

Anorexia Boy Recovery

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

Part I – 2011

BEV MATTOCKS



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The blog posts on which this book is based are written from a personal perspective and express personal opinions and points of view. Therefore they might differ from someone else's perspective and opinions of the same events. However, to the author's recollection, all events described here did take place. To protect identities and respect confidentiality, most names have been changed. Any resemblance of these names to actual persons, living or dead, events, or locales is entirely coincidental. Please note: this book is written as a source of information only and should never be treated as a substitute for advice, decisions or judgment of a medical or other adviser, clinician or practitioner.

Find out more about Bev Mattocks at

www.anorexiaboy.co.uk

anorexiaboyrecovery.blogspot.co.uk

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DEDICATION

This book is for my dear friend, Sue. Thank you for always being there for us despite your own life struggles. You are an angel in the truest sense.

This book is also dedicated to my wonderful son – a young man of remarkable courage, determination and strength.

And, finally, this book is for all my faithful blog followers, many of whom have become good friends.

ABOUT THE AUTHOR

BEV MATTOCKS lives in the north of England with her husband and son and works as a freelance advertising copywriter. She is a member of FEAST UK (Families Empowered and Supporting Treatment of Eating Disorders). This book is based on her popular blog about her struggle to help her teenage son, Ben, recover from anorexia. She writes the blog under the name *Batty Matty*.

For more information, visit www.anorexiaboy.co.uk,
anorexiaboyrecovery.blogspot.co.uk and
www.bevmattocks.co.uk

AUTHOR'S NOTE – JANUARY 2013

Why did I - Batty Matty (Bev Mattocks) - sit down on 5th January 2011 and begin to write a blog about my battle to help my teenage son, Ben, recover from anorexia?

Why did I make the decision to describe ultra-personal thoughts, feelings and events on the internet where anyone can access them? Wouldn't it be better to pack these distressing memories away in a box, forget about them and move onto the next stage of our lives?

On one hand, yes, writing this blog – and this book – has dug up memories that I might prefer to forget. I have flashbacks and sleepless nights as I recall just how horrific this period was. But here are just some of the reasons why I sat down and decided to write my blog: *AnorexiaBoyRecovery*. And, why - two years on - I am still writing.

When my only child, Ben, (then aged 15) first began to exhibit symptoms of anorexia over the summer of 2009, I had no ideas that boys got eating disorders. As the mother of a teenage boy I never *thought* about anorexia. After all, why should I? But this lack of awareness is one of the major reasons why it took so long before the penny finally dropped.

Once I realised that Ben was developing anorexia, I was terrified. I felt isolated. I didn't know where to turn, what to do or what I should know. And yet the information I was finding suggested that anorexia could be a deadly condition - that people could and indeed do die from it.

Yet, unlike cancer or another life-threatening illness, it baffled me that Ben wasn't being fast-tracked into treatment. Good grief, I didn't even know what treatment was available because we were never told. And when, several weeks later, I did eventually get Ben referred we found ourselves on a waiting list that could last for many months.

Each time I asked for Ben's assessment to be speeded up I was met with a brick wall and comments about "limited NHS resources". Part of me even wondered if I was imagining everything because, if Ben's condition was serious, then surely someone would have taken swift action.

But the other part – call it a mother's gut instinct – told me that something was seriously wrong with my son. And if I didn't fight, it would get worse. Ben was disappearing in front of my eyes and I had to do something. But I had no idea what I should, or could, do.

So – at the same time as battling with an escalating illness that was rapidly transforming my son physically, mentally and emotionally – I crammed up on everything I could find about eating disorders. I read, I researched and I called helplines. I also found some "stop-gap" private treatment. That is until events took an unexpected and frightening twist and Ben was suddenly fast-tracked into treatment in early 2010.

The point is: I know how terrifying it is to discover your child has a potentially life-threatening condition and be clueless about what to do or where to turn. Right from the start I was acutely aware that I wanted to do my bit to help other families - not only to direct them to useful resources, but to describe our own personal experience of anorexia. Hopefully, this way, other families could see there was a light at the end of the tunnel, and draw on some of the strategies we used to get there.

