

Anorexia Boy Recovery

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

Part 2 – 2012

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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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JANUARY 2012

A summary of our story in the lead up to treatment

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

being treated for anorexia.

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

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

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

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

I hope this PDF proves useful to you.

Monday 2 January 2012

So, someone asked me recently, what role has Ben's dad played in all this?

I am aware that I don't often mention my husband and his role in helping our teenage son, Ben, to recover from anorexia. That's mainly because, for the first year or so, he was working away from home. Poor bloke - all he ever got was grief over the telephone as we lurched from one crisis to another. "I'll phone dad" was a threat I'd use when Ben's behaviour got completely out of control. Not that it did any good and it only upset his dad who, no doubt, felt pretty helpless on the other side of the country.

At first I felt as if Ben's dad was blaming me for the eating disorder. He still believes that Ben has my dad's OCD-style "gene" which, for some reason, I tend to take personally although that is ridiculous. On bad days I'd respond with "What about *your* family's mental health problems..."

Of course none of this was helpful to anyone.

When Ben's dad was at home it was fantastic to have support in the house. Managing an eating disorder (ED) as (what was in effect) a single parent most of the time was a tremendous strain. Mind you, when he returned we'd often end up having a massive row – ED-induced, of course... But at least with Ben's dad around I was able to take time out now and again. This almost always took the form of me fleeing from the house because I couldn't bear the ED atmosphere any longer, box of tissues in hand, sometimes some cookies or chocolates for company, and I'd drive out to no place in particular knowing that, at some point, I'd have to return home to the ED...

Or I'd retreat to my bed in tears and stay there, like some kind of protective fox hole, while Ben's dad dealt with the latest ED rage or whatever it was.

From a learning curve perspective, Ben's dad read one book on eating disorders. But after that it was down to me to pass on what I had learned. At one point we were

getting mixed messages - our treatment team was saying one thing and yet other ED connected people I knew were saying something else. Ben's dad lurched from favouring one school of thought to favouring the other.

Then he'd accuse me of spending too much time with my "cronies" on the ATDT forum (Around the Dinner Table, for parents and carers of young people with eating disorders – see end of book for a link), despite it proving a lifeline for me. "What do they know?" he'd ask. But then he met up with some of them and changed his opinion. So sometimes we were "singing from the same hymn sheet" and at other times we were at cross purposes.

Despite me telling him over and over again that we, as parents, are not to blame for Ben's illness, he'd often wail: "Is it something we've done? Is it something I've done? Maybe I should have spent more time with him and it would never have happened."

Or he'd accuse me of being "too soft" with Ben and "mollycoddling him", resulting in the eating disorder. Sometimes he felt Ben's school was to blame and we should have sent him to the rough local comprehensive which "would have knocked some sense into him".

As I learned more about eating disorders I'd do my best to explain that none of these things "caused" the eating disorder. It would probably have happened however Ben was brought up, whether or not his dad had to work away from home and whatever school he had gone to.

Ben's dad did find it harder to manage the ED when I wasn't there - for instance the couple of occasions he took Ben to see his parents down south. And both of us went through periods when we felt we simply couldn't cope or go on. Thankfully these periods didn't coincide so we were able to support each other to a certain extent.

On one occasion Ben's dad felt so stressed by an early morning ED rage that he was involved in a near fatal road accident. So, on the whole, I have tried to keep the

worst of the ED from him. After all, he's been the primary breadwinner during this horrible journey and needed to be able to keep a relatively ED-free head at work. I whittled my own self-employed business down to just a few hours a week months ago so, for me, ED management has become my full time job.

But strangely this has meant that sometimes he feels "left out". Ben and I have become such a strong team during the past few months as we've forced the ED out of his life that it's brought us tremendously close. Ben's dad has missed out on this and he feels a bit alienated.

Despite trying to keep him up to speed with progress, Ben's dad still interprets certain behaviours and comments as ED-fuelled when they are not, so I have to put him right.

But all in all we've managed to get through this together and emerge as a reasonably strong unit of three: Ben, his dad and me.

Thank God.

Tuesday 3 January 2012

Back to the university's Disrupted Studies form...

Cue Version One Zillion as I attempt to construct the framework for Ben to write a supporting statement for the *Disrupted Studies* form, explaining more about how the anorexia has affected his studies over the past two-and-a-half years – and why. When I say "framework", I mean something that he can take and put into his own words. It's important to get this right. After all, the university knows very little about Ben's background over and above the limited space allowed on the UCAS university application form.

It's difficult to know what to say without appearing to be too dramatic or risk appearing to "hype things up". You and I know this illness is so incredibly alien to anything the normal brain can comprehend, with a mammoth learning curve, that -

although we know I am not over-dramatising things - I worry it may seem like this to the “uninitiated”. Or maybe I haven’t gone into enough detail?

Mind you, I expect the university will have come across other students with anorexia in its time, so there may be some level of understanding.

Basically I’ve attempted to explain how the illness meant that Ben missed enormous chunks of schooling between summer 2009 and now which doubtless affected his ability to study effectively and may affect his final A-level examination results in the summer.

This will be supported by an additional statement from the school and another from his psychiatrist.

The thing is, I know Ben is easily capable of succeeding on this particular degree course at this particular “red brick” university. The problem is convincing the admissions tutors that this is the case.

If the form does its job then there might be slight flexibility as regards exam grades. Not massive flexibility, but at least some.

In an ideal world Ben will get the 3 x A grades required to take up the offer they have already made him. But it all hangs firstly on the AS Level re-sits he has to do next week and the week after, and then the actual A-level exams themselves in the late spring.

Ben is even prepared to visit the tutors in person if they will see him - to “sell himself” to them. But I very much doubt if they’ll agree to that...

Monday 9 January 2012

Like a bolt of lightning

I was completely unprepared for the way it hit me yesterday - the sheer force of heart-break emotions as, there in front of me, stood “what might have been” or, rather, “what *should* have been” if it wasn’t for the way the eating disorder had

stolen such a massive chunk from Ben's teenage life.

It was *Founders Day* at school; the bi-centenary service. Along the route from the car park, snaking through the school grounds, stood pairs of prefects, all smartly dressed in their school *colours*, guiding alumni, governors - and me - all the way to the gothic school chapel.

Each one of these prefects was from Ben's social group - the young people that had been his bosom pals throughout the first four years of high school and, if it hadn't been for the way the ED robs its victim of their social life and skills, who would still be his bosom pals today.

But this wasn't what hit me like a violent bolt of lightning. It was the fact that *all* of them were there. All of them, except Ben. And they all looked healthy, happy, mature and confident - just like 18 year old senior school pupils should look.

Their school careers had gone from strength to strength, culminating in the role of prefects in the school's most important year since its centenary in 1912. They were the epitome of what I had dreamed for Ben when he won an academic scholarship to that wonderful school, all those years ago. A school that had produced, amongst its current alumni, CEOs of top corporations, law lords, heads of the armed forces and so on.

Mind you, I'd never dreamed of Ben becoming General Sir Thingummy Whatsit or The Lord X of Y. All I'd wanted for him was a happy, supportive place in which to study - a school known for its ability to nurture pupils to achieve their full potential, not just academically but personally, too.

And that had happened. For the first four years, at least. Ben was happy, confident, sporty and academically bright, one of the most popular boys in his peer group and a rising star on the rugby field.

Physically, he was transforming from a boy who'd carried a bit of "puppy fat" into a handsome, athletic young man. I was so proud of him that it hurt.

So here, lining the route from the car park to the school chapel, were all Ben's

friends. One after the other, all the way into the chapel, culminating with the Head Boy: the boy who had been Ben's academic, sporting and social rival yet close friend through those first four fulfilling years at the school, a boy who could have been his school "twin" in almost every way, even physically.

But not now.

Here was what Ben could have been, what he *should* have been, but wasn't, thanks to the ED. Over six foot tall, athletic, confident and oh so grown up.

One by one I acknowledged Ben's friends in that long line up to the chapel, my heart breaking in a way I hadn't predicted.

Ben should have been there with his friends, looking like his friends, behaving like his friends. And I should have been making my way to the chapel as proud as proud can be about the way the school had nurtured my son into "one of the class of 2012".

Instead my heart was breaking at the way the eating disorder had stolen a promising school career from him. The way it had robbed him of his friends and social life. The way it had stunted his growth and physical development. The way it had completely transformed his life, and ours.

I wish I'd stayed at home.

Monday 9 January 2012

The gleaming spires of Christminster

In Thomas Hardy's *Jude the Obscure*, Jude dreams of aspiring to the "gleaming spires of Christminster" (university) which he could see in the distance. For several years, when Ben was small, I'd drive home from work over the high moorland looking towards my own "gleaming spires", as I referred to Ben's school back then.

As a product of the 1970s axing of the UK grammar schools when the girls' high school I attended stopped being a grammar school, went co-ed and went downhill at a fantastic pace and destroyed my own school career, I was determined to give my

son the best educational experience I could afford.

When he was little, I worked as a full-time freelance copywriter, stashing away the cash for the fees. I hated working as a freelancer “in house” where I was never treated as well as the permanent staff, given the worst desk, the worst computer and the worst jobs. They’d work me like a Trojan to get their money’s worth. Yet my drive home would take me up over the moor where, down in the river valley below, I could just see my own “gleaming spires”: the focus that kept me going through all those years.

With any luck and with a heck of a lot of hard graft I could send Ben to private school - the one school in the area where I knew he would not only receive a great academic education but where the ethos was all about nurturing “the whole child”. Unlike my own school experience, he would have every chance of loving every moment. And, after all, school is supposed to be the best years of your life.

I also knew, as I glanced over the moorland to those “gleaming spires”, that before long I’d be able to quit that horrible office and set up my own business from home. It didn’t matter if my income went down because interest rates and the stock market were high. With a little help from a scholarship (pray God he’d win a fee-reducing scholarship!) that school was now within reach.

Around the time I quit that office, Ben did win an academic scholarship. I was over the moon. I revelled in every moment of helping him prepare to become part of the “gleaming spires” community. We were both terribly excited and weren’t disappointed when, aged 11, Ben put on his smart new school uniform and set off for his first day at the school.

Over the next four years he thrived, exactly as we’d dreamed. Better than we’d dreamed. He was usually in the top two or three pupils in his form. He was in the choir, in drama productions and a rising star in the rugby team. He was confident, enthusiastic, respected, popular and extremely happy with glowing school reports from beaming tutors.

Everything I had dreamed about was coming true; the spires weren't just gleaming, they were positively dazzling. Until the ED came along and robbed us of our dream.

Tuesday 10 January 2012

As if to rub salt into the wound...

Like some dreadful pop song you can't get out of your head, the School Song has been playing in my mind on a non-stop loop since it was sung in the school chapel on Sunday. I went to bed trying to push it out of my head. It was there at each of the five or six times I awoke during the night and it is still here this morning.

English public (private) school songs are cheesy at the best of times. Unfortunately, when you consider the Topic of the Moment, this one is all about "friends" - the unbreakable bond of school friendship. *"... Be it to our friends a token of a bond of love unbroken... old and new friends, all we cherish... minds and hearts with love entwining... mindful of her friends for ever..."* etc etc etc etc.

It's as if the ED demon is gleefully tapping away at the school organ, his demons chanting the School Song at me, over and over again... aaaarrgggghh!!!

If you hadn't gathered, I was on a bit of a downer yesterday. I didn't tell Ben; I just said I didn't feel well, and I went to bed early (School Song playing on loop, of course...)

The school term starts today and yesterday I asked him if he'd be spending the whole day at school. "No point," he responded. "No point in standing there all alone over lunchtime when I can be at home doing something useful and with people that actually *talk* to me."

He has completely given up trying to salvage his friendships. He has decided that his social life is beyond help and he will spend the rest of this academic year knuckling down and studying. To hell with his friends, they might as well not exist. Not surprisingly, he hasn't been in contact with any of them over the Christmas

break.

Regardless of what I say, what his dad says or what his therapist says, his mind is set. And he refuses to spend a full day at school because it will mean spending the lengthy lunch hour alone.

Meanwhile he seems to have dropped all the activities that staff set up to help him integrate back into school: a part in the drama production, person in charge of *house* charity fund raising, etc. All the potential new friends who he talked about a few months ago, in the year below, seem to have evaporated into the ether.

“Let’s face it, mum,” he said, “I am not going to have any friends until I go away to university.” And meanwhile that confounded School Song continues to play on loop in my head, especially relevant in this, his friendship group’s final year at the school:

“... *a bond unbroken, to departing friends our token...*” followed by an unpronounceable greeting / parting word in ancient Greek.

I’ve got my own unpronounceable word for this situation, in ancient British...

Me, being me, I can’t just let this lie. I can’t sit here and do nothing. Good God, these friends are *nice* people. Many parents dread their children getting in with the wrong crowd but Ben couldn’t have gotten in with a nicer crowd - girls as well as boys.

It did cross my mind on Sunday whether I should have a quiet word with the girl who’s shown Ben the most support during his illness. But, as my husband rightly said, that might be putting too much pressure on her. Never forget these kids are studying for the most important school exams of their career; it’s not fair to put extra pressure (and possibly a feeling of obligation and - unintentional - guilt) on them.

But what I have done is fire an email off to the school nurse to see if I can pop in to see her. In the early days of the eating disorder, she was a pillar of strength and we became great friends. We haven’t been in touch recently, so it’s a good opportunity to catch up. I can’t think of anyone else I could talk to who might be able to help.

Bloody eating disorder.

Tuesday 10 January 2012

Dieting MAD!!

It's that confounded time of year when all his female friends seem to be able to talk about is *diets* and how few calories they have consumed that day. It is driving Ben *mad!* He finds it really, really difficult to handle being around people that are talking about diets - I mean *really* hard...

He's worried that it triggers off certain ED thoughts and responses in his head. Okay he insists he'd never act on those ED thoughts and responses, but he says all this is making things really hard for him at the moment. As a result he says that things that may seem like old challenges may re-surface when we talk about how the day has been with our Recovery Contract (yes that is still going strong).

And crazily, crassly and stupidly we were in the waiting room of our local CAMHS-cum-ED-unit last night waiting for the drama therapy group Ben goes to on a Monday. On the wall was an NHS poster asking: "Do you know how many calories are in your drink?"

We both noticed it, independently, and couldn't believe our eyes.

I said I should have got out a marker pen and written: "Not bloody enough, that's what!"

(Post script: I called the unit to bring this to their attention and they said they'd investigate.)

Thursday, 12 January 2012

If you don't succeed at first...

If you've read through my blog you will know that the main bone of contention between me and our treatment team (now comprising just the psychiatrist) is that,

throughout the treatment, I have believed that their idea of weight normalisation / restored is *too low* for Ben.

Over the past couple of years I have constantly argued this fact only to be shown chart after chart showing that, at his present weight, he is within the healthy weight range for his age and height.

Currently, the psych is insisting that he is weight restored - and constantly checks that Ben is “happy with” this weight.

That, too, is a bone of contention because I don't believe you can ask a recovering anorexia sufferer to “choose a weight” they feel “happy with”.

Now, I really like this woman and she has worked marvels with Ben. He is in a very different place now from where he was a couple of years ago when we started treatment. Unlike many of the other therapists which couldn't have made it more obvious that they were simply doing the job they'd been paid to do and switched off the moment the session was over, she has built up a great relationship with Ben and comes across as a Real and Genuine Person who truly cares about him. Our sessions almost always run over time and I suspect she's missed many a lunch-hour due to us.

But she's difficult to get hold of in private i.e. without Ben around. Being the NHS, we're not allowed to phone her directly (we have to leave messages which don't always get passed on). We're not allowed to email, either, or just drop in at the unit to see if she's around. This isn't her fault; it's been agreed by the management.

However I have managed to pin her down for a private meeting tomorrow and will be producing a photo montage of 2008 – the year before the weight loss - printed out in A3 colour. To be honest, I don't know why I haven't done this before. In fact I'm busy beating myself up about it.

Is it just me or is it obvious to everyone that sees this montage that Ben's natural build needs to be bigger than it is now? It is also pretty obvious that, over the past three summers (2009, 10 and 11), Ben's overall look hasn't altered much. He was skinny and he still is. Look at his legs - that's what I always look at...

Yet Ben would argue that, back in 2008, he played rugby and did a stack of other sports and that's why he looks so athletic.

He would also argue that, prior to 2007 / 8, he was "fat" and he still believes that's what he could easily return to if he doesn't watch the calories. (Hmn, I say...)

So I shall see what the psychiatrist has to say when I put this in front of her tomorrow morning.

Monday, 16 January 2012

So how did the psych meeting go on Friday?

Well I whipped out the (huge A3 version of the) photo and thrust it onto the desk in front of the psychiatrist. She could see my point. She also told me that it was obvious to her that his bone structure / build needs to carry more flesh.

The long and the short of it is that, yes, she does realise that Ben needs to be heavier, but first he needs to adjust to his present weight, just as in the past he's been given "time to adjust to lower weights" before moving onwards and upwards.

Push for too rapid a weight gain and you risk things going pear-shaped, maybe even unintentionally encouraging some purging, she said. She's seen that happen quite a lot.

I could see her point.

But what I didn't understand was why she keeps implying to Ben that his weight is okay as it is now. Why does she have to say anything at all?

I said that he believes he is now fully weight restored and that it's okay to remain at this weight for ever and ever Amen.

So I asked her if she would mind not doing this. It's counterproductive and it could make things harder for us when we push for additional weight gain.

The trouble is - she leaves in March on sabbatical and we have just four or five sessions until then. So it will probably be me that has to push him a little higher.

I told her that Ben respects her advice enormously and I know that the need for this extra weight would come better from her.

We talked for a whole hour - about weight, about the photo, about the future, about Ben's transition to university and about formulating a relapse prevention scheme.

But again I reminded myself that we have just a handful of sessions left to do all this...

We will be seeing someone else whose job it is to smooth out the transition between treatment and major life changes like going to university or moving into Adult Services, so that's good. Or at least I hope it is.

Anyway, I made my point at the meeting. I kept the photograph in front of us, often interrupting her as I returned again and again to "the perfect physique" from 2008. And I emphasised that, by implying to Ben that his present weight is weight restored, we risk settling for "good enough" instead of "excellent".

Thursday, 19 January 2012

CAMHS sessions going from strength to strength...

...Just as we are about to lose our psychiatrist who is on a sabbatical from March... So we have a heck of a lot of loose ends to tie up before then.

This morning - in response to Ben's remark that, although he was well aware that his "mind was screwed up" at the height of the anorexia, he wasn't entirely convinced his body was in danger - the psychiatrist immediately put him right.

She said that, although it's far easier to pinpoint when girls may be starting to damage their bodies through lack of nutrition, because their periods stop, it's not so easy with boys. However she pointed out to Ben that, with him, there were other factors which were shouting loud and clear that all was not right with his body.

He was terribly thin and underweight, for a start. Twice he developed a

dangerously low pulse rate (29bpm) and was admitted to the local cardio unit for observation. His blood pressure was also very low. She explained why, with anorexics, both of these can be indications that the heart as a muscle is suffering and, in some cases, it can kill.

“This is why I took it so very seriously when you were admitted for the second time,” she said, referring to the time in October 2010 when she came down on Ben like a tonne of bricks and threatened him with possible hospital admission if his weight dropped any further. “Basically your body had begun to ‘eat itself’. Other internal organs can suffer, too.”

As a result of this “kick up the you-know-what” in October 2010 Ben turned a corner and started on the long road to recovery.

She explained how there can be long term effects of anorexia like osteoporosis and how there can be early indications that all is not right with someone’s bones; she’s already had patients who suffer more broken bones than most. Girls can go on to have fertility problems, and so on...

In other words the anorexia certainly was damaging Ben physically as well as mentally.

He seemed happy with this explanation, so he wasn’t overly bothered that he had put on another 0.5kg after reaching what he considered to be his optimum weight last time.

But, thankfully, she never brought up the weight restored subject. At our private meeting last Friday I’d asked her not to do this for obvious reasons.

Anyway, at the next session we’re going to be looking at Ben’s perception of the way he looked before and during the anorexia - and now - using my photo timeline.

It will be interesting to see what he has to say about that.

Well I know what he will say about that. He will say that, back in 2008, he used to play rugby and umpteen other sports seven days a week and so that’s why he had an athletic body.

Now, according to him, he just “sits around most days doing nothing”.

Hmn...

Thursday, 19 January 2012

Answering Anon’s comment on my last entry...

After I published my last post, Anon sent me an interesting comment:

“I was just wondering,” he or she says, “Did Ben ever take supplements, for example *Ensure*? What about his portion sizes at mealtimes? What were they like?”

In answer to the first question about supplements...

No, Ben never took any supplements. He refused. During the early days when I was panicking about getting the calories into him I bought a tonne of *Complan* powder to make into high calorie shakes (a bit like *Ensure*). But, Ben being Ben, he refused point blank to touch it.

All he would drink were milkshakes which he made himself (with skimmed milk...). Anything else was refused. I also had some fantastic recipes which other mums gave me for mega-high-calorie shakes which were refused as well.

At first he reluctantly agreed to drink fruit juice or fruit smoothies instead of water or black tea / coffee. But after the first six or eight weeks of the initial re-feeding, he refused these as well.

The result was that we had to get a tonne of calories into him by other means. And, when you refuse to eat most fats, carbs, etc this means that not only do you get a very unbalanced nutritional intake; you have to eat a heck of a lot of bulk to make up the calories, all of which left Ben feeling bloated and horrible. This was a real problem during the early days.

I say “early days” because, if you check back over my 2011 blog, you will see that after the first six or eight weeks of the initial re-feeding plan, Ben “downed tools” violently and refused to stick to the eating plan any longer. Nothing we or CAMHS did

would make him eat the required calories. Also at this time we lost the services of our (excellent) dietician which made things even more difficult. Over the next half year or so Ben's weight headed south and his ED rages and depression went wild...

To answer the second question about portion sizes:

I'm thrilled to say that, ever since Ben turned a corner in October 2010, his portion sizes have been normal, indeed on the large side. He almost always has a hefty evening meal followed by a large pudding and snack / supper before he goes to bed.

But it wasn't always like this...

In the Bad Old Days, portion sizes were a real issue. Initially our dietician tried to get Ben to eat normal portion sizes instead of counting calories. It didn't work. Being shown pictures of typical portion sizes failed miserably for Ben as he was tempted to hugely underestimate. In the end I insisted we count calories rather than do portion sizes as it was the only way to ensure Ben got sufficient food without cutting back and losing more weight.

Also in the Bad Old Days he'd get really confused as to what constituted a "normal" plate of food. It was as if his brain had switched off the ability to gauge whether what was on his plate was too much, just right or too little.

Every meal time I'd dread putting his plate in front of him for fear of his reaction. Normally he'd slam down his knife and fork, sometimes throwing the food or plate around too, storm out and have an almighty head-bashing and howling ED rage that put the fear of God into me.

Another thing that would set him off would be if any of our portions appeared to be smaller than his. We even got to a stage where I would *weigh out* portions to "prove" that they were all the same and he wasn't getting a nano-gram more than us.

Large portions like this weren't a problem for my husband, but they were for me. I'm only tiny and cramming all this food into my stomach was really hard. If I left anything at all on my plate it would send Ben off into an ED rage again. The amount

of times I'd wail "I'm female, middle aged, my metabolism is rock bottom and I'm only 5ft 3 inches!!!" Remember that at this time we couldn't "condense calories" as we now call it; Ben wouldn't eat fats or some carbs which meant a 600+ calorie meal was pretty huge.

Thank God we are now long past this stage.

Since October 2010 Ben has been eating sufficient calories to (very, very, very) gradually increase his weight. He is no longer terrified of fats or carbs. He will eat almost anything and he often "condenses calories" so there isn't so much bulk.

Importantly, recently, his nutritional intake has been incredibly well balanced. These days I can eat smaller portions than him without comment because he knows how much he needs to keep his weight up and heading towards recovery. And these days meals with Ben are a pleasure, not something I dread.

Friday, 20 January 2012

Food, calories and exercise... how it was then and how it is now, for Anon...

Because Anon's latest questions might also be relevant to other people, I am doing a second post based on our own personal experience. Of course each family's experience will be different and this is no substitute for proper medical or professional advice! But, because it might prove useful to someone, here goes...

Anon asks: *"When Ben eats almost anything, I'm guessing that means saturated fats and fatty foods too?"*

My reply: Some sat fats and fats, but not all. There are still some hurdles that he needs to overcome and, ever since the ED hit, he has always had a huge fear of sat fats, despite the dietician telling him that "good fats" can, in some instances, cancel out "bad fats" (I believe...)

Now, like many ED mums, I hate nutritional labels on food packaging with a passion because it's often the first thing an anorexia patient homes in on - and, with

Ben, it was always the sat fats that shone out in Las Vegas Lights.

He would only buy certain brands of cookies, for example, because they contained lower levels of sat fats. It cost me a fortune when I could have bought supermarket “own brands” much, much cheaper.

But these days, it’s not so bad although I do wonder that, if faced with a plate of unbranded cookies, he would go ahead and eat one or refuse....

Anon asks: *“And since he eats almost anything now, do you think he’d take supplements if suggested to him now? And did CAMHS ever say Ben required supplements to gain weight?”*

My reply: No, CAMHS never mentioned supplements and, to be honest, these days I don’t believe there is any point. Over the last 14 months or so Ben has been eating what must be one of the healthiest, most nutritionally balanced diets on the planet. He is putting on weight and has been for some time, so supplements would probably be irrelevant. But, no, I don’t believe he would take them if required. It took us *months* before he’d agree to take *Fluoxetine* for his co-morbid clinical depression in the summer of 2010.

That’s part of Ben’s personality. He “won’t be told” as we say here in Northern England. He gets that off my dad.

Anon asks: *“Also, do you think Ben would still eat anything if you weren’t counting his calories and just eating food?”*

My reply: This is still a sticking point and it’s something that CAMHS and I will be weaning him off over the next few months before he goes to university. At this moment in time he doesn’t feel quite ready to do this. And, yes, I do think he might end up eating less and therefore losing weight. But it wouldn’t be intentional, unlike in the past. Often he feels very full but continues to eat because he knows he has to have the calories. If he didn’t have that gauge he might be tempted to think he’d had sufficient.

My own personal (and non-medical or professional) opinion (which others might

disagree with) is that, much as I know that counting calories religiously can be a millstone in itself, judging food intake by how full you feel could be dangerous in situations when it's so important that you put on weight and don't lose.

Anon says: *"Is it also four meals a day? Most dieticians etc I've heard about recommend up to six meals a day?"*

My reply: Yes I know that most dieticians, etc recommend 3 x meals, 3 x snacks a day during the re-feeding process and this is what we managed to get into Ben for the first six to eight weeks of re-feeding during the early spring of 2010.

Then one day just before Easter 2010 he refused to cooperate any longer. Unfortunately at that stage we also lost our dietician which meant the food control was passed to the other members of our CAMHS team. Much against my better judgment they allowed Ben to "choose" his own meal combos and also a calorie intake he "felt he could cope with".

Immediately he reduced the number of meals and eliminated all snacks. He cut his calorie intake, too. After all, why would someone in the grip of anorexia "choose" to stick to a high calorie eating regime?

But, because CAMHS was allowing him to do this, I felt powerless, angry and frightened. CAMHS thinking was that Ben had to "want" to recover before he could embrace a proper re-feeding weight-gain regime. Until that time there was little point in us "forcing" him to do this.

"But what if he *never* 'wants' to recover?" I asked the nurse in desperation one day. She just shrugged her shoulders as if to say "Well if he doesn't, then he doesn't and there's nothing we can do about it". I wanted to scream...! What, were we just supposed to leave Ben to his own devices and watch him disappear in front of our eyes without doing anything to stop it? My whole gut instinct shouted NOOOOOOOOOO!!!!!!

Predictably over the following months Ben lost a lot of weight until his weight was far lower than when he'd first been referred by our GP. Also during this time his

mood and behaviours deteriorated. It was a pretty hellish time all round. And, meanwhile, I desperately tried to get CAMHS to support me in re-feeding him text-book style, but they insisted that Ben should “choose” a way of eating he felt “comfortable with”... Ben, not surprisingly, wholeheartedly agreed with them and I quickly became the Big Bad Mum who was trying to make him fat. It was Ben and CAMHS against me...

Week after week he was surprised to discover he'd lost weight when he was certain he'd been eating enough on 1800-ish calories a day. So he'd promise to decrease his exercise or make some other minor changes he felt certain would pile on the pounds. And the next week he'd do the same. Week in, week out... But he continued to lose weight.

“It's all a bit of an experiment to see what works and what doesn't,” CAMHS would say. But, to me, we were seeing a heck of a lot of what *wasn't* working and none of what *was*.

I know CAMHS were worried that if they came down on him too hard he might rebel. He might refuse to cooperate altogether. He might go underground. He might go bulimic. And never forget that, at this stage, Ben was regularly threatening suicide. Better to ease him round to the right way of thinking. So, although half of me screamed at what was happening during this period, the other half kind of saw they had a point. And, curiously, looking back, Ben said this method worked for him.

Then, in the October 2010, Ben was rushed back into the cardio unit with a seriously low pulse rate.

When they found out about this, CAMHS surprised and delighted me by coming down on him like a tonne of bricks. The psych, at least, did a complete U-turn in her approach and from that moment onwards CAMHS (largely, but not exclusively) supported me in the need to re-feed and gain weight.

However by this time Ben had established a way of managing his meals that worked for him. But for the first time in months CAMHS insisted he push up the

calories to a level where he was putting on weight every week. It was a slow process, but it started to work. Gradually, Ben built up his calorie intake based on what the scales were telling him. Because he now trusted the psych implicitly, he was reasonably happy to do what she suggested and slowly began to realise that he wouldn't suddenly "blob out". However he never returned to the 3 x meals, 3 x snacks pattern. Frankly, by this stage I really didn't care how many meals or snacks he had as long as he got the calories!

Anon says: *"Also, in relation to Ben's exercise, how much is he currently doing and was he doing throughout recovery?"*

My reply: As with many anorexia sufferers, compulsive exercising was a real problem. Around a year ago it began to get seriously out of control and I remember him sitting there with the CAMHS nurse listing all his daily exercises. Just when she thought he'd finished, he'd list a whole load more. And then a load more... On his own, he seemed unable to do anything about its iron grip. I knew that something had to be done. It was also around this time that I discovered the Recovery Contract [see back of book for more information]. As part of the Contract we agreed a limited amount of exercise over and above which he wasn't permitted to go. At this stage Ben was totally honest with us. At an earlier stage he probably wouldn't have been.

Every evening we'd go through the Contract, checking that he'd stuck to his calories and exercise limits. Points were taken off if he broke the Contract, but I'm pleased to say he never did.

Today Ben's exercise regime is still much the same. The Contract has helped him get it under control and only do exercise that he enjoys. He manages the exercising, it doesn't manage him. He was always a sporty boy, so he could never give it up completely.

Regarding all of the above... Please note that this is based on our personal experiences and may not be applicable to everyone. Nor should any of my comments ever be considered as a substitute for the advice of a trained medical clinician or

other health professional. All I can say is that, since Ben turned around in October 2010, it has worked for us.

Saturday, 21 January 2012

Today's baking reminds me of Baking Days From Hell...

Ben's about to make amorette cookies, except he's customising them because we don't have any almond paste so he's using marzipan (which the recipe states mustn't use...) So a bit of improvisation is required. In the Bad Old Days this would probably have led to yet another Baking Day from Hell...

Back then, if a recipe went wrong for some reason, I'd know about it.

I'd hear an almighty crash from the kitchen accompanied by an animal howl of "NOOOOOOOO!" followed by "Sh*t! Sh*t! Sh*t!" Something would get thrown across the kitchen or slammed down on the work surface. Ben would stamp his feet and crash something else. Then he'd flee upstairs screaming. Whatever he'd been baking or cooking that day hadn't been a success...

Even the slightest imperfection (e.g. too dry, too soggy, too bland, too oily, too salty or too sweet) would result in an ED rage and Ben would refuse to eat it. Food had to be perfect otherwise it was rejected. Every baking or cooking session had to produce *Michelin* Star type food; otherwise he simply wouldn't eat it.

And he'd never taste-test as he went along because even the tiniest taste represented weight-gaining calories...

Most of the time I'd discourage him from baking and definitely from cooking meals.

So today, when he chose the unconventional amorette recipe and decided to customise it, my heart missed a beat. But then I remembered that it's 2012, not 2009 or 2010. These days if it goes wrong he might be a little irritated, just like you or I might be. But that's all.

And, no, by “customising” I don’t mean the kind of “customising” that he used to do back then i.e. de-calorising a recipe or omitting any oil or fat.

This week he’s made chewy buttery oat cookies, white chocolate “blondies” and a banana and choc chip cake. He’s also cooked a wicked fish, cheese and egg pie and a comforting vegetable and barley stew with cheesy dumplings. Tomorrow it’s a curry, Monday it’s a stir fry in honour of the Chinese New Year and Tuesday it’s a vegetable crumble.

And, yes, he is eating this stuff. Unlike the Bad Old Days when he’d bake a tonne of stuff for me and his dad without touching a morsel of it himself.

Tuesday, 24 January 2012

Like a red rag to a bull...

If there’s one thing that gets Batty’s blood boiling it’s this... The remark: “That’s the trouble with you - you’re doing it all wrong” from my “other half” when I tried to explain (picking my moment, of course, five minutes before he was about to leave for the office in the morning) that Ben’s social problems are going from bad to worse. And that these problems mean he is struggling with ED thoughts and is really down in the dumps. And this is why I need to keep a close eye on him because the last thing I want is a relapse.

So, at 7.15 this morning, the red rag was produced in front of the bull: “You are doing it all wrong,” said my H.

For months and months at the height of Ben’s anorexia it was me that cared for him five or even six days a week because Ben’s dad was working away. Because of his job, my H has only ever been able to attend a handful of CAMHS sessions so I’ve had to deal with those too - and take the flack afterwards when ED raged.

Over the past two-and-a-half years it has been me that’s done all the research into eating disorders, read all the books, talked to all the people, been on the forums and

been in the firing line when the ED made it impossible for Ben to be in school or sent Ben crazy, not forgetting the suicidal phase in summer 2010.

It's been me that's met with his teachers, me that's "walked and talked" with Ben for many an afternoon, trying to make an inroad into his ill mind, me that adopted the Recovery Contract for us which has proved so successful, me that's had to give up a promising career, me that's sorted out all the *Disrupted Studies* stuff for university, me that has to drive the 20 mile round trip to pick up Ben from school every day because he still can't last the day... and so on and so forth...

For the past year Ben's dad has been working locally. However he's been working long hours, often seven days a week late into the evenings. He isn't aware of half the stuff that's been going on recently, or even less recently, because we simply don't get time to talk.

And when we do, it's the wrong moment. Like five minutes before he leaves for work - or when he's exhausted after another 12 hour day.

So this morning Batty the Bull retorted with: "Well if you think I'm doing it all wrong and you can do better, you're welcome to take over!"

Not the best response, really.

Along the way, our "conversation" was peppered with remarks about me "throwing my money away" by sending him to university. "It's a complete waste of time," he said, "Ben will be back home within the year and you'll have thrown nine grand down the drain. I'm telling you it's a total waste of time."

"Okay, so you tell him he's not going to university, then!" I snapped, like you do in these pear-shaped situations... "You sort out something else for him to do."

So not a good start to today which follows a Bad Day yesterday as Ben was in a foul mood in the middle of exams (which he has possibly flunked) and his social life goes from bad to worse.

Wednesday, 25 January 2012

Starbucks with a woman who knows eating disorders inside out...

E is a friend of mine who has lived with anorexia since her teens. She is now in remission and I love it when she always insists on full cream milk in her favourite cappuccino along with chocolate sprinkles (naturally).

I like meeting E for coffee because she always gives me invaluable insights into what it is like to live with an eating disorder. Her experience isn't a carbon copy of Ben's by any means, but - like so many experiences of anorexia - there is a heck of a lot of common ground.

Meeting E also gives me a great opportunity to talk about the issues that have been bothering me lately, as the mum of a teenage boy recovering from anorexia.

Like my mum, I tend to talk pretty loud (I think??) because I'm going deaf in one ear and I noticed that E was responding quietly to anything I said. Was I talking too loud? Was our conversation being overheard by everyone in *Starbucks*? There we were talking about anorexia, mental health, traumatic events and anorexia as a potential killer while everyone around us was catching up on the local gossip or surfing the Net.

I noticed a couple opposite who were obviously on maternity / paternity leave. The dad had the new baby boy on his lap, his face a picture of emotion as he marvelled at the tiny fingers and toes.

What did the future hold for them, I wondered. Would that little boy grow up big and strong like every parent hopes and prays? I hoped and prayed he would - and that the mum wouldn't be talking about the kind of issues we were talking about in several years' time.

Seeing a new family like that always affects me and I'm instantly reminded of when H and I would go places with the new born Ben 18 years ago. Only, unlike that placid little boy, Ben was always screaming blue murder and making it impossible for anyone to enjoy a quiet coffee. Being partially deaf in one ear would probably have

been an advantage back then!

But it was great to meet up with E again yesterday and I look forward to our next meeting.

Sunday, 29 January 2012

Would GPs be so slow in responding if we were talking about cancer?

I went along to an all-day *BEAT* conference in Leeds yesterday, with another ED mum I know well. (See link at the back of this book.) One thing that came across strongly from the various speakers and discussions was the apathy, lack of awareness and sheer dragging of feet shown by British GPs when faced with a young person needing to be referred for eating disorder treatment.

Virtually everyone at the *BEAT* conference who had had an eating disorder, or who was the parent of someone who had had an eating disorder, had experienced a shockingly slow response from their GP at the start.

I've already written about how many times I had to drag Ben to our GP before he was referred for treatment. Also the fact that not once did our GP tell me what treatment was available; it was the school nurse who told me I should get Ben referred to the UK's Child and Adolescent Mental Health Services (CAMHS).

Reluctantly our GP agreed to refer him. You could almost hear him sigh and shake his head at what probably seemed to him like an over-protective mother worrying over nothing. After all, it's not unusual to see a 15 year old skinny boy who is fussy about food - so he wasn't overly worried, simply telling Ben to go home and eat more, then come back in a couple of weeks if nothing improved.

So we went away and we came back when nothing improved only to be told to go away again, eat more and come back in a couple of weeks if nothing improved...

When I eventually persuaded our GP to refer Ben, I had no idea we would have to wait *months* for our first treatment appointment. The GP didn't tell me that. He was

also singularly unhelpful on the various occasions I returned to the surgery, desperate to see if we could get Ben fast-tracked through the system.

Much later on, during treatment, CAMHS asked Ben to go along to the GP for a full medical. The GP (another GP) admitted he hadn't "a clue" what he was "supposed to be doing", obviously completely baffled as to why we were in his surgery.

Yesterday at the *BEAT* conference I listened to experience after experience that echoed my own. But it's not as if nothing has been done to try and resolve the problem. *BEAT* has carried out a massive mailing campaign to GPs inviting them to awareness / training sessions on identifying the early signs of eating disorders.

They got virtually zero response.

Of course there is the odd good GP story to tell. I know of at least one mum whose GP was central in helping her bring her daughter successfully through the eating disorder after she "fired" her local CAMHS.

But I get the feeling that these are the "old school" GPs... the friendly village doctor who knows all his patients by name, not the massive city surgery where you see a different GP every time.

A GP is usually the first point of contact on the road to getting treatment for anorexia - and, because of the nature of the disorder, the young person is already relatively entrenched in the illness before a worried parent makes that crucial first appointment.

It is well known that early medical intervention speeds up recovery. But not only are families having to wait weeks, possibly months, before GPs make that crucial referral for treatment, far too many find themselves on a ridiculously lengthy waiting list before their children get this vital treatment.

By this time the young person's condition has often deteriorated significantly requiring lengthier, more complex treatment and often in-patient treatment.

If our GPs took a parent's concerns more seriously and dealt with them more urgently, and if the young person could then be fast-tracked into treatment, not only

would it increase the chances of a quicker recovery and, in some cases, of survival but it would surely work out much less costly to our UK National Health Service.

Eating disorders have the biggest mortality rate of all mental illnesses and they can destroy young people's lives in other ways, too. And the number of young people with eating disorders is growing at a dramatic and terrifying pace. So they really should be taken as seriously as any other potentially fatal condition.

I'd hazard a guess that if we were talking about cancer, our children would be fast-tracked into treatment. I would also hazard a guess that GPs would show a little more interest if the mailing campaign was an invitation to an awareness or training day on identifying the early signs of a potentially fatal cancer in young people.

Monday, 30 January 2012

“Not suicidal enough”

For some reason at 3am this morning I got thinking back to the time when Ben was suicidal. This was throughout the summer of 2010 when he was at his worst, five months into treatment and ten months after his GP referral. The thought came to mind: “Just how suicidal did he have to be before anyone would take action?”

Obviously our nightmarish summer vacation in France where the ED drove him to swim far out to sea in a dangerous estuary, not caring whether the rip tide pulled him beyond help or not... and where I risked my own life frantically swimming out to try and persuade him to swim back to shore.

No, that obviously wasn't “suicidal enough”.

Then there was the nine hour ferry journey from St Malo to Portsmouth where I followed Ben around the ship like a bad smell, ensuring he was never out of my sight. While other passengers looked over the side admiring the deep blue ocean, I was looking at it for an altogether different reason. I was seriously worried that Ben would jump.

But that wasn't "suicidal enough".

That same summer I caught Ben climbing out of his loft bedroom window, two storeys up, intent on crawling up onto the house roof not caring what happened to him. It took me all my strength to pull him back inside.

Despite frantic telephone calls to CAMHS and emergency meetings with the psychiatrist, that wasn't considered "suicidal enough".

I hoovered up all the medication in the house, anything sharp and the house keys so he couldn't go AWOL like he kept threatening to do, but he physically fought me to the ground and escaped via a window. Thankfully he returned later on.

But, presumably, that wasn't "suicidal enough" either.

Then there was the day when Ben's friend's mum phoned to say she was worried because her son had just got an email from Ben saying, "Give me three good reasons why I should live". Her son was frantic and so was she. Meanwhile Ben was sitting at his PC like a zombie, devoid of all feelings except deep and utter depression. He really didn't care whether he lived or died.

But even that wasn't "suicidal enough".

"So what has to happen before CAMHS takes this seriously?" I asked the Duty Psychiatrist at CAMHS (when ours was on vacation).

Apparently he had to physically harm himself. In other words, he needed marks or cuts of the attempting suicide variety. He needed to actually *do* the act. (And fail, presumably!)

High stakes, huh...

Because only then would they take action and section him.

Until that time there was nothing anyone could do, despite the fact it was just Ben and me in the house; his dad was working away at the time.

I had my friends on 24-hour call, but Ben made threats of what he'd do if I called them round. Ditto if I dialled 999 or attempted to take him to A&E (ER). He held me to ransom. So I did nothing except sit tight and pray. Oh, and desperately call the

emergency out-of-hours doctor to see if they could do anything.

Same response. Their hands were tied by red tape.

And I will never forget the response I got from a member of the CAMHS team during that desperate period when she barked at me: “We are not an emergency service, you know!”

That was in response to my phone calls for help. I just didn’t know what to do. I felt helpless. During this nightmarish summer I really thought my son would die.

No parent should have to go through that.

And no young person should be so desperate that they have to, either.

Tuesday, 31 January 2012

Big meeting at school tomorrow

Tomorrow afternoon I’ve arranged to meet with the Assistant Head, Head of Sixth Form and school nurse about the problems Ben is still experiencing at school. On the agenda will be...

- ★ The fact he still finds it hard to stay in school for full days, except Friday which he manages to do (probably because it’s the end of the week and a shorter day).
- ★ The fact that, because of this, he is missing key schooling in his A-level year which isn’t good.
- ★ The fact that things on the social front are going from bad to worse, already discussed at length with the school nurse a couple of weeks ago.
- ★ What we can all do to attempt to salvage the situation and make the last few months of Ben’s school experience a relatively happy time instead of something he “grins and bears” until he leaves.
- ★ Worst-case-scenarios for if Ben fails to get the required A-level grades. As he

wants to go to university to do *History*, and doesn't want to take a second best option, what is the situation regarding re-sits or even re-doing the year?

So we shall see what happens, hey...

FEBRUARY 2012

Thursday, 2 February 2012

I've just read two really powerful blog posts

The first is from Laura Collins, founder of FEAST (see link at back of book) and author. The other is from Carrie Arnold, former anorexia sufferer and author.

Both focus on the problem that over-18s have when it comes to eating disorder treatment. Far too much emphasis appears to be placed on the sufferer being able to make rational decisions concerning their recovery. As Carrie says: "If you don't want to get better,' patients are told, 'then we can't help you.'"

So, because it's nigh impossible for someone that's seriously sick with a mental health condition like anorexia to "choose" to get better – or simply because they don't realise how sick they are - they are left to get on with their life alone.

The result is that too many of these people remain seriously ill, with serious consequences.

But, hey, they're adults and society believes they are in charge of their own destiny.

Legally, yes, but ethically, no.

Thus far, in our family, we are incredibly fortunate in that Ben, although now 18, has shown no signs of asking us, his parents, to be removed from the equation. He also lives at home.

For the time being, at any rate.

And I like to think that we will continue to be involved in his recovery for as long as it takes, whatever the law says.

However I can see that, in many circumstances and for whatever reason, it would be all too easy for someone to refuse or stop treatment - and for the medical profession to allow them to do this, because it's the law.

Which, as Laura sadly points out, can lead to needlessly distressing results.

Of course it would be brilliant if these very sick adults *could* make rational decisions for themselves and "choose" treatment every time. In the same way that, if you discovered you had cancer, you wouldn't think twice about choosing treatment.

But the distressing fact is that, all too often, they can't make this decision.

By law, someone should be able to make it for them.

Friday, 3 February 2012

Will he, won't he, will he, won't he, will he join the party?

Already he's "feeling tired" and asking me if I wouldn't much rather he stayed at home to save me having to drive out at goodness only knows what hour to pick him up from the club in town where C is having her 18th birthday party.

No, I said, I am more than happy to pick you up and the socialising will do you good.

This, as usual, was Ben emailing me from a school computer this lunchtime - emails that usually start off with "How're you doing?" and often end up with him asking me to pick him up from school.

But today I'm busy, so I can't.

And, anyway, I've agreed with the Assistant Head that he's really well enough now to tackle full days in school.

“Tell him I say he must,” she said at our meeting on Wednesday. “After all, it’s a crucial time for the A2 level students. If he misses more school there’s a chance he won’t get the grades we’ve predicted. We believe he is capable of getting those grades, but to get them he needs to be in school.”

Home is still Ben’s “comfort zone” where he feels he can run and hide.

But I strongly believe it’s time for him to get out there and be with his peers, especially with university looming on the horizon.

However I wouldn’t be surprised if he chickens out tonight and doesn’t go. Or, if he does, he calls me mid-evening to ask me to pick him up early.

I do worry that this urge to run home to his “comfort zone” when under pressure socially may make it harder for him to live away at university later this year.

It’s difficult to know whether “tough love” is the right approach or not...

Sunday, 5 February 2012

“I’m fine as I am!”

I am still gently pushing for extra weight gain so Ben has a “buffer zone” should he be prevented from eating his agreed daily calories for whatever reason (e.g. “freshers flu” at university, etc) - and also because I really, really want him to get back to the size he was before the eating disorder struck. Yet Ben is less than enthusiastic...

These last few kilos are never easy and there is the temptation to say “Okay, you’ve done well, that’s good enough” etc. But why settle for “good enough” when you can have “excellent”? Also why settle for anything that could put him at risk of a relapse, should his weight drop significantly for any reason?

But getting him to buy into the idea is proving very hard. And I feel incredibly frustrated at the bit of the ED that is obviously still present, making him scared of weighing a little more, making him feel “fine” as he is and kidding him that he is

bigger than he actually is.

“If you think *I’m* thin, mum....” he said the other day, referring to a bloke on the telly who was slim, but not as slim as he is. But he couldn’t see that.

Every time we go to CAMHS we plan what Ben will do, calories-wise, depending on the scales outcome. I am trying to push for increased calories if his weight is maintaining, but without success.

Sure, I could sneak extra calories into meals. But that would result in him cutting back when he finds his weight has gone up, so it’s counterproductive.

Wednesday, 8 February 2012

“I’m happy to settle for ‘good enough’...”

...Said the psychiatrist at CAMHS yesterday afternoon. Ben’s mood was very low and he was extremely anxious. He admitted to being tempted to give in to the ED thoughts.

“My mum told me that when I was recovered I’d feel better emotionally,” he said throwing me an accusing look, going on to imply that - because he felt cr*p - he might as well give in to the eating disorder. After all, he felt “safe” there.

They say that you hurt the ones you love most, and Ben certainly succeeded in hurting me. The session was full of accusations along the lines of “My mum insists that xxxx is right” kind of thing and “I don’t know who’s right: the NHS for telling me it’s okay to stick with ‘good enough’ and stay as I am - or the rest of the world that’s telling me I must be properly ‘weight restored’ in order to recover”.

