

Anorexia Boy Recovery

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

Part 7 – 2017

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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.

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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 2017 I was still battling with Post Traumatic Stress Disorder, something that had come about as a result of all those days and months of dealing with my son's eating disorder. So you will find that many of my 2017 blog posts talk about my own journey to recovery – from PTSD.

I hope this PDF proves useful to you.

Best wishes,

Bev Mattocks, December 2017.

JANUARY 2017

Monday, 2 January 2017

When your home stops being a safe place to be

When my son was plummeting into anorexia during the autumn and winter of 2009 and spring and summer of 2010, I reached my lowest point as a mother. Up to 2009, our home had been a safe haven from the world 'out there' - stuff

like work, crime, bad news, even rude people in the supermarket and all those other things that irritate you in life. 'Shutting up shop' for Christmas on the 23rd December, my husband's and son's birthdays, was like shutting out the outside world and sinking into a warm scented bath tub of safety and security.

But with the advent of the eating disorder, all of that went out of the window.

Our home became a battleground where terrible and traumatic things went on. In a way, the outside world that I had so loved to shut out at Christmas became a safer place than those cubic metres within our house walls.

Home was a place of danger and fear, of sudden noises and outbursts, of dangerous activities, even potential suicidal acts.

Our family meals which had always been so cosy (my son used to eat anything and everything!) and a time where we three sat round the dining room table and talked became hell on earth.

Nowhere in the house was safe. Even when my son was out of the house at school I was on permanent Red Alert waiting for the call from school to say that Ben had kicked off in some way. In other words, he appeared to have gone completely crazy.

Driving in the car with Ben wasn't safe either. We had some nightmarish journeys, notably the car trip where he attempted to climb out of the door while the vehicle was moving. Car journeys back from his treatment sessions at CAMHS were always hellish as he 'punished me' for whatever had gone on in the session. Maybe he'd put on a tiny bit of weight which, in his distorted mind, made him believe we were making him obese. Or maybe the psychiatrist had disagreed with me on some point (usually around weight gain) and I became Big Bad Mum who was trying to make him explode with food.

Once inside the house all hell would break loose and, for many months, it

was just Ben, me and the destructive eating disorder because my husband was working away.

During those months and years our house was a dangerous place and, in my head, it has never regained that feeling of security which it used to have.

I think this is one of the reasons why this Christmas was so difficult for me. In the past, I used to go mad at Christmas. Mad in a Good Way. Lots of decorations and lights, loads of Christmas music and carols, tons of Christmas food and lots of excitement and fun.

This Christmas frightened me because my body's and mind's reaction took me by surprise. I knew I wasn't feeling very Christmassy, but that's been the case since that first Christmas with anorexia back in 2009, so it wasn't unusual.

But what was unusual was the sheer enormity of my body / mind response to this Christmas which frightened me so much that I can't put it into words. I can't yet describe how I felt or how I behaved. All I do know is that I stood up, brushed myself down and somehow got through it because I didn't want to ruin Christmas for everyone else. I deserve an Oscar for my acting!!

I'll be talking more about safe places in subsequent posts because having a truly safe place - whether in reality or in your mind - is central to recovery from trauma. Or even a safe person who 'gets it' implicitly and who you can trust to support you one-hundred-per-cent, whether that's a therapist, a relative or a friend.

Monday, 2 January 2017

Want to discover why trauma affects us in the way it does and how to get through it?

I am still reading the substantial but incredibly informative and helpful book *The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma* by

Bessel Van Der Kolk who is one of the world's foremost authorities on trauma and recovery. Really and truly if you want a proper understanding of the effects that trauma has on the mind and body, and techniques and treatments that may help you to recover from traumatic memories, I'd say this is the #1 'bible' on the subject.

The early pages talk a lot about childhood trauma which may not be relevant to people like us who have been through the nightmare of an eating disorder, whether as a sufferer or a carer, but it's worth persevering with the early chapters because the later chapters are excellent.

Most helpful of all (apart from the recovery techniques and why some therapies may work while others do not) is the description of why the brain behaves as it does and its links to the rest of the body (e.g. that knotted feeling you get in your chest during panic attacks).

If you ever feel guilty in some way for feeling the way you do or that you should be able to 'fix it' by 'waking up and smelling the coffee', then please do read this book because it will make you realise that it's not your fault, that recovery isn't straightforward or quick, and that your feelings and actions are one-hundred-per-cent normal for someone suffering from a trauma-related problem like PTSD.

Gosh, the brain is complex - and incredibly wonderful at the same time!!

Tuesday, 3 January 2017

More on the importance of finding a safe place, whether real or imagined

Throughout the months and years when I was battling with my son's anorexia and the accompanying mood volatility and violence, I found myself naturally seeking a Safe Place: somewhere I could escape in order to briefly to calm

down, catch my breath and gather my thoughts - or to help me get to sleep at night. Sometimes these places were real, other times they were imagined. But they did help when things became intolerable and overwhelming.

Taking a walk down the garden to our vegetable patch was one example. There I found myself observing the vegetables 'mindfully' i.e. in the present, objectively and without judgement, and without any intrusive thoughts getting in the way. The 'unsafe' house with all its angst and fear was metres away at the other end of the garden separated from me by a long green lawn. For a few moments I was safe.

On days when observing the veg patch wasn't practical, I developed a mantra (based on the old nursery rhyme) which started like this: "Once upon a time there were three little foxes..." and then went on to describe in detail the beautiful but secret woodland where they lived (and where I was also permitted to go - the only human allowed to do so. When led into the woodland by the three little foxes, I was safe. No-one and nothing could 'get at me' there).

To get to sleep at night, I imagined myself walking through the large private parkland leading to what used to be my grandparents' big stone Victorian house at the other end. I'd mindfully observe what I was noticing via my senses: the lushness of the grass, the smell of newly mown grass, the dampness of the dew on my feet and so on. And also the solitude because it was private, open to residents only. I'd rarely make it to the other end of the park before I was asleep.

These techniques are still used by therapists in my PTSD (Post Traumatic Stress Disorder) therapy today and it's curious how, during my son's eating disorder, I kind of naturally adopted 'mindful' techniques and safe place visualisation without actually realising that similar grounding techniques play a

key role in trauma therapy.

My safe places did - and do - help to calm me down when things got - and get - overwhelming.

Mindfulness is a topic all of its own, of course. I used to flick into mindfulness during scary eating disorder sessions at CAMHS (Child & Adolescent Mental Health Services) when my mind became overloaded with negative emotions and fear. I'd find myself objectively observing the pattern on the therapist's clothes, the clouds crossing the sky outside the window and so on in order to calm me down and stop me from screaming.

There were also 'safe people': a very small handful of selfless, compassionate people who completely 'got' the eating disorder and all its horror and who, in an emergency, I knew I could depend on to rush in and take over. Or just be there for me, without judgement or questions, just quietly and supportively listening, without trying to offer unhelpful advice or solutions.

A prime example is Shirley, the school nurse (who I call 'Sheila' in my book *Please eat...*). With Shirley, it was a double whammy of having a safe person in a safe place. Safe, dependable, caring Shirley in her safe, dependable, cocoon of a medical centre on the first floor of the old 18th century school building overlooking the rose garden, tennis courts and rugby pitches.

Yesterday Shirley posted a photo of herself on Facebook, sitting at a desk. To me, this epitomised the person I'd encounter whenever I entered the security of the school medical centre: Shirley sitting at her desk in front of the old boarded-up fireplace decorated with happy paraphernalia.

Just looking at this photo made me feel safe - and also teary to know that there are people out there who are so very selfless, dependable and loving in an all-too-often frightening and unsafe world.

Monday, 9 January 2017

A short sabbatical to 'self soothe' and get myself on the road to recovery from PTSD

Well, 2017 was supposed to herald my return to work (self-employed) but I took one look at my computer keyboard and went into a panic (damn that PTSD). Nevertheless I made the decision to plough on with that huge and immensely helpful book *The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma* by Dr Bessel van der Kolk, one of the world's foremost experts on trauma / Post-Traumatic Stress Disorder. (This link summarises the book well.) Dr vdK also talks about yoga as an evidence-proven method of helping PTSD sufferers to recover. So I'm planning to do some yoga very soon. Next week, with any luck.

I have also booked a massage, hair cut & colour and plan go back to the gym with a view to getting my fitness back ready for this year's cycling. Plus I'll be seeing my EMDR therapist.

Oh it all sounds so positive and 'self-soothing', but it was really difficult - so much easier to just let the panic consume me and disappear under the duvet for a fortnight.

Difficult to book a massage and hair-do?

Yes, truly.

For the past few weeks it's been difficult to do anything except knit and watch *Downton Abbey* box sets...

Damn this PTSD.

But by hook or by crook 2017 is the year I get rid of it for good.

Tuesday, 10 January 2017

Looking back, what do I wish I'd done differently?

Oh gosh, that's a massive question... I know what I wish our GPs and CAMHS had done differently when assessing and treating my teenage son for anorexia - but me?

The first thing that comes to mind is that I wish I'd been more forceful - both in my interactions with the medical profession and with my son.

First, the medical profession...

I wish I'd pushed for a faster referral from our GP and not put up with all the "eat more and come back in a couple of weeks" stuff. I wish I'd asked our GP what treatment options were available for adolescents with eating disorders in our city because never once was I given any information.

I wish I'd pushed for my son to be seen by CAMHS sooner than he was. Yes I did chase up the referral once it went off and we didn't hear anything for weeks. And I did go mad when the woman from CAMHS told me it could be 18-22 weeks before Ben was seen - and then only for an eating disorders assessment.

But I wish I'd been more forceful. I wish I'd found out the name of a CAMHS manager and given them a call - or visited them in person if they were reluctant to get my son into eating disorder treatment quicker than 18-22 weeks.

I wish I'd done the equivalent of chaining myself to a lamppost.

I wish I'd trusted my gut instinct that Ben's eating disorder was deadly serious and not put up with their brush-offs.

Once in front of CAMHS there's a ton of stuff I wish I'd done differently - mainly along the lines of being more forceful, asking for one-to-one meetings with the psychiatrist to thrash it all out and being clear what I didn't want them to say or do in front of my son.

And having the confidence to stand up for what I felt was right for my son - and what my gut instinct told me was wrong.

I wish I'd pushed harder to discover what eating disorder treatment model they were using (because it seemed very muddled indeed).

Most importantly for me, I wish I'd pushed harder for proper weight restoration. Back to where Ben was before he fell sick with the eating disorder. Never forget that when he was discharged from CAMHS he weighed virtually the same as when he started...

And when they made remarks like “We’re happy to settle for second best if you are”, that “some young people choose to remain at a low weight they can handle” and that Ben could “pick a weight he was happy with” that I'd demanded a private meeting to thrash it out.

Despite the fact that I know I worked blooming hard to get my son well, there is a heck of a lot of residual regret and guilt seven years on from when his eating disorder treatment began.

I just wish I'd had the confidence to push harder for what I believed was right - and still believe is right.

Especially as this is supported by evidence.

Tuesday, 10 January 2017

Why weight restoration in eating disorder treatment must come first - and why I agree with Dr Julie O'Toole on the fact

In her last blog post for 2016, Dr Julie O'Toole of the Oregon-based [Kartini Clinic](#) reminds us '[Why Weight Restoration in Eating Disorder Treatment Must Come First](#)' and why this fact isn't exactly rocket science - yet many people continue to overlook it. As she says: *So why the heck do people seem so impervious to the message that without weight restoration you get nothing?*

And I do mean nothing: no physical recovery AND no psychological recovery. Remember: psychological recovery is about the brain. The brain is an organ of the body; like all other organs it needs fuel to replace broken or used-up cells, and for functioning cells to communicate with each other. Starvation is as bad for children and for any other living thing. This takes no great leap of intellect: you can't become psychologically normal in a state of malnutrition. You don't (or shouldn't) need access to all "latest science" to know this. What happens when you starve any other mammal? Think about it. Why the resistance to this simple message?

When I first came across eating disorder treatment models such as FBT (Family Based Treatment) which insist on weight gain first and foremost, it made sense to me.

But it didn't seem to make sense to our treatment team who put the weight issue to one side while focusing on the talking treatment for my son's escalating eating disorder.

As I've said time and time again, this led to a serious clash as the eating disorder treatment model I wanted for my son (weight restoration first, mind second) was diametrically opposed to the eating disorder treatment model they wanted for my son (whatever that was, I never did find out).

And because they were the professionals, I began to doubt myself. *Maybe they were right. After all they had years of experience of mental health treatment and, presumably, eating disorders. What did I know? I was only a mum...*

Also, because Ben didn't look too bad, they weren't interested in getting him back to the weight he was before the eating disorder struck when he was a healthy, muscular strapping lad. I remember them once saying that they could tell that Ben was genetically slim by looking at me, his mum.

What!!! I wanted to yell. *My slim physique is entirely fake; it takes a constant diet to keep it like this!* (Proven by the fact that ever since Ben's eating disorder I have been stones heavier...)

When a young person has lost as much weight as Ben lost before he ended up at CAMHS it's essential to get his weight back up to where it was before.

Fact.

End of story.

To argue that they could tell Ben was a naturally thin boy by looking at my physique was wrong on every count. To argue that Ben's mental functioning and volatility was there as a result of co-morbid issues like depression was also wrong. Ben's behaviour was a textbook case of how young people can act when an eating disorder is raging. I read about carbon-copy behaviour every day on the [Around The Dinner Table forum for parents of young people with eating disorders](#).

I like to think that if Ben were in front of the eating disorders treatment team today they would do it differently. If they haven't done so already, the *Powers That Be* plan to roll out FBT for adolescents with eating disorders in our city.

Thank goodness.

Friday, 13 January 2017

Remembering wonderful Charlotte Bevan...

This month marks the 3rd anniversary of the death in 2014 of one of the most loving, caring, energetic and strong women in the world of eating disorder support - Charlotte Bevan, the mother of a teen eating disorder

survivor. The best way I can describe Charlotte is to re-post my blog from the 13th January 2014, so here it is: **Boadicea in her chariot, guns a-blazing in the fight against eating disorders and poor treatment...**

On the 9th March 2010, I discovered the [Around The Dinner Table forum](#) for parents of young people with eating disorders. It was like an oasis in a desert. I immediately posted my first post there and, within moments, the second parent to respond was a lady I came to know as 'cjbSuffolk'.

Very quickly, over the next few days, weeks and months, I came to know this lady as 'Charlotte' because she often couldn't be bothered with going incognito. And, anyway, how could anyone go incognito for long who had a habit of swooping in to provide loving support, help, advice and just about anything else she could assist with when a new, desperate parent joined the forum.

Before long Charlotte would be on the forum, email, phone or Skype doing her level best to offer help and support, and often to fight a family's cause when they were up against a less-than-adequate CAMHS or other mental health team.

For example, one evening in early June 2010, my (then) 16-year old son, who was deeply entrenched in his eating disorder, tried to climb up onto the roof of our two-storey house, not caring if he fell off. I managed to pull him back in through the skylight and the rest of that evening was Sheer Hell. Unable to sleep during the early hours, I fired off an email to Charlotte to tell her what had happened.

I knew I could depend on her.

I just knew...

Now, [Charlotte Bevan](#) was famous for being up and about at all hours, probably something to do with being a farmer. But, within no time, she was on

the phone to me offering help and support, and a shoulder to cry on. She'd also been in touch with some of the other ATDT mums who also stayed up well after their bedtime to help.

In the months that followed I only had to hint at an ED-fueled nightmare going on in our house or at CAMHS and Charlotte would be there in a flash, on the phone or Skype, telling me to 'breathe' and put on my 'big girl pants'.

And I know I wasn't alone in getting these Rapid Response calls...

Almost right up until her death, which tragically took place this morning following a long and painful battle with breast cancer, Charlotte was thinking of other families fighting eating disorders. If she wasn't offering direct help on the phone, Skype, by email or on the [Forum](#), she was fighting their cause in some other way.

Charlotte was the kind of person you could imagine wouldn't think twice about chaining herself to some railings and making a fuss to get her point across. She could be loud. She spoke her mind. I once likened her, on the [Forum](#), to Boadicea with her chariot, charging through the battle and flattening the evil ED (and any bad healthcare providers) in her path.

She just cared so much about others.

Yet Charlotte wasn't your typical 'saint' or 'angel'. As far as I know she wasn't religious. She wasn't a 'do-gooder'. She wasn't trying to earn Brownie Points with God, the church or anything like that. She had no 'hidden agenda'.

She was just a Jolly Nice Person Who Cared.

And, in a world of selfishness, greed, hatred and evil, there are few truly genuine and totally selfless people like this.

To say that 'she will be sadly missed' is too lame a phrase.

I, and many hundreds of other people across the globe, are devastated that she is gone from us. Even though, I - like many of them - never actually met her in the flesh. Skype is the closest I ever came to meeting Charlotte.

I very nearly met her once - at the November 2012 [FEAST](#) UK conference where she did a sterling job of helping me to book hotel bedrooms for everyone. She was supposed to be introducing the conference. But she had to give back-word. Her mum was seriously ill, with cancer.

Who would have thought then that, before long, this terrible illness would attack dear Charlotte, too?

No, it isn't fair. It is bloody unfair that someone like this should be taken from her family and all the other people that loved her and who she loved.

My thoughts go out to her family, especially her girls and her husband.

Please consider making a donation to [Charlotte's Helix](#) in her memory.

Wednesday, 18 January 2017

Classic flight or fight - which did I do?

Today my PTSD therapist greeted me with "I'm afraid we've only got 3 sessions left; we've had 17 and it's been limited to 20 in total. Actually, they're just about to cut it to 16 sessions max, NHS funding cuts and all that, so you've been lucky!" So, I replied, *that means that in a couple of weeks I'm going to be thrown out to fend for myself?* "Well, there are other options..." *You mean going private,* I said, *I can't afford it; I'm not able to work at the moment because of the PTSD...*

And then it came. A red mist. "I've got to go," I said, "I can't bear the thought of being left like this!" and I flew out of the room, down two flights of stairs, out into the open, down the street and back to my car where I headed into the

city and out the other side on the motorway for 40 miles before stopping off somewhere and eating an entire box of chocolates in one go.

No point in fighting. I tried that before when the NHS withdrew Ben's dietitian due to cuts. And again when he was discharged from treatment for his eating disorder (when he reached 18) despite not being recovered.

This incident triggered both of those memories.

It also triggered my anger at the NHS which is always bubbling away beneath the surface.

And at the government - especially when it talks about increases in mental health funding.

Really and truly I can see little point in having 2 or 3 more therapy sessions. It's certainly not going to fix my PTSD which, as you know, got worse - not better - over Christmas.

It might even make it worse.

So it looks as if it's down to me to fix this - if indeed PTSD can be fixed by self-help.

I do have a choice, of course.

I can sit here and continue to weep at the craziness of the situation knowing that if it was a physical illness it would probably have been seen through to recovery.

Or I can dose myself up on whatever medication the GP will allow me to have for extreme anxiety and nightmares, and do my level best to get on with life.

Of course I have to choose the latter. And I do have resources hidden somewhere, deep down: the strength and perseverance that I drew on during the years when Ben was sick with anorexia.

Anger is a good motivator, too, and I am permanently angry these days,

especially today.

Thursday, 19 January 2017

If you're not recovered within a set time then - ping! - out you go!

I had the mothers (plural) of all nightmares (plural) last night. The theme was generally along the lines of being left in the lurch at the 11th hour without warning. Hmn, I wonder where that came from...

After the Christmas PTSD difficulties, I told my therapist how worried I was that I'd be discharged before I fully recovered; I was aware that NHS mental health treatment isn't infinite. She reassured me. She also reassured me that the [EMDR](#) (Eye Movement Desensitization and Reprocessing) therapy would fix the PTSD (Post-Traumatic Stress Disorder) and that I would recover.

So yesterday when she dropped the bombshell about only being eligible three more sessions before being let loose into the 'big wide world' to fend for myself, I went into panic mode. No way was I going to recover in just three more sessions. So I fled the building; I just had to get out of there!

I also felt some unjustified 'guilt' at not having recovered 'in time'. Yet I've attended all the EMDR sessions, and all previous therapy sessions. I've done all the homework and read book after book to enable me to understand more about how PTSD and trauma affect the mind and body. In other words, I've been the model patient in every way except when it comes to recovering 'on time'.

I put this down to the fact that the PTSD is really [Complex PTSD](#) in that it has come as a result of sustained trauma over a long period of time - the months and years that I was battling to get my son through his anorexia while at the same time being on the front line of all the violence, outbursts and volatility

that the malnourished brain can throw at a parent. On top of this I was battling with the NHS and CAMHS to (a) get my son into eating disorder treatment in the first place and (b) to attempt to get evidence-based treatment for him rather than haphazard fire-fighting which resulted in even more weight loss and mood volatility. And much of the time I was in the house alone with my son and his violent eating disorder; my husband was working away.

In addition there were earlier traumas which kept intruding into the EMDR therapy, compounding the problem.

As a result, my therapist and I, along with the EMDR, have only been able to focus on one or two isolated events within the eating disorder trajectory.

And so the C-PTSD has got worse rather than better, culminating in the three days over Christmas when it went berserk.

Plus, yesterday's experience just reinforced my on-going and as yet unresolved anger with NHS mental health services which came as a result of battling over Ben's eating disorder diagnosis and treatment. Driving down the motorway yesterday to nowhere in particular I was muttering "I effing hate the effing NHS" over and over again followed by "I effing hate the government", etc etc.

I know from reading books by experts that PTSD isn't really something you can fix yourself. Yes, you can do all the exercises set by the therapist (which I have done), but you can't cure yourself purely through self-help. Indeed my therapist warned me that there can be some dangers in attempting to 'process' trauma through self-administered EMDR.

This is unfortunate.

Anyway, today I feel zonked. As my anxiety reached high levels yesterday evening, I took a sleeping tablet and didn't wake up until 11am this morning.

No, I didn't have a blissful, deep and dreamless sleep; I had at least two epic

nightmares which resulted in me shouting out in my sleep.

Like the other night when I suddenly woke to find myself reciting the Lord's Prayer aloud, Exorcist-style! In the nightmare I was about to be abducted or killed by some kind of evil demon... In other circumstances you might laugh at this, but it wasn't very funny I can assure you...

So what do I do now?

There is little point in having three more therapy sessions as we've really only scratched the surface - and my anger and anxiety are stronger than ever.

PTSD and C-PTSD *is* treatable, but - like anything - only if you see the treatment through to the end. If the NHS only offers a finite number of sessions (16 at present), then you need £60-£100 a week to fund private sessions which, sadly, I don't have.

FEBRUARY 2017

Wednesday, 1 February 2017

I can't fix the PTSD so will have to pay for private treatment

You know me... always trying to fix things (like my son's eating disorder) and refusing to give in. Or at least that's what I used to be like. I really, really hoped that I could fix my C-PTSD (Complex Post-Traumatic Stress Disorder) that I've been struggling with for four years (as a result of the trauma of the eating disorder years when my son was sick). Last week the NHS spat me out to fend for myself because I'd reached the end of a limited number of therapy sessions. I don't blame the therapist who admitted that this isn't the way she

likes to practise. In other words, if the patient isn't recovered in a given number of sessions, then tough luck, they're out on their ear.

Imagine that with a physical illness? Being given time-limited treatment and if you hadn't recovered by the time it was used up, then tough luck.

We who have cared for our children through the hell of an eating disorder for many months and even years, 24/7/365, with no let-up - an illness we were well aware could kill our child - and those of us who have fallen sick ourselves with some kind of mental health condition as a result of the physical / biological impact that abnormally high stress levels have on the brain (as proven by science), will be well aware that mental illnesses can be as serious and as devastating as physical illnesses.

Indeed the brain is an organ, just as the heart, liver or kidneys are organs. Mental illness is in fact physical illness and should be treated as seriously by our NHS. On top of this mental illness can lead to serious physical illnesses and problems. [Read *The Body Keeps the Score: Mind, Brain and Body in the Transformation of Trauma* by world-leading trauma expert Bessel van der Kolk to find out more.](#)

As I said at the start of this post, I like to fix things. I remained strong throughout my son's devastating eating disorder because I knew that if I gave up then the whole thing could crumble around us. When he was discharged from NHS eating disorder treatment too soon it was up to me (and my husband) to take over and do our level best to work with our son to get him well.

The alternative was too horrible and terrifying to contemplate when the word 'suicide' featured almost as frequently as day turning into night.

All three of us - my son, my husband and myself (and doubtless many of you reading this) - know how punishingly difficult it is for an individual to beat

mental illness on their own, unassisted.

I really hoped I might be able to fix my PTSD myself but it is becoming increasingly obvious that this isn't possible, no matter how many books I read or exercises I do, no matter how hard I try.

Three days ago I woke from my sleep hyper-ventilating following a hellish nightmare. Two days ago I was shouting so loud in my sleep that my husband (who was sleeping in the next room because I thrash around so much in my sleep) nearly rushed in to see what was wrong. Last night and the night before I awoke after the usual high-anxiety nightmares. Last night I was having to give something up because I simply couldn't handle it (in my dream this was a university degree). I also had a large wound which I was trying to cover with minuscule sticking plasters (got to be some meaning there!!)

During the day I am finding it harder and harder to get dressed and do normal things. I am well aware that I have changed; I am not the person I was. And I can't fix this myself.

The only solution for me is to pay for private treatment - to beg, steal or borrow from relatives and my pension savings. So this is what I've decided to do. I have no option. I really don't. The alternative is a 'half life' where I slob around the house in my pyjamas all day, or just remain in bed, and I can't bear the idea of that.

I know that PTSD and its more complex 'cousin' C-PTSD *can* be fixed and that *I must get it fixed*.

Just as if I developed a heart problem, diabetes or kidney issues then I'd do my level best to get that fixed; I wouldn't just let the illness take its course without any medical help.

And I wouldn't be expected to.

But that's the thing. Physical illness *is* taken seriously. Medical help *is*

provided. And it is provided for as long as is necessary.

I want the Government and the NHS to recognise that mental health can be *every bit as serious and difficult to fix* as physical health conditions. To offer a limited number of sessions to a patient and then spit them out the other end if they haven't recovered 'in time' is criminal.

Imagine unplugging a patient from a dialysis machine and sending them home without further help because they'd 'used up' the allocated limited number of sessions?

Anyway there isn't much I can do. So by hook or by crook I can hopefully get the cash together to pay for private C-PTSD treatment, but not everyone is able to do this.

For every me there must be hundreds who suffer because they can't afford treatment for their PTSD, eating disorder or other mental health condition.

And in a country where private health insurance is an expensive luxury or job perk, and where the amount allocated to mental health is often laughingly small, our hands are tied.

Thursday, 2 February 2017

Thrilled to have found a therapist who really 'gets it'

Today I spoke to a therapist who specialises in trauma treatment - usually [EMDR](#) (an acronym for 'Eye Movement Desensitisation and Reprocessing') - and especially complex trauma like Complex Post Traumatic Stress Disorder (C-PTSD). Just talking to someone who so obviously 'gets it' was incredibly liberating and after several days of feeling as though I'd been thrown out of the vehicle that was taking me on my journey to recover and forced to stop off at the worst roadside motel in the world, I feel as if a limo has come to pick me up and take me onwards.

Here's what his website lists as typical symptoms of someone suffering from "a chronic or complex trauma":

- Experiencing frequent disturbing dreams
- Have significantly disturbed sleep
- Be socially isolated
- Be trying to 'medicate' or support themselves in whatever way they can
- Be experiencing frequent 'reminders' of the event or people involved
- Suffering from intrusive images and thoughts, which may be reliving the actual event or may be imaginary/invented
- Be expecting 'it' to happen again at any moment
- Be suffering with other, apparently unrelated and often inexplicable symptoms, such as pain, chronic fatigue, anger, depression etc.
- May be suffering from other difficulties and conditions that must be dealt with alongside the PTSD.

I tick all of the boxes!!!!!!

Fingers crossed that, with his help, I will be able to start to get on with my life - and share with you what works.

Monday, 6 February 2017

Should I be blogging about C-PTSD in a blog specifically dedicated to eating disorders in boys and young men?

Yes of course I should be for the simple reason that the latter was caused by the former - the 24/7 of caring for my son as he plummeted into and slowly emerged out of his eating disorder - anorexia - between summer 2009 (when it first became evident to me) and, probably, right up to the end of his first year at university in 2014/15 (when things began to improve quite considerably). The worst period was an 18-month stretch between October/November 2009 and Easter 2011 (when Ben and I began to implement our ['contract'](#) which helped to turn things around). For nigh on 18 months on a daily basis... on an hourly basis... on a minute basis... I was -

- Fighting to halt Ben's descent into an eating disorder that I quickly came to realise could very easily kill him whether through starvation, organ failure or suicide (intentional or non-intentional) - or a combination of all three.

- Fighting against my son who was so gripped by the anorexia that he battled against our efforts to get him well as well as lying, being in denial and a load of other stuff. This is unlike practically any other potentially deadly illness.
- Dealing with his rapidly changing and deteriorating personality as he transformed from the wonderful boy I'd known since his birth into someone I didn't recognise: mentally or physically.
- Dealing with regular outbursts of epic proportions - round the clock. These outbursts were almost always sudden and severe, often with violence and a lot of noise (yelling, bashing, thrashing, etc).
- Fighting to get him diagnosed and treated, then - on being told that he could be waiting 6 months for NHS treatment - frantically searching for 'stop-gap' private treatment.
- Battling with CAMHS (his NHS treatment team - Child & Adolescent Mental Health Services) as I gradually realised that their treatment model was making him worse, not better, with the result that my husband and I felt increasingly alone and up against 'the System'.
- Pretending that everything was OK to an outside world that didn't 'get' eating disorders and where having a child with anorexia can cause stigma and blame.

... and a ton of other stuff that took my stress levels to places I never thought was possible along with a constant ice-cold fear plus a paradigm shift where I slipped into a way of thinking where it was highly likely that my son would die, not unlikely. Like kind of trying to prepare myself for the worst when (not if) it came.

My experience is similar to so many other parents who have battled to get their son or daughter through an eating disorder, whether anorexia, bulimia or one of the many guises that this deadly illness can take on.

It's not surprising that these hours, days, months and years come back to haunt us in a number of ways. Some parents have suffered physical illnesses; others have suffered psychological problems like PTSD (or, more likely, its

chronic 'cousin' Complex Post-Traumatic Stress Disorder - C-PTSD). Or a mix of both.

And, just as we spent all those months fighting to get our children speedy, high quality, sustained evidence-based treatment for their eating disorder, we may find ourselves fighting to get speedy, high quality, sustained evidence-based treatment for our issues, in my case C-PTSD.

This fact in itself adds an *extra layer of 'flashbacks' and negative memories* to C-PTSD - flashbacks to the period where we fought to get our child treated properly along with a growing lack of trust in the NHS and a feeling of hopelessness that they will never fix things. In the same way my son was discharged while he was still sick with his eating disorder - once he reached the age of 18 - I have been discharged because my time-limited C-PTSD treatment sessions have expired. Whether or not I'd recovered by that time didn't enter into the equation, I was out on my ear.

And so this **extra layer** is very real. Being told that "*EMDR [Eye Movement Desensitization and Reprocessing] does work and it will cure your PTSD*" and then being suddenly discharged because my time was up results in a whole range of memories and feelings gushing back into my head: anger, frustration, fear, hopelessness, helplessness, hatred and more.

But to return to the point of this post...

Yes, blogging about both PTSD and C-PTSD is highly relevant to a blog about parents dealing with their child's eating disorder - and the aftermath of it. In an ideal world our sons and daughters will recover from their eating disorders and we will all get on with our lives.

However - and I'd argue that this isn't at all unusual - many parents may find that those years come back to haunt them in some unpleasant way because of the effect that sustained trauma can have on the mind and body, as world-

leading trauma expert Bessel van der Kolk explains in his book: [*The Body Keeps the Score: Mind, Brain and Body in the Transformation of Trauma.*](#)

So the two are very interrelated, which is why you will find that I am now blogging about both issues.

Monday, 6 February 2017

Why standard relaxation techniques are simply sticking plasters

I am so thankful for the friendship and support I have from friends and family. Last week my mum gave me a book entitled 'Quiet Moments', others have recommended hypnotherapy, mindfulness and meditation. While these activities can kind of help someone get a rest from the incessant vice-like grip of fear that is a key symptom of C-PTSD, they are more of a sticking plaster / band aid. This might be why, the other night, one of my regular nightmares was about me trying to cover up a huge wound with the smallest sticking plasters / band aids you have ever seen.

My new (private) C-PTSD (Complex Post-Traumatic Stress Disorder) therapist (who I will be seeing for the first time on Thursday) said on the telephone that 'anxiety' isn't the best term for the physical vice-like grip that C-PTSD can produce in your upper chest. 'Fear' is a better term. Constant, 'red alert', holding-your-breath, ice-cold fear.

That made sense to me.

Relaxation techniques, mindfulness and hypnotherapy tapes are aimed at getting you to relax and free yourself from feelings of anxiety or worry.

My feeling is very different and very physical. And it is in my chest, not in my head. Sometimes it's in my stomach, too, but it's mainly around the centre chest area.

Kind of holding-your-breath fear as you prepare you mind and body for some sudden threat that could come at any second.

Or at any rate that's the way it's manifested itself with me: the primary symptom that results in poor sleep quality and 2 or 3 nightmares every night.

This is also why all the relaxation medication doesn't really work. I can relax for England and yet not be free from this 24/7 physical vice-like grip of fear that's there because, somehow, I got 'stuck'. The fear that I felt for 18 months or so, 24/7/365, has stayed with me, despite the fact that there no longer anything to fear.

Hopefully this fear is what my new therapist will be working on.

Successfully, I hope.

It's so reassuring to know that he 'gets it'. He seems to have a true understanding of what C-PTSD can be like and, consequently, how it can be treated, because C-PTSD *is* treatable.

C-PTSD isn't something that relaxation techniques or medication can cure - and evidence has proved that this is the case. The same goes for psychotherapy / the 'talking treatment'.

In my opinion even CBT (which is often used for PTSD) can't ever be more than yet another sticking plaster when it comes to C-PTSD - another method that may offer temporary respite from the constant physical grip of fear.

So far, over the past four years, I have been offered a combination of many the above from the NHS - none of which has worked. Probably because they will never work for chronic trauma symptoms. So it's not surprising that my C-PTSD is worse than ever.

The most recent course of treatment has been EMDR (Eye Movement Desensitization and Reprocessing) which is evidence-based for PTSD. The

problem was that it only scratched the surface. Also I believe that it opened up a can of worms in that my C-PTSD seems to have got worse, not better.

But, despite the [NICE Guidelines](#) (National Institute for Health and Care Excellence) stating that:

1.9.4 Chronic disease management

1.9.4.1 Chronic disease management models should be considered for the management of people with chronic PTSD who have not benefited from a number of courses of evidence-based treatment.

...I have been discharged from NHS mental health services in worse shape than when I began treatment.

Wednesday, 8 February 2017

When the mental health professionals let you and your child down

On Monday I flicked on the TV and began to watch BBC's Panorama - [Revealed: Britain's Mental Health Crisis](#) which was about "the troubled state of NHS mental health services", the "deteriorating national picture for mental health care funding" and "new figures that show a shocking increase in unexpected deaths of mental health patients".

After just a few minutes, I had to switch off.

I was in tears.

I was in tears at the profound grief of that mother as she visited the flat where her adult son (who suffered from schizophrenia) had killed himself. This was just four days after the event. My heart was right there with her, feeling for her grief and helpless anger as she explained how her son's therapists felt that he wasn't a danger to himself.

But she knew better. She was his mum after all. And no-one knows their child better than a parent.

So when the news came through that her son had committed suicide, she wasn't surprised.

Like so many parents who live with a mental illness in the family, she'd come to expect it.

As a parent you undergo a kind of hellish paradigm shift where your mind clunks down to a new, deep and darker level where you begin to prepare yourself to "accept" that it is no longer a case of "if" but "*when*".

Yet NHS mental health services term these deaths as "unexpected".

*We wouldn't call them that; we'd call them "**expected**".*

From the very first day I took my son to see our GP (September 2009) until his discharge from Child & Adolescent Mental Health Services in March 2012, I never once felt that I could trust the mental health professionals to keep him safe.

And, as his eating disorder grew worse and his moods, behaviour and weight headed further downhill, this mistrust grew even stronger.

My gut instinct and primeval need to protect my one and only child screamed out that the treatment model he was receiving was making him worse, not better.

Yet the treatment team seemed happy with my son's "progress".

But all I saw was a young man who was losing more and more weight and whose moods were getting increasingly volatile and violent.

I was with him 24/7; the eating disorder treatment team only saw him for 60 minutes a week - or less, as was the case during the summer of 2010 when there were big gaps while the therapists took their annual leave.

That summer my son threatened suicide on almost a daily basis. It was

during this summer that he began to behave even more dangerously, like the day he attempted to climb onto our house roof through the attic window.

I managed to pull him back, just in time.

After that - and other threats and dangerous behaviour - I went round the house, hoovering up window keys, medication, knives, wires... hiding them where he wouldn't be able to find them.

I began to look at ordinary places and objects in a completely different and altogether terrifying light.

On one exceptionally distressing occasion I was so frightened by my son's threats that I telephoned CAMHS. Because our psychiatrist wasn't there, I was put through to the Duty Psychiatrist. Distraught and desperate, I asked her what I should do?

Her response was - and I will never, ever forget it: "*We are not a 24-hour emergency service.*"

I was told to take him to A&E.

But of course I couldn't get my son to A&E. He is taller than me, and stronger - and the eating disorder seemed to make him stronger still. And with it came threats of what he would do if I tried to get someone round to the house to help.

Good God, one time I couldn't even stop him from fighting the window keys off me (thankfully a downstairs window on this occasion). He pushed me violently aside, climbed out and disappeared.

As on many occasions, I wasn't sure if he would ever come back.

Monday's Panorama *Revealed: Britain's Mental Health Crisis* - or at least the little bit I did see - reinforced that there must be so many other parents out there who simply don't trust the mental health professionals and who feel that they are going against our gut instincts as parents.

Yet, unless we can afford to pay a king's ransom for private treatment (and who's to say that would be any different?), we have no option but to continue with NHS mental health services.

If indeed it is offered at all.

And when it's withdrawn, whether because of funding or because the NHS believes the patient is no longer a danger to themselves, what can so often happen next doesn't surprise us parents.

My heart went out for that mother and parents like her who have been let down on such an epic scale and have lost a much-loved child.

It was so very much a case of "there but for the grace of God...."

MARCH 2017

Sunday, 5 March 2017

The truth about what it's like to live with an eating disorder like anorexia

It's the end of Eating Disorders Awareness Week and earlier in the week one of my friend's daughters courageously wrote about what it's really like to live with an eating disorder like anorexia. I have her permission to share it with you below. Meanwhile I would like to thank this brave young woman for speaking out about something that was obviously very difficult for her to put into words, but she has done it admirably:

"I don't normally post this kind of thing, and I'm pretty nervous about sharing, but seeing as we're midway through #eatingdisorderawarenessweek, I feel compelled to speak out. This is a cause very close to my heart, being a sufferer myself.

"Eating disorders are SERIOUS ILLNESSES and have the highest mortality rate of any mental illnesses. they are not a choice and you can't 'just eat' or 'snap out of it'. They are biological brain based illnesses and are far from 'just a phase'. Anybody of any age, gender or weight can be affected, eating disorders do not discriminate. They completely suck you dry of any life, leaving you a shell of a human being, they affect every aspect of your life, not just your eating.

I don't like to post about this kind of thing on here normally, but I want to help bring awareness on this subject with the aim to help anyone else out there suffering come forward and seek help and not be afraid. Living with an eating disorder is a living hell. It's torturous. It plays tricks with your mind, it's sneaky, secretive, deceptive and extremely lonely and terrifying to be in your own head. Its only mission is to kill you. I know only too well how scary making the decision to try and recover is, as Anorexia can trick you into believing it's right and it feels like a comfort blanket, a safety net, but in reality it's the total opposite. I've wasted over 10 years of my life to this illness, missed out on all the 'normal' teenage years and now my early adulthood. Please don't put off asking for help, don't be afraid, even your worst day of recovery is better than your best day of being ill. One day I hope I can get over this, for now every single day is a battle and I just have to take things a day at a time, but recovery IS possible and I still have hope. For anyone else suffering stay strong and keep fighting. Sorry for the essay! X"

Friday, 17 March 2017

A heartbreakingly powerful message about mental health



I never met Rosie, but I did meet her mother - at an eating disorders conference in London where I was giving a talk a couple of years back. I first 'met' Rosie's mother through the Around The Dinner Table Forum (for parents of young people with eating disorders) when I joined in March 2010. She was one of the first UK mums that rushed in to offer support and show that other parents were going through what we were going through as 'newbies' in the world of parenting a young person with an eating disorder. It was only later that I learned of her own struggles with ill health and other problems while battling to get her beautiful daughter successfully treated for her eating disorder.

Late last night I received the news, via our FaceBook network, that Rosie - aged 21 - had taken her own life. It happened last month and somehow I missed the news; I've been so tied up with my own issues. Problems that now pale into insignificance compared to what Rosie's mother is going through right now.

Once I started weeping with grief for this strong, caring family, I couldn't stop. Yet another beautiful life had been extinguished by this most deadly of all mental illnesses: an eating disorder. And so young. Far, far too young. Rosie was three years younger than my son.

Rosie wrote beautiful poetry and prose. One day Rosie's mum hopes to get some of it published in memory of her beautiful daughter and I have promised to help. But in the meantime she is keen for the following to go viral - to highlight the serious nature of mental illness and eating disorders. So please taken a moment to read Rosie's message which she wrote three years ago when she was 18. Then please remember Rosie's family in your prayers.

All of this is with the generous permission of Rosie's mum.

Eating disorders

"We are all human - Behind the walls of psychiatric hospitals ('the loony bins') exist the people that have been labelled with mental disorder that by some have been defined as insane.

But where do you draw the line between sanity and insanity?

Yes we are all different we have a different amount of cells in our body and different coloured hair and eyes and skin. But when it comes to it, when you strip away everything what's left is a skeleton, the stability the very structure of each and every one of us.

We may all be individual beings with our own views and perceptions but inevitably we are all the same- human. Therefore inside all of us we hold both sanity and insanity, there is no separation or line dividing those two words; they aren't two different types of people and it doesn't make anyone less of a person if they are under the mental health services.

So just think before you put down or judge.

It lurks in all our bones. Whether with a mental health problem or not, if a heart is still beating then they are alive and every beating heart deserves equality because at the end of the day yes we are all different but we are all the same too - human."

Rosie Flett (21.1.1996 - 11.2.2017)

Wednesday, 22 March 2017

Time to end mental health stigma

Following on from Rosie Flett's tragic death I pledged to blog here as regularly as I can to continue to raise awareness of eating disorders and mental

health. To reinforce this pledge I 'made it public', if you like, on the Department of Health, Lottery and Comic Relief funded [Time To Change website](#) which is building a wall of pledges from people committed to ending mental health stigma. (If you haven't done so already, can I suggest that you [make a pledge](#) of some sort too?)

At the moment it's not easy for me to blog here. My PTSD is still bothering me a lot and my sleep is still interrupted by vivid nightmares. (Like the nightmare I had last night where I was desperately trying to stop my son from killing himself but he wasn't listening...)

But my problems pale into insignificance when compared to what Rosie's family are going through right now. And also the myriad of other families that are facing a young person's suicide, [as highlighted by Jennifer Saunders for Comic Relief on BBC's Countryfile on Sunday evening](#).

On the subject of mental health stigma... I was googling all the various statesmen and other famous individuals who have struggled with mental health problems in the past. People like Winston Churchill, Abraham Lincoln, Florence Nightingale, Charles Darwin and Marie Curie. And many, many more.

Back then there wasn't the same stigma surrounding mental health as there is today. Indeed some people question whether any of the above would have been permitted to be politicians or scientists in today's stigma-driven world.

Yet people also argue that it was *because* of their mental illnesses that these individuals were able to do great things.

On [this website](#) it describes how in the *'book* Black Dog, Kafka's Mice, and Other Phenomena of the Human Mind, *psychiatrist and historian Anthony Storr* wrote: *"Had [Churchill] been a stable and equable man, he could never have inspired the nation. In 1940, when all the odds were against Britain, a leader of sober judgement might well have concluded that we were finished."*

Today various high profile individuals and celebrities are helping to reduce the stigma that surrounds mental health. People like Ruby Wax and Stephen Fry. And, with 1 in 4 people experiencing a mental health problem in any given year, it's a very real issue - an issue that affects pretty much every family out there.

But I imagine there are still some individuals who believe that people who commit suicide as a result of losing their battle with their own internal 'demons' are 'selfish' or in some way to blame for their act.

As any of us who have lived with serious mental illness - whether as a sufferer or as a family member - will be all too aware, mental illnesses can be deadly and once an illness like an eating disorder has its victim in its grip, it's punishingly difficult to break free, even with medication and therapy.

And the 'demons' (as many people like to refer to them) are very, very real and set on destruction. Especially in the case of eating disorders, the most deadly of all mental illnesses.

It's funny that, as I talk more and more about eating disorders, people put up their hands and say: "Me too!" Someone's friend or close relative has an eating disorder or other mental health problem such as OCD.

And yet there is still this crazy stigma surrounding mental illness.

Thursday, 23 March 2017

Parents of eating disorder victims - the Biggest Fear of All

As you know I'm having [EMDR \(Eye Movement Desensitisation and Reprocessing\) therapy](#) for my [Complex Post Traumatic Stress \(C-PTSD\)](#). Unfortunately I've had to go private as the NHS is only permitted to offer 16 or so sessions and if you're not recovered in that time, then... well... to put it bluntly... you're out on your ear. Yesterday I came to the session with a whole

raft of triggers that had occurred since the last time I was there (a fortnight before). Initially after our last session I'd felt elated and light - as if a great big thick cloud had been lifted and the sun had started to come in. I really felt that this was it: the EMDR was working - it was a miracle!

This good feeling lasted around 24 hours until the first trigger (taking my son to an unknown cafe for lunch and him dithering over the menu) pinged me right back into the hyper-anxiety and arousal of the PTSD.

A few days later I had the second trigger: taking my mum to see the emergency GP who turned out to be one of the two GPs I saw when trying to get my son diagnosed and referred for his eating disorder back in Autumn 2009. I found myself sitting in the same chair in the same surgery and - ping! - my mind was 'back there' to the day when Ben stormed out of the surgery ("I don't know why I'm f***ing here - there's NOTHING WRONG WITH ME!") and flew through the streets back to the house while I sat there helpless, asking the GP what I should do.

The GP had no answers.

The third trigger was Rosie's death which I first heard about a week ago today. This terribly tragic event reinforced my Greatest Ever Fear which is that *eating disorders kill*.

Even after years of roller-coasting between remission and relapse, *eating disorders can kill*. And suicide is one of the most common ways that an eating disorder claims its victim.

Rosie's tragic death affected all of us parents (but of course nothing remotely like it has affected her family).

Not only is another eating disorder related death one death too many, but this was our friend K's beautiful daughter. K, who had struggled for so many years to help her much-loved child to recover.

On top of this it reinforced our ice-cold fear that the same could easily happen to us.

Many of us live with the constant fear that our own son or daughter could take his or her life.

My son used to talk about suicide long after his recovery from anorexia was well underway.

Throughout his first year at university he'd talk about suicide fairly regularly. And each time it would plunge me back into that ice-cold fear, especially as he was now living some 40 miles away from us.

