

Anorexia Boy Recovery

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

Part 3 – 2013

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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 2013

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.

Tuesday 1 January 2013

Starting as I mean to go on - revised Contract

My first job of the New Year has been to revise the Recovery Contract in line with everything that needs working on at the moment. The aim is to kick-start the recovery process again after being in a bit of Limboland / Doldrums over the past month or so.

Here's what I've come up with - to be discussed with Ben at some point this afternoon. Remember, I have always positioned our Recovery Contract as something that is mutually agreed. Everything is discussed on neutral ground and no-one is permitted to dictate to the other, lose their temper, etc etc.

And this afternoon we will measure Ben's height to check everything is okay in that respect. Tomorrow we will weigh him and begin our 'fats experiment' which, as you may remember, is to check that - what I believe to be a recent move towards a fat-reduced intake - does in fact include sufficient fat.

We will also be going back to 'proper' calorie counting for a few weeks, just to get back on track.

Basically, everything I will be doing from today onwards is to ensure that Ben's recovery gets its momentum back. As I said to my H this morning: "I have met several former anorexia sufferers, now in their twenties, who are fully recovered and are adamant that they will always do whatever it takes to ensure ED never, ever enters their lives again, including the need to put on sufficient weight, maybe even more weight than they ever imagined they would need to do, and the willingness to eat challenge foods. These young people realise that 'Food is Medicine' and they will do whatever it takes to stay well."

Then I added: "I can't for the life of me see why Ben shouldn't be up there with them, thinking and behaving like this. They are proof that it can be done. It's ludicrous to assume that he could never achieve that, given the right support and treatment. In fact it's more than ludicrous. The problem / trick is to get his mind and

motivation on board - and get his enthusiasm for full recovery back. This is my primary job and driver for 2013.”

Anyway, here is the new Contract (and you can find out more about our original Contract on my blog and in my other books):

#1: Food

X,XXX calories per day (to be agreed)

If fortnightly weight gain goals are not met, calories will be increased by 100 per day (and adjusted if necessary the following fortnight)

#2: Weight Gain / Maintenance

A weekly average of 0.5kg is expected in line with BMI for age / weight / height TBA.

Maintenance weight is the mean within agreed tramlines TBA

Fats to be the mean within government tramlines

Weigh-ins are fortnightly

#3: Mood / General

To agree to working through this with mum i.e. ‘points chat’

‘Do points’ daily again [we have lapsed to weekly]

Make notes of current challenges / issues on mind / fears etc

#4: Exercise

Check it continues on track, within agreed parameters

#5: Rewards - Points system

Food:

★ 1 point per day Ben keeps to agreed calorie and fats total

★ 1 point for every day Ben brings in ‘fatty’ challenge food to maintain fats total

(diet / fat reduced foods don't count)

- ★ 3 points deducted for dishonesty / unacceptable behaviour

Social:

- ★ 3 points for every social activity with friends: pubs, parties, movies, meals, etc (not Games Workshop, school teaching or charity shop). One social event min per week.
- ★ 1 point for every PHAB meeting attended, school and charity shop

Other challenges:

- ★ TBA / discussed - what really does constitute a rewardable moving forwards challenge these days?

Treatment:

- ★ 3 points every time he attends treatment sessions willingly and cooperates
- ★ 2 points for doing 'homework' following treatment
- ★ Up to 4 points for refusing treatment or non-cooperation

Tuesday 1 January 2013

We have just had such a GOOD CHAT - what a great start to 2013

I've just been through my proposed revised Recovery Contract with Ben and he is happy with it. We also had a long and very fruitful chat, using my newly acquired (but still fledgling) 'motivational interviewing' techniques learned from the New Maudsley Approach website. Really and truly this is THE MOST AWESOME way to discuss eating disorder / recovery related things with your child.

The upshot is that Ben feels massively better than he felt a couple of weeks ago when he told me he felt suicidal and we had that dreadful meeting with the private psychologist when Ben was effing and blinding throughout.

He does wonder whether the severe dip in mood had something to do with the way he suddenly came off his medication (*Prozac*) when you're supposed to wean yourself off it slowly.

I also wonder, as you know, whether it could be something to do with a diet that is too low in essential fats, which is why we are beginning the brief 'fats experiment' tomorrow.

He's not too keen on doing that, mainly because it takes him back to minutiae which he is trying to break free from. "I can really see why this may seem like a problem to you - not ideal, and all that," I said. "But you can see why it needs to be done, at least for a few days, just so we can check we're on track." I told him I'd do all the counting; he doesn't need to be involved.

"Thank you for sharing your emotions and thoughts with me recently," I told him. "Telling me you felt really down couldn't have been easy for you. But, as I am sure you can see, it's the only way I can know what's going on in your head and help you. So, thank you, I really appreciate it."

I told him that, ultimately, he is at the helm of his recovery and I am just here to support him when he needs it.

It was a really good conversation. Really positive. Which is why, despite the recent dips, I am convinced that he is doing just fine on the road to recovery. Maybe recovery isn't happening as quickly as I would have liked or anticipated at the start of 2011 one year ago, but we are still facing in the right direction and mutually happy to continue to move along this road together as a close-knit team.

Wednesday, 2 January 2013

Another Good Day, with Good Things happening

Ben is embracing our 2013 Plan enthusiastically. We've been counting fats - and they seem to be on target, so that's brilliant. We are still in agreement as regards the updated Contract and I have introduced new weight / BMI tramlines which he must

keep inside - slightly higher than last year, and they may rise still further, but - hey - let's do this in small bite-sized stages. This way it's easier to get him used to change.

We've agreed to weigh him on Saturday. As you know, he lost 2kg over Christmas and has increased his calories in a bid to put it back on. I have said that his weight needs to move upwards slightly so it's within the new tramlines. "Imagine if you got the Norovirus (winter vomiting bug)," I said to him. The last thing he wants is to find himself facing the old ED behaviours again and I believe he will cooperate fully with me to ensure his weight stays in the right place.

I told him that the calorie total he'd been working with before Christmas was too low for him - proven by the weight loss. He seemed to accept this.

And all this without any stress. Indeed his mood has been positively upbeat over the last day or so making a fabulous change from before Christmas. Maybe it's because the anxiety of Christmas is over - Christmas is notorious for making people with eating disorders feel over-anxious.

Ben has been singing. He's also been posting positive messages on Facebook about feeling happy.

So, thus far, our 2013 Plan is working.

Fingers crossed for the rest of the month!

Sunday, 6 January 2013

Take a deep breath and patiently wait to ask him...

One of the many, many things I've learned in my three-and-a-half year battle to get my son recovered from anorexia is that patience is most definitely a virtue. I am usually impulsive. I react, guns blazing, and think afterwards. Over the years it's got me into one or two scrapes and I know that, as far as eating disorders are concerned, and especially approaching your child about something that's worrying you about eating disorder behaviours or compulsions, needs to be approached with patience, diplomacy and caution - to get them on your side, avoid yelling at each other and

getting nowhere.

As a result I am breathing deeply and donning my “patience hat” until we do our “points” (Recovery Contract) after lunch to find out what was going on at 5am this morning.

H heard some noises upstairs - enough to wake him up and he’s a deep sleeper. He crept upstairs, opened the door to Ben’s room to find him doing his “exercises” i.e. press-ups, crunches, sit-ups, etc.

Now, ever since we knocked the compulsive exercising issue on the head by incorporating it into our Recovery Contract, we have been aware that Ben does exercise. But only within certain allowed parameters (which do include press-ups, crunches and sit-ups). And I trust him to have kept to these over the past 18 months or so.

“I’ll give him the benefit of the doubt,” I said to H when he told me. “It could be that Ben couldn’t sleep so he just decided to do whatever exercise he’d planned for the day there and then.” But don’t worry, I added, I’ll be probing carefully when we do our “points” at lunch.

Having lived in the world of eating disorders for three-and-a-half years I know that exercising compulsively during the night is something that happens frequently. And, if you think about it, exercising at 5am is most definitely NOT normal. Okay you see some crazy people running the streets in the early hours, but - in my mind - that is not normal. Not unless they work odd shifts and 5am is the equivalent of 5pm for us nine-to-fivers.

And especially if you hate exercise like Ben does.

So, you might ask, why does Ben still exercise?

Because, as it does for so many people, it creates endorphins that make him feel happier.

He also likes to keep his body toned, but - he has insisted for the past 18 months or so - in a normal, healthy way.

Yet, when I recently redrafted our Recovery Contract for 2013, I asked him if exercise still needed to feature on our Contract. Was it still an issue? Or had it morphed into normal, ordinary life?

He was adamant that he still wanted it in the Recovery Contract “because it helps me keep the exercise under control”.

So this lunchtime I will be diplomatically exploring the question of whether or not his exercise is “under control” if he’s doing press-ups and sit-ups at 5am...

Sunday, 6 January 2013

So freaking negative...

I am fed up. Fed up with working like a Trojan to help my son reach recovery from his eating disorder while being faced with someone who is so incredibly negative about the outcome - and life in general - that, frankly, I wonder why the hell I bother. It’s not in my nature to give up. After all, this has been my life for the past three-and-a-half years. But, by heck, sometimes I feel like doing so.

We had our “chat” this lunchtime about exercising. The upshot is that he always exercises like this, every day, within the agreed exercise contract parameters. Sometimes he will do it at 7am and at other times he’ll do it earlier - or later - depending on when he wakes up.

“No, I don’t like doing it; I hate it,” he said. “But if I don’t do it I will get fat, purely and simply because I like eating. You’d be amazed at how little other people eat, which is why they don’t get fat. But those that like food in the way I do get fat or obese. This is why I have to do it and I’ve been doing it for the past four years. Good God, I’ve just put on a kilo - and that’s by eating low fat stuff and exercising! Imagine if I’d eaten fatty foods and sat around all day!!”

Hmn, I thought, we’re onto a loser here...

And I was right.

So I moved on to preparations for University, if - indeed - he feels ready to go this

September. Would he feel better taking another year out? No, he wouldn't, he couldn't bear another year treading water and doing nothing.

Okay, so would a transfer to our local university be easier, I wondered? "No," he said, "Because it's a worse course - and I don't want to go there. But on the other hand I can't live away from home. Just being on my own, without you two [mum and dad] for a few hours sends my mood plummeting. When you lot went out to Haworth last Sunday and I stayed home alone, I found it really difficult to deal with. The thought of living in a university room, on my own, is like my worst nightmare." And that's even if he comes home for half of each week.

He also said that, if he went to our local university, "I risk never leaving home and getting 'out there'. I will still be here, sitting with you two in front of the telly with no friends or social life, when I'm 50".

I asked him about the idea of commuting for the first term, but he said he knew that would be "a pain in the ar*e" and he would hate that, too.

So what about lodging with someone, for instance my sister's Sheffield friends, for the days he needed to be at University for lectures. No, he said, he'd hate that too.

So does he actually want to go to University? Yes, he does, because he loves to study and he knows he needs qualifications to do what he wants in life.

"So what do you suggest?" I asked, at the end of my tether but desperately trying to appear calm, laid-back and "dolphinesque", and trying to draw on those questioning techniques I'm supposed to be fine-tuning.

"I have no idea," he said. "Because all the options are sh*t. And thanks for making me feel sh*t, mum."

I told him my aim wasn't to make him feel sh*t but to explore where he is at the moment. Planning for university - or not - is something we need to be thinking about in the coming months, sooner rather than later, unfortunately. Also, I told him I've been aware that his mood hasn't been so brilliant over the past month or so.

"And I hate going to PHAB," he added. "Going there makes me feel cr*p."

“But what about those nice girls you met there? The girls that invited you out on bonfire night (which you went to) and ice skating and bowling (which you didn’t)?”

“They’re not real friends. You talk to them and you just get one word answers. I must have some kind of aura about me that screams out to people, ‘Back off!’”

Oh b*gger, I thought to myself, and then thought to myself again.

Why is he so freaking negative about everything? Especially when I try so freaking hard?

Wednesday, 9 January 2013

Severe writer’s block... durrr... brain like mashed potato...

Sam Thomas of Men Get Eating Disorders Too has asked me to “guest blog” about my newly published book (see right). But my mind has gone completely blank. It’s as if I’ve never put pen to paper (or rather fingertips to keyboard) in my life. The same thing happened when I tried to blog here about a really fruitful “walk and talk” I did with Ben this afternoon. Durrr.... my brain is like mashed potato... I think Batty’s brain is on sabbatical.

If you’ve read my blog you’ll know that every so often I go into “screensaver” mode when my brain just stops, dead, and becomes like a lump of mashed potato. It’s usually after a particularly harrowing period or a period of intense activity. In my case it’s probably because I’ve been frantically proof-reading / tweaking my book prior to publishing, and then proof-reading and doing the same with the 2012 version (and not doing very much about my “Please eat...” book which is on a back-burner until I get around to re-working those final chapters).

Aaarrggghhh! Too much writing! Too much thinking! Too many other things going on at the moment!

And on top of this there’s the little issue of “real work”. You know, the thing you do during the day to earn a crust? The trouble is, when I’m brain dead I can’t do this either. I write for a living, you see. (No, not my books, I make virtually nothing out of

them.)

The thing is, when you have writer's block you just can't write - and it applies to anything. Heck, I can't even sum up enough active grey matter to write a shopping list!

So this afternoon Ben and I took advantage of the first dry, sunny day we've had in weeks to go walking. Just a walk we've done dozens of times before on the "walks and talks" I've blogged about so much: a two-hour circular walk through the grounds of our local stately home, close to the set of ITV's *Emmerdale*. We watched the deer and highland cattle hanging around squelchy looking fields, plus a red kite soaring across the valley towards the swollen river and up to the crags on the hill.

We talked a bit about the ED and how Ben is progressing, which is slowly but surely, despite the ups and downs of the past month or so. We talked a bit about university until he didn't want to talk about it anymore. But, mainly, we just enjoyed being out there in the rare sunshine, sun low on the horizon casting long shadows across the fields.

One thing that did strike me, though, was this...

Going for walks like this in winter often makes me feel what I call "National Trusty". In other words I want to cook and bake wholesome traditional stews, puddings and cakes.

(For my overseas followers, the National Trust is a charity that owns numerous stately homes and gardens, each with its own tearoom or restaurant specializing in wholesome home-cooked food and cakes, and often with an old-fashioned walled kitchen garden growing organic vegetables and fruit. Whenever we visit a National Trust property I always come away fired up to cook or bake good old-fashioned comfort food like stews, nut roasts, wholemeal bread or suet puddings.)

Ben and I talked about my dilapidated Cranks vegetarian cookbooks from the 1980s... all lentils, beans, nuts and wholemeal wholesome everything...very National Trusty... and how we both wanted to cook and bake the lot. Everything. Cakes,

puddings, pies... the works!

It took me back to a time, in Ben's "high anorexia period", when he wouldn't touch anything in those cookbooks, especially the cakes and puddings. Purely and simply because they contained too many fear foods. Stuff like butter and other fatty foods. Or just too many calories. He avoided these recipes like the plague.

But I hazard a guess that if I walked into the kitchen right now and baked everything from those books he'd eat any of them.

That, my dear brain dead, sleep-deprived Batty, is what I call progress and why you should feel extremely optimistic at the moment. If, my dear mashed potato brained Batty, you could feel anything at all.

I think my brain has gone away on vacation.

Maybe I need a vacation.

Or maybe I'll wake up tomorrow morning raring to go, writing for England, or - rather - writing a sales letter for a manufacturing client of mine.

But if my writing head is still AWOL then I'll postpone it and go shopping. Or baking. Or for another walk and talk with Ben if the sun is still shining.

Thursday, 10 January 2013

Brain still pretty mushy, but this is what I've written

Yes I've written that sales letter I'd been putting off - and had a bash at a guest blog for Men Get Eating Disorders Too. Despite my brain still feeling like a lump of cold mashed potato (and probably the colour of the [tasty but disgusting looking] mash-

with-chestnut-puree that Ben rustled up the other evening), this is a sneak preview of my draft:

Blogs are great, but sometimes books are more convenient!

Blogs are great. As a serial diary writer I've been doing this kind of writing since... well... for a heck of a long time: first my teenage diaries, then a regular blog for a regional newspaper, blogs for clients (I'm a freelance copywriter by trade) and - since January 2011 - my blog AnorexiaBoyRecovery about my teenage son's recovery from anorexia.

I love it when someone tells me how much my blog has helped them in their own battle with an eating disorder (I get feedback from anorexia sufferers as well as their parents). 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 with 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 trouble with my blog is that it's very long. I now have 25 months of posts - 418 in total - which are a real pain to click through because blogs aren't like books. You can't just scroll through them from start to finish and you can't easily refer back to something you found particularly helpful or relevant. Worse, much of the earlier information - for example from 2011 - risks getting overlooked altogether.

This is why I made the decision to publish my blog in paperback. The first volume (which includes an edited collection of posts from 2011) is now available on Amazon.co.uk and Amazon.com. 2012 is coming soon, plus Kindle versions of both.

Each book is over 300 pages long, so you certainly get plenty of words for your money!

Even if Ben (now aged 19) and I help just one family fast-track its way through the huge anorexia learning curve and get help, then we have succeeded with these books. And every time a parent contacts me to say how much my blog has helped them, I know it is serving its purpose.

Friday, 11 January 2013

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, I've pasted in the introduction from Volume II of my new book below (2012 posts - see below right for details). This 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.

This is why I made the decision to publish my blog in paperback, in two volumes: 2011 and 2012. This book is a collection of posts from 2012.

I hope it proves useful to you. And, if you haven't already read Part I (2011 posts), then I invite you to read this too.

Best wishes,

Batty Matty, January 2013.

Saturday, 12 January 2013

Amazon, "eating disorders" category DOES exist!

Please, please, please dear Amazon... all I want to do is get my book listed under "eating disorders" within the "social & health issues" within "biography"... yet you have insisted - twice - that there is no such category. But here I am, on Amazon, clicking "biography", "S&H issues" and - bingo! - "eating disorders" appears as a category. It's where all the other eating disorder biographies / autobiographies I've read reside. Yet you insist there is no such category! Aaaarrrrggghhh!

No, Amazon, I don't want to be listed in a different category because you insist that the category I want to be listed under doesn't exist.

IT DOES EXIST!

Pretty please, Amazon, is there anything you can do to list me in this category?

I've just fired off my third email to you, asking you to click onto Amazon yourself and click through to the "eating disorder" category.

Heck, I even described it in "idiot-proof" steps. You can't miss it!!!

Sob... all I want is for my book to be listed under "eating disorders"!

Is this too much to ask?

Sunday, 13 January 2013

Why the H shouldn't an 18 year old stay with CAMHS if they want to?

I've been scouting around the Internet looking for various statistics, including average waiting times in the UK for CAMHS treatment, and ended up on the B-EAT website, reading through a forum. The particular thread I found was started by an 18 year old who was terrified at the prospect of being discharged from CAMHS (who she had been with for 3 years). The only reason she was being discharged was because she had reached 18.

Suddenly she was faced with being torn away from the treatment team she knew and trusted, and who knew her, her background and her illness back to front - to be thrown out into the big scary world of Adult Services. She was terrified. And, from what I read, her CAMHS team didn't seem to know much about what Adult Services would offer her either.

So I scrolled down the thread and found replies from other 18 year olds in the same position: each scared witless at the prospect of being torn from the team they were working with successfully and thrown out the door, purely and simply because of their age.

Now, I suspect this is just a snapshot of what other 18 year olds with eating disorders are experiencing here in the UK. I don't doubt there are some success stories... 18+ young people that thrive in Adult Services or who never quite hit it off with their CAMHS team. Or who, by the age of 18, are recovered. Or, in our case, considered to be sufficiently recovered.

"Tut, tut," everyone says (yes, I've heard it said). "Adult Services... now that's a completely different kettle of fish from CAMHS." Followed by shaking of the head. Whenever "Adult Services" has cropped up in any conversation I've been part of it's conjured up this picture of something quite frightening and very different from CAMHS. And which may not work. Or which has a heck of a long waiting list.

And, of course, where parents are probably excluded from their child's treatment.

Plus, the over 18 child can legally refused to have any treatment at all.

But these young women on the B-EAT thread all wanted treatment. However, importantly, they wanted to stay with their current treatment teams.

It seems absolutely crazy that, if the treatment is working, that additional NHS cash should be spent on moving children up to Adult Services with the associated learning curve - of both patient and clinician. How many sessions do they have to go through before they get back to where they were in the CAMHS treatment?

Worse, how many of our children are slipping through the net at this stage and ending up with an eating disorder that lasts for several years longer than it needs to.

Or kills them.

18 is just a number. And if the child is responding well to CAMHS treatment when they reach 18, then I strongly believe that treatment should continue for as long as it needs to.

Why the heck shouldn't it?

Monday, 14 January 2013

"I miss her so much!" said Ben the other day...

Back on the 15th December, if you remember, I was worried sick that Ben was heading for a relapse - or worse. He admitted that he was considering suicide and then there was that effing and blinding with the private psychologist when he refused to cooperate with treatment. Later that afternoon I curled up in my bed, in the dark, and sobbed my eyes out, worried sick that we were heading for a relapse - and if we did, that there would be no-one to help us, because Ben is over 18 and legally allowed to make his own decisions.

One of the reasons why Ben is so sceptical about further treatment is because he'd established such an excellent relationship with his CAMHS psychiatrist (despite my

own ups and downs with CAMHS over the two years we were with them).

He feels that no-one can possibly understand like she did. She'd become almost like a close friend. To him, she is the only person who could help him; the only person whose advice and suggestions he would listen to. To Ben, her word was gospel in an eating disorder world where it's so damn difficult to get through to your child. State that "Dr S said this, that or the other" and he'd immediately take notice...

All other therapists, Ben believes talk "boll*cks" and are "freaking useless". He's met one or two, after all, and hasn't connected with any of them.

The other day he said to me: "Oh mum, I wish they could wave a magic wand and bring back Dr S, I really do... I miss her so much!"

And so do I.

Yes she and I had had our ups and downs as you well know if you've been following my blog. But towards the end of CAMHS, almost one year ago, we were working pretty well as a team. She knew Ben, she knew how to snap him out of his moods or negativity, she knew exactly what to say and do... She knew me... We both knew her...

The point is it had taken two long years to get us to that point. Two years of getting to know each other inside out, of "experimenting" with various things (like our Recovery Contract), to see what worked best for Ben.

By the time we left CAMHS I would naturally take my cue from her and she would take her cue from me. Back at the start we triangulated like mad, as you well know. But, as we all got to know each other and saw progress, there was a kind of unspoken agreement between her and me. We both knew Ben. We knew what he was like. We knew what did - and didn't - motivate or convince him. I'd back her up and she'd back me up. Boy, did we have ED by the short and curlies!

Okay, from my perspective there's the danger of looking at this through rose coloured spectacles. And, yes, she and I clashed on what she constituted was a Weight Restored level for Ben - which, I believe, is a pretty important thing to clash

on.

But, given time and a few private meetings between her and me, I feel we could have worked on that and gradually nudged Ben upwards. At the start of treatment she didn't listen to me. But by the end she did. And I know she respected me, because she told me so. She told me she "admired" me. (Blush.) And she knew I'd fight tooth and nail for Ben.

Sure, we couldn't help the fact that she was leaving CAMHS on maternity leave. But - in an ideal world - now she's back at work we could request for Ben to continue treatment with her.

In reality, of course, it's not going to happen. Because he is over 18.

But in an ideal world... a world where the "powers that be" recognised the sheer value of a relationship like this in a young person's road to recovery - and the sheer length of time it took to establish this relationship in the first place... they would realise that this made sense.

So much sense that it's screaming out at them in flashing Las Vegas lights.

As Gaby said in response to yesterday's blog post: "It is a protocol which needlessly places our young people at further risk and prolongs the illness if not fully recovered, as you so aptly point out."

Tuesday, 15 January 2013

Assessment bound...

So tomorrow morning Ben goes for his assessment to see what, if any, further treatment they feel he needs. Call me a pessimist but I'm not holding out much hope... And, if he does get referred for some sort of decent treatment, I expect the waiting list will be hellishly long. So, in an ideal world, what would I want Ben to get out of further treatment?

Work on his social anxiety. 19 year old boys shouldn't be sitting at home on the sofa every evening without a real friend in the world. Before the eating disorder, Ben

had so many friends his birthday parties had to be held in two-day shifts. But the anorexia robbed him of all that. These days he has no true friends. Once in a blue moon he'll meet an old friend for a coffee, but that's all. And he says he has nothing to say to them. How on earth will he adapt to living away at university if he has another attempt?

Work on the remnants of the eating disorder. Ben is still afraid of weight gain so that needs sorting out. And he still counts calories and weighs out his food. He still has a certain amount of anxiety when eating out at restaurants or other people's houses where he doesn't know the calorie count and where no end of "nasties" could have been lobbed into the food for all he knows e.g. butter.

Work on his depression. Since Christmas it's not been as bad. But Ben still gets very depressed and, on occasions, suicidal.

So these are the three key areas as I see them.

The problem is that I can't see the assessor treating this as an urgent case.

And what if Ben doesn't connect with a therapist. He's only ever connected with one therapist and that was his psychiatrist at CAMHS. He's met umpteen others over the years, but wouldn't have given any of them the time of day let alone commit to a long series of treatment sessions.

Plus... Ben, being Ben, thinks he knows best and can sort everything out himself.

Which is what he thought at the beginning of the eating disorder.

The thing is, if he couldn't handle any of the private therapists, then I can't see a miracle happening with an NHS therapist.

Unless pigs begin to fly and they agree to refer him back to Dr S at CAMHS.

Wednesday, 16 January 2013

"If you don't want treatment then I can't insist you have it," she said...

...Which is true, I suppose. And, yet again, there we were... Ben and me... sitting in front of a clinician with me looking like the over-protective, "pushy" mother and in

reality wasting my time and energy, first taking Ben to see the GP and then to get this assessment. Not to mention all the trips to the private dietician and psychologists.

But if Ben insists he's fine as he is, then what can I do?

I've always said that I'll fight tooth and nail to get Ben one hundred per cent fully recovered and back to the boy he was three-and-a-half years ago before the eating disorder struck.

But, in reality, how can you fight when your child insists they don't want any further help and they can "sort things out" on their own.

Maybe he can sort things out on his own and maybe it is time for me to back off completely and just let him get along with his life, however he chooses to live that life. Maybe he will be able to shed the remnants of the anorexia and all the distressing baggage that came with it. If so, I will jump up and down with delight.

Basically I have done as much as I can do.

I have helped him to leave university because he couldn't face it and felt suicidal.

I have helped him find things to do in his eleventh hour "gap year".

I have found some of the region's best private eating disorder therapists for him to see.

I took action when he felt suicidal and unable to cope just before Christmas by taking him to see the GP.

And, today, I took him for the assessment with the local Mental Health team.

But he's not interested. And he told the clinician this, saying he was simply there because his mum wanted him to be.

So maybe I'll just back off completely and let him get on with it. I've already made the decision that, if he does want to go to university (and from what he said this morning I'm not entirely sure he does), then he can set the wheels in motion himself. 19 year old men don't have their mothers organising stuff for them.

But I hope that one day he will realise that the only reason I did any of the above wasn't because I was being "fussy" or "nagging". It was purely and simply because I

want him to get his Real Life back.

One hundred per cent.

Wednesday, 16 January 2013

What would have happened if...?

At least Ben is almost recovered so it's not a complete disaster that he is refusing further treatment. But imagine if I'd been the parent of a 19 year old who desperately needed help, but refused? I wonder what would have happened?

Would we still have been "discharged" like we were today? Would the assessor still have insisted that "If X doesn't want treatment then we can't force him / her to have it"? While I, the parent, sat there in fear and despair?

As we all know, eating disorder sufferers are notorious for claiming that there is nothing wrong, that they've got it all under control and don't need help.

Also, back at the start, Ben put on an Oscar-winning performance at CAMHS, convincing them that he was doing just fine when, in reality, he was disappearing down the rabbit hole like lightning.

CAMHS fell for it hook, line and sinker.

Then one day he broke down and confessed that it was all an act.

So I am so very thankful that Ben's situation isn't critical, or anywhere near critical (unless the suicide threats rear their ugly head again...).

Another parent might not have been so fortunate.

They, and their 18+ child, might have been discharged there and then.

Simply because, according to the law and many clinicians, these young people have to "want" treatment before it's given to them.

Saturday, 19 January 2013

Like pushing you-know-what uphill...

Ben's major worry, ever since he began treatment for his eating disorder, three (yes, three!) years ago has been that his weight risked spiralling out of control. When the scales showed a slight gain (because it was never more than a slight gain), that heralded the start of the "spiralling". He risked going up, up, up and away into the upper stratospheres of obesity.

But, of course, this has never happened.

Not in three long years.

Sure, during those years Ben himself changed dramatically.

He went from heavily resisting treatment and help, and plummeting even further down the rabbit hole, to eventually turning a corner in the autumn of 2010 when - following the second admission to the cardio ward and CAMHS' threat to hospitalise him - he began to work with us, not against us.

He went from eating a massively unbalanced and unhealthy diet to eating an incredibly healthy, fully balanced diet. His skin tone improved, he lost the dark rings around his eyes and he gained some flesh around his bones. He had more energy and his mood improved. He felt better and the eating disorder rages and behaviours gradually began to fade away, surfacing occasionally, but - thankfully - only occasionally.

The only problem with this healthy balanced diet was that there was never enough of it.

Not really. Not in my opinion.

But Ben was happy because he felt in control. He still had this morbid fear of his weight going up and up, spiralling out of control. And he still does.

Yet, really and honestly, his weight isn't much different from what it was three years ago.

Especially today when the scales showed he's back down to what he was just after Christmas when he lost 2kg.

To be honest, I am sick and tired of this battle to get the evidence into Ben's head that there's as much chance of his weight spiralling out of control as there is of me becoming President of the United States. I have spent three years battling with this (not counting the months in the lead-up to CAMHS treatment when former rugby player Ben lost one quarter of his original bodyweight).

I am sick and tired of being the "dolphin" who carefully suggests increasing his calories so this lost weight creeps on at a rate that - oh horror of horrors! - he can "cope" with. This is all we ever heard at CAMHS. Ben needs to increase at a weight he can "cope" with. Otherwise who knows what may happen.

Well, I'll be damned, his average weekly weight increase over the entire 110 weeks he was with CAMHS was... as Batty checks back at her diaries from 2010-2012... drum roll...

...ZERO!!!

A great big fat ZERO.

And... cue another drum roll... his average weekly weight increase between then and now has been...

Another great big fat ZERO.

Yes, I know that, during his 110 weeks with CAMHS his weight went up and down - and for six months it went EVEN LOWER, heading towards in-patient admission levels - but the fact is that he weighed the same when he left CAMHS as he did at the start.

And he is still that weight today.

I am so very, very, very weary and sick and tired of trying to gently push this weight up... of quoting all the science and stuff... of sitting him in front of one of the UK's top ED dieticians who also quotes all the science and stuff... of saying that we agreed in the new 2012 Contract that he would increase... of encouraging him to increase his calories significantly... because, Goddamnit, his weight is NOT going to spiral out of control.

And yet he still pretty much maintains.

“I want to see some serious weight gain over the next week,” I practically barked at him this morning. “I want to see at least 2 kilos on you by Saturday.”

He promised to increase his calories.

I’ve heard that so many times before.

I just feel as if I’m banging my head against a brick wall in the week that he assured everyone that he didn’t need any further help because he is managing just fine by himself.

His head is okay, thankfully. His mood is okay, thankfully. It’s just that he finds it impossible to gain weight, remain at that weight and then gain some more. Until he reaches his natural set weight, whatever that weight is.

Saturday, 19 January 2013

Eye of newt and toe of frog...

Apply tree resin, roots of white lilies and dried human waste to the buboes, then cut open the veins leading to the heart before applying clay and crushed violets. This, esteemed clinicians believed, was an effective method of treating the Black Death in the Middle Ages.

Thankfully, in the 21st century, we realise that antibiotics achieve better results.

Why? Because, for goodness sake, there is a shedload of evidence to prove it.

Yet far too many 21st century clinicians are treating our children with eating disorder treatments that are shown to be ineffective, to prolong the duration of the eating disorder and - in some cases - to lead to death.

The evidence for efficacious eating disorder treatment is out there. It’s been out there for quite some time now. It’s been tested, documented and proven to be effective. Just as antibiotics have long been proven to be effective against killer bacterial diseases that used to be treated by quack methods.

Getting my drift yet?

Sunday, 20 January 2013

Got it out of my system

If you hadn't gathered, Bev was having an Angry Day yesterday. Angry at the eating disorder for stealing my son's life. Angry at the snail-like pace of recovery, even though I know there is no other option; anorexia can never be like a bacterial illness where you pop an antibiotic and, hey presto, a short while later you're on the road to recovery.

I was angry at discovering that Ben was the same weight at the end of his treatment as he was at the start, even though I am also aware that, during this two-year period, he did go through many positive changes. The Ben who left CAMHS in March 2012 was most definitely not the same Ben that arrived there in February 2010.

Thank goodness.

Yesterday I was just angry. And that's the thing about blogs; they're 'of the moment'. Sometimes I'm angry, sometimes I'm reflective, sometimes I'm pretty sensible... but other times I may over-generalise as anger or frustration at this illness blinkers my eyes.

Everyone gets angry, I imagine. Everyone makes sweeping statements at some point, I imagine. Everyone fails to see the other side of the coin now and again, I imagine.

And yesterday I was angry.

Which is why I went for a lengthy stroll in the snow-covered local park afterwards to get it out of my system.

Thank you, though, to my blog readers and followers who point out that there is always another point of view. Usually a very valid point of view.

Thursday, 24 January 2013

“How do you feel about using your real name, Ben?”

This is what I asked him yesterday. For the past... ages... he’s been involved in a project run by Oxford University - an online project aimed at helping young people deal with and understand more about a wide range of teenage illnesses and conditions, one of which is teenage eating disorders, in boys as well as girls. I can’t remember when Ben first met their researcher for an interview, but it was ages ago. Now, to coincide with Eating Disorders Awareness Week (11 - 17 Feb), the website is finally going live.

“How do you feel about them using your real name, Ben?” I asked, aware that on this blog and in my (soon to be published) book “Please eat... a mother’s struggle to free her teenage son from anorexia” I refer to him as “Ben”.

This question also came about because one of my eating disorder friends asked me how Ben felt about my book and website? How did he feel being out there in the public eye? How did he feel about the possibility that, in the future, if potential employers, for instance, traced him by his real name that his former battle with anorexia might come back to haunt him?

Well, in the case of my blog, book and websites, I use the name “Ben”. I also use my maiden name, so it’s relatively anonymous.

But the Oxford University project isn’t. Neither was our TV interview with Lorraine Kelly nearly a year ago.

“I don’t care,” he said.

And the concern that, in the future, it might come back to haunt him?

“It’s classed as discrimination,” he said, “Just like a physical disability. Googling around and discovering that a potential or existing employee had a mental illness in the dim and distance past and therefore not hiring - or firing - them. Well, it’s discrimination. It’s illegal.”

But that doesn’t stop the stigma attached to mental illness, unfortunately.

However Ben is adamant that he is completely happy to go under his real name for

the University project. He is also thrilled about my books, this blog and my websites AnorexiaBoy.co.uk and my new website. Indeed he's always nagging at me to do more to raise awareness of eating disorders in boys.

"And in any case, mum," he said. "There are plenty of other former eating disorder sufferers who go under their own name. The Young Ambassadors at BEAT, for instance. And the guy who runs the charity Men Get Eating Disorders Too [or at least we assume it's his real name]. Plus a load of other people."

Me, well, it doesn't bother me if it doesn't bother him. And I don't want to labour the point. He is so enthusiastic about raising awareness of eating disorders and using his own experience of anorexia to do this, that it really is his decision. (And I loved it when he corrected himself: he used the present tense, then promptly changed it to the past tense i.e. "I used to have anorexia...")

As to the question I put to him this morning: "Should I promote my book 'Please eat...' on my main Facebook page as well as my Batty Matty page?"

"I don't see why not," he said. "Most of your FB friends know about the eating disorder anyway. And even if they don't, then they may know of someone who is suffering - or exhibiting worrying signs. You might just help someone."

True. I'll have to think about it.

Friday, 25 January 2013

Ouch, I thought, reading this supplement in the Radio Times, this isn't good...

We get the Radio Times, the 'thinking person's' guide to what's on British TV and radio every week. It was Ben who pointed out the 8 page supplement stapled into the centre of next week's issue: The Fast Diet by a doctor that's been on TV quite a lot. Ouch, I thought to myself, this isn't good...

I know that January is the season of faddy and crash diets, but Ben and I feel there's so much wrong with this one. Especially as it's written by a doctor, backed by 'science' (tests on mice, it appears, plus tests on 33 obese volunteers in the States)

and - presumably - endorsed by the Radio Times (Radio Times is printed on the title page, plus *As first seen in Radio Times*, just in case you want further endorsement).

Apparently you eat normally for 5 days of every week. Then on the other 2 you fast. Women eat around 500 calories a day and men around 600.

And, right at the end, under Who should avoid fasting? it says "...anyone suffering from an eating disorder".

Now I have a problem with that.

As Ben says: "I didn't know I had an eating disorder, not for several months. I knew something was wrong, but I had no idea what. Now, if I'd come across this fasting diet back then, I'd have lapped it up. Especially as it features in the Radio Times which we get every week."

And doubtless he might have been tempted to follow the diet for more than 2 days of every week...

Also, to be honest, would someone "suffering from an eating disorder" really and truly look at this warning at the end of the diet and think: "Oh, I'd better not do this, then." And discard it.

What do you think?

Maybe it's just the fact that these 8 pages in the Radio Times are a snapshot of the book this doctor is promoting (although nowhere do I see the words "Advertisement Feature"...) but I can't help but get the impression that the majority of tests have been done on mice. Not humans. Apart from those 33 obese humans mentioned at the top of this post.

And I was extremely worried by the paragraph: As one of the medical experts interviewed for the Fast Diet book puts it: "There is nothing else you can do to your body that is as powerful as fasting."

The idea is that this particular 2 days on, 5 days off diet is better than complete Calorie Restriction (referred to as CR) is that it apparently offers the "benefits of CR, but without the pain". About CR, the article says: "Calorie restriction (CR) is pretty

brutal; it involves eating an awful lot less than a normal person would expect to eat, and doing so every day of your - hopefully - long life. The reason people put themselves through this is that it is the only intervention that has been shown to extend lifespan...”

Oh, but then it suddenly adds: “At least in animals.”

Does this worry me? You bet it does!

The doctor says that people “began to stop me on the street” and tell him they were doing the 2 days on, 5 days off diet. He also got emails. “Among those emails, a surprisingly large number were from doctors.”

Gah, more ‘official endorsement’ of his diet...

After that, there’s an awful lot about experimenting on mice.

I know that this is just one of hundreds, possibly thousands of crash diets that are flooding the market as they usually do in January. I also know that the vast majority of people that diet are believed to put all the weight back on again. But there is a small minority that are vulnerable and who may find this high-profile Radio Times fasting diet triggering.

And these are the people that I am worried about.

What does everyone else think?

Tuesday, 29 January 2013

10 sermons inspired by Carrie Arnold’s excellent list

My dear friend M posted this link on Facebook to Carrie Arnold’s very excellent list on the FEAST website: Ten Things I Want Sufferers to Know About Anorexia. I was going to write about just one point that hit a nerve with me when I thought, heck, why not do what I did the other Christmas (with the 12 Days of ED Christmas) and write a post a day based on it. So here goes... #1...

1. It’s an illness, not a choice. You don’t have anorexia because you’re a vain control freak on a mega-diet--anorexia is a biologically based mental illness.

The word I'm picking out for today's sermon is "choice". Why? Because, during the two years my son was undergoing treatment for his anorexia, this word was said at virtually every single session. Or, rather, it was used in the plural: "choices".

"Ben needs to learn to make the right choices," they said as Ben continued to lose weight, week after week, during the first summer of treatment after he ditched the re-feeding plan and was given back control of his food intake and preparation. "Doing it this way helps him learn how to make the right choices and see where he's going wrong."

"But what if he never learns to make the right choices? What if he just can't?" I remember replying on one occasion.

But they were insistent that - week after week of discovering that his "choices" weren't always the "right ones" (i.e. he wasn't eating enough to maintain weight let alone increase it) - would teach him which choices were right and which were wrong.

Did it teach him?

Not in my honest opinion.

After Ben ditched the eating plan in the late spring of 2010, his weight gradually headed south. By the new year of 2011 he was at his lowest weight. There followed a plateau when he was getting hellishly frustrated because he felt as if he was in Limbo. Thankfully, thanks to the ATDT forum, in spring 2011 I came across a thread about Recovery Contracts. It was our Recovery Contract, both Ben and I believe, that helped him "learn to make the right choices".

Except that, no, I believe that's incorrect.

I wouldn't phrase it like that.

It was more a case of empowering him to challenge himself - to eat fear foods, go into school, socialise, eat at unusual times and in unfamiliar places and so on. This is what the Contract did.

It wasn't about "learning to make the right choices". It was about getting stuck in and facing his fears head-on, encouraged by our Contract rewards scheme and our

daily chat on “neutral territory”.

To me, that’s a totally different kettle of fish.

Wednesday, 30 January 2013

Sermon #2: Food is medicine, but how do you get it into your child?

Carrie Arnold’s 2nd point on her excellent and informative list is: 2. *Food is medicine. You have to eat in order to get well. You don’t have to like this, and eating may make you feel worse at first. That’s okay. Keep eating.* So the topic for my #2 sermon is inspired by my Text for the Day which comes from my new book:

The crazy thing is that I could save his life. I could get all that lost weight back on in a matter of weeks, maybe even faster. And the even crazier thing is that it should be so ridiculously easy. It seems grotesque - criminal, even - that I am sitting here, in England, in the 21st century, watching my son fade away from malnutrition while bucket-loads of food are all around us. Huge, massive, obscene mountains of food. Cakes, ice cream, bread, pies, puddings, pizzas, curries... Up the road are three enormous supermarkets with shelves piled high with every food imaginable. Down the road are restaurants and take-outs specialising in every cuisine on the planet. Yet my son refuses to eat. Or at least he refuses to eat anything other than the bare minimum needed to keep him alive. I want to punch the wall. I want to kick, scream and shout. I want to get the medical staff to force-feed him and insist that he stuffs his face with life-giving food, even pop a funnel down his throat and pour it all into him.

Recognise that feeling? Walking around the supermarket, looking at the shelves piled high with goodies that, only a matter of months ago, your child would eat without a second thought? Yet now, here you are... surrounded by all that food... food you know can save your child’s life... yet the anorexia demon (as I came to refer to it)

refuses to let them eat it. Never in a million years could any of your fellow shoppers ever guess what was buzzing round in your head as you push that trolley around the supermarket, discounting this product and that because you know it'll send your child into a frenzy.

Do you go for the 'safe' options? The diet foods? Slimline this, that and the other? Your gut instinct as a mother desperate to rescue your child is a huge emphatic NOOOOOOO! Yet you also know that, if you buy the 'standard' or 'high fat' option, they'll refuse to eat it. So, says the logic inside your head, better to get something he or she will eat rather than have him or her sit there and eat nothing. So, much against your better judgement, into the trolley the low fat item goes.

You feel like a traitor, colluding with the enemy. A hypocrite. Or, worse, someone that could be helping your child to stay ill.

Yet what can you do?

I remember when my son, Ben, first started treatment for his anorexia, I requested a re-feeding plan. The nurse dug an A4 printed sheet out of her briefcase. Eating Plan 6, it was called. I always wondered how it differed from numbers 1, 2, 3, 4, and 5...

On it were items like custard and sponge puddings. And, of course, full-fat this, that and the other. Butter, doughnuts and so on...

But what no-one told me was how the heck you're supposed to get these foods into your child when they're sitting there with their mouth rammed closed, threatening to kill themselves if you don't back off.

In fact no-one ever showed me how to re-feed my child with these foods.

Ever.

So we ended up 'tweaking' Eating Plan 6 into a low fat, high carb hybrid that my son would eat. Better low fat food than no food, I figured.

Not a great decision, but, with precious little support when it comes to learning how to re-feed your child, it was all I could do.

Meanwhile every time I went to the supermarket, there I was faced with shelf

upon shelf of 'medicine'... food I knew could make my son well, and make him well faster.

Yet there I was, playing traitor, by colluding with his eating disorder and returning home with bags laden with low fat this and that.

Why wasn't the re-feeding plan seen as very important?

Because my son's BMI wasn't thought to be low enough. Or at least that's the impression I got. Yes, he was out of the 'healthy range' on the official charts, but not massively so.

But - and I will be talking about this topic later on in my 10 sermons - the key thing for me is that, no, my son's BMI wasn't rock bottom. It was low, yes, but always hovering just above the diagnosis criteria for official anorexia.

What they failed to take into account, I believe, is the fact that - pre-eating disorder - Ben was a big, burly rugby player. His anorexia (and, yes, it WAS anorexia... full-blown anorexia...) was triggered by the fact that he lost one quarter of his bodyweight, very quickly.

This, in my mind, looking back, warranted being shown how to properly implement Eating Plan 6.

Thursday, 31 January 2013

Sermon #3: the anxiety-busting course that left us in stitches

Carrie Arnold's 3rd point on her excellent and informative list is: *3. Anorexia often brings "friends" in the form of co-existing conditions such as depression and anxiety. Although it makes recovery more complicated, it doesn't make recovery impossible. Staying healthy means managing both anorexia and any other mental illness you might have.* So the topic for my #3 sermon is: anxiety and how an anxiety-busting course helped Ben, but not in the way it was supposed to..!

As well as a co-morbid depressive disorder, Ben suffered from anxiety. Extreme anxiety. So we were booked onto a 12 week course on anxiety, held at our local in-

patient unit.

On arrival we all had lunch. Or at least everyone had lunch except Ben, because he was the only participant with an eating disorder; the rest had varying degrees of OCD. Faced with an NHS sandwich spread, chips (fries) and crisps (potato chips), Ben just couldn't face it.

Afterwards, the young people would be whisked off for their session while the parents sat in front of a flip chart and someone who talked to us about the ins and outs of anxiety.

At the end we all met up together for a practical anxiety-busting session.

It's this, I'm afraid, that had me in stitches.

There we were, sitting on upright, uncomfortable plastic chairs, while one of the course leaders began to read from a meditation script.

Now, this is something that some people do better than others.

What you imagine is a soothing, soft voice that gradually lulls you into a sense of calm as you slowly drift off into the garden, beach or wherever they would like you to visualise yourself, as you begin to relax... oh so deeply... R-E-L-A-X.....

What you don't imagine is someone who sounds as if they're deliberately reading from a script... almost like reading from an auto-cue except that they've forgotten their glasses and can't make out the words very well... or a bad telesales call... or a schoolchild reading aloud in class from a book they hate...

I'm sorry, but I could help but find this absurd - and very, very funny.

That, and the curious way the parents' course leader handed round chewing gum at the start of each session.

Very odd.

Did these sessions cure Ben's anxiety?

Not in the way they were supposed to.

However Ben and I were coming out of these sessions in fits of giggles... like naughty schoolchildren...

All the way home in the car we'd laugh our socks off. I remember tears of mirth streaming down my face.

Considering that this was during Ben's deepest, darkest phase when we were at loggerheads most of the time... suicide threats... leaving home threats... evil ED rages... especially when in the car together... and I had tears streaming down my face every single day, but definitely not tears of mirth... this was brilliant.

For a short while, on the drive home from those absurd sessions (which we quit eventually), I felt as if I had the 'old Ben' back.

FEBRUARY 2013

Friday, 1 February 2013

Sermon #4: Anorexia is not a BMI

Carrie Arnold's 4th point on her excellent and informative list is: *4. Weight isn't the measure of how sick you are. Not that weight and health have nothing to do with each other, but you can be very ill with anorexia and be at a "normal" weight. Remember, you can drown just as easily in six inches of water as you can in six feet or six miles.* Now this is the point that really hit a nerve with me...

Over the summer of 2009, Ben lost one quarter of his bodyweight. Before, he was a big burly rugby player. He played #3 in the team, a position given to the biggest, toughest boys. After, he was a frail, bony waif who, if he'd attempted rugby, would have snapped in half.

Yet no-one would ever admit that Ben had anorexia. (Except his dad and me, of course...)

The NHS says that: People with anorexia generally have a BMI below 17.5.

