

Friday 25 November 2011

The 12 Days of (ED) Christmas ...

Christmas is a challenge for anyone suffering from anorexia and their family, to say the least.

So in the run up to Christmas 2011 I thought I'd write 12 entries on whatever comes into my head about our own experiences of Christmas (x 2) living with an eating disorder plus how different this Christmas will be. Watch this space...

Friday 25 November 2011

On the first day of Christmas, the ED gave to me... "The Nightmare on Christmas Fair Eve"...

Between 2005 and 2010 I was in charge of organising the school PTA Christmas Craft Fair - a massive event with over 33 stalls, a café, music, games, tombola, raffles and goodness only knows what else, taking place in two halls and a large foyer.

On the day before it was a case of "all systems go" as I helped to transform the various rooms into a Christmas wonderland and ensure everything was ready for a crack-of-dawn start the next day.

The organising itself began in September. It was a huge undertaking made a zillion times worse by the fact that Ben was hurtling into anorexia nervosa. While trying to juggle my freelancing business, the Christmas Fair plus an inner ear virus that put me horizontal for much of October, I was faced with the treble whammy of Ben's rapid and dramatic weight loss, nightmarish mood swings & ED rages plus regular emergency phone calls from school asking me to come and pick up the pieces of whatever chaos the ED had driven Ben to that day.

Oh and back then, of course, we were *still* on the waiting list for treatment, so we could only watch helplessly as Ben plummeted down the helter-skelter towards who knows where.

By then the ED outbursts had become more and more frequent and we were desperate. Two to four times a day we'd have violent destructive outbursts with loud screaming and tearful hysterics. To me it looked as if he was having a complete mental breakdown. He'd throw food around, become violent and crash his head against the wall. He was virtually unable to go to school and had cut himself off from his friends completely.

Of course the ED saved the worst for the busiest and most stressful day of my Christmas calendar: the day before the school Christmas Fair, exactly two years ago today.

Things went pear-shaped from the start. We had the usual nightmare of getting Ben ready for school. By then, every single morning was a battle. Not "your usual" teenage battle, but something altogether worse and far darker.

On this particular day, a screaming and crashing ED rage erupted before we'd even left the house followed by hysterical verbal abuse all the way to the bus stop.

As I dropped him off he slammed the car door violently, still screaming, and fled off down the road towards the bus stop. As usual, I drove back home in floods of tears feeling helpless, terrified and alone.

40 minutes later I got a phone call from the school nurse (who was keeping a close eye on Ben). Ben hadn't arrived at school and none of the students on his bus remembered seeing him that morning. Staff had checked the boys' toilets (a usual bolt hole for Ben) and the school grounds. Also, he wasn't answering his mobile phone. No-one knew where Ben was.

Ice cold panic. Yes, you really do go ice cold with fear.

Ben could be anywhere and I had no idea what to do.

Anyway to cut a long story short, the nurse phoned again to say he'd turned up, but he was in a hell of a black mood. Could I come into school and get him?

So there I was, cramming all the Christmas Fair paraphernalia into the car and phoning around trying to get someone else from the Parents Association to take over the setting up of the Fair. No-one was available; they were all at work. I would have to go ahead and do it, ED or no ED.

30 minutes later I was in the school medical centre helping staff to pacify Ben who seemed to have gone completely insane.

An hour or so later I was in the local supermarket car park bawling my eyes out into a bag of choc-chip cookies, taking phone calls from worried PTA members as I started to delegate all the following day's Christmas Fair tasks. I said I'd come down with a nasty virus. No-one knew what the real reason was.

Meanwhile Ben was still at school. He'd been pacified and was relatively okay. For now.

And, also meanwhile, I was acutely aware that my team of parent, staff and student helpers would be turning up shortly expecting me to direct the setting up of the Fair.

So there I was, at 2pm, knuckling down to transform the school into a happy, jolly, festive winter wonderland while I looked and felt like death.

When concerned people commented, I simply said I wasn't feeling well.

By the evening I was exhausted and, of course, the ED demon had returned with a vengeance as ED rages hijacked the entire evening.

But by now I was on autopilot, knowing I'd got a crack-of-dawn start the next day, ED rage or no ED rage...

