILL find the courage to do it. And as his mood deteriorates as his weight goes down, I strongly believe something terrible will happen.*

*He says he's permanently depressed and the times when he seems okay he's just pretending. It's all fake and not real. The "real" Ben is this depressed, broken down mess.*

*This is a risk we can't ignore – and, as his mother, I certainly can't ignore it. Something urgent needs to be done.*

Thank God he came out of that nightmarish phase!

**Friday, 24 June 2011**

**Yay, successful full day at school yesterday!**

Actually he had no choice because I didn't have a car yesterday, so I couldn't have collected him early. When he got home he was fine. He'd managed his lunch (even if half of it was from *Sainsbury's*) and done a load of socialising and getting involved in activities. Also, he made up for any missing calories later in the evening. So a successful food day, too, at school. School dinners use to be one of my major worries!

"How did you cope with the other stuff?" I asked him. "Like the urge to exercise?" One of the major problems he still has (but is working on with the help of the Contract) is what he describes as "sitting around at school all day, doing nothing". Forget the fact that the brain needs loads of calories and he's moving around school from lesson to lesson; unfortunately he doesn't see it like this yet.

"I found it hard," he replied.

"But you did it and that's what counts," I said. "Surely you've learned by now that 'sitting around in school' doesn't make a blind bit of difference to your weight?"

"Well, we'll see what happens when I'm weighed tomorrow..." he said.

Damn. Does this mean we're back to the knee-jerk cycle of "If I've put on weight it means sitting around at school makes me fat and therefore I need to be at home exercising to ensure I lose the weight again"?

This is a key part of what I've described in previous entries as "going round in circles / downward spiral". And it seems as if CAMHS are doing little to stop it in its tracks except getting Ben to promise to "try harder" for next time.

Today is CAMHS and, to be honest, I'm not optimistic about how they will handle things. But let's wait and see...

Anyway I congratulated him on a Successful Day at School and told him he should feel proud of himself. He's really achieved something.

**Sunday, 26 June 2011**

### **Twinge of the green-eyed monster?**

Okay, let's not beat around the bush. I admit it. Meeting an old gym friend today I felt a twinge of envy as she talked about her forthcoming summer vacation in France - and it's the first time for donkeys' years that we haven't been to France, too. Why no French holiday? A combination of vastly reduced income and increased cost of living coupled with a reluctance to book another holiday after last July's disastrous trip to the Cognac region with ED, the Eating Disorder Demon, in tow.

In today's paper there's a section about the top 100 books to read on the beach. This will be the first year we haven't been on a beach for *years*. But last year I didn't do any reading on the beach. I was too anxious about what anorexia-ridden Ben might get up to. On one side we had the pounding waves of the Atlantic Ocean where it meets the wide Gironde River, so you have to be especially careful about powerful currents which can drag you out to sea.

Yet Ben's anorexia compelled him to swim up and down punishingly completely oblivious of the fact he was being pulled further and further out to sea. He seemed miles out compared with anyone else.

I remember dashing into the sea and frantically swimming out to him to try and drag him back. I was terrified and I quickly realised just how exhausting swimming in such a strong current can be. I managed to reach him and drag him back, but it really was as if the anorexia demon had blinded him to the dangers. Meanwhile I was all too painfully aware of whatever it is that drives parents to put their own lives at risk to save their child from danger. After that I never relaxed on the beach again and

kept an eagle eye on Ben whenever he went into the water.

On the other side were vast sand dunes and a pine forest where Ben went AWOL after one particular “I can’t go on with this life any longer” occasion. I truly thought he wouldn’t come back. Eventually after a very long time he did, but his depression hit rock bottom and after that we kept away from the beach, beautiful though it was...

I remember looking around me, thinking it was nightmarishly surreal being surrounded by families having a normal, happy day on the beach while our family was living out a nightmare. It was painfully surreal...

Coincidentally who should I meet on the ferry journey from St Malo to Portsmouth last July but my friend from the gym, en route back home after a cycling fortnight in Brittany. But even on the ferry I couldn’t relax.

By now Ben’s suicidal / self-harm tendencies were showing loud and clear; something that was to blight the rest of the summer for us. Suddenly I was viewing the swirling deep green water of the Atlantic Ocean on all sides a little differently from other people. I felt anxious the moment Ben went out of my sight...

But that was last year - and this year seeing my old gym buddy again reminded me of good times we’ve had as a family on holiday in France.

Never mind, there’s always next year. And, anyway, my passport has run out.

**Monday, 27 June 2011**

### **More about the surreal world of being a parent of a teenager with anorexia**

In the last blog entry I alluded to the surreal way we sat on the beach in France last summer. All around us families were going about a normal, enjoyable, fun day at the beach while we were in some kind of invisible, nightmarish “bubble”, cut off from the rest. This was how it was for us for an entire year, reaching a nightmarish height last summer.

It was like living in some kind of surreal parallel universe.

For as long as you can, you (attempt to) work as normal (work can be a welcome distraction; anorexia also makes you much more disciplined because you never know when you might have to “down tools” at the drop of a hat).

But what you don't do as normal during what I call the “high anorexia” period is to go to the supermarket normally, eat out in restaurants or cafés normally, drop off and pick up from school normally, watch TV normally, eat meals normally, sleep normally and generally live life as a normal family.

In the surreal world of anorexia, you're painfully aware of how normal other people's kids seem. In the Good Old Pre-Anorexia Days, Ben used to finish the school day like everyone else, laughing, joking and generally messing around. In the Bad Old High Anorexia days, Ben would invariably skulk across the car park alone, a haunted look on his thin face, his school uniform almost falling off his emaciated body.

With “high anorexia”, picking up from school is a lottery because you never know how your child is going to be - reasonably okay or in the depths of depression with tears all the way home. You feel as if you're treading on eggshells.

With “high anorexia” you're constantly expecting a call from school saying Ben is in Medical, can you come and fetch him. Or a text from Ben saying he “Can't go on like this”, “Anorexia's kicking in” or whatever.

After a particularly harrowing day in spring 2010 when I received 22 distressing texts from Ben, we made the decision to take him out of school for the time being, despite GCSE exams being on the horizon. If he flunked them, well, so what... All we were interested in was his full recovery from this dreadful condition.

During the darkest anorexia days, TV programmes were interrupted as we reached another “crisis” and tried to calm Ben down. The cooking of meals had to be “policed” to make sure no “dangerous” foods went into recipes (e.g. cheese, butter, etc).

Calories were counted meticulously and portions measured. Too big or too small a portion and he was thrown into confusion. The kind of confusion that had him

banging his head on the fridge door in frustration. Once, he even cleared the fridge of (reduced fat) cheese, chucking it in the bin.

At the height of anorexia, you're constantly on red alert when asleep, like you were when your child was small. And you go through *Kleenex* as if they were going out of fashion. Imagine crying virtually every day for five months on the trot? If you're a parent of an anorexic, you will know what I mean.

And as you come through the worst of the anorexia and start doing more normal things with your daily life, your parental radar is constantly on red alert for signs of the eating disorder.

The slightest noise and you go into "freeze mode" and the adrenalin kicks in.

You start accepting social invitations again, but dive back into the surreal world when your child freaks out at the food on offer. Meanwhile your hosts are slapping him on the back saying: "Tuck in! You look as if you could do with a bit of fat on you!" Obviously they haven't guessed and they probably think it's the height of bad manners to leave early because you, as a parent, can't face the mouth-watering food either if your child won't eat.

But thankfully that was then; in the past. This summer I don't feel as if we're in some kind of surreal bubble while the rest of the world goes on around us as normal.

This year I feel very much part of that world.

**Thursday, 30 June 2011**

**Anything for a simple life...**

Thank goodness I can trust Ben to not only prepare his own food but also prepare and cook our evening meal, exactly as per the recipe with nothing "omitted" and to successfully and accurately count his calories because all hell has broken loose now my 89 year old dad has finally been discharged from hospital. Aaaarrgggghhh!

It's what's called an "unsafe discharge" in that, apart from a district nurse that visits twice a day, no other care package or practical arrangement has been set in

place. I don't have time to go into detail here as I'm having to sort it all out, but here's what I posted on *Facebook* today:

*Well they've arranged a district nurse twice a day temporarily but I spent five hours yesterday trying to sort everything out and doing the same today when the DN comes back...*

*Not just problems with the PEG food administration [tube direct into stomach] x 4 times a day plus a vast arrange of morning and night medication also to be administered by PEG tube but there's the mobility & continence aspects, too, not forgetting the fact my dad loves to "order my 84 year old mum around" like a servant or secretary and is constantly wittering on about stuff in his OCD-like insistence on micro-managing his life... SCREAM!!!!*

*I can't even BEGIN to imagine how we would have coped with this had it been 12 or 18 months ago ("high anorexia" period), or even six months ago! Times like this bring into sharp relief just how much Ben has recovered from his anorexia and anorexia behaviours / thoughts. These days I know I can trust him implicitly to do what's required without cheating or lying. And last night's home-made salmon teriyaki with seaweed, garlic and rapeseed oil potato crush plus (Marks & Spencer) duck spring rolls and prawn crackers was DELICIOUS!!!! Followed by Ben's awesome sticky apple, apricot and almond cake with ice cream (difficult to know which is better: this cake or the very sticky ginger cake... or the malt loaf which beats Soreen's malt loaf hands-down!!)*

JULY 2011

**Friday, 1 July 2011**

**Lemon meringue pie, spicy Mexican pork and chicken tikka**

All are currently being cooked by Ben - a bizarre combination of smells, but no doubt delicious when they're all finished!

In the "high anorexia days" he wouldn't have eaten *any* of these things.

There are still "no go" foods on his list, however...

Anything too chocolatey or too fatty. Anything with butter or cream. Anything full fat and he still won't drink semi-skimmed milk.

And he would have a problem with anything "off the shelf" in, for example, a cake shop because he couldn't micro-analyse the calories and fat content...

So we still have problems with these things.

And, like every mom of an anorexic teenager, I wish to hell that nutritional labelling had never been introduced - on foods, on websites and in printed recipes.

Goodness only knows how someone with an eating disorder would cope with eyesight like mine; I've long been at the age where I need to reach for the reading specs in order to read the small print.

I couldn't read nutritional labelling on supermarket foods for love nor money, lol...

**Sunday, 3 July 2011**

**Chatting to the same person on the same grassy bank, two years on...**

Yesterday was the school Prize Day followed by the *house* sports day in the afternoon. Last year, at the height of Ben's anorexia, we didn't go to either.

But this year we went to both - and Ben was helping out at the Sports Day, so I spent the afternoon sitting in the sun on the grassy bank overlooking the playing fields, just as I'd done two years ago when Ben was competing in the 1500m race.

And just as I'd done two years ago I got talking to the mum of the boy who Ben had beaten in that race.

“Haven’t seen you around for ages!” she exclaimed, reminding me of how she and I used to gossip merrily away during our sons’ rugby matches every Saturday morning.

And I was instantly reminded of how I’ve been living on Mars for the past 24 months.

Or at least that’s how it feels. I felt like a stranger returning to an old, familiar place, mixing with old, familiar faces. A few knew a little bit of what we’d been through, but others had no idea - and she was one of the latter.

I seemed to spend yesterday avoiding people because I just didn’t want to talk about our experiences. Not to the “uninitiated” at any rate.

Unless you’ve actually left Planet Earth to live on Mars you can’t possibly know what it’s like - and there’s so much misinformation about anorexia and other eating disorders that it’s not like talking about high-profile illnesses.

And I really didn’t want to (a) sound as if I was dumping all my troubles on her by going on and on about it or (b) spend hours educating her on the ins and outs of eating disorders.

From experience I’ve found that talking about eating disorders is often met by the kind of reaction that religious cranks get when talking about hell fire and damnation - or some other subject that makes people feel awkward and want to run a mile.

But, thankfully, she was different and she seemed genuinely interested. Unlike most people, she didn’t automatically assume eating disorders could be “cured” simply by getting the sufferer to “eat more”.

Or that the sufferer must be a faddy /fussy eater or whatever. Nor did she automatically assume that anorexia is simply a “diet gone too far”.

“He’s still very thin,” I pointed out as we gazed towards where our two sons stood talking on the playing field - her son the picture of a “strapping”, sporty 17 year old and my son the picture of, well, something rather thinner...

Together we had watched our sons play rugby on those fields every winter

Saturday morning for five years. Our sons had been good friends, yet rivals on the rugby pitch. They had been equally good at the game, both were *forwards* and had been of a similar athletic build.

In the classroom they had always been top of the class; sometimes it was my son who came top and at other times it was hers. Ben used to go round to their house to play and her son used to come round to ours.

But all that stopped two summers ago when Ben started to exhibit the first signs of anorexia. And as her son continued school, sports and social life as normal, my son didn't.

And with this change, our regular gossips at sports events stopped. Which is why I hadn't talked to her since we last sat on that grassy bank at the school Sports Day in July 2009, just before our family took off to Mars (or somewhere equally alien) for two years.

And why it felt so strange talking to her again, explaining where Ben and we, as a family, had been for the past two years (i.e. to hell and back) while her family life and school life carried on as normal.

**Monday, 4 July 2011**

**Worried about the summer hols again...**

I'm worried that Ben isn't socialising much recently, if at all. Socialising was always a sticky issue with the eating disorder and, after a period of improvement, I worry we've gone backwards on this count. The summer holidays start on Friday and I'm concerned that Ben will spend much of it alone, despite prompts from us to "find things to do" over the summer...

It's all too easy for Ben to spend time with us rather than socialising with people his own age. As a result there's been a huge amount of pressure on us as parents over the last 24 months.

At our stage of life most parents are busy adjusting to the fact that the chicks have flown the nest, or are about to. In our household, the chick is extremely reluctant to leave the cosy confines of the parental nest and socialise with his friends. And the prospect of eight or so weeks depending on (primarily) me for “entertainment” isn’t healthy or ideal.

Last summer Ben was going through the evil stage of “high anorexia”. By then he had completely cut himself off from his friends and wasn’t in a fit mental state to do any successful socialising. The odd attempt at contacting friends was disastrous e.g. when he emailed one of his friends to say “Give me three good reasons why I should carry on living...” Result? An urgent phone call from that friend’s mother telling me how upset her son was at the email and total panic from me!!

The previous summer as Ben started to exhibit the early signs of anorexia, he swapped his friends for hour upon hour at the gym or running around the local streets.

When he wasn’t doing this, he was frantically “de-calorising” and “de-fatting” recipes to “make them more healthy”. The alarm bells had started ringing as it became increasingly clear that things weren’t as they should be...

But I can’t help feeling that he’s at the stage where he *really should* be socialising more with his friends and relying less on us, his parents, for “entertainment”.

**Tuesday, 5 July 2011**

**Trying to pick up where you left off before you took off for Planet ED...**

We had a “heated discussion” last night, shall we say, about the problems Ben is having trying to pick up where he left off with his friends and peers, before the eating disorder arrived on the scene two years ago.

Before the anorexia isolated Ben from his friends, he was one of the most popular boys in his friendship circle and liked by everyone. Okay, he was naturally quiet and reserved, and his friendship circle might be described by his more boisterous peers as

a bit “geeky” or whatever, but - as parents - we couldn’t have been more delighted with Ben’s choice of friends.

In fact he was so popular that Ben’s birthday parties were famous for running over two whole days. The first day half his friends came round for a sleepover. Then everyone met up to watch a movie and have a meal on the Saturday afternoon. Then the other half of the friendship group came back here for a second sleepover. And of course each sleepover was followed by an *enormous* breakfast. After all, we’re talking about growing teenage boys...

After a rocky start on the social scene (following the bullying at primary school) things had been going from strength at his lovely high / senior school. Then - zap pow - in came the eating disorder and put a halt to everything and Ben was jet-propelled to the isolation of Planet ED for nearly two years. During that time his friends matured and changed, as teenagers do. Some friends left the group; others joined.

Right now Ben is finding it very hard to get back into this friendship group. He feels side-lined and ignored. He feels “tolerated” and left in the background. He’s not invited to social events like parties or nights out. His former best friends have now “paired off” with girls, which makes it particularly difficult to pin them down.

He’s concerned his peers still view him as a bit weird because they saw what anorexia could do to its victim’s behaviours and moods at its height. Doubtless they found this disturbing, frightening even. And for ages Ben has felt as if they regard him with sympathy rather than genuine friendship. Also, having been in school part-time over the past academic year hasn’t helped matters.

Back in November CAMHS went into school to talk to a hand-picked group of Ben’s peers during a period when he was finding it particularly difficult to get back into things. It was reasonably successful and seemed to kick-start a not-too-bad trickle of social invitations, and for the first time since anorexia arrived Ben felt included in conversations in the classroom and common room. But all this seems to have ground to a halt and Ben feels incredibly lonely. And he can’t understand why it’s so hard to

pick up where he left off two years ago when he was liked and respected by everyone.

Of course it breaks my heart. I threw loads of practical suggestions into the pot last night, all of which were met with a negative response. So I have no idea what to do next, really. Meanwhile, as I said in my last entry, the summer holidays / vacation starts on Friday and with it - potentially - eight or so weeks of social isolation...

**Sunday, 10 July 2011**

**“Experiments”, “choices” and “mistakes”... aaarrggghh!**

If I had £10 for every time these words have been mentioned over the last 20 months of eating disorder treatment, I'd be rich! I believe our slow progress on the weight gain front, indeed the lack of progress on the weight gain front, is due to our treatment team's insistence on letting Ben “make his own choices”.

So, once again, Ben has lost weight.

On Friday his weight was down by just over 1kg which means he has, essentially, maintained weight since early April (after an initial weight gain which came as a result of me introducing the Contract).

Consistently over the past 20 months we've been told that Ben “needs to experiment to see what works and what doesn't and make his own choices based on the results... sometimes he will make the wrong decisions and other times he will make the right decisions...” etc etc etc.

But, basically, the essence according to CAMHS is that Ben needs to do this independently, himself. It won't work if it's me that's “enforcing” it “as was proven by Ben's initial weight gain when he obviously wasn't ready for it”.

One year ago the team swapped my “no compromise” 3 x meals, 3 x snacks eating plan approach for an approach where the “control” was gradually handed back to Ben. Despite the fact that there followed seven months of consistent weight *loss*, this initial weight gain period is viewed as a “wrong choice” on my part, as a parent. In

other words, I was forcing Ben to eat when he “obviously wasn’t ready” to do it.

Now that Ben is almost entirely “making his own choices” he’s “learning from his mistakes” apparently. But this “wrong choice / right choice” approach simply threw Ben into a yo-yo kind of *Limboland*. Which is where we ended up at the beginning of 2011. He was crying out to the treatment team that he was finding it incredibly hard to move forwards.

Their answer to this was to simply continue the “experimental” approach so, at this point, I decided to introduce a Contract. It wasn’t their idea; they’d never heard of Contracts; it was mine - thanks to some excellent advice and experience from fellow ATDT forum members and sample Contracts on the FEAST website.

The Contract was my cunning “cloak and dagger” way of getting us back on the weight gain track. Because there had been so much “bad press” from Ben and our team on my initial insistence on a 3 x meals, 3 x snacks Eating Plan, I had to find another, “creative” way of achieving the same thing. I knew if I did nothing, we would never leave *Limboland*.

And the fantastic thing was, the Contract worked - and he willingly and enthusiastically cooperated!! But the team simply saw this as happening “because Ben is obviously now ready to make the right choices”.

*No, treatment team, he is not.* And I need more support to push towards a proper daily calorie intake. I don’t believe my son is unusual in that he needs *less* calories per day than the 2500+ calories recommended for adult men to *maintain* their weight, let alone increase - and this is being proven by the fact that Ben is once again losing / maintaining weight rather than showing a consistent increase.

Why oh why couldn’t they have insisted from the start that he needs 3000 calories-a-day or whatever it is he needs to increase his weight at an average of 0.5kg a week, consistently, until he is weight restored?

Why can’t they see that it is *them* that are making the “wrong choices” by permitting everyone to watch while this weight loss / maintenance continues until

whatever time it is that Ben starts “making the right decisions” and convinces himself that, yes, he does need significantly more calories than he is currently eating?

Time and time again I have produced my chart which shows that Ben has lost weight since the start of treatment 20 months ago - for a condition that is supposed to be all about *weight gain*. And I’ve also produced various other charts which show that Ben is still underweight for his height and age. Plus photos that show his “strapping”, sporty physique prior to ED rearing its ugly head which show that Ben never was and was never supposed to be *Mr Puniverse*.

I believe he will *continue* to stay yo-yo-ing up and down with a gradual downward trend if they don’t support me in going for full-on calorie increase - whilst also supporting me with insisting that Ben *does* actually need a higher WR BMI than they think he does.

**Monday, 11 July 2011**

**True soul food on the ATDT parents’ forum...**

I know I keep going on about how much of a lifesaver the ATDT parents’ forum has been for me over the past 18 months, but it’s true. I’ve met so many supportive people through it, from across the globe, and made a number of very good friends here in the UK. Last night I chatted to another UK-based mum of a 17 year old teenager with anorexia and you’d be amazed at how much common ground there was.

I can’t emphasise how helpful it is to talk to other parents who are in a similar position to you. Unlike “lay people”, there’s something incredibly comforting about chatting to someone that really does “get it”. It’s a bit like living in a far-flung foreign land for years then meeting up with someone who has the same language and culture as you.

True soul food... And you can devour it at Around The Dinner Table, the absolutely fabulous forum for parents of children and teenagers with eating disorders and also

its “sister site”: FEAST which is jam-packed with goodies to help your child to recover from anorexia, bulimia and other eating disorders.

**Thursday, 14 July 2011**

### **Sheffield University challenge...**

Yesterday saw us back at Sheffield University, this time looking at another faculty with me taking Ben on an extensive walking tour of my former favourite haunts as a student in that lovely, friendly city.

ED came too, however. Okay it was a faint shadow of its former bullying self, but it was there, tagging along with us throughout the day...

Firstly, there was the fact that we did so much walking when we had a *Day Rider* ticket for the buses and trams. And the fact that I often had to tell Ben to “slow down, this isn’t a route march!” And my feet were killing me by the end of the day (and still are!)

Calories were top of my mind - to make sure Ben got sufficient. And we still need to buy food that I know has sufficient calories to avoid Ben “over-estimating” how many calories are in an item or cutting back on food further along the line.

But the Good News was that it didn’t take us long to choose the *meal deal* from Boots. In the past he’d be chopping and changing, picking stuff up and putting it down, getting as far as the till then back-tracking to painfully try and make another choice. We would have been in there for *ages*!

The other Good News was that, when the sandwich turned out to be a bit lacklustre, Ben still ate it. In the Bad Old High-Anorexia Days, he’d have flung it down, refused to take another bite and generally freaked out.

And the other Good News was that, when the wind blew the packet of crisps all over the grass in the delightful Botanical Gardens, he took it in his stride. Again in the Bad Old H-A Days he would have freaked out. He also agreed to make up for the lost calories later on.

More Good News was that that packet of crisps was extremely calorific - the kind of thing he would *never* have eaten in the Bad Old Days.

So next on my mind was how to ensure Ben made up for the lost calories - something that I imagine wasn't top of mind for the majority of other parents shepherding their 17 year old sons and daughters around the university campus.

In the end we ended up at *Starbucks* with a coffee and biscotti, which I was happy with.

At 3.30pm we attended a departmental talk and, as with the previous university visits, I found myself scanning the other teenagers to see if my son stood out as the skinniest or unusual in any way.

And, again as in previous talks, I couldn't help noticing the boys who were of a similar build, body shape and height to Ben. Or at least boys who were of a similar build and body shape to what Ben might have been had the anorexia not hi-jacked his body for 24 months.

I expect all parents of teenagers with eating disorders can't help but do this comparison and, yes, it is heart-breaking as you wistfully imagine what could have been...

And, indeed, *should* have been...

Like all good universities, Sheffield is asking for three grade A's at A-level. Although Ben has been incredibly successful at keeping up over the last 24 months when he's missed so much schooling, his grades probably aren't quite as high as they should be. Intellectually he is more than capable of getting "straight A's" but Ed has got in the way of this, especially during the AS level exams this summer when Ben scarcely slept at all.

So, right at the end when everyone else had left (including Ben to the toilet), I'm the parent staying behind to ask the staff what the procedure is for applicants who have missed a substantial amount of school through illness (I didn't specify what that illness was...)

I believe they do make some minimal allowances but, as they rightly said: “If he is still only able to do school part-time, you need to be completely sure he is (a) ready to go *away* to university in 2012 and (b) that the illness will not get in the way of his studies or attendance.”