“Well I’m more than happy to settle for ‘good enough,’” said the psychiatrist. “In an ideal world we’d love you to return to the weight and physique you were before the anorexia. But in many people this just isn’t possible. They simply can’t handle it. So we need to come to some sort of compromise and I’m happy for you to stay

where you are. Yes, if you got fresher's flu or something else that results in weight loss you would be underweight because you don't have any 'buffer zone' at the moment. But I'm happy to settle for 'good enough' if you are."

Daggers look from Ben at Big Bad Mom who, I guess in his eyes, is trying to make him fat whereas the nice psychiatrist isn't. "My mum said if I lost weight I'd end up hospital and die," he said accusingly.

"No, I did not," I said. "I said that because you don't have any buffer zone, if you lost weight you could risk heading back into the 'danger zone' if you went too far. You and I have fought tooth and nail to get you to the stage you are now and I refuse to let you relapse. I refuse to go through all this again. Relapse does happen because I've seen it happen."

I was referring to the various families I know who are having to deal with the eating disorder for a second or even third time - and the recovered anorexia sufferers I know who have had relapses and are well aware of the risks.

Ben feels "uncomfortable" now he's "put on all this weight". He feels like he "did before the anorexia" when he carried more weight. He talked as if he'd put on a tonne of weight recently rather than a couple of kilos. And I could feel the eating disorder beckoning with Siren-like lures of comfort and security in its "arms".

Ben felt cr*p and he felt "recovery" wasn't handing him the happiness and contentment he thought it would. He felt betrayed, and it was as if he was saying he might as well have stayed with the ED. So that kind of set the tone for the session and I came out of it feeling horrified and defeated. We didn't speak to each other on the way home.

Saturday, 18 February 2012

A hell of a week...

Apologies for being AWOL for a week or so. Last Saturday at 3.15 in the morning I got a phone call from the hospital to say my dad had passed away. As a result, this week, as you can imagine, has been a hell of a time: supporting my mum (after breaking the news to her), organising the funeral, sorting out official paperwork and all the other paperwork, cancelling / postponing all my freelancing work, taking Ben for a *History* department open day at Sheffield University on Wednesday followed by CAMHS on Thursday - followed by Ben deciding he was “too sick” to go away with the young people from church this weekend, a trip that would have done him the world of good socially.

Oh, and to end the week, husband and I had a hell of a row - about Ben being “sick” and crying out of the weekend, about Ben kicking off with something that closely resembled the ED rage / going to pieces / self-loathing that we’d become so familiar with over the past two-and-a-half years: my fault, apparently, for being “too soft with him”.

So not a good week really.

If I could choose what to do today I think it would be this:

To just sit in front of my computer and tinker away at javascript and html (geeky, I know...), fuelled by occasional slices of some kind of chocolate fudge cake and endless cups of coffee. No interruptions, no guilt, no worrying about other people, no having to plan and cook meals, no supermarket shopping, no housework, no laundry, no talking to anyone, nothing.

And definitely no more paperwork or reminders of the ED.

Some people might think it a bit strange, but the best bit of the week, in a curious way, was going to see my dad last weekend in the hospital’s chapel of rest. Just he and I, dad looking much the same as he did when he was fast asleep - and he’d spent

most of his last few days asleep. I stroked his cheek, brushed back his hair and had a good long chat with him.

I told him I loved him and thanked him for the security he'd brought to my life. The fact that he could always be relied on to be one hundred per cent consistent and dependable, always doing what he felt was best and right.

I told him not to worry because everything was under control - mum, the bills, his finances, appointments, etc. As someone that always liked to be in control of things and do everything correctly and thoroughly, he would have been reassured by that.

Saturday, 25 February 2012

Gradually coming back down to earth...

The past two weeks have been a complete blur of paperwork, bills, solicitors, funeral, work, university visits, sorting out dad's belongings, helping mum, etc etc and I am well and truly exhausted!!!! Meanwhile Ben spent Thursday afternoon being interviewed by a researcher from Oxford University for a new online resource for and about young people with eating disorders. I will let you know when it goes live.

MARCH 2012

Thursday, 1 March 2012

Where do we go from here, treatment-wise?

Today we saw a really lovely lady from CAMHS - someone whose job it is to handle the transition between CAMHS (which is for the under 18s) and Adult Services, university or whatever the transition is. But I couldn't help feeling that I was instructing her about eating disorders, rather than the other way round...

Not only this but Ben was in his “why use 20 words when one will do” frame of mind, doubtless because he felt exactly the same as me.

Thankfully the time to leave CAMHS has coincided with a time when I feel that Ben and I can probably (not “definitely” but “probably”) manage on our own. And if we *did* need any help, I tend to think that Adult Services or some other form of new assistance could do more damage than good at this late stage.

The thing is, I know Ben and his eating disorder better than anyone - except our CAMHS psychiatrist, perhaps, who is leaving and who we have to leave anyway now that Ben is 18.

With the support of this psychiatrist, I have “managed” Ben’s eating disorder 24/7 over the past two-and-a-half years. For a long while now he has trusted me, just as he trusts the psychiatrist. I really don’t think that anyone in our local Adult Mental Health Services would be of any use at this stage.

And, like I said, they could do more damage than good.

No, I don’t entirely like being cut adrift to float out to sea, but it’s better than the other option and it has to happen at some point. Also, there will be trained people to support Ben at university (I sincerely hope), should the worst happen.

So this is really where I take the reins and Ben is in complete agreement.

Tomorrow we see the psychiatrist, probably for the last or last-but-one time.

And although I didn’t see eye to eye with her all the time, she has become a friendly part of our lives and we will miss her. I know Ben will miss her.

But now Mama’s in charge and that’s not a bad thing, really...

Friday, 2 March 2012

Another doom and gloom CAMHS session

Another reason why it’s probably not a bad thing to be leaving CAMHS is that the

past few sessions have succeeded in bringing Ben's mood down to rock-bottom levels.

They have also given the bit of ED that remains the chance to "slang off Big Bad Mom" to the psychiatrist. "*She* told me blah...", "*She* always says blah..." and "*She's* only saying that to because *you're* here," etc. Boy, that ED sure knows how to hurt a mother. But, then, that's ED's job just as it's my job to sit there and take it.

But, hey, I'm well used to being used as a punch bag after all this time. Today, I wanted to punch ED's eyes out when it reared its filthy head with a classic reaction after the scales showed that Ben's weight had maintained rather than dropped.

Why did this make ED see red? Not because Ben *wanted* his weight to drop, surely? No, I believe he didn't at this stage.

It was because, over the last two weeks, Ben has been doing quite a bit of "guestimating" of calories. He's been out for at least three meals where he's had to guess the approx calorie content. He was convinced he'd overestimated the calories and thus would find he'd lost weight today - especially when he said he'd been "doing all that exercise as well"...

But the scales said he'd maintained - and I could feel the ED shrieking at him: "Ha! *You* thought you'd *underdone* it when in fact you'd gauged it *just right*. See how easy it would be to pile on the pounds and become a complete obese blob if you continue to 'guestimate'? Unless you reduce your intake on guestimation days..."

Oh b*gger, said my anti-ED voice, especially as Ben's mood continued to plummet southwards during the remainder of the CAMHS session: hating himself, feeling worthless, feeling isolated and lonely, etc etc. And this mood continued all the way to school where I dropped a silent Ben off for lessons and drove home, wondering whether ED would try to punish him further by persuading him not to eat lunch...

Mind you, it's typical of ED. Just when you think you're getting somewhere, ED sticks its oar in and messes things up for a while. Hopefully only a short while...

Next week it's our final CAMHS session.

It's such a crying shame that, at this late stage, Ben *still* fears the sheer havoc that a couple of extra kilos would wreak to his body and being. He is obviously still petrified of gaining even the slightest bit of weight, despite the psychiatrist saying over and over again that this *will* happen, because weight maintenance is never going to be an "exact science".

I still firmly believe that the ED will leap in with its Siren-like persuasiveness should Ben's weight increase by half a kg or whatever. I worry that it will throw Ben into a frenzy of fear and anxiety, and that he will actively try to lose that tiny amount of weight again.

On the other hand, historically over the past few months I've found that, the further we get from our last CAMHS session the more relaxed Ben seems to be - and the more likely he is to listen to me.

So, like I said above, it's not a bad thing that we're leaving CAMHS next week.

But, like some of my friends have commented on my last entry, I could still use a bit of Good Quality professional support...

Wednesday, 28 March 2012

Okay, I'm back... and I'm angry...

These last six weeks or so have been turmoil, for reasons already explained, and my blog has taken a total backseat in the proceedings. But now I'm back, hopefully without any more breaks. And today I am angry. Actually, yesterday I was angry. And the day before.

Now, I need to give you some background. I am not exactly the most religious and devout person in the world, but - like many people, I guess - I felt that if I was going to get real, genuine support anywhere, during the worst parts of the journey as a mum of a teenager spiralling downwards into anorexia, it was going to be in the church. I also had a gut feeling that we were being "helped" through this, during the

worst times, by “something”. Maybe it was my imagination or just me clinging onto some kind of hope when I was going through hell, but it’s something that has stayed with me ever since.

But - to cut a very long and extremely disheartening story short - the church (or, rather, the three churches I attempted to become part of) let me down. I won’t go into details here because that’s not what this blog post is about. It’s about the fact that our local church has let Ben down, *Big Style*.

During the worst times, Ben, also, was reaching out for some kind of spiritual support and he firmly believed he had found it. Reading through the 60 page transcript of an interview he’s done for Oxford University about his journey through the eating disorder, he states that he believes it was his new Christian faith that brought him through. Without it, he explains, he probably wouldn’t be here today. In other words, he’d probably be dead.

Back in November 2009, during Ben’s rapid spiral downwards, I spent a few months in church #1, but used to come home more depressed than when I set out - and so lonely. The church paid lip service to me, as a newcomer, but after a while I was just left to my own devices. And I don’t think they could handle, or even attempt to understand, the sheer hell I was going through. So I looked around and after a brief fling with a very similar church #2, I decided on church #3.

Now, church #3 hasn’t been all Bad News. Out of it came my fantastic friend, Sue, the friend with breast cancer who has been the most amazingly supportive non-ED related person I have known over the past couple of years.

She was the only person who, on my first visit, spied me sitting nervously at the back of the church, strode over and persuaded me to sit with her. The rest, as they say, is history. However I am all too aware that she, too, feels side-lined by the church. Most of her really good and supportive friends are non-church goers and she is rarely, if ever, visited by church #3 members. When she’s in church, people tap her on the shoulder, ask how things are going, and look all concerned and serious, and all

that. But no-one invites her round or visits her. I just can't get my head around it. Yet, despite this and despite her serious cancer, her own faith is rock solid.

However, although I personally was having problems with church #3, for exactly the same reasons as the other two churches, Ben took to it like a duck to water, which I thought was fantastic. It gave him a focus and he had a new faith which he believed was pushing him through the eating disorder in the right direction. Indeed after my own initial optimism about church #3 fizzled out and I began to attend church less and less (again, because I felt so incredibly isolated, often returning home feeling terrible), Ben continued to go. He went to church virtually every Sunday for 18 months.

I am astonished and amazed at his sheer staying power, especially as - in my opinion - the other young people and the youth leaders weren't offering him any real support or friendship. Not once, I think, did they ever invite him to the Sunday evening youth group, for example. Crazy!

So, in effect, Ben was just going to church, getting something from the pastor's message, sitting in the background in the youth group, maybe chatting to a few adults or my friend Sue, if she was well enough to attend church, then coming back home again.

For months and months and months. What staying power!

Over the last two-and-a-half years, as you know, Ben's social life has dwindled to a complete halt. His school friends side-line him and he is so incredibly lonely and solitary. But, I always thought, at least there is the church - and, surely, Great Things would come out of this... soon...

Then it hit me that he'd been attending that church for all those months, yet he still didn't really know anyone well enough to hold a conversation, let alone get involved in the youth group's social events.

He'd even got baptized (his own decision). But the church failed to follow that up with any spiritual counselling. He was just left to his own devices. And, with a mum

that was having serious doubts herself about her beliefs not to mention Ben still fighting the ED and hating his social isolation, that was never going to be a brilliant place to be.

So my friend Sue (who knows my situation inside out) and I went to see the pastor in January for a chat. We explained everything and the pastor enthusiastically worked out what promised to be the ultimate plan to help integrate Ben into the church and, especially, the youth group. And to get the spiritual mentoring and support he so urgently needed.

But, you know, nothing happened. And this was a couple of months ago.

Then the other day Ben announced that he was no longer a Christian. He removed the cross that had been permanently hanging around his neck. He discarded the Bible he used to carry in his school bag to read on the school bus. He started to eat chocolate again (given up for Lent now there was “no point”) and announced he didn’t believe in God any longer.

What we are left with is a boy who is hurting so much, who feels so incredibly let down by the people he was sure would offer him support and friendship, who believes that any spiritual experiences he had were fake, probably induced by an eating disordered mind or what he terms “the earth’s magnetic forces affecting the front lobes of the brain” (or something along those lines). You can tell he is spiritually dead. It’s almost like when a child finds out too young that Father Christmas doesn’t exist and that it was their dad all the time.

That is it in a nutshell. A long nutshell, albeit... And I am angry. I am angry with all three churches for letting us down. Angry because I believe that no matter which church we chose we would have found the same reception. Angry because the church preaches about reaching out to the community and the suffering, gives money to Good Causes in the Third World or Inner Cities, yet when “the suffering” comes to them they don’t recognise it because they’re all chatting away in their little cliques, reluctant to venture out of their comfort zones.

Even when we explain it in no uncertain terms and appeal almost emotionally to the pastor for help, they still don't "get it".

I am hoping like hell that this utter disappointment and disillusion doesn't spark off another bout of the eating disorder as Ben's glimmer of spiritual hope that kept him going is snuffed out dead.

I spent two years making excuses for the reception I / we were receiving in the various churches - you know, along the lines of the church being far from perfect, run by people who aren't perfect, you know you have to expect that no-one is perfect, not even Christians... and so on and so forth.

But I am no longer making excuses for them.

Friday, 30 March 2012

Fighting for our boys, why I identify with this mum...

Of course I don't condone what Sheffield student Richard O'Dwyer got up to in his cramped student flat (when he created the TVShack.net search engine), but what I do identify with is what his mother, Julia, is going through in dropping everything to fight tooth and nail for her beloved son.

For a start, if there's one thing I've learned in my (nearly three year) fight to free my 18 year old son from anorexia it's that we mothers will fight for our children as if our lives depended on it. No matter what our children have done or whatever crisis has taken over their lives, we will never, ever stop fighting.

And in that fight we will be forced to dramatically change our lives, often giving up promising (and in Julia's case socially useful) careers. Life cannot go on as normal. We are, in effect, born again into a brand new life we could never, ever have envisaged. And we feel helpless as powers seemingly beyond our control threaten to steal our sons from us.

But that doesn't stop us fighting. And doubtless Julia won't stop until she's spent

every last penny and ounce of energy on fighting to free her son, for the simple reason that he is her son, no matter what he has done.

And while I'm on the subject of Richard O'Dwyer, how many people can claim never to have done, or at least been tempted to do, something a little silly or even stupid at some point during their student careers? Something that, looking back with the hindsight of age and wisdom, they're not entirely proud of?

From the painted footprints that mysteriously appeared overnight leading from Queen Victoria's statue near Leeds University to the nearby public conveniences to dumping bubble bath in a Sheffield city centre fountain, and doubtless countless far more questionable, shall we say, activities than these, I suspect there are thousands of former students who have done crazy, silly or just plain stupid things that, if they were older, wiser and really thought about it, they would never have done at all.

Big, small, insignificant or whatever - the fact is that students, in general, have always had a reputation for doing things of varying degrees of stupidity and silliness.

No, being a student doesn't give them a *carte blanche* to see what they can get away with. And, yes, Richard O'Dwyer should have known that his website wasn't such a brilliant way to supplement his student loan. But, after everything that's happened since the police first knocked on the door of his small student flat, I imagine he has more than paid for his "crimes". Hundreds or even thousands of times over.

And I also imagine he is all too well aware of what his mum has been through, is going through and doubtless will continue to go through on his behalf. Just because she is his mum and she loves him.

You know, because of the pain and anguish he has caused to her alone, I would bet my back teeth that he would never, ever do it again.

He doesn't need to be extradited to the States for trial and a possible jail sentence to be more than adequately punished.

I believe he should be given a good ticking off and let go.

For his mother's sake I wish I could wave a magic wand and do this for them.

APRIL 2012

Thursday, 5 April 2012

Been down with a horrible fluey bug for over a week ...

My punishment for juggling too many balls recently, me thinks, but I've been really poorly this week. Thankfully I'm a lot better today and Ben has been so sweet looking after me, serving up non-stop home-made "comfort food" from mini Chelsea buns, chocolate brownies and chocolate mini egg nests to apple crumble and custard, sticky chewy date bars and amoretti cookies to dunk in reviving cocoa. And, yes, he has been eating these things too - and more, including the twice weekly *Graze Box* I now get for him.

It's the Easter weekend from tomorrow onwards and this is the first Easter for ages that I haven't celebrated the occasion. We don't even have any Easter Eggs. Not because Ben didn't want any; he did, and he wanted the most chocolatey of all. But because I've been so poorly I suggested we do the Easter Egg run next week when eggs are reduced in price and celebrate Easter next weekend when we're all feeling better. And when we won't have the visitors in the house which my husband has announced are coming to stay this weekend... (But that's another moan altogether...)

But we don't seem to be celebrating Easter religiously, either. Usually Ben wants to get out the various Easter Story dramas on DVD, but this Easter there's been no mention of it.

And we won't be going to church.

I've had too much on my plate this week to carry on feeling angry or bitter. But I want to make it clear that the church hasn't been unpleasant or condemning to us in

any way; that would make me really angry... They've just pretty much forgotten about us and left us alone.

I just think it's terribly sad that they talk so much about reaching out to help others, at home and overseas. And yet when the people in need come to them unannounced, they're too blind to see it.

Right from Day One I had a problem with this concept.

Thursday, 12 April 2012

All will be revealed on Tuesday morning...

Batty and Ben have been invited to appear on ITV's *Good Morning* show with Lorraine Kelly on Tuesday morning - an interview set up to highlight the growing number of teenage boys being diagnosed with anorexia and other eating disorders. We have a short eight minute slot so it will be like trying to cram a king size duvet into a mobile phone pouch. And, of course, viewers will see us under our real names.

So why the cloak-and-dagger style pseudonyms so far?

Initially it was to protect Ben. But as time went on it was Ben who kept wanting to publicise his fight against anorexia in a bid to help other families of boys with eating disorders.

I've already mentioned the Oxford University project he's been interviewed for which will be appearing on the world wide web in the autumn - a website focusing on a wide range of health issues that affect young people, anorexia in boys being just one of them. I've seen a 60 page transcript of this interview and it's illuminating reading, I can tell you.

So do I keep our fake names on this blog or do I use our real names from Tuesday onwards?

I'll probably stick to the names I've used so far to avoid confusing the issue. And of course not everyone will be watching *Good Morning with Lorraine Kelly* on Tuesday.

I, for one, won't - because I'll be the one sitting on the sofa opposite her stammering, sweating and making a complete fool of myself!

Friday, 13 April 2012

More about Tuesday

I'll see if I can get some kind of video clip sent to me that I can stick on here or on *YouTube* rather than just relying on catch-up TV.

The thing is, I always want to say *everything* at once, so usually end up starting with (and no doubt filling up the allotted timeslot with) a non-starter or red herring. But today I get to see the producer's notes and I understand we'll be prepped for the interview, too.

I just want to get across something that will be useful to other parents who may be worrying that "all is not quite right" with their son, but haven't a clue what to do about it.

To avoid them having to go through the massive learning curve that I went through which isn't ideal when you are also battling this crazy, new illness that your son has contracted.

And of course "Ben" will be there, too, so he'll need to talk as well.

Saturday, 14 April 2012

Our story is important, but maybe not as important as theirs...

The latest news on the telly appearance on Tuesday morning is that it's "on hold" and we won't find out until Monday morning, just hours before our train is due to leave for London, if it's going ahead or not.

The reason is that there's a high chance they might be able to get a showbiz guest on the show. If so, they'll need to use our slot. After all, why spend eight minutes

talking about the terrifying increase of anorexia in teenage boys when you can talk to a celebrity about their latest news?

Forget about the fact that I've been busy juggling appointments, work and so on to free up enough time for us to travel down on Monday and spend most of Tuesday away from home.

Forget about the fact that I don't know whether or not to pack a suitcase or book a taxi to take us to the station.

Forget about the fact that I spent a total of two hours last week talking to ITV researchers about our experience. It's not just about the time; it's about the way going over past memories kind of kicks you in the gut.

And - key - forget about the fact that there is a slim chance, but still a chance, that whatever Ben and I say on TV might help just one parent or teenage boy who happens to be watching the show.

The fact is - if the celebrity / showbiz guest is available - then they take precedence over ordinary people like us, with an ordinary story to tell.

Meanwhile Ben and I have to put everything "on hold", not knowing if we're off to London or not, packing a suitcase we might need to unpack again without going anywhere.

Yes they might reschedule us for some time in the future. But with All Systems Go for A-levels when Ben goes back to school, it may not be practical to take time off to go to London. After all, we're only talking about a few minutes on TV.

Filler, really.

Monday, 16 April 2012

So this is what I plan to say (in case I don't manage to say it)...

Firstly, yes the TV is going ahead. Secondly, this is what I plan to say - just in case I get side-tracked, get stage fright or don't have enough time to say it...

Back in the summer of 2009 my son developed an eating disorder, but it was weeks before I realised this was happening. Yes, he'd been quite plump at primary school. He'd also been quiet and not very sporty, although good at rugby. Once at senior school he became very sporty. It was a school that encouraged healthy participation in sport and pupils who were good at sport carried a kind of kudos. Ben took up loads of different sports, the puppy fat fell off him, he became tall, handsome and athletic, and he became confident and very popular in his social group. He was positively thriving.

Then, over the summer of 2009, everything imploded. It happened gradually and never in a million years did I worry that my son might be developing an eating disorder. Eating disorders happened to girls, not boys. And, anyway, I held the popular (but incorrect) belief that these children simply need a stern talking to. "Just tell them to eat" and not be silly, and they would.

The quicker you nip these things in the bud the better the chances of a swifter recovery. With us, not only did it take ages to realise what was going on, but it took yet more time to persuade our GP that something was wrong. Then we had to wait up to six months for treatment to start. By the time Ben started to receive treatment it was eight or nine months after the first storm clouds had started to gather. Far too long, in my opinion.

Also, during this time, I realised I had to go through a massive learning curve - more intense than anything I'd done at university. I needed to know the latest eating disorder thinking and scientific evidence inside out. I needed to know what to do and who I could turn to, especially during those dark months before treatment started. Heck, I didn't even know what NHS treatment was available because the GP never explained it to me.

Also there's so much rubbish out there about eating disorders, and so much outdated thinking. You have to know how to sift the wheat from the chaff or you could end up barking up a wrong and potentially dangerous tree.

And all this while you're panicking at what's happened to your family and trying desperately to save your child's life.

On top of this, it quickly becomes clear that you, as a parent, are going to have to take the lion's share of your child's treatment and care. To all intents and purposes you become their physician. Remember, your child only spends 60 minutes a week or so with the treatment team. Outside of that time a heck of a lot of damage can be done, very quickly, unless you fight the anorexia or other eating disorder yourself, as a parent - using methods that have been proven to work for other families.

So you have to know exactly what to do - and then you have to do it. You have no choice. And whenever you feel you can't go on any longer, you have to find a second wind somehow - and a third, and a fourth. You are in this for the duration whether you like it or not, because the alternative could be to lose your precious child to this potentially fatal illness.

Because all of this took a heck of a lot of time and energy, at a time when I could ill afford both because of the panic over how to rescue my son from this terrible illness, I want to avoid this happening to other parents of boys with eating disorders.

Through my blog I want to do everything in my power to "fast track" other parents through this massive learning curve, to point them to the good information and support out there and help them avoid what isn't helpful or is plain destructive.

I also want to show that whatever they are going through, the chances are that other parents have been through it too - and to show how they coped. The Plan As, Bs, Cs, Ds... even Xs, Ys, and Zs - even to start at the beginning of the alphabet again if needs be... to find solutions to an illness where logic and rational thinking has been thrown out of the window.

And which could kill your child.

We want our children to survive this illness and develop into happy, healthy, normal adults who don't relapse back into the illness. Anorexia has already stolen years from our children's lives; we refuse to let it steal any more.

For those who might accuse me of being a “control freak” or being “overprotective” of my son, I’d ask what they would do if they found their child was suffering from a life-threatening illness. I’d hazard a guess that they’d fight tooth and nail and basically do whatever it takes, even walk on coals, to save their child’s life as quickly as is humanly possible.

That’s not “control” or “overprotection”, that’s love.

...Or I plan to say something along those lines.

Which is already far too long and a bit like a lecture.

I just want to avoid being dragged down the “size zero media” route, or the “diet gone too far” route - and to get across that eating disorders aren’t just about eating - they’re about all the other changes that take place in a child’s body and mind as a result of the malnutrition.

The way it damages internal organs (e.g. when Ben’s pulse went down to 29bpm... twice...) and bones. The way it can make children suicidal. And the way it can change a happy normal human being into someone who appears to have gone completely insane... day after day after day...

And the way that rational thinking and reasoning go out of the window.

Oh and, of course, the way it can and does happen to boys as well as girls.

Yep, something like that at any rate.

Wednesday, 18 April 2012

Okay, so what DID I get to say yesterday...

That’s the trouble with five minute interviews - you simply don’t have enough time to even get started, let alone say all you want to say. The interviewer needs to ask questions. Plus, there’s often another contributor (in this case, *GMTV*’s Dr Hilary Jones) who needs to say their bit. Oh, and I almost forgot, (shame on me!) Ben needed to talk about the descent into anorexia from his own perspective. After all,

it's not all about Batty Matty! So, in a nutshell, this is what I did - and didn't - cover on the *Lorraine Kelly* show yesterday.

I explained how everything had gone pear-shaped during the summer of 2009 and how Ben started to exercise more, de-calorise meals, cut himself off from his friends and lose weight. How I had no idea what was happening; after, all as far as I knew, eating disorders like anorexia happen to girls not boys. I also thought (wrongly) that anorexia was all about a "diet gone wrong". Just tell them to eat and they would. But, basically, I had no idea what was the matter, so it wasn't until late summer / early autumn that I took Ben to see the GP.

It took several trips to the GP to get Ben referred for treatment. Firstly he was a boy, and so I expect there was quite a lack of awareness that boys get eating disorders as well as girls.

Then there was the fact that Ben didn't look particularly "stick thin" at that stage. Just by looking at him you probably wouldn't think anything was really wrong, especially if you'd never seen him as a rugby player before he lost all the weight.

I knew something was terribly wrong. In the end it was the school nurse who told me about what treatment was available, so I went back to the GP and insisted they refer Ben for treatment.

I knew there would be a wait, but I had no idea it could be up to six months before he'd get treatment. Meanwhile I was helplessly watching my son disappear in front of my eyes.

And of course anorexia isn't just about losing weight; it's about all the other things that are going on as well. It's about the strange behaviours and moods. It's about depression. Ben cut himself off from his friends, he started to behave strangely at school and went off the rails. This, from a boy that had been academically bright, popular and respected by his peers and teachers alike.

And there Lorraine Kelly had to conclude the interview as we were limited for time.

I never managed to explain that, in effect, we didn't have to wait six months for treatment because I managed to get Ben fast-tracked into treatment following the emergency admission to hospital at the end of January 2010 when his pulse dropped to 29bpm.

And, of course, I never managed to talk at all about the road to recovery - or the wonderful, amazing, awesome people that helped us get there (you know who you are, dear ladies at the Around the Dinner Table forum!) and who were a true lifeline - and still are.

Or even my blog and why I write it.

But I did manage to get them to put a link to BEAT and FEAST on the Lorraine Kelly *Twitter* page.

So that was our interview with Lorraine Kelly on the *Lorraine Kelly* show on *GMTV* yesterday.

But at least it gave our "cause" some exposure i.e. raising awareness of the growing problem of anorexia in teenage boys.

And a huge thank you to Ben for enthusiastically agreeing to take part and talk about his experience with anorexia.

Thursday, 19 April 2012

"Points STILL win prizes!"

Without doubt, one of the Number One drivers in moving Ben's recovery forward over the past 13 months has been our Recovery Contract [see end of book to find out more].

I introduced it in March 2011 after a mum in the States emailed me the Contract she uses for her daughter. It worked for them, so - fed up with being stuck in a kind of *Limboland* with Ben at the time - I decided to give it a try. We never looked back - and if you are looking for something to put the dynamite into your child's recovery, it

might just work for you.

I've got a friend who originally got in touch with me because of this blog. She has a teenage son with anorexia and we've been in close contact ever since.

Her son is doing well, but there are still sizeable sticking points - "challenges" he finds hard to overcome like "challenge foods" or whatever. This is exactly what it was like for Ben, so I suggested she try out a Contract, too.

Of course, like anything, Contracts don't work for everyone. All I can say is that it's worked really well for us over the past 13 months. Without it, we'd almost certainly be months behind in progress.

Introduced carefully (i.e. not enforced on your child, and with mutual agreement), it could just work. So what the heck? Why not give it a go?

You'll quickly know if it isn't working or if your child's resisting it, telling lies or whatever.

And if it doesn't work, simply stop using it. You could always re-introduce it at a later date when your child might be more receptive.

I was fortunate in that Ben was enthusiastic about the Contract from the start. I was careful to position it as something that was a mutual venture i.e. not something I was forcing or inflicting on him.

ED, the eating disorder, was - of course - not welcome. But as long as I was sure it was the "real Ben" speaking, I listened to what he had to say and we adjusted the Contract together.

The Contract is very flexible. By this I mean it can be adjusted as and when it needs to be, by mutual agreement (ED not allowed). Back at the start it was pretty extensive with points being awarded for all kinds of things from daily calories to school attendance, challenges, weight gain and keeping to an agreed amount of exercise.

Nowadays, points are awarded for challenges only, because Ben has got the other issues under control, mainly as a result of the Contract helping him to do this.

New challenges have become old challenges before disappearing altogether. Other challenges have been introduced; things I could never in a million years have dreamed that Ben would eat or do when he was drowning in the anorexia.

I don't assign challenges for him, he chooses them himself. Nor do I insist he faces X number of challenges a day, but I do expect at least one proper challenge a day. But, because this is a positive, encouraging exercise, I never show disappointment if he doesn't manage to achieve any.

Talking about the day's challenges is a great time to say "Well done, I'm really proud of you" or whatever else encourages your child to take on more challenges and feel good about themselves.

Of course with our Contract "Points also win prizes". Ben's benefited from it financially yet it never seemed like a bribe. It's been similar, I guess, to rewarding your child for doing housework or mowing the lawn.

He's kept to his side of the bargain and I've kept to mine.

Here's what I said to my friend today (BTW she gave me her permission to reproduce this):

I found with the ED that you have to keep trying. You can't give up and let the ED win, although I know I did on a few occasions... (more than a few actually when you just get so exhausted and end of tether that you think sod it...)

As Ben was recovering I used to say things like "That's the ED speaking and you know I don't listen to the ED" and plough on... I made a point of never going down the "Just try a little bit and we'll leave it at that" route because that's colluding with the ED, too.

This is where the Contract worked really well for us because something like this would become one of the "challenges". We'd talk about it before the event - not

confrontational but when we sat down for our daily “equal footing” chat about how things are going. With the Contract it’s like “No Man’s Land” or neutral ground. During these chats we can each say anything and there’s an unwritten rule that neither of us is allowed to bite each other’s head off - just talk it out sensibly and warmly, but never in an ED-colluding way!!!

I just ask loads of questions, probing and encouraging questions which don’t appear critical in any way.

So, if this was about burgers, we’d discuss what it is about burgers that he’s finding challenging, making it clear (in a non-confrontational / critical way) that burgers are on the menu because burgers are “normal” and we’re aiming at “normal” (“ED’s stolen enough years of your life already and I refuse to let it steal any more. I want you to be normal. You want you to be normal. Burgers are normal - and think of all the other things you’re fine with now that, just a few weeks or months ago, would have been challenges, hey? Burgers are no different, just the latest “challenge” food. You overcame the other challenges and this is no different.”) Kind of thing...

Do you think a Contract would work with you?

Ben swears by it. He says that the Contract, together with his psych and me, is probably the #1 thing that helped him over the past 12 months. He calls it “The Batty Method”!!

If you’d like help with formulating a Contract or talking your son into the concept of a Contract (which Ben embraced straight away, to my delight!!!), just shout! I will do all I can to help because you know I hate ED as much as you do.

Friday, 20 April 2012

Would our Contract have worked earlier in the treatment?

Probably not. Because, at that stage, Ben - egged on by the anorexia “demon” - was actively working against us. Like many people with anorexia, he was also a dab hand at pulling the wool over people’s eyes. As I grew to know the demon’s sneaky tricks, I could usually tell when Ben was lying to us, hiding food or throwing it away “in secret”.

In those days, it was all about deception - leading people to think you are absolutely fine when, in fact, you’re being dragged down the rabbit hole by the ED demon at a rate of knots. In those days, Ben would argue that black was white. At its worst, anorexia makes you completely irrational; logic and common sense go out of the window.

The Contract relies on trust - on both parties knowing that the other is telling the truth and not deceiving them. This is probably why it wouldn’t have worked during the “dark days”.

Also, in those “dark days”, I used to promise to reward Ben with all sorts of things “if only he would try to get better”. And of course it never worked, because he was completely trapped in the eating disorder and couldn’t escape.

It wasn’t until Ben turned a corner in October 2010 that I gradually learned that I could trust him. I could trust him to eat the calories he was claiming to be eating. I could trust him to cook meals in the correct way, without omitting “bad” ingredients. I could trust him when he insisted he was working with us and was determined to recover. But what I couldn’t trust at that stage was when Ben claimed to be doing little or no exercise. Unfortunately.

When you’ve been deceived for so long, trusting your child again is difficult. It’s a slow process and more than once I mistook “the real Ben” for the “anorexia demon” -

and it's something he often picks up on now.

But gradually trust developed. Also, on the whole (with the exception of the odd blip), Ben was working with us towards recovery. So much so that, by the early spring of 2011, it was exactly the right time to introduce something like the Contract.

The main reason it was introduced was because, although Ben had turned a corner, his weight hadn't really increased. In fact it had continued to go down or maintain at a very low level. He found it very hard to fight the "demon" and put the weight back on again. It was exhausting and he often felt like giving up.

By the late spring of 2011 he had reached a plateau. We called it *Limboland* and he just couldn't go any further. It was like being stuck on a little island in the middle of a bog which threatened to suck him down if he moved in any direction.

The other reason was that he was trapped in a vicious circle of compulsive exercise. He was unable to stop exercising or stay still for too long. This meant he was unable to "sit around doing nothing" in school lessons. Planning or worrying about exercise kept him awake at night and it was preventing him from putting on weight.

He was frustrated. He was losing motivation. He had run out of energy. He needed some help.

This is when I came across the concept of a Contract - the "Mountain Rescue Team" which would help him to safety and guide him in the right direction.

He took to it like a duck to water. And the rest, as they say, is history.

But, no, I don't think the Contract would have worked in the "bad old days" of High Anorexia.

Or at least not in the form we developed.

I have come across similar things - not written Contracts, but things along the same lines; "carrots" to the donkey, if you like - which have worked at earlier stages of the illness and pushed the young person in the right direction.

So a carefully put together version of the Contract might just work earlier on in the illness. Providing that the parent finds some way of overcoming the fact that the

eating disorder lies and deceives because, as I know only too well, “I’ve had 2500 calories today” can, in fact, mean “I’ve had a heck of a lot less than 2500 calories today, and the day before, and the day before that...” and “Yes I’ve eaten it all” can mean “I ate half of it and the rest is in a piece of kitchen paper in the kitchen bin”. And, of course, back in the Bad Old Days “sitting around all day doing nothing” didn’t include the fact that we’d gone on a five mile hike or whatever...

Sunday, 22 April 2012

Weight creeping up, but what does ED think of it?

Ben is almost up to 60kg which, in my eyes, is excellent progress. But I’m not so sure that it is in ED’s eyes, that little bit of the eating disorder that’s still left inside Ben’s head, desperately trying for a last ditch attempt to win Ben back into its evil clutches.

Suddenly I found myself trying to “justify” the slight weight increase. “What the heck are you doing?” I thought and immediately changed my tack to: “At this stage you shouldn’t be micro-managing your weight; you should have moved on from that.”

A bit later Ben (or was it ED?) said: “Would you mind not doing what you did the other day, ever again?”

“Which was what?”

“Looking at my legs in that way.”

“What do you mean?”

“When I came in wearing my dressing gown and you looked at my legs ‘in that way’ as if you were convinced I was skeletal. It’s things like this that make it hard for me to trust you.”

If it *was* the ED speaking, then I’d translate that as: “It’s things like this that make it hard for me to believe you’re not trying to make me fat.”

Monday, 23 April 2012

At a loss what to do next...

And so the social isolation continues, and I can't help but feel it's mainly self-imposed. If I thought that Ben was isolating himself from his peers a few months or even a year ago, it is now far, far worse. And, to be honest, I haven't a clue what to do.

Nor had CAMHS. Our psychiatrist's advice was that it seemed to be a case of flogging a dead horse and there was little point in Ben trying to resurrect his strong-as-iron past friendships. Just wait for university where everything would, with any luck, magically fall into place and Ben could start afresh.

At least a few months ago Ben was still going to church and socialising a bit, even though he was right on the fringes of the youth group and, if you've read recent blog posts, you'll know that the church let him down disgracefully. Despite me spending a morning bashing out a social integration plan with the church pastor and him promising wonderful things, nothing happened. Ben stopped believing in God, stopped going to church and no-one from the church has bothered to follow it up. They have let him down Big Style.

Now there is just Ben, his dad and me.

Today I read an article all about cutting the apron strings. How, as your son grows up, he starts to form his own life, becomes more independent and doesn't need his parents as much.

With Ben it's the other way round. He depends on us one hundred per cent for his social life and everything else. He is completely dependent on us and it seems to be getting worse.

Last night I dreamed I was trying to explain it all to one of Ben's school friends. In my dream I was pleading for her help in getting Ben back into his social group.

Heck, I desperately want him to be out there, with his friends. Sleepovers, cinema

trips, meals, parties, band practices, badminton, shopping in town or just having a laugh... all those things he used to do before the anorexia whisked him off to *Planet Zorg* and years of solitary confinement, maybe with even more years of it to come.

How the hell is everything suddenly going to drop into place when he goes away to university? He's missed out on a tonne of late adolescent social skills. He simply doesn't have them. Having been on his own for over two-and-a-half-years, in real terms, he has developed other skills. He tends to "lecture", to talk "at" people and he is always right. He bosses me around, tells me off, demands that I go for walks with him, etc. And the rest of the time he sits in his room either studying or painting his models. Or he's downstairs cooking, baking or playing on his *X-Box* (these days he doesn't even use *X-Box* "Live" to play games with his peers).

His Facebook page used to have lots of "likes" and comments. Now it's just him posting and me "liking".

This is not good - and I have no idea what to do.

We no longer have CAMHS, not that they were much help on this count. I've tried desperately to open doors for him socially and with suggestions for things like summer voluntary work, part-time jobs, etc where he could meet new people, but he doesn't take the bait. And, as the old adage goes, you can lead a horse to water but you can't force it to drink.

And now the insomnia is back on school days. Which means it may still be here when it comes to the A-level exams, just as it messed up his AS Level exams last year.

Actually on Friday night it occurred to me that messing up his A-levels and not getting into university this September mightn't be a bad thing.

It would give us another year to really push for full recovery on *all* fronts, the social interaction front being a priority.

The trouble is, it seems to be completely up to me to come up with a solution, because I can't see it coming from anywhere else - and I have no idea what to do.

No idea whatsoever. Not a clue.

Thursday, 26 April 2012

Plans A, B & C to deal with the anxiety and insomnia

Okay, so Ben is finding it harder than ever to go into school. His insomnia is back with a vengeance, fuelled by anxiety, which means he is missing large chunks of school.

On top of this he has A-levels in a month's time. So what can be done? Well, I've come up with three plans: A, B and C which I'm going to go through with him this afternoon to see if it will take some of the pressure off him.

Plan A: Ben gets his A-levels and goes to university in September

- ★ We draw up a University Contract so I can discreetly monitor how he's getting on (this is a blog post in itself, so I won't go into detail here unless this is a "goer").
- ★ There is the option to leave part way through, if necessary, and pick up where he left off a year later (standard practice, I believe, for universities).

Plan B: Ben gets his A-levels but defers university entry until 2013 to focus on full recovery

- ★ He gets a part-time job or voluntary work to keep him occupied, maybe earns some money, gets used to being out of the house and meeting new people.
- ★ To keep his brain active, and because Ben needs the intellectual stimulation of academic study, he studies online for an additional qualification in an area he's passionate about e.g. ancient history, archaeology, etc.

Plan C: Ben needs to resit some of his A-levels with a view to 2013 university entry

- ★ He attends school on an occasional basis to revise and sit the exams (already agreed with the school).
- ★ He studies online for an additional qualification (see Plan B).

In the meantime I've made a double-length appointment with our GP for next week to review his medication and see what can be done, now we no longer have CAMHS.

Friday, 27 April 2012

Third day of missed school and A-levels less than a month away...

I know Ben managed to study almost exclusively at home for his GCSEs *and* get really good results, but the school says it's very different for A-levels, especially with Ben having to resit some of last year's AS Level exams at the same time. Exams are less than a month away and he's only been in school for a total of eight hours this week...

I can almost hear ED "the anorexia demon" chortling away with glee. "Ha ha," it taunts, "CAMHS discharged him, assuming that everything was now okay and most of the big issues were sorted, insomnia included - but I've left my trump card until three weeks before the all-important A-levels: the insomnia is back!!!! Ye har!!!!"

The moment Ben started his Lower Sixth Form year last September, the insomnia arrived - and it stayed with him all through the school year, right through his June exams. Often he struggled into school to sit these exams having had little more than an hour's broken sleep. Although he miraculously managed to get a Grade A in one of the exams, the rest came back with Ds, Es and even an Unclassified. This, from a "straight A" student...

Up until the Sixth Form, Ben had slept reasonably well - proved by his excellent GCSE results. But insomnia and all the low moods, isolation, anxiety, etc that it brought with it became the #1 problem throughout the whole of the Lower Sixth

Form. CAMHS tried various medications and nothing worked. Because he was under 18, they would only prescribe children's medications which were next to useless.

Then it miraculously faded away over the school summer holidays and I thought it had gone for good.

But now the insomnia is back, Big Style, and it's why Ben is still in bed when he should be waiting at the bus stop for the school bus. And Friday is the only day he manages to stay in school all day. (Usually.)

No, with my Plans A, B and C in place, this doesn't matter academically. Especially as I've also discovered Ben could take an Open University *History* module in a gap year which would count towards his eventual degree and which might stimulate him more than an A-level at this stage.

Make no mistake, I am not "pushing" Ben academically; he himself needs this stimulation. He thrives on it and it takes his mind off the "anorexia voice" (which is still there to a certain extent). I also know that he is pushing himself to do well so he gets into university in September. He sees university as the "magic bullet" that will solve his isolation problems and allow him to start afresh. So if he fails to get in, he will beat himself up about it and feel like a failure.

The main niggle I have is that I feel he still needs some kind of professional support now that he's been discharged from CAMHS. Although I am massively able to cope at this late stage in the anorexia, there is a bit of me that feels "at sea" without CAMHS, despite our (often profound) differences over the two years he was with them.

And I can't get a GP's appointment until a week today to talk about Ben's medication and the insomnia, and to see if there is any support available.

Or maybe we don't need support.

I don't know.

I just know I feel this undercurrent of anxiety and worry which, despite our differences, I could talk about with our psychiatrist who was really great at that kind of thing.

Bl**dy anorexia.

Friday, 27 April 2012

Okay, so this is Batty's NEXT plan...

Thank you, my brilliant blog followers, for coming straight back with some very sensible, helpful and practical advice on what to do about the insomnia / social / all the other disarray that the ED's left in its wake. This is what I've decided to do - and I've told Ben that I'm not "asking" if he'd like to do it, but *telling* him that he needs to do it, so we're doing it, no objections allowed.

Ben, being Ben, says: "Well if therapy turns out to be rubbish and a total waste of your money, which it probably will be, then I'll pull out."

"Well it's worked for 'the girls' [as I refer to my blog followers who have recovered from anorexia] and they strongly suggest it might work for you. So let's give it a go," I reply.

So I've left a voice mail message with JH, a private CBT Therapist who already knows Ben, his history and his CAMHS psychiatrist, to see if she's available for some sessions.

Back in November 2009 when I first discovered that the waiting list for CAMHS could be up to six months and I was freaking out with desperation as Ben's anorexia dragged him down the rabbit hole at an alarming pace, I discovered JH - a private therapist who used to work with CAMHS.

We'd already been to see a private psychiatrist who charged a small fortune. I instinctively knew that he wasn't right for Ben, so I looked around and eventually came across JH.

From the start, she made it clear that there probably wasn't a great deal she could do. Anorexia needed proper treatment from a specialist team like CAMHS. Also, recovery could take years. She wasn't really equipped to help Ben with something so

complex and which required such long-term specialist treatment.

But we agreed that seeing her would be better than nothing at all. After all, she had experience of treating teenagers with anorexia and other eating disorders, and if we were going to have to wait *months* while Ben continued to plummet downhill to goodness only knows where, even death for all I knew, then I had to do something.

And JH did her level best to provide the help and support she could at such an impossibly difficult stage.

We all knew that it was a bit like trying to stop the *Titanic* from sinking by sticking a *Band Aid* over the gash in its side. But it might delay the sinking just long enough to get us through the CAMHS waiting time.

In the event Ben was fast-tracked into CAMHS treatment at the end of January 2010 when he was rushed into the cardio ward with a pulse rate of 29bpm. By now the anorexia was getting serious and so CAMHS stepped in early. So we stopped seeing JH.

But she seems like an excellent starting point for some sort of treatment to ease Ben back into real life and address the confidence, anxiety and social issues.

Of course she may be fully booked up, but we can see.

Sunday, 29 April 2012

Clearing out stuff and getting to the root of the problem

It started yesterday when I did a much-needed clear-out of the back bedroom. I went through a suitcase full of stuff I'd collected over the years: Ben's primary school reports, certificates and other things, and a mountain of bits and pieces I'd collected over the last seven years to form a lasting memory of his years at secondary school - the school we'd all dreamed of him getting a place at and which, before ED the anorexia "demon" arrived, was rapidly becoming the making of Ben.

Faced with all this stuff I became painfully aware that Ben's memories of school

weren't going to be good memories - for any of us. Most of the things I'd collected over the years were, as a result, pointless and there was no reason to keep them: school calendars, concert programmes and tickets, timetables, letters home from the Headmaster, Prize Day leaflets, school summer ball menus and so on and so forth.

So I kept his school reports, photographs, certificates, prospectuses, the letter offering him a scholarship place and the Prize Day leaflet when he won a prize, and sent the rest for recycling. Then I sat down and sighed, and mourned the seven years that could so easily have been the Best Days of His Life if it wasn't for the anorexia that blitzed it all to smithereens, starting over the summer of 2009.

I explored the idea with Ben of further therapy to work on his confidence and social skills - to act as a kind of transition between where he is now and university, to give university and the rest of his life the best possible chance of making up for those lost days at school.

But Ben doesn't want therapy, and our conversation moved onto the reasons why he's not sleeping or going to school: the isolation he feels at school, the way he's so solitary, the way his friends talk over him as if he isn't there, the way they arrange social activities right in front of him but don't invite him. "You know I dreamed of going out for walks in the Yorkshire Dales with my friends when the weather got nicer? Well they only did that over Easter. They went on numerous walks, they went to parties, they went to the cinema, they went shopping... and I wasn't invited to any of these."

It was as if Ben was invisible.

"You know when I stay in school for a full day on a Friday? I just sit there, waiting for someone to talk to me, but no-one does. They're all over there and I'm on my own. It's horrible and I hate it."

"Would it make it easier if I arranged a way for you to finish your A-level studies at home?"

"No, I need to be in school. I need to attend the lessons. Crazy I get on brilliantly

well with the staff. They treat me as completely normal.”

So I explained that, together, we need to find a way of addressing the issues that are causing the anxiety which is, in turn, causing nightmares and insomnia - and which could, ultimately, affect his exams and his dreams of university this September. I also explained that it's no big deal if it does mess up his A-levels, they can always be re-sat and he can aim for 2013 university entry. But I know he's so mega keen to go to university this September.

I explained that having some extra help in the way of therapy might just be a Good Thing. But he insists it won't and it would be a total waste of time. And, like the woman at the private health centre said to me yesterday, he has to want to have therapy otherwise it won't work - and now, as a legal adult, he has to make the decisions himself and commission that therapy. Legally, it can't come from me.