So that was the first day of the ED Christmas.

Saturday 26 November 2011

On the second day of Christmas, the ED gave to me... "Two dozen Christmas tree cookies"...

Back in 2009 in the quest to re-work recipes into "healthy recipes", Ben made a stack of ginger cookies to hang on the Christmas tree: angels, stars, Christmas trees, holly leaves, Santas, that kind of thing, all

with satin red ribbon threaded through a hole made by a drinking straw.

He'd decided that fats could be completely eliminated from the recipe. Fats were the #1 Fear Food and Ben would go out of his way to avoid them.

The cookies smelled wonderful as they were baking. They looked divine. But, not surprisingly, they tasted terrible and were rock hard.

Back then you instantly knew when a recipe had "gone wrong" because there would be an almighty crash in the kitchen as Ben's fist came down slap bang on the work surface followed by "animal" howling and the sound of Ben kicking things or banging his head against the wall.

With the anorexia, everything had to be perfect. Anything that was slightly less than perfect was rejected outright with a violent ED outburst to reinforce it. Anything that was a total failure was even worse. Already by late November 2009 I'd got to the stage where I'd live in dread of anything going wrong with the evening meal I'd cooked. ED would come down on me like a tonne of bricks, punishing me for the slightest thing: too hot, too cold, too big a portion, not tasty enough, too many carbs, too much fat...

So I knew by the noisy reaction that the fat-free Christmas tree cookies weren't a big success. And while my husband and I went on to eat some lovely home-based Christmas stuff like home-made choc chip cookies, mince pies, etc, Ben ate nothing except his usual dried and fresh fruit - all painstakingly chopped into uniformly tiny pieces and arranged on a plate, because that's how the ED liked to do things.

The other evening Ben made this year's batch of Christmas tree cookies - this time cinnamon cookies.

The shapes were the same, the baking smell was the same and the colour was the same. But this time he made them to the proper recipe, fat and all - because that's what he always does these days.

They are the best Christmas cookies I have ever tasted and Ben agreed as he merrily tucked into the broken ones that had stuck to the baking tray.

Sunday 27 November 2011

On the third day of Christmas, the ED gave to me... "The three of us... our strong family unit"...

The other month I uncovered a letter which I wrote to Ben back in the run up to Christmas 2009. By then we were walking on eggshells, terrified of saying anything that might upset the eating disorder and set off an ED rage. The rational side of Ben's thinking had gone completely AWOL and he'd argue that white was black until he was blue in the face. We couldn't talk to him. He wouldn't listen. He couldn't listen.

I was so desperate that I decided the only way I could communicate with him was to write him a letter.

Back then I still thought that, somehow, we could “snap” him out of the eating disorder; that he would suddenly see sense and stop destroying himself then and there. I really thought it could be done. The problem was, I had no idea how. Maybe a letter would work. Maybe when he heard how terrified and upset we were, and how dangerous anorexia was, he’d come to his senses and stop.

Maybe... Just maybe...

So one day while waiting in the car for the school bus I put pen to paper. I wrote that “hopefully I can get it all across better without me or you getting upset” and that the anorexia was “dangerous and must be stopped immediately” and the three of us (dad, Ben and me) would make a decision that “this is going *no further* and will stop” and “we will sort out the issues that have caused it. We will sort out the self-confidence and self-esteem issues via a counsellor who is very experienced in this kind of thing, even if we have to pay”.

I went on to say how “your happiness and *health* are our No1 priority. I want you to know that we will always be there for you, no matter how sad you feel – and we will get the very best and nicest help for you”.

I wrote: “We love you too much to watch this happen which is why, as your loving parents, we need to step in and say ‘STOP! Enough is enough!’“

I still find re-reading the next bit particularly difficult, the bit where I say:

“We will make serious promises to you, as our dearest son, if you make serious promises to us – and keep them.

“You are more important to us than you could possibly ever imagine or even know and we want to stop this nasty thing *now* and help work on the root cause.

“Please don’t think there is no solution because *there is*. Very much so – and in a few months you will be so glad we all made this decision.

