

# **Anorexia Boy Recovery**

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

**Part 6 – 2016**

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

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## **IMPORTANT NOTE**

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

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

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

## Contents – linked to the individual posts

A SUMMARY OF OUR STORY IN THE LEAD UP TO TREATMENT .....	6
A BIG HUGE MASSIVE SNOTTY KIND OF BLOB.....	10
A MIXTURE OF EXCITEMENT AND SORROW .....	12
YAY! THE DOCTOR FROM LEEDS NHS HAS REPLIED TO MY EMAIL. ....	14
WHY IS LEEDS SWAPPING THE OLD TREATMENT MODELS FOR FBT? I CAN'T WAIT TO FIND OUT! ..	16
WHY I'D LIKE TO GO INTO BEN'S OLD SCHOOL TO TALK ABOUT EATING DISORDERS .....	18
GOING OVER AND BEYOND THE CALL OF DUTY... MASSIVELY. ....	20
MORE ABOUT WHY I AM DONATING ROYALTIES FROM MY BOOKS TO 'MAMA SHIRL'S' HOSPICE ..	22
SAY NO TO ONE OF THE MOST DANGEROUS FOOD LABELLING PROPOSALS TO DATE.....	23
SCOTTISH EATING DISORDER INTEREST GROUP (SEDIG) CARERS' CONFERENCE 2016 .....	25
AND WHILE WE'RE ON THE SUBJECT OF BMIs... ..	27
I'M FINALLY HAPPY WITH MY EDINBURGH TALK! .....	28
WHAT'S THE LATEST NEWS ABOUT FBT IN LEEDS / ENGLAND? .....	29
YET ANOTHER ANTI-OBESITY PROPOSAL THAT COULD BE LETHAL FOR EATING DISORDER VICTIMS..	30
SO HOW WAS MY MEETING WITH THE GUY FROM LEEDS CAMHS? .....	31
SO MUCH GOING ON AT THE MOMENT! .....	33
IT'S JUST LIFE... GOING ON AS NORMAL. GOOD NORMAL. JUST LIKE ANYONE ELSE.....	34
SEDIG CONFERENCE IN EDINBURGH WAS REALLY GOOD.....	35
PART #1 OF MY TALK: "EATING DISORDERS ARE NOT JUST A 'GIRL THING'" .....	36
PART #2 OF MY TALK: "EATING DISORDERS ARE NOT JUST A 'GIRL THING'" .....	38
PART #3 OF MY TALK: "EATING DISORDERS ARE NOT JUST A 'GIRL THING'" .....	39

A QUICK BREAK FROM THE TALK TRANSCRIPTS.....	41
PART #4 OF MY TALK: "EATING DISORDERS ARE NOT JUST A 'GIRL THING'" .....	43
WHAT DO MY ELBOW, BACK AND MY BRAIN HAVE IN COMMON?.....	45
BIG FLASHBACKS AT TEATIME.....	47
ONE GOOD THING THAT CAME OUT OF HIS EATING DISORDER .....	48
THIS'LL MAKE YOU GIGGLE .....	49
HOW PROUD AM I OF MY SON? .....	50
AN UPDATE FOR YOU ALL - AND THE FANTASTIC SWEATER!.....	51
IT'S DIFFICULT TO TALK ABOUT THE EFFECT OF THE EATING DISORDER YEARS ON ME.....	52
OVERWHELMED AND COMFORTED BY THE RESPONSE FROM OTHER PARENTS .....	55
MY C-PTSD: A CURIOUS MIX OF NUMBNESS AND ANXIETY.....	56
ONE SMALL STEP AT A TIME - PROGRESS!.....	59
A BLOG POST I NEVER PUBLISHED WHILE SUFFERING FROM NIGHTMARES.....	61
WHO WE WERE AND WHO WE ARE NOW .....	62
EXAMPLE OF A FLASHBACK NIGHTMARE-IN-DISGUISE.....	65
"WHAT YOU NEED TO DO TO FIX IT IS..." SAYS MY HUSBAND, HELPFULLY.....	66
TEXTBOOK CASE OF COMPLEX POST-TRAUMATIC STRESS DISORDER (C-PTSD).....	68
POST-EATING-DISORDER - A DEFINITE SHIFT FOR THE BETTER IN MY SON.....	69
AND NOW IT'S TIME TO FIX ME! .....	70
'PROCESSING' FIVE CRUCIAL MONTHS IN AUTUMN/WINTER 2009/10 .....	72
PROGRESS - SELF-HELP TO GET ME THROUGH THE PTSD .....	73
A WEEK OF MOVING MOUNTAINS!.....	75

THE THAW CONTINUES... POSITIVE NEWS!!.....	76
PROCESSING ALL THE ANGER USING EYE MOVEMENT DESENSITIZATION AND REPROCESSING (EMDR) THERAPY.....	77
AUTUMN 2009 - SOME NOTES I MADE AT THE TIME ABOUT MY SON'S WORSENING EATING DISORDER .....	79
AUTUMN 2009 - NOTES FOR THE PRIVATE PSYCHIATRIST .....	83
OKAY, SO THAT'S ENOUGH OF SIFTING THROUGH NOTES FROM 2009. LET'S LOOK AT THE ANGER.....	85
WHY RED ALERT MODE IS A THING OF THE PAST, PRESENT AND PERHAPS THE FUTURE, TOO. ....	87
ARE YOU A PARENT OR CARER LOOKING FOR SUPPORT FROM OTHER PARENTS OF YOUNG PEOPLE WITH EATING DISORDERS? .....	89
HAVING PROBLEMS GETTING YOUR EATING DISORDERED CHILD TO MAKE POSITIVE CHANGES? ....	93
REVISITING 'THE 12 DAYS OF ED (EATING DISORDER) CHRISTMAS' FROM 2011.....	94
ON THE FIRST DAY OF CHRISTMAS, THE ANOREXIA RECOVERY GAVE TO ME... "A CLOSE SHAVE WITH A TRAIN DOOR" ... ..	95
ON THE SECOND DAY OF CHRISTMAS, THE ANOREXIA RECOVERY GAVE TO ME... "TWO HEARTY BREAKFASTS" .....	96
ON THE THIRD DAY OF CHRISTMAS, THE ANOREXIA RECOVERY GAVE TO ME... "THREE NERDY HOUSEMATES" .....	97
ON THE FOURTH DAY OF CHRISTMAS, THE ANOREXIA RECOVERY GAVE TO ME... "FOUR LIFE-SAVING LETTERS: ATDT" .....	99
BOYS V GIRLS WHEN IT COMES TO 'OFFICIALLY' DIAGNOSING ANOREXIA.....	101
ON THE SIXTH DAY OF CHRISTMAS, THE ANOREXIA RECOVERY GAVE TO ME... "SIX MONTH WAITING LIST ANGST - HOPEFULLY PART-PROCESSED" ... ..	103
THE LETTER I'D LOVE TO SEND TO BEN'S CAMHS PSYCHIATRIST BUT OF COURSE NEVER WILL...	106
ON THE EIGHTH DAY OF CHRISTMAS, THE ANOREXIA RECOVERY GAVE TO ME... "EIGHT CHRISTMASSES SINCE OUR FIRST ED CHRISTMAS" .....	110

THE PROBLEM I HAD WITH GETTING MY SON TO EAT.....	113
TRIANGULATION - THE EATING DISORDER'S FAVOURITE STATE OF AFFAIRS.....	119
26 MONTHS OF EATING DISORDER TREATMENT. TOTAL WEIGHT GAINED? 1KG. ....	123
THE TRIANGULATION GETS WORSE.....	124
FEELING AS IF THE WHOLE WORLD IS AGAINST YOU AND YOUR GUT INSTINCT AS A PARENT .....	129
WHY FBT IS BEING ADOPTED IN SOME NHS AUTHORITIES AS FIRST LINE TREATMENT FOR YOUNG PEOPLE WITH ANOREXIA .....	132
LET'S TRY FBT FIRST - IT'S A NO-BRAINER! .....	135
REMEMBERING MY DEAR FRIEND SUE - THE LITTLE WOMAN WITH THE MASSIVE HEART .....	137
DOES ANYONE OUT THERE STILL BELIEVE THAT PARENTS CAUSE EATING DISORDERS?.....	141
EXCELLENT ADVICE ON HOW TO WEIGH AN EATING DISORDERED CHILD .....	142
DR JULIE O'TOOLE, I WANT TO SHAKE YOUR HAND ABOUT THE MISUSE OF BMIs FOR DIAGNOSING EATING DISORDERS .....	144
SURVIVING CHRISTMAS / THE HOLIDAYS WHEN YOUR SON OR DAUGHTER HAS AN EATING DISORDER .....	146
BOYS GET EATING DISORDERS TOO, YOU KNOW!! .....	147
A NOT SO 'SILENT NIGHT' (OR DAY). WOOHOO, IT'S BEN'S BIRTHDAY!.....	148
A TRICKY FEW DAYS THANKS TO MY C-PTSD.....	149

JANUARY 2016

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

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

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

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

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

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

Before long the puppy fat disappeared to be replaced with an awesome athletic physique. Being good at sport at a “sporty school” also carried a distinct kudos. Soon Ben was one of the most popular boys in his peer group and he revelled in the change. He was good at other sports, too. In the summer

of 2008 – one year before the eating disorder began to manifest itself – he and his dad did the Coast2Coast cycle ride across Northern England, up and down some of the most challenging terrain in the country. Ben was a star on the athletics field and in the cross country running team. In fact I think the only sport he wasn't good at was cricket.

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

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

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

Getting a "six pack" became Ben's Number One goal. Back in the UK he joined a gym and went seven days a week supplemented by yet more gruelling runs plus hundreds of daily sit-ups, press-ups and crunches. Meanwhile he devised even more low calorie, low fat meals. Cooking became a passion. But

at the same time, eating was getting more ritualistic, for example chopping fruit into tiny pieces before carefully arranging on a plate. He was also avoiding certain foods – more foods than he was actually eating.

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

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

It wasn't until late September that I was prompted to take him to the doctor. I simply didn't know what we were dealing with. Was it just a teenage phase or was it something more sinister? Worse – because sometimes Ben would eat and behave normally – was it simply my imagination?

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

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

It took a while for the penny to drop – that Ben was developing an eating disorder. My husband and I were horrified. We didn't know what to do or where to turn. In the end it was the school nurse who told me about CAMHS

(the NHS Child and Adolescent Mental Health Services). So we went back to the GP and insisted Ben was referred right away.

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

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

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

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

Of course I'm not a clinician or an expert; I am just an ordinary mum writing about the day to day experiences of living with a teenage boy recovering from anorexia. But when you suddenly find yourself on this devastating journey, it can be so reassuring to know that others have been along this road too. To know what they went through, to know what signs to watch out for and to

know what worked. And, importantly, during those many false summits and disappointments, to know how they found the strength to continue fighting as they helped to guide their child towards recovery. This is why I write my blog.

But the problem with my blog is that, by the end of 2012, it was getting extremely long. I have no idea how many posts there are in total which makes it difficult for other families to plough through everything. Blogs aren't like books. You can't just read through them from start to finish and you can't easily refer back to something you found particularly helpful or relevant. You're clicking here, there and everywhere. Worse, much of the earlier information – for example from 2011 - risks getting overlooked altogether. And there's some important stuff in there! I know, because I've had so much positive and encouraging feedback from my blog followers.

I should mention here that at the start of 2016 I'd been battling with Post Traumatic Stress Disorder for some time, something that had come about as a result of all those days and months of dealing with my son's eating disorder. As the New Year began, I was receiving treatment for this; by the end of the year I was *still* receiving treatment! So you will find that many of my 2016 blog posts talk about my own journey to recovery – from PTSD.

I hope this PDF proves useful to you.

Best wishes,

Bev Mattocks, December 2016.

**Sunday, 3 January 2016**

**A big huge massive snotty kind of blob**

No, not me. I'm describing my anger, as suggested by my wonderful therapist (who sadly I will have to leave within the next week or so). I still have a heck of

a lot of anger inside me, primarily concerning the way I had to fight CAMHS so very much throughout the 26 months Ben was receiving treatment for his eating disorder. There are so many, many reasons why I'm still angry – but of course much of it is about the past, about things I can't do anything about now.

My therapist asked me to externalise my anger and imagine it sitting on the chair in front of us. How big is it? What shape? What colour? What is it made of? What could you do to make it smaller – to shrink it?

What came into my mind was a huge massive snotty kind of blob, a bilious green colour tinged with muddy brown - wobbly like a thick gel.

I tried various techniques like imagining it discarded in the desert where it would dry out and get smaller. But unfortunately the anger is still very much here.

It has emerged again over the last few days as I've been putting together the script for my talk at the Edinburgh carers' conference in February.

In this talk I will be speaking about how Ben's weight initially went up as he began treatment with CAMHS, after I'd asked them to produce an eating plan (which became known as "Mums Eating Plan").

I will talk about how the eating plan was scrapped after two or three months (I had very little support in implementing it); it was felt that Ben had arrived at a stage where he should take control of his own eating.

As Ben took control of his eating, his weight headed south.

Then, 12 months after he began treatment, he arrived at his lowest weight and only began to increase again once he and I had introduced the contract (see tab at the top of blog for more info).

The result was that, when Ben was discharged from eating disorder treatment after being with CAMHS for 26 months, his weight was exactly the same as when he started.

I have never really understood why this was allowed to happen during what was essentially treatment to help Ben recover from an eating disorder. Especially as I was forever pointing it out to them – the fact that my son was losing weight, week on week.

Oh, occasionally he would gain point-something of a kilogram, but then he would promptly lose it again once CAMHS weighed him which they did at the beginning of every session (in front of him, never "blind"). The fact is that over the period between withdrawing "Mums Eating Plan" and introducing the contract, Ben's weight went down. And it went down over a period of eight months, which is a heck of a long period.

This made me angry at the time and has made me angry ever since.

My anger maybe a huge massive snotty kind of blob that sits there on the chair opposite me, wobbling away, but it's still there – for better or for worse..

**Monday, 4 January 2016**

**A mixture of excitement and sorrow**

**Excitement** to see that my local NHS has seen the light, so to speak, and appears to be pioneering FBT (Family Based Treatment) for adolescents with eating disorders in England. **Sorrow** because we missed out on this fantastic opportunity. But that's water under the bridge; nothing can be done to change the past. However, hopefully, the future in Leeds looks BRILLIANT. Here is the email I've just fired off to the person in charge:

Dear Dr XXXXXX

I'm not sure if you're the right person for me to contact about the following and if not I would be grateful if you could forward it on.

My son was treated by CAMHS in Leeds north-east between 2010 and 2012, for anorexia nervosa. Since then I've become an advocate for evidence-based treatment for eating disorders in adolescence, and especially in males.

I'm well known within the global F.E.A.S.T. community (Families Empowered and Supporting Treatment of Eating Disorders), blog about the subject of boys with eating disorders and have written a couple of books. I also speak regularly at carers' conferences (e.g. at the Maudsley in London); I will be speaking at a carers' conference in Edinburgh in February.

I've been involved in conferences where Prof James Lock has spoken about FBT being implemented across Scotland and, of course, was eager to see the same kind of thing happening in England.

The purpose of this email is because I was looking around the Internet and came across the document "Leeds Local Transformation Plan for Children and Young People's Mental Health and Well-Being, November 2015" and was especially drawn to section 8 "A Community Eating Disorder Service for Children and Young People" where it states that plans are in place to make Leeds "one of the first areas in the UK to adopt Family Based Treatment (FBT) as the main treatment modality for Anorexia Nervosa".

With my son having received treatment for his eating disorder in Leeds, I was really excited to see this development – and I wondered whether it would be at all possible to meet with you (or if not you, someone else who is involved in implementing FBT across Leeds) for 20 minutes or so to talk about what Leeds is proposing.

If possible I would like to do this before I go to Edinburgh at the end of February because I would like to mention it at the end of my talk. The Edinburgh conference is focusing on males with eating disorders and I'm there to talk about my son's experience with anorexia and his journey through to

recovery

I would love to talk about how Leeds is following in the footsteps of what I understand is going on in parts (all?) of Scotland at the moment and talk about how thrilled I am to see this development in Leeds.

I look forward to hopefully meeting with you soon.

Many thanks,

**Tuesday, 5 January 2016**

**Yay! The doctor from Leeds NHS has replied to my email.**

And this is what she said: "It is lovely to hear from you and of your interest in the new children's community eating disorder service soon to be established in Leeds. It would be very useful to involve you in our local service developments as we recognise that the involvement of young people and their parents is integral to the success of any new service plans. I've copied in my colleague who is the clinician leading the service model developments; I think he would be ideal to talk through our Leeds plans with as he has had a key role in identifying the evidence-base treatment to include in the service model." This is so exciting...

Following my revelations, there has been some debate online in the various eating disorder communities of which I am part, queries like will this be true FBT? Where did the Leeds professionals get their training? Was it via the Dr James Lock initiative from the States (described following my visit to the conference in Glasgow a couple of years back – see my 2014 blog post about the feedback from NHS greater Glasgow and Clyde about what's going on in their part of Scotland)? How is Leeds getting its funding?

I, myself, also have lots of questions. For instance I will be interested to hear how the existing mental health clinicians have reacted to the new FBT as a treatment that appears to be diametrically opposite to the eating disorder treatment they have been delivering to date (at least in our experience of treatment for eating disorders in Leeds through CAMHS, of course I can't speak for any other families in the area).

From what I can see from this document, it looks as if Leeds is establishing a dedicated eating disorder service for adolescents (presumably outpatients in the case of the new FBT, because FBT attempts to treat patients as outpatients within a family setting as opposed to in hospital) rather than the multidisciplinary CAMHS service. But this is something I will be asking them about.

It's really is exciting that this is happening in Leeds, the city where my son received his treatment for anorexia, starting back in 2009. As you know, throughout his treatment I pushed to be more involved, as a vital part of the treatment team rather than "just Ben's mum". Or worse, someone who felt they were being regarded as part of the problem rather than part of the solution. (Note: this changed as Ben's treatment progressed and I was accepted, more and more, as an integral part of the "solution", primarily after we introduced our Contract – see tab at top of blog for more information.)

And I would have given my right arm for us to have had support with Ben's eating. Doing this alone was beyond a nightmare. I won't describe it again here, you can find everything in my book.

Also, right from the start, my instincts – and later the information I discovered on the FEAST website and the Around the Dinner Table forum – cried out to push for weight gain/restoration and eating first and foremost rather than wasting valuable time (in my opinion) talking about the courses

and – later – allowing Ben to lose weight for so very long during treatment which was supposed to do the opposite. Plus, the fact that there was never any emphasis on getting Ben back to his pre-anorexia weight.

I tend to think that, in cases where FBT proves to be working, parents will go through trauma, yes, but only with the usual battles involved around trying to get their child to eat and all the general unpleasantness and stress of living with a young person who is suffering from an eating disorder, rather than the constant feeling that they are fighting the "status quo" at the same time, which of course adds immensely to their stress, leading to mental health problems of their own, viz the problems I've been having over the last couple of years. (I really feel for my American friends who have to fight the insurance companies on top of everything, at least in the UK we don't have to do that.)

Most important of all, in cases where FBT proves to be working for the patient, evidence shows that they have a far greater chance of recovery and of sustained recovery, and that this recovery can take place much faster than with traditional models for eating disorder treatment. I won't quote the facts and figures here, my dear friend Eva Musby does that admirably on this webpage where she also describes all the difference methods of eating disorder treatment plus evidence or otherwise on their effectiveness.

**Friday, 15 January 2016**

**Why is Leeds swapping the old treatment models for FBT? I can't wait to find out!**

I'm meeting with the psychiatrist guy from Leeds NHS a week on Wednesday and I can't wait to find out what prompted Leeds to make the changes and move from multi-disciplinary CAMHS treatment for teenage eating disorders to a specialist eating disorders service for adolescents - and to adopt the

evidence-based FBT (Family Based Therapy / Treatment) instead of the methods they were using when my son, Ben, was sick with anorexia.

Just think... All those months when I was pushing for FBT-style treatment as I read up about it on the FEAST website and the Around the Dinner Table forum, but felt as if I was banging my head against a brick wall as Ben was whisked off for yet another individual therapy session with his psychiatrist.

All those months when I was pushing for weight gain, the balanced diet and weight restoration while they were pushing for the "talking treatment", feeling that Ben's illness wasn't that serious. I remember the day that one of them said, "It's not as if he's going to drop down dead tomorrow". And meanwhile Ben's weight went down and down.

All those months when I was trying to convince them that Ben had lost a tremendous amount of weight. After all, he'd been a big rugby player, so it wasn't surprising that his BMI was still "okay". Unfortunately they took this to mean that Ben was pretty much OK, too. And of course Ben took this to mean that he didn't need to eat more or put on any weight. Worse, that he'd been right in thinking that his pre-eating disorder physique was "fat".

I'm not saying that none of this would have happened if we'd had access to FBT. I'm not saying that FBT would have been like the magic bullet that got Ben fully weight-restored and recovered from his anorexia. I'm not even saying that FBT would definitely have worked for Ben; it doesn't work for everyone.

But it would have meant that I probably wouldn't have been fighting CAMHS all those months at the same time as fighting the highly-resistant eating disorder. That in itself took enough energy without the extra conflict on top.

It would definitely have meant that we were working together as a team, on the same side. Which is how it should be.

And, hopefully, I would have had more support in my drive to get Ben to eat

and put on weight.

Quite simply I would have liked to have given FBT a go.

It might just have worked.

So I'll be interested to find out what made Leeds NHS change its mind and swap the old methods for the new ones.

All that fighting for what I believed was right - and I was probably right all along!

**Saturday, 16 January 2016**

### **Why I'd like to go into Ben's old school to talk about eating disorders**

When my son Ben fell sick with anorexia, back in 2009 when he was 15, his school was amazingly supportive. By early 2010 he was finding it increasingly impossible to be in school. He couldn't bear being anywhere near his peers, he was regularly breaking down in lessons and in the school dining hall, he was behaving irrationally and dangerously, he was exercising like mad at any opportunity and he was spending much of his time in the school medical centre rather than in lessons. And, of course, he was eating minimally throughout the day resulting in more and more weight loss.

Ben's dad and I figured that we could get Ben to eat more if he was at home being monitored through breakfast, snacks, lunch and the evening meal. By this time I was having to sit with him whenever he was eating; I couldn't leave him alone.

We also figured that Ben would be calmer outside the school environment. By this stage actually getting him to school each day was a nightmare and he'd rarely stay there for a full day. I was always being called into the school medical centre to pick him up because he'd broken down in lessons, at lunch or

even before he got to registration in the morning.

Finally, we figured that Ben would get more work done if he was at home rather than at school. After all, he was spending much of his time in the school medical centre rather than in lessons. And, in lessons, he wasn't learning anything; his mind was whirring around with calculations on how much exercise he'd need to do to wear off the salad he'd just eaten at school dinners.

So one day we met with the Headmaster to agree a kind of home-schooling regime until Ben felt able to return to school. It turned out to be very, very successful.

Everyone at the school was incredibly supportive. Ben studied at home, even sat his GCSE exams in private, away from his peers, got good grades and continued into the Sixth Form, still mainly studying from home. The school nurse especially was the best support you could ever have (more about that in another post).

Yesterday I was on the school website, reading through a letter to parents written by the new Headmaster, talking about the importance of mental health issues within the school. He says:

... it is perhaps no wonder that 20 per cent of young people in Britain are said to experience a mental health problem in any given year, whilst teenage mental health services are buckling under the strain. In response to these frightening statistics, the school has been working hard to educate its staff over adolescent mental health and wellbeing issues...

So this morning I've put together a letter which I've emailed to the Headmaster's secretary asking if it might help if I came into the school to talk to staff or pupils about eating disorders, especially in boys. I also pointed out that I am meeting with the psychiatrist in charge of rolling out the brand new

evidence-based treatment model for eating disorders in Leeds - FBT (Family Based Treatment). So I could talk about this and how families can access treatment, etc.

Hopefully she will get back to me with positive news!

**Saturday, 16 January 2016**

**Going over and beyond the call of duty... massively.**

As you will know if you've read my book, *Please eat...: A mother's struggle to free her teenage son from anorexia*, "Sheila" the school nurse was one of the most supportive people throughout my teenage son's battle with anorexia. I can't begin to describe how supportive she was, right from the start. It was she who first told me about CAMHS, talked to me about eating disorders and told me to get a referral for eating disorder treatment. It was she who provided a safe haven for my son when he couldn't bear to be in school or had broken down for some reason, which he did on most days during the winter of 2009/10.

It was she who talked with me over the phone or in person virtually every day, always willing to listen and put aside time for us regardless of how busy



she was. It was she who handed me tissue after tissue when I broke down in the school medical centre when the stress and strain got too much for me. It was she who hugged me when I needed to know someone

understood and cared. She even took me out for lunch on one occasion and invited me round to her house for lunch, just so I could vent and lean on

someone's shoulder.

To say that "Sheila" (whose real name is Sister Shirley Crawford of Woodhouse Grove School, Bradford) went over and beyond the call of duty as a school nurse is an understatement. She was an absolute saint and I don't know what I would have done without her.