I agreed and said that if we weren't one hundred per cent certain he was recovered then he'd take a gap year, or two.

So I came away feeling the usual sadness-verging-on-impotent-anger at how the eating disorder has hi-jacked my wonderful, intelligent and beautiful son and messed up this really important and exciting period of his life.

But then I was reminded of the fact that not all successful students enter college or university straight from school.

My sister, who got a higher class of degree than me, entered college as a mature student, without the “standard” academic qualifications, and did very well indeed - and still is.

So all is not lost.

**Friday, 15 July 2011**

**Ben, me, the Contract, kitchen scales and plenty of food, but not ED...**

Okay, so we haven't made it to France this year and, anyway, last year I vowed I'd *never* go on holiday again until the eating disorder was well and truly *gone*. But, having said this, Ben and I are about to embark on a few days away in a country cottage in the Peak District. Unfortunately husband can't come due to work pressures, so he's staying at home.

Of course my main concern is that we will have sufficient food around for Ben to keep to his daily calorie total. We've already done a “dummy run” of what a typical day might look like, food-wise, because I said “I'll just pick up something or other somewhere or other” wasn't good enough as regards the difference between breakfast, lunch and tea calories and the total number required.

He refuses to entertain the idea of little emergency snacks like mini bags of fruit or nuts, etc so I'm off to the supermarket later, without Ben, to stock up on a few emergency bits and pieces just in case... After all, it's not like home where there's always something in the cupboard, fridge or freezer...

My other worry is what ED describes as "sitting around all day doing nothing" e.g. when we drive there and back, and if the weather proves to be too rainy for us to go walking in the countryside. So the Contract will accompany us and points will be awarded for keeping to the agreed plan. The kitchen scales are coming, too, to ensure that Ben doesn't "under-estimate" portion sizes. And before we go, I will weigh Ben to compare with last Friday - and again when we return. We don't see CAMHS for another two weeks, so it's important for me to keep an eye on whether things are going up or down, and adjust the Contract accordingly.

Am I confident things will go relatively smoothly?

I think I am.

And although ED will no doubt try its best to stow away in the luggage, I hope my preparations will prevent it from spending too much - or indeed any - time with us.

Now all we have to worry about is the weather, and unfortunately heavy rain is forecast...

**Sunday, 17 July 2011**

**It's raining, it's pouring... but so far so good on vacation as regards ED...**

It's Sunday evening and it's been raining virtually all day here in the beautiful Staffordshire Peak District which means trying to keep everyone occupied all day ("everyone" includes husband who has been able to come here for the weekend but goes home tomorrow). But, so far, ED has kept a reasonably low profile.

Mind you, I tend to feel that a "normal" 17 year old boy when faced with waiting for his parents to drink up in the cosy local village pub before we go back to the cottage for our evening meal would have had a packet of crisps or peanuts to keep

the “I’m starving!” hunger pangs at bay. They might also have ordered a beer instead of a diet coke. But, hey, things are a million times better than our French holiday last summer when, within minutes or even seconds of arriving, Ben was having an almighty screaming manic ED rage and husband was sitting outside, head in hands, threatening to drive right back to the ferry port...

Ben has kept to the Eating Plan so far, which is good. But he didn’t like all the emergency extras I stashed away like cake, biscuits and sachets of drinking chocolate and so on... (“For the record, mum, can you *never* do that again please?”)

As husband and I discussed in the pub, after Ben had gone back to the cottage to heat up the pork stew and pasta, there’s still something in him that insists on keeping to the calorie total “to the letter” and not going over by one single calorie, presumably in case he suddenly “balloons out” into an obese monster.

You would think that, after two years of proving that this is most definitely *not* the case and having lost weight in real terms over the last year, he would realise that this is most definitely *not* the case - and he would treat himself to one or two extras on holiday, like a slice of cake in a café or one of the delicious home-baked *Bakewell* tarts provided by our generous host...

But you and I know that ED isn’t logical. It’s also behaviour like this that makes us realise that, yes, unfortunately ED is still present, even if it is a shadow of its former horrendous self.

Never mind, so far within the first 30 hours of our week’s holiday, things have not been too bad at all.

Except the weather, of course, which is atrocious.

**Tuesday, 19 July 2011**

**So far, so relaxed... so much better than last year...**

Last summer, in France and especially on a “get away from ED” break I took to Somerset in August, I was so incredibly stressed and anxious my whole body actually

physically “seized up” at one point (unhelpfully when I was driving down the motorway...) This summer’s mini-holiday in the Peak District couldn’t be a starker contrast I am thrilled to say.

Last August Ben and I had just been for our Friday CAMHS session. He was rapidly losing weight, week after week, and CAMHS were failing to do anything to halt it. Ben was also going through his nightmarish ultra-depressed ED-rage suicidal phase - a period where I was seriously worried I would lose him... It was the eating disorder at its worst.

I’d agreed to drive Ben down to Cheltenham where my husband was working at the time. We were staying there for the night and then Ben was going with H to his parents’ house in London while I was heading off to the Somerset coast to (hopefully) get away from ED for a while. But I was so stressed, anxious and tense that my whole body began to seize up as I drove the 200-ish miles to Cheltenham. I had to stop off at every single motorway service station en route to do relaxation exercises; it was as if my whole body (and especially my neck) had contracted some kind of “lock-jaw”.

In Somerset I just couldn’t relax. The trouble with ED is that you can distance yourself from it physically (after all, ED was with H and Ben in London and I was in Somerset in a lovely seaside apartment overlooking the bay) but, as a mother, you can’t distance yourself from it mentally. ED was right there, well and truly with me, haunting every single moment of the day and night. It should have been idyllic but I was in a living hell. So I returned home after one day of driving around the area feeling totally miserable, unable to handle seeing “happy families” enjoying their summer vacation...

This current holiday in the Peak District couldn’t be more different and I am sooooo relaxed; ED simply doesn’t seem to be here now... And in a few weeks’ time I’m taking Ben to that same seaside apartment for four days, hopefully for a similarly relaxed and ED-free break.

**Saturday, 23 July 2011**

**A virtually ED-free holiday, all in all, and 1kg heavier...**

Back home - and I am very pleased about how the week has gone. The eating disorder was virtually absent; the only way you might guess something wasn't quite normal was that Ben was counting calories and I was keeping a discreetly watchful eye on things. Also, Ben is still quite thin. But he is 1kg heavier than when I last weighed him two weeks ago. Compare this to last year when we returned from France having taken CAMHS' advice and "ignored" the eating disorder and "taken a holiday" from calorie counting. Ha ha ha ha.

Why didn't I simply disregard CAMHS' advice back then? Because the decision had been made in front of Ben and there was 2 x CAMHS professionals and Ben versus me, "Big Bad Mum"...

Anyway, back to this week's holiday where I managed things my way and it worked. Our Contract came with us and we continued to do "points" every evening. To save money and make things easier, we had picnic lunches every day. But this lunchtime, Ben opted for the "unknown quantity": a jacket potato with butter and beans at a *National Trust* restaurant. I was a bit nervous when the jacket potato took ages to arrive and wasn't that brilliant when it did. In the past Ben might have thrown a wobbly and refused to eat it - especially when he found out they'd put butter on it. Today he was just like a normal "starving" teenage boy who wanted his lunch, was fed up with waiting and ate every morsel despite the fact it had obviously been baked earlier and re-heated.

Compare this to lunch at a wonderful country inn on the way to Portsmouth (en route to France) last year. When the meal arrived, Ben threw a wobbly, refused to eat it because the fish burger had been fried. In the end he swapped it with his dad's meal (something he did quite a bit last summer...). It was the only way he would eat anything. You could have cut the atmosphere with a knife. And that was only the start of the holiday-from-hell where Ben lost weight and the eating disordered

behaviour ran wild.

Unfortunately, with an eating disorder, and until you are recovered from that eating disorder, you can't take a "holiday" from the food management side of it. You have to persevere with the Eating Plan, just as you would at home. Sure you can "guestimate" food that doesn't come with nutritional labelling, but last week we always agreed on the "guestimation" to ensure Ben wasn't tempted to "over-guestimate".

What you *can* take a holiday from however, at this stage of recovery, is all the nasty side of the eating disorder - the stuff that completely ruined our holiday last summer.

I am thrilled that we have had a very successful week's holiday, without any tension, resistance, depression, angst or whatever. Apart from the usual teenage stuff, but that's only to be expected with a 17 year old. And you can tell when it's teenage stuff and not ED-stuff.

**Monday, 25 July 2011**

### **Back to reality and sorting out all those outstanding ED bits and pieces**

Now that our successful week's holiday is over and Ben has finally ordered his new *Xbox* (putting some of the "points money" towards it) it's back to reality and working on all those outstanding eating disorder bits and pieces that still remain.

This summer it's so important that we work on the social issues which were bugging Ben before the end of term and preventing him from resuming full days at school - and also leaving him lonely over the school summer break. A successful holiday is one thing, but it does nothing to solve some of the other problem issues - social problems being Public Enemy Number One, as we approach Ben's final and potentially most important year at school, not to mention three years at university looming on the horizon...

On Friday we have a CAMHS appointment with the psychiatrist who we haven't seen for a number of weeks. I am going to ask her to focus on the social problems leaving me to focus on the eating / weight side of things. I want her to support me in my insistence that we return to ensuring the necessary daily calories are in place to get back on track as far as the average 0.5kg-a-week goes. I believe she will do this. Or at least I hope she will do this...

The psych is aware that we need to work on the social stuff. However, despite regularly stating that "we need to do some sustained work on x," Ben and she never seem to get around to it. This is because our sessions have had more of a fire-fighting focus over the past 20 months or so, damping down the flames of Ben's immediate reaction to weight gain or loss - or the latest thing that's getting him down.

I feel a strong need to steer things back on course so we see real progress on every single front rather than darting around squirting a fire extinguisher at little fires as they pop up all over the place.

The social / school side of things is the most pressing issue CAMHS need to work on over the summer weeks and probably beyond.

Food / weight gain and restoration / challenges are what I need to focus on, with CAMHS' whole-hearted support.

**Tuesday, 26 July 2011**

### **One of the most successful aspects of our Recovery Contract**

Overcoming "fear foods" and facing other challenges (e.g. socialising, resisting compulsive exercise, etc) used to be a real sticking point - until we introduced the Recovery Contract.

As well as checking the day's calories, keeping an eye on exercise parameters and generally talking about how the day has gone, the Contract encourages "challenges", with points awarded for each challenge, depending on how "challenging" it has been.

Then, when a challenge has morphed into a permanent change and is no longer a

challenge, we switch the focus to something else, all the while focusing on what is and isn't "normal behaviour" and why "normal" is what Ben should be aiming at.

After all, the anorexia has already stolen two years of his life... arguably some of the best and potentially most exciting years of his life... and we don't want it to steal any more.

Every day Ben faces a couple of challenges (or more) which he chooses himself. I never insist he tries to overcome any particular challenge, however I do gently and discreetly suggest / discuss areas where changes could be made or where he might "test the water".

We're currently in Week 18 of the Contract and, although the weight gain hasn't been as consistent as I would like (yet), the challenges are a real success story.

One of yesterday's challenges, for example, was "standing / sitting still all afternoon" which is something the "anorexia voice" still nags him about. He also had a huge "condensed calories" breakfast "even though I felt full half way through, I still did it".

And today's challenges? "I'm not sure yet," he says, "It depends really. I'll be doing this, that and the other, probably to do with my lunch. But the thing is it's no longer a challenge if I'm finding something easy or don't need to think about it."

AUGUST 2011

**Tuesday, 2 August**

**It's (not) funny how certain situations can cause flashbacks...**

Ben's been cooking some scrumptious evening meals for us recently. That is, until tonight's meal which turned out dry and "average". So he took our plates back into the kitchen to make a few adjustments, leaving me at the dinner table for five minutes. Suddenly I was hit by a painful and dramatic flashback to how it would have

been 12 months ago...

Back then, any meal that wasn't "perfect" would have had Ben violently "downing tools" and leaving the room, only he wouldn't have gone into the kitchen, he'd have slammed the plate down, rushed into the hallway and shouted and screamed animal-style while banging his head on the wall. This would have been followed by lots more banging, crashing and swearing plus more animal shouting / groaning and head banging...

Meanwhile I'd be sitting at the dining table paralysed with fear and dread of what was coming next...

It's (not) funny how your memory causes flashbacks and you suddenly feel how you felt in a previous situation. Maybe it's a bit like soldiers who have painful flashbacks when they hear something that sounds like an explosion or a gun firing. Suddenly you're back there, re-living it, and all the bad memories, feelings and reactions come flooding back. I was also painfully aware of how the passage of time had de-sensitised my everyday memory of just how terrible it had been.

Looking out of the window watching a neighbour water her plants while another walked her dog, I had another flashback to the realisation that - while the rest of the world was going on around us as normal - we had been living with a severe mental illness, in a kind of nightmarish surreal world completely separate from everyone and everything else.

Thankfully tonight all Ben had been doing was adjusting the meal. He simply came back into the dining room, calm and normal, armed with two plates of "tweaked" lamb tagine. But while I ate it I was still having mental aftershocks despite the fact that, to all intents and purposes, everything was completely normal.

Oh, and 12 months ago Ben wouldn't have touched "fatty" lamb with a bargepole...

**Tuesday, 2 August 2011**

## **Rock-hard abs, yet without working out 24/7/365 to achieve it**

One of the environmental factors that exacerbated our son's anorexia was the desire for a "six pack" and the kind of rock-hard muscular body that would normally require working out 24/7/365. Although Ben enjoyed some exercise and was very sporty, he insists he was essentially lazy. So he found a "clever" way of achieving his goal: by restricting his food intake.

Why did he want rock-hard abs and an impossibly muscular body? Because, for him, this "look" would make him more popular - not just with the girls but with the other boys in his year group. Okay, he had a very close-knit circle of friends, but to the rest of the year group these guys were a bit "nerdy" and Ben wanted to shed his "nerdy" image. This, despite having always been a shy, quiet, well-behaved boy, quite unlike the hugely confident "devil may care" boys in his year.

Also, Ben's academic "rival" in his year group was a boy who was good at everything. This guy was top of every subject and played umpteen different sports extremely well. He was incredibly popular with the girls and, worse, he had the much coveted "six pack" which, apparently, this boy loved to show off to the girls (the mind boggles...).

Here's something I wrote at the time:

*At the heart of this lies one boy. This boy is the cleverest boy in the year and now, it seems, the most popular, mainly with the girls. The image I get from what my son says is of this boy surrounded by crowds and crowds of adoring girls and boys. He's being hugged by dozens of girls while sending and receiving texts from others. He revels in this adoration and the boys and girls hang on to his every word. In fact the vision I have is so ridiculous that in other circumstances I'd just laugh!*

*Meanwhile my son fades into the background. Everyone ignores him, so he says. He doesn't get hugs. He doesn't get texts. And when he talks to this boy, this boy is*

*often too busy sending and receiving texts from his adoring public to bother with my son.*

*Worse, this boy is muscular, with a "six pack", according to my son.*

*Result = my shy, unconfident son feels that the ONLY way he can compete with or equal this boy is to exercise and diet himself silly so he "becomes" that boy, if you like... By doing this he will get similar adoration and "be loved" (his words) by the girls and others. He says he "just wants to be loved". Of course transforming himself into this boy is an impossible task which is why the situation has got so bad. My son is distraught. I have never seen anyone so distraught and it breaks my heart.*

The desire for the "perfect body" seems to be one of the major environmental drivers that can exacerbate eating disorders in men and boys. It doesn't "cause" the eating disorder; experts now believe that eating disorders are genetic, but it can be the trigger for people that may be predisposed to the illness.

**Wednesday, 3 August 2011**

**It's okay to listen to chilled summer music again!**

Last summer I found it impossible to listen to the usual chilled summer music on my CD player. For one thing I most definitely wasn't chilled and, another, suddenly I found that lyrics had a whole new meaning for me especially if they were about "missing" someone or whatever. Because I missed the real, non-ED Ben like crazy and - at the time - I had no idea if we would be getting him back...

But this summer the CD player is back on again and I'm able to enjoy all those songs I couldn't listen to last year.

**Friday, 5 August 2011**

**Whizzing around Waitrose at a rate of knots!**

Time was (in the “high anorexia” days) when a visit to the supermarket would take *ages*. It would take anorexic Ben ages and ages and ages to choose things, picking stuff up and putting it down, getting it as far as the trolley and even as far as the checkout only to back-track and put stuff back on the shelf and start again... And, of course, the first thing he’d look for would be the dreaded fat content and calories. Today, however, we zoomed around.

Because it’s been so long since we’ve been to *Waitrose* (it’s not our local supermarket and it’s expensive), the contrast between then and now was quite stark.

This time, there was no chopping and changing, no picking stuff up and putting it down, no checking nutritional content, no opting for “healthy” low calorie stuff and no “second thoughts” at the checkout...

We just went in, did our shopping like normal people do, paid for it and went.

Job done.

(He even complained that the fish and chips ready-meal didn’t have enough chips in it.)

**Saturday, 6 August 2011**

**Seaside, here I come - this time with Ben in tow...**

A couple of years ago I discovered a great little bolt hole overlooking a wide bay at the seaside. The sunny, south facing living room looks straight out over the sea, the two bedrooms overlook the sea, everything overlooks the sea - and at night you can lie in bed, staring out across the high tide with the pretty lights reflected in the water.

Over the past 24 months I’ve used it as an “escape” from the eating disorder. I’d leave Ben with his dad and get the train or take the car down to my little seaside retreat.

However although you can distance yourself physically from the eating disorder, I found you can't do it mentally - and last August I had to leave after just 24 hours because I just couldn't relax and enjoy myself. I was as miserable as hell and felt completely trapped by the eating disorder. At that time I really couldn't see any lights at the end of the tunnel. Ben wasn't improving; in fact he was getting worse. And I found it difficult to handle being surrounded by "normal" families having a "normal" summer holiday. So I came back home.

But this year things have improved so much I'm taking Ben along with me.

We've got a great little itinerary planned. We'll take the train there and then spend three days visiting some really interesting places including Plymouth and Bath. Weather permitting, we'll take evening strolls along the prom to watch the tide come in and maybe stop off for a cappuccino or glass of wine at that chilled little bar overlooking the rock pools and peninsula. Also, I always like to do my annual "pilgrimage" to my grandparents' old house - the sprawling Victorian villa where I used to spend every summer of the first 18 years of my life.

But first I must work out what we need to eat. Because we're going by train I can't take loads of snacks and stuff with me, however there is a supermarket right opposite the station and we can eat at *Pizza Express*. So that's my job today... to add up calories for a "typical day's eating" to make sure Ben gets sufficient.

It's especially important as the scales have shown that his weight has remained stable for a couple of weeks and we need to increase!

**Monday, 8 August 2011**

**Okay, so what is the purpose of this blog?**

Some of my contacts have written books on the subject; others write blogs or get into the media. But the *only* reason that any of us "goes public" about our experiences as parents of teenagers with eating disorders is to do our small bit to help others facing a similar situation. We are neither seeking to exploit our children's

eating disorders nor trying to draw attention to ourselves. We are just acutely aware of how precious little information and help there was for us when we started our own nightmarish journeys into the world of anorexia. Even if we help just one desperate parent to find hope then we've done our job.

In the summer of 2009 it gradually became clear that something was seriously wrong with my son. Eating disorders were the last thing on my mind; after all, Ben is a boy and, as far as I knew, boys didn't get eating disorders.

However as Ben's weight hurtled south at a rate of knots, I realised that Ben could be developing anorexia.

I was desperate for help and support but there was nothing out there - especially on the problem of boys and eating disorders.

I felt terrified and isolated. I didn't know where to turn, what to do or what I should know. And yet the information I did find suggested that this could be a deadly condition; that people could and indeed do die from it. Yet, unlike cancer or another life-threatening illness, we weren't being fast-tracked into treatment or given advice. Indeed our GP was reluctant to refer Ben for treatment, and even when he did we were faced with a waiting list that could last for months...

And meanwhile Ben was rapidly disappearing in front of my eyes.

I can't even begin to describe how hellish these first months were with practically zero support, information or advice. I was in a state of total panic.

Then, through trial and error, I stumbled across the wonderful Around the Dinner Table forum and its "parent" website FEAST which offer support and advice to parents and carers of young people with eating disorders.

Through these two channels I received (and still do) enormous support. Most important of all, for the first time in months I was "meeting" other parents of teenagers with eating disorders, some of them mothers of boys with anorexia. Thus began a lengthy learning curve as I was "initiated" into the hellish world of eating disorders and how they are successfully treated.

The point is: I know how terrifying it is to discover your child has a potentially life-threatening condition yet not know what to do or where to turn.

Right from the start I was acutely aware that I wanted to do my little bit to help parents just like me - not only to help direct them to useful websites like the Around the Dinner Table forum and other resources but to talk about my own experiences so they can see there is a light at the end of the tunnel.

I'm not a medical or mental health professional, but what I am is a genuine parent who not only cares about my son and his journey back to health but who also cares about other parents in my situation.

It is no different from a parent who writes a book on the topic and goes public.

It is no different from a parent who gets into the paper and goes public. (Like at least three of my brave friends and their children have done recently.)

It is no different from a parent who gets onto the TV and goes public. (Like other contacts have done recently.)

All these experiences are out there in the "public domain", and the very last thing that any of us is doing is "exploiting" our children or using their illness to draw attention to ourselves.

Imagine if all of us had simply sat back and done nothing? Even if we help just one parent fast-track their way through the massive ED learning curve and get some kind of useful help, we have done our job.

And each of us has the full support of our children in what we are doing.

In fact it was Ben who suggested I start this blog in the first place.

**Friday, 12 August 2011**

**I do wish they wouldn't do that...**

I do wish our treatment team wouldn't tell Ben that it's okay to aim for a sub-optimum final weight because this makes it really difficult if not impossible for me to guide him towards a proper weight normalisation. They should watch a *C&M*

*Productions* video which focuses on why it's so important to get properly weight restored and not settle for partial weight restoration in order to attain full brain healing, have the chance of a life free of anorexic thinking and minimise the risk of relapse.

And in answer to the person who commented asking why can't I "just be happy" with the way things are, I'd say this: *If Ben had any other chronic illness and had every chance of a full recovery, would you not think it negligent of me, as a parent, to refuse him any additional medication or whatever else was required to attain full and complete healing and elimination of the pain?*

**Saturday, 20 August 2011**

### **Ups and downs in the South West**

Ben and I have just come back from five days in the South West. Much of the time everything was fine with Ben overcoming scores of challenges. ED, the anorexia demon, reared its ugly head a couple of times: once in *Tescos* when choosing a *meal deal* for lunch and once, more seriously, in Bath which I will talk about later on when I've finished unpacking and all the other stuff I need to do! But at the end of the day, we (hopefully) kicked ED into touch.

**Saturday, 20 August 2011**

### **ED surfaces in Bath and lunch is a washout...**

"There's nothing I want on the menu," said Ben in the old familiar way... But there was no way I was getting up and leaving. The menu was fine... stuff Ben normally eats at home... and the 18<sup>th</sup> century veggie restaurant in Bath came highly recommended.

So I stayed put and Ben reacted by sitting with his book in silence, refusing the offer of a drink. And when the food arrived, he just stared at it while I tucked into my delicious meal. I knew what he was staring at: the olive oil drizzled all over the side

salad and garnish plus the Bruschetta-style open sandwich also brushed with oil... So he just sat in sullen silence while ED, the eating disorder, refused to let him eat.

I ate my meal and then I ate his meal as well because I didn't want the embarrassment of being faced with a baffled waitress who wouldn't understand why the delicious food lay untouched. Goodness knows what our fellow diners thought, but I didn't care.

I paid for our meals and we made our exit in silence.

Then I frog-marched Ben back to the railway station because there was no way I was going to pay for us to tour the Roman Baths (which was the primary reason for our break). Ben (or, rather, the ED) ranted, raved and wept in full view of everyone in the crowded Bath station and tried to blame me for why he hadn't eaten his lunch ("I only went there because *you* wanted to," etc etc).

"No," I said (amongst other things, including why I was never going to stop working at this until I'd finally banished the ED from Ben's life), "It was purely and simply because of the eating disorder. The eating disorder was at the heart of this".

So I ended up paying for a second lunch in the *M&S* café to make sure he got some food. I "drowned my sorrows" in a coffee and millionaire's shortbread slice, wondering what the hell we were doing in *M&S* when we were surrounded by some of Bath's finest eateries, not to mention the fact we'd already "had lunch". But to Ben's credit, he did choose a load of challenge foods, including a *Mars Bar*, so it wasn't all bad news.