But, because, even at his lowest, Ben hovered around 0.5 BMI above this level, his eating disorder was always referred to as an “anorexia-type” illness, or “EDNOS” (Eating Disorder Not Otherwise Specified). Or he had “eating disordered thinking and behaviour”.

Officially, he never had anorexia.

As Carrie says above, “Remember, you can drown just as easily in six inches of water as you can in six feet or six miles”. And, believe me, Ben was drowning fast.

He was very, very sick. And the signs were screaming out... flashing in Las Vegas lights... that Ben had anorexia, and he had it seriously.

Yet, because he could never be “officially” diagnosed with anorexia, I don’t believe his illness was taken as seriously as it should have been.

Not until he was hospitalised... twice... with a pulse rate of 29-30bpm.

I once asked CAMHS why Ben wasn’t being treated using the Maudsley Approach. Did they ever do Maudsley FBT? Yes they did, they said, but it “only worked with younger adolescents” and those with lower BMIs.

In other words, because of his age (16 at the time) and BMI (not low enough to be officially diagnosed with anorexia), re-feeding Maudsley style wasn’t considered to be appropriate. I pushed for re-feeding at first, and had some success with re-feeding using my (unfortunately tweaked - see other post) version of Eating Plan 6. Yet, three sessions out of every four, I was excluded from his treatment, so I was doing it alone.

As I forged ahead with the eating plan, Ben gained weight gradually over a period of a few months until one day he downed tools and refused to cooperate any longer. So control of his eating and food preparation was handed back to Ben.

Over the next 7 or 8 months his weight headed steadily south as he battled to “make the right choices” and begin to “want to recover”.

Of course I know that the Maudsley approach doesn’t work for everyone. But I believe that, if you feel it has mileage with your child, then you should be given the chance to give it a try. After all, it seems to be the most successful of all treatments

for anorexia, so why not?

But my argument is that, if he'd have been a bit younger or if his BMI had been lower, then he might have done Maudsley-style FBT.

I believe that, because he'd lost one quarter of his pre-ED bodyweight, he did indeed qualify for this approach.

It's almost as if they were saying his illness wasn't as serious as it could be.

Like the common cold as opposed to full-blown swine flu.

Saturday, 2 February 2013

Sermon #5: Not a 24-hour emergency service

Carrie Arnold's 5th point on her excellent and informative list is: *5. Anorexia is deadly serious. Eating disorders have the highest death rate of any psychiatric illness. The "best" anorexic is the dead one.* Not a nice topic to write about, but here goes...

Suicide threats were a regular feature of our family life during the late spring and summer of 2010. Much of the time I was in the house alone with Ben (and the "anorexia demon"); my husband was working away. Here's what I've written in my new book about one of these occasions - an occasion when I was desperate:

Another afternoon I get a phone call from the mother of one of Ben's friends. "I hope you don't mind me calling," she says quickly, "But Tom's just had an email from Ben saying, 'Give me one good reason why I should carry on living'. I felt I should let you know in case... well..." Her words trail off. She doesn't know what to say.

I don't know what to say either. "I'm so sorry Tom had to receive something like this. Ben's been ill. He's not himself. I am so sorry..."

Ben is stony faced when I tell him, not dissimilar to the way he was after the roof

incident. Then, without warning, the demon kicks off at its most magnificent. Ben goes crazy, bashing around the house like a maniac. He seems to have gone completely insane. I call Sue but get her answering machine. My sister is out, too. So I call CAMHS for help. Sarah is on leave, so I speak to the duty psychiatrist. She says there's nothing CAMHS can do "unless he actually inflicts harm on himself or others". She's very apologetic but her hands are tied.

"Can't I just bring him in so someone can calm him down?" I plead, explaining that I'm in the house alone with him, my husband is working away and I'm terrified. But she abruptly informs me that "CAMHS isn't a 24-hour emergency service".

Sunday, 3 February 2013

Sermon #6: Happy to settle for 'good enough'? Noooo!

Carrie Arnold's 6th point on her excellent and informative list is: *6. There is hope for recovery. Many people with anorexia recover and go on to live happy, fulfilling lives... and you can be one of them.*

Ben was getting frustrated at CAMHS as I continued to push for full weight restoration (which I did most of the time, me being me..).

"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," he complained.

"Well I'm more than happy to settle for 'good enough'," said CAMHS. "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 sick or something else resulted in weight loss you would be underweight because you don't have any 'buffer zone'. But I'm happy to settle for 'good enough' if you are."

I have no idea if the plan was to move the goalposts in the future and aim for higher.

But the problem was, Ben was about to be discharged from CAMHS, so we never got to find out.

This conversation is something that's stuck in my mind ever since. Not surprisingly it has made things more difficult for me in the push to get Ben back to his optimal set weight.

The thing is, he absorbed CAMHS' advice like a sponge. This could be bad - as above. Yet it could also have been so very good. Because, if they'd made it clear that "good enough" isn't "good enough" and "excellent" is, then I believe he would have cooperated.

And it would have made my job so much easier once he was discharged last March.

Sunday, 3 February 2013

Why I am donating the first 8 x royalties to eating disorder charities

Some authors give away books for free, but I've decided to donate the first 8 x royalties to two of my favourite eating disorder charities: Men Get Eating Disorders Too and FEAST (Families Empowered and Supporting Treatment of Eating Disorders) (which also runs the awesome forum: Around The Dinner Table for parents and carers of young people with eating disorders).

The first charity - UK-based Men Get Eating Disorders Too - has always been fantastic in supporting this blog and, more recently, in promoting my books. And, of course, the charity does an amazing job; raising awareness of eating disorders in men and boys in a world where eating disorders are still very much associated with girls.

The second charity - FEAST, and its ATDT forum - were a lifeline for me during the dark days of my son's anorexia. But the bad news is that I didn't discover FEAST and ATDT until March 2010, some eight months after Ben's anorexia first began to

emerge, and then it was just by chance when I was googling one day.

I don't want this to happen to other families.

This is why I promote FEAST and ATDT so much throughout my (soon to be published) new book: "Please eat... A mother's struggle to free her teenage son from anorexia". As well as telling our story - before, during and after Ben's eating disorder - one of the primary drivers of this book is to point families to invaluable resources like FEAST and ATDT. Indeed the book is peppered with references to this awesome charity.

I don't want other families to have to struggle alone for so many, many months like we did. Through my book, I want them to be able to go straight to the resources that can help them.

Oh, and the wonderful Laura Collins, founder of FEAST, is reviewing my new book as I write!!

Thursday, 7 February 2013

I am still here! Just...

At the moment I'm not blogging as much as I used to because I'm busy going through (the third?) printed proof of my new book "Please eat..." Now, please don't groan and tell me off for ranting on about my book yet again, but - really - this final stage is crucial. I must get it right. Also, I'm ecstatic about all the great reviews that are coming in - from professionals, other authors and parents. So when is publishing date?

Well I'm still waiting for a few reviews to come in. And my manuscript is still with a couple of people that are reading through it and making comments.

Then I need to tweak the front and back covers, and request a further (and hopefully final) printed proof to check over. I also need to upload a Kindle version and update my Amazon description.

With any luck I will then be able to press the dreaded "submit" button and off we

go!

Phew.

It's been a very busy week.

And now our central heating and hot water have broken down. So I am typing this wearing several jumpers, gloves, boots and a scarf.

In the meantime, here are the reviews to date...

"Please eat... is an essential read for anyone trying to understand more about eating disorders in teenage boys. Bev Mattocks describes the story of her son's anorexia but also provides insight for other families facing this complex illness in a world where anorexia is still associated with teenage girls. Totally recommended." - Sam Thomas, Founder, Men Get Eating Disorders Too

"Bev Mattocks shares her painful personal story so beautifully that the reader feels a deep connection. This will benefit parents in reducing isolation and feeling more powerful in speaking with health providers. This is a powerful account which health care providers around the world need to read before meeting with their first eating disorders patient." - Becky Henry, author of Just Tell Her to Stop

"The world is slowly coming to realise that 'Boys Get Anorexia Too'. Bev Mattocks writes honestly and from the heart about helping her teenage son to overcome anorexia. Like ours, this is another success story of a family working together with friends, school and clinicians to beat this insidious illness. Many families will find great comfort from reading this story as well as much needed energy to fight the eating disorder." - Jenny Langley, author of Boys Get Anorexia Too

"Please eat... made me very emotional, it's hard recalling those moments when you realise something is wrong. I am sure the book will be a valuable resource for many

parents battling with eating disorders.” - Parent

“Please eat... is gut wrenching and touching. It captivated me and I could hardly breathe as I was reading it. I read the first 6 chapters in one sitting. Bev Mattocks has done such a great job of bringing her story to us in a vivid and personal way. I hope this book does very well not only in the UK but also in the rest of the English speaking world.” - Parent

“When I first came across Bev Mattocks’ story, I was in the depths of despair with my daughter’s anorexia which was spiralling out of control. Bev helped me realise, through her blog, that we were not alone. But most importantly, that we could do something to help our daughter recover... that, as her parents, we were part of solution and not the cause of her eating disorder. Bev pointed us towards the Around the Dinner Table forum and the FEAST website both of which have proved invaluable together with Bev’s powerful insight into her son’s illness and determination to help him recover. Her book Please eat... is an empowering book that will help parents and carers everywhere feel more confident that they can do much to help their son or daughter in their fight against anorexia nervosa.” - Parent

“I’ve read the first 6 chapters of Please eat... and it is so moving and engaging. Bev Mattocks has created a totally convincing picture of what it is like, and it’s always respectful of her son, Ben. It certainly educates, so that a parent who’s in doubt would recognise the symptoms. And it’s very easy to read. It reminded me how confusing it can be, at the earlier stages, when the restricting is variable: just when you think your child isn’t eating, suddenly they are... but you don’t realise that it’s because they think they’ve ‘earned it’ through exercise.” - Parent

Tuesday, 12 February 2013

Ben and I, both with red pens at the ready

Ben has decided that he wants to read “Please eat...” before it’s published, so I’ve ordered two final printed proofs - one for him and one for me. Then we can both go through it. Hopefully he won’t want me to change anything; we both went through the draft last summer, page by page, which is why I’ve incorporated his comments into the final book. Fingers crossed he’ll be okay with the additional chapters as I don’t want to change anything at this late stage when I have dotted all the i’s and crossed all the t’s!

He had said that he didn’t want to read through the final book. But now he does, I need to wait for his feedback.

He’s also toying with the idea of writing a parallel book: his story, which would be a really interesting thing to do.

... Which brings me round to the question: what shall I write for my next project?

Friday, 15 February 2013

Yesterday’s debate in parliament about eating disorders

It’s Eating Disorders Awareness Week and, yesterday afternoon, a group of MPs spent three hours discussing eating disorders. I watched it, from start to finish, and was riveted. I believe you can still watch the three hour discussion [here](#). Well worth viewing if you have the time - or just listen to it on your PC while you get on with something else.

Of course there was the usual emphasis on body image, media, etc, but on the whole I thought it was rather excellent. These MPs had taken the time to really get to grips with what eating disorders are about and the problems patients and parents are facing here in the UK, for example poor care at initial presentation level (GPs) and the patchy levels of good care around the UK, not to mention the false economies of poor or no treatment not to mention the cost in terms of lives.

One MP was himself a former anorexia sufferer and talked about his own experiences, dispelling the myth that eating disorders are 'caused' by media portrayal of size zero models, etc.

Oh, and they raised the important issue of older adolescents having the legal right to refuse treatment regardless of what their parents want and having to sign for hospital admission. They argued the case that very ill patients are unable to make rational decisions of this nature and that, given the choice (or rather the 'ED voice's choice'), they would all too often say no to treatment.

They also argued that the other option of 'sectioning' patients can be too extreme mainly (from what I gathered and can remember from watching this debate) because (a) a patient has to be very seriously ill in order to be sectioned and (b) because this remains on patient's medical records for life and can exclude them from certain careers, etc. They argued that there must be a change to the law in order to give parents more power.

I only wish that more MPs could have been present.

Fingers crossed it will have some effect.

Friday, 15 February 2013

University is going out of its way to help - wow!

Wow, what a superb package Sheffield University has put together to help Ben ease back into university in September (if, indeed, he chooses to return). And here it is, in all its awesomeness!

One day in March, we'll be spending a whole day in Sheffield.

First, we'll be spending an hour with the residential support lady (who we met last September after Ben decided to withdraw) discussing the various accommodation options because, if you remember, Ben found the cell-like room of the purpose built student apartments particularly difficult to deal with and isolating. Also the lack of storage space in the kitchen meant that he had to store an awful lot of non-

perishable foods in his room which, when you have a history of anorexia which makes you think about food a lot of the time, isn't ideal.

After that we're visiting the wonderful lady in student services again to talk about easing Ben back into university life. As she says, part of the work her team does is to run activities through Intro Week that appeal to students who find the big alcohol focused events a bit overwhelming or unappealing.

Also, they run what they call Discovery Week, the week before Intro Week, for students who are interested in coming to Sheffield a bit earlier to find their feet. It's quieter and not at all party and booze-focused, and it's something that Ben can commute to from home. Plus, she'll arrange contacts from the various societies that might appeal to Ben e.g. the tabletop war games / Warhammer soc.

After lunch we will be meeting with the eating disorders specialist nurse at the university health service to discuss support should Ben need it at any time, followed by further support which can be offered by the disability advice department (which don't just deal with physical disabilities).

And, finally, at 4pm, we're meeting with two admissions tutors from the history faculty to introduce Ben to the department and also to discuss the possible option of commuting for the first semester - and to examine a typical week's lectures and seminars timetable to see how feasible this might be.

All I can say is... Wow!

Oh, and that - if you are worrying about sending your recovering son or daughter to university this September, and especially if they have a confirmed offer of a place - it might be worth contacting your university's student services to see if they can put together a similar package.

The mistake we made was just to assume it would all be there, in place, and that Ben would find his feet, find people and activities that floated his boat and settle in.

He lasted two days.

Friday, 15 February 2013

I'll say it again... I am NOT exploiting my son or his eating disorder, and he agrees with me.

Me: There's this girl... She's a former anorexia sufferer, or still has anorexia... and she wrote on my Facebook page saying simply 'Exploitation at its finest'. I can only assume she is referring to my new book. In the past she has suggested that I may be 'glorifying' eating disorders and 'publicising and exploiting' your eating disorder, Ben. I deleted the post. I just wondered what you thought about it, Ben...

Ben: Oh no, you should have kept it because then I could reply. I'd love to have replied.

Me: Well you can tell me and I'll put it up on my blog because I know she reads it.

Ben: No, if you do that, then how the heck is she going to know I said it?

Me: Because I'll say that you said it.

Ben: Er, I don't think she'd believe that... Mum, if she's claiming that you exploit me, is she really going to believe something you say? No. Use your brain! I wish I could talk to her.

Me: I've always told her that you are one hundred per cent behind me.

Ben: Mum, she's not going to believe you.

Me: I mean, you are always going on at me to do more to raise awareness of eating disorders in teenage boys and the illness as a whole.

Ben: Mum, she's not going to believe anything you say. This book is about telling our story, to say that it's not girls that get eating disorders. Please don't delete things like this in the future, mum, because I really need to reply, but I can't now that you've deleted it.

Me: This is how I responded to a previous FB message:

My son is right behind me with the blog. It was he that suggested I write it in the first place. Far from glorifying eating disorders, I am writing to help other parents of

teenagers, and especially boys, with eating disorders to show them they're not alone in what they're going through and the various things we did that did and didn't help. This is the primary reason for my blog and I know for a fact I've helped lots of other parents.

I only write about eating disorders, and nothing else, as my blog is exclusively about eating disorders and our journey towards recovery, which has been a team effort, my son and me together.

No, he doesn't read my blogs. He chooses not to, but he does know why I write my blog and wholeheartedly supports me. In fact he's always telling me off for not doing more i.e. not campaigning for better eating disorder treatment, etc.

Also, no, you don't find many blogs written by mothers of teenagers with eating disorders (although there are quite a few out there), and this is one of the main reasons I write it - because, at the start, I hadn't a clue where to turn for help or support. I knew nothing about eating disorders, especially in boys. If I can do anything to fast-track other parents through this hellish and complex learning curve, then my blog is a Good Thing - and I know I have already helped quite a few parents.

Monday, 18 February 2013

Ben is going through my final proof... slowly...

Last summer, Ben and I went through the manuscript for my new book: Please eat... with a tooth comb. However I've changed and expanded it quite a bit since then. So now he's decided to go through it all again, so I ordered 2 final printed proofs which arrived the other day: one for me and one for him.

I've already been through mine. He's still on chapter 4 of his (only another 28 to go... 255+ pages in all...). Not because he's finding problems with it (although there is the odd minor tweak I need to do), but because, I suspect, it doesn't make easy reading for him.

But he's adamant that he wants to read it again. So I will need to wait until he has

finished before I can go ahead and publish.

And I may decide to order another “final” printed proof before I do.

Just to make sure it’s perfect!

Watch this space...

Wednesday, 20 February 2013

Letter I wrote “to anorexia” in Feb 2010

I’ve just unearthed a letter I was asked to write “to the anorexia” at the start of Ben’s CAMHS treatment but which was never followed up at a subsequent CAMHS session, so it ended up in the cobwebby archives of my PC. Here it is, and it’s going into my book:

Evil Anorexia,

I can’t address you as “Dear” because I loathe and hate you more than anything I’ve ever hated before in my life.

You are an evil little sneak that crept into our family, uninvited, even earlier than we thought you had. You saw our happy family. You saw my good looking, bright, sporty, friendly and confident son, in fact you probably homed in on him around the time I was feeling so mega proud that this young man... this handsome individual who girls would pass in the street, admire and turn round to take a second glance... this wonderful, amazing young man was MY gorgeous son. I made him! Incredible!

So you decided to ruin all this. You sneaked in and took over his mind, only you disguised it as normal behaviour for many months so we didn’t realise you were there. Being with Ben every day we didn’t notice the subtle changes, many of which were disguised as “normal” behaviour. It was only when Ben’s grandma visited in September and commented on his appearance that we realised he had changed so much.

Actually, you know, I could write pages and pages about why I hate you so much.

But I'm not going to do that. Instead, I'm going to tell you how we plan to send you packing, to expel you from inside Ben until not one ounce of your evil remains - and I will get my wonderful "little boy" back - before you eat up the rest of his remaining "childhood".

One thing you hadn't banked on was how strong Paul and I are. We're not the kind of parents who give up on things; we're fighters. And we will fight tooth and nail where our beloved son is concerned, the most precious possession we have in the world and our reason for living.

For me, this started when I gave birth. It was a horrible birth - but the bonding I made with Ben took me by surprise. I knew that, given poorer medical care, one or both of us could have died during the birth.

What I felt as we both lay there... me battered, bruised and cut... was a primeval instinct. It was almost animal in its intensity - a case of me and Ben against the world. I knew at that moment that I would love and protect Ben forever and give my life for him if needs be.

And I know Paul thinks the same.

If I were you, evil Anorexia, I'd slink off back to your nasty, dark, damp evil little hole. You don't stand a chance with us. Okay, it might involve some "tough love" on our part - but you know it's not Ben we'd be talking to, it's you. We've known Ben long enough to know who the "real Ben" is. A lot of what we are seeing now isn't him at all; it's you. The thing is, we know when it's you that's talking or lying - you can't get away from us now that we recognise you!

Okay, so there are little things you do because you think that if you've failed with one thing you'll get away with another. Your aim is to stop Ben from eating by hook or by crook - and also make him so depressed he runs to you for comfort. Well, your days are numbered, mark my words. We know who you are and we know what you sound like.

We don't want you in our house any longer. We don't want you in our lives. We

*don't want you in our son. So sod off, you little sh*t, back to where you came from and leave us - and our son - alone and never come back.*

And don't think you can return at any point like when Ben's at university or whatever.

I'm not going to waste any more time writing to you.

Ben's Mum

Friday, 22 February 2013

I am LIVID, LIVID, LIVID. And I know I am not the only one.

Today I read an article in the Daily Telegraph about yet another 18+ teenager with an eating disorder that has been failed by our current system of allowing 18+ young people with serious eating disorders to make their own decisions about whether or not they have eating disorder treatment. Worse, this young woman was discharged because "at 18 she was deemed to be old enough to care for herself". Having reach that magic age of 18, she discharged herself. Within months she was dead.

Other less seriously sick young people are being discharged from eating disorder treatment when they reach the magic age of 18 because their recovery level is considered to be "good enough". If you remember, we were told by our psych that she was happy to settle for "good enough" if my son was happy.

Some, I suspect, have built up good relationships with an effective treatment team only to be cut loose to drift in the big scary wide ocean of Adult Services when they reach the magic age.

Or, like a young woman I heard about the other day, they are waiting for their 18th birthday with great anticipation because they plan to halt the treatment their loving and terrified parents have fought so hard to get for them.

During the UK parliamentary discussion last Thursday this subject was brought up. I know there is at least one MP who is convinced that young people suffering from severe eating disorders should not be permitted to make their own decisions once

they reach 18. Purely and simply because the eating disordered mind makes them unable to do this. We are talking about a serious mental illness after all. And not only this but the most deadly of all mental illnesses.

As has been proven by the above article in the Telegraph.

I know there are lots of parents of young people out there... young people who are about to reach 18, or who have already reached 18, or who are in their twenties or older... who would give their back teeth to have some clout when it comes to whether or not their child needs - and gets- treatment for their eating disorder.

There must be something we can do together. The Act says that Once an individual has reached the age of 18, no one can give consent on their behalf. If they are not competent, clinicians can provide treatment and care, providing this is in their best interests.

All too often this needs to go through the courts which, when someone is seriously ill, can be too late.

But why the hell should such a dramatic and radical change to a mentally ill child's rights take place the moment the clock strikes midnight on their 18th birthday?

Saturday, 23 February 2013

UK parents, I need your assistance please!

Back in the summer of 2009 when my son, Ben, began to show classic signs of anorexia, I had no idea that boys got eating disorders. As a result 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.

Once my husband and I realised what we were dealing with it took weeks before we were able to get a referral from our GP for treatment. After that we were faced with a wait of 18-22 weeks for an initial assessment with CAMHS (Child & Adolescent Mental Health Services).

So, if Ben hadn't been rushed into hospital at the end of January 2010, it could have been Easter 2010 before his treatment commenced.

That is a hell of a long time from first symptoms emerging to eventual treatment.

And, meanwhile, we watched helplessly as our son disappeared off a precipice.

Worse, Ben's illness had been germinating for months before the summer of 2009, maybe even years...

Yet we simply didn't notice because it took us by complete surprise.

And I don't for a moment believe that our experience is unique.

Because I want to avoid other families having to go through a similar wait before their child gets treatment, I want to raise awareness of (a) identifying the warning signs, (b) getting GPs to take swift action and (c) the waiting times experienced by families for CAMHS (and similar) treatment in the UK.

My new book, (working title) *Recognising ED*, will comprise approx 20 families' accounts from when they first realised something was wrong with their child through to GP referral. I want to give a balanced picture, if possible - good as well as bad.

But to do this I need to talk to UK families. So far I have five on board.

If you would be willing to talk to me, in confidence, over the phone about your experiences with a view to being included in my book - anonymously, of course - I would love to hear from you.

This is such an important issue and I believe this book will not only help other families but also help to raise awareness of problems that families have faced with getting referred.

Saturday, 23 February 2013

My letter to our local MP. Get writing!

Please feel free to adapt this to send to your local MP! (the wording for paragraph 2 is taken from of this report, as are some other facts and figures). Here goes...

Dear Fabian Hamilton

Last Thursday a three-hour debate took place in Westminster about eating disorders led by MPs Caroline Nokes, David Burrowes, Tessa Munt and Mary Glendon.

A huge point raised in the debate was whether the current Children's Act should be reconsidered. As things stand a 16-year-old with anorexia is deemed capable of making their own decisions leaving distraught parents with no control unless the patient is eventually sectioned under the Mental Health Act, which then has implications for the rest of their life.

Eating disorders are serious mental illnesses; indeed they have the highest mortality rate of any mental illness. 20% of sufferers die as a result of the illness and 40% never truly recover.

As a parent of a teenage boy who has now recovered from anorexia nervosa, and also a member of FEAST (a global charity for supporting parents of young people with eating disorders) I know just how much a sufferer's mind can go completely off the rails making them incapable of making rational decisions.

The thing with anorexia is that it makes the sufferer unable to "want" help. Indeed they tend to "want" the reverse... for parents and professionals to "back off" and leave them alone... which is why – when they reach the age of 16 or 18 – some sadly discharge themselves from treatment, all too often with devastating results.

Only this week the Telegraph printed an article about one such case – an 18 year old girl that discharged herself and subsequently died. (+ link)

This is far from being a unique case.

Not only this, but loving parents who have actively and successfully been involved in their child's treatment suddenly have no say in the matter once their child reaches 16 or 18. Professionals aren't permitted to talk to them if their child refuses permission which, all too often, is the case. This, in a world, where evidence suggests that Family Based Treatment (i.e. treatment that involves parents in their child's recovery) is the most successful treatment of all. (+ link)

On a personal level, I know of several parents who are having to watch, powerless, as their 16+ child deteriorates yet refuses essential and potentially life-saving treatment.

It shouldn't be happening, but it is.

I am writing to you because I would like you to actively support the campaign which is being led by the above MPs and specifically to support a change to the Children's Act as outlined above.

This is a cross-party issue because, after all, we're talking about young lives which are at stake.

In the meantime here is a link to my regular blog about eating disorders which discusses this issue: (+ link to my blog)

If you would like me to come and meet you to discuss the above in more detail I would be delighted.

Many thanks.

Monday, 25 February 2013

Getting out of my comfort zone...

As I just said on my Facebook page: What is it about contacting the medical profession that scares me so much? Is it because I'm "just a mum"...? Obviously if I'm going to write a book about UK families' experiences of the early months of their child's eating disorder, which would include presentation at their GPs' surgery, then I am going to need to talk to the medical profession in order to take an informed viewpoint. So why does it scare me?

Apart from being "just a mum" and having no medical knowledge except all the masses of stuff I've learned over the past three-and-a-half years - from when my son, Ben, developed his eating disorder up to the present day - I think one reason is because, as a copywriter, I tend to write in quite simple language.

And academics, especially clinicians, tend to have a language all of their own which makes the mum-in-the-street like me feel... well... a bit ordinary and ignorant.

In other words, my writing / speaking style is “primary school” and theirs is “post-graduate”.

Or maybe it’s because I’ve always been scared that professionals won’t take me seriously.

I am just me. Absurdly, in my head, I am still the girl at school who messed around, rebelled and walked out of important exams. The girl that was labelled “arrogant” for speaking up in class. The girl that was sent to stand in the corner on her very first day at school, aged 4, for contradicting the teacher. And the young woman who was once told by her bullying boss that she would “never be anything but a secretary”.

And, more recently, the mum who had to battle with the medical profession to get her concerns about her son addressed.

So why, I absurdly say to myself, would anyone in authority take “me” seriously?

It was the same when I first went freelance, when I dragged my portfolio around all the advertising agencies in my city. There is something in me that makes me doubt my abilities, the ever-present feeling that “I am not good enough” when compared to the “real professionals” out there.

In other words, I am a fake. And one day everyone will realise this.

Which, of course, is ridiculous.

But my lack of confidence, low self-esteem and inherent shyness means that I do find it really hard to push myself out of my comfort zone and get out there.

Feeling this way really annoys me, especially when I look at devil-may-care people around me who don’t give a toss what people think.

Or maybe they do.

Maybe, like me, they hide it quite well.

Tuesday, 26 February 2013

Update on who I’m seeing, when and why

Firstly, I’m meeting up with my local MP at some point next week (probably) to talk

about the issues raised in the letter I posted here a few days ago (primarily over 16s and eating disorders). Secondly, I'm meeting with two of our local GPs to talk about the current situation as regards diagnosing / understanding / recognising / referral for eating disorders. And, thirdly, I am talking with (so far) 17 UK families about their experiences from when they first realised something was wrong with their child through to referral for eating disorder treatment.

The latter is for my next book (working title) *Recognising ED: Families talk about how they first realised their child was developing an eating disorder* (the title of which I need to edit down!!)

If you are a UK family and you would like to talk with me, in confidence, with all names and anything else identifiable changed to protect your privacy, then please do get in touch with me.

I have emailed the Royal College of GPs to see if I can talk to someone there, but have received no reply.

Meanwhile I am still waiting for Ben to make his way through my new book *Please eat...* so I can get it published! As I said before, it's slow progress. He has reached chapter 10. Only another 22 to go...

Apart from that, and one review I would still love to have, it's ready to go live!

MARCH 2013

Monday, 4 March 2013

Disappearing up the proverbial you-know-what...

It's my own fault that I'm juggling so many balls at once, of course. That's me, down to a tee. I always feel I have to be on the go doing something and find it hard to sit down, relax and read a book, say... Then I panic because of the backlog of self-

imposed things that need doing. Like I still haven't made an appointment to see my MP. I still haven't made an appointment to chat to the GPs at our local practice. Etc etc...

But I am gradually making progress on publishing my new book *"Please eat..."* which, hopefully, Ben will finish commenting on soon. And formatting a version for Kindle and another version for other e-readers.

And I did spend an afternoon last week talking with the student niece of a friend for her dissertation on males and eating disorders.

And I have made an inroad into my next book "Recognising ED" in which I talk to - 23 I think the current total is - families about their experiences from when they first realised there was a problem through to referral for treatment.

Plus I've been lurking on the ATDT forum for parents of young people with eating disorders where I'm a mentor.

Oh, and I've been doing my normal paid work.

And later this week Ben and I will be spending the day in Sheffield to formulate a Plan to ease him into university should he decide to give it another go in September. We will be seeing accommodation services, student services, ED nurse in health services, disability services and the admission tutors for his course - a packed schedule from 10am to 6pm, phew!

Which is why I haven't been posting up here that much recently.

But I will do, I promise!

Wednesday, 6 March 2013

Totally and utterly pointless and not what my new book is for.

When I publish my book *"Please eat... a mother's struggle to free her teenage son from anorexia"* next week, I am publishing it to help other families realise that they are not alone in their fight to free their teenage son or daughter from this

devastating and potentially lethal illness. I am not publishing it so six copies of it can sit, unopened and unread, stacked in dusty vaults of the six Legal Deposit Libraries in Great Britain and Ireland.

Also, I have promised to donate the first 10 royalties of “Please eat... a mother’s struggle to free her teenage son from anorexia” to eating disorder charities. After that, any royalties will be used to refund my expenses. Publishing a book isn’t cheap! In other words, I am not going to get rich from this. I probably won’t make any money at all.

But that’s not why I’ve written it.

I have written it purely and simply to help other families.

Yet here I am, having to dip into approx £50 of my initial royalties, maybe even more depending on postage, to mail six copies of my book to the Agency for the Legal Deposit Libraries for them to distribute to the dusty vaults of the Bodleian Library Oxford University, The Cambridge University Library, National Library of Scotland, National Library of Wales and Trinity College Dublin, as required by law and the official letter they mailed to me yesterday.

In addition I am required to send a copy to the British Library. Again, at my own expense.

So that’s six books in total, purchased and mailed at my expense so they can sit, unopened, unread and unloved in six dusty vaults until they rot.

And this, in an age where everyone is being encouraged to go digital. The “paperless society”.

An age where you can set up a secure facility built to withstand every disaster known to man to store and provide essential back-up storage for vital documents and data in digital format. And back it up at several other facilities “just in case”.

So, unless a meteor hits the earth and destroys it completely, your electronic data will still remain intact somewhere.

Yet, in an age where all of this is possible and where it’s getting even more

possible and secure by the day, we writers are still required - by law - to send a box of our printed books to these libraries.

Not lending libraries where readers can actually benefit from the words in these books. But library vaults where they will remain ignored and unloved.

I don't mind the fact that publishing my book *"Please eat... a mother's struggle to free her teenage son from anorexia"* hasn't been a cheap exercise what with ISBNs to purchase, umpteen printed proofs to send off for, websites to set up and all the other expenses that are involved, not to mention my time. I don't mind that at all, because - ultimately - I have written this book to help other families. In the same way I've been writing this blog for two years.

But what I do object to is adding to my expenses, probably by £50 or more, to do this pointless exercise, along with tens of thousands of other writers who are doing the same. Filling up massive buildings that take up valuable space on our all-too-tiny island. And which are, no doubt, funded by the taxpayer.

Okay I can understand if it's Jane Austin's original hand-written work. Or the Magna Carta. But, these days, with the advent of self-publishing and print on demand, there are so many books being published - some good, some not so good, some pretty dreadful I imagine.

And yet all are required, by law, to be deposited at these six libraries until they rot.

It is completely pointless. On so many, many counts.

And it makes me mad.

Thursday, 7 March 2013

Phewee, a heck of a long day at the university

Today Ben and I returned to Sheffield, not having been there since that fateful week in September when he jumped ship and decided to take a year off. Like then, we did the rounds of just about everyone we could do the rounds of: accommodation office, student support services, disability support services, student health services and the

faculty admissions tutors - between 10am and 5pm and I am well and truly knackered!

There is so much support in place for Ben when / if he returns to university this September that really and truly I don't know how much more they could have done. We've organised a different kind of accommodation which he might find easier to adjust to living in... accommodation mentors, 24/7, should things get tricky at any time of day or night... other mentors... an invitation to a pre-intro week week designed to help students like him meet up with like minded students a week before the rabble arrives, with nice quiet events like games evenings, quiz nights, etc i.e. not booze / party focused.

Student Support Services are coordinating a team of people to support Ben in every area of student life. Not sure how useful the Disability Services would be but they do have mental health specialists should things become unstuck.

We met the eating disorder specialist nurse in Student Health Services who seemed really good and suggested Ben meets with her once a week for a chat.

Then we met the faculty admissions tutors who said they'd help to formulate a timetable that would allow Ben to live at home for half the week and in Sheffield the other half, in order to ease him into university life to avoid the "throwing into the deep end" problem that happened last September. He can use our local university library and there is a ton of study materials on the university intranet. Some of the lectures are on podcast, too, so in theory, if he felt more comfortable initially, he need only be in Sheffield from Monday lunchtime through to Thursday afternoon.

In an ideal world he would want to be in Sheffield seven days a week. But this way he has the option of easing himself in at a pace he feels comfortable with, supported by this army of mentors, counsellors, student services and so on.

Now all he has to do is to decide, by July, whether or not he is going ahead. July being the deadline for accommodation.

I am well and truly exhausted!!!

Friday, 8 March 2013

... that one comment can make such a difference...

Ben was in tears this morning. The reason? My (frustrated) reaction to his (frustrated and confused) reaction to a throw-away comment made by the university's specialist eating disorder nurse yesterday. The comment: "Well you look absolutely fine now. I can tell by looking at you."

Also, her heavy emphasis on the "fact" that eating disorders are "an anxiety thing". In other words, solve the anxiety and you solve the eating disorder. Or at least that was the message we were getting.

When we got home we had a peek at a video she'd pointed out to us which the university had produced for eating disorders awareness week. They'd taken a group of (former?) eating disorder sufferers and asked them to talk about their eating disorders. The focus of the video was all about "positive body image".

Also, one of the young women said (something along the lines of): "In the end I got bored with it, so I just stopped." And now I'm better, kind of thing...

Here is the link, make up your own mind.

Ben was in tears because, he says, the one person he thought he could depend on to "get it" across all the various support services we saw yesterday was the specialist eating disorders nurse.

And he felt that she just didn't "get it".

I must admit that, looking back, certain things did concern me. But I put that down to the fact that, after all this time, I know a heck of a lot about eating disorders - from being on the "front line", 24/7 for so long, and from moving in the circles I do. So I thought, well, she doesn't know us, she doesn't know Ben's history and she might just be one of those people that are adept at getting misinterpreted by people or just say the "wrong thing". Like I do, on numerous occasions.

So I referred her to the FEAST website ("A mine of information about everything to

do with disorders”) and Men Get Eating Disorders Too (“Who know absolutely tons about eating disorders in males”).

She knew about BEAT.

Or “BITE”, as she referred to it a couple of times, before I corrected her.

The key is, though, that all of this was a Big Deal to Ben. So much so that it’s almost as if all the other positive stuff from yesterday never happened.

He needed to feel comfortable with this nurse, but he didn’t.

And it’s left him mega confused and disheartened. I believe it may affect his decision whether or not to go to university in September. Or at least that particular university.

It also leaves me so incredibly frustrated that, so late in the day, a throw-away comment like this can be such a Big Deal to him.

Friday, 8 March 2013

Why I feel numb

Three and a half years of living with an eating disorder and watching it systematically destroy my son’s teenage years - all those years that parents have so many hopes and dreams about - has removed any ability I have to feel disappointed. Last September, when Ben left university, I felt deep disappointment and wanted to throttle the eating disorder for doing this to him, for smashing his hopes and dreams as well as ours.

But nowadays it’s as if that part of my brain has become numb. The disappointment, sadness, anger and frustration is there, but it’s like a noise in the distance, difficult to hear, difficult to feel. I just feel numb.

This time last year as Ben was discharged from CAMHS and began to “get his house in order” to kick the eating disorder out of his life for good, move on, start afresh at university and get on with his life, I really believed he could do it.

And, as you’ll know if you’ve read about the excitement and positive anticipation I

was feeling from mid-August through to mid-September, between getting his place at university and depositing him in his university residence, I was as thrilled as any parent.

But you will also know how sad it was to have to remove Ben from university so soon. How we fought to overcome his intense feelings of “failure” and the realisation that the remnants of the eating disorder were still messing up his life.

It’s something he has struggled with since then. And I could tell that he still wasn’t completely convinced that he was ready to try university again. But I could also tell that he so very much wanted to get on and get to university, to begin studying again... Ben is passionate about studying... and to kick the ED out of his life for good.

Yesterday’s experience in Sheffield has hit him hard. His mood is rock bottom and I can sense his own frustration, disappointment and anger that the eating disorder still has a certain hold over certain areas of his life. For example he still has the confusion generated when an eating disorder professional says something very different from what his parents - and everyone else - has been saying for so long.

It makes him wonder who is right. Is this nurse right? Were we, his parents, wrong all along?

Most important of all, it makes him wonder if by looking “fine” and “well” in her eyes, he actually looks fat and should put on the brakes as far as the weight gain goes. If he looks “fine” as he is, then why should he listen to mum who insists he needs to continue putting on weight?

Me, well, I’ve been kicked in the stomach by the eating disorder so many times that I feel kind of numb. Like people who are being beaten up who just lie there and let their assailant continue. Almost as if the inevitable is indeed inevitable. I can’t have any excited hopes and dreams for my child because there’s a high chance they simply won’t happen. Because of what remains of the eating disorder.

And, at times like this, I wonder if these ED remnants are here to stay and f*ck up his life forever.

Saturday, 9 March 2013

A labour of love is finally published

It was back in June 2011 that the school nurse collared me and said: "You should publish your story in a book to help other parents." "What me?" I said. "I can't write a book!" "Why on earth not?" she said. She collared me again in September 2011: "Had any more thoughts on the book?" And the rest, as they say, is history...

This weekend I've taken the monumental step and finally - after all this time - published my new book: *Please eat... a mother's struggle to free her teenage son from anorexia*. All 268 pages of it.

It is available at Amazon.com, Amazon.co.uk and on Kindle via both of these channels. You can still read the first 6 chapters as a PDF here... Later, you'll be able to "look inside" the book on Amazon. (You can already do this with the Kindle version.)

This book has been over 18 months in the making and I don't know how many versions have been in front of my red pen together with at least 6 different printed proofs...

I have been through several packs of typing paper, used up umpteen printer cartridges, cut out new sections and taped them over the old sections in various printed proofs... and then ripped them out, printed out new sections and taped them into the proof instead...

I have read it through on my Kindle, and in PDF format... Notebook and pen in hand, I have made tweaking notes sitting in front of the telly, in the coffee shop, in the car, in the garden, in bed, even in the bathroom. I have sent it to several awesome volunteer proof-readers to whom I owe an immense debt of gratitude, and to a stack of equally generous and kind people that offered to review my book before it went to print. And, of course, I have been through it in detail with Ben.

I have tweaked the front and back covers so the current versions are unrecognisable from the originals, and purchased the rights to use a library image for

the front cover, which I played around with until I was happy with the current depiction. And I have uploaded the whole lot more times than I care to remember to CreateSpace who are printing my book (part of Amazon).

Knowing me, I could continue to tweak and edit from now until Kingdom Come, but the primary reason I have written this book is to help other families struggling with anorexia and other eating disorders.

I figured that the longer it remains in “draft” form, the longer it remains of no use whatsoever to anyone.

So I’ve finally made the decision to publish it.

Which is scary after all this time - and because it includes some of our most intimate and distressing moments as a family battling with anorexia.

Yet so does my blog.

So, in a way, getting “out there” with a book about our experiences isn’t so very different from getting “out there” with my blog, which I’ve been doing since January 2011.

(Yet you can bet your back teeth that - despite all this proofing, checking and editing - someone, somewhere, will find a typo!)

If anyone would like me to mail a signed copy to them for the same price as Amazon, including p&p, please contact me via the contact page on my website to pre-order and ask for PayPal details. (Sorry, I can only offer this facility to UK customers due to high shipping charges.)

If you do buy a copy, and you do like it, then please can you leave a review on Amazon?

Many thanks!

Sunday, 10 March 2013

Putting things into perspective

I am pleased to say that, last night over our evening meal, the talk - from Ben - was

all about going to university. It seems as if he's been able to put the eating disorders nurse's "throwaway comment" into perspective. Yes, to him, she's not someone he would want to depend on if his eating disorder made a reappearance (which it hopefully won't). But, with the plan to initially spend half a week in Sheffield and the other half of the week here, we will be able to monitor him. And, for so very very long, he has come to depend on me to be both "clinician" and "carer". In other words, he may never need to see the eating disorders nurse at all, should the worst case scenario happen.

He is happy with all the other support measures that have been set in place to make it simpler for him to ease himself into university life. Also, the faculty admissions tutor suggested that he pop down to Sheffield and sample a lecture or two, as part of the overall plan to make Sheffield University feel familiar.

So at the moment, he seems to be planning to go back to university in September. He's sorted out the student finance; I delegated it all to him this year. In fact I'm delegating everything to him this year. He needs to do it for himself. Mum needs to take a back seat.

Meanwhile he continues to help out with the sixth form history students at school two mornings a week. He's been asked to mentor a few of them in addition to taking lessons and marking work. He has also been invited on a teaching course over the summer about teaching sixth formers. Plus, he's been invited on the school history trip to Berlin the following summer. So it seems as if the school is keen to hang onto him. And Ben is still keen to train as a history teacher once he's done his degree.

Tuesday, 12 March 2013

Experiencing the Post-Publication Blues?

I think it's because my new book *Please eat...* has taken up so much of my time, energy and emotions over the past 18 months that now it's "out there" and published, I feel kind of weird... And I guess this feeling isn't unique to me. Also, I've

nurtured every word, sentence, paragraph and chapter so very carefully over the past 18 months, that sending my “baby” into the Big Wide World is a real wrench. And, of course, I am worried that no-one will buy it or be interested in our story...

But I guess that publishing it is the easy bit. Now comes the difficult task of promoting it and raising awareness that it is “out there” now.

However, with something as personal as this, there’s part of me that doesn’t want to promote it at all. That almost wants to claw it back and remove it from Amazon.

Which is strange, all things considered...

And it’s this feeling that I’m trying to get my head around today. This curious feeling of Post Publication Blues... The awareness that it’s been a labour of love - of blood, sweat and tears - yet it’s so very, very personal and private. And the first two thirds of my book makes pretty difficult reading as it describes the hell we were going through as a family descending into, and then dealing with, anorexia.

But of course it does. It has to. This isn’t the kind of light, throw-away paperback you might take to the beach.

As Gill Todd (RMN MSc, former Clinical Nurse Leader at the Gerald Russell Eating Disorders Unit, Bethlem & Maudsley Hospitals, London) said when she reviewed it: “This is a wonderful book. It’s quite hard to read because the story is so painful, but easy to read because of the clarity and simplicity of style.”

It was quite hard to write, too. For Ben as well as me who, as you will know, contributed his own bits and pieces to the book.

And now that *Please eat...* is “out there”, it’s quite difficult to come to terms with. Even though I’ve been writing mega personal stuff in this blog for 27 months. Even though the first 6 chapters of my book have been “out there” on the Net for anyone to read in order to get a taster of the content.

So it really shouldn’t be such a Big Deal for me, should it?

Strange feeling, this...

Wednesday, 13 March 2013

Talking with a local GP about eating disorders

Last week I had a chat with a local GP about eating disorder awareness which was quite illuminating. Obviously this is just one GP from just one GPs' practice - a large, established practice in the leafy suburbs of a big northern UK city. Anyhow, this is what she said...

As a medical student at Cambridge, we probably had a couple of lectures on eating disorders, part of our psychiatry studies. As GPs we don't receive any further organised training. However if you have a specific interest in eating disorders you will look them up.

How would you identify a person with an eating disorder, say a parent brought their child in and were concerned about them? Maybe an atypical presentation? Or they're not emaciated or they're in denial?

I'd speak to the parents. I'd also speak to the child, in fact I'd try to talk with the child alone if I could. In a case where the child insists there is nothing wrong and it's simply their parents being overly concerned, I'd talk with the parent. I'd ask why they are concerned. Is it because there are a lot of eating disorders around at the moment, for example at school? What evidence do they have that their child has got an eating disorder. Do they have evidence that they are taking laxatives, for example? Can they see their child not eating? I'd take it from there, really. If I felt it was just a paranoid parent then I'd probably just keep things under review, but if there was good hard evidence for me to go on then I would pursue it as much as I possibly could.

How much awareness do you have of males with eating disorders and children under 7?

I referred a boy for treatment recently. I don't have any experience of eating disorders in the under 7s but I am aware that they happen.

What measures might you take on first presentation for example weight, height, bloods, etc?

I'd definitely measure a young person's height and weight. Depending on age I'd talk to them about blood tests and explain why I felt they needed them. And if I were doing those investigations then I would definitely be referring to a specialist for advice. Knowing how long it can take to get someone seen, I would send off a referral at that point. GPs are just general practitioners; we're happy to help as much as we can but I'd be thinking that they would need to be seen by a specialist as well as seeing me.

I would refer a patient to CAMHS immediately, at that first appointment. If I thought there was some doubt about what was going on or what the family dynamic was then I would maybe see them again for another chat before referring but I'd definitely refer sooner rather than later.

While they were on the waiting list for CAMHS, I'd say "Come back, come back and see me whenever you need to". And if I felt the case was getting more urgent and they were really poorly, I'd see if I could expedite the appointment. I'd phone CAMHS. I have done this with eating disorders and self-harming, so I can make sure CAMHS is aware of how serious I feel the situation is.

What, in your opinion, causes eating disorders?

Oh my goodness! Society, the child's personality, upbringing,... there are so many different causes. So definitely personality traits, anxious personalities, perfectionists, the way society projects the perfect female body in that you "have to be" thin, so peer pressure, bullying and comments from other girls. Also, competitive children, competition with other girls, parents... you know, parents with high expectations who put pressure on children so self-harm is a release. Control, too. One thing they can control is food so they're using food as a control thing.

How much awareness do you have of the latest research showing that eating disorders are probably genetically based and heritable conditions?

Yes, I'd go with that. I'm sure it's part of the spectrum of anxiety and depression and it can be – not all the time, but it can be – a manifestation of that spectrum. I

know there is a genetic basis, so yes. Interesting how you try and winkle out nature and nurture, though. I mean, if you have a mother who is hyper-paranoid about her weight... but, anyway, yep, I'd go with that.

How many GPs in the practice have extensive experience of eating disorders?

I'd say there probably isn't a GP here who has done psychiatry. As a GP you just see what crops up. I mean, we're a middle class, educated GP practice so we might see more eating disorders in middle class well educated girls (and boys) than, say, somewhere with a different demographic.

But I don't know how many eating disorder patients we see or if any GP particularly specialises in eating disorders. You might need to talk with one of our more senior partners. We don't see eating disorders very often; GPs' time is so pressured so, as a GP, you tend to find out more about what you see more of. But if ever I had anyone with an eating disorder and I felt out my depth then I would definitely find out more about the condition.

Wednesday, 13 March 2013

Picking the brains of the Royal College of GPs

...Who were kind enough to send me a lengthy and very detailed response to my enquiry about GP training on eating disorders. (As a background to their function, the College says: "The Royal College of GPs (RCGP) has the role of setting standards for GP training. It does this by setting the curriculum and assessments for training, both of which are approved by the General Medical Council.") Here is what I feel is the most relevant part of their reply to me...