And while she was supporting our family through our years of hell, she was supporting other families at the school through their struggles, too.

What a woman.

Shirley and I are still very much in touch. She is also in touch with my son, always eager to know how he is getting along.

Anyway, last night she was back at the school doing a talk about her volunteer work in Uganda. She used to devote the school summer holidays to flying out to Northern Uganda to work with child and teenage victims of the war.

Then, in 2012, she decided that this was something that was so important that she couldn't simply break off and fly back to the UK at the end of August, leaving vulnerable youngsters who had come to depend on her.

So she sold her house and car, handed in her notice at school and moved to a small remote village in Northern Uganda to work full time with these youngsters. She relies totally on donations to do her work. She doesn't get paid a penny.

Woodhouse Grove School has been incredibly supportive to Shirley, raising money and getting her to speak about her life in Uganda to pupils and staff. (A delegation of senior pupils is going out there to help Shirley during their holidays this summer.) And twice a year Shirley comes into the school to talk at an evening event, which is why I was at the school last night (along with my son, my mum and my husband).

Shirley's project for 2016 is to continue with the foundation of a hospice for children with cancer in an area where there is zero medical support for this illness and where, as a result, 80% of children die. She's retrained so she can offer nursing support as well as the oodles of love that she doles out to these kids who know her as "Mama Shirls".

Shirley is looking for people or businesses to "sponsor a bed" in this new hospice, so this year I have decided to donate the royalties from my books for this purpose.

So in 2016 I will be "Turning Books into Beds" - and my ex art college pal, cartoonist Peter Coupe, is kindly creating an image for me to promote this message here in the blog and on Facebook, etc..

**Sunday, 17 January 2016**

### **More about why I am donating royalties from my books to 'Mama Shirl's' hospice**

In a nutshell, Shirley (the school nurse I call 'Sheila' in my book *Please eat...: A mother's struggle to free her teenage son from anorexia*), gave so much to Ben and me during his long battle with anorexia in terms of support, love and someone I could trust to take care of Ben when he was at school that I wanted to give something back.

And when I heard her speak on Friday about her voluntary work in Uganda I had a brainwave...

The good thing about book royalties (the profits I get from *Please eat...* and *When anorexia came to visit* after costs) is that once you've written and published the books you don't have to do anything to get them.

Apart from hoping that people buy the books, of course.

I'm not saying that I make a fortune from my books about teenagers with

eating disorders. Far from it. But, with the support of people who generously purchase my books in 2016, I will hopefully make enough to sponsor a bed - Bev's Bed - in the hospice which Shirley is busy setting up for children and young people with cancer near her village in Uganda.

A little bit of money goes a long, long way over there...

As Shirley explained on Friday, Northern Uganda (where she lives) has no access to cancer treatment. People have to go all the way to Kampala to get scanned and even then it's just one machine, and an antique one at that.

Cancer care, too, is pretty much non-existent, especially where she lives.

As a result, Shirley says, eight out of ten children die, often needlessly and in appalling agony.

So Shirley is busy setting up a small hospice for children with cancer. She has also undergone some further training to help her provide specialist nursing care to these children.

Everything Shirley does in Uganda is funded by donations from generous people in the UK. So in 2016 my books will be helping double the number of people: the families that purchase the books on eating disorders - and the children in that Ugandan hospice cared for by the wonderful, loving woman they call 'Mama Shirls'!

**Sunday, 17 January 2016**

**Say NO to one of the most dangerous food labelling proposals to date**

According to the BBC website and the Royal Society of Public Health (RSPH): "Labels should be added to food and drink to show how much activity would be needed to burn off the calories consumed, the Royal Society for Public Health says."

When I told my son Ben (who had a lethal exercise addiction when he was sick with anorexia) about this shocking new proposal, he said:

*"If this had been around when I had my eating disorder it would have killed me, and I mean that. I saw it on the News this morning but didn't tell you, mum, because I didn't want to upset you."*

Basically it would have given him the 'green light' to exercise even more than he was doing already. And, if you've read my book *Please eat...: A mother's struggle to free her teenage son from anorexia*, you will know that his exercise addiction went through the roof. Here's the bit where he 'confesses' his exercise addiction to CAMHS (and really the following is just the tip of the iceberg...):

*Ever since the October heart scare Ben has been banned from doing PE at school. Unfortunately he's exercising at home to compensate and to ensure he doesn't "put on massive amounts of weight". It's a kind of purge, almost like a sufferer of bulimia might vomit to control their weight.*

*"Walk me through a typical day's exercising," says Linda as she reaches for a pen and paper.*

*Just when we think he's listed all the "100 crunches, 100 sit-ups and 100 press-ups" for any one day he interrupts with "I haven't finished yet!" Not once, but several times. School days differ from home days, weekends from week days. Ben is exercising from morning to night.*

*By the time he catches the school bus in the morning he's already done 100 crunches and sit-ups during the 60 minutes we rush to get up, showered, breakfasted and out of the house. Meanwhile at school he deliberately makes himself late for lessons so he can run from classroom to classroom.*

*One reason he's still only at school part-time is because he can't handle the thought of "sitting around doing nothing" for the afternoon as well as the*

*morning. When he gets home at lunchtime he pushes himself to do more crunches and repeats these throughout the afternoon - and before and after the evening meal. In addition he's still doing weight sessions most days and going for a couple of runs every week. Meanwhile he can't sleep because his mind is constantly racing as he tries to balance input and output.*

*The bland CAMHS consulting room feels like a bizarre confessional as Ben confesses his entire exercise regime and Linda's piece of paper becomes several pages. Our very urgent task is to find a way of breaking the cycle. It's a Big Ask. I sigh and look at Linda for an answer.*

**Saturday, 23 January 2016**

### **Scottish Eating Disorder Interest Group (SEDIG) Carers' Conference 2016**

I may have mentioned this already, but I'm speaking at the Scottish Eating Disorder Interest Group (SEDIG) Carers' Conference 2016 at the end of next month (Saturday 27th February). The title of my talk will be "Eating disorders aren't just a 'girl thing'"; indeed the main thrust of the conference, I believe, will be about eating disorders in males and in particular eating disorders and anorexia in teenage boys.

The angle I'm taking for my talk is that not only did it take some time for my husband Paul and I to recognise that our son was developing an eating disorder, because we had no idea that boys got eating disorders just like girls do, but that throughout the whole process – from GP referral through to CAMHS treatment and discharge from eating disorder therapy – our son's case wasn't seen as terribly serious or urgent.

I believe the reason for this was that before he fell sick with anorexia his BMI was pretty high; remember he was a 'prop' in the school rugby team. It

was mainly muscle, but undoubtedly it would have put his BMI pretty high up on the BMI scale (because BMI doesn't distinguish between fat, muscle or bone). Indeed I'm fairly sure that many fit and healthy rugby players and other athletes would be considered as "obese" if you applied the rigid BMI scale to them.

So even though Ben had probably lost around a quarter of his bodyweight, increasing to close to a third as his weight dropped to its lowest level halfway through the eating disorder treatment, he was still hovering around or just below the "healthy" level for a BMI.

And yet, as you will know from reading this blog, his anorexia was raging. The list of eating disorder symptoms he was exhibiting was as long as your arm.

So, building on our story, I will be talking about why I believe that there should be less emphasis on BMI as an indicator of seriousness of an eating disorder and of recovery. And also relying on BMI for diagnosis, because boys like Ben may never even reach the low BMI required to diagnose their eating disorder as anorexia nervosa.

I believe that relying solely on BMI as an indicator of seriousness could be dangerous. For example Ben was hospitalised twice with a dangerously low pulse rate – and a low pulse rate is known to be one of the complications of an eating disorder like anorexia. But because Ben didn't look "too bad" to someone that hadn't seen him as a big rugby player and his BMI was relatively OK, his eating disorder and low pulse rate weren't taken as seriously as they should have been.

Unfortunately I won't be able to go into massive detail about this in my talk, I only have 25 minutes or so and within this time I have to describe our story as well!

**Saturday, 23 January 2016**

**And while we're on the subject of BMIs...**

My sister pointed out this article about a friend of hers whose healthy, sporty son was sent home with a letter from school telling his mum that he was overweight. This especially incensed the boy's mother because she herself had been a victim of anorexia as a young woman and understood more than most people about the dangers of the many things that can trigger an eating disorder.

There's a massive conflict at the moment between the drive to do something about the escalating levels of obesity in the UK and the danger that warnings/solutions could trigger the wrong sort of people to lose weight i.e. those predisposed to developing an eating disorder.

The thing is, none of the measures which are being rolled out in a bid to combat obesity seems to be doing any good. Obesity levels are on the rise not the decline, and if these measures are influencing anyone, they are probably influencing young people that wrongly believe they need to lose weight.

I know that teaching in school about healthy eating, BMIs, etc, was one of the many different things that added up to trigger my sons descent into anorexia. He was a big burly rugby player, as you know, and as a result his BMI was pretty high. So when they came to calculate their BMI in a PSHE lesson at school, the alarm bells went off inside Ben's head – his BMI was "far too high" according to the charts.

BMI was created by Belgian statistician Adolphe Quetelet around 1830 as a measure of obesity and adopted by the British government in an effort to promote healthy eating.

That's quite a long time ago.

It's high time it was revised to take into account the vastly varying biological makeup of human beings, not to mention genetics, and the difference between fat, muscle and bone – none of which the BMI scale takes into account.

Yet at the beginning of virtually every CAMHS session after my son was weighed, the CAMHS nurse got out a little calculation wheel, twiddled it around and kindly let my son know what his current BMI was.

And of course because Ben's BMI was usually hovering around the so-called "healthy" range, Ben took this to mean that he was correct in thinking that he was fat – and that there was no need at all for him to put on any weight.

To say that these were the wrong messages is an understatement...

**Tuesday, 26 January 2016**

**I'm finally happy with my Edinburgh talk!**

For better or for worse, I'm a terrible micromanager. And you wouldn't believe the tweaking that's gone into my script and PowerPoint presentation for the talk I'm doing at the Scottish Eating Disorder Interest Group (SEDIG) Carers' Conference 2016 at the end of next month (Saturday 27th February). But I think I finally sorted it out. I think the main problem with my talk (which is called "Eating disorders aren't just a 'girl thing'") is that I've got such a massive story that condensing it into just 25 or 30 minutes has been a bit tricky, to say the least!

I'm not just talking about my son's descent into and recovery from anorexia, I'm also talking about how he's getting along now and also looking at what helped and what didn't on the road to his recovery from anorexia. And all in 25

or 30 minutes!

So it's taken quite a bit of shoehorning and tweaking to get it just right.

Very soon I'll be posting a transcript of my talk on this blog.

I've got this great dictation software on my computer where you just talk into a microphone and it types it up on the screen, making it a doddle to read my notes and – hey presto! – my talk will appear right here!

FEBRUARY 2016

**Monday, 1 February 2016**

**What's the latest news about FBT in Leeds / England?**

That's what I'll be asking the guy who's in charge of rolling out FBT (Family Based Therapy) for adolescent eating disorder patients in Leeds when I meet with him on Wednesday. My home city of Leeds is claiming to be a 'pioneer' in the rolling out of FBT in England and so I can't wait to hear what he has to say about plans for FBT being implemented in other parts of England. Already it's being implemented in Scotland - and England was lagging behind. I'm not sure what the situation is in Wales or Northern Ireland.

According to studies and trials, FBT as an outpatient treatment model for adolescents with eating disorders such as anorexia has a higher and more sustained success rate than other treatment models for anorexia in teenagers and younger children. Of course it isn't successful in every case; eating disorders are notoriously complex illnesses and very difficult to treat. Also, some individuals may not be suitable for FBT for whatever reason. So I will also

be asking him what will happen in these cases.

I also want to know more about Leeds' plans to move away from the multi-disciplinary CAMHS (Child and Adolescent Mental Health Services) service when it comes to treating eating disorders and into a more specialised adolescent eating disorders service.

So watch this space... I only have one hour with him on Wednesday and he only works Wednesdays at the moment! So I really appreciate him sparing the time to talk with me.

**Tuesday, 2 February 2016**

### **Yet another anti-obesity proposal that could be lethal for eating disorder victims**

A major reason why I believe that my son's eating disorder wasn't taken as seriously as it should have been by clinicians from the GP upwards is because his BMI was still within the so-called "normal" range, despite the fact that he'd lost about a quarter of his original body weight.

Just as damaging, was the fact that my son's BMI was calculated in front of him at virtually every CAMHS session. So he was constantly being given the message that he was kind of okay and didn't need to put on much, if any, weight. Because if he did put on weight, he'd be getting "too fat".

So, for eating disorder victims and especially males with eating disorders whose original BMIs can often be higher than a female's (for example, due to sports activities and carrying extra muscle), I believe that using BMI as an indicator of seriousness and of recovery can be unhelpful to say the least. Or indeed using the BMI scale at all.

Let's face it, BMI is a flawed and antiquated formula introduced almost 200 years ago, and which doesn't differentiate between fat and lean tissue

(muscle) content.

So I was concerned to hear that there is a proposal to pay GPs to regularly measure their patients BMIs. As I have said before, this kind of measure can be lethal in the wrong hands i.e. with people who may be predisposed to developing an eating disorder or who already have one.

To be honest, none of these anti-obesity measures seem to make any difference to the rising levels of obesity in the UK. And, in my opinion, they tend to be adopted by people that don't need to, or shouldn't, lose weight.

I really think that paying GPs to measure patients BMIs could cause more problems than it solves – and that it could catapult certain individuals into a dangerous and destructive eating disorder.

**Wednesday, 3 February 2016**

### **So how was my meeting with the guy from Leeds CAMHS?**

My home city of Leeds is one of the first areas in England which is pioneering FBT (Family Based Therapy) as the primary model for treating adolescents with eating disorders in the city. It all goes back to Chancellor Of The Exchequer George Osborne's Autumn Statement in 2014 when he promised an extra £2 billion a year of additional funding for the NHS across various services including mental health. Leeds was one of the authorities that applied for funding and they were successful in their bid. So some of this funding is being used to roll out a new service for adolescents with eating disorders within the Leeds postcode area.

Hopefully, the new service will "go live" at some point this year, but I'm not sure when. Meanwhile Leeds is busy recruiting and training people, supported by Dr James Lock and his team at Stanford University in the States.

Leeds is adopting FBT because of its higher success rate when compared with other models of treatment for adolescent eating disorders. Central to this decision is the simple fact that Leeds wants to ensure that young people get diagnosed and treated quicker, and hopefully recover faster and with a more sustainable recovery, so they can get on with their lives.

So in line with this, hopefully the pathway into outpatient treatment (because FBT therapy for eating disorders as an outpatient-based treatment) will be simpler and quicker than it was for us. And, hopefully it will require fewer sessions overall. Plus, it will provide much more support for the family, especially when it comes to getting the young person to eat. Also, hopefully, the service will be much more specialised towards eating disorders as opposed to the multidisciplinary CAMHS (Child and Adolescent Mental Health Services).

Of course eating disorders are notoriously difficult to treat – and Leeds recognises that FBT might not be suitable for everyone. So other treatment models will still be available for these families.

We talked about a lot more, too, but I can't really repeat it here as it is still very much a "work in progress". The above is just an overall summary.

But all in all this is excellent news for adolescents with eating disorders in Leeds – and we're talking about anorexia-type eating disorders here, because I understand that eating disorders like bulimia aren't necessarily treated using the FBT model. It's also good news for England in general as, hopefully, other areas follow suit, although I have no information about whether or not other areas have plans to do this.

**Wednesday, 10 February 2016**

## **So much going on at the moment!**

If you look back on my blog posts over the last couple of years, you'll notice that they were a bit thin on the ground for a while. That was because of the Post-Traumatic Stress Disorder, etc which suddenly hit me about 27 months ago and which meant that I had to take a break from anything to do with eating disorders because I found it very triggering.

Thanks to the fourth set of therapy sessions (care of the NHS!), I seem to have finally come out the other end. I still have issues with anxiety, but am pretty much able to manage this using all the various CBT/mindfulness tools that I've learned along the way. Unfortunately I haven't been able to fix the nightmares or sleep problems, which means that I do get sleepy during the daytime, but hopefully this will sort itself out before too long. Hopefully...

It's all meant that I've gradually been able to ease myself back into the world of eating disorders. My therapist wondered whether this was going to be helpful for me or whether I ought to pursue a completely different path in "my life after Ben's eating disorder". But I seem to have drifted naturally back into the world of eating disorders, starting with saying "yes" to the invitation to speak at the SEDIG conference in two weeks and lately returning to the Around the Dinner Table forum to offer advice to other families of boys with eating disorders.

Oh, and I've been blogging here of course.

I've also been to see one of the senior staff at my son's old school (yesterday) to discuss ways in which my experience might prove useful in assisting staff to identify the warning signs in boys with eating disorders and to share my experience of how helpful and supportive the school was when my son was sick with anorexia - what I found particularly helpful, etc. So very soon I'll be putting together the bones of a talk for staff at the school.

And today I'm going to Sheffield to meet up with Ben and take him out for lunch. Not because I'm particularly worried about him or he needs to see me, but purely and simply because he's left some stuff at home and needs me to take it down there! And, unlike the first two years at university, he is far too busy to bother coming home at weekends.

Having said this it's always a good opportunity to keep an eye on him and check that he still eating properly!

**Tuesday, 23 February 2016**

**It's just life... going on as normal. Good normal. Just like anyone else.**

Over this last week, my son and I have gone through a heck of a lot. Not to do with his (now thankfully gone) eating disorder, but to do with a GIRL. Let me explain...

Recently he's met this girl and he really likes her. A lot. But last weekend she was behaving a little off-hand and he was convinced that she was trying to dump him. So we went through all of that... all the usual heartbreak plus the added worry (in my mind) that something like this could ping him into relapse – or worse. And of course no one likes to see their child upset, eating disorder or no eating disorder.

But the story so far is that she's been poorly, which is why she hasn't contacted him. Apparently. Hopefully. Or not hopefully, actually, because it's his final year on his university degree and so (in my mind) he'd be better off without the hassle and distraction of romance...

Anyway, the good news is that, despite the upset, he's been behaving just like any normal young man. In fact he has been eating more, not less. He's also been planning his future – doing a master's degree next year, a PhD the

following year and a career as, hopefully, a university lecturer or a professor. Or even a TV historian.

Meanwhile his social group is expanding: he has friends at home, friends at uni and new friends he's made through this girlfriend. Remember the days



when the eating disorder isolated him from EVERYONE but his family? And how tough it was for him to forge a new life with new friends?

He came home at the weekend and what I saw was a completely normal young man without any hint of our old enemy, the eating

disorder. And that was before he discovered that this girl had been unwell and not ignoring him.

I've no idea whether or not the romance is present or past tense by today, but whatever it is I have every confidence that he will just continue to get on with his life and that my natural worries that any upset might set off a relapse into the eating disorder are unfounded.

So that, in itself, is good news.

And as I said to him at the weekend: "Life is so much better without the eating disorder, isn't it?"

MARCH 2016

**Tuesday, 1 March 2016**

**SEDIG Conference in Edinburgh was really good**

On Saturday afternoon I spoke at the SEDIG (Scottish Eating Disorders

Interest Group) conference in Edinburgh about my family's experience of getting my son through anorexia. It was great to see so many dedicated people together from across Scotland – mainly parents who are still struggling with an eating disorder in the family but also one or two clinicians, and the speakers, chaired by the amazing Dr Jane Morris, Consultant Psychiatrist, Eden Unit, Aberdeen.

Everyone who spoke at the conference is doing an incredible job to raise awareness of the issue of eating disorders – and in the afternoon the focus was primarily on eating disorders in males, so it was great to see Sam Thomas from Men Get Eating Disorders Too and Paul Donald from Men and Boys Eating Disorders and Exercise Service (MBEEDS).

I think, because it's a long time since I've told my story on this blog – probably back in 2011 when I began writing it – I'll do a few posts based on what I said at the conference.

So watch this space...

**Tuesday, 1 March 2016**

**Part #1 of my talk: "Eating disorders are not just a 'girl thing'"**

It all started in the spring of 2009 when our son Ben was 15. He'd been quite chubby at primary school and had been bullied as a result.

But at secondary school he got into rugby and developed a new leaner, more muscly physique which he was very proud of.

And because he was the "guy in the rugby team" he was very popular – he had a great group of friends. So during those first two years at secondary school things were going from strength to strength. Life was pretty normal.

But by early 2009 Ben was getting fed up with rugby. However he was

worried that if he stopped, he'd get fat again, lose his new physique and stop being popular. He was worried that he would be bullied again, like he'd been at primary school.

The trouble was, Ben loved his food and he didn't really want to cut back on quantity.

So he had a bright idea...

He decided to swap his normal food for diet options so he could do less sport without putting on any weight.

It seemed like perfect solution!

But of course it didn't work out like that. Instead of doing less sport, he began to do more and meanwhile he was cutting back on his food.

And so the downward spiral began...

During that spring he began to insist on "eating healthily" - swapping our usual recipes for ones with less fat and more vegetables, salads and so on. He also began to cut back on snacks like chocolate, ice cream and crisps.

At school dinners he swapped the hot meal and pudding for the salad bar and fruit - and began to eat less and less there, too. And even though the rugby season was over by now, he was still doing lots of sport.

By the summer of 2009 he was doing running, athletics, swimming, the gym, situps, press ups, cycling, you name it.

But so far the alarm bells weren't ringing. We just thought it was a health kick – in fact we were proud of him, all this dedication.

Back then we didn't know that boys got eating disorders. In fact we didn't know much about eating disorders at all. And so we missed all these early cues.

(END OF PART 1)

**Tuesday, 1 March 2016**

**Part #2 of my talk: "Eating disorders are not just a 'girl thing'"**

Things began to get more obvious over the school summer holidays when Ben was at home and we were with him more.

By this time he was exercising like crazy, every day. He joined our local gym and would run there and back as well as doing all the usual situps, etc.

He developed a big interest in cooking and especially healthy cooking. He'd slim down recipes, cutting out all the fats and carbohydrates and make some quite weird concoctions that tasted pretty disgusting.

He was also isolating himself. I don't think he saw any of his friends throughout the entire summer holidays which was unusual for him.

He was getting snappy and miserable, and not very nice to be around. And of course because he was eating less yet exercising more, he was losing weight.

By this time we were beginning to get a bit concerned about things, but we hoped he'd snap out of it once he was back at school, with his friends and on the rugby field.

But as the summer went on, Ben became more and more obsessive.

He began to buy those Men's Health magazines with pictures of Adonis type bodies and the diet and exercise regimes you needed to do to get a body like that.

But meanwhile he seemed to be unable to understand that if he was doing all this exercise then he needed to be eating more. I even bought him a book all about nutrition for athletes, but he ignored it. It was as if he knew better.

Very gradually began to dawn on us that this "health kick" wasn't normal, and so in the September, I took Ben along to see the GP hoping he'd be able to talk some sense into him.

But the GP failed to pick up on it.

I mean skinny boys aren't unusual. Boys don't get periods which can stop. Ben had no height or weight records to compare him with.

And crucially his BMI was still within the "healthy" range. Never forget he'd been a big guy - a 'prop' in the rugby team. Later we estimated that by this time he'd lost a quarter of his bodyweight, yet his BMI was still registering as "normal".

And it didn't help that Ben was sitting there saying that nothing was wrong – it was just his mum being paranoid.

So he was sent home, told to eat more and come back in a week or so.

Throughout October we went to and fro to the GPs only to be told the same old thing: go home, eat more and come back in a couple of weeks.

Meanwhile all the warning signs were getting stronger by the day...

(END OF PART 2)

**Wednesday, 2 March 2016**

**Part #3 of my talk: "Eating disorders are not just a 'girl thing'"**

Throughout October we went to and fro to the GPs only to be told the same old thing: go home, eat more and come back in a couple of weeks.

Meanwhile all the warning signs were getting stronger by the day. Mealtimes were becoming difficult; everything had to be perfect, weighed out to the nearest Nano gram to make sure he wasn't getting "too much".

Ben began to police my cooking in the kitchen and change recipes, striking through any "offending" recipes with a marker pen, and he would blow a fuse at the slightest thing.

Meanwhile he was exercising like crazy – rugby, cross-country, yoga, situps, press ups and so on. He became obsessed with getting a six pack because he

was convinced that his best friend had a six pack and this is why his best friend was more popular than he was.

He took any excuse to exercise. At school he'd asked to be excused from lessons to go to the toilets only to run around the grounds. He'd run from lesson to lesson rather than walk and in situations where he couldn't exercise, he'd just punch the air.

He was getting out of control at school. The slightest thing would set him off. For example if someone brought some cakes into the classroom to celebrate a birthday, he'd suddenly run out of the lesson and hide somewhere. He could often be found hiding in the boys toilets or under the stairs, in tears. And he was spending less and less time in lessons and more in the school medical centre which had become a kind of bolthole where he could run when things got too much.