I'm not a medical or mental health professional. But what I am is a genuine parent who cares about my son and his journey back to health. I also care about other families facing a similar situation – parents of girls as well as boys.

My son, Ben, has always been one hundred per cent behind this blog. Indeed it was he that suggested I write it in the first place. No, he doesn't read my blog. He chooses not to. And Ben isn't his real name. In fact I don't use any real names apart from references to relevant professionals. ("Batty Matty", in case you're wondering, is my nickname from school days.)

But, as I said above, 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, what signs to watch out for, what worked and what didn't. And, importantly, during those many false summits and disappointments, how they found the strength to continue fighting. Basically, as a parent you have no choice but to fight. You can't just sit there and do nothing.

My blog chronicles how Ben finally responded to treatment and family support - and how, ultimately, the main thing that helped him get through this illness was the fact his dad and I were always there for him, talking with him, encouraging him, developing our very successful *Recovery Contract* (see end of book) and so on.

I'm not trying to project myself as some kind of awesome Super Mum. Many other people write blogs and books, or get into the media, bringing eating disorders out of the closet and into the public eye. By doing this, they help raise awareness of a taboo subject in a society where eating disorders are often shrouded in secrecy, shame and misunderstanding - and where there is still too little awareness of anorexia in males.

Even if we help just one family fast-track its way through the huge learning curve and get help, then we have succeeded with this blog. And every time a parent contacts me to say how much my blog has helped them, I know it is serving its purpose.

Batty Matty, January 2013

ADDITIONAL 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.

JANUARY 2011

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 fro... 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-Mensh 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 sooooo 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 “dolphins” (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-weighting 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-weighting 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 this

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...

APPENDIX

Recovery Contract

The following is adapted from my book: *Please eat... the true story of a mother's struggle to free her teenage son from anorexia.*

On 20th March 2011 I produced a lined exercise book and typed up a draft Recovery Contract with a copy for each of us – Ben and me. Each day we sat down “on neutral territory” and discussed what Ben had eaten, how many calories he had consumed, what challenges he had overcome, how he was feeling generally and whether he had managed to keep within his agreed exercise parameters. It was also a great time to share any thoughts or difficulties, or to ask questions without jumping down each other’s throats.

Crucially the contract wasn’t about penalties; it was about rewards. Not “bribes”, but rewards: gentle encouragement to make small tweaks to his eating and lifestyle – small but significant changes that would help him move forward and feel good about himself. It was also very flexible and could be adjusted at any point depending on progress and current needs. But any changes were always mutually agreed. It was never a case of “mum laying down the law” or “making” Ben do anything he couldn’t or didn’t want to do. He had to be committed to the Contract one hundred per cent for it to work. “Let’s do points,” I’d say, getting out the exercise book and we’d sit down and talk.

Ben got points for eating and keeping to the agreed calorie total, whatever the current calorie total was. He won extra points for eating more and for weight gain: the more weight he gained, the more points he won.

There were points for challenges - challenge foods or meals, or socialising, basically anything he was currently finding difficult. We would talk about why these things were still a challenge and how Ben might overcome them. Gradually new challenges became old

challenges before being phased out altogether as they morphed into everyday behaviour. Then more challenges were introduced - things I could never in a million years have dreamed that Ben would eat or do when he was drowning in the anorexia.

Ben decided on his own challenges but I expected at least one proper challenge a day. Some days he didn't manage this, but – with a bit of discreet encouragement – he'd quickly move on and conquer something else or return to a particular challenge at a later stage.

Ben got points for keeping within the agreed exercise limits, for doing less exercise and for going to school. The longer he managed to stay in school, the more points he got – one point for a part morning, two for a full morning and three for a full day.

Points were deducted for cheating, dishonesty or resisting the Contract in any way. Encouragingly, I only had to deduct points once; the rest of the time was progress. "Point win prizes!" he smiled whenever I added up the points and reached for my wallet.

Later, in the summer of 2012, Ben talked to me about the Contract. "I admit it was a cash incentive at first," he told me. "But gradually it became less and less about money and more about me wanting to get better."