So I said we need to find a way of dealing with all of this in manageable chunks. First the period between now and the end of the A-level exams. Next, the period between then and results. And finally the period between results and whatever happens in September.

And we need to do this together. “Together we've done brilliant and amazing things over the past two-and-a-half years,” I reminded him. “I've become a whiz at finding solutions to problems, no matter how 'hopeless', mainly because I had no choice. If I hadn't found a solution, you could have died. So I became a dab hand at Plans A, B, C... even through to Z and back through the alphabet again if necessary... making the 'impossible' possible.

“You, too, have been brilliant, Ben. After all, there wouldn't have been any recovery if it wasn't for *you* working so mega hard at it. I couldn't have done it for you. We did it together. You were brilliant. You've overcome things that few other people of your own age will ever have to face, and you've done it successfully. You are awesome and strong. And I, as your mother who wants the very best for you, who wants you to make the best out of your life and be happy and go on to achieve

your full potential in every way, and whose job it is to be here to help you at times when you're finding the going tough... well, I want to work with you to achieve this."

I told him to go away, have a think and come back at lunchtime so we can talk it through again. "Never forget that we got where we are today by talking and talking, by bouncing ideas off each other and working together," I said. "As with the Contract; it wasn't me imposing my will on you, it had to be a mutual thing. We worked on all of this together and we can still work on it. And I want to find a way of solving the problems you are facing now. It is my natural instinct as a mother."

Monday, 30 April 2012

Which came first, the chicken or the egg?

I'm sitting here, face now dry of tears, makeup smudged, trying to work out for the life of me when it all started, why it all started and if it could have been avoided. Or would the anorexia have muscled into Ben's life regardless? In other words, was he doomed from the start?

The reason for all of this is because of our conversation this weekend and the way it hit home that if I thought Ben's social life was bad before, it is now completely and utterly dead. So much so that I even doubt if he will want to go to the Leavers' Weekend celebrations at the end of June: final Prize Day, final Sports Day, Leavers' Ball, Leavers' chapel service, Leavers' BBQ and so on. And even if we did go along, it would doubtless be even more painful than the Bi-Centenary chapel service back in January - seeing what "could have been", indeed what "should have been" if the anorexia had never stolen the last (almost) three years of Ben's life.

Ben arrived at the school in Year 7 a shy, quiet boy who knew nobody. His final years at primary school had been marred by some cruel psychological bullying which didn't help Ben's self-esteem, already quite low because of the puppy fat he'd carried as a child.

Day One at senior school was a disaster. Ben arrived home in floods of tears because no-one had spoken to him. He'd just sat alone at break and lunchtime, weeping, wanting to come home.

Fortunately the next day there was a parents' evening where we could talk through any settling-in issues. I had a word with the Head of Year who was lovely. I also met some really nice parents of boys in Ben's form who, I assumed, probably had equally nice sons. They promised to do all they could to get their sons to befriend Ben.

These boys went to work and the rest, as they say, was history. Almost immediately Ben's social life took off Big Style and he became a central player in one of the loveliest friendship circles in the year.

Over the next four years things went from strength to strength as Ben and his social / school career blossomed beyond my wildest dreams. Almost by the day he was getting happier and more confident. He was involved in umpteen school activities, was one of the most popular boys in his social circles, was a star on the rugby field and I've already talked about his two-day birthday parties which were legendary, the final legendary party being in the middle of Year 10 (Christmas 2008).

Ben's school career was exceeding my expectations in every way. I was beaming from ear to ear! Ben was confident, popular and happy. Ben also looked amazing - tall, athletic and handsome.

Now this is my dilemma, which some might say isn't a helpful or productive way to think. In other words I should just accept that the anorexia happened and move on from any pointless regrets or trying to analyse what went wrong.

Would the anorexia have happened no matter what? Or was it only triggered by the fact that Ben lost more than one quarter of his bodyweight very quickly over the summer of 2009?

But then, surely, something triggered that weight loss? Something that wasn't good. Although Ben was blossoming on the outside, inside his head things weren't

quite as brilliant - and it was this that ultimately led to the weight loss.

Were those “things” the anorexia? In other words Ben’s underlying personality, the personality he’d had from birth which, despite blossoming on every front at senior school, was still there in the background? The self-doubt, the lack of confidence, a predisposition to depressed thinking and so on. Would they always have led to the weight loss which led to the downhill slide into anorexia no matter what? Or if he’d never lost the weight would they simply have remained as an undercurrent, as they do with so many teenagers? Yes, never forget we’re talking teenagers here, with all the messy stuff that’s going on in their heads, no matter who they are.

But, because he would never have developed anorexia, Ben would have “grown out” of all this teenage angst and other stuff and maybe learned how to handle the negative side of his thinking. Maybe, because his weight would never have dropped to such a critical level, the anorexia would never have kicked in and he would have continued to go from strength to strength socially and in every other way.

Or would mental health issues have taken over his life regardless, whether in the form of anorexia or another condition such as clinical depression? Purely because he was predisposed to it. In other words it was a disaster waiting to happen - the iceberg that was always going to rip a fatal gash in the side of the *Titanic*...

Or not.

Not very helpful or productive thinking, I know, but I can’t help it.

It’s something that is obviously bugging other parents because I’ve just come across a thread called *Chicken or egg?* on the absolutely brilliant Around the Dinner Table forum. [See end of book for link.]

MAY 2012

Tuesday, 1 May 2012

Time for me to back off...

Anon left a comment on yesterday's blog which, curiously, echoes what has been going through my head overnight.

Last night, over tea, Ben and I had a massive row. Not because of the food but because I was fed up to the back teeth of him playing the "poor me" victim as far as his social life is concerned.

After a lot of heated "discussion", shall we say, it hit me that, yes, I do have to back off a bit now. I can't continue to try and make things work for Ben. I can't "manage" his life any longer. He is 18, not eight. Okay so, in real terms, he may still be 15 or 16 - having been on *Planet ED* for nearly three years - but the time has come when he needs to learn some serious life skills, one of which is the ability to manage his own life and destiny, especially now the eating disorder is well under control.

And he needs to do this himself.

I can't - and, indeed, shouldn't - try to do it for him.

It's not like back in the Bad Old Anorexia Days when I was petrified that if I didn't steer things in a certain direction, he might go completely off the rails and leave home or take his life.

He is now at the stage where he needs to take responsibility for his own future. Because if he doesn't learn how to do this, he will never learn how to successfully be an independent adult.

So a bit of "tough love" is required, me thinks.

After our "heated discussion" I felt exhausted. Today I still feel exhausted and, to be honest, I've had enough of being the person who looks after Ben and tries to ease him back into real life.

Yes, I know I need to keep an eye on the eating disorder, just to make sure it continues to fade away rather than return. But at this late stage in the recovery and

despite all these social and school complications, it should be Ben that takes charge of things.

If he fails to do anything about it and just sits there in “poor me” mode, then that’s his look-out.

So, a traumatic few days, but the outcome is good. I’m going to back off now and take a back seat. Just as I should do as a mother of an 18 year old man.

Time for a paradigm shift...

Thank you all for your fantastic comments on my recent posts - and thank you *Anon* for putting into words what I was already beginning to think anyway!

Tuesday, 1 May 2012

But I will not back off altogether and here’s why...

My dear friends on the ATDT forum pointed out a sad link to a report about a beautiful 19 year old girl who lost her fight with anorexia.

To me, the bit that stands out the most is where her mother says: “...Xxxx was not a child so I could not force her to get help.”

As I say on the ATDT forum: “I live in dread of my 18 year old son relapsing and me being unable to do anything about it because of the law.”

This is why I won’t back off altogether and why I will continue to be discreetly super-vigilant to do my best to ensure the eating disorder never returns.

The thing is, as we all know, getting your child to do anything positive about recovery when they’re neck-deep in an eating disorder is impossible. For a start the chances are they won’t even admit they have a problem. And even if they do, they are often powerless to do anything about it.

This is a serious mental illness we are talking about - an illness where the latest evidence-based research shows that the best success rates are where the parents are involved in the recovery process. Even if the adult child does receive treatment, I

would argue that the parents still need to be involved, just as they were before the child turned 18.

And if the adult child is so sick that they can't "be persuaded to seek professional advice", as was the case with this young woman, then parents, carers and the medical profession need to be able to step in and take action - without the law telling them they can't, because the young person is over 18 and needs to make the decision themselves.

Crazily, there are circumstances where the medical profession wouldn't hesitate to step in to treat an adult in mortal danger - for example following a serious car crash or similar. I don't hear any doctors saying "Sorry but I can't intervene and save this person's life because they're over 18 and I need their permission". They just go ahead and do it.

Yet with anorexia, an illness whose very essence is about keeping its victim in its clutches until every ounce of life is squeezed out of them and where the victim can often refuse treatment quite violently, no-one is allowed to do anything until the illness is so far advanced that it can, sadly, be too late.

In October 2010 when Ben was hospitalised with Bradycardia (pulse rate of 29) for the second time, he tried violently to discharge himself, insisting he didn't need any treatment and nothing was wrong. In the end hospital security and the police had to be called. He underwent the tests he hated so much, presumably because he was still a minor and what I said went.

Like this young woman's mother I said something similar to: *"I tried to warn her that her organs would fail but she just said: 'Don't be silly'."*

Ben said "Don't be silly," but because he was under 18 at the time I was able to enforce treatment.

What would have happened if he'd been over 18?

Monday, 7 May 2012

Tidying up all the loose ends

Ben refuses to see a therapist to tidy up all those loose ends. So although I had a long and fruitful chat with JH, the private therapist we used for a while in 2009, Ben refuses to play ball. However a dear friend of mine has suggested someone else who may be even more relevant and who Ben might just say yes to.

The problems that bother him most are –

- ★ **Social anxiety and isolation** - the need to work on this in the lead up to university entry in September so he can successfully integrate with other students / room-mates.
- ★ **Calorie counting** - Ben is still counting calories to ensure he has sufficient food to keep his weight up but not overeat (see below). But he would find anything over and above this very difficult to come to terms with.
- ★ **Weight** - he still has problems with the idea of increasing his weight; a fear of getting “fat”. CAMHS were insistent that his present weight / BMI is okay (a weight “he feels happy with and can cope with”...)
- ★ **Bingeing** - a fear that he no longer has the mechanism that tells him when to stop eating; a fear that he will get obese as a result - counting calories is a way of controlling this.
- ★ **Social eating** - although the odd meal out with or prepared by friends is manageable, in theory, anything more than that isn't i.e. he would find it very stressful not to be in control of his own meal preparation. He also finds it stressful to eat with friends and anyone with “annoying habits” exacerbates this more (e.g. people that over or under eat, play with their food, etc).

Just to recap quickly... Ben's background is that he was plump, introvert and bullied as a pre-teen, but became very athletic, sporty and popular as a teenager. This led to

the belief that being popular = being athletic and good at sport.

As he started to dislike sport more and more he discovered that, by eating less and eating diet foods, he could maintain his physique without having to do as much sport. However, in reality, he was doing more exercising than ever while cutting down on food and developing all the tell-tale signs of an eating disorder like ritualistic eating, low mood, social isolation, etc.

Over the summer of 2009 he lost one quarter of his body weight and the eating disorder “kicked in” Big Style with ED rages, frightening behaviour, suicidal thinking, school phobia, etc. He didn’t start CAMHS treatment until Feb 2010 (long waiting list) by which time he had plummeted downhill in every way.

After an initial rigorous re-feeding programme where he reached 60kg, he refused to cooperate any longer. This was followed by a significant weight loss, mood deterioration, temporary removal from school (he is still only back at school part-time), etc.

In October 2010 following a second hospital admission for Bradycardia and the threat of in-patient admission, he turned a corner and - between then and now - we have worked together, along with the CAMHS psychiatrist, on gaining weight and changing his mind-set, assisted by a course of *Fluoxetine*.

Although his recovery has come on leaps and bounds there are still a few “loose ends” that need tying up in order for him to live a normal and happy life, as outlined above.

So watch this space to see if this new therapist might be able to help - and if Ben will be happy to see her.

Tuesday, 8 May 2012

Husband and son fighting at 6.30am is not good

Following another anxiety-fuelled sleepless night, Ben decided not to go into school

again today which resulted in H rushing up to Ben's room and both of them screaming at each other. Then H came back downstairs with the old familiar: "I'm sick of all this. Just let him get on with it. If he wants to effing kill himself then let him effing kill himself. It's like being on drugs; he'll never recover. He's stuck with it, for life." And so on...

My H has always been of the opinion that we're powerless to anything except just sit there and let the eating disorder consume Ben until he ends up hospitalised on a feeding tube "because maybe then he'll realise what he's doing to himself and turn it all around. You have to let them reach rock-bottom before they can change..." That kind of approach.

"And I'm fed up of being lied to," he added.

"Pardon me?" I responded.

"Him saying one thing and you saying another."

"Like?"

"Him saying he can go right down to such-and-such BMI if he wants to - and the maximum he should ever be is blah BMI and he's already almost there and at risk of blobbing out."

"Not true. Check the NHS charts. His weight needs to be far higher."

"Well that's not what he says. And he says the ED thoughts are getting stronger because he's putting on weight and is worried he won't be able to stop - or you won't stop him. He blames you for overfeeding him as a child; always giving him food to shut him up."

"That's not true! Yes, I fed him a lot of milk as a baby, but you know what he was like... screaming round the clock... a bottle in the mouth was often the only way to calm him down. But I never did that later on in his childhood." I'd always fed Ben healthy stuff and kept away from junk food. It was Ben that developed a huge appetite which eventually led to puppy fat. But as he became more and more sporty, the excess weight dropped off and a lithe, athletic physique took its place.

But pointing the finger like this is never going to achieve anything. The fact is that Ben developed an eating disorder and it wasn't because I "overfed him as a child" just as an eating disorder isn't "caused" by size zero models in the media.

With H and the eating disorder, it's always been a case of "all or nothing". It's all going relatively okay or it's a complete disaster - a veritable Armageddon where Ben is spiralling downhill at a rapid pace, treatment or no treatment, and nothing anyone can do will stop it happening. All we can do is "let him get on with it" and "if he wants to kill himself, then let him kill himself, I wash my hands of it".

What I do know is that Ben is finding things hard at the moment. The double-whammy of exam pressure and the social problems are making the "anorexia voice" louder. He is managing to cope with it and carry on eating what he should be eating. But he does need help in moving forwards again. It might happen naturally when the exams are over, but there are still quite a few loose ends that need seeing to - as listed in my previous post and which I hope the new therapist can help with.

He does need to work on the fear of putting on any more weight. He does need to work on the fear of not being able to stop eating unless he carefully controls his intake by counting calories. He does need to work on social eating so he can eat out with, or be cooked for, by friends and enjoy it for what it is - a fun social occasion rather than something to get stressed over. And he does need to work on the temptation to give in to the eating disorder which is telling him that he doesn't need to eat as much as he is eating; he can get by on less.

Hopefully this is where further, targeted therapy can help and I am convinced that this new therapist is exactly what Ben needs.

Tuesday, 8 May 2012

Possible telly interview again, out come the cribbing notes...

I hate being on the telly but if it's going to raise awareness of teenage boys and

eating disorders, then so be it - only I'm not sure whether or not this latest interview will be happening. Like all these things, it's always 11th hour and rushed which I find hard to deal with because I like to prepare for things properly, especially with a topic as serious as anorexia in boys. I thought the *Lorraine Kelly* show appearance was 11th hour but this could be even more 11th hour. I managed to get my voice heard on *Lorraine Kelly*, but can I do it again?

Last time I scribbled down a shedload of stuff which I wanted to say. Unfortunately I didn't get the time to say 99 per cent of it. On the telly I described the background to Ben's eating disorder and when we first noticed things weren't quite right. I talked about how we, as parents, had no idea that boys got eating disorders, so we were totally unprepared.

I talked about the length of time it took to persuade our GP to refer Ben for treatment followed by the bombshell that we'd have to wait up to six months for a first appointment. I talked about how anorexia doesn't just affect your weight but takes over your entire life. It affects your mood, it isolates the individual and it made it impossible for Ben to be in school. But this is as far as I got on the *Lorraine Kelly* sofa before my few precious minutes were up.

I never got time to explain how I had to go through a massive learning curve so I could get to know this incredibly complex and much misunderstood illness inside out. Heck, we "anorexia parents" have to know almost as much about eating disorders as the professionals. And they've had years of training in eating disorders and mental health issues; we get just a few days or weeks cramming, reading books and surfing the Net - and during this time we're desperately watching our beloved child disappear down the rabbit hole.

I never got to say that it's so difficult to sift the wheat from the chaff - the fact that there's so much rubbish about anorexia out there; so much hype and misinformation. But when you're new to this thing, how the hell do you know what's right and what's wrong or downright dangerous - or where to turn for help?

I never got the chance to explain how desperate I felt without any support. The medical profession just dumped us on a waiting list and left us to flounder. Thankfully I had the very excellent school nurse on the case who told me what treatment was available and how to go about getting it. But, for the first few months, that's all I had.

I never got the chance to explain what a lifesaver it was when I eventually came across the FEAST website and its forum, Around the Dinner Table. Finally I had found a group of fellow parents of young people with eating disorders from across the globe, many of whom knew their stuff back to front, inside out and could point me in the right direction, towards the right kind of treatment and the right kind of information, not to mention supplying as much emotional support as I could handle.

I never got the chance to explain that, unlike other serious and potentially fatal illnesses, you are essentially your child's physician throughout, making it treble important that you know your stuff and know what - and what not - to do.

Let's face it. Your child sees their therapist for, what, 60 minutes max a week? Outside that time they're with you, their parent, and a heck of a lot of damage can be done in that time unless you are equipped to fight the anorexia yourself using methods that have been proven to work for other families.

Imagine the crazy scenario of sitting back and just letting things take their course over those other 167 hours a week while you let the treatment team do all the work in just 60 minutes? (Yes, that's essentially how it used to be done in the "bad old days", believe it or not.)

And I never got the chance to talk about my blog.

Basically, I never got the chance to explain that my purpose - aside from getting Ben through his anorexia - is to prevent other parents from having to go through the massive learning curve I went through: to point them towards places where they can find the right kind of help and they couldn't make a better start than by registering on the Around the Dinner Table forum and introducing themselves to the other mums and dads.

PS: Yes this interview is going ahead, here at my home tomorrow with a view to being on *Sky TV News* at the weekend. Watch this space...

Wednesday, 9 May 2012

Last night ED said to me when I was cooking tea...

“Did you put just one tablespoon of oil into the bolognaise sauce? Because it’s normal minced beef, not lean mince?”

Now, as we eating disorder parents know, the obvious response to this anxiety-fuelled question would be: “Yes, don’t worry, just one tablespoon and I’ve also drained off all the fat” or something like that... Thankfully I stopped myself in time.

“I’ve just put in what I normally put in,” I said. Matter closed. Take that, anorexia...

But - ouch! - I found myself adding, “Anyway it’s not ‘normal’ mince, it’s lean mince” aware that Ben had been subtly avoiding eating this particular packet of mince for some time... (“We’ve had so much meat recently, mum, it’s not healthy to eat meat all the time” and “I was wanting to save that for a chilli at some point,” etc etc.)

Shame on you, Batty, you know you’re appeasing the ED by saying things like this. What did the Queen Mother say? “Never feel you have to justify what you do or explain yourself” (or something along those lines). And this has never been truer than with anorexia nervosa.

Also I was cringingly aware I was singing the same song, over and over again, at the top of my voice, like I used to do in the Bad Old Anorexia Days of cooking meals, to kind of keep me calm and make things seem as normal and “happy” as possible.

Who was I kidding?

“I’ll get us some parmesan cheese to have with it,” I added, testing the water.

“No, I’m fine,” ED replied predictably, followed by “I wish you’d used less oil because then I could have had some bread with it”.

Aaarrggghhh... why restrict yourself like you are on some kind of slimming diet where you're only "allowed" so many calories? Good God, if an 18 year old teenage boy wants bread with his tea he should be able to have it, without a moment's thought. 1, 2, 3, 4 or more slices. And pile on the parmesan cheese as well. After all, teenage boys are supposed to eat their parents out of house and home. Teenage boys have "hollow legs"!

But not this one.

Should I chuck in some extra oil just to get my own back at the demon ED?

But I found myself thinking, "No point, because if his weight increases significantly at the next weigh-in, he won't be able to handle it".

Not entirely sure that thought wasn't appeasing the ED, too.

The point I'm making? Well, obviously it's an absolute "no no" to appease the eating disorder, yet we all do it to keep the peace. But at the same time we're probably helping to keep the eating disorder here, too. I take my hat off to parents who just plough on regardless of what the ED says or does, because I am guilty of saying and doing things I shouldn't.

Also, why is Ben saying stuff like this when he hasn't said this kind of thing for so long?

There are so many stressors going on at the moment what with the social problems and A-level exams in a couple of weeks that he has admitted that "The ED voice is getting very strong at the moment".

But, thankfully, he has also said that "The good news is that I can recognise it for what it is and use the tools I now have to bat away the ED thoughts. The ED thoughts are there, but I know how to deal with them".

This is Great News. But I look forward to the day when the ED thoughts aren't there at all...

Wednesday, 9 May 2012

A different kettle of fish from the Lorraine appearance

The interview wasn't live so I've no idea how much of the footage *Sky News* will use until I see it (on Saturday, I think). So how did it go? Well, as with the *Lorraine Kelly* show, it's a bit of a blur.

The reporter and cameraman arrived, and we had a general talk about Ben and the anorexia. Then Ben and I were filmed baking flapjack in the kitchen which was a surreal experience, pretending that the camera wasn't there and trying to act as if it was "just another day in the kitchen" until I tripped over a bag of onions (edited out, hopefully...)

Then we were both interviewed in the living room. First Ben, who was absolutely awesome talking about his anorexia and what he'd say to boys or parents of boys may be worried their son is developing an eating disorder - and then me, who was... well... it's a complete blank. I just rambled, hopefully saying something worthwhile along the way.

This was followed by some footage of me supposedly writing my Anorexia Boy Recovery blog up in the back bedroom "office".

Obviously it was different than *Lorraine Kelly* because it wasn't live. Also, it wasn't a "cosy sofa chat"; it was a proper, serious news report for *Sky News* with the aim of alerting families of boys who might be developing an eating disorder like anorexia - talking about the signs to look for, etc, so hopefully the eating disorder can be caught early.

I emphasised how, as parents of a boy, you don't expect your child to develop an eating disorder. It never enters your head. The alarm bells might ring if you have a girl, but boys? Well, if you're anything like I was, eating disorders are completely off your radar. (Well, this is what I meant to say but I think that somehow I said "*Planet Zorg*"...??! Will they edit out *Planet Zorg*, I wonder?!)

I also talked about how my blog aims to fast-track other parents through the extensive “learning curve” which we had to go through as Ben descended into anorexia. One of its jobs is to point them towards the extensive information and support available, like the ATDT forum and FEAST website.

But, apart from that, much of what I said is pretty much a blur with me only aware that I was staring at the interviewer like a maniac and putting on my “old and serious” face. But, heck, people aren’t watching it to see me; rather to listen to what Ben and I are saying (hopefully).

Once it’s screened, I’ll put a link to the video on this blog and *Facebook*. The *Sky News* reporter who interviewed us is also writing a report with the video embedded into it. Hopefully that page will also include links to the various eating disorder support websites e.g. *FEAST*, *ATDT*, *Men Get Eating Disorders Too* and *BEAT*.

So watch this space...

PS: Ben was awesome, but he does say on the news report that he didn’t like me writing this anorexia blog when I first started out. Actually this isn’t true; this blog was mainly his idea. What he meant to say in the report was that he didn’t like me talking to the other mums on the ATDT forum. Why didn’t he like it? Because this was in the Bad Old Days of High Anorexia and, as he states, it was the Eating Disorder that didn’t like it, not the “real” Ben. But he has always been one hundred per cent supportive of this blog!

Friday, 11 May 2012

“I can put a salad together for him if that’s easier”...

...Said my sister-in-law a year ago when we spent a couple of days with her for H’s granddad’s funeral. With so many people arriving left, right and centre, the easiest thing to do was for everyone to have fish’n’chips, the prospect of which, of course, sent the eating disorder into turmoil...

“Er, we might have a problem with that,” I said to her as Ben whispered to me that no way was he going to eat fish’n’chips.

“Well I suppose I could put a salad together for him if that’s easier,” she said.

The kind of thing you’d say if someone was on a diet - slimming or for health / allergy reasons.

But everything in my being cried out “Feed him double portions of fish’n’chips! And while you’re at it pile on the sausages in batter, even the deep fried *Mars Bars*, pies, the works!!!”

If only, hey...

Yet again it became painfully clear that here we are in a world where as much food as you can manage is within instant reach, yet our anorexic teenagers starve themselves like children in the third world.

How many times have I been round the supermarket and thought: “Here I am surrounded by so much food it’s almost obscene. Yet my son is unable to eat any of it.”

It is the most peculiar and disturbing feeling.

And, although they mean well, people that don’t understand eating disorders often make “helpful” remarks like my sister-in-law made a year ago.

So while everyone was getting settled into her house and snacking on cookies, cake and cups of tea... Ben’s ravenous teenage cousins salivating at the prospect of a massive slap-up meal... I whisked Ben off on a walk round the block to come up with a food solution.

Thankfully, by this time he was actively cooperating in his recovery, so the discussion was about how to get sufficient food into him without resorting to the salad, yet without risking the fish’n’chips which I knew for a fact he’d just refuse. Being a funeral gathering, an ED rage probably wasn’t the best thing to happen, so I wanted to avoid it at all costs.

So Ben and I sneaked off to the supermarket to stock up on snacks - and later H,

Ben and I went to the local pub for a meal.

My mother-in-law didn't like it; thought we were being anti-social and blamed it on me.

But who cares because, at the end of the day, it was Ben's recovery and sustained weight gain that mattered.

Sunday, 13 May 2012

Temporary implosion has resulted in a duvet day for Batty...

It's not been a good week inside Batty's head. Thankfully Ben's eating disorder has only been a very small part of it. But all week long I've been anxious and on edge, unable to concentrate, unable to write my blog properly, unable to sleep and - today - unable to get out of bed.

After all that's been going on over the past (almost) three years, I'm no stranger to "implosions" like this. What usually happens is that everything that's been going on comes to a head and my brain kind of says "No more!!!" explodes and shuts down for a day.

Then, the following day, I get up and carry on as near normal as dammit.

In the days of High Anorexia it was a zillion times worse and today's implosion is a mere ripple compared to the time when, after umpteen distressing anorexia-fuelled texts from Ben at school, I smashed an entire dinner service, plate by plate - CRASH!!! - on the kitchen floor before collapsing in the corner in a blubbing heap of tears. Then the next day, as we eating disorder mums have to do, I got up and carried on.

A few weeks later it was my hairbrush that was smashed to smithereens when I hurled it across the spare bedroom. Then, desperate to smash something else, I threw a mirror on the floor. Finally I went into the living room and kicked a waste paper bin into the wall, leaving a permanent dent in the plaster.

If you're the parent of a young person with anorexia or another eating disorder

you probably have your own “implosion” stories to tell. Those occasions when everything gets too much and you break down in a way that, if in public, would surely prompt “the men in white coats” to carry you off and lock you in a padded room.

This weekend’s “implosion” wasn’t because of the eating disorder, although Ben’s struggles to rid himself of the “anorexia demon” have played a part in getting me super-stressed this week.

Really, it’s been an undercurrent of various things that have been bubbling under the surface. The result is that I’ve slept badly (H says that one night I sat bolt upright in bed shouting “NOOOOO!”) which left me feeling wretched during the daytime.

And even when I did sleep, I felt anxious during the daytime, unable to focus or concentrate, or feel any joy or motivation.

The final touch paper was lit when I picked up an email late last night on my mobile to say that a very dear friend of mine is seriously ill, and I mean seriously ill. I’d half been expecting to get such an email but when it came I just... well... imploded.

Ben rushed into my bedroom with “What’s wrong? I heard you crying? You always come and hug me when I’m crying so I came to give you a hug because you’re crying”.

Dear Ben.

Implisions always leave me feeling completely sucked dry of any energy or any motivation to do anything at all.

So I stayed in bed.

But I should be okay tomorrow.

Monday, 14 May 2012

A little woman with a massive heart...

One Sunday back in March 2010 as Ben was busy falling off a cliff into the worst of his

anorexia and I was crying out for help and support, I went along to the local church for the first time. I was desperate for support, any support, anything really...

I spent the next five or ten minutes sitting on the back row amongst people I didn't know. Some people vaguely acknowledged me in a polite kind of way but, really, I was just left alone. "Fight or flight set in" and I was just about to flee from the church when a tiny little woman, no more than 5ft tall, with short spiky blonde hair made a beeline for me across the aisle, face beaming with a massive welcoming smile and insisted I came and sat with her.

After the service when the congregation had coffee, we talked and talked. It was as if Sue and I had known each other all our lives. Instantly she sensed that all was not right and got to the heart of the matter. Right from the start I felt that I could talk to her about Ben's anorexia and she would understand.

Over the next two years we met up regularly, usually round at her house for a coffee. As Ben got worse and I got more desperate she'd sit there listening. Whatever I needed to say, I could say it in front of Sue. Out of all the people I have known on this journey, she is probably the only one who completely understood what was happening to us and who cared, the only one outside the world of anorexia at any rate.

This little woman was the most genuine, caring, loving and selfless person I have ever known. Nothing was too much trouble, and she always had time for me - plus a box of tissues for me to cry my eyes out into when things got too much.

Whenever I tried to turn the conversation round to her problems - the fact that she was suffering from secondary breast cancer, had had a double mastectomy and was beginning to find life a little more difficult than she used to - she had a knack of turning the focus back to me.

The result is that I'd always leave her beautiful and immaculate house feeling as if I'd been to some kind of amazing soul spa. Then I'd immediately feel guilty for allowing her to focus too much on me instead of her, and I'd tell her off.

But that's the kind of person Sue was.

I say "was", because my dear, wonderful sweet friend passed away this morning. The last course of chemo had been too much for her. Already stick-thin, she was finding it impossible to eat. She'd had a persistent cough for some time, was finding it increasingly difficult to breathe and her energy had completely gone; towards the end she could scarcely climb the stairs. And of course she'd lost her beautiful blonde hair to the chemo months ago...

Yet - annoyingly - she still insisted on turning the focus round to me rather than talking about her own problems; problems that were a zillion times worse than mine.

Right up until our last goodbye (which I never, ever dreamed would be the final time I would see her), we were giggling about things. "I'm a rebel," she'd say, with a "naughty" grin on her tiny thin face. "If I want to wear a bright red wig, then I will."

She went upstairs (in the days when she still could), came back down and stood outside the living room door. "Are you ready for this?" she announced, coming into the room. "Ta dar!!" Good God, five minutes ago she'd been blonde; now she was a feisty red-head!

Ever an expert at super high calorie foods, I made Sue a tray of high calorie flap jack and some Chelsea buns in a bid to get her to eat and put on weight. Naively I thought it would make her feel better. Irritatingly, she felt she had to buy me some expensive body lotion as a "thank you". I told her off. But, again, that was what she was like. So incredibly selfless and always thinking of others.

Like the months she'd spent lobbying for better cancer treatment for other patients and addressing medical conferences across the UK and in Europe when she herself was sick. It was always a massive regret to her when ill health forced her to give that up.

But no matter what happened she was steadfast in her Christian faith - initially trusting that God would heal her and, later, trusting that there was a purpose in whatever His plans were...

Naively I thought it was this latest dose of chemo that was making her feel more rotten than usual. She kept telling me it was just the side-effects. Although tests were showing that the cancer wasn't receding, I thought that maybe she simply needed to switch to another chemo; that they'd chosen one she was "allergic to" - or something like that.

You see, my friend couldn't die. She was too much of a fighter. She'd already defied the odds time and time again, forging on ahead and staying alive, despite the fact that the cancer had spread to her lungs, liver and spine.

Crazily I thought that one day she'd find a chemo that would cure her - if they could find a vein to stick the needle into. Like a drug addict, most of her veins were completely knackered and the last lot of chemo was in tablet form: the kind of tablets where the medical teams have to put on special gloves to handle them. That's how very, very toxic they are.

The email from her husband didn't come as a surprise this afternoon. I was almost expecting it, yet hoping it would never, ever come. Ever since the email he sent round late Saturday night I sensed that something was very, very wrong.

It's hard to believe that that feisty little woman with the "naughty" grin and heart of gold is gone.

Goodness only knows what I would have done if I hadn't ventured into that church all those months ago and that tiny woman hadn't taken me under her wing and given me the most amazing, awesome support during the worst period of my life.

Sue always said: "Never forget, if ever you need me - you know where I am."

I wonder where she is now...

Tuesday, 15 May 2012

Something she wrote when Ben was going through a bad patch

What with work, my dad's illness and death, my mum, school and Ben's eating

disorder, I didn't get to see my friend as much as I would have liked to. Also, because of her cancer, we couldn't always go out and do things that "normal" friends would do. So most of the time we just sat in her living room, talking. And, in the days when she could still walk a mile or so, she'd come round here with her sweet little *Shih Tzu* dog, Benji.

So the rest of the time we'd talk over the phone or by email. And she, and later her husband, would send round updates following the latest visit to the oncologist or hospital.

Going through these emails I found something she wrote to me at the height of Ben's anorexia. It might have been during Ben's "suicidal" period when my H was working away and I was left feeling pretty helpless and desperate in the house, alone with Ben and the eating disorder that was trying to destroy him. Sue made me promise to phone her, no matter what time of day or night, if Ben's self-harming threats got too extreme - and she and her husband would rush round to help.

Please be assured of my thoughts and prayers and, if there is anything at all I can do or if you just need someone to talk to, at any time, please do not hesitate to phone me. I really want to support you in prayer and in action as you walk this difficult journey. Please never think that your stress is any less than mine, it is different. I am sure that it must be really difficult for you, as a mother, watching your child go through these struggles. Always remember, even when you are angry and feel that you have failed Ben, that you are the right mum for him as God blessed you with him and him with you. Despite our failings God is faithful and continues to use us.

But I do feel so wretched for not being around to support her more - especially as our problems got less acute and her cancer got worse, so much so that she had to have her beloved little dog Benji adopted by another family that was more able to take

care of him.

Her funeral is in 10 days' time because her son needs to get over from the States and her daughter from London.

I still haven't heard from her H, but I did get an email from their church. And this morning I posted a card through their letterbox along with a note to her husband.

Thursday, 17 May 2012

Walking and talking with Ben in the countryside

Along with the Contract, walking and talking is one of the most important things Ben and I have done over the past couple of years. Back in the days of "high anorexia" we'd do umpteen walks in the local countryside and parks, especially when he was off school semi-permanently. We'd walk and talk once, twice or three times a week, through spring, summer, autumn and winter. Initially, and for a heck of a long time... almost a year... I might as well have been talking in Chinese...

The thing about anorexia is that all logic and rational thinking fly out of the window. You can argue that black is black and white is white until you're blue in the face, but to the anorexia sufferer they are in no doubt whatsoever that black is white. You just can't get through to them.

That's what's so crazy about this horrible illness. On the whole, people with anorexia tend to be highly intelligent and academic. I mean, Ben knows his facts about history, geography, politics, philosophy and all his other favourite subjects inside out, upside down. If you told him something that was ridiculously untrue... like, I don't know... like the Romans actually came from Romania, not Rome at all, they'd never been within a million miles of Rome, ever... he'd think you were barking mad and he'd say "Don't be so ?@*!?!? ridiculous!"

Yet tell him that it's okay to eat cheese, oils or ice cream... and that he needs fats to support his internal organs, let alone the rest of his body, and you have all the

proof that this is the case from the world's leading dieticians, scientists and clinicians... and he'd also look at you as if you were barking mad.

There is something uniquely peculiar about anorexia that blocks out all the truth about food, nutrition and how *not* to kill yourself through disordered eating, yet which lets all the other "obvious" truths of life through as normal.

Like some weird kind of sieve or sunscreen lotion.

So, during those walks through spring, summer, autumn and winter, nothing got through to Ben. I felt as if I was bashing my head against a brick wall. Even if I *did* manage to get him to promise to do something, the promise would be completely forgotten a few hours later and we'd be back to square one.

I really thought that I'd never, ever get through to him and he would destroy himself. Or, rather, the lying, cheating, truth-distorting anorexia would destroy him.

But after we turned a corner in October 2010, I began to see a chink of light.

Maybe all this chipping away at solid stone in the dark had in fact created a tunnel that had gradually extended through the granite mountain and was finally reaching the other side.

So we continued to walk and talk. And the more we walked and talked, the more these occasions were used to massive and positive effect.

The great thing about walking and talking - like the walk we did yesterday above the River Wharfe in Yorkshire - is that you can be distracted by the beautiful things around you so it's not like a confrontational "lecture". It's just the occasional exploration of where he is on his recovery journey and how I might be able to help. No nagging and no lecturing, being able to gauge when "enough is enough" and to change the subject to the gorgeous sunset or whatever.

Like yesterday when we talked about ways to lessen Ben's anxiety in the lead up to A-levels which start next week. More about that later...

Yesterday was a Good Day. In the morning I had a catch-up with the absolutely brilliant school nurse who has followed Ben's eating disorder closely since the very

start. Then in the afternoon Ben and I walked and talked successfully.

We also talked about my friend Sue who died on Monday, because Sue had been very good to Ben over the years. But I'm not sure what's going on in his head about that - and that's yet another blog post... so watch this space...

Saturday, 19 May 2012

Bypassing the small talk and getting to the heart of the matter

When an eating disorder like anorexia is dominating your life and thoughts 24/7, it's really hard to focus on anything else, let alone "small talk" or trivia.

Yet so often, as a desperate parent of a child with an eating disorder, you're forced to suppress this about-to-erupt volcano of emotions to talk about the weather, who won the *X Factor* or some other similarly mind-numbing tat.

At the height of Ben's anorexia, many of my former friends and acquaintances kept a polite distance. They made it clear that the last thing on this planet they wanted to talk about was something as depressing and negative as a serious eating disorder. Not through what they said, but through their body language - or the rapid change of subject or plain awkwardness.

I was desperate for support and for someone close to me to "get it" - to really understand the eating disorder and how it was affecting our family, and my beloved only child, and to just "be there" for us. Most importantly, I wanted this "someone" to *want* to do this, not feel they "should" do this...

Sure I had my sister, who was brilliant, and I had all the awesome mums on the Around the Dinner Table forum. But what I didn't have was a close friend I could depend on one hundred per cent - and more.

So, if I wanted support, the church seemed a good place to start. As I've said before, church #1 kept me at arm's length, presumably unable or unwilling to handle what was going on in my crazy surreal world. So did church #2. And, at the start, so

did church #3 (where I sat on that back pew on that first Sunday about to flee out of the building).

And, if Sue had never turned round in her pew and seen me, I would have left.

In just seconds, she'd sat me next to her, further up the church, and was talking to me. Also, within seconds, she'd already explained that she was suffering from secondary breast cancer and the tumours had spread from her (now removed) breasts to her bones, liver and lungs.

Not because she wanted sympathy but because there must have been something in my manner that told her I wanted to bypass all the pleasantries and get straight to the heart of the matter.

By telling me about her own struggles she was instantly throwing open the door as if to say: "Hey, I'm struggling too and because of this I can empathise with what you're going through."

There was a buffet lunch after the service and we just talked and talked: Sue about her illness and me about Ben's eating disorder. It was as if we had known each other for ever and we just talked and talked... No chit-chat, no trivia, no small talk.

It was exactly what I was looking for and, even though I never really hit it off with church #3, or any church for that matter, I never looked back.

I like to think that, over the two years that followed, our friendship was a two-way thing when it came to giving each other the support we both needed. But Sue had an uncanny knack of constantly turning the focus on me and my problems, of listening to me ramble on about my son's anorexia, the latest eating disorder rage, trauma or whatever.

As the anorexia began to fade away and my life got back on track, Sue's cancer began to do the exact opposite and she began to fade away. I felt so helpless watching her get thinner and thinner, her energy being sucked out of her. She'd supported me so much and there was little I could do for her. Even talking was difficult because of her growing breathlessness and persistent cough. Yet she still

managed to smile brightly and retain her zest for life.

I don't think that once during those two years of friendship we ever talked trivia. Sure, we had a laugh and a giggle, and tried our best to turn negatives into positives. But the very nature of our own individual struggles meant that trivia could never, ever be on the agenda.

In stark contrast to anyone else I have met outside my family or the world of eating disorders.

Wednesday, 23 May 2012

A sunny start to a difficult day...

Today is my friend Sue's day, the day when we "say goodbye" to her earthly body, the body that let her down in the end and imprisoned her, so I imagine that wherever she is, she's pretty darn glad to be rid of it.

It's a sunny day, and listening to the Beach Boys *Surfing USA* on the radio, I wish I could believe that Sue is surfing somewhere, on some amazing blue ocean, her long hair streaming out behind her. (She always longed to grow her original long blonde hair back...)

I've been invited to speak at the funeral - a potted version of what I wrote here last week. Very potted, because I have to be brief and the pastor has a habit of "hurrying people on" if they start rambling..

This is Sue's day - and her family's day. And I am going to close my mind to all the negative feelings I have about that church (church #3 which I've talked about before). This is not the place to explain why I stopped attending earlier in the year, to express how angry I feel about the way they've failed Ben or to feel any emotions towards the people there, except the people that matter i.e. Sue's husband, son and daughter.

I managed my dad's funeral relatively okay in February, mainly because my mum

insisted the church service was held after the crematorium, not before. So there was none of that hearse arriving at the church and coffin being solemnly carried to the front while we all sit and look at it during the service. And, at the crematorium, it's positioned to one side, so - again - you're not facing it.

That's what makes me fill up. And also when anyone else fills up, I always come out in sympathy.

Ben and H are coming along to the funeral, too. Not to the crematorium afterwards, that's just close family and friends (including me).

I don't know what Ben will feel. To a certain extent what's left of the anorexia is still numbing his emotions, so he finds it hard to feel sadness or happiness - just a neutral mood exacerbated by the anorexia's usual gloom.

He is acutely aware of this and says that, when everyone else is sitting around feeling sad about something e.g. a great tragedy on the news, he feels nothing at all.

But I'm sure I will fill up. And, if I do, I will hate it if someone give me a hug or anything, because that's what I'm like. I like to keep my grief and tears private, and deal with it myself. I don't want a hug and, preferably, I don't want anyone to notice.

As long as I hold it together during my brief talk about her, though...

Second time I've been to that crematorium in three months...

Thursday, 24 May 2012

Farewell dear friend...

I hate that part of funerals. You know, when they carry the coffin or casket into church and place it at the front. Knowing that my dear friend was in that coffin made it doubly hard, as did standing at the front of the church mid-way through the service, with her right beside me, as I talked about the difference she had made to our lives.

Actually it was kind of weird. For most of the service I'd been hiding right at the

back, head down, working my way through the tissues, trying to pretend I wasn't there. Then, when it was my turn to speak, it was as if something came over me. I felt an instant sense of composure and calm, of confidence and peace as I walked to the front and placed my notes on the lectern.

Now, I am completely useless at public speaking which is why I never, ever do it. But there I was, animated and composed, reading from my notes and ad-libbing, speaking slowly, clearly and with confidence.

It was truly surreal, it really was. It was as if she was right there beside me, encouraging me, like she did the time she and I went to see the pastor about Ben's socialising problems at church.

This was the first time I have ever stood up in front of a crowd of people and talked about my son's anorexia - and about how Sue had supported me so much over the past two-and-a-half years.

Three other women I'd never met also talked about how Sue had influenced their lives, at other times, in other parts of the country and in different ways.

She truly was an amazing woman, even more amazing for defying the odds and living five or six years longer than medical science said she should have lived.

The support she gave me during the worst part of Ben's battle with anorexia was truly astonishing. Most importantly she took the time to really understand what I was on about. She was the only person I've ever met outside my family and the world of eating disorders that really "got it".

I am so privileged to have known her and to have been invited into her life.

Saturday, 26 May 2012

He almost made it to the Arts Dinner last night...

It had been hard work to get him there. Several invitations from peers and members of staff, in fact I know the staff really, really wanted him to be there. And he made it

as far as the dinner venue itself, in the school hall. I dropped him off and went to the supermarket on the way home. Then he called me. He couldn't handle it and needed to leave quickly...

"Well you'll have to wait until I've finished at *Sainsbury's*," I said, followed by silent "Efferty effing eff" over and over again as I finished shopping for the groceries.

I picked him up from the car park just as the Arts Dinner was about to begin. "You should be up there," I said, pointing to the crowd of students chatting, laughing and drinking on the balcony outside the school hall. "Not here. And you *know* you should be there."

Sorry but I couldn't help adding "If you can't manage five minutes of something like this then how the heck are you going to manage going away to university?" Followed by "No way are you going to university in September. We're going to concentrate on getting this sorted out and until it is, you won't go to university. You can't stay like this; we've got to concentrate on getting you one hundred per cent better".

Probably not the best things to say, but I was angry. Angry with the eating disorder for effing up his life and ruining yet another social event, one of the final social events of his school career.

"The dinner wasn't like I thought it was going to be," he muttered. "No-one was talking to me. I was just standing there on my own."

"But all your friends were there! B and E, and what about A, wasn't she there too? Everyone wanted you to be there!"

Fight or flight, and he chose the latter.

We didn't talk about it anymore and he was fine by the time we got home.

But - aarrggghhh! - he shouldn't be sitting at home with his parents on a Friday night, he should be out there with his friends having fun!

In an ideal world, yes, and in his "previous life" as a normal teenager before the eating disorder kicked in - but not now.

Not for the time being, anyway.

So I was awake again at 4am this morning, working out how much spare cash I have to pay for private treatment now the NHS CAMHS treatment has finished and the medical profession no longer consider him to have a problem.

On Saturday he begins a series of sessions with a dietician-cum-psychologist type lady who specialises in eating disorders - to “tie up loose ends”, whatever they may be.

Tuesday, 29 May 2012

“Get help before they turn 18.”

This is what one mother said when her (recovered 20-something) daughter asked what the “biggest piece of advice she would give another parent” going through what she and her daughter had been through together: “Get help before they turn 18.”

Although the article focuses mainly on what this mother would say to parents of other eating disorder patients in a clinic waiting room, this was the bit that hit home hardest for me.

Ben is now 18 and, without his agreement, I am legally excluded from making any decisions about his treatment or recovery. And, should he refuse to cooperate and choose to starve himself close to death, or even as far as death, then that is his decision. I am powerless.

Just because it's the law.

Thankfully Ben and I have built up the kind of excellent “working relationship” that this mother talks about in her article. Also, Ben's treatment started when he was 16, so Mama Batty was in charge.

But hopefully all this means that, unless something terrible happens, we can come to a mum-friendly agreement on what happens next on his road to recovery. Also, because I hold the purse strings for his university education and he particularly wants

to go to university, that's another "carrot" I can dangle in front of him if necessary.

However, as I've said before, this isn't the case for so many families and the result can be devastating. And, at the moment, it looks as if the law doesn't plan to change in any way.

People who are totally trapped in a dangerous illness that's hell bent on destroying them, right down to their final breath, are allowed to "choose" whether or not they have treatment.

And, meanwhile, their parents and other people that love them and want to save their lives are faced with taking a ringside seat to watch the destruction take place.

Like being gagged and tied up, forced to watch your own child being fed to the lions in some hellish Roman arena.

Just because it's the law.

Like many parents of children in their late teens who are battling with an eating disorder, I live in mortal dread of Ben relapsing seriously, the "anorexia demon" kicking in and Ben refusing point blank to get any treatment, because - as we all know - that's exactly what ED, the "anorexia demon" loves doing best. I have nightmares about fighting to save my child's life yet being powerless to do anything about it.

Just because it's the law.

So, any parent of any teen who is battling with an eating disorder and approaching their 18th birthday, please please please put your foot down and follow this woman's excellent advice in the "letter" she writes to parents of children sitting in that waiting room at the eating disorder clinic.

This way you can, hopefully, take action before it's too late - and stick two fingers up at ED the "anorexia demon" and the law.

Wednesday, 30 May 2012

Big blazer, but a blazing success all in all...

Today was Leavers' Day - when the Upper Sixth Form leave school to start exams - and Ben managed everything okay, I am delighted to say. Photographs, buffet lunch, Headmaster's speech and so on... he stayed the course.

Traditionally the Upper Sixth put on their old school uniforms on this day, and Ben was no exception. The difference is, I guess, that while many of the others have bulked out making their shirts and blazers look like the *Incredible Hulk's* clothes, Ben has not.

In fact in his uniform he could easily have been mistaken for a fourth or Fifth Former.

Like so many teenagers that have been through anorexia, Ben looks very young for his age. And because he's still at a sub-optimal weight (in my opinion), he's also very slight.

I remember buying that blazer back in the third form as Ben started to bulk out into a strapping teenager, thanks to rugby and a love of food. I deliberately chose a slightly bigger size with "room to grow", because I'd heard how much teenage boys grow at this stage and no way did I want to spend £80 or so on another blazer before he reached the Sixth Form.

Initially the blazer was pretty huge, and Ben hated it.