“But meanwhile, *any* time you feel sad or you feel it’s too hard, *please* talk to us – about *anything*. Do not bottle it up – and let us all start thinking positively now, even if it may at first, and even second, seem hard. It’s not just you doing this alone – it’s all three of us... our strong family unit.”

Later on I add: “Will you let us ‘muscle in’ and start the ball rolling towards your wonderful future now?” followed by “Again, I can’t emphasise how much we love you and will be with you over this”. Finally I sign it off: “Big hugs x 10 million and even more, Mum xxxxxxxxxxxxxxxx.”

I could never, ever have known that it would be almost a year before something happened that *did* make Ben turn around and say “yes” to recovery. I could never, ever have known that between writing this letter and then that I would almost lose Ben, not once, but at least three times.

I’m so glad I couldn’t see into the future.

Unless, of course, that future was right now - with us three emerging into the beautiful ED-free sunlight, getting ready for a truly festive Christmas 2011.

Monday 28 November 2011

On the fourth day of Christmas, the ED gave to me... "Four months 'til treatment"...

It wasn't until October 2009, two months on from when the eating disorder first started to visibly manifest itself, that our GP finally and reluctantly agreed to refer Ben for treatment. You see, Ben was skinny, yes. But, to a GP that had never seen him as a muscly, athletic *prop forward* in the school rugby team, a skinny teenage boy wasn't that unusual. Nor was a teenager who appeared to have gone off the rails mentally. After all, "teenage angst" was common. I got the feeling he felt I was an unnecessarily over-protective mother.

Naively I thought we'd get treatment right away. Everything in my being was crying out that our case was urgent. Ben was physically disappearing before my eyes and had changed from the happy social boy he used to be into a mental wreck who often seemed to have gone insane.

It was a shock to find out that we might have to wait until *Easter* before our first appointment.

What the heck were we supposed to do between now and then? How much further would Ben hurtle down the rabbit hole? How much longer would it take to pick up the pieces and re-mould Ben once we finally did see a specialist team?

In the lead up to Christmas 2009 I knew I couldn't just sit there and watch Ben deteriorate; I had to do something. Luckily we had a little bit of private medical insurance we could draw on. Just £500 was available for mental health issues, but it was better than nothing.

So the search was on to find private treatment to fill the gap between now and our first NHS appointment with the CAMHS team.

Not only did virtually no-one in the local private sector have any experience of eating disorders, but - being Christmas - they were all booked up until after the New Year.

Initially we managed to get an appointment with a rather strict and stern "old school" psychiatrist. I knew it was a mistake from the moment we walked into the room and he formally indicated that we should be seated opposite his large desk. I felt as if we were revealing our innermost secrets, feelings and fears to a CEO of a multinational corporation, not a compassionate doctor. That single hour session cost me half of our £500 medical cover.

The slightly Good News was that this guy did point us towards a therapist who worked out of the local private health centre - the kind of place you go for physio, hypnotherapy and so on.

It was deep in snow when we first went to see J. I immediately took a liking to her, and I think Ben did too. I knew we could get on with this woman. The only problem was... and it was a *huge* problem... it quickly became clear that the eating disorder was even bigger than I'd thought it was in that *no way* could one person "cure" it with a handful of weekly therapy sessions. J made this very clear to us and I really appreciated her honesty.

Between then and Christmas we trudged through the snow to meet J weekly until we ran out of

money and she ran out of availability because of the holidays followed by a career change. In between sessions she'd email and phone me to talk things over. Although I knew she could do no more than attempt to plug the hole in the sinking *Titanic* with a band aid, she did her level best and I really appreciated that.

She also said she'd see if she could pull a few strings with CAMHS. She used to work with CAMHS and felt they'd take her seriously when she insisted Ben needed urgent treatment.

I don't know whether or not she was successful because, later in the New Year, something was to happen which did bring our CAMHS treatment forward when Ben was rushed into hospital with a pulse rate of 29.

Tuesday 29 November 2011

On the fifth day of Christmas, the ED gave to me... "Five 'Safe' Recipes"...