The actual delivery of the training is organised by the postgraduate medical deaneries, each of which covers a specific geographical area. Although the College and deaneries work closely together, they are independent of one another.

The assessments that GPs-in-training must complete include a combination of

external examinations which are set by the college and assessments that are performed in the workplace (i.e. the practice and hospital), incorporating assessments of performance and patient and colleague feedback. Once the trainee has passed these assessments they are awarded MRCGP qualification and their Certificate of Completion of Training (CCT), and can then enter independent practice.

Once a trainee has received their CCT and become a fully qualified GP, they are expected to maintain their knowledge and expertise by a process of life-long continuing professional development (CPD). All doctors must undergo an annual appraisal and must re-apply for their licence to practice every 5 years, a process known as revalidation. This process requires the doctor to demonstrate that he or she has kept up-to-date and has undertaken activities to improve the quality of his or her practice. It also includes a review of significant events, complaints and compliments received.

Although the curriculum sets out the skills and knowledge required, the RCGP is increasingly concerned that the current three-year training programme for GPs, which has remained the same duration for over 30 years, provides only limited opportunities for those doctors to receive specialist-led training in mental and child/adolescent health.

GPs-in-training must therefore pick up these skills in general practice settings which takes both time and good quality supervision.

It is not widely known that currently only around 50% of doctors-in-training for general practice have an opportunity to undertake specialist-led mental health or in child health training placements (e.g. based in hospitals or specialist mental health services) during their three-year GP training programme, although this experience can be invaluable if properly focused.

This is significant to the care of patients with eating disorders, of course, as adolescents are disproportionately affected by these conditions and the long-term community-based relationship with the GP is especially important for diagnosis and

treatment of mental health problems.

In response to this, the RCGP has proposed that specialist-led mental health training and paediatric training should become a mandatory part of an extended, four-year core training programme for all new GPs.

This proposal forms a central part of our educational case to roll-out an enhanced four-year GP training programme across the UK. The RCGP's educational arguments have received broad support by patient organisations and professional bodies but now requires implementation and funding – we are currently working up detailed implementation and economic plans with DH and other stakeholder organisations to enable this, although it will ultimately be a decision for the Governments in all four nations.

This work is scheduled to be submitted to Ministers this summer, for their decision late in 2013.

Thursday, 14 March 2013

But **would you ever need the ED nurse, Ben?**

“I must go to Sheffield,” he said yesterday morning.

“Why ‘must’ you go?”

“Because I need to prove I can live away from home. It’s something I need to do; something I need to do for myself. The only thing that’s putting me off about Sheffield is the ED nurse. If, God forbid, I ever had a relapse at university I couldn’t bear finding myself in her clinic only to be told that my eating disorder was anxiety based!”

“But would you ever need to see the ED nurse? After all, for the past year or so I’ve been your clinician as well as your carer. You’ve been your own clinician, too. And, together, we’ve been pretty damn successful. Also, you’re planning to spend half the week at home and half in Sheffield to begin with, and definitely if you ever slipped back into the ED.” I also explained that we’ll be running our University Contract, just

as we planned to do last year. So, if ED ever reared its ugly head again, Ben will need to stick to certain conditions.

So he would never really need to see the university ED nurse. And there are always the university doctors and the other nurse. Mind you, we don't know what their perceptions of eating disorders are like!!

And who's to say the local university eating disorders team is up to speed with the evidence-based latest research on anorexia, hey...

So at the moment, therefore, my money would be on Ben sticking with Sheffield.

Tuesday, 19 March 2013

Busy talking to families about anorexia

Over the past week I've been busy talking to families about when anorexia entered their lives: how they first realised that something was wrong through to treatment. It's been a real eye-opener - and I still have a dozen or so more families to talk to.

What is coming across clearly so far is the fact that being treated for an eating disorder is a bit of a postcode lottery. Some areas of the UK are excellent whereas others... well... "could do better".

Likewise some GPs are clued up on eating disorders whereas others aren't. But thankfully most of those that aren't are eager to find out more - and happy to refer quickly. Not all families went via the GP route, however; they self-referred direct to the treatment providers (e.g. CAMHS). I didn't realise you could do this, but I do now.

The good news is that, so far, in my cross section of families, the initial treatment appointment came through quickly, sometimes in just days. Contrast this to our experience where we were told there would be a 18-22 week wait - and this was AFTER we'd waited for 3 or 4 weeks for a confirmation letter of the referral.

Some areas of the UK have specialist eating disorder treatment centres while others just have CAMHS. There is some really great private treatment available if you can afford it or if you're lucky enough to have good quality medical insurance (usually

a perk that comes with a job).

Also, some areas of the UK have excellent eating disorder support services (which support the whole family), either funded by charity or part charity / part NHS funding.

This is just a snapshot of what I've learned so far. I still have more families to interview. And, of course, my findings can never be "scientific", as such.

But the way it seems to be a postcode lottery really concerns me.

Thursday, 21 March 2013

I continue to be in awe at these brave, generous families!

I am getting a really, really good feeling about my next book - the one where I talk to families about their own eating disorder stories. It's morphed from being more about the early days (up to referral) to being more about the whole story. It's just the way it seems to be developing. And these families are truly amazing!

Not only have they been through hell and, in most cases, come out the other side, but they are willing to share their stories with me for my book. Of course all names have been changed to protect their privacy and identity, just like I changed Ben's name for my book *Please eat...* And the way I wrote the book under my maiden name, not my usual married name.

This exercise also means that families are having to rewind back to memories that are incredibly painful and difficult to deal with. Not just once, when they talk to me initially, but when I send back my draft for them to check over.

It is not easy. Yet they are all doing this so very enthusiastically.

Why are they so keen to do this?

Because they're all eager to do their bit to help raise awareness of eating disorders and the treatment available. Together we are all highlighting the patchy "postcode lottery" nature of eating disorder treatment in the UK.

Yet we're not being critical. It's more a case of just telling it how it was or is. Like I

did in *Please eat...* If it happened like it did, then it did. And hopefully together we can become one of the many voices that are advocating change. On the other hand, some of the treatment families have received has been truly outstanding and it's important that we highlight this, too, as a benchmark for what can be achieved.

It's also very important for us all to demonstrate that we are all normal families. Parents are not to blame for their child's eating disorder. We are just like any other families. Or at least we were before the eating disorder took over our lives.

We are also keen to bring out into the open what it's really like to be parents of a child struggling with an eating disorder - to watch them change in front of your eyes, to gradually realise what you are dealing with and then to get the best possible treatment for your precious child whilst also having to go through the gruelling process of caring for your child at home.

Finally, this new book is a tribute to the young people themselves - those brave, strong, tough girls and boys that refused to give into the eating disorder.

If I could hug every one of "my" wonderful, brave, generous families, then I would.

Friday, 22 March 2013

There MUST BE a united front against the eating disorder

One thing that is coming across very clearly, and it's something that seems so very, very obvious - so obvious it screams out at you - is that the entire treatment team and the parents need to present a one hundred per cent united front against the eating disorder. We parents already know this and, thankfully, so do some treatment teams. But, again, it's a postcode lottery. We don't know this until we find ourselves in front of the CAMHS team (or whatever) we've been allocated. Here in the UK we don't seem to get any choice.

It is vital that we all need to appear to be on the same page, every time we meet. Because the moment the eating disorder detects any discord or dissent in the ranks it will zoom and exploit it. And you've lost the major advantage you've worked so hard

to gain.

And once you've lost this major advantage it's not simply a case of making things a little harder for everyone, it can often f*ck things up completely. Big style and for a hell of a long time. When I say a hell of a long time it can be weeks, months or even years... or even the rest of the young person's life.

Having talked to 13 families about their experiences, I wonder: Are treatment teams aware of this fact?

It's not all bad news, though. Where families and the treatment team are working together in complete unity against the eating disorder, the eating disorder doesn't stand a chance.

Obviously it's not that simple and obviously I've only talked to a tiny proportion of UK families. And obviously, even with the most amazing treatment team in the universe, the eating disorder is going to fight tooth and nail to regain the upper hand, and doubtless it sometimes does - and recovery can take a heck of a long time. But in my mind, when there's a consistently united front, the eating disorder has essentially lost the fight. It is weakened.

On the other hand it only takes a little bit of discord, a slight disagreement, the odd thoughtless "throwaway" comment or downright triangulation... Or the parents not being listened to, not taken seriously or being seriously undermined in their sterling efforts to free their child from this hellish illness... and the eating disorder detects this.

Instantly.

And the moment it does, you're onto a loser.

Because it really is like a battle. Once the enemy detects a weakness they'll exploit it.

But it's not just this, it's the fact that you, as a parent, are with your child 24/7 and the clinicians see your child for 60 minutes a week or even less. Some families are fortunate enough to have more sessions, some as many as three sessions a week. But

you are still with your child for the vast majority of the time, especially if you've taken them out of school and they're not sleeping. Many parents are having to spend the entire night with their child.

So it is obvious that parents have to be the child's primary clinician as well as their carer. It is essential that they are an extension of what is going on in those 60 minutes that's spent with CAMHS or whoever.

And to do this, parents need to know what they should be doing. Not simply to be handed a diet sheet and be expected to make their child eat. After all, if they were able to feed their child then their child wouldn't be in front of the treatment team, would they? Parents need to be shown exactly what to do by clinicians who realise that parents are an invaluable and vital part of the mix. Parents can be their allies, not an annoying appendage.

Also, the moment they realised what they were dealing with, every single one of "my" families crammed up on eating disorders. They read books, they scoured the net, they talked to helplines and anyone else they could find. In a very short space of time these families became experts on eating disorders. Dare I say it, some families appear to know more than the clinicians? Especially clinicians that are multi-disciplinary, and frequently with non-mental health professionals for example A&E nurses and doctors, and some GPs.

So we aren't just "ignorant parents". We are actually pretty well clued up on eating disorders, driven by the primeval desire to save our child's life by whatever means. I always say that I never studied as hard for my university degree as I studied to find out about my son's eating disorder. And, unlike a three year degree, I had to fast-track my way through this complicated learning curve because the longer it took, the longer my child was at risk.

And, while you're waiting for treatment in those instances where the professionals don't believe the problem is as serious as it is, you - the parent - are the only one available to "treat" your child. You can't just sit there and let them fade away. Which

brings me round to the question: Why aren't some clinicians recognising the eating disorder for the serious, life-threatening illness that it is?

But we parents need support. And we need to join up with the treatment team to form well-oiled machines that steamroller the eating disorder out of our children. And because it's one hell of a slog, 24 hours a day, 7 days a week, we also need serious emotional support which often isn't happening. Thank God for places like the Around The Dinner Table Forum. All "my" families tell me it was - and is - a lifesaver.

Certainly some parents have had fantastic support from the services they've been working with and these excellent places should be viewed as benchmarks for other NHS services.

Oh, and don't go on at me about funding. If all of this was done properly the NHS would save money in the long run. And meanwhile lives would be saved, too.

Monday, 25 March 2013

Still talking to people and still writing...

I am so very grateful to all the UK families that have come forward to talk to me about their own experiences of eating disorders. What began as a look at the stage between first realising something was wrong with your child through to referral by the GP, is now focusing on the whole story - from beginning to where families are now. It's just the way it's naturally developed.

This is the book that I want to get up in front of UK health professionals and anyone else that should be aware of what it's like to be a parent, at home, coping with a child with anorexia. And also highlighting the considerable differences between the kind of treatment our young people are receiving - from the outstanding through to the "could do betters" of the ED treatment world.

This book will also help other families to identify the early warning signs, realise that what they are experiencing may be "normal" and know where to find help and support, plus empower them to demand better treatment from everyone along the

line.

I am still eager to talk with people, especially those whose children are now fully recovered.

Everything will be anonymous: all names, places and other things that might identify a family will be changed to protect privacy.

I'm getting a really great feeling about this new book!

Also, if you yourself have recovered from an eating disorder and you think your parents might be prepared to talk with me, I would really, really appreciate it.

For this book, though, I am focusing on UK families only.

Tuesday, 26 March 2013

MP here I come tomorrow...

Tomorrow I am at long last meeting with my MP to talk about eating disorders. I'll be focusing on the 16+ issues i.e. the way parents are eliminated from the equation once a child officially becomes an "adult" - and that these "adults" are expected to be capable of making their own decisions as to whether or not they require treatment. Indeed, whether or not they are ill.

I will talk about the way, once a child reaches 17 or 18, they are discharged from CAMHS, sometimes from a treatment team they are working well with and have built a good relationship with, into Adult Services which means starting the relationship all over again. And who's to say they will end up with someone they "click" with or who is any good? Also, parents who have been an essential part of their child's treatment up to this point are suddenly excluded, unless the child allows them to continue to play a part.

Others who reach the "magic" age of 17 or 18, like my son, are deemed to be sufficiently "recovered" not to warrant transfer to Adult Services, especially if their BMI isn't considered to be specifically low. And follow-up can be non-existent.

I will also be talking about the patchy nature of eating disorder referrals and

treatment across the UK plus waiting times. So far, from my talks with other UK-based parents, it appears that my son's wait for treatment was by far the longest. We were told 18-22 weeks, if you remember, from the date we eventually received confirmation of the GP's referral in the post. So my MP needs to know this, because if we had to wait such a dangerously long time, then presumably other families in our area are having to wait, too.

Thursday, 28 March 2013

The letter I would never send to Ben's friends

Here's the letter I'd love Ben's friends to see, but I would never send because he would go mad! But it feels particularly appropriate right now...

Dear Ben's Friends

Remember the days, back in years 7 to 10, when Ben was at the heart of your social circle? When he'd be fun to be with, go to all your parties and bonfire night celebrations, hang around town, see movies and get involved with things at school? Remember when he was in Buggy Malone with you all? He was awesome, wasn't he?

Then one day Ben fell sick with an illness that's so incredibly complex it's almost impossible to explain unless you've been through it. Anorexia, which is what Ben began to develop during the spring and summer of 2009, just before you all went into year 11, isn't just about cutting down on food and losing lots of weight. As the brain becomes seriously malnourished it begins to behave differently. This is why you saw a dramatic change in the way Ben behaved at school in year 11, why he gradually began to isolate himself from you all and why he eventually left school altogether until year 12. And why he never really returned to school full-time after that.

Please never feel that anything any of you did or said was responsible for the illness. Another complexity of anorexia is that it's hard-wired into someone's brain.

Basically when they lose a lot of weight in a short space of time, it kicks in. If they never lost the weight, then it might never kick in. I like to think of it as a bit like an alcoholic would never know that they were predisposed to alcoholism if they never had a drink.

It is no-one's fault. Why did Ben lose such a lot of weight, you might ask? Well, one of the reasons was the pressure he felt to look good, to have a six-pack, to look like the fitness fanatics in those magazines but without having to do all the 24/7 exercising that goes with it. Cutting down on food seemed the easiest answer and the rest, as they say, is history...

I know that many of you have done your best to try to understand Ben's illness, especially when his medical team came into school to talk to a group of you. At that point we really thought that things would change and that Ben would begin to ease himself back into the social circle he so longed to be part of.

But, 18 months after that meeting, it hasn't really happened.

Yes, on occasions, we thought - wow, this is it, he's back in there, back to normal and things are going to be just as they used to be. Like the end of A levels parties you had. And the History trip to Poland.

Ben is almost recovered from anorexia now. But one of the things that, with him, is so very difficult to shake off is the fear, anxiety and panic that comes with social situations. Knowing Ben as you did before his illness you might find this hard to believe. You might even think he's avoiding you, that he's found a new circle of friends. You might think he's not interested in you anymore.

But, I know for a fact, that he longs to be back where he was before the illness took hold. He longs to be back with you, messing around, going to town, going to see movies... everything you all used to do. But, because of what remains of his illness, it is as difficult for him as it is for some people to enter a room full of spiders.

Meanwhile, he is incredibly alone. He is lonely. He spends every evening sitting on our sofa. He has no friends. And it's not the way it should be for a 19 year old,

especially Ben who - as you well know before his illness - was confident, friendly and fun to be with.

So if Ben fails to turn up to social events, like the school reunion in November and various other events, it's not because he isn't interested; it's because he just finds it so damn hard to do. His illness makes him get incredibly anxious in the build up to the smallest event. So much so that it's easier for him just to say, no, I'm not going.

I want you to invite Ben to all your social events, even create whole new social events so he can be included. I want you to invite him round to your houses, like you used to do, to chat or play games. I want you to get him to invite you around here to do the same. I want you to chat to him on Facebook more than ever so he feels really included in everything. I want you to invite him to spend weekends with you at university.

I just want you to practically drag Ben kicking and screaming back into your social group as you all stand there with welcoming arms.

And I want you to really get to understand his illness and help him to work through this last remaining obstacle. Because, at 19, Ben should be with his friends, not here with us on the sofa every evening.

This is your loyal friend Ben, we're talking about. The boy who was so much part of your lives for so many years and who misses your friendship like hell. You may think that you've all made huge efforts to include him over the past three years. But, unfortunately with the way the illness has affected Ben, it takes much more than that. You have to virtually drag him out of the house physically. And, please, never, never act as if you feel sorry for him.

Ben just wants to be treated like a normal guy.

More than anything else, he just longs to be the Ben he was before the illness struck.

It would mean so much to me if you could help this to happen?

Love from Ben's mum.

Thursday, 28 March 2013

Finally, a full chart of Ben's weight, from start of CAMHS to discharge

I won't publish it here because these days I prefer not to mention specific weights (which might be triggering for other eating disorder sufferers), but this week I finally produced a full Excel chart of the changes in Ben's weight during the 26 months he was with CAMHS. It makes for interesting reading...

Initially, following our first CAMHS appointment in late January 2010, Ben's weight dropped.

As you'll know if you've read my new book "Please eat..." I managed to get him to stick to a weight-gain eating plan for a couple of months or so. It wasn't easy, I wasn't shown how to implement it, and I describe this period in detail in my book, but somehow I did it. And somehow Ben ate everything. The result was that, by the spring, his weight had returned to what it was on the first day of CAMHS.

Until one day in May 2010 when he "downed tools", spat out ice cream on the kitchen floor, and refused to follow the eating plan any longer.

Because Ben couldn't cope with "mum's eating plan", CAMHS decided to let Ben take back control of his eating and adjust the plan to suit him.

Between then and spring 2011 Ben's weight went steadily down. Yes, on occasions, he put on a little weight, but then he'd promptly lose it again - and then lose more.

In spring 2011, because Ben had reached stagnation point, I introduced the Recovery Contract as a result of a thread I'd seen on the Around The Dinner Table Forum where a family had been on this course at the UCSD Eating Disorders Center. CAMHS had never come across anything like this but, thankfully, they were willing to give it a go.

And guess what?

Ben's weight slowly began to creep upwards.

Mind you, it wasn't instant. It took until his discharge from CAMHS in March 2012 for it to return to the weight it was on our first day at CAMHS.

So, he never actually gained any weight at all during the 26 months he was with CAMHS.

Interesting, that.

Friday, 29 March 2013

Discussing "faith-based" eating disorder "treatments" made me think of this...

Some of us have been discussing fundamentalist Christian "faith-based treatments" for eating disorders which I won't go into here. But the general consensus of opinion seems to be that religion can be a great emotional support if you are a believer, but "faith-based treatments" can never - and indeed should never - be a substitute for modern evidence-based treatments for eating disorders. But all of this has brought my mind back onto the subject of religion - and my experiences with the Christian church during the dark days of my son's eating disorder.

As you will know if you've been following my blog, I met my most supportive non-eating-disorder-related friend ever on a chance visit to a local church. Sue supported me for more than two years though some of the worst patches of Ben's eating disorder until her cancer took her away.

But that was the only real support I received from the church. Sue was unique.

It was in November 2009 as Ben began to fall off a cliff during that terrifying early phase... You know, where your child has been developing the eating disorder, but it's been emerging so very gradually... Then all of a sudden - and every family I have talked to has said exactly the same thing - things speed up, so fast you can hardly catch your breath. It is like suddenly being swept away in a tidal wave after just paddling in the deceptively shallow waters for months.

Anyway it was during this period that I was desperate for emotional support. I hadn't yet discovered the ATDT forum and we were just beginning a three month

wait for CAMHS treatment. Ben was getting worse almost by the minute. Life was hell. I didn't know where to turn. I was screaming out for help.

So, as I have said before in this blog, the church seemed the obvious place to get this emotional support.

I tried three churches in total, giving each a fair amount of time to offer me what I so desperately needed. And, whenever people introduced themselves, I always told them what was going in my life. I couldn't help it. At the time I couldn't talk or think about anything else. And often I'd break down in tears while telling them. They either prayed with me there and then... you know, arms around me in a little huddle, that kind of thing... or said they'd go away and pray for me.

And left it at that.

Now as I continue to wrestle with these experiences, having been brought up as a Christian yet having lapsed for a number of decades, it's got me thinking.

Offering to "pray for" people has to be the biggest cop-out there is. As if this is all they need to do to solve the problem. Forget about the practical help, just offer to pray for someone and that'll do the trick.

Hopefully.

If it's "God's will".

But, you know, if God exists then I suspect he would far rather his followers got off their knees, got out of that cosy church, went out into the world and just got on with what needs doing. Like my friend Sue did, who was the shining exception to the rule.

If I were God then I wouldn't want to just sit there and listen to a shopping list of "wants" accompanied by praise for how wonderful I am while my worshippers waited for me to waive my celestial magic wand and provide a solution.

No. I'd want them to cut out the cr*p and get out there. I'd want them to open their eyes to what is staring them in the face. Forget about giving money to distant charities or raising money for the church roof, I'd want them to look around themselves and see where the need is in the world. Where it really is, not where they

“think” it is.

And do God’s real will. Not their interpretation of God’s will.

If I believe in God at all, I believe he is already out there working through people that aren’t necessarily your “conventional” religious believers. Also, not everyone is Christian by birth. Some people aren’t religious at all. But they’re all doing their bit to advocate change, do good and make the world a better place. Like the awesome parents I’ve met in the world of eating disorders.

I could quite easily and willingly believe in, and follow, a God like that.

A God whose way of doing things isn’t a million miles away from the way Jesus Christ would do things (says she adding an Easter dimension to the blog). Okay, Jesus Christ shut himself away for 40 days and 40 nights praying towards the end of his life, but apart from that he got out there and just got on with whatever needed doing.

But praying is so much less hassle, isn’t it?

Friday, 29 March 2013

The conversation I did - and didn’t - have with Mrs X

A little while ago I re-joined the gym after a four year break although, these days, it’s more of a relaxation thing; I spend most of the time in the pool and sauna. Anyway, today, who should I come across but Mrs X, one of Ben’s old primary school teachers. Back in the pre-ED days she and I would chat regularly in the gym changing rooms - she on her way back from school and me on my way to pick up Ben from after-school rugby. We also bumped into each other on the ferry back from France following our disastrous holiday in Cognac in summer 2010 and had a long chat up on deck. So today we had a curious conversation (curious from my perspective because of what I didn’t say). It went something like this:

Me: Hi, I haven’t seen you for AGES, not since the ferry back from France! *[Where, if you wondered why I was keeping my eyes on Ben like a hawk and behaving a bit strangely at the time, it was because I was worried he might jump ship.]*

Mrs X: How is Ben? My two are back home after university. Who would have thought it? Eating me out of house and home, treating the house like a hotel and leaving the place like a tip. You don't realise how much you value your independence until they come back!

Me: Ben is fine. He's in the middle of his gap year which he decided to take at the 11th hour *[in other words, after attempting two days at university and finding he couldn't handle it because of the devastating remnants of the anorexia which he'd already been suffering from for over a year when we met you on that ferry. We'd just returned from the holiday-from-hell but I made out that we'd had a fantastic time, lol!]* He's busy doing lots of voluntary work. Oh, and he's back at W----- School, teaching lower sixth formers would you believe!

Mrs X: Is he! I must tell them all in the staff room, they'll be really impressed!

Me: Yes, he's doing just fine. *[Did any of them ever know about Stephen Z who used to bully Ben in year 6? Did you know about it?]*

Mrs X: I haven't seen you round here for a while?

Me: Well, no, you know what it's like... I decided to take a bit of a break... *[because Ben developed anorexia and we spent the next few years battling with an illness that threatened to kill him. Our lives were hell. It's only recently that he's come through it although he's still not the Ben you used to know. Not Ben who was Captain of his House at your school, who was a Prefect, who won a prize on Prize Day and whose name is etched in gold lettering on the oak board outside the staff room which lists all the pupils that have won scholarships to independent senior schools. Ben is listed as having won two academic scholarships, if you remember, one for W----- School and one for A----- College. Good God, we were so proud of him and so were all of you!]*

Mrs X: So he's off to university in September?

Me: Yes, it's all systems go *[hopefully...]*

Mrs X: Well, take my advice and make sure he calls you once a week just to let you know he's still around. You know what students are like... they forget about calling

home; there's far too much other stuff going on!

Me: I will! *[Too right, I'll be getting him to call me. In fact he'll be living at home for half the week anyway because he is still unable to cope with going away to university full time. And when he is at uni, I'll be keeping a watchful eye to make sure his recovery continues to move in the right direction and he never has a relapse.]*

Ah, I thought to myself, how much water has gone under the bridge since I last met Mrs X in the gym changing rooms... And she would never in a million years imagine that Ben, one of their star pupils and someone she's always had a soft spot for, would develop anorexia nervosa - an illness that would destroy the final three years of W----- School. Oh how I used to keep her up to date in those changing rooms with news of Ben's victories on the sports field and in the classroom....

Saturday, 30 March 2013

"I can tell what Ben needs to look like by looking at you"

... said CAMHS early on in the treatment as I immediately insisted Ben needed to get back to where he was before he lost one quarter of his bodyweight: a big, burly rugby-player. A "forward" in the team. What they were looking at was "manufactured" me - quite short, slim and toned. I looked like the kind of woman that "took care of herself". But this slim, trim figure was entirely due to carefully watching what I ate together with hours in the gym.

But - from what I was gathering - CAMHS felt that, because Ben obviously took after me in looks, then his target weight and appearance should be similarly slim. Never forget that, at this time, Ben was ranting on about the way he'd always been "fat"... or even "obese"... before the eating disorder and it was because "mum used to feed me so much food". As for what his dad looked like? "My dad's fat," said Ben. "He eats all the time and drinks beer."

Before Ben became sick, keeping a trim figure was important to me. As you will be aware if you've read through my blog, I used to have issues with eating and a fear of

getting “fat”. I was on constant diets and every few years I’d have 18 months or so in the gym before getting bored and giving up. I’d already given up the gym membership (as a result of a neck injury) when Ben began to develop his eating disorder.

But, as Ben became ill, I began to eat stuff that I used to save for “special occasions” like biscuits, cakes and chocolate to “prove” to Ben that I, with my slim petite build, could eat all this stuff without getting stressed out. At the start of his anorexia, I thought that if he saw me popping all this food into my mouth then he would think it was okay to do likewise, and his eating disorder would go.

But of course it didn’t.

What did happen, though, was that - as I began to re-feed Ben - I found myself having to have huge meals, too, as we sat around the dinner table together. Ben went through a phase where he even insisted on weighing our portions to ensure I didn’t have one nanogram less than him.

And I’d be expected to clear my plate.

Or else.

I got fed up with complaining that “I’m middle aged, I’m only 5ft 3 and female - I can’t eat as much as a growing man!”

Later, as his mind began to clear, he found it difficult to cope if I asked for smaller portions or left anything on my plate. So I’d cram the food into my poor old stomach and go through Rennie’s like there was no tomorrow.

And I put on weight.

Especially as I was also popping comfort food to help me deal with all the emotional stress. Some of my old “binge habits” returned when I’d Hoover up a load of cupcakes or whatever from the supermarket and sit in the car, miserably stuffing them into my mouth, one after the other, in a bid to cheer myself up.

These days we still eat huge meals. Or, rather, Ben and his dad do and I have a smaller portion. Not because of any “disordered eating” issues, but just because I just

couldn't physically cope with huge meals! Or I leave some of my dinner and heat it up the next day for lunch. And Ben is relaxed and happy for me to do this

I'm back at the gym. These days, however, the focus is relaxation rather than running on the treadmill. It's some nice time out for me to just be myself, play some relaxing music on my MP3, or sit in the sauna, Jacuzzi or swimming pool.

But, going back to what I said at the start, it seems absurd that CAHMS were judging what Ben's final appearance should look like based on my appearance at the time. They also said that, because I'm short and my parents aren't particularly tall, then they didn't expect Ben to grow in height.

"CAMHS said I'm not going to get any taller," Ben said, aged 16.

How on earth could they predict that?

Especially with an auntie who is quite tall, actually. And who, I actually think, Ben takes after more than he takes after me!

Saturday, 30 March 2013

Batty's BIG CHALLENGE for the week is...

... to bring the Contract back into play BIG TIME to encourage Ben to put on weight in the run up to making the decision about university which we need to do by the end of June. Ben has lost nearly 1kg since I last weighed him 2 weeks ago, and so it's all systems go as far as I am concerned to get the weight back onto him - and more. It will be interesting to see how easy or difficult it is for me to get him to play ball...

So I've taken some time this morning to get out the old weight charts again and map out where he needs to be at the bare minimum taking into account the fact that he is getting older. And I have formulated A PLAN.

Now, ideally I'd like him to be in a position where he could throw caution to the wind and not give a damn about putting on weight. I also hate having to focus on numbers at this stage, but I'm damned if I'm going to sit here and allow him to tumble downhill. If he lost 1kg since he was last weighed, then he could easily lose

another... and another... It doesn't bear thinking about and I won't let it happen.

So time for some "tough love" in the guise of Janet Treasure's "dolphin", using our Contract as leverage.

To be in line with the minimum he should be, aged 19.5 years old in the summer, he needs to gain 4kg from where he is today.

Yes, 4kg.

Minimum.

And we have 13 weeks in which to do this.

If he doesn't achieve this by the end of June then it's NO to university this September.

If he refuses to - or simply can't - increase his calories to the amount I want him to increase it to from now until he gets back on track, I will take over cooking the evening meals again (he adores cooking the evening meals).

I will give him an extra 5 points for every day he manages to keep to this calorie total.

I will also give him 15 extra points every time his weight goes up by half a kilo, but I will remove points if it goes down again (to avoid yo-yo-ing up and down like we used to do with CAMHS).

I will insist that he counts calories properly for the time being rather than "guestimating" which he has been doing (and obviously "guestimating" too low).

And we will do the Contract every day, focusing on weight gain challenges.

Whether or not he agrees to the above changes to the Contract will be a measure of how much remains of the eating disorder, won't it?

Ben is out of the house at the moment. But I'll be discussing the above with him later. At this present moment in time if I was to put a bet on his reaction it would be that he tries to persuade me to compromise and agree to a lower daily calorie total.

So I am going to produce a list of bullet points as to why I won't do this; why I won't go for half-measures when it comes to kicking the eating disorder out of his life

for good and why I refuse to let him drift back into an unhealthy weight range. And I have printed out the height / weight charts that prove where he needs to be as he heads towards the age of 20.

In an ideal world he'd say: "Okay, mum, I agree to do all this." And sign on the dotted line.

But I'd hazard a guess that he will panic and resist the idea.

So please don't say anything like: "Go for it, Batty, you rock!" because I may not be able to do any of the above, no matter how hard I try. And it may easily end up as a shouting match as it sometimes does.

I believe he would happily compromise, as described above, but I don't believe he will go the whole hog and do what I want him to do.

But the consequences would be that, if he fails to reach the above weight by the end of June, then he's not going to university, and we will continue to work on it until he does get to where he should be.

I will keep you posted on progress over the next few days and weeks in the lead up to June.

Sunday, 31 March 2013

Gah, husbands!!

Everything was going smoothly as regards me explaining The Plan to Ben yesterday lunchtime when - ROAR! - in comes a huge Sherman Tank in the form of my husband who began to say a ton of stuff that was probably best not said right there and then. Or not said at all, probably. Result? Lots of yelling and crying.

Thankfully, things calmed down after a while. But it has meant having to make a slight compromise on the calories front which I have agreed to do for ONE WEEK ONLY, weighing on Saturday to see how things are going.

The agreement is that if he hasn't put on at least 0.5kg by Saturday then we go up to the original calorie total I wanted.

I have told Ben what (minimum) weight he needs to be by the end of June in order to get the go-ahead for university. If he doesn't achieve it, then we'll take another year off. Ben is uber keen to go to university in September and I believe this is proving an excellent incentive for him to work towards this weight gain. We need to make the decision then because of applying for accommodation.

I have also explained why, now that he is older and young males' BMIs need to increase with age, this week's weight loss could quite easily put him back into the "danger zone" if he isn't careful. I explained how easy it is for the anorexia thoughts to creep back in and said I refuse to let this happen.

He is refusing to let it happen, too. The last thing in the universe he wants is for the ED to creep back in and steal more of his life.

In an ideal world I'd want him to throw caution to the wind and say: "Sure, I'll pig out to ensure I put those kilos on as soon as possible, no problem!" But the fact is that he still finds it hard to increase his calories by a high amount in one go. "It would make me extremely anxious and I'm worried it might trigger a relapse," he said to me.

And a 0.5kg average weekly increase (which he already knows is what the NICE guidelines say) is just about manageable for him. Crazy, if he increased by, say 1kg, in one week, even though he needs to put on 4 or 5 kilos by the end of June to get where I believe he should be on the charts for his height, age and build, this would prove too much for him to handle. Absurdly he is still terrified of spiralling out of control and getting obese.

Hmn.

But Mama Matty will intervene if we ever, even after a couple of weeks, end up in a situation where he increases by 0.5 one week, then decreases by slightly more the next, and so on and so forth. Like he did during that crazy year at CAMHS.

It is so very frustrating that he still thinks like this four years after the eating disorder began to emerge.

But I still have a load of leverage tools in my bag which, because of my husband's Sherman Tank, I never managed to discuss.

And I will be bringing the Contract back to the forefront of things for the next month or so.

APRIL 2013

Monday, 1 April 2013

This rough intro sums up what my next book is about...

Here is my first and very rough draft introduction for my next book: When anorexia came to visit: Families talk about how eating disorders invaded their lives. So, if you're interested in knowing what this new book is about, the following pretty much sums it up. (It's still a draft and I need to check my facts and sources, but it'll give you a good idea.)

At the beginning of October 2009 I took my 15 year old "big, burly" rugby-playing son, Ben, to see the GP. Over the summer months he'd been cutting back on his food, reducing his fat intake and doing excessive amounts of exercise. He'd cut himself off from his friends, was becoming obsessed with cooking and baking, and appeared to be getting more and more depressed. When his grandmother visited in mid-September, not having seen him for several months, she remarked on how thin and pale he looked. Because my husband and I had been with Ben all summer long we hadn't noticed the dramatic change. We knew Ben was behaving weirdly and that he was losing weight, but we really thought he'd shake it off once he was back at school and on the rugby pitch.

But things got worse rather than better.

So I took Ben to see our GP.

Something at the back of my mind told me that Ben could be developing an eating disorder, but this seemed really strange to me. After all, as far as I knew, boys didn't get eating disorders, especially rugby-playing boys like Ben. Also, he'd been brought up in a loving, stable environment. He was extremely happy at school, was very bright and popular with everyone. All this flew in the face of the kind of teenager that I believed developed anorexia. And, anyway, weren't anorexics skeletal? Like the girl I used to see at the gym who everyone used to whisper about.

Ben didn't want to go to the GP. He didn't think anything was wrong with him and he made sure the GP knew this. It took several more visits before we got Ben referred for treatment at CAMHS (Child & Adolescent Mental Health Services), and only then when the school nurse insisted we get a referral. The GP never mentioned what help was available. Indeed he never diagnosed Ben as having an eating disorder.

Every family I have talked with for this book has described this period in exactly the same way. Initially the eating disorder emerges so gradually you scarcely notice anything, especially when you're with your child all the time. And anyway – boy or girl – you just don't expect your normal, happy, level-headed child to get anorexia.

Around the time that you begin to get sufficiently concerned to take your child to see the GP things suddenly take a turn for the worse. And the deterioration is so rapid at this point that you can scarcely catch your breath. By this stage it's as if your child is transforming by the hour, not by the week or month. Eating gets worse or stops altogether, exercising goes stratospheric and, mentally, your child morphs into someone you don't recognise. It's almost as if your child has become "possessed", which is why we always referred to Ben's anorexia as the "anorexia demon".

At this point it is vital that your child gets into treatment immediately. Thankfully most of the families I talked to were fortunate enough to wait no more than a week or so before they saw a specialist. With some, it was just days, especially those children whose downward spiral had rapidly made them so sick they ended up in

hospital. Also, thankfully, our own story from this point onwards seems atypical. Ben was referred to CAMHS on the 11th November 2009, five or six weeks after I first took him to see the GP. By now he had lost approximately one quarter of his bodyweight. But herein lies another niggle. In the UK children's heights and weights are rarely, if ever, measured after babyhood. So there are usually no records for comparison. Ben's class at school had worked out BMIs in a PSHE lesson at some point when he was 14 or 15, so this is the BMI I was going by. But the GP had no records of Ben's adolescent weight or height. And, because Ben didn't look skeletal and was in complete denial that there was a problem, I suspect the alarm bells weren't going off. Also, our GP might have been unaware that – yes – boys do get eating disorders.

Meanwhile Ben was continuing to insist that he didn't have a problem, smiling and saying calmly: "I'm fine. I really don't know what my mum's worrying about." On the final visit to the GP he got so agitated that he stood up, swore and walked out of the surgery.

During the compiling of this book I talked to a local GP to get an idea of how much awareness UK GPs actually have of eating disorders. She told me that, as a medical student at Cambridge, she'd probably had two lectures on eating disorders as part of a psychiatry module. She told me that, as far as she was aware, medical students receive no further organised training but that "if you have an interest then you will look it up".

Also, as far as she was aware, there wasn't a GP in our (city suburban) practice that had "done psychiatry".

She added: "As a GP you just see what crops up. I mean, we're a middle class, educated GP practice so we might see more eating disorders in middle class well educated girls (and boys) than, say, somewhere with a different demographic. But I don't know how many eating disorder patients we see or if anyone particularly specialises in it. I do know that we don't see eating disorders very often; GPs' time is

so pressured that, as a GP, you tend to read more about what you see more of. But if ever I had anyone with an eating disorder and I felt out my depth then I would do more reading on the subject.”

The thing is, as a parent, you expect your GP to be clued up on what they’re dealing with. So if they’re not picking up on something as being urgent, as was the case with Ben’s diagnosis, then you automatically assume they must be right. After all, they’re the professionals. I remember wondering: Am I imagining it? Is it all in my mind? Am I just being the “over-protective” mother?

I expected the CAMHS appointment to come through pretty quickly. In the event it was another three weeks before a letter came through. I immediately called CAMHS to make an appointment only to be told we’d be put onto a waiting list for an assessment – and that it could mean a wait of anything from 18 to 22 weeks. Meanwhile it was as if Ben was disappearing off a cliff. I was terrified.

“Good God, he got seen faster when he broke his nose in rugby!” I remember telling my sister. “18 to 22 weeks is around five months!” I looked back to where we were five months earlier in June. With an eating disorder a lot can happen in five months. “In June we didn’t even know Ben was getting sick!” I told my sister. “Look how far he’s gone downhill since then. Imagine what another five months could do to him? And to us? What if Ben spirals even further downhill?”

But, apparently, there was nothing anyone could do. It was a case of waiting – or going private.

In a fit of desperation we brought in a private therapist who did her level best to stop the rot. But I remember thinking that it was a bit like trying to plug the hole in the Titanic with cotton wool. Ben just spiralled further and further into the abyss.

Then at the end of January 2010, his pulse plummeted to a dangerously low 29bpm and he was rushed into the cardio ward of our big city hospital. It was my lowest point so far. As I looked at my pale, thin son lying there, hooked up to machines, tears streaming down his face as they attempted – and failed several times

– to take blood samples, I really thought my son was going to die.

Nowadays I know that Bradycardia (abnormally low pulse rate) is one of the many symptoms of anorexia. I also know that sudden heart failure is one of the biggest causes of deaths from anorexia. But, despite this, the clinicians on Ben's ward seemed unaware of this link, preferring to attribute this "unusual" spike in Ben's pulse rate to the fact that Ben was very sporty. Yes, Ben was very sporty by this point. But only because the illness was driving him to exercise like mad, virtually round the clock. Not once did anyone in the hospital suggest that Ben needed to be rushed into treatment for his eating disorder.

The first thing I did when we got home was to phone CAMHS and insist that Ben was seen right away. I was so desperate on the phone that they got a psychiatrist to call me back. She arranged for Ben to be seen within the week. So, some four months after I'd first taken Ben to see our GP, we were sitting in front of CAMHS.

Thankfully, as I have said above, it looks as if our story is atypical. I did wonder if it was because Ben is a boy, not a girl, and the medical profession simply didn't expect boys to get eating disorders. But I've talked to families of boys as well as girls, and we still appear to have waited the longest for treatment.

Another thing families assume is that, once treatment starts, their child's illness will be fixed quite quickly. Unfortunately recovery from anorexia can take months, sometimes years.

What the following accounts do show, however, is that when you have a highly knowledgeable and coordinated treatment team that's pulling out all the stops to free your child from anorexia, with clinicians that realise that parents are a vital part of the mix, not an irritating or expendable appendage, recovery appears to come sooner rather than later. It is also important to have a treatment team that focuses on the need to re-feed first and foremost, and to insist that the child eats everything that is put in front of them rather than allowing the child to get by with "safe" foods. "Tough love" also seems to work better than the "softly, softly" approach. By this I

don't mean bullying; just gentle but firm encouragement and a refusal to allow the eating disorder to win – because, given half the chance, the eating disorder will try to consume your child.

But of course the following is only a small snapshot of families' experiences in the UK; other families' stories might be different. Also, this isn't a study of which treatment methods work better than others, which is why I haven't gone into this in too much detail in the paragraph above.

What this book is, however, is a vehicle to highlight the need for swift diagnosis and intervention for eating disorders in adolescents – and for an informed, coordinated approach to treatment. It also highlights what families are going through at home. After all, unless their child is in hospital, they are with their son or daughter round the clock. The clinicians only see them for 60 minutes or so a week.

Also, parents know their child better than anyone else. The sheer strength of the parental instinct should never be dismissed lightly. Parents should always be taken seriously and included in their child's treatment.

I am a mentor on the Around The Dinner Table Forum, run by the global eating disorders charity FEAST (Families Empowered and Supporting Treatment of Eating Disorders). Many of the families in this book say this forum was a lifesaver for them. A regular question on the forum is: "How do I get my child to eat?" You have been given an eating plan and you know what you need to get your child to eat in order to put on weight. The trouble is, your child refuses to eat. Some children even threaten to run away or kill themselves rather than eat.

One of the mums I talked to eventually managed to persuade the CAMHS dietician to come into her home and show her how to get her daughter to eat. They gave her a few simple tips on what to do, but it made all the difference. So much so that she believes that, had she been shown how to do this sooner, it could have saved the NHS months of costly inpatient treatment for her child.

When you realise that your child is developing this terrifying illness one of your

first instincts is to learn as much as you possibly can. I always say that my university degree was a walk in the park compared with the cramming I did on eating disorders in those dark days as Ben plummeted into the illness and we began treatment with CAMHS.

The result is that we parents often know a heck of a lot about the illness and the latest evidence-based treatment which is being rolled out across the world. Some of us have attended conferences where we've listened to the Great and the Good of the Eating Disorders World share their knowledge with us. We also have a limitless supply of knowledge that comes from our FEAST and ATDT network across the world, made possible by the power of the Internet.

In other words, we parents are a force to be reckoned with and need to be taken seriously by the medical profession. We need to be listened to and we need to be as much part of our child's treatment team as the psychiatrist, psychologist or dietician. The medical profession needs to realise that, in many instances, we probably know more than them. This is clearly the case at GP level, for instance, and in other non-psychiatric specialisms.

Another thing this book does is highlight the signs of an emerging eating disorder. None of the parents in this book expected their child to develop an eating disorder. It was always something that "happened to other families". Many of us held the outdated beliefs that anorexics come from dysfunctional families. Thankfully these days we know that anorexia is a biological brain-based illness. In some cases, it is also thought to be heritable. Interestingly, a number of the accounts in this book describe relatives who have also suffered from an eating disorder.

The point is that when you don't expect your child to get an eating disorder you are not watching out for signs. And anorexia can develop so gradually, sometimes for months or even years before any unusual signs begin to show. By the time the penny drops your child's illness can be quite advanced, which is why this book places emphasis on what families were seeing and what, in hindsight, turned out to be clear

signs of an emerging eating disorder.

Finally, as its name suggests, CAMHS is a service for children and adolescents. All too often when a child reaches the age of 17 or 18 they are discharged from CAMHS and either passed onto Adult Services or left to fend for themselves because they are considered to be “recovered”. At this stage vital continuity of care can be cut, sometimes with devastating results. Many of us will have read accounts in the media of young people who were discharged from care at the age of 18 and, because they were now adults, were permitted to make their own decision as to whether or not they received further treatment. Young people have died as a result. Never forget that anorexia has the highest mortality rate of any mental health condition; the charity BEAT says that research shows that one in five eating disorder sufferers will remain chronically ill (Steinhausen, 2002).

The accounts in this book show that outstanding coordination and teamwork can achieve positive results. One account demonstrates how, even when the child was in hospital, her local CAMHS team visited the hospital to keep up to speed with proceedings, as did her GP and even her schoolteachers. This way seamless continuity of care could be ensured once she was discharged from hospital. And it worked. That family’s story is a success story.

So it makes sense that a young person is treated by the same team throughout the entire duration of their illness. Age should not be taken into account. Lives are at stake, as are valuable NHS funds which are being wasted. And no family wants their child to suffer from an eating disorder longer than they need to.

So how is my son, Ben, today? Ben was discharged from CAMHS, aged 18, after 26 months of treatment. He was discharged because he was 18 but also because his psychiatrist was leaving. He wasn’t referred onto Adult Services.

Curiously he was virtually the same weight on the final day of CAMHS as he was on the very first day, so I knew that we still had some way to go to get his weight back up to its pre-anorexia levels. Ben’s food intake had changed dramatically; by the end

of CAMHS treatment he was eating a perfectly balanced diet which, I believe, helped to improve his mood and heal his brain. But there was still a string of outstanding issues in addition to the sub-optimal weight, primarily extreme social anxiety and the ever-present fear of getting fat.

Over the next 12 months he and I worked on these issues together. It's been slow progress, but we are getting there. If we'd have had strong, no-compromise clinical support in getting Ben back to his pre-anorexia weight and working on the outstanding cognitive issues, then I believe we would have got there quicker. But so many young people are permitted to remain at a sub-optimal weight and I, and many others, believe that recovery can never truly happen unless the patient is fully weight restored.

And, once a patient reaches 18 and is legally permitted to choose what they do next, there is very little that the family can do except continue to encourage their child and hope that they will eventually fully recover to lead a one hundred per cent anorexia free life.

Friday, 12 April 2013

Life before ED...

I have a huge purple concertina file box by the side of my desk which has been gathering dust for the past four years. It contains a mountain of historical research I was doing, and had been doing for four or five years, which stopped - dead - when Ben's eating disorder arrived on the scene.

Back in the halcyon days before ED, I'd pack Ben off to school and - on the days when I didn't have any freelancing work to do - I'd get out that purple file and immerse myself in my research.

Whether it was digging through old photographic archives, contacting people and places to do with the family I was researching, visiting key places, or sitting surrounded by boxes of yellowing 19th century correspondence in various university

libraries and archives, or hiring researchers and genealogists to research faraway places (cheaper and less hassle than travelling there myself, especially when I had a school-age child to care for) or digging around in cemeteries (not literally!), I'd escape into my research. I was in seventh heaven when I was doing this!

Getting thoroughly immersed in this detective-like research was 'the' thing I was most passionate about in life back then. Flitting from discovery to discovery it thrilled me right through to my core. I had just made a monumental discovery, purely by chance, just as ED arrived on the scene. One of those 'Eureka!' moments that has you hopping up and down with glee when you're into this kind of thing.

But everything stopped there. And the file has been gathering dust ever since.

And I miss it.

More than anything else I would love to re-immense myself in that file and carry on with the unsolved 'mysteries' and finish piecing together the puzzle.

Maybe when Ben goes to university, hey...

If he goes to university...

If he finally puts up his hands and says: "Okay, mum, I agree to have therapy to sort out those remaining glitches that are still f*cking up my life, making me miserable and hellishly lonely, and possibly preventing me from ever becoming 'me' again."

