

When anorexia came to visit

Families talk about how an eating disorder
invaded their lives

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Emma's story

"These days, she'll come in with a takeout, just like anyone else. She'll grab a burger here and a pizza there, or sit down in front of the telly with a tub of ice cream. She is just a really happy young lady."

Amber had always been a quiet child, preferring a small circle of friends. She was happy, but she'd always had what I can only describe as an air of sadness about her. We put it down to her being thoughtful and quiet. Amber was Amber, happily plodding along through life, head in the clouds and a bit of a dreamer.

She'd never had any issues with food and had always eaten healthily. She was never fussy and never picky. My husband works from home so he would always cook the dinner which Amber and her younger sister, Jade, would eat without any problem. She was a keen club swimmer, training several times a week. She enjoyed swimming but she was never fast enough to swim competitively. As a child, she wasn't tiny; she was always at the top of her growth chart and quite tall. She was just a normal child - neither skinny nor fat, just average.

Looking back in hindsight, Amber wasn't the typical stereotype for classic anorexia, either, in that she wasn't a high achiever. She was, and still is, a very bright girl with a string of exam passes but she has always been content to sit back and do "just enough" to get by.

When she was eight Amber was tested for early onset puberty. Everything came back okay. But it could be that, from this point on, she began to think she might be different from the other girls. By the age of 10 or 11 she was one of the tallest girls in the year and she started saying that she didn't like her body very much. There was also

a bit of bullying that went on in year 6 with some of the other girls - the “cool kids” she called them - and I think there was a bit of pushing and shoving, that kind of thing. She never really spoke too much about it, and Amber and her friends eventually learned to ignore the bullies.

Then when she went to senior school in year 7, she started her periods and, obviously, everything started to grow. Amber didn't like her new boobs. We're quite a voluptuous family and she didn't like it. Then she started saying: “My head's too small for my body.” “Disproportionate” was the word that kept cropping up.

By the time she went into year 9 there still wasn't anything to set off the alarm bells. But every so often I'd catch her looking at herself in the mirror. She'd complain that her head was too small, that she was out of proportion or that she didn't like her body. So I'd say, “You're just going through puberty. Once you've finished growing everything will balance out”. She also stopped swimming at this time as the training sessions were increasing in frequency and began to interfere with her schoolwork. As a result, she lost some muscle tone. I often wonder if this could have been a trigger for the eating disorder.

Year 10 was the year they chose their GCSE subjects. It was also the year that things started to go downhill. Amber had two close friends, both boys, and both emigrated within a couple of months of each other. Amber really missed them. Also, her choice of GCSE options meant that she wasn't in classes with any of her other friends. She became depressed, and that's when it all began.

Just days after starting Year 10 in September 2008, Amber began to push her food around the plate at evening meals. I was working late every night, often not getting back until after everyone had eaten, so initially I wasn't aware of this.

We also had no idea that she was getting up at the crack of dawn, going downstairs before any of us were up, putting a few crumbs of cereal and a splash of milk into a bowl and saying that she'd had her breakfast. Then she'd take her packed lunch to school and throw it

away. But, at the time, we didn't know this was going on; it was only much later, when her worried best friend's mother told me what she was doing, that it all came to light.

Back home in the evening, my husband would put dinner in front of her. She'd eat half of it and say, "I'm too upset to eat". She was really missing her two male friends. Well, we just told her not to worry, she'd get through it and it would all turn out fine.

It got to the October half term. By then I'd left my stressful job and gone freelance, so I was home for dinner at a more regular time each evening. We were due to go to Barcelona for a week with my closest friend and her children and were packing to go. Amber said, "I need new jeans, mum". So I asked her why; we'd only bought new ones a few weeks ago. She said they didn't fit her any longer. My initial reaction was, okay, she's obviously grown; she needs the next size up. So I told her we'd go shopping for a bigger size.

"But I don't need a bigger size," she said, "I need a smaller size". Well, I looked at her and she was standing in her bedroom wearing opaque black tights and black shorts, like girls do. It was as if a veil was suddenly lifted from my eyes. I thought: "Oh my God, Amber, what have you done?" It looked as if she had two strings of liquorice hanging out of her shorts.