The problem with this fear was and is that, even after the eating disorder is in remission, the constant spectre of suicide hangs over a family.

I really don't think it will ever go away.

So Rosie's death affected other parents for two reasons: first and foremost **(and by far the most important)**, it was our dear friend K's much-loved daughter; secondly, it reinforced the knowledge that an eating disorder related death could so easily happen to us too.

Earlier this week one mother told me how, on admission to hospital, the doctors told her that her daughter was "one day away" from death.

Then there was the other mum who collared me after my talk at the 2016 [SEDIG \(Scottish Eating Disorders Interest Group\)](#) eating disorder conference to say: "Your story could be a carbon copy of mine but for one thing. Your son recovered. Mine didn't, he took his own life."

For those of us parents who go on to develop trauma-related issues like PTSD, this constant and very real fear is difficult to 'process'. The problem is that it's part of the past - certainly. But it's also very much part of our *present* and, possibly, our *future* too.

How can we put to bed a fear that is still very much with us and which may

remain with us for many years, perhaps even for the rest of our lives?

The fear that my son could take his own life has and is my Greatest Ever Fear. Remember how, during that terrible summer of 2010 as my son slipped further and further into his all-encompassing anorexia, my mind kind of clunked and shifted down several notches to a twilight world where it became a case of *'when'* and not *'if'*.

You almost find yourself *'adjusting'* (which isn't the right word at all) to the fact that your child may, or indeed will, die.

Having seen what an eating disorder can do, you go through several stages where you, as the parent, lose all hope.

Especially when the treatment your child is receiving for their eating disorder appears to be making them worse and not better.

And when you get to the stage where you go to bed every single night wondering if your child will still be alive the following morning.

The night before last I had the Mother of all Nightmares where I was desperately trying to stop Ben from taking his own life. My pleas were falling on deaf ears. He was intent on killing himself, no matter what. I was pleading and pleading.

On and on it went.

This nightmare was so vivid and distressing that, on waking, I found myself reaching for my *'emergency supply'* of Diazepam just to calm me down. (I rarely if ever take the stuff because it can be addictive; it was prescribed a while ago and I keep it handy for *'emergencies'*.)

As a result I wasn't in a very good place when I turned up for my EMDR session yesterday afternoon and I'm not entirely sure the therapy was any help.

But we shall see.

I am still confident that it may work and help me to process those memories that are in *the past*.

However, as my Biggest Ever Fear will never leave me, does it actually have any real chance of being truly effective?

Thursday, 23 March 2017

"I no longer have to dread the calls in the middle of the night saying she is in hospital again after another overdose"

I hope she won't mind me saying it but I am in awe of Rosie Flett's mother, Kirsten, at the selflessness she is showing at this terrible and tragic time, always with thoughts of others in mind, keen to raise awareness of the devastating effect that an eating disorder can have on a family.

Kirsten has paid the highest possible price. She has lost her much-loved and beautiful daughter. She has received the news that every parent dreads - and, despite having to face the unthinkable, Kirsten wants to do her very best to prevent this happening to other families by speaking out.

No young person should ever have to reach a point where they feel there is no option but to take their own life. Not in a country with a free National Health Service open to all where politicians continually harp on about *more* investment being made in mental health.

Often to us families, at the forefront of mental health issues, it can seem as if there's *less* good-quality help available these days, not *more*.

Eating disorders are the most deadly of all mental illnesses.

They can and do kill whether as a result of complications brought on by starvation and / or by organ failure or by suicide.

Yet there is still a huge stigma surrounding mental health and in particular suicide. Some people, so very wrongly, still think of suicide as a 'selfish' act.

Following on from [my post yesterday](#), Kirsten made the following comment (I have full permission to quote her - as she says: "*People are not going to understand unless people like me speak out.*")

Whilst sadly many still see suicide as selfish, if they have truly seen their loved one fight day after day for a glimmer of hope or just a few minutes respite from the mental torment they are going through then they would understand that those who commit suicide often desperately want to live but just can't find a way to do so without their inner pain, which can be worse in some ways to physical pain.

They are not selfish, far from it. As a mother who has lost my daughter to suicide.. do I think she was selfish?No, it was in many ways an act of bravery as although - yes - I am suffering in so many ways as are other family and friends, I no longer feel so totally hopeless that I can't help get my daughter out of her hell.

I no longer have to see her punish herself through self-harm and starvation and I no longer have to dread the calls in the middle of the night saying she is in hospital again after another overdose, etc.

I know she is no longer suffering and that gives me some peace. Yes I would give anything to have her back but I wouldn't want her to be the way she was before she died, just a shell of my beautiful daughter.

Kirsten says it all here.

Eating disorders are deadly illnesses that need to be treated promptly using evidence-based therapies until the patient is completely free of the illness and any co-morbid issues.

Things should never be permitted to get so bad that suicide seems to be the only way out.

My heart goes out to Kirsten and her family.

Tuesday, 28 March 2017

Such rotten, bad, bad luck - the chance of a lifetime missed because of internet failure!

Initially, once he's finished his Master's Degree in Medieval History, Ben wanted to do a PhD and so he could teach at a university. But the fees are too high. However the other week he met up with his old history teacher from school for a coffee. She told him about a new scheme available at some UK independent schools where you can train to teach on the job - a bit like the Government's Teach First scheme, but at a private school (with potentially less disruptive pupils). And - excitement, excitement - the other week The Dream Job came up: the chance to train as a history teacher at his old school! Wow and super-wow!!

Ben immediately applied and got an interview! He was THRILLED and I shed a tear or two with pride...

... However due to faulty internet, etc he'd picked up the message a day or so late.

He immediately contacted the school to explain and say yes he'd love to come for interview.

But it was TOO LATE!

They'd already held the interviews and chosen someone for the post.

It was a HUGE, MASSIVE DISAPPOINTMENT.

Of course there was no guarantee that he would have got the job if he had been interviewed, but his qualifications are excellent (First Class Degree and Master's Degree). And remember that in his gap year he assisted with teaching the school's sixth form history group for a couple of days a week.

This was the Chance of a Lifetime - something he really deserves and would have been brilliant at.

I feel so very sad for him.

He was so disappointed that he came home early from university for Easter. I picked him up yesterday.

This is such rotten bad luck and there's practically zero chance of a similar job coming up in the future.

So what to do now?

APRIL 2017

Saturday, 1 April 2017

For anyone wondering how Ben is getting along

Yes he is disappointed about the teacher training interview, but he's dealing with it brilliantly. In between the huge amount of studying he is doing for his Master's Degree he's keeping an eye out for job opportunities. He has also submitted an application to UCAS for various teacher training opportunities whether in-school training or the more traditional college route.

Last night he and I went out for a belated Mother's Day meal and he ordered a large pizza with two extra toppings. When we got home he had his usual evening-long snacks - a seemingly endless supply of cereal, dried fruit and bits and pieces.

Today he has his usual friends up in his room for a massive table top war games battle (Warhammer) and it's very noisy! Just like it used to be in the 'old days'.

Plus, he is about to learn how to drive (he has been putting it off for ages but now realises he will need it in order to broaden his career options).

Life is pretty normal, really. Nothing major to report with regard to eating worries or anything like that.

All in all it's Good News!

Wednesday, 19 April 2017

The Catch 22 situation of being a parent in a post-eating-disorder world

I know what parents who are still going through the hell of an eating disorder might say: "Think yourself chuffing lucky, Bev, that you're through this. I'd give my right arm to be shot of this deadly thing that's hi-jacked our family." But for those parents out there who are stuck in my situation, I'd like to describe a little of what's been going on inside my head.

For several years the eating disorder dominated our lives. Totally. 24/7/365. On top of this was the daily fear of death. *A real fear. A justified fear. Eating disorders kill more people than any other mental illness and our child could be next.* Easily. I know this because a friend's daughter took her life earlier this year. The eating disorder 'demons' became too hard for her to bear.

On top of this was the need to be constantly vigilant. And I mean vigilant. Not just 'on the look out' for faked eating or dealing with tantrums, but being on 24/7 RED ALERT waiting for the next primeval sounding scream or thud as my son bashed his skull against a brick wall.

And all the other horrific stuff that went on, round the clock. Stuff that was way, way, way beyond the realms of the 'normal'. I can't go into detail here, it's too triggering for me, so let's get back to the point of this post...

The closest I can come to describe this is what it must be like for a soldier to

return from active duty then leave the army and join 'civvy street'.

The horrific thing that dominated your life 24/7 and defined you as a human being (because of the nature of it dominating your life 24/7 for YEARS) is no longer there.

But what's in its place?

Some bland world where people ask you if you're "going anywhere nice?" when you mention a planned holiday. Or ask you how you are.

Ha ha, if you REALLY told them how you are they'd run a mile.

The rules of the game are that you say: "I'm fine, thanks" or the now more popular American: "I'm good, thanks".

Never ever say "Well I'm feeling really sh!t because the horrific thing that defined me for so many years is gone yet I can't adjust to what's in its place. It is so very long since I was 'me' - the 'real me' before the eating disorder - that I have forgotten who that was. And I've changed since then. Because of my son's anorexia and also just because people DO change over time. So do circumstances. And I no longer know who I am or where I fit in."

The thing that defined me - the eating disorder - triggers me and the PTSD (which I am currently receiving £60-a-week EMDR therapy for) comes hurtling back into my head.

Back in 2012 as my son began to recover from his eating disorder, I felt strongly that my role was to help other parents who were still in the thick of it - by blogging here, by writing articles and books, by appearing in the media and giving talks. That gave me a purpose. And it could STILL give me a purpose. Indeed it SHOULD, rather than running away to hide because, 9 times out of 10, anything to do with eating disorders just sets off the PTSD symptoms, leaving me in a panic and depressed.

So I find it darned hard to do the one thing that could define me in a post-eating-disorder world: the blogging, the writing, etc etc. And most of the people I know and love these days are people I've met along the eating disorder journey, mainly other parents.

So, without the eating disorder, who are my friends?

Which leaves me feeling incredibly isolated and alone because I just can't deal with bland small-talk about unimportant things in life. Not when I've been through something as hellish and all-consuming as an eating disorder in the family.

It's a Catch 22 situation where the post-eating disorder 'reason for being' - advocating for better awareness of and treatment for eating disorders - sets off extreme feelings of panic and depression. Ditto the dear friends I've met along this journey.

The obvious solution would be to 'move on' to pastures new. But what are those pastures new? Any pastures new would be so very bland and 'not me'. I am the person who blogs about eating disorders and uses the experiences with my son to help others. Yet this very thing 'pings' me back into a massive panic and feeling oh so low. The 'I can't get out of bed in the morning before 11am' kind of low. The 'I can't be bothered to shower, get dressed properly, do my hair or put on makeup' kind of low. The 'let's have another duvet day' or pig out on cupcakes kind of low...

I've been reading an article about *what not to say* to parents of young people with eating disorders. Well, here's what you shouldn't say to parents who are trying to acclimatise themselves in a post-eating-disorder-world and find a meaningful role:

"Cheer up, there are people who are worse off than you"... "Think yourself lucky! Your son recovered!"... "Go out and meet people. Join a club. Or a

charity." ... "Go on a relaxing beach holiday" ... "Pull yourself together" ... "Get in touch with your old friends" ... "Stop feeling sorry for yourself" ... "Make yourself do stuff" "Do some exercise" ... "Get out in the spring sunshine" ... "You know, sometimes I think you don't want to 'let go' of the eating disorder"...

And so on and so forth.

Or they just ignore it as if it never took place. Shit happens. Life goes on.

It's a tricky situation and I haven't found the answer yet.

Wednesday, 19 April 2017

Sue, who always had time for me, just to listen, with a coffee and some cake

Someone posed the question after sharing [this article](#) on Facebook: What are GOOD things to say? What would you like to hear other than 'cuppa?' Which immediately brought back memories of my wonderful friend, Sue, who was always there for me during the dark days of my son's eating disorder. Sue, who lost her life to breast cancer five years ago (is it really five years?), who would willingly lend an ear over a coffee and cake. Just after she died, I wrote the following at a writers' workshop in an attempt to describe what Sue was like which I haven't posted online until now:

"This much?" she'd ask, tentatively holding three-quarters of a teaspoon of Nescafe.

"Yeah, that's perfect," I'd say to Sue.

Yet she'd never have coffee herself, preferring herbal tea. She'd keep a stash in her handbag just in case.

And never anything sweet. "I must be the only person in the world who hates chocolate," she'd say, handing me a massive M&S fresh cream éclair with an expression that said 'indulgent Grandma'.

"You spoil me," I'd say, never daring to admit that I loathe fresh cream.

Her house was immaculate. The kind of house where you wouldn't even ask if you should remove your shoes; you'd just do it. Of course her taste wasn't my taste. Tall languid figurines embracing, polished dark-wood furniture with marshmallow cushions, a glass-domed clock and – always – Benji, her Shih Tzu, coiffured within an inch of his life, loyally protecting his mistress on the slippery cream leather sofa.

She herself was dainty, almost birdlike, in smart leggings and a fitted sweater with one of her many scarves draped artfully round her neck in a way I never quite managed to imitate.

"You always seem to get it just right," I said a few days before the cancer finally claimed her. "And I think the red works."

"It's not too Jane Goldman?"

"No, it's more Marcia Cross. I promise!"

"But dare I wear it to church? Or is it a wig too far?"

Wednesday, 19 April 2017

EMDR therapy: what we're working on at the moment

I'm receiving private EMDR (Eye Movement Desensitization and Reprocessing) therapy for the Chronic Post-Traumatic Stress Disorder and we're gradually working our way through things that trigger it off. Over the past three weeks it's been flashbacks to various CAMHS sessions when things were said and done that, in my opinion, made my 16-year old son's eating disorder worse, not better. Amongst the strongest memories are those of the

early CAMHS sessions which began 4 or 5 months after I first took my son to see our GP. Back then, CAMHS didn't seem to think the eating disorder was too bad. Ben was acting as if nothing was wrong and that it was just fussy, anxious mum worrying in the way mums do. He also looked pretty OK in their eyes (except they hadn't seen him as a big, burly rugby player).

This immediately makes the question / thought crash into my mind:

"They were eating disorder experts. They SHOULD HAVE KNOWN that you can't judge whether or not someone has an eating disorder just by looking at them. They SHOULD HAVE KNOWN that people with eating disorders could win an Oscar for play-acting in an attempt to ward off intervention. They SHOULD HAVE KNOWN that just because someone's BMI isn't too low it doesn't mean that an eating disorder isn't raging full pelt. They SHOULD HAVE KNOWN that telling someone to their face that they are doing just fine translates as telling them they are FAT and need to lose more weight."

"THEY SHOULD HAVE KNOWN!!!!"

And this is just one example.

We're working on this anger. This fury.

Yet in a strange way I don't want to lose it through EMDR.

I want to stay angry because, when I manage to get back into eating disorder advocacy again, being angry makes me more effective.

It gets stuff done.

It gets the word about.

Back in those early CAMHS days, I posted the following excerpts on the [Around The Dinner Table Forum](#) (for parents of young people with eating disorders):

CAMHS team really don't think he's seriously bad and it makes me mad because I know differently and he's pulling the wool over their eyes... now

psych has gone off on her hols for 3 weeks so we're all at sea... Last time we saw her she was all smiles and congratulations as S reached a 'healthy weight' for the first time.

Last night we had meltdown... total and utter emotional meltdown as S went to complete pieces and became a weeping, distressed, emotional wreck. I guessed it was on its way due to him being very subdued throughout the day. All hell broke loose at dinner...

We had another meltdown last night with S bashing his fist on the plate so all the food went everywhere followed by 5ft 3 inches me trying to physically restrain all 5ft 11 inches of him from breaking down the door and flying out into the street, me confiscating the house keys and barring the living room doorway... (My husband doesn't get back until late evening as he commutes 100 miles to work and back.)

This afternoon we have a brief session at CAMHS for a weigh-in with the nurse. At the last count the psych felt fortnightly sessions would be appropriate now rather than weekly (!!!!!!!) now that he's come just within the 'healthy' weight range...

Of course my son is convinced he's ballooning out into a huge fat flabby monster, pinching the skin on his abs to "prove" it.

Wednesday, 19 April 2017

The life-saving forum that I joined back in March 2010

The Around The Dinner Table Forum is an amazing forum for parents of young people with eating disorders. In case you haven't discovered it yet, here's what its founder, Laura Collins, said in the Introduction to my second book [When Anorexia Came to Visit](#) about the [F.E.A.S.T. community](#) and its online forum [Around The Dinner Table \(ATDT\)](#):

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 practicing 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.

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!

Wednesday, 19 April 2017

9th March 2010: my first post on the Around The Dinner Table forum

If you're going through the hell of being a parent of a young person with an eating disorder, and especially a boy with anorexia, you might be able to identify with my posts on the [Around The Dinner Table forum](#). This is my first post from 9th March 2010:

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.

His eating disorder became noticeable over the summer (2009) with rapid weight loss (quarter of his body weight), obsessive exercise and strange eating obsessions developing (e.g chopping fruit into little bits which would take ages). I took him to the GP in September but it was late October by the doc took my concerns seriously - and even then I had to practically force him to refer him for treatment.

We live in the UK and the treatment offered by our National Health Service is called CAMHS (Child and Adolescent Mental Health Services). The waiting list is HUGE, so we only began (outpatient) treatment mid Feb 2010.

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... There's no point in listing everything here 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. Yesterday, for example, (the day we ended up with super emotional meltdown as son texted me 20 times from school, mega distressed, with an ultra-distressing evening to follow) I reached the end of my coping and found myself picking up a dinner plate then throwing it across the kitchen until it smashed into pieces (fortunately I was alone in the house at the time...) Today I am exhausted and have made the decision to take son out of school for the time being (he just goes to pieces when he's there and spends very little time in lessons, mainly hiding in some corner somewhere). He has important exams in a couple of months (GCSEs), was an A star pupil expected to excel, but, hey, what can you do, recovery comes first...

What frustrates us is that his psychiatrist doesn't think his problem is too severe. His BMI isn't bad and when he's with her, his behaviour is quite normal. As a result she's started spacing our appointments further apart; we have a 4 week break between our next two appointments. Despite trying to argue the case with her, she's adamant he isn't too bad. As parents we feel as if she's pushed us off a cliff and into free fall... We wonder whether we might have to go private, or if we should stick with the free NHS treatment... We explored private treatment a bit while on the waiting list and weren't impressed with that either. Difficult really... Very difficult, actually...

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...

But reading through the [ATDT](#) posts it's so reassuring to see that recovery DOES come.

Anyway, enough for now. Just thought I'd introduce myself and our problems!!!

PS So glad I found [this forum](#)...

Wednesday, 19 April 2017

More from that ATDT first post in March 2010

When I uploaded that first post on the [Around The Dinner Table Forum](#) in March 2009 I was astonished at the incredible response I got from other parents who had 'been there, done it' or were 'still in there, but doing it' - from the UK and across the English speaking world. I finally felt that I had the support I craved and was amongst people who 'got it'. If you are a parent of a young person with an eating disorder I can't recommend this forum highly enough. It was a true life-saver for me. Here are a few of my responses to the replies I received following [that first cry for help on 9th March 2009](#):

Wow, thanks everyone for your wonderful replies to [my post](#). My son has slowly put on weight, but I'm in a battle with the dietitian over calories v portion sizes (I favour calories short-term because it's the only way to get his weight up; portion sizes did the opposite...)

The CAMHS team really don't think he's seriously bad and it makes me mad because I know differently and he's pulling the wool over their eyes... now the psych has gone off on her holidays for 3 weeks so we're all at sea... Last time we saw her she was all smiles and congratulations as my son reached a

'healthy weight' for the first time. My son took that to mean that he can maintain his weight now at what, to me, still looks very thin and not at all like the strapping sportsman he once was...

Things felt for a while as if they were going well but the last few days, without CAMHS' support, they've gone a bit pear-shaped as anorexic thoughts and behaviours creep back...

It's difficult to know if we should ditch CAMHS... it took so long to move up the waiting list... also for all I know the 'softly softly' approach might be the correct approach... Having been down the private route before CAMHS, I have no idea how we could find a suitable private therapist.

*The trouble is... my son refuses to eat high calorie food (packed with "bad" fats, etc etc) so we end up with loads of bulk and one meal runs into another, fuelling the anorexia's control. Does anyone have any suggestions as to how I can wean him off the diet stuff (fat free yogurts, ultra-low fat spread, etc) and onto high calorie stuff (e.g. normal yogurts, etc - he even has a problem with fat reduced cheese, you see... and of course any cake or pudding with fat in it... despite what the dietitian says about needing 30 percent of fat in daily diet... he just distorts her advice to suit his own twisted version of nutrition...
HELP!!!!!!!)*

Last night we had meltdown... total and utter emotional meltdown as my son went to complete pieces and became a weeping, distressed, emotional wreck. I guessed it was on its way due to him being very subdued throughout the day. All hell broke loose at dinner...

My son said that all the improvements we'd noticed in his behaviour and mood were the anorexia and not the real son. It's been lying to us and 'pretending to be him'.

He confessed to cheating on portion sizes when he's made his own breakfast or snacks, doing secret exercising, etc. All he thinks about is food, all the time, and in between meal times are just times to fill in until the next all-important meal. (Mind you, I knew this... it doesn't come as a surprise.)

Having been off school for 3 weeks (couldn't cope with school, utter emotional breakdown) and remaining off school for the foreseeable future (probably until September), he's getting stir crazy and isolated. I've tried to take him out for nice walks, etc but last night he said he only does these to burn up calories.

I've been aware of the artificial situation of being off school and being so isolated (and bored, despite still studying for GCSE exams); I was waiting for an outburst of some kind. I really don't know what to do or how to handle the situation as he risks isolating himself more and more (though we did have a successfully sociable weekend last weekend). It's an ideal situation for the anorexia to take hold and control him.

Meanwhile we have an age until our next CAMHS meeting. Also he confessed to pulling the wool over CAMHS eyes and pretending to be fine when he obviously wasn't. They've obviously been taken in by this.

On the CAMHS subject... what happens when we go is that he gets whisked off to see the psych who then just drops him off and disappears so, apart from two initial consultations, we never get the chance to talk to her. We talk to a nurse, but I get the impression communications aren't brilliant between the nurse and the psych so very little gets passed on.

If we did decide to go private again, how do we find a good private therapist? Do we go for the full-on psych (at vast expense per hour), a psychologist or a CBT therapist (cheaper!)? Unfortunately money is an issue... Also, what if they were just as problematic as CAMHS?

I really feel "at sea" with all this... desperate for proper, healing care for my son and the feeling I'm not getting it, but don't know how or where to find good care...

Thanks everyone for your wonderful support. Much appreciated. Xxxx

Thursday, 20 April 2017

Refeeding: calories or portion sizes? My second post from March 2010 on the ATDT forum for parents.

During those early weeks of CAMHS treatment for my son's eating disorder, I clashed with his therapists quite a few times on food-related things. One of these things was: *Do we do calories or do we do portion sizes?* The general rule was that we should do portion sizes but the trouble was that my son's food intake was super-low in calories i.e. virtually just salad or vegetables. So a portion of that kind of thing was, in my opinion, going to do naff all when it came to putting on weight. Quite the reverse, in fact. This is why my gut instinct told me to go for calories. This way I could be sure that he was eating enough. Or, at least that was the case as long as I was allowed to take control of his food intake. As soon as this control was passed over to him (as happened just a few months into treatment), his calorie intake went downhill. But that's another story. Here is my second post on the [Around The Dinner Table Forum](#) in March 2009 which asked the question: *Re feeding: calories or portion sizes?*

Our dietitian (who we see every 3 weeks) is anti-calories and prefers portion sizes, showing us vague pictures of portions of rice on a plate (for example). But we're finding the only way to get the required food into our 16-year old son is to count calories. It's worked over the past few weeks and his weight has increased gradually. Plus he feels more in control with calories - i.e. he isn't so

worried he may suddenly 'balloon out'. But I am aware that calorie counting can fuel control issues...

On the other hand, when we tried portion sizes, he ended up losing weight.

He freaks out at large portions. Also anything with fat in it which means the only way I can get the calories into him is to have loads of carbs, then he accuses me of not giving him a balanced meal (he quotes the dietitian so suddenly I'm the bad guy who he can't trust and this is all about trust, etc etc etc...)

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.

And...

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 ton 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...

Anyway fortunately it all ended with him coming down stairs afterwards and sitting quietly next to me, head on my shoulder.

Me, exhausted...

And...

... HE ATE THE DREADED 'STANDARD' YOGURT THIS MORNING with brekky which he would never (x100000) have ever (x100000) done even just a week or so ago... (and - oops - careless me accidentally binned the remaining fat-free yogurt which I found lurking at the back of the fridge so all that's left are the standard yogs...)

... and he had a (albeit it 'skinny') latte at the shopping mall yesterday...

... and he actually came back from the shop yesterday with a Cadbury's cream egg which he plans to eat on Sunday. Will he - or won't he? Watch this

space, ladies...

And...

The good news is that he ate the Creme Egg. 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 my husband'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...)

Today Standard Yog was eaten OK...

Next weekend's "baddie" to be introduced to the diet plan will be a cake containing butter / marg (my son always liked to bake fat-free cakes... no surprises there...)

Thus so far, it looked as if we were making progress and succeeding to get our son to eat more and switch from diet foods to standard foods. But, as you will soon see, it became unsustainable. I didn't have any proper support when it came to re-feeding and eventually my son couldn't handle it any longer. So what happened? Watch this space for more excerpts from those early [Around The Dinner Table forum](#) posts.

Thursday, 20 April 2017

For all the battle-weary parents out there...

We've been having a discussion on the [Around The Dinner Table Forum](#) about how some of us parents are getting along in a 'post eating disorder world' i.e. when our child is either recovered or almost recovered. Most of us

have been left with a brain that's pretty frazzled to say the least and we've been wondering how this compares to others who have been through trauma whether another serious and possibly life-threatening illness in the family or something equally as traumatic.

I can imagine life is pretty hellish for anyone who's been through any kind of sustained 'over and above the call' trauma. So in no way am I claiming that our situation is any worse, just that it's *different*.

The difference for us, as parents of young people with eating disorders, is that we've been fighting so many things at once: we've been fighting a child who doesn't appear to want to get well, indeed who may wish to end their lives. We've been fighting to keep a round-the-clock suicide watch to make sure they don't.

We may have been fighting poor treatment - or unfair or difficult to access health insurance. Or simply fighting to get our child referred for treatment in the first place.

We may have been fighting to keep our careers afloat and our mortgages paid while struggling with sleepless nights and almost daily emergency phone calls from school as our child throws a wobbly and goes to pieces.

Again.

We may have been fighting our significant others who may not 'get it' or be actively colluding with the eating disorder.

We may have even found ourselves fighting with the police or security personnel as our child (uncharacteristically) does something crazy and violent.

And of course we may well have been fighting what, on the face of it, appears like PURE CRAZY MADNESS as our intelligent, wonderful, much-loved child transforms into someone who appears to have totally lost the plot and becomes almost feral. A mindset that insists that black is white and where logic

goes out the window.

And we may have found ourselves *physically fighting our child* as they get violent with us.

The chances are we've been fighting a ton of other stuff as well, the most important of which will have been to *get our child to eat*.

And we've probably been fighting most of it round the clock, day after day, month after month and often year after year, sometimes (God forbid!!!) forever.

It's little wonder we end up a tad frayed round the edges (says she in the Understatement of the Year).

Friday, 21 April 2017

But if you don't have the cash, then what's the point of raising awareness about adult mental health?

Earlier this year I sat down in front of my NHS EMDR (Eye Movement Desensitization and Reprocessing) therapist (for my Chronic Post-Traumatic Stress) only to be told that we had just THREE SESSIONS left. And you know what? I was LUCKY that I'd been offered TWENTY sessions in total; very soon the NHS would CUT these to just SIXTEEN. I was also DOUBLY LUCKY because I'd had a large number of other sessions prior to this - a mix of CBT and psychotherapy (which obviously didn't work, hence why I was undergoing EMDR).

In a blind panic at being thrown from the ship in the middle of a stormy ocean without a lifeboat, I yelled: "No, no, no!!!!!!!" and scarpered down the stairs, down the road, into my car and out onto the motorway where I drove for 40 miles or so before returning home. I didn't answer the phone, I didn't want to speak to the therapist again.

Oh I know that it's not her fault that the NHS appears to be CUTTING DOWN on adult mental health provision at a time when many people, including TV and other media, are busy raising awareness of mental health in a bit to counter the stigma.

*But my point today, after watching another TV programme about adult mental health last night, is: **If you don't have the cash to pay for private therapy, then what's the point of raising awareness about adult mental health?***

Being kicked out after (what would now be) just SIXTEEN sessions of EMDR for your Chronic PTSD just because you didn't recover quickly enough is CRIMINAL.

You can't possibly set a time limit on how many sessions it takes to recover from a mental health issue.

Furthermore, with EMDR the first two sessions (at a minimum) are spent explaining what EMDR is all about and why it's believed to work, and also getting to know and trust the therapist. So that leaves around FOURTEEN sessions to get the patient completely back to normal - or they're spat out of The System and left to fend for themselves.

At this stage you either pay for private help or shut up and put up with it.

I am so incredibly fortunate that my husband and mum are funding my private EMDR therapy with Steve, a fantastic (but private) EMDR therapist who really knows his stuff. He also knows eating disorders inside out, so that's even better - because the C-PTSD has come as a result of all those years of battling to get my son through anorexia.

But I am only too aware that not everyone is as fortunate.

There must be hundreds... thousands... of people out there struggling with mental health problems and receiving ZERO TREATMENT because they've been

discharged by the NHS because their allotted sessions are up. And they can't afford to go private.

Also, if the NHS has cut its number of EMDR therapy sessions from 20 to 16, how long before it goes down to 10... 8... 4... zero?

I am left feeling kind of guilty because I didn't respond to the other therapy I was offered for the PTSD. Yet it's not my fault that it was ineffective.

Now as I undergo pure unadulterated EMDR therapy with Steve it has become clear that the other therapies were no more than sticking plasters (band-aids) on a festering wound. They were never going to get to the root of the problem and cure it. So they were a waste of my time, my therapists' time and NHS funds that could have been better spent elsewhere.

Like on proper, long-term EMDR therapy right from the start.

If CBT and psychotherapy are the sticking plasters of C-PTSD treatment, then EMDR is the antibiotics which will clear up the weeping wound once and for all.

But I am lucky. Others are not so lucky.

EVERYONE should have access to the right mental health treatment for as long as they need it, care of the NHS.

Friday, 21 April 2017

"Nearly at target weight but mind set is way off... what now?" My 3rd post from March 2010 on the ATDT parents' forum.

One of the first things I did, when we found ourselves sitting in front of our local CAMHS team all those months into my son's escalating anorexia, was to ask if we'd be given an Eating Plan. This was met with some surprise, but in the end the nurse rooted around in her briefcase and pulled out a 'typical eating plan'. It was entitled Eating Plan 6 (I've no idea how it differed from numbers 1 - 5). Rightly or wrongly, yet desperate for my son to put on weight, I embraced

Eating Plan 6 with a vengeance and did my best to implement it. But without any support, indeed CAMHS were quite resistant to what became known as 'Mum's Eating Plan', it was never going to work. My son refused to eat anything on the Plan, so I found myself having to tweak Eating Plan 6 considerably. But I did manage to get some weight onto my son during those early months with CAMHS. In late March 2009, I posted the following on the [Around The Dinner Table Forum](#), asking the question: *Nearly at target weight but mindset is way off... what now?*

My son has sneaked through into the "healthy BMI" range and for the first time for MONTHS actually looks pretty normal (if still quite thin). (Thankfully he never got lower than XXX BMI at any one point on this horrible journey...)

The trouble is... his mindset is way, way off "healthy" as you'll see from my other posts... which means we're faced with a new "demon" as all the previous "you must eat to put on weight" stuff becomes obsolete and he panics that he's about to spiral out of control and become a complete blob.

It also makes it masses harder to make him eat anything with fat in it. ("I've put on weight WITHOUT eating fats so why should I eat fats now?" blah blah blah)

It also means we have more "poky / proddy" and looking in mirror sessions than ever as he develops "rolls of fat" on his belly almost by the minute not to mention umpteen "double chins" etc etc etc as he becomes convinced we are dead set on transforming him into Michelin Man like some kind of warped child abuse...

And...

Already the dietitian at CAMHS has become the "goodie" and mum's enemy because "she says I've reached my ideal weight"... unfortunately the psych, too ("Congratulations!" says the psych, all smiles, "Your weight is healthy again!")

How can mum's instinct be right when "the professionals" imply he's virtually there... hey...

Every pound gained results in mum's life being made hell on the drive back home. But to our dietician's credit, she did talk about the w/r where your weight kind of settles. I don't believe we are there yet, but she obviously thinks we're much closer than I do. Conflict isn't good - and my son is sure to take her side, not mine.

This was a really tricky period for me and I was desperate for the professionals to be behind me. Yet because they were kind of sitting on the fence as regards putting on weight, I wasn't sure whether or not I was doing the right thing.

On the one hand I had them - the CAMHS team - feeling strongly that my son wasn't too bad, weight-wise, and that it was his mind that needed attention, not his body. On the other hand, I had my new friends on the ATDT forum, along with the books I was reading, saying that 'Food is medicine' and I needed to get my son back to his pre-eating disorder weight with a balanced diet that would assist his brain in recovering.

With such polar opposites when it came to views on eating disorder treatment and a son who appeared to have completely lost the plot, I simply didn't know who was right or what I should do next.

What I did know, however, was that 'the anorexia demon' (as I'd begun to refer to it) was gleefully siding with the people who weren't insisting that my son eat and put on weight.

It was around this point that I began to think of myself as 'Big Bad Mum' and Eating Plan 6 as 'Mum's Eating Plan'.

And, as you'll know if you've read my book [Please Eat...](#), Mum's Eating Plan was about to be ditched in dramatic form...

Friday, 21 April 2017

"Any lunch suggestions? Run out of ideas!!" A post from April 11th 2010 on the ATDT parents' forum.

What follows is a short thread I posted on the [Around The Dinner Table Forum](#) in early April 2010 asking the question: "Any lunch suggestions? Run out of ideas!!" Unsurprisingly I was finding it mega difficult to get my son to eat using Eating Plan 6 which CAMHS had given me. It was full of all kinds of stuff that he wouldn't have touched with a barge pole: sponge pudding, custard, butter, cheese... The only things I could get him to eat were from his minuscule list of 'healthy' foods like diet this and that, vegetables and fruit. As a result, getting my son to eat enough calories meant getting him to eat a HUGE VOLUME of this low calorie stuff and by the 11th April, around 4 or 5 weeks into CAMHS treatment for his eating disorder, I had run out of ideas.

You know what it's like when you're mega limited to what they will eat and yet you have to pump up the calorie content. Lunch is a particular sticking point with us... what to put in the sandwich or on toast. Even better, how can I secretly sneak in extra calories? (Suggesting butter is no good as he refuses to eat spread of any kind. Or cheese. Or fatty meats. Or anything fried.)

So I thought I'd start a thread on imaginative high calorie lunch suggestions to expand our repertoire... After yet another fight at breakfast I decided to add up his fats (instead of just calories) and found that even on a quite a high fat day like today (with my super-duper chuck-it-all-in shepherd's pie!!!!) he is still only having 59g fat of which 21g are saturates. Here in the UK the government recommends an adult male eating 2500 calories needs 95g fat of which 30g are saturates.

But even with the facts in front of him, he (or, rather, the eating disorder) still argues that black is white...

Evening meals are a great way to pump up the fat content, especially things like shepherd's pie, casseroles and lasagnes - it's just lunch that's a problem. What will he do, I wonder, when I brandish the peanut butter??

This post sounds fairly positive. But it was before my son became ultra-vigilant on what I was cooking and how I was cooking it. More critically, it was before my son was given back control over his food intake during the day. I dealt with the evening meal; he dealt with the rest of the day.

This, of course, was to increase what was already a massive pressure to bump up the calories in evening meals to compensate for the calories he was no longer consuming during the day.

And - with risk of appearing selfish and taking the focus off my son for a moment - it meant that I also had to consume these mammoth evening meals because no way was he going to allow me to consume a grain or rice less than him.

He even insisted on weighing out our portions before the meal to check that I wasn't getting any less than him.

Which, of course, meant that I quickly put on weight (and have never lost it!).

You might ask why I allowed him to control and dominate proceedings in the way that I did?

Well, that is a blog post entirely of its own...

You might also ask why I was getting bogged down in calories and fat content? That's another topic, too.

Monday, 24 April 2017

"The eating disorder fights back" - a second post from April 11th 2010 on the ATDT parents' forum.

Here is a second post from 11th April 2010 on the [Around The Dinner Table Forum](#) (which exists to support parents of young people with eating disorders). What this post demonstrates is the roller coaster nature of an eating disorder: one day things are HELLISH and yet the next there are chinks of light at the end of the tunnel followed by HELL again. It's a bit like a game of Cat and Mouse in that just when you think you're getting somewhere the eating disorder muscles in again and you're back where you started. It also demonstrates the similar roller coaster relationship that I had with the CAMHS team: one minute they were great and the next they were saying stuff that was potentially harmful. (Please note that, as with all these forum posts, I'm only posting my words, not those of the parents who responded, for confidentiality reasons.)

So there were, coming along swimmingly (as you'll see from my other threads) when - pow! - the eating disorder decides to fight back in a bid to get control of my son again.

The problem being that he's now within the "healthy" BMI range (albeit at the bottom end of it) and is putting on weight at what is really a "maintenance" level i.e. ounces, not even pounds.

Ever since we saw the psychiatrist on Friday (who was brilliant, actually...) my son has started to rebel, refusing to stick to the eating plan any longer, body checking, refusing to eat any fats of any sort, constantly arguing with his dad and me (the old irrational arguments that don't get you anywhere) and being in a generally depressed state of mind. (Because he feels he's gaining weight at a fantastic rate and is getting flabby. He wants to take charge of his own meals (no way!!!!) He also feels very tired, though the psychiatrist said this is because his body is still going through umpteen physiological changes as it

tries to heal itself on the inside. She says this is totally normal, but he won't hear of it.)

We feel as if everything we've achieved has been given a real kicking as the eating disorder tries to get control again and drag our son back down to where he was.

It feels as if we're on an elastic lead and have plodded along the road almost at our destination when - ping! - the elastic pulls us right back to where we were a few months ago...

Help!!!!!!!!!!

And...

Thanks everyone for your replies.

Unfortunately we haven't seen the dietitian for over 2 weeks; our meeting with her last week was cancelled because she was sick. I've emailed her a detailed list of what my son had eaten over the past 7 days so she can hopefully work out that he's not getting enough fats / calories and convince him he needs more. Psychiatrist was concerned about his obsession with fats and his belief that his current levels of saturated fats are similar to what obese people eat... this from a boy that has virtually ZERO fat in his diet and refuses to eat anything with added fat, only things with natural fat in them (e.g. he's convinced that bread includes high levels of fats!!!)

Dietitian has never given us a target weight. However I live in dread of her saying he's "arrived" when it's blooming obvious to me that he hasn't.

Sometimes I feel as if we're stuck with this dreadful eating disorder thing forever...

PS I've got [the James Lock book](#) [Help Your Teenager Beat an Eating Disorder]. I'd say eating disorder is like climbing a mountain with loads of false summits...

And...

With us it was (and is in many cases) foods with fat in them. Our son has an irrational fear of fats. But today, having monitored exactly how much fat he is eating, the rational bit of him has agreed that, yes, in essence that makes sense - although the eating disorder is trying to negotiate a halfway house of keeping the fats where they are and not going any higher... Sorry, eating disorder, but I don't negotiate any longer...

With my son, like many of the teenagers on this board, it helps to "announce" in advance what I'm serving up. I do a printout of my spreadsheet, with the calories omitted of course, so he can see what's on the menu for the day. I've been introducing fear foods into the diet gradually to avoid anxiety.

But I'm definitely aware that I should be more forceful - and find it does work when I am. So that's the way things have been today after the weekend's eating disorder fighting back. After he refused point blank to eat his breakfast, he eventually ate it (mind you, I had to threaten to call his dad...) And peanut butter is still on the agenda for breakfast tomorrow with a cinnamon and raisin bagel (plus cereal, etc).

And...

Well how about this...!!! Yesterday morning he ate a peanut butter- covered cinnamon and raisin bagel for breakfast. Then he went into town and (yes I do believe what he said about what he ate there is true, he even offered to send me a photo via his phone to prove it and he came back with the packaging) had a mid-morning snack (proper drink, etc) followed by a soup and baguette in Pret and an iced yogurt with lashings of honey in Bagel Nash. Then he arrived home with a choccie bar from Thorntons (not yet eaten) AND a jar of hazelnut spread (like peanut butter BUT HIGHER IN FATS AND CALORIES!!!) and had that for breakfast today on a bagel. Last night we had a very calorific curry I cooked

(you can slug loads of oil in when cooking curries!!!) and he made a daal which included oil.

An incredible number of victories in just one day!!! The other month he went into total meltdown in Pret and was unable to buy anything. He had to walk out, in a terrible state - one of our worst and lowest ever days with the eating disorder. So yesterday's complete anxiety-free visit was amazing.

Trouble is, I'm now waiting for the eating disorder to fight back again because I know it will, the minute the eating disorder 'whispers' to my son that it's all landing straight onto his belly in the form of FLAB.

But even so... victories... YeeHa!!!!

And I do believe he ate all the above and didn't bin or leave it. I really hope he didn't bin or leave it...

PS I forgot to say... he also came back with some prezzies he'd bought with his pocket money for me and his dad to say thanks for putting up with him through all this... I said the best prezzie of all will be when he's completely recovered...

And...

[Name], I can totally identify with what you're saying! The anxious tension waiting for the eating disorder to rear its ugly head again and then if it does, not being able to handle it - with me, I have to suddenly take time out and drive somewhere convinced that my son will NEVER recover... EVER!!!

But then a day or so later things improve - and, hey, they often improve more than they improved last time round.

One thing, though. There seems to be a pattern whereby whenever we see the psychiatrist or dietitian, my son seriously freaks out and rebels afterwards and is depressed for a day or so. Is this normal? Is it GOOD (i.e. my son will eventually realise that what was said makes sense) or BAD (most of what he

seems to bring out from the meeting is related to the weighing scales session and his weight gain as opposed to anything else that was said - or at least that's how it seems...)?

And...

You are all wonderful, as ever... thanks!

Lots of stuff here about not letting our teenagers take control of their own eating too soon. How soon is too soon, I wonder / worry? At the moment I have total control over his breakfast and I draw up a daily food plan spreadsheet (I don't print out the calories column of course...) But often my son will switch a snack, for example, to one of the same calories, just something different he fancies. Should I let him do this? Also, mainly because this entire thing is so exhausting when you're trying to run a home, family and still cling onto your home-based business by the skin of your teeth, I do let him do the occasional bit of cooking or baking, but not much and nothing like dinner or lunch, mainly snack items or puddings. Should I do this too?

Bit worried that I may be colluding with the eating disorder by doing this... or it might be harmless. Would welcome your advice from your own experiences...

Thanks again.

And...

We went to see the psychiatrist this morning and I feel a bit uncomfortable about it... it was a one-on-one session with my son so I sat in the waiting room. My son came out all smiles, eager to tell me that the psychiatrist felt he'd arrived at his weight restoration point and that it was high time we adults stood back and let him take more control - in fact she wants a family meeting with us because (according to my son) she feels we are being too strict and should relax our 'hold' more... My son loved that, as you can imagine!!!! In fact it's the first time he's come out of a CAMHS meeting in a good mood!!!

Hmn... as far as I'm concerned the jury is out on that one... we've known our son all his life and have been with him 7 days a week on this hellish journey. OK some of what she says may be true and we do need to relax a bit (because naturally we're scared he'll 'ping' back into the depths of anorexia and will naturally eat less than he needs...) To be honest, I think it's early days and she's been a little too confident...

Suddenly I feel it's my husband and me versus my son and the CAMHS team... and also I'm scared they'll discharge him too soon...

Just wondered what you guys think???

And...

I do get the feeling the psychiatrist doesn't listen to us parents and sees us as needlessly worrying and 'fussy' / paranoid. I've felt that since the start, really. I don't think she likes me!!!!

My son has been in a very sunny mood all day and is actually looking like a 16-year old boy should look these days. I found an old photo of him taken back in November and the difference is incredible - did he look TERRIBLE back then, or what!!!!

Also we went clothes shopping this afternoon and he actually asked me to swap the XS size tee shirt for a Small because the XS was too tight, and he didn't bat an eyelid. A few months ago he would have freaked out that he was getting fat.

Also, he is planning to go back to school a week on Wednesday and looking forward to having a laugh with his mates. A bit different from the day I smashed the plate on the floor after getting 22 distressing texts from him - the day I took him out of school because he couldn't handle it, or his being with his friends.

I think going back to school will be the telling time seeing as school was a key driver in how all this came about and he's been in the artificial environment of home for a couple of months or so. Not only will he have everyone staring at him (as kids are prone to do....) but he'll have to cope with school dinners and all the other stuff that used to freak him out...

However I really am getting the feeling we are seeing the light at the end of the tunnel. But my husband and I will remain ultra-vigilant, if not as obviously so as in the recent past to gauge whether what the psych says is true or not.

And...

I have copied and pasted your wise advice for future reference when we have our aforementioned Family Session. I really appreciate it!!!!

Yesterday the psychiatrist handed me a photocopy of a printed summary of Janet Treasure's kangaroo / rhino / jellyfish / St Bernard / dolphin carer personalities - but I have already read [the whole book](#) [Skills-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method] so nothing new there... but it does imply our CAMHS follow the Maudsley Method though nothing has been said (we really don't get any time to ask these questions at our very brief one hour sessions (now moved to fortnightly instead of weekly...) and she won't give me her email; I have to email the admin woman who hopefully passes stuff on, though I never get any acknowledgement from the psychiatrist that she's read what I send her...)

My son gets on very well with her, though, which is important - easier for her to win him over to a non-eating-disorder way of behaving.

[Name], we had to wait MONTHS for our first CAMHS session, too, and went private to fill the gap - with a CBT therapist who was OK, but very difficult to pin down for an appointment! Plus we saw a very fierce private male psychiatrist - I think I prefer the CAMHS one to him!!!!

So, during April, the eating disorder went up and down like a roller coaster as did my relationship with the CAMHS team - and I never was sure which treatment model they were using or if they were just 'winging it'. What I do know is that I wasn't included in every session; often it was a one-to-one between my son and the psychiatrist. Sometimes I'd be called in at the end for a summary; sometimes I wouldn't. And sometimes I'd be given what were called 'parenting sessions' by the CAMHS nurse which, by the nature of them, immediately made me feel really guilty, as if we were the cause of the eating disorder and were being given 'parenting sessions' to show us how we should act as parents.

It was very difficult for me to pin down either member of the CAMHS team after a session. During the session, if I was included, I was only too aware that there were just *60 precious minutes* which wouldn't give me time to voice my concerns and, anyway, I didn't want to do this in front of my son for obvious reasons. Then at the end of the session they'd disappear as if in a puff of smoke.

The only way I could contact them outside the sessions was to email the 'gatekeeper', the lady at the desk, who would hopefully leave a message in their pigeon hole. As I said above, I was never sure whether or not they received my messages. We weren't permitted to contact them direct. It was almost as if parents were viewed as a nuisance.

Monday, 24 April 2017

"Fats phobia again..." - a post from April 21st 2010 on the ATDT parents' forum.