Because I am fed up of sitting here with the hands pointing to five to the hour permanently when I long, more than anything else, to help nudge them towards the hour, towards the day when Ben is finally fully recovered and back to his old self.

And I can get my own, old life back too.

Friday, 12 April 2013

A very brief fantasy letter to the medical professionals

Dear GPs, CAMHS, the local hospital and everyone else I came across in the course of my son Ben's anorexia and all those other medical professionals out there, I am

putting a book together where I talk to approximately 20 families across the UK about their own journeys through anorexia and you know what?

Early intervention, GP & general hospital awareness, parental knowledge & empowerment, and good, evidence-based treatment plus parental involvement, respect and support adds up to a faster and more sustained recovery for the young person - and less of a drain on ever-decreasing NHS resources.

Late intervention or mis-diagnosis, GP & general hospital ignorance, parental lack of knowledge or empowerment, and poor, outdated treatment where families' instincts and wishes are ignored or overlooked adds up to a much, much slower and more painful recovery with a high instance of relapse for the young person - and more of a drain on ever-decreasing NHS resources.

This screams out from the pages of my manuscript as if emblazoned in Las Vegas lights.

What do you have to say about that then?

Thursday, 18 April 2013

Talking to ECHO about their self-help intervention for carers' project

As part of the background research for my new book "When anorexia came to visit, families talk about how an eating disorder invaded their lives" I talked to Rebecca Hibbs of the ECHO (Expert Carers Helping Others) project to discover how this is helping parents and carers across the UK deal with the emotional and practical pressures of looking after an adolescent with an eating disorder. (Thank you, Becky, for talking with me!)

Batty: As I think I told you I am writing a book where I talk to 20+ families about their experiences of helping their child overcome anorexia and all the resources that helped them along the way. I wondered if you could talk to me about the ECHO project?

ECHO: It's a project that provides a self-help intervention for carers of outpatient under 21's with a primary diagnosis of anorexia or EDNOS with an anorexia sub-type. We've got 35 or 40 sites involved in ECHO, many of which have CAMHS units. Any new referrals they get in - who are eligible in terms of age and diagnosis - will be offered the intervention. We then get their contact details and, if they are willing, take them on.

Participants (families and carers) are randomly divided into one of three 'arms' of the study:

- Arm #1 receives treatment as usual (with follow-up questionnaires)
- Arm #2 receives the ECHO self-help intervention pack which includes this book by Janet Treasure
- Arm #3 receives the ECHO pack plus regular support from a dedicated expert carer over the telephone.

Batty: What is the aim of the intervention?

ECHO: The idea is that if we can improve the way carers cope and lessen their distress then this will have a positive knock-on effect on the patient.

Batty: Is it a new thing?

ECHO: No, it's been running for a while. The idea behind it is the Interpersonal Maintenance Model that Janet Treasure et al came up with in 2006 which recognises that carers' responses to the illness may perpetuate eating disorder symptoms. The theory behind the intervention is that, if we can teach carers the skills they need to best to deal with those behaviours at home, then this is going to have a positive effect on the patient.

Batty: That sounds great. I am just wondering why I, personally, was never offered this facility by CAMHS?

ECHO: It depends if the services are in the ECHO project; not all sites have got involved in the project. We have only taken on the sites that asked to be involved.

Batty: It sounds like a really fantastic idea and something that I could have used and I know “my” other families [interviewed for my new book “When anorexia came to visit...”] could have used it too, but it seems such a shame that we didn’t have access to it.

ECHO: It’s only been rolled out for about a year now so it might have been that it wasn’t around back then. When I said it’s been “running for a while” what I meant was we have another project running alongside it where we look at carers of adult patients with severe, chronic and enduring anorexia. We are now running this relatively new project to see if we can catch it earlier while sufferers are outpatients and adolescents. If we can, then hopefully the patient’s illness will have be less protracted.

Batty: How is ECHO funded?

ECHO: The Research for Patient Benefit fund.

Batty: Does it finish soon?

ECHO: We’ve ended the recruitment and all the baselines have been done. These are then followed up at six and 12 month points. The intervention usually happens between the baseline and the six month period and then we look at the questionnaires between the parents / carers at 12 months as well as six to see whether it’s had any effect and, if so, which of the three arms was most effective.

Batty: So do you have plans to roll it out across the whole of the UK permanently?

ECHO: That’s the aim but we need to prove it works first. We’ve been in collaboration with the SUCCEED foundation and the 5 DVDs that we’ve got running at the moment are actually quite old now because it’s taken so long to roll it out. SUCCEED have funded a brand new DVD featuring professional actors which has been written with Janet Treasure and a couple of expert carers. This is the DVD that was shown at the FEAST conference in November. We’re hoping that we can pilot that and then run out another project involving that DVD.

Batty: If it’s proven to work and you run it out across the country how will you get

all CAMHS sites involved?

ECHO: That's a really good question and one which we're going to have to think about and work on, probably alongside SUCCEED's new DVD. Obviously the Janet Treasure book is readily available on Amazon and we need to sort out what will happen about the telephone coaching.

Meanwhile here is a list of all the sites from whom we recruited participants for the ECHO project. (We advertised ECHO at meetings/conferences etc and these were the sites that chose to take part.)

- Aneurin Bevan Health Board
- Avon and Wiltshire Mental Health Partnership NHS Trust
- Bedfordshire and Luton Mental Health and Social Care NHS Trust
- Birmingham & Solihull Mental Health Foundation Trust
- Black Country Partnership NHS Foundation Trust
- Bradford District Care Trust
- Calderdale and Huddersfield NHS Foundation Trust
- Cambridgeshire & Peterborough NHS Foundation Trust
- Cheshire and Wirral Partnership NHS Foundation Trust
- Central Manchester University Hospital
- Cornwall Partnership NHS Foundation Trust
- Coventry and Warwickshire Partnership NHS Trust
- Derbyshire HealthCare NHS Foundation Trust
- Dorset HealthCare University NHS Foundation Trust
- Dudley & Walsall Mental Health NHS Trust
- Gloucestershire 2gether Trust
- Humber Mental Health Teaching NHS Trust
- Hywel Dda Health Board
- Kent and Medway NHS Trust

- Leeds Partnership NHS Foundation Trust
- Leicestershire Partnership NHS Trust
- Lincolnshire Partnership NHS Foundation Trust
- Norfolk and Waveney Mental Health NHS Foundation Trust
- North Bristol NHS Trust
- North East Lincolnshire PCT NHS Trust
- Northamptonshire Healthcare NHS Foundation Trust
- Nottinghamshire Healthcare NHS Trust
- Oxford Health NHS Trust
- Powys Local Health Board
- Royal Bolton Hospital
- Sandwell Mental Health NHS and Social Care Trust
- Sheffield Children's NHS Foundation Trust
- Sheffield Health and Social Care NHS Foundation Trust
- Somerset NHS Health Partnership
- South Essex Partnership University NHS Foundation Trust
- South London and Maudsley NHS Foundation Trust
- South Staffordshire and Shropshire HealthCare NHS Foundation Trust
- South West London & St Georges Mental Health NHS Trust
- Suffolk Mental Health Partnership Trust
- Surrey and Borders Partnership NHS trust
- Worcestershire Primary Care Trust
- Worcestershire Mental Health Partnership NHS Foundation Trust

Saturday, 20 April 2013

A huge thank you to "my" 20 wonderful, generous and courageous families!

I continue to be immensely grateful to the 20 UK families that have contributed their

stories for my new book *When anorexia came to visit, families talk about how an eating disorder invaded their lives*. But you'll have to wait a month or so before it's published. In the meantime, here is the draft introduction to give you a taster and to show how wonderful these 20 families are...

The second chapter of my book *Please Eat... A mother's struggle to free her teenage son from anorexia* begins: "We should have picked up on it sooner."

The question is: could we - or any of the families I interviewed for my forthcoming book *When anorexia came to visit* - have "picked up on our child's eating disorder sooner"?

When I first took my 15 year old son, Ben, to visit the GP at the end of September 2009, the signs of an emerging eating disorder had been clearly evident for some months.

The problem was that none of us recognised them.

Even before the signs emerged, the eating disorder was busy germinating deep in the inner recesses of Ben's mind. He says he can trace it back to at least 12 months before, if not earlier.

The fact is that you don't expect your child to develop anorexia or any other eating disorder. You don't expect it to happen to your ordinary, happy, close family. And, in our case, and a couple of the other cases in this book, you don't expect it to happen to your son.

Anorexia isn't like a normal medical condition where recognisable symptoms are there for all to see: a broken bone, a worrying lump, blood loss or whatever - the kind of issues that GPs deal with on a daily basis. And, although eating disorders often feature in the media, they rarely focus on the lesser known signs and symptoms, preferring instead to major on shock tactics such as stereotypical skeletal photographs. On top of this there is the popular misconception that eating disorders are "caused" by anything from bad parenting and size zero fashion models to faddy

eaters and even private schooling (how many reports begin with: “Privately educated XXXX...” ?)

So, during the early months as the illness began to manifest itself, none of the families in *When anorexia came to visit* had any idea what they were dealing with. Nor did their children. I mean, it’s not as if my son sat down one day and decided to “get anorexia”. He was as clueless as any of us. And, anyway, these days we know that anorexia is a biological illness, not a lifestyle choice.

But we didn’t know this back then.

Indeed none of the families in this book fits the stereotype of the dysfunctional family with the child who is going off the rails and chooses, perhaps as a “control thing”, to starve themselves to death. Before anorexia came to visit they were just ordinary happy families living ordinary happy lives. And our children were normal. So there was no reason on this planet why any of us would be watching out for the classic signs of anorexia. This is why we couldn’t have “picked up on it sooner” unless we’d known what to look out for.

None of us knew that a whole package of horrors comes with an eating disorder. It’s not just about cutting back on food and losing weight, it’s about crushing depression, vicious mood swings, violent self-harming, suicide threats and social isolation as your child transforms into someone you don’t recognise, right in front of your eyes. Our son even developed a different voice: a slow, low, deep monotone that used to chill me to the core.

We weren’t aware that an eating disorder creeps up on its victim ever so slowly, so slowly that it’s almost undetectable until it’s got a firm hold. We didn’t know that, in the early months, an eating disorder can disguise itself as a passion for healthy eating and / or exercise, or a passion for cooking. Or, in the case of our son Ben, all three.

None of us knew of the devastating effect that anorexia would have on the whole family - from the sufferer themselves through to siblings, parents, grandparents and the extended family. Not just for a brief few weeks or months, but sometimes for

years.

And we didn't know that you don't always have to be a skin-and-bones skeleton to have full-blown anorexia.

But despite our obliviousness to the early signs, most of the families I interviewed expressed feelings of intense guilt. "Why didn't we notice what was happening?", "Why didn't we act sooner?" and "Why didn't we trust our gut instincts that something was wrong?"

And herein lies another problem.

In the making of this book I talked to GPs, medical students, even the Royal College of General Practitioners, and there seems to be very little formal training in eating disorders. Our local GP said she "probably had two lectures" as a medical student at Cambridge.

The thing is, when you take your child to the GP, you expect them to know what's wrong and take action. So, when a GP fails to identify an eating disorder or assumes it's "just a teenage phase", you begin to doubt your own instincts.

And, meanwhile, your child can be in complete denial that there's anything wrong. So sometimes it can be just you, the parent, fighting a lone battle to get your child diagnosed and referred.

Thankfully, once referred, most of the families in this book saw a specialist treatment team like CAMHS (Child & Adolescent Mental Health Services) very quickly, sometimes within the week. Out of all the families in this book I think we had to wait the longest. It was four months before we saw our local CAMHS and only then because the assessment was expedited when Ben's pulse plummeted to 29 and he ended up wired to machines in the cardio unit of our local hospital.

One of the many reasons why I decided to write this book is because I wanted to see how our story (described in my book *Please Eat... A mother's struggle to free her teenage son from anorexia*) overlaps with other families' experiences across the UK.

Of course each family's circumstances are different. Yet so much of what we've

experienced is similar. Not just in terms of the warning signs but in the way the illness transformed our children into people we scarcely recognised, mentally as well as physically. And, of course, the sheer uphill struggle of trying to get them to eat again.

In this book you will read some truly uplifting accounts: those stories where intervention was swift and the illness was tackled by a highly coordinated and focused team of clinicians using the latest evidence-based treatment.

But you will also read about families who experienced the other end of the spectrum - the “could do better” of NHS mental health services. With these families recovery didn’t come as quickly; some are still a “work in progress”.

I often wonder where we families would be now without the power of the internet. Would we still be totally ignorant of the latest evidence-based treatment? Would we simply accept the outdated notion that eating disorders have to last for several years, if not forever? Would we still believe that eating disorders “aren’t really about food” and are “a control thing”? Would we still be dragging our children to dozens of pointless sessions as the therapists attempt to identify the “reasons why” the eating disorder developed and talk them out of the illness? Would close family relationships have disintegrated as parents, wrongly labelled at best as dysfunctional and at worst as abusive, needlessly blame each other for “causing” the illness?

There is an online resource called FEAST (Families Empowered & Supporting Treatment of Eating Disorders), originally set up in the USA by Laura Collins, author of *Eating With Your Anorexic* (who was kind enough to write the Preface for this book) and nowadays operating globally via the power of the internet. FEAST and its online forum, *Around The Dinner Table (ATDT)*, is run by parents and carers for parents and carers. Today FEAST is widely respected by some of the world’s leading eating disorder professionals and its website is a mine of information on the latest evidence-based treatment, research and resources. Thanks to FEAST and other resources like the UK eating disorder charities, BEAT and ABC (Anorexia & Bulimia

Care), families can educate themselves about the latest advances in the treatment of eating disorders in a way that was previously impossible.

The ATDT forum is a place where families can come and feel immediately welcome, among families who understand exactly what they are going through and who can offer support. Here in the UK alone we have established a truly awesome network that works with other charities like BEAT and leading eating disorder experts to advocate better treatment for our children and enhanced support for parents and carers.

Virtually every family in this book says that FEAST and ATDT were lifesavers. It is also thanks to the people I've met through FEAST and BEAT that I have been able to gather together these 20 powerful, insightful and challenging stories.

Through this book, we want to show other families that they are not to blame for their child's illness. Eating disorders are biological illnesses, not lifestyle choices. And, yes, eating disorders are about food - lots of it, being administered by strong, loving, dedicated families who are refusing to accept that their beloved children are "in this for the long haul". We know that you can't "talk someone out of an eating disorder"; you can't wait for someone to "want to get better". And we recognise that parents are a vital part of a successful, highly coordinated treatment team. We are part of the solution, not the problem.

We want to show other families what is "normal" in the world of eating disorder behaviour. Distressing and terrifying, yes, but relatively "normal" for a child in the iron grip of anorexia. And also what is normal as the brain begins to get re-nourished and gradually heals and returns to its pre-anorexia state.

We also want to show that, no matter what you are going through, other families have been through it too - and successfully come out the other side.

Getting your child through an eating disorder is one of the toughest and most distressing things you will ever do as a parent. But re-visiting painful memories is unbelievably tough, too. Yet each of the families I interviewed for this book willingly

volunteered to come forward and describe their own struggles with anorexia. Not only did they agree to talk frankly about their experiences, they agreed to read through the various drafts I sent through for checking. In other words, being involved in this book meant having to re-visit distressing memories not once but several times over. This takes courage and commitment. It also demonstrates how much these families care about others - families they have never met who will read this book and hopefully draw inspiration, strength and knowledge from its pages.

This book could never have been written without the help of these 20 fantastic families. In many cases all I have done, as the author, is edit the transcript of a taped conversation or tweak a detailed written account. So, strictly, I should be calling myself editor, not author. "My" 20 families have written this book, not me. And I am immensely appreciative of their help, dedication and input.

Of course I must also thank the young people themselves for demonstrating the courage, grit and determination to fight this illness and win. Being a parent is tough, but being someone who has fought to break free from this insidious illness is even tougher.

Our sons and daughters are truly awesome.

And so are their parents.

Saturday, 27 April 2013

Nearly there with my new book "When anorexia came to visit"

My new book *When anorexia came to visit: Families talk about how an eating disorder invaded their lives*, is almost complete! Janet Treasure has written a Foreword, Becky Henry (author of *Just tell her to stop*) has written a Preface, Laura Collins (Founder of FEAST and author of *Eating with your anorexic*) has written an Introduction - and then there are 20 individual family stories plus a snippet from my own story at the back.

I'm still waiting for a few revisions from a couple of families, but it won't be long

before I can send off for the first printed proof and give it a thorough read-through.

I am immensely grateful to the families that have willingly contributed to this book either by answering my initial questionnaire, writing their own account or allowing me to interview them over the phone. Not only have they had to re-live their own distressing story by doing this but they've had to re-visit it again when checking through my draft. "My" families are awesome.

You will read about some good treatment experiences and terrific outcomes, but you will also read a few which weren't so positive but which will hopefully have a happy ending before too long.

I know that there can never be a one-size-fits-all approach when it comes to eating disorder treatment and that they are notoriously difficult to treat, but - judging from the 20 stories in my new book - it really is a case of good treatment equals a good chance of a good recovery.

When anorexia came to visit: Families talk about how an eating disorder invaded their lives will be published in the summer. Watch this space!

Tuesday, 30 April 2013

Updating you on what's happening in our family life at the moment

It's been a while since I've given you an update on Ben. To be truthful, I've been keeping a bit of a low profile in our household on the ED-front. In other words I've tried to keep things as near normal as possible. No mention of weight, no mention of calories, no getting out our contract and "doing points" as we still do on occasions. All of which is a Good Thing.

However on Thursday Ben starts (what I hope will be) a course of around 10 or 12 CBT sessions with a psychologist on social anxiety with a view to easing him into a successful re-attempt at university in September.

And university is still on the cards. Sheffield University, that is, not our local university which was an option if he felt he couldn't live away from home.

Next week Ben is off to Sheffield to attend a lecture so he can get a feel for what that side of student life is like. And, either this month or next month, he will need to apply for accommodation again.

The plan, if you remember, is for him to spend half the week in Sheffield and half at home, hopefully spending more and more time in Sheffield as time goes on.

So that's where we are at the moment.

Ad in early summer we have our mega holiday month. Ben won a luxury holiday in Cornwall in Dorset Cereals' Spin the Bottle competition - and then we have two weeks in Italy.

It's the first time we've been abroad since the Holiday From Hell in France in summer 2010, described in my book *Please eat... A mother's struggle to free her teenage son from anorexia*

Fingers crossed it will be 100% different.

MAY 2013

Wednesday, 8 May 2013

I'm speaking at this conference in November

This is the conference I'm speaking at in November. It's being run by Professor Janet Treasure OBE and Gill Todd under the umbrella of Kings College London and the South London And Maudsley NHS Foundation Trust:

National Carers Conference in Eating Disorders

Friday 22nd November 2013

Prof. Janet Treasure OBE and Gill Todd invite you to a day discussing:

“Anxiety and Emotional Escalation”

at

The Wolfson Lecture Theatre, The Institute of Psychiatry, 16 De Crespigny Park,
London SE5 8AF (Nearest station Denmark Hill)

Start: 09.00

Finish: 16.30

Cost: £60.00 per person.

- A special focus will be on how Carers manage their feelings of self-blame, shame, disappointment and guilt.
- Prof. Janet Treasure and her research team will present their emerging findings and new directions in relation to their work on the ECHO project.
- A Carer’s recovery story and the implications for assessment and treatment of boys in particular.
- Discussion & Questions.
- Further presentations to be confirmed.

Wednesday, 8 May 2013

I realised I was jealous and angry

Having talked to 20 families for my new book *When Anorexia Came To Visit: Families Talk About How An Eating Disorder Invaded Their Lives* (published this summer), it became clear that some families had received an exemplary approach to treatment from start to finish - from GP through to eating disorder recovery. Others had received a haphazard, slow, messy, outdated and often counter-productive approach. Guess which approach was more successful? And you know what?

I realised I was JEALOUS of the first group.

I also felt ANGRY.

Jealous because I - and many of the other families in *When Anorexia Came To Visit* - received the second type of approach. But it took us all a while to realise what was going on and then we had to fight with all the “but I’m just a parent” emotions as we dared to challenge the professionals. We ended up fighting the eating disorder, fighting for our child and fighting the system - all at the same time. And, meanwhile, we were fighting to learn as much about the latest evidence-based treatment for eating disorders as possible in a crazily-paced cramming session that’s like the Reduced Shakespeare Company on steroids. We were forced into being the unwilling CEO for a Gordon Ramsay’s Kitchen Nightmares sort of business, slaving against the odds to get our child through this illness while being hindered by incompetent and ignorant teams at almost every stage.

Angry because it’s our children that are being affected. We’re not just talking about a bad cut that gets poorly treated by a nurse then gets infected so your child needs a course of antibiotics and maybe some remedial first aid to put it right; we’re talking about their lives. And not just the fact that an eating disorder can steal years from a young person’s life, but the fact that it can steal that life. In other words, eating disorders kill. Oh I could go on and on with comparisons with other life-threatening illnesses like cancer along the lines of “if it were cancer we wouldn’t expect haphazard, slow, messy, outdated and counter-productive treatment” but I won’t.

I will just say that I feel JEALOUS and ANGRY.

And I don’t doubt that quite a few of “my” families who received the latter approach also feel very BITTER. Especially where their child’s recovery is still very much a “work in progress” or where they feel completely stuck.

Oh I know I could also go on about the fact that eating disorders are notoriously difficult to treat, that a one-size-fits-all treatment is never possible and that a treatment team that works for one family may not suit another. Blah blah blah.

Which brings me around to my final emotion: SADNESS. Although I want to celebrate with the families that have told me their success stories, I want to hug the families who feel as if they're banging their heads against brick walls of all varieties - from poor clinicians through to a particularly challenging and complex case of anorexia, sometimes with co-morbid issues going on as well. I feel so very sad for these lovely families who had so many hopes and dreams for their beloved children only to find themselves entrenched in years of hell.

But hopefully these "works in progress" will soon become success stories and I'd like to return to these at some point in the near future, maybe in a year or two's time, to see how things have progressed.

All of the above are why I want to get *When Anorexia Came To Visit: Families Talk About How An Eating Disorder Invaded Their Lives* in front of the clinicians that need to read it.

Wednesday, 8 May 2013

Wow, this was such a weird experience!

Ben has a history of horrible in-growing toenails. We thought they'd been fixed long ago, but recently they've reared their ugly heads and so it was off to the chiropodist today which was a really weird experience.

There I was, taking Ben to see a healthcare professional, and immediately and instinctively I knew I could trust him to know his stuff implicitly, get the job done well and give us the best advice. So I just sat there and let him get on with it. And, meanwhile, Ben explained to the chiropodist what was wrong, in detail, so the chiropodist could get a good picture of what was going on, from Ben's perspective, and put it right.

It was just so weird!

You have to understand that, over the past four and a half years, I haven't accompanied Ben to see anyone except mental health professionals (excluding a

hand specialist and broken nose specialist in September 2009 following an argument with a wall and a rugby ball - but that was before I took Ben to see the GP about the eating disorder).

It just felt so very odd to be sitting in front of a health professional trusting them to know what they were doing and to do it right, without even having to think about it. No hackles rising, no feeling that I'm going to have to fight to get good treatment, no sense of the clinician fumbling around in the dark "experimenting" with this, that and the other treatment to see what might work - and, of course, no Ben denying anything is wrong or actively working against the professional and me.

And yet again I found myself up against the incompetence of the NHS - or at least at GP level.

We saw a private chiropodist because the GPs' receptionist told me in no uncertain terms that chiropody was no longer available on the NHS. She snapped my head off as if I'd requested a boob job on the NHS.

Yet the chiropodist says there is an NHS podiatry team that Ben needs to see - and he needs to be seen urgently as his ingrowing toenails are seriously complex and pretty nasty. And he thinks an appointment should come through pretty quickly once he's sent off a referral.

(Unlike Ben's eating disorder where we were told there would be an 18-22 week wait, hey...)

But I still can't get over the almost spa-like, relaxing experience of being with a clinician who obviously knows his stuff inside out and who I felt I could trust implicitly to solve my son's problems.

Thursday, 9 May 2013

Okay, maybe I should clarify things a little

I recognise that I wasn't clear as to exactly why I was jealous and angry in this post - or, rather, which camp I felt Ben belonged to: the former or the latter. Great

treatment and outcome versus not-so-great treatment and not-so-great outcome.

I think we lie somewhere in the middle, and here's why...

At GP level, the service was very poor. Our GP seemed to know little about eating disorders, didn't latch onto the fact that Ben had an eating disorder and it took me a month to get him referred for treatment.

At the next level, the service was appalling. Approximately one month on from the referral I received a confirmation letter from CAMHS. On phoning I was told that we could have an 18-22 week wait before Ben was seen by them - and that would only be an assessment to work out what kind of treatment they felt he needed. Meanwhile, as you may have read in my book *Please eat...* Ben was metaphorically falling off a cliff.

At non-mental healthcare level, the service was poor. Ben was in hospital twice with Bradycardia (pulse rate 29) yet on neither occasion did the professionals make the link between low pulse rate and anorexia, despite the fact that I explained that Ben had anorexia. We were told that athletes' hearts tend to be so fine-tuned that they often beat slowly and, because Ben was sporty, this was probably the reason "in the absence of any other reason". Yes you could say that Ben was "sporty" - the eating disorder meant he was compelled to exercise round the clock. There seemed to be zero awareness of eating disorders or dietary needs while in hospital. You can read about the first hospital admission here: the first 6 chapters of *Please eat*

At CAMHS level, the service was... mixed and confusing. Initially the focus seemed to be on the "talking treatment" and delving into the "reasons why" Ben became ill. Meanwhile I persevered with a meal plan which I had to tweak because Ben refused to eat most of the stuff on it. I received little support in administering this plan and when Ben refused to cooperate any longer, he was given back control of his eating. Before long he was preparing every meal except the evening meal main course. Over the following 12 months his weight (and everything else) headed south as CAMHS tried to "prove" to Ben that his methods weren't working and were resulting in lost

weight, not weight gain. Meanwhile I felt as if I was fighting the system and fighting Ben's deteriorating mood as he went into a suicidal phase and his behaviours went extreme. It was what I now refer to as The Summer From Hell.

However later on in our treatment, from the October onwards probably, I began to get along better with CAMHS and became recognised as an important part of the team which was going to get Ben through this illness. They supported me when I introduced our Recovery Contract, for example, which resulted in Ben's weight going up steadily again and improvements on all fronts.

On the downside, Ben was discharged once he reached 18. Our psychiatrist was also leaving. His weight was the same as when he'd first started treatment, but his mood had improved immeasurably.

At post CAMHS level, the service was virtually non-existent. Ben's weight wasn't low enough to qualify for Adult Services. We were offered a transition worker who would see Ben a few times to attempt to help him in the transition to university, but Ben didn't get on with her at all. So, instead, it was just him and me working together using our Contract and bringing in the occasional private therapist to help tie up the loose ends. Things have moved slowly forwards, as described at the end of *Please eat* and they are still moving slowly forwards. I'd say that, over the last six months or so, Ben has gone from 99 per cent recovered to 99.5 per cent recovered. He is currently seeing a private CBT therapist to sort out his social anxiety - a legacy of the eating disorder - to help make his second attempt at university more successful than the first one.

But the Good News is that he is still seeing her and he is still pushing himself to overcome the last remaining glitches.

Having written about other families' experiences for my new book *When Anorexia Came To Visit*, there are a few instances where families have had a good, coordinated experience from GP through to recovery. There is one account in particular where everything worked like a well-oiled machine to drive the child towards recovery and

also support the parents.

There are other accounts of clinicians who have been amazing. One bit in particular made me smile: *"I dread to think what the outcome might have been if we hadn't had someone as formidable as XXXX on the team. She was great. Mind you, my daughter hated her with a passion. She was very, very strict and you couldn't pull the wool over her eyes. She didn't care whether you hated her or not. She said she wasn't there to be liked; she was there to get my daughter well. She was absolutely brilliant."*

I feel a little jealous and angry because I wish we'd encountered similar support at every level of the process.

Hopefully this book will help to change the tide.

Monday, 13 May 2013

So carers should be screened for depression, say doctors' leaders?

Why has it taken 'the powers that be' so long to come to this conclusion? As parents / carers of a young person with an eating disorder depression is no stranger, as many, many other parents will testify. But, I would like to ask, what good would it do?

Back in the summer of 2010 when I went to my GP with depression 12 months into my son Ben's eating disorder when he'd reached suicidal stage, all I got was a prescription for Fluoxetine and a referral for a maximum of 10 counselling sessions with a counsellor.

Almost daily Ben was threatening to kill himself and sometimes he would try - for example the time he climbed onto the roof. I had reached the stage where I was so stressed that I literally physically locked and could scarcely move. I couldn't work and I couldn't even drive safely. Some days I'd go to bed wishing I could go to sleep and never wake up.

The counselling sessions were useless.

It was like trying to plug the gash in the Titanic with a cotton bud.

All the counsellor did was hand me sheet after sheet of print-outs about anxiety and stress - the kind of stuff I could have easily found on the internet for myself.

The advice was obviously based on treating stress caused by situations like work or marital problems, things that - albeit it not easily in many circumstances - could be solved.

Quit the job or leave the partner.

But you can't leave your child when they're so very sick, can you?

You can't clock off at 5pm and go home and drown your sorrows in a glass of wine.

You can't take the day off sick or get a sick note from the GP.

I kept telling the counsellor that there was no solution - apart from my son getting well again. And, at that point, this looked like a heck of a long way off. That is, if he didn't kill himself before then.

Oh, and there was another problem.

I kept having to cancel our appointments because they were during the day when I was caring for Ben. Sometimes - well, much of the time - he'd kick off and it wasn't safe, or indeed possible, to leave him.

So in the end I had to cancel so many appointments it just wasn't worth going.

And in case you're visualising a cosy sofa-style chat in a pleasant, darkened room, think again.

These sessions were held in a GP's surgery on one of the worst council estates in the city. The inside of the surgery was as run-down, depressing and deprived looking as the concrete jungle outside. She sat one side of an old battered desk and I sat on the other, on uncomfortable upright chairs, the walls covered with posters warning of the dangers of smoking, drinking and STDs.

And then I'd leave with a pile of print-outs which I used as scrap paper.

The fluoxetine proved much more helpful.

Tuesday, 14 May 2013

Looking across the dinner table at Recovery

It suddenly dawned on me last night as Ben and I sat across the dinner table eating Italian bean, aubergine and red pepper stew on buttered ciabatta with parmesan cheese (and, in Ben's case, a boiled egg on top) that I was looking in the face of Recovery.

For the first time his body and face look fleshed out properly. For the first time he looks very similar to the photograph I have of him sitting in the same position back in the December of 2007 when he was 14. He is a little thinner, but then he's not playing rugby these days. Or any sport for that matter.

And Ben looked happy and was behaving normally, planning the social activities that he is slowly easing himself into as a result, I think, of the CBT sessions he's having every Thursday.

I guess I could pick out a few things that still wouldn't be exactly right. Like the fact that on some days (not all days) he will keep a tab on calories to make sure he's not eating too much - or too little.

But these are minor details which I am sure will fade over time, just as all the other glitches have faded.

I was wondering why I'm finding it really difficult to stand up and say: "My son, Ben, is now completely recovered from anorexia." And I think the reason is this...

It's almost by saying this I feel as if I'd be tempting fate. It's almost superstitious; as if - by not saying it - Ben won't ever relapse. Yet if I said it - ping! - he'd begin to go back downhill again.

This is ridiculous, I know.

Pure superstition!!

Tuesday, 21 May 2013

A letter I wrote to CAMHS in 2011 about getting Ben WR

This is a letter I wrote to CAMHS in June 2011, 15 months into my son's treatment for anorexia: As of last Friday, Ben is now XXkg (BMI XX. However I am concerned that, as a result of last Friday's session, Ben now believes he is Weight Restored and that CAMHS consider him to be physically "recovered". I am hoping he has misinterpreted this message.

I am aware that weight normalisation and BMI are difficult to calculate as they differ for each individual and fluctuate over the day, week and month. I agree that Ben is now within a safe and reasonably healthy weight range, but this is different from being completely Weight Restored. WHO says the minimum BMI for a boy of his age is around 21.5 and the average is between 21 and 25. Ben is below this.

To allow Ben to maintain his weight below normalisation or to "choose" a weight "he feels comfortable with" is to allow Ben to remain ill. It leaves no room for manoeuvre should he fall sick or wish to resume his pre-ED sports regime. Also, the risk of relapse is far greater.

As a guide to the Pre-ED Ben (and not the "fat" Ben he often refers to), he was a keen athlete (see attached photos). He did the Coast-2-Coast Cycle Run, played rugby, did cross country, swam, trained at the gym and won the 1500 metre race at school sports day. Although he did suffer from "puppy fat" as a child, he slimmed down in his teenage years and developed a healthy, muscular, "strapping" physique. To get back to something close to this level, he still has a few more kg to go.

I know that full nutrition and weight restoration alone will not cure the eating disorder, but full recovery will never occur until Ben reaches the correct level of weight normalisation. Periods of time spent at a sub-optimal weight are associated with a protracted course of illness. Also, weight normalisation is only the beginning of maintenance of a moving target as Ben's metabolism changes and / or he grows.

Over the past 11 weeks the Contract has been successful in moving Ben forwards out of a rut and in achieving gradual but consistent weight gain. I would be

devastated if, after all we have achieved and are continuing to achieve, Ben was permitted to remain at a sub-optimal weight.

I am aware that it isn't going to be easy to get Ben to buy into this idea. As you know, he has a deep seated fear of getting "fat". His perception of his body is still different from reality in that he believes he looks heavier than he actually is. He also believes that, at just a few kg extra, all the symptoms he associates with being "fat" will return: discomfort, sweating, body dysmorphia, etc.

Ben is aware that we, his parents, don't agree that he has arrived at Weight Restored just yet. But he is adamant that CAMHS believe he is now at a level where he can maintain and successfully recover. I hope he has got this wrong...

Saturday, 25 May 2013

Anger and a pressing need for change means book #3 is germinating inside my head

And this time I may write it in collaboration with the UK eating disorders charity ABC (Anorexia & Bulimia Care) with whom I am having a series of very nice, friendly and fruitful conversations. This is part of an email I sent to ABC's Director, Jane Smith, today:

The angle I want to take on the over 18s is the way that things can go haywire at that age if they're still undergoing treatment, yet no longer qualify for CAMHS. As well as knowing a few families that have gone and are going through a post-18 nightmare, not to mention the fairly recent publicity in the media about post-18 deaths due to patients being able to make their own decisions as to whether or not they have treatment, I was particularly worried by some forum threads I read on the BEAT website where 18 year olds were clearly terrified at the prospect of having to move into adult services when they knew and trusted their existing treatment team, and were working very well with them.

It seems absolutely crazy to insist on a complete change purely and simply because of their age and nothing else. And many of these young people find change so difficult to deal with. Worse, in a world where excellent treatment teams seem to be... er... not as widespread as they could be, shall we say... if you have a great team that's working wonders for your child then you should darn well stay with them!!!!

Wednesday, 29 May 2013

Ah the dulcet tones of Xbox Live in our living room...

Four years ago, Ben stopped playing Xbox Live with his friends. He used to do it all the time, but over that summer of 2009 as the eating disorder began to take over his life, he just stopped. Instead, he played on the Xbox in solitude. Today, however, he's hooked up to Xbox Live again, laughing and yelling with glee as he "fights" a couple of friends on some game or other.

And these are new friends, not the old friends who virtually deserted Ben. These are friends he's met down at Games Workshop.

It's yet another development in Ben's Life Without ED, as the eating disorder fades even more into the distance.

Then tomorrow he and I leave for Cornwall, for the sea-view holiday he won in a competition.

Bring on the Cornish pasties!!

JUNE 2013

Wednesday, 5 June 2013

Thick, calorie-laden Cornish clotted cream on scones with strawberry jam

This is what Ben suggested we treated ourselves to after our coastal walk yesterday (Ben and I are on that free holiday in Cornwall which he won in Dorset Cereals' Spin the Bottle competition).

So the two of us sat there, in the tea garden of a sweet little watermill deep in a wooded valley, demolishing a huge luscious cream tea comprising two huge home-made scones, thick clotted cream and strawberry jam - plus a massive pot of tea with milk.

And, as you can imagine, I was doing internal cartwheels of delight.

And there was no guilt afterwards - just a quiet comment from Ben about having just done a "major challenge". But no guilt or regret.

When I get back home I'll post up the photos on my Facebook page!

PS For those of you that don't know what Cornish clotted cream is, it's like the thickest, almost solid whipped double / heavy cream you can imagine - almost as solid as butter. Cream doesn't get any creamier than clotted cream!!!!

Thursday, 13 June 2013

Yes, I agree with this new blog, FBT is dang hard...

A new blog from the Kartini Clinic in the States is really great. And parts of it reflect what families have said to me in my research for my new book *"When Anorexia Came To Visit"*. The thing is, with any other illness with such a high mortality rate, you would automatically expect to hand it over to the professionals and let them get your child through it. You wouldn't think twice about that and you certainly wouldn't attempt to do it at home. However, because - in so many cases - FBT (Family-Based Treatment) for eating disorders has been shown to lead to a positive outcome with anorexia and some other eating disorders, this is what we families are expected to do. And it is dang hard.

However I would argue that it is even harder when you don't have the support you're meant to have with true FBT and you are, in effect, taking on the role of the professional because those professionals simply don't know their stuff - or are following outdated treatment models.

Some of the families in my new book found themselves with no option but to ditch treatment teams altogether and battle it out on their own.

Of course this wouldn't happen with any other illness with such a high mortality rate. But it does with eating disorders. And not because we, as parents, choose to take on such a terrifying and demanding job.

True FBT might be danged hard, but going it alone because you have little choice is even harder, especially when the stakes are so high.

JULY 2013

Wednesday, 3 July 2013

Apologies for the long absence!

Ben and I spent a week in Cornwall (the one he won in a competition), spent a week back home before jetting off to our main family holiday in Italy. We came back at the weekend. So apologies for not writing any blog posts. And, in case you're wondering, my new book *When Anorexia Came To Visit* where I talk to 20 UK families about their experiences of living with an eating disorder will be published at the end of this month. Meanwhile my other book *Please eat...* which describes our own story is selling steadily on Amazon.

Wednesday, 3 July 2013

Reporting on our first holiday abroad since the Summer From Hell in 2010

If you've read my book *Please eat...*, you'll know that the summer of 2010 was an absolute nightmare - and it began with a fortnight's holiday in France. CAMHS had told me to back off and not talk about food for the duration. We were told to "go away and have a normal, happy family holiday". Ha ha ha ha, I hear you all say, as if you can take a "holiday" from your child's eating disorder!

Not surprisingly the holiday was a nightmare with Ben threatening suicide and a very dangerous episode at the seaside, described in my book. And lots more hellish things besides. It was truly horrible, and the rest of that summer just got worse as Ben's weight, mood and behaviour headed south.

As a result, we haven't dared book a "proper" family holiday abroad since then.

In 2011 I gingerly booked 2 separate last-minute weeks at holiday cottages not too far from home followed by a few days in Somerset with Ben. Things went OK. There were a few ED-related incidents but on the whole I was pleased.

In 2012 we booked a fortnight in the Cotswolds and Forest of Dean. It was a success.

So, for this summer, we took a deep breath and booked a fortnight in Tuscany.

The contrast between this holiday and the French holiday of 2010 couldn't have been starker.

Ben ate normally. He even took over all the catering and we ate some amazing food - better, I suspect, than many restaurants. His mood was fine, except for the usual teenage boredom that tends to slip in when teenagers are on holiday with their boring parents who want to do boring things like read around the pool.

But it was normal.

And, unlike the 2010 holiday, he didn't swim 100 lengths of the pool every day followed by a run in the heat. He did a bit of swimming. But, again, it was normal.

Friday, 12 July 2013

Keeping a close watch...

We still weigh Ben every 2 weeks, just to be sure that things are continuing to move in the right direction - and, over the past month, he has lost weight on both occasions. He is now back to the weight he was in April 2012, just after he was discharged from CAMHS. And, remember, he was discharged from CAMHS at the same weight he was when he started CAMHS treatment. He is 4 - 5 kilos lighter than he should ideally be at his age and height. So I am keeping a very close watch...

To be honest I was shocked. Mind you, he "looked" slimmer. Yesterday we were talking with our neighbour, a nurse who saw us on the Lorraine Kelly show on TV last year and therefore knows about Ben's history with an eating disorder. She asked him how he was doing now. He said "Fine". But I could tell she was looking at him closely...

However he seems OK in himself. So, thus far, it's a case of "state not weight".

But, as I told him in no uncertain terms this morning, he is "that close" to slipping back into the danger zone. Indeed, if I was to be brutally honest, I would say that today's weight is actually inside the danger zone.

I reminded him that it's not just about "getting ill again". It's about the fact that his heart doesn't like it when he's at a low weight, as anyone who's read my book *Please Eat* will know.

He has promised to increase his intake by 200 calories a day. I wanted him to increase by more. But Ben being Ben (which was always a problem in our journey through anorexia) he is strong-willed and stubborn. It's very hard to get him to do anything he doesn't want to do.

"But you promised last time that you'd increase your calories and put on weight," I reminded him.

But it appears that he'd cut back a little because he hasn't "been doing any exercise" because he had 2 toenails removed last week.

But he has. He's been doing his weights. He did them yesterday.

However, so far, I'm not too worried as his "state" seems fine. There isn't a hint of the old anorexia behaviour.

So far.

I am away from Saturday until Friday, and have insisted that the moment I get back I will weigh him. And if he hasn't increased, then I will take "serious measures".

I have also hinted (or, rather, told him) that university is off the cards if his weight remains low.

I will ask his dad to keep close tabs on him next week.

Monday, 15 July 2013

Just me, a park, some wood pigeons and a squirrel

In my book *"Please eat... A mother's struggle to free her teenage son from anorexia"*, I talk about how - during the most stressful moments of my son's eating disorder - I'd take time out at the end of the garden, watching the vegetables grow. We have a long garden, so it was a fantastic way to truly "walk away from the eating disorder", even if it was only for a moment or two. But there was another place, a place I'd imagine myself going to on those frequent nights when sleep evaded me. Yesterday I went back there - to the real place.

There is an old Victorian metal gate set into limestone walls. It leads into a beautiful private park - the park opposite my late grandparents' former house on the hillside at Weston Super Mare. Because it's a private park for residents only, tucked away in a very secluded part of Weston's hillside, there was never anyone there. Except me. And I used to love being the other side of that wall, in that park, surrounded by manicured rose bushes and shrubs, and grass covered with daisies.

During those sleepless nights at the height of my son's anorexia, the only way I could get to sleep was to escape from reality. I'd imagine myself going up to that old gate, opening it, walking through and closing it again. Once in the park, I was cut off from the outside world. I was safe.

I'd use a technique where I'd imagine what the grass felt beneath my bare feet. I'd make a daisy chain, carefully examining each petal. And I'd gradually make my way through the park, listening to the wood pigeons with the sound of seagulls in the distance. Usually I'd fall asleep before I reached the gap in the wall which led up to my grandparents' house in the tiny private cul-de-sac with its handsome 19th century villas.

Yesterday I went back to that park. And, unlike last time I went there, I ignored the "private" sign on that gate, opened it and walked through the park again. Just like I used to do when I was a teenager, many many years before the eating disorder invaded our lives - a private, peaceful place where I felt safe and secure. And, just like in my imaginings, I kicked off my flip-flops and felt the grass beneath my feet, even if it was tinder-dry and parched with the summer heat.

And I knew that I wouldn't care if anyone challenged me about trespassing in a private park.

But they didn't, because - just as it always used to be - there was just me.

And the wood pigeons and the odd squirrel.

Saturday, 20 July 2013

Batty embarrasses herself in the hotel restaurant...

I'm still trying to work out the reason why, when served up with a pretty cr*p meal in the hotel restaurant I was staying at during my week's get-away in Somerset and Devon this last week, it set off the waterworks. Big style. And I haven't been so embarrassed or angry with myself since the time the same thing happened in church (described in my book "Please eat... A mother's struggle to free her teenage son from anorexia"). The more I tried to stop, the worse it got! And all because of some soggy roast potatoes. But why?

That's what I've been trying to figure out. I mean, I was so very relaxed during this break, so it wasn't as if I was teetering on the brink waiting for the proverbial last

straw to break the camel's back, so to speak...

Here's why I think it was...

This was the first time I had been away from home, on my own, indulging myself in a relaxed way, since before the eating disorder. As you will know if you've read my book, I tried to get away from it all a couple of times. Both times I failed. The second time I was so wound up with anxiety that my body physically locked into position, like a kind of lock-jaw, and I could scarcely function.

So this time it was going to be perfect, come hell or high water. Which is why, when the food was cr*p at the hotel which had cost me a pretty penny, it was the last straw.

Also, I'd just met up with two people who had been profoundly affected by eating disorders: one was a former sufferer who is now recovered and the other was a mum, still struggling with her daughter's eating disorder. What with this, and proof-reading the final version of my new book *"When anorexia came to visit"*, I got thinking about this bl@@dy awful illness in probably a little bit more depth than is good for me.

Additionally, that day I'd been to the beach. It was the first time I'd been to a beach since the terrifying episode described in "Please eat..." when Ben and I ended up in dangerous territory, too far out from the coast, in unpredictable estuary currents. Although it was great fun to be at the seaside again after three years and I've always loved wading and splashing out into the sea more than most other things in life (except for during the "Summer From Hell" described above, when the seaside took on a whole new and terrifying personae), I was - in general - looking back at the beach to check my belongings were safe. This is key, I think.

I wasn't looking out to sea...

But then I turned round and looked out to sea... across the vast expanse of blue towards the horizon.

And, suddenly, I had a flashback as I remembered just how far out Ben had been

swimming during that terrifying episode - his arms going round and round like a motor, not caring how far the rip-tides took him out to sea. That was the summer of suicidal thinking. The summer when Ben didn't give a flying you-know-what about what happened to him.

Actually, I wonder if that was the trigger at the hotel dinner table on Tuesday night rather than the other two things I've mentioned above.

It's difficult to say. The mind does funny things.

But whatever the trigger was, it happened. Thankfully I was sitting outside on the terrace, so I was alone, until a family came and sat on the table right next to me while I was still frantically trying to stop blubbing into my tissues.

And - oh so embarrassingly - I was still blubbing when the head waiter came over to see why I'd complained about the meal. Also, embarrassingly, I found myself trying to explain **why** I was blubbing!

Oh just stop, Batty, you are digging yourself in even deeper!!!!

Ouch, ouch, ouch!

I kind of prodded my way through the replacement meal they gave me, not really tasting it. And I asked to take the dessert up to my room, eyes downcast, wishing to hell I'd brought my sunglasses down with me.

The next day and for the remainder of the stay, I was relieved to see that it was a different team of staff.

I couldn't have faced them again!!!!

And, the next day and thereafter, I was fine. No more upset.

Odd, that.

Monday, 22 July 2013

Phew! At last "When Anorexia Came To Visit" is published!!

I've spent the weekend updating the manuscript for *When Anorexia Came To Visit* where I talk to 20 families across the UK about their experiences of living with an

eating disorder - and yesterday I published the Kindle version of *'When Anorexia Came To Visit'* by Bev Mattocks. It's also available on Kindle at Amazon.com. Meanwhile...

I am speaking at the Institute of Psychiatry in November at Prof Janet Treasure's and Gill Todd's 'National Carers Conference' (telephone their organiser on T: 01256 704117 M: 07733 260 475 to book a place).

Plus, Ben and I are doing a slot for BBC North's *'Inside out'* programme about the growing issue of males with eating disorders.

So things are getting busy, especially as I crank up the speed of promoting my new book to the people that need to read it: families and clinicians.

And, of course, I could never have written this new book if it wasn't for the 20 families that have generously and bravely contributed their often painful and distressing stories, and the fantastic people that wrote the Foreword, Preface and Introduction: Professor Janet Treasure OBE, Becky Henry, author of a similar book that describes the stories of families in the States: *'Just Tell Her To Stop: Family Stories of Eating Disorders'* and the amazing Fairy Blogmother herself, Laura Collins, founder of F.E.A.S.T. (Families Empowered And Supporting Treatment of Eating Disorders) & the Around The Dinner Table Forum & Author of *'Eating With Your Anorexic'*.