"Never mind," I'd say, "You'll grow into it - and I can't afford to buy another blazer".

But the irony was that - despite initial weight, height and muscle gain as his rugby and other sporting activities went from strength to strength - the anorexia kicked in at the end of the Fourth Form. So instead of growing into his blazer, he did the reverse.

By November 2009 it swamped him.

Along with the blazer, his school jumper, trousers and shirts seemed to get bigger

as he got smaller. So I had to buy smaller clothes to avoid him looking ridiculous. But I never bought a new blazer, no matter how massive it looked. Not at £80+ a shot.

I was kind of hoping that, two years since he last wore that blazer, it would fit better. Miraculously he'd have filled out and it would hang perfectly.

But it didn't. In fact it didn't look much different to how it looked the last time he wore it. But, then, it always was a huge blazer...

The only difference was that the boy inside looked much healthier, with a happier expression on his face.

But it was definitely still a boy's face and distinctly different from the other Sixth Formers whose blazers were bursting at the seams with the sleeves half way up their arms.

But, hey, let's celebrate the fact that he went into school today, and yesterday too. And he ate with the others at the leavers' buffet and took part in the photographs.

That in itself is progress.

JUNE 2012

Friday, 1 June 2012

A course of private treatment sessions, starting tomorrow

Both Ben and I are well aware that there are several "loose ends", shall we say, that need tidying up - and that he has reached a plateau where he needs a little help to move forwards. So tomorrow we start a series of private treatment sessions to try and sort this all out and get things moving again, towards full and complete recovery.

The problem is that Ben was discharged from CAMHS in March when the psychiatrist went on maternity leave. He had also reached the age of 18 which put

him outside the remit of CAMHS. So the decision was made to discharge him rather than moving him to Adult Services - because I was told that “Adult Services wouldn’t have him” at his present weight and level of recovery.

The GP, too, didn’t seem to think there was a problem and that Ben would “grow out of it, given time”.

In other words, time would heal and there was nothing practical or useful that the professionals could do.

But we are stuck.

We’re stuck with all the social issues; the fact Ben is one hundred per cent socially isolated, relying exclusively on his dad and me for his social life and entertainment. Otherwise, he is on his own. And he doesn’t seem to be able to “go out there, get involved with things and make friends” as we really wish he would do.

Having been on *Planet ED* for nearly three years now and - at the same time - isolating himself socially, suddenly being dumped at university in September, away from home, and in potentially challenging social situations: Intro Week, room-mates and so on, three years of missing out on social skills may prove to be a real problem.

Then there’s the eating. Sure, he’s eating “enough” calories to maintain his weight and, perhaps, very slightly gain weight, and he’s doing this without any problem at all.

The problem is that he is still counting calories, weighing food, checking nutritional content, etc and unable to break free from this. He is fine when he knows what’s going into his meals but not so fine when it’s been cooked by someone else or we’re eating out.

The odd non-calorie-counted meal is fine. But he wouldn’t reach for the butter to put on his bread, for example. Or choose “normal” ice cream (as opposed to “light” ice cream), although I have seen him eat mayonnaise which was obviously not the “light” version and, yes, he does have the odd *Solero* ice cream which isn’t “light”, either.

But no way would he go out for a slap-up curry, a meal at *Pizza Hut* or any “unhealthy” restaurant or take-out. Not even on a one-off basis, although he does have the odd fish’n’chip meal in a pub. But this is when he’s eating with us. Eating with his peers and friends is ten times harder.

And he would find it virtually impossible to eat meals his room-mates cooked for him, unless they, too, use “healthy” ingredients and don’t include too much fat or oil. So, while everyone else is eating in a group, I predict he will be eating alone. He will be the “odd guy” measuring, weighing and counting while the others just sling it on the table and tuck in without a second thought. And it’s not as if he’s obese and doing this; he is very slim and doing this. It will seem odd.

Most important of all, it’s not a normal way to behave. He can’t carry on like this, controlling his intake and weight for ever. But I believe that, if left to his own devices, this would be the case.

So tomorrow we are seeing U, a dietician who is highly experienced in the world of eating disorders with an eating disorders CV that reads like *War & Peace* - all thanks to the recommendation of a dear (ex-anorexia sufferer) friend of mine. To a certain extent, I believe that U is also experienced at dealing with some of the psychological issues that underpin all this. So I have high hopes, providing Ben continues to cooperate.

But, as I have said to him, these things need to be sorted out - or at least be well on the way to being sorted out - before he goes to university. And I am the one with the purse strings.

No Bank of Mum, no university.

(Oh and a huge thank you to my dear late dad who is paying for these private sessions!!)

Sunday, 3 June 2012

Really good session yesterday with the new dietician

Yesterday Ben and I spent an hour with the new dietician, putting her in the picture about Ben's anorexia and the stage he is at now - plus all the remaining challenges, as outlined in my previous blog post. It was really good and she "got it" immediately. But, then, I expected she would. After all, she seems to be one of the region's leading eating disorder dieticians and has also been on the telly several times (talking about eating disorders and working with people with anorexia, etc).

Ben tends to be extremely cynical about clinicians. The only person he ever really trusted, and he came to trust her implicitly, was our CAMHS psychiatrist. As a result, he accepted everything she said as "gospel". But I have high hopes that the same will happen with this new clinician. She did a fabulous job of winning him over yesterday and gaining his trust. Without that, it would never work.

Already she has introduced the concept that he will need to weigh more as he gets older i.e. between now and 21, and 25.

"But I'm not going to grow in height," he said.

"It doesn't work like that," she said, explaining that men between the ages of 18 and 25 "bulk out" - they develop muscle mass naturally, and muscle weighs more. In other words, he won't be "getting fat", he will just be building muscle and this is something that happens naturally to older teenagers as they mature into full grown men.

She also covered a host of other issues that are worrying Ben. Like the concern that, if he doesn't count calories, he may eat "too much" or "too little". If he eats "too much", he "might not be able to stop", will balloon out and become obese.

And also the fact that, although people who were overweight as children do have a tendency to be overweight as adults, the fact is that the more you maintain your weight at the "right weight", the more the chance your body will adjust to that as being your ideal weight, making ballooning out unlikely.

She pointed out that at this stage it's difficult to say what Ben's natural set weight as an adult should and will be. It's not an exact science and everyone is different, with different genetics, skeletal frame, muscle mass and so on. In other words, one-size-fits-all BMIs aren't helpful (to say the least!) when determining the right weight for someone. Music to my ears...

She accepted that, yes, Ben does have a good understanding of nutrition. Yes, he does eat very sensibly and eats an excellent and very balanced diet. He also loves eating and isn't afraid of eating any more, or of eating the quantities required to keep his weight up.

So those are Good Things.

She will be working on the eating out socially issues, the problems he has with eating meals that haven't been prepared by him (and calorie counted), the problems of watching other people eat who may eat strangely or in a disordered way so it doesn't bother him as much as it does now, and loads of other things.

I can tell that Ben was taking in what she was saying, and accepting it as fact, just as he did with his psychiatrist once logic and rational thinking had returned to his mind.

It's very similar to the stuff our original dietician talked about with Ben, right at the start, before she was withdrawn because of financial cuts. Our psychiatrist tried her hardest to take the dietician's place, but - let's face it - she's a psychiatrist, not a dietician so we missed out Big Style on all these dietetic facts that so appeal to Ben and will help him conquer his remaining irrational fears about getting fat, controlling calories, weighing stuff and eating certain foods.

So great stuff, all in all. Brilliant! I am one happy Mama!

Sunday, 3 June 2012

This is a bit peculiar... or is it? I can't decide...

As you may have seen from my *Facebook* page, Ben is being given a couple of awards at the school Prize Day (to be held at the end of the month). One is the *Extended Project Qualification* Prize. Okay, that's brilliant. But the other is the D---- H----- Prize for Overcoming Physical Difficulties. Now, I can't quite decide whether that's really great or whether it's just kind of weird...

I know the school means well. It's always positioned itself as a school that nurtures "the whole child", not just focusing on academic achievement. It encourages and rewards a whole load of other things, too, one of which - in the case of this award - is obviously the courage and determination to overcome physical difficulties.

If he'd fought to overcome something like cancer or was disabled or something, then fine, that would be okay.

But there's still a shedload of stigma attached to eating disorders (and, anyway, you and I know anorexia isn't a "physical difficulty" ...)

Yes I know that pretty much all his peers know he has had anorexia, but the rest of the school probably don't. Nor the parents.

Which begs the question: will people ask him or us what the "physical difficulties" he's overcome actually are?

Not that I mind at all. But I'm not sure how Ben thinks about it. He hasn't said, and I haven't raised the question. The reason I haven't raised the question is that, if Ben's completely cool about it, I don't want to put any negative thoughts into his head.

So I can't decide whether it's really great that his efforts are being publicly recognised - or really crass.

I know they mean well. They mean very well. In fact, over the past two-and-a-half years, the school has bent over backwards to help Ben and me in every possible way they can. Last week I took a big bunch of flowers to the Assistant Head for all the hard work she's done, going way beyond the call of duty.

And it's not just her. All the senior staff have been concerned. The other day I bumped into the Deputy Head who spent quite a long time chatting to me about Ben. I also touched base with the school nurse the other week who has been brilliant over the past couple of years. Plus, Ben's subject tutors have also been superb.

Maybe I should be giving them an award for the *Most Caring Secondary School!*

Just not sure about this particular award...

Monday, 4 June 2012

He is actually quite touched by the award...

So I subtly asked him what he felt about the two Prize Day awards and he said nothing about thinking it's peculiar or anything like that. And when I prompted him about how he felt about that particular award, he said he felt very touched by it and felt grateful to the school for recognising his fight to overcome the anorexia. Good. That put my mind at rest, so it's only me that's unsure how I feel about it. But what he did say was this...

"I know I should be thrilled and elated at getting these awards," he said. "I'd have been gutted if I hadn't got any at all. But the problem is I still feel that numbness. Whenever I should be happy or sad about anything, I just feel, well, completely numb. I know I *should* feel happy, sad or whatever, but I just can't feel anything at all. And I know the school is showing me that it really cares about me; I just wish I could feel thrilled about it."

This numbness is classic eating disorder. It happens to so many anorexia sufferers, but it's such a shame that Ben still feels this way, almost three years since he first developed his anorexia.

I suggested that some extra talking therapy might be useful. But he isn't interested.

"I'm sure things will improve once I'm out there doing the things I like with people

that like the same things as me,” he said. “Like *Warhammer*, when I go to university.”

“Well as long as you *do* get out there and get involved,” I added.

But the good news is that he is actually quite pleased with these awards. Well, as pleased as he can be when he feels so numb.

And the other good news is that he is happy to continue with the new therapy sessions with U, our new dietician.

Wednesday, 6 June 2012

A reminder of why I write this blog...

Why do I write this blog? Why do I talk about ultra-personal things here on the Internet, in the public domain, where anyone can see it? Especially when a third party is involved i.e. my own teenage son? What does he think about it? Does he read my blog? Am I maybe a little too obsessed with eating disorders, maybe even glorifying them to a certain extent, rather than putting it all away in a box, forgetting about it and moving onto the next stage in our lives? Here’s just one reason why I write this blog, based on a post from August 2011...

I’m not alone in “going public” about our fight to get our teenage son fully recovered from anorexia. I know many other parents that write blogs and books, or get into the media, bringing eating disorders out of the closet and into the public eye - and, just as important, doing our small bit to help others facing a similar situation.

Right at the start, I had no ideas that boys got eating disorders. As the mother of a teenage boy, anorexia didn’t feature on my radar. And I guess it must be the same for many parents of teenage boys. You simply don’t expect anorexia. You don’t even *think* about it.

No, I hadn’t a clue that boys got anorexia which is why it took me quite a while before the horrific penny finally dropped.

Once I realised that Ben was developing the dreaded “A” word, I was terrified. I

felt isolated. I didn't know where to turn, what to do or what I should know. And yet the information I did find suggested that this could be a deadly condition - that people could and indeed do die from anorexia.

Yet, unlike cancer or another life-threatening illness, we weren't being fast-tracked into treatment or given advice. Indeed our GP was reluctant to refer Ben for treatment, and even when he did we were faced with a waiting list that could last for months.

Any desperate phone calls to the GP asking what I should do or where I could get interim help were met with a shrug of the shoulders and a look that must be so familiar to parents of boys with eating disorders that says "over-protective mother worrying about nothing". A look I've come to recognise over the years...

So if we weren't going to receive professional help for at least five months, I had to do something. I had to educate myself on everything I could find about eating disorders, and I had to do it quickly. And all this while struggling with a teenage son that was disappearing in front of my eyes.

The point is: I know how terrifying it is to discover your child has a potentially life-threatening condition and not knowing what to do or where to turn.

Right from the start I was acutely aware that I wanted to do my little bit to help parents just like me - not only to help direct them to useful websites like the Around the Dinner Table forum and other information but to talk about my own experiences so they can see there is a light at the end of the tunnel.

I'm not a medical or mental health professional, but what I am is a genuine parent who not only cares about my son and his journey back to health but who also cares about other parents in my situation. It is no different from a parent who writes a book on the topic and goes public. It is no different from a parent who gets into the paper and goes public. It is no different from a parent who gets onto the TV and goes public.

All these experiences are out there in the "public domain", and the very last thing

that any of us is doing is “exploiting” our children or using their illness to draw attention to ourselves. In fact most if not all of our children support us in what we’re doing.

Imagine if all of us had simply sat back and done nothing? Even if we help just one parent fast-track their way through the massive ED learning curve and get some kind of useful help, we have done our job. And every time a parent contacts me to say how much this blog has helped them, I know it’s serving its purpose.

Next time: Why I *continue* to write this blog...

Thursday, 7 June 2012

Why I STILL write my blog...

I’ve already explained why I started my blog, what Ben thinks of it and its two main purposes i.e. to help other parents of boys with eating disorders realise they’re not alone on this journey, and to help raise awareness of the fact that boys get eating disorders, not just girls. Here’s why I continue to write my blog, despite my son having been discharged from anorexia treatment in March and being well on the road to recovery...

For a start, a blog needs to be kept up to date - something to do with search engines, I think. Not exactly sure of the techie science, but I know a blog needs to be kept up to date. And I worry that the people that need it won’t find it if it’s languishing on page #1 million of Google or I’m not posting new links on *Facebook*. So this is Reason #1 why I still write my blog.

Reason #2 is that, although Ben is massively recovered from anorexia, he is not fully recovered. There are still underlying issues that need sorting out - presumably similar issues to what other families may face during the latter stages of anorexia. So, as well as all the posts about our descent into anorexia and back out again, Ben’s recovery is still a work in progress and therefore still worth writing about.

Reason #3 is that it's not just about Ben; it's about me, too. It's about how I dealt with past issues on this journey in and out of anorexia. Things that maybe I haven't yet written about, for whatever reason, and which I want to jot down "on paper" for use in my book (when I get around to writing it...). And the blog seems as good a place as any to do this.

It's about how I continue to adjust to "normal life" now we're through the haze of "high anorexia". Remember the anorexia stole three years from my life as well as from Ben's. And the other day I read that parents who come through a trauma such as a child's serious illness take longer to adjust back to "normal life" than their children.

My life has been "on hold" for three long years and getting back into the land of the living isn't easy or quick. And if I'm going through this, I guess other parents may also go through it. Hopefully they will read this blog and say "Me too!" In the Land of ED, you can feel very isolated as a parent and you need to know that there are others out there that "get it".

But someone commented the other day that perhaps the reason I still write is because I can't imagine my life without the anorexia. In other words, I can't let go.

This is not true. I write for the reasons stated above.

And, when I do eventually adjust back to "normal life" and Ben is one hundred per cent recovered from anorexia and living a full, happy and healthy life, then it will be time for me to write my book.

But I'll always be involved in the world of eating disorders, together with the many great friends I've met on this journey - purely and simply because that's what we do, and may always do.

In the same way many people continue to campaign for other causes, long after the illness or whatever it is has left their lives.

So there will always be something for me to write about.

Thursday, 7 June 2012

Raising awareness of eating disorders through this blog...

This post is in response to a comment about whether, through this blog, I might be wrongly publicising and exploiting eating disorders at the expense of my son's privacy and his need to free himself from his connections with anorexia as he recovers. Here's my response...

Firstly, let me say that my son has always been one hundred per cent behind this blog. It was he that suggested I write it in the first place and he's always nagging at me to "do more" to help raise awareness of eating disorders in a society where eating disorders are often shrouded in secrecy, shame and misunderstanding - and also where there is still too little awareness of eating disorders in teenage boys.

Ben himself has been actively and enthusiastically involved in a project which Oxford University is putting together about the various health issues that affect modern teenagers, one of which is eating disorders in males. It's something he did himself, off his own bat, without any input from me. It will be published in the autumn.

In other words, this is what he chooses to do. Some people may wish to put the anorexia experience behind them and move on. Ben prefers to get active!

He has also tried to become a Young Ambassador for BEAT (but unfortunately they're not taking on any new Young Ambassadors at the moment).

My way of raising awareness of eating disorders in boys is to write this blog which will eventually be used to write a book. Other parents I know also write excellent blogs about eating disorders and do a host of other things to raise awareness of the condition. In fact I am awestruck by some of the things they do. It makes me with my little blog feel incredibly humble.

But I do know that, through this blog, I have helped several other parents of teenagers with eating disorders and especially parents of boys with eating disorders.

At the end of the day, that is the primary purpose of this blog.

The secondary purpose is to raise awareness of anorexia in boys, like the two recent TV interviews, each of which came about as a result of my blog.

Yes, one might call that “publicity”, but I call it “raising awareness”. The more the real issues and facts of eating disorders are brought before the public eye, the better - especially with so much misinformation out there about EDs, the kind of thing you read about in sensationalist glossy magazines.

Ben doesn't read this blog. He chooses not to. And Ben isn't his real name. In fact I don't use any real names in this blog apart from references to relevant professionals, etc. (“Batty Matty” is my school nickname!)

But, as I said in my last blog post, when you suddenly find yourself on this devastating journey as a parent of a boy with anorexia, it can be so reassuring to know that others have been along this road too. To know what they went through, what signs they should have looked out for, what worked and what didn't, how they successfully handled particular situations - and how they failed, but dusted themselves down the next day and started all over again. And how they got the strength to do it.

Most importantly, how their child responded to treatment and family support - and how, ultimately, the main thing that helped Ben get through this was the fact I was always there for him, talking with him, encouraging him, developing our very successful Recovery Contract and so on. I'm not saying this to boast or project myself as some kind of awesome Super Mum, but simply putting down on paper what Ben said to me recently and which he also says in that Oxford Uni project.

This - and raising awareness of eating disorders in boys - is what this blog is about, and why I believe it is a Good Thing.

And also why it has 18 year old Ben's full and unconditional blessing.

Sunday, 10 June 2012

Final week of A-level exams...

We will both be glad when this week is over. Ben has three exams this week, all morning exams, which isn't brilliant now the insomnia has returned. Worse still, two of the exams are back-to-back, one after the other. So if he doesn't sleep the night before, it'll be a nightmare.

"Look, you know it doesn't matter at all," I said, hugging him this morning.

"But it matters to me," he said. "It matters to my sense of pride. If I mess them up I will feel I have failed."

"But, really, it doesn't matter at all," I repeated. "If you mess them up, then so what? Just re-sit them next year."

"But I really want to go to university this year. I want to launch myself back into everything, make a fresh start and begin to live my life again. I couldn't stand having to wait a year."

"You never know," I said, "A year out could be really good for you - as long as you grab it by the horns, do stuff, get out there and so on. It might turn out to be one of the best things you've done. The thing is, university might be brilliant. I hope it's brilliant. But it's important you don't see it as a 'cure all'. It might not be brilliant. Or it might take a while to settle in. So another year of sorting stuff out mightn't be a bad idea after all. And, anyway, loads of people take a year out before going to university."

We are going to go shopping on Thursday when I pick him up from his last exams. "Then can we go to that new bar?" he asked as his dad promised to buy him a pint to celebrate.

And if he doesn't get his grades, then what the heck? Unless he makes a real hash of it and has to re-sit the whole year, then the school says he can use its facilities on an ad hoc basis. Staff will be happy to give him practice papers to do and to mark

them, give advice and so on. They say this kind of thing isn't unusual at all.

Really, I don't care whichever way. I have always said to Ben that the most important thing for us is for him to recover fully and to be healthy and happy.

Sod the exam grades!

Monday, 11 June 2012

Ooooh, I am so excited!

FEAST, the "parent" website of the Around the Dinner Table forum is organising a two-day carers' conference here in the UK in November - and I am so excited about it!

FEAST started out as an American website, but these days it reaches out across the globe. It has a huge following here in the UK and, over the past 30 months or so, I've become very close to dozens of other parents of young people with eating disorders, many of whom will be at that conference.

Although some of us have met up over the months, we haven't all been together in the same place at the same time - apart from online. So it will be amazing! All those people I've chatted to, who have been with me through thick and thin, always there to provide a shoulder to cry on or some emergency support and advice at 2am, or whatever... we'll finally be getting together! Or at least most of the UK contingent will be.

FEAST (UK) have organised some amazing speakers and workshops for the event including the incredible Professor Janet Treasure (of the Maudsley Hospital) and Susan Ringwood (CEO of BEAT). So, with any luck, we should come away fired up with the latest scientific research, evidence and advice.

PS. I've volunteered for the job of allocating bedrooms in the (amazing Victorian Gothic mansion) hotel.

Thursday, 14 June 2012

Efferty efferty eff - insomnia as predicted...

This morning sees the final two A-level exams. Worse, because of a timetable clash, they're back-to-back, which means three solid hours of writing about Religious Studies and then Politics. As predicted, Ben's insomnia kicked in - KERPOW! - overnight. Result? He was a total zombie this morning...

I keep telling him and telling myself that it doesn't matter. Of course everything might work out fine... the gallon of strong coffee he drank for breakfast might kick in and he might cope brilliantly. Or by some fluke (aided by the various *Disrupted Studies* and *Special Consideration* forms) he'll get his university place anyway.

But he can always re-sit the exams next year at his leisure.

As I have said before, it might turn out to be the best thing that could happen what with another year to focus on full recovery, at home, before going away to university.

But let's not think about Plan B just yet. Let's wait until the August results come through and meanwhile work on Ben so he doesn't beat himself up so much if he doesn't make the grades.

"Be thankful we're not pushy parents," I reminded him the other day. "We're not pushy at all! It doesn't matter a jot to us what results you get. We know you will have done your best under the circumstances - circumstances which are out of your control and not your fault."

But I know he will beat himself up about it, because he feels driven to achieve perfection and will feel like he's let himself down, Big Style.

It's so frustrating to know you have an extremely bright child who should easily get straight A's across the board - and who, under normal circumstances, is predicted to get straight A's.

But who, because of the lasting effects of the anorexia, may not.

Meanwhile I am completely zombie-ish, too. At the moment I'm going through an

ultra-anxious phase where every night is fraught with really horrible nightmares - the sort where you end up shouting in your sleep. Last night was no exception as my anxiety levels go sky high. Every day this week I've felt zombie-ish.

Why? Well there's Ben and his exams plus the uncertainty of what will happen over the next 12 months. Then there's my 85 year old mum who's on her way to Europe right now for her first vacation for years and her first without my dad. Also, she's sold her house and had an offer accepted on a flat - so it's going to be all systems go over the next few weeks. She's lived in that house since the day they got married.

I'm still getting over the death of my friend Sue, and my dad. And, for some unknown reason, my confidence levels have taken a dive, work-wise, which is completely irrational. Probably because, when I feel zombie-ish and my mind's on other things I can't work properly.

Want to sleeeeeeeeep!

Thursday, 14 June 2012

Yay, good news all round!

Good news! Incredibly, he was smiling when I picked him up from the exam marathon at lunchtime. "The exams were okay," he said. "I didn't manage to finish the conclusion to the last Politics essay and my hand is knackered from writing solid for three hours, but apart from that - fine." So, at his suggestion, we went to the local designer shopping outlet.

Good news! We had lunch in *Pret* and he went for a massive salad (not a low calorie one), and tipped all the dressing over it. In the Old Anorexia Days, the oily dressing would have remained untouched. And, in the Very Bad Old Anorexia Days, he wouldn't have been able to choose anything on the menu at all. He would have fled the restaurant in tears.

Good news! He had a bread roll (but not butter), then went back to buy a huge pack of toffee popcorn which he ate as we walked around the mall. In the Bad Old Anorexia Days, he wouldn't have gone for the roll, nor would he have eaten popcorn so casually. Eating had to be at set times and in a set place, otherwise he couldn't handle it.

Good news! When I eventually left the shoe shop (after trying on zillions of shoes), there he was wandering around with a large *Starbucks* hazelnut flavour Frappuccino. In the Bad Old Anorexia Days he wouldn't have bought it period, especially a large one, and even if he had he wouldn't have been able to walk around drinking it like that. He would have had to sit down in the coffee shop; everything had to be perfect.

Good news! We went into *Thornton's* and he bought a load of chocolate to replenish his chocolate supply. In the Bad Old Anorexia Days, Ben used to be drawn to chocolate shops like a magnet, never to buy, just to "admire" the chocolates - and then go round admiring them again, maybe picking up the odd packet with a view to buying before promptly putting it down again and fleeing the shop.

And finally, **Good news!** When the assistant came round to ask if we wanted to try a *Chocolate Smile*, he said "Yes please!" and popped one into his mouth. That amazed me because I think it's the first time since the ED arrived that he's said "Yes" to free food samples.

Who would have thought it this morning?

(Oh, and *good news*, I don't feel half so zombie-ish.)

A-levels are finally *over*!!!!

(And my mum has reached Luxembourg safely. So that's two things to tick off my anxiety list.)

Saturday, 16 June 2012

Boiling down the events between Oct 2009 and Jan 2010

The four months between October 2009 and late January 2010 are the most complicated months to describe in the book I'm writing about our journey in and out of anorexia. It's also difficult going back to this period - the period between when the penny finally dropped that Ben was developing anorexia through to the day he ended up in the cardio ward with a pulse rate of 29 which fast-tracked us into treatment the very next week.

So much stuff happened. It was like being on a terrifying rollercoaster which we couldn't control and which was dragging us forwards, up and down, to and fro, round and round, so fast we could scarcely think.

Not only was Ben deteriorating at a fantastic pace; but we were having to go through a massive learning curve from knowing zero about eating disorders to knowing more than many general practitioners. And, talking about general practitioners, we were getting precious little help from medical professionals as we sat impotently on that 18-22 week waiting list for treatment.

This was the period when Ben went from being the strapping rugby player and athlete he'd been in July, at the end of the previous school year, to something more akin to a skeleton to the astonishment and concern of the school sports staff.

It was the period where all the baking and cooking that had gone on over the summer vacation had to stop as Ben began to cut down recipe content to the bare minimum resulting in fat-free, low calorie, tasteless food. He'd get agitated in the kitchen and at the supermarket, policing my supermarket trolley to make sure nothing "unhealthy" went into it. He was banned from the kitchen, but insisted on accompanying me to the supermarket, much against my better judgement.

This was the period when he excluded himself from his social circle at school, following the summer months when he'd cut himself off from his friends in favour of punishing sessions at the gym. Where his moods and behaviour became increasingly

erratic and frightening, especially around school situations and, of course, food.

Meanwhile all we could do as parents was to watch helplessly as the eating disorder swept our son away like a huge tidal wave.

Oh, and wait for that letter to arrive from CAMHS with the date of our first assessment while we dabbled with private treatment which was like trying to mend the gash in the *Titanic* with a *Band Aid*.

Not an easy period to write about, and especially not easy to get across the sheer desperation we were feeling. And fear. There was an awful lot of fear.

Tuesday, 19 June 2012

Good grief, there is so much stuff!

In my rough draft I am up to the period between our first CAMHS session at the end of January 2010 and the day Ben “downed tools” in March - the day he spat out half a tub of ice cream onto the kitchen floor and refused to work with the 3 x meals, 3 x snacks eating plan any longer. And what a lot of notes and other info I’ve got to plough my way through!

At this rate, it’s going to be like *War & Peace* (which, actually, is quite a good analogy when you come to think of it, LOL...)

But it’s also helping me to get my head round exactly what was going on then and why, after the initial weight gain on the eating plan, Ben’s weight went on to plummet downwards as CAMHS allowed him to take back control of his own eating. At first his weight remained pretty stable. But as the ED took back more and more of the control, it headed south eventually settling at Ben’s lowest ever weight.

Boiling down exactly what CAMHS were doing at this early stage, treatment-wise, is difficult. From what I can see, looking through my notes, my ATDT forum posts and from delving into the cobwebby archives of my own recollections, Ben was doing a pretty good job at pulling the wool over CAMHS’ eyes, something he later admitted

to doing.

So what they were initially seeing was Ben gaining weight and sticking to the meal plan, and actually creeping into the “healthy weight range” (“Congratulations! You’re weight restored!” they smiled at one point) together with a reasonably compliant and relaxed Ben during CAMHS sessions (most of which I was excluded from in those early stages).

Meanwhile I was seeing something completely different, especially following each session when he’d punish me all the way home for force-feeding him unnecessarily when he was “perfectly okay” as he was.

ED, always the Master of Deception, hoodwinked CAMHS into believing that Ben was doing just fine. They were probably thinking that his case would be one of the fastest recoveries they had ever seen. So much so that they actually began to space out our appointments. At one stage we went for four weeks without a CAMHS session.

I believe I was viewed as the overprotective mother. They never actually said this to my face, but I got the distinct impression this is what they were thinking. I fussed too much. I nagged him too much which wasn’t “helpful” to Ben. And, look, he was doing pretty darn well, wasn’t he?

For quite a while I definitely got the feeling that they felt I’d blown the whole anorexia thing out of proportion and that his case was, in reality, quite mild. Also, because of his climbing BMI, it was no longer clinically classified as *anorexia* as such, more of an EDNOS (Eating Disorder Not Otherwise Specified).

Meanwhile, behind the scenes, ED the anorexia demon squealed with glee and made my life hell.

Now please don’t get me wrong. I don’t want to appear to be playing the “Blame Game” here or vilifying our treatment team in any way.

Looking back, and boiling everything down, I really and truly believe that they only had a small snapshot of what was going on - and that snapshot was what the ED

allowed them to see during the 60 minute sessions.

They were completely fooled. It was as simple as that.

Thankfully, over the next six months or so, ED began to reveal its true ugly nature to CAMHS and we began to work together as a strong team towards Ben's recovery. Okay we weren't always "singing from the same hymn sheet", but we were usually managing to get back to the "same page" after a bit of debating, arguing, meetings with me, to-the-point letters and so on.

Saturday, 23 June 2012

Oh I can't concentrate so I'll write this instead...

Every time I settle down to do some writing, someone interrupts me. I can't write unless I'm left alone, so I've given it up as a bad job for today. What I need is to hire a picture-postcard cottage overlooking the sea, sit down there - alone - with my laptop and write that book.....!

Meanwhile I've been asked to do a review of another mum's recently published book about her family's journey in and out of anorexia. They want 400 words by mid-July, so that's on my "to do" list as well.

Today Ben and I went to see the private dietician for the third time. Outside the clinic it was kind of weird to see our old dietician from CAMHS standing there, beside the new one. She takes private patients now. I wish she'd been doing that when she was first axed from our CAMHS team back in spring 2010 because we'd have signed up right away.

Inside the clinic we also bumped into the therapist Ben saw while we were on the CAMHS waiting list back in late 2009. So a bit of a spooky *déjà vu* experience, all in all...

The session with our new dietician went really well and I was amazed at how much ground we covered. The idea was to work on the outstanding bits and pieces about

diet, weight and food to help Ben manage the transition to university life successfully. Ben soaked up her every word like a sponge. Brilliant.

The difference between now and the Bad Old Anorexia Days was acute. Back then the dietician, and anyone else for that matter, would say that black was black and here's all the evidence to prove it - yet Ben was unable to see it that way. Afterwards he'd distort whatever was said to fit the ED's own twisted view of things. He would argue that black was white until he was blue in the face. Nothing went in. Or, at least if it did, it was so distorted by the ED as to be unrecognisable.

This is why we covered so much ground today, and why we did it so successfully. In the past it was just a case of drip-feeding the information until, months later, he finally "got it". This is yet more proof that Ben is pretty much recovered. Not completely, but pretty much. Which is why we haven't set another appointment with the dietician just yet. We might not need to. And, considering all the stuff we've been through, the stuff that I'm re-visiting again now I'm compiling my book, I am pretty damn pleased with that.

Monday, 25 June 2012

Hip hooray, the party is a stonking success!

"I think Ben's going to bottle out of J's party," hubby said to me on Saturday. "I can tell, he's getting all nervous and agitated."

"I don't think so at all," I said. "He seems absolutely fine. I am convinced he will go."

And I really did feel that he was fine. I wasn't getting any of the Old Anorexia vibes which precede bottling out of social events. Ben seemed to be raring to go.

And he did go. And the party was a stonking success, albeit aided by some cider, wine and so on, but not in excessive quantities.

"I learned my lesson last time," Ben laughed, remembering his hideous hangover

after L's party, the last party he went to.

"The best bit was the psychedelic chill session where I sat in this room with my old friends, talking about deep stuff," he said mysteriously.

His friends told him how glad they were to see him, and - fuelled with a bit of "Dutch courage" - Ben explained what had been going on, and why he'd been keeping his distance for so long. Or at least I think that's what was said.

Ben also ate, just like any other normal party-goer. Also, during the chill session he decided to make toast and marmalade, so he did. He also made an inroad into J's crumpets at some unearthly hour of the morning, and had breakfast, then came back to a day of normal eating, without any problems at all. ("Even though by the end of the day on Sunday I wasn't really hungry I still made myself have all my calories," he said when we did our - less regular than usual these days - Contract points session on Monday.)

And, most importantly, the post party period was free from any guilt or stress. So often in the past (although social occasions couldn't really be described as "often" thanks to the anorexia's self-imposed isolation) what appeared to be a good time would be ruined when Ben returned home. The guilt would come in waves. And before long he would be beside himself with guilt at how much he'd eaten and drunk, convinced he'd been bingeing on food when he'd simply been eating like a normal guy. The guilt and regret would far out shadow any enjoyment. It was a terrible shame.

But this time there wasn't any of that.

"Oh and by the way, L, Z and K are going to Sheffield Uni, too," he said, delighted, "In the same halls of residence as me".

"Brilliant," I said, mainly "brilliant" because this was evidence of a normal conversation with people rather than hovering on the outside, keeping silent. "It's always useful to have familiar faces around when you're settling in somewhere new, if only so you know there's somewhere you can drop in for a coffee. And you never

know, they might have gorgeous flatmates!”

Social events feature heavily on Ben’s calendar this week.

First there’s the school *Politics* trip to London mid-week, followed by W’s birthday (watching football on a big screen TV in the city centre!), then there’s the rehearsal for Saturday’s Prize Day.

Saturday morning is Prize Day itself, the final Prize Day of Ben’s school career, followed by the Leavers’ Ball, for Upper Sixth Form leavers like Ben and their parents - a black tie affair with sit-down dinner. This year Ben won’t be participating in Sports Day which takes place in the afternoon. The last time he did was in 2009 when he won the 1500 meters race, just as his eating disorder was beginning to take root and his exercise levels were about to go off the scale.

Then there’s the Leavers’ Service in the school chapel on Sunday morning - not the best of timings, considering we won’t have got home from the Ball until the early hours...! This is followed by a special buffet for students and parents. And a few days later it’s the three day *History Department* trip to Auschwitz.

I really, really hope that it’s a success and that the remnants of ED don’t sneak in to spoil things. Please, please, please let Ben’s schooldays end on a high and let him re-join his social group, not as an outsider, but as Ben used to be before the eating disorder: one of the most popular and liked boys in his peer group.

Friday, 29 June 2012

The Big Weekend starts tomorrow...

Ben’s been at school this afternoon, rehearsing with the other prize winners for Prize Day: the order they need to sit in before they file up to shake the hands of whichever dignitary will be presenting the prizes.

In the Good Old Days before the anorexia stripped Ben of his confidence and social skills, he and his friends would sit with the other pupils listening to speech after

speech, playing what they call “Prize Day Bingo”. Every time the speaker said a typical-prize-day phrase on their list (e.g. “the school is going from strength to strength”), they’d check it off, trying not to giggle. I wonder if the dignitaries guessed...

Then tomorrow evening it’s the Leavers’ Ball. Ben’s sitting on a table with his old friends. I hope and pray he has fun. Ben’s not a drinker, but he could do with a few glasses of cider or wine to help him break the ice.

We’re sitting on a table with the mum I mentioned in a previous post - the mum I used to stand next to on the touch line when Ben played school rugby on Saturdays. Her son and mine, who were great friends, used to compete with each other in the classroom and on the playing field. They were the same height and build. Now her son is huge. He still plays rugby. And he’s Head Boy.

Then on Sunday it’s the Leavers’ Service in the little gothic school chapel followed by a buffet meal for the leavers and their families.

To be truthful, I think it’s all going to be rather hard for me, surrounded by parents of Ben’s peers who’ve emerged from their school career relatively normally. Everywhere I look I’ll be reminded of “what could have been” if the anorexia hadn’t hijacked the second half of Ben’s school life.

While Ben was at the rehearsal I popped over to the medical centre with a bunch of flowers for the school nurse. Right from the very first day that Ben started to behave strangely at school, in the autumn of 2009, she’s been a tower of strength.

Whether it was rescuing Ben from the boys’ toilets where he was lurking when he should have been in lessons, sitting with him as he ate his Eating Plan packed lunch, walking and talking with him round the school grounds on days when he just couldn’t cope or providing a refuge during those months when Ben couldn’t bear to be near another young person, she has been absolutely brilliant.

And of course it was she who first told me about CAMHS and suggested I get Ben referred for treatment.

I am eternally grateful.

JULY 2012

Sunday, 1 July 2012

A bitter sweet weekend, all in all...

Everyone was pleased to see Ben at Prize Day, the Leavers' Ball and the Leavers' Service and Lunch today. At one point there seemed to be a constant trickle of staff coming over to me to say how pleased they were that Ben was there. One girl gave him a massive hug outside the chapel after the service this lunchtime, tears in her eyes.

I would say that seventy per cent of the time Ben was back in the bosom of his friendship circle. Not right at the heart, often on the edge of the circle, but at least he was there - and they were glad to see him.

Occasionally, and especially at Prize Day, Ben kept a bit of a distance. But never forget all these school activities over the course of one weekend were a big challenge for him. He rose to the challenge; he even did the "conga" with the others, snaking around the marquee last night after dinner, huge smile on his face, before taking the microphone to sing the ending of "Love Train" with the karaoke style band.

Oh, and he had no problems with eating his dinner, or the Leavers' Lunch today.

The "bitter" part was the usual feelings I get when I'm reminded of how the anorexia robbed Ben of everything that was good about his school and social career. After four years of going from strength to strength on every front - academically, confidence, self-esteem and socially - the anorexia swooped in and switched the engines into reverse.

So while his peers carried on through their final three years at school and

continued their journey into adulthood, Ben stood still. Not only was he on *Planet Zorg* for nearly three years but the starvation has left him looking much younger and slighter than everyone else. Hopefully he will catch up.

So there was bound to be a large element of “what could have been / should have been” this weekend.

But we have experienced other aspects of the school which we would never have done if it wasn't for the eating disorder: the superb pastoral support and friendship of many staff members, notably S, the school nurse, who I've hugged goodbye several times these last few days.

Well it won't really be goodbye, because I'll be keeping in touch with her. She is an amazing, lovely woman and someone I don't want to lose as a friend.

Monday, 2 July 2012

The art of letting the positive outshine the negative

This morning Ben and I had a long, very fruitful and positive chat about this and that. “The thing is,” as I said to him, “As you can imagine over this weekend, as a parent my mind was on a roller coaster. It was so easy to get bogged down in all the ‘What could have beens’, instead of focusing on all the positive things that have come out of this experience and as a direct result of it”.

Ben's mind had been doing similar things, too. “I know for a fact that if the anorexia hadn't struck three years ago, I *would* have continued to go from strength to strength. I *would* have continued to be at the hub of my social group and been the life and soul of the party. Heck, I'd probably have been made Head Boy!”

He wasn't saying this to boast, but to show what had been going through his mind as he, more than any of us, was aware of what the anorexia had stolen from him.

“But you wouldn't have had the insightfulness and empathy with others that have come as a result of the anorexia,” I pointed out. “And I do believe that when you go

back in future years to school reunions everyone will see the transformation which has come as a result of you working hard to ensure that the ED doesn't steal any more of your life. When staff see what you, personally, have achieved through your own endeavours as an individual, I expect they'll be just as proud of you, if not prouder, as they would be of any former pupil that went on to become famous, worthy or whatever. You've had to fight to overcome something far more difficult than any of them will hopefully ever have to do. And, as you always say, it wasn't dad and I that did it for you; you did much of it for yourself. Come here for a hug, I'm so proud of you!"

I also explained to him that I often look back to the little girl who, on her very first day at school, aged four-and-a-half, had the confidence and self-esteem to contradict her new teacher when that teacher pronounced her name incorrectly. That little girl was sent to stand in the corner all through her very first playtime break. But she never regretted having the confidence to stand up for herself. I talked about how this was the "raw" me, if you like, the "real" Batty, before the world knocked all the self-confidence and self-esteem out of me - which, future teachers did very successfully as I grew into a teenager.

"Look back on the 'raw' you, the 'real' you, the 'you' that you were in those four years before the anorexia struck when you were going from strength to strength on every front: socially, spiritually, confidence, self-esteem, academically and so on. Then blend this with the good that has come out of this hellish experience: the insightfulness, the empathy with others, etc and, as you say, the forty year old brain inside an eighteen year old's head! Blend the two together, the two parts of the 'real' Ben, and the result is awesome! And it's not as if you'd be faking it, *this is* the real Ben!"

And as I hugged him on the sofa, just after breakfast, I felt as if I was hugging an extremely strong young man.

Monday, 2 July 2012

What I said to the school yesterday

Following on from the bunches of flowers and cards I've taken into school, hubby and I decided it was time to write a letter to the Head to thank the school for its support over the last three years. I thought I'd share it with you...

We would like to thank you and the school for your help and support during Ben's illness. Everyone, without exception, has been amazing and many staff have gone way beyond "the call of duty" to help us, especially Mrs XXXXXX, Miss XXXXXX and Mr XXXXXX who have all been outstanding.

Ben's tutors, too, have been exceptionally supportive, especially during the period when he was away from school in year 11 and when he attended part-time in years 12 and 13.

The Plan of Action you suggested worked flawlessly and, with the support of tutors and Heads of Year, Ben was able to study for - and sit - his GCSE exams without any stress. We are also grateful for the assistance received during his AS and A-level exams, and with university entrance applications.

As parents it hasn't been easy watching Ben transform from a boy who was going from strength to strength in every way between years 7 and 10 to a boy whose illness robbed him of many of the positive things in his school career.

Ironically, just before Ben's anorexia manifested itself, we were going to write to thank you and the school for bringing Ben out of his shell and boosting his confidence and self-esteem. We were both delighted and astonished at the

transformation we were seeing. Following a difficult period at primary school, which included some psychological bullying, Ben appeared to be thriving on the “W----- School treatment”. Then the anorexia struck, so we never got the chance to write that letter.

One of the primary motivators that kept Ben going through his anorexia was his academic study. It gave him focus and purpose during those dark days when the anorexia had him in its grip. Most importantly, it showed him that his life has a purpose – and a future. In addition, knowing that his tutors genuinely cared about his progress, and about him as an individual, helped him enormously. W----- School was very much part of the success story that was Ben’s recovery. Additionally, the school’s flexibility allowed Ben to ease himself back into his studies and social life at his own pace. And throughout, Mrs XXXXXX and Miss XXXXXX went out of their way to help in every way they could.

Like the parent whose letter was read out at Prize Day, one of the main reasons we chose W----- School for Ben was because of its reputation as a caring school – a school that nurtures and values the whole child, whatever that child’s strengths or weaknesses.

During Ben’s first four years, we witnessed W----- School at its best as Ben’s confidence, self-esteem and happiness went from strength to strength. During the final three years when Ben was struggling with anorexia, we witnessed W----- School at its “better than best”. W----- School supported Ben - and it supported us, his parents. As we remarked to each other after Prize Day, Ben couldn’t have been in a better place.

We would like to thank you again and would like to wish you and the school all our

very best wishes for the future.

Wednesday, 4 July 2012

Two fingers up at the eating disorder again!

Following on from the extremely sociable weekend, Ben is planning to meet up with some of his old mates this afternoon to go and see *Spiderman* at the movies.

Then on Friday he's meeting another old mate for lunch in town.

Meanwhile he's joining a *Warhammer* club, starting on Sunday afternoon.

(*Warhammer*, in case you don't know, is about painting plastic fantasy / *Lord of the Rings* figures and playing table top war games with them. Or something like that. It's Ben's #1 passion.)

And today he's off to see if he can get a part-time job, probably voluntary, e.g. charity (thrift) shop, to get some experience of store work. Plus, he's very keen to go on a barista training course (as recommended by my dear friend C), so he can work in coffee shops, restaurants, etc when he's a student.

Then next week he goes to Poland, on a three-day school trip to Auschwitz.

So it's two fingers up at the ED again and all systems go towards getting his life back from its grasp and getting used to being with his peers again, ready for university.

And he decided to do all this before I offered to award him extra points to encourage socialising (in our Recovery Contract).

Which reminds me... 18 months since its launch, how is the Contract doing these days?

To be truthful it's been on a bit of a back burner recently. But that's the great thing about the Contract: it's flexible, so when you feel you no longer need it so much, you just use it less.

Last week Ben asked if we could do it a bit more regularly again because he finds it really helpful to conquer challenges.

These days there aren't so many "fear foods", it's mainly challenging situations which could be having what he calls a "condensed lunch" when he knows he won't be having as much later in the day, or not counting calories for a day. And now we're adding points for social interaction. But, as Ben says, "I was planning to do all this anyway," which is excellent news.

Also, "doing points", as we refer to it, has always been a useful exercise.

It gives us time to talk, on neutral ground, because - right from the start - we agreed that when we "do points", no-one will jump down the other's throat.

There will be no yelling, no criticism, no lecturing, no dishonesty, just an open and honest two-way conversation on neutral ground.

This is one of the reasons why it has worked so well.

"We'll 'do' a version of 'points' via *Skype* when you're at university," I said yesterday. "At first you'll find I'm quite vigilant, probably contacting you most days to check how things are going on the ED front. But, as you settle in and get stuck into a routine that works for you, I'll contact you less and less, and eventually leave it up to you to contact me... or not. How does this sound?"

He said it sounded fine. "And I'll be able to help you with any problems you're having, like what to do when your room mates have left ten tonnes of washing up in the sink and you need to cook your meal!" I added.

"And you can order all your supermarket food online via our account, once a week, and buy other bits and pieces as and when. You know what you need to do. You know what you need to eat, when and how often. I know you will do it. And I'll be here to give you encouragement when and if you need me."

But I won't be on his case all the time, just keeping a discreet and diplomatic eye on Ben, playing it all by ear, knowing when to back off and when to be vigilant.

And when, God forbid, to take action if the demon ED decides to have a bash at

ruining things.

Thursday, 5 July 2012

Batty goes into a trance and deals with some issues

I've been seeing a therapist for a few weeks in a bid to get a handle on the extreme anxiety I seem to be feeling most of the time.

Lately I've been having nightmares, the kind where you realise you're shouting in your sleep, or sitting bolt upright, or both, and it leaves you feeling rotten for the first few hours of the following day. I've also come out in a host of skin conditions, all thought to be stress-related.

My therapist seems to think it's a kind of post-traumatic stress, as a result of the three years of dealing with Ben and his anorexia. I tend to agree. So today she decided to do some hypnotherapy on me.

At first it felt a bit weird and I felt a bit silly sitting there opposite her, eyes closed, the traffic buzzing outside the room above the health food store where she holds her sessions. She was going to put me into a state of deep relaxation and then do something I think she called a "Re-wind" technique. The idea is that you set two anchors: both when you were in a Good Place, kind of sandwiching the bad bits you want to deal with in between.

I think she was expecting me to choose a small snapshot of Ben's eating disorder with a "good" anchor either side.

Unfortunately I had to take a massive chunk of the experience, almost four years to be precise. I set the first anchor at the time when I took a photo of an athletic Ben standing on top of a mountain in southern France. Ben was at his peak: confident, athletic, handsome and popular.

The second anchor was yesterday when Ben arrived home from seeing *Spiderman* with his old mates, full of the joys of spring, laughter in his eyes, no different from

any other teenage boy that had spent the afternoon messing around with his mates.

“Think of a safe place,” she said, “A place where you can ‘go’ while I take you into this deep relaxation.” I decided on a garden, my grandfather’s garden - a large vegetable garden climbing up a hill with a huge retaining limestone wall at the back and a greenhouse leaning against it. I could almost smell the earthy scent of the potting sheds and see the wicker baskets full of freshly picked carrots and potatoes.

Then the therapy started. At first I didn’t think it was going to work, but was gradually astonished at how trance-like I was beginning to feel, and how very relaxed. I really did feel as if I was in a deep, deep sleep, yet completely aware of the sounds going on around me.