This is another thread from April 2010 which I posted on the [Around The Dinner Table Forum](#) (which exists to support parents of young people with

eating disorders), this time about my son's fear of fats, my increasing stress levels and despair, plus the fact that we couldn't take our eyes off him for a moment (see summary at end). It was just one nightmarish roller coaster and I have no idea how I managed to go on from day to day, not helped by a local GP who was completely disinterested in the fact that my son had anorexia nor the fact that we had large gaps between CAHMS sessions.

We were going along quite well with our son eating one or two 'red light' foods with fat in them (but only getting around half the recommended fat intake per day and one third of sat fats) when rebellion set in again.

I feel like a stuck record with the bit about research showing you need fats for sustained recovery and brain repair, etc etc... all we are interested in is your recovery... this is non-negotiable... etc etc etc. Yet he is actively avoiding 'fatty' foods again e.g. the standard low fat yogurts we introduced to replace the fat-free yogurts - and with this comes endless questions as to whether my (kept well out of his sight) calorie total is accurate, etc. "How will we ever move onto portion sizes like the dietitian wants us to?" I ask, "without you losing weight because you'll naturally be eating less?"

How can we let our son take control of his own eating, I ask myself privately, without him cheating or cutting back or avoiding stuff? The psychiatrist wants to 'tell us off' for not letting him take some control back and is setting up a meeting to talk this through with us.

I wonder whether this backslide into problem behaviours is related to our son's decision to go back to school next week (after 2 months away)?

Meanwhile I won't let the eating disorder bully us in any way. I am sticking my ground and telling my son that there is no negotiation over what he eats.

And...

It all ended in meltdown last night which is (thankfully) something we haven't had for a few weeks (we used to have it virtually every day). You know... striding out of the room, banging head on front door, slapping head with fists and crying out in animal voice. My son says it's his way of getting the eating disorder out of his head and getting himself back in control, but it's a really distressing way to do it!!!! My son is well aware when it's the eating disorder that's doing the talking and arguing whereas my son knows what's rational and sensible (he says).

We see the dietitian today after a month's absence so it will be interesting to see what she has to say... Not seeing the psychiatrist until next Friday. My son still plans to go back to school on Wed, but it does worry me that we'll snap back to where we were last time he was there (the plate smashing day for me...) Also, it will mess up the eating plan re. morning and afternoon snacks (my son says he doesn't want to do lunchboxes. Trouble is, at his school ALL the kids have school dinners and no-one has lunchboxes so he stands out like a sore thumb and doesn't want to...

Shall I give the above a couple of days to see how it goes? And if the food side of things isn't working, resort back to the Plan A we had before which was for my son to have supervised break snacks and pack lunches in medical centre? Trouble is, that works against the whole idea of going back to school which is to integrate back into the social scene. Having been away from school for 2 months, he's been pretty isolated and we worry he'll become too almost reclusive...

How do we know when is the 'right time' to go back to school? My husband thinks it'll be a total disaster...

Would appreciate your (always so wise!!!) advice!

And...

Well, our meeting with the dietitian today never happened because she'd forgot to put it in her diary... so by the time we see her next week it will be FIVE WEEKS since we last saw her (because she was ill last time and before that it was Easter)...!!!! I don't know why we bother... I know as much about nutrition as she does, I could do the dietitian bit!!!

Anyway back to school... Much of it is me being nervous about flipping back to how it was on plate-smashing day (see photo) and the weeks that preceded that... the weeks when I'd get deluged with distressing texts from my son who'd be lurking in the school toilets or hiding in the corner of the common room... interspersed with phone calls from the medical centre asking me to pick him up.

The good news in a way is that the first day back is the only full day back that week (Wed). On Thursday we're seeing the dietitian in the afternoon and on Friday afternoon we're seeing the psychiatrist. So, if necessary, on both occasions I could pick him up BEFORE lunch.

En route to our non-appointment today we picked up a couple of large paninis from the deli. My son chose beef and mustard (still averse to cheese...) and ate it all without batting an eyelid. After the non-appointment we went for a walk in the countryside and had one of our long chats - always a good place to talk to the real Ben without the eating disorder rearing his ugly head, though the eating disorder did appear briefly in a discussion about biscuits: I said I'd know Ben was recovered (and I could relax more on meals and meal plans) when he didn't insist on McVities (which has less sat fats than supermarket brands) - Ben (aka the eating disorder) started to quote all the sat fats involved and how he'd (apparently) only need 3 supermarket digestives to zoom off the sat fats scale into the danger zone... So I changed the subject.

Re pastoral support at school... We have the medical centre and 2 very supportive school nurses, one of whom is positively saintly and who I want to

give a great bit bear hug to, she's been so brilliant. Trouble is, she's not there every day. The head of year is very supportive and understanding. So is the Headmaster (but not really the ideal pastoral support!!!) School dinners comprise the standard stodgy stuff (hot something or other with cakey pud with custard) and a salad bar / jacket spuds / beans / fruit / yogurts, that kind of thing. My son will go for the latter...

I was really hoping for some advice on all of this from our dietitian today... Mind you, next week isn't so bad and at least we'll have one school dinners experience to do a debrief on...

And...

Phew... have we been through the mill since Monday! It was obviously too soon for my son to start school but he had no choice with a 2-day GCSE art exam...

All weekend he was getting more and more anxious and anorexic behaviour started to surface as he tried to avoid food, body checked, was seriously depressed, etc... we had a massive meltdown on Sunday, big-style which ended up with me taking some time out to rush round to my sister's for some tlc while my husband coped with Ben...

On Monday morning Ben was in pieces as we drove to school. It took ages before he summoned up the courage to run across the car park into the art block. To cut a long and harrowing story short, his mood was rock-bottom by the end of the day. OK he'd managed to brave the school dining hall and had (apparently) eaten some lunch and his morning snack, but he'd been secretly doing pressups during his exam (which he was sitting separately from the others)... and the social aspect at lunch and break was a disaster. Basically he was trying to remain invisible.

Today we had the same nightmarish start with loads of body checking ('rolls of fat'), pulling out of his hair in frustration at how 'fat' and 'ugly' he looked, followed by a stressful drive to school followed by the car-park-to-art-block problem again... However his mood was better when I picked up up at 4pm (phew!), though he confessed to doing the secret pressups again... (At least he's telling us about all this...)

Socially things were slightly better, but it's all so very fragile and the 'better' was mainly because one of the girls gave him a friendly hug.

Not sure if he'll be back at school again until the main GCSE exams which he will be sitting separately from the others. I've left it open, trying not to pressurise him in any way. Same goes for whether or not he goes back in Sept for the 6th form, or if he goes to another school, or takes a year out to completely recover or whatever. Who knows, we'll all just play it by ear and set up several options depending on how things are in early Sept...

But it's distressing that certain eating disorder behaviours and thoughts that we thought had gone were actually simply dormant and reared their ugly head again in such a vivid way...

And such a shame that he'll miss all the end of year parties that you get at the end of the 5th form, even a formal dinner hosted by the Headmaster. This evil eating disorder has robbed him of all this kind of stuff... the things you would normally look back on with nostalgia as an adult, remembering your school days... Before the eating disorder arrived and messed things up, Ben was having such a good time at school, too...

It makes you wonder if we'll ever be free of this horrible illness...

And...

Thanks so much for all your hugs.

What WAS good yesterday after school was this... Back in the Bad Old Days, I'd feel devastated when my skeletal son made his way towards my car in the school car park. Boy, did he stand out amongst all those 'normal' boys with his Belsen-like body, dark rimmed eyes, stooped figure and yellowing skin.

But yesterday, 2 months on since he was last in school, I noticed the change IMMEDIATELY. The boy making his way to my car didn't actually look much different from the other boys. He looked... well... almost NORMAL.

Anyway... tomorrow we have the dietitian's appointment (after FIVE WEEKS of not seeing her due to cancellations, etc), so weigh-in time again... And Ben had some routine blood tests taken today to check everything is OK.

I'm taking myself off to the seaside for the weekend ON MY OWN (and I don't care if it rains).

He he he he, this weekend the eating disorder will have my 'no-nonsense' mother-in-law to contend with as Ben and his dad drive down to London to see her. The eating disorder won't stand a chance with her lasagnes, curries, fish'n'chips and casseroles with her standing over him, arms folded, until he eats up every scrap...

She is totally committed to helping Ben beat this horrible condition (after all, she's the one that first urged me to take him to the GP).

And...

Thanks for all your comments, yet again...

I am really pleased with the way our meeting with the dietitian went today. She was spot on and to coin a horrible phrase, absolutely 'singing from the same hymn sheet' as me. I kept saying: "So what you are saying is... blah blah..." to reinforce the message to Ben - and I believe it went in.

Trouble is, Ben has grown in height and hasn't increased in weight, as today's weigh-in showed, which has brought his BMI back down. So we are

doing a 2 week 'test' where we increase the calories by 200 a day (even though she prefers portion sizes, she is happy to do calories for the time being because it's the only way Ben feels in control in what is "a very out-of-control time for him") and we are also to increase some fats. Wisely, she called it a 'test' so as not to freak him out too much as he was having a real problem adjusting to the idea of losing his beloved skimmed milk...

She explained all the reasons why boys need fats: to increase testosterone and muscle (which I kept reinforcing, knowing that he's keen to increase both and that this info might just be the motivator he needs...)

Crucially, she also said she felt that Ben needs to be given the 'tools' to handle whatever it is that caused the eating disorder in the first place, to make it easier for him to embrace the food change (otherwise you're just plastering over the cracks, etc etc) - and she'd have a word with the psychiatrist about that. I hope she does!!!

Anyway, here comes the rain as I swan off to the seaside.

And...

Well here I am at the seaside and I don't belieeeeeve it, I've got a tummy bug!! So I'm sitting in bed looking at the (rainy) sea view and worrying about Ben and the eating disorder.

Been on the phone to my husband who's looking after Ben this weekend at his mum's house and he's having major problems. Most of the time it's me that does the eating side of things, so my husband is having problems even getting Ben to eat 1500 calories or so, let alone the 2700 we're supposed to be on at the moment. And Ben is refusing to eat, especially fats which the dietitian says is mega important for him right now...

So I'm busy planning my onslaught for when we all get back home. What I really need are 'sneaky' ways I can add circa 200 calories of pure fat to Ben's diet (which is quite carbs-heavy at the moment due to his refusal to eat fat).

I've already been given quite a few fat suggestions by you all on this website, but trouble is they're mainly things Ben would spot a mile off with his keen eye for anything that's had fat added... If he's refusing point blank to eat the extra fat he's been told he must have, how do I get it into him? Force-feeding a 16-year old boy who's taller than me isn't easy. I can't hold him down...

Advice for this week's fats onslaught much appreciated...

And...

My husband had a nightmarish weekend with Ben at his parents' house. He isn't used to 'managing' this at all and quoted me some pretty hair-raising situations in restaurants, pubs, etc which involved meal swapping, tears, tantrums, refusing to eat and generally wasting a lot of money, energy and emotion. The result was Ben came back noticeably thinner and my husband noticeably older. But meanwhile I spent the weekend drawing up a new eating plan based on our meeting with the dietitian last week - higher calories and introducing fats to very near Government max levels without increasing the carbs (as they were pretty high). In other words, a reasonably balanced diet.

And I've stuck to it like glue, throwing scientific facts at my son whenever he resists plus a great deal of love, etc - very 'dophinesque', really...

But, boy, has it taken a lot of time, energy, etc - I'm exhausted - especially counting fats now as well as calories in the background on my beloved spreadsheet (what would I do without Excel, hey...). AND I've got him to eat NUTELLA, full-fat FLORA spread, (almost) SEMI-SKIMMED MILK (i.e. Sainsburys orange milk as a half-way house... no more skimmed...), ICE CREAM (wow!!!) and FLAPJACKS WITH FAT IN... with me being totally open and honest about

these rather than hiding them. Facing his fears head on and all that...(Not showing him any calorie or fat counting of course - that's just between me and my spreadsheet...)

I think this may just work. The glitch will be, of course, when he tries school again (which he is hoping to do next week) and the dreaded (lack of) snacks and school dinners come into play... (he wants to try some school before the GCSE exam study break and there are only 2 weeks to go...)

Of course I can't go on counting like this for ever, but hopefully this will get him used to the fact that, yes, he CAN eat all these dreaded things and STILL be within government fats / sat fats guidelines. i.e no danger of suddenly ballooning out into the obese...

I feel like some kind of bulldozer muscling in and taking over, putting right the mess that happened over the weekend and the fact that his BMI had slipped below XX anyway.

In 30 mins we go to the GP for blood test results and a physical examination. Interested to see what he says.

And...

Re. school... the big problem is that we live too far away for me to go in and supervise lunch and snacks. Ben refuses point blank to have a pack lunch and, in the few times he did when he was in school before, the nurse wasn't always around to supervise or make sure he DID actually go to medical centre to have his lunch and not go AWOL... I know for a fact that if he does school dinners he will have the same old stuff (salad, jacket potato and maybe a couple of tablespoons of baked beans followed by fruit salad...)

Ben also refuses point blank to move to semi-skimmed milk. We will eventually get there, but I may need to filter it in unseen for a while to prove that it won't send him off the scale... When we saw the dietitian last week, he

broke down in tears at the dreadful prospect of semi-skimmed so she and I decided to compromise with orange top 1 per cent... That's how bad his fear of fats is...

The good news is that for the past 3 days he's followed the new diet plan successfully but it's so artificial (all the adding up of calories and fats) that we can't possibly go on like this forever. For me, it's to check he's getting ENOUGH calories and fats. For him, it's to check that he's not getting too many!!!

PS he had the GP checkup this morning which was a total waste of time as the GP didn't seem remotely interested in his eating disorder. But the blood tests came back OK, if a bit low on iron. I could have strangled the GP (the original GP is away on extended leave).

It's difficult about school because he's at that critical stage i.e. GCSE and hates the idea of maybe taking a year out and joining the 6th form one year on (i.e. being with a younger year group) or having to join a 6th form college. The 'carrot' is his current 6th form in September and for him to return we must be pretty darn confident that it will work or he won't go, mainly because, being a fee paying school, I can't afford to pay a term's fees only to find he can't face school. And the local state 6th forms are full, so they aren't an option, either.

He has been taking work home and getting study notes from teachers, but it's not the same as actually being in lessons so we'll just have to see how the exams go. He's sitting them separately from his peers to reduce the pressure.

So far this week has been successful re. calories and fats - but I'm exhausted and stressed, and starting to show physical symptoms of stress / anxiety (e.g. IBS, rashes, etc) - am seeing a therapist in a week's time... Funny how all this costs you a fortune in food, too! I've had to cut down my work to just a few hours a week (self-employed) which means my income is pretty minimal, meaning there's the stress of that as well...

Today we see the psychiatrist for a 'family meeting'. I just know she's going to 'tell us off' as parents - bit of triangulation going on here with the eating disorder having won her over to his side i.e. she thinks she is talking to Ben but it's really the eating disorder speaking... (which Ben has admitted to us...)

I had a horrible nightmare last night. In it we got allocated a new psychiatrist of the 'old school' variety, really scary and strict, telling me off and shouting at me that I should be feeding Ben far more than I am, especially fats. I ended up screaming at her: "How the heck do you expect me to get the food into him when he refuses to eat it?" and Ben was carted off by 'the men in white coats' to a prison-like inpatient unit with this terrible woman in charge while I tried desperately to give him a hug to show I love him... Aaaggghhh I woke up in a terrible sweat...!!!

Pasting this text in here I can almost 'feel' the stress that I was going through during this period when I was so desperately trying to get my son to eat a balanced diet. When it came to food, Ben's mind had lost much of its logic. It was as if black was now white. A topsy-turvy world that defied reason.

It also describes how difficult it was for Ben to be in school at this time and how he'd almost completely cut himself off from his friends. Plus, it also describes the unreliable nature of some of the CAMHS visits - sessions were cancelled, the dietitian forgot to make a note in her diary, people were on holiday and so on. And there is some of the triangulation that tended to go on at CAMHS as the eating disorder 'sided' with the people who appeared to be on its side.

It was getting to the stage where we couldn't take our eyes off the game plan for a moment for fear that our son would rebel and head backwards.

At this stage we were also seeing the CAMHS team (psychiatrist and nurse) fortnightly. Why only fortnightly? Because they felt he was doing So Well and didn't need weekly sessions.

Hmn...

Tuesday, 25 April 2017

"Rebellion, actively cutting down" - a post from 10th May 2010 on the ATDT parents' forum.

This is a thread from 10th May 2010 which I posted on the [Around The Dinner Table Forum](#) (which exists to support parents of young people with eating disorders). I desperately needed advice on how to get my son to eat as he'd arrived at the stage where 'Mum's Eating Plan' was about to be thrown out of the window. We really had done well, food-wise, up to this stage even though it had been really tricky. God only knows what I would have done without the support I found on the ATDT forum. I daren't even guess how things might have panned out... This thread also shows the roller coaster or cat-and-mouse nature of the eating disorder. Just when you think you're seeing progress it all goes t*ts-up again.

So there we were, going along nicely on the higher calorie diet with higher fats and Ben seemed to be adjusting to it well (give or take a few minor arguments). Until today...

*... when he's suddenly "not hungry". Refused to eat an egg with his lunch ("too hard boiled"), refused to eat date and walnut cake 'pudding' ("too dry") and refused to eat ice cream as a substitute for the cake ("just not hungry"). When I insisted he ate something and calmly explained the reasons why he needs to (again...), he blew up and shouted "OK if you want me to eat ice cream, then I'll eat the whole f***ing tub", preceded to attempt to do so then promptly threw up over the kitchen floor. (I made him clean it up...)*

I don't know if this is just a blip or if he is really genuinely "not hungry" or if it's the eating disorder talking, knowing he's about to be back at school for exams (funny how he started to cut back on food before his other exams 2 weeks ago...). And now I'm stuck with this food he won't eat (cake and ice cream) - but I can't force-feed him...

Help!!!!

And...

How do you feel about forfeits/punishments - of the "You will stick to the eating plan exactly as I put it in front of you or you won't do blah blah blah..." variety?

Just wondering if this works or is a waste of time - and not very caring or compassionate of me, really. But I feel mad when I lose a battle against the eating disorder like I've done today.

The exams are GCSEs so there's no flexibility unfortunately...

Several of you have mentioned high calorie shakes, but I'd love advice on how to get them into my son as he's very vigilant about his shakes - he always makes them so if I were suddenly to present him with a shake, he'd be suspicious... If only...

We're back to the fats phobia which makes it really hard to get sufficient calories into Ben without adding loads of bulk. The moment I introduce something higher in fat (e.g. the date and walnut cake), he refuses to eat it. He was OK with ice cream, etc for a while, but is now rebelling...

And...

My son is the king of switching meals / snacks at the 11th hour although I never let him change the evening meal - and always check he's not 'downsizing' on calories or fats.

Today, when he calmed down, we negotiated a 'rescue plan' to bring the calories back up again - and he walked in here a while ago with a bag of sweets he was munching (although he's had the bag for AGES, he hasn't really eaten any of them. Maybe it's his way of saying sorry for the havoc the eating disorder caused at lunchtime, hey...)

PS That date and walnut cake isn't at all dry, in fact it's delicious and I scoffed it up myself.

Unfortunately, as ever, having studied those recipes it seems that most have ingredients my son wouldn't entertain in a zillion years. I could introduce them sneakily, but (a) that's not recommended, really, and (b) he would immediately know they were there by taste, texture, etc. For example I couldn't simply hand him a high cal milkshake and say "Drink".

Meanwhile he still refuses to eat stuff, having had 5 very successful days on the higher calorie / fat diet plan given by the dietitian. Now he is refusing to budge and, as you will see from my other thread, the only way he'll agree to eat (some things) is to take back some of the food preparation control himself. I said if he loses weight, then I immediately take back control and I imagine the calories will need to increase to make up for lost weight. I feel helpless and feel there's nothing else I can do without clamping his mouth open and force-feeding him.

Yesterday was his first day back at school since Feb (apart from the 2 art exams) and it was successful. Today we had our most normal school run in MONTHS! No visible anxiety at all and no hesitation getting out of the car at school, even though he was early. And he's already planning camping with the boys this weekend and says he's going to the school prom and party afterwards. This from the boy that couldn't even talk to his friends just a few months ago, let alone entertain the idea of school.

But I know it's all very fragile and could shatter with just one 'wrong' comment or look from a peer... As I always say to myself these days (my new mantra): "It's not over till the fat lady sings"...

(Oh yeah, me being the fat lady, I guess, with all this extra food inside me from all these hi-cal meals)

Tuesday, 25 April 2017

"Pear-shaped and very, very messy" - a post from 16th May 2010 on the ATDT parents' forum.

A week after I posted on the [Around The Dinner Table Forum](#) about the [ice-cream incident](#) everything imploded. Ben was allowed to take back control over his eating with the caveat that if he lost weight, then I would take back control. Meanwhile there was a heck of a lot of triangulation going on with the dietitian appearing to say one thing and the rest of the CAMHS team saying another. On top of this I had my husband siding with CAMHS, so I really did feel like the Arch Baddy in the proceedings.

I was just so very confused. My gut instinct (and advice from the ATDT forum) was screaming out that Ben needed to have everyone 'on the same page', working against the eating disorder to get the weight back on and for us - as a united team - to be taking control, pushing together and never taking 'no' for an answer and definitely no negotiating.

But it wasn't happening. Had it happened I still feel to this day that we could have been one fantastic and successful team, especially as Ben got on well with the psychiatrist. But instead, I believe I was seen as part of the problem, not part of the solution - and it was punishingly difficult to pin down the psychiatrist to discuss our views and indeed discover what kind of treatment model she was implementing.

Last week, if you remember after 6 very successful days sticking to the higher cal / fats eating plan, Ben 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 psychiatrist has been 100% behind Ben's desire to take back some of the control whereas I've been 100% sure he isn't ready to do so.

Triangulation, with me as the 'baddy'.

Anyway, we saw psychiatrist on Fri followed by the dietitian (separate meeting i.e. psychiatrist and dietitian aren't together). Psychiatrist is still behind Ben'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 he was refusing to do the eating plan). Meanwhile dietitian is completely on my side, unhappy about Ben taking this control and reinforcing why this diet plan was prescribed and needs to be followed. Reluctantly however after Ben'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 Ben 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 psychiatrist 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 psychiatrist telling Ben 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, Ben 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 psychiatrist or dietitian appointment for another fortnight. And if Ben 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!!!

And...

Until the weigh-in on Friday when Ben knows that if he hasn't put on the lost weight I take back 100% control... I am trying to control it in the guise of him doing it but I'm there in the background 'strongly recommending' he has x, y and z... sounds odd, but I think for just 3 days it will have to do.

Already Ben is trying to negotiate for more time, but I said a Big Firm NO and blamed it on the dietitian ("I can't go against medical advice... it's as if you had cancer, were prescribed chemo and hated it, asking me to stop it... I'd have to say no, because it's been prescribed for you and I'd be negligent, etc etc to do that" blah blah stuff along similar lines...)

I said at some point in the hopefully near future, he'd be given another chance to take control back... when he's ready... and so on...

I had to go and pick him up at lunchtime at school today after an end of 5th form English lesson celebration which went pear-shaped when cakes were

brought out... Ben couldn't handle it and freaked out... but things had been heading downwards since he got up this morning. I tried to prevent him going to school, but he insisted. And he is adamant he will try school again tomorrow. Thankfully just 2 days of school to go before exam leave.

Meanwhile he's trying to mirror the diet plan again, which I guess is better than refusing to eat... roll on Thursday's weigh-in... For the first time I'm actually hoping he's LOST weight giving me the ammo to take back 100% control.

Meanwhile he's getting super-stressed about the end of 5th form day tomorrow with Big Lunch with 5th form and Headmaster followed by talent competition. You could say I should keep him away but he's insisting he goes. He won the talent competition last year, but I'm really worried that this year he will flip and something horrible will happen as his eating disorder-led desire for perfection kicks in. But he insists on going...

I shall be SO GLAD when tomorrow is over, followed by the weigh-in on Thursday when things can return to "normal" with any luck and I can concentrate on kicking the eating disorder out of our lives.

As Ben is sitting his GCSEs separately from his peers, hopefully that shouldn't create too much extra stress (other than the usual, normal GCSE stress...)

I'm reluctant to change psychiatrists - how do I know it won't be a case of 'out of the frying pan...'? Plus Ben has built up a good rapport with her which he'd need to build up again. Plus, it sends out the message to Ben that we don't believe the psychiatrist is doing it right after all (so who's to say that any psychiatrist is right)...

For all I know she may be doing a wonderful job, in a low key 'softly softly' sort of way... after all, Ben has definitely improved over the past 3 months... and, as the school nurse says, at least he is talking to her (as opposed to sitting

there with his mouth clamped shut). It's really hard to know what to do... I think I'll give it a little longer and see how things go. If alarm bells start ringing very loud, then I'll have a re-think.

The staff at school have been brilliant. Meanwhile Ben is wound up like a coil at the moment, biting my head off at the slightest food/eating plan-related question, even when put as subtly as possible!

Never mind, in 30 mins time I have MY first appointment with a therapist to try to kick my anxiety / stress into shape...

And...

Ben got weighed today, as planned, and had put on 0.1kg (remember he lost 0.7kg last week and a little the week before). Before I could say anything the nursing assistant rushed in with: "Well I think he can continue monitoring his own food intake for another week". So that's what I had to do, couldn't argue the case in front of Ben - we must appear to be singing from same hymn sheet and all that...

It worries me alot that if he put on 0.1kg this week and continues to eat how he is eating it will take him SEVEN WEEKS to get back to where he was before the 0.7kg weight loss!!!!!!

And...

I've had a very stressful week. Ben 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 Ben get on with

things his own way) over and over again while Ben accuses me of behaving like I am 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 (so I can arrange a meeting without Ben present and also move our dietitian appointment forward from next week to this).

And I know on Fri when we see the psychiatrist she will whisk Ben off to be weighed followed by a session between her and him while my husband and I see the nurse (who never seems to pass our concerns on to the psychiatrist, 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 Ben, my husband and a CAMHS team that all want to do it very differently than my gut instincts shout out and I am very, very depressed about it all. (So much so I had to rush out of church on Sunday in tears because, for some reason, it just got to me... it was SO EMBARRASSING with everyone staring at me... followed by a day of feeling terrible, with my husband continuing to criticise my handling of this. I'm almost wondering if they're right and I'm just potty or a control freak. I feel totally helpless!)

PS I never did get that anxiety / stress therapy. Last week turned out to be an assessment with another 6-8 weeks until I get a (max of 6) appointments. I went to the GP about it on 30th March, so it's a heck of a wait.

And...

Tomorrow is the weekly weigh-in and Ben's psychiatrist session. My husband and I plan to grab the psychiatrist before she disappears in a puff of smoke to set up a private meeting between us and her, without Ben, to see what her gameplan is - and to suggest that extra CBT help for the severe anxiety might be useful (even if we have to bring that in privately).

If we aren't happy with the results, then we'll take it from there. Difficult to switch treatment teams because you never know if they're going to be better - or worse! Difficult to get GP on our side as she's on long-term leave and we have several GPs, but I'm going to ask the receptionist if any specialise in eating disorders and if they do, to see them and talk.

All credit to him, Ben has been trying very hard to eat within the eating plan and things are leaps and bounds ahead of what he used to be like - massively different. But tomorrow's weigh-in will tell if it's working or not. If he's lost or just maintained, then I need to take control. If the psychiatrist zaps in first with a "carry on as you are and just try to eat a little more" type of thing, then Ben has agreed with me that I can monitor his intake from a calorific point of view to check he's getting sufficient calories. So hopefully whatever happens tomorrow I will feel more confident that at least some element of control has been regained.

But, importantly, my husband and I need to talk to the psychiatrist separately at some point very soon to see what her plans are - from eating through to the confidence, anxiety, etc issues.

When I look back over the past few months I can see massive changes for the better, despite the setbacks that send my stress levels stratospheric, so that has to be a Good Thing. And they've all taken place since we started therapy, not before. So the psychiatrist and her team must be doing some good.

But the biggest issue really is addressing the severe social anxiety problems. Ben is fine when he's not in school, but the moment he goes back then - zap, pow! - he's off the rails again. So we're strongly going to suggest introducing a third party therapist, suggesting s/he 'complements' what the psych is doing.

Thanks everyone, once again, and watch this space...

And...

At Friday's weigh-in, Ben had PUT ON 0.6 of a kg so he's now put back all the weight he lost - and this has been under his own steam. So we are trying for another week to see what happens, but this Thursday we'll be seeing the dietitian and the key issues for me are his fear of certain fatty foods (including semi skimmed milk) (and cheese - at the weekend he deliberately asked for a meal WITHOUT CHEESE in the pub) and fear of generally overdoing it and ballooning out.

The (diplomatic) suggestion of external CBT therapy didn't go down well with the psychiatrist!!! But Ben is starting a weekly anxiety group run by CAMHS at their in-patient facility next week. We are also arranging a meeting between the psychiatrist, my husband and me for next week to take stock of everything.

So that's where we are at the moment...

And...

*I should have known better. Took Ben for a hair cut because his hair had grown out of control over the past few months; thought - in my naive, misguided way - it would be good for him. But his body dysmorphia kicked in with a vengeance and he went MENTAL afterwards, effing and blinding, shouting, weeping, walking the streets and generally going OTT because it looked "cr*p". I feel like kicking myself. With GCSEs next week, I should have known better than to interfere. Boy, am I beating myself up about this - and son is out of control...*

MAY 2017

Tuesday, 2 May 2017

Update on how the C-PTSD therapy is coming along (and Ben)

As you may know, I'm currently undergoing (private) Eye Movement Desensitization and Reprocessing (EMDR) therapy for the C-PTSD annoyance. So far, Steve, my therapist has been brilliant and everything is progressing OK. Generally I feel a lot better. The key word here is *feel* because, for so very many months (over a year... or longer!) I couldn't actually *feel* anything at all. It was as if my brain was numbed and I was simply going through the motions of just about everything in life that involves feelings (stunning walks by the sea, cycling in the beautiful countryside, being with friends and loved ones...). At the same time I was in panic mode, on a kind of 'red alert', which is sort of odd when coupled with numb feelings, but that's PTSD for you.

The numb feelings left quite a while ago, whilst still under the care of the NHS. What is left is the anxiety / 'red alert' feelings which go up and down. I have good days, I have bad days and I still have the odd very bad day.

Steve reminded me what the NHS therapists had taught me which is to *allow* these feelings to come through as it's all part of the memory processing. The trick is not to suppress them or feel you 'shouldn't be having them'. Or, worse, to feel that you are in some way 'weak' by not being 100% OK.

I can tell that things are improving because I've been able to work more - and get really enthusiastic about it. I've got a bit of my old drive and passion back!

Whereas in the autumn I was seriously wondering whether I might have to

stop work altogether and retire early, I am now doing the exact opposite. I have done an html refresher course and redesigned my business website from the ground up. I have taken on more business and my clients seem delighted. I am about to launch a second website.

I may... I just may... but probably not just yet... think about writing a sequel to my book [*Please eat... A mother's struggle to free her teenage son from anorexia*](#) talking about Ben's recovery from his anorexia and how I dealt with the aftermath - because I know I'm not the only parent to suffer the after effects of so many years of battling with a deadly eating disorder in the family.

And I've been blogging and replying to parents' questions on the [Around The Dinner Table Forum](#) (which is there to support parents of young people with eating disorders).

No way could I have done any of this six months ago.

Yes, as I said above, I have bad days. And bad evenings (evenings tend to be tricky as they still trigger memories of when Ben would go crazy). Some mealtimes, too. Sometimes I can be mega-triggered by something whereas at other times nice memories creep in rather than reliving the eating disorder hell.

On the whole things have improved enormously.

Steve, my therapist, and I still have things to work on, of course. At the moment I seem to be stuck on the CAMHS sessions - those first sessions between February and October 2010.

We will continue to attempt to process these memories tomorrow.

Meanwhile, Ben goes back to university tomorrow for the final term of his Master's Degree. Today he's at a PGCE teacher training interview day at a local university.

He is a natural teacher. He has a gift for bringing the subject to life. And he is

a walking encyclopaedia of history!

Earlier this morning I dropped him off at the interview - the same route I used to take when taking or picking up him from school. No bad triggers. Quite the reverse. The route triggered good memories instead.

So it's all good news so far...

Tuesday, 2 May 2017

"Dietitian axed from our CAMHS team" - a post from 3rd June 2010 on the ATDT parents' forum.

So, back in spring 2010, there we were with this triangulation going on - the dietitian appearing to say one thing and the rest of the CAMHS team saying another. Then on 3rd June I got a shock. Our CAMHS dietitian announced she'd been axed from the service. I burst out into tears in front of her! And when I got home I posted on the [Around The Dinner Table Forum](#) (before writing letters of complaint to the NHS Commissioners who were unsympathetic).

I can't believe it, I just CAN'T BELIEVE IT, but our adolescent mental health services have, in their wisdom, axed the dietitian from CAMHS teams treating outpatients. Only inpatients will receive nutritional advice from a qualified dietitian. Considering that eating disorders are about... FOOD!!!!... and distorted ideas about food plus it's all about putting on weight and learning to eat healthily and with a normal, undistorted attitude towards food, dietitian aren't just essential, they're VITAL. But I don't need to tell you guys this...

It's been suggested I write a letter for our psychiatrist to hand to the axeman/woman. The psychiatrist has complained, too. We have just one more appointment with the nutritionist before the axe falls.

Considering the INCREASE in eating disorders over the past decade and the high mortality rate for eating disorders, this kind of cutting is a disgrace and is putting children's lives at risk. It's not only a DISGRACE, it's CRIMINAL.

PS And this on an evening when my son is refusing to eat his tea, any of it, because the onion I'm making into a veg tomato pasta sauce is 'swimming in oil' (1 tablespoon) and yesterday he cut off all the fat off a slice of bacon, leaving just a small bit of meat. This is the boy that our local NHS has decided doesn't need an eating disorders dietitian any longer.

Me, I'm afraid I'm back to plate smashing because I have a boy who refuses to eat his evening meal, I have nothing else to give him and instinct says I shouldn't give in to the eating disorder anyway. And the rug has been pulled from under our feet with the dietitian axe.

Oh, yeh, and my husband blamed me for yesterday's meltdown where I ended up an emotional wreck. Today = same wreck, so I can expect same unhelpful comments no doubt about why I should be more 'upbeat' and 'chirpy' about all this.

Back in my past life when I was normal, I used to write letters to the paper, get on the radio, etc about things that bugged me (and how trivial they all seem now!!!!)

Obviously this is what I am going to have to do again.

Hey ho...

I have fired off a revised letter to 'the powers that be' today, as a formal complaint. Considering that the dietitian only spends one day a week with adolescent eating disorder patients and the majority of those are in-patients (which is continuing), I tend to feel that the remainder of the time she spends with outpatients is pence, really, in terms of fund savings. Axing this service seems crazy. But it seems it was only ever going to be a 12 months contract,

ending now, unless 'the powers that be' decided it was sufficiently important to make it into a permanent post - which they obvious didn't. But we were NEVER TOLD this was the case so it came as a bombshell.

PS Just googling private dietitian in our area (UK) and can't find a blooming thing... anywhere! Anyone know how I go about finding one specialising in eating disorders? I thought it would be simple...

More feedback from the psychiatrist on the axing. She says this particular CAMHS is the only one in the city with dietetic support anyway, the other teams don't have any at all.

The psychiatrist also feels that we've almost reached the end of our need for a dietitian anyway (!). So I said I'd have no choice but to go private as I definitely feel we need dietetic input for some time to come!! She was very sympathetic and I know her hands are tied.

I've finally heard from (the Head of our city's) CAMHS about whether or not they will be reinstating our dietitian and the answer is that the "Commissioners say no"...

I spent 30 minutes on the phone to her going bonkers - or rather stating my case in black and white with flashing Las Vegas lights.

So it's time to get out my chequebook, dip into my savings and pay for a private dietitian...

I am hopping mad. I feel like committing murder - or worse! I wouldn't wish an ED on my own worst enemy, not even the Commissioners themselves and their children (who, obviously, have never been through the experience we have been through as parents...)

Thursday, 4 May 2017

What happened that night...

On the 3rd June 2010 I posted on the [Around The Dinner Table Forum](#) (for parents of young people with eating disorders). The subject was that the dietetic support had been withdrawn (from my son's eating disorder treatment) and you can read what I said in [yesterday's blog post](#). That evening... or, rather, at some unearthly hour the following morning... I posted on the forum again. I was distraught because of what had happened earlier that night.

Following some issue or other, Ben had fled up to his loft bedroom screaming. Not unusual. But instinct told me I needed to rush up there after him.

I arrived in the nick of time.

The upper half of his torso was already out on the roof tiles as he heaved the rest of his body up.

I rushed in, grabbed his legs and pulled him back in.

It wasn't easy because, at the same time, he was pulling in the other direction.

"What the hell were you trying to do?" I yelled after I'd managed to pull him back in.

"Climb onto the roof, of course!" he said in that usual deadpan / blank way he did when I knew it was the eating disorder speaking.

I remember trying to hug him, but he just stood there, like a zombie, his arms at his side.

Here's what I posted on the [ATDT forum](#) in the small hours of the next morning (initially I removed the first part because I didn't want to worry other parents):

Last night my son got into such a distressed, depressed and "manic" state... worse than anything from the "dark days" before he started treatment... (it's been bubbling under the surface for days)... that he rushed up to his loft bedroom after a particularly gruelling fight (over the amount of oil I was using to fry an onion to make a pasta sauce).

Instinctively, a few moments later, I went after him to find him climbing out of the velux window. I had to pull him back in. I can't even begin to describe the evening we had after that... I reached my lowest-ever point as a parent and believe I went beyond what any parent should ever have to experience. Hell? That would seem like a pleasant vacation!

Even if he didn't plan to kill himself (which he insists he didn't - says he was just going to climb onto the roof) he could so easily have slipped. It's a heck of a long drop to the ground, from 3 storeys... The outcome would not have been good.

*Today we see the psychiatrist, so I'm firing off an urgent note to her which I've been carefully writing since 3am this morning (can't sleep). When CAMHS opens at 9am I will call the receptionist and say that I believe he is at risk and why the psychiatrist **MUST READ** the attached note before our 11am session.*

I have said this is a risk we can't ignore. Even if he doesn't intend to kill himself, he could easily get into a distressed frame of mind where he does, unintentionally. (We all know the suicide statistics for eating disorders...) I have insisted that the psych prescribe medication. What shall I do if she refuses? What shall I do if she just insists we continue with our one-hour sessions once a fortnight? That's a joke!!!!

Really, what shall I do if she doesn't take this seriously? She already thinks I'm neurotic, but last night put the fear of God into me. I believe I nearly lost my son.

My stress levels have gone off the scale. And they were already sky-high due to CAMHS axing the dietitian from our team. What on earth are parents supposed to do in this kind of situation? Everyone jokes about "sending for the men in white coats to take you away", but in reality WHAT DO YOU DO in a situation where your child is so distressed they're doing something like he did? Who do you call? Do you dial 999 and if so, who do you ask for?

And - later that day...

Thank you to everyone that emailed me today... I just wanted to say a massive thank you for rallying round with so much support, advice and genuine friendship.

For the first time I feel the psychiatrist understands where we are coming from and her session this morning (although tricky to start with considering my son wouldn't even open his mouth) was conducted extremely professionally, sensitively and with results in that he left the premises 90 minutes later upbeat enough to suggest he and I have a picnic in the park, which we did, and it was lovely.

The upshot is that, although still definitely very low, his mood has improved enormously since last night and this morning. The psychiatrist has not prescribed any anti-depressants; she offered to do so but he refused so we've decided to revisit that next time we see her which is next Wednesday, then the week after. So last night's incident has resulted in our fortnightly appointments reverting back to weekly. Plus she explained clearly what we should do if something like that should happen again (God forbid...) i.e. who we should contact depending on how serious we judged the situation to be - and what would happen in each instance if we did.

She also got right to the grass roots bottom of the main issues that are worrying my son and came to the conclusion that so far he'd been extremely

skillful in pulling the wool over her eyes (which, as you know, is what I said ages ago...). And he admitted that, yes, that is the case.

So although last night was pretty nightmarish to say the least, I feel that some good has come out of it in that it may actually be a watershed in our son's eating disorders treatment... for the better. I really hope so.

I'll keep you posted on how my son's mood progresses. Me, I have calmed down and I'm quite surprised that I don't feel totally wiped out. Amazed and astonished, actually.

And...

Thank you XXXXX and XXXXX for staying up way beyond your bedtime [to help me]... I was thinking today that, if it wasn't for the eating disorder coming into our lives, so many GOOD things would never have happened. I can't list them all here, and many are very personal, but it has shown me just how genuine, loving, totally selfless and generous people can be - people that don't even know me! Goodness only knows what you must be like with your non 'virtual' friends, you must be amazing!!!!

I have another friend (who lives locally) who I've become very close to, directly as a result of the eating disorder (long story...). She has no connections with eating disorders, but despite having (not good) secondary cancer, she's been the most amazing and incredible support - the kettle is always on whenever I need shoulder to cry on. All of this makes me feel very humble...

So far things are reasonably OK here apart from the fact my son is on his usual 'low'. My BIG HUGE WORRY is that next week which is the first of the 2 GCSE weeks and which is when my husband is working away again, could be potentially very sticky. I hope and pray that all will go smoothly, but I'm going to get some reinforcements lined up in case they don't. (Above friend plus my sister who's also been great support.)

Thanks again, all of you... I hope I can return the favour some time - seems to always be me that is doing the taking and not the giving here.

Thursday, 4 May 2017

The urgent letter I emailed to CAMHS that morning

In an ideal world, I'd have picked up the phone first thing in the morning and talked to the CAMHS eating disorder treatment team. But we weren't allowed to call them direct; we had to send emails and hope that they'd get passed on. So I sent the following email and called the CAMHS receptionist with the urgent instruction to make sure our psychiatrist saw it right away. Thankfully she did and later that day we were sitting in front of her, as described in [my previous blog post](#).

Urgent – Ben at risk

Last night Ben had a serious breakdown which was worse than anything he's had before.

At around 8pm I found him in a severely distressed and 'manic' state trying to climb out of the Velux window in the loft. Half his body was already out; I had to pull him back in.

To me it looked as if he was going to kill himself although he later said he was 'just going to climb onto the roof, but he didn't really care what happened'.

Had he climbed onto the roof he could have easily killed himself by slipping and falling. There is no doubt about that. It's a very high roof with a very long drop to the ground.

I believe that it was ONLY my swift action that prevented him from climbing out and falling. Last night Ben could have very easily been killed.

Over the past few days it's as if he's been catapulted back to where he was in the winter, before the treatment – if not worse.

He has been severely depressed and with increasing 'manic' behaviour – and his old anorexic behaviour has come back with a vengeance. It may be the looming GCSEs, but whatever it is, we need to take very fast action before something serious really does happen.

Last night I was so terrified I nearly called 999 – for the clichéd 'men in white coats' to 'take him away'. I have no idea what a parent is supposed to do in this situation.

In short, I believe Ben is in danger of getting himself into a situation where he is so distressed he (perhaps unintentionally) kills himself.

This is no 'neurotic mother' over-exaggeration.

I believe while Ben is as depressed and distressed as he is at the moment that he is at serious risk.

*This is something that **MUST NOT BE IGNORED.***

*If he does kill himself, or sustain serious injury, I believe it will be as a result of a spur-of-the-moment act when he is too distressed to think clearly or rationally. It may not be premeditated, so we **CANNOT** accept his word that he would 'never kill himself'. It **MUST** be taken very seriously indeed.*

Anorexia is well known to have the highest mortality rate of any psychiatric disorder – and many of these deaths are due to suicide.

This is a risk we can't ignore – and, as his mother, I certainly can't ignore it. Something urgent needs to be done.

A short-term solution may be to prescribe medication while he gets through his exams and hopefully prevent him from getting into such a distressed state that he does (maybe unintentionally) kill himself.

But what then? Where do we go from here?

We need an urgent meeting with you (without Ben). My husband is working away next week, so it would just be me.

Also urgent advice on who to call / what to do in an emergency (including night time) should the above happen again.

Friday, 5 May 2017

Keeping your child safe when they're a danger to themselves

I wish I could say that when my son was under the control of the professionals (GP, CAMHS, the local hospital, etc) that I trusted them implicitly to keep him safe. But various things happened along the line that removed this trust. Then the other month I heard the tragic news about a friend's daughter who had been under the care of the professionals for her eating disorder yet had managed to take her own life. This week the media has been full of the equally tragic news of [15-year-old Pippa McManus](#) (coincidentally a friend of a friend) who, just five days from being released from The Priory, threw herself under a train.

Of course for every failing there will no doubt be scores of success stories: young people who have received exemplary care for their eating disorder and who were indeed kept safe, whether as an in-patient or out-patient.

It's difficult enough to keep your child safe when you're caring for them yourself, at home, as I found. And, doubtless as Pippa's parents found, too, when she fled from the family home to the local train station.

One evening my son attempted to climb onto the house roof. It was a pure coincidence that some kind of sixth sense made me arrive in the nick of time and pull him back in.

Once he fled from my car, as it was moving. The trigger? The local hair salon had messed up his hair. It was some time before he returned home.

Then there was the night when he packed his bags and announced he was leaving home. Thank God his dad was there at the time and managed to talk

him out of it.

And the afternoon when a friend's worried mother phoned to ask if I was aware that Ben had messaged her son to say "Give me one good reason why I should carry on living".

Despite hoovering up medication and harmful objects along with house and window keys, he still managed to climb out of a conservatory window and flee down the street screaming.

All I can say is thank God we don't have a railway station nearby.

So it's punishingly difficult even for the parents to keep their child safe.

But you do expect the professionals to have the manpower and expertise to prevent your child from harming themselves - or worse. Especially when they're in an in-patient facility.

And you do expect that, if they're discharged back home, that a proper follow-up care package has been put together to keep them safe.

It is frightening when the eating disorder messes with your child's mind and makes them want to take their own life. It is ten times as frightening when the professionals say that unless your child actually DOES something, they can't do anything about it other than to do a risk assessment to check the child's intentions.

But of course by then it could be too late...

Friday, 5 May 2017

"De da de da de da... ED still going strong..." - a post from 14th June 2010 on the ATDT parents' forum.

By this point I was getting tired - as can be seen from the following thread which I posted on the [Around The Dinner Table Forum](#). I'd arrived at the not-so-ideal stage of bribery and threats, mainly because I simply didn't know what

to do. Sometimes I felt CAMHS was on my side while at other times I felt as if it was the CAMHS team, my son and the eating disorder ganging up against me.

I had a major problem getting my son to eat sufficient food to put on weight - and to continue to put on weight gradually (as stated in the NHS NICE guidelines). My son now had control of most of his eating; I was only permitted to prepare the evening meal. The idea was that if he continued to lose weight then I would get control back. The trouble was that he would lose weight a few weeks on the trot, and then put a little back on which meant he kept control of his own eating.

Yes the charts may have been showing an overall weight increase by this point but, as I say below, this was because of the weeks where I had control of the eating - the weeks when I'd managed to get quite a bit of weight back onto my son before 'mum's eating plan' was withdrawn.

I felt really alone. My husband was working away much of the time and, as can be seen below, it was really hard to get hold of anyone from CAMHS to voice my concerns. The only opportunities I got was when Ben was present, which was far, far from ideal.

Also, over the next 8 or 9 months, my dad would get increasingly sick, eventually passing away in February 2011, so there was all the stress of having to deal with that on top.

Not a great time... and it was about to get worse...