Tuesday, 23 July 2013

An excellent cross-section of families from across the UK

There are many Good Things about my new book *When Anorexia Came To Visit*. The best thing of all is that these 20 wonderful families willingly volunteered to share their personal stories with other families they've never met in order to give them hope. But the other Good Thing is that I believe these 20 accounts represent an excellent cross-section of families from across the UK (looking primarily at restrictive anorexia nervosa).

We have families from all areas of the British Isles: England, Scotland and Wales - and all ages, from the age of around ten to the early twenties. We have families of boys as well as girls. Two of the accounts are about boys which kind of reflects what is going on in the statistical world in general.

We have families where the young person is now fully recovered - and families where it is still a “work in progress”.

Not surprisingly, the former is usually where the family has received swift and effective evidence-based treatment and good parental / family support. The latter is usually where the family has received a less excellent level of care. Again, this reflects what seems to be going on across the UK and, doubtless, the world in general. Some treatment providers are outstanding whereas others aren't. Some are following the latest evidence-based treatment models whereas others are still following outdated or redundant approaches. In some cases it's difficult to work out what the approach actually is - as was the case with our own story, described in my book *Please Eat*.

We have families that live close to excellent specialist eating disorder treatment facilities while others are referred to more generalised services like CAMHS (Child & Adolescent Mental Health Services). Whether or not you have to wait for treatment varies, too, as does the length of time it can take before a GP diagnoses an eating disorder and refers the young person for treatment.

In some areas very little is available. In other areas, there appears to be nothing at all. So some families are being forced to go private. In the best case scenarios the NHS funds this private eating disorder treatment - or the family has adequate private health insurance to cover the enormously costly fees. In the worst case scenarios families are forking out tens of thousands of pounds (or more) of their own money to pay for treatment which, in a country with a National Health Service, should be available - free - to everyone.

All of the above is why this new book describes such a good cross-section of what is going on out there, in the UK, with eating disorders, in 2013, even though I have

only talked to 20 families.

Not only does *When Anorexia Came To Visit* highlight what is happening in the world of eating disorders treatment in the UK, but - of course - it has been written to help other families: to help them identify the warning signs of eating disorders sooner and take action, and to empower them to demand the best possible care for their child and be included - as routine - as a vital part of the treatment team.

Thursday, 25 July 2013

No, success in life isn't about what you 'look like': why this report is so wrong...

I love Beat, the UK eating disorders charity, I really do - like most of my eating disorders network. Yet, yesterday, this report was brought to my attention. And, I can tell you, it's raised a few eyebrows amongst the eating disorder community so far. I am not the first person to blog or comment on it...

It is so wrong, on so many counts.

Despite their different sizes, these women look pretty near perfect - as if to say "You look perfect once you recover from an eating disorder". And, just to make sure, we'll give you a spray tan, too. Because bodies without spray tans aren't quite so perfect...

Well, sorry, but not everyone looks perfect. Eating disorder or no eating disorder.

So people that haven't quite 'come up to scratch' for whatever reason... maybe, genetically, they have unusual body shapes, maybe they're post-menopausal like me and long to have a washboard stomach but know they haven't a hope in hell of achieving it, maybe they have surplus skin left from being huge while pregnant, also like me. Nothing short of surgery would sort out my problem - and I am sure that many, many women across the UK - post eating disorder or not - have this problem.

And when my well-meaning son, Ben, says: "But it doesn't matter what your belly looks like, mum, you're ancient - and dad loves you as you are", it does matter to me, and I mourn the body I used to have when I was 25, even if that body was

'engineered' to a certain extent through unusual eating patterns...

But I put it to one side and tell myself that there are more important things to think about than my 'middle', my growing wrinkles, my bingo wings or whatever. And, anyway, it's 'who' I am, not 'what I look like'.

Which isn't what this report conveys...

And just to go back to the paragraph above...

At 25 I went through a bulimic phase. I had already been through restricted eating phases since the age of 17. So the great body I had back then was 'engineered' to look great. If I'd left it to nature i.e. without food issues, then I would have been bigger.

Yet I looked good. Like the women in this photo. My point is that it doesn't convey what might be going on inside the person - a person might have an unhealthy or even dangerous relationship with food and yet look physically 'perfect' like any of these women.

And here's another thing...

I have a network of a hundred or so friends from across the world, some recovered eating disorder sufferers and others parents of eating disorder sufferers. I have only met a handful of these 'in the flesh'. I have no idea what they look like except for their Facebook photos, and even then the photos are sometimes disguised.

Yet they are all wonderful people, and I really really like and admire them.

Regardless of what they might look like in their bra and knickers.

And I know for a fact that some of the women I know don't look too great at the moment through illness and surgery.

Yet I don't like them any less.

If anything I like them more.

And, because of illness and surgery, they can't climb Everest or whatever else the report says that these women have done (as if to endorse that there's more going on in their lives to celebrate their recovery from an eating disorder than standing in

front of a camera half naked and that, therefore, this justifies the camera shot and report).

So, please Beat, remove a report that implies that success is down to how you look at the end of the struggle, whatever your own personal struggle may be.

It isn't.

Thursday, 25 July 2013

University bound in September!

If you've read my book *Please eat...*, you will know that, last September, Ben attempted university, but was back home within days on an impromptu gap year. Initially we weren't sure whether or not he'd choose to take a second gap year, but yesterday he made the final decision that - yes - he's going to university this September. And this time it's going to work out OK.

This time I'm taking a back seat deliberately. I've been letting him make all his own arrangements. This way he becomes more independent and also responsible for whatever action he takes. He clicked the 'check, check, check' buttons on the university accommodation Terms & Conditions yesterday - and he is aware that, this time, if he decides to opt out there will be no refunds.

Also, this time, the money is coming out of his own funds, care of some rather wise investments my late grandmother made decades ago in the last century which now yield some attractive dividends, and which my mother has handed over to Ben. Yesterday I told him he'd have to draw on this money to pay for his accommodation. So he's having to take charge of his own finances rather than the 'bank of mum'.

(Curiously, it's a large corporation in Australia that is paying for Ben's university accommodation, via the share dividends!)

Also, this year the university plan is slightly different.

Last year, Ben insisted he was leaving for university and wouldn't return home at

all until Christmas.

But, as you know, he was back home within two days.

This year, he's booked a slightly different kind of apartment - bigger and in a different apartment block. And, because he won't have lectures on Fridays, he will initially come home for long weekends until he feels comfortable enough to remain in Sheffield for full weeks. We only live a 40 minute train ride away.

But everything - lists, packing, bank accounts, etc etc etc - is being organised by Ben while I take a back seat.

And, unlike last year, I'm not so anxious about getting all the food equipment and supplies ready so he has no excuse not to eat - because I know he will eat regardless, and he is already familiar with the local supermarket, uni coffee shop, cafe and so on.

Plus, he is in a far better place overall this year.

So, with any luck, it should work out OK!

Thursday, 25 July 2013

"I'm happy, I have 'sort of' friends at last!"

... said Ben yesterday. To which I responded: "They're not 'sort of' friends, they're real friends." To which he replied: "Well they're not the kind of friends you can talk about old times with, because I haven't known them that long." "But that doesn't stop them from being real friends," I said. "At some point, your original friends were new friends and you had no common history to be nostalgic about."

As you may know, ever since the eating disorder arrived in the summer of 2009, Ben cut himself off socially. Gradually his old friendship group drifted away (which I have always felt a deep anger about because I feel they should have 'tried harder'), and Ben was left friendless.

For a long time.

And, not surprisingly, it got him down.

It's only fairly recently that he has begun to establish a brand new friendship

group: people he's met through his favourite hobby, *Warhammer*. Nowadays he meets up with them fairly regularly. And, when he does, he always returns home happy.

Hopefully he will keep this group of friends when he goes to university, especially if he's planning to come home at weekends.

And, also hopefully, he will make similar new friends at university, perhaps through the Warhammer society at the university.

And, in my opinion, these are already 'real' friends, not 'sort of' friends.

It's all Good News for Ben!

Saturday, 27 July 2013

It's simple: all we want to do is to get our child well again

Let's face it. All we parents want to do when we present our child in front of the NHS treatment team we've been allocated is to get our child well again - and as soon as possible.

Many of us know nothing or very little about the bureaucracy behind NHS mental health treatment provision - or the various treatment models which may be used on our child.

We just want to get our child well again.

So we assume that the provision is there for us and that it will work. Just as we would if we were - God forbid - presenting our child in front of a cancer treatment team.

During those weeks or months as the penny begins to drop that there is something seriously wrong with our child and we make the decision to take them to the GP... followed sometimes by weeks of waiting for treatment... we may - if we have the time and energy while reeling from the fallout of a child plummeting into an eating disorder like anorexia - have dipped our toes into the water of the vast vault of information out there on eating disorders.

But - like the treatment - we just want to get to the heart of the matter: to find out what is wrong with our child, why it may have happened and how to get them well again - quickly and permanently.

This morning it struck me that there is a ton of information out there, much of it scientific or academic, jam-packed full of treatment descriptions, acronyms, lists of experts, books to read and so on. It can be impossible to know where to start, especially when you're being referred to a plethora of links to other resources which link to other resources and so on...

At the end of the day, we parents usually aren't healthcare professionals or medical scientists. We are just parents of children that we love and want to restore to full health again.

And we want to be sure that the treatment our child receives will achieve this.

Often, we arrive at the first treatment session optimistic that this is it - the first rung of the golden ladder to recovery. A few sessions and - ping! - our child will be well again.

Yet as time goes on (and for some families this clanging realisation dawns faster than for others) we all too often realise that this isn't going to be the case. We are told that our children are "in this for the long haul". And that nothing can be achieved until they arrive at a stage where they "want to get better". If they never arrive at that stage, then there is little that can be done. Sorry but...

So everyone just sits there, bewildered, unsure what to do next, faced with a child that is unable to "want to get better", yet who, underneath, is crying out for help.

And, when we begin - horror of horrors - to doubt the professionals' judgements and treatment methods, in a way that I am sure we would rarely do if it was another illness like cancer, we don't know where to turn. If the treatment team we've been allocated don't follow modern evidence-based treatment methods, then what can we do? And, anyway, how do we "lay" parents know whether or not they're following up-to-date methods? Many of us are not aware that there is a whole range

of treatment methods for anorexia, and that some of these are the polar opposite of others.

Radically so.

But, even in the event that we become lay experts on modern evidence-based treatment for eating disorders, here in the UK you're pretty much stuck if your allocated treatment team isn't following that model. On the whole you can't pick and choose treatment like you can in other countries. You get what you're given - or you go private at an eye-wateringly high cost.

And I know this is happening because I've been talking to families during the compilation of my new book *"When Anorexia Came To Visit"*. I have also talked to many other families about their experiences with NHS treatment for eating disorders, some of it excellent, some of it woefully inadequate.

All of the above was mulling over in my head this morning and led to an idea.

It's a pretty big and daunting idea, and will require some more thought and a lot of work on my part.

But the seeds have been sown.

Watch this space.

Sunday, 28 July 2013

Getting ready for university

Before Ben can return to university in September, he needs the "OK" from the university medical centre. This is because his one-year Leave of Absence was on medical grounds. So, no doubt, he'll be travelling down to Sheffield within the next week or so for an assessment. Goodness only knows what this assessment will comprise of, but hopefully they'll say and do the right things.

Also, he's planning to book onto the university's Discovery Week. This is the week before Intro Week (when all the new students arrive and run amok with drinking, clubbing, etc). Originally introduced for students living at home in Sheffield, so they

don't miss out on all the Intro Week stuff which is going on in the university residences, etc, and international students, it's a week of quieter events and useful talks about university life.

The university bills it as "a range of social events and information sessions during the week before Intro Week. Taking part in Discovery Week gives you a great opportunity to settle into university life, meet likeminded people and make lots of new friends. You will have the chance to find your way around campus and the city, before the busy Intro Week starts the following week. You can arrive and take part in Discovery Week at any point during the Week, picking and choosing from a range of information sessions, activities and social events that you're most interested in. You can take part in as many or as few as you want."

So hopefully this will be an opportunity for Ben to ease himself into student life before the onslaught of Intro Week.

And I am ensuring that Ben arranges and organises all this stuff on his own, without my help, as I take an increasing back seat in his life.

Wednesday, 31 July 2013

It is NOT a get-out-of-jail-free card; parents are NOT to blame for their child's eating disorder

There is a lot of debate going on today as a result of my recent *Mumsnet* guest blog post as to whether or not parents are to blame for their child's eating disorder. Naturally, I state that they are NOT to blame - and no-one, anywhere will convince me otherwise, especially with all the latest neuroscience research coming through showing that anorexia patients' brains appear to be wired up differently from "normal" brains, reinforcing the belief that eating disorders are biological illnesses and not lifestyle choices. But I won't go into all the science here; you can read an excellent article on the subject by clicking this link.

Poor parenting, in some cases, might - and I emphasise the word ****might**** - be

one of the triggers that lead an individual losing weight and which, if predisposed to developing an eating disorder, might lead to anorexia or another eating disorder, just as any “trigger” which causes someone to lose weight might do.

If you read my new book *When Anorexia Came To Visit*, you will read about families where children lost weight for a number of reasons - from bullying to dieting, illness to over-exercising, or some kind of life trauma or event.

The way I always like to explain it to people outside the world of eating disorders (no-doubt far, far over-simplified) is that “When someone who is pre-disposed to developing an eating disorder loses weight and that weight drops to a very low level, the eating disorder ‘kicks in’”.

But to say that parents “cause” their child’s eating disorder or are to “blame” is appallingly wrong. Just as parents don’t “cause” any illness. Okay you might say that passing on genes might “cause” someone to develop a mental illness like an eating disorder (research shows that over 80% of eating disorders are thought to have genetic roots), but we can’t be blamed for our genes!

However, an eating disorder like anorexia is one of the few illnesses where society routinely points the finger at the parents. What did the parent do to cause their child to get sick?

And if it’s not said to the parents’ faces, it’s implied by “that look”. As parents of children who have been through an eating disorder, many of us will be familiar with “that look”. And it immediately makes us feel inadequate and guilty in a way that no other illness would do. Can you imagine getting “that look” if your child was found to have a defective heart, for instance? Ridiculous!

Thankfully, throughout my son’s eating disorder, no-one ever said anything to my face. But I got “that look” many times. The first time was from our GP and I’ve had it many times since, notably the occasion (described in my book *Please eat...*) when Ben was going crazy outside the hospital while police, security staff and a doctor were trying to get him back inside for cardio tests. As a parent you almost feel

compelled to “justify” the reasons why the eating disorder may have developed and your - once immaculately-behaved child is acting in this way - as if to scream: “It wasn’t me!!!!”

Many of the parents in *When Anorexia Came To Visit* describe appalling instances where the finger was being pointed at them by the medical profession.

At best, parents describe being asked what they, as parents, were doing to prevent their child from eating. At worst, the child was checked over for bruising. One girl was asked by a nurse if there was anything she would like to tell her now that her “dad wasn’t present”.

When Ben was badly bullied at primary school, a number of years before the eating disorder emerged, we took him for counselling. I was appalled that the counsellor seemed more interested in me and my history. Apparently I had passed my own “anxieties onto Ben” which had, she implied, set Ben up to be bullied.

Ah, how many of us parents have heard the “passing on anxieties” stuff?!

I will end this post with a quote from one of the chapters in my new book:

“I could see the consultant making little notes, concluding that anxiety was the problem in the family and that our son was feeding off this atmosphere. Well of course we were anxious! Our son was behaving strangely, was losing weight and we were sitting in front of a team of mental health professionals. What parents wouldn’t be anxious?!”

AUGUST 2013

Monday, 5 August 2013

We must get this book out to the people that need to read it!

My new book *When Anorexia Came To Visit* describes the experiences of 20 families in the UK battling with an eating disorder and the obstacles they had to overcome in the UK's provision for adolescent mental health. This isn't just a book for parents, it's a book that the health professionals themselves need to read: doctors, Child & Adolescent Mental Health Services teams (CAMHS), psychiatrists, psychologists, therapists, politicians - everyone. The problem is, how do we get it to them?

Telling people about *When Anorexia Came To Visit* isn't like other books in that it's not a case of me, the writer / compiler, wanting to make money from it. Any money I make (and I only make a nominal amount per copy) goes towards the free copies which I send out to eating disorder charities and other people - plus other costs.

So, by helping me to get the word out there that *When Anorexia Came To Visit* exists and NEEDS TO BE READ, you're not making me rich. What you are doing is helping to spread the word that there are serious gaps in UK mental health provision and training for eating disorders treatment, all of which need to be addressed to help other families access the good quality treatment they deserve.

At GP level, doctors are failing to diagnose eating disorders, dragging their heels when it comes to referrals, or admitting that they know very little about this illness - the biggest killer of all mental health conditions.

Post-referral, treatment is patchy depending on where you live. Some people have access to excellent specialist eating disorder services while others get referred to a more generalised service like CAMHS which can sometimes be where things come unstuck. Some families don't have access to any eating disorder treatment at all - or are forced to go private. And everything can so easily fall apart once a young person reaches the age of 18 and is moved onto Adult Mental Health Services - or where a young adult is unable to recognise that they are ill and refuses further treatment.

Treatment methods and models vary. Some have achieved better results than others with this cross-section of 20 families who come from across the UK including

Scotland and Wales, and who include boys as well as girls.

Sometimes families are included in adolescent treatment for eating disorders and sometimes they are not. And, all too often, families simply aren't being given the vital tools to know how to feed their anorexic child, prevent purging and deal with the terrible rages and extreme behaviour that an eating disorder like anorexia can bring.

Also, all too often, families are encountering problems with other health services and especially A&E, where staff appear to know little about eating disorders.

Across the board, health professionals - including mental health professionals who should know better - are saying the wrong things, the kind of comments that make us parents draw a sharp intake of breath.

And, in some truly awful instances, the finger is being pointed at parents, suggesting that the eating disorder is a result of abuse.

Obviously *When Anorexia Came To Visit* only documents the stories of 20 out of the thousands of families in the UK that are struggling with a son or daughter with an eating disorder. But I believe it's a very good cross section which gives a balanced picture of what is happening within the world of eating disorders in the UK today.

This is why this book needs to get out there to the people that need to read it so they can see what goes on, from the family's perspective, both in a clinical setting and at home.

Tuesday, 6 August 2013

My latest guest blog - for NEDA in the States

I am thrilled to have been guest blogging for NEDA (National Eating Disorder Association) in the States about our story:

Eating Disorders Aren't Just a "Girl Thing"

A few months ago, my 19-year old happy, healthy, anorexia-free son handed me a "thank you" card. Inside, Ben had written that his eating disorder had been "a

struggle fought together not against each other". He wrote that I was "a shining example to the world that love can overcome anything" and that "we would not be here today in such a state of contentment" if it had not been for my "sheer strength of willpower and motherly love". Finally he thanked me "for being the one that never gave up".

Well, the floodgates opened and I wept buckets!

Four years earlier, in 2009, I didn't know that boys got eating disorders. So, when Ben's passion for exercise went extreme and he began to insist on "healthy" eating, I had no idea what we were dealing with. Nor did Ben, because it's not as if he sat down one day and "decided to get an eating disorder".

Ben, his dad and I live in the UK. His dad has always been into rugby and was thrilled when Ben took up the sport at high school. Ben had been overweight as a child, but – once on the rugby field – he blossomed into a handsome, athletic teenager. Ben was bright and popular. He had everything going for him.

Then, over the summer of 2009, things began to change. At first it was gradual – so gradual that we scarcely noticed anything was amiss. We were vaguely concerned about Ben's increasing passion for fitness; these days he was spending most of his waking hours at the gym or running, doing sit-ups and so on. And when he wasn't exercising, he was "slimming down" recipes and counting calories. By the end of the summer, food-loving Ben's diet had become extremely restrictive.

He was also losing weight.

Worried, I took Ben to the doctor. It took several visits before Ben was eventually referred for treatment and, even then, I had to insist on a referral. The doctor never officially diagnosed Ben as having an eating disorder. To be honest, I think he thought I was an over-protective mother...

Once I realized what was wrong, I was terrified. And the more I learned about eating disorders, the more terrified I became. Worse, I was told by our British National Health Service that we could have to wait 18 to 22 weeks for treatment. A

quick calculation told me that it could be Easter before Ben got help: a full six months on from our first visit to the doctor.

With an eating disorder a lot can happen in six months. By Christmas, I was so frightened by what I was seeing that I hired a private therapist to help. But it was like trying to plug a hole in the Titanic with cotton wool. Ben was sinking too fast. And I was quickly realizing that eating disorders are not just about losing weight, they may also be about crushing depression, vicious mood swings, violent self-harming, suicide threats and social isolation as your child transforms into someone you don't recognize. Ben even developed a different voice: a slow, low, deep, emotionless monotone that used to chill me to the core. To be honest, it was as if he'd become "possessed".

Things continued to deteriorate. By January, Ben was a shadow of his former self: physically and mentally. He was an emotional wreck who fought tooth and nail to avoid going to school or doing anything other than work on the obsessions and compulsions that were part and parcel of his eating disorder. But, despite pleading with our doctors to speed up Ben's referral, I was told there was nothing they could do. The private therapist was having little success and all the other private eating disorder therapists in the area were fully booked.

At the end of January, Ben was rushed into the hospital with a dangerously low pulse rate. I really thought I was losing him. I got straight on the phone and demanded that Ben was admitted for eating disorder treatment immediately. It worked; we were given an appointment for the following week.

Eight months later, following what I refer to as The Summer From Hell as Ben's weight, moods and behaviour plummeted to new depths as a result of Ben being given control of his eating as the clinicians waited for him to "want to get better", Ben ended up back in hospital, his pulse back down to dangerous levels again. Thankfully, it proved to be a turning point. Things very gradually began to improve from that moment on.

18 months on, Ben was discharged from eating disorder treatment, ironically at the same weight he was when he started, 26 months earlier. There was no follow-up. It was simply Ben and me, left to our own devices, working as a team to bring him to full recovery and get the weight back on. Through our own determination and refusal to give in to this devastating illness, we succeeded.

Nowadays, Ben and I want to do everything we can to help other families to identify the signs of an eating disorder in boys and empower them to demand good, evidence-based treatment, wherever they live. In March 2013, I published our story: *"Please eat... A Mother's Struggle To Free Her Teenage Son From Anorexia"*. Possibly uniquely, Ben also contributed to this book. Occasionally my own story pauses and Ben's voice takes over describing what he was feeling during a particular incident and why he behaved in a certain way. Ben says it feels as if he was in a coma, as if he was asleep during those terrible years. But he is now wide awake, restored to health and happiness, with new friends and a glowing future ahead of him at one of the UK's top universities.

I am immensely proud of my awesome, strong and courageous 19-year old son!

I've also been guest blogging for other eating disorder sites, too, and Mumsnet, and when I get a moment I will paste in the links here. Bit busy today, having just returned from a lovely day with one of the mums who contributed her family's (positive ending!) story to my new book *When Anorexia Came To Visit* and who found resources like FEAST and the Around The Dinner Table forum via this blog, well over a year ago.

Thursday, 8 August 2013

Our message is about HOPE, but we can't ignore the fact that this is a deadly illness

It's a really hard stance to take: talking about hope with eating disorders and the fact that recovery IS possible. And I am always elated when I hear about another young person who has come through an eating disorder successfully. Yet we can never

escape the fact that this is a deadly illness; indeed eating disorders have the highest mortality rate of any mental illness. And today I heard of another young individual who lost their fight. It's the kind of thing that has us all kicking furniture with anger at the way this insidious illness steals victims from a beautiful and promising young life - and from their loving, supportive families.

I never met Matt Ryd, a musician and eating disorder activist from Chicago. Indeed I hadn't even heard of Matt Ryd until I read about his passing via the Men Get Eating Disorders Too charity (based in Brighton, UK).

I clicked the link and saw a friendly-looking guy, kind of dishevelled, with glasses, the kind of guy that brings out the motherly instinct in us older women. The kind of guy you just know you're going to like. And, if I had a daughter, he looked like the kind of guy I wouldn't mind her bringing home.

I also clicked onto some of his music and liked what I heard. Very much so. Have a listen to this track which, if you download it, donates \$1 to NEDA - the National Eating Disorder Association I guest-blogged for earlier this week (ironically on the subject of males with eating disorders).

Yet Matt Ryd was battling with anxiety, depression and an eating disorder. On August 4th he lost his life to the illness. And my prayers and thoughts go out to his parents, family and friends - and everyone else that this kind of news affects.

Because, although we prefer to promote the message that recovery is possible and that there is hope, sometimes an eating disorder wins. And it makes those of us who continue the fight want to kick things and punch the wall with frustration and anger at the way this evil illness can be so very all-consuming and suffocating, especially when combined with co-morbid conditions as appeared to be the case with Matt.

The fact is that, although we strive to promote the message of hope, we can't ignore the fact that an eating disorder can kill. If it doesn't kill through starvation, then it can kill through complications like heart failure, or suicide.

We all hate this devastating illness which is why I, and hundreds of other eating

disorder activists, continue fight for better and earlier diagnosis, better funding, better training, better treatment and better awareness of this most deadly of mental illnesses in order that less lives will be lost and more young people will go on to lead long, fulfilling and happy lives.

And if anyone is ever irritated at the way I keep posting up news, threads and links to information (like my books) on just about any eating disorder or health related social media tool I can find, there is only ever ONE REASON why I (and all the other eating disorder activists) do this.

To aim to win the fight against eating disorders so families like Matt's family do not have to go through the terrible experience that no family on this planet should ever have to go through:

Being torn apart by the loss of a promising, talented, much-loved and cherished son or daughter.

Thursday, 8 August 2013

These days, these are the ONLY battles that go on across a table...

Remember those Bad Old Days when I used to dread our evening meals? The days when Ben would down tools and go crazy, usually triggered by something as "simple" as there being too much choice on the table. And he would rant and rave in the hallway, kicking things, banging his skull until I worried I'd hear the sound of splintering bone and yelling in that deep, dark, hopeless way that an eating disorder can sometimes make its victims do? Meanwhile, I would sit there at the table, tears streaming down my face, unable to cope and feeling utterly helpless and terrified?

These days, suppertime is back to what it should be: a family meal at the dining room table. A time to talk about how the day has been. A time to laugh. A time to share the latest mouth-watering menu from our kitchen, prepared by my talented son Ben.

And last night, as Ben sat at the dinner table, tucking into creamy tuna pasta and

French bread, he said:

“I was thinking... It’s the first time in four long years that I feel totally and completely happy and content. I have friends. Real friends. I have fun with them and meet up with them several times a week. These friends like me and I like them. We have a laugh. We play *Warhammer* together. Life is really good right now.”

For almost four years Ben suffered from severe social anxiety as his eating disorder forced him to isolate himself from his peers. If you’ve read this blog you’ll know how punishingly hard it was for Ben to get back into socialising again and build up a new friendship circle.

Until quite recently, he would sit alone at home, painting his *Warhammer* figures and watching TV with us. And I used to worry myself sick about it.

But lately he has built up a new circle of friends. Also, he has put himself about so he is well known within the Northern England *Warhammer* circuit. He won a couple of awards the other week and his impeccably painted miniatures are on show in the store window in the city centre *Games Workshop* shop. They feature on the *Games Workshop* website and blogs. Ben is becoming famous within the world of North UK *Warhammer*!

And with this has come this new friendship group. These guys play games together, huge table-top fantasy battles that can take hours, like they did yesterday afternoon.

Indeed, these days, these are the ONLY battles that go on across a table...

And, after each trip to *Games Workshop*, I open the front door to Ben (he always forgets to take a key!) and he stands on the doorstep, grinning from ear to ear. “Good time?” I ask. “Yes, fantastic,” he replies.

It’s not just a far cry from how it was back in the Bad Old Days of anorexia; it is a complete and utter turnaround.

Sunday, 11 August 2013

11th hour trip to London to meet Becky Henry

Our fantastic network of parents of young people with and recovered from eating disorders spans the globe. Although I feel I know so very many of them as well as any of my local friends, I have only met up with a handful of them 'in the flesh'. Tomorrow I'm meeting up with Becky Henry who wrote the preface for my new book *When Anorexia Came To Visit* along with one of the mums who contributed her story to the book. The three of us have never met in person, yet we've 'talked' via the Net on many, many occasions. So I'm thrilled to have got hold of an 11th hour cheap-ish train ticket to London and back.

US-based Becky Henry is the founder and president of the Hope Network which offers support to caregivers of someone with an eating disorder. She is also the author of the book *Just Tell Her To Stop*, "an amazing collection of stories from families who shared what it is like to live with and support a person with an eating disorder".

It was this book that inspired my book, *When Anorexia Came To Visit*, and - before I wrote it - I asked Becky for her advice. She was also kind enough to write the Preface which talks about why these three books describing families' experiences (the other being Australian June Alexander's *My Kid Is Back – Empowering Parents to Beat Anorexia Nervosa*) are so important. All three highlight what life is like for a parent of a young person suffering from an eating disorder - all the issues we have to face beyond the confines of the consulting room in our struggles to get our children well. By showing other families what worked for us, and also highlighting the warning signs of an eating disorder, we can hopefully help others to successfully get through this devastating illness.

Meanwhile I'm really excited at finally meeting Becky Henry in the flesh - and the other mum, too!

Monday, 12 August 2013

A great little book for parents who are just embarking on this journey

Jane Smith, Director of the UK eating disorders charity *Anorexia & Bulimia Care (ABC)* has sent me a copy of her book *The Parent's Guide to Eating Disorders*. It really is a great little book, especially for parents who are just embarking on this journey and know very little about eating disorders. I've just left a review on Amazon and here is what I've said about it:

For most parents there is a period when you know something is wrong with your child, but you're not quite sure what it is. Is it an eating disorder? And, if so, what on earth do I do? If you're like me, and many of the other parents I talk to, you will probably know very little about eating disorders at the start. Suddenly finding yourself on this frightening journey can be terrifying. How did I fail to pick up on the signs? Am I to blame? How on earth did my child develop this horrible illness? How do I get good, effective treatment for my child? What role can I play in helping my child to recover? And, most important of all, how long will it take to get them well?

This is why "The Parent's Guide to Eating Disorders" is such a great book, answering all your questions and providing guidelines on what to do next. It also includes dozens of quotes from real families about how they dealt with a particular situation. It really is the perfect book for those early days - and to guide you along the way as your child embarks on the road to recovery. Unlike some books, it's not huge. It's the kind of book you can keep easily handy, even carry around with you for 'moral support' if necessary! And, yet, it includes pretty much everything you need, for quick, easy reference. No waffle, no lengthy scientific explanations, just to-the-point useful, helpful advice that you can dip in and out of whenever you need to.

Because this is another great thing about this book. Back at the start, when I knew nothing about eating disorders, I had to go through a huge learning curve, cramming

up on everything I could find about eating disorders on the Net. Some of it was good, some not-so-good, and some of it downright scary. It took an enormous amount of time and effort, like suddenly finding yourself thrown onto a Masters Degree course in an unfamiliar topic, and one that you wouldn't study through choice!!! And all this at a time when, really and truly, you need to be focusing your energies on your child and getting them well. So having a book like this to hand removes the need to do all this cramming. It also provides you with good information, without you having to sift out the wheat from the chaff yourself. It is a real time-saver!!!!

As the author of two books on eating disorders, including one that describes my own experience as a parent of a teenage boy recovering from anorexia, I wish I'd had this book with me during those terrifying early days. I highly recommend it!

Tuesday, 13 August 2013

Five hours of putting things to rights, from both sides of The Pond

With our already rip-off UK rail fares set to rise yet again, I was lucky enough to stumble across some really cheap last minute tickets to London. So yesterday - Monday - I hopped on the train to Kings Cross where I was met by one of the mums who contributed to *When Anorexia Came To Visit*. Then a quick tube train to Liverpool Street Station where we met up with Becky Henry who'd been to Norwich to visit the eating disorder charity, BEAT. Then another tube to Covent Garden (where Becky was alarmed to discover the only route to the surface was via lifts / elevators or a spiral staircase). After that, we sat down and talked until early evening when I had to leave to get my train back. What a day!

Each of us is part of the wider global network of parents, counsellors and therapists that are doing their level best to advocate for better awareness, better funding and better treatment for eating disorders for our sons and daughters. It was great to share and compare our experiences of eating disorder treatment here in the

UK with Becky's experiences in the States. And each of us is keen to promote the experience from the family perspective. In other words, what it's really like to struggle to get your son or daughter through an eating disorder at home, beyond the confines of the consulting room.

As parents, we know our children best. We've known them since birth. And, when they are sick with anorexia, bulimia, EDNOS or whatever eating disorder they may be suffering from, we are the ones that care for them round the clock. But we are aware that families don't always get the recognition and support they so desperately need - and, in too many cases, parents - who, increasingly in more enlightened circles, are being recognised as an essential part of eating disorder treatment - are being instructed to back off and leave everything to the professionals.

The three of us shared good experiences and not-so-good experiences. I talked about some of the good examples of excellent eating disorder treatment described by some of the families in my book, *When Anorexia Came To Visit*. There is one story in particular which stands out as a really great example of how eating disorder treatment should be approached.

The other mum talked about how the University of California San Diego is achieving excellent success rates through its intensive (although expensive) family therapy programmes. I said what I have said over and over again which is: "Call me naive, but if there are outstanding treatment models out there that are achieving unprecedented high levels of success, then why the heck are they not being rolled out everywhere?"

To me it makes sense that if something is working, then other healthcare providers should do their level best to copy it.

I am sure that this is naive old lay mum me saying this, because - if it was possible - then it would have been done.

Surely?

I talked about my concern at discovering that other parents in my city, struggling

with children who are seriously ill with an eating disorder, have never heard of Janet Treasure, the Maudsley Approach, Lock & LeGrange and so on and so forth. Why on earth are parents not being referred to these resources? Or to any resources for that matter?

Anyway, yesterday, I was thrilled to hand over a copy of *When Anorexia Came To Visit*. Two, actually, one for the mum to give to Norman Lamb, UK Minister of State at the Department of Health, when she meets with him shortly.

I also gave Becky a copy, because she wrote the Preface for the book - and my book was inspired by her book: *Just Tell Her to Stop: Family Stories of Eating Disorders*.

Well, we talked and talked... for five hours... It was the most amazing day.

And I am really glad that I got discount rail tickets, because if I'd paid the full £98 return I would have been really naffed off by the fact that the return train was late, it was crammed full to the rafters and all on-board refreshments had been cancelled.

Sunday, 18 August 2013

Reading between the lines at the party...

Chit chat chit chat... Yesterday saw my H and me at a large party to celebrate an old friend of my H's 50th birthday, in Kent. The last time I'd seen many of these people was when Ben was little and we lived in Kent, so all of us were doing a lot of polite-conversation catching up. Most had teenage children; indeed many of them were at the party. And all of them were tucking into the massive buffet and taking advantage of free drinks before they left for a night out on the tiles.

So, as you can imagine, there were a heck of a lot of "Oh you know what teenagers are like... hollow legs! / He can eat for England!!!" remarks, as the kids - mainly boys - knocked back stupendous amount of food and drink.

Occasionally a parent would introduce their offspring to us with comments like: "Last time you saw him he must have been 2 years old?" Followed by comparisons

about being rugby mad, getting huge and generally being a typical boisterous teenager. One boy, especially, was massive - a true 'prop forward' in rugby.

So H and I joined in this kind of conversation. We had to, really, because it would have been inappropriate to say: "Well actually everything went all pear-shaped with Ben when he developed anorexia, lost one third of his body-weight and we went through three years of hell."

Instead we just said that he used to love rugby, but gave it up because he got bored with it. And Ben is a fabulous cook; he loves his food. Cakes, biscuits, pies, you name it... It's like living in a Michelin starred restaurant! And, no, he isn't at this party because he's at home. He's got his mates round. Well you know what it's like when they get wind that their parents are going away for the weekend and they've got the house to themselves! Chortle, chortle.

Well, in a way, it was all true. Ben did used to love ruby and he did get bored with it. Only, because he did, he devised new and ever more imaginative ways to ensure he ate less food so he wouldn't "get fat". And, then, instead of doing less sport, he did more. This, coupled with the reduced food intake, sent his weight spiraling downwards and he went onto develop anorexia. Yes Ben is a fabulous cook and he does love his food. And he does make cakes, biscuits and pies, and it is like living in a Michelin starred restaurant. But, up until recently, they've been carefully calorie counted which you wouldn't expect from a growing teenage boy. And, during those early months, he "slimmed down" recipes so they were fat-free and low in carbs. It was a million light years away from those teenage boys tucking in at the party. I doubt if they'd know the meaning of the word "calorie".

Yes, Ben did have his friends round yesterday afternoon. But you know what? It's the first time he's had his friends round for over four long years. And it's a different set of friends; his old friends have deserted him. This group is very new and we are thrilled to see Ben making friends again and inviting them round to our house.

So, while this group of teenagers were laughing, joking, eating and drinking like

teenagers do, our teenage son was learning how to socialise all over again, having been in isolation on Planet Zorg for a number of years.

But of course we said none of that, and no-one was any the wiser that our son, Ben, was any different from their lads.

Saturday, 24 August 2013

“No evidence whatsoever for a genetic connection”...?

Dear University Eating Disorders Researcher, Yesterday Ben and I were interviewed by the BBC for *“Inside Out”*, to be screened in late September. As part of the slot, the BBC is also interviewing several eating disorder experts, one of which is you. So I was a little concerned when I was told that, in the course of your extensive research, you had found “no evidence whatsoever” for a genetic connection for an eating disorder. So I would like to point you towards the following resources, which are widely available, and have been compiled by recognised global leaders in eating disorders treatment, understanding and research.

The first are James Lock (Director of the Eating Disorders Program for Children and Adolescents at Stanford University, California) and Daniel Le Grange (Director of the Eating Disorders Program at The University of Chicago Hospitals), co-authors of the highly respected book *“Help Your Teenager Beat An Eating Disorder”*.

On page 61, under the heading “It’s Biology!” they say:

“Eating disorders are three to five times more common in families in which a person is found to have such a disorder, than in families in which no one has had an eating disorder” and goes on to talk about the research that reinforces this concept, followed by “So, vulnerability to eating disorders appears to be inherited”.

The following paragraph also talks about heritability at length.

So, dear researcher, do please take a look at this book.

Also, an invaluable resource published only last year, which boils down a mountain of information on what is going on in the field of eating disorders research at the

moment is *"A Collaborative Approach To Eating Disorders"* edited by June Alexander and Janet Treasure, with contributions from SIXTY-TWO of the world's leading experts on eating disorders.

If I was conducting serious research into eating disorders this is one of the first books I'd get hold of. So, please dear, dear researcher, do get hold of a copy. It's readily available on Amazon.

In it you will find a stack of evidence about why, in many cases, eating disorders are thought to have genetic roots. Carrie Arnold, in her Introduction to the book, says: *"Research reveals that genetics comprise up to 86 per cent of the reason a person develops an eating disorder (Klump et al 2001; Lilenfeld et al 1998)."*

Actually, look at those dates. This isn't recent research. It's been around for a while, so I am really surprised that you haven't found any evidence for a genetic connection.

There is a lot more, too, in this book - too much to quote here. So please do send off for it.

Also, when writing my latest book *"When Anorexia Came To Visit"*, quite frequently relatives have eating disorders or other mental health issues. We have mental health issues in our family, too, so the genetic connection makes total sense to me.

So, dear researcher, please dig a little deeper. I think you'll find that there is quite a bit of evidence that points towards a genetic connection.

Saturday, 24 August 2013

Why didn't the cardiac consultant make the connection between a slow heart and anorexia?

Yesterday, while we were being interviewed for BBC's *"Inside Out"* programme, it struck me again: why the hell didn't the heart consultant at the Leeds General Infirmary make the connection between a slow pulse rate and anorexia when our son

was rushed into his cardiac ward in January 2010 (see my book *“Please eat...”*)? Especially as today I came across this excellent article which describes the connection in no uncertain terms. Surely, as a heart consultant at a leading hospital, he should have made the connection?

Instead, he was more interested in the fact that Ben was sporty. He told us that athletes’ hearts can slow right down so, in the absence of any other reason for Ben’s pulse dropping to 29 beats per minute, that was probably the cause.

“BUT BEN HAS ANOREXIA!” I said, several times.

But the penny didn’t drop - neither with the consultant nor the other medical staff on the ward who were monitoring Ben and trying to work out why his pulse was so dangerously low.

Indeed, they seemed to know very little about eating disorders, which is really odd seeing as how Bradycardia (very low pulse rate) is so common with the illness. And that heart failure is one of the biggest killers of people with an eating disorder.

The more I think about it, the more puzzling (and frightening and shocking) it is that none of the staff I spoke to on the cardiac ward at Leeds General Infirmary made the connection.

The article I refer to above (from the Cleveland Center for Eating Disorders) says:

In general, as one loses weight one loses muscle mass. With the loss of muscle mass there may be loss of heart mass as the heart is a muscle. ... To conserve heart muscle and thus keep the entire body functioning as well as possible there will be a slowing of heart rate, called bradycardia. Bradycardia can be very dangerous and is one of the leading causes of illness, hospitalization, and death for those with eating disorders. Heart rates in the 40s or lower are particularly dangerous. ...

Sometimes there is confusion about the relationship of heart rate and exercise. Many patients erroneously believe, and are told, that a low heart rate is evidence of being

an athlete. There are no studies showing that significant and rapid weight loss is normal for an athlete or healthy for the heart. The confusion usually results from the fact that, in general, athletes with low heart rates have low heart rates because they have gained significant muscle mass, including mass in their heart, and their heart does not have to beat as often to provide adequate oxygen and blood for the body. This is most definitely not the case in situations of weight loss, starvation and smaller than normal hearts. One should never assume that in the presence of an eating disorder that a low heart rate has anything to do whatsoever with athletic ability. A low heart rate is almost always due to the illness itself. ...

SEPTEMBER 2013

Tuesday, 3 September 2013

The walk we did in spring 2009 brings back memories

Four-and-a-half years ago, Ben, my H and I did a 9 mile circular walk around some of Dartmoor's more challenging terrain. It was the spring bank holiday week in 2009 and already the seeds of Ben's eating disorder were beginning to germinate in his mind. The only problem was that none of us realised this was happening; not me, not my H and not Ben himself. Today we did the same walk and got talking about what was going on in Ben's head during those early days.

Ben pointed to the two Dartmoor Tors ahead - both high peaks that we knew would be a challenge to climb in today's heat. "I can't believe that, back then, I ran up both of those. And when we had lunch, I only ate a banana and a plain ham sandwich." And it was a hot day like today.

I have a photo of Ben standing perched on some rocks at the top of Longaford Tor,

taken on that walk. Little did any of us know what we were about to go through - or how long it would take us to come back out of it. All I was seeing at the time was a happy, healthy 15-year old boy who was super-conditioned, preparing himself for the onslaught of preparation for school sports day: the day that Ben won the 1500 metre race, described in my book "Please eat..."

At the end of today's walk, we returned to my car which was parked at Two Bridges, taking a look at the West Dart River which was flowing crystal clear, cold and fast under the bridge.

Yes, a heck of a lot of water has flowed under the bridge since we last stopped off at that spot.

Wednesday, 4 September 2013

Hopefully I am going to be on BBC Radio 4's Woman's Hour next Wednesday talking about this blog!

I have a clear memory of being with my mum in our kitchen at home, sometime in the early 1960s. We'd just had lunch, it was a freezing cold day and the coal fire was blazing away in the kitchen grate. I was probably painting some exotic work of art at the time, aged around 3 or 4, and my mum was listening to *Woman's Hour* on what was then the Home Service. If my memory serves me right, *Woman's Hour* was always preceded by a children's story - *Listen With Mother* - which I used to await with excitement every day. At such a young age, *Woman's Hour* wasn't quite so exciting, but my mum used to listen to it religiously. And now I have been invited to be a guest on *Woman's Hour* (which is still going strong all these years later). I must tell my 86-year old mum when I get back from Devon.

All I know at the moment is that *Woman's Hour* want to talk to me (and presumably others) about my blog (and their blogs): campaign blogs about bringing up children; blogs that make a difference. I know that my blog has made a difference to many families, because of the feedback I get. And some of the mums who've

contacted me are now close friends who I meet up with every now and then, when I happen to be in their neck of the woods or if they're in mine.

I started writing my blog in January 2011. The aim is, and always was, to help other families, primarily parents of boys with eating disorders because there is still precious little awareness out there that boys can get eating disorders just like girls. I want to help other families to identify the warning signs of an eating disorder early and take swift action, because the sooner they get help, the sooner their son can get on the road to recovery.

I also want to raise awareness of gaps in The System: those areas where treatment for, and diagnosis of, eating disorders could, and indeed should, be improved. And to help parents to demand good, modern, 21st century, evidence-based treatment for their children rather than outdated approaches that should have been thrown out with the Ark. And I want to show families that neither they nor their child are to blame for the eating disorder. Eating disorders are biologically based brain illnesses, not lifestyle choices. And they are not caused by "bad parenting".

As with my book *Please eat...* this blog tells our story - how my son descended into anorexia and eventually recovered, and the strategies and resources we found helpful, for example the wonderful Around The Dinner Table Forum for parents of young people with eating disorders which many families insist was - and is - a lifesaver.

I don't just get contacted by parents of boys with eating disorders; I get feedback from parents of girls, and people suffering or recovered from eating disorders, and not just in the UK but across the globe.

Of course my blog is just one of many written by parents of young people with eating disorders. All of us do it for the same reason: because we don't want other families to have to go through the nightmare experience we went through. And part of that nightmare experience was lack of awareness which meant we didn't identify our son's eating disorder sooner and the GP didn't diagnose and refer our son

sooner, for the same reasons. Plus the long wait for treatment - and the fighting I had to do once treatment began, and so on and so forth.

I don't want any family to go through what we went through, and this is why I write my blog.

Thursday, 5 September 2013

The interviews that never happened...

I'm not sure whether or not I'm still being interviewed on *Woman's Hour* next week. The other week I was also interviewed for a piece for the *Mail Online* and spent ages on the phone to their reporter, but I haven't heard any further. Then, a year ago, Ben and I spent an afternoon being filmed for *Sky TV* news and nothing came of that, either. Are we just bad at being interviewed, simply not photogenic, or is the issue about boys and young men with eating disorders just "not news"? Mind you, we are still appearing on BBC's *Inside Out* later on this month along with Sam Thomas of *Men Get Eating Disorders Too* and various experts.

Saturday, 7 September 2013

Dear Media, What you don't realise is this...

Dear TV, Radio, Magazines, Press, etc... What you don't realise when you cancel a planned news item about boys with eating disorders - or even when you don't cancel - is this...

Every time someone like me, or my son Ben, agrees to participate in a news item, be it TV, radio, press, etc, is that we have to re-visit parts of our lives that, to be honest, we'd rather not.

Why is it difficult for us?

Because, by re-visiting the years when my son was being strangled by the most deadly of all mental illnesses - the lethal anorexia nervosa - it causes trauma.

A heck of a lot of trauma of the nastiest variety.

On the surface this trauma results in us feeling pretty cr*p following an interview. Kind of low and depressed, that sort of thing. And, often, towards the end of a lengthy interview - for instance the interview for BBC's *Inside Out* the other week - we can begin to flag. (If they screen the bit where Ben and I walk through our local park, apparently chatting happily to each other, what we are actually saying is: "Just a few more minutes more... Just hold onto the thought that if we help just one family by doing this, then it has to be worth it.")

Several times over.

Deeper down, for me at least, it can result in lurchingly unpleasant flash-backs and nightmares - a bit like Post Traumatic Stress Disorder. In fact it probably is a form of PTSD.

However, if we know that what we're doing has the potential to help other families, then we both feel that it's worth it.

It's when we spend hours being interviewed and / or filmed for articles or bulletins that get cancelled or never take place that it really cuts us to the core. We've just spent the past X hours re-living a nightmare and re-opening old wounds - and for what?

Nothing.

But it's not just about being interviewed. Planning interviews can also dig up demons that have been suppressed.

So when an interview is suddenly cancelled at the 11th hour for whatever reason - like next week's interview with BBC's *Woman's Hour* - it's not simply a case of: "Oh never mind, at least I don't have to cancel that dental appointment or bother about getting into the Leeds studio on Wednesday morning" - it's a case of digging up demons again.

Also, even though Ben wasn't being involved in this interview, it makes me feel all protective towards him and so very aware of how brave he is at insisting that -

together - we raise awareness of the problem of eating disorders in teenage boys by sharing our own traumatic story. And, like any parent, I hate my courageous, compassionate and wonderful son being messed around by taking part in interviews that are never used.