**Saturday, 20 August 2011**

**And now for the Good News...**

... Which is the sheer number of food "challenges" Ben did while on our mini-break in Somerset and Devon. Included in the blitz on "fear foods" was: a *Mars Bar*, two packets of high calorie / fat crisps, a *Solero* lolly, *M&S* "ultimate" sandwich and a meal from *Pizza Express*. Plus, apart from the blip in Bath, everything was very

relaxed - a complete contrast to last time I visited that apartment overlooking the sea.

**Monday, 22 August 2011**

### **School is just two weeks away... But which school?**

So we're faced with this decision: would it be easier, less stressful and more enjoyable for Ben if he went back a year at school and re-did his Lower Sixth year?

Why?

Because last year he missed so much school (at least 60 per cent) that it messed up his AS level exams (we got the results last week).

So it means having to do several re-sits alongside the pressure of studying for the A-levels themselves *and* applying for university, etc.

The only problem would be that it would mean changing schools in order to do this. But, on the other hand, the new school is more local, is an excellent school and it would mean Ben could "start again with a clean slate" without his peers passing judgments based on past eating disorder behaviours and so on.

So this week is Decision Time and I've told Ben that the *only* person he should consider when making this decision is himself. He shouldn't make decisions just "to please" other people, be it his current school or his parents. He should choose what he feels would be the easier, less stressful, more relaxed and potentially enjoyable route.

Also, no-one is pushing him to go to university. He can make that decision later, when he feels ready.

My gut feeling is that he will opt to stay where he is which would mean extra studying and extra lessons. In an ideal world, this would be "do-able", but if something like the insomnia kicks in when he starts back at school, things could go pear-shaped.

After all, he'd need to be in school full time in order to cope and, thus far, he's only

managed one or two full days at school...

The other potential spanner in the works is the problem of “sitting around all day at school doing nothing” as he puts it. But he’s now at a stage where he can deal with this quite successfully.

He’s discovered that he doesn’t suddenly start to balloon out on “so many” calories when he’s sitting in lessons as opposed to exercising at home. This side of things is, thankfully, pretty much under control now.

So we’re having a meeting with the sixth form Head on Wednesday to see what she thinks.

What does Ben think? There are pros and cons for both options. Like me, he’s unsure which would be the best solution.

The trouble is, with school just two weeks away, we can’t hang around too long before we decide what to do!

## **Thursday, 25 August 2011**

### **Exam results season made me think...**

Even though Ben wasn’t at his best for his AS level exams in June (insomnia), he managed to sit them with his peers without any problem at all. The previous year (GCSEs) it was a different story (although, thankfully, no insomnia which didn’t kick in until the following term). Also, with the start of sixth form a year ago, he made the decision to go back to school full time. It wasn’t a success. Ben pushed himself too hard and quickly reached “burn out” stage. By half term we’d decided to take him out of school again and for him to go in as and when he felt he could.

I know that school and exams can be worrying and stressful for parents of teenagers with eating disorders, not to mention for the teenagers themselves, so here’s a bit of feedback I gave to another parent recently which may help other people too:

*After a long period away from school in his GCSE year Ben decided to go back to school full time in the sixth form. From the start he pushed himself very hard - a case of "all work and no play" which included avoiding his friends and over-working in the library through break, lunch and spare periods.*

*Not surprisingly by half term he had "burned himself out", was hugely unhappy and so we had a re-think about a better way of approaching school which ended up being a case of Ben going in as and when he felt he could and doing work at home when he felt he couldn't. This way we hoped to gently ease him back into full days at school while getting him re-established with his peer group socially.*

*The previous academic year had seen Ben's descent into the eating disorder. By the February of GCSE year we'd decided to take him out of school altogether meaning that he studied for his exams from home. When it came to the exams themselves, Ben was allowed to sit them separately from everyone else with an individual invigilator. This way we avoided any problems of (a) Ben freaking out and ruining his own chances and (b) Ben freaking out and freaking everyone else out too! It worked very well. Also, because Ben was finding it impossible to be with his peers at the time, careful timing meant he never actually needed to meet other students: before, during or after his exams.*

*When it came to the AS level exams this year, Ben was well enough to sit them as normal with everyone else. The only problem was that he wasn't sleeping so was knackered throughout which has been reflected in his grades (his GCSEs were surprisingly good considering how little time he'd been in school that year...)*

*There was a "Plan B" in place just in case he chickened out at the 11th hour; a separate exam room was available. But, in the event, he didn't need to use this.*

*Many of the ED teenagers I know of tend to be “driven” to study hard for exams and get stressed out. Taking time out from school definitely helped things - plus the exam arrangements. And I never nagged him about revision or getting into school. Basically I didn’t give a monkeys about the exam results; all I wanted was for Ben to get well and I made this clear to him throughout.*

*Oh, and the school was also able to arrange “special consideration” for results that may be affected by the illness. It doesn’t make a massive difference to grades, but can move things up a few per cent everyone at school feels the candidate “could have done better”.*

*Basically what you need is a very supportive school. We were lucky in that respect and still are. Ben’s AS levels were a bit dodgy, but he’s being given the chance to re-sit them where necessary. Also, fingers crossed, he may actually make it back to school full time when term starts in a couple of weeks...*

**Friday, 26 August 2011**

### **Odd experience - Ben strides through the “Fat Camp”**

Every summer a teenagers’ residential *Weight Loss Camp* hires the school premises - and yesterday, en route to a meeting with his tutor to talk about his AS exam re-sits etc, and before I could stop him, Ben ended up striding right through the middle of it. It was a strange and unsettling experience. Here was a teenager who was desperately trying to put on weight heading right through a crowd of teenagers who were desperately trying to lose it.

I’m not sure what I feel about that. And today, on the *News*, they’re talking about health professionals demanding that the government starts taxing junk food in a bid to combat the rising problem of obesity. The report said that two thirds of today’s

teenagers are obese - and this number is growing all the time.

Yet we all know that, at the other end of the spectrum, there is a group of teenagers who are suffering from anorexia nervosa - and this number is also growing all the time. But there was no mention of this on the news report and I don't see any of this obsession with "healthy eating" being geared towards helping teenagers that develop anorexia, etc.

So it's a weird kind of balance. At one end we have teenagers whose parents would love nothing better than to remove all nutritional labelling on packaging so their anorexia-prone children can't examine the calorie and fat content in minutiae. And for the government to stop all this talk about "unhealthy eating" which, no doubt, reinforces some kind of distorted logic in the mind of an anorexia sufferer.

Ditto all these programmes on the telly that focus on getting fat people thin, not to mention the massive banners up at school during the summer term advertising the fact that the "Fat Camp" will be taking over the school during the vacation.

And at the other end, we have a rising problem with obesity that all this nutritional, "healthy eating" and "fat camp" emphasis appears unable to stop. And I imagine taxing junk food won't suddenly make people reach for the *Weightwatchers* ready meals.

Yet to my son, Ben, and no doubt many others, this reinforces the distorted thinking that tells him that all the food they're talking about is "BAD" and must continue to be avoided or he'll end up like the teenagers he walked amongst yesterday.

Food for thought...

**Friday, 26 August 2011**

**The eating disorder goes back five years at least...**

The pressure of school on the horizon prompted Ben to explain in detail why school = pressure because it reduces the opportunity to exercise. And reduced opportunity to

exercise still = the need to consume less calories in order not to “balloon out”. So he decided to fill me in on the history of why he had an eating disorder *long* before anyone realised it...

The conversation started with: “Mum, why did you let me eat so much when I was a child?” Ben’s reaction to his past as a slightly overweight child has always been at the heart of what he believes triggered the weight loss which led to the development of the eating disorder.

There is no doubt he had an enormous appetite as a baby and child, and used to make our lives hell if we didn’t feed him (healthy food). But for years we simply assumed this was a healthy appetite. While Ben’s peers were fussy around food and preferred junk food, Ben’s “healthy appetite” made me as proud as punch.

However as he grew older (around age eight or nine) he began to put on weight. We just assumed it was “puppy fat”. He never got “fat” or “obese” as society interprets it today, but he was more fleshy than his peers. Being a quiet, shy boy who was prone to being bullied, he also associated this bigger body with “being unpopular”. For him, popularity = being thin, because all the popular boys were thin. He wasn’t as “popular” as them and was often side-lined by the boisterous kids; therefore he blamed it on his weight.

During this time his dad also encouraged him to play club rugby on Sundays. Ben was extremely good at the game, but hated it, mainly because, as he says, he “couldn’t be bothered”. He claims to be the kind of person that hates exercise and felt he was being forced into the rugby, just doing it “to please dad”.

Ben was bullied in the final year at primary school. Thankfully things improved when he moved up to secondary / high school and he got in with a really great circle of friends. His obvious talent at rugby meant he was immediately press-ganged into the rugby team which meant playing rugby on Saturdays as well as club rugby on Sundays plus sport and rugby activities on all five of the other days of the week. So, in effect, Ben was now doing around six times as much sport as he’d been doing at

primary school - and that sport was extremely physical.

At this stage (age 11-12) he hated what he saw as an “over-large” body. He was a *prop forward* in the rugby team - a position given to the “big guys” and he hated being seen as a “prop kind of guy”.

However he quickly cottoned on to the fact that all this exercise meant he was losing weight.

By the time he was 13 or 14 he'd slimmed down to the “perfect” athletic physique. We and everyone else simply assumed this was Ben growing up and losing all his “puppy fat”; a natural occurrence, and indeed this might be fact. But that wasn't the way Ben's mind was seeing it.

Ben had always loved food. Lots of it. And the other thing he cottoned on to at this stage was the fact that, thanks to all this exercise, he could eat as much as he wanted yet still maintain “the perfect physique”.

The only problem was, it meant having to carry on with the rugby, etc which he was starting to seriously hate. But no matter, it meant he could eat. So he forced himself to do a string of other sporting activities as well, in and out of school. Also he was getting more and more popular within his friendship circle. So his mind was telling him that having the “perfect physique” = being the centre of attention. Being fat didn't; viz the lonely, bullied years at primary school.

Without anyone realising it, Ben began to look more closely at the various equations involved. He started to analyse food content and had a fit when he “discovered” calories for the first time and found out how much his favourite foods contained.

So his mind went through this thought process: “I hate exercise with a passion but I have to do it in order to eat what I want without putting on weight, because if I put on weight I'll be fat, ugly and no-one will like me... *However* I've just discovered that much of what I eat can be ‘slimmed down’ either in ‘diet’ or low fat forms or by eating different kinds of food. So it figures that I can still eat loads of stuff but,

because I won't be taking in as many calories, I don't need to exercise as much to maintain 'the perfect physique' and stay popular. Result? I get the best of ALL worlds! Eureka!!!"

The only trouble was he started to crave certain foods. Again, without anyone being aware of it, he'd eat entire packets of biscuits, bags of dried fruit and huge chocolate bars. And with this came the "purge" reaction of needing to exercise to counteract it so he didn't put on weight. So, although half of him was nagging him to eat low calorie stuff, the other half was craving cakes and chocolate - in large quantities.

By the time we went on holiday in July 2008 he was swimming 100 lengths of the pool every day and doing sit-ups, etc while to all intents and purposes maintaining a normal "healthy teenage appetite". Yet, looking back, he says he was trapped in a "binge / purge" cycle.

This was followed a month later by the *Coast2Coast* cycle ride with his dad. This gruelling up hill, down dale cycle ride across England gave Ben the "green light" to eat even more because of the sheer number of calories he was burning every day.

The ride exhausted him, but he was thrilled at the results he was seeing in his physique which, in his eyes, was now "perfect". He also had a girlfriend and wherever he went he was eyed up by girls. And at school he was more popular than ever within his friendship circle (although he remained naturally quiet and shy, because this is who Ben is).

So yet again, this voice inside his head was telling him: "Look, this is proof. The more you exercise, the more you can eat without it having any effect on your body. In fact the recent cycling (coupled with consuming zillions of calories every day) has actually given you the 'perfect physique' you've been craving for - and see how popular you are now with everyone, especially the girls!"

However, deep down, Ben was hating exercise more and more. It wasn't enjoyable. It was a chore. It was the thing that enabled him to eat more without

getting fat and this is the sole reason for doing it.

Yet he was at the height of his popularity resulting in the biggest and most boisterous birthday party he'd ever had, at Christmas - a party that lasted a whole weekend. At this party Ben consumed an enormous amount of food and scoffed all the chocolates and sweets he was given as gifts. As parents we were thrilled at what we were seeing. A load of teenagers having fun, messing around and eating like horses, which is what growing teenage boys do after all, isn't it?

But inside Ben's head it was a different story.

Painfully aware that he'd just consumed an entire box of truffles given to him by a friend on top of stacks of biscuits, crisps, pizzas, puddings and massive breakfasts, he looked in the mirror and saw a fat boy looking back at him.

Or at least a boy who was fatter than he'd been during the summer of the "perfect physique".

To us, of course, he looked no different. And we didn't notice anything wrong. In fact Ben seemed to be going from strength to strength, excelling in sports, being praised by his sports teachers, excelling academically, spending loads of time with his friends, taking a starring role in the school drama production and so on.

What we were seeing was a boy who'd arrived at the school aged 11, quiet, shy, slightly overweight and with a history of being bullied, transformed into a handsome, athletic, talented, happy and popular boy with a normal healthy appetite for a growing teenager.

What he was seeing was a boy that wasn't exercising enough because look how much weight he was putting on, so he needed to exercise *more* in order to carry on eating as he wanted to because OMG what would happen if he carried on "getting fat"? His popularity would vanish in a flash and he'd be back to where he was at primary school.

So, if he didn't have an "eating disorder" in the accepted sense, he had definitely developed a "disordered" attitude towards eating, exercise and body image which

was playing havoc inside his head.

We first noticed a problem during the summer of 2009, as described in umpteen different entries in this blog so I won't go into it again.

The point is: We didn't realise that, for four or five years *before* this point, the foundations had been set in place for Ben's eating disorder. He'd been having "disordered eating" thoughts for *years*; what we were seeing in that summer of 2009 was just the tip of the iceberg starting to become visible - there was a heck of a lot of stuff that had been going on beneath the surface for some time.

And meanwhile the equations continued to go on in his head along the lines of: "I hate exercise but I don't want to get fat. So how about I *reduce* my food intake because that way I won't need to exercise as much yet I would avoid getting fat?"

... followed by Ben cutting out breakfast, then he'd cut out puddings, then he'd decide to simply have plain salad for school lunches ("I love food - so look how much stuff I can cram onto my plate yet it probably totals no more than 10 calories so I can *gorge* myself without having to worry about exercise!")

And meanwhile he was losing weight and liking what he was seeing.

But that was the point when it all started to go seriously wrong.

He is very aware of the fact that all these "good intentions" suddenly went pear-shaped on every front.

He couldn't stop himself losing weight. His mind was changing and instead of maintaining or increasing his popularity he was withdrawing into himself and from his friends. Meanwhile he was thinking about food more and more; in fact it was taking up most of his waking hours - and keeping him awake at night.

He still loved food as much as he ever did, if not more so, but he just couldn't eat it. So he started to ritualistically chop his food up into small pieces because (a) it took a long time to do and (b) it kidded him that he was eating more stuff than he was - so he needn't worry about putting on weight.

Modern research and thinking on eating disorders believes that certain people

have an “anorexic gene” (or similar) which kicks in when the body reaches a low enough weight - and this could be what happened to Ben at this point.

He had reached the point of no return as he spiralled downhill in every sense.

The point of this post is to show how Ben’s thinking and life experiences led to this point and why even now, at this advanced stage of recovery, his mind has to almost be “reprogrammed” bit by bit until he adopts a normal, healthy attitude towards food, physique and exercise. This is definitely happening, but it’s still a “work in progress”.

**Monday, 29 August 2011**

### **Fighting the exercise compulsions**

In the run up to the new school term we are fighting the exercise compulsions because that’s the main thing that, according to Ben, keeps him awake at night on school days. Why? Because all night long he’s trying to work out how he can fit enough exercise into his day while “sitting around at school doing nothing” (as he puts it). Not only is that incredibly stress-inducing but he is well aware that it isn’t “normal”, that it belongs to the eating disorder and that it has to go from his life.

So this week, while we’re on our final summer *staycation* (in a lovely little cottage high up on a hill in the Peak District) Ben is working on eliminating the compulsive exercise. (His choice.)

The compulsive exercise problem was getting out of hand around Christmas / January time which is one of the reasons why we developed the Recovery Contract - that, and because Ben was in *Limboland* and we needed to find a way out of it. We agreed certain exercise parameters over and above which Ben agreed not to go.

This has worked well for the past six months but, even though he only does a fraction of the exercise he used to do in his “high anorexia” period, it is still exercise that he doesn’t *enjoy* doing - as opposed to “normal” exercise which he *does enjoy* doing e.g. walking in the countryside or playing badminton with friends.

So, this week, we have agreed that he will do *zero* compulsions; just our daily walks in the countryside which is “normal” for us to do on vacation.

Ben wants to see what this change will do to his weight gain.

What is left of the irrational “anorexic voice” tells him that, by eliminating the compulsions, he will put on loads of weight when eating the same number of calories.

So he wants to see if this is true or not.

Likewise he wants to do a week at school to see if “sitting around all day doing nothing” will result in a surge in weight.

Of course you and I know it won't. But Ben needs to “prove” this to himself and it's something he's been doing with everything, especially the challenges, over the past months and it's worked well.

Challenge after challenge after challenge has only resulted in a normal weight gain - and not a fast weight gain at that. So he's proved the “anorexic voice” wrong on that count. And the more he proves it wrong, the more he “sticks two fingers up” at the “voice”.

However resisting the compulsion to exercise isn't easy.

In fact it's bloody hard and this has shown in his mood this week which has been low.

But at least he's been open about it.

Today I suggested he use his granddad as a role model in this. My husband's father was an alcoholic but successfully recovered several years ago. I reminded Ben of how difficult it must have been for his granddad to eliminate the booze from his life. But he did it. And he hasn't touched a drop of alcohol for years.

I said: “You are addicted to exercise like granddad was addicted to booze. He gave it up. It wasn't easy. In fact it was bloody hard. But he did it and so can you.”

And he nodded his head in agreement because he really admires his granddad.

SEPTEMBER 2011

## **Saturday, 3 September**

### **A tricky week in Derbyshire....**

The week got progressively worse as Ben's mood deteriorated. It was a combination of school lurking on the horizon and resisting the need to exercise compulsively. Some days were okay, but ED was still there - like on Thursday at *Chatsworth House* café where he suggested "sharing" our lunch and "donated" some of his "full fat" cheese to me.

While I tucked into a *Magnum* ice-cream and millionaire's shortbread, he tucked into a *Milky Way* and a banana. Okay, up until recently even a *Milky Way* would have been too scary for him which does go to show that we've come so far in so many ways. Yet ED is still in control over many areas of his life which hammers home the fact that we are still in this for the long haul. It's not over yet - and it won't be for quite a while.

Most other days he just skulked around, miserable as sin.

By Friday morning his mood had deteriorated into "melt-down" with "effing and blinding" shouting, tears and deep depression. So I decided to call it a day. We packed our things and came home a day early. Here at home I feel pretty darn tired - as if I've been through a very strenuous and demanding week rather than a relaxing vacation...

On the plus side, I believe he did resist the urge to exercise compulsively. But the week wasn't entirely exercise-free. After all, we went on a walk most days and the Peak District isn't exactly the washboard-flat Norfolk Fens...

Some may accuse me of colluding with the eating disorder but before we went away we agreed to modify the Contract to make it easier for Ben to manage the

holiday and resist the urge to exercise. By reducing his daily calorie intake by 100 the idea was that it would reduce the additional stress while “experimenting” to see if his claim that - every time he kept to his daily calorie total he felt compelled to exercise thereby “using up” the extra calories - was true or false. The scales would tell (we’ve still to weigh...)

In the event it didn’t reduce the stress but it did mean he was able to resist the compulsions. But I feel as if I’ve negotiated with the ED which isn’t ideal...

And now he’s saying I also agreed to reduce his daily intake by a *further* 100 calories when he returns to school because, at school, he really will be “sitting around all day doing nothing” and this way he’d reduce the stress to manageable levels and find it easier to sleep.

I denied agreeing to that and insisted that any decision will be made based on what the scales say this weekend...

So he said that any weight gain would “destroy him” and that he had “put on tonnes of weight” recently. I pointed out that his weight is the same as it was 14 months ago. Between then and now it has been significantly lower. And so on...

But I wasn’t in the mood for either discussing things calmly and in a “dolphinesque” way - or having an argument.

So we just packed the car and came home, via *Meadowhall* shopping mall where I drowned my sorrows in a shoes purchase and a couple of bottles of *M&S* wine for later, leaving him to try and find a snack he would eat “for pudding” because “*You say I must eat*”.

Hmn...

Time out while I bring in fresh anti-ED troops...

**Saturday, 3 September 2011**

**Staying on at the same school**

I never told you which school option we eventually decided to go with. Well, after

two long chats with Ben's tutors, we decided the best option was for Ben to stay where he is and plough on with his A-levels whilst doing some AS Level re-sits. Will it work? Only time will tell when the school term begins next week.

It's Ben's final year at school and the final year in what should have been the "perfect" school experience. Well, it *is* the perfect school and his experiences there had nothing to do with the development of the eating disorder. Ben's anorexia would have developed whichever school he was at; indeed at his current school he was arguably in a far happier and more supportive environment than he could have been if he'd gone elsewhere. And, over the past couple of years while we've been fighting the anorexia, the school has been outstanding in its support and understanding - and, no doubt, will continue to be so this coming year.

This academic year is really special. It's the 200th anniversary since the school's foundation and it's thrilling that Ben will be in the most senior year during the celebrations. It would have made me incredibly sad if we'd made the decision to remove him and for him to start the sixth form all over again at the local school. And the only reason why we would have made that decision would have been because we couldn't afford an extra year's school fees.

And, no, we are not wealthy. Having loathed every moment I was at a state high school it was always my dream to send Ben to a lovely school, even if that meant working hard and making financial sacrifices. When he was accepted on an academic scholarship with reduced fees I was delighted - and the school has been the very best possible place for him over the past six years and especially over the last two years.

I'd always known the school had a reputation for being a "caring" school and for supporting its students through virtually any crisis. But when we started out there all those years ago I could never have envisaged in what way and to what extent it would have supported us. I just hope that the eating disorder doesn't steal too much of Ben's final year away from him. It's already stolen two years of his school life and that's more than enough.

**Sunday, 4 September 2011**

**Onwards and upwards...**

So, all that swearing and tears on Friday morning and it turns out Ben had *lost* 0.6kg while we were away. So I asked him what he planned to do about it. Without any prompting he said he was increasing his daily calories back to where they were for the next four days, however he'd be dropping them down again when he starts school on Wednesday, for the three remaining days of the school week. But thankfully not to the extra low level he reckoned we'd "agreed on" the other week...

So there are good and not-so-good things there. Also I know he has been doing a little bit of exercise today. However the agreement is that the moment any of it becomes compulsive, then it stops. ("In your heart of hearts you know when it's enjoyable and when it's compulsive, Ben"...)

I also insisted that if his weight has maintained or only increased a tiny bit by the end of next week, then the calories increase every day, school days included. But first we need to get Ben back into school full time... something he has so far only managed on a couple of brief occasions at the end of last term.

**Monday, 5 September 2011**

**Unsettling glimpse into my past life as a "normal" person...**

This morning I drove my sister to a physio appointment at the local health club / gym where I used to be a member in my past life as a "normal" person. Sitting in the *Starbucks* coffee shop in the foyer I watched people go by, gym bags in hand. Some were new faces, others I recognised by sight. It was a strangely unsettling reminder of my past life "before all this stuff kicked off"...

At first I found myself thinking: "Hey, now things are so much better I could join the gym again and pick up where I left off 2+ years ago, sort out the excess weight

and flabby bits that have appeared as a result of eating the huge evening meals and other things you end up eating as a parent of a young person recovering from an eating disorder.”

But then the “new me” kicked in - the person who’s spent the last couple of years realising that it’s not the way you look that counts; it’s what goes on inside and how you spend your time. I might have far flabbier abs than I had during those gruelling days on the treadmill. I might have sprouted “bingo wings” and “love handles”, but what the heck? I’ve helped my son recover from his eating disorder, I write this blog and I’ve built up a whole new circle of fabulous “cyber” and local friends who have far better things to do with their time than worry about what they look like or go to the gym.