"Right, on the scales," I said immediately. So I got out the scales and discovered that she'd lost a stone. I was shocked. I said: "What have you done? I know you've been upset but you mustn't lose weight because of it."

It never even crossed my mind that she was sick. So we went away on holiday and the changes became more and more apparent because we were in close quarters all the time. She'd sit at breakfast saying, "I can't eat this, I'm not hungry, I feel sick". Lunch would be in a restaurant and she'd sit for ages trying to find something to eat. In the end it would be an omelette or something like a simple green salad. As for evening meals... All of a sudden, because we were with her 24/7, it dawned on us that there was a problem.

I'll never forget the day we went to a theme park. Although it was

October it was still reasonably warm. We were queuing for a ride when Amber looked at me and said she didn't feel well. She passed out. She simply collapsed in the queue and my husband had to pick her up and carry her out. Once she came to she said, "Dad, I'm fine," and told us all to go back on the ride. But the moment she stood up, she passed out again. She was taken to a medical centre, next to the theme park, and hooked up to a drip. The nurses looked at her and remarked: "She's extremely thin..."

I said that I knew this and told them how much weight she'd lost recently. So they looked at her and said, "You've lost too much weight. You have to put it back on". My husband came in at that point and I think this was his dawning moment, the realisation that this was his "little girl", lying there, so pale and thin, hooked up to that drip. Our younger daughter Jade also came in. As soon as she saw her big sister she burst into tears. By now we were in no doubt that we had a serious problem on our hands.

I remember crying with my close friend: "What on earth am I going to do? Do you think Amber's getting anorexia?" Meanwhile Amber promised us that she'd try to eat. By this stage she had missed two periods but, at the time, I put it down to stress.

Back home we didn't take her to the doctor immediately because we were worried it might make things worse. So, instead, we tried to make her eat. I did give the GP a call, however, and filled her in on what had happened. I told her that Amber had lost a lot of weight, that she'd been very depressed and I didn't know what to do. I think I was still trying to avoid saying, "I think my daughter's got anorexia or an eating problem".

Our GP was lovely. Her initial reaction was to agree with me that Amber was probably suffering from stress and depression. She said that she'd written it all down in her notes and asked us to monitor Amber for a month. If things got worse, then we must bring her straight in. So we spent November trying to avoid the obvious and trying to get her to eat. At this point I was getting up in the morning and making sure I was downstairs before Amber. I'd also contacted

the school and told them there might be a problem. By now, the Head of Year had noticed Amber's weight loss and change in personality and wanted to do everything she could to help. They allowed Amber to come home for lunch. We only live half a mile away, so my husband would stop work, pick her up, make sure she had her lunch and then take her back to school for the afternoon session. But despite desperately trying to stop the weight loss, Amber's weight was still going down. We were puzzled. We had no idea that she was getting up in the middle of the night to do sit-ups in her room, so that was obviously affecting the weight. But at mealtimes she would sit there and I would see her eating, so I thought things must be improving. To be honest we were still in a kind of denial, yet deep down I think we knew what was happening.

We saw the GP again in December. Amber had lost another half stone and the GP put her on antidepressants which didn't really make any difference. She was becoming more and more withdrawn, more and more psychologically ill and pulling away from us.

The GP asked us to come back in a week. It was literally just before Christmas. I'd been doing some research on the internet and I'd found Laura Collins' book: *Eating With Your Anorexic*. I cried buckets over it! Even today I still get teary when I think back to this time because it's still so emotionally raw. As a mother, it never heals.

I know now that parents aren't to blame for their child's eating disorder. But back then I racked my brains trying to figure out where we'd gone wrong. I couldn't understand it. Our family was loving, kind and caring. We'd never had any problems and we weren't dysfunctional in any way. Yet even though I know that we weren't at fault, I can't help feeling guilty that I didn't insist on a referral sooner, especially after reading Laura's book and realising what we were up against.