Ben was continuing to isolate himself. He kept coming home from school saying he felt disconnected with his friends. Getting him into school in the morning became difficult and in the evening he would sit on the sofa and pinch the skin on his stomach claiming that he was fat, and he wasn't just a little bit fat, according to him, he was bordering on the obese. It was as if he'd lost all sense of rational thought; every minute of the day his brain was focused on his body.

Meanwhile I was googling the symptoms and everything was pointing towards an eating disorder. Of course I was devastated. I quickly got to realise that eating disorders can kill; there was lots of scary stuff out there – and yet it was a whole new world to me. There was a heck of a lot for me to learn.

At the end of October the school nurse called me in. She said Ben had been seen pushing himself in the gym on the machines as if he was in a kind of trance. Staff were getting worried at the amount of weight he'd lost and the

change in his personality and behaviour. And although the nurse had never seen an eating disorder in a boy, to her the classic signs were there.

She told me all about CAMHS because those were the people that would fix it, who would get Ben well. She told to go home, call the GP and demand an urgent referral, which I did right away.

So we got a referral which was sent off to CAMHS at the end of October.

It took a whole month before the acknowledgement letter came through from CAMHS. I called the number on the letter only to be told that it would be 18 to 22 weeks before Ben could be seen – and that was just for an assessment, not the treatment itself.

Of course I was absolutely devastated and in a complete panic by this time. I told the woman at the end of the phone that this was serious, told her everything that happened, the way he'd deteriorated so quickly and the way he was getting thinner and thinner. But she just said there was nothing she could do, we would just have to wait our turn.

END OF PART #3

**Thursday, 3 March 2016**

**A quick break from the talk transcripts...**

After my SEDIG (Scottish Eating Disorders Interest Group) conference talk on Saturday about eating disorders in boys, one mum in the audience stood up. She said: "You've just told our story - it's identical. Except for one thing. Unlike your son, ours didn't make it; he passed away, aged 19." My jaw dropped. And with it came a rush of emotion. Here was I, describing our recovery story. There she was, reinforcing the fact that eating disorders can kill. They are deadly diseases. And no matter how punishingly hard you work as a parent to

get your child through it, the eating disorder can claim them in the end.

I know some of us felt some guilt. Like survivors' guilt, I guess. Our sons and daughters pulled through; this mum's son didn't. Yet here we were, talking about how wonderful it is that our sons and daughters recovered from their eating disorders.

This courageous mother now takes drama productions into schools to explain about eating disorders in a way that engages young people while getting the message across.

What a woman! My heart goes out to her and my admiration knows no bounds.

Yet this is proof that the spectre of death is never far away. Eating disorders have the highest mortality rate of any mental illness. Research has shown that up to 20% of people with chronic anorexia will die as a result. Suicide is one of the most common causes. Heart and organ failure are common causes, too, and death from complications arising from prolonged starvation.

We, as parents, might expend every last ounce of energy and determination to get our sons and daughters through this horrible illness. Yet tragically some of our children won't survive anorexia, bulimia or another eating disorder.

My blog is about bringing hope to parents to show that boys (and girls) can recover from eating disorders.

Yet it is also about reinforcing the fact that so much more needs to be done to support our children - to get them diagnosed and into treatment quickly, to ensure that treatment is evidence-based, to ensure full recovery and weight restoration before discharge from treatment, and to follow up afterwards to ensure sustained recovery.

And, as was discussed at the SEDIG conference on Saturday, to continue with treatment, with the same treatment team if they're working well with the

patient, until whatever age - never to kick someone out of treatment simply because they've reached the 'magic' age of 18.

Plus, for red-flags like suicide threats to be taken much more seriously rather than simply conducting a 'risk assessment'. Or, as happened with us when I called the Duty Psychiatrist at CAMHS when my son was doing dangerous things and I was terrified he would take his life, to be told abruptly "We are not a 24-hour emergency service".

I don't know the details of this young man's eating disorder or why he so tragically passed away.

But I do know that his mother is one strong woman doing what she is doing by continuing to raise awareness of eating disorders.

I couldn't do it.

I feel humble next to her.

**Monday, 7 March 2016**

**Part #4 of my talk: "Eating disorders are not just a 'girl thing'"**

*So... Just to summarise so far... My 15-year-old son Ben developed anorexia over the summer of 2009. In the September I took him to the GP but it was the end of October before a referral was sent off to CAMHS (the UK-based Child and Adolescent Mental Health Services). It took a further month before I heard back from CAMHS only to be told that it could be 18 to 22 weeks before he was seen, which would take it up to around Easter time. I was told there was nothing they could do to speed things up and we would just have to wait our turn...*

By this point, Ben was heading downhill at a rate of knots – like a nightmarish rollercoaster. We didn't recognise our son any longer; he had completely changed: his looks, his personality and his behaviour. And now we

were being told that it could be 4 or 5 months before he'd get treatment.

Already we'd seen how far he could deteriorate in 4 or 5 months and I thought: Good God, by the time Ben is seen by CAMHS, he could be dead!

I kept going into the GPs' surgery and phoning CAMHS to see if anything could be done to speed things up only to be told again that nothing could be done, we would just have to wait our turn. It was as if no one seemed to care.

By the Christmas of 2009 Ben was completely consumed by the eating disorder.

By this time, it was all about input, output, input, output – 24/7 - how much exercise he'd need to do to burn off whatever he'd eaten. There was very little room inside his head for anything else.

He was getting painfully thin. He had dark rings round his eyes and he was oh so pale. He was permanently cold and his hands had gone red and scaly, yet all the doctor did was to prescribe creams for the skin.

Ben was getting violent, especially at mealtimes which were an absolute nightmare. He'd throw food around, he'd "down tools" and rush out into the hallway, charging up and down the stairs, banging his head against the wall and screaming. And he developed this low, slow, monotone of a voice that was totally different from his own voice. We called it "the voice of anorexia". It used to put the fear of God into me and send my blood cold. And every evening, he'd be there, on the sofa, pinching the so-called rolls of fat on his stomach and claiming that he was incredibly fat.

Yet still no one seemed to care.

Then at the end of January I got a phone call, not from CAMHS but from the school nurse who said Ben's heart was doing "funny things" and he needed to be taken into hospital.

He spent the next 24 hours wired up to just about every machine on the

planet. His heart was beating dangerously slowly, at 29 bpm.

I remember sitting there, in that hospital, with the very real, ice-cold fear that I could lose my son - that the rapidly developing anorexia could kill him.

END OF PART #4

**Tuesday, 8 March 2016**

### **What do my elbow, back and my brain have in common?**

Back in August I had a bike accident. I broke my elbow and herniated a disk in my lower spine. Meanwhile I was onto my fourth (or was it my fifth?) course of therapy for the PTSD, anxiety and depression I'd developed two-and-a-half years before - a delayed result of my brain attempting to cope with what it had been through during the years when I battled to get my teenage son through anorexia.

It took around 12 weeks for my elbow fracture to heal. Eight months on I am still working on the tail-end of the disk herniation, very gradually easing myself back into normal tasks and even sport (I can't wait to get back on my bike, for example, but will need to rehabilitate myself with care).

Healing my elbow and back was also helped along by doing all the exercises recommended by the experts.

Likewise, I have been doing all the exercises recommended by my therapists for the PTSD, anxiety and depression (CBT, mindfulness, etc).

All these exercises - elbow, back and brain - have helped enormously. But it's been slow progress. You can't 'wish' or 'will' the recovery along; you have to wait for the body to heal itself in its own time.

And what was even more helpful was learning that the brain thing is actually a very physical issue. In another blog post I described the PHYSICAL changes

that occur in the brain when an individual goes through prolonged stress and trauma.

So just as I am mindful of what I do - and don't do - with my back right now (i.e. I'm not back on my bike yet), I need to be mindful of what I do - and don't do - with my brain.

Both need to be eased back into normal life gradually and with care.

And both will let me know if it's not the right time to do whatever I would like to do.

For example I'm finding it OK to ease myself back into the world of eating disorders - GRADUALLY. There are things I can and can't do. My brain sets off a kind of red warning light if I'm doing too much too soon.

Speaking in Edinburgh was fine; I could manage that. Blogging is fine, too, on the whole. But the 'red warning light' began to flash when, for instance, I agreed to get involved in a series of interviews for a new book on eating disorders.

I'd gone too far. My brain let me know. A big red STOP light came on and I had to send my apologies. It was a little too much too soon. Just as getting on my bike and cycling 20 or 30 miles would be a little too much too soon for my back.

There are other things I find I can't do yet - like getting involved with other new eating disorder groups. Suddenly things seem 'too big' again. The world of eating disorders seems so massive and the illness seems such a huge and mountainous problem - and so devastatingly cruel to families - that my brain says "NO, NOT YET!!"

And the way it does it is through a kind of high anxiety state - like a rabbit caught in the headlights. I just stop and can't function. I have to say no, sorry, I can't do this yet - and I just want to run away and bury myself under the duvet.

Of course I feel guilty because I see others doing it all - going over and beyond the call of duty, so strong, so determined, doing so much good out there. How come they can do it, but I can't? I used to be able to do it after all... Guilt...

But I have also learned that whatever it is that was going on inside my head is something that can happen to strong people (as Dr Tim Cantopher explains so beautifully in his wonderful book *Depressive illness - curse of the strong*). We have pushed ourselves way over and beyond what normal people would need to do in their lives and our brains have blown a fuse. Unfortunately that happened to me.

Just like my elbow and back, the brain is a physical part of my body and it takes time, care and specialist exercises to heal.

I have to keep reminding myself of this fact.

**Wednesday, 23 March 2016**

**Big flashbacks at teatime....**

It's curious how the brain gets 'stuck' in the 'fight or flight'/Red Alert response, isn't it? Take yesterday teatime for example (or evening meal, to non-Yorkshire people out there!) Paul and Ben were eating fish in breadcrumbs, chips and mushy peas. Ben commented on the fact that Sainsbury's mushy peas weren't a patch on Batchelor's mushy peas. Then there was a silence. And the 'stuck' part of my brain suddenly went into FREEZE. I mean F.R.E.E.Z.E...

Why? Because in the 'bad old days' when Ben's anorexia was raging, he'd make a comment on something about the food not being right (too hot, too cold, too tasteless, too fatty, too little, too much, too dry, too salty, too... you

name it) and then there'd be silence.

AND THEN ALL HELL WOULD BREAK LOOSE as Ben would crash his knife and fork down on the plate, maybe throw food around, definitely storm out of the dining room shrieking like a wounded animal, yelling, bashing his head against the hall wall, charging up and down stairs...

And meanwhile I'd be sitting at the dining table in floods of tears, my pulse thumping in my ears, feeling hot and cold, dreading what would come next.

And that's how my brain reacted last night. Just because of an innocent comment about mushy peas and a period of silence... Before Ben carried on eating as normal.

Meanwhile inside my head I was busy doing every CBT and mindfulness technique known to man to bring my fear back to normal levels.

So, no, the PTSD hasn't gone, despite all that therapy.

But at least I'm able to recognise it when it happens and know why it happens, and observe how my body responds.

And to continue with the helpful self-help books.

APRIL 2016

**Sunday, 3 April 2016**

**One good thing that came out of his eating disorder**

My son is currently writing his university degree dissertation and studying for his final exams at the same time as applying for a Masters degree and obtaining funding for it. Phew! But I have to say - his time management skills

are awesome, they really are. Top notch. Helped, of course, by the fact that he's passionate about his subject: history. While other students leave things to the last minute and panic, the wheels of his time management ability are turning smoothly and on time. I am so very proud of him - and admire his dedication and organisational skills more than you could imagine!

Much of this ability comes from the months when he was off school, in his GCSE year (2010). Work was sent home from school and he was basically distance-taught by his teachers. He passed his GCSE examinations with flying colours having organised himself and kept to deadlines. The following summer he worked on an Extended Project - about the Romans - and got an A grade, which was required as part of his university acceptance offer.

Again, all of this was organised by Ben himself.

His dedicated and time management, intelligence and ability, are astonishing.

I wish him every success as he takes his final university examinations this summer and goes on to study at Post-Graduate level.

Back in 2012 when he first attempted university and stayed for just 2 or 3 days, who would have thought he would have had such staying power?!

But, on the other hand, part of this comes from the way he learned staying-power-on-steroids as he refused to let the eating disorder consume him and fought for recovery.

I am one proud mama.

**Sunday, 3 April 2016**

**This'll make you giggle**

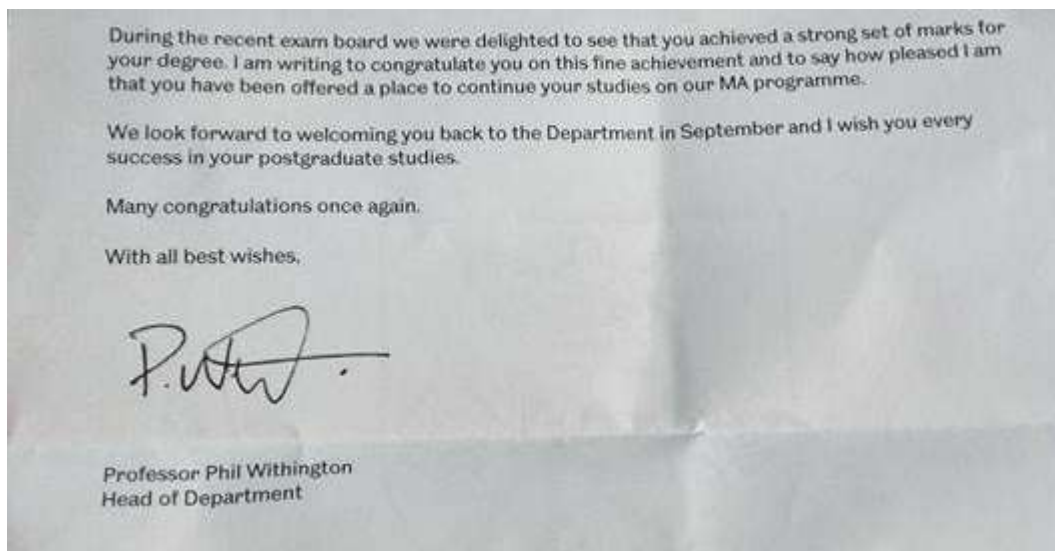
I just said to him: "I'm so proud of you, all these time-management skills and

all that." "What's brought that on?" he said, suspiciously. So I told him I'd blogged about it and so on. "Aw, thank you!" he said. Then, giggling (in a little boy's voice): "Okay, mummykins... I've been such a good little boy, can I have five million pounds, please? Like NOW! In CASH!!!"

That's another bonus. He's got his fabulous sense of humour back, too.

JULY 2016

**Tuesday, 12 July 2016**



**How proud am I of my son?**

Remember that 18-year old young man who only lasted a few days at university in September 2012? Who found it impossible to cope with the culture shock of embarking on such a hugely different stage of his life when he was still in the later throes of his eating disorder?

OCTOBER 2016

**Sunday, 30 October 2016**

**An update for you all - and the fantastic sweater!**

I'm well aware that I haven't been blogging very much over the... well, for quite some time... and it's been difficult to get myself to pick up where I left off (more about that later). On the Ben front, everything is going swimmingly. He is back at uni, now studying for his Masters Degree and sharing a house with the same guys as last year. One of his home-based friends has joined the uni this year, so that's added to his growing list of student friends. He's been voted onto the committee of the university fantasy role-playing society for the third year running and has joined two further nerdy societies at the uni. So life is very busy for Ben and such a massive contrast with the way things used to be when he was battling with anorexia.

Recently I knitted a sweater for him (he gives me 'shopping lists' of sweaters he's seen which he wants me to re-create!) and was delighted when it was a little on the tight side. Not the normal reaction for spending days on a complicated cable sweater only to find it doesn't have much room for manoeuvre when it comes to natural growth, but for me this was a cause for celebration!

So I've knitted the next sweater a little bigger!!

Ben is eating well and has been on a drive to put on weight and cast off the boyish appearance which has stuck with him since he fell sick with anorexia back in 2009 at the age of 15. Last time he was home he definitely looked more grown up and generally better. His behaviour (and his behaviour throughout

the whole of the summer break from uni) has been 100% normal and upbeat, full of drive and ambitions for the future.

Seven years ago we were descending into anorexia hell at a rate of knots. Today couldn't be more different, which I hope is encouragement for all those families that are still struggling with eating disorders, especially eating disorders in boys and young men.

So what should I write about now, if I'm able to keep this blog going? Updates on how Ben is doing, yes of course, as an encouragement to other families. But, also so others can identify with us as a family who've been through anorexia hell and out again the other side, those issues that have been left and which I, as a parent, am struggling with on a pretty big scale.

More about this in my next post.

In the meantime, please do download the FREE PDFs of this blog - available to download [here](#) The reason I put these together is because an online blog is really tricky to navigate around, especially if you want to read the whole story from the start. The PDFs make it much easier, so please download them as I know they've helped other families to find hope.

**Monday, 31 October 2016**

**It's difficult to talk about the effect of the eating disorder years on me**

I've talked about this on and off for the last couple of years or so - the PTSD-symptoms I've been having following my battle to help my son overcome his eating disorder. For quite a few months everything was relatively OK; I wrote my book, and a second book; I did talks on eating disorders; I appeared in the press, on the radio and TV talking about eating disorders in boys; I attended eating disorder conferences and, of course, I blogged here regularly. Then one

day everything changed. I can pinpoint the actual day.

Or, rather, the actual evening.

I was sitting with my mum and sister in an Italian restaurant around Christmastime. Gradually I realised that I wasn't quite 'there'. It was as if I was observing the whole occasion. I found it difficult to speak, and my brain had gone completely numb. I just wanted to get the hell out of there, get home and hide.

The next occasion was when I returned from an eating disorders talk in Edinburgh by the famous James Lock, author of *Help Your Teenager Beat an Eating Disorder*. I felt overwhelmed, I found it difficult to blog and even more difficult to talk about it.

It was like being a rabbit caught in the headlights, unable to move or do anything. Most frustratingly of all, I didn't feel anything. Or at least not positive feelings.

I felt numb and dissociated from things.

Paradoxically at the same time my anxiety levels began to rocket as I continued to be on 'red alert' round the clock.

I also began to have almost nightly nightmares. Not flashbacks to Ben's eating disorder but anxiety-fuelled nightmares of extreme situations where you're being prevented from doing things by a seemingly monumental list of obstacles. And also really horrible nightmares featuring death, evil and so on. The kind that affects your mood for the whole day.

As a result I was waking up in the morning feeling as if my brain had been pulverised overnight.

To cut a long story short, I began to have therapies. After a few months of private therapy I was lucky enough to be accepted by the NHS. Since then I've had a range of different therapies and am currently in Secondary Care

receiving a second course of Eye Movement Desensitization and Reprocessing (EMDR) therapy from, ironically, the same therapist that Ben saw private back in December 2009 when we were on the list for NHS eating disorder treatment. I have also read a library of self-help books on PTSD, dissociation and depression.

EMDR is evidence-based for successfully treating PTSD, however over the past weeks I've felt worse not better (but my therapist has been absent for a few weeks, so that might be contributing to it).

I am desperate to get rid of this unpleasant and debilitating problem.

It's been really difficult to motivate myself to write this blog again. The reason I decided to go ahead and write is that I can't be alone in feeling this way after all those years of struggling with my child's eating disorder. I know other parents have experienced physical illnesses following the years of battling, perhaps also as a bodily reaction to the stress and other stuff that high anxiety and intense 24/7 fear, etc etc etc puts on the mind and body.

I really would be interested to know if other parents have felt (or feel) as I do - so I don't feel so alone with this and also so, in some way, I can use this blog as mutual help so we can all recover.

I don't have any particular plans for the blog and there is a chance I may find I can't write at all because of the numbing / dissociative / depressive effects of the PTSD (I'd rather call it Complex PTSD, by the way, which is how 'they' are beginning to describe the results of sustained trauma rather than a single one-off trauma).

Another reason I may not write is that there's an intense need to keep all of this secret, to pretend that nothing is wrong to the outside world, to go through the motions of being perfectly fine, which is what I tend to do when I'm out there in the outside world.

For the past couple of weeks, however, I haven't been out there in the outside world. I've kept inside the house, primarily in my office-cum-spare-bedroom, like a sort of hermit.

Which isn't how it used to be and isn't how it should be...

**Monday, 31 October 2016**

### **Overwhelmed and comforted by the response from other parents**

If you're one of my Facebook friends you'll know that I've received a huge response from other parents as a result of yesterday's post about my struggles with PTSD (or Complex PTSD as I like to call it - the brain's response to sustained / prolonged trauma). I am far from unique; other families that have struggled with eating disorders experience this too. Of course everyone's experience is different, just like their experience of eating disorders is different. But I expect there are many common denominators.

Writing my blog yesterday, after a long break, was difficult. But I did it, which is quite a Big Thing for me at the moment. Since returning from a week's cycling in September I've found myself hurtling into 'hermit' mode, mainly sitting propped up on the bed in the spare bedroom which doubles as my office and general dumping ground, knitting.

I've done an awful lot of knitting over the past year. More than I've ever done in my life. Strangely it seems to be one of the few things I can motivate myself to do and concentrate on for more than a few minutes.

I've had to cut back on work, too. Luckily for me I work for myself, from home, so I've been able to focus exclusively on my long-standing clients rather than take on new clients. There is a temptation to retire (after all, I reached the grand old age of 58 on the 20th), but I need some income!

And if I did retire there is the worry that I might spend all my days and nights on that confounded spare bed, knitting!

I've also been reading about Trauma, on and off, as much as I am able. I am currently reading Professor Gordon Turnbull's book on the subject. He's one of the UK's leading pioneers on PTSD which is a relatively new science here in the UK, dating back to the mid-1980s.

There is an awful lot about PTSD in the military, as you would expect. And people who have experienced prolonged childhood or domestic abuse. And people who have had 'one off' traumas like car crashes and so on.

But, so far, I haven't read anything about the trauma experienced by parents as a result of prolonged caring for someone with a severe illness such as anorexia or one of the other eating disorders.

Please note that everything I write in this blog is, of course, based on my own experiences. Yours might be different, but hopefully you will be able to at least identify with all of this and find comfort in some way.

Thanks for reading!

**Monday, 31 October 2016**

### **My C-PTSD: a curious mix of numbness and anxiety**

During the months and years when my son's anorexia was at its worst and he was at his most volatile and violent, I was caring for him alone. My husband was working away. Okay, he was back at weekends which did take some of the strain off me, but for quite a long time he didn't 'get it' which raised a risk of him 'undoing' any good that had been done. Eating disorders have a habit of encouraging triangulation within a family and 'taking sides' with the person most likely to allow the illness to continue its destructive path. And so I found

myself taking on the lion's share of the care - and, as a result, the flack that was hurled back at me from the eating disorder. There were all the other issues, too, like fighting to get him treatment and battling to find a common ground with his treatment team so we were all 'on the same page' and not colluding with the eating disorder or undoing any progress that the other may have achieved.

**Don't get me wrong:** I'm not implying that I was uber-courageous and noble by caring for / coping with my son while my husband was working away and that my experience of caring for a son or daughter with anorexia was far worse than any other family's experience of living with the many, many issues that an eating disorder can throw up (excuse the pun).

It wasn't. All our experiences are unique and hellish. But what ties us together is the love and fear that drives us, as parents, to get our child through this terrible thing.

What I'm trying to say is that during the period when my son's anorexia was at its worst, I developed a technique for switching off.

It was the only way I could cope for another day... another hour... minute...

I'd say to myself "I have no thoughts on this" which acted as a trigger to shut down my emotions. Sometimes I'd wander off to the bottom of the garden and examine the vegetables growing. Other times I'd just sit there. Or curl up on the bed.

This shutdown became part of everyday life and a very 'normal' reaction for my brain - and it's got stuck.

While my son carries on re-building his life and making up for all those lost years, I am still in shutdown mode.

Not now and again, however, but much of the time.

Underneath the shutdown is a sea of anxiety: a dual layer with numbness at

the top and whirlpools of anxiety underneath.

Kind of like a thick sheet of ice covering an area of rip tides and strong currents.

My brain has got stuck there. And at night when I'm asleep it's as if it's all let off the hook. The anxiety is given a green light to play havoc, which is why I have such vivid nightmares and why the themes recur over and over again.

I've already mentioned the Pure Evil nightmares which involve really evil scenarios where I'm trying to escape from Pure Evil of some kind or another and where there is a genuine likelihood that it will get me in the end. This kind of nightmare pulverises my brain and makes me feel terrible for much of the following day, not to mention dog tired.

Then there are the anxiety themes, always involving desperately needing to do something or get somewhere but with countless obstacles in my way. Or exams I haven't revised for, play lines I haven't learned, that kind of thing.

And finally there are the 'loss / grief' nightmares which usually revolve around a final day at school school (reflecting the loss of Ben's promising school experience and my own as deputy chair of the school PTA) and other places / things that meant a lot to me but which I lost.

All of the above is surprisingly insidious. By this I mean that it has surprised me that, just as I thought things had reached a climax with the C-PTSD, it gets worse. I really hope it doesn't get worse than this: the numb hermit-like existence where my whole being has been anaesthetised, yet with this underlying torrent of anxiety.