Once I was mentally sitting in that garden, she asked me to place the two anchors.

The idea then was to rewind rapidly from the second anchor back to the first: from Ben full of the joys of spring yesterday to Ben at his peak, high up on that mountain almost four years ago. It wasn’t easy re-winding through all that time. Most of it I missed, but she said that’s okay. It really was just like a videotape being rewound back, the scenes passing quickly in front of your eyes.

When I got to the first anchor, I had to lift my finger, and she’d tell me to fast-forward to the second anchor again. And this continued for quite some time, before she brought me out of the trance.

“The trouble was,” I told her afterwards, “I had to pick such a massive chunk of time. Nearly four years. I had to do this because I couldn’t find anywhere within the eating disorder experience that I could place the first anchor. It was all horrible. There weren’t any ‘good times’. I felt coiled up like a spring every single day. I felt as if I was going to implode. So I had to look further back, to the time when I remember Ben at his best, before the seeds of the eating disorder sowed themselves. Because, although Ben began to show signs of the eating disorder over the summer of 2009, the seeds had been germinating silently for months. So the French mountain was one of the last times when I believe Ben was totally ED-free.”

Did the therapy work?

I've no idea. But it did make me feel fabulously relaxed afterwards!!

Friday, 6 July 2012

A reply from the Headmaster

Oh, I already miss that school now Ben has officially left. For the past seven years it's been part of my life almost as much as it's been part of his. Four fantastic years followed by three very difficult years. Yesterday I got a reply from the Headmaster to the letter I wrote to him at the weekend. Here is an edited version:

I count it a privilege to have been able to play a part in making it possible for Ben to complete his secondary education and to have been able to provide whatever support we could throughout a most difficult illness.

I hope that you will keep us informed of Ben's progress over the years ahead (or nudge him to!) because we will be genuinely interested in following his future career; and should we be needed at any time for further advice and support you know where to find us!

Thank you for your support of Ben and the school throughout his time here. At the new parents evening I refer to the "journey" that starts in Year 7; we never know how difficult (or easy) that journey is going to be but being able to be part of that with so many young people and families over the years is one of the best things my job involves.

Wednesday, 11 July 2012

Ben's gone on a school trip to Auschwitz and I'm home alone

There's something strange and bizarre about someone with (or recovered from) anorexia going to visit a Nazi concentration camp, isn't there? Someone whose starvation was self-imposed (or rather ED-imposed) in a place where millions of people's starvation was regime-imposed... Yet both sets of people were immediately surrounded by a world where there was more than enough to eat, yet - for very different reasons - they were prevented from having it. Meanwhile I'm enjoying the welcome sense of freedom that comes from having three days to myself.

Over the past (almost) three years I've been looking after Ben most of the time, especially during the long periods of social isolation. So whenever I've been working or doing other things, I've felt guilty - or had to split myself between work, etc and Ben's needs. Being on my own, with no-one to answer to, has been extremely rare.

Ben is also quite bossy. He'll tell us to turn down the TV or our music (weird, I know, considering it's supposed to be parents that tell their kids to turn down the volume), or he'll tell me off for snacking on occasional rubbish like chocolate cookies or cake. Or for having a glass of wine mid-week instead of keeping it for weekends. Sometimes it's as if he is the parent, not me.

He also likes company when he's eating all his meals, so I can't eat when I feel like it.

So I'm just enjoying having a few days to myself, to be repeated this weekend when hubby and Ben go away for a medieval weekend somewhere in Leicestershire.

Saturday, 14 July 2012

1kg lighter, but apart from that... NORMAL!!!

Sitting in bars eating ice cream and drinking beer, going back to the hotel with M, having a "deep conversation", falling asleep, being woken up by J, N and P crashing loudly into the room later on with some of the girls, everyone going down to the girls'

room on the floor below, some of the boys smoking on the balcony (not Ben!), irate teacher striding down the corridor, knocking on the door and giving them a massive telling off while standing there in his underpants...

And that was just one night. Ben might have returned 1kg lighter due to bad meal planning (not his fault), but apart from that... *normal!!!*

This, as you can imagine, is music to my ears.

Not once, it appears, did Ben feel left out of the crowd or disorientated from everything that was going on. He got stuck in and had a fabulous - if exhausting and pretty sleep-deprived - time in Krakow.

The meal planning was terrible. The meals in the cheap hotel (breakfast and dinner) were inedible from what I hear, and this is a genuine, non ED-fuelled impression. So they all went into town and did what teenagers normally do i.e. mess around eating this and that, double ice creams, pretzels, chocolate, sandwiches, beer, that kind of thing.

Ben did eat a proper meal on Thursday lunchtime when some of them went to an Italian restaurant. And the previous night when they went bowling and the rest of them ate nothing in particular, Ben bought something from *MacDonald's* because he knew he had to eat. And Ben who rarely drinks alcohol had another beer.

So it didn't surprise me when the scales showed a 1kg loss. We are already working on that, so don't worry...

("It's good in a way, Ben, because it's showed you just *how easy* it is for you to lose weight in a couple of days if you don't eat properly. I know it wasn't your fault and I know you did your best to eat what you should; but it shows how quickly you could lose weight if you were sick at any time or if there's any other reason why you can't eat in the usual way.")

But what's so brilliant about these few days in Poland is that Ben was more *normal* than he's been for three years. Remember it's now exactly *three years* since the anorexia first began to show itself, during the summer vacation of 2009 - the summer

when Ben's exercising and "healthy eating" went extreme and he completely cut himself off from his friends, an isolation that was to last for years.

So this trip to Poland makes me happy.

I only wish he'd remembered to take some photos with the camera I loaned him for the trip!

Friday, 20 July 2012

I told you we'd do it!

One week on from the 1kg weight loss during the school trip to Poland and Ben has put it all back on - plus a little more too. And he is happy with this which is excellent news.

This week he also met up with a friend for lunch and is doing some voluntary work in a local charity (thrift) shop as we speak.

He is also planning to do something curious called "Mince Week" with his friends M, Z and J next week, although it sounds a bit ominous: J's parents are away on vacation for a week and "Mince Week" takes place every evening.

No, it's nothing to do with "mince" (i.e. ground beef). I think it's more a case of sitting around drinking beer and talking about the meaning of life. I just hope they don't do "other things" as well, because I know what teenage boys are like...

What all of this is saying to me - and hopefully to you, too - is that this is *normal*.

NORMAL, NORMAL, NORMAL, NORMAL!

Which continues to make me one happy mother.

Meanwhile I've been busy working on my book about Ben's journey into and out of anorexia. It's really coming on now. I mean *really* coming on. But I can see why it can take months to write a book - they usually say around a year, don't they?

So it's going to be at least the New Year before I get it published - in paperback and on *Kindle*.

Monday, 23 July 2012

Not skimmed, not semi-skimmed but FULL CREAM milk!

Back in the days of “high anorexia”, and ever since really, a major sticking point was milk. One of the early signs that Ben’s eating habits were changing for the worse was when he switched from normal coffee and tea to black coffee and tea - around three years ago. Before then, we’d always had either skimmed or semi-skimmed milk in our fridge.

When Ben was put on a weight gain eating plan, he refused point blank to have any milk except skimmed milk. The closest we ever got him to having semi-skimmed milk was during the early stages of seeing our dietician (spring 2010) when he agreed to try the “orange” top milk which is a half-way house between skimmed and semi-skimmed.

Even getting him to do that was like pushing you-know-what uphill.

Semi-skimmed became a “danger food” to Ben and he refused point blank to ever have it. And the minuscule bit of skimmed milk he’d add to his drinks scarcely made any difference to the colour of the tea or coffee.

As for full cream milk... Well... I might as well have been suggesting he drink poison. Not in a zillion years did I have a hope in hell of getting him to drink full cream milk.

Until today.

Today I sent him on a morning’s training course to learn barista skills so he can get a part-time job. Cappuccinos, lattes - and a host of other coffee types I can’t pronounce plus “proper” hot chocolate i.e. made with real chocolate and milk - he drank his way through the lot.

And all of it contained full cream milk.

Yes, he found it challenging, and yes he did adjust his lunch calories to take all this

into account, but he did it all the same.

I wish I could go back in time and talk to the frazzled mother that was me two to three years ago, give her a huge hug, tell her everything's going to be okay and let her know that not only would Ben go onto drink skimmed milk and semi-skimmed, but he'd drink a bucketful of full cream milk as well! Unheard of!

AUGUST 2012

Sunday, 12 August 2012

An ED-free holiday, and now for the next stage...

We've just returned from two weeks holiday in the south west - a completely ED-free holiday, I am pleased to say - and, following today's weigh-in, Ben hasn't lost any weight. Great stuff. And now for the next stage, which is all about...

...A-level Results, which come out on Thursday.

If Ben gets his grades then he'll be going to Sheffield University in September. So, in anticipation of Good News, the two of us have been working on a University Contract. The purpose of this is to ensure Ben continues to move in the right direction and to agree on various emergency measures if there are any blips. Most important of all, its purpose is to allow us to take action whenever warning bells sound to avoid a full-blown relapse. It is based on a Contract from the FEAST website and is based on the stage Ben is at now.

Hopefully we will never need to use what I've referred to as the "Serious Clauses" below...

This is what we've agreed:

★ The daily calories required for a gradual and sustained weight increase in line

with official height / weight / age charts.

- ★ To increase daily calorie intake if this isn't achieved.
- ★ The absolute minimum weight we will allow at any one time.
- ★ The absolute minimum "emergency" weight we will allow e.g. if Ben is sick or there is another emergency that results in a serious weight loss.
- ★ To take emergency measures to restore Ben's weight which may include calorific drinks, chocolate bars, "condensed calories", etc.
- ★ Because we recognise that life at university can be haphazard and unstructured, Ben agrees to make up for any lost meals, puddings, snacks, etc by adding the lost calories to the following day.
- ★ For Ben to accurately weigh himself every fortnight, as now, and to truthfully inform mum of the result.
- ★ To catch up with mum on *Skype* once a week, or more often if necessary, to "do points" (our Contract) and to discuss progress.
- ★ If Ben's weight drops below the minimum "emergency" weight (above) he has a max of seven days to actively demonstrate that he is putting the weight back on, returning to weight restored level within a maximum of 10 days.

The Serious Clauses

- ★ If Ben's weight isn't increasing, Ben will come home on the Friday after lectures and spend the weekend working on weight gain, returning to university on Monday morning.
- ★ If home weekend doesn't result in weight gain, then Ben agrees to increase his daily calories until he is weight restored again, returning home the following weekend if necessary.
- ★ If weight loss reoccurs, this process will be repeated.

- ★ If Ben's weight continues to drop below the "emergency" minimum following two consecutive fortnightly weigh-ins and he fails to retain the lost weight as agreed above - or if he begins to show any of the old eating disorder behaviours e.g. resistance, mood swings, etc - then Ben agrees to withdraw from university for the current year, re-joining the following year. In other words, we will work on getting him well before a full-blown relapse gets the chance to take hold.
- ★ Ben agrees to see the university treatment providers / counsellors, etc, as, or if, necessary.

As with our normal Contract, the above will be adapted as necessary.

Thursday, 16 August 2012

He got his place at university!!

So Ben's place at university has been confirmed - his first choice, a straight "yes" decision from the university. I have been jumping up and down and screeching with delight like a deranged toddler. I think Ben is pleased - the trouble is, his mind is still slightly numbed from the leftovers of the anorexia. It's something he's had a problem with over the past three years: the inability to feel positive emotion in the way most other people would, especially at such an important and excellent result.

It may be because he narrowly missed achieving the A-level grades he was expecting. But, remember, our psychiatrist, the school and Ben provided detailed support information about his disrupted studies i.e. the fact that he'd missed well over half his schooling over the past three years. Not to mention the fact that while he was studying for his GCSEs, AS levels and A-levels, he was also battling with a devastating illness. Yet through sheer determination he refused to let his studies suffer.

Unfortunately he couldn't control the anxiety and ED-fuelled insomnia that kicked in for the AS and A-level exams which meant he sat each exam with very little sleep.

But they've said "Yes"!

And I am immensely grateful to the school for their support - especially the Head of Sixth Form and the school nurse. I am grateful to the CAMHS psychiatrist for her support in Ben's university application - and the university itself for being flexible and human - and recognising that Ben had what it takes to study a single honours degree at a top "red brick" university, a degree that normally asks for AAA entry.

Most important of all, though, I am proud of Ben.

"You've got into one of the best universities by proving to them that you have what it takes to succeed. You have a glowing future ahead of you - and you're not going to let the ED mess it up in any way, are you? Just tell the ED to f*ck off!" (Please excuse my language!!)

Soon I'll come back down to earth and we'll start planning everything else that needs to be planned. And the most important thing of all is to ensure that, no, the remains of the eating disorder don't mess it all up for him. 30 miles away from the university, I will be behind him all the way - keeping a discreet eye on things and quietly gauging when - or if - to intervene and provide support. Armed with the University Contract we discussed the other day, which we'll go through again in a few days' time. Meanwhile I have a list of people to tell: school, school nurse, family, friends and our CAMHS psychiatrist. I know my dear friend Sue would be thrilled, too. Hopefully she is looking down on us with one of her huge smiles!

Friday, 17 August 2012

At last - back in his social circle

Surprisingly Ben didn't have a hangover this morning after L's BBQ last night where he consumed vast quantities of cider from 5pm onwards before phoning me at 11pm

for a lift home, too drunk to go onto the nightclub some of them were planning to go to. It was a happy but very tipsy Ben that sat in my car on the way home, feet on the dashboard, stinking of booze and chatting away about the fantastic evening he'd had.

So this morning I asked him: "Did it feel like the old days again? You with your old friends, talking in the way you used to, no anxiety or anything?"

"Yes it felt totally normal. We had a really good time - and everyone was mega pleased to see me. M said they'd missed me over the past few weeks, so I told him we'd been away on holiday. On Saturday night we're going out again."

"To do what?"

"Sit in the woods and chill."

"Okay..."

"If it rains on Saturday then we'll do it on Tuesday instead."

"Did everyone get into the university they wanted to get into?"

"Yes, and M got better grades than he thought so he's re-applying for a better course. And I spent ages arguing with C about whose cat was the most beautiful - hers or ours."

"Did you eat?"

"I had some kebabs and loads of tortilla chips, tonnes of sweets, too, like flying saucers and jelly babies."

"With cider... Yuk!"

"Four cans and one bottle." Ben rarely drinks, so his lack of a hangover surprised me. "But I knew it would be like this so I made sure I ate more during the day to compensate."

Rewind back to the spring when Ben was still finding it really hard to integrate with his friends and had almost given it up as a bad job. "We're all going away to university in September, so what's the point of making the effort?" he'd say.

Back then I could never have predicted that things would pan out like this - as normal as normal can be.

Saturday, 18 August 2012

Where were we approx 18 months ago?

This is the question someone asked me yesterday - another mum of a teenage boy with anorexia whose recovery isn't as far advanced as Ben's.

She also asked me why it was that everything seemed to be falling into place so quickly for us at the moment, mainly in regard to Ben's socialising which - as you will know - is something that's been a massive problem over the past years.

I am sure she won't mind me giving you a version of my reply to her...

18 months ago would be the Christmas after Ben turned a corner in the October (2010). But he was still finding everything very hard.

(As a reminder, Ben had had a heart scare in early October. CAMHS took this extremely seriously and said they wouldn't hesitate to hospitalise him if necessary i.e. if he continued to decline. This put the fear of God into Ben and prompted a complete U-turn.)

Following this, Ben's attitude to recovery changed, but he was still completely imprisoned by the anorexia thoughts - in other words, he wanted to do stuff but "it" wouldn't let him. He was also trapped by a crazy amount of compulsive exercising. And he was still losing weight.

As a result, by the early spring of 2011, he'd reached a plateau and was incredibly frustrated and disillusioned with things, having tried so very hard to move towards recovery but finding so many obstacles in the way. I was worried he might give up - and no-one seemed to have a solution.

The first chink of light came when one of the CAMHS team probed into exactly how much exercise he was doing - a shocking amount, and it became painfully clear how completely and helplessly imprisoned he was by it. She suggested we write down daily limits over and above which he agreed not to go. Desperate to free

himself from the shackles of the exercising, he agreed to give it a try. It wasn't easy, but he knuckled down and kept to his side of the bargain.

It was this, I guess, and the desperate feeling on my part that we needed something else to kick start the recovery process that prompted me to search on the ATDT forum where - by chance - I came across a thread about Contracts. And the rest, as they say, is history....

Earlier today I was thinking about the question as to why Ben seems to be improving so quickly all of a sudden. The answer is that everything just seems to be naturally falling into place. After such slow progress after so long, it seems kind of odd for this to happen, I guess, but it has.

But, of course, I am vigilant. Discreetly so, at this point. But I am vigilant. And I will continue to keep a watchful eye on things as Ben goes away to university next month.

Monday, 20 August 2012

Forgive me father for I have sinned...

Today is the second session of reading aloud some of the chapters in my draft book so Ben can correct me on anything I've got wrong and also provide a fresh insight into what was going on in his head at the time. His choice - after all, as he said, "I'll be reading it anyway so I want to be sure you've got things right".

He immediately picked up on the following section which refers to the early days of his anorexia in November 2009:

By now I loathed cooking. From the moment I walked into the kitchen I'd be on Red Alert. The slightest creak on the staircase and I'd throw the mince, tomatoes or whatever into the chopped onion which I'd dared to fry in oil. I'd stir vigorously to remove any sign of oil and then stir it again before I served it to make sure the oil

was still invisible. And all the time I'd pretend to be acting normally.

Sometimes I'd even find myself nervously humming songs in a bid to distract Ben from what was going on in the kitchen. At Christmas 2009 I remember singing Winter Wonderland over and over again until I was sick to death of it.

I'd keep "contraband" like extra cheese or whatever hidden away in strange places like in the oven, ready to slip into the mix as soon as the Food Policeman was back upstairs, my body ramrod straight with tension in case I was found out - frantically tasting the food to make sure the extra ingredients weren't detectable. If in doubt, I didn't add anything.

"You deceived me!" Ben interrupted.

I was well aware this was the first time I'd confessed to adding extra stuff to my cooking. Not that I felt he ever really needed to know.

However, because I knew that Ben would be reading my book anyway, I decided I might as well risk coming clean.

"Yes, I admit I did do this back then," I responded. "What mother wouldn't? Heck, Ben, you were hurtling off a cliff - I was fighting to save your life. I'd have done anything to save you. All parents would do it. You'd do it if you were a parent, I guarantee it."

"But I thought I could trust you."

"You could and can trust me, Ben, and you know that. But back then, during the early stages when you lost a quarter of your body weight in a couple of months, I was terrified that the anorexia would destroy you. It would have been negligent of me to sit there and do nothing."

So it was a difficult one, confessing to the "sin" of adding extra cheese, oil or whatever to the recipe. But I think Ben understands why I did it.

Saturday, 25 August 2012

I can't stop being excited about university ...

Anyone would think it was me going away to a jam-packed full week of Intro Week events at university in a couple of weeks' time. I wish it was. Beach parties, film shows, tea parties, chocolate tasting, wine tasting, scuba diving, Buddhist meditation, mask making, quizzes, radio DJ-ing, ghost tours, treasure hunts... I want to do it all! And, thankfully, so does a socially-starved Ben. Blimey if he doesn't make some great friends within that first week I'll eat my hat!

And, hopefully, during this packed schedule he will find time to eat properly. A fellow ED mum suggested I pack a few pre-frozen meals to see Ben through those first few hectic days. So, in the week before, we'll save an extra portion of everything we cook and freeze it.

Meanwhile Ben's weight is continuing to creep up slightly. He's put on half a kilo since the last scales session a fortnight ago. I'm not convinced he's totally happy with that, but I am.

It's going to be really hard watching Ben go to university after we've spent so much time together over the past three years during his illness. But I am painfully aware that it's time to call it a day on the helicopter parenting and take more of a back seat. A discreetly watchful back seat. And, as a back-up, my sister works in Ben's university city once or twice a week, so she can keep a discreet eye on him too.

On the bed in the spare room is a mounting pile of boxes and bags, packed with pots, pans, cutlery, crockery, food, toiletries, cleaning products and all the other stuff he'll need at university. Add to this his bedding, clothes and study materials / stationery and we'll need to hire a truck to get him there!

This is his future and he is so excited about it - the future the eating disorder didn't want him to have, the new friends it didn't want him to make and the achievements

it didn't want him to clock up. But it's going to be so strange when he's gone.

Sunday, 26 August 2012

Let's talk a bit about my own problems with food...

Someone posted a link to this article today which talks about the way eating disorders are believed to have a genetic link i.e. if you, the parent, have had an eating disorder then there's a far higher chance your child may be genetically predisposed to developing an eating disorder too. So let's talk about me this time...

Ben knows I had "issues", shall we say, with eating in the past. He is convinced I had an eating disorder and this is one of the main reasons why I've always "got it" and been able to understand and help him.

Naturally I've always been in denial. I did have disordered eating, but I'm not convinced it was ever an eating disorder as such. But please feel free to draw your own conclusions...

I was a relatively normal child - strong-willed, independent and never one to follow the crowd, and a bit of a tomboy - but normal. Ish.

Then I became a teenager.

I hated the changes I was seeing in my body: the periods, the growing breasts and the way I seemed to be putting on weight. I began to hate my body with a passion. And, with it, my confidence and self-esteem took a nose-dive, exacerbated by a particularly unpleasant scene one lunchtime on the hockey field when, aged 12, the whole year group ganged up on me as I attempted to "evangelise" to them (a result of having been "converted" by a group of older Christian fundamentalist teenagers).

I remember the whole year group in my all-girls' school crowding me into a corner of the field as I crumpled to the ground in floods of tears, screaming for help.

The geography teacher rescued me and gave me a strict talking to about religion and why I shouldn't impose my views on others.

After that incident, I was regarded as a bit “weird”.

So I shut up shop and isolated myself.

Our girls’ grammar school then went co-ed and became a comprehensive school, doubling in size overnight. I faded into the background and became invisible. I could often be found at break time hiding behind the lockers. Sometimes the rowdy boys from the less academic classes would find me and taunt me. It was their idea of fun.

I began to get tummy aches, coughs, colds, bad periods... anything to be allowed to go home or stay off school sick. I begged my mum to let me come home for lunch rather than stay for school dinners and face the hellish loneliness of a lunch hour on my own.

A new girl joined the school. We were both overweight and quiet, and we got on like a house on fire. She baked a wicked tray of gingerbread which I used to wolf down, which didn’t do my constant battle against the bulge any good. Then one day her dad got a job in another part of the country, she moved away and I was back on my own.

I ate for comfort - and wrote a detailed teenager diary which I began in the third form (aged 13). I’d hate myself for being overweight, feel crushingly lonely and isolated, and wish that - like the other girls - I could get boyfriends, wear fashionable clothes and look slim and pretty.

In the mid-1970s, slimming was all the rage, and my mum (who was also battling with her weight) and I were on a permanent yo-yo diet. Mum would produce those diet cookies which were supposed to replace a meal - and a myriad of curious diet products like crispy cotton-wool rolls, dry crisp-breads and the newly fashionable yoghurt. But they always left us hungry. I know I cheated - scoffing cookies, cakes, cooking chocolate and anything else I could find in her cupboards. She probably did, too.

I felt convinced that if I was thin, then I’d be a better person. I’d be more in control, I’d be popular, I’d be confident and my parents would be proud of me. I used

to daydream and the story always began with: “Once, when I was older, slimmer and prettier...” Was some of this due to a feeling of “never being good enough” because it was always made clear that my dad wanted a boy and I was born a girl?

Meanwhile I was hating school more and more. I’d have hysterical outbursts in class or on the sports field. I loathed sport and hated wearing the short gym skirt which showed off my fleshy thighs and made me feel self-conscious when it was my period. I was always the girl that was the last to be chosen for teams.

I stayed off school more and more with one “illness” after another. Teachers would call home, concerned. I think the Latin teacher actually came round to our house one day. Mum said she was worried the truancy inspector would come round, too, but he never did.

I also had frequent emotional outbursts at home - not dissimilar to ED rages. I seemed to have a knack of making my mum break down in floods of tears. She’d collapse on the floor, unable to cope with me, and my dad would say: “Look what you’ve done to your mother!”

By the Lower Sixth Form, aged 17, I was a nightmare.

I’d completely isolated myself and found it virtually impossible to be in school. (Sounds familiar?) I’d tremble with fear as I walked into a classroom full of my peers or flee noisily out of the grounds and to the comfort of home. I contemplated suicide and retreated to the sanctuary of my bedroom. My teenager diary is jam-packed full of all this angst.

In the end my parents called in a therapist who came to the house to see me. It proved to be a turning point - the beginning of the transformation of the ugly duckling into the swan. But it was also the start of an even bigger battle with food that would remain with me for years.

That’ll do for today. Watch this space for more...

Monday, 27 August 2012

Becoming a “swan”, but at some cost???

The therapist I saw in early 1976, aged 17, was under the impression that I was too self-focused and needed taking out of myself. Being with people less fortunate than (relatively affluent, middle-class) me might make me snap out of this introspection. So she suggested I join the local PHAB group.

As the name suggests, PHAB - Physically Handicapped Able Bodied - was a group where people with physical disabilities met with people without (mainly young people, like a kind of youth club), did activities together and had fun. They met in a large community hall every Friday evening.

The woman in charge of the local PHAB group had been pre-brief on my problems. Knowing I played the guitar she suggested I teach it to some of the disabled girls. In theory, great. In practice, a complete disaster. Or at least that’s how it was for the first five or six meetings.

My dad would drop me off at the building and I’d flee across the room heading for the ladies’ toilets (bathroom) where I’d stay until it was time for him to come and collect me two hours later. I did this week after week, terrified of facing that crowded room of people in the same way I couldn’t face people at school.

The woman in charge tried to entice me out. Initially she’d coax me out of the toilets and into her office where she’d talk to me and try to calm me down. Gradually she drip-fed me (what we would call “exposure therapy” these days): 10 minutes in the main hall, maybe playing board games with some people, then back into the safety of her office for a quiet chat. A few more minutes with the others, maybe teaching the girls guitar, then I could retreat back again. I wasn’t allowed to retreat back to her room until I’d done the allotted 10, 15 minute and eventually 60 minute stint.

Initially it was almost physically painful - the fear of being in the big room with all these strangers was so intense. But gradually I became acclimatised to it. And

gradually I became one of the crowd, openly accepted by everyone and feeling part of the friendly PHAB “family”.

Not everyone without physical disabilities was “normal”; looking back there were quite a few with mental health issues of one kind or another. But what everyone had in common was that they were really, really nice people. And incredibly genuine.

So what has this got to do with disordered eating?

That spring of 1976 was a gradual turning point for me. I became used to being with people, making friends and having fun. I realised that people didn’t have to be scary at all - and, most importantly, I was accepted at face value. There was none of the keeping me at arm’s length which there was at school.

Somehow I got in with the best crowd of all - the crowd that sat on the back table by the door - a fabulous group of people who would become long-term friends. Some were disabled, some had other issues, some had no obvious problems at all. But we got on like a house on fire. Incredibly I was volunteered for the PHAB committee, in charge of publicity.

As I got popular, I also began to lose weight. To be honest some of it was the fact that there were so many good things going on there was no need to comfort eat. But I was also enjoying the new, slimmer me I was seeing. Newly slim and with a new haircut and clothes - and newly confident - I felt like a completely new person. Every evening after tea I’d skip dessert and take myself off on a long cycle ride up and down the hills of the local countryside. I counted calories religiously (no more than 1000 a day) and devised low calorie ways to satisfy my insatiable desire to eat (for example a favourite of mine back then - whipped egg white, whizzed up blackberries and low calorie sweetener - made a virtually no-cal dessert).

I went from a large size 14 down to a 12, 10, 8... One day I found I could fit into kids’ clothes quite well and was over the moon. I also used to revel in the way the weight loss resulted in a smaller bust size and eventually scarcely any bust at all. Remember how I hated those boobs? I stopped wearing a bra because I didn’t need

to. I cut my hair short and was even mistaken for a boy on a few occasions which both embarrassed and thrilled me.

That July I went on a course at the local university - an exchange with French students who were partnered with selected Sixth Formers from all over the city.

This group of French and English kids spent two weeks having the most fantastic time in what was turning out to be the long hot, dry summer of 1976.

There were a few other girls from my Sixth Form, too - girls I'd never had any contact with before and who, because I'd hidden myself away for so long and looked so different, actually thought I was a new girl at school!

We became close friends. And these new friends made friends with my PHAB circle. It was brilliant!

And meanwhile I continued to slim down, seeing my new slim body as the reason for this phenomenal change. If I ever got fat again, then - ping! - I'd be jet-propelled back to the land of the lonely and ignored.

Which is almost a carbon-copy of how Ben felt about his (fleshier and lonely) primary school years compared to the way the first four years at secondary school transformed him into a popular, athletic swan.

More to come, when I get around to it...

Monday, 27 August 2012

The grey period at the start of Ben's anorexia...

I am having problems describing the "grey period" in my book: the months between when the penny eventually dropped that, yes, Ben was developing anorexia to early 2010 when I first discovered the ATDT forum (when, of course, all my thoughts are documented for me to refer to in the forum archive).

Apart from memory, this is virtually all I have: a collection of emails to my sister and forum posts I made at the time (other forums where no-one ever responded).

The following is copied and pasted in its unedited entirety from these notes:

My wonderful 16 year old son has gone from being a strapping rugby-playing, healthy eat anything lad to a thin, gaunt boy who's well below the minimum for his build and height. All the signs point towards an eating disorder and the doctor agrees. If he's lost more weight by the time he returns to see the doc in 2 weeks, she says it'll be a referral. I tend to think this is inevitable...

If you've had a similar experience I'd appreciate any advice you could give on getting over this. All I want in the whole world is for my wonderful son to be back to who he was again instead of this food-obsessive, compulsive, frantically exercising boy who's a physical shadow of his former self. Underneath it, he's very unhappy and I feel helpless. It's all to do with image and self-esteem, of course. Goes back to cutting remarks from girls on him being too fat. He believes that if he loses weight he'll suddenly become popular with the girls and his peers. Of course he won't listen to a thing we say about it...

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

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

We can't eat normally any more.

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

Followed by...

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

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

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

Worse, this boy is muscular, with a "six pack", according to my son.

Result = my shy, unconfident son feels that the only way he can compete or equal this boy is to exercise and diet himself silly so he "becomes" that boy, if you like... By doing this he will get similar adoration and "be loved" (his words) by the girls and others. He says he "just wants to be loved". Of course transforming himself

into this boy is an impossible task which is why the situation has got so bad.

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

PS Have had a long chat with Ben and worked out a recovery structure with professional help back-up if things don't improve within two weeks. We already have a referral underway for NHS help, but it may take 20 weeks (!!!!!), in which case we'd have to pay for private treatment as a stop-gap until then. Mainly we need to change his mind-set towards (a) his body (so stick thin is seen as unattractive rather than attractive) and (b) how he handles peer issues at school and his need to be "loved" and "popular".

I hope I managed to drum into him how vital this is and that there is no negotiation with this. I have set "reward stages" along the way, the top reward being the double bed he wants and other rewards being activities he wants to do - and I've promised I'll do activities outside my normal comfort zone, too. I may even take snowboarding lessons...!

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

for his physique. The good thing is he was receptive, unlike the other night...

The main issue is changing his mind-set so he views a physique like when he came back from the Coast2Coast cycle ride, for example, as the perfect body he should be aiming at - and not this geeky thinness - in fact we want to change his mind-set so he does view this kind of body as geeky because I know that geeky is something he wants to avoid like the plague (because he worries his circle of friends are viewed as geeks).

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

Tuesday, 28 August 2012

Batty is on a guilt trip...

I know that parents don't "cause" their child's eating disorder and we shouldn't feel guilty about it. But, as I am discovering at the moment as I write up those early stages when I was trekking with Ben to see our GP, I can't help but feel guilty.

No, I know I'm not responsible for the fact that either me or my husband - or both, which is probably likely in our case - may have passed on a genetic disposition for anorexia to our son. So I don't feel guilty about that. Or at least I shouldn't feel guilty about that...

But what I do feel guilty about is that I should have picked up on Ben's emerging anorexia sooner.

However, because of my complete ignorance of the illness and the warning signs -

plus the fact that it never entered my head that boys can get anorexia - it took months before the penny dropped that something was seriously wrong.

First there were the “hidden months”, when the illness was already germinating inside his head. With a teenager it’s so easy to mistake this for the usual teen problems. We certainly did.

And, as Ben always says, it’s not as if he sat down one day and decided to get an eating disorder. He had no idea what was happening either. The descent into what turned out to be anorexia was pretty scary for him, too.

Then - in our case some six months later - there are the months when the eating disorder begins to show above the surface, but you’re not sure what it is. You’re concerned, you know something isn’t right and the warning bells are kind of going off. But then something will happen that makes you doubt your concerns. Like a few “normal” days or whatever. Or still the impression that this is just “teenage angst”.

This is why it took me so long to take him to the GP - early October, when the germination began the previous Christmas.

And even then I didn’t push for referral. This is why I feel guilty.

Firstly, I fell sick with an inner ear virus which put me virtually horizontal for a month. My brain was like mush and I couldn’t think (or walk!) straight.

So I was seeing the GP along with Ben - both of us with illnesses without any obvious physical symptoms. I began to doubt my own judgment. Did I have that *Munchhausen* thing where you’re compelled to fabricate illnesses to gain attention? A crazy and irrational worry, I know, but it was there at the back of my head - and in my GP’s eyes. (But that might just be me being paranoid.)

Then you have a patient who refuses to believe they are ill and who insists to the GP that it’s just his mum being paranoid... visit after visit...

And - importantly - although I knew it was something to do with under eating and over exercise, I still didn’t know what I was dealing with, even though it gradually became clear.

So I feel guilty that I didn't push for urgent, early treatment. Oh, sorry I forgot... I didn't even know what treatment was available until the school nurse told me. So how could I push for it?

And even when I did find out about treatment, no-one told me there would be an 18-22 week wait.

Yet I feel this guilt.

Irrational guilt, I know. But guilt, nonetheless. How could I, as a good parent, have acted so slowly? Not until Ben ended up wired to machines on the cardio ward at the end of January 2010 with a pulse rate of 29 did he eventually get fast-tracked into treatment.

One of the main reasons why I am writing this book is to alert concerned parents of boys earlier and help them to trust their gut instincts - and then push for treatment. Even if they have to chain themselves to the surgery railings.

SEPTEMBER 2012

Saturday, 1 September 2012

Aren't our children amazing?

Okay, so although I had food issues as a teenager and a 20-something, and okay I dabbled in a bit of bulimic behaviour on occasions, but - thankfully - I never developed a full-blown ED. Yes, I did have awful issues which I've described in recent posts, and yes writing about these made me feel vulnerable - like airing my dirty washing in public and opening a Pandora's box of stuff I've been trying to blank out all these years. But these "confessions" have also done something else... something really strange...

Admitting all this stuff honestly and out in the open, for all to see, made me realise how brave our own children are when, like Ben, they "go public" about their own

battles with eating disorders. Yes I know that one in four people will suffer from a mental health problem at some time in their lives and, therefore, society should accept mental health problems as readily as they would a physical illness or disability.

But the fact is that mental health problems like eating disorders are still a fairly taboo subject that many people might prefer to hide under the carpet.

Admitting you've had - or have - "issues" which "normal" people don't have and which might shock "normal" people and make them think you're a bit weird and "a weak person" - well - this takes guts.

I am not saying I was brave in coming clean about all this stuff, I'm talking about our children and the way they're not afraid to talk openly about their battles with eating disorders.

For our children to openly admit to the world that they are suffering from anorexia or another eating disorder, and describe the complex and terrifying cognitive changes that are part and parcel of the illness, is a bloody courageous thing to do.

Not only this but to admit there is a problem in the first place.

And then work like a Trojan to overcome it, made more difficult by the fact that the eating disorder constantly beckons you back into the false comfort zone of its clutches.

The point I'm trying to make here (probably not very successfully and I am sure you could do better) is that - for our children to (a) admit there is a problem, (b) talk about that problem in detail, often permitting us and mental health practitioners to delve into the deepest and most private recesses of their minds and (c) not be afraid to "go public" about it, like Ben has with my book, on TV and in the interview he did for Oxford University, or like other people have done in their first-person published accounts, or when they fight for better eating disorder treatment – well, it takes serious guts. Our children are amazing!

In fact I don't think there's a word in the English language which would describe their sheer strength of character.

They put “normal” people to shame.

Monday, 3 September 2012

Basking in the sunshine...

It's not too many weeks ago that I was still anxious about how Ben would cope with being away at university - eating, thinking and socially. But I'm astonished at how rapidly he has moved from the last little bit of the woods out into the brilliant sunshine. He is so normal. In every way. And I have every confidence that, if he continues like this, university will be the making - not breaking - of him.

So with just two more weeks to go until we 2012 parents dump our offspring off at university, I am just like any other mother: piles of stuff on the spare bed - pots, pans, cleaning stuff, etc - and making the most of the two remaining weeks we have together.

But I already I sense he is growing up. Already he is becoming independent and putting a natural distance between himself and me, just as any 18 year old or young adult would. After all, why the heck would you want to mix with boring 50-somethings like us when you can have fun with people your own age!

“Another senior moment,” he says as my menopausal brain makes me put the breakfast cereal in the fridge.

He is like any other teenage boy taking the mickey out of his parents.

And I have every confidence he will eat properly and be able to successfully manage his intake during a busy Intro Week - and the following week when everyone gets down to the serious business of studying.

We hope...

I really hope I can look back on this post a year from now and know I was right to feel so confident and take a back seat.

Meanwhile I am looking forward to my first real freedom for three years: free to

do whatever I want to do.

Wow!

Tuesday, 4 September 2012

What was he thinking of?

Literally! I've been picking Ben's brains to discover what was going on in his head when he had anorexia.

Here is Part One of the result (based on the notes I made while he was talking and which will eventually be used for parts of my book)...

***Me:** Back in autumn 2009 when we were on the waiting list for CAMHS treatment and decided to get private "stop gap" treatment, how did you feel about it?*

***Ben:** I realised there was a problem. I knew I needed treatment but didn't like to admit I needed it.*

***Me:** How did you feel about me constantly pushing for treatment?*

***Ben:** To be honest I didn't think it was that urgent. I knew I wasn't feeling good mentally, but as far as my body was concerned, I was happy where I was. I didn't think it would or could get any worse. At this BMI I didn't need to worry about my weight any longer... about whether I'd get fat... so there was much less pressure. I felt unwell, but I just thought it was "one of those things" i.e. pretty normal. But I admit I was worried about all the fuss I was creating.*

***Me:** What about when you cut out fat from your diet?*

***Ben:** I wanted to eat fats - for example I really wanted to eat chocolate, so I made sure everything else I ate was zero or minimal fat just in case I wanted to treat myself to some chocolate. But I never did treat myself... I never felt able to... yet I still felt compelled to allow for it "just in case".*

***Me:** And the ED rages? For example when you got violent against me e.g. if I came into your room following an outburst?*

Ben: I didn't want to talk. I needed time on my own to think. When you saw me looking like a zombie, staring blankly into space with no emotion, it was me trying to think, trying to come up with solutions and calm down. It was hard to calm down with you buzzing about getting distressed. I just wanted to be left on my own. On the other hand, sometimes my thoughts would get really bad - deep bad thoughts - and it probably wasn't such a bad thing that you were there.

Me: *Deep bad thoughts?*

Ben: Like the time I nearly climbed onto the roof. Suicidal thoughts, I mean...

Me: *Did you ever really plan to kill yourself? Either on purpose - or by accident - like when you nearly climbed onto the roof?*

Ben: I did think of it and I did want to do it, but I have a fear of pain. If you hadn't pulled me in from the window, I would probably have pulled myself in - I was too scared of pain. This is why I never cut myself like some anorexia sufferers do. During the summer of 2010 I was mega depressed. I didn't know what to do. I was aware that I was causing so much pain and trouble. By the time I joined the Sixth Form in September I'd calmed down a bit - or, rather, I'd deflected the depression by working like a Trojan academically, trying to take my mind off it so I didn't go insane, but instead I burned myself out by October.

Me: *You were at your lowest weight at that point - lower than when we first took you to the GP and lower than when you first saw CAMHS. How did you feel about your body?*

Ben: I knew I'd lost a lot of weight but I felt fine. It was just the stress of trying to keep it like that. If I accidentally lost more weight, then I'd feel okay at that weight because - basically - I did feel okay. Kind of. So I thought "Well I'll stay here, then". But it was difficult to maintain and I was constantly thinking about how to maintain it. Yet as I lost more weight that stressed me out too. By the summer of 2010, although I was seriously depressed and losing weight gradually, I was - in fact - eating a far more balanced diet. The psych had explained to me all about the biological

reasons why I needed to eat, and needed to eat certain stuff. By this stage it went in. A few months before it wouldn't have gone in, but it did then. So I felt that, although I was losing weight, I was actually making progress on the challenge foods. This is one of the reasons why the holiday we had in France that summer went so pear-shaped...

Wednesday, 5 September 2012

Summer 2010 and afterwards

"The French holiday that July was a nightmare," I said to Ben yesterday morning. "Meltdown after meltdown after meltdown, right from the first moment we arrived. How did it feel for you?"

Ben: You and dad kept focusing on the eating disorder all the time when, if you'd looked a little closer, you might have noticed that I was doing all kinds of good challenges. I felt like shouting: "Look at what I'm doing! No way would I have done these things even a month ago, yet you're ignoring it!" Remember that time we went cycling on the coast? I changed into my cycling gear and you burst into tears?

Me: *That was because, seeing you standing there in your underpants, you looked so terribly skinny. Then, in the cycling gear - the same gear you'd worn on the Coast2Coast cycle ride the summer before and which hugged your body like cycling gear does - you looked so thin. The clothes just hung off you. It broke my heart to look.*

Ben: It affected me, too, you know. I was thinking: "This is what the last year has done to me!" I was angry with the anorexia - angry with the way it had robbed me of my Fifth Form year and my friends. I wanted to challenge myself, to begin to try and escape from the anorexia's clutches. I didn't calorie count on that holiday, not because I was purposefully cutting back, but because I saw it as a progression. I knew I couldn't count calories all my life; if I wasn't careful calories would ensnare me in the same way as the anorexia and the exercise purging. Also, you didn't seem to

notice the good days - like the day we spent in Cognac at the jazz festival in the park. I needed encouraging. I needed you to say: 'Wow! You're doing really well!' but you didn't. You and dad were super-stressed all the time, biting my head off and going on about food, focusing on the negative rather than the small positive changes. When we arrived at the villa and I went mad, it wasn't because of the anorexia, it was because I really didn't want to do target shooting with the host. I mean, we'd just arrived after a long journey. I wanted to chill. And this bloke was trying to get me to rush out and have a go at target shooting with his kids. Dad wanted me to do it, too. But I didn't. That's why I went mad.

***Me:** Obviously back then, dad and I were worried sick about you. Remember we'd been battling with this terrifying illness for 12 months and had been seeing resistance after resistance to treatment and normal eating patterns. We were also worried sick you would take your own life. In fact, over that summer, suicide was top of my mind.*

***Ben:** I'd have found it so much more helpful if you'd been able to calm down and talk to me, without confrontation and without all that obvious anxiety. You know, like that "Dolphin" you've always talked about? Guiding and gently encouraging me to move in the right direction rather than bursting out into tears and shouting at me. Seeing you and dad upset didn't help at all. It's unfortunate, but eating disorders don't just screw up the mind of the child, they screw up parents' minds too. You and dad were paranoid and needed to start recognising the positive changes in me, to praise me and so on. I'm not saying that I was remotely "cured". I'm not even saying that I'd definitely turned a corner at that stage. Far from it. But I was beginning to want to get well. Oh I knew I couldn't change instantly, the anorexia thinking was far, far too strong. Also I couldn't just push the anorexia thinking out of the way. I felt that it was "me", even if it wasn't really. I needed to deal with it. Which is why I spent so much time on my own - I was thinking, trying to deal with things. Yes I was depressed, but I was also trying my best to deal with things my own way. It would have been far better to talk about it without confrontation. To work on it together,*

for me to admit the eating disorder thoughts and deal with them rather than pretending they didn't exist. This is where our Contract [which we introduced the following spring] helped so much.

Me: These days the general thinking is that you can't wait for eating disorder patients to "want to get better". What do you think about that?

Ben: If I'd got a lot worse, then I admit I would have found it virtually impossible to turn a corner without more - er - forcible outside help. But you have to recognise when someone's mind begins to change. I needed to be able to admit I had a problem, not to be told I had a problem forcibly (even though I knew I did). That summer I was beginning to change, I just needed you to recognise it.

Wednesday, 12 September 2012

Just four days to go till university...

Things are going so normally here in the Matty household, it's difficult to get used to. A normal mum nagging a normal teenage son about normal things: "Promise me you won't walk home on your own late at night", "Don't forget to put your wallet in a safe place so it doesn't get stolen", "Remember to buy toilet roll and milk", "Don't put the whites in with the darks in the launderette", "Don't drink too much"... blah, blah, blah...

Nag, nag, nag... I imagine I'm just like any other mum in the run up to university. All those little things that you've always done for your child and probably shouldn't - like ironing, sewing on buttons and washing clothes... and always being there to lend him a spare tenner when he runs out of cash...

But - yes of course - there are the other issues which are unique to us as a family with a child that's recently recovered from anorexia...

Walking through a series of typical chaotic Intro Week days, food-wise... taking a few frozen meals to see him through those first few evenings... making sure his

luggage is packed with pots, pans and store cupboard staples like tins of tomatoes, rice, pasta, cookies, soup, tuna, cereal, herbs, spices, lentils and other stuff he can create a quick meal from in minutes. Plus we'll be shopping for fresh stuff like milk, bread, etc. But I guess this, too, is something that "normal" families do on the way to university.

I hope he ends up with nice flatmates in a friendly apartment block. Not too many flatmates - not one of those apartments with 12 bedrooms where everyone fights over the cooker, fridge and freezer. A smaller apartment would be better. I hope none of his flatmates have curious eating habits, because that kind of thing still sets off the ED thoughts. People who eat rubbish, are on constant diets, talk about diets constantly or are fussy - or who just don't eat.

And I hope they don't "borrow" key items of his food, leaving him short - because the nearest supermarket (and only a small supermarket at that) is a 20 minute walk. I imagine the lure of Ben's latest batch of chocolate brownies sitting in the fridge when you've just come back from clubbing at 3am might prove too a little too tempting for some...

I hope everyone he meets is friendly - and he's friendly to them. The last thing I want is for him to end up isolating himself in his room. We've been through all that at school; I hope and pray it will be onwards and upwards from here...

On bar or disco nights I hope he drinks a little to steady his nerves. Not loads, but just a little. And not to get into the habit of doing this... But - because he does have a habit of sitting there without a drink while everyone else tucks in, and he gets tense and anxious while they begin to mellow - a little bit of "Dutch Courage" mightn't go amiss...

He's organised a mentor - a boy from the year above who is there to look out for him during those first few weeks and months. This boy has a best friend with anorexia, so he "gets" the illness more than most, I guess.

There are also accommodation mentors - students from the year above whose job

it is to help new students settle into their apartments.

And with a diary jam-packed full of activities during that first Intro Week - from beach parties, BBQs and discos to scuba diving, quasar, Buddhist meditation, jazz, radio DJ-ing, ghost walks, pub crawls and treasure hunts - he's bound to meet people that float his boat. Plus, two of his school friends are in the same apartment complex as him. And the little girl he once insisted he was going to marry... back in nursery, aged just three... is going to be at the other university in the city, a stone's throw away. He knows, because he met her in the record shop yesterday. Good God, she's changed in the past 15 years!

Saturday, 15 September 2012

Warning: get out the tissues before you read this post...

Yesterday evening after tea, Ben suddenly appeared in the living room armed with brightly wrapped gifts and cards. "These are to thank you for everything you've done for me over the past 18 years and especially over the past three years," he said as we stood with open mouths.

He'd bought us both boxes of chocolates and a card. In it he told us that he loved us "immensely" and wanted to thank us for helping him through his illness as well as nurturing him through his childhood to prepare him to "leave the nest". He said we'd prepared him better than any other parents could and that we're the best parents of "all the mums and dads out there". And he thanked us for being there for him when he was "hurt, down or sick" and filling him with the confidence to lead his own life.

And as if that wasn't enough to make us fill up...

... He produced a third card and gift. "These are for mum - to thank you for getting me through this."

"But dad helped you get through it too!" I said, not wanting dad to be left out...

"But you were the one who was with me 24/7 during the dark days. Without your

encouragement I mightn't have got through this, let alone be on my way to university on Sunday. I just wanted to thank you especially."

Cue gallons of tears...

In the card he talked about the way we'd fought the struggle together, not against each other, but against the illness. He talked about my love being a "shining example to the world that love can overcome anything". He talked about the "sheer strength of willpower and motherly love", told me I am "the most amazing human being I know", above "all other idols in my list of admiration". Finally he thanked me for "being the one who never gave up".