I can honestly say that our doctor was the best GP you could have wished for. She saw us through all of this. All three of us went back to the GP just before Christmas. Amber was still losing weight and by this time she was also uncommunicative. I said: "This isn't just

depression; I know she's got anorexia." I told the GP that I knew wholeheartedly what we are dealing with and that Amber needed a referral. We live quite close to a major hospital in south London which has a specialist eating disorders service, so I asked if Amber could be referred there. The GP said she thought this was possible, but Amber would need to go through CAMHS first. So she referred us to CAMHS and asked us to come back after Christmas.

Christmas Eve was the last meal that I can remember she ate properly. It was with all our family. My close friend and her family were there too. Amber just sat there shaking her legs because, by this point, she had the "jiggling legs" where you can't sit still. She would sit on the edge of her seat with her legs going up and down, and I'd put my hand under the table to try and stop them from jiggling. She spent the rest of the day crying on the sofa. Her sobs were endless and gut wrenching; they didn't even sound like normal cries. All she would eat was instant porridge and raspberries. She spent the next three or four days like this. She even thought we were putting calories in the water

Thanks to Laura's book I'd discovered F.E.A.S.T. and its forum Around The Dinner Table. I joined on Christmas Eve. The forum helped us enormously because we knew we weren't alone. I'd put up a post, not knowing what I was going to get back and suddenly there would be a dozen or so other parents who had been through this, all offering support. It was the first time I'd actually put up my hand and said, "Please help me!" and from that point on I knew we weren't alone. We started to follow their advice which was basically to get Amber to eat.

Psychologically, however, Amber was in meltdown. Shortly before Christmas she'd self-harmed using a knife. It was the first time ever that she'd seen her dad cry. Terrified, we hid everything we felt might prove a danger to her. We even took the locks off the bathroom doors. And, because she would scratch herself in the shower, I insisted on sitting with her while she showered. It was as if she'd had a complete breakdown.

By this time Amber was crying continuously from the minute she woke up until the minute she went to bed. This continued for two solid weeks. She slept with me every night until I was so exhausted that I wasn't eating properly either! So my husband and I began alternate night shifts. He said he didn't care if people said anything about sleeping in the same bed as his daughter; sleeping in our arms as she had when she was a baby was the only time she was at peace.

When the time came for our families to return home after Christmas, I remember crying: "Don't leave us! I can't do this by myself!" I needed my mum, I needed my mother-in-law and I needed my sister. So we set up a rota and my sister moved in with us, mainly to look after Jade, because our energies were taken up with feeding Amber.

The moment Christmas was over we took her back to the GP and insisted something was done urgently. The GP said she'd try to speed up the CAMHS appointment. CAMHS called me and an appointment was set for early January.

CAMHS were brilliant. They called me every day. Between us, we all realised how sick Amber was to such an extent that, in the event, she bypassed CAMHS altogether and went straight to the adolescent eating disorders centre at the hospital in south London.

We took her there in early January. She was given an ECG but they couldn't find a heartbeat; her rhythms were so low. They couldn't get blood, either, and her weight was registering as shockingly low. By this time her clothes were just hanging off her, her hair was falling out in clumps and she looked like a skeleton.

It took 40 long minutes to get a vial of blood. I think this is when my husband and I reached our lowest point. Suddenly it hit us - the sheer horror of realising how much weight she'd lost. Yet I just couldn't get her to eat, and there was nothing I could do. I felt so incredibly helpless.

I remember asking the treatment team what we were supposed to do, and they simply said: "She just has to eat." We were to sit with her and try to calmly ensure that this is what she did, even if it took

all day. They told us that Amber was severely anorexic but, because she had fallen sick so quickly and got help, they were confident of a full recovery, stressing that the quicker she regained weight and got above their weight criteria, the better the outcome could be. They put her on anxiety medication to calm her, as well as antidepressants and stressed how vital fats were for her malnourished brain. I remember her meal plan was full of full-fat milk, butter and cream!

The illness had her in a stranglehold. She couldn't even feed herself. If I gave her anything to hold, even a spoon, she'd scream and drop it as if it was white hot. So we started to spoon-feed her, just like we used to do when she was a baby. It was heart-breaking.