The *Woman's Hour* cancellation was particularly hard for me, personally, because all the emailing to and fro was carried out during our late summer holiday, time spent with Ben, far from the 'madding crowd', before he attempts university again in a couple of weeks.

I wouldn't normally have replied to emails whilst on holiday, but I did on this occasion because I felt so strongly about another chance to raise awareness of the issue of males with eating disorders.

These are some of the reasons why the *Woman's Hour* cancellation affected me and made me angry and tearful, even though it's usual for the media to mess people around like this.

Unacceptable, but usual.

And, in the case of *Woman's Hour*, it appears to be because the campaign blogs they are featuring on Wednesday's programme make better news than mine. "So, sorry, but we no longer require you," kind of brush-off.

But it wasn't as if *Woman's Hour* said "we might possibly need you"; it was a definite.

This is what makes me mad.

So, dear Media, if you are going to do this kind of 11th hour cancellation because you've come across something far more newsworthy than boys suffering from deadly illnesses, then please don't lead families down the garden path.

It hurts and it's traumatic. And the only, only, only, only reason we allow ourselves to have old wounds re-opened and go through this kind of experience is to help others like us.

Not to be messed around by the media.

Sunday, 15 September 2013

So what's going on inside my head?

I only wish I knew. Which is why I'm booking back in with the counsellor I saw for a number of sessions last year when things were getting a bit too much like a cat's cradle inside my head. This, and the fact that I'm just getting over a goddamn awful bout of gastroenteritis (yuk!), and the fact we were on holiday last week, is why I've been keeping a low profile recently. But I decided it's time to put pen to paper again, so to speak.

There is so much knotted and tangled up inside my head at the moment that, most of the time, all I want to do is stand frozen to the spot, like a rabbit stuck in the headlights. Or sleep. And when I'm not doing that I'm "spiralling", which is something I'm all too familiar with. I think others might call it anxiety or panic attacks. Plus I'm not sleeping well, feeling light headed and generally naff. And low.

Then I feel guilty because I know there are others far worse than me. For instance my dear long-term supporter and mentor Charlotte who has terminal breast cancer. How dare you, I admonish myself, feel cr*p when you should be so very grateful to be alive and well?

And other parents whose children are neck-deep in an eating disorder and who are fighting The System tooth and nail to get some kind of treatment to save their lives.

How dare I feel sh*t, when I have every reason on this planet to be thankful to be where I am right now?

So I haven't written anything here because I feel as if I'm being oh so selfish.

The thing is, try as I might, I don't seem to be able to do anything about it. And I, of all people, should know that we humans can't always get our brains, moods and behaviours back on track simply by giving ourselves a slap on the back and telling ourselves to "snap out of it".

I went to the GP about it on Friday and he put me back on Fluoxetine which I first

went on during the Summer From Hell in 2010 and eventually came off some time in the spring. He said: "Do you have any family support?" "Well no, not really," I said, because I'm loathe to moan about my woes to my worked-to-death, stressed-out husband, my elderly mum or anyone else for that matter. So he told me to take plenty of exercise, take Fluoxetine for four weeks, then see if I need to up the dose.

Today I decided to book in with Christina, a lovely (private, unfortunately) counsellor I saw last year after my friend Sue passed away. I figured I needed a little help in unravelling the tangle that seems to have frozen me into a deep apathetic paralysis.

I know that some of it is due to the anxiety of Ben leaving for university in a week's time. This time last year I was so excited about it. But then we had all that stuff where he couldn't handle it. I worry it might happen again. I don't think it will, but it might. And I'm not really noticing any excitement or planning on his part which is kind of worrying me... Almost as if he's in denial that he's going. Maybe I'm wrong...

So I know that's one thing.

But there's a whole lot more: fallout from the eating disorder, trying to pick up the pieces of my career again in a business world that's changed in the last four years, having too much going on at once and wanting to run away from it all and just sleep...

And, on a totally materialistic level, living in a house which has gone to the dogs during the eating disorder... Paint swatches on the hall and staircase which we tried out but left during Ben's illness... And a general tired look throughout the whole house which would take £thousands to put right, £thousands which we don't have after four years of recession and my income dwindling from pretty damn good to pretty damn disastrous...

And could it be that, just being in the house, brings back bad memories? Which is why I've been away from it so much this summer?

I don't know.

Oh, and there is this deep-set feeling that is overpowering me at the moment. I feel like a huge failure. You may shout back that “Good God, Bev, you’re not a failure, look at all you’ve done over the past four years?!” etc etc.

But I feel as if I’ve failed. Failed at my career which seems to have disintegrated during the years that I haven’t been able to focus on it. Failed at getting my son better sooner - and getting more weight back onto him. Why, over four years since it all started, can’t he just say “What the hell” and stuff his face with Mars Bars or whatever to get those few remaining kg back on? And more?

And then I feel anger at CAMHS who, I feel, were largely responsible for making him believe that “good enough” is good enough and who were never really concerned about getting him back to his pre-anorexia physique.

Which, although Ben still remains 99.5% recovered, thank goodness, there are still glitches that need fixing and they’re the same glitches that have been around since he was discharged from CAMHS over 18 months ago.

Oh blimey, there is so much going on in my head that isn’t good that I’d better stop right here!

Monday, 16 September 2013

Thank you everyone who rallied round with FB comments and emails

It’s made me quite teary, actually, when I think of how many people responded to my blog yesterday when I was feeling cr*p. I am so grateful to have such a wonderful network of virtual and real people (I know, you’re all ‘real’, but you know what I mean...) I am feeling so much better today, especially after a swim, sauna and session

in the Jacuzzi (even if I did get told off by the pool attendant for sitting in it 'too soon'!)

So I have bought myself a waterproof MP3 so I can swim around listening to chilled music and imagine I'm not in our local health club but somewhere with a stunning view, preferably with a chilled beer waiting for me when I get out and onto the veranda. (Dream on...)

And I've booked another few sessions with Christina, the counsellor I saw last year. She asked me how Ben was getting on at Uni. I told her it didn't happen, but that he's off to try again this Saturday.

Which brings me round to that subject.

I think he's been keeping quiet because he's just organising it all in his own way, contacting the people he needs to contact and sorting out lists of stuff.

It's kind of weird because, as a parent, I'm getting all the emailers I got last year from accommodation, about moving in and so on. So, on Saturday, it will be a repeat performance of this time last year which will be kind of spooky.

I have no idea how it will turn out, but my fingers and toes are crossed!

Friday, 20 September 2013

Keeping a low profile in the run up to uni...

Without a crystal ball I can't possibly predict how university is going to turn out - in this, Ben's second attempt, starting tomorrow. I've been keeping a bit of a low profile on the topic because, well, that's just the way it seemed to pan out. Remember how I was so excited last year? Packing stuff and excitedly discussing intro week events, buying tickets for Ben to go to events and so on? Well, this year I've done none of that. Apart from dragging out last year's luggage which has been stashed away under various beds, on shelves and in the spare room, and going through it, I've done very little. Except the odd bit of nagging e.g. "Have you found out when W is moving in?"

(W is an old friend from school who left at the end of the 5th form and is going to Sheffield, too.)

For all of us I think it's a case of playing it by ear. We are here if Ben needs us. I can pop down for a coffee or a walk whenever he feels the need. Or he can come back here. Our house is open, and he knows that. I will just leave it up to him.

But I (and no doubt Ben as well) can't help but be extremely apprehensive about what the next few days (let alone weeks or months) have in store. For any young person, let alone someone with Ben's history, it is a daunting experience as their whole life lurches into a completely new phase.

And I can tell that Ben is apprehensive; it's only natural.

So my way of coping with it seems to be to kind of anaesthetise my mind against it and not to think about it. To take it hour by hour rather than week by week, and let it all happen organically. Ben knows what he has to do to make a go of it this time. He knows he mustn't lock himself in his room because if he doesn't get out there and find it, it's not going to come to him. Well, it might. Like his old friend W who's living in the student residences down the road.

I've told him that he won't be the only one. Everyone is in the same situation. Unsure, homesick, worried about what image they are portraying to others, texting friends and home. "Remember when we saw the lady at student services last September?" I reminded him. "How she said we wouldn't believe the number of people she's seen this week already."

So he's not the only one. He needs to look through the facade that others are putting on and realise that they're all in the same uncertain boat. And that, by making overtures to people he feels he may not like, not only might he find he actually does get on with them but he will meet other people through them, too. A kind of snowballing social network that is university life.

And he is aware of all the various student support services on offer. Whether or not he will take advantage of them or just 'stew' is another thing.

I am aware that it's going to be bloody tough for him and all I can do is stand on the sidelines, observe as objectively as possible and provide the odd bit of moral support when required.

That's all I can say really at the moment.

To keep my mind off things, I'm meeting up with Sam Thomas from *Men Get Eating Disorders Too* tomorrow morning as he's in Leeds today. We're meeting for a coffee tomorrow morning. Ben isn't due to leave for uni until after lunch.

Sunday, 22 September 2013

Reporting back

So... There we were, doing a repeat of last September which felt kind of weird. Same apartment complex, different block / flat, bigger room - nice and sunny, with 2 windows, a fridge, sink, 2 hobs, double bed and large bathroom, plus shared kitchen / living area with 4 other boys. We met one of the boys who seemed nice, if quiet (and looking oh so lost!!!), and his parents. Yet, predictably, our son just sat in his room, unpacking in complete silence before sitting at his desk, logging onto the wi-fi, and gradually spiralling downwards into deep, dark depression.

This brought on another feeling of "been here, done it before"...

Paul and I went outside to the main meet-and-greet area where a local farm was serving freebie ice creams and helped ourselves to a couple of enormous cones. Then I spotted some people with 'mentor' badges and so I made a beeline for them. Got talking to the lady who said she was in charge of the accommodation mentors. After a couple of minutes the penny must have dropped because she said: "Are you Ben's parents?"

She's the person who hot-footed it up to Ben's room last year following an emergency phone call from me following several distressing communications from him which included the word "suicide"... So she remembered him well.

We had a long chat about support and she handed me a list of events which are

specially aimed at students who, for whatever reason, find it harder to fit in and settle. Unlike the other intro week events, these include a member of Student Services or Counselling who's there, discreetly, for whatever purpose is required - or just to "be there". One of these events is the 2-hour War Games society meet-and-greet in the Union coffee bar on Tuesday evening and I know for a fact that Warhammer-mad Ben will go to that. And she said that the mentors would be doing the rounds over the weekends, introducing themselves to students - and that students like Ben would be flagged up as needed additional monitoring.

Anyway, there we were, with Ben just staring at his desk, spiralling deeper and deeper into black gloom.

"What would you like us to do?" we said. "Go and leave you? Or would you want to come out for a meal with us?" By this time it was well after 6pm and he didn't much look as if he was about to cook himself a meal...

"I don't know," he said, several times, which - reading between the lines - meant "Probably"...

So that's what we did. We took him down to the Ecclesall Road area which is where one of the main Sheffield Hallam University campuses is located. This is a marvellous road lined with trees, cafes, restaurants, bars, pubs and quirky shops - quite continental in feel - and last night it was buzzing. (And we walked past the bank ATM machine which swallowed my card one night in 1977 when I was too drunk, following a party, to remember my PIN number!!!)

Anyway we were told we could have a table at Nandos in 30 minutes, so we went to the pub and had a quick beer, which made me feel a lot better! And everyone - in the pub and in Nandos was so, so, so friendly and welcoming - so different from Leeds.

I had a couple of glasses of wine, in quick succession (Paul was driving!), which made me feel much more relaxed!!!

Very quickly Ben's spirits began to rise and he was normal Ben again, tucking into a

massive butterflied chicken with corn on the cob, ratatouille and salad followed by a large tub of frozen yoghurt. Then we dropped him off at the student flats before driving the 40 minutes back home.

So that was that.

And that is all I can say for now...

Watch this space...

Monday, 23 September 2013

Night of the Negative Vibes...

We didn't get 'the phone call' until 6pm, but immediately I recognised the tone... Exactly like last year... Ben rock bottom and in tears, with a small voice with short "Mmn"s every so often... He couldn't be bothered to go out to the event at the Union "because it will probably be sh*t". He had "nothing in common with his flatmates", those he's seen. "Two of them keep themselves to themselves with their room doors shut." He hasn't been to see his friend W who's moved into the student flats down the road "because he's going to a paid event this evening with his new flatmates". Etc etc etc etc...

It makes me so frustrated that I can dole out the most sensible and do-able advice on the planet but he refuses to take any of it on board, preferring to take the "woe is me" stance and to hide himself away in his room, stewing in negativity and hating being there.

He wouldn't go and see the residential mentors who are on duty between 6 and 8 every evening precisely to deal with this kind of thing because "I wouldn't have anything to say to them" and "they'd just tell me to go out to events and meet people". Plus I can almost guarantee that he won't seek help from any of the other student support services we met in the spring - all of whom are geared up to handle situations like this.

And how he can conclude that he has "nothing in common" with 2 boys he's only

just met and who are, doubtless, equally lost (judging by L's face on Saturday), is beyond me...

So he just wandered around Sheffield on his own all day, then spent the evening locked away in his room.

Great.

And, not surprisingly, he is as miserable as sin.

I know it's hard. I know he (and many others) aren't into the boozy partying culture, but there are plenty of other 'fringe' events designed specifically for people like him where he is so very likely to meet people on his wavelength. That is, if they're not all stewing locked inside their rooms, too...

And, as for the flatmates that are "keeping themselves to themselves" and haven't come out of their rooms... Well... I imagine they're probably saying the same thing to their parents about Ben...

I know, I know... If it were you or me, we'd bite the bullet, take our courage in our hands and knock on their doors to see if they fancy a cuppa. We'd get the other boys together and say: "Hey guys I imagine we're all feeling a bit sh*t, so let's all put the kettle on and have a cup of tea together." Or a beer.

But, as you and I also know, you can lead a horse to water...

It just feels like a spookily similar re-run to last year so far. But this time I can't let him give up. Last year when he left he said he felt like a complete failure. Imagine how he'd feel if he quit second time around? And this year, of course, there are no refunds. To quit is bloody costly. We're talking £thousands. Which is why we make 100% certain with Ben that he was 100% certain he was ready to go this time.

So I imagine we'll get another call this evening along the same lines...

And then, tomorrow, when I drive down to drop off the things we couldn't get in the car...

It just makes me so frustrated that we have the solutions and have suggested them to him, yet he doesn't take them on board yet expects us to sympathise with

the “woe is me” negative vibes. Which we do, of course, because that’s what anxious parents do, but it frustrates me NO END!

Not to mention the worry that his panic, depression and anxiety will resurrect the eating disorder...

Monday, 23 September 2013

Let’s rewind to September 1977...

It’s September 1977 and I’m en-route to Sheffield Polytechnic to begin an HND in Business Studies. I couldn’t get into halls of residence and so - after looking around at some truly awful accommodation including one flat which was basically just a room with 3 or 4 bunk beds! - me and a girl from my school found a flat owned by a rather unpleasant (and, worse still, racist) lady called Mrs M. (Who, being racist, made sure we were white females before allowing us to sign the tenancy agreement.) Unfortunately there were literally no other options, so we had no choice but to move into the dreadful Mrs M’s poky little flat.

The flat comprised the ground floor of a Victorian terraced house on a main road the other side of the city centre from Studentland and it was awful. It was freezing cold, draughty and damp with mice and silverfish, and we weren’t allowed to put any posters on the wall or personalise it in any way. And we had to share a bedroom.

Very soon the girl and I fell out, leaving me feeling even more lonely, marooned in this horrible damp flat miles from anywhere on an HND course which, it turned out, was totally wrong for me. I hated every minute.

Thankfully a couple of rooms came up in a hall of residence - for me and my roommate. But getting out of the tenancy agreement wasn’t easy because we had to find replacement tenants which had to be white (shocking but true!!) and, if male and female, had to be married.

Actually, one of the *Human League* band took on the lease with his girlfriend (I never did find out if the dreadful Mrs M discovered they weren’t married...).

The hall of residence was pretty awful, too. Because I'd moved in late, everyone knew each other. The design was cluster blocks rather than 'corridors' and I shared a landing with one other room occupied by a truly awful girl who went out to the local pub every night, came back paralytic invariably with several of the 'locals' from the pub in tow, usually old enough to be her father... And the noise they all made in her room...

So I was on a course I hated, living in a hall I hated. I was the one closeted in my room, desperately unhappy and on the point of leaving.

Every weekend I got the train back to Leeds and camped out at an ex-boyfriend's house. He soon got fed up of the arrangement, and of me, especially one day when we somehow ended up in bed together. I was in floods of tears about how horrible my life was in Sheffield. And you know what he did? He kicked me out of bed, told me to sort myself out - and practically threw me out of the house - because he knew I needed to stop moaning and do something positive about it.

Mortified (but, looking back, I know he did it for the best) I went to see the counselling service who found me a room in another hall of residence and suggested I switch to a degree course that interested me.

By late October I was living in Broomgrove Hall, Sheffield, and studying a BA History of Art at the Poly-owned art college up on the hill at Psalter Lane.

A group of girls on my new course immediately took me under their wing and some of them were living in my hall - so I immediately felt at home. And things kind of improved immeasurably from that point on.

Tuesday, 24 September 2013

A very productive day all in all

Today was the day I drove down to Sheffield with some extra things for Ben and an opportunity to touch base with him. It began with a pretty depressed Ben meeting me in the student residences car park. I dropped off the stuff and we walked down to

the cosy cafe in the Botanical Gardens, which is the cafe we sat in last year (if you've read Please eat... it's the cafe where he broke down in tears about hating being at uni - and so did I...)

"OK, talk to me..." I said, and waited.

Over the next hour he told me all the negative things, how he was finding it punishingly hard and so on and so forth. Meanwhile I took on board all the experience from last year, the wonderful advice I've received from followers of my blog and my Facebook page plus the wisdom that comes with age, and spent the next few hours - as we walked into the city centre, bought lunch and sat outside listening to a busker playing chilled jazz music in the sunshine - turning negatives into positives, encouraging him, picking up on all the positive things he has done and the moves he has made, and so on and so forth.

By the time I left him, back at the student residences, at 2.15, he was in a much more positive mood, making plans for the next few days and beyond.

And of course I made sure he knew how proud I was of him. I told him I understood that it's bloody tough, I really do. And I am enormously proud of all the things he HAS done rather than choosing to stay in his room, which he could so easily have done, but hasn't.

He has talked to his flatmates (OK, not extensively and he still reckons he doesn't have much in common with them, but "they're nice"). On a similar subject I said that, as with school or in a job, the very fact that you are in the same place doing much the same thing gives you common ground in itself - and something to talk about.

"And every new face you meet becomes a face you can smile and say 'hi' to next time you see them. Before long you'll be seeing people you know everywhere you go, people who will ask you to join them at the table for coffee in the student union - or who you will invite to join your table, etc etc."

He has been to see his friend W, who used to be at his school. W texted him while I was there to ask Ben to help him fix his computer. Ben is going down to W's

residences tomorrow, to a free shop where they unload all the stuff last year's 3rd years didn't want to take home, and then he plans to invite W round to lunch. They have plans to play badminton together - yesterday they both went to find the uni sports centre to see what was on offer.

He met up with a couple of girls who seemed nice, after registering for his course yesterday. They all happened to be in the Sainsbury's round the corner afterwards and the three of them got chatting. The bad news is that they all arranged to meet at the jazz night last night. Ben went, but they didn't. Of course he took this badly; as if they'd stood him up and didn't like him. I said there are umpteen reasons why they didn't turn up, but that almost certainly wasn't one of them, especially as they'd all had coffee, too, yesterday.

Anyway, the good news is that he actually went to the jazz night, which I wasn't at all sure he would do, and he stayed till the end. He sat with some postgraduate students who seemed quite nice. But he was devastated the girls didn't turn up.

He pointed out how "everyone" was walking around in groups "as if they already know each other". I said that, if he looked more closely, he would see that "everyone" wasn't. For every group of students walking the 30-minute walk between the uni and the residences, there were several who were on their own. And some didn't look too happy. "And there are probably tons of others, shut away in their rooms, feeling pretty cr@p," I said. "You are not alone, and, anyway, girls tend to go around together more easily when they just meet; it's what girls do", because the groups were mainly girls.

We went through his plans for the next few days, which are good, starting with the *Wargaming Society* meeting tonight which, fingers crossed, will open a lot of doors friendship-wise.

And then he's planning to come home on Friday night after the *History Soc* social, returning on Sunday night or Monday morning for the first week of lectures.

I drove back down the motorway feeling pretty exhausted but as if I'd done a really

good day's work!

But much of what I said today really is thanks to all the great advice I've had from my virtual friends over the past few days. I just felt as if I was saying all the right things and I also felt as if it was being taken on board.

We were talking about the uni counselling services, the mentors, etc and he said that the only advice he truly ever felt comfortable with and took on board was our advice. So I said that, if this was the case, then I wanted to know that any advice I was giving him was being taken on board and acted on, "because you know that the advice I am giving you is good advice".

We talked about us being a team, like we were as he recovered from his eating disorder. "I am here whenever you need me," I said. "But I won't call you; you call me. I will take a back seat unless you need me, but if ever you do, I am here, and I am willing to drive down for a chat whenever you need to unload."

He said how grateful he was for me coming down and how much better he felt after our talk.

I gave him a big hug and told him how proud I was of him. "This transition to university is bloody hard, but not as hard as conquering the eating disorder which was the hardest thing you have ever done or ever will do. And you did that. So you can do this. You and I are two pretty strong people, you know, and a damn good team."

And in answer to his confusion as to whether to study for a PhD or not, I said: "Hang on a minute... That's 3, 4 or 5 years away! Let's focus on the next few days and weeks first!"

Wednesday, 25 September 2013

The firefighters may be on strike today, but not firefighter #1 i.e. meeee!

So I got a phone call at 9am from Ben, so upset I couldn't tell what he was saying, so I had to ask him to breathe and repeat slowly. It seems that this morning he had what

turned out to be a phishing email from someone pretending to be Student Finance England and he provided them with all the details they asked for (ouch!)... only to get an email a few mins later from the uni warning that a phishing email was going round, by which time it was too late. He was beside himself, so I calmed him down as best I could and called his bank to put a block on everything, followed by student finance. Then I grabbed my car keys and drove down to Sheffield where we spoke to student finance's fraud team and went to the uni branch of his bank to sort everything out. By lunchtime everything was duly sorted out. New bank account being set up and new student finance log-in, etc. Phew.

And I calmed Ben down, telling him that he wasn't to let these bastards mess everything up for him. No, he wasn't going to quit uni just because of some cyber criminals on the other side of the world. And everything was OK now, I repeated. They won't be able to access his account because it's been shut down. It could have happened to everyone. I told him about the time my credit card was cloned, for instance. These criminals are clever. Yes, the email and website looked identical to the student finance site because that's what phishing is. And I told him that neither the bank nor student finance would ever email to ask him to provide confidential information. Now, of course, he will be super-vigilant, which is a good skill to learn.

Another good life lesson learned is that often really crappy things can happen to mess up your plans. Like this morning he'd planned to go to this free shop where they distribute last year's 3rd years' unwanted household items. Instead we spent the morning doing the above. "But don't let them stop you from going on the treasure hunt this afternoon or the quiz night tonight," I said. "Just pick yourself up, dust yourself down, tell yourself it wasn't your fault and could have (and probably has) happened to anyone, and it's all fixed now."

I told him he was too strong to let evil people like this mess everything up. "I know you're strong and stubborn because of the way you boss me around at home!" I said with a smile and a hug. "Yes it's a bastard that it's happened to you of all people, but

I imagine there are hundreds of students who have fallen for the same scam. At least we did exactly the right things and no harm has been done. Hassle, yes, but no harm.”

And I had a sandwich with him in his room, and a coffee, then said my goodbyes so he could get ready for the treasure hunt.

Phew.

Boy, was I knackered after that! And after yesterday.

At the moment he is so on edge and stressed that it's so easy to tip him over into distress/panic mode. But he has been on the treasure hunt and has PM'd me on FB to say it was good and he'll tell me about it on Friday when he comes home for the weekend. And he's still planning to go to the quiz night tonight and a comedy night a bit further afield tomorrow night.

And last night's Wargames/Warhammer meeting went well, thank God.

The Bad News is that this morning's stress got to him so badly that he felt compelled to go for a run in the park...

Anyway, the firefighting is over for a second day....

Thursday, 26 September 2013

Welcome to the rollercoaster...

Up we go... woosh! Down we go... lurch! Then up again... And all the time feeling sick to the pit of our stomachs about what's going to happen next. This week sure is turning out to be a rollercoaster, but - thus far - both Ben and I have managed to keep Ben hanging on in there and on track. From what I can see from the pics someone's posted on his FB page, yesterday afternoon was a 'high' on the rollercoaster stakes. Let's hope things stay up there for a while... or longer...

I am so very proud of my son. Despite the mega blip yesterday morning which risked effing up everything, he and I worked to get him back on track, to package the incident in a box, put it on a shelf, and move on. Because we weren't going to let

some w*okers who were set on destroying my son's happiness and security through cyber-crime to eff up the rest of his life.

Or, rather, as a very good friend of mine said a moment ago: "Bin it altogether: into the incinerator with that hiccup. Over, done and gone."

When I left Ben yesterday lunchtime I was hoping he would go on the Treasure Hunt in the afternoon, starting in his student residences and exploring the neighbourhood. He did. And from the photos on his FB page he had fun, doing strange things in a small team with lemons across the S10 area of Sheffield!

So far I don't know how the quiz night went last night. And tonight is a comedy night at a venue a little further afield. (Will he realise he needs a ticket to get in? I'm keeping a low profile and leaving this up to him.)

What all these events have in common is that they are specifically aimed at those young people who find the booze / party / disco culture a bore and who, maybe, find it harder to fit in and make friends for whatever reason - and for students who live at home, in Sheffield, and therefore don't benefit from the flat-mates culture of student residences.

All these events are cleverly designed to get like-minded people together so, even if you don't make life-long friends, at least you recognise a familiar face next time you see it. And I notice that the other team members from yesterday's treasure hunt are now friends on his FB page, which is good news.

But I know it is bloody hard for Ben. The toughest thing he's done since fighting the eating disorder, especially since he has only recently started to gingerly test the water again socially. He really is undergoing a baptism of fire this week!

And, so far, he has stayed the course. I, personally, have no intention of allowing him to quit - unless the eating disorder rears its ugly head again.

I wish I didn't have this worry as well, but - with Ben's history of anorexia - I have.

And, please God, no phone call today...

Well, at least not 'that' kind of phone call.

Friday, 27 September 2013

“Imagine a game,” I plan to say to him this weekend...

“Imagine a game where the prize is £1000 to spend on *Warhammer* products, however in order to win the £1K you are only allowed to make positive statements. Any negatives result in lost points. The idea is that you look back on the the week that’s just gone and make statements about how it’s been, what you’ve achieved, how you’ve felt, etc - but they have to be positive. OK, let’s start...”

So let’s say he buys into the idea of this ‘game’ (OK, no real financial prize, it’s just hypothetical), this is the kind of thing I would say:

- You actually went to university.
- You took us up on the offer of a meal on Saturday night and we had the best meal we’ve had for ages, with lots of chatting and smiles. And you ate heartily.
- On Sunday you didn’t sit around stewing in your flat; you got out there and explored the area - and when you got lost, you asked for directions.
- You have made contact with your flatmates.
- You have made contact with the mentors.
- You gave Mrs Head Mentor permission to communicate with me if required.
- On Monday you met those girls following History registration - and you went for coffee with them.
- On Monday evening you went along to the jazz night and stayed the course, and talked to post-grads.
- Okay, the girls didn’t turn up, but - during our talks on Tuesday - you accepted that there are probably umpteen reasons why they didn’t turn up but it almost certainly wasn’t because they didn’t like you.
- You interacted superbly with me on Tuesday when I came down to see you.

You didn't yell at me and you were open to attempting to see the positive side of things rather than shooting me down in flames with a string of negatives. When I left you I was smiling all the way home. I even smiled at our neighbour.

- You went to the Wargames night and met some new people who, doubtless, will become familiar friends - and you will meet all the Wargaming students that weren't at the event i.e. 2nd and 3rd years, and hangers-on from past years. The Soc now has 3 meetings a week rather than just one. In theory, in addition to studying, there is the opportunity to live, eat and breathe *Warhammer* all week long, far more than you could ever do in Leeds. And you can use the skills learned from making friends with the Leeds boys to make new friends with the Sheffield crowd.
- Wednesday saw a massive blip - a real test - an unexpected sledgehammer that risked ruining everything, and this on top of all the general stresses and strains you were experiencing. But you did exactly the right things and we dealt with it successfully, both of us. And by the time I left you had chosen to move on from it and carry on 'business as usual' rather than letting it consume you and spoil everything.
- From this episode you learned how to deal with an emergency - a difficult emergency. And how to come out the other side. And how to deal with the bank and student finance. It was a massive learning curve and a real test - but you passed with flying colours.
- You continued with your plans, to go to the treasure hunt in the afternoon and, from what I can see on the photos, you had fun. You now have 2 more friends on Facebook through it.
- Then you went to the quiz night and talked to people.
- I am not surprised that by Thursday you were pretty exhausted, but you hung on in there and made the decision that you will continue to 'go for it'.

- This week has been a baptism of fire. You have socialised more than you have done since before the anorexia struck - and all at once, like jumping in at the deep end, in a swimming pool full of man-eating sharks. You could have stayed in your room, but you didn't. You got out there and did it regardless of how terrified you were feeling, and I totally understand that you were so terrified you felt physically sick. But you did it.
- As you start lectures and develop a routine, it will become easier and more familiar - and you will see people you recognise and feel comfortable with. You've made changes in your life before and they haven't been easy; the #1 change being the change from being consumed by the anorexia into taking on all the challenges involved in kicking the eating disorder out of your life. That was bloody hard, but you did it. Proof of your strong will and determination.
- Compared with many of the other students for whom this week has been relatively easy, for you this week has been like climbing Mount Everest in the worst possible weather conditions, scaling the most challenging side of the mountain. And now the week is over you can plant your flag up there, on the summit, with pride, knowing that you battled on up there, without giving up and arrived at your goal. How does this make you feel about yourself? (Remember the rules say you must only say positives.)

Saturday, 28 September 2013

I am proud of my son I think I may just explode!

So he made it! He got to the end of Intro Week at university and has come home for the weekend, for a breather and some 'space'. And it was a very happy, vibrant Ben that I picked up from the railway station yesterday evening followed by what seemed like hours of Ben recounting all the things he's done this week and people he's met. It

could have been so very different, couldn't it?

To be honest, as I am sure you can imagine, I was dreading picking him up. I found it hard to focus on anything yesterday, which is why, as a distraction, I did some more work on my 1970s teenage diary - setting up a blog and Facebook page. Being in the 1970s, so to speak, took me away from present-day worries!

Anyway, back to 2013. Not only has Ben done all those things I listed in yesterday's post, but he's done a ton more as well which includes joining all the 'nerdy' societies like Wargaming, Role-Playing Games and so on. With any luck he'll be living, breathing and eating nerdiness with other nerds and will have no need to bother with any of the disco / boozy / partying brigade that are completely alien to him.

Also, one of my Anon followers will be delighted to hear that he has taken him / her up on his / her advice and joined the Christian Union, and been to the welcome event at his student residences, which he enjoyed.

Through all these activities he has already built a pretty big database of familiar faces and people to sit with at events, walk back with to his student flat, and have lunch with. All of which he has done over the last few days.

Now he is faced with the daunting prospect of lectures and STUDYING, and is worrying how on earth he's going to fit just the studying into his day; he claims he will need 36-hours a day to do everything...

But, thankfully, he has met quite a few senior students and post-graduates who will be able to advise on how they handled and organised the workload. One post-grad has already completed a History degree, so he will be the perfect person to talk to!

So, despite the - at times horrific - rollercoaster of a week which we've all had, Ben has made it.

It could so easily have been a week of hanging on in there by the skin of his teeth, shutting himself away in his room and hating every minute of it, but - despite the downs, and stomach-churning nerves - he has made himself get out there and do

stuff.

And meet people he gets on with and who get on with him.

This, from Ben who has only recently dipped his toe in the water as regards socialising, after so many years of the eating disorder's social isolation.

Really and truly, getting Ben socialising again was one of the biggest and last-remaining legacies of the anorexia, and this week he has truly been 'baptized with fire' in that respect.

Ben, you rock!

OCTOBER 2013

Wednesday, 2 October 2013

He's having a tricky week...

It's the first week of lectures and things are a bit tricky. OK, doubtless they are tricky for virtually every new student, but I know that Ben is finding it particularly tough - and he isn't in the best frame of mind.

For a start, lectures kicked off with a topic that doesn't interest him, and he had to produce a presentation on it. His personal tutor is a 'dragon' and so is the seminar tutor he saw yesterday. And the wargames society, which we thought would be a saviour, turned out to be cr@p. Or at least last night's meeting was.

The result was that Ben was Facebooking me at 11pm feeling pretty naff, after a depressing two days.

So things are pretty poor on all levels. I don't think he's socialising much, if at all. And he's unhappy with this first taster of the degree course.

And I worry that it will reflect in his eating - and lower his mood. He has already said that he is too busy and stressed to think about eating. But - thankfully - he is eating, only he's not eating enough and has lost weight over the past month.

So I am monitoring things closely and may have to make a few decisions if things don't turn around soon.

The stress-on-all-fronts obviously flicks a switch somewhere inside his mind and we need to flick it off again before it causes any damage.

Friday, 4 October 2013

It turned out to be a relatively good week, thankfully!

Today - Friday - I met up with Ben in Nando's in Sheffield for lunch before driving him home for the weekend, tons of dirty washing and all. Yes I was apprehensive, but I needn't have worried. After a rocky start to the week, things seem to have gone relatively well. Okay there's a ton of reading and studying to do, but that's to be expected. But he's been doing it, and he's been eating, and he's been socialising.

Tuesday night was tricky as the Wargaming Society didn't turn out to be as good as he'd anticipated. However the Roleplaying Soc on Wednesday went swimmingly well, packed with people on the same wavelength as Ben. He had a fantastic time. Thursday he went to the residences Christian Union meeting. That didn't go too well, so CU is out for the time being - primarily because it felt like Sunday School and not really up independent-thinker Ben's street. So he's going to give Thursday's Wargames group another go. Then there's the Assassins Society next Tuesday. (Don't ask...!) And he's met up with quite a few people in some of his seminar groups that he's clicked with.

So, all in all, things are moving forwards in the right direction.

Phew!

And it was a light-hearted Ben that chatted to me all the way home in the car, explaining the intricacies of how the Assassins Society works (don't ask...) and so on.

He also looks healthy, which was my biggest worry what with him having lost weight last week. And he ate a suitably big lunch at *Nando's*, including 2 pots of frozen yoghurt for dessert.

Now to get the washing machine on for the first load...

(How did I get talked into driving him back on Monday instead of him getting the train? Via the supermarket?)

Saturday, 19 October 2013

Two weeks on - an update on university life

I've been AWOL for a bit, haven't I? It's now two weeks since I wrote about the *Nando's* visit, so here's an update on life at Sheffield University...

Ben has had a bit of a tricky time settling into uni, especially this week just gone which - at times - seemed as if things were about to go pear-shaped again. By this, I mean Ben leaving university again, like last September.

Thankfully, though, things improved in the second half of the week as Ben got to know people better and socialise successfully.

But, much of the time, his mood has been low, which had been stressful for everyone. And, to be truthful, I am pretty sure that the ED voice is knocking loudly at the door with its promises of helping Ben handle the anxiety and stress. This is another reason why I've been keeping a close eye on him and neglecting my blog.

So far, thank goodness, I believe he is managing to keep the 'anorexia demon' at bay - anorexia, which loves nothing better than to zoom in when its former host is vulnerable, with its Siren-like singing to lure Ben onto the Rocks of Relapse.

I know he's finding it tricky: to manage and handle the stress of university coupled with the stress and change of living away from home. Thankfully he can cater for himself and, so far, he has been eating properly, if a bit haphazardly which is part and parcel of university life with its timetable of lectures and seminars.

So he has been eating, which is good news.

The problem is that he isn't eating enough and his weight is still on the low side where it has remained for the past month. So far, he seems unable to get the weight back up again and I am keeping very close tabs on this, made easier by the fact that

he is here at home at weekends for the time being.

But - all in all - he is doing so very well on every count (except weight gain). And the last few weeks really have been a 'baptism of fire' for Ben.

My advice to any family who is wondering whether their recovered son or daughter is ready for university is to really be aware of just how much of a shock to the system going away to university is - and how easy it can be to say yes to the soothing but false lure of the eating disorder voice. Which is why we are keeping such a very, very close eye on Ben over the coming days and weeks, primed to take immediate action if he finds he isn't strong enough to keep the anorexia voice at bay...

Sunday, 27 October 2013

How's Ben doing at university?

The Good News is that Ben's weight is up; he is successfully managing to eat more, which is so fantastically excellent, considering how easy it would be for him to give in to the lure of the former Anorexia Voice as he struggles to settle in at university. And it is a struggle for him. But, considering he missed out on years of social skills as the eating disorder kept him isolated at home, he is doing marvellously.

It is true that he is having problems on this front. He sees "everyone" around him, all milling around, having "made friends", while he still struggles. Yet I tell him over and over again that he won't be the only one that's finding it hard. I also say that I expect there are some students who have locked themselves away in their rooms since the beginning of term, and those who will already have left, like Ben did last year. Yet, despite his social anxiety, he has made himself get out there and socialise.

OK, it's not always been a success.

The Warhammer Group turned out to be a no-hoper; too many of what he refers to as "Power Gamers". In other words, ruthlessly ambitious people intent on winning the table top battles at any cost and who aren't interested in beautifully painting

their models like he is and who don't thrive on the imagination side of the hobby.

The Christian Union turned out to be "like Sunday school", so that was a no-goer, too.

The Salsa Dancing evening was a nightmare for him as everyone paired off and he was left alone. In the end he fled.

But - despite an uninspiring meeting this past week - the role-playing society has come up trumps. Here Ben is meeting people who are on his wavelength, fellow "nerds" as he calls them. These are the kind of people that should be at the Warhammer Group, but aren't. Probably for the same reason that Ben isn't.

He gets on with a boy on his course, sits with him in lectures and has been to two student union quiz nights with him and the boy's flatmates. However he's worried that the boy's flatmates "ignore" him as if he's "not there".

And he seems to get on with some of the people in his seminar group.

So this is all Good News, considering what Ben has been through and could have done (ie. locked himself in his room), but - to his credit - didn't.

But he is still coming home for long weekends. Four days on and three days off. I think this is his way of coping with it and, hopefully, one day he will stay for a weekend.

At the moment he has a heavy cold, which doesn't help his mood, which is on a bit of a downer along the lines of "not really liking uni life" and being "different" from "everyone" else - convinced he's a bit odd or that people don't or won't like him.

So, all in all, at the end of October, it's a mix of good and not-so-good news. But, as I said above, the Good News is that Ben's weight is up and he's trying to make a go of it this time round. It's hard, but I trust he has what it takes to keep on trying until everything begins to fall into place.

Tuesday, 29 October 2013

Let me describe Ben's university room to you

Ben's university has two purpose-built large residence 'villages', constructed about 5 years ago on the site of the old 1960s tower-block halls of residence I was so familiar with in my student years. Ben lives in one of these 'villages', approximately 30-minutes' walk from the university and on a regular bus route (although why 2 different bus companies have to run this single bus route is a crazy mystery to me, meaning that Ben's season ticket for free travel on First Buses isn't accepted by Stagecoach Buses...) Anyway, to Ben's room...

It's in a cluster block of 5, sharing a main kitchen / dining area with 5 other boys, although 2 of them - international students - seem to keep to their rooms most of the time. The other 3 "live on pork pies and pot noodles", according to Ben...

The block comprises 3 'standard' rooms with ensuite shower rooms, like the one Ben started off in last September but found so cell-like, and 2 'studio' rooms which are more spacious (and expensive!), with a bigger bathroom, a double bed, small kitchen sink with window above, fridge, microwave, kettle, toaster, food / utensils storage cupboard and 2-ring hob. So Ben, who is in a studio room, can either cook in his room or in the main kitchen / diner with its bigger cooker, 2 large fridges and 2 large freezers.

Ben's room is on a corner, so it has two windows, which means that when the sun is shining the room is sunny and bright for most of the day. If you look directly out of the main window, just between two other apartment blocks is a gap which leads the eye up onto wild moorland. (Just.) On misty or rainy days, this view disappears.

The hilly area surrounding the student 'village' is what would have been the city's genteel residential area in the 19th century - large stone houses built by the city's wealthier industrialists and commercial businessmen, now offices, residential houses and apartments, university accommodation and buildings, a couple of independent schools, a huge state school, an elegant 19th century park, churches, the other student 'village' and lots and lots of trees.

Between the residences and the university is an area comprising shops, cafes, restaurants, small supermarkets, pubs and bars.

Back at the residences, Ben's room is cosy and warm, and new - and, when I've been there, immaculately clean and tidy, especially the kitchen area, which is more than can be said for how he leaves the kitchen at home.

Hmn...

Tuesday, 29 October 2013

'Motivational interviewing' works so well!

I always think it's a bit of an odd term: Motivational Interviewing... It conjures up an image of job interviews, with the interviewer kind of attempting to get some sort of sense out of the job applicant! But, of course, motivational interviewing isn't that at all. Gill Todd and Professor Janet Treasure describe it really well on this website (www.thenewmaudsleyapproach.co.uk). And, motivational interviewing is what works so very well with Ben and me, when we walk and talk - or, in the case of Sunday, have a coffee and blueberry muffin in Starbucks, and then walk and talk through our good old friend, the local park.

"It's like when you take your iPod headphones out of your bag and they're all tangled up in a huge mess which is a nightmare to unravel," said Ben, munching away on the blueberry muffin and sipping his frothy pumpkin spice latte coffee. "There's so much going on inside my head: lectures, seminars, essays and getting them in on time, socialising, getting used to staying out late in an evening, making sure I eat enough, cooking, shopping, finding my way around the area, course reading, thinking about accommodation for next year - and now this voluntary work experience they expect you all to fit in as well. Aaarrggghhh, the pressure!"

"So much going on... I really understand. It must be so hard trying to juggle all these things at once - your head must feel as if it's going to explode!" I responded. "I wonder if, amongst all of this, there is something that could go... maybe the

voluntary thing? Just to give you a little more space to think?”

“But employers expect to see that you’ve done voluntary work at university.”

“Employers certainly favour a CV that shows you’ve done worthwhile and relevant voluntary work,” I said. “But, think about it... You spent 2 whole mornings a week last year teaching at your old school. Not teaching primary school kids, but sixth form history groups. Your teachers trusted your knowledge and ability enough to trust you with such a senior group of pupils. Employers will love that. So you have a head start over other students who’ve just left school and haven’t done any volunteering. And, think about it, there’s no way any university student would have the time to put in as many hours as you put in last year - and you were working in the charity shop as well! So I would say that - no - you don’t need to do voluntary work this year. Already your CV reads like an impressive War and Peace...”

“Worrying about accommodation next year is tough, I know, especially as everyone else seems to be talking about it. So how about talking about it with your new friends? Asking them what they are planning to do? Are they indeed doing anything? And have a chat with the accommodation mentor lady to talk about booking into uni residences again next year - she’s on the main desk at 6pm every evening, so it’s just a case of popping down there from your flat. It would take you all of 5 minutes. And that would tick another item off your list of stuff.”

Whether or not he will take me up on the above advice is another matter, but the key is the identifying with what he’s feeling bit and repeating it back at him, rephrased, before gently offering advice. Or at least this is what works with us.

NOVEMBER 2013

Friday, 1 November 2013

36 hours later and I am EXHAUSTED!

It went from Ben in pieces, rock-bottom depressed, about to quit Uni and hide himself away for the rest of his days... 36 hours ago... to a hopefully successful fix and a relatively relaxed and happier Ben. Thankfully no eating disorder was evident at any part of the proceedings; indeed he scoffed back 700 calories over lunch in Starbucks without batting an eyelid.

Yesterday was a nightmare all day long, with me rushing down to Sheffield to attempt to fix things and Ben in the least possible receptive frame of mind i.e. doom and gloom, nothing will work, woe, woe, doom, gloom, everyone hates me, I'm a failure at making friends, my life isn't worth living, and so on and so forth... And screaming that he hated uni, didn't know who he was or what he wanted to do with his life - if anything. OMG it was a nightmare.

Meanwhile I stayed totally calm and talked to him, even if he wasn't talking to me most of the time. Or to Sam, the lovely head residential mentoring lady who I managed to collar for an hour's meeting. Ben just sat there, in silence, in gloom, staring at the floor...

The deadline for quitting and paying no fees is Monday which means we were cutting it fine. So I immediately came up with a Plan A and a Plan B: A = quit now and take another year's Leave of Absence and try again next year. B = carry on BUT ON CONDITION that we set up a highly structured support package via Student Services that he MUST engage with.

The aim of said package would be to support him on every emotional level and help him manage his time without burning himself out with over-studying. And also to help him meet like-minded people and make friends.

And, most important of all, to be happy.

"Have I ever been wrong? Have my plans ever failed?" I kept saying, confidently.

And today we came back and had an hour's meeting with the truly awesome Emily of Student Services to set up a structured plan involving a number of people, groups and organisations as well as getting Ben a new, more sensitive personal tutor.

I knew I could count on her to come up trumps.

Now it's just a case of Ben engaging with the plan - and she made it clear to him how important it is that he DOES engage with the plan.

And this is the point where I, the mum, would prefer to back off and let him prove that he can do what he has promised to do.

The first port of call is for Ben to meet with a guy called Rob who is some kind of mentor who will help him manage his time, work out a good life / work balance and offer general pastoral support. In a past life Rob was a psychiatric nurse, which isn't a bad thing.

Plus, Emily is setting up all manner of other things, too, which should help.

More about what the problems have been, later. But, thankfully, none of it has been eating disorder related.

Saturday, 2 November 2013

The cruel legacy of the eating disorder

One of the key things with an eating disorder is that it tends to isolate its victim. Before Ben developed anorexia over the first few months of 2009 when he was 15, he was top-dog within his social group. He had a lovely set of friends. He was hugely popular. But over the summer of 2009 he began to cut himself off from his friends. Very quickly, throughout the rest of 2009, Ben isolated himself. By early 2010 he couldn't even bear to be in the same room as his peers. Within a month or so we'd removed him from school altogether.

Although Ben did see his old friends now and again, for instance at the Year 11 school prom, he found it massively difficult to socialise and then only when he'd had a few drinks (and Ben doesn't like drinking). The eating disorder demanded his full and undivided attention. It wanted Ben to itself and it held him within an iron grip. So - as well as facing the problem of eating, weight, crushing depression and evil moods, and Ben's powerful exercise compulsion - we faced this huge problem of social anxiety.

Extreme social anxiety.

For months... years... while Ben's friends grew up and did all the things that 'normal' teenagers do, Ben stayed at home, on the sofa with us, night after night after night.

It was a really difficult nut to crack, and this was one of the reasons why university failed last September.

But, back home last autumn, Ben threw himself into getting out there. He did voluntary work and - more recently - he very gradually established a small network of new friends through his hobby, *Warhammer*.

However it was a very slow and difficult process.

While his friends grew up and learned all the late teen and young adult social skills as they went along, Ben missed out on this.

All credit to Ben that, from Day One at university this year he has made himself get out there and get amongst people. It has been massively tough for him, a true baptism of fire, but he has persevered.

But he is still suffering from this gap in his skillset plus the social anxiety and fear, and low mood / self-esteem plus anxiety-fuelled lack of sleep - all legacies of the eating disorder. To other people he may come across as a bit 'different', even a bit 'odd', even 'arrogant' sometimes as he attempts to behave like everyone else and make friends.

He gets on with a guy on his course and a few other acquaintances. But, he insists, most people ignore him or deliberately avoid him. He feels unlikeable, odd, 'that weird guy'...

And this week it got to him, big-style, which is why we had the nightmare 36 hours described in my previous entry.

I really hope that through Emily's and Rob's plan, Ben will be able to find people who are very similar to him. Emily says we wouldn't believe the number of students she's already seen this semester with virtually carbon-copy problems. Lots have left already and others have scarcely emerged from their rooms.

Having this support, and these mentors, will help Ben interact with other people and have people he can fall back on for support and guidance when things aren't going too well.