I found it difficult to concentrate on much else for the remainder of yesterday evening, I can tell you...

I don't expect there are many young people going away to university this week who have expressed love for their parents like this.

He is a remarkable young man, in so many ways...

Monday, 17 September 2012

Efferty efferty efferty eff...

Within hours of dropping him off at university I got the first message saying he didn't fit in with the other guys in his apartment and felt lonely... Then this lunchtime I got another message. I can always tell when something's up because his first message is always something like "Hi," and that's all.

He feels he's not ready to start university, feels on a different planet from everyone else, feels out of his depth socially having been isolated for so long while everyone else grew up. He feels as if he's years behind and way, way out of his depth. His natural instinct, because of the anorexia, is to isolate himself rather than putting on a brave face and going out there...

I spoke to him on the phone and he was in floods of tears saying he hated

“everything”. His room feels like a prison cell and he didn’t enjoy the beach party.

So I got on the phone and spoke to someone in charge of the accommodation complex, explained the situation (i.e. about the anorexia, depression, etc) and then someone else called me back to find out more - except they couldn’t say a great deal as, until 18 year old Ben gives his permission (which he will do), the *Data Protection Act* prevents them from communicating with me.

Having said this, I did have a good chat with them...

The upshot is that they’re sending someone round to see him in his room, hopefully around now - someone skilled in counselling / mentoring. We need to see if it’s salvageable i.e. if he will stay - or go.

The problem is that we will need to decide within the next four weeks to avoid any financial implications. But if he does decide to withdraw, he can pick up where he left off in 12 months’ time.

It’s early days, of course, and things may improve.

But they may not. Whatever he decides I am sure we can make the best of a bad situation. After all, I am used to Plan A, B, C, Ds... I am the Arch Problem-solver!

If possible, we need to avoid a knee-jerk reaction - the instinct to flee back to the safety of home.

But it may happen.

Or it may not.

I expect he’s not the only one to be feeling pretty cr*p once it all sinks in that they’ve left home and they’re in this little apartment room on their own...

Watch this space, I guess...

Wednesday, 19 September 2012

So here’s what really happened...

Things got progressively worse and by Monday evening Ben was sobbing down the

phone to me, in pieces. I'd spent the day organising various counselling and mentoring people to see him, but by the evening he was in a terrible state. So the next morning saw me meeting him over coffee in a café near the university...

I went armed with a Plan A and Plan B. Plan A was how to remain in Sheffield and hopefully ease himself into things. Plan B was what would happen if the situation was non-salvageable. Both hastily put together by me before I drove down there.

Poor old Ben looked like a rabbit caught in the headlights. He felt way, way out of his depth and simply couldn't cope. He was in floods of tears and I ended up battling back my own tears as we sat opposite each other over our coffees.

I kept calming him down, telling him that this was a "meeting", like our Contract meetings i.e. on neutral ground where we can say anything and, indeed, must say anything - everything in this instance. Nothing held back.

The upshot was that he had thought he was ready to go away to university - and I know he was mega excited and positive about the prospect. It was a major focus, something to look forward to and aim for - the chance to start afresh. Boy, was he looking forward to it!!

But when push came to shove, as they say, the reality hit him: he wasn't ready. Far from it. On so many accounts, too numerous to go into here but which included maturity, social skills, aversion to the student booze / partying culture, isolation, less than ideal room-mates (all male, five in total including him and two foreign students), a cell-like room, feeling suicidal and the fact that he had to store a lot of food in his room due to a small kitchen - bad news for someone with ED inclinations... Not to mention room-mates quizzing him about his eating habits (eating lots and regularly, and cooking)... and eating alone in his room when he still feels anxious if he's not eating with us... and horrendous homesickness... and so on, and so forth... and more... He just wasn't ready for university. The trouble is, none of us realised it until too late.

Had he not had the eating disorder background plus all the co-morbid

complications that went with it i.e. clinical depression and past suicidal tendencies, then I would have insisted we work on keeping him at university - maybe changing accommodation, and definitely reining in all the various support services to help.

But - with the double whammy of Ben's unhappiness and ED history, and university fees of £9,000 pa - it simply wasn't worth persuading him to give it a go. If he found he couldn't cope later in the term, for instance, we'd be financially liable for quite a big sum of money...

However Ben is still very keen to go to university, and still keen to be in Sheffield, but now isn't the right time.

"Okay," I said, deciding I was flogging a dead horse as regards Plan A, "If you leave then you leave with conditions. Firstly you agree to further therapy to ensure you are ready to try again in 12 months' time. What I don't want is for you to run away and bury your head in the sand about the issues that still need dealing with. Secondly you get a job. If you can't get paid work, then you get voluntary work. Thirdly, we work on helping you to become more independent and less reliant on us. Fourthly, we go and see various university support services now. We need to tell them what's going on and we need to talk about the possibility of leaving your place open for 12 months. They might have some options we haven't thought of".

He readily agreed. Enthusiastically, I am pleased to say.

So we began the rounds, starting with the accommodation mentors and ending with student services. I was amazed at the speed with which everyone saw us; no need to wait, and everyone was incredibly supportive and awesomely helpful. And, yes, they did have options we hadn't thought of which will hopefully make it easier for him next year.

Because Ben had already registered at the university, they will be keeping his place open. He has been given a Leave of Absence on medical grounds. He is officially a student of the university, but is just taking a year off sick (for want of a better way to describe it). A year, initially. Hopefully only a year...

Next September he will commute from here to Sheffield to begin with, until he settles sufficiently to move into accommodation. There isn't a great deal of contact time on his course, so it wouldn't be too bad. It is workable. The university says they can even tweak his timetable to take into account the commuting. And these days stacks of information and study materials are available on the university intranet from any location.

We'll find a different kind of accommodation, something more suited to him, maybe in a shared house or whatever rather than the artificial environment of halls of residence. I don't know, but we'll cross that bridge when we come to it. Meanwhile he would hopefully ease himself into things socially by joining carefully selected societies e.g. debating and his model making / war games society.

And Student Services said they could draw up a special support package for him to ease him into university next year - physically walking him round all the various support services and introducing him to them, etc, as well as meeting his course tutors.

Today we saw the course admissions lady and completed all the various paperwork required. And moved the rest of his stuff out of his room (all that squirrelling away of stuff over the summer, hey...)

Meanwhile I've been in touch with CAMHS because we need a letter from them to support the Leave of Absence and also to talk through options in Adult Mental Health Services as regards dealing with Ben's other issues. Someone from CAMHS is calling me back tomorrow. Watch this space...

If NHS help isn't available, then we'll go private.

But, with a term's accommodation rent to pay (ouch!) because we're tied into a contract, I'd rather we go via the NHS.

A busy and stressful few days with lots of thinking on my feet.

But Ben is wholeheartedly behind me with Plan B.

Oh, and I said to him: "Well done for having the courage to admit things weren't

going right and you aren't as okay as we would all have liked to think you are. That takes courage. Well done." Far better than just festering without telling anyone and getting more and more miserable until things get even worse.

Thursday, 20 September 2012

Onwards and upwards, Ben...

A dismal Ben greeted me this morning in the kitchen, saying he felt like a failure and "useless". So in came Mama Matty to instantly (hopefully) put him right on that count, reinforcing the fact that he's been so courageous to admit there was a problem right at the start, rather than letting things spiral downwards... There must be loads of new students who aren't being so courageous and really should make the decision to jump ship while it's still early days and resume when they're in a better place. Like the obviously ED girls we saw walking around the university yesterday... (whose parents must be worried senseless)...

It also took a lot of guts to admit that, yes, there are still issues which need dealing with and which he can't fix, even though over the past few months he really thought he could. And these may need professional help - mainly on the social / confidence front plus a few underlying ED issues. If we can't get NHS help then I know who to bring in privately. Sod the expense. This time we're going for Gold.

As to his dismal comment that "everyone else" is out there, at university, forging ahead in life and all that rubbish, I responded that "everyone else" *isn't* out there, at university. Quite a few of his friends have taken a gap year - and he is now taking a gap year, just like them. And when the "everyone else" who began this year has finished university in three years' time and is sitting around miserably trying to get a job, he will still be at university - *and* he will have valuable work experience behind him which he gets this year. So he'll have a head start. And also, hopefully, the UK economy will be in a better place in four years' time.

And he will be that little bit more mature. And so many people have said that taking a gap year is *good*. So many *good reasons* to do it.

I told him to get out the 2012/2013 diary I'd bought him for university and use it to plan his days, initially job hunting. It might be a paid job or it might be voluntary. Far better to do a voluntary job you enjoy than a boring paid job you hate - and far better to do something useful, where you're needed and are doing good. Actually, he said this to me before I said it to him.

He already has formal barista training behind him and he spent the summer working part-time in the charity shop up the road.

He's applying for a weekend vacancy at *Games Workshop* - his passion, where they sell, paint and play with *Warhammer* fantasy battle figures. But he recognises he might not get it, and even if he does it might not be immediate. And it's only a weekend job.

"So why don't you get down there to *Games Workshop* and offer to work as an 'intern', for no pay? They know you already, so there's no ice to break. Tell them you've decided to take a gap year and couldn't think of a better way to spend it. If they say no or they don't know, then get onto Head Office. Pester, pester, pester until they're so sick of you they give you a job. I know this works because it's how I got into my own career and how I set myself up as a freelancer - by putting myself out there, by phoning people (in the days before email!). It's scary and it took me way, way out of my comfort zone (the world's #1 Shy Person, that's me) but I had to do it. No choice. And it worked."

I came up with loads of other ideas, too, which we are going to list and work through.

Meanwhile the two of us have been working on his CV this morning. But, wherever possible, I want him to do stuff for himself. I don't want to do it for him.

Onwards and upwards, as they say...

"And let's make this a bloody brilliant year for you, Ben!"

Friday, 21 September 2012

What I know now that I didn't know this time last week

So what went wrong? So much, on so many counts. Which is why our brief flirtation with university life this week may be a useful learning curve for other parents wondering whether or not to send their post anorexia / eating disorder teenager off to university or wait another year, or even longer...

Maturity

It's as if Ben has stood still for three years - physically, mentally and socially. Not only does he look 15 or 16 years old or even younger (thanks to the way anorexia stunts physical development) but he behaves as if he is. While his peers have grown up and gone through a myriad of different experiences as they matured into independent young men and women, Ben has stood still. Seeing him at university amongst his peers was like seeing a school kid who was way out of his depth. Ben was like a fish out of water. Totally and utterly.

Social / Living

I had this rosy idea that Ben would find himself in a nice apartment sharing with a range of students - some great, some not so great. But it would be okay, hopefully even fun. And everyone would be milling around the apartments so it would be virtually impossible to isolate yourself. They'd plan meals together, socialise together, etc. Okay so they might not turn out to be bosom pals, but then there's always the apartment across the corridor and the others up and down the stairs. And there were so many activities arranged for Intro Week, he was bound to find people he got on with. Yes, he would probably be homesick, but hopefully he'd quickly get into the swing of things. Ben thought so, too. We were both terribly excited about it

and very positive. Ben had mapped out exactly what he would do, even down to getting onto the accommodation events organising committee and doing loads of other things to get involved.

We also thought that by choosing a smaller flat of just five rooms it would be more “cosy” than a bigger 7-12 room flat. In the event, fewer room-mates reduced the chances of sharing with someone you “click” with. A mixed apartment would have been better, too. Ben’s apartment was all male.

The apartment block had two flats on each floor. And security and fire regulations meant there were three different locked doors before you got as far as your room. Unless you propped your door open with something heavy, it would immediately close, leaving you completely alone.

It was a small room, like a prison cell. Modern and smart, but isolating. And, unlike the old fashioned halls of residence where there were always people walking up and down the corridor, a small apartment behind all these locked doors can be even more isolating when no-one’s there, you’ve got an ensuite so you don’t even see people on the way to the bathroom or your room-mates keep themselves to themselves. Or you just don’t get on with them. Because, after all, you’re being thrown into a flat with a group of complete strangers. If you’re not naturally the Life and Soul of the Party, then this can be a Big Problem.

It’s potentially even more of a Big Problem if you have a history of anorexia or another eating disorder. In Ben’s flat there was precious little cupboard space in the shared kitchen / dining area which meant he had to keep most of the non-perishable food - and utensils - in his room. Being surrounded by food and reminders of food, 24/7, in such a confined space can be pretty challenging for someone with an anorexia history to say the least...

Cooking is challenging, too. Yes I made sure Ben went armed with everything he needed to be able to prepare meals - from utensils through to the food itself. But when push came to shove, there was nowhere to store it - so it’s not like home

where you can simply reach for the tin opener, pan, lid, garlic crusher, wooden spoon, chopping board, knife and ingredients and prepare the meal. Then get out your plate, knife and fork, etc to eat it.

Oh, and when several others need to cook their meals, too, you're having to wait your turn for the stove, etc - and cope with a sink full of someone else's dirty dishes.

Then there were the curious looks from his room-mates - and questions like "Why do you eat so much for breakfast?", "Why do you bother cooking when you could get a takeaway or eat in the bar?", etc, etc. Difficult when you're someone with an eating disorder...

And it's not just the questions, it's the awareness that the others aren't eating as you would like them to be eating. Other people's eating habits really affect Ben.

Plus, when your natural instinct is to run and hide, you end up eating alone in your cell-like room. Throughout his anorexia, Ben ate with us, as a family. Suddenly eating on his own was a massive culture shock. Not a great way to ease yourself into university life.

Ben's not into boozy, noisy partying and clubbing - and unfortunately the majority of intro week events are like this. You either hang around awkwardly with all the others... people you don't know... and pretend to be having fun when you're desperately hating it inside, or you retreat to your solitary room. Then you're woken up by noisy, drunk people returning home at an unearthly hour which, as well as annoying, reinforces the knowledge that they've had fun and made friends, and you haven't.

As a result of all this you freeze up. You find it even harder to socialise. And never forget you've been on *Planet ED* for three years so your social skills and confidence are shaky to say the least. So you keep yourself to yourself, not just in the accommodation and at social events, but during course registration and so on.

Then the old worries kick in like "How the hell am I going to manage to sit still through a day's lectures when my natural urge is to exercise? A legacy of the eating

disorder which I'm still fighting to keep under control?"

Not to mention the fact that Ben never did manage full-time schooling during the three years of his anorexia. There was always the option to bottle out. You don't get this option at university. Not unless you want to fail the grade or take a Leave of Absence.

No wonder Ben felt so incredibly lonely. He was like a fish out of water; a rabbit paralysed in bright headlights.

I should have realised this would happen, but I was too optimistic.

I should have realised there were still far too many unresolved issues that need sorting out.

I should have realised the Ben, as he is now, even (almost) recovered from the anorexia, is still different from his peers in so many ways.

And I should have realised that going to university is one of the most stressful things that can happen to a young person, let alone a young person with a history of mental illness like anorexia...

As we drove away from Sheffield the other day it was blatantly obvious that this could never have worked for Ben. Not at this stage. Hopefully in the future. But not now. No way.

Friday, 21 September 2012

With hindsight, what I would do if we were applying to university again?

It's almost the time of year when this year's (British) Upper Sixth Formers head to open days at universities across the country, just like we did last year. So, knowing what I know now and taking into account that Ben was "almost" (but not fully) recovered from anorexia at the time, what would I do differently?

It's so easy to get carried away; for you and your child to get excited about this new experience. After all, the universities want to "sell" themselves to you and they'll

make these open days as action-packed as possible: talks, sample lectures, accommodation and campus tours, free refreshments, etc.

It's also easy for your child to see this as a fantastic chance to make a fresh start... to put the eating disorder or anorexia behind them and begin again, in a new environment with people that don't know their history and who haven't witnessed them at their worst. This is true. But maybe this fresh start needs to come a little later?

I know Ben and I got carried away. We got really excited about going to university. CAMHS said they couldn't see any reason why Ben shouldn't be ready for university in September. Other people did, too, even school. Yet some people questioned it, including my dear (late) friend Sue. Even the university admissions tutor when I had a chat with him. "If he's only managing school part-time do you really think he'll be ready for university?" he asked. But I thought because a *History* degree doesn't have too much contact time, it'd be like being in school part-time anyway.

Wrong.

Because you're at university full-time, regardless of how much contact time you have.

You're at university 24 hours a day, seven days a week - away from the familiar environment of home and the people you know.

Throughout the three years that Ben has had anorexia, I've been his primary carer, helping to guide him towards recovery on a daily basis. I thought we'd be able to continue this care from afar, via *Skype*, *Facebook*, phone or email.

Wrong.

Nothing beats face-to-face contact when you're checking for those little signs that all is not well - and then coming up with solutions to solve them.

I also thought that being a relatively local university - just 40 miles away - would make things easier to "manage".

Wrong.

40 miles is a long way when your child mentions the word “suicidal” and you’re desperately trying to get someone to go and sort him out. When you eventually do find the right student support service, you have to explain all about your child’s illness and the reasons why you believe they might be at risk. It takes time.

And I wouldn’t even think about sending your post-anorexic child off to a university further afield. Imagine this week if Ben had been at a university hundreds of miles away!

Oh, and there’s also the little problem that, because your child is 18, university staff are not actually allowed to talk to you without your child’s permission. Thank God that, for us, Ben stayed on the phone so he could provide it. And he continued to give his permission to all the other Student Services we needed to deal with over the following two days.

But your child is within their rights to refuse to give permission. I can’t imagine being faced with a situation like that...

So if we were trekking round university open days now and deciding when to apply, what would I do differently?

Basically I wouldn’t even consider letting my child go away to university until I was one hundred per cent sure they are one hundred per cent recovered - and have remained ED-free for a number of months. ED-free, for us after this experience, includes being able to successfully integrate socially and attend school full-time.

Be one hundred per cent sure they are being one hundred per cent honest with you about their readiness for university. No rose coloured spectacles, no being carried away by the excitement of all those open day freebies and activities. Ben thought he was ready. So did I. We were both wrong.

Taking your child out of university, even early on in the process, isn’t easy. We were lucky to have a very supportive university (who, incidentally, have written to say they won’t be charging us for a term’s accommodation rent). They also saw us immediately - every Student Service we needed to see - and were tremendously

supportive and helpful, truly going that extra mile.

Talking to them in so much depth also prompted them to promise to put together a special package to make it easier for Ben to adjust to university when the time comes for him to try again.

Other universities might not be so supportive.

Saturday, 22 September 2012

Excellent suggestions from the university Student Services team

Until we met with the two ladies from Student Services on Tuesday we'd never even thought about commuting as a potentially successful way to ease Ben into university life: commuting for the first term, or even the first year, while he finds his feet and establishes a friendship circle.

This way Ben has the best of both worlds: the security, familiarity and routine of home coupled with the university experience plus the academic stimulation he thrives on so much. It also helps us, as parents, to wean ourselves off his company so we can all learn to be successfully independent without so many shocks to the system.

We only live 40 miles away from Sheffield and there are several direct trains an hour, taking an average of 40 minutes station to station. Then it's a quick hop onto the tram platform at Sheffield railway station and a speedy five minute tram ride which drops him right outside his Faculty. No walking to bus stops or hold-ups as buses navigate the traffic - trams have priority. The only spanner in the works is getting from our house to our local railway station which adds another 30 minutes to the journey.

Because his *History* degree programme has far less contact time than many other degree programmes, he'll only be commuting Monday to Thursday. And lectures don't begin before 10 or 11am, sometimes even later. In between lectures and

seminars he'll have the time to find his feet within the university environment and hopefully make friends - and stay on for evening activities if he wants to, with a focus on the kind of activity that will appeal to him i.e. non-boozy / non-clubbing.

If he needs to stay overnight, then there's always the option of finding part-time lodgings. My sister mentioned that she knows a family in the city that takes in occasional lodgers. Or even sleeping on a friend's floor!

If it all works out, then he might consider moving into accommodation after Christmas. Or waiting until the second year. Or not. Whatever.

The only pressure is that he will need to decide within the first five weeks whether he's going to stick with the course - or be faced with having to pay back a percentage of the £9,000pa fees... Up to five weeks into the first term, there is no charge.

And, without any accommodation fees to worry about, there's no pressure on that front, either.

Plus, Student Services and the *History Department* are offering to draw up a full support plan to ensure Ben has access to whatever assistance he needs. Towards the end of this academic year he can visit Sheffield and be physically introduced to the various support services so he knows exactly where to go and who to see if there's an emergency. And, of course, we've already met the lovely ladies in Student Services who couldn't have been nicer.

Or he might decide to take another year off or not go to university at all.

It's early days, of course, but it's fantastic to know that there's this flexibility.

I wish we'd thought of it first time round. Having said that, it's still very clear that Ben isn't ready for university yet.

Meanwhile he has a job interview on Monday and another possible interview coming up. For paid work.

Good on him to get the ball rolling so quickly.

Sunday, 23 September 2012

Independence and conflict

In less than a week since he left university Ben has already independently set himself a stack of challenges and completed them. And, increasingly, I am saying: “You have to do this yourself; I can’t do it for you” or “Sorry I can’t do that; I am busy”. Occasionally I will throw the odd suggestion into the pot... potential activities he isn’t aware of, for example local debating or history groups - and then leave it to him to do the groundwork.

Already this week Ben has applied for jobs - and has a first interview tomorrow morning. He has applied to be a volunteer in his favourite political party, enquired about becoming a singer in a tribute band and is planning a regular Thursday night activity to do with his *Warhammer* hobby.

Meanwhile I’m here to offer encouragement and positive thinking.

But, as Ben said earlier this week without any prompting: “I’m aware that, at this stage, it’s important that we all start to live independently. You and dad pursue your interests and I’ll pursue mine.”

Meanwhile we need to get some additional therapy for Ben: to tidy up the remaining loose ends of the eating disorder and work on his social anxiety, self-esteem and confidence - and encourage independence. Unfortunately this means going back to our GP and getting a referral, but if he refuses or it’s going to be a long wait, then we will go private.

Also, meanwhile, there’s the problem of how Ben’s dad is coping with all this. Or not coping. He sees the quitting of university as a major disappointment which reinforces his concern that Ben will never completely recover - that he’ll never be able to socialise properly, never be able to hold down a university course or a job, never be able to break free from rigid eating and will end up as a lonely recluse. In other words, it’s all doom and gloom, and we’re wasting our time. “The problem is,” he said angrily, “Ben’s had it all handed to him on a plate. He’s never had it tough. He

needs to get out there and live in the real world for a change". Etc etc etc...

Yesterday there was quite a bit of private "effing and blinding" coming from my husband's shed as he took his frustrations out on the leaking roof he was patching. There were also threats to leave if things didn't improve because he'd "had enough" and wanted his "effing life back"...

Ben was well aware of this and sat gloomily in the living room, convinced he is a disappointment to his dad. "I'm not the rugby-playing son he wanted - the boy who has loads of friends, gets into all kinds of scrapes and gets drunk" in response to my husband's "When I was your age I was out with my mates doing this, that and the other..."

Hmn...

OCTOBER 2012

Tuesday, 2 October 2012

Driving to a strangely familiar place...

Ben's been in touch with his school to see if they need any help over the coming year - and today he's gone in to lend a hand. So it was kind of strange driving back to the old place with Ben dressed in his Sixth Form suit, just like last year. Except it wasn't just like last year...

There was no stress or angst. Or exams to worry about. And it's Ben who's arranged all this, not me. So it's what he wants to do. I only hope he proves to be useful and doesn't find it too boring. I also hope he gets invited again so it becomes a regular event.

I also hope it's a way to get back in with the friendship circle from the year below, students that weren't in the firing line for the old disturbing anorexia behaviours.

And who, as a result, tend to be more welcoming and accepting than his own peer group.

Then on Friday Ben has a second interview for a (paid) weekend job with *Games Workshop*. He's already sailed through the first (telephone) interview. I eavesdropped on it and was amazed at how well he did it: so mature, so confident and so professional. Wow!

Meanwhile he has a few other voluntary job applications in the pipeline.

But most important of all, I want him to ease back into a social life. He's already met up with a few of his friends that are taking a gap year, but nothing more than that.

I'll let you know how he gets on...

Tuesday, 9 October 2012

Jobs, voluntary work and social activities...

Ben's doing really well with setting up activities for his impromptu gap year. This morning was the second Tuesday morning he helped out at school, doing a bit of teaching practice with the Sixth Form *History* and *Politics* groups and loving every minute.

He also went to a second interview at *Games Workshop* on Friday for a Saturday / Sunday job. No news yet... Plus he's applied for a couple of voluntary jobs - and taken his CV round the local shops and cafés, and those not-so-local, too. One café even got him to make a coffee to prove his barista skills!

Nothing is progressing on the social front, unfortunately. So I've set him the challenge of arranging to see at least one friend this week.

And nothing's progressing on the NHS referral front - for additional therapy to sort out the underlying food / social issues that prevented him from staying at university. So I've been in touch with some private therapists. I haven't heard anything yet

except from the dietician - the same dietician Ben saw over the summer.

In the meantime, to help things along we've tweaked our famous Contract so it's relevant to the challenges Ben is facing at the moment - mainly social anxiety challenges.

So that's it for the moment, really...

Thursday, 11 October 2012

Woo hoo! It's what makes this all worthwhile...

It's fantastic when I get an email or message from a parent of a young person with an eating disorder, or the young person themselves, about how my blog and / or website have contributed in some way towards their recovery from anorexia or another ED. I'm not saying this to boast. Not in the slightest! It's just that this kind of message makes my day, especially when I'm not feeling very motivated or a bit down.

I've been feeling a bit naff recently and you've probably noticed I haven't been blogging much. I've been feeling really low and apathetic. Kind of depressed. I've been finding it really hard to get my act together and *do* things. As a result I've spent a heck of a lot of time procrastinating and doing very little - freelance work, social life and just about everything else. I've also been sleeping very badly and having nightmares; the kind of nightmares where you wake up shouting... And now I've got a cold.

It's probably something to do with fallout after Ben's three-year struggle with anorexia. A sort of mild form of post-traumatic stress. Or at least that's what the therapist I saw over the summer thought.

And over the past month it's been "all change" as Ben comes back home after the brief flirtation with university.

I've been busy working with Ben on all the outstanding issues and encouraging him

to find jobs, volunteer and socialise - and meanwhile find some kind of therapy for him. It looks as if we'll have to go private...

But when someone contacts me with their Good News about recovery from anorexia - whether it's a parent or a young person - it makes me feel *brilliant*.

If I can be of some use in a young person's recovery from anorexia or another eating disorder, no matter how small my contribution, I am happy. Because, after all, that's why I write this blog and why I'm writing my book.

Talking about my book... That's another thing I haven't been able to focus on over the past few weeks...

I really need to give myself a bit of KUTA therapy to get me going again. (Kick Up The A*@\$ therapy.)

Thursday, 11 October 2012

Points are still winning prizes!

Ben says that the #1 thing that helped him the most over the last 18 months or so has been the Recovery Contract which we set up in March 2011. And, albeit much tweaked over the months, it's still going strong - at Ben's request. We don't do it as often... maybe once a week at the most... but it's still proving to be useful.

Following Ben's brief flirtation with university last month, challenges tend to be more about facing the things that are going to help him adjust to university life in the future, hopefully next September. Ben's keen to go back to university and is eager to do everything in his power to ensure it's a success.

So these days when we do the Contract we talk about Ben's plans for the week. We discuss what he's already done and how things have turned out, and set more challenges for the week to come.

For example this week's challenges are: To investigate becoming a singer in a band, to meet someone socially, to phone about a couple of volunteering

opportunities and to go to *Games Workshop* tonight for their weekly games evening.

He's also added in extra challenges himself, ad hoc, like doing the rounds of another shopping centre near our home to see what paid jobs are available. He's already been round scores of shops and cafés, unfortunately with no luck. But he's done his level best, armed with his CV and barista certificate.

Plus he's already working at his old school on Tuesday mornings, as a teaching assistant in Sixth Form *History* and *Politics* classes.

And we're still looking at the different options for further treatment to work on social anxiety and tie up the loose ends of the eating disorder - all the stuff that prevented him from remaining at university this year.

Getting treatment, private or NHS, isn't as easy as you would think. Both have waiting lists and I really don't hold out much hope for the NHS option, although he has an assessment on Monday.

Ben hasn't been weighed for some time now. I think it was almost a month ago. And I'm keeping quiet. He seems fine. Yes he's still relatively slim, but not skinny. In other words, the alarm bells aren't going off. Not yet, at any rate.

Friday, 12 October 2012

Clocking up more successes...

Good news - Ben did go to his *Warhammer* gaming club last night and enjoyed it. (And then came home for a plateful of *M&S* fish'n'chips with peas followed by two puddings.) Today he's talking to a local museum about volunteering. Then tomorrow evening he's going to see one of his friend's bands in the city centre. Meanwhile we've arranged to see a former CAMHS (eating disorder specialist) psychologist next week to tidy up all the loose ends.

Private, yes. But I'm hoping my dear late dad will pay for the treatment... Pretty please, mum... Otherwise it'll come out of my savings.

Ben also has an appointment for an NHS assessment on Monday, but I'm not holding out much hope there. It's only an initial assessment. Whatever he eventually gets referred to may have a lengthy waiting list and will probably be low level counselling with a finite number of sessions e.g. 10 or 12.

I had NHS counselling in the summer of 2010 when Ben was going through his worst anorexia patch and it was useless. Lots of form filling, questionnaires and taking home dozens of photocopied sheets - the kind of info I could have found on the Net. Also, you don't get to choose your therapist. It's a case of pot luck.

This is why we've decided to go ahead with the private treatment.

Last night I talked to the psychologist on the phone and she sounded great. So fingers crossed... And because she specialises in eating disorders we may not need to bring in a private dietician.

Ben wants me to be involved in the sessions, just like I was at CAMHS, and the psychologist is happy with this. I've told her about our Recovery Contract and the way it's been so successful. She also asked for a potted history of Ben's anorexia to date.

"But the good news is," I told her, "He's come out the other side. He's very keen to work on the outstanding issues - the niggly things that prevented him from staying at university, mainly on the social anxiety / integration front. Plus the odd bit of fallout from the eating disorder which came to light when he had to cater for himself and eat in student accommodation, is away from his usual eating routine and is surrounded by stored food in his room (because of lack of space in the shared kitchen). When he was discharged from CAMHS in February he thought he could handle things himself. He thought he was ready for university. But when he got there he realised he wasn't. Far from it. And he realised he needs help to overcome these issues".

Of course Ben hasn't spoken to her yet. And at the end of the day he needs to feel comfortable with her. So fingers crossed there, too...

But so far everything seems to be going pretty much to plan. Okay we're hampered by the lack of paid jobs in a recession, but - hey ho - at least there are voluntary opportunities. When I sat in that Sheffield coffee shop with Ben the other week and set out the caveats for leaving university and taking a year off, one after the other, in writing, he agreed to cooperate.

And so far he has. Willingly and admirably.

Saturday, 13 October 2012

This is what I said in Tesco's car park yesterday...

"I've been blogging about it and I thought it was time I told you to your face - I am so very proud of everything you've been doing since you left university last month. All those caveats we talked about in the coffee shop... you've kept to every single one of them - and more. And you've kept on going. There's no stopping you, Ben! Paid jobs, voluntary work, working at school, social life, clubs... you're doing it all. And you've asked for further treatment, because you yourself have admitted that you need it. Wow! I am so proud of you. I am thrilled. I am *beyond* thrilled!"

"I couldn't have done it without you, mum... I mean if I'd left university and you'd just sighed and resigned yourself to me wasting my life or something like that...."

"I haven't done it, Ben, you've done it. You've done all this stuff yourself."

"I wouldn't have been able to do it without you..."

"We are a team, you and me. A strong team. We work together like a well-oiled machine."

"But I haven't really achieved much, regarding the jobs..."

"That's not your fault. There's a recession on. And you've done really well to have not one but two interviews for the *Games Workshop* job. You would have had an interview at *Starbucks* on Monday if it wasn't for the *Starbucks* reshuffle following the other shop's closure. And you're working at school once a week. Plus, you're

actively pursuing all the voluntary jobs - only today the museum said they'd love to have you as a volunteer. Also S said there might be a vacancy going in the sandwich shop at the station. I'm impressed, Ben. Really impressed."

He gave me a great big hug.

Wednesday, 17 October 2012

Damn those scales!

It's a month since he was last weighed and he's continuing to very gradually put on weight. Now, to you and me, that's a Good Thing. It's a blooming *brilliant* thing. But - surprise, surprise - it's not Good News to Ben.

"Every time I've got on the scales recently I've put on weight!" the ED demon wailed. "How the heck am I supposed to go out and eat meals and stuff when I find I'm putting on weight so fast?"

I'd avoided the scales for weeks. But, to be honest, I was worried he might be *losing* again. So I reluctantly agreed to weigh him.

I wish I hadn't.

Damn, why is it still such a Big Deal to him at this late stage of recovery? Should I allow him to cut back so he maintains rather than continues to gain? And possibly risk a downward slide? Bin the scales? And not know whether or not he's losing weight? It's a Good Thing we've booked some sessions with our new ex-CAMHS psychologist (who used to specialise in eating disorders before she went private). I'll call her Dr Joanne here, so you know who I'm talking about over the coming weeks.

I know there are other issues bothering him, too. Mainly because, despite really trying hard, he's finding it hard to find things to do during the week.

He's working at school on Tuesday mornings, and - hopefully - he'll continue his *Warhammer Club* on Thursday evenings and Saturday afternoons. But he's still not met up with any of his old friends (he didn't manage to go and see his friend's band

on Saturday). He's still not heard about the *Games Workshop* weekend job or any of the voluntary posts he's applied for, despite following all of them up several times. And, even though he's taken his CV round to scores of local shops, bars, cafés, etc - he still can't find any paid work. So, not surprisingly, he feels quite deflated and down. Which is probably why he was prompted to weigh himself... Damn those scales. Damn the legacy of the eating disorder.

Wednesday, 17 October 2012

This is what I used to think in the olden days...

I used to think: Maybe we should watch more news reports about children starving in Africa? Children who would do anything to be able to get food? Or get him involved in Good Deeds like working with the disabled or underprivileged? Maybe that'll make him realise that some people have more to worry about in life than whether or not they might have put on a nano-kilogram and - pow! - their life suddenly isn't worth living.

That's what I used to think in the olden days.

I used to think that eating disorders were selfish - that the young person with anorexia or bulimia was vane... over-obsessed with their appearance. Good God, let's watch some TV programmes about people with disfigurements or terminal illnesses. That'll stop them thinking about themselves all the time and make them see sense. Selfish boy (or girl)... Can't he / she see what they're doing to us, his / her parents? Let's break down in floods of tears in front of them. Surely that'll make them realise what they're doing?

That's what I used to think.

Look at all the terrible things that depriving your body of healthy, life-giving food can do! The way your internal organs suffer... the way your skeleton can take on the bone density of someone decades older! Listen to this as I read aloud to you about all

the horrible things you could be doing to your body. You say you're "eating healthily", but - hey - look what you're really doing to yourself! That'll make them see sense and knock this on the head.

Yes, that's the sort of thing I used to think.

"That's the trouble with him," my H would say (and still does occasionally). "He's had everything handed to him on a plate. A private education. Material goods. A loving, supportive family environment. Things many other young people would give their right arm for. He's selfish. What he needs is a good firm kick up the ar*e."

Ah, if only eating disorders were that easy to resolve...

Thursday, 18 October 2012

If it worked for me, it might work for him...

Back in 1975 when I was in the Lower Sixth Form at school my own mental health took a nose dive, although in those days it went undiagnosed. For two whole school terms I hid from the world, unable to interact with my peers. I was rock bottom depressed, suicidal at times, and used to self-harm (not a lot, but a bit).

I'd flee from social situations and lock myself in my bedroom. I'd avoid school wherever possible with a long list of "illnesses" that meant I had to stay at home. And when I had no choice but to go to school, I pleaded with my mum to let me come home at dinnertime so I didn't have to face socialising. At break times I'd hide behind the lockers or take refuge in the art room. It got to the stage where I couldn't even sit in class comfortably - the urge to flee and hide was so very strong.

As the months went on things became even worse. I'd have sudden extreme angst outbursts - at home and at school - a bit (or a lot) like ED rages. I remember my mum collapsing in a heap of tears, several times, with my dad shouting: "Look what you've done to your mother!"

In those days, I was accused of being selfish - of being too introspective and self-

obsessed. That, according to the GP, was the problem.

I drove my family to distraction - and in the end they brought in a counsellor who visited our home in an attempt to turn things around and take my mind off my “own problems and think of other people” instead of myself.

I don't remember any of what she said or did - except the suggestion that I join a club called PHAB, for physically handicapped and able bodied young people. As their current website says: “It is a social gathering for people with a physical or mild learning disability together with able-bodied friends... PHAB's aim is to promote and encourage people of all abilities to come together on equal terms, to achieve complete inclusion within the wider community.”

So, extremely reluctantly, I went along to PHAB for their Friday evening get-together.

It wasn't a success. Not at first, at any rate.

The urge to flee was so strong that I'd charge across the large meeting hall and lock myself in the toilets (bathroom) for the rest of the evening. And I did this week after week, until the person in charge persuaded me to come out.

I remember pouring my heart out to her in her office; everything that had been going on with me over the past months. I felt hugely vulnerable and almost “naked” confessing everything to a complete stranger. Depressive illnesses like this are such a private thing.

Within no time she'd discovered I played the guitar and arranged for me to teach a group of disabled girls for half an hour every Friday. After that, I could flee back to the toilets if I wanted. “But, hey, actually I notice you're good at art - and we need someone to take charge of publicity. How about joining our committee and getting involved? Or maybe you could sit on the door and take subscriptions at the start of the evening? We're desperate for help...”

And the rest, as they say, was history.

Of course it wasn't an instant transformation - but gradually transform I did. By the

summer I was part of the “in crowd” that sat on the table at the back of the hall. We took turns in taking subscriptions. I organised publicity and helped with fund-raising. One of the older girls who had her own flat threw an 18th birthday party for me. I went from strength to strength.

PHAB still meets on a Friday evening - same time, same place. And at 3am it came to me that it wouldn't do Ben any harm to give it a go.

And, like I was, he would be required to stick it out. Back in 1975 if I'd had a choice I'd have done a runner after my first visit, second visit or third... But I was told I had to stick it out. And I did.

Now I'm not saying that I think PHAB would be good so “selfish” Ben can “think of other people's problems instead of his own”. I know that's an out-dated way of thinking. I think it might be good because places like PHAB are far more accepting of people with “issues”, whatever those issues may be. And, if it's anything like it was in my day, they'll work actively to help the young person integrate and be useful. Plus, it will get Ben out of the house and into a social situation. It might just work. It's worth a try at any rate...

Monday, 22 October 2012

Moving forwards still...

Last night I looked at Ben and, for the first time for years, I felt I was looking at the “old Ben”. And, thankfully, he seems to have come to terms with the slight weight gain and appears to be continuing to eat as normal. He didn't get the *Games Workshop* paid job, but he's agreed to volunteer as a helper at the PHAB club on Friday evenings.

We went along to PHAB on Friday. It was strange to be back there after 36 years. Mind you, it wasn't the same building - the original and another since then have been burned down over the years... It was pretty scruffy and run-down, but it was still

PHAB. And it was still run by this amazing woman called Ann who must be well into her seventies now, yet is still rushing around organising and motivating people like someone 40 years her junior. In fact I was mega impressed with Ann - the kind of selfless person that's 101 per cent dedicated to what she does, like the people you get on *Secret Millionaire* on the telly.

The other volunteers seemed great, too. As I said to Ben: "There's much more chance of meeting people like you there. After all, if these people were the clubbing / getting drunk sort then they'd be out clubbing and getting drunk on a Friday evening, not taking time out to help at PHAB."

Ben is still chasing up the other volunteer openings. Incredibly no-one has got back to him, despite him nagging them. However he's also arranged to work at the charity shop again on Thursday and Friday mornings, mainly for something to do. And he's chasing up the few friends that are still in our city (i.e. not at university or overseas on a gap year) to see if he can meet up with them.

On Friday morning we met with our new psychologist, Dr Joanne, who seemed to be really good. I wasn't sure whether Ben agreed with me, judging from the fact he refused to speak to me afterwards. But, then, Ben was always like that after CAMHS sessions before brightening up later on in the day. Once I managed to get him to speak he said: "I feel about as sh*t as you can get. I feel like doing myself in."

Fine... "Don't you say things like that to me," I replied, "Not after all we've been through, you and me". The main thing that was getting him down was his relationship with his dad, which came out at the session. He feels that he's not "the son my dad wanted"... "the going out and getting drunk, rugby playing, getting into trouble kind of son".

"Do you really think your dad would have wanted a son like that?" Dr Joanne asked. Also, he worries that his dad thinks he's sitting around doing nothing when he's actually doing his level best to find work, etc. But once I'd managed to get him to talk about it, he seemed fine. Anyhow, he's seeing her again a week today - to work

on easing him into university in September. I don't just want him to "muddle through" university; I want him to thrive there. So that's what we'll be working on. Meanwhile, it was my birthday on Saturday - and Ben cooked a surprise three-course meal for six. It was amazing!!

Saturday, 27 October 2012

PHAB is a success

Last night Ben went to his first PHAB meeting and had a really great time - which is excellent news when our #1 priority over the current 12 months is to get him out there into the community and help him re-learn all those social skills he used to have before the anorexia hit.

So this week he's done the usual Tuesday morning volunteering as a classroom assistant at his old school, Thursday and Friday mornings in the charity shop and Friday evening at PHAB. Plus Thursday evening playing war games at *Games Workshop*.

And then on Monday we've got our second meeting with Dr Joanne to work towards re-entering university next September.

Meanwhile I'm not too sure about Ben's idea about commuting to university next year. Yesterday I did a "dummy run" because I was meeting a friend in the same city and, to be honest, I wouldn't want to do that bus + train + tram run every day, especially if I only had one lecture...

A better idea, in my opinion, is to work out some way of Ben living at university with the option of coming back home if he needs to, maybe at weekends to begin with. Two of his close friends are starting at the same university in September, so there is the possibility that he could get an apartment with them which would be a great way to ease him into things.

But, hey, that's a long way off - and things are moving so fast here on the

“everything” front that we can’t predict what will happen.

The excellent news is that everything Ben and I agreed when we sat in that little café on the second day of university, when Ben pleaded with me to come home, is being done: additional treatment, new social challenges, jobs (albeit voluntary, but who cares) and general independence.

His mood has had some serious dips, but much of this - I think - is because of the length of time it’s taken him to fix up voluntary work plus the fact there isn’t any paid work out there.

He’s been round virtually every shop and café in our area - and beyond - and there’s nothing.

And voluntary jobs have taken *ages* to get back to him, which is why he’s decided to go back to the charity shop, and why I felt that PHAB wouldn’t be a bad thing to do. But in general everything is *good*.

Sunday, 28 October 2012

Why do I attend Ben’s new psych sessions?

Once we’d arranged to see Dr Joanne, the new psych, I asked Ben if he’d like me to sit in on sessions “as an observer and occasional contributor” or if he’d like to see her alone. Frankly I didn’t mind which. Since Ben turned a corner in October 2010 we’d always seen CAMHS together because, as Ben said, we were working on this “as a team”. And Family Based Treatment has been proven to be more effective than individual therapy. But, at this stage and at his age, I recognise that he needs to become more independent - indeed it’s essential that he does.

Ben insisted he’d like me to be there. “After all we’re still very much a team,” he said. “You being there will save me the hassle of explaining to you what was said and done. I want you to know what was said and done because, without this, how can we continue to work together as a team?”

Fair enough. For the time being at any rate. At least for this week's session.

But, if at any point, it becomes clear that my presence is superfluous or Ben doesn't want me there, then I will stand aside. Indeed I plan to be less and less involved to enable him to become more and more independent - especially as he will need to be able to manage any therapy independently once he returns to university. This is part of The Big Plan. And, of course, being 18 Ben has the legal freedom to refuse to involve me if he doesn't want to.

So at the moment I'm sitting in on the sessions. Time will tell whether I will continue to do this or not. Like everything in the way Ben and I have worked to rid him of the eating disorder, it is flexible and can be adapted to suit the stage we're at.

One thing I am good at doing during these sessions, however, is getting any discussions back on track when things digress or go off on an irrelevant tangent. Kind of like being in the chair at a debating society.

We're seeing Dr Joanne tomorrow morning to discuss what areas need work - with a view to dealing with the remnants of the eating disorder and easing Ben back into "normal life" and successful re-entry to university in September.

Monday, 29 October 2012

Dr J gets to the heart of the matter

So far I like everything about Dr Joanne (except the fact she is so expensive!). Her background is CAMHS - not from our city but from a neighbouring town. I only wish we'd had her as Ben's therapist from Day One. Within 20 minutes or so of our (second) session with her today she'd got right to the heart of the matter i.e. the key problems that still remain from the eating disorder.

Although Ben has been moving forward on so many fronts - and we all give him credit for this - there are still some niggly issues and they are things that could prevent him from complete recovery, or at least make complete recovery far slower

than it needs to be which risks messing up even more of his life than the eating disorder has messed up already.

These are sticking points that came to light when Ben dropped out of university last month. Mind you, they are things I was already aware of which is why I always say that Ben is “almost” recovered rather than “completely” recovered.

Today I was reminded of the day when CAMHS said, “I’m happy to settle for ‘good enough’ if you are, Ben,” as we approached discharge from their services because of Ben’s age and the fact our psych was leaving.

Big Smiles all round. Except for me, that is. As I said to Dr Joanne last week, “‘Good enough’ isn’t ‘good enough’. ‘Fully recovered’ is.”

Subject to Ben agreeing to continue treatment with Dr Joanne they will be working on the eating issues that are preventing Ben from resuming a full life - the way he still needs to structure his evening eating in a certain way i.e. main course of the main meal at 7pm, pudding at 8pm and snack at 9pm. Okay these days it’s not as rigid as that. But it still makes it difficult for him to go out in the evening or alter his evening routine too much. And it got heavily in the way during those few days at university.

They will also be working on the way Ben still thinks about food pretty much all the time, over and above most other things. Also the way he is worried about putting on any more weight. “I have a wardrobe of clothes I can’t get into now,” he told her. “Also, when I went out for a run the other day someone shouted ‘Run fat boy run!’ to me. Why would they do that if I wasn’t putting on weight? I think about food all the time. I keep wanting to eat i.e. snack over and above my calorie limit [he still counts calories which is another sticking point...] and then I feel greedy.” He used the word “greedy” a few times.

He is worried that his weight will spiral upwards out of control. Yet at the same time he is worried that if he cuts back on food it will do the opposite and risk dragging him back down into the eating disorder. “So I feel as if I’m between a rock and a hard place,” he said.

“Can you tell in advance if you’ve put on a kilo?” she asked.

“Oh yes,” he replied. “And I feel cr*p. I have a naturally big frame, you see, and so a little bit of weight makes me look far bigger than I actually am. I also have a round face which looks worse if I put on a bit of weight. When I was a few kilo lighter my features were much sharper and I preferred that.”

Hmn, I could see Dr Joanne thinking. “Do you think I would be able to notice if you put on a kilo?” followed by: “What we need to do is to work on getting you from ‘here’ to ‘there’, from where you are now in terms of rigid thinking, food and weight worries, etc to a position where you don’t worry and are sufficiently free of the anxiety and restrictions to allow you to resume the kind of life you want to lead - and the kind of life you would need to lead to have a successful time at university. We don’t expect change to happen overnight, it needs to be achieved in small manageable steps - like you did before, with CAMHS, where you made a small change and then adjusted to it before making another small change. Although you might think you haven’t come on very far over the past few months and feel in a bit of a rut I suspect that if you compared where you are now with where you were then you would see quite a big change - a positive change. And you are already doing so many positive things, like the voluntary work, PHAB and so on.”

I nodded my head in agreement.

Don’t get me wrong, these aren’t massive sticking points. Not massive when you compare them to the enormous sticking points we’ve had to overcome in the past, and I believe Ben is completely able to accept what she says rather than rebel against it as he would have done in the Bad Old Days. We are at a very different place, a much better place. It’s just that I am aware that there are still several sticking points - issues that need ironing out so that one day soon we will all know in our heart of hearts that Ben is “completely recovered”. And when Ben is completely recovered he will be able to resume a normal life again, like the life he led before the eating disorder struck. Fingers crossed Dr Joanne will be able to help tidy up these loose

ends and lead Ben towards full and permanent recovery. If the money doesn't run out before then. And if Ben agrees to continue seeing her.

Wednesday, 31 October 2012

In two minds, need to have a chat with Ben...

Okay so Dr Joanne "got it" very quickly the other day but I've been mulling things over and keep going back to the time when, near the end of Ben's CAMHS treatment, I felt as if the therapists were simply opening can after can of worms rather than actually helping to move things forward.

Now, this wasn't their fault. It had probably just reached the natural end of what they could do for Ben. Together he and I have always been very good at devising our own ways of moving forward, for example the Contract and our regular walks / talks. Bringing in a third party that doesn't know us is almost like an educational exercise - of them, not us. And in the process it means that Ben is having to go back to places that are quite dark - places he may wish to move on from and never re-visit. So, if this is the case, any therapy could work against Ben rather than in his favour.