Ah I wish it were as simple as being able to 'get a life', 'wake up and smell the coffee' or 'snap out of it'.

Because if it were that easy, I would have done it by now, believe me.

I hope other parents can identify with this..

NOVEMBER 2016

**Wednesday, 2 November 2016**

**One small step at a time - progress!**

This morning the cat woke me up from my slumbers demanding to be fed and I was abruptly jetpropelled from the land of dreaming to the real world. I was dreaming. Not a nightmare, but a dream. Some paper had been blown off my desk in the breeze and Shirley ('Sheila', the school nurse in my book) picked it up and read it. I was busy explaining to her that, although not brilliant, this was the first piece of creative writing that I'd been able to put together for MONTHS, if not YEARS, and that it had been really difficult to write, yet easy in a way, as that part of my brain felt as if it was thawing from the ice of numbness, dissociation and general deer-in-the-headlights inability to do very much except knit.

Just as the regular nightmares stay with me once I'm awake, this dream stayed with me too. The fact that my brain, in sleep, was aware that I'd made a definite change - a step forward - and it felt good.

Yes it 'felt' good. Remember feeling anything at all has been tricky for some time.

The other day, I wrote a couple of blog posts for the first time in ages. Today I am writing this. Yesterday a wonderful dear friend responded to my 'cry for help' with a questionnaire which she'd put together. The aim, as I gathered from going through it, was to get me thinking and to attempt to extract positives from what I am doing now as opposed to when I was completely

anaesthetised by this PTSD.

To see current actions and thoughts in a positive light. To turn them from negative into positives.

I found myself responding to her carefully worded questions quite fluently.

I could write. For a while the 'deer in the headlights' had gone.

And, although it's not a Quick Fix, I do believe her help helped me quite dramatically and I would like to say a massive Thank You to her (you know who you are, dear friend!)

It was almost like tricking my brain into feeling and doing stuff without actually realising I was doing it - and to embed the realisation that I'd been doing certain positive things for quite some time.

When I was convinced that I was the 'deer stuck in front of the headlights', I didn't actually realise that, at the same time, I had been making tiny positive steps.

Like making the decision to write my blog the other day.

Like accepting the invitation to meet up with another dear friend this afternoon. And another in December who I meet up with two or three times a year. Both are fellow mums who have battled to get their children through an eating disorder and with whom I have established firm friendships over the years.

So these steps are Good. And a massive Thank You to those wonderful people that have got in touch with me whether via my Facebook page, this blog, text or email to try and help.

**Wednesday, 2 November 2016**

## **A blog post I never published while suffering from nightmares**

I came across this draft blog post which I never published - from April 2016, on the subject of nightmares and lack of progress from the professional therapy I'd been undergoing. Really, it's as true seven months on as it was then. The difference, though, is that I don't feel quite so helpless and I'll tell you why in another post very soon, once I've 'tested the water' so to speak because I don't want this to be another "This is it, I feel soooo much better..." (end of 2nd paragraph). In the meantime, here is that draft post from mid-April 2016:

*Over the past two years I've had a bundle of different therapies for the PTSD-like, anxiety-led symptoms that began to develop a year or so after my son went into remission for his eating disorder. Following each therapy, I've thought: "This is it, I feel soooo much better, fixed, sorted, I can start to forget about the past and look to the future - and just get on with my life."*

*But it appears not to be so...*

*Weeks or months after each therapy, the feelings return. This year I had the worst nightmare I have ever had in my entire life - and I am no stranger to nightmares; I have them every other night, sometimes every night.*

*Sometimes more than once in one night.*

*And all of them are anxiety-led.*

*You know the kind of thing... missed trains, exams you haven't revised for, school lessons you've missed, forgetting lines on stage, getting lost in London Underground-style tube networks, needing to be somewhere urgently when you're miles away and struggling slowly through a sea of glue-like mud, needing to call someone urgently and forgetting the*

*impossibly long telephone number after the first few digits, not being able to find a working bathroom / toilet... the list goes on and on.*

*But the worst are the ones where I am kidnapped by maniacs who are going to kill me.*

*And all of these are so very real.*

*Which means that I often feel like a zombie first thing in the morning after an appalling night's sleep. When I wake up my mind feels as if it's been through a cement mixer overnight. I feel traumatised.*

*Sleep medication doesn't work. It makes me sleep, but it doesn't stop what my brain decides to do during those sleeping hours. Neither does any amount of CBT exercises or mindfulness, nor self-hypnosis nor any of those sleep hygiene things you can do.*

*It's as if, once asleep and free from all CBT-like mindfulness control, my mind thinks: "Bingo! I can go C.R.A.Z.Y. now... I am F.R.E.E. to do what the heck I want and wreak havoc."*

*Which it does. Admirably.*

*And no-one seems to be able to do anything about it.*

## **Friday, 4 November 2016**

### **Who we were and who we are now**

Seven years ago my life began to change in a way I could never in my wildest and most frightening nightmares have imagined. My 15-year old son was hurtling downhill into anorexia nervosa and getting worse by the day... hour... minute. The medical profession wasn't listening to me; after having finally got a referral from our GP for my son to be treated for his eating disorder we were waiting for a reply from CAMHS (Child & Adolescent Mental Health Services). I

expected that reply to come by return, but it would be another three weeks or so before we would hear anything. And even then it was only to be told that my son was being put on a waiting list and it could be 18-22 weeks before treatment for his eating disorder began. It was the start of years of battling to get my son well again: battling with the illness and battling with the medical professionals.

*But what of the 'me' I'd been before?*

I'd been a successful freelance copywriter, running my own business from home. I was also Deputy Chair of the school PTA, actively involved in fund raising and running the PTA website and publicity. I was busy, busy, busy and maybe a little too 'driven', something that comes from the perfectionist traits I had back then.

Of course all of this ground to a halt as my son became consumed by the anorexia. Getting him well was my sole priority from then onwards. My life was put on hold.

Seven years on my family has been through and emerged from hell. My son is now 23, studying for a Masters Degree and juggling his studies with a big social life. He has moved mountains. He is getting on with his own life and I wouldn't have it any other way.

But, having been entrenched in the eating disorder experience for so very many years, I am now struggling with the questions: Who am I now? Where do I go from here? What is my purpose in life?

Initially I was also asking things like: How do I get my old self back? How do I pick up where I left off seven years ago?

Then the other day one of the friends (who rushed in to help when I blogged for the first time for months with a 'cry for help' as I struggled with this PTSD that's been bugging me for a couple of years) came back with this question:

"Do you really want to go back to being the person you used to be?" And she helped me look at the person I have become versus the person I used to be seven years ago.

Suffice to say that my friend helped me realise that, rather than being in a void, not knowing who I am or where I am going, I have already begun to realise who I am and where I am going. Most importantly, who I want to go there with i.e. the circle of friends I want to have around me. Those dear, true, kind and compassionate friends who make me feel cherished and good about myself.

These are friends who I have met over the last seven years as a direct or indirect result of my son's eating disorder. Friends who 'get it', who have suffered with their own post-trauma fallout and who will never judge, only encourage.

The main point I'm trying to make is that seven years is a long time. Even without the eating disorder experience my life would have changed in some way. With the eating disorder experience my life has changed enormously. I have also made friends who I would never have met under different circumstances.

I am not the same person as I used to be. Nor should I want to be. Indeed why on earth would I want to be?

And, contrary to what I might think, I am already in the process of moving on to the next chapter in my life and it has the potential to be better and more fulfilling than the 'old life' ever used to be.

When I emerge from this confounded PTSD thing.

Hopefully I am already beginning to emerge.

**Sunday, 6 November 2016**

## **Example of a flashback nightmare-in-disguise**

Last night I was kept awake by Bonfire Night revellers until 3am. Yet from 3am onwards I managed to squeeze in 3 nightmares: (1) a Pure Evil nightmare where a serial murderer is on the loose, (2) a 'moving house' nightmare (regular anxiety-generated theme) where the removal men are about to arrive but I haven't packed anything and keep finding things that need packing, have run out of boxes, etc etc and don't actually WANT to move house in the first place, and (3) an example of a flashback nightmare-in-disguise. Flashbacks - and flashback nightmares - are a classic symptom of PTSD. However my flashback nightmares have always been slightly different from the 'textbook' version.

Rather than being a frame-by-frame re-run of traumatic events they 'represent' the events. In last night's dream I was living in a student apartment. When I went to bed I found the bed was full of men (!). I was screaming at them to get out, that this was my flat and not theirs, but no-one was listening to me. So I fled to a kind of Help Desk. By this time I was in a real state, crying, shouting, etc - yet the man behind the Help Desk was completely ignoring me, serving people who had minor problems e.g. lost keys, etc.

No-one was listening to me, no matter how loud I yelled and wept, and no matter how frantic I became.

The setting was obviously nothing to do with the trauma of dealing with my son's eating disorder, but it was very clear to me that the emotions and the 'being ignored' / 'trying to get myself heard' situation was a flashback to those months when I was being ignored by the medical profession: when I was desperately trying to get my son diagnosed and treated for his escalating anorexia... when I was trying to persuade the 'powers that be' that my son needed to be seen urgently, not in 6 months' time... when I was battling with

'less helpful' advice from his treatment team, even that I was being blamed for his eating disorder because I was an 'anxious parent' (show me a parent who isn't anxious when faced with a potentially deadly eating disorder!!!!).

And so on and so forth.

For so long, no-one was listening to me, no matter how much noise I made. And, as time went along, it became clearer and clearer to me that my son's life was at stake.

This element of left-over trauma may be something that my therapist and I could focus on at this week's EMDR (Eye Movement Desensitization and Reprocessing) session on Friday.

To be honest, the jury is still out as to whether EMDR will work for me or not. Despite the evidence for its efficacy, I am sceptical. But time will tell, I guess...

**Sunday, 6 November 2016**

**"What you need to do to fix it is..." says my husband, helpfully...**

"What you need," he said (having just returned from 10 days on the Goan coast), "is a holiday. We'll fly to Goa and you can spend a couple of weeks relaxing on the beach, maybe have a massage or do some yoga... That should fix the PTSD." "No, it doesn't work like that!" I explained for the Nth time running. But at least his 'helpful advice' for curing PTSD is better than: "Snap out of it / wake up and smell the coffee / get a life / there are people far worse off than you." At least he doesn't say that kind of thing.

So this morning I attempted to explain at length what PTSD is and what it can feel like. Or what it feels like to me. And why, if things like lying on a sandy, sun-kissed beach could fix it then I'd be doing that, believe me!

The problem, as I explained, is that at the moment I couldn't even get as far as that beach.

The very thought of planning a foreign holiday would be 'too big' and I would panic.

Even the thought of planning a romantic weekend away here in the UK.

But I suggested that going out for a romantic meal would be do-able - and enjoyable.

Only with him, not with company, though.

Well, not at the moment. Maybe in the near future or however long it takes to fix this thing.

If the cash-strapped NHS doesn't kick me out before then; I am only permitted a finite number of therapy sessions...

Just like an eating disorder, the sooner PTSD is treated, the sooner the patient can recover. The longer it's left, the more entrenched it becomes, which is why it's proving difficult to shift my particular strain of PTSD which has been going on for at least a couple of years now.

And, like an eating disorder, the patient can 'want to recover'. The problem is that - also like an eating disorder - they're unable to do much about it without expert professional assistance (although I am trying damn hard by reading self-help books and getting my head around the science behind the effects of trauma on the brain).

If you do get a chance, and you think it would be of use, get hold of a copy of Professor Gordon Turnbull's incredibly illuminating and readable book *Trauma* - quite a weighty volume, but really excellent in helping the reader to get their head round the causes of, effects and treatment of PTSD. (He was and is one of the UK's leading pioneers of PTSD understanding and treatment.).

**Wednesday, 9 November 2016**

### **Textbook case of Complex Post-Traumatic Stress Disorder (C-PTSD)**

I've been busy reading up on Complex Post-Traumatic Stress Disorder (C-PTSD) - "a type of post-traumatic stress that results more from prolonged stress than it does from one-defining, life-threatening event" and how it differs from 'Simple' Post-Traumatic Stress Disorder (PTSD). Although there is overlap, C-PTSD symptoms are slightly different - which is good news for me as, for some time, I struggled to understand why my particular brand of PTSD wasn't a textbook case. Take my nightmares, for example, and flashbacks, neither of which are visual carbon-copies of the actual trauma itself, more 'representations'.

I won't go into detail here; I started, but got bogged down in what was fast-becoming a scientific blog and that's not what I want to do here. Suffice to say that I appear to be pretty much 'textbook' when it comes to C-PTSD and, as such, a more complex type of treatment is required (which can include EMDR). A kind of 3-prong approach which can take much longer than 'standard' EMDR.

It would also explain why all the other therapies failed to deliver results - something that appears to be common with most C-PTSD sufferers.

Both PTSD and C-PTSD are a 'nurture' rather than 'nature' problem. They aren't mental illnesses, as such, more the brain's normal reaction to abnormal events.

Will my EMDR sessions achieve results?

Really, I need to ask my therapist how much she knows about C-PTSD because, surely, you need to know about the problem you are treating even if it is related to PTSD?

**Thursday, 10 November 2016**

### **Post-eating-disorder - a definite shift for the better in my son**

Anyone who's been in my situation, as the parent of a young person recovering / recovered from an eating disorder, will know: reporting something like this feels a little like 'tempting fate'. However here we go... Since the early summer or even earlier, I've noticed a definite shift in my son. A shift for the better. A shift that's pushed him over that '99.9-percent recovered' mark that I've found myself referring to over the last couple of years. A shift that has pushed his eating habits into the ranks of the 'normal' and his appearance from 'still on the thin side' to absolutely fine. A shift that has lifted a huge weight off my shoulders as I worried about relapse and / or that tiny remnants of his eating disorder may still remain.

He looks better. He appears to feel better. Despite the punishing workload of his Masters Degree, he seems to be happy and successfully finding his place in the world. He has a good circle of friends, both at home and at university.

When he's at home (which he is at the moment because it's the university's November Reading Week) he cooks the evening meal. Wonderful concoctions. Normal concoctions. And huge quantities, far too huge for little me to eat. Plus he often serves up his portion with 'extras' like bread followed by snacking throughout the evening.

And he's been finishing my meals for me when I can't eat the large quantities.

The other week we had lunch in a pub and he squeezed a large dollop of full-fat mayonnaise onto his meal, something he would have avoided until relatively recently.

And he did it without batting an eyelid. Without hesitation or anxiety.

Parents sometimes contact me to say that their son is well on the way to recovery from their eating disorder, but they're worried at how many small but important remnants remain. Such as isolation and lack of social skills. And being 'too thin' or still restricting certain foods or quantities.

It's curious how it's the same old things that tend to take the longest to fix, primarily the social isolation that the eating disorder can bring with devastating results to the sufferer. And getting their weight up to a normal level so they no longer look like an adolescent waif.

Hopefully our experiences will show that there is hope, that these remnants of an eating disorder can be fixed. Yes, they do take time, but they can be fixed. And, over the past 3 or 4 years it's been my son who's fixed his own issues while I've taken a back seat, occasionally quietly voicing any concerns, but generally letting him do the work for himself.

He is one strong young man!

**Thursday, 10 November 2016**

**And now it's time to fix me!**

I've been blogging and it's been difficult (because of the C-PTSD which tends to make me panic at the prospect of doing 'big things' and retreat), but I've made myself do it. Taking a tip from the Recovery Contract which my son and I did to help him through the final years of his eating disorder, I've drawn up a list of challenges and am rewarding myself every time I do one of them. £1 goes into my piggy bank to go towards a self-soothe activity, probably a fully-body massage.

I'm not overloading myself. I'm taking it slowly and gently, pulling back whenever I get the 'too big' anxiety warning signs. Whether or not it will work,

I don't know. But it's worth trying.

I'm also reading up on Complex Post-Traumatic Stress Disorder, although there appears to be precious little out there, especially in print. Recognition and understanding of this common issue seems to be very much in its infancy.

But, then, it's only 20 years or so since civilian understanding of and treatment for PTSD was rolled out in the UK with the military variety was only rolled out a decade earlier.

I am keen to fix this thing. After all, it's been going on for so long - at least two years, in varying degrees with a long list of different therapies, none of which have worked but which have given me a big insight into techniques that may help me through a panic attack or whatever. Techniques like Mindfulness and CBT. Or Psychotherapy. In my experience, these techniques are a way of managing the symptoms on a short-term basis. They are not a cure. And sometimes it's easier just to pop another Beta-Blocker pill instead!

It's frustrating that I don't seem to be able to fix this for myself i.e. I need professional help. But I am fortunate enough to be receiving free 'secondary' NHS care with my EMDR therapist (next appointment tomorrow). And to have some good friends who 'get it' and always try to help.

You know me... always wanting to fix things, to find a solution where other solutions have failed. My son's eating disorder was a prime example.

And now I need to fix my own issues.

But I am aware that I need to do this gently.

So that's enough blogging for today.

**Friday, 11 November 2016**

## **'Processing' five crucial months in Autumn/Winter 2009/10**

Something that's been coming to the surface loud and clear over the past week or so is the anger, helplessness and powerlessness I felt during the months from September 2009 to the end of January 2010 when we were trying to get my son diagnosed and treated for his escalating anorexia. This helplessness and panic has come across in my nightmares as well as in the daytime, which is kind of strange because I've been feeling pretty numb at the same time.

Today my therapist and I looked at those months in detail while I held the little EMDR clickers in an attempt to 'process' the emotions and store them away as history rather than present day angst.

I was going to write about that period here, however I've already written about it many times in this blog.

To be honest, I just can't go 'back there' at this very minute; I spent quite a lot of time 'there' this morning, going through how I was feeling and attempting to change my feelings of helplessness and 'should have tied myself to the railings' (because no-one was listening to me) into feelings that I did the very best I could, given what I knew about eating disorders at the time.

We also talked about the panic I felt as I realised that, if the NHS wasn't going to treat my son anytime soon, I'd have to find private treatment for his eating disorder. And being in the terrifying situation of not know where on earth to begin.

How curious that I chose the person who is now my EMDR therapist! She was working as a private CBT therapist back in 2009. It's really helpful that she remembers that period well even though, as she admitted, there was little she could do to help as my son was sinking pretty fast by that stage.

I think she's as shocked as I was and am about the way I was ignored and my

son's anorexia was treated so very lightly, almost as if it were the common cold rather than a deadly illness.

So there I was today, in the EMDR session, kind of acting some of this out in the way I might do today if I came across that GP who wasn't listening to me but was listening to my son who was insisting that he was absolutely fine and it was just his overprotective old mum worrying unnecessarily...

I said that I'd feel 10 feet tall and the GP would be tiny. I'd be prodding him with my finger, reading the riot act and physically shaking him, then forcing him to sit through hours or days-worth of eating disorder training conferences. I'd also force him to read my book while I sat there and watched him.

Anyway, apologies if this post isn't very fluent and clunks along a bit. My brain feels like mush after this morning's session and my eyes are sore.

**Tuesday, 15 November 2016**

### **Progress - self-help to get me through the PTSD**

I am reading 2 books simultaneously, both by world-leading experts and pioneers of research, development and treatment of PTSD and its cousin C-PTSD (Complex Post-Traumatic Stress Disorder - which I am currently suffering from, triggered by the years of battling to get my son through his eating disorder). One is Professor Gordon Turnbull's *Trauma - From Lockerbie to 7/7: How trauma affects our minds and how we fight back* and the other is Bessel van der Kolk's *The Body Keeps the Score: Mind, Brain and Body in the Transformation of Trauma*. Obviously, with something like trauma, no two causes are the same. Also, in the second book, there is a lot of emphasis on childhood trauma and abuse. But the point is that, regardless of the cause of the trauma reaction, the symptoms and treatments of PTSD and C-PTSD are

very similar.

One thing I found very helpful this morning is this... In his book Prof Turnbull describes how he was doing some group work. Most of the patients recovered very quickly and he was puzzled as to why one or two didn't - and also why successive treatments hadn't worked for other people who appeared to be 'stuck' in their PTSD.

He delved a little deeper and asked these patients if there was a relevant and significant trauma experience that they hadn't talked about; perhaps something from childhood.

Anyway, the long and the short of it was that - yes there was - and when treatment doesn't seem to be working it's well worth digging a little deeper to see if there's anything else lurking in your memory bank.

With me there are two incidents that stand out, both of which may be responsible for setting my brain up to be hyper-vigilant and on 'red alert', a state that I was in most of the time when my son was suffering from anorexia, especially as his moods became more volatile, violent and extreme. At the same time I was constantly walking on eggshells so as not to trigger off a potentially even more alarming and upsetting episode.

But this hyper-vigilance and 'walking on eggshells' wasn't something that was new. It goes right back to my childhood. I don't want to describe the particular incidents here. Suffice to say that one incident was a 'one off'; the other was ongoing on a day-to-day basis. (But I will add that I'm NOT talking child abuse here, just in case you are wondering.)

For the first time today, I faced these decades-old incidents head-on, and had a go at processing them using EMDR techniques.

I can't explain more here, but I really believe it helped. I may need to talk this through more with my therapist on Thursday.

**Friday, 18 November 2016**

**A week of moving mountains!**

This week I have felt sooooo much better. I am feeling again. I have more motivation. I just feel free, like I've pushed my way out of a dark room and into the spring sunlight. I've done things I've found impossible to do over the past months: I've blogged, I've agreed to go away on a long weekend break with my husband (rather than heading for the safety of the back bedroom!), I've done some cooking, I've even made big inroads into reigniting my freelancing business after not being able to face work for months. I've also felt calmer, deep down inside which is where it's so important - the place where I was constantly anxious and on 'red alert'. My sleep has been more refreshing. Yes, I've still had nightmares unfortunately and I am still shouting in my sleep, but we're talking small steps, and this week has definitely been a move in the right direction.

I attribute it to the excellent therapy I've been having from my NHS EMDR therapist, supported by the two books I talked about in my last blog post. Plus, of course, the good friends who rushed in to assist when I put out a cry for help the other week.

I see the period where my son was suffering from anorexia (7 years in all if you count the years I've been struggling with PTSD) as a definite watershed in my life. There was a 'before' and there will be an 'after'. I am not the same person. Not at all. And I'm not journeying through the 'after' with the same friends as I did in the 'before'.

Yesterday I took a car-load of stuff to the charity shop and the council tip - some of it part of the life I no longer live, stuff that isn't part of my future

(including loads of clothes I'll never be able to get into again now that I am no longer a serial dieter).

The act of clearing out is a Big Step, too, as it's something that would have seemed 'too big' until very recently.

But there IS part of the 'old me' that I want to be part of the 'new me' and that's the 'me' that wakes up in the morning full of drive and enthusiasm, wanting to rush to the computer to blog about something, whether it's my business blog or this eating disorders blog.

And that is the 'me' that woke up this morning!

It's a major miracle!

**Saturday, 19 November 2016**

**The thaw continues... positive news!!**

The following is an edit of a comment I added to my Around The Dinner Table forum post about PTSD in parents and carers after the eating disorder has gone:

*I must say that EMDR, administered and monitored properly, seems to be doing the trick. It is evidence-based. At first I was mega sceptical - it sounded like some kind of weird mumbo jumbo technique, but it does work!*

*I am finding, as I go on, that the key is to take small steps and draw back whenever you feel like running before you can walk, as I am prone to do!! I say to myself "Woah!!! Time for a cuppa."*

*For MONTHS... well a couple of YEARS really.... everything felt 'too big' and over the past months I've been withdrawing more and more and becoming dissociated and mega numb without any feelings, negative or positive - and with regular nightmares / night terrors.*

*But as the therapy starts to work I am definitely thawing out and beginning to feel again. It feels really odd and wonderful at the same time!*

*For the first time for ages, I've been able to visit this forum, blog (biz and eating disorder blogs), go out and do stuff, even de-clutter the house! All of this would have sent me scuttling for my duvet and knitting up until very recently, so this is definitely progress and I am so fortunate in having a supportive husband.*

*So positive news, all in all!*

PS: For those of you that don't know, Around The Dinner Table is a FANTASTIC and supportive forum for parents and carers of young people suffering from eating disorders. It was a lifesaver for me when my son was sick with anorexia. So if you're a parent of a young person with an eating disorder, please visit this wonderful forum and its 'parent' website F.E.A.S.T (Families Empowered and Supporting Treatment of Eating Disorders)!

**Monday, 21 November 2016**

### **Processing all the anger using Eye Movement Desensitization and Reprocessing (EMDR) therapy**

Over the last couple of Eye Movement Desensitisation and Reprocessing (EMDR) therapy sessions, we've been attempting to process all the anger relating to that period between September 2009 and January 2010 - the period that starts with our first visit to the GP followed by several more visits to the GP in an attempt to get my son's escalating eating disorder diagnosed and treated. There is a heck of a lot of anger inside me - and I can feel it welling up now as I write this blog post today.