Because what none of his university peers realise, of course, is that Ben is 'learning on the job'. Unlike them, he isn't coming to university with years of life experience. He has been on Planet Zorg for three or so years, completely removed from normal teenage development. And so he is having to learn these skills now, at this late stage, and it's bloody hard - and it can come across as fake, arrogant, weird or whatever.

I really hope that Ben engages with Student Services' Plan - not just for a few weeks but throughout the whole year, especially when it comes to exam time.

Monumentally tough as it is for him, Ben has insisted that he wants to stick it out at university, so it's up to him now to use the tools we have provided for him to make it work.

You wouldn't believe how much I long, long, long, long for it to work and for this horrible legacy of the eating disorder to go and for Ben to be happy and popular again.

As I said to him: “During those first four years of secondary school, you had four years of being mega popular and having loads of friends, so you’ve got it in you and it’s genuine. No way could you have faked four years of being the most popular guy in your friendship group. So it’s just a case of finding that old Ben again and dusting down old skills that are still there somewhere, and drawing on them again. Basically, back then, people liked Ben and they liked him alot. And I’m not surprised, because you’re a lovely guy - the kind of guy people would love to have as a friend. And this can happen again, because this is the ‘real Ben’.”

But it’s not easy. And it’s heart-breaking to watch him struggle.

Sunday, 3 November 2013

The time has come to practice emotional detachment

Emotional detachment or detachment with love is something that’s practiced within the sphere of addiction i.e. carers or loved ones of individuals who are addicted to alcohol, drugs, gambling, whatever. It is the point where you detach yourself from attempting to protect them, to change their behaviour or do things for them. (Termed ‘enabling’.) It is the point where you make the conscious decision to ignore that phone call for you to pick them up from the pub or where you refuse to pay the fine for your addict child with the result that your child is forced to spend some time in jail.

Detachment with love is not about abandoning your loved one; it is about knowing where to draw boundaries about what ultimately will help them and what won’t; what is practical, positive assistance and what is destroying your own emotional and physical well-being by taking control when, actually, taking control may be preventing them from learning to stand on their own two feet -

and experiencing the consequences / difficulties / challenges of doing so. When a carer constantly 'enables', both parties suffer. The addict fails to take ownership for their own actions or non-actions, and the carer burns out emotionally and physically. It is a lose / lose situation.

Over the past few days I've been juggling thoughts and emotions around in my head, knowing that I was finding it punishingly hard to be Ben's 'manager', if you like, and devoting all my emotional and physical energy and resources into his well-being.

Or at least what I hoped would be his well-being, if he actually did what is required of him over the next few days / weeks / months.

Because, after all, I can't do it for him. Only he can do this.

And I was feeling cr*p: exhausted, burned out, depressed and hopeless, longing to arrive at that point where the 'old Ben' would emerge and the legacy of the four-year eating disorder / post-eating disorder would disappear. Where Ben would look the same and act the same as he used to, surrounded by dozens of close friends who admire, love and respect him - and who adore his company. When the old Ben would be back for good and I could take a back seat knowing my job was complete.

So, late last night as my mind descended into another low mood, I Googled "How do I stop loving my son?"

Now of course I didn't strictly mean that; I will love Ben until the day I die, but it was the best way I could describe what I was feeling i.e. the need to distance myself emotionally at this point - and thankfully I found what I was looking for, and it was this: detachment with love.

Although it seemed to be related to carers, partners etc of addicts, this kind of approach seems to be exactly what is required in our household at the moment.

Or look at it another way...

I am the harbour pilot who has carefully guided big ship Ben out of the tricky port and into the open sea / ocean. He now has the tools to negotiate that ocean, even when the weather is stormy, and is up to him to help himself, to learn how to pick himself up when things don't go as planned, without relying on mum to rush in and rescue.

As regards settling in at university, last week I set in place everything that will allow Ben's life at university to work, as long as he engages with this and does what he needs to do.

If he doesn't, then I can't rush in again to fix it, because it wouldn't be helpful for him.

He needs to find his own way now. Of course I am here providing support and love at a distance, but I will not firefight or rescue, because I have done everything that can be done, and can do no more - without hindering Ben's growth and emotional / social development.

It's a kind of "tough loving", if you like, yet with a bit more compassion.

I have taught my fledgling to fly but I can't fly for him. Only he can do that.

Time to take a back seat.

Monday, 4 November 2013

Over to Ben...

So we saw Rob today, the former psychiatric nurse who now works for the student counselling service. As planned, I kept quiet unless Rob asked me something. Ben conveyed everything to Rob really well. So where does he go from here?

To be honest, I'm not entirely sure. I was expecting a kind of bespoke

support package to be drawn up then and there, but it was a bit vaguer than that. Mind you, Rob asked all the right questions and it does take time for someone to get their head round Ben's history and current state. We spent around 90 minutes with him and Ben is seeing him again next Monday.

I expect Rob needs to have a think about what is best for Ben and then get in touch with him. He did suggest one or two things, like going to see the GP because Ben will need a diagnosis of some kind to be able to access some of the support services.

If he gets a diagnosis, I imagine it will be somewhere on the anxiety spectrum with a bit of depression thrown in. Thankfully Ben continues to eat OK.

After a sandwich lunch in the city centre, I dropped Ben off at his flat, hugged him and told him that it's over to him now to make a go of it. He was a bit teary when I left.

Ben has decided to take up Emily's middle option which (I'm not sure if I explained) is to extend the 4th November fees deadline by a further 2 weeks. If a student quits before 4th November they are not liable for any tuition fees. After that date, they are liable for various percentages, starting with 25%. And 25% of the £9000pa fees is a lot.

However there is a way round this, if the faculty agree - and, in Ben's case, they have. If he doesn't attend any lectures or seminars, or hand in any work, over the following 2 weeks, he will still not be liable for fees if he subsequently decides to quit. If he does continue, the faculty will support him in catching up, and - anyway - some of the lectures are available as podcasts, so Ben can still 'go to lectures', in effect. And the second week is a 'reading week'. Anyway, so he wouldn't be missing anything that week.

But it is important that he stays in Sheffield as much as he can so he can put

the things into practice that will help him make the correct decision.

This gives him a bit more flexibility and removes some of the pressure.

All I can do is hope that the bits of the plan which Emily promised to chase up work out OK and that Rob comes back with something helpful and structured, and that Ben sees the GP - and that the GP is helpful.

And that, by some miracle, Ben is deluged by new friends this week...

Because, if things continue as they are, I'm not at all sure he will stay...

But I mustn't let it get to me because I am detaching, right? For my own sanity, well-being and health as well as Ben's.

Tuesday, 5 November 2013

"Beverley is such a worrier..."

"Detach... detach... detach..." I have been saying to myself, over and over again, for the last 24+ hours. And it is so very difficult, especially since I've had no news from Sheffield during this time. They say that "no news is good news", but unfortunately that's not the case with Ben and uni. Well, not at the moment at any rate. And I am a natural worrier. I always was. Like the time my little sister got locked into our Granny's bathroom when we were small.

I clearly remember pacing up and down outside the bathroom door, weeping and worried sick. Yet when the handyman arrived and climbed in the bathroom window to 'rescue' my sister, there she was, calmly eating Polo mints, cross-legged on the floor, without a care in the world.

"Beverley is such a worrier," they would say...

That particular Grandma was a mega-worrier too. I only had to sneeze as a child and she was convinced I was about to drop dead.

So is detachment the same as forcing yourself not to worry?

No, I don't think so.

As a parent, it's natural to worry or be concerned.

But over-worrying or trying to work out how to solve things you can't solve isn't helpful.

Neither is zooming in to either take over or 'help'. Unless it is a true emergency, of course.

I think that detachment is all about accepting the fact that it's natural to worry and keeping an eye open for a true emergency while setting yourself free from the kind of worrying that's destructive, not constructive or a waste of time, energy and emotions. In other words, there are some things you can change, but it's pointless worrying about things you have no control over.

Detachment, as I see it, is also about knowing when to let your child tackle their own problems and find solutions, when to allow them to face scary situations, when to allow them to learn from the consequences of any actions they take - or don't take.

I've been doing a lot of CBT visualisation which seems to kind of establish the right sort of balance for me.

When I was small, steam engines still ran on British Rail and we'd take the steam Devonian express train to Weston-Super-Mare every summer (where my other Grandparents lived). On the other side of Birmingham, at Bromsgrove, is a steep bit of track called the Lickey Incline which steam trains couldn't get up without help from 'banker' engines which would literally push them up the hill from behind. At the top, the express train would continue on its journey, parting company with the buffers of the 'banker' engine which would toddle off back down the hill to wait for the next train.

This is the image that I bring to mind when I want to emotionally detach. I've pushed Ben up the hill and now he's continuing the journey on his own.

But, of course, I'm always here to push him back up the hill in a true emergency, should he need it.

Wednesday, 6 November 2013

Rewind to 27th June 1996, Ben goes to nursery school...

Thursday 27th June 1996: Ben's first day at "Ding Dong Bell School" (as he calls it). (This is going to hurt me more than it hurts you...) Here I am visualising him heartbroken, thinking I've deserted him... I primed him well and asked him where he was going today, then where I was going (shops!) (the easiest thing to say!). Then the fact I was coming to get him after lunch. Thus far, no-one's phoned to beg me to come and pick up an uncontrollable toddler who's trashing the place and bashing other kids...

Friday 28th June: He didn't want to be there this morning (his second Intro Session)... Wouldn't take his coat off. Wanted to "Go back to house".

Yet he enjoyed yesterday. Told me all about it. He's got a little peg for his coat. He ate all his dinner and pudding. He did drawing, watched Playdays, did something with a frog (?), had cereal ("pops") on something at lunch time, played with bricks and on the bikes and did gluing. I wish I was a fly on the wall able to see him enjoying himself (or not...)

Just think, 34 years ago it was me starting at that very same nursery... it seemed bigger then and it had outside toilets. We had to take our own biscuits and didn't get lunch (I don't think). I ran away one day. If the gates weren't locked, I bet he'd do the same. Not because he was unhappy, but because he suddenly decided he wanted to do something else and be independent. Just like me.

Wednesday 10th July: He still cries when I leave him at "school". None of the

other tots cry. Apparently, he's fine 10 minutes later.

He tells me everything he's been doing - primarily what he had for pudding. "Pink... strawbreez..." (turned out to be trifle).

I get some time to myself (although Ben thinks I go "to shops" every time I drop him off at "Ding Dong Bell School". I always seem to end up getting him "a little something" (my words); this week it was a plastic "Bambi's daddy" (his words) and "baby penguin" (to go with "daddy penguin"). I had to put spots on their tummies so they had spotty tummies like the "Pegeez" at Harewood Bird Garden.

He's been helping me cook with his new Thomas apron. he's like the "Gallopig Gourmet" in the speed he likes to do things and I find it quite exhausting, plus having to stop him dropping the whole lot on the floor. 'We' made a lemon meringue pie yesterday and he was very proud of his cooking. It had banana in it. I said, "Put the banana slices in the pastry shell, don't eat them" so he took out the one he'd put into his mouth and chewed a bit, and put it in with the other slices in the pie! (Not one to serve to guests!)

In just two weeks of "school", Ben's behaviour towards other children has vastly improved. He appears to be learning the art of playing with friends, as opposed to fighting for sole useage of everything.

Friday, 8 November 2013

Proud of him

Well, his week wasn't as I predicted. I predicted a doom and gloom week as Ben is given a 2-week extension on his decision on whether to stay or go. But, so far since he arrived home yesterday evening for a long weekend, he's been relatively upbeat, which is a major improvement on this time last week!

He hasn't been out that much, but he hasn't kept himself too solitary. And, to my immense surprise, he announced he'd taken part in some auditions for BBC's University Challenge!

He is already talking about the weeks ahead, and not in a way that implies he will be leaving anytime soon.

So there you are.

That's all I can really say for the moment because I've not been probing.

But what I did do when he announced that he'd put on more weight, was happy about this, but that it had been a tough week on the settling into university front was to give him a big hug and tell him how immensely proud I am of him.

Tuesday, 12 November 2013

A spot of deja vu...

So I dropped off a silent and uncommunicative Ben at the train station yesterday, university-bound. Then I went swimming, came home, had lunch and answered the doorbell... to Ben who wasn't saying anything about why he'd appeared on the doorstep, but "the soup and baguette I had in *Pret* were awesome!" A throw-back to the time he went AWOL on a school trip to Manchester.

Then yesterday evening he was fine, if still silent about what he was doing here.

Then today I dropped off a silent and uncommunicative Ben at the train station, university-bound... again...

Which, of course, meant that yesterday he missed his second appointment with Rob in the student counselling services which I'd put all that effort into

setting up as part of Emily's Support Package.

Which, if he was in 'flight mode' which he obviously was, he probably needed more than anything yesterday.

I didn't say much to him; part of the attempting to emotionally detach, a decision made after spending two days in Sheffield the other week setting up a support package for Ben with Emily and Rob - to make settling into university as trouble-free as possible for him.

Yet he fails to turn up to see Rob.

The thing is... he has made the decision to be there i.e. not quit, yet he is failing to keep his side of the bargain when it comes to the Support Package.

Kids, huh...

Wednesday, 13 November 2013

Some home truths and a lot of 'effs'

When Ben pinged back yesterday evening... again... I played the strong, silent type. Indeed the only words I uttered between the station and home were "Could do," in response to his question "Do you want me to put your chicken dinner in the oven?"

I felt angry, exhausted, deflated, numb and helpless, but in a kind of strict-but-good schoolteacher / GP kind of way. And, probably for the first time for years, I really didn't care how I responded, as long as I responded in a calm but strong, forceful, neutral schoolteacher / GP kind of manner i.e. not yelling or getting upset.

No more words were said until the two of us sat down opposite each other for dinner. Eventually Ben said: "I did something thinking on the train home" and explained that he'd decided to stay at university for the time being. This

week is 'Reading Week', so most students seem to have gone home and Sheffield is pretty quiet. It is also the final week in which he can leave without having to pay any tuition fees. But he has decided to stay "because I need some structure in my life" and "because I'm f****d if I'm going to let all the work I've done over the past few weeks go to waste". He said he might leave at Christmas, maybe, and pick up in a year's time.

But he wasn't saying it in a strong, determined, defiant kind of way; more of a 'poor me I'm so rock-bottom depressed I might do anything' kind of way. For example: "The reason I'm back home is because I was so f****d off to be back in my room today that I didn't trust what I might do to myself."

Anyway, to cut a long dialogue short (lasting around an hour), I reminded him that I'd put all the foundations in place for him to help himself get out of this hole: Emily's plan, etc. But he hadn't followed these up. And he'd missed his appointment with Rob on Monday, and hadn't arranged a GP's appointment as instructed by Rob last week.

"But Rob was only going to ask me how my week had been..."

"Er, Rob is a former psychiatric nurse; he's hardly likely to spend an hour talking with you about what the weather was like last week or whether you got that essay in on time. He is there for you to talk to him like you're talking to me now so he can point you towards the right combo of therapists and support. But you failed to turn up."

And kind of from then onwards the dialogue deteriorated into a "I've f****d-up that, too. Just like I've f****d-up my life. I've f****d-up everything I've ever done" sort of thing... Plus: "I f****d-up by letting the eating disorder take me over and f**k-up the past four years of my life" and "I'm going to f**k-up the rest of my life, too. I'll always be depressed. I'll never make friends, never get married..." etc.

Followed by me explaining in no uncertain terms... again... why he can't blame himself for the eating disorder. How was he to know that's what was beginning to consume him back in 2009? By the time he did, it was too late, and he can't be blamed for that. Anorexia is a biologically-based illness not a lifestyle choice.

And, if he is depressed, then he should do something about it. "You refused medication which would have been a great help right now to raise your mood while you settle into uni. You refused to engage with any of the private therapists I paid for - and refused to engage following the NHS mental health assessment last year. And you missed the appointment with Rob. So you can't just sit here and go on about how you've f****d-up your life and will continue to f**k it up in the future. In Sheffield you have a mountain of support available - and all for free; the best support you'll ever have in your life: Rob, counsellors, the disability support team, Emily, Sam, the live online support service, etc etc, yet you've done nothing to help yourself. Now you come home and expect me to say 'Poor you' and pat you on the head while you sit there saying 'Woe is me' etc."

Sorry, but that's what I said. Still in a calm, kind of neutral way. And every time he retorted with yelling, I just told him not to swear at me as I'd done all this stuff for him, dropped everything to put everything humanly possible on a plate in front of him to help him help himself, but he hadn't taken it up.

And, yes, if he was going to eff, then I was going to eff, too.

"I lost all my friends because of the ED and f****d-up my sixth-form years at school," he lamented.

"And I f****d-up some of my sixth-form years, too, for a very similar reason."

"You only f****d-up fifty per cent of it."

“Well, I f****d-up fifty per cent too much. And I decided that I wasn’t going to f**k-up the upper sixth year, too, so I made myself do something about it.” (And if I remember correctly, it was a talk in a very similar tone to this one that made me stand up and take charge of myself back then, realising that the ‘woe is me’ attitude was no longer getting the right response.) “So, yes, the eating disorder f****d-up those years of your life, but what you should be doing is saying ‘I refuse to let it f**k-up the next five years. I want to stand there in five years’ time, look back and know I did something to help myself and I made a success of it’.”

“I also f****d-up with every girl I ever went out with.”

“Well, I f****d-up with every boy, until I met your Dad.” (Resulting in me having nightmares last night about two particularly distressing years of my life which I’d blanked out of my brain, as if they never existed.)

Etc etc.

“You and I are the same genetic make-up,” I continued. “Or at least I thought we were. But I must have been mistaken because I’m not seeing any of the ‘I’m not going to let this eff up the rest of my life and so I’m going to do something about it’ strength here; none of my strength which I thought you’d inherited.”

“Well you never had years of your life f****d-up so you never had to be that strong.”

“Oh yes I did. What about the years when you were sick? I had to be massively strong, because if I gave up, you could have died. I had to keep going for the both of us and fight for your recovery. Day after day. Week after week. Year after year.”

Then I did the old finger-prodding-on-the table-to-make-a-point gesture.

“But where I did f**k up, if the truth be told, was by allowing CAMHS to

settle for 'good enough' when it came to your weight restoration and full recovery. All of us - CAMHS and me - were so bl**dy scared of what you might do if we pushed you too hard that we let the ED get away with it. We settled for the 'easy' option because we were terrified you'd pull out of treatment, run away, harm or kill yourself. I let myself be held to ransom and I f****d it up by doing this."

And, my demeanour said, I am no longer scared. I am no longer treading on eggshells. I am no longer afraid to speak the truth. Which, afterwards, it struck me was a bit of a watershed moment for me - a kind of liberation.

Then it was all the old "all therapists are rubbish" stuff and he's "stuck with this depression for life" followed by me saying he never gave any of them a chance and, no, he isn't stuck with depression for life because people get treated for it. If a therapist is rubbish, then you fight to find one that isn't. You don't just walk away and think 'woe is me, I'm going to be like this forever, all therapists are rubbish'."

"But I am so depressed..."

"Then DO SOMETHING ABOUT IT. Don't just sit here at home this week, book an appointment with Rob and another with the GP to talk about medication and therapy. 'Reading Week' is a quiet week so you should be able to get an appointment. Buy a day-return ticket to Sheffield on the train. Help yourself."

Blah blah.

"And now go and do something to cheer yourself up, Ben."

So he did.

Wednesday, 13 November 2013

Looking back at my first ATDT forum posts in 2010

On the 9th March 2010 I discovered the Around The Dinner Table forum which supports parents and carers of young people with eating disorders. And I posted my very first post. I was worried sick because, after just a month of treatment, CAMHS didn't seem to think that Ben's case was too serious. Already they were suggesting spacing out our appointments to fortnightly and the psychiatrist had gone on leave for three weeks.

What frustrates us is that his psychiatrist doesn't think his problem is too severe. His BMI isn't bad and when he's with her, his behaviour is quite normal. As a result she's started spacing our appointments further apart; we have a 4 week break between our next two appointments. Despite trying to argue the case with her, she's adamant he isn't too bad. As parents we feel as if we've been pushed off a cliff and into free-fall...

and

The CAMHS team really don't think he's seriously bad and it makes me mad because I know differently and he's pulling the wool over their eyes... now psych has gone off on her hols for 3 weeks too so we're all at sea... Last time we saw her she was all smiles and congratulations as B reached a 'healthy weight' for the first time. B took that to mean he can maintain his weight now at what, to me, still looks very thin and not at all like the strapping sportsman he once was...

This was the beginning of the fight for me to get Ben fully weight-restored as opposed to settling for just within the healthy range according to the official

charts, which wasn't anything like the pre-eating-disordered Ben.

And, as you will know if you've read my book *Please eat...*, shortly after this Ben admitted that he was deceiving CAMHS - or, rather, the eating disorder was deceiving CAMHS. He, or 'it', was "play-acting" at the CAMHS sessions, pretending to be perfectly OK.

Yet the moment we'd leave the CAMHS unit - whoosh! - all hell would break loose as he'd undergo a Jekyll-and-Hyde-style transformation into 'the demon'...

Thursday, 14 November 2013

The benefit of hindsight... how I wish I could help the 'me' of 2010...

Continuing to take a look back at my ATDT forum posts from when I first joined the community... Throughout March 2010 I am still having problems with getting CAMHS to realise that Ben's eating disorder is as serious as it is. The CAMHS team comprises a psychiatrist, a nursing specialist and a dietician who we see every so often but never at the same time as the psych and nurse. I am having real problems convincing them that Ben is seriously sick. He has lost around one quarter of his pre-anorexia weight; he used to be a big, burly rugby player - a 'forward' - before the eating disorder struck and, by March 2010, he's a shadow of his former self. And, at the end of January 2010, his pulse plummeted to 29, which I understand is a pretty dangerous level. Yet CAMHS appear to be happy with Ben's 'progress'...

... And I had another meltdown last night with B bashing his fist on the plate so all the food went everywhere followed by 5ft 3 inches me trying to physically restrain all 5ft 7 inches of him from breaking down the door and flying out into the street, me confiscating the house keys and barring the living room

doorway... (My husband doesn't get back until late evening as he commutes 100 miles to work and back.)

The strain is taking its toll. This morning, after a particularly bad start, I got a call from my husband (on the motorway on his long commute) saying he'd just driven into a large truck at 70 mph and written off his car, lucky to come out of it alive... He'd been so wound up about the situation at home that he wasn't concentrating...

This afternoon we have a brief session at CAMHS for a weigh-in with the nurse. As you know, the psych is on holiday and we don't see her for another fortnight, not having seen her for the previous fortnight (4 weeks without the psych in total... and the nurse will be on hol next week, so we're on our own completely from this evening).

All we get when we voice our concerns to the nurse is the infuriating nodding of head sympathetically, you know, that kind of counselling where they just agree with you rather than taking proper action. Basically she has said she has to go with the psych's decision on everything... and at the last count the psych felt that fortnightly sessions would be appropriate now rather than weekly (!!!!!!!!) now that B has arrived just within the 'healthy' weight range.

I can't for the life of me see how an hour's CBT-ish session with the psych every so often will cure B of this terrible thing. I feel as if we're stuck with it forever, not knowing if we're getting the right kind of help or not... I have NO IDEA if we're getting the help we need or need or not, really I don't, and there doesn't seem to be any way I can gauge whether or not we are...

Knowing what I know now, how I wish I could go back in time and be there to help the 'me' of early 2010 and fight for the need for sustained, regular treatment for Ben, focusing on weight-gain first and foremost through a balanced diet and insisting that CAMHS back me in getting Ben back to his pre-anorexia weight.

Next Friday I'm speaking at the *National Carers Conference in Eating Disorders* at the *The Institute of Psychiatry*, London. I plan to round off my talk with 'my biggest regret' and 'our biggest success'.

Guess what my biggest regret was?

Thursday, 14 November 2013

Why it was so hard to fight for Ben in 2010...

There are several reasons - these are just a few of them...

1. I still didn't know much about eating disorders; as the parent of a boy developing anorexia, I was going through a huge learning curve and only discovered the awesomely supporting and informative FEAST community and its ATDT forum in March 2010, some 6 months after I first took Ben to see the GP. Far from being 'just another internet forum', the FEAST community and its messages are respected by leading eating disorder specialists, researchers and practitioners across the world. In other words, they know their stuff! Yet, when I first discovered FEAST, I felt sure that, somehow, CAMHS must be right and FEAST must be wrong, as their messages / approaches appeared to conflict. And not just conflict a bit, but be at polar opposites i.e. FBT / Maudsley focusing on full nutrition first and foremost (FEAST) and the Talking Treatment (CAMHS) with less emphasis on full nutrition / weight restoration.

2. I was a wee bit scared by finding myself in front of The Experts, and especially a psychiatrist with a string of impressive qualifications. After all, I was just a mum, a newcomer to this horrible illness, anorexia. As far as I was concerned, what did I know? How could I contradict the professionals? Especially by quoting 'something I'd found on the internet'...

3. After some initial teething problems, I actually began to like the psychiatrist. As a person. I mean, she was really, really nice. And, as time went on and she began to get to know Ben well, he and she got on like a house on fire. He took on board what she said as 'gospel'. And, unlike so many disinterested medical professionals, I felt that she really did care about Ben and went out of her way to extend our sessions if needs be and to arrange emergency sessions as and when we needed them (after it became clear that Ben had been deceiving them and all was NOT well inside his head...) Looking back, I really should have taken advantage of the fact that she was nice, liked Ben and - eventually - began to respect me to a certain extent, and fight for full weight restoration for Ben, and full and complete recovery before he was discharged. Especially as Ben trusted her and took her word as 'gospel'; it could have been massive leverage in his fight for full recovery. But by the time this happened, it was too late. Ben had reached the age of 18 and the psych was leaving CAMHS. It was literally the 11th hour... too late...

4. I was just so bloody exhausted! It's easy to look back in retrospect and wish you'd done this, that and the other, but the fact is that dealing with the worst of an eating disorder is mentally, physically and emotionally draining in every way. In such circumstances you, as a parent, can only do 'so much'. This is why you need a rock-solid treatment team behind you who can deal with the stuff that you simply can't - like getting him to eat, and getting the weight back on.

5. I was fighting Ben (or the 'Anorexia Demon') at home. He was taller and stronger than me, and would get physically violent. People would tell me to take him to A&E (ER) when things went totally pear-shaped. But tell me how little me was supposed to bundle tall, strong, violent Ben into the car and get him to A&E? Or even if I did get him into the car, how to keep him in it? Yes, in theory, I could have called an ambulance or my friend Sue's husband, or my sister's partner to help restrain him. But the 'Anorexia Demon' is a whiz at emotional blackmail. "Get help and I will run away / kill myself / whatever" it would spit at me - and I knew that it meant it.

6. I couldn't get Ben to eat. He refused to eat most of the foods on the eating plan which I'd managed to get off CAMHS and he had a habit of turning mealtimes into Armageddon. Getting him to eat without expert help was impossible. It's as simple as that.

7. I was just relieved that he was turning up for CAMHS sessions. He could so easily have refused to go along and then what? So, often, it became a case of appeasing the 'Anorexia Demon' by going along with it and keeping it happy rather than risk Ben dis-engaging with treatment, running away - or worse.

8. Initially, CAMHS didn't take it so seriously (as described in the posts below). Also, Ben was led to believe that his BMI was OK... it was within the 'healthy range' on the official charts. In a letter to me the psych said: "First and foremost, it is important to note that Ben has not at any time strictly met criteria for a diagnosis of anorexia nervosa, as his weight has never dipped to a point sufficiently low..." This, when the 'Anorexia Demon' was raging! He was never blind-weighed or checked if he was cheating when it came to weigh-ins, and he was always weighed fully dressed (without shoes). As a result, many CAMHS sessions tended to be spent firefighting Ben's extreme reaction to putting on a tiny bit of weight. Unsurprisingly, CAMHS sessions went relatively

well when he'd lost...

9. For the first few months we saw a dietician every couple of weeks or so - and she supported me in what I believed we needed to do. And then she was withdrawn because of funding. I cried when I heard. I fought to have her reinstated, complained to the NHS, had a long and fruitless conversation on the phone with Someone Important at CAMHS, and with the psychiatrist, but no-one felt that Ben needed dietetic help at this stage. In a letter to me the psych said: *"We have reflected on how much you valued the dietician's input and would have wished for that to continue. I would re-iterate that the purpose of her sessions was to evaluate Ben's diet at the point of referral and make recommendations as to how he could move to a more appropriate, varied diet without prescription or excessively strict detail. I believe that you, and Ben, are fully aware of what constitutes a healthy diet, and the dietician's useful sessions served to reinforce your already sensible grasp of what we would aim for."* Actually, I would hazard a guess that many parents and their anorectic children are fully aware of what constitutes a healthy diet, similar to how an alcoholic or drug addict knows that their habit is harmful... but this doesn't mean we can get our child to eat!

Friday, 15 November 2013

Walking unaided... hopefully...

As a result of my 'tough talking' the other night, Ben made an appointment to see Rob which is scheduled for this morning. He is also seeing the university GP, hopefully for some meds and other solutions to help with the depression. Also, he went back to Sheffield yesterday, seemingly OK, and stayed there overnight. So watch this space for news...

Sunday, 17 November 2013

On the whole the Daily Mirror article was accurate...

So how much of my published interview with the Daily Mirror this week were my words and how much were the Editor's words, after the (very nice) journalist agreed the final version with me, but did warn me that the Editor would give the final go-ahead before publication and, sorry but no I couldn't see the post-edited version...

Bev Mattocks' son Ben developed an eating disorder at 15 trying to emulate ripped models he'd seen in his dad's fitness magazines.

Kind of what I said, but not exactly.

"Ben had muscles because he played rugby but he was desperate to have a six-pack. He was swimming and running every day, and he was doing sit-ups, press-ups, crunches and other things," Bev explains.

Accurate.

"He became riveted by his dad's magazines – they had a big influence.

Well, they were just one of many factors and my H didn't buy loads of these men's health mags, just a handful.

He didn't have any time to do anything else, he refused to eat fatty foods and became very isolated."

True.

Photo of Ben Mattock Recovering:

(No it's not, it's a photo of Ben the previous summer.)

Like Paul, it was difficult for Ben to get help even when Bev was right on the case. She says: "I took him to see our GP and he told Ben to go away and eat something."

GP told Ben to go away, eat more and come back in a couple of weeks.

In January 2010, Ben's heart rate dropped dangerously low and he was admitted to hospital but again Bev's concerns were brushed aside. "I'd researched anorexia online and I knew heart failure was one of the main killers. A consultant told us athletes tend to have very low heart rates and because Ben was sporty that was what was happening," says Bev.

Yes.

But she insisted he was referred to the Child and Adolescent Mental Health Services, where he was finally -diagnosed with anorexia.

Actually he was never diagnosed with anorexia because his BMI was never low enough, which is one of the key points I want to raise when it comes to the problems of getting males with eating disorders taken seriously by the medical profession.

Ben, now 19, is back to a normal weight and is in his first year at Sheffield University studying history. Bev, who has written books about his anorexia, says parents should be aware of the dangers. "I didn't know boys got eating -disorders," she says.

Correct, although Ben could do with weighing a bit more...

"We weren't looking out for the signs but boys can suffer from body image issues too."

I never said the second half of this sentence. I also reinforced the point that the drive for fitness and a six-pack, and the men's health mags, weren't 'causes' of his eating disorder, they were just some of the triggers.

Bev Mattock tells parents to trust their instincts – if you have a gut feeling something is wrong, then it probably is.

True. (NB Mattocks has an 's')

She says: "Take your son straight to the GP if he is losing weight, over-

exercising, getting obsessed with 'healthy eating', cutting back on food he would normally eat, getting depressed or generally down and opting for exercise over socialising.

Correct.

"Don't be afraid to be pushy – demand a referral to specialist eating disorder services or Child and Adolescent Mental Health Services. Visit website feast-ed.org which is packed with resources for parents and carers. It's also worth joining their online forum, Around The Dinner Table. You'll find incredible support there, it was a lifesaver for us."

Correct.

On the whole it's accurate, but there was so much more I said... so much that I felt was extremely important when it comes to highlighting the fact that males and boys get eating disorders.

But I am well aware that space was limited and there were other stories to report as well as ours.

Saturday, 23 November 2013

Driven by love, not red-tape

I have spent the last couple of days mixing with some of the most amazing, loving, caring, passionate and selfless people I have ever met. Of course I've met some of them before (for example at the 2-day Nottingham FEAST conference in November last year), and I already 'knew' many of them from the online community of people that are passionate about making a difference in the world of eating disorders: parents, former sufferers and professionals. And, although eating disorders is such a massive topic that a one-day conference, like the National Carers Conference in Eating Disorders I attended

yesterday at the Institute of Psychiatry, run by Professor Janet Treasure, Gill Todd and the Maudsley & Kings College London, can't ever hope to do more than chip away at a huge iceberg, it did a bloody good job! But what stood out for me most, on reflection, is this...

There are a heck of a lot of people out there, both salaried and unsalaried, lay people and professionals, who are working like the clappers to make positive, lasting and effective changes in the world of eating disorder treatment and the quality of the care that parents provide at home, through outstanding evidence-based education and guidance.

From the meal the night before (where around 30 of us dined at the invitation of the truly amazing Professor Janet Treasure OBE and the equally wonderful Gill Todd) through to the conference itself the following day, I found myself amongst strong, passionate people that... well... CARE.

And they don't just care, they are working tooth and nail to drive research forward to come up with ever-more effective ways of eradicating this toxic illness - eating disorders - from our children's lives, whether the child is 8, 18 or 58.

Yes, they are all hampered by NHS budgets and red-tape, but it was clear to so many people yesterday that the latest trail-blazing approaches to the treatment of eating disorders could save the NHS £millions or even more. Not only is the family brought in to play a major role in the treatment of their child, taking some of the pressure off the professionals and ensuring that the child receives good, evidence-based treatment 24/7 from those that love them most, but this kind of family-based treatment can often avoid costly in-patient admissions. And, of course, families do it for free.

And, for those of us who couldn't give a hoot about the money side, because we believe the NHS should pull out all the stops to save our children's lives no

matter what it costs... research is showing that, on the whole, this kind of treatment leads to a quicker, more effective and most lasting outcome.

Plus, it saves more precious lives.

So not only could the NHS save a pot of money and dramatically cut the waiting lists for treatment by freeing up the professionals' time, but our children would get good treatment sooner, recover quicker and enjoy a better quality of life with less chance of relapse.

Of course I can hear 'the powers that be' piping up with: "It's not that simple! The NHS doesn't work like this! Funding... red tape... poor inter-department and inter-Trusts communication... 'old ways' and so on..."

No, I'm sorry, but to me, as a parent who gets irritated by red-tape and likes to KEEP THINGS SIMPLE and sweep all the clutter and crap out of the way, this seems like a no-brainer.

But, of course, thus far it's only happening in tiny pockets across the country - and over the past couple of days I've met people who are the driving force behind this push for change.

I hope and pray... and hope and pray that I can play a part in this along with trail-blazers like the amazing parents' advocate and eating disorders treatment pioneer Charlotte Bevan and other parents... that this kind of thinking will be rolled out across the country very, very soon, making a massive inroad into the recovery rates for eating disorders in the UK.

Sunday, 24 November 2013

Read a transcript of my talk

In November 2013 I gave a talk at the National Carers' Conference on Eating Disorders at the Institute of Psychiatry in London, hosted by Professor Janet

Treasure OBE and Gill Todd. The point I wanted to make was that, as parents of a teenage boy with an eating disorder, we had to overcome several hurdles; not all of which are unique to boys, but many are. This is a transcript of that talk...

Back in 2009 when my son, Ben, was 15 he developed anorexia. The trouble was that, back then, my husband and I had no idea what was happening because we didn't know that boys got eating disorders. In fact we didn't know anything about eating disorders - and neither did Ben; he'd probably never thought about eating disorders in his entire life. The result was that none of us understood the subtle changes that were happening to our son which probably started around the end of 2008 and the beginning of 2009, just as Ben turned 15.

Back at primary school, Ben had been quite overweight and he'd been badly bullied as a result. So, in a bid to build up his confidence, his Dad took him along to one of those Sunday morning rugby clubs. Ben trotted along every Sunday and he was actually very good at it. He was picked as Number 3 in the team, a position given to the biggest, toughest boys. Gradually Ben's puppy fat was replaced with muscle, but he was still a big lad - a typical rugby player, really.

At the age of 11, Ben won a scholarship to a fantastic independent secondary school with a reputation for sport, especially rugby. He was immediately picked for the rugby team and quickly became a star. Indeed, for the first three-and-a-half years of secondary school, everything appeared to be going from strength to strength. Ben was popular; he was "the guy in the rugby team" which carried a lot of clout amongst his peers. He established a lovely group of friends and, as we watched other teenagers go off the rails, Ben just

seemed to blossom. We really thought we'd got off lightly. We thought: "Wow! We can't believe it; our son's going from strength to strength. We've avoided all the teenage angst business!"

How little did we know... because three-and-a-half years into secondary school we arrived at that point at the beginning of 2009 when things began to subtly change inside Ben's head.

The problem was that, although we didn't know it at the time, Ben was getting bored with sport. He was playing an awful lot of sport, not just rugby; he was doing swimming, badminton, cross country... he was doing virtually every sport under the sun and, frankly, he'd had enough.

The other problem was that he loved his food and doing all this sport meant that he could eat an awful lot without piling on the pounds. You see, Ben was terrified of "getting fat" again, like he'd been at primary school. He associated that period with being bullied, unhappy and unpopular.

Then, one day, he discovered nutrition - probably through a combination of PSHE (Personal, Social, Health and Economic) lessons at school, television programmes on healthy eating and the men's health magazines which my husband used to buy. These would feature photos of Adonis-like men with rippling muscles and six-packs, along with the appropriate diet and exercise regime. Ben devoured these magazines as if they were going out of fashion. And, as he read about nutrition, he began to think: "Good grief, I eat an awful lot! You wouldn't believe how many calories I consume!" Then he examined the fat content of what he was eating and was absolutely horrified.

It was then that he had a Eureka moment. He began to think: "If I substitute all the high calorie, high fat foods I'm eating for low calorie, low or no fat versions, then I'll be consuming the same quantity but with less calories, meaning that I won't get fat - so I can cut down on the sport!" It seemed like

the magic bullet.

So this is what was going on inside his head, probably for the first six months of 2009. Meanwhile there were other subtle changes taking place. Unbeknown to us he was cutting back on school dinners, going for the salad option rather than the cooked meal; fruit for dessert rather than sponge puddings and custard. He was cutting out breakfast, too. But his Dad and I had no idea that this was going on. I mean, why would we? Why on earth would we be looking out for something sinister in the eating habits of our healthy, happy, rugby-playing son who had eaten everything that was put in front of him since the day he was born?

It wasn't until we went on holiday to France in the July of 2009 and were with Ben 24/7 that the changes became more apparent. Ben was doing an awful lot of exercise. He was swimming up and down the pool every day, he was going for runs, he was doing lots of sit-ups and press-ups. He was refusing to eat the kind of stuff he'd normally eat on holiday like ice creams, biscuits, cakes, bread and butter, and meanwhile he was still reading those men's health magazines which he'd brought along with him.

Rather than being worried, however, we were impressed with Ben's apparent dedication to health and fitness - so much so that my husband offered to sign him up with the local gym. Back in England, Ben went up to the gym every day, pushing himself on the machines and supplementing this with gruelling daily runs plus umpteen sit-ups, press-ups, crunches and so on.

But we just saw it as Ben wanting to get into top-to-toe condition, ready for the rugby season in September. He was just about to go into year 11, GCSE year, when everything cranks up a gear in rugby; the game gets much more physical.

But as time went on, we began to be aware of other things - behaviours that

began to set off the alarm bells. For instance, we subscribe to the BBC Good Food magazine and the minute it arrived Ben would snap it up and re-write all the recipes. He'd cross out things and announce that "No, you don't need oil!" or whatever. He'd put great big crosses through recipes that were total no-no's - cakes, pies, fried things and so on. Meanwhile he was meticulously analysing the nutritional content, in recipes and on food packaging. He was going for low fat or no fat foods only. It was just this obsession with healthy eating. It was all, "Mum, you should be eating healthily, Mum you don't need biscuits, Mum we're all going to have a healthy Christmas dinner this year, we're going to have fat-free sushi and things like that instead of the normal meat and two veg".

He was cooking an awful lot, too, devising all manner of low or no fat recipes, some of them pretty unpalatable and dry. He began to get ritualistic in the way he would prepare his desserts. Ben had always prepared his own desserts, mainly because he would eat so much more than his Dad and me. But, by the end of the school summer holidays in 2009, he was doing odd things like chopping fruit into tiny pieces and carefully arranging them on a plate. It would take ages - to arrange and to eat. In fact he was eating an awful lot of fruit; fresh and dried. Fruit and salad, really, and vegetables. Oh, and he was cutting himself off from his friends. I don't think he'd seen any of his friends all summer long which was really unlike Ben who'd been so popular since he started secondary school.

Meanwhile his mood was dropping. He was getting snappy, depressed and most noticeable of all he was losing weight. By the end of the summer he must have lost around a quarter of his bodyweight, which brings me to Problem Number 1 when you have a boy.

For a start my husband and I didn't know that boys got eating disorders and

so we weren't looking out for one. Ben didn't know that boys got eating disorders, either, so he didn't recognise an emerging eating disorder in himself. He knew that something was going on inside his head but he didn't know what it was.

So there we were, encouraging all this healthy eating and sport and yet, by the time September came along, we knew that something was wrong but we didn't know what, especially as Ben was losing weight - and didn't seem to be able to eat more to compensate.

I'd say, "Look, Ben, if you're doing all this exercise then you need to be eating a heck of a lot of food. You need all these proteins, and all these fats, and you need a balanced diet". But he'd always come back with some "science" that he'd invented as to why no, no, no he had to have low fat stuff or no fat stuff, why fats were bad and did all these horrible things to your body. He'd insist he had a low metabolism and so he didn't need to eat all this stuff.

Anyway at the end of September I decided to take him along to see the GP. Ben was changing; he was not the boy he used to be, physically and mentally. I thought that maybe the GP would talk some sense into him and get him to stop this silly "healthy eating" nonsense. However this led to Problem Number 2: I don't think the GP recognised it as an eating disorder, either.

I mean, let's face it - skinny boys aren't unusual, nor are fussy eaters, especially boys. Boys don't get periods so there were no periods to stop. Ben hadn't been weighed and measured regularly throughout his life and so there was nothing to compare with. And the GP wasn't familiar with Ben; he hadn't seen him as a rugby player. Ben rarely visited the GP, because he'd always been so very healthy.

Also, crucially, his BMI was still "just" within the healthy range. Remember,

Ben had been huge. He'd been a big, muscular prop forward; we used to joke that he was made from concrete. And now he was a skinny waif, a shadow of his former self, and yet his BMI was still "just" within the healthy range.

Also, Ben was in denial.

He sat there in the GP's surgery saying: "There's nothing wrong with me, it's my mum, she's making it all up, she's paranoid." He was sent home, told to eat sensibly and come back in a few weeks. This happened a few times throughout October. On one occasion he stormed out of the surgery shouting, "I don't know what I'm f***ing doing here!"

Meanwhile I was beginning to panic. I was Googling the symptoms and every time I did, eating disorders came up, anorexia especially. And, oh, it was like a bombshell; I was devastated. Ben was transforming in front of my eyes. And he wasn't just losing weight. By the end of October 2009, he was becoming crushingly depressed. He was becoming out of control, at home and at school. I was forever being called into school to pick up the pieces and take Ben home because he'd got out of control, he'd locked himself in the boys' toilets or he'd thumped a wall and broken his hand as he did on one occasion. Or he was in floods of noisy tears.

One day he charged out of the school dining room and headed for the river at the bottom of the playing fields. The reason? He simply couldn't stand being in the dining hall surrounded by food and people eating.

He'd ask to be excused from lessons to visit the bathroom, only to run around the grounds because his exercise cravings had got too intense.

He was experiencing vicious mood swings: really deep, dark depression and violent behaviour, especially at mealtimes which were a nightmare. He even developed a different voice: the voice of the eating disorder which was low and slow, expressionless and monotone, almost evil. It sounds crazy but it was

as if he was possessed. We even began to refer to it as the “demon”.

Meanwhile Ben was continuing to isolate himself socially; by this time he’d totally cut himself off from his friends - Ben, who’d been the most popular boy in his group.

He was also insisting over and over again that he was fat - and he wasn’t just fat, he was getting so “disgustingly, horribly fat”. He would sit on the sofa and pinch the “rolls of fat” on his stomach. He’d be in floods of tears about how “obscenely fat” he was, even verging on the “obese”, yet all we saw was skinny Ben who was disappearing before our eyes.

We’d say things like: “Look, that’s just skin, not fat!” But he couldn’t see it. He was becoming totally irrational in his thinking - and he was losing more weight.

On one occasion the school nurse called me in because Ben had done something or other. We had a chat, and she told me all about anorexia. She also told me about CAMHS and insisted that I go home, call the GP and get an urgent referral for Ben. So I did. This would be around the end of October and led to Problem Number 3...

I don’t think Ben’s case was seen as urgent. It took a whole month for the acknowledgement letter to come through. I called the number on the letter expecting to book an appointment. Instead I was told he would be put on a waiting list; it could be 18-22 weeks before he was seen by CAMHS. A quick calculation told me this could be Easter.

Now, as many parents who have battled with an eating disorder in the family will know, the illness tends to creep up on its victim, ever so slowly at first, and then all of a sudden it goes - whoosh! - and everything falls of a cliff. It begins to escalate at a horrific pace. It’s so fast, it’s like a hellish roller coaster that you can’t stop. By Christmas I was getting really, really frightened.

And the GPs couldn't do anything to speed up the CAMHS assessment. I was desperate.

Thankfully I managed to bring in a private therapist in the run up to Christmas. She was a CBT therapist. I'd read somewhere that CBT was a good "cure" for eating disorders, so I thought, well, maybe a few sessions with her will turn things around.

Unfortunately they didn't; they didn't do anything, really. By now, Ben was too entrenched. By January he was a shadow of his former self. He was an emotional wreck. His life revolved 100% around food and exercise - input, output, input, output...

He was also finding it increasingly impossible to be in school. Every day I found I was having to pick him up early because something had happened; he had got into some scrape. In the end we removed him from school altogether. Thankfully the school was incredibly supportive. The staff were absolutely fantastic.

Shortly before we took him out of school, I received a phone call from the school nurse. Not unusual; by this time I was hearing from her virtually every day. This time she said, "Look, I think you should come in quickly because Ben's pulse is really low and I'd like the hospital to see him".

So I charged into school, grabbed Ben and rushed him to the local hospital where he was hooked up to machines and they took blood. Then they put him into an ambulance and took him down to the specialist cardiac unit at the other big hospital in our city where he was wired up again.

This led us to Problem Number 4... And, looking back, it's something I'm still puzzled about. It's that the cardiac staff didn't seem to make the connection between a slow heart and an eating disorder. The consultant said: "Well, I understand Ben is very athletic and we find that athletes' hearts tend to slow

right down because they get so fine-tuned. So in the absence of any other reason, I assume it's because Ben's sporty." And so, because the various tests were coming back clear and his pulse had stabilised, Ben was discharged.

I was terrified. After all, you can't see what's going on inside your child's chest and, unless you take their pulse every minute of the day, how would you know if it dropped again? I didn't feel reassured by what the consultant had said, either, because - yes - Ben was very sporty but only because, by this time, exercise was a means of purging. He was exercising to extremes, much more than his increasingly emaciated body could cope with. He hadn't an ounce of fat and he'd lost all his muscle, and of course the heart is a muscle. So, to me, it figured that this was what had caused the heart scare.

The first thing I did when we got home was to call CAMHS. I explained what had happened and insisted that Ben was seen right away. Thankfully a psychiatrist came on the line and said, "Yes, yes, I understand, I'll see Ben on Monday. Bring him in at 8 o'clock".

Oh, I thought, "Phew...! Finally the lifeboat has come to rescue us; everything's going to be alright. CAMHS will fix it quickly". And I assumed they'd probably fix it in 10 or so sessions. For some reason I had this figure in my head that it would take a handful of sessions to get Ben back to normal.

...Which led to Problem Number 5...

When I took Ben into CAMHS on the Monday morning and they were actually seeing him face to face, I don't think they thought it was as serious as it was. You see, by now his BMI was only "just outside" the healthy range. Worst of all Ben was behaving impeccably. He was playing the model patient. So what they were seeing was someone who looked okay, whose BMI was relatively okay and who was behaving okay.