I have a kitchen cupboard jam-packed with recipe books and four more drawers packed with *Good Food* and *Delicious* magazines with two drawers reserved for the Christmas and New Year issues from the past 10 years. This year we've been doing what we'd usually do i.e. plough through all of the festive recipes, shortlisting the most yummy for our own build-up to the Big Day. On Sunday morning, for instance, Ben surprised me with a "De da!!!!" moment as he revealed the chocolate log cake he'd made the day before. That afternoon he made mince pies and various sweet and savoury Christmas biscuits. I'll be making a third stuffing for our turkey - with a Spanish twist: chorizo. But it wasn't like that in the build-up to Christmas 2009...

Back then, working out weekly menus was a nightmare, let alone working out what we would eat over the festive season.

I'd flick through all my recipes, discounting the vast majority because I knew that (a) Ben would refuse to eat them and (b) he'd throw a wobbly at the very prospect of them appearing on the weekly menu.

Anything with cheese was out. Fats, of course, were eliminated and anything that needed to be fried. Curiously nuts and potatoes were okay, but I couldn't mix potatoes with, say, bread because that would mean "too many" carbs. I remember a veggie burger and oven-baked potato wedges I served up which ended up being slammed down on the table in a furious ED rage because of the mix of potatoes, bread and breadcrumbs (in the burger) on one plate.

Puddings and cakes were out - unless they were fat-free. And umpteen other things that, thankfully, have slipped my mind two years on.

Virtually all festive foods were "out", except lean turkey meat and why the heck did we need to use oil to roast the potatoes when Ben reckoned it could be done "more healthily" without?

He would police the kitchen to check there was no "contraband" in the fridge, freezer or larder.

Everything had to be zero fat and if an “extra lite” version existed then we had to buy that. Our local supermarket’s “extra lite” mayonnaise was particularly bland...

He’d throw an ED fit if he caught me frying anything on the stove. Even frying an onion in a tablespoon of oil was a criminal offence. Why fry when you can dry fry?

The slightest globules of oil would be described as “swimming in fat” and violent refusals to eat the evening meal.

Or he’d stress out all day at the prospect of a “fear food” being slipped into our dinner. I remember a serious problem with my plans for smoked mackerel burgers. *Had I seen how much fat was in mackerel?!!!*

I’d try to remove nutritional labels from food packaging. But by then Ben knew calories off by heart. And, anyway, removed labels set the alarm bells ringing in his head. I wouldn’t have removed the labels if they were “okay”, would I?

I tried to black out the nutritional content of recipes, but that also set off the alarm bells - and, of course, he knew the calories by heart anyway.

And in a house as small as ours it’s virtually impossible to lock him out of the kitchen.

Before the eating disorder, cooking was one of my big passions. Especially cooking in the run-up to Christmas. At the height of the eating disorder I came to hate and even fear cooking, choosing a handful of five or so “safe” bland recipes in an attempt to keep the peace.

Last year in 2010 it was better.

This year it’s virtually back to normal.

Bring on Ben’s delicious chocolate log cake!!!!

Wednesday 30 November 2011

On the sixth day of Christmas, the ED gave to me... “Six friends a-staying x 2”...

Ben kept out of the limelight at primary school, preferring to stick to one good friend. But by secondary school he’d blossomed from a shy, slightly overweight “duckling” into a mega popular, handsome and athletic “swan”. In fact he was so popular within his new friendship group that his annual birthday parties, just before Christmas, were legendary.

On the last day of term school finished at lunchtime. I’d pick up Ben plus half a dozen friends and we’d make our way down the school driveway, car windows wide open as Ben and his friends leaned out of the window shouting “Merry Christmas!!” to everyone they saw. I’d put the old favourite Christmas songs on the car CD and we’d all sing along on the half-hour journey home.

Back at our house they’d all disappear up to Ben’s large loft room, only coming down for supplies of drinks, crisps, cookies, cakes, etc and, of course, an enormous evening meal followed by the World’s Biggest Breakfast the next morning. After all, they were growing teenage boys, weren’t they? I was astonished at how much food they put away.

Saturday afternoon was the switch-over when we met up with the *other* half dozen friends at the local cinema complex, watched a movie, went for a massive *Pizza Hut* meal (the kind where you can help yourself to endless ice cream and sprinkles, which - of course - they all did).