I am angry with the GP for not diagnosing an eating disorder, failing to inform me about treatment for eating disorders and failing to refer my son

urgently for eating disorder treatment. I am angry with the NHS for putting my son on a massive waiting list for eating disorder treatment. I am angry with the hospital (where my son was admitted in the January when his pulse plummeted to 29bpm) for not recognising the link between an eating disorder and a slow pulse rate (Bradycardia) and also for not understanding that it was critical that my son ate food while he was in hospital. And I am also angry with myself.

I am just ANGRY, ANGRY, ANGRY!!!! And it really is a HUGE anger which has taken a number of EMDR sessions to try and process.

As I say above, I am angry with myself - for not doing more during that period. For not 'chaining myself to a lamppost' and refusing to budge until my son was referred for urgent treatment for his escalating eating disorder.

So my therapist and I have been examining this (false) belief - that I should / could have done more - and have been working on changing it around to the belief that **I did the best I could given what I knew about eating disorders at the time.**

*We've been looking at the 'me' back then.*

Firstly, the 'me' back then believed that people in authority, e.g. doctors and other medical professionals, knew best. Who was I? Just a mum, after all! So, although my gut instinct was beginning to scream out that my son was descending into something quite frightening, part of me trusted what the GP was saying. Part of me trusted that we did need to wait and see how things go. And how on earth could I know what treatment was available for my son if the GP wasn't telling me?

Secondly, I knew naff all about eating disorders. But as it became more and more apparent that Ben was developing anorexia, I began a HUGE cramming session on everything I could find about eating disorders. Obviously this took a

heck of a long time - to locate, to read and to digest. And this was at the same time as trying to run a business and home, dealing with an inner ear virus that had me horizontal for much of that October and responding every five minutes to my son's increasing volatility, both at home and at school.

Thirdly, I was still under the impression that this (what I assumed was an eating disorder) might be fixable - by persuasion, arguments, proving to my son that he needed to eat and wasn't fat, and so on. That this was only a temporary blip. And, anyway, boys didn't get eating disorders, surely?

Fourthly, the 'me' now is the 'me' with the benefit of hindsight and knowledge. So I can never judge the 'me' back then by present day standards.

In other words, *I did the best I could given what I knew about eating disorders at the time.*

So I shouldn't feel any guilt or failure.

I'll talk about the other anger - the anger at the GP, etc - in another post.

## **Monday, 21 November 2016**

### **Autumn 2009 - some notes I made at the time about my son's worsening eating disorder**

Here is a collection of notes I made during the autumn of 2009 - the period when my son's escalating eating disorder was beginning to get more serious. Some of these are what I posted on a forum at the time (not the Around the Dinner Table Forum; I hadn't yet discovered that.) I've pasted it in here as an example of how I thought we could possibly 'fix' the eating disorder early on - and also to show how he was changing. I think this must have been in the November because it talks about a referral being underway.

*Basically my son feels the only way he can become popular at school is to get*

*thin - it's the only thing he can control - but he admits it's not working.*

*My wonderful 15 year old son has gone from being a strapping rugby-playing, healthy eat anything lad to a thin, gaunt boy who's well below the minimum for his build and height. All the signs point towards an eating disorder. If you've had a similar experience I'd appreciate any advice you could give on getting over this. All I want in the whole world is for my wonderful son to be back to who he was again instead of this food-obsessive, compulsive, frantically exercising boy who's a physical shadow of his former self. Underneath it, he's very unhappy and I feel helpless. It's all to do with image and self-esteem, of course. Goes back to cutting remarks from girls on him being too fat. He believes that if he loses weight he'll suddenly become popular with the girls and his peers. Of course he won't listen to a thing we say about it...*

*I feel if we could get to the bottom of the self-esteem issue, we'd be half way there, but I feel so very, very helpless.*

*We've just had yet another row about my meal plans for this week as he refuses to eat anything that has an ounce of fat in it - and spends stacks of time in an almost ritualistic way chopping up fruit into tiny bits to eat.*

*We can't eat normally any more.*

*My son and I are very close, and this breaks my heart - and I'm sure he knows it is. I want him to be happy - and healthy.*

*We had a terrible night last night as everything came to a head. Increasingly, he's 'disappearing' into the crowd and becoming isolated, distancing himself from his (very nice group of) friends. And he is very, very, very distressed. I can't emphasise how distressed he is and it's something I wouldn't wish any parent to have to experience.*

*At the heart of this lies one boy. This boy is the cleverest boy in the year and*

*now, it seems, the most popular, mainly with the girls. He is also part of my son's circle of close friends. The image I get from what my son says is of this boy surrounded by crowds and crowds of adoring girls and boys. He's being hugged by dozens while sending and receiving texts from others. He revels in this adoration and the boys and girls hang on to his every word. In fact the vision I have is so ridiculous that in other circumstances I'd just laugh!*

*Meanwhile my son fades into the background. Everyone ignores him, so he says. He doesn't get hugs. He doesn't get texts. And when he talks to this boy, this boy is often too busy sending and receiving texts from his adoring public to bother with my son.*

*Worse, this boy is muscular, with a '6 pack', according to my son.*

*Result = my shy, unconfident son feels that the ONLY way he can compete or equal this boy is to exercise and diet himself silly so he 'becomes' that boy, if you like... By doing this he will get similar adoration and 'be loved' (his words) by the girls and others. He says he 'just wants to be loved'. Of course transforming himself into this boy is an impossible task which is why the situation has got so bad.*

*My son is distraught. I have never seen anyone so distraught and it breaks my heart. I feel totally helpless and don't know what to do. I would do anything to help him - but he needs to learn how to handle this situation which won't change (i.e. the boy will always have his adoring public), and realise he's a person in his own right, and get his own different group of friends.*

*PS Have had a long chat with my son and worked out a recovery structure with professional help back-up if things don't improve within 2 weeks. We already have a referral underway for NHS help, but it may take 20 weeks (!!!!!), in which case we'd have to pay for private treatment as a stop-gap until then. Mainly we need to change his mind set towards (a) his body (so stick thin*

*is seen as unattractive rather than attractive) and (b) how he handles peer issues at school and his need to be 'loved' and 'popular'. I hope I managed to drum into him how vital this is and that there is no negotiation with this. I have set 'reward stages' along the way, the top reward being the double bed he wants and other rewards being activities he wants to do - and I've promised I'll do activities outside my normal comfort zone too! (e.g. we'll hold board games evenings, etc - I may even take snowboarding lessons...!)*

*Although it won't be an overnight 'quick fix', and will probably have serious relapses, we have to move forward now. I explained why, as loving parents, we need to do this. I also outlined the physical damage he could do to his body should things deteriorate - and he, more than many teenagers, is aware of the need for a healthy balanced diet. Also that, by doing what he has been doing, he is actually achieving the REVERSE to what he wants to achieve i.e. be attractive and admired for his physique. The good thing is he was receptive, unlike the other night...*

*The main issue is changing his mind set so he views a physique like when he came back from the coast2coast cycle ride, for example, as the perfect body he should be aiming at - and not this geeky thinness - in fact we want to change his mind set so he DOES view this kind of body as geeky because I know that geeky is something he wants to avoid like the plague (because he worries his circle of friends are viewed as geeks).*

*As he constantly compares himself to his friend, who has a normal sporty physique, it's important to change his mind set so he views his C2C-type physique as equal to this if not better. This is our challenge (and where we may need outside assistance...) Any advice on how we could get him to change the way he sees himself in the mirror would be brilliant...*

**Monday, 21 November 2016**

### **Autumn 2009 - notes for the private psychiatrist**

The following is from my book (Please eat... A mother's struggle to free her teenage son from anorexia) about the period when I was getting desperate for treatment for my son's escalating eating disorder. He was on a long waiting list for CAMHS (Child & Adolescent Mental Health Services) treatment and so I felt the only option was to go private.

*I DECIDE TO START AT THE top and go for a private psychiatrist. Psychiatrists seem to be the most expensive so, logic implies, their treatment must be the most effective. This means Ben will get better faster. Or at least that's the way my mind is working in the run up to Christmas in 2009. Eventually I find a psychiatrist that can see us over the busy festive season.*

*Friday afternoon sees us sitting opposite a rather stern, smartly dressed gentleman as the clock ticks away on the first £250 of our insurance money. But, after asking a lot of questions, it appears he'll simply be supervising the treatment. He hands me a list of suitable therapists to contact - the people that will do the real work. "Then, in a few weeks' time, you can come back and tell me how you got on." Not at £250 a shot, we won't, I mutter under my breath. I take the expensive list home.*

These are the notes I took along with me:

#### **HISTORY**

- Started to notice a difference in the summer when Ben cut himself off from his friends a lot. He didn't have them round as much as he used to and spent a lot of time in the gym exercising, but not actually enjoying it. It was as if he felt compelled to exercise. On holiday, he didn't eat the usual ice creams, etc.
- By October, Ben was getting very thin. He'd grown from being a strapping rugby-playing, healthy eating boy to a thin, gaunt, pale boy who was well below the minimum for his build and height.

- His eating became increasingly obsessive and ritualistic, sticking to certain foods e.g. salads, fruit and dried fruit, spending ages chopping them into small bits before eating. All 'bad' foods were completely cut out of his diet.
- Meanwhile he was frantically exercising to burn off the food. He'd frequently look at himself in the mirror, hating what he saw, and claiming that the rolls of skin on his stomach when he sat down were fat. All we were seeing was an almost skeletal, gaunt, pale, ill-looking boy. Everyone from the family commented on the change.
- It got to the stage where we couldn't eat normally as a family – rowing about food, etc. Ben was 'policing' the fridge and everything I cooked. He'd scour recipe books for zero fat recipes. Anything containing oils, butter or cheese was off bounds. He also reduced his carbs intake to virtually nothing.
- I took him to the doctor who explained the dangers of under-eating. She said he must increase his weight before a second visit, but on the second visit he was very depressed at the slight increase in weight, immediately exercising like mad to lose it – yet hating the exercising.
- As he got thinner, he withdrew more into himself. He's always been a fairly quiet and shy boy, but his self-esteem and confidence plummeted to an all-time low. He also lost his sense of fun, becoming very serious and morose. As he distanced himself from his friends and became increasingly miserable, his peers began to distance themselves from him – it became a downward spiral. The more he tried to do things which, in his eyes, should make him more popular, the more they did the exact opposite. As a result, he became very distressed and depressed, and more obsessive than ever about food and exercising.
- Increasingly, I was picking him up from school and he was in a terrible state, extremely distressed and depressed, convinced everyone was ignoring him – in an extremely 'black' mood which would take AGES for us to get him out of. Very distressing for us as he'd often take it out on us too.
- The staff at school mentioned it to me. The Head of Year mentioned that the sports staff had commented on Ben losing the 'bulk' he needed to be in the rugby team. Other sports staff were concerned at the way he was 'punishing himself' in the gym.
- Around mid-November, things came to a head after two particularly bad weeks. In desperation I had a talk with the school nurse who had a long talk with Ben which seemed to do some good.

- For the first time, he actually admitted there was a problem and explained how trapped he felt by it all – and how it wasn't actually achieving what he had set out to achieve, and that it was a 'control' issue. He felt almost imprisoned by it all. But he felt he didn't have the personal strength to get out of this alone. We decided he needed professional help and the doctor referred him to CAMHS (eating disorders), however the waiting list is 18-22 weeks. This is why we have gone private.
- After lots of long talks and support from us, his eating began to improve, although it's still far from perfect as he still cuts out the 'bad' foods from his diet. He is so afraid that he'll get out of control with eating that he will become fat (like his 'puppy fat' days at primary school). In my mind, he is still under-eating – but it HAS improved but he needs to lose this need for control, this fear of eating the 'wrong' things. He needs to lose his obsession with food.
- His self-confidence and self-esteem seem a bit better; there are less 'bad' days at school. However I believe that the slightest 'You're fat' accusation or peer pressure could undo all the good that's been done... We are not out of the wood yet.
- I believe that it's the self-confidence and self-esteem that needs working on. He needs to see beauty from within as being far more important than the physical image. If his self-confidence and esteem grow, hopefully the attitude to food will follow. I feel we are treading on eggshells a bit and the improvement he's undergone is fragile.

## QUESTIONS

- What kind of therapy does he need and with whom?
- How long will it take / how many sessions?
- Obviously Ben's wellbeing is uppermost in our minds but because this is private, we need an idea of how much it may cost.

**Monday, 21 November 2016**

**Okay, so that's enough of sifting through notes from 2009. Let's look at the anger...**

So why did it take an emergency admission to the cardiac ward at our local

hospital to get my son finally seen by CAMHS (Child & Adolescent Mental Health Services)? (At the end of January 2010.)

Back in late September / early October, why did it take the GP so long to realise that, yes, this is an eating disorder and, yes, it needs to be referred for eating disorder treatment right away?

Why did it take the school nurse to tell me all about CAMHS and eating disorder treatment - not the GP who told me nothing?

Why did it take a telephone call to the GP from my husband to force him into sending off a referral?

Why did it take nearly a month for the CAMHS acknowledgement to come through to us - and TWO WEEKS after the date on the letter?

Why was I told that we'd have to wait 18-22 weeks for Ben to be assessed - with no date given for the start of the actual eating disorder treatment? Why did CAMHS refuse to budge on this despite my rantings?

Why did the GP ignore my pleas to get Ben seen urgently? Why did he seem quite happy to let us go private because we were so desperate?

Why did we have to go private in a country with a free National Health Service?

Why didn't the cardiac staff in the hospital in late January 2010 clock on about the link between anorexia and Bradycardia (low pulse rate)?

Why did they do nothing to get Ben to eat while he was in hospital?

Why did they look blankly when I said that he was developing anorexia?

Why did it take this heart incident to get him seen by CAMHS - and only then when I phoned them to tell them what had happened?

***Why, throughout, was no-one listening to me or believing me?***

Why indeed?!

This is why I have this 'old' anger and why it needs processing.

**Saturday, 26 November 2016**

**Why Red Alert mode is a thing of the past, present and perhaps the future, too.**

Yesterday at my therapy session we were talking about how, given certain triggers, my mind and body instantly 'ping' back into Red Alert mode - something I was doing on a daily, if not hourly basis when my son's anorexia was at its worst, and also right up through his first year at university - a period that was very tricky and accompanied by several mentions of the 's' word which put the fear of God into me. I told the therapist that reactions like this are very difficult to fix as they are not necessarily in the past. The anger against the GP and other medical professionals from that period in Autumn / Winter 2009 is in the past and therefore more straightforward to process using EMDR (Eye Movement Desensitization and Reprocessing) techniques. That's what makes it different.

The reason the Red Alert is in the past, present and future is that I will always have a massive fear that my son will relapse and that his eating disorder will return. It's not an irrational fear; I know of several young people who have relapsed back into their former eating disorder.

I also worry that my son may mention the 's' word again during periods when life gets tricky. Any hint at anything like this automatically pings me back into Red Alert and High Fear. I cannot 'go back there', I told the therapist. Ever. I simply can't.

Next week she wants to work on two of the main triggers that ping me into Red Alert - the kind of Red Alert that affects my entire body and mind. If you have a son or daughter with an eating disorder you will know exactly what I mean!

These triggers are: sudden loud noises - bangs / crashes and my son's primeval scream. No it wasn't a scream, I told her. More like a yell. No not a yell, just an animal sound. Loud, deep, fearful and primeval.

Both of these are triggers that send my blood cold, my heart pounding, my skin perspiring, my chest tightening and my mind zooming to places that are darker than the darkest night.

I also talked about texts and Facebook messages from my son that start with: "Hey" or "How's you?" because they almost always herald some bad news.

I told her about the period in early 2010 when I got umpteen texts from my son at school which resulted in pushing me over the edge. That was the day I smashed the dinner service on the kitchen floor, crouched into the foetal position in a corner of the room and cried until I could cry no more.

I still find it very hard to deal with texts or FB messages that begin in that way.

Take this morning for instance when one came through from Ben.

He's having problems at uni. He's struggling with the MA and uncertain about his future. He feels sapped of confidence.

Uh oh, I thought, and immediately pinged into Red Alert mode despite telling myself that this kind of crisis is a 'normal crisis' that anyone can go through. It is not eating disorder related. Or at least I hope not.

And, at nearly 23, my son needs to find his own way in life and learn how to navigate himself through crises. Although my natural instinct is to rush in and attempt to fix things, I know I wouldn't be doing him any favours in the long term.

But this is an example of why the Red Alert issue isn't a past problem, it also applies to now - and may still apply in the future.

This is because there is ALWAYS the entrenched ice-cold fear that something could take us 'back there' or send my son back into depression resulting in the 's' word again.

That is my biggest fear in life.

**Sunday, 27 November 2016**

**Are you a parent or carer looking for support from other parents of young people with eating disorders?**

In early 2010, some months into my 16-year old son's escalating eating disorder (anorexia nervosa), I discovered a life-saving resource after a chance search on Google. It was the F.E.A.S.T. website (Families Empowered And Supporting Treatment of Eating Disorders) and its online forum Around The Dinner Table (ATDT). Through this wonderful resource I found the rock-solid support I needed from parents across the world who had 'been there, done it' and also those who were still battling to get their sons and daughters through the hell of an eating disorder such as anorexia, bulimia or EDNOS (eating disorder not otherwise specified).

I am still friends with many of the 'stalwarts' of this wonderful community - virtual friends on Facebook and also friends who I meet up with now and again for coffee or over lunch.

I wish I'd discovered F.E.A.S.T. earlier during that terrifying period when I realised that something frightening was happening to my son and that that 'something' was probably an eating disorder like anorexia.

This is why one of the purposes of this blog is to direct other families to this supportive and informative resource so they don't have to face their child's escalating eating disorder alone.

In the Introduction to my book *When anorexia came to visit - Families talk*

*about how an eating disorder invaded their lives* - Laura Collins, the Founder of F.E.A.S.T. (Families Empowered And Supporting Treatment of Eating Disorders) and Author of "Eating With Your Anorexic" explains about the F.E.A.S.T. community and its online forum Around The Dinner Table (ATDT). I am sure Laura won't mind me reproducing this Introduction here (which explains more about the ATDT forum for readers of this blog who may not be aware of its existence):

I hear lots of questions when a parent realises their child has an eating disorder. The question that comes up most often is: "Where can I find other families who have survived this?"

Before the diagnosis, few of us will have talked with another family facing anorexia, bulimia or another eating disorder. So when we discover our child is sick, we can feel alone, isolated and frightened. We want to know that there is hope; that our child will recover - and we want to meet other parents that have faced the crisis and come out the other side. Indeed talking to families that have survived an eating disorder can be one of the most encouraging and empowering comforts during difficult times.

Bev Mattocks has collected together just some of these stories, many from a very special place: the Around The Dinner Table forum - an online forum run by parents for parents. ATDT (as it is often known) began in late 2004 with only one member: me. I started it because I envisioned a community of parents helping other parents to survive this devastating experience. I knew that the internet was an ideal place because it's low-cost, open 24 hours, international and anonymous. When a mother or

father is desperately searching for information and inspiration the ATDT forum is like a lighthouse on a stormy night, showing the way to safety. What started out with me asking my relatives and friends to “please post something” is now a longstanding institution with thousands of families that have come to us for support.

The generosity of the community that developed at ATDT continues to amaze me. There are caring folks there at all hours to offer leads to information, provide inspiration or simply a friendly shoulder to cry on during stressful moments. These fathers and mothers give willingly of their experience and show genuine compassion for one another. The number of readers always exceeds the ones writing so we know that the experiences of our users have a wider impact and will continue to do so for years. ATDT is run by a wonderful group of volunteers. The moderator team - or “Mod Squad” - know our vast archives inside out and can refer a new parent to relevant “threads” whether current or past. British, Canadian, American, New Zealand or Australian families find one another, families facing similar symptoms find one another, and those living near enough to actually meet for coffee form invaluable local support networks across the globe.

By using the power of the internet, even with its drawbacks, ATDT has been able to offer support that is found nowhere else. Many practising clinicians tell us they learned of a new technique, book or other information source from reading the forum. I regularly hear from parents that ATDT was an essential tool in their family’s success. Indeed many of the families in *When Anorexia Came To Visit* describe ATDT as a

“lifesaver” during the darkest days.

Because we are a peer-to-peer environment, one of our rules is that we are limited to our own experiences. We do not tell other parents what to do or how to think. We share our stories so that others can use our experiences in making their own decisions. This isn't always easy: at times every one of us wants to say, “You should...”

The limitation of an online forum, however, is that each story is told in individual “threads” over time. Rarely can you follow a family's whole story through one “thread.” This is what makes a book like *When Anorexia Came To Visit* so important. I applaud Bev Mattocks for gathering these stories and giving these 20 wonderful families a voice.

Of course with such a complex illness and widely differing personal circumstances, every story is different. Nonetheless there will be overlaps and elements that families will recognise and identify with. Like me and countless others, you will read these stories and find yourself nodding your head and saying “Me, too!” as you hear about families undergoing similar experiences to your own.

4

May these stories, and these brave families, offer you the hope and inspiration you need and deserve in the fight for full and sustained recovery. Your story, too, is yet to be told!

*Laura Collins, Founder of F.E.A.S.T. & Author of “Eating With Your Anorexic”*

**Tuesday, 29 November 2016**

## **Having problems getting your eating disordered child to make positive changes?**

A few years ago I attended a conference / workshop for parents of young people with eating disorders. Gill Todd - RMN MSc, former Clinical Nurse Leader at the Gerald Russell Eating Disorders Unit, Bethlem & Maudsley Hospitals, London - was talking about a therapeutic approach known as Motivational Interviewing (MI), used by clinicians to inspire motivation for change and which is believed to be especially helpful for people with eating disorders who may be ambivalent about change. I firmly believe that MI is a fantastic tool to have when you're a parent trying to get your child to take the next step on the road to recovery from their eating disorder. It's a great tool to use when things seem 'stuck', when you feel as if you're going round in circles or when you simply want to SCREAM at the lack of progress!

Gill and her well-known colleague, Professor Janet Treasure, OBE PhD FRCP FRCPsych, talk more about Motivational Interviewing techniques and how they can be applied in an eating disorder situation on the New Maudsley Approach website which you can find [here](#). Click on Practical Skills to find out how you can begin to use this technique for yourself.

A good pocket resource which explains more about Motivational Interviewing and provides examples of the kinds of questions that are believed to promote positive behaviour change is *How To Do Motivational Interviewing: A Guidebook* by Bill Matulich. This guide is written for therapists and isn't specifically about eating disorders, more about a range of problems where Motivational Interviewing can be used to good effect (e.g. alcoholism). But all of the approaches can be adapted for use with an eating disorder.

This article by Janet Treasure also explains more about Motivational Interviewing and how it can inspire change.

The only problem with Motivational Interviewing (as I have found) is remembering all the basic techniques! But I guess that the more you use it, the more these techniques / questions become second nature. I personally discovered Motivational Interviewing too late - when my son was well on the road to recovery. I W-I-S-H I'd discovered it during those early days when I was still arguing with my son, convinced that I could 'prove' to him that his eating



disordered thoughts were incorrect / irrational. Those days when I thought he'd be able to snap out of it and see sense. And also - importantly - those many, many, many days when he was completely 'stuck'.

DECEMBER 2016

**Wednesday, 7 December 2016**

**Revisiting 'The 12 Days of ED (Eating Disorder) Christmas' from 2011**

2011 was our third Christmas with the eating disorder. (My teenage son gradually developed his eating disorder over the spring and summer of 2009; then throughout autumn and winter 2009/10 his anorexia began to accelerate at an alarming pace.) At the end of November 2011 (when my son was on the road to recovery from anorexia) I began a series of posts entitled 'The 12 Days of ED (Eating Disorder) Christmas' based on our experiences over the previous 12-18 months. I only got as far as 10 days as more current issues took over the

blog. However you can download a PDF of the 'The 12 Days of ED (Eating Disorder) Christmas' posts from my blog - and if time permits I might do 'The 12 Days of ED (Eating Disorder) Recovery Christmas' for this year, hopefully completing all 12 days!!!.

**Wednesday, 7 December 2016**

**On the first day of Christmas, the anorexia recovery gave to me... "A close shave with a train door" ...**

As my son's recovery from the eating disorder gathered strength and pace, there is one incident that stands out - an incident that, at any time during his eating disorder, would have freaked him out Big Style: the day he caught a train by the skin of his teeth, lost his ticket and successfully dealt with an irate ticket collector. The blog post is from March 2015 and can be downloaded from the same place as you downloaded this PDF.

When Ben had anorexia, everything had to be 'just so'. Meals had to be eaten at a specific time (e.g. lunch at 12 noon) and in a specific place (e.g. at the dining room table) or he'd freak out. Any sudden change to his daily timetable catapulted him into anxiety hell. The same went for any upsets over and above normal daily life. (That is if daily life for girls and boys with eating disorders can be normal..!!).

One of the key indicators that my son was recovering from his eating disorder was when he was able to eat at different times and in different places (e.g. in the car). And on top of this when he was able to successfully handle a tricky situation, just like any other quick-thinking young man.

In March 2015, when Ben caught the train home from university by the skin of his teeth and was ticked off by the ticket collector when he very nearly got trapped in the closing train door AND THEN lost his ticket AND THEN had no

cash to pay for a replacement (causing the ticket collector to get irate), he thought on his feet and solved the problem admirably, without getting into a tizz.