Okay so we are very fortunate that Dr Joanne "gets it", especially in a therapy world where so many people just don't "get" modern evidence based eating disorder treatment. But she is never going to "get it" as much as we do, purely and simply because she is a third party. It's not her fault, but that's the way it is.

Of course in the Bad Old Days Ben - and other young people with eating disorders - need treatment. Lots of it. But in our case especially I wonder whether we can actually work on these outstanding issues ourselves rather than needing to involve a therapist?

I'm in two minds about this. Part of me says, yes, we need Dr Joanne's services - and I am extremely impressed with her, she's great! But another part of me says we probably don't. We can do it on our own, just as we've been doing since Ben was

discharged from CAMHS in February.

Dr Joanne did say that some people find it more helpful to “dip in and out” of her services rather than sign up for a set number of sessions. Especially, in Ben’s case, later in the year when he nears the time when he will be thinking about whether or not to give university another try - this is when her services might be more appropriate or useful, working on the social skills and giving him a “toolkit” to cope with the myriad of different challenges he will face at university. And by that stage he will hopefully have moved on from the various eating disorder fallout issues that still remain.

So I need to have a chat with Ben about it, about how he feels. Although our session the other day revealed a bundle of outstanding issues that still need addressing, I also wonder whether Ben was actually dealing with some of these in his own way, quite successfully. And it’s something that, if monitored over the next few months, might happen naturally.

This is what I’ve been mulling over since I wrote the last blog post.

Watch this space...

NOVEMBER 2012

Thursday, 1 November 2012

What “they” don’t tell you about Weight Restoration. Or maybe I missed it?

Getting your child through an eating disorder is damn tough, we all know that. But what happens when they reach their set weight / weight restored level?

What no-one ever told me is how your child is supposed to come to terms with it once it happens. Their weight is okay, but obviously it’s been going up for some time. What if it continues to go up? What if it never stops? That’s the kind of fear that’s spinning around their head.

CAMHS always said to Ben: “Don’t worry, we’ll never let your weight spiral out of control once you are weight restored.”

Fine.

The trouble is, when that finally happened - i.e. within the last month or so - CAMHS were no longer around. Ben was discharged in February because he was 18 and because the psych was leaving.

And, for two years now, Ben has been eating with a view to weight gain. His weight has gone up and down, as you would expect, but the general trend has been upwards, especially over the past few months. So much so that he now looks just like the old Ben. Without the seven-days-a-week training / rugby physique (because exercise became a compulsion, so he’s had to keep it to the bare minimum), but definitely absolutely fine.

He is finding it very hard to come to terms with where he is now. He loves food and doesn’t want to eat less than he’s been doing. Yet something inside him (the “anorexia demon”?) is telling him that if he continues like this he will continue to pile on the pounds and get fat.

In his mind, his weight gain diet was restrictive. In other words, he would like to have eaten even more than he did. And the prospect of eating less than he’s eating now in order to maintain his weight has sent his mood plummeting.

The experts always said that Recovery is all about getting to a place where you don’t think about things like this any longer. Food begins to take its normal place in everyday life rather than dominating it. Gaining the odd extra pound or two is no longer a worry. But what “they” didn’t say is how you get from where Ben is now - weight restored (although some, like me, might dispute that) and anxious about continuing to put on weight - to where he should be - weight restored and content.

A bit like in the Bad Old Days, right at the start, when “they” tell you your child has to eat cream cakes and custard, etc in order to put on weight, but fail to tell you how the hell you’re supposed to get cream cakes and custard, etc past their rammed-

closed mouth.

So I have put a post on the Around the Dinner Table forum to see how other parents of young people recovering from eating disorders coped with this stage.

Watch this space...

Friday, 2 November 2012

Excellent suggestions from the other ED mums

I knew I could depend on “my mums” on the Around the Dinner Table forum to rally round with advice. It’s months since I posted anything - I haven’t needed to - but it’s the good old mums who “know me” who responded, the mums who were immensely helpful when I first joined. So, coupled with my own gut instinct, this is what I plan to do...

For the time being we’re putting Dr J “on hold” and seeing if we can bring in the private dietician we saw back in the summer. Ben got on very well with her. He liked the “scientific” approach far more than the “talking therapy” approach. Science equals indisputable facts. Talking therapy equals airy fairy boll*cks.

In his opinion at any rate.

Also, a dietician might be the right person at the moment given that he needs to be convinced that his weight won’t spiral out of control now that he’s (almost) weight restored. He needs to know the science about why his body will be changing at his age, and will continue to change for some years to come, and why this may mean weight gain. It’s perfectly normal, because bodies change as we grow older and become adults. Teenage boys “bulk out” into men. The weight increase is usually down to muscle rather than fat - and it’s a natural thing. You can’t stop yourself turning into the adult you are meant to be. You can’t hold back time. Just as I can’t stop my middle-aged body turning into a post-menopausal body, *sans* waist! It will happen, whether I like it or not! But, in Ben’s case, it doesn’t mean his weight will

spiral out of control given that he's not exactly over-eating.

The dietician talked about this last time we saw her. I believe a little more discussion on this topic wouldn't go amiss right now.

Also more talk about how the body behaves once it's reached its "set weight" - and how this is the weight it will always attempt settle at, whether that's up or down. And how, over the first year or so of being weight restored after a lengthy period of starvation (as with anorexia), the body takes quite time to "settle down". During this time the weight can spike up and down quite dramatically as the body gradually adjusts to a set weight where it attempts to stay.

Or something along those lines.

In other words, from what I remember the dietician saying earlier in the summer, once you reach your set weight and you've been that set weight for 12 months or so, there's far, far less likelihood that your weight will suddenly shoot up, or shoot down. It will stay around the same level.

And the more it stays around the same level, the more the post-anorexic brain gets used to being like this.

This is my interpretation of what the dietician said earlier in the summer, at any rate. And I'd like her to go into this again with Ben, to help put his mind at rest and help him move forward without anxiety - and with less risk of relapse as a result of the fear and anxiety of his weight potentially spiralling out of control.

It was one of the mums on the forum that suggested we bring in a dietician again. And the more I think about it, the more sense this makes. Other mums agree, too.

Oh, and I forgot to say, when I weighed Ben this morning (for the first time for three weeks or so) his weight was static. Unsurprisingly, his mood has lifted quite a bit...

Monday, 5 November 2012

Am I still angry with the church?

Am I still angry with the church about the way they failed to embrace Ben when he was crying out for friendship and support last year? Do I still feel the bitterness I felt in March when I wrote a blog post explaining why I felt the church had let him down?

Thankfully Ben has come on leaps and bounds since then without the support of the church. And, despite a brief period of announcing he no longer believed in God, he does still has a “faith”. He still believes in God. In fact he says if it wasn’t for his faith he wouldn’t be here today. In other words, he might have taken his own life. Seriously.

Yet, for the past eight months or so, he has come to the conclusion that he may never find the support he needs in the church. In a way “the church” and his “faith” aren’t one and the same thing. He remains incredibly disillusioned. And I remain incredibly sad that the church failed to take action and give Ben the love and support he so desperately craved from them. And disillusioned, too. Disillusioned enough to have no desire to return to church. That church or any church. Because I felt the previous church let us down, too. Or let me down, should I say, because - back then, at the time when Ben was disappearing down the rabbit hole so quickly - it was me that so desperately craved friendship and support.

The other day the pastor left a voicemail message asking how Ben and I are getting along. He has no idea we feel the way we do. And I haven’t heard from him since my dear friend Sue’s funeral back in May.

So I’ve arranged to meet with him and will be there in an hour from now.

What I am going to say at this meeting I have no idea. I just want to explain why we haven’t been there for so long, but I want to do it in a nice way, not in a bitter and twisted way.

But I really think he should know.

Watch this space to find out how I get on...

Tuesday, 6 November 2012

Church meeting went well

I wasn't asking for anything. I wasn't expecting anything. I just explained that I felt I owed it to the pastor to explain why we suddenly disappeared from the church and why we haven't been back since. And he seemed to appreciate my honesty.

I wasn't bitter or angry, just pleasant, relaxed, open and honest about how Ben felt the church had let him down. As a result I'd been angry with the church back then. Ben had trotted along to church religiously every Sunday morning for over a year yet they failed to reach out to him.

I explained - for the second time, because the first time was the time that Sue and I went to see the pastor earlier in the year - that, because of the legacy of his illness, Ben finds it very hard to make social overtures himself. He's not the kind of guy to run up to people, slap them on the back and announce: "Here I am, guys!!" Not by a long shot. He needs people to reach out to him. He needs to feel involved and needed. Yet, one day, all this trotting along to church just got too much for him. He was doing all the giving and getting side-lined while the youth group got on with things in the way they had always done.

"You see Ben isn't like the others," I explained. "He didn't grow up in the church with a family that went to church every Sunday. Attending church was something that was very new to him and he went of his own accord rather than through 'habit' or family pressure. He wasn't clued up on the 'ways of the church' like the other young people are." In other words, he was an outsider. "He also had his own very strong beliefs which sometimes clashed with the standard doctrines of 'the church'. Yet to him they were - and are - very real. On the few occasions he voiced them, he felt as if he was being shot down in flames."

I went on to explain that we both still have a faith. "But we just don't seem to get

along with 'the church' as such. We're just not 'churchy' people and don't seem to be able to find what we are looking for or need in the established church." Thinking of the Friday night PHAB club, it was clear that Ben has been made more welcome in secular organisations. They are giving to him what the church failed to do.

We also talked about my friend Sue who passed away in May and how, without her around, coming along to church was so much more difficult for me. When Sue wasn't there, few people talked to me - or to Ben. Often I'd arrive home feeling worse than when I set off which isn't the way church should be. It was the same in the other church - the church I went to before I came here. Worse, in fact, which is why I left. Back then, it was me that was crying out for help and support. Ben was going through a very dark patch. Yet no-one seemed to "get it" or wanted to "get it". They backed off and it was all polite conversation or discussions about praising God, evangelising, doing good and helping the needy in third world countries. Yet here was someone right in their midst who was needy - for very different reasons. Yet they failed to recognise it.

So the conversation was a bit about Ben and a bit about me. "I don't really know where we go from here. I don't expect or want you to do anything, as such. I just thought I owed it to you to explain where we've been all these months – and why."

And he seemed to appreciate that.

It hasn't changed the way I've been thinking about the church over these past months. I didn't expect it to. I just feel that it's one more thing that's ticked off my "to do" list.

I don't feel guilty any longer. In fact I don't really feel anything.

Thursday, 8 November 2012

I'm keeping quiet and quietly observing...

Remember I said Ben was finding it hard to come to terms with weight increase? I

haven't said anything to him since we last spoke about it... and he "effed" and "blinded" about it... I'm just observing. Ever since he weighed himself and discovered that his weight had maintained for three weeks rather than increasing further, his mood has been much, much better. In fact his mood has been pretty darn good, really.

Of course it might have nothing to do with the weight maintenance. I haven't approached the subject. I think it's better to keep quiet. I don't want to open any cans of worms. He might just be going through A Good Patch.

He's been out and about socialising quite a bit. Friday was PHAB club, Sunday he met up with old school friends for a meal at *Nando's* and Monday was Bonfire Night - two of the girls from PHAB invited him to a fireworks display in a park near where they live and he had a really great time.

He's been in touch with an old school friend who's doing a gap year in Africa to see if she would like to share a flat with him at university in September - and she's said yes. That will make it easier for him to ease into university. She's a lovely girl - quiet and shy like him, so it will probably make her introduction to university easier to handle, too. They both love cooking and eating similar food, and have a similar philosophy on life. Before the eating disorder came onto the scene three-and-a-half years ago they used to be an item. But they split up because both were too shy to make the relationship work! Oh, and her family moved to another city after Year 11. But they've remained the best of friends.

Meanwhile Ben's been working at school for two mornings this week and is back at the charity shop today and tomorrow - and at *Games Workshop* tonight playing *Warhammer* games, then PHAB on Friday evening. And on Saturday morning he raised £50 collecting for PHAB outside our local *Marks & Spencers*.

The psychologist sessions are still "on hold" and we've arranged to see the dietician in December (she can't see us before then). So hopefully we can work on the food / weight issues that still bother Ben. Famous last words... but all in all things

are looking pretty good. And so is Ben. I just love the way his face and body finally looks much as it did before the eating disorder struck. I do hope he is coming to terms with what he sees in the mirror and the way his clothes fit, because he looks wonderful! Oh, and I forgot to say, he has volunteered to appear on a *BBC3* programme about body image later in the month. Watch this space for more details...

Sunday, 25 November 2012

How shall I begin to describe the FEAST(UK) conference?

I've just returned from two amazing days surrounded by caring parents, professionals and the Great and the Good (and the Positively Awesome) of the UK Eating Disorders world. I can't even begin to describe what we learned and discussed, it would take far, far too long.

So here are some bullet points based on what shone out of this conference for me - not just via the talks, presentations and workshops, and the panel questions-and-answers sessions, but by me talking to other parents about their individual stories:

- ★ Eating disorders are biologically-based brain conditions i.e. the brain is “wired up wrong”, thought to be genetically based. Although environmental factors might trigger eating disorders, they don't *cause* them. And most important of all, parents are not to blame.
- ★ Successful treatment focuses around food first (re-feeding) and brain second - not the other way round.
- ★ Given the right treatment and support, full recovery is possible and there is no reason why anyone shouldn't recover from anorexia, bulimia or any other eating disorder.
- ★ Eating disorder treatment in the UK is a post-code lottery. We heard about the

Good, the Bad and the positively Ugly of UK eating disorders treatment - from the delegates themselves.

- ★ From what delegates were saying, it appeared that far too many treatment teams are following outdated methods. Imagine if this was cancer? Imagine if clinicians weren't keeping up to date with the latest trail-blazing advances in the world of cancer research and treatment?
- ★ It appears that GPs receive very little training about eating disorders yet they are usually our first point of contact as parents. Crazy.
- ★ From what delegates were saying, all too often families are not being taken seriously at GP level and had to fight for their child to get referred for treatment.
- ★ Once referred, the waiting list for NHS treatment is often far too long. Correct me if I'm wrong, but I think we personally must win the prize for the longest wait at 18-22 weeks for an initial assessment, let alone treatment? (Although, as you know, we were eventually fast-tracked into treatment when Ben ended up in the cardio ward with a pulse rate of 29bpm.)
- ★ Delegates discussed how the quality and delivery of NHS eating disorder treatment in the UK appears to vary wildly. Dangerously so, in some cases.
- ★ All too often patients appear to be getting discharged too early especially in the case of 17 or 18 year olds who have reached the age limit for CAMHS treatment. Many are being left high and dry.
- ★ Parents are having to fight too hard to get (a) treatment and (b) good and effective treatment. You shouldn't have to fight for this while you are fighting to save your child's life. You shouldn't have to fight for prompt, good and effective treatment, period. I heard some horror stories, I really did...
- ★ Young people are dying. Needlessly dying. But the alarming fact is that they are dying. I talked with one parent – a nurse – who had been with a young person during the final hours of the illness. It broke her heart.

★ And yet learning about what works and what doesn't, and the ins and outs of eating disorders, can be so very simple. We know because we've just spent two days doing this via a range of speakers including Professor Janet Treasure, Gill Todd, Susan Ringwood of *BEAT* and a host of others who rank amongst the world's best when it comes to successfully treating eating disorders through to full recovery.

We listened to presentations and talks, heard about the latest research, listened to parents' testimonials, heard about highly successful support groups that are springing up across the country (albeit all too thinly spread and even more thinly funded) and underwent a series of practical workshops that got us all thinking about how we, as carers, can successfully help our children recover from this devastating illness.

Okay, it's probably not *that* simple - but I, personally, learned enough over those two days to know what works and what doesn't.

Just knowing what doesn't work is vital, I believe, because all too often our children are being given outdated treatment - and / or GPs aren't identifying the eating disorder when first presented to them.

I believe that the children of those parents that were able to come along to the FEAST conference and learn all this stuff have an excellent chance of being helped towards recovery by informed and trained parents.

But I worry... no, it makes me angry and furious... to think that all this education might be messed up by eating disorder professionals that are still following Stone Age treatment methods, not to mention serious underfunding, especially when it comes to establishing support groups for parents and children.

All we need to do is get clinicians and the NHS hierarchy to undergo similar education and our children's eating disorders could be dealt with effectively and permanently, and no-one need ever die.

All we need to do...

In an ideal world...

Friday, 30 November 2012

And the Super Challenge of the Day is...

... For Ben to successfully manage working in the local deli / café over the Friday lunchtime shift today, to still eat the right number of calories and to go to PHAB this evening. Why do all three things add up to Super Challenge of the Day at this stage in Ben's recovery from anorexia? Here's why...

This week Ben began his first paid job in the local deli / café. So far he's done a morning shift and an afternoon shift, but today is the first lunchtime shift. And - because it's Friday lunchtime, the busiest day of the week - it will be a baptism of fire. But not only for the reasons that "normal" people might assume i.e. coping with the stress of working in a busy café on their busiest lunchtime of the week.

Ben didn't sleep last night. The old familiar insomnia was back as his mind did somersaults through the dark hours working out how he was going to manage his eating given that he's working 10am to 2pm and will also need to have an early evening meal in order to get to PHAB on time.

Not only this, but he'll be surrounded by people eating and the urge for him to stuff his face with food, too, will be strong - not to mention the out of control feeling that, if he did, he might not be able to stop. And meanwhile he needs to ensure he gets some proper lunch of his own at some point.

Okay, he's coped with people eating and buying food on the other shifts – after all, it was his personal choice to apply to cafés for work - but lunchtime is different, especially Friday lunchtime. The urge for "flight" will be incredibly strong... And he knows that if he does, then his new job - the paid job he fought so hard to get - will be in jeopardy. Not to mention the fact that this kind of issue, at this stage in his

recovery, bothers Ben a lot. “Fight” instead of “flight” will be difficult.

Being tired as a result of no sleep always sends his mood plummeting. And I anticipate he will attempt to get out of going to PHAB this evening, using the excuse that he’s tired and he needs to eat his evening meal later than 6pm. (Ben still feels more comfortable eating at or just after 7pm.)

So the Super Challenge of the Day, I told him, is to get through today, doing everything that needs to be done.

In life, I said, he will be faced with days when he can’t have lunch at a set time and in a comfortable, cosy environment. University lectures might run over lunch, so might business meetings and so on. Having your lunch “on the hop” is a skill he needs to learn in order to cope with days like these. And today is a great opportunity to practice.

I told him I will be immensely proud of him if he manages it all - and I’ll give him extra “points” (our Contract). The anorexia has stolen so much from his life already, I told him, it’s time to fight back and show the world (and himself) that he can stick two fingers up at the remnants of the eating disorder, especially at this stage in recovery.

Meanwhile, Batty is anxious. But Batty mustn’t show any anxiety should Ben not manage to see the Super Challenge through. Batty must remain calm, collected, positive and supportive using all those skills learned at the FEAST conference last week.

My latest mantra is “What Would Gill Todd Do?” (or say). Those who were at the conference will know that Gill Todd is the most awesome coach when it comes to teaching parents and carers the skills to deal with their child’s eating disorder. The kind of skills / comments / questions that have been proven to work.

And never forget that if it doesn’t turn out and Ben needs to go through this experience again, he will have learned from whatever the outcome is today. As Gill said, sometimes you feel as if you’re simply going round and round - revolving doors -

yet never forget that every time you get back to a certain point both you and, more importantly, your child will have learned something from this experience last time round.

DECEMBER 2012

Saturday, 1 December 2012

Tired, but bursting with “endolphins”

One thing that made us all giggle at last weekend’s FEAST conference was when we were talking about the good endorphins that people get from doing exercise. Except that one mum got her tongue twisted and came out with “endolphins” instead which made everyone laugh - because we’d been talking about the different animal personae that carers adopt - Janet Treasure’s “dolphin” being the ideal analogy i.e. you guide and encourage your child slowly, gently and discreetly through the rough seas towards recovery.

By the end of yesterday I was bursting with “endolphins”. I was tired; I’d been incredibly anxious all day but was keen not to show it. All Ben saw (hopefully) was a calm “dolphin” who was encouraging him to face his fears and get through the day.

And I’m delighted to say he managed it.

Yes, he found it difficult working on a busy Friday lunchtime shift, surrounded by people eating fantastic food. But he managed to structure his own eating around the shift - and get through it. For a while he tried to get out of going to PHAB in the evening (“Mum, do I have to go to PHAB?” “Yes you do.” “What if I can’t move by then?”)

But he went to that too - and had an early evening meal with puddings and snacks when he got back home at 9pm.

On the way back from PHAB I adopted Gill Todd's "affirmation"-style talking, learned last weekend. "I'm aware how difficult today was for you, Ben, but I just thought I should let you know how proud I am of you that you did it." etc.

And today Ben is fine.

Tuesday, 4 December 2012

Ben is no longer working in the deli / café...

Okay, so what happened? Ben was asked to work Saturdays but told the owner he couldn't because he has a medical appointment on Saturday mornings. But he didn't feel he could tell her what the appointment was for (he's seeing the private dietician for a few sessions). I don't think the owner believed him because she insisted on knowing what the appointment was for. But he didn't want to tell her. He arrived home quite upset, declaring that he never wanted to work there ever again...

Nothing we could say would persuade him to re-consider. So he went to see her today and explained he had a "mental health issue" which he is receiving treatment for on Saturday mornings. He wasn't specific. She wasn't too impressed. So they parted company and he went back to the charity shop to offer his services again, just like he was doing before he got the deli / café job - plus an extra shift on Sundays in the run up to Christmas.

And so endeth Ben's first paid job!

Wednesday, 5 December 2012

It could be seen as discrimination, but...

Ben is adamant that he doesn't want to return to the deli / café to work. He says he couldn't work for someone that is obviously so unsympathetic about his condition. Mind you, I said, she doesn't know the full story. I suggested that maybe she should

know, but...

... He insists that he wants to draw a line under it.

I have told him that, legally, because he has been under formal treatment for so long he is classed as disabled and therefore, legally, an employer isn't able to discriminate against him; indeed they should be more accommodating, rather than less, according to UK law - and this applies to part-time workers just as much as it does full-time workers.

Mental health issues like these are, by law, considered to be the same as physical disabilities and, as a result, the same employment laws apply.

Employers are not allowed to ask about your health at interview stage or prior to giving you the job, either. And they are required to make provision for you to go for necessary medical treatment.

I suspect, too, that Ben is legally permitted to be paid for the hours he has already worked there and to have a reference.

However she didn't dismiss him, he quit. Went he went to talk to her about it yesterday he said that, considering his mental health issues, he probably wasn't suited for the job (ouch!) and, apparently, the parting was on mutual terms (ouch again!) She wasn't sympathetic. I guess she just wants someone who can do the job, not someone who could be a millstone round her neck... Yet you and I know she isn't allowed to make employment decisions based on this assumption.

But Ben won't go in and sort things out. He doesn't want to ever see the owner again or set foot on the premises. And, as I expected, he most definitely doesn't want me to get involved.

He says he doesn't care if he doesn't get paid or get a reference. So I guess we have to leave it there.

Meanwhile he's thrilled to be back at the charity shop. He loves the manager - and knows that she's no stranger to mental health issues in the family. He says he'd rather work for her, unpaid, than work for the woman in the deli / café and get paid!

And I guess it's his decision.

Friday, 7 December 2012

Hmn... dietician bound tomorrow...

Tomorrow morning we're seeing the private dietician with a view to sorting out the remnants of Ben's eating disorder. I also wonder whether we need to go back and see the private psychologist for a few sessions. Ben is still avoiding social situations. Tonight he announced he's not going to PHAB. "Look, just not tonight!" he barked at me a few moments ago. He still hasn't got his zest for life back and seems down in the dumps much of the time. To be honest he is blooming miserable.

Another thing we'll be doing tomorrow is checking on his weight. Last week he lost 1kg if you remember, and I want to be sure he's put it back on. Yesterday it looked as if he was making a concerted effort to do this but I have no idea whether "something" was beating him up about all the snacks he was having. If he's put on more than 1kg he could find it hard to come to terms with.

This is why we're seeing the dietician - to help him adjust to being his present weight and adjust to any weight gain in the future, whether that weight gain is the result of natural weight gain as he grows older and bulks out - or the result of just overdoing it on the food front for a short while. Like most people do now and again.

He is still depressed. He's always been prone to depressive moods and the eating disorder made it worse. But he just doesn't seem to be able to throw it off. Yet when we saw the psychologist for those few sessions last month, it put him into an even worse mood.

So it's difficult to know what to do.

Let's start with the dietician and take it from there.

Oh, and next Saturday is the school reunion - the Class of 2012, many of whom are now back from university and gap years ready for Christmas. Hopefully he will go,

and hopefully he will stay for the whole evening. Meanwhile Ben sits on the sofa in front of the TV every night. It's not good and it makes me very anxious.

And it's why I still can't say, hand on heart, that Ben is "fully recovered". I always say "95 per cent recovered" or "99 per cent recovered", depending on how things appear at that particular moment in time.

It's also why I keep a beady eye on him as I have a pathological fear of relapse.

Sunday, 9 December 2012

Pillar to post...

Yes, the session with the dietician went well, but she's not sure how helpful she can be to Ben at this stage. Perhaps, she suggested, it mightn't be a bad thing for Ben to see a psychologist colleague of hers to see if there are any other underlying issues that need addressing, in a different way - say - through the use of DBT (*Dialectical Behaviour Therapy*).

Much of what she said at our session made sense, especially as regards the way Ben finds socialising so challenging. And also why he finds it hard to move away from the "safe" environment of his eating routine - and why food is the most important thing in his life. I got the feeling, from yesterday's session, that Ben would sacrifice social, academic life and a career if they got in the way of his routines.

Ben's moods still aren't brilliant. But, then, Ben always had mood issues, right from the day he was born. He was a screaming baby. He didn't like playing with other toddlers and would give them "daggers" looks. In other words, approach me at your peril!!

He had one good friend at primary school - a boy just like him. Quiet, imaginative and very different from the other boys who would kick footballs around the yard. It's a real shame that this boy moved away, because he would probably have been a friend for life.

Ben's mood tends to be generally low. But sometimes it swings so it's very high. It's either one or the other, never in between. All or nothing.

And, of course, he finds it very hard to socialise or hold down relationships (e.g. with girls). He misses the usual social cues which others give off and tends to "lecture" or "talk at" people, rather than hold a rolling conversation. But this could simply be because the eating disorder isolated him so much during those crucial developmental years.

He has an encyclopaedic knowledge of a range of subjects (history, philosophy, religion, etc) but also tends to have very strong opinions, which aren't always accurate. He also bosses me around; sometimes I feel as if I'm the errant child and he's the strict adult! Again, this could simply be because he never learned "how to be an adult", alongside his peers like most other young people do.

He was part of a very strong social group during the first four years of secondary school. He was "top dog" and very popular indeed. As he always said: "I would get concerned if I'd never been through this popular phase. But I have been popular, and for four whole years. So I must have been doing something right!"

So it's all a bit confusing.

But a chat with the new psych wouldn't be a bad thing.

Monday, 10 December 2012

Waiting for two proofs of my new book

Okay, so this weekend I thought, "Sod it, time to press the 'submit' button and get a proof of my new book *Please eat... A mother's struggle to free her teenage son from anorexia* to check over". Otherwise I will be here for *months* micro-proof-reading the manuscript and making minuscule changes, yet at the same time overlooking obvious errors. I think this is part of "the genes" - the bit of my brain that's very similar to Ben's and definitely similar to my dad's.

Yesterday I was reading Carrie Arnold's *Decoding Anorexia* (which, incidentally, is mega illuminating for anyone with an eating disorder or anyone caring for someone with an eating disorder). In it she talks about why many eating disorder sufferers, especially those with anorexia, have a history of perfectionism. She also talks about the scientific evidence that eating disorders like anorexia are biological illnesses that are heritable i.e. they're genetic (and can be triggered into life by external factors or events).

As Carrie describes in her book, the perfectionist in her requires everything to be one hundred per cent right. One slight error and she feels as if she's failed; the kind of flaws that most people don't just overlook but actually welcome in other people. In other words, people actually prefer others to have flaws, imperfections and make errors. They feel uncomfortable being around people who are, or who appear to be, "perfect".

But "perfect" is how I am with my book. And it's how I approach my work as a copywriter, too. This is why it takes me so darn long to write anything. This approach also applies to a tonne of other aspects of my life (and Ben's, and my dad's) which are becoming as clear as day now I've read Carrie's book and done this additional research.

For example I have a morbid fear of just one typo appearing in my book. One slight error and I will feel as if I've failed. I will feel stupid. I will feel as if everyone will think I'm stupid, useless, etc. And, of course, I always feel that I'm a pretty cr*p writer, even though I do it for a (very successful) living, have a string of great testimonials as long as my arm and all the evidence points towards the fact that I am actually pretty good at my job.

Micro-managing my writing in this way often means that errors *do* slip through the net. It's the classic "can't see the wood for the trees" scenario; I find it hard to see the bigger picture. And publishing my book scares me in case I do let something slip through the net unintentionally.

Finding it hard to see the bigger picture is why my dad, Ben and me - although very creative - could only ever draw or paint tiny pictures or art work, all in the most minuscule detail. Give us a huge canvas and demand that we fill it - and we'd be lost! No, we'd run a mile! Or we'd have to divide it into tiny sections. But, then, if 99 per cent of these sections were perfect and one wasn't, then, well... it'd end up in the bin or have to be re-done.

And I won't even begin to describe how this approach affected my organisation of the school Christmas Fair which, as Deputy Chair of the PTA, I was in charge of for five years... I must have driven the others crazy!

Anyway, this weekend I decided to bite the bullet and click that "submit" button and send off for printed proofs of my book. I've ordered two, from different printers so I can check quality, etc to see which is best. Then I will micro-read it again.

Aaarrggghhh!

Monday, 10 December 2012

Why I have written my new book

Here's an interview about why I have written my new book...

Bev Mattocks' new book "Please eat... A mother's struggle to free her teenage son from anorexia" tells about her struggle to free her teenage son, Ben, from the eating disorder, anorexia.

We talked to Bev about why she feels so strongly about highlighting the issue of boys and eating disorders. Bev's son (who she's named Ben in the book and in her popular blog) began to exhibit classic signs of anorexia during the spring and summer of 2009, aged 15.

“I had no idea that boys got eating disorders,” Bev says. “So I didn’t recognise the warning signs. I knew something was wrong and that it appeared to be getting worse, but I had no idea what ‘it’ was. As the parent of a teenage boy you don’t expect your child to get anorexia. You don’t even think about it.”

The alarm bells began to ring during the summer of 2009. “But it wasn’t until late September or early October that I was prompted to take Ben to the doctor. You see, I hadn’t a clue what we were dealing with. I just knew something was very, very wrong. His mood was going downhill, he was cutting himself off from his friends, he was becoming fussy about food, he was decalorising meals and making “super-healthy” options i.e. completely fat free - and he was losing weight, very, very quickly.”

Bev took Ben to see the GP. “But of course GPs don’t always recognise the signs of eating disorders in boys. Ben didn’t look terribly thin; that’s the key point. Unless you’d seen him before when he was a big rugby player you’d probably just think that he was a normal skinny boy. After all, skinny boys aren’t unusual and don’t tend to set off the alarm bells in the same way they might if it was a teenage girl.

“The GP basically said go away, eat more and come back in a couple of weeks. The GP said this to us two or three times – and I didn’t know what treatment was available for eating disorders; I was never told. In the end it was the school nurse who told me that Ben was probably developing an eating disorder and that I should get him referred to CAMHS (Child and Adolescent Mental Health Services). So my husband called the GP and insisted that Ben was referred immediately.

“We assumed we’d get instant treatment for the anorexia. By now I’d discovered that eating disorders are a potential killer. I mean, if they suspected cancer we’d be

fast-tracked in front of a consultant. In the event we were horrified to find ourselves on a waiting list that could last 18 – 22 weeks, that’s almost four months. Meanwhile Ben was spiralling downhill at a rate of knots because you wouldn’t believe how quickly they can go downhill. I didn’t know where to turn. I was desperate because my child was disappearing in front of my eyes.

“Ben was doing strange things. You see, anorexia doesn’t just affect your weight, it affects your mood and your behaviour. He was becoming out of control at school when he’d always been the kind of boy who’d been top of his class, towing the line, very academically bright and well-liked by his peers and teachers. He’d transformed into someone we didn’t recognise. At home he was exhibiting terrifying behaviour, almost every day. It was a nightmare.”

Bev explains that, with boys, it’s not always just about cutting back on food. “Ben became addicted to exercise, just as an alcoholic can get addicted to drink. And I don’t just mean the odd run or game of rugby; I mean serious exercise.” This, together with the starvation, resulted in Ben losing one quarter of his bodyweight.

“We’re talking about a former ‘forward’ in the rugby team,” she points out. “A position given to the biggest, toughest boys. By the autumn of 2009 his coaches were getting worried about his weight loss. I was worried that if anyone tackled him on the rugby field he’d snap in half.

“While we were on the waiting list for treatment we received no assistance or advice from the UK health services. All my husband and I could do was stand and watch, helpless, as the eating disorder threatened to consume our son. It was only when his illness took an unexpected and frightening turn that Ben was eventually fast-tracked into treatment.

“The point is: I know how terrifying it is to discover your child has a potentially life-threatening illness – and to discover that it’s been developing undetected for months. I know what it’s like to feel isolated, helpless and totally clueless about an illness that has the highest mortality rate of any mental health disorder. And I know what it’s like to have to wait for treatment while your child disappears down the rabbit hole in front of your eyes.

“When I sat down to write this book I was acutely aware that I wanted to do my bit to help other parents and carers – not only to identify the warning signs of anorexia but to show that there is a light at the end of the tunnel, and to describe how we got there. And also to highlight the importance of early intervention and effective treatment for young people with eating disorders, wherever in the world you live.

“My son, Ben, has always been one hundred per cent behind this book. He is always nagging at me to ‘do more’ to help raise awareness of eating disorders in a society where the illness is often shrouded in secrecy, shame and misunderstanding - and where there is still too little awareness of eating disorders in teenage boys. He has read every single word in this book and made valuable contributions of his own.

“Even if we help just one family identify the signs of eating disorders in boys and overcome this devastating illness then we have done our job.”

And also...

Bev Mattocks is talking about her new book “Please eat... A mother’s struggle to free her teenage son from anorexia”...

What made you write this book?

“More than anything else I wanted to raise awareness of eating disorders in boys, especially anorexia, and also to highlight the typical early warning signs of anorexia in boys so parents and carers can get swift treatment for their sons. Of course many of these signs also apply to girls who might be developing anorexia or another eating disorder, so this book is for parents of girls, too.

“I must point out that one thing that this book isn’t, though, is a medical book. It is purely and simply our story. In other words I don’t talk about specific eating disorder treatment options and so on. And, of course, it must never be substituted for proper medical advice!”

When did you first realise there was something wrong with your son?

“15 year old Ben was getting increasingly concerned about his appearance. At first we thought it was just typical teenage angst, but after a while we began to realise there was more to it. Over the summer of 2009 Ben began to take an interest in ‘healthy eating’ and calories. He was also doing more exercise than ever and cutting himself off from his friends. His mood was dipping and, most significantly, he was losing weight.

“By September 2009 my husband and I were getting worried, but it was a visit from my in-laws that eventually prompted me to take Ben to see our GP. My mother-in-law hadn’t seen Ben for months and was shocked at the difference in him. This was the first time I wondered if Ben was developing an eating disorder and the thought put the fear of God into me.”

What did you do next?

“I made an appointment to see our GP. But I was confused because on some days Ben seemed absolutely fine. He was behaving okay and eating well. Yet on other days it was as if he’d totally transformed. To be honest, sometimes I wondered if it was all in my mind. Was I imagining it? Would everything rectify itself once the school summer holidays were over and Ben was back on the rugby field and eating school lunches?”

“At first the GP wasn’t overly concerned. Ben was sent home with instructions to ‘eat more and come back in a couple of weeks’. This happened two or three times. And each time we went to see the GP Ben denied anything was wrong. I was sure the GP thought I was a fussy or overprotective parent.

“And to be frank, Ben wasn’t skin and bone. But here in the UK children’s weights and heights aren’t monitored past toddler stage, so the GP had nothing to compare him with. Also, he’d never seen Ben on the rugby field. Ben used to play Number 3 which is a position given to the biggest, toughest boys. And maybe the GP had never come across a boy with an eating disorder before. I just don’t think the alarm bells were ringing inside his head.”

When did Ben start treatment for his anorexia?

“Well it took us quite a few weeks to get Ben referred. We knew nothing about treatment for eating disorders in the UK and the GP hadn’t explained anything to us. In the end it was the school nurse who told me about CAMHS – the UK NHS-based Child and Adolescent Mental Health Services. They’re the people that usually

deal with eating disorders like anorexia, bulimia and EDNOS in the UK. So my husband called the GP and insisted on a referral.

“What we didn’t realise then was that the waiting list would be so long. It took a few weeks for the acknowledgement to come through by mail and when it did we were told the wait for eating disorder treatment could be 18 – 22 weeks. As you can imagine, we were horrified. And terrified!

“So the timescale looked like this... At the end of September I called for a GP’s appointment, we saw the GP in early October followed by more appointments throughout October. In November we got the acknowledgement and the estimated start date for treatment was April. That’s around six months in total which, as you can imagine, could be lethal considering that eating disorders have the highest mortality rate of any mental illness. Basically we were being told that all we could do was wait.

“I nagged the GP’s surgery and CAMHS to see if the appointment could be speeded up, but to no avail. Of course we couldn’t just sit there and watch our son slide downhill at a rate of knots, so we arranged some private stop-gap treatment. It wasn’t ideal; the private therapist did her level best to stall the escalating anorexia, but it really didn’t do much good.

“In the end we got seen by CAMHS in early February, sooner than we’d anticipated. But it took a terrifying development in Ben’s anorexia for this to happen. This is described in the first chapter of the book which then looks back on the journey that got us to that point – and then from thereon to recovery.”

How long did the eating disorder treatment take?

“Ben was with CAMHS for 24 months until just after his 18th birthday. Unfortunately he was discharged at that point because 18 is the cut-off age, and also his eating disorder therapist was leaving. After that we brought in a number of private eating disorder therapists to tidy up the remnants of the eating disorder.

“Why didn’t we continue anorexia treatment through the NHS? Because we were told that Ben’s weight wasn’t low enough. Someone, and I can’t remember who, said: ‘At his present weight there isn’t a doctor in the land that would refer Ben for eating disorder treatment.’ This was because, by then, his weight was within what the NHS charts consider to be a healthy range. I took Ben to the GP, but he felt that Ben would just ‘grow out’ of the eating disorder now that he was so advanced towards recovery. So it was a case of getting additional treatment privately – or nothing.”

Did the treatment work?

“It took a long time. At first I wasn’t convinced it was the right treatment for Ben; I wanted to see some serious emphasis on weight gain but instead the emphasis was more on talking therapy. Nevertheless I continued to push for weight gain, but in the end Ben rebelled against a weight gain eating regime and began to lose more weight. It took another frightening turn in Ben’s anorexia for him to eventually turn a corner and begin to work with us all towards recovery. And, even then, the progress was slow.

“Again, looking at the timescale of things... Ben turned a corner in October 2010 and it wasn’t until February 2012 that he was discharged from treatment. This wasn’t anyone’s fault, I don’t believe; it is purely and simply because it does take so

very long to recover from anorexia.”

How is Ben doing these days?

“It is now December 2012 and I’d say that Ben is 95 per cent recovered from his eating disorder. There are still some loose ends that need tidying up, but he’s managing very well. His weight is back to normal, he’s eating a healthy, balanced diet every day and he has his exercise under control.

“He was set to go to university in September, but decided to take an 11th hour gap year. He admitted that, yes, there are a few bits that still need sorting out – so this is what we’re concentrating on this year. The great thing is that, for the past 18 months or so, Ben has been actively and enthusiastically working with me. As I keep telling him, we are a fantastic team!”

What does Ben think of the book?

“Ben has been actively involved in the book. Once I’d written the first draft, I went through every chapter with him so he could check that everything is accurate from his perspective. While we were doing this, I found myself jotting down what he was saying and I’ve incorporated much of this into the book, too. He was coming up with some very useful feedback. He has always been 100 per cent behind the book. But now that it’s finished, however, he doesn’t want to read it. He says that he ‘doesn’t want to go back there’. It’s too dark a place and he wants to move on. Oh, and of course, Ben isn’t his real name. Most names have been changed to protect privacy.”

Wednesday, 12 December 2012

Why do I feel strangely naked today?

Why? Because the wonderful Becky Henry, author of *Just tell her to stop...*, coach and public speaker on eating disorders has generously offered to give the final draft of my book the “once over” and write a review (hopefully a good one!). And, boy, do I feel strangely naked!

Just emailing my draft to someone from the States has been a Good Exercise in viewing the draft with different eyes.

For instance I’ve picked up on quite a few phrases that maybe a US audience might find difficult to understand - and no doubt Becky will point these out to me.

I’ve also picked up on a couple of typos (ouch!) - and no doubt she will point these out to me, too.

But, then, that’s what this exercise is all about.

Most important of all, however, I hope she likes it. I hope she thinks it reads well, is engaging and absorbing, and does the job i.e. helps parents of other teenage boys (and girls) to identify the warning signs and take action.

Like I took action (and solace), three years ago, when I read Jenny Langley’s book *Boys get anorexia too*.

The other weekend I met author and mother Jenny Langley and told her how much her book had helped me back then. Indeed it was the first book I read on eating disorders; my sister dug out a link to it and suggested it might be a useful book to buy.

So I did. And it was.

Plus, as I say in my own book, I kept on flicking through to the end - the Happy Ending where Jenny’s son recovered, went on to university and to lead a normal, happy life.

He is still enjoying this normal, happy life, I am thrilled to say.

But, meanwhile, I nervously await Becky Henry’s feedback on my book...

And, boy, this ice-cold frosty December morning isn’t the best time of the year to

feel strangely naked!

Thursday, 13 December 2012

Just how did they plan to do that?

Looking back through old blog entries I came across one where I talk about how CAMHS always promised that, once Ben was discharged from treatment for his anorexia, they would monitor him for at least 12 months to check that everything was continuing to go in the right direction. Sorry, but have I missed something?

Ben was discharged in February. Yes we had a woman come to the house to talk about how she could help Ben in the transition to university (which, in the event, wasn't much help at all), but that's all.

It certainly wasn't what I'd call "monitoring for 12 months".

Reading through the printed proof copy of my new book, "Please eat...", and going back over previous blog posts (with a view to editing them and putting them into a book), I am angry again.

Angry at the way this promise was never followed up.

Many a time Ben was also told that CAMHS would help him adjust to being weight restored when he got to that point. "Don't worry, we will never let your weight spiral out of control," they said. This gave him reassurance and put his mind at rest.

Yet none of this happened.

Yes, Ben is "almost" recovered. But I've been saying "almost" recovered for some time now. The same old loose ends are still extremely loose - flapping around like mad sometimes. And we need someone to help us tidy them up.

I can only hope that the private psychologist we're meeting with on Saturday can do this. Or, at least, identify any permanent co-morbid issues that are preventing Ben from achieving those final few per cent of recovery. So, like Jenny Langley (author of *Boys get anorexia too*) said to me at the FEAST conference the other weekend when I

asked her how her son is getting on these days, I can say - with confidence - that Ben is “One hundred per cent recovered” from the eating disorder.

The good news is that, from having talked with this new psychologist at some length on the phone, I am pretty confident that she can sort out Ben’s remaining issues.

But, then, I thought this about the first psychologist. (But Ben didn’t get on with her.) And the dietician. (Who I believe can still help, only I can’t afford to pay for two private therapists.)

And the trouble is, this new psychologist is the most expensive of all at £100 an hour. Ouch! I can’t afford too many sessions with her!

The other route, of course, is to go back to the GP. But, then, we risk ending up on a massive waiting list again with who-knows-what therapy at the end of it. Probably just counselling. Like the completely useless NHS counselling I received when I was going crazy at the height of Ben’s anorexia.

Once the Saturday morning session with the new psych is over I will work out whether it’s worth going back to the GP. If the psych can actually make a formal co-morbid diagnosis, then that will definitely help.

Just to remind you... the issues we are dealing with are (1) Ben’s fear of socialising and lack of social skills (which could simply be due to the fact that he’s been isolated for so long), (2) His constant thinking about food (which isn’t necessarily a negative thing, these days, but it does dominate his thoughts and may affect his ability to focus on future study, jobs and relationships) and (3) The eating issues that came to light when he was at university for those two days plus the worry that his weight will spiral out of control - plus, of course, helping Ben to ease himself into university.

Now, nothing has been done on that count. Nothing at all. And this is what this “gap year” was all about.

I feel frustrated, stuck and - potentially - broke at the prospect of £100-per-hour treatment sessions.

Friday, 14 December 2012

Can I complete my book “Please eat...”? I’m not sure if I can...

For a week or so the old instincts have been nudging me, homing in on the fact that All Is Not Well with Ben. Thankfully, we’re seeing the new psych tomorrow and I have every hope that she will be exactly the right person for Ben. So, completing my book, talking about “recovery” feels a bit, well, hypocritical at the moment. It didn’t a few weeks ago, but it does now, I am sorry to say.

Something is wrong with Ben. His mood has been rock bottom for some time and he’s making no attempt to socialise. Yes, he’s still teaching at school two mornings a week and working in the charity shop, but everything else seems to have gone out of the window.

And it didn’t help when he said that, for the past three days, he’s been feeling suicidal...

Now, that took me back to places I never wanted to go again. How can I talk about my son being fully recovered when he’s talking about things like this, claiming that one hundred per cent of his day is taken up with thoughts about food at the exclusion of everything else: relationships, friendships, work, study... He’s still rigidly counting calories and biting my head off. But at least he is eating. Or at least I think and hope he is eating. He seems to be. I haven’t noticed anything that sets off the alarm bells. So at least that’s good.

On top of this he still feels numb. That numbness that came with the anorexia and never seemed to really leave.

It’s as if his emotions have been anaesthetised. The positive emotions, that is.

Three years ago when we were on the waiting list for CAMHS treatment and I decided we had no option but to call in a private therapist as a “stop gap”, I was desperate. But this was in the run up to Christmas and getting appointments was

virtually impossible. I think we had one appointment before Christmas and then nothing until way into the New Year.

I tend to think it will be the same with this psych.

Who, coincidentally, we are seeing at the same place we saw that first private therapist, three long and hellish years ago.

So the first thing we're going to be talking about is the "S" word and Ben's worsening depression.

Now, as my good friend M has suggested in response to my last post, Ben's symptoms do sound very eating disorder-esque.

My theory is that, yes, he did need quite a bit more treatment from CAMHS. When he was discharged we managed quite well for a while and he was busy, what with exams and all the end of school socialising.

Then came university. Or, rather, there went university. And, after that, things were relatively okay and he embraced all those conditions I'd set him - job, socialising, etc.

But, over the past few weeks, it's all come to a halt. Very much so.

It's probably why I've been having nightmares every night and why, last night, my body was so tense I couldn't sleep at all.

And why I just can't get into the Christmas spirit this year.

And why I don't feel as if I can complete my book just yet.

Fingers crossed I'll be able to get going on it again very, very soon.

Saturday, 15 December 2012

Ding dong (not so) merrily on high

So there I was, writing about all the positives that are coming out of this experience at the moment when off went the alarm bells inside my head...

"F*ck it!!!!" came the loud shout from Ben's bedroom accompanied by a fist

slamming down on his desk.

“What’s all that about?” I said, going upstairs (clang, clang go the bells in my head).

“Trying to write a f*cking blog about food like U [the dietician] told me to do and the f*cking computer’s not doing what it should be. I’m not f*cking bothering!”

To be frank, I’m not sure that a blog about food is what he needs to be doing right now... despite the dietician suggesting he redirects his obsession with all things food to doing something positive with it, like writing a blog.

As he ignored me and looked like death at his keyboard, I said (much more calmly than I felt):

“Today we begin to move forward again. And, you know me, I won’t stop until you’re through this and back in a better place. I do this because I love you, no other reason. You know what I’m like. Also, you might find me being a little more forceful over the next few days or whatever, more than I have been over the past months. But the only reason I’ll be doing this is because I love you and want to lift you back up there again. Oh, and we’re leaving at 11.30 to see the psych.”

Silence.

“Ben, can you respond please?”

Silence.

“Ben, I know that you may feel you need to take it out on me and dad. But it’s not nice and it hurts us, and you know we love you.”

“I know you love me.”

“So I’ll see you at 11.30.”

Grunt.

“Can you respond, please?”

“I just did!!!!”

Goes back to painting his models.

I think we’re going to have to go in at the deep end this morning and forget all about getting S, the new psych, to assess him. We’re going to have to go straight in

and get some action.

Clang, clang, clang...

And you can bet your back teeth he won't go to the reunion at school this evening...

Sunday, 16 December 2012

Where shall I begin?