And what kind of messages would I be giving out to my son if I started counting calories again and “having to go to the gym” regularly? Remember back in the summer of 2009 when he “had to go to the gym” every day as he got thinner and thinner and more angst-driven by the escalating anorexia?

In fact one of my last memories of the gym was, ironically, that of a young woman I used to see punishing herself on the treadmill followed by just about every other cardio machine in the building.

I’d see the other gym regulars looking at her. “How can they permit someone like *that* to use the gym?” they’d whisper, glancing at her very obviously anorexic physique. “It shouldn’t be allowed...”

And I used to wonder why that emaciated woman wanted to look like that? Couldn’t she see how impossibly skinny she was? Where did she get her energy from? And like the other women, I’d glance at her from time to time, hoping she wouldn’t notice me staring.

Two-and-a-half years on I think very differently - about the gym and about that young woman I used to see pushing her emaciated body to the limit.

So, sitting there in *Starbucks* this morning, I realised that - no - the gym isn’t for me

at the moment. There are far more important and useful things I can do with my time and energy. And who gives a damn about being a few pounds heavier than I was then? As long as I am healthy, my son is healthy and we are happy then that's all that matters.

**Tuesday, 6 September 2011**

**So small, so cute, so many hopes and dreams for their future...**

Remember how it was on your child's first day at "big school"? A small child in an over-large, brand new school uniform. New shoes shiny and unscuffed. Sports bag with crisp folded sports kit, sports shoes without a micro-gram of mud. En route to a kind of Utopia High School where everyone is friendly and bright, excelling at sport and great at music. And in this Utopian setting your child would thrive on every level. It may only be Day One but in your imagination he's already Head Boy - a handsome, strapping 18 year old admired and respected by staff and pupils alike, a star of the rugby team and an ace at cricket. He'll emerge with a string of A-star qualifications, be snapped up by the best universities and come out with a brilliant degree before embarking on a fabulous career and family life...

That was me, seven years ago, dreaming as the school bus carried Ben to school for his first day.

Thankfully he had four good years at school before the one outcome I could never have dreamed of stole two whole years out of my son's school life.

This time last year I wasn't dreaming; I was full of dread and apprehension as he attempted to return to school after a nightmarish year where we ended up removing him from school completely. And although the 2010-11 year wasn't as bad, he still ended up being absent for much of the academic year as his anxiety reached new heights.

So what will happen tomorrow as Ben begins his last ever year at school?

I honestly don't know.

Thankfully, though, I'm not feeling dread or apprehension this time round because I know we can cope with the outcome, whatever it is.

And if I'm dreaming of anything, it isn't that Ben will excel academically or on the sports field; it's purely and simply that his last year at school will be okay - and that he'll re-integrate successfully with his friends and become happy and well.

Who gives a damn about qualifications, taking the lead in the school play or wearing a Head Boy's badge? In my mind, by facing his anorexia head on and refusing to give in to it, he has already achieved something far, far superior to anything he could have achieved at school.

Exams can always be re-sat. University can be entered as a mature student - or not at all, if that's his wish. Instead, let's focus on the things that *really* matter this year like full recovery in every area of his life.

**Friday, 9 September 2011**

**Putting on my "normal" hat again, if only for one night...**

Tonight I will act normal. As I help out at the school PTA's *Welcome Evening* for new parents not one of those parents will have any inkling of what I and my son have been through over the past 26 months.

I will chat happily with parents, answering questions like "What year is your son in? Has he enjoyed his seven years at the school?" just like a normal person.

To them, I will just be a normal parent, a normal member of the school PTA, no different from anyone else.

And I will graciously accept the gift of flowers from the Chairman of the School PTA in recognition of my support now that I've decided "the time has come to resign" from the committee.

Everyone will applaud, assuming I'm leaving because "A-level year is such a busy year, you know, what with all those university open days and applications, revision and so on".

It's only right that Mrs Matty focus on getting her son through his A-levels and into university. Good Old Mrs Matty, what would we have done without her? She does the Christmas Fair, website and everything, you know.

Yet none of these new parents will realise what else I was up against while I was battling to organise "the Christmas Fair, website and everything" over the last couple of years... Like the day before the 2009 Christmas Fair, for example.

That morning I'd been urgently called into school by the medical staff because Ben had gone completely off the rails. And I spent the rest of the morning sitting in *Sainsbury's* car park in floods of tears, ringing round the Committee trying to get someone else to take the Fair off my hands.

That afternoon I was like a ghost or a robot as I helped set up the Fair. And that evening I was in pieces. (So was Ben...)

And that's just one example...

When I handed in my resignation earlier in the summer, the Chairman said she was surprised I hadn't resigned sooner.

But tonight no-one except a small select few will know the real reason for my resignation.

And no-one but a small select few will understand the concerned looks I get from staff "in the know" as they ask me "how are things coming along?"

**Saturday, 10 September 2011**

### **New Parents' Evening**

Well everything went much as described. I got my flowers, the New Parents chatted away, the Headmaster gave his usual speech (7th time I've heard it now...) and a lot of free wine was consumed by those that weren't driving. And I wore my "normal parent" hat all evening. Except when talking to those few people "in the know", out of hearing of anyone else...

First there was the Deputy Head who took me aside to say staff had been

suggesting ways that Ben could become more involved in things this year to help him integrate back into the social side of school. The Music teacher wants him to audition for a lead role in the seniors' musical. And Mr C said Ben had been given the job of Charity Coordinator for his *house*.

Then I bumped into S, the school nurse. I've got to know her so well over the past couple of years that we're on hugging terms. I've even had lunch with her a couple of times and been invited to her house. She's been a true tower of strength to me in ways I could never hope to repay. In fact I'd love to stay in touch with her after Ben leaves the school.

"Any more thoughts on writing a book about your experiences with Ben?" she asked. Actually I'd forgotten about that. But it's another of the reasons I keep all the notes, forum threads, letters, emails and blog entries to do with the eating disorder, so in the future I may be able to put it all together into something of use for other parents.

Finally I served wine next to P, another PTA member who's been great support (she's the one I spent ages on the phone to while sitting in *Sainsbury's* car park in tears the day before the 2009 Christmas Fair).

Not many other people know. To explain the reason why I've been keeping a relatively low profile for the past couple of years, the PTA Chairman told the rest of the committee I'd "been ill". (Her decision; to be honest I don't mind people knowing the "real reason".) So last night everyone was commenting on "how well" I was looking compared to last year...

In his speech the Headmaster said "Over the next seven years you will come to know each other very well, seeing the same faces at every parents' evening..."

True. I've seen the same faces at every parents' evening over the past seven years. Last year wasn't too bad, but the previous year I was painfully aware of how different Ben looked to his peers; of those guarded glances from other parents as they pretended not to stare.

After all, they'd seen Ben over the years, too. And back then the transformation into the anorexic Ben was too dramatic to ignore. I was also painfully aware of how Ben kept close to us, ignoring his peers completely when, pre-anorexia, he and his mates would go off somewhere to mess around before Mr J marched in to tell them off.

We haven't had a sixth form parents' evening this year yet. Hopefully it will be no different from how it would have been had anorexia never hi-jacked our lives. It's our last year at school and Ben is in the 2012 leavers' year which is the year of the school's bi-centenary with various celebrations. So I'd love it to be a good year...

**Sunday, 11 September 2011**

### **Touching base on how things have been this week**

Yesterday I had a chat with Ben about how this first week at school has been. I also weighed him because, if you remember, I agreed that - for the first three days back at school - Ben could reduce his calories by 100 a day. Why did I agree to something that may appear as "colluding" with the eating disorder?

Because Ben needs to eliminate as much of the anxiety as possible that comes as part and parcel of easing himself back into school.

There was a caveat to this temporary calorie reduction, however. I'd weigh him at the end of the week and the following week's intake would be based on the results. My plan is to ease him back into school, adjusting his intake up gradually until he's gaining consistently. In the end he'd gained this week anyway, so we've agreed a duplicate week next week.

What I must be careful *not* to do is to "feed" the mind-set that the "cure" for school and social anxiety is a reduction in food intake...

School's not been too bad this week. Not perfect, but not anywhere near as bad as it was one year ago (and we won't even talk about where we were one year before that!)

But it's a case of gently easing him in, touching base regularly to check that the delicate balance of socialising, eating, exercise, sleeping and anxiety levels are relatively *okay* and doing whatever it takes to put things right if they're not.

My main concern is the social side of things, so I'm keeping a close but discreet eye on this...

And, you know, we haven't had a CAMHS appointment for a month... So I really hope they work with me, not against me, when we see them this coming Friday.

**Monday, 12 September 2011**

**Memory is a funny thing...**

It's funny how the human memory manages to "forget" or at least "blur" many of life's traumatic experiences. It sounds strange but, for some reason, I find it really hard to recall how I really felt - day in, day out - during the Bad Old Eating Disorder Days.

I forget just how bad things were and how petrified I was. I forget how I came to "accept" that Ben might die, if not from the complications of self-starvation then by ending his own life. I forget how I used to break down in uncontrollable tears several times each day - and how, on some days, things would get so stressful that I'd be reduced to a total wreck, like the day I smashed an entire dinner service, plate by plate, on the kitchen floor, then collapsed in an hysterical, weeping heap in the corner.

Not to mention the day I had to pull Ben inside by the legs when he decided to climb out of his *Velux* loft bedroom window onto the roof not caring if he fell. Or the two emergency hospital experiences with Ben wired up to machines...

In fact the Bad Days were so frequent that I can't possibly list them all here. What you see above was just the tip of the iceberg. But I believe it's vital that I don't forget. This is why I've kept copies of everything I've written on the subject: emails, letters, notes to medical people, my threads on the ATDT forum (for parents of young people

with eating disorders), this blog and so on - and now some new stuff that's come to light (more about that in a moment...)

In some way I'd like to use it to help other parents of teenage boys with eating disorders.

If nothing else, then at least to show that there is a light at the end of this terrible, dark tunnel. And, in the case of this blog entry, to show that your memories of the Dark Days will fade and, at some point in the future, it will dawn on you that life is pretty damn near normal. Or at least a zillion miles away from what it was like at the eating disorder's height.

My dear friend, S (the school nurse), reminded me on Friday that she'd suggested back in June that I put it all into a book. Maybe I will. But I've got *so much stuff* that it's hard to know where to start!

Meanwhile, something else has come to light which has prompted me to suggest that Ben gets involved in all this at a "grass roots" level.

The other day he produced an exercise book. "My diary from 2009. Just to prove how far I've come since then." There weren't many entries "because I got to the point where I couldn't even write, the anorexic thoughts were taking up so much space in my head".

But even though there aren't many entries, it's interesting to read what Ben was going through, from his perspective, back in the summer of 2009 when the eating disorder started to manifest itself (even though it had actually been present for some time before that, as can be seen from this entry).

I suggested that, when he has a spare moment, he uses these diary entries as a base for writing about his experiences ("Not loads of stuff, Ben, just a page and a half of A4-ish."). And he's very keen about the idea of a book. "Just think, we'd get onto the telly, we'd become rich and famous!!"

I don't think so, Ben...

Especially if the said book is to be self-published...

**Tuesday, 13 September 2011**

**Something isn't right with school...**

One week into the academic year and, to be honest, things seem identical to a year ago when everything went pear-shaped on the return to school. Yesterday he was as gloomy as hell; today his mood has reached rock bottom and he won't talk about it. Already he's making excuses to get out of all the activities he planned to get involved in this term. And, predictably, he is isolating himself...

He has tomorrow afternoon off. So if the weather is fine, and even if it's not, I'll suggest we go for a walk and I'll attempt to get him to talk about it. Frankly, if school is getting him down so much, then he's better off out of it while we focus on recovery full-time. But I'd need to know now so I can negotiate with school for some money back (if they will give me any...)

Also, it would be vital that Ben keeps occupied if he's out of school and the best option, I think, would be to continue with his A-levels via distance learning. But, again, I'd need a swift decision to avoid a missed year and avoid the risk of Ben having nothing to do for an entire academic year which would send us all stir crazy. At the moment there aren't any jobs and, even if there were, I don't really feel he'd be able to hold one down right now. And, anyway, he's extremely academic and needs to use his brain.

Meanwhile he's gone off to a meeting at church. He was going to chicken out of that, too, but changed his mind at the last moment... However anyone would think he was going to a funeral when I dropped him off at the church... Gloom, gloom, gloom.

And when he's in this frame of mind, his eating suffers... It's as if the anorexia instantly recognises the *Achilles heel* and zooms in to play the toxic friend who pretends to provide a solace.

Ben scarcely saw his friends over the summer because they were "always busy" or

“no-one is around”. Now, at school, he claims his friends are always “on duty” (as prefects) so there’s no-one to go around with. Or “everyone has gone home” or “they’re all in lessons”.

This is one of the things we haven’t conquered yet; the social destruction that often comes part and parcel of anorexia. After improving for a while back in the spring / early summer everything started to go downhill again following the summer exams.

And it makes me so, so sad to look back to the pre-eating disorder days when Ben was Top Dog in his circle of friends. Everyone wanted to be Ben’s friend and so many boys came to his birthday parties we used to have to hold them on *two days* to accommodate everybody!

Yet here we have a self-isolating, lonely and depressed boy who should be going from strength to strength in every way.

This is something Ben will need significant treatment for; it’s not something I can solve.

Meanwhile I’ll let you know what happens when or if we talk tomorrow...

### **Wednesday, 14 September 2011**

#### **Probing to find out what’s wrong...**

As I thought, it’s school that’s the problem. And, also as I thought, it’s the social side of things that’s causing the most angst. The main problem is that Ben feels he’s being ignored and side-lined. Or if people *do* talk to him, then it’s only because they “feel sorry” for him.

One thing that really got him down the other day was everyone whispering about a party at someone’s house this weekend. When Ben asked about it the reply came back “Oh it’s way too complicated to explain...” And let’s face it; no-one wants to be in a situation where you have to *ask* to be invited...

Getting back into the social side of things is so hard when you’ve been “AWOL” for

some time - in Ben's case 26 months or so. Everyone else has been getting on with their life like any other teenager - having boyfriends and girlfriends, going to parties and clubs, hanging out around town, sleeping over at each other's houses, etc - while Ben has stayed at home dominated by the anorexia.

Not only this, but over the past couple of years his behaviour in school has been very strange to say the least. Not recently, but disturbing enough in the past to doubtless make some of his peers keep their distance. Unless you "get it" about eating disorders, I guess this can be frightening and alienating. Sure, the CAMHS team went into school last November to talk to his close friends about Ben and his eating disorder and things improved for a while. But now it's as if they've forgotten this ever took place.

When you're well on the road to recovery from anorexia, it's so difficult to pick up where you left off. What makes it most upsetting is that, before the eating disorder took over, Ben was Top Dog in his social group. Now he feels as if, to them, he doesn't even exist.

He says he's got quite a few acquaintances but no "real friends like I used to have before the anorexia," and it breaks my heart.

I feel like getting hold of his friends and shaking them, asking them why they don't make the move and include him in things as it's *so important* now he's heading towards recovery and wants to be involved again.

But when you're nearly 18 the last thing you want is the embarrassment of your mother talking to your friends.

The Good News is that Ben hasn't cut down on his calories. Yes the urge to cut down is there and is no doubt triggered by the social anxiety, but he's said a big emphatic "NO" to it and carried on eating.

**Thursday, 15 September 2011**

## **Living a double life**

For the first half year or so of living with the anorexia, I lived a double life. Here at home and with the few people “in the know” I was living a nightmarish life as the mum of a teenage boy rapidly descending into anorexia and all the frightening behaviours and medical problems that come with it.

To everyone else I was simply the mum of a teenage boy who was going through “the typical teenage phase... you know what teenagers are like! LOL” kind of thing.

Back then I used to write a regular blog for a regional newspaper. So to my readers, too, I was this “other person” going through the trials and tribulations of bringing up a teenager with a dash of good humour thrown into the mix.

The nearest I got to the distressing reality of what was actually going on was a blog post I wrote after Ben had been rushed into hospital with heart problems (in Jan 2010), exacerbated by the rapid weight loss and lack of nutrition. Of course I was maintaining a light-hearted approach; no-one had the slightest idea what was really going on.

Here it is:

### ***Not a week I want to repeat...***

*How's your week been? Mine's been one of those where everything goes out of the window because you get a call from the school nurse saying your son should go to A&E... fast!*

*Worse, it isn't a broken nose (like last time), or a broken hand (like the time before), it's Ben's heart which is doing “funny things” and beating at half the rate it's supposed to.*

*Mine stops as I start to panic. And it's totally true you go ice cold when you get this*

*kind of news...*

*For the first time ever in the history of visiting A&E we're spirited past the usual queue. In a flash, Ben's covered in sticker things and wired to a machine. Next, he's wheeled into a cubicle where they jab a massive needle in his arm to take loads of blood while still monitoring his heart on the machine that goes beep.*

*And because his arteries are like mine i.e. difficult to locate, they have a heck of a job trying to get the big needle in. Ben's had some pretty hair-raising things done in his time, what with in-growing toenails, several teeth out, the various bone breakages and so on, but this is the first time I've seen him actually cry...*

*Me... well... If you've ever been in a similar situation, a zillion thoughts rush through your head from "I must ring his dad" to "This is my only child and this is his only heart"...*

*Suddenly I'm at the nurses' station saying "Excuse me, I don't feel very well – they're sticking needles in my son". A glass of water later and a "Pull yourself together, Batty!" pep talk to myself and I'm on the phone to Ben's dad saying, "I don't think there's anything to worry about, but..."*

*Next we have a succession of important looking doctors frowning, taking notes and repeatedly checking the machine. "Smile and tell me it's all okay and we can go home!!" I will them to say. But instead they say he needs to be transferred to the specialist cardio unit at the other hospital in our city.*

*I say something stupid like: "What shall I do with my car? It's in the pay-and-display car park." They give me a withering look.*

*So while Ben's being transferred by ambulance, I'm busy moving my car to somewhere I can call a cab to take me to the city centre. (Nowhere to park and who knows how long I will be?)*

*It's like a nightmare. The traffic is horrendous. The only cab number I've got can't be here for 30 minutes. So I have to drive to my mum's, borrow her phone book and explain what's happened without worrying her.*

*Cab after cab say they'll be AGES... Finally I find one that can be at mum's in five minutes, but the traffic is in gridlock. Eventually I arrive to find Ben lying in a ward with three old men who sound like they smoke 60 a day.*

*And so it goes on... wires... monitors... doctors... nurses... questions... heart x-rays...*

*Me analysing the staff's body language for clues as they're predictably non-committal with what they say.*

*Oddly, Ben seems to be pretty okay except for the massive needle in his arm and the constant beeping of the machine. In fact he's so okay he makes me go down to the shop to get him something to eat because the hospital sandwich they've given him looks as if it's six weeks old.*

*Then he sends his dad down to get some more food!*

*It's funny how your mind works. Half of it panics with visions of cardiac arrests, heart transplants and worse...*

*The other half thinks, well if they're allowing him to eat they obviously aren't planning to operate. And, he's at this end of the ward, not that end (the "emergency" end). And, he's not seeing the consultant until the morning; if it was critical he'd be seeing him now. Stuff like that...*

*At 8.30 pm Ben's dad and I have to leave and we're exhausted. None of us has a good night's sleep. I'm up at 4am, head hurting, half wondering if I'll receive an emergency phone call... Meanwhile Ben's trying to sleep with a massive needle in his arm, surrounded by old men snoring like pneumatic drills.*

**BUT IT ALL TURNS OUT OKAY!**

*By the time the consultant does his rounds, Ben's heart has stabilised, there doesn't seem to be anything physically wrong with it and he's allowed to go home. Not many clues as to why it might have happened except that sometimes sporty teenagers can get dips in their heartbeat.*

*But of course if he ever feels "strange" again, he's to come straight back. But, thankfully, the consultant doesn't seem unduly concerned.*

*Mind you, I'm expecting the kind of mature, larger-than-life consultant who strides into the ward, James Robertson Justice / Sir Lancelot Spratt style.*

*What we actually get is someone who looks like a sixth former. Can I trust his opinion, I wonder to myself like you do...?*

**Friday, 16 September 2011**

## **“Long time, no see” they will think this evening...**

One of the first things I did as Ben plummeted downhill into anorexia was to look for support: practical support, emotional support, spiritual support, any support! And, like some people, I was drawn to seeking it in the church despite the fact I hadn't been to church for 25 years or so...

But it didn't turn out quite as I expected and one year ago I stopped going. Tonight, however, I've accepted an invitation to be at the launch of a community event the church has been working on for some time - and I feel a bit strange about going back...

Back in 2009 and 2010 I tried three churches in total, none of which “floated my boat” mainly because, there I was, desperate for emotional support which I assumed I'd find in the church when, in reality, I found myself faced with people who were pleasant enough, but who often left me standing alone while they chatted in their usual friendship groups.

It's something I found hard to get my head around.

Here were three churches talking endlessly about their “mission” to reach out to the community to help those in need.

Yet when someone who was massively “in need” turned up on their doorstep, they seemed blind to it.

Oh, everyone politely asked how things were going once I “came clean” and explained our situation. I was even invited to some social events and to people's houses for coffee.

Yet I was always kept at a polite arm's distance with the distinct impression that my problem wasn't something they wanted to or indeed were able to deal with.

If I could just chit-chat about everyday stuff like everyone else, then that would be fine, but here I was dumping something altogether new into the pot and I don't think they knew how to deal with it.

The result was that I used to go to church services and feel incredibly lonely -

especially afterwards as people gathered for refreshments.

I'd just stand there totally unable to engage in everyday smiley chit-chat when my brain was exploding with all the heartache and emotions that go round your head as a parent of a child whose life you're fighting to save.

I'd return home feeling really naff and I'd wonder why I'd gone to church in the first place. After all, wasn't religion supposed to make you feel uplifted?

So I stopped going. Especially after a couple of embarrassing episodes (at churches #1 & #3) where I ended up in floods of tears.

The first time it happened the preacher was talking about the importance of families and children - and I'd find myself looking at all these young families with children, then wonder how the heck our family ended up in the hell we were in.

I can't remember what caused the second breakdown, but I ended up fleeing from the church in tears...

Tonight I will be returning. Why am I choosing to return?

Two reasons, really.

Curiously, despite the fact that I stopped going to church, Ben continued. He'd come along with me a couple of times, but wasn't really "into it" back then.

However once I stopped going, he kind of started - and he's taken himself along there most Sundays ever since. Tonight he is helping out with the community event and he's persuaded me to go (and to the event tomorrow and the service on Sunday...) (He's still to really get "in" with the other youth group members, though...)

The other reason is that there was one massive exception to the polite-distance welcome I received and that was an amazing lady called Sue.

I met Sue at Church #3 (tonight's church) the first time I went. She was the one who saw me sitting alone at the back about to flee and came over, scooped me up and invited me to sit with her.

Over the next weeks and months, and still to this day, we are firm friends. She is one of the key people that has given me masses of emotional support over the past

18 months and she still continues to do so.

I've mentioned Sue before. She's the one with secondary breast cancer and it seems to be getting worse. But, being Sue, she's always ultra-chirpy and smiling. Typical.

One of the reasons why I think we get on so well is the fact that both of us have been going through such traumas. While the rest of the church appeared to be living pretty normal lives, ours were both abnormal. And out of this has come a rock-solid and supportive friendship.

So I guess in a way I did find what I was looking for when I nervously ventured into church #3 all those months ago. But it will be interesting to see how tonight goes and if I'll still feel a bit of an outcast as regards the other people in the congregation... I hope Sue goes. It really depends how well she feels...

Mind you, these days, I'm great at jolly chit-chat conversation. Now the fear has gone...

## **Sunday, 18 September 2011**

### **Ben's long-standing relationship with food...**

Ben was a "screaming baby". If he didn't have a bottle in his mouth he would scream blue murder. With a bottle in his mouth he was as happy as Larry, and he'd take at least 60 minutes to finish each bottle. This meant I had a breather of an hour or so before the incessant screaming would get me down so much I'd shove another bottle in his mouth...

Apart from probably feeding him more than I should have done, I ensured I was a "text book" mother. I did everything right. Once Ben was weaned, I fed him pure fruit juices from the health shop. I made a succession of incredibly healthy pureed foods using *Annabel Karmel's* baby recipe books as a guide. I never fed him sugary snacks, crisps, chips or anything bad like that.