The first I heard of it was when I picked him up from the railway station and he sat there in the passenger seat, eating a large lunch he'd bought from M&S, explaining why he was eating so late.

"Boy, have I got a story to tell you!" he said, and proceeded to describe what had happened on the train while stuffing food into his mouth.

Without doubt, this is the kind of experience that would seriously have freaked him out when he was under the influence of the eating disorder. But on that day he just took it in his stride - and with humour.

**Thursday, 8 December 2016**

**On the second day of Christmas, the anorexia recovery gave to me... "Two hearty breakfasts" ...**

I can't remember when my son first began to have not one but two breakfasts every day. I think it may have been back in 2012 as he pushed for recovery from anorexia after the introduction of our fantastically successful 'Contract' at Easter 2011 (see blog). And, as far as I am aware, he has continued to consume double breakfasts ever since.

The same goes for evening snacks. When he's at home, he'll sit in front of the TV after our evening meal and snack through till about 9pm - healthy but calorific snacks, the kind of food that helped to restore a balanced diet. He firmly believes that his fully balanced diet helped to heal his brain and put him on the road to recovery from his eating disorder.

Back in the Bad Old Days when my son was very sick with anorexia, I remember being invited round for drinks at a friend's house. One of the

women was going on about how her son had his breakfast at home before picking up his mate from a house down the road. Unbeknown to his mum, the boy was consuming a SECOND breakfast at his mate's house before the boys continued on to school.

At the time, this story broke my heart; I was only too well aware that it was difficult to get my son to eat any breakfast at all, let alone two. While the other people were laughing at this 'amusing' tale, I just wanted to flee from the room.

But now my son has double breakfasts, too. OK maybe it's not fried bacon sandwiches or sausages, but it is stacks of cereal, dried and fresh fruit, nuts, sometimes toast or rolls, that kind of thing.

And the first time my son rushed downstairs in the morning exclaiming "Mum, I'm STARVING!!", I felt as if I'd won the lottery.

**Friday, 9 December 2016**

**On the third day of Christmas, the anorexia recovery gave to me... "Three nerdy housemates"...**

One of the most difficult problems to fix with my son's eating disorder was his social life and skills. Right from the start - that summer of 2009 when his emerging eating disorder began to be more evident - he had isolated himself from his friends. The boy who'd been so popular and whose birthday parties had to be held in shifts he had so many friends, became friendless and alone. As his anorexia got worse, he couldn't even bear to be in the same room as his peers. Basically, his eating disorder took over his life; there was no room inside his head for friends.

Ben's social life was very difficult to fix. Although he dipped in and out of school and friends get-togethers in the sixth form, he was never really part of

that group ever again.

It wasn't until his second year at university that he really began to re-establish himself as part of a strong social group, both here in his home town and at university.

He's made his new friends through his passion for nerdy stuff like RPG (Role Playing Games) and fantasy tabletop war games such as Warhammer. Being a prominent member of the university RPG society, he got to know a ton of boys who shared the same interests as him. Last year he shared a house with four of these friends; this year he's living with three of them in a typical student terraced house where the living room is wall-to-wall nerdy stuff: board and card games piled high, lists of who's won what blu-tacked to the wall, nerdy posters of fantasy sci-fi things and so on.

It's a weird world, but one that - as a parent - I'd far rather have than a house full of students who go out and party late / get drunk all the time. Ben doesn't drink and all the boys seem to prefer an evening's nerdy talk around a Star Wars board game than sitting in a pub.

Take last Thursday for example. I was in Ben's living room waiting to take him home for the weekend. Meanwhile Ben and his three nerdy housemates 'talked shop' about goblins, dwarfs, space creatures, monsters, beasts and goodness only knows what else. It was a language that I didn't understand. But they all seemed happy enough - and that's what it's all about.

I remember the days when, as Ben battled to get through his eating disorder, he'd worry that he'd never find friends with the same interests and that he'd be solitary forever. But he has found friends. good friends - both here in our home city and away at university.

**Friday, 9 December 2016**

## **On the fourth day of Christmas, the anorexia recovery gave to me... “Four life-saving letters: ATDT”...**

Back in March 2010 I wrote my first post on the online forum that was to become a true life-saver for me and my family as we pushed to get our then 16-year old son through his eating disorder and out the other side: ATDT (Around The Dinner Table).

That first post began: *My wonderful teenage son was handsome, confident and popular (especially with the girls!). He was also very sporty, a star player in the school rugby team and the fastest runner in the year. He was also admired throughout the school for his fabulous singing voice....*

It went on: *My son's extreme behaviour started around November - the manic outbursts, head banging, distorted arguments, free fall into some kind of mental breakdown kind of state, totally isolating himself from his friends, problems at school, obsessive exercise, refusing to eat, the works... no point in listing as I'm sure you'll know exactly what I mean... It is now March and we have lived with this escalating nightmare for months now. Goodness only knows how long this road will be... The stress and strain on us, as parents, is massive.*

Several heart-breaking paragraphs later it ended: *I am sure that every one of you reading this will know what I mean when you feel heartbroken seeing your once beautiful, confident, intelligent, friendly, popular child descend into this wreck of a human being who spots the calorie content on some ciabatta he's supposed to have for tea, becomes a quivering wreck of sobbing, banging head against the wall as if he's about to break his skull...*

Over the following months and years ATDT and the wonderful, selfless parents and carers that run it and post on it were to become firm friends, always rushing in with advice and support during the darkest hours as I posted

desperate thread after desperate thread. Even during the night - those lonely, solitary hours at 3am when I'd find myself unable to sleep and hugging a mug of cocoa in the living room with my laptop - there would always be someone there; that's the beauty of a truly global forum for parents of young people with eating disorders.

I got to know many of the UK-based mums very well - by their real names via Facebook. I also met up with many of them for coffee, up and down the country. I still do. Yesterday I spent what has now become an annual get-together with one of the mums as we do lunch, various coffees and Christmas shopping in a city that's half-way between our respective homes.

I've also met up with some of the international mums and others in the global eating disorder community when they've visited the UK. I've made so very many friends, each of whom is a very special person, selfless and caring, always willing to rush in and help during the various 'blips' we've experienced as my son worked towards recovery from his eating disorder.

And a special mention has to go to Charlotte Bevan - a UK mum who consistently went 'over and above the call of duty' when it came to supporting other parents until she was tragically taken from us after a long and brave battle with breast cancer. Charlotte was one of the mums who responded to my first cry for help on the ATDT forum with 'love and hugs'.

I still visit the ATDT forum, mainly on the look-out for parents of boys with eating disorders because we're still quite a rarity. Eating disorders seem to mainly affect girls, but more and more boys are falling victim to anorexia, bulimia and the many other variations of an eating disorder. I look out for parents of boys with eating disorders in the hope that I may be able to help in some way by showing that I've 'been there, done it' and come through the other end. As I've always said, the reason for writing this blog is because I don't

want other families to go through what we went through. If my scribblings here can help in some way, then it's all been worth it.

But all credit must go to the wonderful and amazing Laura Collins, the American mum that founded ATDT in the first place along with its 'parent' website F.E.A.S.T. which has loads of excellent information for mums, dads, parents, carers, relatives and families of young people with eating disorders.

So if you're a parent of a boy with an eating disorder, please introduce yourself on the ATDT forum. I guarantee you'll be so very glad you did!

**Saturday, 10 December 2016**

### **Boys v girls when it comes to 'officially' diagnosing anorexia**

I have a letter in front of me from CAMHS which was mailed to me at the end of that terrible summer of 2010 when my son's eating disorder and associated violence, volatility and dangerous behaviours were heading downhill at the speed of light. His weight was heading south, too. I have the weight chart to prove it. Terrified of where things were heading, I wrote to CAMHS and the letter I have in front of me is their reply.

The letter pretty much centres around the fact that, because Ben *"has not at any time strictly met criteria for a diagnosis of anorexia nervosa, as his weight has never dipped to a point sufficiently low..."* and that Ben *"has, from the outset, been at the point at which re-feeding (in its truest sense) was unnecessary"*, focusing first and foremost on weight gain was not a priority.

Also, *"although he successfully gained weight under the original diet plan, with much of the decision-making removed from his hands, our experience of the last few months is that this was an unbearable and unsustainable situation for Ben"*.

What????!!? A young person with an eating disorder finding re-feeding 'unbearable' and 'unsustainable'? Like, durr... Show me any young person with anorexia who finds re-feeding straightforward!!!!

Anyhow, I will say it again and say it loud and clear: with males, their original BMI can be higher than with girls, especially if they are sporty (muscle) and have a history of eating their parents out of house and home as young men are prone to do.

In my son's case he was a rugby player - a 'forward', the position given to the biggest, toughest guys. Ben also loved his food. As he moved through his teens he lost the puppy fat he'd had at primary school and became all muscle, built - as we used to joke - 'from concrete'. Despite what he used to tell CAMHS over and over again, Ben wasn't "fat" before the anorexia struck, he was physically fit and healthy.

The year before the anorexia he'd completed the gruelling Coast-2-Coast cycle ride with his dad. Shortly before the anorexia, he'd won the 1500 metres in the school athletics. That spring we'd hiked across Dartmoor. He was all muscle, so his BMI would have been quite high before he fell sick with anorexia.

I have always said that I believe my son had lost around one quarter of his body weight by the time he was admitted to CAMHS. Under their care his weight continued to drop gradually (after an initial rise as a result of 'Mum's eating plan'). This letter was mailed to me in September 2010. By February 2011 his weight was to fall to its lowest level since childhood.

Yet his BMI was never sufficiently low to be 'officially' diagnosed with anorexia.

Thus, re-feeding (and subsequent weight gain) wasn't deemed as urgent.

I have always believed that this was a huge mistake, that CAMHS should

have looked at where he was before he fell sick with the eating disorder (i.e. a muscly sportsman) and pushed to get his weight restoration level somewhere close to that. Instead, Ben's weight on discharge from CAMHS in 2012 was pretty much the same as it was 26 months earlier, on admission.

I also believe it is a mistake to gauge whether or not a young man has anorexia based on BMI. Just because "his weight has never dipped to a point sufficiently low" for anorexia diagnosis, it didn't mean that Ben didn't have anorexia. He did. And he had it bad. Very bad.

Throughout that summer of 2010, his anorexia was raging

And just a few weeks on from this letter, Ben would be in hospital with a pulse of 29 having passed out at school.

Good God, this was a boy whose weight had nose-dived and who had lost much of his pre-eating disorder muscle and fat. I suggest that this is common in many young men out there which may be one of the reasons why some males slip through the net when it comes to getting a diagnosis for anorexia and receiving urgent treatment.

And, yes, re-feeding is going to be difficult. Show me any young person with anorexia who's happy to eat!

**Sunday, 11 December 2016**

**On the sixth day of Christmas, the anorexia recovery gave to me... "Six month waiting list angst - hopefully part-processed"...**

This time we're talking about me. Four years ago round about now I began to feel a bit strange - kind of numb and dissociated from what was going on around me. Eventually this was diagnosed as Complex Post-Traumatic Stress Disorder (C-PTSD). Anyway, as you may know, I've been receiving various therapies, private and NHS, and am currently undergoing EMDR (eye

movement desensitization and reprocessing) which aims to 'process' some of the most troubling elements of the trauma. The element we've been focusing on most recently is the anger I feel / felt at how long it took for my son to be diagnosed with anorexia (see last-but-one post as to why he was never formally diagnosed with anorexia) and the various obstacles along my way e.g. GP, CAMHS waiting list (potentially up to 6 months, hence the tenuous title of this blog), etc. Suffice to say that although the anger will never go (of course it won't, it's only natural!), it should be a little easier for me to deal with now and here's why...

***Self-blame.*** I don't blame myself as much for not pushing harder to get my son diagnosed and into effective treatment for his eating disorder during those dark days of autumn / winter 2009 when he was 15. I did the best I could given what I knew at the time. I was new to eating disorders. It had only recently dawned on me that boys get eating disorders too. While battling with the medical professionals, I was going through a massive learning curve, cramming up on everything to do with eating disorders while gradually realising that there wasn't a 'one-size-fits-all' treatment. Plus, there was precious little out there about boys with eating disorders. And, for the whole of October, I was virtually horizontal with a debilitating inner ear virus. **The EMDR has helped me to realise that I was not to blame for the length of time it took to get my son in front of CAMHS.**

***People in authority are right.*** Wrong! I was brought up to believe that people in authority are RIGHT and that I, as an ordinary human being, am WRONG. This black-and-white assumption is incorrect. I might be 'just a mum' (albeit a graduate businesswoman), but as I ploughed on through the eating disorder learning curve (unfortunately I wasn't to come across the brilliant FEAST website and ATDT forum until later) I actually began to know more

about eating disorders than our GP and other people who were implying that my son's case wasn't urgent.

For me it was vital that I do this - my son's life was at stake. So if I had to cram round the clock, I was prepared to do it in order to get an understanding of this horrific and potentially deadly illness. And, if the NHS wasn't going to do anything about my son, then I damn well was. The alternative was too terrifying to think about...

Today - 7 years later - I know a heck of a lot about eating disorders and effective evidence-based treatment, especially when it comes to boys with eating disorders. Just because I don't have a medical qualification it doesn't mean that I'm not an expert on eating disorders. The EMDR therapy instilled in me that **I am an equal, not 'just a mum'** and that people in authority are not always right.

Trusting my gut instinct. I have realised that my instinct as a parent is the most important thing of all. I know my child better than anyone else.

My gut instinct was telling me that my son was getting sick and becoming worse by the day. The EMDR therapy has helped me to 'big up' this instinct by visualising myself as 10-feet tall and the GP as tiny. There I am (in the visualisation) towering above the GP, stating my case loud and clear. Beside me (in the visualisation) is the school nurse - the first medical professional that really 'got it' and who remained my #1 support from the medical profession throughout the eating disorder. In my visualisation she is there to reinforce what I am saying because, during EMDR, I still found it difficult to visualise myself as an equal ('just a mum') to the GP ('authority'). **As a result of the EMDR I feel much stronger as a person.**

*However... this processing isn't complete.*

The problem is, as I will be telling my therapist this week, my raw anger has

moved on to what took place during those first months at CAMHS....

**Sunday, 11 December 2016**

**The letter I'd love to send to Ben's CAMHS psychiatrist but of course never will**

Dear Ben's Psychiatrist,

First let me say that the bouquet of flowers we gave you on our final visit in 2012 really was to say thank you - genuine thanks for being such a nice person, for going 'over and beyond the call' when it came to CAMHS sessions running overtime and for truly empathising with my son. As the months went on, any professional disinterest evaporated. I believe you really cared for my son. I know you liked him. And I hope I'm right in saying that, throughout those final months of CAMHS treatment for my son's eating disorder, you treated me as an important and valued part of the treatment team. You listened to what I was saying, especially after we introduced our 'contract' and you saw it was working.

It's because you are such a nice person that I find it difficult to be critical of those first months at CAMHS - those 8 or 9 months up until my son ended up back in hospital with the heart issue. I am also aware that as a CAMHS psychiatrist you were multi-disciplinary; you didn't just deal with eating disorders and you probably had little if any experience of dealing with boys with anorexia. I am also aware that we're talking about the years before our city rolled out FBT (Family Based Treatment) for eating disorders which, from the evidence, appears to suggest a better outcome for young people with

eating disorders. Back then, our CAMHS didn't offer the Maudsley Approach / FBT.

During those first few months with CAMHS it took a while for you to 'get it' - to realise that my son's eating disorder was very serious. It also took a while for you to realise that my son was play-acting, pretending to be relatively OK while convincing you that his mum was being over-anxious and over-reacting. Remember when you suggested that we might only need to see you fortnightly? If only you knew what that did to my panic levels!! Aaarrggghhh!

During those first months, the boy that you were seeing wasn't the same as the boy outside the CAMHS sessions. He was a great actor! You should have seen him when we left CAMHS. He'd punish me all the way back and at home, especially if he'd put on weight. Why did you ever let him know what the scales were saying? Why didn't you weigh him 'blind'? Maybe we'd have had fewer fire-fighting sessions...

Also during those first months, I felt that you weren't taking me seriously, that you saw me as over-anxious and unhelpful. I'd actually challenge any parent not to be anxious when faced with a potentially deadly illness in their child. Yes, I was panicking and perhaps trying to get too much accomplished too fast. But what I really needed to see was a Plan: an A-Z Treatment Model that made sense to me. Throughout my son's treatment I never really felt that there was a Plan as such. More a case of reacting to his current moods and weight, and pacifying the eating disorder.

I wanted you to get him to eat. My research had shown that 'food is medicine' and that getting a proper, balanced diet into my son was vital leading to weight gain. But I needed help in doing this. I couldn't get him to eat. Mealtimes were a nightmare. He was stronger than me and he could be violent. I needed hands-on support with an eating plan and in our home at

mealtimes. Yes my son found re-feeding "unbearable and unsustainable", but I'd argue this is the case for everyone with anorexia until they begin to engage with the weight restoration programme. Instead, I felt that I was 'Big Bad Mum', perpetrator of 'Mum's Eating Plan', while CAMHS were telling my son that it was OK to give it up because his weight wasn't too bad. During these early days at CAMHS there was an awful lot of triangulation and, to be truthful, I felt as if it was CAMHS and the eating disorder (in my son) against me: Big Bad Over-Anxious, Panicking, Food Wielding Mum.

I know that much of The System that was CAMHS and the NHS was out of your hands. Things like making it difficult for parents to contact therapists and then making it even MORE difficult. Also, when the dietetic service was withdrawn. Plus the criteria for official diagnosis of anorexia nervosa which may have led to my son's weight loss not being taken as seriously as I believe it should have been.

On a more positive note, I also believe that round about September / October of 2010 you and I began to land on a similar page. First there was that meeting I had with you where I went through point after point that was troubling me - the first time I truly felt that I was getting through to you and that we were beginning to see eye to eye. I believe this meeting was something of a watershed.

Very shortly after this came Ben's (second) admission to hospital with the slow pulse rate. At the CAMHS session that followed I really felt that - for the first time - you were coming down on the anorexia like a ton of bricks. Ben needed to engage in recovery or he could be sectioned. The relief I felt was massive. For the first time for ages I felt safe. I felt that you 'got it' and would do whatever it took to get my son through this nightmare.

However I know that treating someone for an eating disorder is never going

to be linear. I also know that it must be incredibly stressful and difficult for the therapist. If only it was a case of being able to pop a few pills and - bingo! - the patient is on the road to recovery.

But I do believe that, during those final months at CAMHS, the treatment was more effective because we were working as a team rather than triangulating. I am so grateful that you were happy for us to try out the 'contract' from Easter 2011 onwards and that you worked with me to keep Ben on the straight and narrow.

*However...*

Ben trusted you. He liked you. He felt motivated to engage with you as we pushed towards recovery. You know what I wish? I wish you'd pushed for full weight restoration based on Ben's pre-eating disorder weight. Ben always insisted that he was 'fat' before the eating disorder (how he used to go on about that, hey!!). Yes he'd had puppy fat at primary school, but for the 3 or 4 years before the eating disorder he'd been a normal strapping teenager. He wasn't fat at all. It was all muscle. So there was no reason on this planet why we shouldn't have worked to get his weight back up there.

But I know there were also other reasons why Ben's treatment ceased when it did. He'd reached the age of 18 and therefore no longer qualified for CAMHS treatment. He said no to the idea of adult services treatment; you are the only therapist he has ever trusted. He wouldn't engage with anyone else. You were also taking a sabbatical from CAMHS at that point. And so Ben was discharged at a low weight and with many eating disordered thoughts still going round his head.

I only wish we'd had longer at CAMHS and that you could have seen the treatment through to full weight restoration and brain healing. Especially now that our local NHS is adopting the FBT model. Knowing what we all know now, I

truly think that we could have moved mountain.

*You had unique leverage when it came to getting my son well.*

I truly regret that circumstances prevented us from completing the exercise. Working alone with Ben, without your support, was very difficult during the post-CAMHS months. Ben and I did it in the end, but one of the things we never managed to do was to get Ben's weight back to what it was before the eating disorder. Sure, he's OK, he's healthy, he eats well and all that. But the fact that he never got properly weight restored constantly worries me because there is little room for manoeuvre should anything happen to make him lose a lot of weight very quickly. And he still fears 'getting fat again' despite the fact that we're talking about the puppy fat of pre-pubescent years and not the years in the run up to the eating disorder.

Ben listened to you. He respected you. He liked you. I believe you could have got him properly weight restored. We both miss you!

Lots of love and good wishes, Ben's Mum

**Monday, 12 December 2016**

**On the eighth day of Christmas, the anorexia recovery gave to me... "Eight Christmasses since our first ED Christmas"...**

2009... 10... 11... 12... 13... 14... 15... 16... It's eight Christmasses since our first Christmas with the eating disorder. At Christmas 2009 my now 16-year old son, Ben, was on the waiting list for CAMHS treatment for his eating disorder; he'd been on the waiting list for a month and it was a couple of months since the GP had sent off a referral. Ben was seeing a private CBT therapist in a bid to stop his escalating eating disorder falling off a cliff. Despite the therapist's best efforts (ironically the same therapist I'm currently seeing for EMDR therapy), it didn't work. Ben got worse. By the New Year of 2010 he was a

shadow of his former self. He'd become volatile and violent, he'd developed a slow, low, monotone of a voice - 'the voice of ED', as we called it, his eyes were dark and blank, he was painfully thin, his skin was dry and transparent, and he had bruises on his back where he'd put his bony body through umpteen sit ups which he did several times a day.

Christmas Eve was a nightmare, as described in my blog for 2009, but Christmas Day itself wasn't too bad. It was as if the eating disorder had decided to give us the day off. But it was back with a vengeance on Boxing Day.

If we thought that Ben was thin that Christmas, he was to become even worse by the following Christmas: Christmas 2010. Although he himself had made the decision to push for recovery back in the October (following a threat to 'section' him after a second hospital admission for heart issues), the eating disorder was so very powerful that he was unable to do anything. His weight continued to drop and by February 2011 it had reached its lowest point.

Christmas 2011 was somewhat better. I'd been writing my blog for 12 months, so you can read about it in the archive or by downloading the free PDFs on my blog. Ben was in the Upper Sixth Form at school and, with any luck, on his way to university the following September. We'd been doing our 'contract' since Easter 2011 which meant that Ben had put on weight. He was also looking and feeling a heck of a lot better, but there were still quite a number of outstanding issues yet I knew that, because he'd reached the age of 18, he was about to be discharged from CAMHS treatment.

Ben wasn't quite where he'd planned to be by Christmas 2012. He'd planned to be at university, but - after a few unsuccessful days - he'd decided to take a gap year. He and I were busy working on the outstanding issues which needed fixing before he was ready to go away to university. The main issue was the social aspect. The eating disorder had isolated Ben and he needed to re-learn

his social skills and build a new circle of friends. A blog post from December 2012 sums up the year admirably, so there's no point in me repeating everything here. Christmas 2012 also saw the very first signs of what was to become my Complex Post-Traumatic Stress Disorder. In this post I talk about how I'd begun to feel a bit weird: numb and yet very anxious and fatigued; the nightmares had also started. Who would have thought that four years on I'd still be receiving treatment for C-PTSD!!!

Here's how I began a post on Boxing Day, Christmas 2013: If the 'me' of Christmas 2009 could have looked into a crystal ball and seen our family Christmas of 2013, I would have positively exploded with hope. Christmas 2009 was the first Christmas that ED, the eating disorder demon, sat alongside us, uninvited, at Christmas Dinner (and all the other Christmas meals and festivities). Yesterday, on Christmas Day 2013, I can proudly say that the eating disorder was nowhere to be seen. And I hope that our experience of emerging from an eating disorder, will offer other families hope for the future.

I didn't write a post for Christmas 2014 - my PTSD meant that it was difficult to blog, to write, to read... I hadn't blogged since the September. I don't even appear to have any photos. Ben was doing well, though. He was well into his second year at university and had built up a lovely group of new friends. I seem to remember that we treated all of them to pizzas at Pizza Express for Ben's 21st birthday!

Then Christmas 2015 was 12 months ago. Ben was in charge of the cooking, something he's been doing for a couple of Christmasses. He also did all the catering for Christmas Eve - all wonderful stuff, especially the sticky toffee date pudding with creamy butterscotch sauce. It was awesome!! This is how I summarised Christmas 2015 in my blog: I think we had one of the best Christmases we've had since before my son fell sick with anorexia... It was the

kind of Christmas I could never in my wildest dreams have imagined when my son was sick with anorexia.

**Monday, 12 December 2016**

### **The problem I had with getting my son to eat**

By March 2010 I was getting desperate and although we'd been seeing CAMHS for a month, I wasn't getting any support with the eating plan that I'd asked them to give me. It was jam-packed with all kinds of things that my son wouldn't eat in a million years. The same goes for the self-help eating disorder books I was busy reading.