Then the whole sleepover process would be repeated with this other set of friends followed by yet more endless supplies of cookies, drinks, etc and an equally enormous breakfast on Sunday morning.

Phew! What a weekend. Like I said, these parties were legendary.

Ben's final sleepover birthday party took place on the last day of the Christmas term in 2009.

This time only a handful of boys came back with us from school and the party only lasted one night. They did go to the cinema, but they didn't go to *Pizza Hut*. Instead, they came back for a meal that Ben had carefully chosen.

By then Ben was neck-deep in the eating disorder and had completely distanced himself from his friends. Over the Christmas term his behaviour had become increasingly distressing, frightening and crazy. I could tell from those friends' eyes that they weren't quite sure what to expect.

The atmosphere was subdued to say the least.

Ben had chosen the menus. The evening meal had been slimmed down as had the breakfast. "They won't want all that," he said, "No need for this, no need for that"... Of course the boys tucked in, but Ben didn't.

That evening it was uncannily silent up in Ben's bedroom as the boys played quietly with computer games rather than jumping up and down on the bed, screeching, charging up and down stairs, and spraying each other with water from the ensuite shower hose.

They all went to bed on time which was unheard of. One boy had already gone home, phoning his mum around 9pm because he didn't "feel well"...

Just after midnight a loud noise woke us with a start.

Ben was rushing downstairs, howling like a wounded wild animal, hurtling towards the living room.

We jumped out of bed and rushed downstairs to see what the matter was.

Ben was in a terrible state: weeping, howling... ED at its most impressive...

Apparently one of his friends had made some innocent comment about something which had hit a nerve and this was the result.

The next day it was a group of silent, sheepish looking boys that slunk downstairs for breakfast, trying to make polite conversation.

It was a relief when their parents turned up to collect them. And I remember what stood out starkly, apart from their subdued mood, was how big they all looked compared to waif-like Ben. I also tried to avoid the parents' shocked looks. After all, it was a long time since they'd seen Ben. It was as if they didn't recognise him.

Or maybe it was just me being paranoid.

But looks can speak volumes.

Thursday, 1 December 2011

On the seventh day of Christmas, the ED gave to me... “Seven treatment sessions?? Or eight?? Nine??”...

When we met up with that stern private psychiatrist a few weeks before Christmas 2009, I’d written out a couple of pages of notes and questions.

These were the questions:

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

You see, back then, I honestly thought someone could tell me approximately how many sessions Ben would need to “cure” him of the eating disorder.

I thought a skilled specialist practitioner would be able simply examine him, diagnose him and say: “Hmn... I think we can do it in seven or eight weekly sessions,” or whatever.

I really did.

How could I have known that, two full years on from then, we would *still* be seeing our treatment team? Thankfully, being the UK, the CAMHS treatment team is NHS-funded, so we don’t have to pay.

We only had to pay for the private “treatment” Ben received as a “stop gap” while we were on the CAMHS waiting list.

Seeing as we only had £500 a year available from our medical insurance to cover mental health issues, I have no idea what we would have done without the free NHS treatment.

Over the past two years we’ve had a crippling recession to deal with - and Ben’s dad was out of work.

CAMHS and I may not have always seen eye to eye over the months we’ve been with them, but I am eternally thankful this Christmas season that the treatment was free and unlimited.

Friday 2 December 2011

On the eighth day of Christmas, the ED gave to me... “Eight billion snowflakes falling”...

It was Ben’s birthday, a couple of days before Christmas 2009. We’d been to the cinema followed by a (reasonably stress-free) curry and were driving back home. The snow was falling thick and fast, and eventually my sister’s car got stuck, so she had to drop us off several streets away. This meant making our way through deep snow back to our house.

A white Christmas is extremely rare in our part of England, so it was extra-special - trudging up the middle of the silent street past house after house of twinkling Christmas lights.

The only person that wasn't instantly transported into magical child-like memories of Christmas past was Ben. That's because ED kind of numbs your positive emotions. He was desperate to feel "Christmassy", but couldn't feel a thing. It was as if his brain was anesthetized.

At the height of the eating disorder, Ben couldn't feel emotions like love, happiness or pleasure. He was completely numb.