Definitely been 4 days of "several steps backwards" in the Matty household, starting with lunch at the (new) CAMHS Anxiety Group on Friday (2 bites out of a sandwich = his lunch), followed by cutting back all day on Sat because of a huge Indian party in the evening when in fact he ate virtually nothing despite being "encouraged" to do so by our poor hosts who had no idea what was preventing him from tucking in to their incredible food, followed by more cut-

backs on Sunday and a MASSIVE OUTBURST of angst and distress followed by more of the same today.

I said (which I probably shouldn't have): "Will you promise me something? When you're a man and you're through this and you look back and realise how much you hurt me and your dad, will you come back and say sorry?" Reaction? Bashing around the house, shouting like an animal and swearing - like he used to do in late winter. Oh, and he's continuing to lose weight yet CAMHS still insist he needs to take responsibility for his own food (except evening meals which I do).

*Oh, and my 88 year old Dad was rushed into hospital on Friday night extremely ill and is still there, so I'm stressing out on that count too. But the eating disorder, of course, as we all know, is incredibly selfish and self-centred and doesn't give a d*mn about the fact I'm heartbroken that my beloved Dad might pass away...*

Ah well, that's the eating disorder for you...

And...

Thanks, everyone. I weighed my son this morning and he's hovering around the same weight. But he and I are working towards INCREASING his intake, with me (hopefully) winning him over to the idea that I need to keep a FIRM EYE on his intake, that he needs to INCREASE his intake and if he loses weight, then it's back to the eating plan with a vengeance - DESPITE what the CAMHS team says ("The psychiatrist is a psychiatrist, not a dietitian" I tell him). If he doesn't regain weight, I also say, he won't lose these eating disorder thoughts and behaviours and it could also affect whether he returns to school in September (which he is very keen to do).

But I can't help thinking, it's like a Merry-go-Round where I keep coming back to the same point over and over again, but not really getting anywhere at all.

No news on Dad yet - will get his test result this afternoon.

And...

Trouble is, as we all well know, we may be the ideal captains for the ship but will our children listen to us 'mere parents'? If nothing else, the 'professionals' are almost like school teachers in that our children are more likely to listen to them. The trick, of course, is to make sure those professionals say what your gut instincts want them to say.

Actually, if anyone has any TOP TIPS on how to get our teenagers listening to what we say without biting our heads off or refusing point blank to listen, I'd welcome them!!!! Hey ho...

And...

Meanwhile he's been ranting and raving this lunchtime, crashing around, animal shouting, tears, tantrums and threatening to kill himself - all because of a chicken and avocado sandwich followed by tonight's meal which will be pork meatballs with Parmesan cheese, pasta and tomato sauce.

I rang CAMHS, but they're all in meetings. I rang his Dad who had a long chat with him on the phone. I said "This time I'm taking full control over your eating... from tomorrow... it's back to the calorie counting", with him then refusing to do so accusing me of "Ruining his life" and refusing point blank to eat ANYTHING. So definitely feeling we're on a Merry-Go-Round, always coming back to the same place - and to think it's almost our first anniversary of the eating disorder nudging its way into our lives... Hey ho, time to pop another couple of "Mothers Little Helper" pills (that's for me, he refuses to take medication point blank).

Oh and I used the threat of NO SCHOOL PROM - I can get a refund on that suit as it still has the labels on it. I anticipate a big drive from him to LOSE WEIGHT in time for the prom... already that suit hangs off him...

And...

I am not negotiating with the eating disorder - have told son I can return his suit to M&S on the day of the prom if necessary. Ideally I wouldn't send him to the prom but he was so insistent as "everyone in the year is going" etc etc. I've stated that he needs to gain half a kg a week, no negotiation, until we get proper weight restoration which is higher than the "vague" target CAMHS have never set us.

This time I am setting it. Another condition if he doesn't play ball is no 6th form in September, instead he'll take the year off and go in a year late with the year below. If he DOES play ball he'll get his Xbox mended at long last plus other bribes.

We are still on for the meatballs and he did eat his sandwich in the end after I pretended I was you, Charlotte, asking myself how you would respond / behave!!!! You wouldn't stand for any nonsense, I am sure - visions of a kind of Boadicea character charging against the eating disorder in your chariot, swords a-blazing. And it worked, because he ate the sandwich and I laid down new ground rules, non-negotiation-style, afterwards.

And...

Meanwhile I'm back from our weekly CAMHS session and son has LOST 0.8kg so I said to the psychiatrist: "My son has consistently lost weight, week on week, and this is supposed to be a weight gain diet not a weight loss diet. How much weight does he have to lose before CAMHS sweep in and do something about it?" to which she said "I'd like him to continue taking control of his own eating; he's doing so well and the general trend is weight increase, so I'm not

unduly concerned. If he continues to lose loads of weight, then I might be concerned" to which I said "The only reason there's a trend towards weight increase is because of the weeks I spent controlling the eating plan which is when he gained weight. During the whole period that he's been in control he's only gained weight once. Also, I'd like to aim at a higher target weight of XX-XXkg" to which she said "Where did you get that figure from? We're happy with the XX-XXkg 'tramlines' the dietitian set" to which I said "This is a figure based on height / weight plans and also because in September he plans to take up rugby again and wouldn't be able to do it with his present build; it is also based on how he used to be before anorexia kicked in" to which she produced her own height / weight chart to prove that I was wrong... And all in front of my son who was LOVING the triangulation because she was saying exactly what he wanted to hear and making 'baddie' mum look pretty darn stupid.

No comment.

And...

After a lot of hard thinking this weekend, I've made the decision that this week is the week we drive forward towards our destination rather than pointlessly and endlessly driving round and round the block. I have formulated A Plan which aims at ironing out all those niggly areas where I wasn't doing so well as a parent of an eating disordered child.

The Good News is that son has said the psychiatrist has said this week is his Last Chance to put on some serious weight before the Eating Plan kicks back in - and he knows it. But he has said it won't kick back in as he WILL put on weight. Not convinced... not convinced at all... and in a way hoping he will lose again so the psych supports me this time round and we're all on the same page for a change.

And...

Can't get hold of the psychiatrist... May have to do with the 'family meeting' next week if I can't pin her down before then... Meanwhile my son is having a quick weigh-in this Thursday.

He bites my head off when I try to find out what he's been eating (exact quantities) - like the eating disorder beast screaming at me to back off... But today I decided I needed to keep a tab of EXACTLY what's going into him, calories-wise, and so far it's under X,XXX a day. But he went crazy when I challenged him about it.

I DO believe the psychiatrist will let me take back control if Ben has lost weight again this week.

I am fighting, ladies...

PS (later) I've laid the cards on the table with Ben and told him that he has approx 10 weeks to go until school begins and the 6th form. At 0.5kg gain per week, he could get to XX kg if he starts now.

If, when CAMHS reinstate the eating plan when he's lost yet more weight this Thursday, he fails to stick to X,XXX cals per day, putting on this 0.5kg a week, and fails to get to a min of XXkg ("fat" as he calls it) by 1st September he won't go into the 6th form, he will take a year out and join the year below in the 6th form in 2011.

So he said in that case he won't go back to school ever again, at all. He admitted that he simply does not want to put on weight and said CAMHS would accuse me of being the 'baddie' again (i.e. CAMHS is on his side, Big Bad Mum is not).

So I said school or not (and 'not' would mean having to get a job because I'm not supporting him) that weight restoration is not negotiable. The road to weight restoration can either be slow and gruelling over many months, going round in circles, just as we are now, with no school and no future... OR he can

do it the easy way and stick to the eating plan, as outlined, go into the 6th form (which in reality he longs to do) and go to university to do history (which he also longs to do). But either way the goal is weight restoration whether he likes it or not.

He is not speaking to me now and looking forward to his buddies at CAMHS telling me off. (He says "I'm going to tell the psychiatrist about you!", primary school style...)

I am at my wits end. I really don't believe he will go for the eating plan and will continue to lose weight until we're back at Square One... or worse...

Still trying to get hold of psychiatrist for a private meeting... have written up my notes now based on all the above advice...

Friday, 5 May 2017

Oh how I can feel the desperation, fear and helplessness I felt back then!! A post from 23rd June 2010 on the ATDT parents' forum.

This truly was the start of the hellish summer of 2010. My 16-year old son Ben was sliding downhill in both weight and mood. I felt increasingly gagged by CAMHS and under instructions to take a back seat, to not talk about food and to focus on things that were "helpful" to Ben instead.

It seemed as if it was very much Ben, CAMHS and the eating disorder versus me. The triangulation continued with my husband who was also taking sides. And much of this in-fighting was done in front of Ben. The eating disorder loved it!!

It is so very important with an eating disorder that everyone - parents and treatment team - form a united front against the eating disorder. But, in our case, it simply wasn't happening. Meanwhile, I was becoming increasingly terrified and desperate, as if the rug was being pulled out from under my feet.

Over the following months my mind would clunk down several levels and arrive at a dark place where no parent should ever have to go: a state of mind where, with ice-cold horror, you accept that you may lose your child. A deathly dark place where it becomes a case of "when" and not "if".

It was a terrible time and God only knows what I would have done if I'd never discovered the support and love from the parents on the [Around The Dinner Table Forum](#). It was a true life-saver.

I thought it warranted a new thread... Charlotte and a few others will know what I mean when I say we had another night like the one we had a couple of weeks ago (think "roof"). 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 a foot. There resulted THE MOST TERRIBLE NIGHT with the eating disorder at its most "magnificent" and "satanic". Me, on the phone to the emergency doc asking for advice, but Ben refusing to go to A&E (ER) to see the psychiatric team.

My husband phoned half-way through and tried to talk to 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 run smoothly if it wasn't for me "going on about food", so these outbursts and moods only happen because of me.

And he's banned me from talking to my "cronies on that forum" because "what do they know? All situations are individual and everything they say goes against all the professional advice" (i.e. CAMHS' advice).

So I'm banned from mentioning food ("How do we treat an eating disorder and not mention food?" I asked.) He 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... and now every time we have one of these eating disorder fits, he's going to blame me. And no way will he look at any of the info you send through... he hates you all!

In the end Ben went to bed in a fake relaxed mood (undercurrent still there...). The eating disorder was no doubt jubilant at the fact I was surrounded, General Custer Style, enemies around me, all fighting on the eating disorder side.

I am in an impossible situation. Today I'll try again to get hold of CAMHS but this time to insist that I believe Ben is at risk and insist they write a prescription for anti-depressants. Then I need to persuade Ben to take them (which will be impossible).

Meanwhile what do I do? This could be threatening our marriage as my husband 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 when 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 CAMHS, and last night between me and his Dad.

Game, set & 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 (except you all, of course...)

And...

The CAMHS team knows I don't see eye to eye with them and said as much today when we popped in briefly in a bid to get them to try and get my son to speak when he had shut up shop completely today.

He walked out of the session and the psychiatrist told me to my face that she thought I wasn't completely happy with the treatment so I told her we're just going round in circles and not getting anywhere.

My main aim today, though, wasn't to talk about how we can all get on the same page and advance forward, it was other more urgent stuff and in a curious way it seems to have slightly pulled my son out of his dark mood though it didn't stop him barking at me to make sure I used no more than one tbsp of oil in our evening meal and generally cut down as he has been generally doing since he "took responsibility" for his own eating.

However I have it on record now that the Eating Plan will be back if he's lost weight when we go for his proper CAMHS session tomorrow - and no doubt then all hell will break loose as we know the eating disorder hates eating plans. Next week I've insisted on a family meeting with a session of just husband, me and CAMHS to thrash things out.

And...

Apparently Ben has lost a little bit of weight (how much, I wasn't told...). But yesterday CAMHS weren't "unduly concerned" about this weight loss 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...)

Now, according to CAMHS 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 Ben and what isn't".

And, it seems from what they have told my son, 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, CAMHS said that, for him and his build, a weight gain of 0.Xkg 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 they don't know what his build is - they never saw him playing No 3 in the school rugby team! As Charlotte said on my other thread, if he played rugby at all now, let alone No 3, he'd be snapped in half...)
(Teeth are now ground down to the gums...)

Oh, and because it's the summer, apparently we should take things "a bit easier" all round... (Get me some false teeth will you...)

And...

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 (surprisingly successful) school prom, looking so thin and pale, even my husband realised that we're getting nowhere.

However he had a caveat which was that maybe CAMHS has some "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 eating disorder being sorted out. NB I HASTEN TO ADD THAT THIS IS WHAT HE THINKS, NOT ME, as

my gut instinct plus all the info / books I'm reading say it should be completely the other way round!!!!

Meanwhile Ben is refusing to speak to me about food AT ALL because of CAMHS 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 (think I said that) 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.

We are insisting on a private meeting with CAMHS this week - half an hour of thrashing it out on Friday.

THE THING IS... I SHOULDN'T HAVE TO HAVE THIS BATTLE IN ADDITION TO THE BATTLE I'M HAVING WITH THE EATING DISORDER... IT'S MAKING IT A ZILLION TIMES HARDER AND I'M REACHING BREAKING POINT!!!

Meanwhile I'm heartbreakingly watching my dear son slide downhill...

Sunday, 7 May 2017

The animal instinct to 'protect our young' kicks in when we see our child suffering

I am not a scientist or a physician, but - as a mother of a boy who's been through and recovered from anorexia - I know what a punishingly difficult illness this is to treat successfully. I've read a ton of stuff over the last 8 years as well as attending eating disorder conferences, talking with eating disorder

professionals and mixing with other parents who have been through an eating disorder in the family. What comes across clearly is that some treatment models work for some families whereas other models work for others. And some are more evidence-based than others, especially when it comes to treating adolescents with an eating disorder. So, to me, it's not rocket science that clinicians employ the evidence-based model first and if that isn't working, then try something else.

Here in my home city, there's been a massive shift in the approach to and treatment of eating disorders recently. If an adolescent were to present today they probably wouldn't get the same approach that we got all those years ago. These days, in our city, treating adolescents with eating disorders has become much more of a specialised discipline and families are much more involved in the process.

It is so difficult for a parent entering the horrific world of eating disorders for the first time.

We know nothing. We weren't expecting this to happen, especially if we have male children.

But, when we see our child in danger, the animal instinct kicks in - that instinct that, in my case, I first experienced the moment my son Ben was born 23 years ago. The instinct that we will fight for our child, even walk across hot coals to ensure their survival when faced with danger. And, with an eating disorder, it doesn't take too many trawls around the Net to discover that eating disorders can be fatal. So the "I'm going to get my child through this even if it kills me" instinct kicks in even stronger.

It's something you see in nature - the mother lion protecting her cubs from danger and so on.

So, when you're going through treatment for an eating disorder and this

instinct says that your child is getting worse and not better, you feel a primeval need to fight, to question, to understand why this particular treatment method will save your child's life.

And when you see their weight heading south and the eating disorder behaviours and moods getting stronger, you start to panic, and with this panic comes the ice-cold fear that your child could die.

On top of this you are darn tired. Exhausted.

My point? As you'll have seen if you've been reading my recent posts which look back at the early months of CAMHS treatment for my son's eating disorder, I was very frightened. I also felt helpless. On top of this there was the need to understand why this particular treatment model was right for my son. Pinning down the CAMHS team to ask questions was extremely difficult and I never did discover which treatment model they were using.

Added to this were the messages that whatever I was doing wasn't "helpful" to my son and that I should take more of a relaxed attitude - a back seat, if you like.

Yet my gut instinct was screaming out to do the exact opposite. Especially as I was with my son 24/7 whereas the CAMHS team saw him for just 60 or 90 minutes a week, and not every week at that. Yesterday I found a note I'd made at the time which said that CAMHS were thinking of moving the sessions to *monthly* rather than weekly...

What I was seeing at home wasn't the same thing they were seeing at the treatment sessions.

I don't for one moment believe that if I had taken a back seat and stopped talking about food or insisting that Ben ate that it would have helped him to recover faster.

As Ben's mum, knew him better than anyone else. And, like mothers of

many species, there is the primeval need to keep your young safe - and alive.

Unless you are a mother you could never understand this instinct.

So this is why I was panicking and questioning so much during this critical time in Ben's eating disorder treatment.

Not getting in the way. Not undermining the therapy. Not causing triangulation.

Just desperate to save my son's life.

Sunday, 7 May 2017

Something's been bugging me all weekend...

Of course I can never, ever expect to read every fellow parent's blog about eating disorders. The same goes for any books they may publish or articles they may write. But I do know why I, and the other blogging mums who I know, do it. To raise awareness of eating disorders (in my case that boys get eating disorders) and to help other parents identify symptoms, get speedy help and to find support from other parents who've 'been there, got through it'.

No other reason.

We could do other things - go shopping, go out with friends, do hobbies or further our careers, etc etc - but we choose to raise awareness for the simple reason that we don't want other families to go through what we went through.

It's also why parents give their time to found, run or mentor on forums like the [Around The Dinner Table](#) and its parent site [F.E.A.S.T.](#)

We are not scientists. Many of us are not health professionals. But we are *parents* and in the main, when it comes to blogging, we are mothers.

As mothers it is our natural animal instinct to do anything, even walk on hot coals - or worse, to save our child's life.

Unless you are a mother, you could never understand this powerful instinct.

And because we don't want other mothers (and fathers) to go through this experience... or at least to get through it faster... we blog to raise awareness, to help parents identify eating disorder symptoms and get speedy, evidence-based treatment as well as much-needed parental support.

Having a child with an eating disorder can be a very frightening and lonely place to be for the parent. And I, for one, don't want other parents to feel as isolated and terrified as I did.

If, in some way, my blog - and my books - help another family, then it's all been worthwhile. And I imagine it's the same for many other parents who blog, write, give talks, appear on the TV or radio, etc.

I am not crazy and I do not believe I am to blame for my son's eating disorder - and my son would wholeheartedly agree. He has ALWAYS said that I was a great mother, all through his life and especially throughout his eating disorder. As he was about to leave for university in 2012 he gave me a card which said: "Thank you for being the one who never gave up." It brought more than a few tears to my eyes...

So why has this been bugging me all weekend?

I know that everyone's experience of an eating disorder is different. I also know that families are different and that there are good and bad parents. But, having read something a few days ago, I wanted to stand up for mothers who blog about eating disorders along with mothers who write books about eating disorders and mothers who give their time and energy to support other mums who are going through this terrifying experience.

And fathers, too.

Meanwhile we parents keep our eyes and ears open for any new research on eating disorders. We read the science stuff. We watch other families as they

attempt to find the right treatment model for their child. We keep abreast of any advances and so on.

Added to this is our own experience. And, during this experience, we were learning. We were cramming up on the science and making informed choices. We were listening to experts speak at conferences. And we still are.

But our primary purpose as 'mummy bloggers' is to do our bit to raise awareness of eating disorders, to help other parents to know that they're not alone and to get speedy help.

And on the way we may find it cathartic to blog - an attempt to 'make sense' of the eating disorder and to process it in our mind.

Monday, 8 May 2017

Hmn... feeling a little murderous... - a post from 1st July 2010 on the ATDT parents' forum.

In June 2010 we received the bombshell that our helpful dietitian was being withdrawn due to funding issues. Very quickly the shock turned to anger and I posted the following (edited) thread up on the [Around The Dinner Table Forum](#). I'd hired a private dietitian to replace her. However I quickly realised my mistake; the private dietitian simply didn't have sufficient experience in dealing with eating disorders and, on top of this, CAMHS were cross with me for going behind their backs and doing this.

Meanwhile I was so very, very angry about everything as can be seen below. I was also panicking and desperate; it was as if no-one was listening to me or taking my concerns seriously. It also shows how difficult it was to contact the CAMHS team, relying on the secretaries to pass on messages which they didn't always do. *(Please note that I've removed any reference to specific weights, BMIs or calories.)*

I am so mad I could strangle someone!!!!

As you know, our UK NHS dietitian has been withdrawn so we're having to go private - and "the powers that be"[the NHS Commissioners] refuse point blank to let us keep her.

As you know, my son has lost weight consistently over the past 6 weeks after being handed back responsibility for his own eating. Last week CAMHS said that they weren't "unduly concerned because his weight is nowhere as near as low as it was when he started treatment on 18th February". (As you know, we've insisted on a private meeting with the psychiatrist tomorrow to thrash this out.)

I now have in front of me a print-out of my son's weight "gain" since he started treatment in February, provided by our dietitian at our final meeting with her today.

Contrary to what CAMHS said last week, he is Xkg LOWER than he was at the start in February. And last week when she made the above statement, he was X.Xkg lower than he was at the start in Feb. So I just don't get it.

AND that's not taking into account the fact he has grown in height since then. In real terms, his BMI has dropped from XX.X to XX.X in the 3.5 months we've been receiving outpatient treatment. I am sure you will all be in unanimous agreement that we should be looking at a significant WEIGHT INCREASE, not DECREASE!!!!

All the above has made me SO MAD I think I mightn't just smash the rest of our dinner service this time, I might trash the whole house!!!!

And later...

I am completely numb after our meeting. The long and the short of it is (and the psychiatrist didn't know I had planned this meeting as the secretary hadn't

passed the message on or my email!!!! And we're not allowed to email or phone direct):

- *Yes she does Maudsley FBT (Family Based Therapy) but only when patients are close to in-patient status and she believes our son was taken on at a stage that was far less severe, hence the early decision to allow him control of his own eating.*
- *She says my graph is misleading because it doesn't go down to Zero - it starts at XX.X BMI. By that she means that it wouldn't look so bad if there were loads of white space below it.*
- *Yes, if my son continues to lose more weight she will step in and insist we take back control but in the meantime he should try to adhere to the extra XXX-XXX cals per day insisted on by the dietitian (ie we shouldn't take back control) (already we're seeing him chicken out of that, just one day on... with a pitifully small portion at teatime).*
- *She says that, when compared to "the population as a whole" he is well within healthy limits so I shouldn't be so concerned (despite my telling her that his pre-anorexia weight was far, far higher, stuff about rugby, etc - and the secretary forgot to forward the pre-anorexia photos I sent through to her so she hasn't seen those yet).*
- *And before long she was focusing on me and I suddenly realised she had diagnosed me as a kind of neurotic mother who, presumably, is worrying over nothing.*
- *Meanwhile, although my husband was guns blazing on my side, he's now moving to CAMHS' camp saying that our son's situation is different from other people, so in a way the psychiatrist is right...*

- *And there was loads more said that I can't recall because I am totally exhausted and numb.*

But she didn't like it...

Mind you, neither did I.

And...

We had a terrible time just getting him within the MINIMUM calories yesterday which the dietitian said is a no-negotiation RULE... not 1 calorie below XXX extra cals, she said, preferably XXX extra cals per day. We got to around XXX cals and he wouldn't budge. The eating disorder just won't let him and I have told that to the psychiatrist until I'm blue in the face.

I have to have a think about my next move with the psychiatrist as I woke up this morning (after a pretty restless night) realising my brain was actually on MAXIMUM and couldn't take any more thinking (especially when my husband started to ask me what tiles I fancied for the new bathroom... that almost tipped me over the edge...)

Also, I am fighting on this other front re. the dietitian so have started a new post to gather ammo to fight "the commissioners" (who have withdrawn the funding), get into the media and do just about anything else I can do to fight.

With my vacation looming in 2 weeks (ha ha ha, Ben was in a fit last night about eating on holiday... boy are we looking forward to that... NOT!!!), there's not much I can do on either front, but it's a good time to start gather ammo for both.

I've bought a large A4 notebook and at the front I'll make notes for my ammo to fight CAMHS and at the back I'll make notes for my ammo to fight the dietitian issue.

If I have any energy...

Monday, 8 May 2017

"Screaming, shouting and bullying" - a post from 5th July 2010 on the ATDT parents' forum.

I was getting so very, very tired, feeling utterly powerless and my morale was at rock-bottom. At CAMHS I was being given the impression that Ben's eating disorder wasn't too bad yet the hours... days... weeks... months... I was spending with him at home was telling me something very different. Although my gut instinct screamed out for me to do something... to take action and insist that Ben eat... I was getting all these messages that I should be doing the exact opposite and taking a far more relaxed attitude about food: to trust Ben to be eating for himself and to shut up about food.

My husband's thinking was that CAMHS were the experts and if Ben ended up in hospital, then that's just the way it had to be. Maybe it'd be a kind of wake-up call. I wasn't so convinced. I'd hoped that the trip to the cardiac ward in January might be a wake-up call, but it wasn't.

I was just so very terrified that my son would head south in every respect: weight, mood, behaviours and overall health. My instinct was to jump right in and do something about it. So on the 5th July, shortly before our holiday / vacation in France, I posted the following on the [Around The Dinner Table Forum](#).

I'm fed up to the back teeth of shouting and screaming sessions and the feeling that I'm being bullied by the eating disorder and my son. The slightest mention of food, eating, etc and he goes crazy, screaming, shouting and slamming doors, threatening to phone our psychiatrist to tell on me (the psychiatrist who has insisted we keep talk about food to a minimum and keep it

low key "because it's not helpful to your son"). (Tell me HOW do you help your child recover from an eating disorder by doing that??!!)

As he continues to lose weight, I feel powerless and helpless. I am also painfully aware of what all this is doing to me, physically and mentally. I am shattered and almost feel like giving up and letting him continue the downward spiral towards hospital.

And...

Thanks everyone for your kind replies. It's difficult to 'prepare and serve' the food when the only bit I'm 'permitted' to manage (thanks to CAMS' decision) is the evening meal (with Ben buzzing around me like a mosquito). That's what frustrates me so much... seeing him serve up his breakfast, snack (rare) and lunch... he does try hard but the eating disorder always manages to put the brakes on.

Today I am just knackered and suffering from anxiety and lack of sleep (due to anxiety). And doing too much. Need to take time out, probably.

Monday, 8 May 2017

"Holiday / vacation... and the eating disorder came too..." - a post from 2nd August 2010 on the ATDT parents' forum.

In early August we arrived back in the UK after the 'holiday from hell' in France and I posted the following on the [Around The Dinner Table Forum](#). I'd been instructed not to talk about food; indeed to take a break from the eating disorder for the duration of the holiday. So every time I mentioned food Ben screamed these instructions at me. Yet right from the 'word go' we had serious issues starting off with a nightmare lunch at a pub en route to Portsmouth.

It was one heart-breaking experience after another culminating, on arrival at our hired villa, an Almighty meltdown which resulted in my husband in tears

threatening to return to the UK the following day. And so it went on...
meltdowns... shouting... suicide threats...

Oh yes, the eating disorder was a well and truly present stowaway on our holiday / vacation in France the past 2 weeks... Result = XX weight loss on top of the XXkg weight loss the previous week.

We only had 3 threats of "ending it all" plus several complete emotional "meltdowns" and generally cutting back on food, refusing ice creams, treats, etc and doing compulsive exercising plus not being able to cope with travelling days when he was "doing nothing" (i.e. hadn't earned the "right to eat") - and meals out were an absolute nightmare. It was as if every single eating disorder trait had waited for our holiday, deluging us with the eating disorder at its nastiest and most vicious.

With normal holidays, you leave stressful things like work, etc behind. With the eating disorder you take it all with you. While the sun is shining and all around you are having fun, you're in a horribly surreal parallel world.

My stress levels were stratospheric...

No more holidays until the eating disorder is well and truly gone.

And...

At the last count, CAMHS was talking about only needing to see Ben once a MONTH from now onwards because he'd made such smashing progress.

Needless to say we will be disputing that decision...

Good news is that, so far, fingers crossed, Ben has slipped back into the eating regime without too much fuss (after unsuccessfully trying to negotiate meal changes with me repeating "Come back to me when you're weight restored and you can make some meal choices, but not until then".)

We have a lot of weight to put back on as, apart from 2 weeks of weight gain, he has lost weight consistently since mid-April!!!!!!!!!!!!!! So much for

CAMHS' "once a month" decision, hey... goodness only knows why she came to that conclusion....

Shocking, when you realise he's been losing weight for so long!!!!

And...

Back on the straight-and-narrow eating plan worked so well yesterday until he found out he almost had XXX calcs too many because I'd overlooked some earlier food. He went absolutely ballistic (as if he'd have metamorphosed into Billy Bunter overnight if that had happened), screamed that he couldn't live here any more, started packing his bags and we had to Hoover up the house keys to stop him leaving home.

What on earth do you do in these situations? Continuous flying-off-the-handle threats of doing himself in and / or leaving home at the slightest thing.

So last night was yet another 2am dressing-gown-and-cuppa for me because I couldn't sleep - worried sick. Charlotte I would call you but he's around and would hear...

Have left a message for our psychiatrist to call me...

And...

Psychiatrist always says that nothing can be done unless he actively "does something"... and she insists he isn't clinically depressed and won't insist on anti-depressants (says he has to agree to take them and he won't). Our hands are tied and it is so frustrating - and terrifying.

And...

*He is refusing point blank to "play ball" and just screams at me to "B*gger or f*ck off", saying the only reason he's still at home is because his dad told him he had to stay (my husband threatened to dial 999 if he left with his bags). Son won't talk to me unless it's screaming. It's as if he hates me.*

Unfortunately his BMI is too high for hospital admission and it would take some weeks of weight loss for him to get there but this is the way I feel it is heading and it breaks my heart.

Meanwhile I'm cancelling work and all appointments or visits anywhere because I can't leave him for a moment. I daren't.

How will we ever get to mental recovery / weight restoration?

Monday, 8 May 2017

At the end of my tether in August 2010...

As the summer of 2010 went on I became more and more depressed, exhausted and frightened. We weren't having our regular CAMHS sessions as the treatment team were taking their own vacations. I was also having to rely on emails sent to the CAMHS secretaries if I had any concerns. Following our return from France, I sent the following message to CAMHS as a summary of where I felt things were heading.

Holiday update - August 2010

Ben's mood is lower than ever and virtually every eating disorder behaviour came out on holiday, so much so that we couldn't help but comment which, of course, made things worse.

The result was that we lurched from low mood to us treading on eggshells to complete emotional meltdown to yet more suicide threats and back again, several times.

Meanwhile, Ben cut down on his meal sizes, refused treats (except 1 ice cream), reverted back to zero fat foods wherever possible, drank zero milk, exercised compulsively, couldn't handle travelling and eating ("not doing anything" and therefore not earning the right to eat properly) – and eating out was a nightmare every single time.

On our return – Ben’s deteriorating mood

Ben’s mood has continued to deteriorate and we are banned from any involvement in his eating or mentioning food. The only thing I’m allowed to do is to cook the evening meal.

Yet he is still extremely anxious to have control over evening menus and also how I cook the meals (i.e. keep fats / oils to a minimum – he feels I might “make a mistake” and put too much oil in, etc). So he tends to examine recipes and hover round, getting very anxious.

Mood-wise, he continually flies off the handle and it’s as if he’s punishing us, refusing to talk to us or cooperate in any way.

He regularly threatens to leave home and nearly did the other night – bags packed. I believe he was seriously going to leave to go goodness only knows where...

He says there is “no point” to his life.

He also went AWOL during a particularly evil mood swing which lasted 36 hours but thankfully returned (still in the evil mood). But I was sufficiently frightened to call CAMHS for advice. Unfortunately you were off sick, so I spoke to someone else.

*He insists he “just wants to be left alone to get on with my life, even if that’s a sh*t life”. It’s almost as if he’s lost belief that he will ever recover and will be stuck with this horrible thing forever.*

Meanwhile the anorexia’s grip is stronger than ever and we’re very aware of it trying to re-gain control of every aspect of Ben’s day.

Ben says he thinks about food all the time at the exclusion of virtually everything else.

His social life has suffered and we have no idea about what will happen about school in September.

He also failed to turn up at his voluntary work on the first day. (Remember, I organised some work on the library's children's reading scheme.)

Food

Ben continues to lose weight yet he is trying to follow his own eating plan. He has lost all the weight he gained during that one week – and more. (Weighed on our scales.)

He naturally cuts down portion sizes, eliminates many foods and exercises compulsively to “earn” the “right to eat”.

Left alone he is unable to eat the quantities he needs to put on weight and – now without the dietitian's input – is not having his distorted food / eating attitudes challenged, so he is not learning anything.

He has only gained weight during one week since 28th May.

With regard to what is helpful to Ben...

He would prefer it if we made no mention of anorexia / eating plans / weight gain / CAMHS, etc and just left him to get on with it. But, as mentioned above, this only results in him losing weight. Also, it is impossible NOT to talk about food now and again yet he sees this as “going on at” him.

We, as his carers, have no choice but to mention these things in passing which often results in him flying off the handle at the slightest comment so we feel as if we are treading on eggshells all the time, terrified he will either kill or harm himself – or leave home. How do we perform our parental role with regards to recovery if he refuses to let us talk about anything to do with the eating disorder and food?

If his own eating regime fails to put on weight, what do we do? We can't see him cooperating with any weight gain diet.

Tuesday, 9 May 2017

"Mum hatred, threats to run away, etc" - a post from 3rd August 2010 on the ATDT parents' forum.

Just in case you're wondering who 'Charlotte' is... the mum I refer to in these early [Around The Dinner Table Forum](#) posts... she is, or rather *was*, the most amazing and supportive fellow-mum you could ever imagine. Before she passed away from breast cancer in January 2013, Charlotte Bevan supported many, many families, not just here in the UK but abroad, too. She was almost invariably the mum who popped up first with support, help, advice and a shoulder to cry on whenever new members to the ATDT forum posted for the very first time. She would also call us on the phone whenever we posted up an emergency cry for help. On top of this Charlotte was constantly advocating for better treatment and a whole range of other things to help families facing an eating disorder. To find out more about Charlotte, [click here to go to the post I wrote after hearing about her death](#), back in January 2013. Meanwhile, below is a post I wrote on the ATDT forum on the 3rd August 2010, during the 'summer from hell'.

Charlotte already knows about this (bless her, she's amazing, we've been on the phone and email today), but I wondered what everyone else's experience is of Mum Hatred when your son or daughter refuses to speak to you and hates you with a vengeance making it impossible for you to support them through this. It's something that's materialised in the last few weeks.

Also, Ben has gone AWOL on several occasions, today climbing out of the window because I wouldn't produce the house keys. Luckily he returned, but he refuses point blank to speak to me and I can't see this improving. It's impossible to do meals or anything as he's also refusing to eat (or just eating what and when it pleases him). Last night he packed his bags (for the second time) screaming he was leaving home, but stayed after long discussions with his Dad.

Today he said the only reason he'd stayed was because his Dad had told him of the consequences of running away (i.e. police, etc).

Charlotte has given me some wonderful advice which is invaluable and a huge thanks to her. Just wondered what other parents' experience of this is.

This is a horrible situation.

Later

Yes, thank you XXX. And Charlotte, of course... so much good advice there I thought it was a good idea to start a new thread for me and for current eating disorder carers.

I long for the day when I'll get a hug "just because I love you" like someone said on XXX's old thread which brought tears to my eyes.

And...

Thanks, everyone. He is calmer today. But we are living on a knife-edge.

Ben has banned us from talking about food or participating in any way with his eating. If we do, he explodes. So we can't carry on feeding him as normal because he won't let us.

All we can do is to hope we get some sense out of CAMHS when we see them on Friday after a 4 week absence but I imagine it'll just be more of the "try and eat more" / "He just needs some space and that's why he's threatening these actions" sort of stuff plus the finger pointing at me, the neurotic mother.

And...

He is in a much better mood, thank God, and has unpacked his bags... and has actually hugged me back, but I am having to be oh so so so careful what I say and do in case it all kicks off again. I wish we had the money to go private but it's so much a case of "how long is a piece of string" that we'd probably run out of dosh pretty quickly. Also, as I have said before, how do I know the grass will be any greener, hey...

CAMHS [the Duty Psychiatrist I spoke to when I was terrified my son would take his own life] say they are not an emergency service and we can't just drop in when we feel like it. And of course I'm tarred as neurotic and guilty of not giving son "space".

And...

Friday was so bland I can't really describe it here, I can scarcely remember what was said except CAMHS didn't seem unduly concerned about the continuing weight loss, preferring to focus on Ben's depression over the next few weeks. But I guess they have to focus on that too. I did keep repeating over and over again that I want them to focus on BOTH issues - weight and depression. My husband is delighted with what they as "the professionals" say. Somehow they always wins him over and I am Big Bad Batty once again, ploughing a lonely furrow, and "going against all the professional advice" (to quote my husband).

How can I complain when the only ammo I have is Ben's weight loss. Already with regards to the loss of the dietitian I have seen all of them close ranks - amazing!!!

But meanwhile Ben is trying hard to eat well and is managing to eat XXXX-XXXX cals per day which is better than nothing...

Thanks for all your responses, by the way. I am really touched...

And...

Just got a double prescription for medication so I can "Keep calm and carry on" (to coin a wartime phrase I saw on a cushion which I nearly bought yesterday). I voiced all my concerns to the GP (one of the oldest and most experienced in our practise) yet all he did was nod his head and say very little. The phrase "closing ranks" came to mind....

Even he said that eating disorder treatment is all about addressing mood / mind issues first and with the improvement of these comes weight gain, while all the books I'm reading say it should be the other way round... Meanwhile Ben's mood is rock bottom today and I dread another showdown... He has lost all his joy and zest for life and I can't remember the last time he smiled or laughed genuinely; he just skulks around the house looking like the world's about to end.

And...

I can't get in touch with the psychiatrist on the phone (I've left loads of messages) so here's the email I'm sending her (which I have to do via the receptionist - no direct contact with her permitted):

Ben's depression

Ben is "low" all the time; he only used to get ultra-depressed and in complete despair every so often. Now it's virtually every day, all day. It has nothing to do with me "going on at him" because I've kept completely quiet, rarely mentioning food, anorexia, etc.

I believe he's reached a new dark and dangerous mood cycle and could do something silly very easily. This puts me on a knife edge every minute of the day and I am seriously worried.

He is not just back-sliding, he's going backwards rapidly. We've seen some very abnormal anorexia behaviours and the "animal cries" / crashing around / uncontrollable weeping at mealtimes are back.

I would like to see Ben on medication and I would like you to promote the idea of this to him - if for no other reason than to make it easier for me to take care of him when his mood deteriorates dangerously. He can't do this on his own; he needs help. And he is, without doubt, getting much, much worse.

Ben's weight loss

I am still not clear what CAMHS plan to do about this. At first it appeared that CAMHS would step in if Ben lost weight consistently. But this hasn't happened. At this stage, I would like to be clear about what action you plan to take next.

Ben's weight has gone down consistently since 28th May. He may not be at a dangerous level now but he could be before too long.

He refuses to let us take control or even talk about food / eating / anorexia so we can't encourage him to increase his food intake.

As a weight gain regime this obviously isn't working and it could get serious if left unchecked.

If the plan is to change his mood first and with it will come the weight gain, then this could take months. Surely his weight could be at dangerous levels by then?

And with the weight loss comes mood deterioration and the return of old anorexic habits and behaviours.

As a parent I am seriously worried and need to know what your plans are to turn this around.

PS: in the end I spoke to her on the phone and all of what she said sounded OK (except she said it's all a case of what Ben wants, not what we want because he's not a little boy any more.

Later...

We seem to have entered a new and very dark phase whereby it's unusual for Ben to be "normal" in his behaviour and most likely he's crashing around the house, screaming, swearing, crying out like an animal... the works. The slightest thing can bring this on and I am finding it a mega strain (to say the least) while my husband is working away and there's just me. If I bring any other adult into the equation, he just walks out. I have explained this to the

psychiatrist and re-explained it to her, with the usual response. Before, it used to be a case of he was like this now and again. For the past couple of weeks it's been the other way round and I really can't cope. I am taking 5 days off next week as my husband takes Ben to the inlaws again and I escape to my little "bolt hole" by the sea like I did in June. I seriously worry that I won't want to come back. Really and truly I feel like running away myself...

And...

In an ideal world, I'd go for longer, but with my husband working away, there's only me.

My husband took Ben to the inlaws back in June and there were some major problems around food / mood, so they've seen it all before so hopefully they will be prepared. I just feel the need to delegate everything, lock, stock and barrel. Last time I did this Ben texted me with a "I can't stand this any longer" but thankfully it was resolved though it made my "time out" pretty stressful.

Telling my GP anything seems to be pretty useless as they are really not in the slightest bit interested as was demonstrated when I visited my GP and voiced my concerns earlier this week. Just sympathetic head nodding and no action, regardless of what I said. But he did give me a prescription for Fluoxetine (Prozac).

We have 2 more psychiatrist sessions before we go away, the first being tomorrow. Yet again psychiatrist has said that if Ben continues to lose weight she will step in and insist that I take back control of certain eating elements. So I asked when that would be, but she said there isn't "a specific cut off point"... We shall see what happens tomorrow. Had a nightmarish morning with Ben in a heck of a nasty, evil mood. So that's one good day this week and the rest all pretty hellish.

And...

The trouble is Ben is getting to the stage where he is now refusing point blank to have treatment or anything to do with anything medical. We had to virtually carry him to CAMHS this morning and that was only because my husband arrived home just as I'd given up. Despite now being diagnosed with clinical depression (finally, at long last) he refuses to take medication. He refuses to go to the GP. He refuses anything.

And...

My husband "read the riot act" to CAMHS on Friday and overstayed his welcome by an hour! For the very first time, they seemed worried about Ben and went into detail about the damage he could be doing to his body, said he MUST gain weight this week or I take back control of the eating. I think the penny has dropped with that, yes, this is serious and, yes, they must take what we parents say seriously. I felt quite confident when my husband came home and told me all this in depth. Also, Ben stayed in the entire session despite threatening to walk about after 5 mins. He seems to have taken what was said seriously and is eating more. We have another session on Wed, so will see what happens. Me, I was totally and utterly in pieces after last week which was our worst week to date. Spent most of the week in bed as it made me feel physically ill. Not ideal, I know, when we're supposed to be strong, etc but some things just really take it out of you.

Friday, 12 May 2017

"Still can't get son to eat enough..." - a post from 8th September 2010 on the ATDT parents' forum.

The summer of 2010 was a nightmare on so many fronts - and if you drew a straight line on his weight chart from the middle of May to the date I posted the following on the [Around The Dinner Table Forum](#) (8th September), you

would see a steady drop in weight. With this came a deterioration of mood and behaviours yet CAMHS were insistent that Ben had arrived at a stage where he could manage his own food intake. In fact they were keen for him to do this right from the start.

By the September I was worried sick about where this was heading. One day the CAMHS nurse said to me that he "has to *want* to recover". So I asked her: "What if he *never* wants to recover?" and she just shrugged which, not surprisingly, sent me into an even great panic. It was all about Ben having to "learn to make the right choices".

But how long would it take for him to "learn to make the right choices"? How much more weight would he have to lose before that happened? Just as crucial: could I, as his mum, handle a situation where his moods and behaviours got even more disturbing, distressing and terrifying than they were by this stage? By September 2010 (which was 12 months on from when I first took Ben to see our GP), I felt as if the two of us were about to free fall off a cliff.

All I can say is Thank God I had the support of the mums and dads on the [ATDT forum](#), because without them I would have felt so very, very isolated and alone.

An update... nothing much has happened except continued weight loss while my son has been under the 7 months treatment from CAMHS (gained weight for first 3 months, then started the downwards spiral).

He refuses to do an Eating Plan administered by me. I do evening meals and that's all. He will just about make XXXX calories (where he maintains or loses weight gradually) but refuses to go over and above that for fear that he will put on weight rapidly. Nothing in his psyche has changed over the months with regard to that.

Please don't tell me that I "must just take over" or persuade him; he's the most stubborn boy in the world and also manipulates me with threats of leaving home or doing himself in if I so much as suggest an Eating Plan administered by me. And meanwhile CAMHS keep saying they'll intervene if he loses more weight, but they don't. And they won't support me doing the Eating Plan preferring to let my son make the choices. (I have written a to-the-point letter to them and asked for a private meeting to discuss why this is being allowed to happen.)

And now he's back at school with all the potential weight loss horrors of school dinners (no-one takes lunch boxes and he refuses to do things differently from everyone else).

I have got to the stage where I am panicking and very frightened of where this is going.

Any advice would be appreciated.

Thanks.

Friday, 12 May 2017

"Son back in school but still isolating himself..." - a post from 20th September 2010 on the ATDT parents' forum.

In September 2010, my son Ben went back to school after months of being at home - into the Lower Sixth Form. It wasn't a great success. The eating disorder was still raging. He found it difficult to handle the fact that he was "sitting around doing nothing" (i.e. not burning up so many calories). He found it difficult to integrate back into his friendship group and isolated himself by studying frantically in the library during breaks and free periods.

On top of this he wasn't sleeping. In fact insomnia became a major problem as the constant maths were going round and round inside his head: input,

output, input, output. How much exercise would he have to squeeze in to work off whatever he'd eaten that day... And meanwhile, despite promises to hand back control of his food intake to me (constant promises throughout the whole of the summer), CAMHS simply weren't doing this.

In mid-September I'd had a private meeting with the psychiatrist. I'd made a long list of points I wanted to talk about and almost marched her through them. Because time was limited, I steered her back on track whenever she went off on a tangent. The meeting was a success; I conveyed my worries and concerns. So I really hoped that we'd be working much closer as a team, working against the eating disorder to get Ben well.

This is a post that I put up on the [Around The Dinner Table Forum](#) on the 20th September.

We took our 16-year old son out of school in February after months of problems (thanks to the eating disorder he just couldn't face school; he couldn't even face walking across the car park or being seen). He'd also cut himself off socially from his friends. However over the past few months he's re-established contact with many of his friends - not fantastically so, but at least he's made an effort, went to the cinema or town with them, etc in the summer, etc.

The week before last he went back to school into the 6th form, but has admitted he is completely isolating himself socially, avoiding the common room, has "nothing to say" to his friends and spends free periods, break and lunchtime studying in the library. He also goes into lunch on his own. Obviously this is worrying me a lot - help!!!

And...

He's not sleeping, either. Slept well at the weekend of course.

Also, refeeding is a real battle as he simply won't buy into the idea of eating the calories he needs to put on weight. He always eats all his meals (which is

great news) - but he's cutting down on school dinners and is resisting the 'extras' he needs to bump up the calorie total.

PS Things are improving with CAMHS - I had a long and fruitful meeting with the psychiatrist last week but obviously time will tell...

And...

He is loving the school work, thankfully. But, yes, we need to sort out supervised lunches, maybe with a vigilant staff member?? It's difficult when son is so old i.e. he can't be supervised by 6th formers because he is one. He refuses point blank to lunch with me in the car park! CAMHS say they will take action if he loses this week as the 'culprit' will obviously be school dinners.

And...

He is finding it doubly hard because of the compulsive need to exercise and since he started school he's (quote) "sitting around doing nothing all day" therefore doesn't feel the need to take in sufficient calories. That, plus the lack of sleep (he's off school again today, absolutely exhausted).

Re exercising... He used to do games on a Wednesday afternoon but now that's been changed to community service which has depressed him quite a bit. After the summer he's finding the transition to being at school and not being able to exercise at will very hard to take and it dominates much of his thoughts.

And...

He is still not sleeping and is pushing himself to go into school. His mood is rock bottom and he's noticeably cutting back on food in denial about needing to eat, put on weight and recover. Hopefully this is something we can get CAMHS support on at our meeting tomorrow, but it's a really difficult situation because he refuses NOT to go to school (and needs the mental stimulation), but is isolating himself, depressed and not eating. I am fed up of fights over getting

him to eat stuff and worried about his low mood and lack of sleep. He looks TERRIBLE.

And...

Ben saw the psych today while my husband and I saw the psychiatric nurse who works with her. The psychiatrist is much more serious about intervening than the nurse who is of the opinion that Ben has to embrace the need for change before any change can take place and there's little we can do if he refuses to cooperate (except watch him head downhill towards IP status, presumably) - and hope that somewhere along the line he will suddenly "get it" and turn a corner.