Meanwhile, I'd also discovered the Around The Dinner Table forum (for parents of young people with eating disorders). The forum was generally advocating FBT (Family Based Treatment) otherwise known as The Maudsley Approach - a model that didn't bear any resemblance to the treatment my son was getting at CAMHS. Indeed it seemed like a complete reversal: food first, brain second rather than brain first, food second.

I posted on the forum, asking whether I should be focusing on CALORIES or PORTION SIZES. Our dietitian was insisting on portion sizes. But, with a boy who wouldn't eat any fats and minimum carbs, portion sizes were always going to be a loser from the start. A portion of salad or veg simply didn't have the weight-gaining clout of a portion of steamed pud and custard, macaroni cheese or whatever.

The advice (from the mums on the forum) was to plate up meals myself and to ensure they had loads of calories in them. 'Magic Plate' (used in The Maudsley Approach / FBT) is where you simply put the food in front of your child and sit there until they have finished.

Sadly that wouldn't have worked for us as I explained in replies to their messages:

*The trouble is... I can't force feed him these things and he refuses to eat them. He won't open his mouth. And then he goes off into one of his out of control screaming / head banging sessions. Keeping him seated at the table doesn't work because he just escapes or smashes his fist down onto the food, mashing it up so it's inedible (and then escapes).*

*In our small house, keeping him away from the fridge is impossible and in the fridge are products covered with nutritional labelling. If I remove the labelling or try to cover it up, he knows I'm hiding fats I don't want him to see.*

*Occasionally I can sneak things like butter into the mashed potato, but his taste buds have become SO fine-tuned into noticing when it tastes different, he immediately knows when I've added stuff.*

*Our latest battle is to try to get him to eat Low Fat Yogurts (115 cals per pot) as opposed to Zero Fat Yogurts (75 cals per pot). I anticipate BIG FIGHTS about that...*

*I have NO IDEA how I can get him to eat higher fat things without literally force-feeding him which is impossible when he's nearly 6ft tall and pretty strong, and I'm only small. Help!!!!*

*I can tell him that there is evidence to suggest fats help with depression, etc*

*until I'm blue in the face but I might as well be speaking Chinese... ESPECIALLY as his weight has just slipped through into the "safe" BMI range WITHOUT the need for these "extra fats" (as he says...) so giving him fats now at this stage, he insists, will make him balloon out into a monster... He feels they are totally unnecessary.*

*The toys were thrown out of the pram again at lunchtime when faced with a beef sandwich, "dripping" with fat followed by a seemingly endless and pointless argument with my response consistently along the lines of "I am not arguing, this is the way it is and that's final" etc etc etc etc... then threats of what he will do when he's next weighed and has ballooned out into a ten tonne monster, all my fault and all thanks to my extreme diet plan which, apparently, would horrify the dietitian and he's going to make sure she knows I'm mistreating him / fattening him up so much.... "Fine, OK, do that, see if I care" say I, etc etc etc...*

*The bad news is that on Day 2 of the Standard Yogs I caught him trying to bin half a pot (I intercepted it and made him eat it) so on Day 3 when it was H's turn to monitor breakfast I told him to be vigilant... which he wasn't... until he looked in the bin and found a piece of kitchen paper containing most of the yog which should have been eaten with the cereal... So we are being super vigilant now, like prison warders (which is what I am normally but H hasn't been so strict; now he knows why he needs to be...)*

*So how did I get my son to put on weight? I didn't. Well I did initially as I persevered with the eating plan, sans support. But within a month or so it was decided that 'Mum's Eating Plan' was too stressful for my son. It was dumped.*

My son took over preparation of all meals except the evening meal. The idea was to trust him to be eating what he claimed to be eating. If the CAMHS scales showed weight gain, then he was obviously making the right choices. If they showed a loss, then he was making the wrong choices. This way he would learn how to make the right choices... And, anyway, CAMHS weren't too worried about his weight; a month or so on the eating plan had tipped his BMI back into the 'healthy' range.

Just.

But it was too much independence and trust, too soon. Not surprisingly my son wasn't eating nearly as much as he needed to be eating in order to put on weight. He lied about how many calories he was consuming for breakfast and lunch. He disposed of food. He policed the kitchen as I prepared evening meals, analysing them scrupulously for anything that had been sneaked in and weighed every meal to ensure he wasn't getting a Nano Gram more than me.

From this time onwards, his weight gradually dropped - and I stood there watching, feeling heart-broken and powerless.

***So why did I fail to get my son to eat and put on weight in those 9 or so months between the withdrawal of 'Mum's Eating Plan' and the point when he reached his lowest weight?***

Purely and simply because I didn't get any support with eating. My son was too wilful and strong for me. His dad was working away much of the time and so it was little me against tall him - and you'd be surprised at just how physically strong Ben could be! On top of this there were threats to run away and suicide threats. I was powerless.

CAMHS preferred the 'talking treatment' - the 'right / wrong choices' based on what the weekly weigh-in was saying. As a result if he gained a little weight he promptly lost it again after a frantic 'fire-fighting' CAMHS session. If he lost

weight, the CAMHS session went more smoothly.

To be successful, I would have needed someone to come into our home at mealtimes, someone properly trained in getting the patient to eat. I would have needed full support in the CAMHS sessions and for us to present a united front against the eating disorder. Instead I was made to feel that my actions were 'unhelpful' at best and interfering, even harmful at worst. My son was absorbing these messages like blotting paper: mum's food obsession = bad, CAMHS softly-softly approach = good. And, anyway, most of the sessions were individual with the occasional family session - or with me being invited in for the final ten minutes.

To be successful in getting my son properly weight restored, I would have needed my son to be weighed 'blind' so the CAMHS sessions (and the 'mum punishment' afterwards) weren't so reactive, for me to be in charge of all meals magic-plate-style with hands-on CAMHS support and for CAMHS to insist on gradual weight gain until he reached his pre-eating disorder weight. A weight gain of 0.5kg a week is what is suggested in the NICE guidelines. Yes, on occasions my son did gain 0.5kg a week and sometimes slightly more. But then, after a fire-fighting CAMHS session, he'd lose it again - and more.

Trying to get my son weight restored on my own was never going to work, especially when he was being informed that his weight had just tipped into the 'healthy' range. And also (on one occasion) that apparently some people choose to stay at a low weight because they find it easier to handle. Plus (on one occasion) that Ben might find it easier to choose a weight he felt he could cope with.

With this kind of message why on earth would my son ever be motivated to eat a normal balanced diet and gain weight?

*It makes me exhausted just to think about this lengthy period and the sheer*

*helplessness I felt as I watched my son's anorexia get worse together with CAMHS sessions where the clear message to me was to 'back off' on the food wielding front.*

This is what the Maudsley Parents website says about the more traditional, non-FBT models for eating disorder treatment:

*More 'traditional' treatment of AN [anorexia] suggests that the clinician's efforts should be individually based. Strict adherents to the perspective of only individual treatment will insist that the participation of parents, whatever the format, is at best unnecessary, but worse still interference in the recovery process. In fact, many proponents of this approach would consider 'family problems' as part of the etiology of the AN [anorexia]. No doubt, this view might contribute to parents feeling themselves to blame for their child's illness. The Maudsley Approach opposes the notion that families are pathological or should be blamed for the development of AN [anorexia]. On the contrary, the Maudsley Approach considers the parents as a resource and essential in successful treatment for AN [anorexia].*

In our situation I don't know what I could have done. I did everything I could. I made my concerns clear at CAMHS. I posted on the ATDT forum (goodness only knows what I would have done without this support!!). I tried my damndest hardest to get my son to eat. I couldn't have done any more than this and it makes me so very, very sad knowing what I know now about evidence-based treatment not to mention the fact that my city is now adopting FBT (Family Based Treatment) as the preferred treatment model for adolescents with eating disorders.

If only they'd done this back then.

If you're struggling to get your son or daughter to eat, take a look at Eva Musby's videos for parents on YouTube, each very watchable and incredibly useful. She's also written a great book - Anorexia and other eating disorders: how to help your child eat well and be well - endorsed by many parents and professionals. Google Eva Musby.

**Tuesday, 13 December 2016**

### **Triangulation - the eating disorder's favourite state of affairs**

Back in 2010, as we neared the point where my son was given control of his breakfast, lunch and snacks and 'Mum's Eating Plan' was dumped, there was some super-triangulation going on. By this I mean that different people were saying different things. Eating disorders love this. What eating disorders find tricky is when everyone - both parents and everyone in the treatment team - is 'on the same page', presenting a united front against the eating disorder.

Another thing that eating disorders love is for people to argue with the patient - to try and rationalise, explain, bribe, bargain, reason, etc. An argument with someone entrenched in eating disordered thinking is an argument you are never going to win. As a parent or carer you need to demonstrate that you are in complete control. You are the boss.

As the wonderful mum Charlotte Bevan advised in her reply to my forum post below, don't argue, just sit there until he eats, saying things like: "Food is your medicine, I love you more than the eating disorder, Hmmmmmmmmmmm - repeated endlessly!" One mum said she tended to "blank out" what the eating disorder was saying, treating it as "white noise".

But back then, I was terrified of where my son's eating disorder was heading - and not 100% confident in CAMHS which was kind of scary seeing as they

were responsible for potentially saving my son's life.

We were triangulating. On one hand, our psychiatrist was keen to pass food control over to my son, but the dietitian (who we saw separately) wasn't. My husband was kind of floating between the two much of the time. Then there was me, wielding the 'dreaded' Eating Plan, keen for my son to put on weight and get back to where he was before the eating disorder struck.

This edited version of a thread I posted on the Around The Dinner Table forum in May 2010 describes what was going on at the time and is an example of both triangulation and trying to reason / bargain with the eating disorder:

*Last week, after 6 very successful days sticking to the eating plan, my son refused to eat the meals and snacks I put in front of him. The only way I could get him to eat was to allow him to take back some control over his intake and strike a deal that if he LOSES weight by his weigh-in next week, then I take back total control. The psych has been 100% behind my son's desire to take back some of the control whereas I've been 100% sure my son isn't ready to do so. Triangulation, with me as the 'baddy'.*

*Anyway, we saw psych on Fri followed by the dietitian. Psych is still behind my son's desire to take control despite the fact he had LOST 0.7 of a kg on Friday (which must have happened during the 'pear shaped' days when my son was refusing to do the eating plan). Meanwhile the dietitian is completely on my side, unhappy about my son taking this control and reinforcing why this diet plan was prescribed and needs to be followed. Reluctantly however after my son's protests, she agreed that he could continue with the 'deal' with the caveat that if he hasn't put back the lost weight by Friday's weigh-in, then I take back control and the strict eating*

*plan kicks in with a vengeance.*

*It all started well, with my son mirroring the eating plan on Friday. But then on Sat he went on his camping trip with his friends - great from a social point of view, but terrible from a food point of view. When he got back, he was just like any other boy who'd had a fun weekend with his mates which was good... initially... but then things quickly spiralled out of control as he started to tot up his calorie intake, checking calories on the Web, etc - and he went into total panic, convinced he'd been 'bingeing', disgusted at himself and generally beating himself up about this so-called 'binge' and refusing to eat any more food today, also refusing to let me take back control and reinstate the eating plan which all my instincts scream that I should be doing. I can't clamp his mouth open and force-feed him - and the eating disorder just spits back at me that I can't go against what the psych has instructed. So what can I do?*

*Things have gone totally pear shaped and very, very messy. It's not come as a surprise and I'm mad at the way the treatment team have been handling this with, on one hand, the pscyh telling my son that yes it's great he's taking more control and, on the other, the dietitian insisting he isn't ready (which I agree with). Plus, because of this, my son is getting some pretty dreadful mixed messages. So much for 'all singing from the same hymn sheet'...*

*We have a weigh-in with the nurse this week, but we don't have a pscyh or dietitian appointment for another fortnight. And if my son hasn't put on the lost weight, then who's to say he will stick to his side of the 'deal' and*

*allow me to reinstate the eating plan. Help!!!*

*I've had a very stressful week. My son continues with his version of the eating plan and screams at me if I make so much as a whimper about what he's eating. Meanwhile I am sure he isn't eating enough (to put it mildly...) (He is trying quite hard, but he really isn't eating enough, but I guess Friday's weigh-in will be the telling time.)*

*I've had massive arguments with my husband who keeps accusing me of "Going against all the professional advice" (which is to let my son get on with things his own way) over and over again while my son accuses me of being a control freak because I can't handle losing control of the eating.*

*Meanwhile I can't get hold of the CAMHS team or the dietitian, having emailed, phoned, arranged for the nurse to leave messages in pigeon holes, etc. No-one is getting back to me.*

*And I know on Fri when we see the psych she will whisk my son off to be weighed followed by a session between her and him while H and I see the nurse (who never seems to pass our concerns on to the psych, or at least it never seems that way). By the time we see them at the end of the session, she'll have said something like: "He's lost a little weight, but I feel he's doing SO WELL we'll let him carry on as he is... I've told him to try a little harder to eat more..." sort of stuff.*

*I feel as if it's just me, surrounded by my son, husband and a divided CAMHS team and I am very, very depressed about it all.*

**Tuesday, 13 December 2016**

**26 months of eating disorder treatment. Total weight gained? 1kg.**

It is as clear as day to me that my son should have gained a substantial amount of weight during the 26 months of eating disorder treatment with CAMHS. My gut instinct (as well as common sense) told me that we needed to get his weight back to where it was before the eating disorder struck in order for the weight restoration element of his eating disorder treatment to be considered complete. Remember, contrary to what he'd been telling his therapists over and over again, Ben wasn't in the slightest bit fat before the eating disorder developed. Yes, he'd had quite a bit of puppy fat at primary school but that was yonks ago. In 2009 when Ben's eating disorder began to emerge, he was 15.

Terrified at where things were heading during his eating disorder treatment, I did a spreadsheet of his weekly weights between the first eating disorder treatment session and the last. He was exactly the same weight on discharge as he was on admission.

Actually this is not strictly true. He was 1kg heavier on discharge than he was at the start.

If you do the maths, this averages out at a weekly weight gain of 0.00925kg over 26 months. The NICE (National Institute for Clinical Excellence) guidelines say: *'In most patients with anorexia nervosa, an average weekly weight gain of 0.5–1 kg in inpatient settings and 0.5 kg in outpatient settings should be an aim of treatment. This requires about 3500 to 7000 extra calories a week.'*

As I have said before, the problem was that CAMHS weren't too concerned about Ben's weight whereas I was. They hadn't seen him before he fell sick

whereas I had - I knew my son better than anyone else. And CAMHS may have believed him when he claimed to have been "fat" beforehand. So this might explain why the weight issue was put on a back burner.

The problem is that, while growing up, Ben's weight and height were never officially measured before the eating disorder struck. There was no need; he was healthy and fit - and he looked fabulous. As a result I had nothing to show the CAMHS team except a few photographs. There were no concrete figures.

But there was one exception, a year before Ben fell sick when, in PSHE lessons at school, they worked out the students' BMIs. This is how I know that Ben had lost around one quarter of his body weight when he started at CAMHS. But it wasn't anything that was 'down on paper'; I just remember him telling me about it very clearly. (And sometimes I wonder whether this was the trigger for his eating disorder. As a rugby player and regular sportsman, his BMI would have been quite high when compared with his peers, potentially conveying the message that he was 'fat'...)

Although there are many common elements between both sexes, there are some elements and presentations that are unique to young men and boys with eating disorders. I would like every eating disorder professional and GP out there to spend some time on the Men Get Eating Disorders Too website which describes the common symptoms in males with eating disorders. This is the page which talks about anorexia in boys and men.

**Saturday, 17 December 2016**

**The triangulation gets worse...**

How I wish I could go back to late June 2009 and hug the 'me' that I was then. Judging from my posts on the Around the Dinner Table forum, I was desperate.

Truly, utterly and completely desperate, feeling totally powerless and lost. This was the month that my son 'took back control' of his own eating when it was decided that 'Mum's Eating Plan' should be dumped. It was also the month that the dietitian was withdrawn.

This was the month that my son attempted to climb onto the house roof and began to feel suicidal. By the end of June the triangulation between me, my son and CAMHS had gone into overdrive. On the one hand, we had what my son claimed that the psychiatrist was saying during their individual sessions. On the other, we had the discord between the three of us during 'family sessions' or the 10 minutes at the end of individual sessions when I was sometimes invited into the room for a summary. We also had those occasions where I'd try to grab the psychiatrist to express my concerns, away from my son. And then we had my husband which created triangulation and discord at home.

We were about as far away from being on the 'same page' as it is possible to be; it was like polar extremes. And, as we know, eating disorders love triangulation. Such situations enable the eating disorder to thrive and 'take sides' with the person or people who are most likely to make life easy for them.

In late June 2009 I was posting on the ATDT forum:

*I am in an impossible situation. Today I'll try again to get hold of the psych but this time to insist that I believe my son is at risk and insist she writes me a prescription for anti-depressants. Then I need to persuade my son to take them (which will be impossible). Meanwhile what do I do? This could be threatening our marriage as my H blames me for Ben's outbursts and accuses me of "going against all the professional advice" because the CAMHS team "obviously know what they're doing and look what happens*

*they you try to do it your way". This was after having agreed with Ben that we'd go back to the eating plan if he loses weight again this week. At the end of the evening Ben denied agreeing to it - and refused to do so saying he'd laugh in my face if he actually put on weight this week. And meanwhile he's seeing the triangulation between me and the psych, and last night between me and his dad. Game, set and match to the eating disorder, definitely. And I've no idea what to do now. No idea. Feel totally and utterly defeated with everyone against me.*

And also:

*Yesterday the psych wasn't "unduly concerned" about weight loss at our session today as, despite his consistent weight loss recently, he is "nowhere near what he was when the treatment started" which, I take it, is a "good sign because he's done so well". (Note, I write all this with gritted teeth...)*

*I'm being told that we need to take the focus off the eating and concentrate on the psychological side of recovery because "I think it's time focus less on the eating side of things and more on working together as a family to see what is helpful to son and what isn't".*

*And, it seems from what my son is telling me, that I am probably the reason why he got anorexia in the first place - by being an overprotective mother and by passing my own anxieties to my son. (My teeth are grinding themselves down now, they're so gritted...)*

*Worse, according to my son this morning, the psych said that, for him and*

*his build, a weight gain of 0.5kg a week is totally unreasonable and we shouldn't expect that. (Despite the fact that, when I was in control of the eating plan, he gained weight consistently at that pace, often more. And despite the fact that she doesn't know what his build is - she never saw him playing No 3 in the school rugby team!)*

*My teeth are now ground down to the gums... Oh, and because it's the summer, we should take things a bit easier all round...*

Not surprisingly, I was having difficulties sleeping.

*Been up since the crack of dawn this Sunday morning... couldn't sleep, I was so wound up about it all, especially following our evening meal yesterday which catapulted us back at least 8 weeks - and when we saw the photos of our son at the school prom, looking so thin and pale, even my H realised that we're getting nowhere.*

*However my H wondered if CAMHS have some kind of "hidden agenda" as he calls it whereby they concentrate on working on the reasons behind the eating disorder before working on the re-feeding which, hopefully, should come naturally as a result of the reasons behind the eating disorder being sorted out.*

*Meanwhile my son is refusing to speak to me about food AT ALL because of the psych criticising me for "going on" about food and feeling we "should focus less on food and more on what is helpful to son as regards how you and your husband approach this and talk to him".*

*And all his old little eating disorder tricks and behaviours are coming back... up to now they were gradually slipping back into his routine, but over the past week it's as if the floodgates have been opened and - woosh!!!! - in they all come.*

*And meanwhile he lost weight again on Friday so since he took back control of his own eating at the insistence of CAMHS 6 weeks ago he has only put on weight during ONE of those weeks; the rest he's lost it. My alarm bells are ringing so loud I feel as if I'm going to explode.*

I feel so very, very sad for the mum I was back then. All I wanted was to get my son well and I couldn't understand what CAMHS were trying to achieve through the eating disorder treatment. All it seemed to do was to make my son lose weight and make us all fight because of the triangulation. Plus, there was a lot of implied blame - that the eating disorder was my fault as a mum because I was 'over anxious'. (Well I'd challenge any parent in an eating disorder situation not to be anxious...)

I couldn't 'back off' because my gut instinct screamed out that the eating disorder was getting worse, not better. It was my duty as a loving, caring parent to ensure that my son was getting the kind of treatment that would make him well, but things were getting worse at home (which CAMHS never saw of course) - moods, behaviour, yelling, banging and crashing, refusal to eat, suicide threats, eating and weight - and I couldn't for the life of me see how the eating disorder treatment was working.

So, although I was helping to triangulate by disagreeing with CAMHS and pushing for things they wanted to put on the back burner (eg weight gain and a balanced diet), I couldn't help it.

I needed to trust my gut instinct as a mother and that's what I did.

**Saturday, 17 December 2016**

### **Feeling as if the whole world is against you and your gut instinct as a parent**

As a parent, you know your child better than anyone else and Ben and I had always been close. So when he got more and more sick with the eating disorder in the early summer of 2010, despite four months of CAMHS treatment, my gut instinct was screaming out that things were WRONG!!

Now that the eating plan had been dumped, my son's weight was heading south again; he'd lost exactly 3kg in four weeks (I have the weight charts to prove it). He was also getting more and more violent, volatile and manic - and he was taller and stronger than me, so I couldn't restrain him. My husband was working away from home so most of the time it was just Ben and me in the house. Or, rather, Ben, the eating disorder and me.

I felt as if the whole world was against me: CAMHS, my husband and my son. Yet, because of my iron-strong gut instinct, I simply couldn't accept their advice to 'back off' and to stop talking about food and eating.

My gut instinct said this was WRONG and that an adolescent who had lost around one quarter of his bodyweight (and 3 kg in the past four weeks) and who had changed beyond all recognition - mentally and physically - needed re-feeding with a proper balanced diet in an attempt to get his body and mind back to where they used to be before the eating disorder struck. Or at least to get his body back there so that we could then work on the mind - the kind of treatment an adolescent might get if offered Family Based Treatment (FBT) otherwise known as the Maudsley Method.

But no-one was listening to me. Instead they were telling me to 'back off'. In

other words, to shut up and stop going on about eating and food while my instinct yelled out NOOOOOO!!!!

On 23rd June 2010 my son's eating disorder was raging and here's what I posted on the Around The Dinner Table Forum:

*Some of you will know what I mean when I say we had another night like the one we had a couple of weeks ago [when my son attempted to climb onto the house roof, not caring if he fell off]. Only this time my husband is working away so it's just me...*

*No roof, but an email to a friend, distressing enough to have the friend's mum calling me to warn me something was afoot. [Ben had emailed a friend asking for reasons why he should continue living. Not surprisingly the friend was traumatised by this and it resulted in the friend's mother calling to tell me what had happened...]*

*All this resulted THE MOST TERRIBLE NIGHT with the eating disorder at its most "magnificent" and "satanic". Me, on the phone to the emergency doctor asking for advice, but my son refusing to go to A&E (ER) to see the mental health team. [And I wasn't physically strong enough to carry him there...]*

*My husband called me half-way through all of this and tried to talk to my son to bring him out of his mood, then I took the phone and my husband started to blame me for these eating disorder moods because apparently everything would be easy-going and running smoothly if it wasn't for me "going on about food", implying that my son only has these outbursts because of me.*

*And my husband has banned me from talking to my "cronies on that forum" [the Around The Dinner Table forum] because "what do they know? Everything they say [usually about the need for re-feeding and seeing if he can be treated using the FBT / Maudsley treatment model] goes against all the professional advice" (i.e. CAMHS' advice).*

*So I'm banned from mentioning food ("How do we treat an eating disorder without talking about food?" I asked!!!)*

*My husband just wants to let Ben carry on as he is. If he gets bad enough to be admitted as an in-patient then so be it, let the professionals deal with it because "they know what they are doing and you obviously don't!"*

*I ended up hanging up on him as it was blame, blame, blame... Ben heard the whole conversation and now every time we have one of these eating disorder fits, he is going to blame me. And no way will my husband look at any of the info you sent through... he hates you all!*

*In the end my son went to bed in a fake relaxed mood (undercurrent still there...). The eating disorder no doubt jubilant at the fact I was surrounded, General Custer Style, enemies around me, all fighting on the side of the eating disorder.*

Thankfully once my husband was back home for a few days and I was able to talk to him in depth and he had time to read through the various books and talk to some of the parents on the forum, he began to come around to my way of thinking so I didn't feel so alone.

But on the 23rd June 2010 I felt gagged. No-one was allowing me to talk about eating or food - yet, from what I was reading and learning, not to mention my gut instinct as a mother, that was the NUMBER ONE issue that I needed to be talking about and working on.

**Sunday, 18 December 2016**

### **Why FBT is being adopted in some NHS authorities as first line treatment for young people with anorexia**

A couple of years ago when I went to Glasgow to hear James Lock (of Stanford University) speak about the evidence for FBT (Family Based Treatment) as an effective treatment model for adolescent eating disorders, I found myself wanting to jump up and down with agreement. But at the same time I also felt immense sadness and fury at the fact that back in the day we, along with numerous other adolescents and their families, were not offered FBT. Back then many UK treatment teams were still adopting the more traditional Adolescent-Focused Individual therapy (AFT) for adolescents with anorexia nervosa. Thankfully times are slowly changing and these days more and more local health authorities are rolling out FBT as first line treatment for young people with anorexia - our home city included. Indeed the evidence for FBT goes back to 2010 (and even further; Maudsley family therapy was initially devised at the Maudsley Hospital in London two decades ago) when, according to Prof Lock, "[researchers found that] family therapy for anorexia more effective than individual therapy".