I'm not sure how to write this. I have enough material for 100 blog posts after yesterday and, frankly, today my emotions, energy and mind are in shreds. Lowest and highest points yesterday?

Highest. When H and I took some time out to drive up into the Pennines and visit a tiny village brewery to pick up some Christmas beer, stopping off at the packed local inn for a beer before driving along the dark, winding, hilly roads back home. Everywhere you could see twinkling Christmas lights in the darkness. And if you come along to that remote village inn this coming Friday evening you will hear the Loxley silver band playing Christmas carols. Meanwhile, mulled wine was on sale and special festive beers brewed in the little micro-brewery up the road. Everyone was jovial and festive. Everyone except us.

Lowest. When I took a looking-like-death / thunder / and threatening suicide Ben along to see the private psych and he just sat there looking like death / thunder, etc in between effing and blinding at the (very nice and highly recommended eating disorder specialist) psych and refusing to continue the 60-minute session after 40 minutes. Followed by a conversation between me and Ben on the way home about suicide.

God only knows how I did it, but some kind of heavenly inspiration must have come to me over lunch because I conversed calmly and dolphinesquely with Ben, copying the techniques Gill Todd taught us at the FEAST conference in November.

Inside my emotions were on a roller coaster. Outside I was the calm, supportive dolphin.

But, later, when H and I drove up onto the Pennines - or, rather, drove back from the Pennines - I got angry. Furious. Livid. Angry with the eating disorder for stealing three years of my son's life and threatening to sneak in and steal some more.

Frustrated and impotently angry at having the means to save him, right here. One of the best (and most expensive!) eating disorder psychs in the region - yet he refuses to see her again. Or anyone, for that matter.

He claims he is a failure and we think he's a "little sh*t" (quote). Of course we don't think this at all, but he's convinced we do. He is beating himself up about whatever's going on at the moment and feeling that the world, and us, would be better off without him.

As I said yesterday, I've had a hunch that something was up. Like all things ED-related it creeps up on you when your eye is off the ball. Interestingly, one of the major things that Ben and I feel certain changed his mind-set initially and over the long term as he progressed onto recovery was his change in diet. From going to a low or no fat diet during his initial "re-feeding" (because he refused to eat anything else and no-one was giving me any support or assistance to wean him off low calorie food) - which I believe messed up his mind, because everywhere on the Net it shows that science has proven that a no or very low fat diet interferes with the neurons or neurotransmitters in the brain and can lead to depression, outburst, anger, etc... From going from this kind of diet to a fully balanced diet with the right kind of fats in the right quantities, his mood changed. Or at least it had until six weeks ago-ish.

He has admitted that, over the last six weeks or so, he has been drastically reducing the fat in his diet again. Remember, he's been doing all the meals - because I trusted him to do it... he'd done it for so many months so very successfully, and he enjoys cooking immensely. But he's been secretly cutting back on fats and we've been mainly eating veggie-based meals. Result? His mind is messed up again. Or so I

firmly believe. Meanwhile his weight hasn't really changed much, because he has been having the calories (good news) - only not in the form of fats (bad news).

When I was being dolphinesque yesterday, he seemed to accept this as a probable reason why he felt so cr*p.

But, anyway, after getting back from our trip out to that little village (Ben didn't come), I took to my bed, just like I used to do in the Bad Old Days and bawled my eyes out for hours and hours. By the time I went to bed for real, I felt mega cr*p. I was awake at 3am feeling mega cr*p and I awoke this morning feeling mega cr*p.

Much of the mega cr*pness comes from the morbid fear of having to go "back there"... Even remotely having to go "back there"...

With Ben threatening to kill himself over the last few days I've been back to places, mentally, that I never ever wanted to go ever again. I have experienced that ice cold sheer dread, that total fear that you will lose your child to this effing awful illness. And the frustration of knowing that you have the means to save him... like the lifeboat sailing right up to the sinking ship... but the captain says "No thanks lifeboat guys, I'm happy to go down with the ship".

More later.

PS I'm on a fats-finding mission... Mama Matty is going to swoop back in (if the ED will let her and give up threatening suicide i.e. "If you do xxxxx I'll kill myself.")

Sunday, 16 December 2012

£70 on "medicine" down at Tesco's

"Food is medicine", as we all know. So I've just returned from *Tesco's* armed with salmon in various guises, other oily fish, chocolates, custard (to make ice cream), turkey steaks and a stack of other stuff. I went alone so I didn't have the "We don't need that... it's too expensive" voice in my ear. And, thus far, he seems totally relaxed at what I'm doing.

“It’s funny because I feel completely fine today,” he said calmly earlier, demonstrating to me how he’s changing his diet back to what it was during the “good months”.

But driving down to *Tesco* I continued to be stunned at the sheer appalling behaviour demonstrated at the psych appointment yesterday. Effing and blinding at a complete stranger like that. It’s shocking and, if he didn’t have “an excuse”, it’s the kind of behaviour that would get him grounded for a year.

Also, telling your mother over and over again you plan to kill yourself isn’t such brilliant behaviour either.

Especially just before Christmas.

Whatever happens from now onwards I’ll be keeping a very watchful eye on things. From a distance, though, and discreetly - because I learned long ago that this is the most effective way to deal with Ben. To know when “enough is enough” as regards food talk, despite the maternal instinct to nag him senseless.

What *is* good about it, though, is that it reminded me to keep my eye on the ball and also to take early action whenever the alarm bells start to ring.

And not to be afraid of taking action - not to let the eating disorder bully me.

Oh, and Ben never went to the school reunion last night.

But that didn’t surprise me.

Sunday, 16 December 2012

Three young people failed by the NHS

Saturday morning is obviously eating disorder and other mental health issues morning at the private therapy clinic. On duty yesterday were the two dieticians - the one we saw last week (the one on the telly) and the one we used to see at CAMHS before her funding was withdrawn. (Back then, she didn’t do private work; I wish she had because we’d have snapped up her services immediately.)

Also on duty were the eating disorder psychologist who Ben was seeing and the CBT therapist we saw three years ago while on the CAMHS waiting list.

There, with us in the waiting room, was a stick-like teenage girl (waiting for the dietician) and a teenage boy (waiting to see the CBT therapist). In all, three young people whose parents are - presumably - being forced to go private because - presumably - the NHS isn't delivering what their children need, for whatever reason: poor treatment, no treatment, lengthy waiting lists or whatever.

Meanwhile that particular private clinic (which offers a range of alternative therapies and counselling services) has set up its own specialist eating disorders team comprising some of the best eating disorders professionals the city has to offer. Charging from £70 an hour upwards.

It was set up, I assume, is because there is "a need".

And there can only be a need if our dear children are being failed by the very National Health Service that should be protecting them.

For free.

We dare not even think of all those young people out there whose parents simply can't afford to go private...

As we all know, eating disorders have the highest mortality rate of all mental health disorders. In other words, they are a potential killer.

Can you imagine if our children were suffering from another life-threatening illness, for instance cancer, but were being forced to go private - or simply do without?

There would be a public outcry.

Monday, 17 December 2012

A thumping good use for a spare £100!

As you know, Saturday's psych session cost me £100 and any subsequent sessions

with her would have cost me £100. So, as Ben refuses point blank to have any more sessions with her or with anyone else (and no I don't have a spare £100 to fritter away on whatever I wish, I am not dripping in money by any stretch of the imagination)... I had a light-bulb moment earlier this morning...

During the past three years I have learned almost as much about eating disorders as some clinicians, I suspect. I don't mean the experts like Janet Treasure et al, but general clinicians. I know for a fact, for instance, that I know masses more about eating disorders than my GP and various other people I've met on this journey. Or at least that's the way it seems.

Cramming my poor already-overloaded brain with all this stuff about anorexia was a huge learning curve. Not one I chose to follow but one which I had no choice but to jump in at the deep end around this time three years ago and cram up on all the information I could find in a bid to learn about what it was that was destroying my son - and what I, as a parent, could practically do about it, especially as, at the time, we were faced with an 18-22 week wait for treatment and were being left to our own devices.

Or, rather, the devices of the evil ED which was doing its level best to drag my son down the rabbit hole.

This learning curve has continued by reading literature, mixing with other parents and eating disorder experts, being an active member of FEAST (Families Empowered and Supporting Treatment of Eating Disorders) and its forum, Around the Dinner Table, which is a mine of information, with many of its members having direct access to some of the world's best and most knowledgeable eating disorder experts and clinicians, literature, research, etc.

For instance I am, as we speak, reading what I now believe to be one of the most important books on the science behind eating disorders that I've ever seen.

And I know that others will agree with me.

If you want to know about eating disorders and why they do what they do and -

most importantly - why you, as a parent, are *not to blame*, then get someone to give you Carrie Arnold's *Decoding Anorexia* for Christmas. (Pricey but worth every penny.)

Anyway... back to what I was on about...

As a result of this massive enforced learning curve, I was able to do my bit to help my son recover from his eating disorder.

I learned the proven techniques and the science behind his anorexia. No, I didn't bring around his recovery exclusively; we had help from CAMHS, of course. But, on occasions, I found myself steering his treatment towards what I felt would be more helpful for him - a prime example being the Recovery Contract which worked wonders and turned months of weight loss into months of weight gain. After all, we parents know our kids better than anyone else!

So, if my son refuses to have any more professional treatment because he thinks that "all clinicians are f*cking useless" (quote from what he said to the psych on Saturday) and "talk f*cking b*llocks"... that all they do is "just delve into your f*cking past and f*cking useless stuff like that", then why shouldn't I use the money I squirrelled away for private treatment to pay for self-help books so I can learn how to deliver the best and most useful therapy myself?

As I said above, we know our children better than anyone. And - thank God - for the past 24 months Ben has been listening to me. If I choose the right moment, that is. Our "walks and talks" are usually the best times, and when we do the Contract.

Blimey, I could get a bundle of self-help books for just one session with that psych.

In an ideal world, Ben would read them and help himself. But I know Ben and I know he won't bother. Because Ben always "knows best". Like he did on Saturday morning.

So I will read and digest them myself and converse with him accordingly. No wonder they say that "Family Based Therapy" is the best!

PS And in case you hadn't gathered, Batty's emotions are on a roller coaster this weekend. My frustration with eating disorders, "the system", my son's "poor me"

attitude and just about everything else is making me want to thump something!

But - unlike in the Bad Old ED Days when I used to impotently thump anything within my reach when I was angry and frustrated (walls, mirrors, bins...) - Batty doesn't thump things, she takes action.

Tuesday, 18 December 2012

Tricky challenge for the New Year...

The wonderful private dietician we've been seeing has sent me a print-out all about fats - and why they are *essential* for health and won't make you fat. It is incredibly illuminating reading - the proverbial "light bulb moment". Well, it is for me. Whether or not it will be for Ben is another matter because, as we all know only too well, Ben and other fats-avoiding eating disorder sufferers know better than the science.

When Ben was going through his worst period, he would argue that black was white until he was blue in the face. Like many people with anorexia, he'd instantly understand the logic of just about every scientific fact in the universe... except those associated with eating and getting well.

It's like arguing that the world is flat when everyone for generations knows - and has proof that - it is round.

Yet anorexia sufferers will insist it's flat. Period.

And I tend to suspect that if you literally took them round the world to physically prove this, they would still find an argument against it.

Fats were always Ben's main sticking point. Fats were evil incarnate. They are the main thing that he cut out of his diet at the start, eating a virtually fat-free diet which not only led to rapid weight loss but which - I suspect - also helped to lower his mood significantly.

"How do I get him to eat fat?" I'd plead on the ATDT forum and at CAMHS over and over again. "You just do" came the response. They were obviously doing it

successfully with their children. Fats were going into their daily diet like there was no tomorrow. Yet I couldn't get an ounce of the stuff into my stubborn child. He simply refused to eat it. Or he'd go crazy and almost kill himself with violent head-bashing and so on. And never forget that Ben is taller and stronger than me.

I felt - and still do feel - a complete failure when it came and comes to getting "proper" fats into my child. If the truth be told, I feel personally responsible for keeping him where he is. Simply because I'm "too scared" to do much about it. The anorexic part of Ben, and also part of Ben's natural personality makeup, is to "always be right" and to bully me into "agreeing" with him in order to keep the peace. And, as I discovered over the weekend, to keep him from doing something dangerous.

(If, indeed, he was planning to do something dangerous. You never know, do you? And it's not something you want to call his bluff on...)

To be truthful, my husband and I are getting sick of being "bullied" and told how to behave as Ben snaps at us for some reason or other. Good God, we're the parents!!!

Anyway... Ben is still frightened of fat, as demonstrated by the recent reduction in fats in his diet.

Yes, he claims he's incorporating them back into his diet. But, frankly, his diet is still a low fat diet even though Ben claims he is "getting all the fat I need".

Back in the spring of 2010 when Ben was battling with the initial re-feeding plan (which he eventually ditched) I got to the stage where I was adding up the fats he was eating to "prove" to him how much fat he needed and wasn't getting. It was a hell of a job, micro-management at its worst, and I wouldn't recommend it to anyone that wants to stay sane. But I wonder if I need to do it again. I'll position it as a "test". A short-term "test". Because that's the way the professionals get patients to try things without freaking them out too much. CAMHS used to call it a "test" or "experiment". And that kind of concept appeals to Ben.

Public Enemy Number One for Ben is saturated fat. But the dietician's print-out talks about why sat fats are "absolutely necessary for a whole host of bodily

functions” and are not “the enemy”. Of course Ben would say (or rather bark at me) “I’m already getting enough sat fats”.

It goes on to compare cultures where sat fats are consumed in abundance, yet these cultures display “significantly lower” rates of heart disease and cholesterol levels than in western countries. The difference, it says, is that they also eat a lot of unsaturated fats as well. So, rather than “just restricting saturated fat as was the advice around 15 years ago” we should be *increasing* the “good fats” in our diet.

The print-out also talks about why, these days, low fat diets are not recommended and why, especially for eating disorder patients, they can lead to unhealthy imbalances in dietary intake. In fact the print-out says: “It’s a very odd concept that fats are ‘bad for us’.”

The dietician says: “We never advise low fat diets now - at least 30-40% fat... there is no evidence for low fat.” A low fat diet is one that is “around 35% fat or less; diets that go lower than about 25% are not healthy”.

“Should I buy low fat products?” asks the print-out. “No!” it shouts in response, explaining about all the nasties that go into these products to make them “look”, “feel” and “taste” the same as standard fat products. “Fat does not make you fat,” it says. “In fact you need the essential fatty acids found in fat to live.”

Ah but I’ll never forget the occasion when the CAMHS dietician tried to wean Ben off skimmed milk... He broke down in floods of tears at the prospect of semi-skimmed. We tried him on “orange top” (a half-way house), but he couldn’t even handle that. I am sorry to say that we are still on skimmed milk.

I know for a fact that if I suddenly cleared the fridge of these low fat products he simply wouldn’t eat the standard equivalent. He would also be extremely anxious. As with the weekend’s performance this is another example of where the eating disorder still has a hold on Ben - and why it’s often referred to as the “bully” because of the way it “bullies” the carer into taking the easier option because the alternative, the carer perceives (and don’t get me wrong, it might be an accurate perception) is

worse - for example the threat of suicide.

So the eating disorder “bully” has you by the short and curlies.

Scream, scream, scream!!!!

So this is my New Year Resolution: to work on *fats*. And the day I manage to wean Ben off all those horrible low fat foods (Flora Lite, Fat Reduced Cheddar, Low Fat Mayo, Skimmed Milk, etc) - and when he willingly eats these things as opposed to “because *you* say I have to”... and when they become a normal part of his diet i.e. he doesn't even think about it - is the day when I can well and truly say, hand on heart, that I believe Ben is fully recovered.

Until then, I can't.

And it's not just a case of getting over the fats issue; it's a case of proving to him at the same time that a few extra kilos won't be the end of the world. Because you can bet your back teeth that, if I introduce these standard fat products and Ben does put on weight, he will go absolutely crazy. Which is why we still need support. Yet he refuses to have any.

Good God, have I got my work cut out for the New Year.

(Says she gloomily with her head on the desk...)

Tuesday, 18 December 2012

And here is my New Year Resolution!

Adjustments to our Recovery Contract in the lead up to university and *life*...

New Challenges (mandatory):

- ☆ 1st Jan week - with mum carefully monitoring current fat intake to ensure it's within 30-40% of daily intake
- ☆ 2nd Jan week - adjust diet up to this level if required, still carefully monitoring it for the week

- ★ Monthly session with dietician to check on fats progress / weight maintenance / increase in line with age
- ★ Adjusting to weight going up and down rather than being constant (tramlines)
- ★ New “fear food” challenges if required e.g. semi-skimmed milk, full fat cheese and yoghurt
- ★ Moving the focus away from food 24/7 (work with dietician)
- ★ Introducing other things to his life to replace food obsession
- ★ Socialising / filling spare time in day / evening - set weekly tasks
- ★ Making his own decisions and choices instead of me making them for him
- ★ Walks / talks to talk these things through and ensure continued momentum
- ★ Regularly review need for psych support

Wednesday, 19 December 2012

So far, so good...

This is what makes it so different, these days, to the days of High Anorexia when Ben’s mind jetted off to *Planet Irrational*... Thankfully, in general, Ben is happy about my Big Plans for New Year.

Mind you, I’ve only touched on them. Drip-feeding is always the best way with Ben and (what remains of his) anorexia.

So, the first week of January we’ll be doing my “little test” to gauge how much fat he is actually having in his daily diet, on average, adjusting it in the second week of January.

The aim, I said, is to work on his mood and turn things around.

And I have hinted that we’ll be working full steam ahead to help him with socialising and the other issues that still remain.

The only thing he’s not keen on is weaning off low calorie foods (skimmed milk, low fat Flora margarine, etc). But I’ll leave that until we see how his fat-intake levels are.

He's also not overly keen on the idea of putting on more weight, although I have shown him the charts which say he needs to increase over the coming year.

Mood-wise, he's been fairly normal this week. I can still scarcely believe his behaviour at the weekend and the pit of fear and dread it catapulted me and his dad into.

But he's done this before. Been relatively okay for ages. Then something would start rumbling beneath the surface eventually spewing out in the form of some sudden scary, atrocious behaviour. Almost as if he's letting off steam.

I know he'd been planning to go to the school reunion on Saturday night - a reunion of *The Class of 2012*. But the closer it got the more evident it became that he was dreading it.

Not just because he still feels uncomfortable amongst his former friends and school-mates, but because he knew that most if not all of them would be going on about the fantastic time they've been having this year - at university, at work or in their gap year.

In contrast, he feels pretty sh*tty about how he's handled this year, what with leaving university after just two days and not being able to get or hold down a paid job.

So I don't think he could handle the reunion. Once he'd decided not to go, with our blessing, he seemed to calm down a lot.

Of course we've told him over and over again that he isn't a "failure", as he thinks he is. Good grief, he's done loads since September and, until recently, has stuck to every single one of the conditions I set him in return for taking him out of university.

Recently, though, he's fallen into a rut. The momentum has stopped. And I know he is aware of this.

Which is why, after Christmas, we need to get it moving again.

As I said to Ben yesterday: "We're a strong team, you and I. We've got this far by working together, and by talking and listening to each other. We will continue our

work in the New Year. I believe you can do it, and I'm here to help you, just as I've been doing over the past three-plus years."

Wednesday, 19 December 2012

Waving goodbye tonight

If you've read through my blog you'll know that one of the most supportive people on our anorexia journey was the school nurse.

It was she who first told me about what treatment was available for eating disorders and, basically, held my hand while I was going through some pretty nightmarish experiences as Ben slid into anorexia during the late autumn of 2009.

She also went out of her way to help Ben in whatever way she could, letting him use the school medical centre as a bolt hole when school got too much for him, even spending hours walking with Ben around the school grounds in attempt to calm him down.

Since then she has continued to be a fantastic support and always eager to catch up on how things are progressing. Also, it was the nurse who first suggested I put our experiences into a book (the book which I am still tweaking and which will be published soon).

She is leaving the school today. Over the past few summers she's been working with rescued child soldiers and AIDS children in Uganda and she has now decided to focus on this full-time.

So tonight the school is hosting a special presentation in her honour. Naturally Ben and I will be there.

I suspect other families and current and former students will be there, too. Because I imagine there are many others who are eternally grateful for her support and genuine compassion.

She will be sorely missed at the school. However I tend to think that the children in

Uganda probably need her more than British school children.

Wednesday, 19 December 2012

Frustration!!!!

Over lunch we've just had another chat about things, using our Contract as a base for the discussion. I have outlined, again, what I plan to do in 2013 - and why. And also why he can trust me to not "go mad", "deceive" him and why I will - as I said to him - "do what's needed to get you where you need to be. You need to trust me on that. And you know why you need to get there."

But, oh, I could scream when he said: "Some days, though, like when we're having lamb or whatever, I'd prefer to only add half a tablespoon of oil to fry the onions in, not a full tablespoon".... *scream!*

"I'm a bit concerned that you're thinking this way at this stage," I responded. "Most people just lob in the oil, butter or whatever - and they certainly don't go for half tablespoons of the stuff. Not unless they're on a strict slimming diet - and you're not."

"But I am getting all the fats I need..."

"That's why we're doing the experiment in January," I said. "To see if you are. And one day you'll have more, and another you'll have less but it needs to always be over the minimum. We are focusing on getting your brain healed and getting your life back."

Scream!

And especially "scream" considering that it is now approximately 26 months since he first "turned a corner" in the recovery stakes. 26 months of slog and he still worries about bl**dy tablespoons of oil used to fry onions for the evening meal!

I know CAMHS and I didn't always see eye to eye, but I do miss their input - and it's nearly a year since Ben was discharged because he'd reached the age of 18.

He still believes he doesn't need any further professional help. But it is so incredibly hard for me to sort all this out alone. The fact that he is still arguing over half tablespoons of oil makes me feel as if I have failed. Sometimes I wonder whether we'll be in exactly the same place this time next year.

If it was any other illness then your child would work with you hammer and tongs to ensure full recovery. But, as I think I said earlier, with eating disorders it's like the lifeboat sailing up to the sinking ship and offering to save everyone on board. But they refuse.

Crazy, but that's the way it is.

The even crazier thing is, as I said to my H on Saturday afternoon... what exactly is he still so afraid of? That he'll put on a few extra kilo and "get fat"? And then what? No-one will like him? He'll become unpopular? Like he used to think at the start when in pursuit of the all-important 'six-pack'.

Hello-o-o-o-o...? It's the eating disorder that's decimated his social life and popularity. Being skinny has ruined three whole years of his teenage life!

If it was you or me then we'd want to kick it out of our lives as fast as we could. Blimey if I thought a few extra kilo could heal my mind and make me want to live life again to the full... to get me back where I was all those years ago when I was the most popular boy in my social circle... I'd be eating food as if there was no tomorrow! Especially at this late stage. *Bring on the pizzas and pies!*

Has he learned *nothing* from this experience, I wonder? Can't he see how much the ED has stolen from his life? Why is he hanging onto it for dear life? Why can't he just say, at this stage, "Okay, mum, you do whatever it takes. You know what you're doing. Here, I am putty in your hands, do your stuff, rid me of the ED"?

Get my drift?

I just find it soooooo hard to understand.

Sigh...

Thursday, 20 December 2012

I am privileged to have known this woman

Last night the huge school theatre was packed with well-wishers for the school nurse's leaving presentation. What quickly became clear is that there were scores of other families who she'd helped - way over and above the call of duty. And the funny thing was, I suspect each family felt that they were the most important family to her. Unlike many other clinicians, she didn't always keep a "professional distance" when genuine love, humanity and compassion were needed. She is loved by hundreds, probably thousands of people.

One mother stood at the front, talking about the way the nurse had been amazingly supportive to her and her family when her daughter developed a serious heart condition. It could have been our family she was talking about, only it was a different illness and a different situation. Just as with Ben, she had opened the medical centre as a "bolt hole" for when this girl was being bullied by her peers about her illness. (Some children are really horrible, aren't they?) And the nurse and this family became very close.

"I can't describe what it's like to hold your unconscious daughter in your arms, seeing her turn blue in front of you," the mother said, choking back the tears, describing one of the lowest periods in her daughter's illness. It was the school nurse who helped her come to terms with the illness, pick herself up, dust herself down and do what needed to be done. In other words, to find the courage and strength to face it and deal with it as best she could - and help her daughter towards a recovery. And the nurse was always there, at the end of the phone, email or text, or in person, to provide extra support and advice - or simply a shoulder to cry on.

It all sounds so familiar. Like the time the nurse invited me round to her house for lunch. And the other time she took me out for lunch so I could chat. She didn't have to do that. It wasn't part of her job description. But she did. And I suspect she did it

for many other people. As someone said: “Her house is like an ‘open house’. There are always people there - friends, neighbours, people from church, former school pupils and families...”

“Big hug!” I said to her as we left, giving her a massive bear hug and wishing her all the best for the future. “I can’t thank you enough for what you’ve done for us.”

She wanted to know about the book. After all, it was she that insisted I write it in the first place.

“I’ve got a published proof,” I said. “But I want to re-write some of it. Parts of it just don’t get across exactly how bad things were - or how good once things began to turn around. It feels a bit flat. I’ll be doing some more work on it.” I promised to mail a copy out to her in Uganda when it’s finally finished.

Why has she decided to leave everything - a comfortable house, lovely job, good income, friends and family - for a village in Northern Uganda? (“I’ve insisted on a sit-down toilet,” she said. “And a big table where I can sit down and talk to people.”)

“It was one of the boys in this photo,” she explained during an illuminating power-point presentation. “He’d seen both his parents killed in front of his eyes and would sit there silently, blank eyes, no emotion. And he’d shrink from human contact.” During the summer that she was in the rescue village, she gradually began to get through to this boy. It took weeks and weeks, and it wasn’t until the penultimate day of her stay that she finally got a result.

“We took the boys swimming,” she said. “I decided to place a towel around his shoulders. He didn’t need a towel, of course, out there it’s so hot you just dry naturally, but I thought, hey, I’ll just do this and see what happens. And almost immediately he pulled the towel around his shoulder and nudged himself over to me for a cuddle. Probably his first warm human contact since his parents were killed. It was at that point that I realised you can’t just dip in and out of this thing. You can’t just go for eight weeks or whatever, do some good and then come home. By coming home I was breaking that precious new bond and I found it difficult to handle.” That

was when she decided she had to do this full time.

And, you know, she's not being paid for it. She is depending on prayer and her rock-solid Christian faith to see her through the next few years.

Plus, as her (equally amazing and also on the school staff) brother suggested to us, tiny monthly donations from friends and other contacts. As he said: "She's worked out that she can live there and do her work for just £500 a month. If 100 people each pledged £5 a month, then she can do it."

What a woman. What a faith.

Friday, 21 December 2012

Everything is going okay...

Following last weekend's outburst, everything seems to be going okay - almost as if Ben had "let of steam"... which is what he claims it was. As I write, he is singing at the top of his voice, about to walk up to the local charity shop where he works on Friday mornings. Our diet has improved this week in that we've had more fats, especially Omega fats which are good for the mood. Plus, Ben has agreed that the GP can refer him for further NHS treatment.

The contrast between yesterday's GP visit and ones we've had in the past couldn't have been starker. I put the GP in the picture about Ben's eating disorder / mental health history, described the depression from last weekend, the suicidal threats and the outburst at the psych session. I also told her that Ben's been seeing private psychs and a private dietician. Plus, I told her that Ben wants to come off the *Fluoxetine*.

Then I let Ben take over as she asked questions. He was very positive and articulate. And, importantly, very open to her insistence that he does need further mental health treatment. I was waiting for him to protest, but instead he was obviously taking everything in.

And I am so pleased she didn't go down the "If Ben doesn't want treatment then we can't make him have it" route.

In fact I was quite impressed. I only wish we'd seen her three-plus years ago when we first went to the GP about Ben's emerging eating disorder.

The only thing that niggled me (and Ben, for that matter) was when she said: "You look well. You look healthy. A lot of the teenagers I see don't look so good; they have cancer and so on. You are fortunate to be healthy and well - and maybe thinking about others less fortunate than you might help to raise your mood."

Dear GP, Ben is not strictly "healthy and well", not inside his mind at any rate. His body might be "almost there", if still a bit on the thin side. Ah, if only remedying mental health issues was as straightforward as thinking of people who are worse off than yourself...

Sorry, but one of the reasons we are here is because Ben can't feel any emotions at the moment, except extreme ones. He has just said that he can't feel joy, happiness, sorrow, empathy, sympathy, etc.

But apart from that - and the fact that he is still socially isolated (scream!) - things really aren't too bad at all.

Saturday, 22 December 2012

As this year draws to a close...

It's been a hell of a year in so many ways. Thankfully, despite slow progress and the odd blip (some more blip-ish than others) if you met Ben right now you would think he is a normal boy looking forward to his 19th birthday tomorrow (movie and a meal) and to Christmas with his family. This week he hasn't appeared anxious; indeed he's been relatively chilled. This is fantastic news, especially after last weekend. But what about this year, hey?

First, in February my dad finally passed away after a long illness. Despite this, it

was a shock and I really do miss him this Christmas, even though - as a quiet man - he always took a back seat over the festive season. What I do remember acutely, though, is when I was a child at Christmas. Dad would be off work for a week and I have memories of building snowmen with him in the garden, painting together (he was very creative) and listening to him read stories to me. He loved the *Just so* stories by Rudyard Kipling; my favourite - which I used to get him to read over and over again - was the *Elephant's child*. And I suspect it was dad that put together our Christmas stockings which miraculously appeared at the end of our beds - full - on Christmas morning.

In March, Ben was discharged from CAMHS because he'd reached 18. Also the psych was leaving on maternity leave. Despite our ups and downs with CAMHS over the 25 months we were with them, I felt - and still feel - as if we were being cut adrift in the ocean to fend for ourselves. It's one of the reasons why I believe Ben's recovery has been slower this year. Thankfully, the GP has just referred him for further mental health therapy.

My dear friend, Sue, passed away in May. I miss her, too, at this time of year. She and her husband spent last Christmas with us. She was getting increasingly anxious about having to buy, prepare and cook a Christmas meal, so I invited her round here instead. I have some lovely photos of seven of us at the dining room table on Christmas day: tiny Sue sitting by the window smiling - and, later, in the living room as we all exchanged gifts. I hope I helped to make her last Christmas special in some way...

2012 was the year that Ben did his A-levels and won his place at university. But it's also the year when he came back from university after just two days. At the moment I'm really not sure if he'll be ready to try again in 2013; it might need another year.

2012 is also the year when we spent quite a bit of money on private treatment for Ben without really achieving very much. It could have worked; only Ben wasn't really cooperating. Last weekend was a prime example. But, looking back, his behaviour

wasn't unlike the behaviour occasionally exhibited at CAMHS, even long after "Ben turned a corner". He'd often get into a heck of a mood during the sessions and I have a hunch it was because he didn't feel the discussions were relevant. I know he especially hated (and hates) it when therapists delve back into his past to find a "cause" for the anorexia.

2012 is the year when I completed the first proof of my book: *Please eat...* I have two printed proofs sitting in front of me as I write. But I'm not publishing it yet. Having been through my 2011 blog posts in detail recently (with a view to publishing them), my book still needs a bit of work. Hey ho... I've been working on it for a year!!! I've just sent off for a printed proof of my 2011 blog posts which will make a useful reference tool for editing / expanding *Please eat....*

Why am I published my 2011 blog posts? Because the PDF on the right is really too long to print out and I thought it might be easier for people to read it and refer to it in book-form. Later in the year I'll publish the 2012 posts in the same way. And, following that, I plan to publish my own teenage diary from the 1970s! Oh, and there's still a biography I've been working on for *years* which needs writing up - nothing to do with eating disorders!

Saturday, 22 December 2012

What about Batty, though? What's going on?

Another reason I've found it so hard to complete my book in the way I would like is because, for the past couple of months, I've feel really weird. I've felt kind of numb, almost as if I'm observing life from a distance rather than being part of it. The build-up to Christmas has felt really strange, almost as if it isn't happening. It's felt like one massive effort to do anything and "get in the mood". Why do I think this is?

It could be because I'm still on the *Fluoxetine* and I know that, before, it made me feel a bit numb. So maybe it's time to wean myself off it. And yet at the same time

I've been incredibly anxious. I keep having to tell myself to "Stop it!" whenever I feel the spiral of panic about to spring off in my head. What am I panicking about? Last weekend, obviously, I had a reason to panic. But, on the whole, I should be feeling pretty okay. Yet I'm not feeling "low" in the conventional sense. Just numb. Just "going through the motions" like a machine.

As a result I'm finding it difficult to write. My emotions, my feelings, my passion... all the stuff I put into my older blog entries which becomes clear to me as I re-read them... it's gone curiously AWOL. It's not because I don't want to write; I do. It's because I'm so very, very numb that I can't.

And I'm tired.

Most nights I'm having nightmares. More often than not I'll wake my H up by shouting something in my sleep and moaning and groaning.

These nightmares usually take the form of either finding myself in the old family home (which mum sold and moved out of in the summer), realising I shouldn't be there and having to explain my presence to the new owners. Or suddenly realising my dad's on his way home and he'll find that we've sold the house and disposed of a load of stuff. Or the new occupants are making structural changes (which they are) and - horror! - what will dad think when he finds out!? Plus finding it difficult to handle all of this, because it was my family home for the whole of my life. A kind of anchor that I no longer have, exacerbated by dad's death this year. Even though dad could be really irritating, he was still an "anchor". He was always there, no matter what.

Recently I'm finding it very hard to relax. I can't sit down and read. If I do, I'm doing nervous / anxious things like biting my nails (disgusting!) or twisting my hair. It's as if I'm on permanent red alert. Yet at the same time I feel completely numb.

Thank God my sister is doing Christmas Day this year because I wouldn't be able to get my head round organising Christmas Dinner and Day.

This is really strange because, normally, I'm the one that goes mad at Christmas

with all the sparkling lights, decorations, music, treats, food, etc etc etc...

The best way to describe it is that my brain feels like my old laptop. I'd press the "on" switch and it'd whir a bit, ready to boot up, and then just fizzle out to nothing. That's how I feel.

I am completely numb.

I do hope it's only temporary...

Wednesday, 26 December 2012

2kg down, but wheels already in motion to put it back on again

I would hazard a guess that there are very few of our children with eating disorders that actually gained weight over Christmas, despite their worries, year upon year, that they will get fat... I might be wrong, but it always seems to be the case in our house. Yesterday was our fourth Christmas Day with ED. Can you believe that? But the good news is that...

... despite the scales telling him he'd lost 2kg since he was last weighed, the wheels are already in motion to put it back on again. He immediately volunteered to have an extra 200 calories a day for a week and, so far, he's playing ball. Quite willingly, in fact. Which is why, even though it's our fourth ED Christmas, it is tonnes better than last Christmas, the one before and most certainly the one before that.

Ben was anxious in the lead up to the Big Day, but not as anxious as I've seen him before. However he still wanted to know what the menu was, in detail. Of course I didn't collude with the ED and was suitably vague.

But we couldn't help notice that Ben was selective in what he ate over Christmas dinner.

Having said this, he did eat a decent meal, and also had a second helping. But he didn't have any Christmas pudding, despite having made it himself - and he just snacked on dried fruit and roasted chestnuts for the remainder of the day.

Would it have been different, I wonder, if he'd known he was 2kg down?

And we went out for a meal on the 23rd - Ben's 19th birthday.

I can't believe we've had the eating disorder for four Christmas Days now...

I do hope all my blog followers had a reasonably good and ED-free Christmas...

Wednesday, 26 December 2012

Seeing at it's Christmas, let's be angry with the church again...

Yesterday my travels took me past "that church" several times - the church Ben and I attended for a year or so. My attendance was sporadic, but Ben attended religiously, walking the 30 minute walk there and back every Sunday morning over an 18 month period. As you know from previous blog entries he went out of his way to try and fit in, and to get spiritual help - and the church failed him. Read more about it here.

Despite me explaining this to the pastor in November (and earlier, in January), the church has done nothing to attempt to win Ben back. I guess I kind of hoped they'd make a move and get in touch with Ben, invite him to a few activities, talk to him, include him... Especially with Christmas on its way. Good God, there must have been at least one young people's Christmas activity or event they could have invited him to!!!

But we heard nothing.

So that's twice in total over the past 12 months that I've been to see the pastor to ask him to help Ben, because - back then - Ben was crying out to be included in the church. And twice that the pastor - and the church - has failed him.

And, yet, I suspect they continued with their cosy Christmastide build-up - the cosy cliquey family that talks so much about "reaching out to the community" and the "needy", and doubtless does in the missionary money they send abroad, but when someone right on their doorstep reaches out - just about as obviously as you can reach out to someone - they do nothing.

And continue to do nothing.

In November I asked on this blog if I still felt angry with the church.

I didn't back then. Well, not really.

But I do now.

Especially as it was one of the only social outlets which Ben has actively sought out over the past couple of years. And persevered with.

Now he lonelier and more solitary than ever - and without the spiritual "hope" he had for so many, many months.

I remember the day he gave up trying. It was as if someone had switched the lights out and there was darkness. And it's probably not a coincidence that Ben's mood took a nose-dive afterwards and still hasn't recovered. Viz last weekend as a prime example.

This boy had hope. But in early 2012 he lost that hope - and I believe it has been one of the contributing factors to a slowing of his recovery this year.

I think this is one of the reasons why I've felt so numb this Christmas. I am angry with the church and with religion. Yet Christmas is all about religion. At least it is to me. Otherwise there is little point in it. I certainly don't celebrate the festive season to keep the supermarkets and department stores in profit. And I don't much see the point of celebrating mid-winter like the pagans do. Mid-summer, yes, but not the deep dark dank cold rainy mid-winter. But Christianity... well... it really is what Christmas is all about.

But when that very religion has let you down so disgracefully and you and your child are hurting as a result... well, sorry, but I'm not entirely sure why I'm supposed to be celebrating?

Thursday, 27 December 2012

Why do they insist on doing it?

Yet again I'm hearing of a family where the treatment team is insisting on what the parents believe to be a sub-optimum weight for their daughter as far as full Weight Restoration is concerned. I can't count the number of similar complaints I've heard from families, ours included.

So why do eating disorder treatment teams insist on doing it?

At one point, my H and I gave our team the benefit of the doubt. As they'd always gone on about drip-feeding scary concepts to my anorexic son so they didn't freak him out, we assumed - for a while at any rate - that maybe this was their plan with references to his WR weight. In other words, they'd get him to the next level before drip-feeding the concept of moving onwards and upwards.

Maybe they were. The problem was that my son was discharged almost a year ago once he reached 18. So the drip-feeding - if indeed that's what was planned - was never followed through. Instead my son was left insisting that it's perfectly acceptable to aim for and remain at a weight "he feels comfortable with", a weight that is just within the so-called "safe" or "healthy" range. Yes, he agrees his weight will need to increase slightly as he grows older, but only in relation to his current weight i.e. 2kg more between now and his 20th birthday in 12 months' time.

Yet over Christmas he lost 2kg which pushed him back into the "unhealthy" weight range which just goes to show how easy it is to slip back again.

Not only this, but if you try to maintain your weight at a sub-optimal level I assume your body will always be fighting to attain its natural set weight which could actually be far higher.

And someone who is still terrified of edging their weight up by a few kilo is someone that isn't fully recovered, is it?

As someone once said when I blogged about the time one of our treatment team said: "Some young people choose to remain at a low weight and if that's what they

want, then that's perfectly okay" (or something along those lines)... read "Some young people choose to remain sick".

Before the eating disorder muscled its way into Ben's life he was a strapping 12 stone rugby player. He played Number Three in the team - a position given to the bigger, stronger, more muscular boys. This was when he was 14 / 15 years old. He looked fantastic!

12 stones equal 76kg. Mention this to him these days and you risk your head being bitten off as he barks: "That was purely because of the rugby. I don't play rugby any more or do any sport for that matter [except the odd run and free weights sessions] so you can't expect me to be that weight again!"

Fair enough.

But we can expect his "set weight" to be significantly higher than it is at the moment - and this is the massive challenge facing us this year.

And it's not as if I can go along to the GP and ask the GP to "prove" to him that he needs to weigh more because each time we attempt to get a medical professional to do this they can't see any problem with his current weight.

As CAMHS said to me shortly before we were discharged: "There isn't a GP in the land who will argue that Ben's weight is too low." The reason being because "the charts" say he is within the "healthy range".

Which leaves my H and me fighting a lone battle - just as other families are doing as their children hover around the "healthy" weight range, dipping in and out every time they lose weight for whatever reason: illness, Christmas anxiety, other anxieties, etc.

Friday, 28 December 2012

"Why are you obsessed with his weight? It's only 2kg", comments Anon. Here's why...

Don't get me wrong... I welcome all kinds of comments on my blog. Often, like the comment I received the other day, it inspires me to write about why I do the things I do and worry about the things I worry about. So when Anon posted "Why are you obsessed with his weight ? It's only 2kg" [about Ben's 2kg weight loss over Christmas] I couldn't resist responding here...

When, as a parent, you've been fighting your child's anorexia for three-and-a-half years, any weight loss sets the alarm bells ringing.

After all, it was steady weight loss... which crept in almost unnoticed... that triggered the eating disorder in the first place. Gradually, over a period of ten months or so, Ben somehow managed to lose one quarter of his bodyweight at a rate of just under 2kg per month. So when he loses 2kg in one week, I naturally get anxious.

When he began treatment I insisted on implementing an eating plan which resulted in 3kg of this lost weight being re-gained before Ben "downed tools" and refused to cooperate any longer. I wasn't supported by our treatment team. Control of his food intake was handed back to Ben because it was felt that this would be "more helpful" to him than "mum's eating plan".

Over the following ten months he gradually and consistently lost weight again until - in February 2011, 13 months after he began treatment - he reached his lowest-ever weight. But again the weight loss was so gradual that the alarm bells didn't appear to be ringing in the clinicians' ears. Half a kilo here, point one of a kilo there... So, again, a loss of 2kg in one week makes me want to take swift action.

Twice Ben was hospitalised with a dangerously low pulse rate (29bpm). Heart failure is one of the most common causes of death in eating disorders. The heart is a muscle after all and former rugby *prop forward* Ben had lost a massive amount of muscle as well as fat.

As *Eatingdisordersonline.com* says:

Rapid weight loss as can occur with Anorexia Nervosa can cause dramatic, unhealthy, and dangerous changes in the heart and sharply increase cardiovascular risk. Anorexia has been associated with mitral valve prolapse, supraventricular and ventricular dysrhythmias, long QT syndrome, Bradycardia, orthostatic hypotension, shock, chronic heart failure (CHF), and even sudden cardiovascular death.

These fancy scientific words describe a variety of conditions, but in general, the heart of an Anorexic or person who engages in restrictive eating patterns and experiences significant weight loss, will take a physiologic beating. The heart muscle may be weakened in a variety of ways leading to low blood pressure, an irregular heartbeat, a slow heartbeat, and even sudden death.

When you've sat beside your child's hospital bed... not once but twice... worried sick that their heart might give up any moment, weight loss takes on a whole new and deadly meaning.

I still have regular flash-backs to the days when I was convinced that something - either self-inflicted (e.g. suicide) or a side-effect of the anorexia (e.g. sudden cardiovascular death) - would rob me of my precious son.

All of the above have been primary drivers in my fight to help my son recover from this devastating illness and ensure that, if he does lose weight - whether as a result of illness, anxiety or food restriction - it is quickly reversed.

Ben has said: "The anorexia stole three years from my life; I'm not letting it steal any more" which is why he, too, is keen to kick the anorexia out of his life and reverse any unexpected weight loss. He knows that I am a vital part of "our team" (as we refer to him and me versus the ED) and knows exactly why I do what I do.

Thank God I never sat back and thought "Well, it's only 2kg..." or whatever...

Someone who doesn't understand what we parents-of-anorexics go through might accuse me of over-reacting.

But, to be frank, I'll do all the over-reacting I need to ensure my son not only stays alive, but eventually gets his proper, full, fun-filled and rewarding life back.

Sunday, 30 December 2012

Comparing notes with my mother-in-law

Back in September 2009 it was my mother-in-law who suggested I take Ben to see our GP. She lives abroad and doesn't see us that often, so when she saw Ben following the summer of Drastic Weight Loss in 2009 she immediately noticed the difference. We, on the other hand, had been with him every day. As a result the dramatic weight loss wasn't as evident.

She's been with us for the past few days and today she and I had a chat. We don't always see eye to eye, but I guess that's not unusual with mother-in-laws and daughter-in-laws. But what we do have in common is that we've both had to deal with sons with mental illnesses. Hers (my H's brother) was diagnosed as bi-polar and her family went through a terrible time a few years ago.

Back then, long before the eating disorder arrived in our family, I didn't "get" what was going on. I wasn't sympathetic, especially when she'd drive up to see us for a few days only to rant and rave about the latest chaos caused by her son who was quite ill at the time.

I just wished she'd shut up and stop going on about it. And, like many outsiders to the world of mental illness, I felt she must be to blame.

I feel bad about that now. Today is the first time we've really talked about it as I don't see her very much. But we have a heck of a lot of common ground. The difference with her, however, is that her adult son refused to let her be involved in his treatment. Like the eating disorder, he was often irrational; merrily arguing that

black was white. She went through a horrendous time. I am so fortunate that, so far, Ben is happy for me to be involved in his recovery.

We talked about how it's ridiculous that, legally, parents can't be involved if their 18-plus offspring don't want them to be.

She says that she often felt she was to blame for the illness. However I assured her that, knowing what I know now about mental illness, it is probably a genetic thing. These are biological illnesses and something to do with the brain being "wired up" differently. We parents are not to blame.

As I said, we don't often get the chance to talk with each other. She lives abroad most of the year and in London occasionally, with her daughter. We live in the North of England.

Also, we don't always see eye to eye. But sometimes we do and we get on okay. Like today.

But I still feel bad about the insensitive way I used to handle things when she was going through such a terrible time with her son.

Monday, 31 December 2012

Firing on all cylinders ready for the New Year

It's the final day of 2012 - and the end of my blog posts for this year. Tomorrow we begin our "fats experiment" whereby we spend a couple of weeks closely analysing (and adjusting) fat and calorie content of Ben's intake, preceded by a weigh-in session. I will also be measuring his height. Then, each week in the New Year, I will be introducing new challenges / experiments / tests / whatever with a view to making 2013 the year that Ben really does recover fully and permanently.

I am a Mum on a Mission and am raring to go. We will also be adjusting our Recovery Contract to take into account everything that needs tweaking for 2013 with a view to moving Ben onwards and upwards.

Yesterday my H said to me: "I don't believe Ben will ever fully recover." Now, as you can imagine, this was like a red rag to a bull as far as I was concerned. H believes I am wasting my time and energy. "Well," I told him. "I will continue to do whatever it takes to get Ben well. I will fight tooth and nail. And if I fail, then at least I will have tried my hardest." Basically Mama Matty doesn't take "no" for an answer. Failure is not an option.

But, first, let's get through the "fats experiment". Then, next week, Ben is being assessed for further treatment on the NHS. Good grief, that assessment appointment came through a tad faster than when I first asked our GP to refer Ben for treatment back in the early autumn of 2009. Remember how I was told we'd be looking at an 18-22 week wait? And that was from the date I received the acknowledgement that CAMHS had received the referral.

Mind you, this is just an assessment. There might be a wait following that. And, of course, we have no control over who Ben is referred to. I will be pushing for eating disorder treatment. But I'm not holding out much hope. Unfortunately the Yorkshire Centre for Eating Disorders doesn't take people on with BMIs of higher than 17...

... Which, of course, is ludicrous because - during his entire eating disorder - Ben's BMI never got that low. Yet he had full blown anorexia. At one point his weight was one third down on his pre-eating disorder weight. So, presumably this means that a heck of a lot of adults are slipping through the net, being refused treatment because their BMI isn't low enough.

But I will ensure I'm present at the assessment to make sure the assessor knows exactly what needs addressing. And, with all my years of experience behind me, I instinctively know when the professionals are talking rubbish, don't take us seriously or treat me like an over-protective mother worrying about nothing.

I will be in a fighting mood, believe me.

Monday, 31 December 2012

Your essential ED-beating toolkit for 2013

If you've never visited *The New Maudsley Approach* website and read through it in detail then I strongly suggest you do, in preparation for whatever it is you need to do to help your child recover from their eating disorder in 2013. It is packed full of tools and techniques for carers to use - evidence-based stuff that's aimed at helping you to get the best response from your child at a time when it can seem as if all they're doing is resisting logic and action.

You will find a tonne of skills which you can learn and use to - hopefully - achieve results. Many of these, for instance questioning / listening / motivational interviewing techniques, are tools we learned at the FEAST UK conference back in November - taught by Gill Todd and the very excellent and awesome Professor Janet Treasure. And they are *brilliant*.

As part of my Mission for 2013 I will be practicing these skills to enable Ben to move forwards, believe in himself and come to see full recovery and LIFE as something that's attainable and which he and I can work on successfully in partnership.

Plenty of meat for more walks and talks in the countryside, me thinks, in 2013.

When it eventually stops raining and the mud dries out a bit!