As a toddler, Ben continued to eat a perfectly balanced diet and he enjoyed every

morsel. If his next meal wasn't ready pronto he'd go bananas, start screaming and playing up. By now his nickname was the "Angry tomato"; his face was always bright red from screaming!

He'd throw screaming tantrums that were so loud and disturbing (for us and everyone else around him) that, against my better judgment but to maintain some kind of maternal sanity, I'd put a plate of something or other in front of him just to shut him up. It usually worked.

When Ben had grown out of the screaming in public phase and we could start eating out without the rest of the pub or restaurant giving us daggers looks, Ben hoovered up whatever child's meal was on the menu. It quickly became clear that children's portions simply weren't enough for his huge appetite so he "graduated" onto adult portions far sooner than most children. And ate every single morsel. Plus an adult-sized pudding as well.

And I'd look at all those "fussy" children pushing vegetables round their plate and eating like sparrows (which was the case with virtually every child that came to our house for a meal or birthday party) and feel so proud! My son wasn't a fussy eater. He'd eat virtually everything in sight without leaving a single scrap.

He loved my cooking, just like his dad. Both of them would sit at the table (we always ate at the dining room table) and Hoover up my latest culinary creation. I was delighted.

However I was aware that Ben wasn't exactly a skinny child. He'd been a "bouncing baby", always wearing clothes of a slightly older child. Yet he wasn't "fat"; he was the kind of baby that old ladies would admire.

Time and time again, old ladies would say things like: "I just had to come over and tell you what a beautiful baby you have," and Ben would beam at them, basking in the admiration.

At primary school Ben discovered "junk food" (care of other children's parties) and stodgy school dinners - and he couldn't get enough of those either.

However by the age of eight or nine I was aware that Ben was starting to carry quite a bit of “puppy fat”; probably too much, really.

But he just loved his food...

A massive increase in sports activities at high school meant Ben gradually lost all that “puppy fat” to be replaced with an awesome physique. Now, instead of the old ladies, it was the girls that would admire him while I basked in maternal pride thinking: “This handsome, strapping boy is my son!”

So Ben’s life has comprised polar opposites as far as food is concerned:

The first 14 or 15 years when he loved food with a passion and put away enormous quantities of the stuff, gleefully hoovering up whatever was put in front of him and usually asking for “seconds”.

... And the following two-plus years when he *still* loved food with a passion but avoided eating it as much as he possibly could. In just three months over the summer of 2009 he lost one quarter of his bodyweight and the handsome, muscular, strapping boy became an anorexic waif.

Also, the incredibly healthy and fit body started to show the strain. His bones protruded like a concentration camp victim; his skin became dry, red and scaly; his hair started to thin out; his pulse dropped to a dangerously low 29bpm on a number of occasions... And goodness only knows what was happening to his other internal organs.

Back in the days when I used to feed him on health shop fruit juice and incredibly healthy home-cooked baby food I used to feel so proud that my son would grow up tall, fit, strong and healthy without any of the unhealthy attitudes towards food displayed by his “fussy” peers.

Unlike many of them him he wouldn’t have a body potentially compromised by years of eating the wrong kind of thing.

Yes, I felt sure I was giving him the very best nutritional start in life which would hopefully lead to a lifetime of physical and mental health.

Funny how things turned out...

**Monday, 19 September 2011**

**“Is it something we’ve done? Is it something I’VE done?”**

This is what Ben’s dad said over and over again - and still does on “bad” days. It’s also what I used to say sometimes. “Did I over feed him as a baby or as a child? Was it my fault he developed an insatiable appetite and got a little bit plump towards the end of his primary school years?” The general consensus of expert opinion is that parents *do not* “cause” their child’s eating disorder; an eating disorder is far too complex to have such a “straightforward” single cause.

These days, experts reiterate again and again that *parents are not to blame* for the anorexia, bulimia or other eating disorder. Instead an eating disorder is thought to develop as a result of a variety of issues - what I interpret as a “toxic mix” of genetic make-up and general disposition exacerbated by a mix of external environmental factors.

In our particular case I believe the “toxic mix” comprises a bit of my dad’s tendencies towards OCD, perfectionism and self-imposed isolation - and my husband’s family’s predisposition towards addiction and some mental health issues. On top of this is the fact that Ben got quite plump as a child and was bullied at primary school. Mind you, I believe he would have been bullied whatever size he was; unfortunately he was that kind of child.

As a baby and toddler, Ben was *loud* and inconsolable most of the time. He found it virtually impossible to “play nicely” with other babies and toddlers at *Mother and Toddler Groups* and so on. Instead he’d either sit there with a face like thunder which instantly told any intrepid little two year old about to make friends with him to “back off or else”. Or he’d scream blue murder, so much so that we’d have to make a quick exit. I was the mum the other mums looked at in horror; the mum with the “uncontrollable child”.

Yet by primary school, Ben had gone to the other extreme. He was incredibly quiet, shy and serious, the kind of boy who'd make one good friend (a similarly quiet, shy boy) and keep a million miles away from the boisterous boys who'd play football and generally mess around.

Also, for a reason we could never fathom out, Ben's confidence was at an all-time low. All of this made him an obvious target for bullying and by the final year at primary school Ben was already seeing a therapist about confidence and his fear of school.

We nearly took Ben out of school and had found a place at another school if he wanted it, but it was so close to moving up to high school that Ben insisted he wanted to stay. Thankfully the bully went to another high school, so he left Ben's life for good.

Ben had a couple of issues with some unpleasant boys at high school, but these were quickly quashed by a zero tolerance approach to bullying and the support of a high school with a tremendous ethic. As I've said before, Ben thrived during those first years at high school before the eating disorder hi-jacked his life.

But deep down Ben was still essentially quiet, shy and serious. He still lacked confidence and had a low opinion of himself - inside and out. And he'd never quite been able to shake off an underlying depressive nature.

He always says that, having been overweight as a child, he dreaded becoming the "fat boy" again. So he did everything in his power to ensure that would never happen. Even though, to people on the outside, Ben was incredibly popular within his peer group, Ben himself wasn't too certain. Something inside him began to nag that a sure fire way to gain the true popularity he craved, especially with the girls, was to "get a six pack" and develop the kind of perfect physique he saw in *Men's Health* magazines.

When he looked like this everything would be perfect. He'd be uber-confident and everyone, especially the girls, would love him.

And the rest, as they say, is history.

The point?

I believe a number of factors triggered Ben's eating disorder. His genetic makeup, his general disposition and a mix of environmental factors from childhood puppy fat to bullying.

There is nothing that we, as parents, could have done to avoid the eating disorder developing. I believe it would have happened no matter what. Or it would have manifested itself in some other way - like addiction, clinical depression or OCD.

So, as I keep having to tell Ben's dad, "No, you are *not* to blame. It isn't anything you or I did - or didn't do. It just happened..."

**Tuesday, 20 September 2011**

**Why did it take 22 weeks from the first GP visit to our first CAMHS appointment?**

In the world of spiralling rapidly downhill with anorexia, 22 weeks is a heck of a long time. A heck of a lot can happen and the chasm can be a heck of a lot deeper than it was several months before. So, in theory, there's a heck of a lot further to climb back than if the issue had been addressed urgently when we first took Ben to the GP in September 2009. And meanwhile we, who were completely ignorant about anything to do with eating disorders, hadn't a clue what to do or even if we *could* do anything to prevent our son jet-propelling himself into a physical and emotional hell.

The more I think about it, the madder I get.

Here in the UK everyone, except the super-wealthy that can afford it, is forced to opt for state-funded NHS treatment. Even though some of us do have medical insurance (we did at the time), it often excludes mental health issues. Or (like ours) it covers you for something like a measly £500 a year. This wouldn't even buy you three sessions with many UK-based private psychiatric professionals.

And, being the NHS, there is usually a lengthy waiting list. Unless you're fast-tracked through the system because the GP believes you have something potentially

life-threatening.

Hang on a minute... Don't eating disorders have the highest mortality rate of all psychiatric illnesses? Didn't I read somewhere that one in five people actually die as a result of their eating disorder?

Don't these facts alone qualify it for a teeny weeny bit of an emergency in a medical professional's eyes?

I don't doubt that in some areas across the UK and the world, this is indeed the case. Teenagers are whisked off to hospital or treatment urgently. And they do say that early intervention can lead to early recovery.

But we had a treble problem.

Firstly, our local NHS waiting list for eating disorder treatment tends to be around 18-20 weeks. Not from the first time you take your child to the GP and not even from the first time you persuade your GP to refer your child to this service (called CAMHS here in the UK). The waiting time doesn't even start once CAMHS acknowledges receipt of the referral. It starts once they write back to you to tell you that, yes, you've been accepted for the waiting list. With us, this letter came in late November 2009, over two months from our first GP visit.

I estimated we wouldn't be starting treatment until Easter.

Secondly, Ben's BMI wasn't dangerously low. Sure, we as parents were painfully aware that he'd lost one quarter of his bodyweight in three months, but the GP only had our word for it. Here in the UK, you see, children don't undergo regular medical / weight checks like they do in the States. If this had been the case then maybe our GP would have heard the alarm bells ringing out loud and clear, and acted then and there. Especially as I was describing a "text-book" case of eating disorder style behaviour, compulsions, rituals and moods.

And thirdly, Ben had the disadvantage of being a boy - and, hey, surely it's girls that get eating disorders, not boys? After all, skinny boys aren't unusual. Skinny girls with all the associated behaviours, etc maybe warrant closer scrutiny, but surely not

boys?

Anyway, whatever the reasons why it took so long for Ben to be referred for treatment, the fact remains that it took several return visits to the GP before anything was done.

And even then we were only referred to CAMHS at my insistence.

The GP hadn't even talked to us about what help was available; it was the school nurse that told me all about CAMHS and insisted we get referred.

Meanwhile I had to wait for another GP's appointment to become available. (At our busy local medical practice you're lucky if you can get an appointment the same week, let alone urgently.) Then I had to twist our GP's arm to get Ben referred to CAMHS. I had to make a nuisance of myself to get the referral my gut instincts cried out was essential if we were to put the brakes on this hellish decline.

In late January 2010 we got a letter from CAMHS with our first appointment: 16th February.

Between September when we first visited our GP and the arrival of that letter our family had been living in hell, watching our son's rapid mental and physical decline yet powerless to do anything about it (after we'd spent a shed-load of money on private "stop gap" treatment which turned out to be a waste of time).

Then, shortly after we received that letter, Ben was rushed into hospital with a dangerously low pulse of 29bpm described in another post).

The next day I fought tooth and nail to get him an earlier CAMHS appointment. And I succeeded. By the end of the week, 22 weeks since I first took Ben to the GP, he was sitting in front of a couple of eating disorder professionals and treatment had finally begun.

**Tuesday, 20 September 2011**

**Why didn't I take action sooner, you may ask...**

That's what some people may be asking if they've read the last post. How come (a) I

didn't drag Ben to the GP sooner, when his unusual behaviour and weight loss started to manifest itself, and (b) I didn't fight tooth and nail to get him referred right away to CAMHS? How come if an eating disorder is so serious and potentially deadly didn't I do either of these?

This is why...

Why didn't I drag Ben to the GP sooner than September 2009? After all he began to behave strangely as early as July? The fact is that, as the parent of a boy, the idea that my son might be developing anorexia nervosa never entered my head. It was way, way, way off my radar; about as far as you can get.

I had no idea what was wrong with him. But whatever it was, I truly believed it was something that could be fixed fairly easily and quickly with a bit of no-nonsense straight talking. A bit like teenage "angst" gone too far. Imagine dragging your adolescent son to the GP to complain about teenage "angst"? Nah.

Also, when you're with someone all day, every day, as I was during the school summer holidays of 2009, you don't notice the drop in weight so acutely. After all, we rarely if ever weighed Ben. Why should we? And here in the UK it isn't something that's routinely done at school or at the GP's unless your child is sick. It took a visit from my in-laws in early September before Ben's shocking weight loss was hammered home. His Grandma saw a dramatic difference from the last time she'd seen him. She was worried. Then I got worried. But we had no "before" weight to compare him with apart from a general idea that he weighed around 10 or 12 stones.

Why didn't I push for an immediate referral to the CAMHS treatment team? Well, for a start I didn't even know CAMHS existed. And at this stage I still had no idea that Ben was developing anorexia. Anorexia was something that happened to girls. I'd never heard of it happening to boys before. And our GP certainly didn't give any indication that Ben might be anorexic. Instead Ben was given a "pep talk", warned about the dangers of under eating, told to eat more and come back in a fortnight. Time after time.

It was only when I started to do some frantic research on the Internet that Ben's symptoms seemed to match those of an eating disorder. The thought that Ben could have anorexia knocked me for six.

And then I got sick.

Throughout the whole of October and some of November I was struck down with an evil ear virus which meant I was virtually horizontal for the duration. I couldn't drive, I couldn't supermarket shop, I couldn't cook, I couldn't even stand up for long periods without almost keeling over in nauseating waves of vertigo.

So it was Ben that took over some of the cooking. And as a result we ate his newly concocted "healthy meals". Also, I wasn't able to pay as much attention to Ben as I would have liked. It was almost comical, the way that one day it'd be me taking Ben to see our GP, then the next it would be me seeing the same GP about myself. I think we seriously confused him!

But of course it wasn't comical at all.

Thankfully by mid-November the virus had gone and I was able to resume my life as normal.

Except I wasn't, because Ben's eating disorder was now going full pelt.

But thankfully by then I'd insisted the GP refer Ben to CAMHS.

So that's why everything happened in the time frame it did.

## **Wednesday, 21 September 2011**

### **The hardest bit of cramming I ever did**

As a freelance advertising copywriter working for countless organisations in very different market places, cramming up on information is second nature. Often I have to get to grips with a client's entire business pretty much instantly in order to write a meaningful website or whatever. Everything from scientific instruments to complicated software platforms... I've crammed up on them all. Likewise it was second nature to cram up on baby and toddler care during Ben's first few years of

life. But eating disorders proved to be altogether different...

Now, I am neither a clinician nor an eating disorders professional, I'm just a plain common-or-garden mum and I can only write from that viewpoint.

But once I realised that Ben was hurtling into an eating disorder, the urge to cram up on information immediately kicked in. The trouble was, I quickly became aware that everywhere I looked I was getting mixed messages.

Also, unlike baby and toddler care, which naturally puts the well-being of the child first, no medical team swooped in to explain exactly what I should do and when, starting *right now*.

So, initially, I was left with the internet.

And, like any condition you look up on the internet, there's a tonne of different stuff out there - some of it purporting to be written by "experts", some by parents of children with eating disorders, some by the patients themselves, and most of it pretty darn terrifying. Not just in terms of the short and long-term prognosis, but in terms of the way it all conflicted with each other. And that's not even mentioning all the sensationalist newspaper headlines and articles about eating disorders...

Even the various *help lines* I stumbled across offered conflicting advice. Hell, here I was, faced with an illness I was rapidly learning could actually destroy my son's life, yet I had no idea which advice to follow, if any. Or even if it would work. I didn't know of any other families with teenagers with eating disorders, so I couldn't talk to them. And, as you'll know from the previous posts, I was getting precious little help from the medical profession.

As a result, those first few months of cramming were a case of trial and error.

Thankfully a number of people came to my rescue.

The first was the school nurse who, as you might expect, had some experience of teenagers with eating disorders. Not boys, though. Just girls. It was she that first talked to me about the help that was available. It was she that told me about CAMHS - the eating disorder treatment available through the NHS for teenagers in the UK.

My GP didn't even mention it.

The second was a private therapist and former CAMHS employee we hired as a "stop gap" in December 2009. Although I found "stop gap" treatment pretty useless... a bit like trying to bail out the *Titanic* with an eggcup... this therapist did help push my learning curve in the right direction.

The third came in early 2010 when, just through pure chance, I stumbled across the Around The Dinner Table forum and its "parent" website FEAST. This forum offers advice and support for parents of teenagers with eating disorders. It has members, moderators and mentors from all over the world and, from the very first moment I discovered it, I knew I'd struck gold.

Another excellent thing about ATDT and FEAST is that the parents that run and moderate it have close links with the world's leading eating disorder specialists, so they're pretty clued up on the latest evidence based treatment, thinking and publications.

The ATDT forum enabled me to finally home in on the information that mattered and filter out that which didn't. It also enabled me to talk to people that had been through this experience and come out the other end successfully.

I discovered that, even though Ben is a boy and that all our children had been catapulted into this mess for a variety of different reasons, their eating disorder behaviours and thinking were uncannily similar. Likewise, the kind of recovery approach that worked tended to be similar. Not identical in every case, of course, but very similar.

I only wish to heck that I'd found this forum sooner. Six months sooner, ideally.

The point is... I spent months cramming up on information I wasn't entirely sure was current or even accurate. And the sheer amount of conflicting stuff worried me. After all, my son's life could be at stake here. And, unlike other medical conditions, the sufferer can actually *resist* or *refuse* treatment. You're not just fighting an illness, you're also fighting your child, which is really weird until you "get used to it".

I am not saying that the ATDT parents possess the “magic bullet” that “cures” eating disorders at a single stroke. Or that they know as much as, or more than, clinicians and other experts.

What I am saying is that the forum guided me towards the latest thinking on eating disorders - an illness whose treatment has changed quite radically in recent years.

Yet it’s also an illness that is so complex, not even the world’s leading experts claim to have the complete answer. I get the impression things are still very much at “experimental” stage, the tip of a monumental iceberg. Yet certain methods *do* seem to work as we in the Matty household have discovered on our own journey. This is why, over the past 18 months or so, I’ve felt sure we are doing the right thing for our son.

So to conclude... (before I start rambling further...)

I’m a dab hand at cramming information quickly and boiling it down into what matters and what doesn’t.

Yet cramming up on eating disorders was one of the hardest things I have ever done.

Hopefully the good thing about the ATDT forum and this blog is that it will enable other parents to find their way onto the Recovery Road a little sooner than we did.

**Wednesday, 21 September 2011**

**Ye har! The Recovery Contract is six months old this week!**

And, yes, we are still doing it. And, yes, it is still doing what it’s supposed to do. And yes I am quite a few quid poorer as I’ve “traded in” all those yummy scrummy points for cash!

- ★ YES Ben is sticking to each day’s agreed calories
- ★ YES Ben is only doing “permitted” exercise
- ★ YES Ben makes himself do daily food & social challenges, sometimes several in

one day

- ★ YES Ben is going to school every day
- ★ YES we feel as if we are moving forward rather than entering limbo
- ★ YES we agree the calorie plan for the following week depending on what the scales say

It's all written down and agreed, so no-one can claim we never agreed to do such-and-such.

So, six proven months on, I'd say the Recovery Contract is a success!

Get out the champagne!

**Saturday, 24 September 2011**

**School is still proving difficult and the insomnia is back...**

The insomnia is back. The anxiety-fuelled sleeplessness that wouldn't go away last year and which started the moment Ben returned to school last September. So far, this term, things hadn't been too bad on that front. But now the insomnia is back and, just like last time, it's all because of school. Also, in the place of last year's and the previous year's regular texts, I'm getting emails from Ben as he sits at a school computer filling in his time during free periods, break time and lunch.

Sure, they're by no means as distressing as the old texts used to be. But they speak volumes about how lonely he is feeling at school. How he is finding it really hard to integrate with his friends and other peers, so much so that he often gives up and heads for the computer room or somewhere in the school grounds or wherever.

On the odd day he isn't too bad, but most of the time his mood is pretty low. Day after day after day after day. And, unlike everyone else, he doesn't seem to be bothered about planning for university entrance next year, or even all the studying he needs to do for his AS Level resits and current A-levels. He doesn't seem to have a focus or know what he wants to do with his life.

He prefers to write or paint his models. Yes, he's even started taking them into school to distract him from everything and give him something to do. Both solitary activities.

It's incredibly heart breaking to watch all this going on. Part of me is tempted to remove him from school altogether. But the other part says that would be running away and wouldn't achieve anything. At this stage Ben needs to face his fears. Our psychiatrist calls it *Exposure Therapy* and she is all for him carrying on, no matter what. I tend to agree, regardless of how hard this is for us all.

He still only does a few full days, mainly because two out of five days have free afternoons. But yesterday was the first day he asked me to pick him up early when he *did* have lessons in the afternoon. I felt as if we were running away.

At times like this you can't help but look into the future and wonder what it will hold.

Will he come out of this, ease back into the social network, resume friendships with old friends and make new ones? Will he, like most teenagers his age, have a jam-packed calendar of parties, discos, meals, cinema trips, hanging around or whatever? Will he get a girlfriend and settle into a happy, normal relationship? Will he get his A-levels, go to University and remember it as one of the best periods of his life?

Or will he drop out of school and / or Uni? Or never even go to Uni? Will he become even more solitary and lonely, his mood and depression deepening every day? Will his ED kick back in with a vengeance as it lies to him about being a "safe haven" in which to take shelter from the world? Will he get a job, hold down a job? Will he marry and have kids? Or will he become a recluse, still at home with us by the time he is 40 or 50, looking back at a life which ED guaranteed would be the Promised Land, but which turned out to be a bare, featureless wasteland?

I know that this kind of gloomy thinking goes on in the heads of parents of teenagers with eating disorders. Harriet Brown talks about it in her excellent book

*Brave Girl Eating*. But she also talks about her utter refusal to let that happen to her child.

The trouble is, as far as school and social integration go, I feel helpless. I want to shake Ben's friends violently and tell them how much he needs them, not just to be there for him and include him, but to talk to him, *really* talk to him, and listen to him, and for God's sake *not* to treat him as if he's different, or sick, or someone they feel sorry for because I know Ben *hates* that.

But mothers can't talk to their (almost) 18 year old child's peers. That would be too weird. And anyway he wouldn't want me to.

Nor does he want CAMHS to go in and talk to his peers, like they did last November - a move which proved very successful for a few months...

Maybe I'll have a word with my friend S, the school nurse and see what she thinks. It would be nice to talk to her anyway about how things are going.

So, as we enter our *third* year of problems with school, I wonder when it will end. Or if Ben's final year at school will simply be something he struggles through and forces himself to do, whilst being ignored by his friends and sitting alone sending emails to me.

**Monday, 26 September 2011**

**I've been reading Harriet Brown's "Brave Girl Eating"...**

And I'm astonished at how identical our experiences are. Virtually every thought that goes through Harriet's head has gone through mine in the last 26+ months. Virtually every ED behaviour exhibited by her daughter, Kitty, was carbon-copied in Ben.

Harriet even battles with old versus new treatments (and explores the reasons for favouring the *New Maudsley Approach*) [see end of book] and why, when her treatment team claimed Kitty was Weight Restored, Harriet's gut instinct told her she had a bit further to go. Just like us.

Page after page after page, our experiences are virtually identical - right down to

us both smashing dinner plates on the kitchen floor when things got too much. It's uncanny.

But reading that book has reinforced my own decision to press on with this blog. Although my experiences may differ from other families, I am sure there will be overlap. I am convinced that other parents will exclaim "Me too!"

Even if my ramblings don't help their children get better faster, then at least it's reassuring to know someone else has been through what you are going through: that you are not "unusual" in any way in the irrational world of eating disorders. And, most important of all, that there is light at the end of this very dark tunnel.

Harriet's book also makes me angry. Angry that I didn't get the one hundred per cent support I needed from my treatment team when pushing for weight restoration first and foremost which lies at the heart of the *Maudsley Method*... that passing food control back to the patient too early is wrong and that, no, we can't wait until a seriously sick child "wants" to get better before taking action. I'm also angry that I didn't push harder for this. Harriet did and she got the support she needed.

On the other hand, living in the UK we are incredibly fortunate to have our National Health Service, despite all its shortcomings and seeming lack of consistency when it comes to treating eating disorders in different areas of the UK.

This means we get our treatment completely free whereas Harriet, like so many US parents, has to battle with her insurance company at the same time as battling the ED. Thank goodness we didn't have to do that.

I'm two thirds of the way through the book at the moment, so I can't comment on what comes next. But, like Carrie Arnold's *Running on Empty*, I find it hard to put down.

**Tuesday, 27 September 2011**

### **Three hours of brain storming about school...**

Yesterday was another difficult day with Ben sending emails at break time and lunch. In the end he asked me to pick him up, so I did, but I insisted it had a “caveat” and that would be to spend the afternoon having a brain storming session about what to do next...

Like our Contract, it would be a two-way thing. Me asking for his input and him asking for mine. We’d write down every possibility on sheets of scrap paper, no matter how crazy or extreme, and scatter them around the large loft room floor. Then we’d go through them, discussing the pros and cons of each, and hopefully reach some kind of solution.