My son's treatment for anorexia began in 2010, so in a way it's not surprising that we were never offered FBT as a treatment model. It was still being researched and - as far as I am aware - only really adopted by some clinicians in the States (despite the fact that it was first pioneered at London's

Maudsley Hospital here in the UK). My problem was that I was discovering more and more about the evidence for FBT (mainly via my US-based contacts along with clinicians from the Maudsley itself) which is why my views clashed with those of CAMHS during my son's eating disorder treatment. Their approach (AFT) and mine (FBT) were diametrically opposed which led to serious triangulation and discord.

I am not saying that FBT is a 'magic bullet', nor that it suits everyone. But there appears to be more evidence for FBT than AFT. And, when faced with an illness that could kill your child, I'd bet my back teeth that any parent would want to try the treatment method for anorexia with the most evidence of success!

Below is a reply to some questions I sent to NHS Greater Glasgow & Clyde about why, in 2013/14, Glasgow & Clyde decided to roll out FBT as first line treatment (from my blog post of 21st March 2014). I'm doing this because it helps to demonstrate that research has found that "a family-based approach was twice as effective as individual therapy for treating adolescent anorexia patients" (from a James Lock article about the evidence for FBT).

*The other day I emailed Charlotte Oakley, Clinical Lead, Connect-Eating Disorders, Glasgow & Clyde, Scotland, for more information on Family Based Treatment for eating disorders being rolled out across Scotland. I am immensely grateful to her for taking the time and trouble to reply at length, for allowing me to post the following info and for clarifying the situation which will hopefully help my blog followers to understand what is being done in Scotland - and why. Or at least in Greater Glasgow & Clyde - because, as Charlotte says, she "cannot speak for all of Scotland" although she suspects that other areas are "likely to be the same".*

*Charlotte says: "The position in Scotland is, briefly, that in NHS Greater Glasgow and Clyde we decided to implement FBT (Family Based Treatment) as first line treatment for young people with anorexia / atypical, and to that end we first had Professor James Lock over to train in 2010.*

*"Since then we have been monitoring our progress to enable us to be as proficient as we can in the treatment. In 2011 the East of Scotland had Professor Lock to train (Lothian, Borders, Fife health boards). Last week he trained the rest of the health boards from the West and North of Scotland.*

*"Therefore, in theory, all children and young people in Scotland should have access to a person trained in FBT (Family Based Treatment). (He may be coming back to do more training in September with the eastern health boards.)*

*"We had a fantastic week at the Scottish Parliament [Scottish Eating Disorder Research Network Meeting - 25th February 2014, Scottish Parliament, Edinburgh] as part of Eating Disorders Awareness Week, and from that I think we will progress with sharing of practice and learning across CAHMS in Scotland, some thing that we have already started with FBT"*

*I asked her whether alternative eating disorders treatment models would still be available in Scotland for families who, for whatever reason, prefer not to go down the FBT route. She said that, yes, this will be the case and that "families are given the treatment options, including the evidence base for each, to decide what is the best fit for them."*

*Finally I asked her: "What convinced you that FBT is the way forward for adolescent treatment, especially with an illness that is notoriously difficult to treat and where 'one size may not fit all'?"*

*She said: "FBT has the best evidence base and the manualised approach enables implementation, as a way of training clinicians, in what we hoped was an effective way and which I think turns out to be the case. I agree that one size*

*may not fit all but there are fundamental elements of the eating disorder that are the same which makes FBT a perfect fit for example a lack of motivation to change by the sufferer and the need for re-nourishment before someone is cognitively able to do any individual therapeutic work. Studies show that FBT is a very acceptable therapy to families, for example we have only a 7% drop-out rate."*

*Thank you so much, Charlotte, for clarifying the situation (from the viewpoint of NHS Greater Glasgow and Clyde).*

**Sunday, 18 December 2016**

**Let's try FBT first - it's a no-brainer!**

As I say in my last blog post: I am not saying that FBT (Family Based Treatment) is a 'magic bullet', nor that it suits everyone. But there appears to be more evidence for FBT than AFT (Adolescent-Focused Individual therapy). And, when faced with an illness that could kill your child, I'd bet my back teeth that any parent would want to try the treatment method for anorexia with the most evidence of success? It's a no-brainer, really. Like, why in a million years would you choose to initially go for a treatment model that didn't have as much evidence to support it? Especially when, with an illness as deadly as anorexia, your child's life could be at stake?

Yes I know that FBT (Family Based Treatment or the Maudsley Approach) doesn't work for everyone; eating disorders like anorexia are notoriously difficult to treat. This is why, as I understand it, those eating disorder services in the UK that have adopted FBT as first line treatment for girls and boys with anorexia also offer other treatment models.

Just in case, I guess.

Things change so quickly in the world of eating disorders. Which is why, back in February 2010, when my son and I sat in front of our new CAMHS team, we weren't offered FBT. Instead we were offered the more traditional Adolescent-Focused Individual therapy (AFT) for adolescents with anorexia nervosa. Or it might have been a kind of hybrid eating disorder treatment; it was never clear what the treatment model was, but it did include some CBT (Cognitive Behavioural Therapy).

This is one of the reasons why we clashed. I was advocating FBT because I was learning about the emerging evidence while they were insisting on AFT (or whatever it was) because they believed it to be the most successful model for them, to date.

Our views were diametrically opposed which was never going to be a good mix.

The Good News is that our local CAMHS and eating disorder services have spent the past year getting ready to roll out FBT as first line treatment for young people with anorexia. So if Ben and I were to sit in front of the same treatment team today or other treatment teams in the UK who have adopted FBT as first line treatment for anorexia, I expect we would be offered FBT.

As a result I would have been heavily involved in the treatment process rather than being viewed as interfering, instructed not to talk about eating and to 'back off' and take a back seat.

I strongly believe that the outcome for my son could have had the potential to be more successful - and he could have achieved full weight and mind restoration rather than "settling for good enough".

And there would have been none of the implied finger pointing and blame.

OK, FBT might not have worked for us. But I would have darn well liked to have given it a go! Why the heck wouldn't I? Why the heck would I have said

"Oh no, actually I prefer the other method, the one with less evidence of sustained success"?

As a first line treatment model for adolescent girls and boys with anorexia, choosing to try FBT is a no-brainer, surely?!

**Sunday, 18 December 2016**

### **Remembering my dear friend Sue - the little woman with the MASSIVE heart**

A week today it will be Christmas Day. On Christmas Day 2011 I invited my dear friend Sue and her husband round for Christmas lunch. Sue's secondary breast cancer had got worse. It had spread all over her body and she was worried that she simply wouldn't have the energy to 'do' Christmas that year. So I invited her round to ours for lunch and for as long as she felt able to last through the afternoon. Five years on I am remembering Sue, that little woman with the massive heart who took me under her wing in 2010 when my son's eating disorder was making it really difficult for me to cope with life. In order that newer followers of my blog can learn what a fantastic, awesome and totally unique woman my friend Sue was, here is a blog post I wrote in May 2012, five months after this Christmas Day:

#### ***A little woman with a massive heart...***

*One Sunday back in March 2010 as Ben was busy falling off a cliff into the worst of his anorexia and I was crying out for help and support, I went along to the local Baptist church for the first time. I was desperate for support, any support, anything really...*

*I spent the next 5 or 10 minutes sitting on the back row amongst people I didn't know. Some people vaguely acknowledged me in a polite kind of way*

*but, really, I was just left alone. 'Fight or flight set in' and I was just about to flee from the church when a tiny little woman, no more than 5 ft tall, with short spiky blonde hair made a beeline for me across the aisle, face beaming with a massive welcoming smile and insisted I came and sat with her.*

*After the service when the congregation had coffee, we talked and talked. It was as if we had known each other all our lives. Instantly she sensed that all was not right and got to the heart of the matter. Right from the start I felt that I could talk to her about Ben's anorexia and she would understand.*

*Over the next two years we met up regularly, usually round at her house for a coffee. As Ben got worse and I got more desperate she'd sit there listening. Whatever I needed to say, I could say it in front of her. Out of all the people I have known on this journey, she is probably the only one who completely understood what was happening to us and who cared, the only one outside the world of anorexia at any rate.*

*This little woman was the most genuine, caring, loving and selfless person I have ever known. Nothing was too much trouble, and she always had time for me - plus a box of tissues for me to cry my eyes out into when things got too much.*

*Whenever I tried to turn the conversation round to her problems - the fact that she was suffering from secondary breast cancer, had had a double mastectomy and was beginning to find life a little more difficult than she used to - she had a knack of turning the focus back to me.*

*The result is that I'd always leave her beautiful and immaculate house feeling as if I'd been to some kind of amazing soul spa. Then I'd immediately feel guilty for allowing her to focus too much on me instead of her, and I'd tell her off.*

*But that's the kind of person she was.*

*I say 'was', because my dear, wonderful sweet friend passed away this morning. The last course of chemo had been too much for her. Already stick-thin, she was finding it impossible to eat. She'd had a persistent cough for some time, was finding it increasingly difficult to breathe and her energy had completely gone; towards the end she could scarcely climb the stairs. And of course she'd lost her beautiful blonde hair to the chemo months ago...*

*Yet - annoyingly - she still insisted on turning the focus round to me rather than talking about her own problems; problems that were a zillion times worse than mine.*

*Right up until our last goodbye (which I never, ever dreamed would be the final time I would see her), we were giggling about things. "I'm a rebel", she'd say, with a 'naughty' grin on her tiny thin face. "If I want to wear a bright red wig, then I will."*

*She went upstairs (in the days when she still could), came back down and stood outside the living room door. "Are you ready for this?" she announced, coming into the room. "Ta dar!!" Good God, five minutes ago she'd been blond; now she was a feisty red-head!*

*Ever an expert at super high calorie foods, I made her a tray of high calorie flap jack and some Chelsea buns in a bid to get her to eat and put on weight. Naively I thought it would make her feel better. Irritatingly, she felt she had to buy me some expensive body lotion as a 'thank you'. I told her off. But, again, that was what she was like. So incredibly selfless and always thinking of others.*

*Like the months she'd spent lobbying for better cancer treatment for other patients and addressing medical conferences across the UK and in Europe when she herself was sick. It was always a massive regret to her when ill health forced her to give that up.*

*But no matter what happened she was steadfast in her Christian faith -*

*initially trusting that God would heal her and, later, trusting that there was a purpose in whatever His plans were...*

*Naively I thought it was this latest dose of chemo that was making her feel more rotten than usual. She kept telling me it was just the side-effects. Although tests were showing that the cancer wasn't receding, I thought that maybe she simply needed to switch to another chemo; that they'd chosen one she was 'allergic to' - or something like that.*

*You see, my friend couldn't die. She was too much of a fighter. She'd already defied the odds time and time again, forging on ahead and staying alive, despite the fact that the cancer had spread to her lungs, liver and spine.*

*Crazily I thought that one day she'd find a chemo that would cure her - if they could find a vein to stick the needle into. Like a drug addict, most of her veins were completely knackered and the last lot of chemo was in tablet form: the kind of tablets where the medical teams have to put on special gloves to handle them. That's how very, very toxic they are.*

*The email from her husband didn't come as a surprise this afternoon. I was almost expecting it, yet hoping it would never, ever come. Ever since the email he sent round late Saturday night I sensed that something was very, very wrong.*

*It's hard to believe that that feisty little woman with the 'naughty' grin and heart of gold is gone.*

*Goodness only knows what I would have done if I hadn't ventured into that church all those months ago and that tiny woman hadn't taken me under her wing and given me the most amazing, awesome support during the worst period of my life.*

*She always said: "Never forget, if ever you need me - you know where I am."*

*I wonder where she is now...*

**Sunday, 18 December 2016**

**Does anyone out there still believe that parents cause eating disorders?**

If so, I would like to direct them to this superb article by Julie O'Toole, MD - Founder and Chief Medical Officer, Kartini Clinic for Children and Families, which sets out the rock-solid scientific evidence for eating disorders being brain disorders and that "parents are part of the therapeutic solution, not the source of the problem". For Dr O'Toole, the "take-home message that biology sends us is that not only do parents not cause eating disorders, schizophrenia, autism, and other brain disorders, they couldn't cause them if they wanted to".

Yet I suspect there may still be clinicians who point the finger at parents: poor parenting, over-protection and so on. Dr O'Toole includes links to some truly dreadful outdated citations which blame parents. Conclusions range from "Maladaptive paternal behavior may play a particularly important role in the development of eating disorders in offspring" to "this study lends evidence to the clinical contention that high-concern parenting in infancy is associated with the later development of anorexia nervosa. This may derive, in part, from aspects of unresolved grief" and "these results support the growing literature on the interrelationship between disordered family relationships and eating disorders."

A number of years ago Becky Henry, US-based author of "Just Tell Her To Stop: Family Stories of Eating Disorders" told me of an occasion when, at a high-profile conference on the neuroscience of eating disorders, "a psychotherapist who had been working in the field for many years leaned over to me and said: 'There may be some truth in what these two are saying but if it

weren't for pathological parents, we wouldn't have eating disorders."

On top of this I often hear parents blaming themselves for 'causing' the eating disorder. "Where did we go wrong?" and so on.

I strongly suggest that anyone who still wonders if parents are to blame for eating disorders reads Dr O'Toole's article from start to finish.

She says: "As a pediatrician I saw every kind of family: highly functional, highly dysfunctional, and everything in between. And guess what? Once we began to observe parents of patients with anorexia nervosa, we saw every kind of family, not one kind, as had been taught for years. It turns out, the Emperor had no clothes: there was no "anorexogenic family". This clinical observation, not yet supported by published studies (in fact, flying directly in the face of the commonly cited literature) was essential in establishing a treatment paradigm which involved parents in re-feeding their own child."

Parents are "a crucial element of the solution", not part of the problem, which is one of the reasons why modern evidence-based treatments like FBT operate "on the principle that parents need to be in charge of and involved in re-feeding their child".

PS: Interestingly, from what I can see, none of the above outdated citations talks about boys with anorexia, just girls / daughters. A further clue to why this kind of thinking is so outdated?

**Monday, 19 December 2016**

### **Excellent advice on how to weigh an eating disordered child**

Every week directly before our hourly CAMHS session Ben was weighed in an ante room. He was told his weight. It might have gone up slightly - or down. If it had gone up, even by a tiny amount, the entire CAMHS session would be

hi-jacked by panic and anxiety that his weight was ballooning out of control and that we were "making him fat". Worse, that his weight would continue going up and up without ever stopping and he might explode, Mr Creosote style. As a result he would spend the following week making adjustments to ensure that the needle was pointing in the 'right' direction at the next scales session.

All of this meant that there was a lot of talk about weight at the CAMHS sessions - the nurse with her little cardboard wheel which she'd move this way and that to work out his BMI and the psychiatrist trying to pacify Ben as he reacted to what the scales were telling him.

In my book *Please eat*, I quote Ben as saying: "Everyone hates me. I'm so fat and ugly it's disgusting. You're making me fat. CAMHS is making me fat. Everyone is making me fat. You just want to keep on force-feeding me until I explode. You're torturing me! My life is hell - I don't know why the f\*ck I'm alive!"

That was typical talk at the time.

On top of this there were never any checks to see if Ben was cheating the scales in any way. The only items of clothing he was ever asked to remove were his shoes and outer jacket, so we never knew Ben's true weight; the weights noted on his charts were fully-clothed weights, jeans and all.

So in real terms Ben actually weighed less than what the scales were telling us. This makes me feel quite panicky, even now...

In her excellent blog Dr Julie O'Toole of the Kartini Clinic talks about how to weigh an eating disordered child.

I would argue that this is how Ben should have been weighed.

It would have saved an awful lot of firefighting at those CAMHS sessions where his weight has gone up slightly.

It would have avoided talk such as "letting Ben choose a weight he feels happy with" (yes, that was said!) and "we're happy to settle for 'good enough' if you are" (ditto).

My son might just have attained his pre-anorexia weight which, sadly, he never did.

Remember, he was discharged from CAMHS after 26 months weighing just 1kg more than when he had started eating disorder treatment.

And that was with his clothes on.

**Monday, 19 December 2016**

**Dr Julie O'Toole, I want to shake your hand about the misuse of BMIs for diagnosing eating disorders**

I am LOVING Dr Julie O'Toole's blog and, in a recent blog post, she echoes what I have said about BMIs being used as an indicator of the seriousness of an eating disorder both at diagnosis stage and throughout treatment. She gives a terrific example of how reliance on BMI charts could prove potentially dangerous when assessing certain adolescents, especially those whose pre-morbid BMIs were above the so-called 'norm' yet who ate healthily (i.e. they didn't overeat). The same could apply to young people who carry a lot of muscle e.g. many males. Say the individual then goes onto lose a substantial amount of weight very quickly (for whatever reason), begins to get hooked on the idea of continuing to lose weight and gets taken to see the GP or paediatrician. The GP calculates the patient's BMI and the only alarm bells that are ringing is that this patient's BMI is too high and they might need to lose weight. See why this could be dangerous? Especially if the patient is presenting with typical eating disorder symptoms?

Hmn, sounds familiar. My son's pre-morbid BMI was high (a muscly 'forward'

on the rugby pitch). He then went on to lost around a quarter of his pre-morbid body weight very quickly. By the time he stood in front of our GP and most certainly by the time we first attended CAMHS, the anorexia symptoms and behaviours were raging.

Just as scary, he began to develop Bradycardia (abnormally low pulse rate). Of course without any thorough medical checks this was never identified. The first we knew of it was when the school nurse wisely took my son's pulse in January 2010. Within a shot, I'd whisked him down to our local city hospital and he was transferred to our other hospital - the one with the specialist cardiac ward. By that time his pulse rate was registering 29bpm.

Yet throughout the whole eating disorder experience, my son was getting damaging messages - from our GP and from CAMHS.

All those messages about his BMI being relatively OK, about "slipping into the healthy BMI range", about CAMHS not being overly concerned about his weight and about not having reached the point where his illness could be officially given the 'anorexia' label... All of these messages translated inside his head that he wasn't sick enough, that his weight was too high and that he was fat.

And, by trying to get him to eat, I - as his mother - risked making him obese.

By the autumn of 2009 (that time when we were to-ing and fro-ing from the GP and trying to get a referral for eating disorder treatment), my son was exhibiting all kinds of physical and visible symptoms in addition to the mood volatility, violence, weight loss, fats phobia and refusal to eat properly.

His skin was bone-dry, flaking and red. His hair lacked lustre. He was as white as a sheet. He had dark rings round his eyes. He wasn't sleeping. He lacked energy. And then, as I have already said, he went Bradycardic as well.

But none of this was picked up on.

All anyone was interested in was what the BMI charts were telling them.

And the BMI charts were telling them that my son's eating disorder - if indeed it was an eating disorder and not simply 'eating disordered thinking' coupled with low self-esteem and mood - was relatively mild.

**Tuesday, 20 December 2016**

### **Surviving Christmas / The Holidays when your son or daughter has an eating disorder**

Needless to say, the combination of Christmas / The Holidays / Hanukkah or whatever your festive celebration and an eating disorder like anorexia or bulimia can be a nightmare. No, not 'can be'; it IS a nightmare. I know. I've been there, done it. I've watched my son starve himself in the run up to "all that food" and then meticulously check how much he ate on Christmas Day, counting calories to ensure he didn't 'overdo it'. I've watched him eat a little too much and then punish himself afterwards for being "greedy" and "binging". I've been on Serious Red Alert in the knowledge that the slightest thing could result in banging, crashing, yelling, moaning and slamming his head against the wall.

I've pretended to my guests that all is perfectly OK while knowing perfectly well that earlier in the day I was balling my eyes out. I've acted as the perfect host, cooking the Christmas Dinner on a kind of Red Alert / Numb Autopilot and then gone through the motions of eating it while being painfully aware that my son was picking at things or avoiding stuff. And I've pretended to enjoy all the present opening and other festivities throughout the Big Day when all I wanted to do was to curl up in a ball under my duvet and weep.

So I truly feel for other families who are approaching Christmas Day on Sunday with fear and heart-break. I really do, which is why I am blogging today.

I wish I had a magic solution, but I hope that it's just helpful to know that you are not alone, that others have 'been there, done it' and - most importantly - got through it in the end.

I've been searching through Dr Julie O'Toole's very excellent Kartini Clinic blog for posts on surviving Christmas / The Holidays / Hanukkah / New Year with an eating disorder in the family and there are quite a few which you might find helpful. So do Google Dr Julie O'Toole and the Kartini Clinic and do a search on the blog itself.

**Friday, 23 December 2016**

### **Boys get eating disorders too, you know!!**

Someone please hand me a megaphone because I want to yell out loud that MEN AND BOYS GET EATING DISORDERS AS WELL AS GIRLS AND WOMEN!!!!!! Because, in a study that was pointed out to me this morning, it's all about women and eating disorders. Again. No mention that men and boys struggle with anorexia, bulimia, etc, too.

Why is there still so little recognition of the fact that boys get eating disorders just like girls? Eating disorders ARE NOT just a 'girl thing'. Increasingly, statistics are showing that there are more and more boys with anorexia, bulimia and other eating disorders.

But whether it's about women or boys and men with eating disorders, IMO this article which, initially, sounds optimistic isn't so hopeful when it points out that "around two thirds of women with anorexia nervosa or bulimia nervosa will eventually recover from their eating disorders" because it goes on to say that "an average of nine years after entering the study, almost 63 percent were recovered an average of 22 years later".

22 years...

That's 22 years out of a life, around a quarter of the average lifespan, which is far, far too long.

**Friday, 23 December 2016**

**A not so 'silent night' (or day). Woohoo, it's Ben's birthday!**

It's Ben's 23rd birthday today. Before he developed anorexia back in 2009 this day was usually loud and noisy with the sound of umpteen boys laughing, yelling and generally messing around up in Ben's attic room. You see, Ben's birthday parties were legendary. Indeed so many friends were invited that his parties had to be held in two shifts - countless friends one day followed by countless other friends the next with a sleepover inbetween. Then, during the years of the eating disorder, the house fell silent - apart from the final birthday sleepover when his anorexia had begun to rage and we had Ben hurtling downstairs in the middle of the night screaming and weeping because something had upset him. The following day was subdued as the boys' parents collected them from our house. The contrast between emaciated eating disordered Ben and his normal friends was heart-breaking. His friends stopped coming to our house after that and Ben's birthdays were solitary affairs with just the family. I remember his 18th birthday being especially poignant as he told us how down and depressed he felt - to be 18 and have no friends to celebrate with...

Over the past few years Ben has built up a new circle of friends - and another circle of friends at university. When he's back home, these friends descend on our house in varying numbers for games of Warhammer or Dungeons-and-Dragons-style Role Playing Games (RPG).

Today all of them are here. The hallway is full of boys' shoes and coats, and there is a lot of noise coming from Ben's bedroom.

Positive noise. Whoops, cheers and laughter. Just as it should be. And, despite not being about to hear myself think here in my home office, I wouldn't have it any other way.

And, like the Good Old Days, Ben and I shopped for various snacks and drinks so that everyone could munch their way through the day.

Good on Ben to rebuild his life and friendships.

May his 23rd year be his best year yet.

### **Wednesday, 28 December 2016**

#### **A tricky few days thanks to my C-PTSD...**

I can only say that the C-PTSD (Complex Post-Traumatic Disorder) came on with a vengeance from sometime on the evening of the 23rd until early evening on Christmas Day itself. It was quite frightening as I have never felt like that before: raging PTSD symptoms on full pelt - the works. And I had no control over it. Well, that's not strictly true. I had a choice: either to hide under the duvet for 48 hours or emerge and 'do business as usual'. I chose the latter as I didn't want to spoil everyone else's Christmas and we were entertaining the family at our house.

I let my husband and son know what was going on, just so they knew. Thankfully Ben was cooking Christmas Dinner and I press-ganged my husband into helping him out and organising all the other stuff. So I didn't have to do a thing except calm myself down and at least put on a festive front for everyone.

So I was really fortunate to have people with me who 'get it' and rush in to help.

But really and truly the all-singing-all-dancing PTSD took me by surprise and frightened me. And it was such a massive, huge contrast to how I usually am at Christmas (the eating disorder Christmases excepted).

Strangely, the moment Christmas was over, the symptoms largely went away, leaving only the 'usual' day to day PTSD stuff that's been going on for some time now.

I can only assume that Christmas itself was an enormous trigger. Probably what did it were the 2009 and 2010 Christmases when I was on auto-pilot, especially Christmas 2009 which was our first Christmas with the eating disorder.

This Christmas pinged me straight back there into the centre of the eating disorder hellishness of Christmases 2009/10 - and some.