Most importantly, the Contract gave Ben the kick-start he needed to get out of the rut and move on. It came at exactly the right point on his journey towards recovery.

* * *

Not everyone advocates cash incentives, however. Some may feel they sound too much like "bribes". Cash rewards may also be difficult to implement if your child has siblings (because of jealousy); Ben is an only child so it made things much easier.

But whatever you choose as a reward, 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 and revise it.

Certain parameters and goals are set out which need to be achieved within agreed time frames. The individual earns “rewards” in the form of “points” which add up to a worthwhile reward which could be a sleepover at a friend's house, a trip out or whatever it is that floats your child's boat.

Obviously the aim is to drive recovery forward with continuous momentum and prevent what I've come to refer as “pussyfooting around” or treading water. Also, typing everything out on paper “sets it in stone” – so much more effective than verbal agreements which can be quickly forgotten or denied.

Finally, a written Contract is a good discussion point, allowing carer and child to regularly review progress – neutral ground where it's agreed that no-one is permitted to shout or yell at the other, and the “anorexia demon” is well and truly banned.

RESOURCES

Websites

www.aroundthedinnertable.org – The *Around the Dinner Table* forum provides support for parents and caregivers of anorexia, bulimia and other eating disorder patients

www.feast-ed.org – *FEAST* is an international organisation of and for parents and caregivers to help loved ones recover from eating disorders by providing information and mutual support, promoting evidence-based treatment, and advocating for research and education to reduce the suffering associated with eating disorders

www.b-eat.co.uk – *Beat* provides helplines, online support and a network of UK-wide self-help groups to help adults and young people in the UK beat their eating disorders

www.mengetedstoo.co.uk - *Men Get Eating Disorders Too* is a UK based charity dedicated to representing and supporting the needs of men with eating disorders

www.maudsleyparents.org - *Maudsley Parents* is a US based volunteer organisation of parents who have helped their children recover from anorexia and bulimia through the use of a family-based treatment known as the Maudsley approach, an evidence-based therapy for eating disorders

www.kartiniclinic.com - the *Kartini Clinic* is a US based medical and mental health treatment facility dedicated exclusively to the treatment of eating disorders in children and young adults - this website includes a stack of useful information, videos, etc

www.drSarahRavin.com – *Dr Sarah Ravin* is a US based eating disorders therapist whose website includes a highly informative blog plus other useful information

www.anorexiaboy.co.uk – my website which talks about our fight to help our son recover from anorexia

www.youtube.com/user/CandMedPRODUCTIONS/videos - C&M Productions' eating disorder resource for carers promoting evidenced based treatment and hope

www.thenewmaudsleyapproach.co.uk – an excellent resource for professionals and carers of people with eating disorders

Books

Skills-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method - by Janet Treasure
Help Your Teenager Beat an Eating Disorder - by James Lock and Daniel Le Grange

Treating Bulimia in Adolescents: A family-based approach - by James Lock and Daniel Le Grange

Decoding Anorexia: How Breakthroughs in Science Offer Hope for Eating Disorders - by Carrie Arnold

Brave Girl Eating: The inspirational true story of one family's battle with anorexia - by Harriet Brown

Eating With Your Anorexic - by Laura Collins

Just Tell Her to Stop – by Becky Henry

Running on Empty: A Diary of Anorexia and Recovery - by Carrie Arnold

A Girl Called Tim: Escape from an Eating Disorder Hell - by June Alexander

Boys Get Anorexia Too – by Jenny Langley

Hope with Eating Disorders: a self-help guide for parents, carers and friends of sufferers – by Lynn Crilly

Blogs

anorexiaboyrecovery.blogspot.co.uk – the blog which I began writing in January 2011

ed-bites.blogspot.co.uk – a super blog by Carrie Arnold, author and recovered former anorexia sufferer

www.lurassoapbox.net – a fabulous blog by Laura Collins, founder of FEAST and ATDT

charlotteschuntering.blogspot.co.uk – a blog by Charlotte, one of the ATDT members