Both of us agreed that it would be best to leave any solution overnight, or even for a few days, rather than take a knee-jerk reaction to the situation.

So that’s what we spent the next three hours doing and, thus far, the conclusion is this...

No, Ben doesn’t want to leave school now, take a year off and then return, either to school or sixth form college.

Yes, he wants to persevere where he is and trust things will improve over time.

I insisted on a “caveat” because we can’t simply “cross our fingers” and hope things will get better. So far, if anything, things have got worse and Ben spends most of his time in solitary confinement in the study room, library or hidden away in the school grounds. Neither of us want Ben to simply grit his teeth and struggle through this final year at school, hating every minute and feeling as lonely and depressed as hell. If we could turn the situation around somehow, then let’s go for it.

So we came up with a list of four practical actions we could take which might just work. And if they don’t, then we’ll have another session and come up with more.

So that’s where we are at the moment.

**Thursday, 29 September 2011**

## **Beautiful healthy hands**

“Look at my hands!” said Ben in the car as we were waiting for the school bus this morning. “Look how great they look!” He spread his fingers out to show me. Smooth, healthy, blemish-free hands “except where I nicked myself with my model knife,” he added. I’ll tell you why this brought tears to my eyes...

Over the past couple of years, Ben’s hands have been in a terrible state. Red raw and bleeding, especially between the fingers and on the knuckles. The skin was always dry and flaky. Even two sets of prescription cream including steroid lotion made no difference. And, of course, you could see the bones and joints clearly under the pale, unhealthy-tinted skin.

Today his hands were perfect (except for the model knife scrape). Not only is he consistently eating just over the required number of calories for an adult man (a slight increase on last week) but those calories comprise the most healthy, nutrient-rich, balanced diet on this planet. And it shows. Not just on his hands but on his face, too.

And, although he should ideally weigh a little more than he does now, it is wonderful to see flesh on his bones. His spine is still visible to a certain extent, but nothing like the gnarled bumpy spine that used to protrude from his back complete with angry red sores caused by too many sit-ups. Those sores are still visible, but only as brown scars which will hopefully fade with time.

Looking at him today was a bit like looking at our cat and knowing you’re feeding her the right stuff because her coat is sleek and shiny, and her eyes are bright.

I told him it was probably because, before, his body was desperate to get hold of any nutrients that were put into it, so things like skin plus loads of other body parts suffered. I reminded him of when our psychiatrist warned him that his body was, in effect, “eating itself”.

Now, as a result of a good 10 months-worth of healthy, balanced, nutrient-rich food intake, it is visibly transformed. Hopefully any damage which might or might not

have been done to any other organs in his body will also be reversed. I'm no doctor, I don't know and I can't see into his body. But hopefully everything is okay.

**Friday, 30 September 2011**

### **These days a "six pack" isn't so important**

Two years ago when he was spiralling into the eating disorder at a rate of knots, Ben was obsessed with comparing himself with another boy at school. So much so that Ben used to get incredibly upset and distressed about how this boy was stealing the limelight whereas Ben was disappearing into the background. If it wasn't so obviously distressing for Ben, his descriptions of this boy's apparent behaviour would have been funny...

This boy was hugely competitive, brilliant at every kind of sport and always top of the class in every academic subject. He was tall, handsome, muscular and athletic, constantly surrounded by an entourage of admiring girls to whom he would (according to Ben) routinely show off his muscular "six pack" to gasps of admiration and amazement.

Meanwhile (according to Ben) this boy would be constantly receiving text messages from other admiring girls while sending texts to yet more besotted women. The other boys in the year thought he was wonderful and wanted to be his friend. The staff thought he was wonderful. Everyone thought he was wonderful.

But Ben couldn't handle it.

I know that experts believe that the quest for the "perfect" body image doesn't "cause" eating disorders, but with Ben this situation was definitely one of the triggers. Don't get me wrong: in no way am I blaming this boy; it was simply a case of Ben wanting the girls to "love him" (as he put it) in the same way. Because the girls seemed overawed by this boy's physique, Ben wanted to look the same. He was also convinced that this Adonis-like body was what gave the boy his confidence. If Ben had a "six pack" like this boy, then he'd be popular and confident, too.

This was reinforced by the Adonis-like images Ben saw in men's glossy "health" magazines. To be popular and successful socially, you needed to look the part.

Ben had spent the entire summer of 2009 trying to build up his physique by swimming, running, weights and the gym. The trouble was that, unlike this boy who loved sport, Ben had come to hate it, only seeing it as a means to an end.

Ben says that he suddenly realised he could reach his goal faster by eating less because this would mean he wouldn't need to exercise as much.

For a time it worked.

Then he figured that if he ate *even less*, then he'd be even less shackled to the endless exercise routines.

The trouble was that with the reduction in food came rapid weight loss and with the weight loss came muscle loss. This meant that the "six pack" he craved never materialised as his body quickly became skinny rather than athletic. This in turn made him exercise *even more* instead of *less*. Result? A vicious spiral downhill. And with this vicious spiral came all the eating disorder behaviours, rages and moods, not to mention the way an ED loves to isolate its victim. So instead of becoming *more* popular, Ben was fading into the background on every count.

(Here I must emphasise again that in *no way* am I pointing fingers and blaming this poor boy for "causing" Ben's eating disorder. If it hadn't been him, the trigger would have been someone or something else; that's not what this post is about.)

These days this boy is still around, of course. He still has his awesome athletic physique and he's still good at everything including getting the girls. But the big difference is that Ben doesn't give a damn. I know that because of the way he mentioned him in passing yesterday. Ben's priorities and outlook have changed dramatically in the past couple of years.

Ben still likes the idea of having a "six pack". But he's also found, especially now he's two years older and more mature, that six packs don't get the girls or make you more popular.

Valuable, lasting relationships go a little deeper than that!

OCTOBER 2011

**Monday, 3 October 2011**

**Around the Dinner Table... literally!**

On Friday evening Ben and I met up with another mum (and daughter) I've "met" through the Around the Dinner Table forum (for parents of young people with eating disorders). We were joined later by another woman I've got to know through this circle, someone who has recovered from anorexia and who I've already met for coffee a couple of times.

So there we were, all sitting "around the dinner table" in *Pizza Express* and none of the other diners or staff would have been any the wiser that anything was or had been wrong with three members of our party. To all intents and purposes we were simply a group of friends having a good time.

Of course if you'd listened a little closer you might have heard the phrase "eating disorder" mentioned in passing. But mainly we were talking about other things. And meanwhile the two teenagers (who had never met before) ate pizzas and drank wine without any outward signs of stress. The only people who could detect the almost invisible signs of anxiety were us mums. But, then, we have a sixth sense built into our DNA.

One of the good things to have come out of this nightmarish journey is new friends: other mums that "get it" and for whom the irrational and distressing behaviours that come with ED have been as much a part of their lives as mine.

But, thankfully, on Friday night these behaviours weren't evident - just two normal, healthy looking teenagers tucking into pizza while enjoying other people's

company “around the dinner table”.

Just as it should be.

### **Monday, 3 October 2011**

#### **Does your own internal voice chip in with this kind of thing on “bad” days?**

On Friday Ben claimed his insomnia was “cured”, after a reasonably good couple of days at school. His mood was up, too. But by Sunday it was back down again, just like last Sunday. And of course with it came the insomnia which meant that by this morning (Monday) Ben was in a hell of a mood. In fact the only words he said to me this morning as I took him to the school bus were “Shut up!” Better than “Shut the Eff up!” I guess...

As a parent, you never do get used to the ED treating you like a piece of dirt, do you? Okay, this kind of behaviour isn't exclusive to ED teenagers; virtually all teenagers are truly horrible to their parents at some time or other. But when ED, the Eating Disorder, is involved it's a heck of a lot worse because you're painfully aware of just how much time and love you've invested in kicking the ED out of your child's life only to get verbally slapped in the face.

And it's not just that... At times like this all those worries surface again which is your own internal voice telling you that there is still quite a way to go in the recovery stakes.

This morning, my internal voice has been saying: “No way is he going to university next year; he wouldn't last five minutes!”, “What the heck do I do now; after all we spent three whole hours last week talking through the school problems and we're back to Square One”, “It's because his weight hasn't increased at all over the past month - and never forget he is *still* lighter than he was when he first started CAMHS treatment in February 2010... why oh why oh why, Batty, don't you muscle in and *make* him eat more?”, “What the heck is he going to do next year if he *doesn't* go to uni?”, “Why, in our *third* year of the eating disorder does he *still* worry himself sick

that eating a few extra calories will make him blob out into a fat monster?” and - finally - “You’ve failed. You’re into your third year now and you’re still battling with the eating disorder. Let’s face it, you’re still going to be battling with it 6, 7, 9, 10, 15 years from now. Ben will never leave home, never have a family of his own, never achieve his potential...” blah blah blah blah...

Does your own internal voice chip in with this kind of thing on “bad” days?

And I will be extremely surprised if I don’t get an email or text from Ben before lunchtime today saying this morning is “very difficult” and / or can I come and pick him up?

Because we had a similar scenario this time last week, there is the temptation to worry that we’re back into the “usual” routine i.e. Ben’s mood is rock bottom all day Sunday followed by a sleepless night followed by a pain-in-the-butt mood on Monday morning followed by miserable isolation at school followed by me having to pick him up early followed by some kind of solitary activity in the afternoon. Tuesday is similar, but by Wednesday things generally improve.

Then the whole merry-go-round starts again at the weekend...

PS He called at break time and asked me to pick him up at 12.20, saying the afternoon’s teacher “isn’t here and I’ve done all the work for the lesson, anyway”. Not sure I believe him...

### **Wednesday, 5 October 2011**

#### **Tricky few days...**

The last three days have been quite tricky. Sunday was the same as the previous Sunday in that Ben’s mood hit rock bottom as Monday’s school loomed ahead. He didn’t sleep on Sunday or Monday nights, and on both Monday and Tuesday he phoned me at break time. On Monday I picked him up at lunch, but on Tuesday I persuaded him to stay for the full day. Oh, yeh, and on Monday night he and his dad

had an almighty row...

It all started with Ben announcing on Monday afternoon that he was going to embark on the *500 Year Old Diet* i.e. only eat foods that people ate 500 years ago, cutting out all “processed” foods like ice cream, chocolate and crisps.

Immediately I said “No” because each of these items are things he uses to boost his calorie intake without adding bulk (which fills him up too much).

Also, Ben’s move towards a “healthy diet” had been responsible for him losing a quarter of his body weight right at the start, over the summer of 2009. So he and I had a row about it.

The *500 Year Old Diet* reared its head again in the evening and again I said “No”.

When Ben wouldn’t listen to me, I did the age-old trick: I chickened out and went to fetch his dad. All hell broke loose...

The Good News was that, even with all the screaming, effing and blinding going on, it was clear that this was very, very different from the ED rages we used to experience back in the “bad old days” of the anorexia.

Instead it was just like “your typical” clash between teenage boy and his dad.

Okay, most families would find this incredibly distressing, because it was really horrible. But to me, because it wasn’t an ED rage and could so easily have been, it wasn’t quite so bad...

The Bad News is that it didn’t solve the problem of school and Ben’s social anxieties, and Ben was as miserable as sin again on Tuesday while I racked my brains on what to do next.

Which I’m still doing...

**Thursday, 6 October 2011**

**Why I’m not putting all this behind me... yet.**

While some parents may wish to put the whole eating disorder experience behind them and move on, for me it’s always been different. Since late 2009 I’ve been

making notes, writing forum entries and lately this blog, all with a view to putting this information to some kind of practical use in the future.

It was the school nurse who first suggested I write a book to (hopefully) inspire other parents who have realised their son is suffering from an eating disorder; to show them that there is a light at the end of the tunnel and also how we, as a family, dealt with all the various aspects of our son's anorexia.

Over the past couple of weeks I've been busy collating all this information into date order in a kind of narrative which will act as the basis for a book.

With over 100 pages of A4 notes, it's kind of scary and difficult to know where to start. Also the hardest part is what I call the "fuzzy period": Sept - Nov 2009 when Ben was rapidly disappearing "down the rabbit hole" (as Harriet Brown aptly puts it in *Brave Girl Eating*) when I was coming to terms with what was happening and when Ben was going through distressing and dramatic changes on every front: weight, mood, behaviour and social interaction.

Although I did make some notes (mainly emails and lists) the mind has a funny habit of blanking out distressing periods like this. And although Ben's behaviour was hideous and terrifying, I find it very hard to remember it in detail.

Some might say this is a Good Thing: evidence that it's time to move on and put all this behind me. But if I'm going to write a book, I need to come to terms with that "fuzzy period", recall what took place and try to understand it all.

It's not just because of the book. I, personally, need to get my head around it in order to be able to move on. But, for me, moving on won't be moving away from eating disorders completely.

It's a bit like my friend, Sue, who has cancer and who will always be actively involved in working with other women with breast cancer. As a sufferer she has invaluable first-hand experience that clinicians and medical professionals can never have.

Likewise I, as the parent of a teenage boy with anorexia, have invaluable first-hand

experience that I can bring to the table.

Okay I am not a clinician and the purpose of my book won't be to educate people about the science behind eating disorders. It won't be jam-packed with facts and figures or detailed information on different treatment methods and research; there are plenty of excellent books that already do that job.

My book will simply tell it as it was, describing how things unfolded and how we fought tooth and nail to halt our son's decline into serious anorexia - and how he eventually came through it.

Meanwhile I'm still trying to piece together that "fuzzy period". I think my emotions (which were on an extreme roller coaster at the time) are the most difficult thing to recall, to be honest.

Strange that.

## **Monday, 10 October 2011**

### **It's 12 months since Ben turned a corner...**

12 months ago Ben was sitting in front of our CAMHS team. For the first time since he'd started treatment eight months before, they came down like a tonne of bricks and insisted Ben increase his weight, starting immediately.

The reason? The previous day Ben had collapsed at school and been rushed to hospital again with a dangerously low pulse rate... the second time this had happened in eight months.

Not only this but he'd completely freaked out in the hospital: "ED rage" at its worst and most violent, kicking stuff around, swearing, shouting, fighting and trying to discharge himself by running out of the hospital. In fact it was so bad that he'd had to be physically restrained by medical staff, security and eventually, outside the hospital in full view of a gawping public, the police.

The ED rage had a side-effect in that it brought his pulse rate back up to an

acceptable level. The medical staff ideally wanted to admit him again for observation, but now that his pulse rate was back up, he was eventually discharged - but on the condition that he undergo regular ECG and blood tests at our GPs' surgery.

The following day CAMHS took all of this very seriously. The atmosphere was completely different with direct, straight-talking along the likes of "we insist you do X or there is a real chance you could end up in hospital".

They explained to him, why, with his pulse rate so low, they might not need to wait until his BMI was sufficiently low enough to warrant admission to the eating disorder unit; they could act sooner if they needed to. I remember the word "sectioning" being used...

Ben had been losing weight consistently since the beginning of May: five months of steady weight loss. Up to this latest heart scare, the advice had simply been to "experiment" to see what worked and what didn't until he learned how to "make the right choices" which would, hopefully and eventually, turn things around.

But all five months of "experimenting" had achieved was consistent weight loss. By the beginning of October 2010, Ben's weight was lower than it had ever been, even lower than when I had first taken him to our GP 13 months before.

Low heart rates are seen quite frequently in people suffering from anorexia because of the damage that starvation causes to the heart muscle. CAMHS explained to Ben their concern that his body was literally beginning to "eat itself" and this could result in long-term if not permanent damage - or worse.

Although I was worried sick about these implications, I was also thrilled that CAMHS were finally taking things seriously enough to say "Enough is enough".

And it must have hit a nerve with Ben, especially as he hated hospitals with a vengeance by now. Additionally, he'd always told me that he could control his weight so it never got low enough to warrant admission to the unit.

Now CAMHS were implying they could admit him right now if they felt he was in danger. Ben (or, rather, the anorexia that had taken Ben over) hadn't banked on

that...

From that moment onwards Ben turned a corner, quite dramatically and visibly in fact. 12 months on, although we've had our ups and downs, he is still doing in the right direction. And, touch wood, his pulse rate continues to be healthy.

Also, despite not always seeing eye to eye with them, CAMHS and I got along a heck of a lot better after that point. Not only did I feel they were taking Ben's condition seriously, they were taking my concerns seriously as well.

So that's what we were doing 12 months ago. A blessing in disguise?

**Wednesday, 12 October 2011**

### **Making an inroad into my book**

Phew, I am tired! Over the past few weeks I've been collating all the written information I've kept about Ben's journey into anorexia: around 24 months of info comprising forum posts, blogs, letters, notes, lists, emails, charts, etc etc.

Then I did a *Timeline* and put it all into date order. Next I edited all down into a basic narrative followed by a chapter breakdown with rough notes of what may go into each chapter.

Then there's the tone of voice to think about, and the approach. What I don't want to do is to over-sensationalise or over-dramatize it in any way. Yet, on the other hand, I don't want to do the complete opposite. Nor do I want to compromise Ben in any way although he is 100 per cent behind me.

Getting the first couple of chapters underway has been tiring but cathartic - a kind of "exorcism", if you like.

But, knowing me, I'll edit and edit and edit again before I'm even vaguely happy with the result.

It's going to take a long time to write!

**Thursday, 13 October 2011**

## Upper sixth form parents' evening last night

Two years ago Ben and I went to the fifth form parents' evening. It wasn't brilliant. Ben had been away from school for quite a while, unable to face anyone or anything, let alone a school full of teenagers. So going along to the 2009 parents' evening, two years ago, was a bit of a challenge - for both of us.

Two years ago I was painfully aware of Ben's dramatic physical transformation since many of these parents, or their children, last saw Ben. The parents I knew tended to be either those of Ben's friends or the parents I used to chat with on the rugby touch line every Saturday morning. Ben used to play Number 3 in the rugby line-up and later Number 8: both *forward* positions usually given to big, strapping lads which is exactly what Ben was back then.

So the difference at parents evening two years ago would have been acute.

Then, of course, there was the fact that Ben was obviously avoiding everyone's glances or approaches as he skulked around the assembly hall looking as miserable as sin - and quite ill. This, from a solid boy that was known for hurtling down the rugby pitch like a steamroller, ball in hand, and flinging himself on the grass, placing the ball over the touchline.

Last night at the 2011 parents' evening, although Ben is still very thin, the difference wasn't so acute. Ben's mood was better and his social interaction, although not great, was better. He looked much healthier and, instead of being worried, his teachers were delighted with his progress: on every level.

The rugby contingent was there again, of course. And because Ben hasn't had any contact with any of them since he quit rugby in Autumn 2009, I was still acutely aware of the contrast, especially as these huge boys are now virtually fully grown men.

But, hey, let's not look back with regret on "what might have been". Ben says he never liked playing rugby anyway.

**Sunday, 16 October 2011**

### **Contract still valid?**

That's what I was wondering, so I had a chat with Ben yesterday to see what he thought.

I explained that we'd achieved so many of the things the Contract had set out to do e.g. getting Ben out of *Limboland*, ensuring he doesn't cheat on calories, easing him back into school, getting the exercise under control, putting on weight and doing daily challenges e.g. eating fear foods, etc.

So, this far on in recovery, was the Contract still valid?

Ben surprised me by saying a big emphatic yes. He still finds it really helpful to have this structure in place and be awarded points for sticking to it and challenging himself.

So we'll stick with the Contract as it stands for a while longer before either ditching it or adjusting it to suit changed circumstances.

**Sunday, 16 October 2011**

### **Adjusting to "peacetime" after two-plus years of war**

The closest I can get to describing how I've been feeling over the past week or so is this...

It's kind of how it must have felt to civilians adjusting to life in peacetime after World War II. Suddenly the threat is gone: no air raids, no killing, no worries that Hitler will invade, etc etc.

Yet for some people, I imagine, the adjustment to peacetime wasn't easy. Okay, so maybe I'm completely wrong, but I'm trying to find a parallel for how I feel at the moment.

ED the anorexia demon has gone for good (fingers crossed...) Ben has no problems eating the required calories and increasing them if necessary in order to slightly

boost his weight until he (shortly) reaches full weight restoration.

I am no longer terrified that he will run away from home, harm himself or take his own life. In fact I could go on for hours about the stacks of ED-related things that no longer take place in our lives as we enter the world of normality and peace.

This is the End of the Tunnel. The place where “the light” is which I longed to catch a glimpse of for so long.

We have come through this terrible thing and out the other end into the sunshine.

Yet why do I feel so strange about it?

Why aren't I jumping up and down with glee, cracking open the metaphorical champagne and letting off the fireworks?

I don't know. I guess I'm just finding it hard to adjust to a quiet life in peacetime after two-plus years of being at war.

After all, at its height and for a heck of a long time stretching from months into years, Ben's anorexia and associated behaviours dominated every waking second of my life.

Curiously, it's almost like finding yourself out of work or finding your skills have become obsolete.

But it is the strangest of feelings, it really is.

**Friday, 21 October 2011**

**Still adjusting to “peace time”...**

This week has been really weird for two reasons: (1) I feel as if we've definitely reached a watershed in terms of recovery and (2) this watershed is exactly one year on from when we reached our original watershed i.e. Ben completely turned a corner in terms of working with us towards recovery rather than against us.

It's also been my birthday so, like last year, it's been a really great birthday present.

Everyone has commented on the difference in Ben: CAMHS (who are delighted),

my family and Ben's teachers at school. Okay so Ben lost a little weight this week, but - in line with what he and I agreed the previous week - he's increasing his calories to compensate for it.

I really do feel as if I have finally got "my boy back" after two-plus terrible years.

Ben himself says it feels really weird because, to him, it's as if he's still in the fifth form at school rather than the Upper Sixth - purely and simply because he's missed two years from his life. And, yes, he does seem - and look - younger than most of his peers.

But of course I'll be keeping a discreet but close eye on things to check they continue to move in the right direction...

**Monday 24 October 2011**

### **Why recovery is like renovating a house**

This thought came to me this morning. For us, recovery from anorexia is like renovating a house - one of those *Help My House is Falling Down* type houses on that telly programme. It's been a heck of a job to get it looking anywhere near normal, not to mention all the essential and time-consuming structural work you've had to do behind the scenes.

Right now, our "house" looks pretty good. Or at least it does if you don't look too closely. Maybe the architrave around the kitchen door still needs another lick of paint. There are slight cosmetic cracks in the plasterwork where the new brickwork has settled. The living room wall is still missing a piece of wallpaper behind the curtains and the state-of-the-art new bathroom shower has all the workings in place, but the actual shiny chrome shower attachment is still waiting to go up.

However it's all cosmetic. The horrendous rising damp has been sorted out, the sagging roof has got new rafters, felting and insulation. The dry rot underneath the bathroom floor has been fixed. And the serious subsidence that was threatening to reduce the house to a pile of rubble has been underpinned securely and (we hope)

permanently.

The building inspectors have been in and given our “house” the thumbs up and we are able to live here comfortably and safely.

It will take a little while... maybe even a little longer than a while... to sort out the little glitches: the “snagging” as my engineer husband would call it. But it’s nothing that can’t be done over a free weekend with a few bits and pieces from the local DIY store.

And, of course, we’ll keep an eye on all those structural nasties that have been fixed - just to make sure they’re well and truly gone for good.

After all, you wouldn’t want to do all that hard work only to find your “house” starts to sink back into the foundations in 12 months’ time, would you?

**Tuesday 25 October 2011**

**As far as the east is from the west...**

Out of the blue on Sunday morning I found myself en route to the church I first went to almost two years ago (during the long wait for treatment for Ben’s anorexia and while Ben himself was rapidly and dramatically falling off a cliff).

I only went to that church for three months. Although I was crying out inside - no - *screaming* inside for help in a way only a parent can, I found the people I met at that church didn’t or just couldn’t “get it”.

The problem was, I think, that the sheer depth, helplessness and unusual nature of my problem took them way beyond their comfort zone.

They seemed to find it easier to talk about helping the needy (street people, third world, etc) than get to grips with something they found hard or impossible to understand... or just downright weird... anorexia nervosa.

Anyway, for some reason, I found myself back in that church on Sunday.

I crept in and sat at the back. I didn’t particularly want to be noticed or for people to ask “How are things these days?” if they recognised me.

The reason I was there, I think, was to experience the sheer stark contrast between how I was feeling when I sat in that church two years ago compared with how I am feeling now.