And, because of what the eating disorder was doing to Ben and our family life, I found it hard to get into the Christmas spirit, too.

That year I didn't send any Christmas cards. I didn't feel like cooking Christmas dinner, so my sister offered to do it instead.

I simply went through the motions because "that was expected".

But that night, walking home in the deep snow, peeking into houses decked with holly and twinkling lights, I did feel Christmassy.

For a little while anyway.

Before the ED swooped in to ruin our Christmas Eve.

Saturday, 3 December 2011

On the ninth day of Christmas, the ED gave to me... "Nine Lessons and Carols"...

Three o'clock every Christmas Eve afternoon I have an appointment with *BBC Radio 4* in our dining room. It's the world-famous *Festival of Nine Lessons and Carols* live from *Kings College Chapel, Cambridge*. At 3pm precisely, the presenter announces that a chorister will step forward and lead the choir up the chancel singing the first verse of *Once in Royal David's City*.

Every single Christmas Eve, I take myself off into our festive dining room, table already set for Christmas dinner, switch on the fairy lights, light some festively perfumed candles and listen to this broadcast. Just like my mum and grandma before me.

At 3pm on Christmas Eve 2009, however, I was blubbing my eyes out into a box of tissues as the ED raged through the house screaming and shouting about something that had set it off.

As ED continued to rant and rage, and Ben's dad tried to calm him, I just sobbed and sobbed, thinking of us - yet also thinking of all those other families who, for whatever reason, were missing their child that Christmas. Suddenly I felt part of this terrible crowd of mothers and fathers whose only Christmas wish was to have their "little boy" or "little girl" back.

At least my "little boy" was here in our house with us - and hopefully we'd get him back properly one day.

Unlike the other mum who I came across shortly after Christmas 2010 whose daughter went into

hospital with severe anorexia and didn't come back.

So ED might have spoiled my Christmas Eve traditions, but at least I had a lot to be thankful for.

Sunday 4 December 2011

On the tenth day of Christmas, the ED gave to me... "Ten swans not swimming"...

Winter 2009/10 was the winter of the Big Freeze in our part of the UK - the year the huge lake in our local park froze solid which, of course, meant that its resident swans were unable to swim on it. But meanwhile Ben and I continued our regular walks from our house, through into the park, round the lakes and back home - a route we've trudged many, many times during the eating disorder.

Autumn would lead to winter which would lead to spring and then summer - and for a whole year we'd do that walk which was also a great opportunity for us to talk about things.

For an entire year I felt as if I was flogging a dead horse. No matter what I said, it fell on deaf ears. Ben was unable to see logic or reason. He would argue that black was white until he was blue in the face.

In the Big Freeze that followed Christmas 2009, Ben really *was* blue in the face. Having lost so much weight he felt the cold more than most people so he wrapped up warm against the freezing temperatures.

And I was painfully aware that, beneath the chunky sweater, jacket, hat, scarf and gloves was an increasingly emaciated body.

His illness became even more noticeable as we stopped off at the park café for a warm drink (black coffee for Ben, naturally...).

On display were its famous yummy cakes and bakes: chocolate fudge cake, carrot cake, millionaire's shortbread, coffee walnut gateau...

As usual, Ben was drawn to these like a magnet. Not to eat them, of course, but to admire them - as you or I might admire works of art hanging in a gallery. He'd just hover there, mesmerized by the cakes, serving staff coming over to ask if he'd like to order a slice, and giving him odd looks when he shook his head, yet continued to stare...

Then he'd come over to where I was sitting and insist I come and "admire" the cakes as well.

I refused.

There we were, in the Christmas and New Year season, living in the Western World with festive food abundantly available yet my son was starving himself.

But, fortunately for the swans just outside the café, someone had broken a large section of the ice so they could swim around a bit, fighting with the ducks and other wildfowl for the chunks of bread being tossed into the water by young families.

At least the swans were enjoying their food.

Thursday, 8 December 2011

That's enough of the 12 days of ED Christmas...

Not wanting to labour the point too much I decided to stop at *Day Ten* and move onto something more current.

[I deleted the rest of this – you can read the whole of 2011 if you click on the free PDFs link on my blog]