After a couple of weeks they even talked about spacing out the

appointments to fortnightly. And I was thinking “No!!” because, you see, Ben was immaculately behaved at the CAMHS sessions. But the instant we left the building - whoosh! - it was like Jekyll and Hyde. He would transform into a monster and would punish me all the way home. Once inside the house he’d revert to this evil, vicious, demon-possessed thing. This transformation took place every time we went to CAMHS. But, of course, CAMHS didn’t see any of this.

Also, Ben was mainly having individual sessions with the psychiatrist who would disappear at the end before I could grab her for a word, so it wasn’t as if I was able counteract what he was saying or doing in the sessions. Also, we had no direct contact with the therapists by phone or email; we had to leave messages which would be placed in their pigeon holes and hope they would call us back.

This led to Problem Number 6 which was that, because - I think - Ben didn’t look too bad and his BMI was still relatively okay, the focus wasn’t on re-feeding. The emphasis was on the talking treatment, of talking to Ben until he wanted to recover. I wanted an eating plan, because I knew he’d lost a quarter of his bodyweight and he was not the boy he had been; he was a shadow of his former self. I wanted to feed him up and put all the lost weight back on. I just wanted the old Ben back.

Then in March a wonderful thing happened. I discovered the Around The Dinner Table forum and F.E.A.S.T. This really was the lifeboat in the stormy sea. The support I received from fellow parents coping with children with eating disorders was amazing, as were the links to resources and information. The more I talked on the forum and the more resources I read through, the more my instincts were proved correct - primarily that I needed to get the weight back onto Ben and get his brain healed and nourished through a healthy,

balanced diet. This was the way that I was going to get him well.

The trouble was, my hands were tied. I had the knowledge, I knew what needed to happen but I had no means of doing it. I asked CAMHS for an eating plan and they dug out a photocopied sheet for me. But, apart from that, I received little support in implementing re-feeding. As a result, I had to tweak the plan almost out of recognition because Ben wouldn't eat half of the foods on it. Thick slices of toast, butter, sponge puddings, donuts, cream, custard... I hadn't a hope in hell of getting him to eat that kind of stuff!

Anyway, by hook or by crook, I did manage to get Ben to eat more food: three meals and three snacks a day. We had two or three months of absolute hell, but I managed to get some weight onto him. But then, around May or June, he "downed tools" and refused to continue with the eating plan.

CAMHS said okay, because it was felt that the eating plan was too stressful for Ben. It was too much for him to cope with at what was "already a very out-of-control time for him". So it was felt that it would be easier if we backed off a little and didn't place as much emphasis on food, and concentrated on the talking treatment, of finding out the reasons why the eating disorder had come about and teaching Ben how to make "the right choices".

And so, towards the end of spring and the beginning of summer, Ben gradually took back control of all his meals except the evening meal which I would prepare. The three snacks went out of the window immediately and he cut back on everything else. As a result, over the summer of 2010, Ben lost weight.

As his weight went down, his mood went down too. He began to get really depressed and his behaviours became extreme and increasingly violent. If I thought they'd been extreme before, they were nothing like they became over this period, the summer I now refer to as "the summer from hell".

He threatened suicide on a number of occasions and exhibited risky behaviours. He tried to climb onto the house roof at one point; I had to pull him back in. He simply didn't care what happened to him. One day he sent an email to a friend saying, "Give me three good reasons why I should carry on living". The first I knew of this was when the friend's frantic mother telephoned to warn me.

That summer it was just Ben and me, because Ben's Dad was working away from home. It was me, alone in the house, with Ben and the demon. I was terrified because he was getting physically violent. I'm only small and he's tall. Even though he was very thin by this time, he was still very strong. On one occasion I rang CAMHS because I was petrified of what he might do and I was unable to control him. Our regular psychiatrist wasn't there but I spoke to the duty psychiatrist who promptly informed me that "We're not a 24-hour emergency service, you know!" I just felt so very, very frightened and alone.

Things started to get worse and worse - and worse. Then, in the October, Ben's pulse plummeted again and he passed out at school. He was back in hospital. But this time he was violent. He tried to discharge himself. He had to be restrained by security staff and the police were called because - thankfully - the doctor told Ben that he wasn't going to discharge him until he'd located the cause of the dangerously slow pulse. He said that Ben could either come back and have the blood tests done voluntarily, or he could be carried back and have them done by force.

Meanwhile Ben was kicking things, he was shouting and swearing, and he had to be restrained by the male nurses. It was horrible, horrible, horrible. I could see everyone looking at me thinking, "Can't you control your son?" And there I was longing to shout, "This isn't what Ben is like; he's normally really, really well-behaved, he's just not this person at all".

Unfortunately the understanding doctor's shift ended and another doctor was brought in who took one look at the violent, swearing Ben and fled! The nurses took Ben's pulse which was now relatively normal again as a result of all the violent activity. Ben was discharged.

Thankfully this incident led to CAMHS taking the situation very seriously. They told Ben that if he deteriorated any further, or his heart continued to be problematic, then they wouldn't hesitate to hospitalise him, and meanwhile he'd need to visit the GP for regular ECGs and blood checks. The word "sectioned" was used.

Ben was so frightened by this incident, and at the prospect of being forcibly hospitalised, that he made the decision to work with us, rather than against us. Attitude-wise it was a turning point.

The problem was that, when push came to shove, he was unable to do anything about it. He was so trapped by the vice-like grip of the eating disorder that he simply didn't have the strength to fight it.

So November went, December went, January went and round about February 2011, Ben's weight reached its lowest level since before the eating disorder. By this time he was exercising round the clock. He was stuck in a kind of Limboland and nobody had any solutions - CAMHS didn't know what to do, I didn't know what to do and Ben didn't know what to do. He was getting frustrated at the way nothing seemed to be moving forward on the recovery front. Meanwhile I was worried that he was about to give up. He was getting violent at the CAMHS sessions; violent with frustration more than anything else, throwing tables and chairs around.

And then, round about Easter, I was on the ATDT forum when I came across a thread about something called "contracts".

This family (from the States) had attended an intensive therapy programme

at the University of California San Diego Eating Disorder Centre. And one of the programme components was something called Behavioural Contracting.

From what I could gather, this seemed to be a system of rewards and incentives which would encourage progress, and assist the individual in facing and overcoming challenges and hurdles, hopefully leading to very gradual recovery. I was so inspired that I told Ben about it. I said, "Look, I believe we should give it a go. Nothing else has worked, so let's try this as a last-ditch attempt". Thankfully, Ben was so desperate to stop treading water that he said "Yes".

It turned out to be the best decision we made.

We decided to implement a system of points which would add up to cash. I certainly don't advocate cash rewards for everyone but it worked for Ben because he wanted a new games console. We developed a kind of currency whereby three points equalled £1.

Ben got points for weight gain. He got points for eating sufficient food - the more he ate, the more points he got. He got points for keeping his exercise under control, within certain agreed limits - and for facing fear foods and overcoming them. He got points for things like socialising and for getting back into school; the longer he stayed at school on any one day, the more points he got.

So that, loosely in a nutshell, is what our contract looked like.

Now it's important to point out that this wasn't a bribe or punishment; the contract was just a gentle encouragement as we worked together as a team. We'd get together at our contract meetings, as we called them. We'd agree that neither of us was permitted to yell at the other. It was simply a time to chat rationally, without the eating disorder "demon" being present.

We also began to go on lots of leisurely walks together. We'd talk about

stuff, about how the contract was going and so on. Very, very, very gradually we began to see progress - very subtle changes, extremely slow, often painfully slow. But they were positive changes. Everything was improving. The only problem was...

...And it was Problem Number 7. I wanted a bigger push on the weight gain front. I was desperate to get Ben back to his pre-anorexia weight. But it was all about being happy to settle for "good enough". I was told that some individuals "choose to remain at a low weight" because it's "easier for them to cope with". Now, for me, "good enough" isn't good enough. Fully recovered means fully weight restored.

But, thankfully, now that Ben was eating a far more balanced diet as a result of overcoming fear foods, especially fats, his thinking became more rational and his mood began to improve. So, very gradually over the summer, autumn and winter of 2011, things moved slowly forwards. Then, in March 2012, Ben - now 18 - was discharged from CAMHS. I checked his records and noted that he was the same weight on discharge as he'd been at the start of treatment. Remember he'd put on a bit of weight at first and then gradually lost weight until we introduced the contract. Then it had begun to gradually creep up again. As a result, when Ben was discharged after around 26 months of treatment, he was the same weight as he was at the start, and this concerned me.

There were a number of other outstanding issues, too. Sure, we'd moved mountains, but there were more mountains to move. However, because Ben had been discharged, we were left to our own devices. The months that followed were very tough, including one failed attempt at university, but we managed to plough on together: Ben and me, working together as a close-knit team.

Then, in September 2013, Ben attempted university for the second time and this time he stayed.

I was so proud! By now Ben was eating properly. If his weight ever dropped, he'd put it back on again. Remarkably for someone that had been socially isolated for so long, he threw himself into the social side of university, despite being terrified. It was punishingly tough for him. It's hard enough for any new student, let alone someone like Ben with all his baggage and social anxiety. It was as if Ben had been on Planet Zorg for three or four years. Ben said he felt as if he'd been asleep.

Back in 2011 I began a blog to help other families of boys with eating disorders, because I didn't want them to go through what we had gone through. I wanted to help them to identify the signs of eating disorders in boys and to take urgent action, to know how to approach their GP and demand a speedy referral followed by good, evidence-based treatment - and to demand full weight restoration.

This led me to the publication, in March 2013, of my book *Please eat... A Mother's Struggle To Free Her Teenage Son From Anorexia* which describes our story in depth, closely followed by *When Anorexia Came To Visit* in which I talk to 20 other families about their experiences of an eating disorder.

So to summarise...

First, my Biggest Regret (apart from Ben getting the eating disorder in the first place)... It is that Ben was never pushed to get back to his pre-anorexia weight. He left treatment at the same weight as when he began.

Why do I think this is?

One of the many reasons may have been because CAMHS hadn't known Ben at his pre-anorexia weight. His start / finish weight was still "just" within the healthy range on the charts. Also, we were all scared of "the anorexia bully" if

we pushed Ben “too far”; we were worried that he might disengage with treatment - or worse.

The good news was that Ben got on well with his psychiatrist and took on board much of what she said. I truly believe that if she’d pushed for full weight gain, he would have listened to her. But these final kilos and the other outstanding issues were left to me to sort out, and it was tough. I really don’t believe that you can cut a child off from CAMHS treatment, simply because they’ve reached the “magic” age of 18. Although we could just about see the finishing line at this point, we weren’t there yet. Ben needed further treatment, but he didn’t get it. Also, now he was 18, the law permitted him to make his own decisions as to whether or not he continued with therapy. But we got there in the end. It was slower than it should have been, and tougher. But we got there, the two of us, because basically we’re strong people who refuse to give in to the “ED”.

What was our Biggest Success? The contract, of course! And it was all thanks to information that I found on the ATDT forum.

Certainly, this kind of contract wouldn’t work for everyone, but it came at just the right time for us - when Ben was stuck and unable to move on. It helped him to escape from Limboland, gradually gain weight, face and overcome fear foods, conquer other challenges and control his exercising (from Day 1 of the contract he managed to keep his exercise within strict limits). It helped him to ease himself back into school. And it helped Ben and me to work together as a close-knit team to kick the anorexia out of his life. Ben says the contract is the Number 1 thing that helped him to recover.

In June 2013, Ben won a holiday in Cornwall in a competition, so he and I drove down there. Ben suggested we have a clotted cream tea in a café attached to a picturesque watermill. As I watched him consume the scones,

clotted cream and jam, and add full-cream milk to his cup of tea, I took the photograph I thought I'd never take.

In fact I took several, mainly because I couldn't believe this was happening - Ben munching his way through a Cornish cream tea, at his suggestion, without a hint of anxiety or hesitation. This was the boy who - on one occasion - collapsed in a heap of noisy tears because he couldn't face the idea of semi-skimmed milk, or even "orange top", a half-way-house between skimmed and semi-skimmed. And here he was, in these photographs, with the arch dairy "baddie" of them all... clotted cream!

Well of course I was delirious with delight. Yet on the surface, I pretended it was just a normal occurrence. (But later I told him how incredibly proud I was of him!)

Today, in late 2013, Ben continues to eat and cook amazing things - healthy, balanced meals that help him continue to put on weight. These days he does virtually no exercising. He is still thinner than he used to be and we are still working on those last few kilos - both of us. But, on the whole, it's working. Ben says that he never, ever wants to go back to the hell that was the eating disorder, the devastating leech-like parasite that destroyed so much of his teenage life.

And, believe me, neither do I!

Wednesday, 27 November 2013

Update, plus the book I'm about to read

Not much has happened on the university front this week. This is because Ben has been off sick with some kind of fluey bug. Thankfully he has kept eating, and has also put on weight which is excellent news. So, with any luck, it's back

to uni next week and, also with any luck, back to the attempt to build up a new network of friends. Meanwhile, he is well enough to cook dinner for tonight and is doing a stew with dumplings, the kind of meal I could never imagine him eating in the Bad Old Days of his eating disorder.

I've been kind of quietly busy this week. Busy with my copywriting work and getting in touch with some of the people I promised to get in touch with following Friday's conference.

And updating and expanding my Bev Mattocks website.

I have also ordered a book with a similar title to my book *Please eat... A mother's struggle to free her teenage son from anorexia*. This book, by a US mum, Susan Barry, and published in June 2013, is entitled: *Dying to be perfect: A mother's story of her son's battle with anorexia*.

The difference is that whereas our story has a happy ending, hers doesn't. As the very first chapter explains before looking back on his all-too-brief life, her beautiful son, TJ, passed away from complications of his eating disorder at the age of 22. Addicted to exercise in a similar way to Ben, he was doing his daily sit-ups and crunches, in his apartment at university, when his heart simply gave up.

It's going to be difficult reading and it isn't a book which I could have read when we were in the throes of Ben's eating disorder, primarily because of my constant fear that I would lose my son to the illness, especially with the issue of the heart and Ben's history of heart problems at the height of his anorexia.

But I know that now, at the end of 2013, I will find it easier to read an account as tragic as this one. I don't doubt that the tears will flow, and I will keep you posted on my progress as I have a gut feeling that it's going to be an important book in the global fight to raise awareness of eating disorders in boys and men.

Thursday, 28 November 2013

What every parent dreads... but what a mother!

Losing your beautiful child to an eating disorder is every parent's worst nightmare when battling with this horrible illness. It is something that is constantly at the back of our mind as we watch our child disappear and transform in front of our eyes, physically, mentally and emotionally. And, unlike virtually any other potentially fatal illness, eating disorders - and especially anorexia as it advances and begins to consume the young person from within and take hold of their minds - has the patient fighting against treatment and support. It's not that they don't want to get better, it's just that they can't without a heck of a lot of highly skilled professional help. This is made exponentially worse once a young person reaches the age of 18 and is legally permitted to choose whether or not they receive and / or engage with treatment. If, indeed, that treatment is any good.

I'm already half-way through *Dying to Be Perfect: A Mother's Story of Her Son's Battle with Anorexia* by Susan Barry which describes her son's losing battle with anorexia. In the four years leading up to his 18th birthday it appears that her son, TJ, simply 'played the system', a bit like Ben did. If you remember from my book *Please eat...* Ben succeeded in deceiving CAMHS for some time, convincing them that he was actually relatively OK. So much so that they began to space out our appointments just weeks into treatment. I was terrified they were going to discharge him.

If anorexia can succeed in deceiving the mental health professionals, then it's got a pretty easy job of convincing everyone else they come into contact with that nothing is wrong.

Which is why, in their ignorance, sports coaches continue to let these young people exercise round the clock when, in fact, it could kill them. Back in autumn 2009, not once did Ben's cross-country running coach ever tell him to stop flogging his increasingly emaciated body to exhaustion twice a week.

And all the rugby coaches did was to move him down to a less demanding team. I thank God that he broke his nose and was invalided out of rugby before he snapped in half. Why didn't I raise my concerns with the coaches? Because, for ages, I - in my ignorance - simply didn't know what we were dealing with. As the parents of a sporty, health-conscious, intelligent teenage boy, it can take months and months for the penny to drop that your boy has an eating disorder, by which time they are already disappearing in quicksand.

TJ, Susan Barry's son, managed to keep his weight at a certain level for four long years, convincing everyone that he was just fine, if a little skinny. Then, once he arrived at the age of 18, he was legally in charge of his own destiny and the anorexia said "No". Fight tooth-and-nail as she might, his mother was unable to help. Legally, her hands were tied. All she could do was watch as the anorexia made it impossible for her son to act on her increasingly-impassioned and imploring pleas.

TJ was well aware of what was happening to him (described in extracts from TJ's diary during this period). He was well aware that he looked terrible because of the extreme weight loss, well aware that the anorexia was forcing him to exercise round the clock and well aware that he was deceiving people whenever he was able. This is the nature of anorexia. It wants to get a vice-like hold on its victim, withdraw him or her from the outside world and strangle and consume him or her until there is nothing left but skin and bone. And the law is happy to allow this to happen because, after all, an 18-year old is an adult, at liberty to make their own decisions.

The law is happy to allow our children to die.

I have said this before that it's way-past-high-time that the law in the UK, the US and other countries stopped treating seriously ill anorexic patients in the same way they treat other adults when it comes to data protection and free will. Unlike virtually any other illness, the patient will often fight tooth and nail against treatment of any kind. While they're still a minor, at least the parents can fight on their behalf, but come midnight on their 18th birthday the parents are kicked out of the equation forever.

It's not that Susan Barry didn't love her son enough. Good God, she loved him to distraction, as much as any good parent loves their child - as much as I love Ben. And she tried as hard as she humanly could. Of course she did! What parent wouldn't walk on hot coals to save their child's life? Yet, because of The System and the insidious nature of this lethal illness, she was able to do little more than just watch as her son wasted away in front of her eyes.

And it wasn't helped by thoughtless comments and actions by the various professionals with whom her son came into contact, from college staff through to clinicians who should have known better.

Then one day she received that telephone call that every parent dreads...

My heart goes out to Susan Barry, an incredibly brave, courageous and loving mother who has put together what must have been an almost impossibly difficult book because she doesn't want other families to go through what they went through. She wants to educate people on what anorexia is really like, deep down, and how it transforms our children's minds, not just their bodies. And she wants to raise awareness of the crazy over-18s law that puts the patient in charge of making their own decisions when it comes to treatment.

And she continues to fight so other parents' children can be saved.

What a woman.

DECEMBER 2013

Friday, 6 December 2013

Be careful what you wish for...

One of the best things I did this year was to publish my books, primarily *Please eat* and *When anorexia came to visit*. Once I got into the swing of things, I was on a roll. I immersed myself in it and loved doing it. And, for the past few weeks, I've been umming and ahing about what to write next, toying with a number of different routes.

Personally I've reached a real crossroads in my writing career. For the past 25 years I've been a professional advertising copywriter (freelancing for the past 15 years or so), but the recession, Ben's eating disorder / post-eating disorder issues, and more recently Google's SME-destroying decision to catapult my business website from page #1 to page #goodness-knows-only-where, have pretty much reduced my business from a successful concern to... well... er... quieter, shall we say...

So I wondered whether to take a year off and do an MA in Creative Writing at one of our local universities. This way I can fine-tune my authoring skills, under expert guidance, to a professional level from a perspective of continuing to write about eating disorders, do ghost-writing, articles, etc, and even maybe some fiction. And perhaps take my freelance copywriting business in a new direction, too.

Since publishing *When anorexia came to visit* in September, I've felt a real

lack of focus and purpose. I've spent loads of time procrastinating and waiting to be 'inspired'. I've devoted oodles of time to Ben and his university problems, too. The result is that I've been feeling pretty down, kind of like there is no focus in my life - well, not a positive focus at any rate.

I just know I want to write and write and write. But not necessarily copywriting which I can do with my eyes closed. I want to write about real, worthwhile, life-changing things. And I want to do it professionally i.e. not self-publish.

I just need some proper guidance.

So next week I'm going to talk to the guy in charge of the (full or part-time) MA to test the water.

I have to laugh, though... (in an ironic kind of way...)

In the spring of 2009 I was feeling as if my life had lost its purpose and focus. I'd fallen out of love with my copywriting business and with the masses of work I used to put into the school PTA. So, although I am not a religious person, I said: "OK, God. If you're there, give me a purpose in my life. Give me something I can really get my teeth stuck into."

And the rest, as they say, is history...

They also say: "Be careful what you wish for lest it come true...".

Sunday, 8 December 2013

Ultimatum agreed by all

The bad news is that, probably due to the gastric flu-ish bug Ben had the other week, he'd lost weight when we came to weigh him this weekend. As a result his weight is hovering around a too low level. Any lower and things could get tricky. The good news is that he is actively working on re-gaining the weight

plus the extra kilos he needs to gain as he approaches the age of 20 in a couple of weeks' time. Because we are all well aware that a further drop could prove tricky, all of us (Ben, Paul and me) have agreed an ultimatum.

If Ben doesn't reach a given weight by the end of term in two weeks' time, he will apply for 12 months Leave of Absence from university. We will then embark on an intensive weight gain regime whilst working on the other bits and pieces that Ben is finding difficult, primarily social anxiety / social skills, probably with the help of a therapist.

He will then return to university in January 2015 and pick up where he left off. If that's what he wants to do.

He may decide to take a Leave of Absence anyway, but I trust him to push for the weight gain he needs to get him back to a safe level.

Thankfully there are no eating disorder behaviours, thinking, etc going on. Also, we all discussed this rationally and sensibly without any yelling.

The reason he may decide to do it anyway is that university is proving a tad too difficult for him at the moment. Not the academic work, but the social side of things - and his low mood. Despite the fact that, before the eating disorder, Ben was 'top dog' in his enormous circle of friends, the eating disorder robbed him of all of this - and it has proved the #1 most difficult thing to sort out in his life.

And, to be honest, the university experience isn't working very well. Especially when coupled with the low mood / depression.

But I am keeping an emotional distance making it clear to Ben that he needs to help himself nowadays. And, if he sees a therapist, then he is responsible for sticking it out, independent of me.

Monday, 9 December 2013

2013 was Meeting New Friends year!

I was just thinking about how many friends and contacts from my enormous eating disorders network I've actually met in person this year, most for the first time! Wow, it has been amazing.

First, there's C who I meet up with on a regular basis because she lives locally. Then in early summer I met up with two friends in London, people I felt I knew well, but had only ever met on the internet, initially via the Around The Dinner Table Forum (for parents of young people with eating disorders).

In mid-summer I met with another mum, in Devon... twice! In the summer I also met up with P, a mum who've I've met on a number of occasions and also J, while I was visiting Somerset.

Then in November, in London, I met a load of contacts at Janet Treasure's eating disorder conference - some for the first time and some I've met before, at other conferences and through the network.

And finally last week I met up with J who came up to Leeds especially to see C (above) and me!

Oh, and I talked with 20 mums for my book *When Anorexia Came To Visit*. So, for the ones I hadn't met before, we got to talk for the first time, even if we didn't get to 'meet in the flesh'.

I hope I haven't missed anyone!

Tuesday, 10 December 2013

Let's talk about PTSD (Post Traumatic Stress Disorder)

For over a year now I've been experiencing disturbing thoughts / behaviours which, when I look at MIND's page on post-traumatic stress disorder (PTSD) or

post-traumatic stress syndrome (PTSS), appear to sum up exactly what is happening to me. I've known this for quite a while, but haven't wanted to admit it. Why not? Because, curiously, I feel as if what I've been through doesn't "deserve" the label of PTSD. After all, I haven't been involved in a war or an horrific event like the London bombings. And no-one has died. (Except my Dad and my friend, Sue.)

"All" I've had to deal with is a number of years of battling with my son's anorexia. Plus, I am so very fortunate on so very many counts. As a result I feel as if I don't "deserve" to feel like this, and I feel extremely angry with myself for being so "selfish / self-centred". Thus far, my self-help approach has been to "Stop thinking about yourself and just snap out of it!"

So let's look at what MIND describes as the symptoms of PTSD...

Reliving aspects of the trauma - vivid flashbacks (feeling that the trauma is happening all over again), intrusive thoughts and images, nightmares, intense distress at real or symbolic reminders of the trauma.

Yes, check the box. Nightmares are proving a problem at the moment - the shouting variety. Over the course of just two nights this week, I woke myself and my husband up twice by shouting loudly. At least one of the nightmares was about Ben. In it, I was resorting to physical violence to get him to resist a relapse back into the eating disorder and to successfully socialise at university. I've been having this kind of nightmare for well over a year. I remember requesting a single room at the FEAST eating disorders conference last November because I was concerned I'd keep a room-mate awake with the noise.

And, you know, I still crumple up when I see physically healthy, happy,

“normal” teenage boys and young men - aware that this is what Ben “should” have been like and probably would have been like if it wasn’t for the leech-like nature of the eating disorder and the way it’s left him looking as if he’s still 15, with depression and severe social anxiety.

Avoiding memories - keeping busy avoiding situations that remind you of the trauma, repressing memories (being unable to remember aspects of the event), feeling detached, cut off and emotionally numb, being unable to express affection, feeling there’s no point in planning for the future.

Yes, check the box. Keeping busy!!! Ha ha, I’ve been drowning myself in activities e.g. writing. Look how quickly I put together my last book! Not because I “rushed it” in the truest sense, but because I worked incredibly intensively with long, intensive days, focusing on the minutiae to get it right. And even then I missed a couple of really obvious typos (now corrected!) which made me feel like kicking myself.

Emotionally numb, yes. Been there, experienced that, still do. And the affection bit. And the future bit, worrying if the legacy of the eating disorder will stay with us forever. Plus the acute feeling that Ben’s eating disorder ate up important years of my life as well as Ben’s. At 55, I am not getting any younger.

Being easily upset or angry - disturbed sleep, irritability and aggressive behaviour, lack of concentration, extreme alertness, panic response to anything to do with the trauma, being easily startled.

Yes, check the box. Cue dinner the other night with me deliberately dropping a

red-rag-to-a-bull type remark into the conversation. Result? A massive shouting match which was 100% my fault and unnecessary.

Disturbed sleep - yes, nightmares (see above). Plus repetitive dreams - anxiety-fuelled dreams. Also I wake up several times, every night, and find it difficult to get back to sleep. So I am permanently knackered.

Lack of concentration... kind of weird when teamed up with "keeping busy", but that's the way it seems to be going... Lots of procrastination at the moment, lethargy, feeling that you "just can't be bothered" and that whatever it is you are about to embark on is just "too big".

Panic response: being on Red Alert most of the time. I've come to refer to it as "spiralling", because it feels like one of those Catherine wheel-type fireworks you light and which starts by slowing going round and round before - whoosh! - breaking free of the pin that's holding it to the wall and shooting, spiralling, into outer space. This "spiralling" seems to be there virtually all the time these days, in the background, being suppressed by me. And every time I get in touch with Ben, or vice versa, or he comes home for the weekend I dread what he's going to say as regards the dreadful week he's had (as a result of the social anxiety) - I am on Red Alert.

Startled, yes. Sudden loud noises, etc are really distressing. Like when Paul's watching the football on the telly and his team scores. "Yes!!!!" he suddenly shouts at the top of his voice! And whenever I hear anything that's remotely like the noise that "ED rages" used to make, I completely freeze. Like a rabbit caught in the headlights, in sheer, ice-cold terror. Again, it might just be something like Paul and Ben watching the footie on telly and someone scores or makes a stupid move.

All of which is why I went to see the GP on Friday - one of the senior GPs. I've been on ADs for a while, but now he wants me to self-refer for therapy.

But, you know, I feel such a fraud. I really, truly feel that I don't "deserve" to feel like this. My son is alive. I am alive. We are all healthy. I should be thrilled. I should be over the moon. I should be on Cloud Nine rather than behaving / reacting in this way.

Get a grip on yourself, woman!

Wednesday, 11 December 2013

So how's the support package going at university?

Not very well, to be honest, after all those positive vibes. And it's not just their fault; Ben isn't contacting people when he could be. He is sometimes, but not as much as he could. And, sadly, he says that the counsellor guy is "rubbish". Plus, we haven't heard any more from Emily as regards the Wargames group.

Having said this, Ben has seen the university GP and got some meds. He has persevered with the counsellor guy, but we are now trying out someone privately to see if this will help him with his social anxiety and depression.

University is just so very, very stressful for any new student, let alone someone with Ben's massive baggage. In my opinion, I would think very, very carefully before sending your eating disordered child - or recovered eating disordered child - to university before they are totally ready. Even though you might think they are ready... and, remember, we did last summer in 2012 and were proved wrong... they might not be. This year, my eyes were open wider and I've been watching carefully.

But, to be truthful, I am disappointed with the university's support which promised to be outstanding.

If the student doesn't constantly reach out to take advantage of these services, then they don't seem to come after him. It appears to be a one-way

thing. And people with mental health issues can hesitate to reach out, at least in the case of Ben...

So the 'jury is out', so to speak, about which direction Ben's university experience will go from here.

And try as I might to 'detach with love' (see previous posts), it is bl**dy hard and bl**dy stressful and anxiety-provoking at this end.

It is also terribly sad and disappointing, know that your child isn't really enjoying the experience.

Or maybe even hating it.

Thursday, 12 December 2013

"Post" Traumatic Stress Disorder implies that it's "in the past"...

Not in any way belittling the Post-Traumatic Stress Disorder (PTSD) struggles of people who've been through a severe trauma that happened in the past i.e. it has been and gone, and is no more... I'd say that there is another branch of PTSD which is a combination of past and present, which is particularly tricky to deal with or go through. This is when the primary trauma has taken place, but that isn't the end of it. There is still an element, or elements, that are present. So not only are you re-living past events, you are living present day events, too. In other words, it's a double-whammy of horribleness.

I think this is why my symptoms (for which I consistently score 100% in PTSD online diagnosis questionnaires) may have become stronger since Ben went away to university.

In addition to all the stuff in the past (described in all its gory detail in my book *Please Eat...*), there is the awareness that Ben, who was slowly improving on all counts: weight, mood, attitude to life and so on, has slipped backwards

since he went away in September.

To be honest, I imagine this is very common when a former eating disorder sufferer goes away to university. I don't believe it is unique to Ben. But it is worrying.

With trauma that is "in the past", I guess the therapists can ultimately convince your mind that it's "been and gone". It is no more, and it is unreasonable to be on constant Red Alert in case the past trauma re-occurs. The chances of being involved in a terrorist bombing more than once in the Western World, for example, are fairly low.

Yet with an eating disorder, the parent has all the horrific stuff from the past which, as is the nature of PTSD, tends to surface as PTSD after a time-lapse i.e. not straight away. (Apparently, immediate PTSD is easier and quicker to fix.) But they also have troubling things that are going on in the present which may or may not lead back down the rabbit hole, to Square One.

As a result you aren't just on constant Red Alert, you are on Double Red Alert, or even Treble Red Alert - for things past, present and future, and - unlike the terrorist example above - it is a realistic worry.

And realistic worries that could actually happen (and we all know how easy it is for a former eating disorder sufferer to slip back) aren't the kind of worries that a therapist can persuade you, by whatever means, are irrational or unreasonable.

They could be real.

So I'm not entirely sure how it can be treated...

Which reminds me... and this will make you smile...

Back in the summer of 2010... the "Summer From Hell" when Ben was doing risky things and threatening suicide most days, and had basically gone OTT and into the outer stratosphere on eating disorder behaviours... I had some

counselling sessions on the NHS in an attempt to calm me down so I'd be a better carer for Ben i.e. for me to stop screaming with panic and fear internally. (And, not infrequently, externally.)

The very young counsellor approached it as she might approach someone who was suffering from stress at work. In other words, there is always the option to move jobs. And at least, when you're home in the evenings and weekends, you can take a breather and gather your thoughts together.

I didn't seem to be able to convey to her that caring for someone in the grips of anorexia, at its most violent, vicious, irrational and suicidal, simply isn't like this...

You have to laugh...

And today I am being assessed (over the phone) again.

We shall see what happens.

Sunday, 15 December 2013

A curiously liberating week, all in all

Firstly, this week seems to have gone better than expected for Ben at university. He's been socialising and he's been working hard at re-gaining those few lost kilos. His team even won the uni Christmas Quiz at the student union on Thursday night. The week ended with Ben inviting me to take him out for lunch at Nando's where he ate a large plate of chicken salad with pitta bread and olives on the side, followed by two large helpings of chocolate frozen yoghurt, followed by snacking on a large tub of popcorn all the way home. Ben's mood was up and his Monday session with a new counsellor (to work on depression / social anxiety) seemed to go well. The only downside is that his weight has only gone up very slightly. So this week, he is intent on eating even

more in a bid to get up to the weight he needs to be at 20-years old. His birthday is a week tomorrow.

For me, it's been a curious week which, when I look back, has been both liberating and enlightening. As you know, I was well aware that all was not well inside my head and that, following some research into the symptoms, it was probably some kind of Post-Traumatic Stress Disorder type thing, kicking in some time after Ben had climbed out of the 'rabbit hole' and things were moving along much more smoothly.

This can be the nature of PTSD. It can kick in weeks, months or even years after the major trauma.

I decided the trigger probably was Ben going away to university in September and the various teething troubles he's experienced which have led to me having to resurrect some of my old Ben-management skills and a fair bit of anxiety, while doing my best to 'detach with love' from Ben and encourage him to be independent and responsible for his own actions.

Earlier this week, as you will know, I felt particularly 'strange', especially when dining out with my mum and sister on Tuesday night. The PTSD-like symptoms were positively screaming inside me, yet outside I was kind of numb and frozen to the spot.

On Thursday I spent one-and-a-half hours being assessed over the telephone by a member of the local primary mental health team. The diagnosis, she believes, is PTSD and it needs treatment, so I've been put on a waiting list.

Meanwhile, I've been reading a lot about PTSD and it's been kind of liberating.

Just like an eating disorder, it is thought to be biologically-based. Prolonged exposure to trauma / stress is believed to 're-programme' the brain so it gets stuck in alarm-mode. Rather than explain it here, this excellent article explains

the way the brain gets 'stuck'. And to unstick it, the brain needs some outside help i.e. therapy. But simply recognising it as a biological thing - in other words it is 'not my fault', is not something to feel ashamed of or think of as a weakness, and not something I can just 'snap out of' or do relaxation exercises to overcome - is the first step in helping the brain get back to 'normal' mode.

So all of this has been really positive and I feel a lot better because of it. Of course my brain is still stuck on 'red alert', but at least I know that steps are being taken to reverse this - on an external help basis (therapy), and through self-help.

Sunday, 15 December 2013

Triggers...

Talking about PTSD triggers... Just when you think you've got your head round what's going on inside your head, you get triggered by something. Yesterday's trigger was a link someone had put to a report on Sky News about a university rugby team and their latest star player. Guess who this player turned out to be? If you've read my book, *Please eat...*, you will know him as Ben's friendly rival, Kieran. Ben's friend and rival on the rugby and sports fields, and in the classroom. Whoosh! A kind of unpleasant explosion went off inside my head.

"And Ben was better than Kieran at rugby, too," said my husband wistfully.

Which takes me back to that blog post I wrote in early July 2011 about the time I spent an afternoon chatting to Kieran's mum while the two of us watched the school sports day - the sports day two years after the one where Ben beat Kieran in the 1500 metres, also described in my book.

At the moment these flashbacks to 'what could / should have been' had the eating disorder not consumed the last three years of Ben's promising school,

social and personal life - and almost his physical life as well - seem to have a particularly unpleasant effect.

They always did make me feel heart-broken. But at the moment, they also exacerbate the alarm button feeling which, as described in the last post, is stuck on red.

Wednesday, 18 December 2013

To all those of you who are finding this Christmas difficult...

Christmas 2009 was a nightmare for our family. I spent Christmas Eve in floods of tears, listening to Carols from Kings on the radio, something I used to do on Christmas Eve with great joy. Christmas 2010 was a nightmare, too. I remember cooking Christmas dinner in tears - the result of a screaming match between Ben, his dad and me over some food issue. Christmas 2011 was better. It was also my friend Sue's last Christmas and, unable to raise the energy to cook a meal for herself, she spent the day with us. Thankfully last Christmas, at my sister's house, Ben tucked into a big Christmas dinner. The cat came along, too, for the day and we had a fantastic time. As for this Christmas?

The Bad News is that I am completely emotionally numb, probably as a result of this PTSD-type thing that's going on. It's a real shame, because I just feel as if I'm observing from afar, like a Martian might observe curious earth activities. I go through the motions, but there is no emotion.

I am well aware that this Christmas will be tricky for a lot of people - outside the world of eating disorders as well as inside it.

I know of families that will be visiting their children in hospital on Christmas Day. The eating disorder has made their children so sick that they simply can't be discharged back home. Not even on this, that most special of days.

And if they were discharged for the day, any of us who has lived with an eating disorder at Christmas will know that it's a tremendously stressful and distressing time.

It is the one day in the year when the Western World goes mad, as far as over-indulging in food is concerned. We eat until we can eat no more. And then we complain about indigestion, force some more food and drink down ourselves, pass wind, and fall asleep in front of Dr Who.

Another slice of chocolate log, anyone?

There are so many ways that this heightens the contrast between everyone else and the individual suffering from an eating disorder. Here they are surrounded by all the food they could eat... the food that could make them well... even save their life. Yet this illness forces them to starve themselves. Sometimes to death.

Perhaps they are also surrounded by relatives that simply don't, can't or won't understand. People of the "Just tell her / him to eat for God's sake!" mindset.

Uncle Fred slaps her / him on the back exclaiming: "You look like you could do with a square meal inside you! Tuck in!"

Meanwhile cousins Thingy and Whatshisname descend on the festive fare like vultures, demolishing everything in sight while she / he picks at a satsuma.

Ah, teenage boys must have hollow legs... I don't know where they put it all!

And then there is the stress. The constant pressure of being on Red Alert in the knowledge that your child could flip at any moment. And it's virtually impossible to feast and celebrate when your child is sitting at the dinner table staring at an untouched plate, tears streaming down their face. Or causing a scene.

Meanwhile, the other guests may attempt to pretend it's not happening.

Oh, and you, as a parent, have flashbacks to the days when your child was little - the excitement of Santa having visited, the thrill of chocolates and snacks. Preceded by school nativity plays or carol concerts. And as they get older, Christmas parties. Or, in our case, Ben's birthday party. Ben's birthday is two days before Christmas.

Which makes it even worse when the eating disorder is around...

But, you know, I'm finding this post really difficult to write. Not because it brings back painful memories, but because I currently feel nothing at all.

Except empathy for other families entrenched in this devastating illness this festive holiday season.

May your next Christmas be exponentially better.

My thoughts are with you.

Sunday, 22 December 2013

The wrong kind of library is demanding my books!

This has happened with all my books. First I get a request from Edinburgh to mail five copies of the book to the legal depositories of the five UK and Ireland non-lending libraries. Then I have to do the same for the non-lending British Library. This exercise costs me around £50 every time I have to do it, for each book. Yet all they do with these books is to store them in some deep, dark vault for ever and ever. They are of no use to anyone whatsoever. So, in effect, the royalties of the first 25 copies of every book I publish go to fund this pointless exercise. In a digital day-and-age this practice is ludicrous. But it is British law, so I have to go along with it.

What rubs salt into the wound even more is the fact that, back in the summer, I went into my local public LENDING library (a different thing

altogether from the above storage libraries) to ask if Leeds City Libraries would be willing to put my books onto their shelves.

I was told that the only way I could get them onto the shelves would be to donate copies. So I said, okay that's fine, because all I want to do is to help other families facing this deadly illness.

So they asked me to leave my books with them and they'd send them down to the 'powers that be' at the central library or wherever for them to OK things.

However this would only get one copy of each book into 'the system'. Presumably if I want more books on more library shelves then I'd have to donate more copies. And, of course, this would only be on the shelves of Leeds City Libraries, not any of the hundreds of other public lending libraries across the UK.

Although I love donating my books (as I've done with various eating disorder charities across the UK, etc and would, in an ideal world, love to do for every lending library in the UK), I can only donate 'so many' copies before I end up seriously subsidising my activities.

Which brings me back to our local lending library in Leeds...

I've been checking the Leeds lending library catalogue and, despite leaving my books with our local library in the summer, I don't appear to be on it yet. And I'd already contacted the Leeds Central Library to chase this up, but received NO reply.

So I popped into our local library on Friday to ask why. It is now several months since I first took in a copy of *Please eat* and *When Anorexia Came To Visit*.

No-one had any idea, and suggested that maybe the books had been shredded as being 'unsuitable' for public lending libraries.

Well, I was furious!

Not only are these copies that could have been put to better use, but here we have the six UK non-lending libraries hounding me for copies of my book... the latest being the British Library today... just to bury them in some deep, dark, dusty vault never to be seen again.

Yet I can't get my books onto the shelves of the libraries where they will be of most use: public lending libraries.

But - and I just don't get it - our local library has lots of independently published books on their shelves, many of which look pretty amateur and cover obscure topics.

Also, the Eating Disorders section contains all the books that sit alongside mine on Amazon e.g. Harriet Brown, Lynn Crilly, etc.

But not mine!!

And THE ONLY REASON I want to get my books onto those shelves is so that they help other families.

As I said (loudly) to the useless assistant in the library: "I DO NOT WANT OTHER FAMILIES TO GO THROUGH WHAT WE WENT THROUGH. MY SON NEARLY DIED."

Grrrrrrrrrrrrrrr.

Thursday, 26 December 2013

Here's to hope for your Christmasses yet to come

If the 'me' of Christmas 2009 could have looked into a crystal ball and seen our family Christmas of 2013, I would have positively exploded with hope. Christmas 2009 was the first Christmas that ED, the eating disorder demon, sat alongside us, uninvited, at Christmas Dinner (and all the other Christmas meals

and festivities). Yesterday, on Christmas Day 2013, I can proudly say that the eating disorder was nowhere to be seen. And I hope that our experience of emerging from an eating disorder, will offer other families hope for the future.

Ben was 20 on the 23rd December and we celebrated at Pizza Express, just as any normal family would celebrate a birthday. Ben cooked a fantastic turkey pilaff for our evening meal on Christmas Eve along with assorted snacks. And, meanwhile, he worked his way through various boxes of chocolates and a chocolate advent calendar.

Then, on Christmas Day, Ben cooked the entire Christmas dinner with all the trimmings - and it was absolutely perfect. This was followed by Ben's home-made sticky toffee pudding with toffee sauce and ice-cream. He had at least two helpings.

Then, in the evening, we shared some savoury snacks (indeed he insisted on MORE than I'd originally planned). And then Ben had not one, but TWO puddings in quick succession, just like he does every day these days. Oh, and he roasted chestnuts on the open fire, gathered in the woods on Christmas morning when the three of us went for a brisk walk in the sunshine.

And all without an ounce of anxiety. It was a normal, happy family Christmas - the eating disorder well and truly kicked out of our lives.

Christmasses 2009, 2010 and 2011 (to a certain extent) all saw the eating disorder putting a damper on the festivities. 2009 and 2010 were especially bad.

Truly awful, in fact.

Back then I could never have imagined in my wildest dreams that my stick-thin and anorexia-engulfed son would come through this devastating illness - and that we would have a perfect, eating disorder free Christmas.

What was on Ben's (entirely home-cooked) festive menu yesterday?

Slow-cooked braised venison in a rich red wine, onion & mushroom gravy (we decided to give the turkey a miss this year), fruit & nut stuffing, posh pigs in blankets (i.e. posh chipolata sausages wrapped in bacon), red Brussels sprouts and sliced carrots tossed in herby butter, turmeric & polenta roasted potatoes, redcurrant & port jelly, and horseradish sauce, followed by the sticky toffee pud!

Here's to HOPE for all families battling with a young person with an eating disorder. They can come through it and you will enjoy the best Christmas you've ever had. Just like we've just done.

Friday, 27 December 2013

The 2nd letter I would never send to Ben's friends

Back in March, I wrote a letter which I would love to have sent to Ben's friends, but of course never did. Instead I wrote it down here, in this blog. Now I feel that it's time for a second letter which I also will never send, and here it is...

Dear Ben's Friends,

Remember the letter I never sent you back in March? The one where I pleaded with you to invite Ben to social events again and welcome him back into your friendship group with open arms? The fantastic, big, strong group of friends which Ben was so much part of in the first four years of secondary school, before his anorexia took him away from you all?

The letter where I explained more about Ben's eating disorder and why it isolated him for so long - and also why it resulted in him behaving strangely

and, often, in a frightening and distressing way?

The letter where I also explained just how punishingly tough it has been for him to make new friends and re-establish friendships with old friends, because of the extreme social anxiety that was a bi-product of his illness and which still remains?

Sadly, you all went your separate ways: to university or into careers. And, although you all continue to meet up now and again - the Christmas Eve get-together at the S Arms being a prime example - you rarely invite Ben.

It is as if he never existed.

The boy who was so central to your social circle and who everyone liked so very much.

Instead, Ben has to find out from Facebook, via various uploaded photographs, that these get-togethers took place. Like Christmas Eve in the S Arms.

Everyone was there. The whole friendship group. Everyone. Except Ben.

And it hurts Ben exponentially.

And it hurts us, too.

It also hurt Ben that so few people wished him a Happy 20th Birthday, via Facebook, just before Christmas.

Perhaps you think that because Ben hasn't got in touch with you very much over the past year that he's having a fab time elsewhere, with a new group of friends. Maybe you feel he isn't interested in you anymore. Or, worse, maybe you have forgotten this young man who you all used to like so much.

The fact is that Ben still longs to get back with you all. Back to how it used to be. Okay you're no longer at school. But he misses you all a heck of a lot. And he misses the great times you all used to have during those first four years at secondary school.

But the thing is, he still finds it so very hard to make friends - and re-establish links with old ones.

So, next time you all meet up, please invite Ben.

As I said last time, Ben just wants to be treated like a normal guy. More than anything else, he just longs to be the Ben he was before the illness struck.

It would mean so much to me if you could help this to happen?

Love from Ben's mum

Monday, 30 December 2013

And so the third year of my blog draws to a close...

584 posts on, I am just about to come to the end of the third year of my AnorexiaBoyRecovery blog! Around this time, three years ago, I knew I wanted to start writing about my experiences of helping my teenage son overcome anorexia, but I was really nervous about setting up a blog and making our struggle public.

I remember sending off sample posts to various people from my eating disorder network who I knew I could trust to come back with an honest opinion. I took on board their helpful feedback, primarily that the focus should be on attempting to help other families who are struggling with this devastating illness, not by providing medical, therapeutic or treatment 'advice', because - of course - I am 'just a mum', but simply by describing our own personal journey into and out of the eating disorder, and writing about what we, in our own personal circumstances, found helpful.

More than anything, I wanted to show other families that there is hope. Back in 2011, my son was still emerging from his eating disorder. We were still overcoming countless hurdles. But the general trend was onwards and

upwards. And, despite a number of set-backs (which is only to be expected), the trend continued in a positive direction.

The other purpose of my blog was - and is - to point families towards help. I, like many parents of young people with eating disorders, found invaluable support through the F.E.A.S.T. website and its bottomless treasure-chest of resources, most important of all, its wonderful and supportive forum: Around The Dinner Table.

Of course as I said above, I am neither a clinician nor an expert; I am just an ordinary mum writing about the day-to-day experiences of living with a teenage boy with 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 trouble with my blog is that it's very long. I now have 36 months of posts - 584 in total - which are a real pain to click through because blogs aren't like books. You can't just scroll through them from start to finish and you can't easily refer back to something you found particularly helpful or relevant. Worse, much of the earlier information - for example from 2011 and 2012 - risks getting overlooked altogether. And I believe there is some important stuff in there!

This is why I made the decision to publish (an edited version of) my blog in paperback in two volumes, both of which are available on Amazon (search author name 'Bev Mattocks') and quite cheaply as Kindle downloads.

And, when I get time, I may publish a third volume containing the 2013

posts.

I was also able to draw on my blog (and other stored information) for my book: *Please Eat*, which describes our family's journey through anorexia.

Even if Ben (now aged 20) and I help just one family fast-track its way through the huge anorexia learning curve and get help, then we have succeeded with these books. And every time a parent contacts me to say how much my blog has helped them, I know it is serving its purpose.

So, thank you everyone for following and reading my blog - and for commenting on it. I have no idea what 2014 will bring, but I hope it will continue to offer hope to other families... hope that this evil illness can be overcome and that your child will recover.

Here's to a Good New Year!