Not wanting to sound religious, it came to me almost like a bolt out of the blue: the contrast. The contrast between the internal screaming and desperation of two years ago as I helplessly watched my wonderful child fall off a cliff into the swirling depths of anorexia, not knowing how far he would have to fall before we got our first treatment appointment; I had been warned it might be five months before we saw anyone.

Back then, the ice cold feeling of fear, desperation and panic was ever-present.

It was as if we were standing in the path of a volcano which had erupted and our chances of getting out alive were pretty slim.

And I could never have known what horrors were to come between then and Ben turning a corner 12 months ago.

It's probably best I didn't.

But let's return to Sunday as I sat in that church, feeling powerfully serene and calm, my wonderful son beside me looking healthy and happy.

The sermon was based on *Psalms 103* and the part that stood out for me flashing in Las Vegas Lights was verse 12: "...as far as the east is from the west, so far has he removed our transgressions from us."

Replace the word "transgressions" with "danger" or "anorexia" and that sums up how I felt: the stark contrast between two years ago in this church and Sunday. It was as far as the east is from the west. That far. About as far as you can get or ever imagine.

Anyway, Ben and I crept out of the church at the end, as we'd planned.

We may never go back, but it was kind of weird that we ended up there on Sunday.

Read into that what you may...

NOVEMBER 2011

**Tuesday, 1 November 2011**

**That old water stain on the ceiling is showing through the new paint...**

Or, to move away from the house renovation analogy, our arch enemy the ED reared its ugly head a little bit this morning with: "I feel awful because I've just binged on top of my usual breakfast" when I reminded Ben that he needs to see his tutor in period 4 at school today to finalise his university application form.

So I responded to the ED voice with: "Let's concentrate on what is important in your life overall, not what isn't. When you're old and grey and on your deathbed, and you look back on your life, what you will remember is what a fantastic time you had at university *not* that on Tuesday 1st November 2011 you had a 'binge'."

To which the ED voice replied: "Not if I'm on my deathbed because I'm obese."

To which I replied, in a manner that implied the conversation was over: "Ben, there's as much chance of you getting obese as there is of me becoming Pope."

Time to get out that stuff you spray over old water stains to stop them seeping through your beautiful new white paint...

Oh, and in case you're wondering, a "binge" isn't what you or I might call a binge. For me, a binge is ploughing my way through an entire box of Belgian chocolates followed by a couple of slices of chocolate fudge cake. To Ben it's simply eating a little more than he would normally eat. And, anyway, you can bet your back teeth he'll include it in his daily calorie total.

Be warned, ED, I am being extremely vigilant. The house renovation is not complete yet...

**18 November 2011**

**My apologies - I've been AWOL for a couple of weeks!**

It's been something to do with the adjusting to our new life without the ED, or at least without ninety nine point nine per cent of the ED.

Suddenly it's as if we've emerged into the open sunlight after years of living in a dark underground pit. Or as if we've been released from jail and are having to adjust to life on "the outside". It's not easy. In fact it's quite a learning curve!

From my perspective, I am a different person from the woman that started off on this horrible and long journey - so it's not a straightforward case of picking up where I left off in the summer of 2009. I am a better person, a more relaxed person, a more empathetic person and a more insightful, less self-centred person. I am literally older and wiser! Also, having faced and fought the eating disorder head-on for so long, most of the things that fazed me before don't even come onto my radar now.

Also, the world has changed since mid 2009. We've been through a horrendous global recession and, in Europe, it seems to be getting worse, not better. Up to 2009, and even into 2010, my freelancing business was going from strength to strength. I'd built it from scratch and earned enough to send Ben to a fee paying school and pay for lovely holidays.

The recession and the eating disorder hit me at around the same time. In a way this is good, because both would have decimated my business on their own. So if the eating disorder had never struck, my business would still have suffered a near fatal blow - and vice versa. Also, my husband would still have lost his job and been out of work for several months, now working on a far lower salary. So our household income is now less than half what it used to be and meanwhile the cost of living has soared.

All this means that I am now in a position where I'm trying to adjust to a world and lifestyle that is very different from the one we used to have.

It's also meant some re-training so I can mould my business into something that's

more relevant in a recession-hit world.

Oh, and I've been doing the usual keeping tabs on Ben (from a discreet distance), with fortnightly CAMHS sessions. And I'm delighted to say that the treatment team and I are on the same page and things are going swimmingly.

Plus we've been busy sorting out Ben's university applications for next year - and Christmas is just around the corner.

Phew!

This is why I haven't written for a while. But I will write because I believe we're going through an important stage in the recovery process and we are almost there!!

### **Wednesday 23 November 2011**

#### **Improved school social situation - an impossible ask?**

No matter what Ben does, his school friends still treat him differently and it's continuing to get him down. After much deliberation about it at CAMHS and at home, we are almost reaching the point where we wonder whether it's never going to happen and that this final year at school is, from a social perspective, a complete write-off.

Ben has done his level best to talk to his friends and be "normal", but he's still left out of things and ignored. As a result he spends most of his school day alone which means he is still coming home at lunchtime, unable to handle a whole lunch hour on his own.

Why are they doing this? There could be several reasons. One is that they've seen the anorexia at its worst. They saw a popular, athletic, fun guy transform literally overnight - or at least over the summer vacation - into a physical and mental wreck. They've been on the receiving end of some terrifyingly unpredictable behaviour. To them, I guess, it's as if their close friend had gone insane.

They know he's been receiving psychiatric treatment and still is. They are still seeing him leave school at lunchtimes and not return until the next day, and sit in the

corner of the common room alone. And his physique is still a shadow of the rugby *prop forward* he was for so many years.

So maybe, to them, Ben isn't recovered. Perhaps, to them, he is still "the crazy guy" who is capable of doing virtually anything - and the only thing that is predictable about this "anything" is that it will be abnormal, extreme and frightening.

Only he isn't like that any longer.

But they don't know that.

For our family, the eating disorder learning curve was *massive*. Like most people, behaviour like this had never featured on our radar. We didn't even know it existed. I guess it is the same for his friends and they can't be expected to understand it or know the dynamics behind it.

Our psychiatrist doesn't seem to be able to come up with a solution either.

Basically Ben wants to be seen as *normal* and treated as *normal*. As he said yesterday: "If I'd never known life as a popular social animal I probably wouldn't miss it. But I have and I want to be back there again. Back to where I was before this hit me in 2009."

He has started to blame himself for the eating disorder which hijacked his life for two-and-a-half years. Hopefully the psychiatrist managed to explain why it wasn't his fault. The ED would have happened no matter what.

But he's beating himself up about his theory that if he hadn't cut down on food and increased his exercise he would never have reached the low body weight and poor nutrition which may have been responsible for the anorexia kicking in.

There are so many, many reasons why it is *not* his fault and he shouldn't beat himself up about it, but that it's another blog entry altogether.

But, for now, he is missing out on his final year at a wonderful school and is so very, very lonely.

At least, as he says, when he goes to university he will be starting a clean sheet.

No-one will know about his past and will accept him at face value. Hopefully real

life can start again.

I hope so.

**Thursday, 24 November 2011**

### **ED changes people**

Without a doubt, an eating disorder changes people; not just in the way it devastates lives, but in the way you - and those caring for you - emerge completely different.

I've already talked about how it's changed me as a parent, making me into a better, more tolerant, caring and insightful person with her priorities in a better place (hopefully!!)

Likewise, Ben is a very different young man from the teenage boy whose life was hijacked by the eating disorder in 2009.

Sure, he is two-and-a-half-years older which, in teenage terms, can seem like a lifetime. But he's transformed in many other ways, too, which - without the ED - might not have happened.

He, too, is more caring, thoughtful and insightful. He is extremely philosophical about things, thinks very deeply and maturely about the life issues that really matter, and has become quite spiritual in his own "typically Ben" individual way.

He is also very strong, as anyone overcoming an eating disorder has to be. After all, he's gone through experiences that most other teenagers will never have to go through. In religious terms (if you like) he has fought the devil and won.

Like many traumatic events in life this makes you think very differently. Trivia seems... well... oh so trivial. Every moment of life cries out to be lived to the full.

When you've "lost" what amounts in Ben's case to one seventh of your entire life on this planet, not to mention suicidal tendencies that threatened to snuff out your life altogether, there's a heck of a lot of lost time to make up for.

Meanwhile life just trundles on for the other teenagers in his social group and they find it hard to accept this "new" Ben who thinks and acts a bit differently from the

way they do.

And, I guess, there's always the worry that - because he's emerged differently and is still receiving treatment - he may still be under the thumb of the eating disorder; a volcano about to erupt at any moment.

We know he's not, but unfortunately they don't.

**Friday 25 November 2011**

**The 12 Days of (ED) Christmas ...**

Christmas is a challenge for anyone suffering from anorexia and their family, to say the least.

So in the run up to Christmas 2011 I thought I'd write 12 entries on whatever comes into my head about our own experiences of Christmas (x 2) living with an eating disorder plus how different this Christmas will be. Watch this space...

**Friday 25 November 2011**

**On the first day of Christmas, the ED gave to me... "The Nightmare on Christmas Fair Eve"...**

Between 2005 and 2010 I was in charge of organising the school PTA Christmas Craft Fair - a massive event with over 33 stalls, a café, music, games, tombola, raffles and goodness only knows what else, taking place in two halls and a large foyer.

On the day before it was a case of "all systems go" as I helped to transform the various rooms into a Christmas wonderland and ensure everything was ready for a crack-of-dawn start the next day.

The organising itself began in September. It was a huge undertaking made a zillion times worse by the fact that Ben was hurtling into anorexia nervosa. While trying to juggle my freelancing business, the Christmas Fair plus an inner ear virus that put me horizontal for much of October, I was faced with the treble whammy of Ben's rapid

and dramatic weight loss, nightmarish mood swings & ED rages plus regular emergency phone calls from school asking me to come and pick up the pieces of whatever chaos the ED had driven Ben to that day.

Oh and back then, of course, we were *still* on the waiting list for treatment, so we could only watch helplessly as Ben plummeted down the helter-skelter towards who knows where.

By then the ED outbursts had become more and more frequent and we were desperate. Two to four times a day we'd have violent destructive outbursts with loud screaming and tearful hysterics. To me it looked as if he was having a complete mental breakdown. He'd throw food around, become violent and crash his head against the wall. He was virtually unable to go to school and had cut himself off from his friends completely.

Of course the ED saved the worst for the busiest and most stressful day of my Christmas calendar: the day before the school Christmas Fair, exactly two years ago today.

Things went pear-shaped from the start. We had the usual nightmare of getting Ben ready for school. By then, every single morning was a battle. Not "your usual" teenage battle, but something altogether worse and far darker.

On this particular day, a screaming and crashing ED rage erupted before we'd even left the house followed by hysterical verbal abuse all the way to the bus stop.

As I dropped him off he slammed the car door violently, still screaming, and fled off down the road towards the bus stop. As usual, I drove back home in floods of tears feeling helpless, terrified and alone.

40 minutes later I got a phone call from the school nurse (who was keeping a close eye on Ben). Ben hadn't arrived at school and none of the students on his bus remembered seeing him that morning. Staff had checked the boys' toilets (a usual bolt hole for Ben) and the school grounds. Also, he wasn't answering his mobile phone. No-one knew where Ben was.

Ice cold panic. Yes, you really do go ice cold with fear.

Ben could be anywhere and I had no idea what to do.

Anyway to cut a long story short, the nurse phoned again to say he'd turned up, but he was in a hell of a black mood. Could I come into school and get him?

So there I was, cramming all the Christmas Fair paraphernalia into the car and phoning around trying to get someone else from the Parents Association to take over the setting up of the Fair. No-one was available; they were all at work. I would have to go ahead and do it, ED or no ED.

30 minutes later I was in the school medical centre helping staff to pacify Ben who seemed to have gone completely insane.

An hour or so later I was in the local supermarket car park bawling my eyes out into a bag of choc-chip cookies, taking phone calls from worried PTA members as I started to delegate all the following day's Christmas Fair tasks. I said I'd come down with a nasty virus. No-one knew what the real reason was.

Meanwhile Ben was still at school. He'd been pacified and was relatively okay. For now.

And, also meanwhile, I was acutely aware that my team of parent, staff and student helpers would be turning up shortly expecting me to direct the setting up of the Fair.

So there I was, at 2pm, knuckling down to transform the school into a happy, jolly, festive winter wonderland while I looked and felt like death.

When concerned people commented, I simply said I wasn't feeling well.

By the evening I was exhausted and, of course, the ED demon had returned with a vengeance as ED rages hijacked the entire evening.

But by now I was on autopilot, knowing I'd got a crack-of-dawn start the next day, ED rage or no ED rage...

So that was the first day of the ED Christmas.

**Saturday 26 November 2011**

**On the second day of Christmas, the ED gave to me... “Two dozen Christmas tree cookies”...**

Back in 2009 in the quest to re-work recipes into “healthy recipes”, Ben made a stack of ginger cookies to hang on the Christmas tree: angels, stars, Christmas trees, holly leaves, Santas, that kind of thing, all with satin red ribbon threaded through a hole made by a drinking straw.

He’d decided that fats could be completely eliminated from the recipe. Fats were the #1 Fear Food and Ben would go out of his way to avoid them.

The cookies smelled wonderful as they were baking. They looked divine. But, not surprisingly, they tasted terrible and were rock hard.

Back then you instantly knew when a recipe had “gone wrong” because there would be an almighty crash in the kitchen as Ben’s fist came down slap bang on the work surface followed by “animal” howling and the sound of Ben kicking things or banging his head against the wall.

With the anorexia, everything had to be perfect. Anything that was slightly less than perfect was rejected outright with a violent ED outburst to reinforce it. Anything that was a total failure was even worse. Already by late November 2009 I’d got to the stage where I’d live in dread of anything going wrong with the evening meal I’d cooked. ED would come down on me like a tonne of bricks, punishing me for the slightest thing: too hot, too cold, too big a portion, not tasty enough, too many carbs, too much fat...

So I knew by the noisy reaction that the fat-free Christmas tree cookies weren’t a big success. And while my husband and I went on to eat some lovely home-based Christmas stuff like home-made choc chip cookies, mince pies, etc, Ben ate nothing except his usual dried and fresh fruit - all painstakingly chopped into uniformly tiny pieces and arranged on a plate, because that’s how the ED liked to do things.

The other evening Ben made this year’s batch of Christmas tree cookies - this time

cinnamon cookies.

The shapes were the same, the baking smell was the same and the colour was the same. But this time he made them to the proper recipe, fat and all - because that's what he always does these days.

They are the best Christmas cookies I have ever tasted and Ben agreed as he merrily tucked into the broken ones that had stuck to the baking tray.

### **Sunday 27 November 2011**

#### **On the third day of Christmas, the ED gave to me... "The three of us... our strong family unit"...**

The other month I uncovered a letter which I wrote to Ben back in the run up to Christmas 2009. By then we were walking on eggshells, terrified of saying anything that might upset the eating disorder and set off an ED rage. The rational side of Ben's thinking had gone completely AWOL and he'd argue that white was black until he was blue in the face. We couldn't talk to him. He wouldn't listen. He couldn't listen.

I was so desperate that I decided the only way I could communicate with him was to write him a letter.

Back then I still thought that, somehow, we could "snap" him out of the eating disorder; that he would suddenly see sense and stop destroying himself then and there. I really thought it could be done. The problem was, I had no idea how. Maybe a letter would work. Maybe when he heard how terrified and upset we were, and how dangerous anorexia was, he'd come to his senses and stop.

Maybe... Just maybe...

So one day while waiting in the car for the school bus I put pen to paper. I wrote that "hopefully I can get it all across better without me or you getting upset" and that the anorexia was "dangerous and must be stopped immediately" and the three of us (dad, Ben and me) would make a decision that "this is going *no further* and will stop" and "we will sort out the issues that have caused it. We will sort out the self-

confidence and self-esteem issues via a counsellor who is very experienced in this kind of thing, even if we have to pay”.

I went on to say how “your happiness and *health* are our No1 priority. I want you to know that we will always be there for you, no matter how sad you feel – and we will get the very best and nicest help for you”.

I wrote: “We love you too much to watch this happen which is why, as your loving parents, we need to step in and say ‘STOP! Enough is enough!’”

I still find re-reading the next bit particularly difficult, the bit where I say:

“We will make serious promises to you, as our dearest son, if you make serious promises to us – and keep them.

“You are more important to us than you could possibly ever imagine or even know and we want to stop this nasty thing *now* and help work on the root cause.

“Please don’t think there is no solution because *there is*. Very much so – and in a few months you will be so glad we all made this decision.

“But meanwhile, *any* time you feel sad or you feel it’s too hard, *please* talk to us – about *anything*. Do not bottle it up – and let us all start thinking positively now, even if it may at first, and even second, seem hard. It’s not just you doing this alone – it’s all three of us... our strong family unit.”

Later on I add: “Will you let us ‘muscle in’ and start the ball rolling towards your wonderful future now?” followed by “Again, I can’t emphasise how much we love you and will be with you over this”. Finally I sign it off: “Big hugs x 10 million and even more, Mum xxxxxxxxxxxxxxxx.”

I could never, ever have known that it would be almost a year before something happened that *did* make Ben turn around and say “yes” to recovery. I could never, ever have known that between writing this letter and then that I would almost lose Ben, not once, but at least three times.

I’m so glad I couldn’t see into the future.

Unless, of course, that future was right now - with us three emerging into the

beautiful ED-free sunlight, getting ready for a truly festive Christmas 2011.

## **Monday 28 November 2011**

### **On the fourth day of Christmas, the ED gave to me... “Four months ‘til treatment”...**

It wasn't until October 2009, two months on from when the eating disorder first started to visibly manifest itself, that our GP finally and reluctantly agreed to refer Ben for treatment. You see, Ben was skinny, yes. But, to a GP that had never seen him as a muscly, athletic *prop forward* in the school rugby team, a skinny teenage boy wasn't that unusual. Nor was a teenager who appeared to have gone off the rails mentally. After all, “teenage angst” was common. I got the feeling he felt I was an unnecessarily over-protective mother.

Naively I thought we'd get treatment right away. Everything in my being was crying out that our case was urgent. Ben was physically disappearing before my eyes and had changed from the happy social boy he used to be into a mental wreck who often seemed to have gone insane.

It was a shock to find out that we might have to wait until *Easter* before our first appointment.

What the heck were we supposed to do between now and then? How much further would Ben hurtle down the rabbit hole? How much longer would it take to pick up the pieces and re-mould Ben once we finally did see a specialist team?

In the lead up to Christmas 2009 I knew I couldn't just sit there and watch Ben deteriorate; I had to do something. Luckily we had a little bit of private medical insurance we could draw on. Just £500 was available for mental health issues, but it was better than nothing.

So the search was on to find private treatment to fill the gap between now and our first NHS appointment with the CAMHS team.

Not only did virtually no-one in the local private sector have any experience of eating disorders, but - being Christmas - they were all booked up until after the New

Year.

Initially we managed to get an appointment with a rather strict and stern “old school” psychiatrist. I knew it was a mistake from the moment we walked into the room and he formally indicated that we should be seated opposite his large desk. I felt as if we were revealing our innermost secrets, feelings and fears to a CEO of a multinational corporation, not a compassionate doctor. That single hour session cost me half of our £500 medical cover.

The slightly Good News was that this guy did point us towards a therapist who worked out of the local private health centre - the kind of place you go for physio, hypnotherapy and so on.

It was deep in snow when we first went to see J. I immediately took a liking to her, and I think Ben did too. I knew we could get on with this woman. The only problem was... and it was a *huge* problem... it quickly became clear that the eating disorder was even bigger than I'd thought it was in that *no way* could one person “cure” it with a handful of weekly therapy sessions. J made this very clear to us and I really appreciated her honesty.

Between then and Christmas we trudged through the snow to meet J weekly until we ran out of money and she ran out of availability because of the holidays followed by a career change. In between sessions she'd email and phone me to talk things over. Although I knew she could do no more than attempt to plug the hole in the sinking *Titanic* with a band aid, she did her level best and I really appreciated that.

She also said she'd see if she could pull a few strings with CAMHS. She used to work with CAMHS and felt they'd take her seriously when she insisted Ben needed urgent treatment.

I don't know whether or not she was successful because, later in the New Year, something was to happen which did bring our CAMHS treatment forward when Ben was rushed into hospital with a pulse rate of 29.

**Tuesday 29 November 2011**

**On the fifth day of Christmas, the ED gave to me... “Five ‘Safe’ Recipes”...**

I have a kitchen cupboard jam-packed with recipe books and four more drawers packed with *Good Food* and *Delicious* magazines with two drawers reserved for the Christmas and New Year issues from the past 10 years. This year we’ve been doing what we’d usually do i.e. plough through all of the festive recipes, shortlisting the most yummy for our own build-up to the Big Day. On Sunday morning, for instance, Ben surprised me with a “De da!!!!” moment as he revealed the chocolate log cake he’d made the day before. That afternoon he made mince pies and various sweet and savoury Christmas biscuits. I’ll be making a third stuffing for our turkey - with a Spanish twist: chorizo. But it wasn’t like that in the build-up to Christmas 2009...

Back then, working out weekly menus was a nightmare, let alone working out what we would eat over the festive season.

I’d flick through all my recipes, discounting the vast majority because I knew that (a) Ben would refuse to eat them and (b) he’d throw a wobbly at the very prospect of them appearing on the weekly menu.

Anything with cheese was out. Fats, of course, were eliminated and anything that needed to be fried. Curiously nuts and potatoes were okay, but I couldn’t mix potatoes with, say, bread because that would mean “too many” carbs. I remember a veggie burger and oven-baked potato wedges I served up which ended up being slammed down on the table in a furious ED rage because of the mix of potatoes, bread and breadcrumbs (in the burger) on one plate.

Puddings and cakes were out - unless they were fat-free. And umpteen other things that, thankfully, have slipped my mind two years on.

Virtually all festive foods were “out”, except lean turkey meat and why the heck did we need to use oil to roast the potatoes when Ben reckoned it could be done “more healthily” without?

He would police the kitchen to check there was no “contraband” in the fridge,

freezer or larder.

Everything had to be zero fat and if an “extra lite” version existed then we had to buy that. Our local supermarket’s “extra lite” mayonnaise was particularly bland...

He’d throw an ED fit if he caught me frying anything on the stove. Even frying an onion in a tablespoon of oil was a criminal offence. Why fry when you can dry fry?

The slightest globules of oil would be described as “swimming in fat” and violent refusals to eat the evening meal.

Or he’d stress out all day at the prospect of a “fear food” being slipped into our dinner. I remember a serious problem with my plans for smoked mackerel burgers. *Had I seen how much fat was in mackerel?!!!*

I’d try to remove nutritional labels from food packaging. But by then Ben knew calories off by heart. And, anyway, removed labels set the alarm bells ringing in his head. I wouldn’t have removed the labels if they were “okay”, would I?

I tried to black out the nutritional content of recipes, but that also set off the alarm bells - and, of course, he knew the calories by heart anyway.

And in a house as small as ours it’s virtually impossible to lock him out of the kitchen.

Before the eating disorder, cooking was one of my big passions. Especially cooking in the run-up to Christmas. At the height of the eating disorder I came to hate and even fear cooking, choosing a handful of five or so “safe” bland recipes in an attempt to keep the peace.

Last year in 2010 it was better.

This year it’s virtually back to normal.

Bring on Ben’s delicious chocolate log cake!!!!

### **Wednesday 30 November 2011**

#### **On the sixth day of Christmas, the ED gave to me... “Six friends a-staying x 2”...**

Ben kept out of the limelight at primary school, preferring to stick to one good friend.

But by secondary school he'd blossomed from a shy, slightly overweight "duckling" into a mega popular, handsome and athletic "swan". In fact he was so popular within his new friendship group that his annual birthday parties, just before Christmas, were legendary.

On the last day of term school finished at lunchtime. I'd pick up Ben plus half a dozen friends and we'd make our way down the school driveway, car windows wide open as Ben and his friends leaned out of the window shouting "Merry Christmas!!" to everyone they saw. I'd put the old favourite Christmas songs on the car CD and we'd all sing along on the half-hour journey home.

Back at our house they'd all disappear up to Ben's large loft room, only coming down for supplies of drinks, crisps, cookies, cakes, etc and, of course, an enormous evening meal followed by the World's Biggest Breakfast the next morning. After all, they were growing teenage boys, weren't they? I was astonished at how much food they put away.

Saturday afternoon was the switch-over when we met up with the *other* half dozen friends at the local cinema complex, watched a movie, went for a massive *Pizza Hut* meal (the kind where you can help yourself to endless ice cream and sprinkles, which - of course - they all did).