That wound me up and I said surely they had a duty of care to intervene now, before things get to that level. School dinners are the obvious problem, so - with a bit of pushing and straight talking from me - I suggested that we should consider either pack lunches in a supervised / private environment OR seeing if the school can plate up a meal like they might do for people with special dietary requirements. I guess this will be up to me to sort out. I am disappointed CAMHS aren't taking direct action; last week they promised they would if he lost more weight.

At the end of our separate sessions we all got together and I felt the psychiatrist was far more prepared to intervene and try to turn things around than the nurse. But, because Ben had only lost 0.3kg this week, I didn't feel they were seriously stepping in to take action, more a case of leaving it another week "to see how it goes". And next week the psychiatrist is away, so Ben and I are both seeing the nurse.

Meanwhile Ben is off school again due to exhaustion / lack of sleep and his mood is LOW.

Conclusion? I am pleased and surprised he hasn't lost as much weight as I thought he would have lost - which means we must be doing something right. If we can sort out the school dinner problem, we may be able to see a turnaround on the weight front. But I am disappointed that CAMHS aren't intervening directly on that count and I can't understand the nurse's attitude that there's little we can do unless Ben actually wants to cooperate.

If we're not careful, he will continue to lose weight gradually - and because it's gradual and not sudden, CAMHS won't see it as serious. But he's been losing weight in this way since the beginning of the summer and IT ALL ADDS UP!!!

To be honest, I feel CAHMS have let me down after all the promises last week following my private meeting with the psychiatrist.

Having said all this, I still feel confident that the psychiatrist WILL intervene...

And...

We were having alternate individual and family sessions with the psychiatrist but she is keen to do some intensive CBT work with my son - hence the separate nurse appointments for us.

School is being great about Ben being there when he can, but not when he can't and sending work home for him so he doesn't get left behind. It also keeps him mentally stimulated which he needs.

Ben and I are having a chat today about the best way forward with school dinners. He would miss too much if he just went in mornings only. It's not me pushing him because I'm not; it's him being mega keen to go in rather than being at home.

Friday, 12 May 2017

Notes from my meeting with CAMHS in September 2010

In September 2010, I requested a private meeting with the CAMHS psychiatrist. It had always been really tricky to pin down members of the CAMHS team outside of Ben's treatment sessions when he wasn't around. Usually it was a case of grabbing them for a few minutes as they were about to dash off. So I went along to this meeting armed with a clear list, agenda-style, of what I needed to talk about. I remember asking the psychiatrist how long we had, expecting her to say 20 or 30 minutes. When she said "an hour" I nearly danced with joy.

All in all it was a very successful meeting and I'd say that it marked a kind of turning point in my relationship with CAMHS, or at least with the psychiatrist who, despite everything, I was actually starting to like and respect as a person. Her attitude towards me had changed, too - much more friendly and willing to listen.

Here's the 'agenda' I took along to that CAMHS meeting.

Ben's weight loss / the future: *What is your intervention action plan and what safety nets do you have in place? Early intervention makes sense.*

Giving me back control is great on paper but (a) he refuses to cooperate and (b) he believes he can cut down on intake on school days because he's "sitting around doing nothing". How long can we give him a choice and how can we implement a stricter regime successfully given his hatred of the eating plan? Surely the time for "What does Ben want?" is over? But I can't enforce this on my own.

He refuses to have X,XXX calories and finds it impossible to do this, despite promising he will. I am powerless and can do nothing except sit back and watch while he presses the self-destruct button and heads downhill.

Exercise – compulsion: *He still does his usual sit-ups and weights. He insists on going for a run at least once a week and on doing PE at school. (For example he's exhausted through lack of sleep and the only reason he insisted on going into school today was because it's PE.) How long will you permit him to exercise? When does it get dangerous? What if he refuses? I can't prevent him going for a run. He is addicted to exercise.*

The in-patient unit: *What is his current BMI? What is the BMI for IP admission? How much more does he have to decline before he is admitted? Some CAMHS offer early intervention at a higher BMI for 6/8 weeks; do you? Obviously the cost to the NHS is potentially far greater the longer he needs to be an in-patient.*

If he doesn't get that far, how can we turn things around as he refuses to cooperate and is rigidly trapped in his eating rules / calories / precision-weighing foods?

Me: *I am getting to the stage where I am unable to cope or look after him properly on my own. He is bigger than me and very stubborn. I wouldn't be able to prevent him running away or self-harming. And I can't physically force him to eat or stop exercising. Under my care he risks deteriorating as I simply can't get him to cooperate which leaves me demoralised, depressed, exhausted and very frightened.*

School: *Ben's anxiety is resulting in sleep loss – he can't sleep on school days and is exhausted. Yet he is forcing himself to persevere, exhausted and joyless – every morning / evening is a nightmare / miserable situation and it's just not sustainable. We can't go on like this.*

School dinners: *He is still cutting down. How will you intervene? Again, he refuses to cooperate. Action plans?*

CBT [Cognitive behavioural therapy]: *Because of the co-morbid nature of the condition [depression and eating disorder], will your sessions be focusing on depression AND food?*

Tuesday, 16 May 2017

Parent support: what helped us and what might help you

I've been thinking about the support that was available for parents when my son, Ben, was sick with anorexia - because I, like most parents, was desperate for help even if that help was just a sofa, a cuppa and a friendly ear. I really hope that there is more support these days because parents really shouldn't have to go through this distressing, confusing and life-changing experience alone.

It's approximately 8 years (spring / summer 2009) since Ben first began to display signs that I now know were relatively typical of a male descending into an eating disorder: anorexia, in his case.

At the time we completely missed the signs because we didn't know that boys get eating disorders. Subjects like anorexia were about as far off our radar as you can get. In fact it was my Mother-in-Law and my sister who confirmed that my worries could be the sign of an eating disorder. My Mother-in-Law lives some distance away so it was really my sister who provided the most support as far as our family was concerned. I didn't want to worry my elderly parents, so I only told them what needed to be said at the time.

So, by the Autumn of 2009, I had **my sister** who was always ready to provide a shoulder to cry on.

I had **Shirley, the school nurse** ('Sheila' in my book) who was the person who first suggested I ask for a referral to CAMHS (Child & Adolescent Mental

Health Services) and who went to provide support that went way, way, way over and above what she might be required to do as a school nurse. Support for me, as well as for Ben. In fact it makes me cry when I recall how truly wonderful she was (and still is!)

And of course there was **Ben's dad** who was as worried (and as ignorant of eating disorders) as I was.

I can't remember how but I also discovered a UK charity called [ABC \(Anorexia & Bulimia Care\)](#). I called them and they were fantastic. I remember talking to another parent who'd been through an almost carbon-copy experience to what I was going through. She also sent me a pack of free information by post which was really helpful.

Unfortunately the UK eating disorder charity [B-eat](#) wasn't as responsive. The impression I got at the time was that they only supported the eating disorder sufferer, not the parents, although I am sure this wasn't the case; I think I just spoke to a particularly unhelpful person.

At some point along the line I learned about a parent support group at a local NHS eating disorders centre. The only problem - and it was a BIG problem for me - was that they met between 6 and 7pm. My husband was working away, so there was no way I could make 6pm - 6pm was when we had our evening meal, as I imagine it was for many other parents, too. And it was imperative that I was there to ensure Ben ate some food. It always seemed a crazy time to have a meeting for parents of young people with eating disorders! So, unfortunately, that was a non-starter.

Then, later on in the process, I met [my wonderful friend, Sue](#). Sue, who had breast cancer yet insisted on being an incredible support. Again, I feel teary when I think about Sue (who tragically passed away almost exactly five years ago).

In March 2010 I discovered the [Around The Dinner Table Forum](#) and [FEAST network](#) which supports parents of young people with eating disorders and which was a true lifesaver for me.

But, apart from the parent group that met between 6 and 7pm, I wasn't offered any support from our NHS. The GPs weren't interested. CAMHS only offered what it termed 'Parenting Sessions' with the CAMHS nurse while Ben had a one-to-one session with the psychiatrist. These sessions just made me feel more helpless as well as a little bit to blame - the 'anxious parent' and all that... And no-one seemed interested in learning about the [ATDT parents' network](#) which is kind of odd seeing as how it's so vital that parents find support in order to have the strength to support their child through this punishingly difficult time.

So if you're a parent reading this post, what would I recommend in terms of support?

Always, always, always the [ATDT Forum](#) and its parent site FEAST. I feel so very strongly about this that I almost want to frog-march parents into this network of incredible people - parents just like us, across the world, who have 'been there, got through it' yet who willingly volunteer their time to be there for other parents.

If you live in the UK then [ABC \(Anorexia & Bulimia Care\)](#) is also well worth a call, as is [B-eat](#). In the States, there's the [National Eating Disorders Association \(NEDA\)](#). And wherever you are, the famous [Kartini Clinic](#) has a wealth of information plus a [fabulous eating disorders blog](#). [Dr Sarah Ravin's blog](#) is well worth a read, too.

On top of this there are some superb books on evidence-based treatment for eating disorders; you can find an extensive list of resources [by following this link](#) on the FEAST website.

I hope this helps!

Wednesday, 17 May 2017

Why I hate BMI as an indicator of the severity of an eating disorder - or even that an eating disorder exists in the first place

In my PTSD sessions we are going round and round in (necessary) circles as my head tries to process the issues I was having with CAMHS during the first 7 or 8 months of my son's eating disorder treatment. One of the main pictures I keep getting in my mind is of the CAMHS nurse twiddling her cardboard BMI (Body Mass Index) indicator wheel every week. For CAMHS, as with many medical professionals, BMI is still trusted as an indicator of healthy weight, despite the fact that - at a so-called 'healthy BMI' - an eating disorder can be raging.

BMI was devised in the 1830s by Lambert Adolphe Jacques Quetelet (1796-1874), a Belgian astronomer, mathematician, statistician and sociologist, (NOTE: No reference to being a medical professional!!) as a measure of obesity. It was subsequently adopted by health professionals on both sides of the Atlantic as the default formula for deciding whether or not a person is a healthy weight.

That's quite a long time ago.

And it was devised as a measure of obesity.

It's high time that this out-dated and flawed formula 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.

As [Medical News Today](#) points out: *"BMI ... does not measure your overall fat or lean tissue (muscle) content. ... The measurement is flawed, especially if the person carries a lot of muscle ... Short people being told they are thinner*

than they really are, while tall people are made to think that they are fatter than they are."

And so many people in the eating disorder community have been affected by this insistence of STILL using a formula that's nearly 200 years old!

It can be SO VERY damaging when an eating disorder patient is told that their BMI is "within the healthy range" or that it's "just slipped into the healthy range" or "healthy".

In the case of my son, this information was conveyed with added "Congratulations!" and big smiles. As if he'd suddenly recovered.

Of course to him, the message was that he didn't need to continue to put on weight. He'd reached 'weight restoration'. Worse, that he was 'fat'.

As a result he immediately cut back on his food intake and lost weight.

Not surprising, huh...

When my son fell sick with anorexia in 2009, aged 15, his BMI was pretty high; remember he was a 'prop' in the school rugby team.

It was probably mainly muscle (i.e. he didn't even remotely 'look fat'), 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 body weight, 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.

Longer, probably.

This is why I - and many others in the eating disorders community - believe that there should be less (or even no) emphasis on BMI as an indicator of seriousness of an eating disorder and of recovery. And also the reliance on BMI for diagnosis, because boys like Ben may *never* even reach the low BMI required to diagnose their eating disorder as anorexia nervosa - or for in-patient treatment.

And, of course, BMIs can be completely irrelevant when it comes to diagnosing or judging the severity of deadly eating disorders such as Bulimia.

Going back to the EMDR sessions (currently being used to treat my PTSD)... That confounded BMI wheel appears in flashback after flashback. It symbolises all the things that were wrong with my son's eating disorder treatment (although there were elements that were OK, but we're talking *wrong* here - potentially damaging stuff) and which, in my opinion, prolonged his suffering unnecessarily while making it ten times harder for me to play my role in helping him to recover.

The above are just some of the reasons why I hate BMI as an indicator of the severity of an eating disorder - or even, in some cases, diagnosis.

In other words, there are still some medical professionals and GPs out there (as a friend of mine can confirm) who believe that, if your BMI is above a certain level, then there's nothing to worry about.

Sunday, 21 May 2017

"Unpleasant scenes at A&E....." - a post from 8th October 2010 on the ATDT parents' forum.

October 2010 was a pivotal moment in both the CAMHS eating disorder treatment and Ben's attitude towards recovery. But it began badly. One morning the (other) school nurse called me to say that Ben had fainted in the sixth form common room and his pulse was abnormally low (again). There followed a massive battle for me to get Ben to A&E because he refused to go, claiming he had faked the fainting.

Eventually I got him there only for him to flee out of the building before being restrained by security staff and the police. It was not a good day. But the end result was that CAMHS were as serious as I've ever seen them; with this being Ben's second heart scare I think they were almost as worried as I was. With threats of hospitalisation if Ben didn't put on weight, Ben's attitude to recovery underwent a transformation. The down side was that, although he might 'want to recover', the eating disorder and exercise addiction were too strong for him. But I definitely see this event as a definite watershed in both CAMHS treatment and Ben's drive towards recovery. I posted the following on the [Around The Dinner Table Forum](#).

Yesterday was one of those days when I was in need of a seriously stiff drink by the end. My son's still not been sleeping and was in a terrible state (as usual) when he went to school: tearful, etc. The school nurse rang mid morning to say he had fainted and his pulse was only 37, so could I come and get him. I did, rang CAMHS who recommended ringing our GP who said to take him to A&E so I did. (Back in March a similar thing happened and he was in A&E followed by overnight observation in cardiac ward due to heart rate of 29bpm. Discharged following morning, heart sound and heart rate higher.)

Doc at A&E did tests, was worried (heart down to 31), wanted to take blood. Ben went crazy, screaming, tears, etc... claimed his fainting had just been a fake to attract attention ("to make people take notice of me for once")... walked out... doc chased after him saying he couldn't discharge him because he was high risk and if he didn't willingly do the blood tests he'd have to be forced to do it (explained this very calmly and nicely, a wonderful doc!!!). Security personnel ran over, then the police arrived who accused Ben of behaving like a 6-year old and if he didn't they'd call for reinforcements!. In the end they persuaded him to do the bloods...

3 hours later cardiac doc came down and said they wanted to keep him in for observation overnight again. Ben threw another wobbly, swearing and kicking trolleys, refusing to comply. Had to be restrained by staff. Cardiac bloke went off to ask the Consultant what to do. Fortunately by the time he came back Ben's heart rate had gone back up to 65 (and bloods were OK) so he was discharged and we went home, but they said ben has to get the 'once over' from our GP in 2 weeks.

What a day!!!!!!

And today we see CAMHS so I shall relay it all to them. Hopefully they will take serious intervention action today or else I will be the one throwing the wobbly.

And...

CAMHS did take it very seriously and also the fact that he had lost 0.9kg this week. We are now on a strict, monitored eating regime to be re-evaluated on Friday subject to what happens this week, weight-wise. If he doesn't gain, then things will be stepped up. The psychiatrist said that basically if Ben didn't cooperate and put on weight and 'trod water' for yet another week or so then, because of all the nasty stuff that happened yesterday, she would consider

sectioning him for hospitalisation which, she said, wasn't a nice prospect for him. She also wants him to have regular ECG and blood tests with our GP. As you know from above, Ben has a pathological fear of blood tests and everything that goes with them, so this in itself was sufficient to motivate him. I've never seen him so motivated and keen to cooperate!! He and I have set up a no-negotiation plan for this week. Also if school meals don't work, then they will be closely monitored too. Also, he's going in only part-time to school on some days now rather than full time.

The decision for the time being was made for him to continue PE at school which I'm not too happy about but their logic was that if we forbid it then he's more likely to go underground and do potentially more dangerous exercises. However I have emailed the school to ask them to make PE staff aware of EVERYTHING that's been going on. It may be that they feel he shouldn't do games at all.

Also CAMHS say school would have done better calling an ambulance rather than calling me to pick him up and then me having to fight with him for nearly 3 hours to get him to go to A&E in the first place (in the end I had to call his Dad who's working away and Dad had to threaten to drive home if he didn't go).

CAMHS were about as serious and pro-active as I've seen them... ever.

And...

Thanks, everyone. So far Ben is very keen to stick to our eating plan. Fingers crossed it lasts more than a few days... I think the idea of early hospitalisation frightened him ("No way will I ever get bad enough to be an in-patient", he would say...). That, and the fact he lost 0.9kg in a week when he was convinced he would put on weight. (He was 'proving' to us that he had the amount of calories he needed sussed...)

I've made school aware of everything that's happened; the Head of 6th form even replied today (Saturday)... and replied to my second email.

She says Ben's friends were really scared and freaked out when he fainted on Friday. Ben claimed in A&E that the fainting was faked. Me, well, I'm not sure whether it was or not. I do know he was totally knackered from a week of lost sleep. The A&E doctor didn't believe his "faking it" story and kept asking questions about what happened when he passed out.

And...

Just to update you...

The GP won't prescribe any sleeping tabs as Ben is under 18 and also tabs could open up a whole new can of worms re. potential addiction and the "hangover effect", acc. to GP.

Ben has been into school Monday morning (came home because he was too tired).

Tuesday morning (we've agreed Tues mornings only for the time being and he just made this, even though he was knackered).

Wed morning (for the first time he slept and he was like a different person - and he got on well with his friends / peers for the first time for AGES!)

Today (Thurs), no sleep again, so off school.

Friday is CAMHS followed hopefully by some school. But we're not doing too well on the school front... and the sleeping is TERRIBLE.

A 'plus' is that he's stuck to this week's XXXX calories every single day without much resistance. How much he weighs tomorrow will tell us what we need to do next - increase it by 100 a day or whatever.

A 'minus' is that so far he hasn't had to eat his packed lunch in school as he's been at home for each lunch. 'Plus' because that's easier and he always eats up, 'minus' because successful pack lunches (and the new increased quantity) is

as yet untested - and Ben says he'll find it really difficult to eat in school. Any probs, and he'll be monitored in the medical centre.

The school nurse, who is positively saintly, is doing everything she can to help - and CAMHS are coming in to school to talk to the year group about eating disorders (subject to asking Ben how they'd prefer him to approach this so there's no stress or embarrassment).

PS his pulse is back within the 60s but the plan is for school to call an ambulance if it dips to the low 30s again.

JULY 2017

Monday, 10 July 2017

Lots of things to catch up on!

It's all been a bit quiet here recently. That's because I've been focusing on fixing the C-PTSD (Complex Post-Traumatic Stress Disorder) which I've been battling with for at least 3 years. After several therapists and therapy models, both NHS and private, I do believe it's finally been fixed (fingers crossed, famous last words and all that...) 18 sessions with Steve, my excellent private PTSD therapist (using EMDR - Eye Movement Desensitization and Reprocessing), seem to have worked wonders. Of course it's early days and I'm taking things slowly as I gradually rediscover who the heck I am after all this time and where I go from here. "Gradually" being the operative word. So more on this shortly...

Today Ben starts his driving lessons, something we never did because of the eating disorder, university and so on. He also starts his PGCE Teacher Training Course in September at a local university.

As part of the application, he had to get a letter from the GP about any mental health issues. We were a bit concerned about what the GP might say as regards the eating disorder. But, hey, of course! Guess what?! Ben never did have an eating disorder! Well, not according to the GP's letter.

This is because, of course, (as can be typical with males and especially sporty males like Ben was) Ben's BMI was always too high to be 'officially' diagnosed with an eating disorder. This, despite - as you well know - raging anorexia nervosa.

So that's good to know... that my son never had an eating disorder, as such...

Hmn.

Thursday, 13 July 2017

Honoured to be invited to be a Trustee of the Men Get Eating Disorders Too charity

I've known Sam Thomas, founder of the charity [Men Get Eating Disorders Too](#), for some time. We occasionally meet up at conferences and so on. Sam does an amazing job. Not only is he the founder of this incredible charity but he campaigns tirelessly across the country, on TV and radio and in the press to raise awareness of the fact that men get eating disorders. If there's a report about males and eating disorders, then the chances are that the reporter will be interviewing Sam!

So I was thrilled this week when Sam asked me if I'd like to be on the Board as a Trustee. I immediately said yes. I haven't a clue what I will be required to do but whatever it is I know it will be as part of this amazing machinery that Sam has created nationwide (and further afield) with his charity Men Get Eating Disorders Too.

More news as I get it!

Saturday, 15 July 2017

News release going out to local press / media in Yorkshire

Leeds mum invited to join the board of national men's eating disorders charity

A Leeds mum who became a campaigner after her teenage son developed anorexia has been invited to join the Board of a national men's charity tackling eating disorders. Bev Mattocks Osborne, who spent several years fighting to get her son through anorexia is joining the charity Men Get Eating Disorders Too (MGEDT) as a Trustee. [Men Get Eating Disorders Too](#) was founded in 2008 by Sam Thomas as a response to the lack of awareness and adequate information and support for men and boys battling with an eating disorder.

Bev, who has authored two books on eating disorders - including a first-hand account of her son's struggle to recover from anorexia - and a blog aimed at helping and supporting other parents of boys with eating disorders, says: "Being invited to become a Trustee came as a bit of a surprise. I immediately said 'Yes!' I have met Sam Thomas of MGEDT on a number of occasions, often when we were both speaking at conferences on eating disorders. I have been inspired by his dedication at raising the profile of this important charity."

Back in 2009 when her son began to show typical signs of anorexia, Bev, like many people, was completely unaware that males can get eating disorders. "As a result I didn't recognise the warning signs," she says. "I knew that something was very wrong with my son, but I had no idea what it was. Once the penny dropped, I struggled to get my son officially diagnosed with an eating disorder and referred for treatment. When he did eventually get referred we were told

that the waiting list could be 18-22 weeks. Meanwhile my son was getting worse by the day.”

Bev doesn't want other families to go through what they went through. “To have to hang around for months watching your child – whether male or female - head towards possible death because they can't access treatment is something that no parent should have to endure. This is why I have campaigned via my books, blog, talks and media appearances to raise awareness of the fact that boys get eating disorders and that eating disorders can be deadly”, she says.

Today, Bev's son is fully recovered and has just completed a Master's Degree at Sheffield University.

Sam Thomas adds: "Typically eating disorders are perceived to be conditions that affect only females – this is far from the case. Between 10 and 25 per cent of those people experiencing eating disorders are male. The work of Men Get Eating Disorders Too aims to get males and eating disorders on the agenda by campaigning and raising awareness."

Bev will be joining the new Chairperson, Plymouth-based mental health campaigner and fellow mum of a son who has battled with an eating disorder, Debbie Roche, and other new trustees including campaigner and mental health spokesperson Danny Bowman and James Down, campaigner and member of the cross-party group for eating disorders at the Welsh Assembly.

Saturday, 15 July 2017

In many ways I've fixed the PTSD but in other ways it's still very much around

It's not surprising, really, that some of us parents will find that the eating disorder comes back to haunt us in the guise of medical issues either with our

body or with our mind. In his book [*The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma*](#), world trauma expert Dr Bessel van der Kolk talks about how trauma literally reshapes both body and brain, "compromising sufferers' capacities for pleasure, engagement, self-control, and trust".

I know of several parents who are struggling with PTSD-type symptoms - or, to be more accurate, C-PTSD (Complex Post Traumatic Stress Disorder) symptoms. The latter - C-PTSD - is the result of having faced long-term trauma as opposed to PTSD which may occur as a result of a single traumatic event.

As you'll know if you've followed this blog, I've been struggling with C-PTSD for a few years along with trying to find a treatment provider and model that could fix it. I've had various CBT and psychotherapy sessions and, more recently, EMDR (Eye Movement Desensitization and Reprocessing) both through the NHS and with a private therapist.

Altogether I had 34 EMDR sessions!

The EMDR was hugely effective and helpful. After 18 sessions with the private therapist, I am 'going it alone' to see how I get on. We've 'processed' a mountain of stuff that was still going around in my head causing flashbacks, nightmares and a stack of unpleasant and debilitating symptoms. For example on Christmas Day things were so bad that I almost didn't get out of bed.

I'm not ready to go into more detail just yet. Perhaps in the future I might be able to write another book about my son's recovery from anorexia and the legacy that I struggled with - i.e. the C-PTSD.

But at the moment I'm just taking things slowly, step by small step.

It's been a Big Thing to say 'Yes' to the invitation to become a Trustee of the charity Men Get Eating Disorders Too. But it's also testament to how much I've progressed since I first started EMDR 34 sessions ago. Just a month or so ago I wouldn't have been able to face it. It would have seemed 'too big'. Even now it

seems 'big', but I am better able to face it and hopefully contribute something useful!

I may say that I've 'fixed' the C-PTSD. In many ways I have (or, rather, my therapists have). But I'm not over it. And it could come back.

So I'm just taking things a small step at a time. And I know that my therapist is always there if I need a few more sessions.

Thursday, 20 July 2017

Processing anger - and the cardboard BMI calculating wheel

During the 18 weeks I was with Steve, my EMDR (Eye Movement Desensitisation and Reprocessing) therapist, we processed a ton of stuff relating to my son's eating disorder. (We picked out the key issues that were haunting / bugging me still in 2017 in the hope that, by focusing on these, other issues may get processed at the same time.) One of the major issues was anger. I mean, ANGER. Even **A. N. G. E. R.** Anger at those in the medical profession who made my life more difficult as the parent of a teenage boy with anorexia and, I believe, may actually have *prolonged* my son's eating disorder.

I wasn't too sure that I wanted to lose this anger, though. The anger made me more motivated to blog and write about eating disorder awareness. It made me more confident e.g. to speak about eating disorders at conferences. And I felt justified at feeling this anger. I couldn't see how 'processing' it through EMDR or any other post-trauma therapy model might remove it. In a way, I didn't want it to be removed.

But it was a kind of impotent anger. Anger at stuff that was now history. Anger at attitudes that may no longer exist as medical professionals become increasingly aware of and educated about eating disorders (especially in boys

and young men) and newer, more evidence-based treatment models are introduced for dealing with eating disorders in adolescents (e.g. FBT - Family Based Therapy).

So, as regards my anger, there was a dilemma. On one hand I felt empowered by the anger and felt that it was very much part of who I've become following my son's eating disorder. On the other hand I felt trapped by it as my brain re-visited various key situations over and over again, like nightmarish revolving doors, solving nothing and re-living everything.

Steve asked me to bring to mind a memory that epitomised this anger - simply what kept coming into my mind when I felt angry. *What did I see?* ("I see the CAMHS nurse twiddling with a cardboard wheel to work out my son's BMI following the weekly weighing session," I said. *Ben has been told his weight and how much he has gained or lost since the previous week. The nurse is calculating his BMI and it's smiles all round because his BMI has just slipped back "into the healthy range". I say smiles all round, but my son isn't smiling and neither am I. I know for a fact that he will 'punish' me all the way back to our house afterwards and go crazy once we're indoors [which brings other memories to mind]. Then he will spend the rest of the week trying to lose the "massive weight gain" of a few points of a kilogram.*)

Steve asked me to hold that picture in my mind as he did the EMDR stuff (moving two fingers in front of my face at varying speeds - sounds weird and mumbo jumbo-ish, but that's how EMDR is carried out - read more about it [here](#)). At this stage he didn't want me to describe the event verbally, just to see where my mind took me.

Other events kept ping-ponging into my mind, primarily at CAMHS, but I kept going back to this confounded BMI wheel and the smiles on everyone's faces. ("Ben's done so well!" they were saying...)

Steve asked me to score how strong my emotion was in the hope that it would reduce from a '10' (out of 10) to zero. And if not zero, then what did I think was holding me back from a zero?

Although we successfully processed a lot of stuff that was still very much present and still raw in my head, I'm not certain that we processed all the anger. And that may be because I am purposefully hanging onto it. In a post-eating disorder world, this anger feels kind of part of me. It also makes sense to me that I will always be angry at all the obstacles that were thrown in our way - from the GP visits onwards. It wouldn't be realistic for the anger to disappear, I explained to Steve. And this is why I don't believe we would ever get it to a zero.

But hopefully what I feel now, following EMDR, is a *more productive* and *healthy* anger in that things have moved on since 2009/10. In our city (and also thankfully in some other areas of the UK), treatment for eating disorders has improved. Parents are seen as part of the solution, not part of the problem. Children are weighed blind and - I hope! - there is not so much emphasis on BMI as an indicator of the severity of an eating disorder. Put simply, the treatment model that would be used today is very different from the treatment my son received all those years ago.

So, although I still have my anger, it feels as if it's in proportion to everything rather than being out of control, very 'now' and raw. A healthy 'past-tense' anger rather than an obsessive, impotent anger. It's an anger that can be stored away in a box and put on a shelf rather than an anger that permeates every cell in my body and brain.

And the cardboard BMI calculating wheel has long been pulped and recycled as toilet paper.

Saturday, 22 July 2017

Eight years ago my son was heading into an eating disorder, but I was blissfully unaware...

Eight years ago this summer, my 15-year old son, Ben, was beginning to descend into something that was way, way beyond anything that had ever entered my psyche; something worse than my worst nightmares. But of course I was blissfully unaware that he was developing a potentially deadly eating disorder: anorexia. What I *was* aware of, however, that Ben was getting increasingly fussy around food. Ben, who used to eat anything and everything, had suddenly become mega health-conscious and an expert on 'healthy' nutrition. He'd also developed a passion for cooking which, at the time, I applauded. I even found it amusing as can be seen from the following blog post which I wrote on the 22nd July 2009 (8 years ago today!!) as part of a series for a regional newspaper and which I was reminded of this afternoon as Ben pummelled the dough for pizza:

Hubble, bubble, Ben is in trouble...

There's something horrible in my kitchen. It 'pops' every so often and smells like... well... to be totally honest... like baby sick. Well, worse, actually.

The reason is that 15 year old Ben has suddenly decided to start cooking stuff.

The other week he made me buy a River Cottage cookbook on bread-making and ever-so-wholesome goodies have been coming out of my kitchen ever since.

As you can imagine everything smelled divine.

Until he got to Chapter Six.

Here the book introduces the concept of 'wild yeast'. Now, I naively assumed this must be a bit like wild garlic. Something you pluck from the hedgerows, add to flour and water and - hey presto - you get bread.

But apparently not.

You 'grow' it at home which, of course, is bound to appeal to any man's 'chemistry experiments in the shed' instinct.

The only problem is this stuff isn't being grown in the shed; it's being grown in my kitchen.

And it stinks.

It also makes noises as it occasionally 'pops', a bit like home brew, threatening to bubble over across my kitchen floor like some kind of swamp-like alien life form.

Basically it's flour and water that's been left to 'ferment' until it looks like a cross between Weston mud and volcano lava.

And the more it ferments, the worse the smell gets.

"So how long is this stuff staying in my kitchen?" I demand.

"Oh around 12 years or so", he replies nonchalantly.

Gulp.

Apparently there's a baker in Dorset that's had his for 30 years. Worse, the book warns that "it may be with you for life".

Oh brilliant. That's going to make me really popular with visitors, not to mention business clients that visit the house. Me, trying to quickly explain what it is before noses begin to twitch and they start looking at me...

But meanwhile this stuff is gurgling away in my kitchen and smelling to high heaven.

And I've a feeling it's going to get worse.

Apparently you're supposed to 'feed it' every three to four days, then discard

some and keep the rest, presumably making bread with it at some point.

And if the smell is anything to go by, goodness only knows what the bread will taste like...

Or indeed what colour it will be.

But hopefully the novelty will wear off and he'll go back to baking nice-smelling bread with the more visitor-friendly fast-action yeast.

Otherwise as soon as he goes back to school, that stuff is going down the sink.

Saturday, 22 July 2017

Another post where I was blissfully unaware of what was happening...

Here's another post which I wrote for that newspaper back in the summer of 2009 as I continued to be blissfully unaware that my son, Ben, was sinking into an eating disorder. Had I been aware that boys and men can get eating disorders, then the alarm bells might have been ringing, but it was a couple more months before they began to tinkle - purely and simply because I was completely ignorant of eating disorder symptoms, especially in boys. If you've read my book, [*Please eat...: A mother's struggle to free her teenage son from anorexia*](#), you'll recognise some of this text which I adapted for one of the chapters.

What's Ben cooking up now?

Wow! I think we've just moved into a Michelin starred restaurant. Since 15-year old Ben discovered he's a 'natural' at cooking, you wouldn't believe the dishes we've been served up for dinner!

Last night we had wine, oil and thyme roasted butternut squash stuffed with

Moroccan couscous (17 separate ingredients) plus a watercress and tomato salad with horseradish dressing which he rustled up to go with it.

On Saturday it was melt-in-the-mouth griddled rump steaks with Scotch bonnet pepper sauce and mushroom and pimiento side. Accompanied by fresh aromatic herb and olive oil bread – and all made by Ben's fair hands!

Lunch was pittas stuffed with a delicious mix of tuna, peppers, cucumber and salad with marmite dressing. Desert was slow baked rice and sultana pudding infused with star anise and cinnamon sticks, served with warm apricot coulis.

There's even a breakfast option of (low fat) blueberry and apricot muffins with chopped fresh fruit and yoghurt.

***Comment:** Although Ben was serving up all this stuff, if I'd looked a little closer I would have noticed that he was avoiding eating it - or only eating a little, accompanied by tons of plain salad.*

In fact the only thing that hasn't been a massive success is the sourdough bread mentioned earlier in this blog. (Yes, it tasted like sourdough, but it was a bit brick-like. And I never could quite shake off the feeling I was eating that evil-smelling concoction that's been gurgling away in our kitchen for over a month...)

Meanwhile cookery books are the new X-box as Ben makes long lists of what he's going to cook next.

("You won't have to cook for the next 12 months, Mum!" / "Suits me", I say, brain-dead from umpteen years of slaving over a hot stove every night.)

Plus, he's watching all those cookery programmes that seem to have come back into vogue recently. Hairy Bikers, Jamie Oliver, River Cottage, Levi Roots, Nigel Slater, Master Chef... he's glued to them all.

He's even started to love aubergines, courgettes and mushrooms which were the only three things he refused to eat.

I am now in the enviable position of having a teenager that will eat ANYTHING! And the healthier (and usually spicier), the better.

Comment: *Although I thought he was eating everything, he wasn't - and the new passion for vegetables was all about reducing calories.*

This of course has led to Ben become a kind of Food Policeman. If I want to treat myself to sinful stuff like cookies or chocolate I have to literally 'sneak' them into the house and hide them.

When he comes shopping with me he whips the offending items out of the trolley and back onto the shelf – Rolo soft-bake cookies being the latest casualty that never made it into my mouth. ("You don't need that, Mum!" he barks. "Yes I do", I whine, "I've had a bad day...")

Comment: *The start of the 'food police' insisting on coming shopping with me to the supermarket and policing what I was buying to ensure it fell within his increasingly rigid standards.*

And woe betides if I suggest we take short cuts with ready-made sauces or spice blends. "That's cheating, Mum!" / "Yes but it's quick, Ben..."

But one thing Ben doesn't seem to have mastered is the art of clearing up after himself.

The kitchen permanently looks as if a bomb's gone off and suddenly he's far too busy with school work to do the washing up ("It's GCSEs this year you know, Mum.")

And whenever I need something from the cupboard or fridge it's vanished, absorbed into the latest culinary delight.

So what's on the menu in the future? Sushi plus healthy things in filo pastry on Christmas Eve, and he's even offering to cook Christmas lunch.

But no mince pies, chocolate logs, gooey creamy goodies or Christmas cake as, apparently, we're all going on a health kick...

Comment: He talked a lot about how we were going to 'eat healthily' at Christmas. But never in my worse nightmares could I have predicted that, by Christmas, Ben would be neck-deep in an eating disorder that was escalating out of control. Our lives were about to be turned upside down.

Monday, 24 July 2017

Still the newspaper blog, this time disguising the real reason why my son was rushed to hospital...

At the end of January 2010, my (now 16-year old) son, Ben, had been on the waiting list for eating disorder treatment for a while. His descent into anorexia had been rapid and, if you've read my book [*Please eat...: A mother's struggle to free her teenage son from anorexia*](#) you'll know that, at the end of January, he was rushed into hospital with a dangerously slow pulse rate of just 29 bpm. Meanwhile I was still attempting to write the light-hearted blog for that regional newspaper. So the following post disguises what was really going on and the sheer horror of it all (with notes in red made today).

Not a week I want to repeat...

How's your week been? Mine's been one of those where everything goes out of the window because you get a call from the school nurse saying your son should go to A&E... fast!

Worse, it isn't a broken nose (like last time), or a broken hand (like the time before), it's Ben's heart which is doing 'funny things' and beating at half the rate it's supposed to.

Mine stops as I start to panic. And it's totally true you go ice cold when you get this kind of news...

For the first time ever in the history of visiting A&E we're spirited past the usual queue. In a flash, Ben's covered in sticker things and wired to a machine.

Next, he's wheeled into Resus where they stick a massive needle in his arm to take loads of blood while still monitoring his heart on the machine that goes beep.

And because his arteries are like mine i.e. difficult to locate, they have a heck of a job trying to get the big needle in. Ben's had some pretty hair-raising things done in his time, what with in-growing toenails, several teeth out, the various bone breakages and so on, but this is the first time I've seen him actually cry...

Me... well... If you've ever been in a similar situation, a zillion thoughts rush through your head from "I must ring his dad" to "This is my only child and this is his only heart"...

Suddenly I'm at the nurses' station saying "Excuse me, I don't feel very well – they're sticking needles in my son". A glass of water later and a "Pull yourself together, Bev!" pep talk to myself and I'm on the phone to Ben's dad saying, "I don't think there's anything to worry about, but..."

Next we have a succession of important looking doctors frowning, taking notes and repeatedly checking the machine. "Smile and tell me it's all OK and we can go home!!" I will them to say. But instead they say he needs to be transferred to the specialist cardiac unit at the other hospital in our city.

I say something stupid like: "What shall I do with my car? It's in the pay-and-display?" They give me a withering look.

So while Ben's being transferred by ambulance, I'm busy moving my car to somewhere I can call a taxi to take me to the city centre. (Nowhere to park and who knows how long I will be?)

It's like a nightmare. The traffic is horrendous. The only taxi number I've got

can't be there for 30 minutes. So I have to drive to my mum's, borrow her phone book and explain what's happened without worrying her.

Taxi after taxi say they'll be AGES... Finally I find one that can at mum's in five minutes, but the traffic is in gridlock. Eventually I arrive to find Ben lying in a ward with three old men who sound like they smoke 60 a day.

And so it goes on... wires... monitors... doctors... nurses... questions... heart x-rays...

Me analysing the staff's body language for clues as they're predictably non-committal with what they say.

Oddly, Ben seems to be pretty OK except for the massive needle in his arm and the constant beeping of the machine. In fact he's so OK he makes me go down to the shop to get him something to eat because the hospital sandwich they've given him looks as if it's six weeks old.

Comment: Incorrect. The reason why he wouldn't eat it was that it didn't come up to his perfect standards (but, yes, it was a pretty unappetising sandwich). I panicked, knowing that he needed to eat, so I dashed down to the shop, spending ages there trying to pick out something which he might just eat - like fruit.

Then he sends his Dad down to get some more food!

Comment: Actually that's correct. More fruit.

It's funny how your mind works. Half of it panics with visions of cardiac arrests, heart transplants and worse...

The other half thinks, well if they're allowing him to eat they obviously aren't planning to operate. And, he's at this end of the ward, not that end (the 'emergency' end). And, he's not seeing the consultant until the morning; if it was critical he'd be seeing him now. Stuff like that...

At 8.30 pm Paul and I have to leave and we're exhausted. None of us has a

good night's sleep. I'm up at 4am, head hurting, half wondering if I'll receive an emergency phone call... Meanwhile Ben's trying to sleep with a massive needle in his arm, surrounded by old men snoring like pneumatic drills.

BUT IT ALL TURNS OUT OK!

By the time the consultant does his rounds, Ben's heart has stabilised, there doesn't seem to be anything physically wrong with it and he's allowed to go home. No clues as to why it might have happened except that sometimes sporty teenagers can get dips in their heartbeat.

***Comment:** Incorrect. It doesn't turn out OK, as you and I well know! But it is correct in that the consultant didn't know why this had happened. The fact that Ben was developing anorexia didn't flash up any warning bells (despite Bradycardia - low pulse rate - being one of the complications of an eating disorder). On learning that Ben did a lot of sport (he was addicted to exercise, as a means of purging calories), the consultant said that some athletes have low pulse rates, so that was possibly the reason. The fact that Ben was developing an eating disorder and any exercise was for purging purposes only was ignored.*

But of course if he ever feels 'strange' again, he's to come straight back. But, thankfully, the consultant doesn't seem unduly concerned.

Mind you, I'm expecting the kind of mature, larger-than-life consultant who strides into the ward, James Robertson Justice / Sir Lancelot Spratt style.

What we actually get is someone who looks like a sixth former. Can I trust his opinion, I wonder to myself...?

Monday, 24 July 2017

A post from 21st June 2011 - disagreeing with the CAMHS treatment team

For a heck of a lot of time during my son Ben's treatment for anorexia, I was at loggerheads with the treatment team. They'd say one thing and my gut instinct (plus everything I was reading and hearing) said another. Since then I have never stopped believing that certain things that were said in front of my son were harmful. Here's a post I uploaded to this blog in June 2011, 16 months into Ben's treatment for anorexia.

16 months of treatment and how effective has it been?

*As you know Ben has come on leaps and bounds on the behaviours / mood front over the past 8 months. He is also managing lots of 'fear foods' which used to freak him out. But I can't help thinking that the treatment has been a bit odd... In fact it's difficult to pinpoint exactly **what form** the treatment model is. Yes, our 2-person treatment team is brilliant at listening and asking questions. They're also great 'fire-fighters' in a crisis and very nice people, too. The psychiatrist's assistant in particular is very good at taking notes. At first I thought the purpose of this copious note taking was so they could go away, have a meeting and formulate a strategic plan of action. But 16 months on she's still taking notes. We've had loads of promises about the need to focus on this, that and the other, but - unless these things are like some kind of hidden machine working away in the background - I still haven't a clue what the Big Plan is...*

At first, back in February 2010, the team didn't take us very seriously. Or at least that's the impression I got. Yes Ben was underweight for his age and height, but not disastrously so. (Let's forget the fact they hadn't known him when he was a strapping athlete and rugby player...)

I was kind of treated like a paranoid mother and made to feel as if I was

making a load of fuss over something that really wasn't too bad at all.

Because his weight wasn't dangerously low, there was minimum focus on the need for weight gain and maximum focus on the cognitive side of things i.e. talking about the past, talking about our issues as parents, talking about Ben's problems with socialising, being in school, anxiety, etc. But just talking about it, really... (and taking notes).

Oh and emphasising that Ben had to "want to recover" before he would.

But importantly I wasn't really supported in my powerful gut instinct that the primary focus should be on getting the weight back onto Ben - and that we shouldn't stop until he was well and truly Weight Restored.

It was always a case of suggesting it might be "easier for Ben to handle" if we arrived at a weight "he could cope with", even if that was well below his previous weight. Ben was (and is) asked what kind of weight he'd "be happy to settle at".

*The assistant even once said that "some people just **choose** to settle at a lower level and stay there, so they do. After all, it's their choice, no-one can force them. By this stage they are adults making their own choices."*

But in those first few months of treatment I had no idea that this kind of approach probably wouldn't get us anywhere. Indeed the weight issue has proved a positive 'spanner in the works', especially recently. Ref the assistant leading Ben to believe he'd "arrived" at an acceptable weight the other week and ref this week when Ben was told that "medically you DO need to weigh more than you do now. Probably not as much as your mum would like you to weigh but somewhere inbetween".

This has been bugging me ever since and has led me to ask exactly how we are benefiting from the professional treatment.

If all it does at the moment is make Ben depressed and undermine my efforts

to gently push Ben towards a proper weight level, is the treatment of any use?

I am tugged in so many directions.

On the one hand I have the treatment team saying this, that and the other.

On the other hand I have all the latest evidence-based research and my fellow eating disorder mums plus leading eating disorder experts saying that the focus must be on weight gain first and foremost with the cognitive side taking second place.

My own experience has shown that Ben flourished once I put my foot down, challenged the treatment team and started to follow my gut instincts on the eating / weight gain front.

The [ATDT forum](#) and [FEAST](#) website have been especially helpful and supportive here. What they don't know about 21st century eating disorder treatment isn't worth knowing! And this approach has worked for so many of their children.

I first put my foot down back in September and we gradually experienced a turning point in the recovery process which started around October and continued.

I put my foot down again earlier this year when I realised that we'd reached a plateau / Limboland. So I formulated our [Recovery Contract](#) which saw Ben gain weight at an acceptable weekly level over a number of weeks.

It can't be a coincidence that his current resistance to weight gain started at exactly the same time as the team challenged my concept of weight restoration and then made that other unhelpful comment last week.

Eating disorders love triangulation between parents and professionals - and, obviously, the eating disorder is going to take the side that implies they can "finally settle" at a weight they are "happy with". In other words, don't listen to mum who's insisting you need to weigh even more.

Translated into eating-disorder-think read: "Don't listen to mum who is trying to make you fat."

Tuesday, 25 July 2017

Eight years on it seems as if nothing has changed...

Last night's [BBC Panorama programme](#) was about men, boys and eating disorders. On the whole it was an excellent programme even though, for some unknown reason, they didn't mention the charity [Men Get Eating Disorders Too](#). All the way through I found myself nodding my head. It all sounded so depressingly familiar: the typical symptoms, the lack of awareness from GPs and other medical professionals, BMIs still dictating access to treatment, long waiting lists while the patient gets even more sick, problems of accessing treatment for the 18+ age group, stock responses from NHS trusts that had failed patients, lack of Government investment, needless deaths... and the 'icing on the cake', Secretary of State for Health Jeremy Hunt declining to appear on the programme to comment...

It seems that very little has changed since my son first fell sick with anorexia eight years ago.

This sad state of affairs... no, this **DISGRACEFUL** state of affairs had me despairing.

Basically it seems as if nobody gives a toss.

Nobody gives a flying you-know-what about eating disorders, not just in men and boys but in girls and women, too.

Nobody gave a flying you-know-what when my son fell sick eight years ago and they still don't today.

Sorry to be blunt, but it's true.

AUGUST 2017

Thursday, 3 August 2017

Are you, the parent, having a spot of bother with PTSD following the eating disorder?

I first mentioned PTSD (Post-Traumatic Stress Disorder) three-and-a-half years ago at the end of 2013 in [this blog post from December 2013](#). And, as you'll know if you've been following my blog, I've been struggling with PTSD ever since. Or, more accurately, C-PTSD (Complex or Chronic PTSD - the result of lengthy exposure to trauma). I also know of other parents of young people with eating disorders that are currently struggling with trauma-like symptoms. As their son or daughter recovers from the eating disorder, they - the parents - find themselves debilitated with this confounded C-PTSD thing.

It's because of this double-edged sword aspect of an eating disorder - the young person's struggle with and eventual recovery from anorexia, bulimia or another eating disorder, coupled with the parent's struggle with and eventual recovery from C-PTSD - that I've been writing about both topics in this blog.

I'm a firm believer in the effectiveness of [Eye Movement Desensitisation and Reprocessing \(EMDR\)](#) therapy as an evidence-based treatment model for C-PTSD (and PTSD). I had 30+ sessions of EMDR recently and it really helped to process all the 'old stuff' that was constantly going around my head like a cement mixer.