Then the whole sleepover process would be repeated with this other set of friends followed by yet more endless supplies of cookies, drinks, etc and an equally enormous breakfast on Sunday morning.

Phew! What a weekend. Like I said, these parties were legendary.

Ben's final sleepover birthday party took place on the last day of the Christmas term in 2009.

This time only a handful of boys came back with us from school and the party only lasted one night. They did go to the cinema, but they didn't go to *Pizza Hut*. Instead, they came back for a meal that Ben had carefully chosen.

By then Ben was neck-deep in the eating disorder and had completely distanced

himself from his friends. Over the Christmas term his behaviour had become increasingly distressing, frightening and crazy. I could tell from those friends' eyes that they weren't quite sure what to expect.

The atmosphere was subdued to say the least.

Ben had chosen the menus. The evening meal had been slimmed down as had the breakfast. "They won't want all that," he said, "No need for this, no need for that"... Of course the boys tucked in, but Ben didn't.

That evening it was uncannily silent up in Ben's bedroom as the boys played quietly with computer games rather than jumping up and down on the bed, screeching, charging up and down stairs, and spraying each other with water from the ensuite shower hose.

They all went to bed on time which was unheard of. One boy had already gone home, phoning his mum around 9pm because he didn't "feel well"...

Just after midnight a loud noise woke us with a start.

Ben was rushing downstairs, howling like a wounded wild animal, hurtling towards the living room.

We jumped out of bed and rushed downstairs to see what the matter was.

Ben was in a terrible state: weeping, howling... ED at its most impressive...

Apparently one of his friends had made some innocent comment about something which had hit a nerve and this was the result.

The next day it was a group of silent, sheepish looking boys that slunk downstairs for breakfast, trying to make polite conversation.

It was a relief when their parents turned up to collect them. And I remember what stood out starkly, apart from their subdued mood, was how big they all looked compared to waif-like Ben. I also tried to avoid the parents' shocked looks. After all, it was a long time since they'd seen Ben. It was as if they didn't recognise him.

Or maybe it was just me being paranoid.

But looks can speak volumes.

DECEMBER 2011

**Thursday, 1 December 2011**

**On the seventh day of Christmas, the ED gave to me... “Seven treatment sessions?? Or eight?? Nine??”...**

When we met up with that stern private psychiatrist a few weeks before Christmas 2009, I’d written out a couple of pages of notes and questions.

These were the questions:

- ★ What kind of therapy does he need and with whom?
- ★ How long will it take / how many sessions?
- ★ Obviously Ben’s well-being is uppermost in our minds but because this is private, we need an idea of how much it may cost?

You see, back then, I honestly thought someone could tell me approximately how many sessions Ben would need to “cure” him of the eating disorder.

I thought a skilled specialist practitioner would be able simply examine him, diagnose him and say: “Hmn... I think we can do it in seven or eight weekly sessions,” or whatever.

I really did.

How could I have known that, two full years on from then, we would *still* be seeing our treatment team? Thankfully, being the UK, the CAMHS treatment team is NHS-funded, so we don’t have to pay.

We only had to pay for the private “treatment” Ben received as a “stop gap” while we were on the CAMHS waiting list.

Seeing as we only had £500 a year available from our medical insurance to cover

mental health issues, I have no idea what we would have done without the free NHS treatment.

Over the past two years we've had a crippling recession to deal with - and Ben's dad was out of work.

CAMHS and I may not have always seen eye to eye over the months we've been with them, but I am eternally thankful this Christmas season that the treatment was free and unlimited.

### **Friday 2 December 2011**

#### **On the eighth day of Christmas, the ED gave to me... "Eight billion snowflakes falling"...**

It was Ben's birthday, a couple of days before Christmas 2009. We'd been to the cinema followed by a (reasonably stress-free) curry and were driving back home. The snow was falling thick and fast, and eventually my sister's car got stuck, so she had to drop us off several streets away. This meant making our way through deep snow back to our house.

A white Christmas is extremely rare in our part of England, so it was extra-special - trudging up the middle of the silent street past house after house of twinkling Christmas lights.

The only person that wasn't instantly transported into magical child-like memories of Christmas past was Ben. That's because ED kind of numbs your positive emotions. He was desperate to feel "Christmassy", but couldn't feel a thing. It was as if his brain was anesthetized.

At the height of the eating disorder, Ben couldn't feel emotions like love, happiness or pleasure. He was completely numb.

And, because of what the eating disorder was doing to Ben and our family life, I found it hard to get into the Christmas spirit, too.

That year I didn't send any Christmas cards. I didn't feel like cooking Christmas

dinner, so my sister offered to do it instead.

I simply went through the motions because “that was expected”.

But that night, walking home in the deep snow, peeking into houses decked with holly and twinkling lights, I did feel Christmassy.

For a little while anyway.

Before the ED swooped in to ruin our Christmas Eve.

### **Saturday, 3 December 2011**

#### **On the ninth day of Christmas, the ED gave to me... “Nine Lessons and Carols”...**

Three o’clock every Christmas Eve afternoon I have an appointment with *BBC Radio 4* in our dining room. It’s the world-famous *Festival of Nine Lessons and Carols* live from *Kings College Chapel, Cambridge*. At 3pm precisely, the presenter announces that a chorister will step forward and lead the choir up the chancel singing the first verse of *Once in Royal David’s City*.

Every single Christmas Eve, I take myself off into our festive dining room, table already set for Christmas dinner, switch on the fairy lights, light some festively perfumed candles and listen to this broadcast. Just like my mum and grandma before me.

At 3pm on Christmas Eve 2009, however, I was blubbing my eyes out into a box of tissues as the ED raged through the house screaming and shouting about something that had set it off.

As ED continued to rant and rage, and Ben’s dad tried to calm him, I just sobbed and sobbed, thinking of us - yet also thinking of all those other families who, for whatever reason, were missing their child that Christmas. Suddenly I felt part of this terrible crowd of mothers and fathers whose only Christmas wish was to have their “little boy” or “little girl” back.

At least my “little boy” was here in our house with us - and hopefully we’d get him back properly one day.

Unlike the other mum who I came across shortly after Christmas 2010 whose daughter went into hospital with severe anorexia and didn't come back.

So ED might have spoiled my Christmas Eve traditions, but at least I had a lot to be thankful for.

### **Sunday 4 December 2011**

#### **On the tenth day of Christmas, the ED gave to me... "Ten swans not swimming"...**

Winter 2009/10 was the winter of the Big Freeze in our part of the UK - the year the huge lake in our local park froze solid which, of course, meant that its resident swans were unable to swim on it. But meanwhile Ben and I continued our regular walks from our house, through into the park, round the lakes and back home - a route we've trudged many, many times during the eating disorder.

Autumn would lead to winter which would lead to spring and then summer - and for a whole year we'd do that walk which was also a great opportunity for us to talk about things.

For an entire year I felt as if I was flogging a dead horse. No matter what I said, it fell on deaf ears. Ben was unable to see logic or reason. He would argue that black was white until he was blue in the face.

In the Big Freeze that followed Christmas 2009, Ben really *was* blue in the face. Having lost so much weight he felt the cold more than most people so he wrapped up warm against the freezing temperatures.

And I was painfully aware that, beneath the chunky sweater, jacket, hat, scarf and gloves was an increasingly emaciated body.

His illness became even more noticeable as we stopped off at the park café for a warm drink (black coffee for Ben, naturally...).

On display were its famous yummy cakes and bakes: chocolate fudge cake, carrot cake, millionaire's shortbread, coffee walnut gâteau...

As usual, Ben was drawn to these like a magnet. Not to eat them, of course, but to

admire them - as you or I might admire works of art hanging in a gallery. He'd just hover there, mesmerized by the cakes, serving staff coming over to ask if he'd like to order a slice, and giving him odd looks when he shook his head, yet continued to stare...

Then he'd come over to where I was sitting and insist I come and "admire" the cakes as well.

I refused.

There we were, in the Christmas and New Year season, living in the Western World with festive food abundantly available yet my son was starving himself.

But, fortunately for the swans just outside the café, someone had broken a large section of the ice so they could swim around a bit, fighting with the ducks and other wildfowl for the chunks of bread being tossed into the water by young families.

At least the swans were enjoying their food.

## **Thursday, 8 December 2011**

### **That's enough of the 12 days of ED Christmas...**

Not wanting to labour the point too much I decided to stop at *Day Ten* and move onto something more current which is the continuing niggle over whether or not Ben will be ready to leave home for university in September 2012.

So far he has received offers from all five of his university choices and needs to whittle them down to just two by May: a "firm" choice plus an "insurance" choice as a back-up.

Both are asking for 3 x A grades at A-level.

So what happens if he doesn't get these?

For a start he needs to successfully re-sit most of his AS levels from last summer (which he failed, mainly because he was quite ill during exam week). Without good grades at AS level he won't achieve A's at A-level as they count towards the results.

Will the universities offer any flexibility considering the mitigating circumstances

which has meant Ben missing what amounts to almost three full terms of schooling due to his anorexia?

They might. But on the other hand they might not if student numbers are high.

So it all feels like a bit of a gamble.

Of course Ben could have applied for universities which aren't asking for such high grades. But he needs the intellectual stimulus and resources offered by these superb universities. Also two of the universities are relatively local, one being in our home city which is very convenient should we need to keep an eye on Ben's recovery during this period of upheaval.

So I feel as if we're taking a bit of a gamble by whittling it down to the two courses which require AAA grades.

I guess if he doesn't achieve AAAs and there is no flexibility for "mitigating circumstances" then he can always take a year off to re-sit the exams.

It's not me being a "pushy parent"; it's the fact that academic study, and in particular his chosen degree subject, is one of the key things that has kept Ben going through his illness. It is his passion!

**Friday, 9 December 2011**

**We are assuming Ben will go away to Uni...**

I had a frank and useful conversation with Ben yesterday about whether or not he feels he will be ready to live away from home at university and successfully manage his own food and recovery.

We need to decide over the Christmas period because, if he'd prefer to put our home city as his main choice, then we need to apply pronto for a special scheme that takes into account interrupted studies and the need to attend a local university.

Ben has always preferred the other university. He likes the city, the atmosphere, the location, the accommodation, the teaching staff, the facilities and the course. Everything, in fact. And he doesn't want to let the ED get in his way.

He sees Uni as a fantastic opportunity to draw a line under the anorexia and move on. He insists, quite rightly, that he can manage his own cooking and - hopefully - food intake.

He already does a lot of this here, managing all his meals including - on some days - the evening meal.

He is brilliant at frugal supermarket shopping and frugal yet nutritionally balanced meal planning - and he is content to continue on his required daily calorie intake and keep a watchful eye on his weight.

We will ensure there is a good “special needs” support team in place at the university should he need them, and also so they can keep an eye on his weight and well-being, too.

And the university is only 35 or 40 miles away on a direct railway line / motorway so it's cheap and easy for him to come home if he needs to - or for us to visit him there.

We talked about all the exciting things that he is looking forward to at uni: all the clubs and societies he will join so he can make friends with people that have the same interests, the meals he will cook, the student halls where he will live, the quirky local shops and cafés nearby, and so on.

I could tell the other day at our local uni that he wasn't terribly interested. So it's pointless making him go somewhere when he would much rather be somewhere else.

I don't imagine this decision will change. So it's a case of working towards Ben living away from home in September. And, just to make sure everything does go to plan, we might set up a *University Transition Contract* similar to one on the FEAST website.

**Tuesday, 13 December 2011**

**Five resits in January...**

Last summer the tail end of the eating disorder helped Ben to flunk his AS level exams. As a result he has no less than *five* resits in January. And he needs to get good grades in order to get the grades he needs in this summer's all-important A-level exams. So, basically, if he doesn't do very well then he can kiss goodbye to his university choices. No pressure, then...

The Good News is that the 10 months or so of insomnia seem to be at an end. Ben sleeps relatively well these days. And the insomnia was particularly bad during the AS exam weeks last summer and almost certainly responsible for the poor results. Doing public exams when you've had zero sleep, night upon night upon night, is no joke...

Ben still wants to go away to university, so we're not applying for that scheme I mentioned last time. No point. But we will be sending in some evidence to the Admissions Team supporting his "mitigating circumstances" i.e. a letter from the CAMHS team and another from school staff.

Two years ago Ben was already absent from school more times than he was present. And when he was present he was unable to function. He'd be hiding somewhere, throwing a wobbly or going to pieces in the medical centre. And of course he had virtually zero nutrition fuelling his body and mind.

After a very rocky start back at school in January 2010, I decided to remove him "for the duration". He simply couldn't be in school.

Over the next couple of terms he studied for, and sat, his GCSE exams separate from everyone else. Studying was done at home, work was emailed home by staff or I'd arrange to pick it up from school. Exams were sat in a private room, away from the other students.

During this time he was falling down the rabbit hole at a rate of knots leading to the height of the anorexia over the summer of 2010.

And you will know very well that it's not simply a case of not being in school and

everything is okay... Far from it. It was as if the devil himself had taken over my wonderful son, driving him to self-destruction.

But I don't need to go into detail about this here.

He attempted to return to school in the September, now in the lower sixth form. This was when the insomnia kicked in big style and, again, he was away from school more times than he was present.

In October 2010 he turned a corner and things improved in that he was able to go to school most mornings. Not all mornings, but most.

In spring 2011 I introduced our Recovery Contract which awarded him points for (a) managing a part-morning at school, (b) a full morning and (c) a full day. Full days didn't happen at that point. But by the start of the upper sixth form in September, he was managing to go all mornings - and often all day on Fridays, too.

This is still the situation and I don't see it changing really.

As a result he has missed a massive amount of schooling over the last two-and-a-bit years.

But Ben being Ben has stayed motivated academically - or as much as he has been able.

Let's hope he gets through those critical resits in January and gets the grades he needs for Uni in the summer.

Failing this let's hope that the university will be sympathetic to his circumstances and allow a slipped grade or two.

**Wednesday, 14 December 2011**

***It's not like a physical illness...***

The thing with anorexia or any other eating disorder is that it's not like a physical illness. Sure, people can "see" that you're losing weight at a rapid pace, but I believe that most people just don't realise that there is a mass of other really nasty stuff going on as well: messy emotions, erratic and sometimes violent behaviour, irrational

thinking, compulsions, obsessions, personality changes and a total inability to cope with normal life. It is not simply a “diet gone too far”. It is not something that “any sensible person” could “just snap out of”.

All of this, and probably a load more besides, adds up to the reason why our children are at a disadvantage when it comes to things like sitting important exams and qualifying for university. I expect that many of them, like Ben, are more than capable of doing top degree programmes, the kind that requires AAA grades. But, through no fault of their own, they get poor grades or - like one of Ben’s AS level exams - a U classification (fail)...

When I talk to school teachers and university admissions staff I wonder just how much they really “get it”.

If I was standing there explaining that my son had spent the past two years battling with cancer, then I often wonder if they’d be more sympathetic to our case.

I could be wrong, of course. They *do* appear to be sympathetic but, when asked how much flexibility there is should Ben fail to get the grades he is capable of getting, it’s all, “Well it really depends how oversubscribed we are”. In other words, there’s not much chance of them allowing slipped grades when they’re being swamped by AAA students.

What about the fact that people like Ben really *are* capable of studying an AAA course at a “red brick” university? Not just capable, but supremely knowledgeable and passionate about their chosen subject?

That they *need* this intellectual stimulation. It is part of their makeup, it is what makes them tick, it is what makes their lives worthwhile and gives them focus. Academic study was one of the only things that ran like clockwork at a time when everything else in Ben’s life was going pear-shaped.

Not to mention the rock solid fact that students like Ben have mastered important independent learning skills - something that is key to succeeding at university. Other fantastic skills they’ve mastered include self-motivation, focus, research and

evaluation abilities, deep thinking, time-management and the ability to work through periods when you feel pretty rubbish or are ill.

So I asked an admissions tutor the other day if, in the event that Ben didn't get his grades, they might consider interviewing him so he can prove to them just how capable he is. I know he'd love to have this opportunity and I know his passion and sheer depth and breadth of knowledge would come across loud and clear.

No, was the answer.

So, if he doesn't get his grades and there is no flexibility to allow for the fact he's been battling in a physical and emotional hell for the past two years while studying for critical exams, then it may be a case of having to resit the exams until he *does* get the grades.

Or go into clearing and opt for a uni he doesn't want to go to.

Please don't let him have to resit those confounded AS level exams *again*...

**Wednesday, 14 December 2011**

### **Detective Mama makes a discovery**

You know I'd never have known about this if I hadn't delved a little deeper and done some trawling around the Web... The fact that Ben's first choice of uni now has what is called a *Disrupted Studies Form* which deals with exactly the kind of issue I've been ranting on about. It's brand new, introduced this year.

Ben has been (conditionally) accepted by two courses at this uni and neither of their admissions teams informed me about this form despite the fact that I telephoned both to discuss Ben's situation.

It took a Google search this afternoon for me to make the discovery.

Result? I have talked to the Man in Charge of the form and he was really, really helpful.

I've also been in touch with school to talk about the element of the form which they need to fill in.

Now I know what we need to do and I also know that, hopefully, there just might be some flexibility if Ben fails to get his grades in the summer.

Good old Mama Matty, hey...

**Thursday, 15 December 2011**

**Funny how our relationship with CAMHS has changed so much...**

Funny how, for the first 12 months of our relationship with CAMHS, I felt as if we had two completely different agendas. I had serious problems consolidating the messages I was getting from my various professional and lay ED contacts and those I was getting from our CAMHS team. At times I felt totally at odds with them. Often I used to wonder whether they were colluding with the eating disorder rather than kicking it into touch.

Then just over a year ago something changed. Or at least it did with the psychiatrist (out of a CAMHS team of two).

For me the watershed was when Ben was rushed into hospital for the second time with a dangerously low pulse rate in October 2010. Suddenly the psychiatrist zoomed in, took charge of the ED and, instead of following the “you need to *want* to change” route, she adopted the “you have *no choice* but to change *right now* or I could, in my professional capacity, hospitalise you sooner rather than later” route. This put the fear of God into the eating disorder and into Ben - and for the first time he said *no* to the ED. We haven’t looked back since.

Between then and now, despite the odd disagreement which is only natural, the psychiatrist and I have been “singing from the same hymn sheet, on the same page” (to coin a phrase that makes me squirm but which sums it up well). For the past few months we’ve got on astonishingly well and I really like her. In fact I’m going to miss her when she leaves her job in March - aarrggghhh! that was news to Ben and me today!!!!

The Good News is that we have almost reached the point where we don’t need to

see CAMHS at all. And, anyway, Ben is 18 next week and about to go to university. But what it will mean is that we have to work with someone else between March and when Ben does go away. Maybe March is the opportunity we need to make the break and say Goodbye and a Huge Thanks to CAMHS, knowing that someone is there if we need them. Okay, not the psychiatrist we've come to know so well over the past two years, but someone.

In a strange way I'll miss CAMHS. And I am eternally grateful that, here in the UK, these two years of treatment have been completely free.

**Wednesday, 21 December 2011**

### **Four nights in Edinburgh**

Ben wanted to go to Edinburgh for his 18th birthday, so we did - and we've just come back. I was aware of the ED being there in the background a little bit. Not a lot, but definitely there. And it got me thinking that we still have issues that need ironing out before we can truly claim that Ben is "recovered".

For example, Ben's mood is still generally low and, like our second week in the Peak District in the summer, this frustrated me. Edinburgh was positively sparkling, the atmosphere was lovely, but Ben often looked as if he was at a funeral. His emotions are still being numbed by the eating disorder.

He managed to get through all the food he needed to get through including eating out, but he did say no to some things - for instance the cooked breakfast on the train on the way back home, opting for toast and jam (no butter) instead. But, in general, the food choices he made were good and included a slab of iced Christmas cake, a large iced bun and a chocolate covered marzipan bar - plus a huge curry and a pizza.

Ben said that it had been a challenge "not to exercise" while we were away, despite the fact that we walked *miles* and *miles* every day. If that's not exercise, then I don't know what is! And I noted that he took the stairs instead of the escalator at the railway station - carrying a heavy suitcase...

Also, he still has this irrational fear that something terrible will happen if he puts on a few extra kilo - basically that he will be fat. And what we are seeing is someone who is most definitely on the skinny side of slim... But he doesn't see that... still...

**Thursday, 22 December 2011**

**My "little boy" is 18 tomorrow!!**

18 years ago this evening things were moving... fast. I'd been having contractions for 24 hours and had already been down to the hospital only to be sent home because I wasn't ready. Then at 10pm my waters broke and it was back to the hospital for a *long* and *painful* labour until Ben decided to appear at lunchtime the next day - coincidentally his dad's birthday, too.

So tomorrow my "little boy" is 18. I can't believe it! He will be an adult in law. He will be able to vote, drink in a pub and get married without our consent. I guess that, if he wanted, he could also refuse to continue his ED treatment - and / or involve me in the process. Thankfully I know he won't do that.

**Tuesday, 27 December 2011**

**"I'm alright, Jack"**

I was tempted to write about what a wonderful Christmas we've had compared to the last couple of years. Okay it wasn't perfect and the ripples of ED were still there, but I could have gone down the happy and thankful route. Then I read my dear friend C's latest blog entry and was prompted to write something completely different.

Yes, we are enormously fortunate in that our son is almost recovered. Yes, we are hugely lucky that Christmas Eve and Christmas Day were fun. Yes, I loved seeing my son tuck into his Christmas Dinner, Christmas Pudding, Christmas Cake, chocolate log cake, chocolates and umpteen other things he wouldn't have touched with a barge pole a couple of years back.

But forget about all that “I’m alright Jack” mentality.

The stark truth is that while our children recover there are others, right now, that are descending into anorexia at an alarming and dangerous pace. And who knows how long it will take them to come out the other side. If at all. Last Christmas I was reading desperate posts from a mom on the Around the Dinner Table forum as she helplessly watched her daughter disappear down the “rabbit hole”. By February (I think it was) the daughter had lost her fight.

This Christmas I read C’s blog about another desperate mom who is being told that her daughter can’t be medically assessed until January - yet as long as she continues to eat her 600-ish calorie intake a day and drink water she “should” be okay for the next 10 days.

So while we mums are enjoying our first ED-free Christmases there are others out there that are helplessly watching their children disappear in front of their eyes. And it this terrible merry-go-round will go on and on and on and on - until eating disorders are taken as seriously as any other potentially fatal illness.

**Thursday, 29 December 2011**

**Such a big topic I hardly know where to start ...**

Although a dear friend of mine succeeded admirably in her latest blog, we, ED-connected friends across the world, are starkly aware that young people are dying from eating disorders; my blogging friend has learned of four deaths in the past six weeks alone - and one of these was tragically on Christmas Day.

It seems that in so many cases eating disorders aren’t taken as seriously as they should be. Young people are being put on ridiculously long waiting lists while others are being refused instant hospital admission because it’s the wrong time of year i.e. Christmas or they’re not deemed to be “sick enough” or their BMI isn’t “low enough to warrant admission”.

And some of these young people are very ill indeed. Young people are suffering

and even dying when medical professionals should be pushing them towards recovery - not pushing them away from the treatment they so desperately need.

Other young people's eating disorders are being needlessly prolonged because medical professionals are waiting for them to "want" to recover, colluding with the ED or simply being too soft.

As I said in response to the above blog post:

Like you, we were put on a ridiculously long waiting list for treatment and all I could do during this time was to helplessly watch my son deteriorate rapidly – which he did. It took an emergency admission to our local cardio unit with a pulse rate of 29bpm for me to finally persuade CAMHS to see us a few weeks sooner than the original appointment.

Just as bad, our GP didn't take us too seriously. Skinny boys with faddy eating habits aren't unusual, after all. It was some time before we managed to get a referral to CAMHS.

Thankfully, as you know, we have virtually emerged out the other side of this long, dark ED tunnel. But had my son's heart *not* picked up after that emergency admission and had CAMHS *not* seen us sooner than originally planned, then who knows what the outcome might have been?

These teenagers should be fast-tracked into treatment in the same way they would be if they had another potentially fatal illness. I am guessing that if our GP had suspected something like cancer we would have been jetted off to hospital within days.

**Saturday, 31 December 2011**

**And so a whole year of blog posts draws to an end ...**

Thank you to all my blog followers and all the lovely comments and feedback you've sent me over the past year. I wish all of you a wonderful New Year. May it bring all that you wish and hope for, and may it be enormously better than 2011.