EMDR has helped with nightmares, flashbacks and a whole manner of other C-PTSD symptoms. There's still stuff left - primarily a horrible anxiety that sits in the centre of my chest like a fist-sized pulsating, strangulating blob. I still

find it hard to tackle 'big things' - like big work projects and so on.

And processing all those bad memories from the eating disorder years left me with a massive hole in my life. After all, I'd spent eight long years, first battling to get my son diagnosed and referred for eating disorder treatment followed by the equally-as-traumatic struggle to get him recovered.

Following his recovery, the C-PTSD (as insidious as the eating disorder) began to take over my head and filled it, jam-packed-full, with nightmares, flashbacks, memories that felt so very raw and 'present' rather than 'past', and a stultifying fear that my son would relapse back into an eating disorder.

So when the EMDR sessions processed much of the 'old' stuff - the memories, nightmares, etc - it left a *massive* gap. There were still issues that needed fixing, but there was also this growing realisation that I had no idea 'who I was' or 'where I was heading' in a post-eating disorder world.

I am currently working my way through a practical workbook by Michele Rosenthal entitled '*Your life after trauma - powerful practices to reclaim your lost identity*'. I have high hopes that it will help me to figure out who I am and where I go from here as well as helping to fix the remaining C-PTSD issues.

Because I know that there are other parents struggling in a similar way, I plan to (continue to) write about my road to recovery here.

I hope it helps! So watch this space...

Thursday, 3 August 2017

My 'negative trauma story' re-written into a 'positive trauma story'

One of the first exercises in Michele Rosenthal's workbook '*Your life after trauma - powerful practices to reclaim your lost identity*' is to re-write / change your negative trauma story i.e. a short description of your current feelings

about who you are as a result of going through the trauma (in our case the 24/7/365 stress of getting our son or daughter through an eating disorder). I jotted down my own version and it ended up looking something like this:

I've had several years wiped out of my life. I feel no-one takes this as seriously as they should. I can't handle trauma and I'm terrified of my son relapsing back into anorexia. I know I simply wouldn't be able to cope. On top of this, I feel a massive void inside me along with a strong and constant feeling of panic and anxiety.

I no longer know who I am or where I go from here. I don't even recognise myself anymore. I feel like a 'non person'. I feel like a massive failure for 'allowing' myself to get like this and weak because I've been struggling to shed these horrible feelings for three-and-a-half years - including several different courses of therapy from CBT and 'talking therapy' to EMDR.

I 'should' have been able to recover from C-PTSD quickly and successfully. By this stage I 'should' be getting on with life and work, picking up where I left off eight years ago. Instead, I'm still like a frightened rabbit in the headlights. Things still seem 'too big' to take on, I still have panic attacks and I still have a habit of isolating myself which doesn't do me any favours on the friendship front.

With the help of the workbook, I have re-written / changed this 'story' to the following:

I've learned a heck of a lot over the past eight years - more than I've ever learned in my entire life. I've learned to be more empathetic and selfless. I've made TRUE friends, closer than any friends since school.

I stuck with getting my son through anorexia and - yes - I made a success of it. I 'never gave up' [referring to something Ben wrote on a card to me: 'Thank you for being the one who never gave up']. It is partly due to my 24/7/365

perseverance and refusal to give in that he is now fully recovered, just completing a Master's Degree and about to embark on a teacher training course. It is also partly due to my encouragement that Ben now has a large circle of friends and is happy once again. Most important of all, he is getting on with his life. Ben and me, we've been an awesome team! Together we fought the eating disorder and won!! Wow, wow, WOW!!!

Over the past years I have also learned that people like me as a person, I mean REALLY like me and this is a major revelation for someone that didn't like themselves very much or believe they were likeable. I am infinitely likeable and nice. I've learned to be myself and not pretend to be someone I'm not. I am no longer nervous in public; indeed I've spoken THREE TIMES in public!!!! I've even written two books!

I have also learned that if you reach out to the right people in dark times, they will respond in ways I never imagined. I have experienced humanity AT ITS VERY BEST. As with 'wartime spirit' and 'camaraderie', you learn who your true friends are and make new ones - fantastic, true, loyal friends who you would never have encountered in other circumstances. This is REAL LIFE. Good things... VERY good things... can come out of horrendous things.

I have also learned a lot about my ability to respond to and weather trauma. Rather than not coping, I DID cope, right to the bitter end, and it was the most worthwhile thing I have ever done. There are a host of other characteristics that I developed during this period that I will be able to put to massive use in the future.

Rather than not knowing who I am, I know this:

** That I have played a special role in people's lives as their friend and support,*

just as they have been a friend and support to me

** That I'm the kind of person who refuses to give in*

** That I'm the kind of person who fights for what they believe in*

** That I'm a bl@@dy excellent mother*

** That people like me a lot, that I'm a likeable person*

** That people can depend on me and trust me*

** That it's OK to not quite know who I am or where I go from here - it will gradually become evident with some work*

** That it's OK to still feel some C-PTSD symptoms - the 'plastic' brain has undergone big changes over the past eight years so it's not surprising that it may take some time to re-mould it into the person I will be in the (hopefully near) future. But it will re-model itself because science has shown that the brain is 'plastic' and can change.*

I found re-writing my 'trauma story' to be quite liberating. Not an instant 'cure' by any stretch of the imagination, but the first step on the exciting adventure of discovering the post-trauma me.

Of course doing something like this may not work for you, but, hey, let me throw it into the pot - it might just work for someone else out there!

Thursday, 3 August 2017

Do we parents really want to 'pick up where we left off' before the eating disorder struck?

Most probably not. Or at least that's the case with me. My journey through my son's battle with anorexia stripped away all the cr@p and superficial stuff of life to allow me to draw on those 'core' resources that have always been part of me and to use them to get my son through the eating disorder. I threw aside all the clutter and trashy stuff, and what emerged was the real me

because there simply wasn't any room in my life for anything that wasn't part-and-parcel of the core resources I needed to get my son well.

Eight years on since Ben first fell sick with anorexia, I have changed massively. The world has changed, too. During this time we've experienced the recession. We lost our confidence in bankers and other professionals who we thought were rock-solid and dependable. In our family, our incomes took a nose-dive as a result of the recession and the eating disorder pretty much landing on us at the same time.

As a family we also lost our confidence in yet more professionals who we believed to be rock-solid and dependable: the medical professionals. The GPs (for not recognising Ben's emerging symptoms as an eating disorder, for not diagnosing him, for not referring him for treatment, indeed for not informing us that any treatment was available)... Child & Adolescent Mental Health Services for putting Ben on a stupendously long waiting list for treatment after taking ONE MONTH to get back to us after our GP was eventually persuaded to refer Ben for eating disorder treatment. And for my 26-month battle with CAMHS as my gut instinct as a mother screamed out that their treatment model (whatever it was, we never did find out) appeared to be causing more harm than good.

In early 2012 I lost my dad. The family house I'd grown up in was sold as my mum moved into a 'retirement apartment'. I lost that security that had always been there. It wasn't perfect, but our family life (and especially my dad) was always rock solid and dependable.

Then, a couple of months later I lost my new best friend, Sue, to breast cancer.

So who was I before the eating disorder and recession struck?

The pre-eating disorder me was optimistic. My freelancing business was going from strength to strength. My son, Ben, was going from strength to strength at school and in life in general. Everything felt secure and dependable. As a family we felt that we'd got things just as we wanted them to be. All three of us - my husband Paul, Ben and me - were happy and content. And meanwhile the wider family - my mum and dad, and my sister - continued to live life as they'd always done.

And then, gradually over the first eight months or so of 2009, everything changed.

It was to be a complete paradigm shift across virtually every area of our lives.

That established sense of security and dependability evaporated and in its place was an illness that I quickly discovered had the potential to kill my teenage son and destroy us as a family.

Once you've been through something like a serious, deadly eating disorder, or indeed any other prolonged trauma experience, things can never be the same again.

So even if I wanted to 'pick up where I left off' eight years ago, I wouldn't be able to. The world has moved on and so have we.

Actually, you know, I don't think I want to be that pre-eating disorder, pre-C-PTSD person again. I've changed massively. I've discarded all the skin-deep unimportant stuff. For the past eight years I've been focusing almost exclusively on what really matters in life.

So it's going to be a case of pick'n'mix, of working out which parts of me I want to take into a post-eating disorder, post-PTSD life and discarding the rest, just as you would with trash you no longer need or old clothes you'd take to a charity shop.

I like to think of it as a kind of 'adventure', not a 'journey'. An exploration of who I really am rather than desperately trying to work out if I'm anyone at all.

Much like my regular cycle rides, discovering who I am and where I go from here is an exploration - like trying out new lanes and routes, climbing new hills, enjoying new views from the top, taking in the sights, scents and sounds of the British countryside as I cycle from A to B. But also accepting that, along the way, I may find myself cycling along some muddy tracks when the road might have been a better option - or the 'stunning view' from the top turns out to be of five ugly power stations belching out steam (like it was the other Sunday!!)

Rough with the smooth and all that...

Friday, 4 August 2017

Digging around to find the 'raw me' as a foundation for my life from here onwards

When I was 10 or 11, I used to walk back from orchestra rehearsals on a Saturday morning (violin...) via Woolworths in the city centre. Woolworths was famous for its 'pick'n'mix' sweets (candy). I'd pick a bit of this, a bit of that until I had a bag full of my favourites. Beginning to reconstruct a post-trauma life uses a CBT (Cognitive Behavioural Therapy) technique (from Rosenthal's book *Your life after trauma*) that's a bit like pick'n'mix.

This technique helps you to see the wider picture of who you really are, at the core. The 'raw you', if you like. And to home in on the characteristics you want to keep and discard those negative characteristics or thought processes that you don't - those traits that may have come about as part of the trauma, weren't true to the 'real you', are no longer relevant at this point in your life, were just downright destructive, and so on.

I have been homing in on a time when I believe I was the 'real me'. The 'core me'. The 'raw me'. The 'me' before life's changes pummelled me this way and that. This 'raw me' re-emerged during my son's eating disorder as I struggled to get him diagnosed, treated and recovered from anorexia. There was no time for all the nonsense that had built up over the years: shallow stuff, trivia, pretending to be who I wasn't... trash like that. All this stuff was stripped away as the 'raw me' re-emerged to focus on my son's recovery from anorexia.

*Indeed it didn't take long for me to realise that the eating disorder had the power to kill my son. During the summer of 2010, especially, my 24/7 focus was 100% about trying to prevent him from killing himself, either by dangerous accident or intention. At times like these, you find yourself stripped down to the bare essentials: those inner resources that are needed right then, **at that moment in time**. I imagine it's how most people react when faced with extreme threat or danger.*

Looking back over the wider picture, my life looks kind of like a sandwich. There's the 'raw me', aged around 3, 4 or 5 years old, and the older 'raw me' which emerged as a result of my son's eating disorder and my subsequent struggle with C-PTSD. In between is a mountain of squished-in, mashed-up stuff: some good, some bad, but the bulk of it isn't who I am today, as the mother of a 23-year old young man who has recovered from a hellish battle with anorexia.

The younger 'raw me', aged 3, 4 or 5, was confident. She stuck to what she believed to be right and challenged what she believed to be wrong. She was infinitely independent, refusing to go along with the crowd and, instead, preferring to do her own thing. Even at such a young age she challenged the establishment. In her case she simply couldn't understand why, as a girl, she

wasn't permitted to do 'boys things' at school like woodwork. So she set up her own woodwork classes, in the cloakroom, at breaktime (aged around 5 or 6).

Indeed she didn't really understand why she needed to go to school at all. At the age of 3 she walked out of kindergarten school, striding down the road towards home (before being scooped up by a neighbour who took her back!!) At the age of 4 she could already read like someone much older. She worked at a far faster pace than her peers. At the age of 5 she was sent to stand in the corner of the classroom during breaktime - on the very first day of infant school. Her crime? To correct the teacher's mispronunciation of her name. "It's MattOCKs, not MattUCKs, Mrs Macintosh."

That was the start of (mainly) school whittling away at her confidence and independence, and all those other raw characteristics. By her teenage years, this girl had become a very different person. Totally unrecognisable.

Years of suppression and knocking the confidence, self-belief and independence out of her had taken its toll. My teenage diaries are jam-packed-full of angst, loneliness, school phobia and depression followed by rapid weight loss at the age of 18 (sounds familiar??) and other eating-disorder-type behaviours in my twenties.

The girl who could read before the age of 4 left high school, aged 18, armed with just two grade E 'A-levels', two failed 'A-levels' and zero ambition.

And so the messy bit in the middle of the 'sandwich' that was my life back then continued into my twenties and early thirties...

It seems so very obvious to me now, doing these CBT exercises, that the 'me' that emerged over the eight years that we fought my son's eating disorder, followed by my own struggle with C-PTSD, was that 'raw' me again. The pre-school 'me'. All those characteristics that had been hidden away for 40-50

years came back to the surface. All the other stuff was naturally discarded and stripped away as being irrelevant, even a hindrance, to the tasks in hand.

Rosenthal's book takes you through exercises that help you establish who the 'real self' is and to reconnect with it as a foundation for constructing the post-trauma 'you'. You're not building a new identity, as such, it's more of a case of drilling down to who you really are and building on that, which is probably why the subtitle of the book is *Powerful practices to reclaim your identity*.

Reclaim being the key word here.

I've found these exercises immensely helpful, liberating and empowering.

Kind of like building the foundations of finding out who I am and where I go from here, and discarding all the trashy stuff that's no longer relevant to my life.

If it were the Woolworths 'pick'n'mix' that would be anything with coconut or liquorice in it. Yuk.

Friday, 4 August 2017

So what is my son, Ben, up to this summer?

I just thought I'd give you an update on how Ben (now aged 23) is getting on with life now that the eating disorder is well and truly behind him...

In June, Ben finished the teaching element of his Master's Degree and moved out of his shared student house and back into the family home.

Over the summer he's been busy writing up his MA dissertation which needs to be handed in to the university in early September. He's also been doing an intensive learner driver course and seems to be a 'natural' behind the wheel, although - so far - I haven't allowed him to drive my car!!!

In between all of this he's been seeing his friends and, by the sound of it, they seem to be having a whale of a time.

Plus, he's still cooking for us in the evenings. A mountain of amazing meals which bear little relation to the reduced calories/carbs/fat meals he was busy cooking eight years ago in the summer of 2009.

Then, in September, he begins a teacher training course.

Phew! He's a busy guy!

Tuesday, 15 August 2017

Basking in some serious 'me time'

One thing I have learned in the aftermath of my son's eating disorder is to 'allow' time for myself. For so many years I focused on One Thing Exclusively: my son, and his recovery from anorexia. Then, as his recovery from anorexia began to come on leaps and bounds, I blogged like crazy here, wrote books, did talks and other stuff in the world of eating disorders.

Then came the PTSD... And, increasingly with it, a sense of not knowing who I was post-eating disorder or where I was heading in life.

Over the past two or three years I've taken 'time out': a week away here and a week there to get my head together. A week without deadlines, without business clients, without anything to do with the world of eating disorders, without obligations, without timetables, (hopefully) without too much anxiety and, most importantly, without guilt.

Making yourself take 'time out' for yourself and yourself only isn't something you, as a parent in a post-eating disorder life, should feel guilty about.

It is an essential part of the healing process.

Even if it's just a luxury massage or a hair-cut...whatever takes your fancy... 'time out', in my opinion, is vital.

For me my perfect time out is a week hidden away in a country cottage with my bicycle. Like last week, where I spent a week in a pretty little cottage in East Devon, cycling during the day and chilling out in the evening.

No deadlines, no timetables, no having to think about anybody else except me.

And the weather...

Because, unfortunately, for much of the week it was torrential rain.

But I still got out on my bike.

And, actually, I experienced some amazing sights, sounds and smells: the countryside in the rain, little villages with thatched cottages with smoke curling out of the chimneys... Strangely it's the rainy bits I remember most, in a Good Way. That feeling of being completely cut off from the world, there in that hidden valley in the torrential rain. And when I feel completely cut off from the world like this, I feel calmer and more balanced.

Definitely a Good Thing To Do.

Tuesday, 15 August 2017

I still find visits to the GP triggering...

Every time I walk into our GPs' surgery, I get SO VERY ANGRY. Today I had to take my mum in to see a GP and - zap, pow! - my anger took off into the upper stratosphere.

My son, Ben, and I spent so much time in that surgery **not** being diagnosed with an eating disorder.

I, too, spent so much time there desperately trying to speed up his

assessment for eating disorder treatment.

And, during treatment for his anorexia (which, according to his medical notes, was never formally diagnosed as an eating disorder), we found ourselves back there several times.

A notable instance was when his treatment team wanted him to have a full physical medical and the GP simply said "I haven't a clue what I'm supposed to be doing".

Then there was the occasion when Ben went along to renew his prescription for antidepressants. The GP told him that more exercise was the answer to depression. This, when we were working like the clappers to rid Ben of a chronic purging exercise addiction - one of the last things to get fixed on his journey to recovery.

"I wouldn't trust them to diagnose the common cold," I said to my mum this afternoon. "But, okay, I admit that's probably because this place reminds me so much of when we were here with Ben."

But it's true; I don't trust them.

Not an inch.

And the anger I feel every time I visit the place - or, indeed, anywhere else that's NHS-run for reasons described elsewhere in this blog - is HUGE.

Wednesday, 16 August 2017

Being triggered by the receptionist at the GPs' surgery

I think I know what triggered me yesterday. My 90-year old mum had been trying to call the GP all morning but (as usual) the line was constantly engaged. So I drove up there to see if my mum could see a GP ASAP.

There I was, facing the surgery receptionist, trying to get something done.

The best she could do, said the receptionist, was to get a GP to *telephone* my mum (a lot of good that would do when she needed a physical examination!!). Or I could bring my mum in to see a practice nurse (no GPs available, sorry).

Throughout, I just felt that she just didn't care. She didn't care that a 90-year old lady was sick. That we can never get through to the surgery by telephone. That we have to wait at least three weeks to see a GP if we do eventually manage to get through...

It was as if, well, that's the NHS for you, our hands are tied, what can we do? As if we patients are meant to feel, well OK, that's alright then, the NHS is in a mess, there are no doctors available, no-one has any time and if you do see a GP the chances are you could have done a self-diagnosis over the internet.

I got the impression that that's just the way things are these days. Like it or lump it.

That afternoon (mum went for the practice nurse option rather than the telephone call) mum and I were surprised to see the waiting room so very empty. With GP appointments so few and far between, we expected the surgery to be jam-packed with people. But there were just three other patients.

"Maybe they're all busy trying to get through on the phone!" I said to mum cynically.

The receptionist told me that we could have made an appointment online. I said the website says you need a PIN number to access it which we need to get from reception. She said, no, you don't need a PIN.

But I've just checked the website and she is wrong.

No surprises there. It's not the first time I've been misinformed by the person on reception and when I complained, they just closed ranks and denied it had ever happened.

These gatekeepers make me mad because it triggers memories of when I was so desperately trying to speed up Ben's referral for eating disorder treatment and also to get him diagnosed (which never happened). Getting an appointment with the GP was a nightmare and when we eventually did, the GP simply didn't recognise an emerging eating disorder or give me any information about the treatment available.

Ben was just told to go home, eat more and come back in two weeks.

I got 'that look'. The 'fussy, overprotective mum' look...

In the end, we had to twist the GP's arm to get a referral for eating disorder treatment. And, when no confirmation letter arrived from Child & Adolescent Mental Health Services (CAMHS) during the following four weeks and I kept going into the practice to see if they could speed things up, I was met with this brick gatekeeper wall.

Ditto when we eventually did get an acknowledgement of referral for eating disorder treatment and were told the wait could be 18-22 weeks.

The best they could do, when I eventually managed to speak to a GP about the problem, was to give me a list of private mental health services.

No-one was budging. It was a case of 'like it or lump it'. We had to wait. Like everyone else. This is the NHS, you know... There was nothing anyone could do. It was as if I was being a nuisance. 'That look' again...

And yesterday, as I tried to get my elderly mum seen by someone at the surgery, it all came flooding back.

Thursday, 17 August 2017

New diagnostic video from the Kartini Clinic featuring presentation of an 11 yo male with restricting anorexia

Morgan O'Toole, CEO of the excellent US (Portland) based [Kartini Clinic](#), got in touch with me to send me [this link](#) to the first of a series of videos they are making about males with eating disorders. This particular video, presented by Dr Julie O'Toole, Kartini Clinic founder and Chief Medical Officer, is about how to recognise eating disorders in boys. Here's what they say in the description:

This video shows a 12 year old boy who has struggled with classical anorexia nervosa, including fear of fat, self-denial, increased and compulsive exercise, weight loss and intrusive thoughts of worthlessness and shaming. He is also an excellent student, excels at sports and is personally very tidy. He comes from an intact, highly functional and supportive family and there is a family history of OCD and perfectionism. He is able to talk about 'voices' telling him not to eat and what to drink. There are no symptoms of psychosis or delusions except for the delusional belief that he is fat.

Morgan says: "We hope to produce a series of these shortly; we already have raw footage of an adolescent transgender patient (female to male) we think would be very topical."

He's also added me to various mailing lists e.g. their newsletter, etc and added my book [Please eat: A mother's struggle to free her teenage son from anorexia](#) to their reading list.

Let's spread the word and raise awareness of boys and eating disorders - as well as raising awareness of how to recognise eating disorders in boys!

Thursday, 17 August 2017

"Does my son have an eating disorder?" Yes, I was asking myself that same question back in 2009...

"Is my son developing an eating disorder?" "Does my son have an eating disorder?" It's the question that many parents of boys ask themselves as they notice unusual behaviours in their son's eating habits, attitude towards food and, perhaps, an increased focus on exercise.

Many people don't expect their sons to develop an eating disorder. Many people still think that eating disorders like anorexia and bulimia are a 'girl thing'. But the fact is that more and more males are being diagnosed and treated for eating disorders. Yes boys do get eating disorders - and my son was one of them (now thankfully recovered).

A few months ago I did a talk about eating disorders in boys in Edinburgh and the following bullet points are from my presentation - typical signs that a boy may be developing an eating disorder:

- Intense exercise without pleasure
- Dieting / avoiding widening range of foods
- New interest in 'healthy eating'
- Obsession with nutritional labels
- Eliminating fats / carbs from diet
- Increased interest in cooking
- Ritualistic eating
- Belief that 'getting fat'
- Social withdrawal
- Losing weight

Unfortunately our GP failed to recognise my son's symptoms as 'text-book signs' of a male developing an eating disorder. It wasn't helped by my son

sitting there in the surgery denying that anything was wrong. I got 'that look' from the GP - the 'look' that says 'overprotective, fussy mother'...

[You can download a PDF of the slides from my Edinburgh here...](#)

[You can read a transcription of my presentation here...](#)

And [here's a post on the subject](#) *Could my son have an eating disorder / what should I do if I think my son has an eating disorder* which I wrote back in 2011.

Friday, 18 August 2017

"How to Weigh an Eating Disordered Child or Teen" Blog by Dr Julie O'Toole of the Kartini Clinic - why our CAMHS team did none of this

I'm on the US Portland-based Kartini Clinic mailing list. I have a huge admiration for them - they speak such sense. Today they sent me a link to a blog post entitled "[How to Weigh an Eating Disordered Child or Teen](#)" by Dr Julie O'Toole.

When my son, Ben, was being treated by CAMHS (the UK-based Child & Adolescent Mental Health Services) the weekly weighing session was always a huge problem. If Ben had put on weight then the entire therapy session would be spent fire-fighting his severe anxiety and panic. If he'd lost weight, then everything would run smoothly.

From reading various information on the Net and as a member of the [Around The Dinner Table Forum](#) for parents of young people with eating disorders, I had a gut feeling that my son should have been weighed differently. Dr O'Toole's blog post endorses my concerns - here are my comments on what she says:

"When we discharge a patient from Kartini Clinic back to their primary care provider, it is usually with the instructions for weekly blind weights for about a

month, then, if stable, every two weeks, then monthly for about half a year."

None of this happened with Ben despite his weight on discharge being the same as when he began treatment. Also, he was never weighed blind; he was always told his weight which caused big problems.

"Remember that weights are a source of extreme anxiety for children/youth with eating disorders and, to the extent that weight gain/stabilization is seen by families as the only "real" benchmark of progress, pressure on the patient to falsify it in order to please others will be strong. Nonetheless, weight restoration is critical, critical, critical in recovery —even though it's not everything."

With Ben there was no emphasis on weight restoration. Quite the reverse. He was told that he could choose a weight he felt happy with and that some young people choose to remain at a low weight. As I said above, his weight at the end of 26 months of treatment was the same as it was when he began eating disorder treatment.

"Any patient who has web access will be aware of multiple ways to falsify their weight; you need to safeguard them against this overwhelming temptation by weighing them in a predictable, unvarying way (see below)."

No checks were ever carried out and Ben was simply told to remove his shoes and jacket before standing on the scales.

"I would encourage you not to share a patient's weight with them, but rather to carry their anxiety about weight numbers for them (with their parents, of course). Don't make a big state secret out of it, just say something general like, "You're doing a good job, we're pretty stable," or "We're headed in the safe direction."

CAMHS always shared Ben's weight with him and I believe it is one of the reasons why he lost weight under their care (before gaining it again as a result

of our [Contract](#), taking his weight back to where it was when he began treatment).

"Taking a weight is just like taking any other vital sign, which is what it is. Do it professionally, privately and kindly."

Yes, I agree, they did this.

"Always weigh the patient on the same scale. If you have multiple scales in your office, mark one discretely (fingernail polish works, just a dot)."

They did this too.

"Always weigh them in a gown with no underwear and with their back to the scale."

Never, never and never.

"Please do not weigh them in the hall."

Ben was weighed in a private room, so that was good.

"Educate your nurse or medical assistant to say nothing while taking a weight or afterward, and to write it down away from the patient; do not leave the chart in the room."

No, Ben was always made aware of his weight (see above). And the nurse would get out her cardboard BMI wheel to calculate his BMI. "Congratulations, you've just slipped into the healthy BMI range," they would say. Of course the eating disorder interpreted this as: "You've got fat!" and Ben would promptly lose weight again.

"Weigh the patient after a void. Check the specific gravity of the urine in order to assess for any degree of water-loading; if the urine specific gravity is 1.005 or less, ask them to void again before weighing them. If it remains that dilute, abort the weighing and have a talk with them and their parents about over-drinking prior to a weight being taken. Let the parents help them prevent this."

Never and never.

"If you have concerns about your patient wearing weights, ask them not to bring any bags, purses, etc into the exam room while they change into a gown. Once they leave, discreetly check the wastebasket for discarded heavy items."

Never.

Hmn...

Saturday, 19 August 2017

Still angry with CAMHS...

Reading through [the Kartini Clinic blogs](#) I find myself nodding my head at every click. I also find myself seething with anger (yet again) at the outdated way my son was treated for his eating disorder and the constant triangulation between the CAMHS treatment team and me, with my son 'siding' with whoever was more likely to allow his anorexia to flourish which was usually the treatment team.

I wish, wish, wish I'd been more forceful and stood up for what I believed in... what I was quickly learning about eating disorders and the latest evidence-based treatment. But, let's face it, 99% of the time any communication between me and the treatment team was in front of my son which only made the triangulation worse - and the eating disorder loves things like that.

I was allowing them to take sole charge of my most precious possession: my son. Trusting them, in effect, to save his life. And yet, under their care, my son's weight dropped and his distressing behaviour got worse. He also ended up back in hospital with Bradycardia (an abnormally slow pulse). Let's not beat around the bush, if his heart had given up, he'd have been D.E.A.D.

Or if he'd gone ahead with his numerous suicide threats.

Or if I hadn't stopped him from climbing onto the house roof and he'd slipped and fallen three storeys onto hard tarmac.

Or if I hadn't rushed out to sea in those rip tides in the Gironde Estuary as my son swam like a robotic machine, ever further away from the shore, in a bid to burn off calories. If I hadn't been able to get him back to shore, neither of us would have been here today. And that is no exaggeration. Watching the TV documentary about the RNLI last week brought it all back - the sheer power of strong waves and rip tides, pulling people out to sea...

Suddenly I was there again, in that water, feeling goddamn exhausted while trying to talk my son into swimming back to shore with me. Treading water as I did it, bobbing up and down in the choppy water, pleading with him to stop this crazy swimming and return to shore. Even today he doesn't realise how traumatic this experience was for us both; all he was thinking about was swimming off those calories.

And this was the summer of 2010 French holiday where I had to promise CAMHS beforehand that I wouldn't mention eating disorders or food. It was, according to CAMHS, an opportunity to take a break from the eating disorder and enjoy our family holiday.

As if you can 'take a break' from something as serious, distressing and damaging as that...

As if you can help someone to recover from an eating disorder without mentioning food...

The trouble was, there was no alternative to CAMHS. It was a case of CAMHS or nothing. And I really didn't feel as if I had the strength to get my son through his eating disorder alone.

But I often wonder whether I should have fired CAMHS and done what my dear (late) friend Charlotte Bevan did which was to work with a good GP on

getting her daughter well. She'd lost confidence in the NHS treatment model for her daughter's anorexia which was making her daughter worse, rather than better. So she rolled up her sleeves, fired the team and enlisted the help of a great local GP as a support.

However the above rant is yet another example of 'what might have been if...' which, of course, isn't helpful to anyone.

Mulling over the past... water under the bridge and all that... does nothing except make me hopping M.A.D. It also brings back PTSD-like anxiety and panic inside my head.

But, the thing is, I can't stop being angry. And the more I learn about modern eating disorder treatment models, the angrier I get.

Saturday, 19 August 2017

'Old' medicine versus 'new' medicine

Thinking about all that triangulation between me and CAMHS back in 2010-2012, I was wondering why on earth the treatment team wasn't up to speed with the latest developments in the world of eating disorders. And this goes for any treatment team that is still working with older treatment models and especially those eating disorder treatment models that view parents as part of the problem rather than part of the solution.

If it was a cardiac consultant / surgeon, for example, you would expect them to be completely up to date with the latest advances in heart treatment and surgery. Likewise an oncologist, or indeed any medical professional dealing with physical illnesses.

Yes, they are busy people, but that's no excuse for not keeping abreast of what's going on out there, especially if newer treatment models are being

proven to be more effective for many people.

So I've been puzzling about why the same doesn't appear to be the case with some mental health professionals.

The thing with the treatment of eating disorders like anorexia in young people and especially teenagers is that there's been a complete 360-degree shift in the way treatment is approached these days. The world over, and especially in the States, and now in parts of the UK.

As Dr Julie O'Toole says in [this article](#): *Old medicine sets the parents up as passive recipients of the doctor's (or therapist's or dietitian's) wisdom. The new medicine makes us all collaborators in our journey towards optimal health.*

Old medicine preferred to talk the patient out of the eating disorder and to wait until they 'wanted' to recover. New medicine focuses on getting a balanced diet and sufficient calories into the individual, getting the weight back up to where it used to be, if not slightly higher, while giving the brain time to heal and become more rational and hopefully more open to change.

Of course 'new medicine' like FBT (Family Based Treatment) doesn't work for everyone, but it's working for many young people. And enlightened health authorities here in the UK are transforming the way they deal with eating disorders in young people. Even my local NHS mental health services have done a complete turn-around in the way they approach anorexia and other eating disorders in the under 18s.

But I wonder why, during the time that my son was receiving treatment for anorexia, the professionals showed little signs of keeping up to speed with what was going on. Or at least that was the impression I was getting. Instead they appeared to be doing things the way they'd always done them. And, more often than not, what the CAMHS nurse was saying would contradict what the psychiatrist and dietitian were saying, which didn't help matters.

[Do, do, do take time to read this rant/vent by Dr Julie O'Toole about outdated treatment models for eating disorders.](#)

Saturday, 19 August 2017

"I am only a mum" - but, wow, the power of that role in eating disorder treatment!!!

Commenting on fellow mum [Jen's guest post on Charlotte Bevan's CharlottesChuntering blog](#) about some eating disorder professionals viewing parents as 'interfering', Laura Collins (founder of [FEAST](#) and its forum: [Around The Dinner Table](#)) says (in relation to Jen's statement that she's 'only a mum', yet she knows more about eating disorders than some professionals):

"I am only a mum"

You are a mum, no "only" about it. It is the most important thing. Even with broken systems and loopholes -- and EVERYONE has those -- having parents who get it and know what they're dealing with is a greater power than all the authorities.

We are all fighting for those authorities to see that "a mum" or "a dad" are the first, last and most important allies. Let's not stop fighting. We're making progress and need a GREAT DEAL MORE. The parents who have been fighting do so in hope of others joining until no parent has to deal with doubt, deflection, division, or alienation.

The disease is hard enough. Fighting the system, too, should be unnecessary!

Yet I (and doubtless other parents) am very familiar with that 'closed shop' look one can get from medical professionals when (as they possibly interpret it) we appear to be 'telling them how to do their job'.

But the fact is that many parents *do* know a heck of a lot about eating disorders and the latest evidence-based research and treatment. Although we

may not have formal medical or mental health qualifications or training, many of us have crammed up on the ins and outs of eating disorders and treatment over the months and years. Many of us are also educated professionals, albeit in different sectors.

We are intelligent, informed beings. We have brains.

We also have the unique advantage of being the parent of the young person with the eating disorder. We are with them round the clock and have been with them since birth. The professionals only see them for an hour or so a week, and have only known our children for a short time. So who knows the young person and their eating disorder best? We parents, of course.

And we instinctively know when something isn't right, for example when our child begins to exhibit unusual behaviours and attitudes around food, eating, exercise and weight. We recognise mood changes; we know what is normal for our child and what isn't. We know how much they should weigh - we've seen them at their best and we know when they are way too thin. We also have that unique characteristic that an unrelated professional can never have: a parent's instinct.

We are our child's best ally in the fight to get them through an eating disorder. Our unique mixture of expertise, staying power and love plus the fact that we're with our children 24/7/365 should be harnessed, encouraged and supported to make optimum use of all those hours we are with our child.

The outdated 'parentectomy' model of treatment where we, as parents, are asked to 'back off' and leave it to the health professionals to care for our children has NO PLACE WHATSOEVER in 2017.

We parents are also uniquely equipped to be able to talk to medical and mental health professionals about eating disorders from a parent's perspective. Having read volumes of information, talked and worked with

other families and eating disorder professionals, and attended countless eating disorder conferences hosted by the world's leading eating disorder experts, not to mention fighting on the front line of our child's eating disorder 24/7, we know our stuff.

And it's insulting, upsetting and worrying when some medical professionals 'close ranks' or immediately respond with that 'closed shop' look, as if there's nothing that we mere parents can teach them.

The 'holier than thou' approach.

I have been on the receiving end of that 'look' and got that 'closed shop' response from various medical professionals including Ben's treatment team, other mental health professionals and our GPs. It was clear that they didn't welcome the information I was showing them or telling them about. And I very much doubt if they read anything I gave them, for example free copies of my book.

It was as if the shutters had come down.

They are the experts. We are 'mere parents', lay people and amateurs... what do we know?

Monday, 21 August 2017

The approach to eating disorder treatment in UK is changing - Good News!

Of course many CAMHS services here in the UK have changed the way they treat eating disorders in adolescents. My local CAMHS services is one of these. Outdated treatment models for eating disorders are being replaced with the latest evidence-based treatment with other treatment models available for young people for whom the Maudsley-inspired Family Based Treatment turns out to be unsuitable. This is fantastic news and whenever I hear about this I

find myself wanting to shout: "See? I was right?!"

I guess we were amongst the last, in our city, to be treated using older models of eating disorder treatment (although I never did find out which particular model our CAMHS team was practising).

Kind of like the last few buildings and paintings being produced before a huge art renaissance.

I expect that what our treatment team did back then was what they considered to be right at the time. And professionals must be sick to the back teeth of critical parents who appear to be upsetting the apple cart.

I don't doubt that our triangulation was damaging for my son, but what came across was the need for me to keep quiet. What I was advocating for 'wasn't helpful' to my son. Certainly my silence and complete cooperation with the CAMHS team would have avoided conflict and triangulation. We would have presented a unified front which is what should happen when treating eating disorders.

But I simply couldn't sit there and see my son getting thinner, lighter and more 'crazy' in front of my eyes.

Having my gut instinct proved right isn't an arrogant thing. It's not a 'two fingers up at the old school of eating disorders treatment models' kind of thing or even 'two fingers up at CAMHS'. It's more of a 'I wish they'd listened to me and been open to what I was saying and wanting to do' thing. I wish I had been valued as a key member of the treatment team and seen as part of the solution rather than part of the problem.

Those fortnightly 'parenting sessions' where I saw the nurse while my son saw the psychiatrist separately made me feel like a terrible mother.

However the Good News fact is that, here in the UK, treatment models for eating disorders in adolescents are changing.

Slowly but surely.

Which, I truly hope and pray, is Good News for families who are undergoing or are about to start treatment for their son's or daughter's eating disorder.

I often wonder whether our now FBT-trained CAMHS team look back on past years and think, yes, there was some truth in what that annoying parent was saying...

Tuesday, 22 August 2017

Son or daughter about to leave for university or college? Worried about how they will cope? Links to my blog posts about my son's experience at university

I've put together some links to past blog posts which describe how my son got on at university. In a nutshell, my son went away to Sheffield University in 2012. He lasted 2 or 3 days before he was back home for an impromptu 'gap year'. One year later he made a second attempt which, despite a rocky first year, was a success. He is just completing his Master's Degree from the same university. So if your child is going away to university this September and you're a bit worried - or it doesn't work out - check out the links below to see what worked (and what didn't!) for us. Ultimately our story is a Very Positive One even though it starts off a bit negatively...

September 2012 (these link to my actual blog):

[Preparing for university](#)

[After dropping him off](#)

[Ben returns home and takes an impromptu 'gap year'](#)

[We start to plan the 'gap year' to make it as productive as possible](#)

[Writing about what I learned in the process](#)

[What would I have done with hindsight?](#)

[Student Services help us formulate A Plan](#)

[Helping Ben to become more independent](#)

[Ben starts to do useful stuff during his gap year](#)

Spring 2013

[The university, Ben and me start to plan for success, second time around\]](#)

[Ben and I meet up with the various student services to formulate A Plan](#)

[The university nurse puts a \(thankfully temporary\) spanner in the works](#)

[More thoughts on the university nurse's comment](#)

[Putting it all into perspective](#)

[More thoughts as we plan for university](#)

Summer 2013

[Beginning to prepare for university](#)

September - December 2013

[Keeping an open mind on the eve of departure](#)

[Ben leaves for university again](#)

[Echoes of last year...](#)

[Sorting stuff out during those early days...](#)

[OMG, just days into university Ben falls prey to a phishing email -](#)

EMERGENCY

[Rollercoasting through that first week](#)

[Supporting Ben with hopefully helpful advice](#)

[Ben survives the first week](#)

[Helping him to cope with a tricky second week](#)

[... which wasn't actually that bad, really... some positives!](#)

[Two weeks on - an update on university life](#)

[More news on how he was coping](#)

[... and how I was helping him to cope using Motivational Interviewing techniques](#)

[OMG, things go pearshaped...](#)

[The legacy of the eating disorder - problems socialising and getting to know people](#)

[How I attempted to detach myself from being too emotionally involved as it was all doing my head in!](#)

[Proud of him, but it's doom and gloom at uni...](#)

[Going back to Sheffield after a weekend at home... doom and gloom...](#)

[The road gets rocky](#)

[Hopefully mama's Tough Love approach is working](#)

[More rocky road stuff...](#)

[How was the university support package coming along?](#)

I didn't write any more about university in 2014, not even Ben starting his second year. The reason was that I was beginning to come down with PTSD and felt pretty rubbish. But, to summarise...

Ben moved into a university-owned house for the second year. He didn't know anyone in the house and it was a bit of a dump. But he was very positive when I dropped him off for the start of the university term. We had our ups and downs, but on the whole it was a positive year. Ben met and made new friends within the 'nerdy' circle and was even voted onto the committee of the nerdy Role Playing Games (RPG) society. He and his new friends found a house to share for the following year and in September 2015, Ben left home for his final degree year at Sheffield. During this time I wrote a few blog posts about our experiences to help other families who might find themselves in a similar situation.

[Thrilled to see these young people heading for university!](#)

[When university didn't work out, the first time round](#)

[Worried I may appear too negative!](#)

2016

[One good thing that came out of Ben's eating disorder which was helping him in his studies](#)

[Overflowing with pride as Ben graduates with a first-class honours degree and makes plans to return to Sheffield to do a Master's degree in September](#)

[An update on how he was getting on back at university in 2016](#)

Which almost brings us up to date. Ben finished his Master's Degree in June but has been spending the summer writing up his dissertation. Leaving Sheffield for the final time was sad for both of us but he decided that this September he is going to study at a local university for a PGCE. He did wonder about returning to Sheffield, but his decision was purely based on which course felt right.

He is still in touch with his friends from Sheffield and will no doubt meet up with them in the future. Meanwhile his circle of friends at home is stronger than it's ever been.

So, all in all, a Fantastic Outcome!!!

Wednesday, 23 August 2017

I really, really want to write a sequel to my book 'Please eat...' but I just can't...

It's been on my 'to do' list for some time now. After all, it's been four years since I published the story of my son's struggle with and recovery from anorexia: [Please eat...](#) But every time I decide that, yes, this is the day I'll start work on the sequel, I open up the folder I've created on my PC, have a quick read of the final chapter and epilogue (written in 2014) of *Please eat...* and

quickly close it again.

I just can't do it. It seems 'too big'. When I think of the work I put into *Please eat*, I just go into panic mode at the thought of doing it all again. Even though, of course, the sequel will be largely positive stuff except, probably, my own emerging issues with Complex Post-Traumatic Stress Disorder (C-PTSD). This is probably why I can't face it yet. Writing my blog is far simpler and 'do-able', as is responding to parents' issues on the [Around The Dinner Table Forum](#) (for parents of young people with eating disorders).

It's so very frustrating. On the one hand, getting my life back together after my son's eating disorder, and following massive inroads into the C-PTSD issues, things should be more positive than they've been since 2008. But on the other hand, I'm still struggling with things, despite the enormous amount of help I've had, both from NHS and private therapists.

I really thought that my private therapist, Steve, had 'fixed it' once and for all. That all I had to do now was to work out where I go from here, just get out there and embrace life in a post eating disorder, post PTSD world. But I'm becoming increasingly aware that there are still issues that need fixing, because if everything was OK then I'd be able to get on with life and do stuff, wouldn't I?

I have been naughty, though. I haven't looked at any of the self-help books since before I went away cycling a couple of weeks ago. So I really should make an effort to continue working through these to see if they make any difference.

And of course I *have* made inroads. Not very long ago I wouldn't have been able to face writing this blog. There are large gaps in my blog archive where it just seemed 'too big'. Ditto helping parents on the Around The Dinner Table Forum.

It's just that, as regards the immediate future, I feel this massive block. As if I

know that a fantastic life is out there, easily within reach, with so many things on my 'to do' list including writing that book sequel and doing a ton of business development stuff because no way am I ready to retire just yet. But I just can't move on. It's as if I've suddenly ended up in a grimpen mire muddy bog during a country walk: I can see where I need to be, but I just can't get there.

I'm stuck.

And there's still a heck of a lot of anxiety and panic. Old stuff, of course, because there isn't anything to be anxious about. Also flashbacks. I can't abide it when there are sudden noises in the house such as a shout, cheering a football goal on the TV or my husband striding noisily around the house as he gets on with the decorating. Noises like these take me back there...

But surely after umpteen therapy treatment models and sessions I should be OK now. What is it about me that is so very tricky to fix when, according to what I'm reading in the experts' PTSD books, some people have just take a handful of - say - [EMDR](#) (Eye movement desensitisation and reprocessing) sessions and - hey presto- the cloud lifts and they're OK?

Wednesday, 23 August 2017

My son's MA dissertation is almost complete!

Over the past few years I have been astonished and impressed at how my son, Ben, has knuckled down to studying and organising his time like a true pro. For someone for whom anxiety was a massive issue during his eating disorder, Ben sailed through three years of undergraduate degree, course work, dissertation and exams followed by 12 months of a master's degree, course work and now a dissertation that he's been working on flat-out and diligently over the summer break to be handed in (hopefully!!) next Friday.

Ben's time management has been awesome as has his dedication and staying power. There have been glitches, of course, notably the lengthy period when he was adjusting to life at university back in 2013/14.

But on the whole he's got on with things. He's got on with all the reading, studying, lectures, seminars, essays, revision, etc with (from my perspective as a parent looking on) minimal anxiety.

He's just knuckled down and done it.

That was also his approach to recovering from the eating disorder - to kicking out those remaining remnants while at the same time adjusting to university life away from home.

The same goes for his staying power in rebuilding his social life and circle of friends. You may remember that getting his social life back on track was one of the trickiest issues that he faced as he recovered from anorexia.

Even during that first year at university he was convinced that he'd never meet people who were like him, with the same interests (nerdy gaming stuff). He was a very lonely young man.

But he did meet people like him. Lots of them. He got out there and joined university societies and met a fantastic group of new friends. In fact he became so popular within the university RPG (role playing games) society that he was voted onto the committee two years in a row (or was it three years?) The student houses where he lived with his university friends were jam packed with nerdy things: sc-fi stuff, fantasy board games, Warhammer models, etc etc. Yes, if you could have seen the pile of board games in their living room... it was massive. They'd all get together for a couple of evenings every week and have a fun gaming session, whether RPG or board games.

Back home, he established a similar group of friends. In fact sometimes his university friends meet up with his home friends and vice versa. All of this with

Ben as a kind of hub at the centre, coordinating and organising, just as it used to be with his circle of friends at school, before the eating disorder robbed him of his friends and social life.

So, as my son plans to get his MA dissertation bound and handed in, I am feeling like one Very Proud Mama.

But the thing that has stood out the most is Ben's sheer staying power and dedication - to making a success of everything: recovery from anorexia, university and friends.

Ben is the person who's done it all - who's made a success of everything and who's said a big emphatic N-O!! to the eating disorder and all the nasty stuff that came with it.

Friday, 25 August 2017

UK waiting times for eating disorder treatment are getting worse, not better, according to The Times

"In Coventry and Warwickshire, which had the longest waiting times, patients waited on average for 14 weeks last year to see a specialist... despite extra money from the government to cut waiting times", says [this article](#) in today's Times newspaper. The Times also discovered that "Some trusts were still using BMI readings to decide whether to accept a patient for specialist treatment, despite Nice saying that they should not after criticism that this risks turning people away because they are not thin enough".

We know only too well about the panic of having to wait weeks and weeks for eating disorder treatment. You may remember that, following the eventual referral from our GP, we waiting a month before the acknowledgement letter came through from CAMHS only to be told that we'd have to wait a further 18-22 weeks before my son was seen for an assessment, let alone the actual

treatment.

It is a tragedy that, eight years on, young people are still having to wait so long before getting treatment for an eating disorder. The report gives an example of a young woman who had to wait "five months for an appointment and a total of eight months until anorexia was diagnosed".

Like us, her desperate parents ended up taking her to a private clinic.

"She said: 'The illness can take hold quickly and by the time my mum had gone to the GP it had taken hold. When I had to wait months, it carried on getting ingrained. If I had been seen straight away I don't think the recovery time would have been as long.'"

Same here.

And, as you will know if you've been following my blog, I'm a great believer that using the ancient BMI model as an indicator of the seriousness of the eating disorder is **WRONG, WRONG, WRONG.**

Especially in boys who, if sporty, might have had a higher BMI to begin with. (Don't even get me started on the subject of BMIs again...)

It's shocking that in eight long years little appears to have changed when it comes to treating young people with eating disorders.

SEPTEMBER 2017

Sunday, 3 September 2017

Eating disorder recovery? Is your child 'stuck'? Do they need something to nudge them forward? This solution worked for us, so it might just work for you...

Recently a mother emailed to ask if I had any tips for what to do when your child is 'stuck'. Your child has got 'so far' in their eating disorder recovery but -

for some reason - have found themselves 'treading water', unable to move forward. Here's an edited version of my reply, in case your son or daughter is 'stuck' and needs encouragement to continue to move in the right direction towards eating disorder recovery.

My son got well and truly stuck in the spring of 2011. By this stage he was desperate to recover from anorexia, and he'd done really well since he began working towards recovery back in October 2010. But he'd reached a stage where the eating disorder was just too strong for him.

He'd reached a frustrating plateau, a 'no-man's land' where he was stuck.

Nobody had any suggestions or ideas. Not me, not CAMHS (his eating disorder treatment team), not anyone - and Ben was getting to the 'let's throw stuff around the therapy room' stage, he was so frustrated. I remember the occasion he hurled the coffee table at the psychiatrist before walking out of the room.

Then, around Easter 2011, just by chance whilst on the [Around The Dinner Table forum](#) (for parents of young people with eating disorders), I came across a post from another mum who'd tried out something called a Recovery Contract with her daughter based on something they do at the renowned [University California, San Diego, Eating Disorders Centre](#).

All of us, including Ben, were eager for Ben to start moving forward again - and I got a gut instinct that this might just work for him.

Ben agreed, which was really great because there was no resistance. By this stage he really, really wanted something to help him move forward and so, together, we were able to devise our own version of this Contract and you can find a load of stuff about it on my blog. There is also [a dedicated page](#) along with various posts around Easter 2011 (pasted in this PDF below...)

If your child is stuck, I wonder whether something like this might work for you, if introduced carefully and gradually? Another reason why my son bought into the idea of the Recovery Contract was because I positioned it as the two of us working together as a team rather than me 'laying down the law'. Also, importantly, by this stage in his eating disorder recovery, I could trust him to be telling the truth (which wasn't always the case earlier on in his eating disorder).

We also made a rule that no-one was allowed to yell, walk out or other nasty stuff during our 'points sessions', as we called them, which was when we'd talk about challenges he'd managed to overcome since we last 'did points'; anything he was having problems with and any new challenges he felt able to take on. If he wasn't successful, then no matter, we could revisit that particular challenge when he felt better able to take it on.

It was a very gradual process but essentially enormously positive. It wasn't a bribe, more a crutch to help him move forward after being stuck for so long. Yes, with us the points added up to cash (because he was desperate to have a new Xbox) but other people offer rewards like evenings out, sleepovers with friends and so on.

My son says that initially the eating disorder Recovery Contract was all about the cash, but gradually, as we began to see results, it became less about the rewards and more about the recovery. Since he recovered from his eating disorder he has always said that our Contract was the #1 thing that helped him to recover and I completely agree.

If you're at a loss for ideas on how to reignite your child's recovery, then a similar Contract might just work for you? Please feel free to contact me if you'd like to ask any questions about how we went about it, although you can find a

lot about it on my spring 2011 blog posts (which can be download in PDF form [here](#)).

You can also find more about our Contract if you read down here...

Recovery Contract



Page updated 19.4.12

People often ask me about our Recovery Contract - a concept that my son, Ben, says was the #1 thing that helped him to recover. I discovered all about Contracting via a link from a parent on the [ATDT forum](#) back in 2011. After chatting it over with Ben, we decided to give it a go, so we put together our own personalised Contract. By this time Ben had reached stagnation in his eating disorder treatment and was desperate for something to help him kick start his recovery and help him to take control of his exercise addiction. The Contract worked brilliantly across all problem areas, almost from Day One.

On 20th March 2011, I bought a lined exercise book and every day we sat down 'on neutral territory' and discussed what Ben had eaten (in brief), how many calories he'd had, what challenges he'd overcome and whether he'd managed to keep to his agreed exercise list.



It was also a good time to share any thoughts or any difficulties, or for either of us to ask any questions, without biting each other's heads off. The key is to keep calm and for this 'meeting' to be equal, in 'No Man's Land' (but of course ED is banned!)



As the parent / carer, you have overall control. The idea is for this to appear as a joint effort in which they can participate and have views / opinions. It's also a fantastic opportunity to really talk about what's going on.



“Let’s do points”, I’d say, when we had a quiet 5 or 10 minutes in a day – or even every other day.

The Contract has been a very positive thing, full of encouragement and low on penalties. We compiled the contract together (although, in reality, I engineered it to go the way I wanted...)

Slowly but surely...



Any part of the contract can be adjusted at any time depending on progress, but it needs to be mutually agreed (i.e. not appear to be mum inflicting her will on child).



The first part of the contract (#1 - #3) sets out the parameters. #4 lists the rewards / points.

#1: Eating

- Here I note down the agreed daily calorie amount. (Not everyone deals in calories, so it needs to be something where you both agree how much will be eaten in any one day.)
- I also note any agreed adjustments if, on weighing weekly or fortnightly, he's lost, maintained or put on weight. (Usually we'd agree to increase by 100 a day if he'd lost weight and 100 every other day if he'd maintained – until we got back on track to a gradual weight increase or reached an agreed Weight Restored.)

#2: Weight Gain

- How much weight you expect him to gain each week or fortnight (in our case although we aimed at 0.5kg a week it actually worked out at nearer 0.26kg per week)

- When he will be weighed and where (e.g. every Friday morning at CAMHS)

#3: Agreed Exercise – to be reviewed as necessary

- Out of control compulsive exercise used to be a big problem with Ben. He didn't know where to stop and was doing a ridiculous amount. So we wrote down a list of 'agreed exercise' over and above which he was not allowed to do.
- He wasn't allowed to carry forward 'un-used' exercise to another day.
- *Penalties for going over the agreed weekly list.*

#4: Rewards – Points system

"Points win prizes!" was Ben's mantra. 3 points = £1 and we'd keep a running total based on the points system below. Occasionally he'd withdraw 'points money' to spend on stuff (like his models or whatever).

This is what attracted Ben most to the idea of the Contract – a great way to save up for stuff! Also, at a time when he was feeling unable to control things like eating and exercise, or go into school, points gave him the encouragement and boundaries he needed.

Yes it was a bit expensive at first, but it was worth it! As things improved, some challenges were removed because they were no longer challenges. These days all he gets points for are new challenges only (not calories, exercise or anything

because that's been under control for a while). But again all this was mutually agreed.

We also wrote down the number of points that can be deducted for dishonesty and how many get deducted for what. (Note: we rarely had to deduct points.)

Food:

- 1 point per day Ben keeps to current calorie total
- 2 points for every day Ben exceeds current calorie total by a min of 200
- *Points deducted for cheating, etc*

Challenges:

Challenges are a fantastic way to get them to face their fears e.g. fear foods, etc – and give them a go.

1 point for each challenge. These might be: fear foods, socializing, a challenging meal, eating between meals, 'condense calories' (as Ben calls it), eating out successfully, 'sitting around doing nothing' (as Ben calls it) followed by a big meal, etc etc.

It's not just a case of asking them to list the challenges but to talk about why they were a challenge, how he felt about overcoming them and how brilliant it is that he overcame them.

And of course, new challenges gradually become old challenges, then phased

out altogether.

As Ben discovered that doing challenges didn't mean massive weight gain, indeed sometimes he didn't put on any weight after a challenging week, the challenges stopped being something he was afraid of.

School:

- 3 points for every full day
- 2 points for every full morning
- 1 point for every part morning or full afternoon

Exercise:

- 1 point per day Ben keeps to exercise part of contract
- 3 points for any non-exercise day
- 3 points deducted for dishonesty
- *2 points deducted when DON'T have 200 calories on extra exercise days*

Weight gain (serious points here!!!!):

- 20 points for every fortnightly weigh-in session Ben incs by 1kg
- 18 points for every fortnightly weigh-in session Ben incs by 0.9kg
- 17 points for every fortnightly weigh-in session Ben incs by 0.8kg
- 16 points for every fortnightly weigh-in session Ben incs by 0.7kg
- Less than 0.7kg = zero points
- *Don't deduct points for losing weight – keep this a positive contract*

The above contract to be adjusted accordingly subject to regular parental monitoring of progress.

Signed _____ (Ben)

Signed _____ (Mum)

Date: _____

Monday, 4 September 2017

Controlling an exercise addiction as part of an eating disorder

Eating disorders in boys (and girls) aren't just about cutting back on food; there can also be a host of other issues - and one of the big issues that many families face is an addiction to exercise which can be punishingly difficult to fix.

With my son, Ben, exercise acted as a kind of purge - not unlike Bulimia with its vomiting / laxative purging. He felt the need to micro-manage input and output: whatever went in (food and drink) had to come out in the form of exercise. Often entire days (and nights) could be centred upon input, output, without any room inside his head for anything else.

I'm a regular contributor on the [Around The Dinner Table forum](#) (for parents of young people with eating disorders). If our experiences about recovering from an eating disorder can help other families who are facing similar challenges, then that's a Good Thing. And one of the regular issues facing families is this addiction to exercise.

Here's an edited version of some replies I made this weekend on a post created by a parent who was struggling to break their daughter's addiction to exercise (***IMPORTANT: Please note that exercising with an eating disorder can be potentially dangerous so be sure to check with your child's physician first***):

As part of his eating disorder, my son was addicted to exercise - you wouldn't believe how much he used to pack into every day! Or maybe you would... He would even ask to be excused from school lessons to 'go to the bathroom' only to run round the block instead. He even did sit-ups in his art GCSE exam when the invigilator wasn't looking. Addiction to exercise as part of an eating disorder was a massive problem for us and he admitted that he took any opportunity to exercise, even punching the air if standing still. He also admitted that he HATED exercising, but the eating disorder wouldn't let him stop.

The exercise addiction wasn't easy to fix; indeed it took longer than most of the eating disorder issues to fix but we finally did it by officially agreeing that he could only exercise within certain parameters and once he'd done that he wasn't permitted to do any more. This made it easier for him to control the exercising rather than the exercising controlling him. In an ideal world I'd have liked him to stop exercising altogether (because of the dangers as well as the fact that it burned off vital calories), but I could see that, with him, it simply wasn't going to happen and so the agreement (which was part of our 'famous' eating disorder [Recovery Contract](#)) helped to contain it. And it worked very well.

[This post from my blog](#) describes the extent of his eating disordered exercising:

And [this page](#) describes how we incorporated exercising into our eating disorder Recovery Contract.

As I said above, in an ideal world we would have stopped all exercise, but (for various reasons including the fact that our treatment team were advocating for limited exercise) I could see that wasn't going to happen. **HOWEVER it is so important that you keep an eye on your son or daughter because I am sure that there are some situations with an eating disorder where even a small amount of exercise could be dangerous.**

With us it was also very important that my son was telling the whole truth and nothing but the truth as regards to how much exercise he was doing. Thankfully we'd arrived at a stage where I could trust him and, to be honest, he was so relieved to have something that would allow him to control his out-of-control exercising. It was also important that we could discuss any problems he was having with keeping within the parameters. But I honestly believe that he stuck to it which is brilliant.

As time went on he naturally began to exercise less. These days, now aged 23 and recovered from the eating disorder, he'll just do a handful of situps every day which I think is pretty normal for a young man. He no longer feels that dreadful urge to exercise or get upset because he's 'been sitting around doing nothing' all afternoon / day / hour, etc. So the exercise problem became increasingly easy to deal with as he recovered from the eating disorder.

I hope this encourages other parents - but do keep a close eye on your child's health if they have an eating disorder and are still exercising, won't you? I would strongly suggest checking with your GP / paediatrician / physician that, in their opinion, it's safe for your child to exercise. Exercising can be dangerous.

[Here's what the Kartini Clinic says about exercise and anorexia.](#)

Monday, 4 September 2017

An extract from my book about my son's addiction to exercise

While I'm on the subject of [controlling an exercise addiction as part of an eating disorder](#), here's an extract from my book [Please eat...: A mother's struggle to free her teenage son from anorexia](#) which describes the extent of my son's addiction to exercise (during his struggle with an eating disorder).

COMPULSIVE EXERCISING IS still top of our 'to do' list. I'm well aware that it's bad, but I have no idea how extreme until one CAMHS session with Linda in early spring.

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 [the CAMHS treatment team nurse] 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.

'What if we draw up some parameters?' she suggests to Ben. 'We allow you to do a limited amount of exercise every day and you agree not to exceed this.' It seems such a simple solution to a seemingly unsolvable problem. Between us we devise a structured regime of exercise over and above which Ben isn't permitted to go.

'Then, over the next few weeks, we'll monitor the effect it's having on your weight to prove that less exercise doesn't mean you'll get fat,' Linda adds.

Ben agrees to the trial.

The following week Ben and I walk around a local lake. Watching the wildfowl silhouetted against the setting sun, we talk about exercising and how he's making a real effort to cut back. Now he has the structured 'exercise plan', as he calls it, he's finding it much easier to manage. Instead of spiralling out of control he now has parameters and - incredibly - from Day One, he sticks to it. And the more he sticks to it, the easier it gets. And the easier it gets, the less exercise he feels compelled to do. I feel like shaking Linda by the hand.

On our walks Ben and I talk about easing him back into school. What are the biggest challenges? How might he overcome these? We talk about socialising and the importance of the friendships he's developing with his most supportive friends. We also talk about eating. What's been difficult? What's been easy? What challenges has he set himself? Have they been successful? We also look at the difference between Ben's eating several months ago and his eating now.

And the way his pulse rate is now relatively normal. Most importantly we talk about why a life without anorexia feels so attainable whereas only a few months ago it seemed impossible. Best of all Ben admits that he's finally enjoying our walks for walking's sake; not as a means of burning off calories.

[We incorporated this exercise plan into our eating disorder Recovery Contract. You can read more about our Contract here...](#)

Please note that exercising with an eating disorder can be potentially dangerous so be sure to check with your child's physician first.

Monday, 4 September 2017

I've just been reminded of this wonderful poem my son wrote following his recovery from the eating disorder

On the [Around The Dinner Table forum](#) (for parents of young people with eating disorders), some of us have been thinking about the way the eating disorder is like a separate entity to our sons or daughters. In our house we used to refer to the eating disorder as 'the anorexia demon', 'the demon ED [eating disorder]' or 'the ED voice'. It reminded me of this poem which my son wrote following his recovery from anorexia; the poem is aimed at 'the ED voice'...

Never Again

*Four years of torture, four years of pain,
Four years of worry, envy and shame.
You promised us love, you promised us life,
You promised us glory, not discomfort or strife.
We worked through the day, we worked till we cried,
We worked till I realised that you had lied.
Our life became hidden, shrouded in fears,*

*Our life was unworthy, hollowed by tears.
You took our passion, took pleasure with pride,
You took away our love and forced us to hide.
Fearing our friends, fearing our fate,
Fearing ourselves with anger and hate.
You watched us grow cold, you watched us grow thin,
You watched us in misery with that cold-hearted grin.
Yet now rid of you, rid of your pain,
I have one thing to say to you and that is; never again.*

Monday, 4 September 2017

To exercise or not to exercise? The dangers are real...

Having posted two posts about the problems we had with compulsive exercising when my son was suffering from anorexia - and having read through [Dr Julie O'Toole's excellent article about the dangers of exercising with anorexia](#) - I must add that, yes, there is a real danger that exercising can kill. There is no easy way to say this: eating disorders do kill and one of the biggest killers is heart failure. And we should know... My son ended up in hospital not once but twice with Bradycardia (abnormally slow pulse). So, knowing the potential dangers, why did we allow him to continue to exercise?

Really and truly I wanted my son to stop exercising altogether. Full stop. And, to be honest, I grimaced when our CAMHS nurse suggested that my son limit his exercise as a way of getting it under control.

Now, I don't know whether this was good advice or bad advice. I am no cardiologist. But I do know that, for months if not years, I worried myself sick that my son's heart would give up.

And this wasn't just me being over-anxious.

For us it was a case of 'being stuck between a rock and a hard place'. In our

situation, I believe the only way we could have prevented my son from exercising would have been to mount a 24/7 watch on him, including those times when he'd go to the bathroom / toilet and all night... at school... everywhere...

His compulsion to exercise was so very strong that we would have had to chain him down.

And I believe this was why the CAMHS nurse suggested that we allow limited exercise as a means of getting it under control.

It was a risky decision, one that could have had disastrous results. But thankfully with us it worked and it helped my son to recover from the exercise addiction that was such a powerful element of his anorexia.

So, as I emphasised on the other posts, ***PLEASE NOTE that exercising with an eating disorder can be potentially dangerous so be sure to check with your child's physician first.***

As [Dr O'Toole says](#): "If you have had the wrenching experience of standing next to parents who have lost their child to anorexia nervosa, you will be humbled ... and terrified."

And yes *I have* stood next to parents who have lost their sons and daughters to anorexia.

And yes *I was* humbled... and terrified.

There is no nice way to put it: eating disorders can and do kill.

But thankfully recovery is possible and my son is an example of this.

Please approach anything like exercising with extreme caution where an eating disorder is involved.

Monday, 4 September 2017

An update for you all - and the fantastic sweater!

Well, one thing my son Ben ISN'T up to at the moment is starting the post-graduate teacher training course (PGCE) which he was to have begun this week. Basically, he's spend the entire summer working on his Master's Degree dissertation which has to be submitted on Wednesday. He's put a heck of a lot of work into this and, to be honest, the poor guy needs a bit of a breather. Also, because of the dissertation, he's not been able to prepare for the PGCE in any way. So it made sense to postpone it.

He asked the university admissions people if he could 'defer' the course for 12 months, but it appears that he can only *withdraw* and re-apply, should he still wish to, next year.

Making this decision has taken a huge weight off his shoulders and removed a lot of anxiety.

(NOT eating disorder related anxiety, I hasten to add; that has long disappeared.)

And having some breathing time isn't a bad thing. It worked with his last-minute 'gap year' between school and university in 2012. He managed to fill that year with lots of useful stuff.

Meanwhile he is exploring a number of different options as a career along with possibly working as an unpaid intern in a company in order to get some experience which he can include on his CV.

Other options include taking a stop-gap job such as bar or shop work while he sorts out what he wants to do.

He is also learning to drive and has booked his driving test for next month. Yesterday he drove me to a designer outlet 25 miles away (and back) to buy some new clothes "to replace those I've grown out of".

Words like that are music to the ears of the parent of a young person who's

come through anorexia.

Back in the 'bad old days' of the eating disorder, having to buy bigger clothes sizes would have said one and one thing only: "I am fat!!!"

Now it just says: "I need new clothes because, at 23 going on 24, I'm a growing man."

And here's another thing...

The exclamation "I'm knackered! I've just spent 11 hours sitting at my computer!!!" [writing the dissertation] means exactly that in a post-eating disorder world.

In the 'bad old days' he would have been full of remorse and angst for spending "11 hours sitting around doing nothing" i.e. not burning calories.

So it's all good stuff here in the Matty household.

In the meantime, Ben is busy cooking our evening meal, singing at the top of his voice.

And, as I have said elsewhere in this blog, when Ben is singing, all is right with the world.

Wednesday, 6 September 2017

Are you a parent or carer? Are you new to the world of eating disorders?

Whether it happens suddenly or gradually, realising that your son or daughter has an eating disorder like anorexia or bulimia is devastating. At a time when you're desperately seeking help for your child and wondering how you can help as a parent, you're also faced with a massive learning curve - because, unless you've experienced an eating disorder before, the world of

eating disorders is probably about as far off your radar as you can get. Just like it was for us.

Back in the Autumn of 2009, when it became evident that my 15-year old son was spiralling into anorexia, I remember cramming up like mad on everything I could find to do with eating disorders. I needed to understand what my son - and we, as a family - were facing. I needed to know how to stop him sinking even further into the illness. I needed to know what treatment was available. Most important of all, I needed to know how to get him well.

The more I discovered about eating disorders the more I understood the URGENCY of finding good, evidence-based treatment for my son.

I remember thinking that I'd never 'studied' so intensively and so urgently at any other period in my life. Not even in the final year at university.

But, then, I'd never been faced with a situation where the person I loved most in the world could actually die.

I'd never been so terrified in my entire life.

At a time like this, the last thing we parents have energy for is cramming up on eating disorders; we want to be able to focus 100% of our energy on our child and their recovery.

This is one of the reasons why I started my blog, because I wanted to help other parents to 'fast track' their way through the huge learning curve so they can get on with the business of getting their sons or daughters back to full health.

Another reason for this blog is to point parents to resources that I found invaluable - and also other parents who can offer support and advice.

It was pure chance that, in March 2010, I discovered the online forum for parents of young people with eating disorders: [Around The Dinner Table](#) plus its 'parent' website: [FEAST](#).

As I've said over and over again on this blog: the [ATDT forum](#) was a lifesaver for me.

Not only did I find other parents facing the same or a similar situation, I found parents who'd 'been there, got through it'. Reading other families' success stories gave me hope at what seemed like a hopeless and helpless time.

The [ATDT forum](#) is different from any other forum anywhere, in my opinion, in that these are real people, parents just like us, not just 'faceless' nicknames.

One of its most active UK members, the wonderful [Charlotte Bevan](#) (who tragically passed away from cancer a couple of years back), took things a stage further. She'd introduce parents to each other via Facebook and also put UK parents in touch with each other via phone or email. I met a lot of amazingly supportive parents this way, people who I still meet up with and keep in touch with today.

So if you're new to the world of eating disorders, the very best advice I can give you first is to join the [Around The Dinner Table Forum](#) and introduce yourself as a newcomer. You'll find that other parents will rally round to help, just as they did with me and countless other parents across the globe.

The forum's 'parent' website [FEAST](#) is also a mine of information on the latest thinking and treatment of eating disorders.

In addition, I've cut and pasted all my blog posts since 2011 into a set of PDFs [which you can download here](#). Hopefully scrolling through the PDFs from 2011 onwards, visiting [FEAST](#) and introducing yourself on the [ATDT forum](#) will go some way to fast-tracking you through the learning curve so you won't have to do all the research yourself.

It will also put you amongst a caring community of other parents who will rally round to do their best to help and advise.

(PS: Here's a link to [my Facebook page](#) and another link to the [Around The Dinner Table Facebook page](#) - the latter is a 'closed' page so you'll need to be approved by the administrators.)

Friday, 8 September 2017

University with an eating disorder? To take a gap year, or not?

It's that time of year again when young people are heading off to university. If you remember, my son headed off to Sheffield University in September 2012, six months after being discharged from eating disorder treatment. The CAMHS nurse said she "couldn't see any reason why he wouldn't be ready to go to university in September". Me, well I was a bit less sure. And in the event, as you may remember if you've been following my blog, Ben lasted two or three days before he was back home for an impromptu 'gap' year. Here's an edited version of something I wrote on the [Around The Dinner Table forum](#) (for parents of young people with eating disorders) about that gap year and why it was a Good Decision for my son.

When we packed up Ben's belongings and moved him out of his university apartment (just days after moving him into it), I reminded him of the condition I'd made if he were to defer his degree for 12 months.

He was to put the year to good use. He was to get a job, whether paid or unpaid, he was to get back into a social network and he was to work with me on overcoming all the niggly bits that remained of his eating disorder. The idea was that, by September 2013, (if he still wanted to go) he would be better prepared to handle university and its pressures.

This is what I wrote on the [forum](#) (edited):

During his unplanned gap year my son volunteered at a local charity (thrift) shop. He also got in touch with his old school to see if he could do some teaching practice for free. So he was doing both these activities.

We also encouraged him to get out there and meet people and during this year he made some fantastic friends with whom he shared the same hobbies. But most important of all, when my son wasn't doing all these things, he and I worked on moving him forwards so he would hopefully be ready to make a second attempt at university the following September.

Even though on the face of it the second attempt at university in September 2013 was successful, and because my son was now in a position where he was eating properly and regularly without the need for me to supervise (and I knew I could trust him to do it), he still had some MAJOR teething problems during that first year.

In fact it got to the stage where I'd dread getting a Facebook message from him because it would terrify me, especially if the 's' word was mentioned, which it was on a number of occasions... "Ping!" Facebook Messenger would go and I'd go cold with dread...

As part of our Big Plan to better prepare Ben for university re-entry in 2013, we'd met up with the various university support staff to draw up a support package. The Accommodation Mentor especially was massively supportive. She and her team worked till 9pm on most nights. I'd fire off an 'emergency!' email to her or call her and she'd dash round to Ben's apartment and have a chat. He also made use of the university counselling service and signed up with a fantastic GP at the university medical centre. Plus, he came home every weekend. All of this made things easier. But I won't pretend that it was plain sailing. He struggled - and so did we, which was why he readily agreed that I

could contact support services direct in an emergency. (Because he was over 18 he had to give his written permission for me to do this.)

Somehow he got through that first year but goodness only knows what would have happened if he'd stayed at university the first time around in 2012. The best thing we did was to take him out once we realised that it wasn't going to work.

My point is that, even when my son was to all intents and purposes 'ready' for uni the second time round in 2013, it was a huge culture shock coming after years of eating disorder imposed isolation. On top of this he seemed so much younger and less mature than the other students - in body and in mind - another legacy of the eating disorder which had resulted in a kind of freeze-frame of his life.

Really, in my opinion and with hindsight, a young person needs to be fully recovered from an eating disorder before attempting something as challenging and tricky as going away to university.

(But the Good News is that, thankfully, the second year was a heck of a lot better and the third year... well... by this time he was loving it! So much so that he stayed an extra year to do a Master's Degree.)

[Is your son or daughter about to leave for university or college? Are you worried about how they will cope? CLICK HERE for links to posts about my son's experience at university.](#)

Tuesday, 12 September 2017

"Me too!" - comments from parents, for parents, on F.E.A.S.T.'s 'Nourishing Words' blog

When a family finds itself facing a devastating eating disorder like anorexia or bulimia, it can be so reassuring to know that you're not in this alone: to read

about other families' experiences, to discover what did and didn't work for them and, most important of all, to discover that young people *can* recover and go on to lead normal and fulfilled lives.

On the [F.E.A.S.T. website](#) you will find a link to a 162-page PDF of a (now archived) blog made up of (almost daily) quotes from [Around the Dinner Table Forum](#) member posts. As F.E.A.S.T. says: "These words are just as inspiring today as they were from October 2010 to July of 2014."

Like countless others, you will find yourself nodding your head and saying "Me, too!" as you read about similar experiences to your own. Hopefully these experiences will offer you the hope and inspiration you need in the fight for your son's or daughter's full and sustained recovery from their eating disorder.

This 162-page document includes input from parents of boys with eating disorders as well as girls. It starts in October 2010, around seven months after I joined the [Around the Dinner Table](#) forum (after Googling things like 'support for parents of teens with eating disorders', 'eating disorders in adolescent males', 'eating disorders in boys'), so some of these posts are from parents who I still keep in touch with today.

To read words of wisdom from parents and other caregivers on the [Around the Dinner Table Forum](#) from October 2010 to July 2014, [read the Nourishing Words Archive PDF](#), or follow the link below:

<https://web.archive.org/web/20151002211644/http://temp.feast-ed.org/Forum/NourishingWordsBlog.aspx>

Thursday, 14 September 2017

What is FBT (Family Based Treatment) for eating disorders? What is the Maudsley Approach? Here's an excellent guide...

One of my fellow [Around The Dinner Table](#) parents has put together this excellent guide which explains what FBT (Family Based Treatment for eating disorders otherwise known as 'the Maudsley Approach') is all about. Many families have found this evidence-based eating disorders treatment model to be extremely effective. This parent has kindly allowed me to reproduce her guide here.

She says: "Many of us (not all) here follow (or have followed and been successful with) the Maudsley approach (FBT), which follows these guidelines:"

1. You prepare meals
2. Do not allow your child in the kitchen during meal prep
3. Your child should not go grocery shopping.
4. Toilet before meal and no toilet for at least an hour afterwards.
5. If purging is suspected, use an open door policy in the bathroom, or have them count or sing whilst in there. And no flushing
6. Do not negotiate - whatever you serve has to be eaten
7. Use whatever leverage you have - phone, Internet, tv - whatever they hold dear is to be removed if they refuse to eat, until they have eaten. If they're older and are not financially independent, this is your leverage
8. Separate the two - Your child is not the eating disorder
9. Detach yourself from the situation during meals. Do not get drawn into emotional discussions. THIS IS NOT UP FOR NEGOTIATION
10. Remember that your child wants to recover - the eating disorder is stopping them
11. Your child needs your permission to eat. They need you to stand up to

- the eating disorder as they do not have the strength to do so themselves
12. 3 meals and 3 snacks per day (supervised) - do not deviate from this. Add time limits to the meals (as a guide/goal!). Ours (and the hospitals) was 30 mins for meals and 15 mins for snacks. In the early days this could extend A LOT. I made my Ds meal times the same as they'd be at school so that when she transitioned back to full time it would be easier and less anxiety provoking.
 13. High calories are needed throughout refeeding with lots of full fat dairy. Some need as much as 6,000 cals with hyper metabolism, but the norm would be minimum 3500-4000 cals (for you to track not your child)
 14. When they know you will not negotiate, I promise you will see the weight lifted from their shoulders... If only for very short periods
 15. BE THE CAGE that keeps eating disorder away from your child
 16. When food is eaten be mum / dad again and have cuddles if they'll let you
 17. 24/7 supervision - I slept with my D for 4 months - this will protect against them purging through vomiting or exercise. Many patients will exercise alone at night for hours on end when nobody else is awake.
 18. All sport may need to stop in the early stages, and for those who compulsively exercised this could be long term.
 19. Be consistent, consistent consistent!
 20. Don't congratulate them after a meal or say 'well done' - just cheer inwardly! Likewise when (for girls) their period returns!
 21. Learn from others. I found this website with stories of other parents journey through recovery to be extremely helpful - <http://www.maudsleyparents.org/familystories.html>
 22. Recommended reading: ['Brave Girl Eating' by Harriet Brown](#)

23. Be prepared for resistance, and lots of it! You will find your own way to manage this, but NEVER back down. Any compromise is a win for the eating disorder. Remember, you have to see the beast to slay beast!
24. Making decisions / choices is extremely difficult for them (painful to watch). This is true in areas outside of food too. If you've tried to hand over some control of a meal or snack and notice that they are struggling, that is an indication that it is too soon and that you need to be making those decisions for them.
25. Sometimes distraction helps during meal times. That can come in the form of games, TV, music. Whatever it is you control it and it only continues with eating.
26. Lean on us - you have 24/7 support here as [FEAST/ATDT](#) is international
27. In some cases FBT isn't an option, generally if there are comorbidities such as ASD and BPD (Borderline Personality Disorder) . It may just be that FBT needs to be tweaked, or that a different approach is needed. There are many here who have found ways to work around those comorbidities or who can advise on an alternative approach which worked for them.

OCTOBER 2017

Tuesday, 10 October 2017

Here's what my son, Ben, is saying on World Mental Health Day today

If you've not seen it yet, you live in the UK and you don't think it will trigger you, BBC3's recent drama *Overshadowed, A vlogger's life spirals out of control*. The reason? Her new "best friend" Anna. You can [watch it here](#) on BBC iPlayer.

This is a very real portrayal of what an eating disorder like Anorexia can be really like, written by a former sufferer who plays 'Anna' in the drama (the 'eating disorder voice').

The incident in the friend's bathroom is particularly reminiscent of our own experiences with Anorexia; it reminds me of the time when my son had his friends round for a sleepover on that first Christmas with the eating disorder in 2009. Something set him off and he came screaming downstairs in the middle of the night in a similar state to Imo in Episode 6.

Today is World Mental Health Day and this is what my son has posted on his Facebook page:

It's World Mental Health Day today so I wanted to raise awareness of an illness which nearly destroyed my life and is haunting millions of people around the world. This drama mini-series by BBC Three really evokes how insidious and soul-destroying it can be, however it can be beaten and for anyone out there who is suffering from this, there is future for you if you fight it.

I love my son!!!

Sunday, 15 October 2017

Overwhelmed and comforted by the response from other parents

One thing my EMDR (Eye Movement Desensitisation Reprocessing) therapist said at the start of treatment was that, as well as throwing up key memories of dealing with my son's often violent eating disorder, EMDR would probably bring old traumas back to mind. He was right - and I know I'm not the only (post-eating-disorder) mum who has experienced this.

It might be a traumatic birth experience (as it was with my son, Ben), the sudden death of a loved one, being in or witnessing a serious car accident or a myriad of other past traumas... whatever is lurking in the dark recesses of the

mind, unprocessed, then it could come to light during the EMDR treatment.

I have a theory (and it has evidence to back it up) that it's like a jar of stuff. Each trauma adds to the contents of the jar and then we're faced with the months or years of battling with our child's eating disorder, 24/7/365, all of which is crammed into this jar until - BOOM! - it explodes and the 'jar' (our mind) is all over the place like some kind of den of writhing snakes.

And we begin to suffer from Complex Post-Traumatic Stress Disorder.

EMDR as an evidence-based treatment for Complex Post-Traumatic Stress Disorder does work although, at the start, I wasn't convinced. All that finger moving in front of my eyes seemed like a load of mumbo-jumbo rubbish.

But it does work.

What it doesn't do, in my experience, is to completely eradicate all the traumatic memories. But, then, you wouldn't expect it to. You are hardly likely to forget several years of 24/7 trauma!

But what it does appear to do is to sort out the jumble mess in your head and begin to compartmentalise it all. Like on one of those TV shows where the cleaners move in on a chaotic house and leave it clean and tidy as a new pin.

Well, maybe not as dramatic as that. In my experience there is still a lot of stuff going on, but it's not as 'messy' and 'front of mind' as it was at its worst.

And there are experiences that I kind of don't want to process. A prime example would be my anger at CAMHS for some of the things they did and said that were damaging to my son and his recovery from anorexia. And the NHS in general: all the stuff I go on about ad infinitum on this blog about the GP not recognising a blossoming eating disorder when it was staring him in the face, the length of time it took to get Ben referred and into treatment plus the sheer lack of empathy shown by the NHS and the fact that no-one seemed to care.

That 'drawer' of stuff is still very much at the front of my mind.

I was chatting to another mum recently and we both agreed that it's as if we don't want to file away certain memories, almost as if by doing so we would be belittling the whole eating disorder experience. By having 'war wounds', so to speak, it's as if we are still saying: "Look what we went through for all those years, day in, day out, round the clock." We don't want people, and indeed ourselves, to 'forget' that all this horrific stuff happened. It was part of our daily lives for so very long and it will always be part of our present lives and who we shape up to be in the future.

Unless you've 'been there, done it' this is very difficult to explain in words.

My therapist asked me why I didn't want to file all that anger away. Was it actually benefiting me by keeping it at the front of my mind? Was I becoming a tad 'bitter and twisted' about things?

No, it's not like that. It's the foundation of why I write this blog, why I respond to posts on the [Around The Dinner Table Forum](#), why I talk about eating disorders and so on.

Because it's not as if everything is sweetness and light on the NHS mental health front as regards treatment of young people with eating disorders in 2017. Certainly some enlightened NHS Trusts have introduced modern evidence-based treatment for eating disorders (such as Family Based Treatment - FBT) as well as aiming to see new patients quickly.

But there are others that are still doing things the old way. Not only can it prolong an eating disorder but it can result in deaths, whether from suicide or organ failure. I know because all too often I hear about young people here in the UK who have been failed by The System. I heard about one young teen this week whose heart suddenly gave up.

And it makes me mad.

Which is one of the reasons why, despite compartmentalising much of the

trauma memories, I want to keep my anger alive so I can continue to write and talk in a bid to make some kind of difference, in my own small way.

Sunday, 15 October 2017

Struggling to cope in a post-eating-disorder life? You are not alone...

Because I know I'm not alone in having struggled with serious trauma symptoms as our family emerged from the anorexia years, I've decided to write the occasional post about what I found myself going through from around 2015 onwards. It will be about the (Complex Post-Traumatic Stress Disorder) symptoms and how I coped (or didn't cope) with them in the hope of helping other parents to identify with similar experiences. It will also be about other stuff that was going around in circles inside my head. Most importantly the aim will be to show you that you are not alone in feeling like this.

In September 2015 I downloaded a free app for my phone called Diaro and began to jot stuff down every day. Just notes and things to get stuff off my chest. These blog posts will be based on (some but not all of) my Diaro entries.

I say 'some but not all of' because, obviously, there are some thought processes that I want to keep private.

Sunday, 15 October 2017

"Will my son always be stuck standing short of the 'finish line'?" I asked myself in September 2015

In September 2015 I was toying with the idea of writing a sequel to my book [Please eat... A mother's struggle to free her teenage son from anorexia](#) and I wrote this in the Diaro app:

The book will be about me

Rather than my son. Mainly. How I coped (or didn't) with getting my life back. The blips we had, my worries about his weight and relapse. He is not the person he used to be and it's upsetting. But might he have been this person regardless?

At the time I was obviously wondering if 'almost there' was where my son would always be and that he'd never get back to being the person he was before the anorexia hijacked his life.

I was worried that he would never get the weight back on him, never eat 100% normally, never stop counting calories and weighing out food, and so on.

It's a question I often see from parents on the [Around The Dinner Table Forum](#). This wondering if we're asking too much in seeking full and unconditional recovery from the eating disorder and that, if some (less enlightened) treatment teams imply that some young people always stop short of the finish line and that this is the best we can expect, they must somehow be right.

Yet we have battled to get our child this far; we owe it to them to help them recover fully and get their lives back.

My son was told "We're happy to settle for 'good enough' if you are, Ben" and that "Some young people choose to remain at a low weight because they find it easier to cope with".

When I heard these words my whole being screamed out: "Noooooo!!!!!"

Yet, by September 2015, six years after Ben's eating disorder first emerged, I was still saying things like: "My son is 95% recovered." I simply wasn't able to say the words "fully recovered" despite enormous advances having been made and despite Ben being 'almost there'.

I would say that it took a further two years, almost to the present day, for me to look at Ben and think "Yes, this is what full recovery looks like". The

flesh was back on his bones, the light was back in his eyes, the smile was back on his face and the food was still being eaten properly and normally.

I believe that full recovery from an eating disorder is possible and that families should NEVER be told that they may have to settle for 'second best'.

That limbo-land where the finish line is in sight but where they stop short.

If we - treatment team, parents and the patient themselves - have fought tooth and nail to get this far, why the hell should we stop here?

But that final push wasn't solely due to my encouragement and support; it was almost entirely down to my son who refused to give up and pushed himself towards and across that line, and began to live life as it should be lived: to the full.

Without any signs of the eating disorder.

Well done, Ben.

Monday, 16 October 2017

Saturday night it was about catching trains, last night it was about exams... I still have high-anxiety nightmares

I have to catch a specific train but everything is preventing me from doing so: I'm at the wrong station, I haven't bought my ticket, there's a queue for tickets that's moving at a snail's pace, there's no information on platforms and no platform numbers, I'm waiting for people to catch me up... and so on and so forth... Or, like last night, I'm about to sit the most important exam of my life yet I haven't done any revision. I haven't even been to lessons. I know zero about the subject. There are other variations on the high-anxiety nightmare, but these are the two most common nightmares I've been having for the past eight years or so.

In my diary app on 3rd September 2015 I wrote: *Sleep: Quality has been bad*

ever since. Forgotten what a proper night's sleep is. Dread going to bed. Lack of sleep contributes to the inability to do stuff. Too darn tired. Just so very very tired. To the core. Fatigue. Burnout.

Sleep evaded me throughout my son's eating disorder. Often I'd be sitting on the sofa at some unearthly hour with a mug of Ovaltine, in some kind of shock and despair.

But, as my son recovered from anorexia, my sleep went the other way and the 2015 diary app entry was written some six years after my son's anorexia first emerged.

For a while my GP prescribed sleeping pills, but I was only permitted to take these as a short-term solution. I now have a load of other sleep-inducing prescription medications. But the Good News is that, these days, I can get to sleep quite easily with the very minimum of medication, something that was unheard of in the Bad Old Days.

So that's a definite improvement.

I also wake up at a decent time.

So that's an improvement, too.

But I still have anxiety nightmares which may or may not be linked to the Complex Post-Traumatic Stress Disorder which I was battling with for so many years following my son's anorexia.

However the Overall Good News is that I've improved a heck of a lot since I wrote that diary app note in 2015.

I love it when I can see improvements like this!

Saturday, 28 October 2017

It's vital that the parents get support when their child has an eating disorder

The other day I was having a discussion with a friend about how both of us had little or no support during the months and years that our children were suffering from anorexia. It was almost as if, as parents, it was our job to 'just get on with it'.

The fact that, outside the treatment room, we were having to deal with the hellish nightmare of an eating disorder in the family, hour in hour out, day in day out, month in month out, year in year out was pretty much ignored.

In my city there *was* a group of parents of eating disordered children who met together every so often at a local eating disorders unit, but it met at 6pm which was useless when you're faced with the Big Meal of the Day at 6pm. It's OK if there are two adults in the house, but with my husband working away it was just me, my son and the eating disorder. So I never got to go along to any of those meetings.

Some weeks, while my son had a private session with the CAMHS psychiatrist, I was given what were referred to as 'parenting sessions' with the CAMHS nurse. It was as if I was partly or even wholly to blame for my son's eating disorder and these sessions were mainly about instructing me to be less anxious (because, apparently, I was passing my anxieties onto my son and that was a Bad Thing). Or just instructing me on how to be a Good Parent.

As opposed, I assume, to a Bad Parent.

As far as I was concerned, I *was* a Good Parent. I'd *always* been a Good Parent. But this kind of session had me questioning myself, my emotions, my behaviour and my attitude towards my son.

Rather than being empowered and supported, I felt as if I was being 'told off' and criticised.

Or that's what it seemed like to me.

And I'll never forget the occasion when faced with the age-old comment "he has to *want* to recover" (before anything can happen), I responded with "What if he *never* wants to recover?" only to be met with a shrug of the nurse's shoulders.

I was absolutely and completely terrified. And, yes, true fear *is* ice-cold.

Living with a son or daughter with a serious eating disorder is the equivalent of hell on earth. And, as parents, we're faced with that hell on earth round the clock. The toll it takes on our own mental health and stress levels is exponential. It almost makes me want to laugh out loud when I remember those instructions that my being 'over-anxious' wasn't 'helpful' to Ben and that I was a 'naturally anxious person' who 'went on about food too much'.

Thankfully in more enlightened eating disorders treatment services, parents *are* supported. Brilliantly. But in other cases I imagine there are still parents like me who are given zero support and just expected to get on with the job.

When coupled with finger pointing and implied blame that job is made a million times harder than it is already. Especially when our child sides with the treatment team and joins in the blame game.

May all parents everywhere get the support they need and deserve.

Parents can also find excellent support on the [Around The Dinner Table Forum](#) which is run by parents for parents of young people with eating disorders.

Monday, 30 October 2017

Why are some eating disorder treatment teams still using outdated treatment models?

I feel a mixture of anger, sadness and fear when, in the modern world, in 2017, I hear about advice that's being given to parents of young people with

eating disorders that's so very out of date. Advice like we received eight years ago along the lines of *'Don't keep going on about food, it makes him/her anxious... it's not helpful to him/her'*. Worse, for food to be pretty much taken off the agenda except for playing a small 'bit part' role in the background. Or, as we were told just before the Summer of Horror in 2010, to *'take a break from the eating disorder'* for the duration of our two-week family vacation. Can you believe that?

For some time now, evidence-based treatment for anorexia in adolescents has focused first and foremost on eating and food. Until the child is nutritionally stable, food takes centre stage. You can read more about how FBT (Family Based Treatment of Anorexia Nervosa, also known as the Maudsley Approach) works [here](#).

I firmly believe that it was the instruction NOT to *'go on about food all the time'* that helped my son's weight to drop consistently once 'Mum's eating plan' had been dumped during those first few weeks at CAMHS when my son gained weight.

As I have said before on this blog, my son was exactly the same weight on discharge as he was on admission.

That, in my opinion, doesn't constitute recovery from anorexia.

Of course FBT doesn't work for everyone. Eating disorders are so very complex that you can't depend on a blanket 'one size fits all' approach. But evidence has shown that for many adolescents the FBT / Maudsley approach works for anorexia. Which is why more and more enlightened eating disorder treatment professionals are being re-trained in FBT. The more traditional *'they have to WANT to recover before anything can happen'* and *'it's not about food'* approaches have gone out of the window.

Worse, the approaches that point the finger at parents as being the root

cause of the eating disorder or *'passing their anxieties onto their son/daughter'*.

So I feel so very, very sad for parents who are new to the horrendous world of eating disorders, firstly because they're having to go through this hell and, secondly, when it becomes clear that their treatment team appear to be following more traditional, outdated treatment models.

As a parent your gut instinct is that you want your child to eat first and foremost. You want them to put on weight. Especially when, as was our case when my son was admitted to hospital with Bradycardia (abnormally slow pulse rate), dangerous physical symptoms start to appear. As I remember saying back then: "This is my only child and he only has one heart."

So when you're finally sitting in front of the eating disorder treatment team you automatically assume that what they are proposing to do is right and completely up to date with modern evidence and research. Just as you would if you were sitting in front of an Oncologist or any other medical expert.

It can be so confusing and indeed terrifying when the treatment appears to be going against your instinct and also against what you are reading about treatment models like FBT. With me I felt absolute panic plus, as time went on, the gradual realisation that this treatment wasn't going to help my son. The only thing it DID do was to make him get on with his psychiatrist like a house on fire as sides were taken against *'mum who's always going on about food'*.

I'm sure there is a ton more that can be said on this subject, but I'll stop here for now.

NOVEMBER 2017

Sunday, 5 November 2017

What's making me jump for joy today?

Remember how the eating disorder stole my son's social life as well as so many other things in his life? Remember how, for a very, very long time, he was unable to go to school or meet up with his friends? How, gradually, the boy who'd been so popular became so very isolated and alone, so much so that on his 18th birthday in December 2011, he was virtually in tears because he was celebrating alone with just me and his dad?

Since then Ben has rebuilt his social life, at home and during the four years he was at university.

These days he has a great circle of friends.

Last weekend he visited a friend who's away at uni and is visiting another friend at his university next weekend. He's also joined a brilliant 'Meet Up' group where he's making even more new friends.

And when he's with his friends everyone is laughing and making a noise - the complete opposite to those isolated eating disorder years.

Then last night he went to a bonfire party hosted by - yes! - his old school friends. That network of boys who used to come round to our house every Christmas on Ben's birthday and have fun.

Everything about the experience was NORMAL.

In the not so distant past Ben would have chickened out at the last minute, made some excuse and stayed at home with us. Last night there was none of this as he headed off for the bus. A taxi brought him back at goodness only knows what time this morning. (All credit to him that he texted me earlier on to say how he was getting back - we mums do worry, don't we!)

He had a fantastic time. Many of his old friends were there and he was able

to catch up with what they're doing now everyone is turning 24-years old. And hopefully he'll be meeting up with them again very soon.

Meanwhile his freelancing job is going OK and he has a couple of other interviews, too, for what he calls 'the perfect job' - a career he could only dream of when he was sick with anorexia.

And meanwhile, right now, Ben is busy cooking in the kitchen (no, not diet food) and singing at the top of his voice. As I've said on this blog before, when Ben is singing all is right with the world.

I do hope that this news gives hope to families who are where we were all those years ago, that there IS life after an eating disorder.

Sunday, 19 November 2017

Two bits of news!

The first bit of news is that [my new eating disorders website](#) is up and running. I still need to do a few tweaks and add some more pages, but the 'look and feel' is there now. (I know I updated it a short while ago, but I wasn't happy with it, so I've given it a refresh as well as adding a security certificate for safer browsing.)

The second bit of news is that I've just returned from a weekend in Brighton where I met up with the other new Board members of the national charity [Men Get Eating Disorders Too](#). A month or so ago I was invited to join as a Trustee.

I arrived late on Friday, just after their annual eating disorders conference which, unfortunately, I wasn't able to attend, but I understand it went really well.

It was great to meet up with Men Get Eating Disorders Too founder Sam

Thomas again who I keep bumping into at various eating disorders conferences and also to meet the other members of the team. Our new Chairperson is a mum like me who's been through the hell of an eating disorder with her teenage son, so we already had a heck of a lot in common. We also love cats.

And we also have roots in the city of Sheffield.

All of us are looking forward to helping the charity to expand and also raise money to do what they do best which is to help raise awareness of the fact the men and boys get eating disorders and also to provide much-needed assistance and peer support to males who are suffering with eating disorders.

You can read more about [Men Get Eating Disorders Too on their website here](#).

Monday, 20 November 2017

Just when I thought the PTSD had almost been fixed...

If you've been following this blog you'll know that I've had problems with Complex Post-Traumatic Stress Disorder which began a few years ago. Last year I had 30+ sessions of EMDR (Eye Movement Desensitisation Reprocessing) therapy which helped a lot in that it 'processed' many of the memories of Ben's eating disorder years. That's not to say that I 'forgot' these memories, I could never do that, but what the EMDR *did* do was to let my brain realise that these events / memories are in the PAST and not in the PRESENT, making them a little less traumatic to deal with.

The trouble with C-PTSD, however, as my EMDR therapist explained to me, is that it can be compounded by earlier trauma. He warned that stuff that had been locked away in my head for years or even decades might come to the surface. Layer upon layer of trauma may have been one of the reasons why my

brain went "Boom!" in the first place following my son's eating disorder nightmare. Layer after layer of stuff had been crammed into my head until the fuse short-circuited as Ben moved along the road to recovery from anorexia.

There are at least a couple of earlier traumatic events that took place in my life and one of these reared its ugly head last night as a text-book PTSD nightmare of the screaming variety.

The trigger was a photo I saw yesterday evening of a family member who'd just given birth. It reminded me of a photo my husband took of Ben and me, 24 years ago this Christmas, an hour or so after Ben's birth.

The photo was enough to trigger a horrendous nightmare. I was screaming and shouting, and thrashing (judging from my aching limbs). This morning I woke up with a brain that felt as if it had been stuck in a blender and then splattered all over the wall.

Giving birth to Ben 24 years ago was a horrendous experience that should never have happened in the way it did. These days I would have been given a Caesarean as a matter of course; back then I wasn't.

I won't go into detail because that wouldn't be helpful to me. Suffice to say that in my nightmare I was tied down with my legs up while medical staff mutilated me with knives. No anaesthetic, no humanity, I was simply a piece of meat to be cut up to get the baby out.

In my nightmare I could see the medical teams heading for me with scalpels and knives. I was powerless to stop them cutting me over and over again - great big gashes and gouges without anaesthetic. It was a 20th century torture chamber. I screamed and screamed.

Which is pretty much how it was at the time - and that was just the tip of the iceberg...

The Registrar who was responsible for this was known by hospital midwives

as "the butcher" and they were always putting in complaints about him. But at least he wasn't the doctor who gave me the epidural that didn't work - the bloke who stank of fags and booze, who'd been hauled out of a Christmas party.

I have always felt extreme anger towards those medical staff who I believe were negligent and inhumane. My anger at medical teams during my son's diagnosis and treatment for his eating disorder compounded this anger. So much so that I find it very difficult to trust doctors, etc to know what they are doing and to care... I mean *really* care in an old-fashioned humane family doctor kind of way... about their patients.

And meanwhile there was all this trauma which has been there, inside my head, for 24 years and which came out so violently during my sleep last night.

I may need some more EMDR sessions...

DECEMBER 2017

Friday, 1 December 2017

Sometimes I can talk or write about eating disorders and sometimes I can't...

It's funny how sometimes I can visit the [Around The Dinner Table Forum](#) (for parents of young people with eating disorders) and blog here, and sometimes I just can't. Sometimes I can talk about what we call 'the ED years' (the years my son was suffering from anorexia) and sometimes I just can't. And sometimes I can update my [eating disorders website](#) and sometimes I just can't.

This week has been one of those 'just can't' weeks when my anxiety and depression has been pretty high (both a legacy of 'the ED years'). It's been one

of those weeks when I've had to *really push myself* to take a step forward, even to get out of bed on some days.

Of course this kind of mood makes me feel guilty. It makes me feel as if I've failed in some way to 'recover properly' from the PTSD and other issues that came as a result of the years struggling with my son's anorexia.

After all, I've had *masses* of therapy sessions over the past few years: CBT, EMDR, psychotherapy... Private and NHS... and I *still have* bad days.

So I did myself a favour. I Googled things like 'How chronic stress affects the brain and body' and read up on the evidence-based science behind why my head still feels this way.

I found it really helpful to read about the physical changes that can take place in the brain following prolonged exposure to stress along with the various chemicals and hormones that are released which can affect the entire body (e.g. cortisol).

Doing this is a great way to shout out to myself that the way I feel and have been feeling ISN'T MY FAULT, just as many physical illnesses aren't anyone's fault.

Would someone feel guilt at developing, say, pneumonia? And if it got worse would they feel that they 'shouldn't' still have it and 'should have recovered faster' following treatment?

Of course they wouldn't! And the same goes for mental health problems such as those that can occur as a result of chronic / prolonged exposure to stress.

During our child's eating disorder, many of us parents were under extreme stress 24 hours a day, 7 days a week, month after month, even year after year.

So is it any wonder that our minds and bodies have been affected as a result? Indeed I believe that it would be unusual for us NOT to be affected in

some way, even long after the eating disorder itself has faded away.

And, as I have found, the impending Festive Season brings its own Pandora's Box of bad memories.

So I need to be kind to myself and remind myself that stress has made changes in my brain and released a host of nasty brain chemicals. It's what the brain does under such circumstances; it is science; it is a physical thing and nothing to feel bad about.

After all, we feel bad enough at times like these *without* the totally unnecessary double-whammy of beating ourselves up at the same time.

Tuesday, 5 December 2017

Again, on the topic of PTSD, why PTSD therapy will never work for parents like us

I've been feeling frustrated that, after all the therapy sessions and treatment models I have received over the past few years for Post-Traumatic Stress Disorder (PTSD), I still feel the way I do. So I began googling and came across something called Continuous Traumatic Stress Disorder (CTSD).

PTSD is all about issues associated with a one-off trauma, for example a car crash or a terrorist attack.

C-PTSD (Complex or Chronic Post Traumatic Stress Disorder, which I've talked about a lot in this blog) is about issues associated with prolonged trauma, for example childhood or relationship abuse, or - in the case of parents like us - the issues that have come as a result of the years of battling with our child's eating disorder.

[CTSD \(Continuous Traumatic Stress Disorder\)](#) or CTS (Continuous Traumatic Stress) refers to issues that have come as a result of a prolonged trauma that is either *still happening* or which *could potentially re-occur* at any stage in the

near or far off future.

This, to me, made so much sense because I very much doubt if there is any one of us who isn't terrified of our child relapsing back into a serious eating disorder and all the horrors that this could bring with it.

It isn't a case of us being needlessly paranoid. It is a real fear about a real problem that really could happen. Relapse is an all-too common feature of an eating disorder. Sadly I know personally of many families where the eating disorder, or at least elements of the eating disorder, have returned. And there will be many families who are battling with relapse that I don't know of personally.

My C-PTSD therapist, Steve, tried to get me to accept and believe that, now my son appeared to be well, the eating disorder had left our lives never to darken our doorstep again.

But that simply isn't true. Well, it might be true. I hope it's true. But relapse is so very common that many, many parents feel the need to keep their eye on the ball. Their body is in a constant state of, if not 'red' alert, then at least 'orange' alert.

So if the worst should happen and the eating disorder was to return, we would be prepared.

Like in those horror movies where everyone thinks the bad guy has been killed when in reality he's about to crash through the door for a second and potentially more deadly attack.

This is why many people call recovery from an eating disorder 'remission' rather than recovery, as they might with cancer or other illnesses that have the potential to flare up again.

While googling CTSD (Continuous Traumatic Stress Disorder) and CTS I was interested to note that conventional PTSD treatment models may fail to work

for the simple reason that the trauma is still present, albeit dormant.

This makes so much sense because how the heck can we 'process' our anxiety and fear as being 'in the past' when they are very much here in the present?

Thursday, 7 December 2017

Trying to describe why this is Continuous Traumatic Stress Disorder, and wondering what can be done about it...

Each of the therapists I had for my (what I assumed was and what was diagnosed as) PTSD (Post-Traumatic Stress Disorder) attempted to get me to believe and accept that my son's eating disorder, and all the horrors that came with it, was in the past. The idea was to 'process' the nightmarish memories so my brain began to accept that it was history and I could start to live a post-eating-disorder life free of nightmares, anxiety, fear, dread and all the other stuff that was causing nasty symptoms and making me feel 'strange' and 'trapped'.

And, yes, if you take the eating disorder years memory by memory - for example the memories of my son swimming out to sea or attempting to climb onto the house roof - then these memories, as individual memories, are indeed in the past.

But the effects of the trauma go much deeper than that.

There is the constant fear, [described yesterday](#), that my son may relapse. This isn't the same as - for instance - having been in a car crash or terrorist incident and living in fear that it might happen again at some point in the future. Yes it might. But then it might not. Indeed in some cases there is a high probability that it might not. And living life primed 'just in case' is no life at all.

I believe that our fear, as parents of young people in remission from a

serious eating disorder, is different, which is why it needs to be classed as Continuous Traumatic Stress Disorder (CTSD or CTS).

My therapists were talking as if my son was / is 100% recovered, eating fish-n-chips and cream cakes without batting an eyelid, living a fabulous eating disorder free life and generally skipping into the sunset with a huge smile on his face.

If only this were so...

Instead, I'd be lying if I didn't admit that he - and, as a result, we - has been left with a big legacy from the anorexia years.

The co-morbid depression is an example. He is still on SSRI antidepressants. He still has mega "downers". Like yesterday, for instance. Downers where it only takes me to catch a glimpse of his dark look, hear him yell out in frustration or hear him tell my husband that his "life isn't going anywhere" and I'm right "back there".

Right back there, in the land of the deep, dark, ice-cold, stultifying dread.

I sit at the dinner table opposite a depressed Ben and I'm "back there" in the same seat and at the same dinner table as in the eating disorder years when mealtimes were too horrendous for words.

I sit on the sofa, near a depressed Ben and I'm "back there" on the same sofa and in the same room as those frequent evenings when he'd scream out, pinching the skin on his skinny belly claiming to be "fat".

Last night I told my husband that these incidents take me "back there" and make me want to "just flee". He replied: "Well go then", which I didn't think was very helpful...

This morning I was wondering how CTSD is treated - or if indeed it can be treated because it's almost like treating someone for radiation sickness when they are living in an ongoing radioactive environment - so I googled for more

information and came across an article which lists the symptoms. I have many of these symptoms. You can see this [article here](#)>>

So what can be done about it? I really don't know, because what I don't want to do is to throw more money at therapists who, although they may take the edge off some of the problem, aren't addressing the real underlying issue which is that, like it or not, this is an ongoing thing.

Friday, 8 December 2017

"Life stops until you eat," say the eating disorder experts

It was [F.E.A.S.T.](#), I think, that coined the excellent phrase: "Life stops until you eat" - a phrase which I've heard many, many times on the F.E.A.S.T. forum, [Around The Dinner Table](#), when it comes to getting your eating disordered child to eat. On Tuesday, the US-based Kartini Clinic's Dr Julie O'Toole [blogged about the same topic](#). The topic talks about how to *continue* to get your child to eat and put on weight once they've been discharged from formal treatment for their eating disorder. In a nutshell, whenever they resist, you tell them that "Life stops until you eat". As Dr O'Toole says: "*No friends, no going out, no cell phone, no parties, no car, no clothes shopping, no college visits. The first job is to nourish the body and all else comes after that.*" Indeed the focus of [Family Based Therapy](#) (FBT) as an evidenced-based model for the treatment of anorexia in adolescents is, first and foremost, "Life stops until you eat".

How I wish I'd had this information to show to Ben's eating disorder treatment team back in 2010-12. As you may know, with Ben's treatment, food and eating came secondary to the "talking treatment". Ben had to "want to recover" before anything could happen. He would, in theory, begin to eat sufficient food once he saw "what the scales were telling him" every week. The

scales would "prove to him" that he needed to "eat more to put on weight".

At our very first CAMHS (Child & Adolescent Mental Health Services) session in early 2010, I asked if there would be an eating plan for Ben. I took this for granted, based on what I'd been reading, along with my gut instinct as a mother who had already been battling with my son's eating disorder for several months before Ben began treatment.

CAMHS fished around in their files and produced something called *Eating Plan 6* which required the patient to eat all sorts of high-calorie foods that I knew Ben would never eat in a million years.

Not without some serious support from CAMHS, literally sitting down at the dinner table with us.

But this didn't happen and, to get Ben to eat more food, I had to tweak the eating plan considerably. However I did manage to get him to put on a few kilos during those first few months with CAMHS.

But, as Ben's anxiety rocketed as a result of the weight gain, it was decided to withdraw "Mum's eating plan" (as it became known) as it wasn't proving "helpful" to my son. Instead, Ben would prepare his own meals (except for the evening meal which I would prepare). This way he would gradually learn how much he needed to eat to put on weight, as proven by the weekly weighing sessions.

Meanwhile, once a week (or once a fortnight after just a few months at CAMHS), Ben saw the psychiatrist individually while I saw the CAMHS nurse for what were called "parenting sessions" which, to me, were all about making me a better parent and, importantly, showing me how to be less anxious about the whole thing and back off a little on the topics of food and eating.

At one of these sessions I was informed that Ben had to "want to get better" before any change could take place.

So we waited and waited for Ben to "want to get better" while he reacted to whatever the scales were telling him. *Weight loss* was followed by a relatively relaxed CAHMS session whereas any weight gain would result in the entire session being hijacked by the need to pacify a frantic Ben who would promptly cut back on his food intake to avoid getting "fat".

If only the approach had been "life stops until you eat".

If only I'd been viewed as a good parent who was only anxious because I'd already been going through hell for several months before we arrived at CAMHS and I was well aware of the dangers of eating disorders.

If only the focus had been on getting Ben to eat first and foremost, of getting full nutrition into him and getting him back to his pre-anorexia weight, not settling for "good enough", suggesting he could "chose a final weight he felt happy with" or "what some young people prefer to do" which was to remain at a lower weight, a weight that they can handle without too much anxiety.

It should have been a case of "life stops until you eat".

At the start of treatment, during treatment and - if necessary - following treatment.

But it wasn't. And Ben was discharged after 26 months of treatment at the same weight he was when he started.

Friday, 8 December 2017

A catalogue of disgraceful and avoidable failings that led to this tragic outcome

My mum pointed out [this newspaper report](#) today about a teen who was "left to starve in her university flat". Yet again we have what appears to be an avoidable death from a deadly illness - anorexia - that seems to have come

about through a catalogue of failings by the NHS.

At the end of the article we get the usual promises about plans to invest £loads-of-money in eating disorder treatment to avoid tragedies like this happening again. But I don't doubt that they will happen again... and again... and again - and it's one of the reasons why I, and others, fight to raise awareness of the deadly nature of eating disorders and the, all too often, less than ideal treatment.

And even if the £loads-of-money funding does get spent in the right places and young people's lives are saved as a result, it doesn't make this tragedy any easier for this young woman's family to bear.

The same goes for other families that have lost a son or daughter from an eating disorder.

Such as a friend of mine who lost her daughter while that daughter was under the care of the NHS.

As parents entering the alarming and terrifying world of eating disorders for the first time, we trust the professionals to do everything that is required - and more - at every stage of the process: swift diagnosis and referral, excellent evidence-based treatment by rigorously trained and experienced practitioners, discharge from eating disorder treatment ONLY when as close as possible to 100-per-cent recovered and meticulous, closely monitored follow-up to ensure the young person is kept safe and continues on the road to recovery.

Quite simply, we trust the professionals with our much-loved child's life.

We also trust any peripheral professionals to understand the deadly nature of eating disorders and to take effective action - for example GPs, surgery nurses, emergency departments, other hospital departments, ambulance personnel and so on.

And, in the case of young people at college and university, we also trust the

on-campus NHS professionals to know what to do.

After all, eating disorders aren't unusual amongst students and, often, students are having to cope with their eating disorder away from home, away from hands-on support from their parents or carers.

In 2012, as soon as it became evident that my son had left for university too soon after discharge from treatment, we brought him back home and he took a gap year, despite our treatment team saying that they couldn't "see any reason why he wouldn't be ready for university".

The following spring we worked closely with the university to put together a support package which, on the face of it, was excellent. But with the best will and the best support package in the world, it is always going to depend on the young person SEEKING HELP - of being aware that they are sick and need support.

Those of us who have faced an eating disorder in the family will be all too aware that, often, the last person to realise that there is a problem is the patient themselves.

The [newspaper report](#) says:"The report said the student had been let down by every NHS organisation tasked with her care, some of whom later sought to hinder investigations into their mistakes."

It makes me hopping mad.

Saturday, 9 December 2017

Turning stuff on its head, the "myth of motivation in adolescent eating disorder recovery"

I clicked onto [this article](#) today and it made me laugh in a kind of grim ironic sort of way. The author talks about "how I've sat with many worried parents, desperate to do what is right for their adolescent child, who say, 'I really want

her to get help, but it's just not the right time. She has to want to get better."". It goes on to explain why parents need to learn that eating disorders are serious brain illnesses and the reasons why none of us can simply can't wait for them to "want to get better". Indeed why, waiting for them to "want to recover" is a dangerous myth.

What made me laugh in a grim and ironic kind of way was the fact that, with us, this was turned on its head. Instead of the *parents* believing that the child had to "want to recover", it was the *eating disorder treatment team* that believed this. I, as the parent, just wanted them to get him to eat.

At one point I responded to this with: "But what he if *never* wants to recover?" and they just shrugged their shoulders as if to say "well, that's just one of those things".

They didn't actually have an answer.

It made me see red.

It still makes me see red.

How I wish I'd had this article to brandish in front of them to prove that they were wrong in this belief. Dangerously wrong.

Only today I was having coffee with some parents facing an eating disorder in the family. From what I was hearing, treatment of eating disorders in our city has improved enormously since I found myself battling with my son's treatment team as well as battling with the eating disorder.

These days parents in our city receive evidence-based FBT (Family Based Therapy) which, while I'm on the subject of things being turned on their heads, is a treatment model that's turned the treatment of anorexia in adolescents on its head.

Back in the olden days it was all about attempting to talk the young person out of their eating disorder and waiting for them to "want to recover". Once

they began to "want to recover" they would be more willing to eat and put on weight.

Today, in enlightened eating disorder treatment services, the immediate and urgent focus is on food, eating and weight gain because you *simply cannot talk someone out of their eating disorder; you cannot wait for them to "want to recover"* and you certainly *cannot wait for them to reach rock bottom before any change can take place.*

As the article says: "The idea is that in order to be helped, the person suffering has to reach the lowest point and, having lost everything, be willing to seek and accept help from others. Fortunately for the millions of individuals who suffer from eating disorders, this is not the truth. When it comes to adolescents with eating disorders, it's in fact a misguided and dangerous falsehood."

Monday, 11 December 2017

The podcast that every GP needs to listen to. Full. Stop.

Dr Erin Parks of the UC San Diego Eating Disorder Center (recognised as a global centre of excellence in eating disorder treatment and research) has produced a [podcast that every GP needs to listen to](#) - or indeed anyone who wants to know the truth about eating disorders, including the estimated percentage of males suffering from eating disorders in the 21st century.

Even if, as a GP, you have a good understanding of eating disorders or your knowledge needs updating, this pod cast will answer all your questions about the different eating disorders that are out there, what kind of personalities tend to develop eating disorders, what the latest scientific research and brain imaging are saying about the causes and presentation of eating disorders, and

those treatment models that can result in a better outcome for the patient.

Basically Dr Parks walks you through the latest research and thinking on the neuro-biological, emotional and psychological reasons for eating disorders.

She also talks about how it can be difficult for males to get diagnosed with eating disorders, why males are thought to make up as much as 40-per-cent of eating disorders patients and why males can be misdiagnosed and slip through the net.

As the GP is often the first port of call for parents concerned that their son or daughter might be developing an eating disorder and, because faster referrals and treatment can lead to better outcomes, it's vital that GPs are aware of just about everything that is discussed in this excellent podcast.

Tuesday, 12 December 2017

In this day and age there is no reason for any GP NOT to recognise the signs of an eating disorder I

From having spoken to other families, it seems that it's a case of 'luck of the draw' as to whether you see a GP that understands eating disorders or a GP that doesn't. [This report from the Independent newspaper](#) backs up this assumption.

When I took my son to be diagnosed back in Autumn 2009, the GP didn't recognise the signs of an eating disorder. While putting together my book *Anorexia came to visit - Families talk about how an eating disorder invaded their lives*, I did my own research about GPs and eating disorders. Our local GP said she "probably had two lectures" on mental health and eating disorders as a medical student. Another medical student specialising in psychiatry was surprised to learn that males get eating disorders. And a representative from the RCGP told me that: "Currently only around 50-per-cent of doctors-in-

training for general practice have an opportunity to undertake specialist-led mental health or in child health training placements".

GPs are often the first point of contact for someone with an eating disorder and in this day and age there is no excuse whatsoever for anyone to "slip through the net" as a result of a GP not recognising the signs of an eating disorder.

Today there is so much information around about the latest evidence, advances, discoveries and research into eating disorders that there simply is NO REASON ON THIS PLANET why GPs, and indeed any medical professional who may come into contact with eating disorders, shouldn't know the facts.

Yesterday I posted [a link to a podcast](#) where neuroscientist, Dr Erin Parks of the UC San Diego Eating Disorder Center talks about "the range of eating disorders... as well as their neurobiological, genetic, and psychological roots". She talks about the typical "personality traits [that] are associated with such disorders, and how science has shed light on the development and treatment of various conditions on the eating disorder spectrum. [She also addresses] some of the myths surrounding eating disorders and what science has to say about them."

Basically this 47-minute podcast is a fantastic way for anyone to fast-track themselves through the eating disorder learning curve. I guarantee that anyone listening to it will know more at the end of those 47 minutes than they did at the start.

Let's face it, these 47 minutes could save lives...

The great thing about podcasts is that you can listen to them when you're in the car, in the bath, preparing a meal or waiting for a train. This podcast is just 47 minutes long, yet I believe it could be the most important 47 minutes that any GP could spend because, with eating disorders on the rise, the chances are

that they are going to come across someone with an eating disorder at some point.

Wednesday, 13 December 2017

Talking with other parents that 'get it' is so helpful and reassuring, in this case our battles with C-PTSD

Yesterday I met up with a dear friend who I originally 'met' through this blog. Like me, she had a teen with anorexia, and her experience of an eating disorder in the family was very similar to mine. So we hit it off right away when we initially corresponded by email and, later, met up in person.

My son and her daughter are now thankfully in remission from anorexia ('remission' or 'recovery'? I feel like it's tempting fate to say 'recovery'...) - and now our experiences are overlapping again. We are both suffering from PTSD (Post-Traumatic Stress Disorder) as the result of those years of battling to get our children through their eating disorder.

For some time now we've been debating about exactly what it is that has been going on inside our heads.

Is it PTSD? Well not really, because PTSD tends to occur after a single traumatic event, for example a serious car crash or being involved in a terrorist incident.

Well, OK, then, is it C-PTSD (Complex or Chronic Post-Traumatic Stress Disorder)? C-PTSD can occur after sustained trauma, for example childhood or marital abuse, and - of course - armed forces combat. Yes there's no doubt that we have been faced with sustained trauma.

But we're both tending to agree that what we have is Continued Traumatic Stress Disorder (CTSD or CTS) as [I described last week](#) because, although the primary trauma has gone (the eating disorders appear to be in the past), there

is the ongoing fear that the eating disorders may reoccur.

Relapse from an eating disorder is common, which is why we, as parents of young people who have suffered from an eating disorder, feel a need to keep our eye on the ball 'just in case'.

This is so we'll be ready to home in and fight, the moment there's any minuscule hint of any eating disorder behaviours in the near or distant future. If anything should re-occur we'd want to nip it in the bud as soon as possible.

And so our minds and bodies are in a state of continuous alert, albeit in varying degrees. For me I'm thankful to say that, currently, this alert and readiness is very low level.

But it's still there. We can't box it up, put it on a shelf and forget about it...

So there is this alertness mixed with all the other horrible symptoms that can come with C-PTSD and indeed any disorder on the post / continuous trauma spectrum.

Both of us have had, and are having, a very similar experience. Many of our symptoms are carbon copies of each other's.

Something like this is pretty horrible to go through, but what IS good about it is that we both 'get it'.

And, whether you're talking with other parents about eating disorders or the fallout that can affect our own minds following our child's eating disorder, it is always going to be massively helpful and reassuring to know that the other person 'gets it'.

Thursday, 14 December 2017

Is this blog actually of any use in the wider scheme of things, I wonder...

Ever get the feeling that you are a tiny drop in a massive ocean? Yesterday,

while I was trawling around the internet for the latest news on eating disorders, it suddenly hit me that - year upon year - we read reports about avoidable failures in eating disorder treatment, promised funding that never seems to materialise at grass roots level, failures of governments to take eating disorders seriously, media interest in eating disorders at times like Eating Disorders Awareness Week but at no other time, and - worst of all - deaths that should never have been allowed to happen.

Sometimes it seems as if nothing has changed and it's the same old merry-go-round year after year. And at times like these I really wonder whether minuscule activities like my blog are doing any good.

I feel like a grain of sand in the Sahara.

I know that, in reality, it's a case of lots of tiny ripples adding up to a tsunami. None of us can Change The World as individuals, but we can do our tiny bit to help to raise awareness and create change. Collectively, I hope, this adds up to quite a lot.

But when I see the same old stuff being reported year after year... when I hear the same accounts of avoidable tragedies, lack of awareness and understanding, and terrified families facing situations that are beyond their wildest nightmares... I get so disheartened.

I have always said that the primary purpose of this blog is to help other families to identify the symptoms of eating disorders in boys and get prompt, evidence-based help. The other purpose is to help raise awareness of the fact that boys and men get eating disorders, just like girls and women.

And I know this blog has helped some families.

But it doesn't stop me from being disheartened on occasions and wondering if, after blogging here for seven years (since January 2011), I'm simply writing stuff that no-one will ever read - and that my activities are so tiny and

minuscule that they couldn't possibly be of any use in the wider scheme of things.

Monday, 18 December 2017

Good news / Bad news... why I've got mixed feelings this Monday morning

First the Good News... Before the anorexia hijacked my son's life, Ben was at the centre of a fabulous circle of friends. Ben's birthday is in December and he'd get his friends round for a two-night sleepover with food and a cinema trip squeezed in between. It was a two-night event because Ben had so many friends that we simply couldn't get them all into his room. So half would come on the Friday night and swap with the other half for the Saturday night.

The final sleepover was just before Christmas 2009. At the time Ben was rollercoasting into anorexia and the sleepover was a disaster with Ben freaking out in the middle of the night, upsetting and frightening the whole household.

I prefer to remember Christmas 2008, 12 months earlier, when Ben held the final 'normal' birthday sleepover. This was the Christmas before we realised that anything was germinating inside Ben's head. The two-night sleepover was as riotous, fun and food-fuelled as ever.

Then came the eating disorder years - those years that robbed Ben of his friends and forced him to isolate himself, resulting in extreme social phobia, so much so that in early 2010 we had to remove him from school.

Ben never really got those friends back and it's only recently that he's begun to get back in touch with them again.

I remember Ben crying on his 18th birthday because it was just family. No friends, sleepovers, no parties, no trips to the cinema, no meals, nothing.

Although we tried to cheer him up with a weekend in Edinburgh, it was still a very depressing time, not to mention heartbreaking for us as parents.

As the eating disorder began to disappear, Ben began to make new friends and, this weekend, these friends came round for a sleepover followed by a cinema trip yesterday to see Star Wars.

It was just as riotous as the pre-eating disorder days and I should have been thrilled.

But I couldn't help noticing that, on the Saturday night, when the other boys sent out for pizza, Ben nipped up to the local Sainsbury's and returned with a diet meal.

While the others tucked into pizza, Ben tucked into a 'Be Good To Yourself' curry.

It is this incident that has remained with me since then.

Ben obviously still has anxiety about eating certain foods, especially when he doesn't know how many calories are in them.

It's left me feeling really low because why the heck, more than eight years since the eating disorder first emerged, is he still counting calories and avoiding certain foods? Why does he still go for diet foods? And why won't he talk to me about it when I challenge him?

I would hazard a guess that the answer lies in the fact that he weighed himself a month or so ago and told me he'd put on 5 kilos, taking him over and above the low weight which CAMHS insisted was right for him. He is still terrified of creeping over and above this weight even though, as a pre-eating-disorder teen, he was never ever that weight.

I would hazard a guess that this is what the problem is.

That, and Christmas looming, with all its food...

Tuesday, 19 December 2017

Two meltdowns in one day...

Ben was in a heck of a mood all of yesterday - a true 'downer'. The first meltdown was at lunchtime and the second in the evening. I didn't even mention the diet meal from the weekend until part-way through what ended up as a shouting match between him and me. He insisted the diet meal choice wasn't anything to do with any of this. (I'll put that into the 'pending' file inside my head for now as there's only so much I can deal with at once...)

Ben is already on anti-depressants and has been since the eating disorder treatment days. Now he believes he is suffering from a raft of different mental health problems which, in the end, we managed to boil down to just a couple of possibilities.

But whatever the problem is, or problems are, I continued to say that he needs to get a proper diagnosis followed by proper medication (if applicable) and therapy. I said that there's a limit to how many times we can be sympathetic if he isn't doing anything about it.

There was a ton of stuff came up which I can't even begin to blog about here and probably shouldn't for privacy reasons.

Suffice to say that I found it mega heart-breaking not to mention triggering. It was as if my head was screaming at me that it couldn't go through anything even vaguely resembling what we'd already been through in the eating disorder years. I had a huge impulse to flee. So I got in my car and just drove...

In the evening - this time with my H there - we had a similar "discussion".

Sadly he didn't enjoy his birthday weekend at all. He felt blank. Nothing. Zilch.

Anyway to cut a very long story short, as a starting point I told him to self-refer to the NHS for a diagnosis.

Watch this space to see if he does...

I don't believe he will opt for therapy. He has a real negative thing about therapists possibly as a result of a university therapist who was about as much use as a... well... who wasn't that brilliant.

Meanwhile, please can I fly off solo to a remote desert island somewhere and come back in the spring? Because I sure fire don't want to "do Christmas" this year.

Tuesday, 19 December 2017

A bit of a tricky one, this...

For so very long I claimed that my son was anything ranging from 95% to 99.99% recovered from the eating disorder that emerged in 2009, was treated between 2010 and 2012, and then self-managed from then onwards after discarding various private therapists. Or even that my son was / is "in remission".

The thing that was holding me back from saying 100% recovered was this insistence on counting calories every single day, opting for diet meals / products and a reluctance (but not refusal) to dine at restaurants which don't have an online calorie chart. Quite often he's gone for the salad option even if, on the positive side, that salad option usually appears to be quite weighty in calories.

I have challenged him about this several times and his response has always been that, by doing this, he can eat loads more food. In other words, he gets more food for the calories.

It's not that he's been cutting back on the calories; in fact he's put on weight. 5 kg at the last count.

He still has two breakfasts, lunch and dessert, evening meal and dessert plus snacking through the evening.

So he is eating enough.

But what he does appear to be doing is controlling that eating to ensure he doesn't eat "too much" for fear, presumably, of "getting fat".

It's a tricky one, this, because on the one hand you know he's getting enough food and eating healthily while on the other hand you know that he is controlling his intake.

This is why I've always felt nervous when claiming that my son is fully recovered from his eating disorder.

And, of course, none of this was helped by CAMHS permitting him to aim for a lower target weight because his interpretation of that is that it was the correct / healthy weight for him.

Tuesday, 19 December 2017

The questions I don't have the answer to. Do you?

What constitutes full and absolute recovery from an eating disorder? Can anyone ever fully recover from anorexia without the risk of relapse? How many "recovered" individuals still count calories and control their food intake, albeit while eating enough to put on weight and / or maintain? Can anyone ever lose the fear of "getting fat", especially if they continue to put on weight? Can anyone ever be shot of the so-called co-morbid mental health issues like depression, Aspergers, bi-polar and so on? Is there anyone on this planet who is completely symptom-free of any of these things? And, if so, is that what

constitutes full recovery from anorexia? Should we never be talking about "recovery" from anorexia, rather "remission"?

I don't have the answer to any of these questions and I wonder if any of you do, because it's really tricky to know when something isn't OK and when it probably is OK - or at least the best we, as parents and carers, should ever expect.

Which takes us back to CAMHS' famous "we're happy to settle for 'good enough'" comment.

When should we parents be worried? Should we ever take our eyes off the ball? Are we going to be walking on eggshells and fraught with anxiety until our dying day? Will we continue to battle with issues of our own such as C-PTSD or whatever it is you want to call it?

Are our own battles with trauma-related issues untreatable because they may not ever be part of the past, rather part of the present and future.

I really, truly and honestly don't know.

In an ideal world, we'd be watching our 100% recovered, symptom-free, happy child skipping into the sunset, a marvellous fulfilled life in front of them.

But is this too much to expect?

Wednesday, 20 December 2017

Hopefully things will move in the right direction

Yesterday Ben self-referred himself to our local NHS mental health team - I'd told him that he needs to get properly and accurately diagnosed so that he can seek the right help, whether that's medication or therapy. Although, as I said before, there are still sticking points with Ben's reluctance to give up calorie counting and insistence on going for diet meals on the (rare) occasions we

don't cook at home. But I do believe that he isn't going backwards as far as the eating disorder goes. I believe that the other mental health issues (Aspergers? PTSD? Bi-Polar?) are separate problems. Having said that, I am keeping my eye firmly on the ball.

These days Ben's weight is pretty OK and for the past four or five years he's been eating a very healthy balanced diet. It's just this calorie-counting sticking point and the fear of throwing caution to the wind as regards eating.

We had a chat about it all yesterday when he was in a better mood. I wanted to kick the wall when he began to quote his CAMHS psychiatrist, though. "She said this... she said that..." (about Weight Restoration) so, to him, her words are gospel...

Aaarrggghh!!!

Friday, 22 December 2017

"I should have been able to fix the anorexia" Ben said yesterday

I was just about to cancel Christmas due to the all-pervading sense of gloom in our household when Ben walked into the room and began to talk about what's been bothering him. Yes, he suffers from depression (we already know that and he's on a low dose of anti-depressants) and we also wonder whether he may have PTSD. After all, why wouldn't he suffer from it? He went through the prolonged trauma just like we did. However we've both decided to wait for an official diagnosis and then take it from there. He has agreed to do whatever is required to help him manage it, whether that's medication or therapy - or a combination of the two.

What was so sad, though, was that he feels responsible for the eating disorder. He feels that it was his fault that he didn't pick up on it and "snap out

of it" during that summer of 2009 when the ugly green shoots began to emerge. He feels that he is to blame for all those "stolen years" from our family's lives and for "messaging up" my head with PTSD and so on.

"You weren't to blame," I said, "You know eating disorders are a mental illness. It's the way your brain is 'wired up'. Genes are involved and you can't help your genes. It's like you can't help having blue eyes or freckles; they are part of your makeup. These things are PHYSICAL. The brain is PHYSICAL. Of course it is - it's part of the body.

"Or look at it this way... If you'd had a childhood illness, for example leukaemia, which meant having to put our lives on hold to support you through it, would you blame yourself for developing it? No, of course not, that would be crazy. The eating disorder was no different."

"But I should have been able to fix it when it started," he insisted.

"Ben, *none* of us knew what we were dealing with back then. We didn't know that boys get eating disorders. We didn't recognise the signs - signs which I now know are textbook symptoms of emerging anorexia, especially in boys. This is why I blog - to help other parents to recognise the signs. If you'd developed anorexia today, you'd have been diagnosed, referred and into treatment - *evidence-based* treatment - far, far faster. I really believe this. But none of us is to blame for this not happening back then."

This is just one of the topics that came up in our long (and hopefully fruitful) conversation yesterday and it's one of the reasons why I believe that the issues Ben is struggling with at the moment are not a relapse back into the eating disorder.

That, at least, is Good News and I feel a heck of a lot better for it.

And for our talk.

Friday, 22 December 2017

Mourning the "lost years"...

Ben feels a deep, deep sadness at the way the anorexia stole so many years out of his life - and out of our lives, too. There's a real sense of mourning the "lost years": the years from 2009 onwards. He hates the way the eating disorder isolated him from his friends and all the fun things he could have done during those last three years at school. Although he still sees his old school friends on occasions (like tonight, for instance), it's nothing like it used to be, with Ben at the centre of things. He still feels that his friends treat him as "different" and he hates this.

In fact he hates the eating disorder with a vengeance.

He hates what it did to him.

He hates the way it destroyed so much of his life when things had been so promising.

He also hates the way society is so geared up to "the way you look", the body beautiful, the perfect physique and so on. Although society's obsession with body image doesn't *cause* eating disorders it can trigger weight loss as young people strive to be what they are not. But they *aren't* airbrushed perfect people. The world is full of beautifully "imperfect" bodies. Perfect bodies only happen in Photoshop.

Thankfully only a very small percentage of people who diet go on to develop an eating disorder because, it's believed, they are "predisposed" to developing the illness. In other words, it's down to the way their brains are "wired up".

And, as was demonstrated during World War II in [the famous Minnesota Starvation Experiment](#), substantial weight loss and starvation can result in the brain beginning to behave strangely which is when the "textbook symptoms"

of an eating disorder can emerge.

It was this social pressure to "look perfect" - the drive to get a six-pack and a beautiful body - that resulted in Ben, who had always been highly critical of himself, losing weight.

And then losing more.

Until he simply couldn't stop.

As I said to him yesterday, things might have been different if he had developed an eating disorder today, in 2017.

In our city, young people with eating disorders are (in theory) fast-tracked into The System much, much quicker. They also receive evidence-based Family Based Treatment (FBT). So if Ben had developed an eating disorder today (and we'd been aware of the symptoms), he might not have lost so many years to the anorexia.

But, as I also said to him, we can't change the past.

And, despite everything, there are Good Things that came out of the experience: Ben's fortitude and courage as he refused to let the eating disorder steal any more years from his life is a major example.

He fought and overcame an illness that can and does kill.

This mourning of the "lost years" is another reason why I don't believe that Ben is heading for an eating disorder relapse.

But, of course, I will always keep my eye on the ball "just in case"...

Sunday, 24 December 2017

What a contrast to the solitary eating disorder years...

Late yesterday evening we finally managed to pin Ben down to give him his birthday presents! Ben was 24 yesterday and had spent the past 24+ hours

partying with his friends, both old and new. After dropping off the final friend at their house, he popped into the supermarket and returned with a feast of party food which we ate together in front of the fire and TV after handing Ben his birthday presents.

And this time, Ben had actually enjoyed himself!

What a contrast to the solitary eating disorder years...

I have photos of past birthdays and Christmases... 2009, 2010, 2011, 2012... Ben opening his presents alone without any plans to do anything except spend the day with the family.

So the contrast over the past couple of days has been massive.

And very positive.

I wish you all a peaceful, happy and eating disorder free Christmas.

Tuesday, 26 December 2017

'Twas the night after Christmas and all through Bev's head, everything was stirring and about to kick off big-style... Delayed PTSD panic attacks after Christmas.

I know from experience that Christmas / the Holidays can be a tricky time for parents of young people with eating disorders and so I very much hope that the eating disorder didn't interfere too much with your festivities. I know how distressing it can be to watch the world going on around you, preparing for Christmas just like any other year, while, inside the house, the eating disorder is running riot. I was "there" at Christmas 2009, 2010, 2011 and, to some extent, 2012.

Following those years I've battled with my own demons at Christmas thanks to C-PTSD (Complex / Chronic Post Traumatic Stress Disorder). The worst C-PTSD Christmas attack was last year when I couldn't do anything. No cards, no

carols, no Christmas Eve carol service and - if I hadn't made myself get out of bed and "just get on with it" - no Christmas Day. The [2016 C-PTSD attack](#) took me by complete surprise and just goes to show how you can't always control what the body / brain needs to do.

So I was kind of surprised this Christmas Eve and Christmas Day to feel relatively OK. Not 100% OK but a million times better than last year. I listened to carols, I went to the Christmas Eve carol service and I survived Christmas Day.

Until the evening...

And, worse still, *the night*.

It was almost as if my brain needed to blow a fuse.

As if, unbeknown to me, it had been simmering away all day waiting to explode.

During the night I had a series of panic attacks - the sort that wake you up shouting or gasping. Some were so bad that I couldn't get back to sleep for some time afterwards. I felt truly traumatised.

As a result I am knackered today and ache all over. (And, no, I didn't overdo the festive vino on Christmas Day!!!)

So this morning I found myself Googling "delayed panic attacks", "delayed anxiety attacks", etc and discovered that this isn't unusual. It's as if the brain simply has to do its stuff at some point and so it does it at a time when the individual is most relaxed - at night. Or, even better, when they are asleep because in sleep there is no conscious or unconscious effort to suppress the anxiety.

Curious, that.

So if this has happened to you over the Christmas period, rest assured you are not alone.

Tuesday, 26 December 2017

"Is today proving that I'm fully recovered from the eating disorder?" said Ben on Christmas Day

"Is today proving that I'm fully recovered from the eating disorder?" said Ben yesterday (Christmas Day) evening. I gave him a massive hug in a response. Really and truly if you had been a fly on the wall yesterday, nothing in Ben's behaviour would have hinted at any history of anorexia. Ben enthusiastically devoured more than one helping of Christmas dinner followed by a couple of helpings of Christmas pudding, white sauce and Christmas ice cream - and continued to snack for the rest of the day.

And so I am not at all sure how this triggered my evening / night time panic attacks, but it may simply have been the fact that it was Christmas. Also we were celebrating Christmas at my sister's house which is where we spent Christmas Day in 2009, our first and worst Christmas with the eating disorder. So that may have acted as a trigger, too.

But the Good News is that Ben was absolutely fine - mood wise and food wise.

Thursday, 28 December 2017

Shaking hands with his old school teachers / rugby coaches

Last year I didn't do anything on Christmas Eve; I was in the throes of a C-PTSD attack. But this year Ben and I actually made it to the annual carol service which is held in the school chapel every Christmas Eve. We've attended it every year since 2005 (except for last year and one year when it was cancelled due to snow), even through the eating disorder years. This year was the first time,

since the terrible Christmas of 2009 (when Ben was roller coasting into anorexia), that I haven't felt triggered in some way.

We arrived just as the congregation was singing 'Hark the Herald Angels Sing' and squeezed into a pew beneath the upstairs balcony. On our left was Mr J, one of the Deputy Heads (now retired) and Ben's former rugby coach from one of the years before his eating disorder emerged. On our right was Mr H who'd been head of rugby back then and who was one of the first people to voice their concerns that something was very wrong with Ben.

By that time (Autumn 2009) Ben had lost a heck of a lot of weight and, as the eating disorder's vice-like grip got stronger, his behaviour began to get out of control. Amongst a long list of other distressing and out-of-character things, Ben had been seen in the school gym, exercising like a robot. Mr H and one of the other PE staff were getting increasingly worried which was why they had a word with Shirley, the school nurse, and why she called me in for a chat which resulted in my husband calling the GP and insisted on a referral for eating disorder treatment.

But, this Christmas Eve... 2017... here I was singing Christmas carols next to Ben who looked absolutely amazing and was in a Good Mood. I could see the two girls in the pew in front of us taking sneaky looks and I felt was a tremendous sense of pride at having such a good-looking son, not to mention a son who'd excelled academically at university and - MOST IMPORTANT OF ALL - a son who had kicked the anorexia out of his life.

Then, after the service, both rugby coaches came straight over to shake Ben's hand and ask how he was getting along. Mr H commented on how "very well" Ben looked. The contrast between the Ben of Christmas 2009 and - worse, due to the loss of even more weight - Christmas 2010 and this Christmas Eve was evident for all to see.

Meanwhile, I stood there, bursting with even more pride as Mr J instructed me to "make sure you bring him along every Christmas" and I replied with: "These days it's *him* who brings *me* along!"

Friday, 29 December 2017

When your concerns that your son or daughter is developing an eating disorder aren't being taken seriously

The thing is, we parents are unique. We know our son or daughter better than anyone else in the universe. We have lived with them since the day they were born, and for the nine months beforehand. We have watched them develop and change at every stage of their young lives. So if things start to go wrong and the alarm bells begin to ring inside our heads, our unique sixth sense picks up on it and we begin to worry.

Okay, some of us may not immediately recognise the early signs of an eating disorder like anorexia. Back in summer 2009, my husband and I didn't. At that time we didn't know that boys get eating disorders, just like girls.

But even so, as the weeks went on, we knew there was something seriously wrong with our son. As the weight loss and associated behaviours became worse, we began to Google the symptoms.

'Anorexia' and / or 'eating disorder' came up every time.

The point is that, as parents, by the time we take our son or daughter to the GP, we may be pretty certain of what we are dealing with.

It may also become clear to us that the eating disorder has been germinating inside our child for some time.

This means that, by the time we take our child to see the GP, the eating disorder can be quite advanced.

Never forget that you can't tell if someone has an eating disorder just by

looking at them. It's not as if our children don't develop anorexia until they are skeletal thin. The green shoots can sprout months or even years before they get to this stage.

Indeed it is possible to be seriously ill with anorexia and yet 'look relatively OK' to people who haven't known the child from birth.

As parents, no-one is better placed than us to recognise when something is seriously wrong with our child and, like any potentially deadly illness, we expect healthcare teams to take urgent action.

Just as they would if we were visiting the GP with a worrying lump or bleed.

SO WHY ARE THERE STILL GPs AND EATING DISORDER TREATMENT TEAMS THAT AREN'T TAKING THE CLASSIC SIGNS SERIOUSLY?

Why are families *still* being sent away and children still being left to get even more entrenched in an illness than can and does kill?

Why are our concerns, as parents who have known and nurtured our child from birth, *still* not being taken seriously?

Why are GPs and other professionals *still* listening to our children but not to us when it's a recognised fact that many young people believe they are perfectly OK when they are, in fact, very sick indeed? Why are we *still* seen as 'helicopter parents' getting 'over anxious' over nothing?

Why are there *still* parents who have to virtually chain themselves to railings in order to get something done?

Why are parents *still* having to fight the medical profession at the same time as fighting for their child's life?

It is time that every medical professional from the GP upwards was thoroughly schooled in eating disorders and their treatment. *Evidence-based treatment* such as FBT, not older treatment models that have been proven to be less effective for many adolescents with anorexia.

Because until this happens, there are *still* going to be far too many young people who will slip through the net and end up in hospital on the end of a tube.

Or worse.