Oh, Amber would scream and weep; it was like having the exorcist child in the house. Her eyes would change and go dark and hard. We'd watch a curtain come down in her brain. But ultimately, with our help, she did start to eat. I think she knew she was so very ill. And you know why I believe she wouldn't feed herself? Because if we fed her then she could *blame us* for making her "fat"; she wasn't *making herself* "fat", if this makes sense.

She'd resist. She'd refuse to eat. But we persisted. We'd sit with her, chop up the food and persuade her to eat it. I downloaded a mountain of calorie-laden recipes from the F.E.A.S.T. website and put all kinds of things into the other meals: cream, butter and oil, basically making everything as calorific as I could. An American friend sent over tubs and tubs of high calorie instant breakfast drinks and I'd feed Amber ice cream and milkshakes.

Between the January and February, we managed to get a stone back onto her. So she did very well. As she became better nourished, we began to see glimpses of the "old" Amber; not the one who'd been consumed by anorexia. But she still couldn't feed herself. Also, I was horrified to see that, with her new-found strength, she became more vocal and resistant.

One awful day in mid-February I'd gone to school to pick up my youngest daughter, Jade. My sister was here at home. It was snack time, and my husband had given Amber a milkshake or something,

but she refused to drink it. Suddenly Amber lashed out and whacked my husband around the face, getting violent and screaming profanities. I walked in with Jade to find my sister, who'd been helping out, sitting on the kitchen floor crying. My husband was in his study with the door shut and Amber was up in her room, rocking on her bed. It was hell.

At the time we were visiting the hospital three times a week. At first Amber would just sit there glaring at her therapist through her fringe and muttering. But, as she began to regain some weight and her brain became better nourished, she began to engage with him more. He explained that, once she was more weight restored, he could begin the real work of therapy.

Amber's therapist would ring us on the days we didn't attend to make sure everything was okay. When we told him about the violence, he said, "Bring her in, bring her food and we'll sit behind two-way glass and watch what she does". So this is what we did. There, in the hospital, my sister and I tried desperately to get Amber to eat a sandwich and feed herself a yoghurt, which she found virtually impossible. She sat there holding the spoon in her shaking hands, unable to put it in her mouth, before screaming and throwing it to the floor, while they watched. Our words of encouragement that she could do this were met with swearing and screaming: "I know I can do it, I just *don't* want to!" This was when they said she needed to be admitted to a specialist unit.

They made a phone call and got her into a specialist adolescent eating disorder unit on the other side of London. It was miles away from where we live, but they insisted it was the best place for her. She went pretty much the next day.

I think she thought we'd never do it, that we'd never leave her in that unit. And it still affects her to this day. If she carries any scars from this period I think it's that we took her and left her there.

I'll never forget the day we took her along. My husband put her suitcase in the car. She was screaming and crying because she didn't want to go. She was holding onto the door. My husband had to

literally pick her up and put her into the car. That was just, oh, so very hard. But we did it. I have never felt so heartbroken or alone as I did at that time.

Thankfully the unit wasn't like a hospital at all. It was an old house. It was cheerfully decorated and felt quite homely. But I couldn't help noticing that it had bars on the windows and so on.

But, really, they were lovely. The nursing staff and the doctors were great and Amber made some good friends, several of whom she is still in touch with today. And they're all mostly doing okay.

When she was admitted, she was actually in a better state of health than a lot of the children that were there and for that reason she'd keep saying to us: "I don't belong here! I'm not like the other girls. I'm bigger than the other girls so I can't be that ill. I don't need to be here!" And she'd repeat this every night when we visited. It broke my heart. And I was just so very, very tired. After all we were doing a 140-mile round trip every night through some of London's worst motorway traffic. It became a routine. We'd set off at around 4pm and usually arrive for around 6pm so we could eat dinner with her. Then we'd have to leave at 9pm and could arrive home at anything up to 11 o'clock at night. It was a tough time.

I had to laugh, because people would tell us that having your child in hospital is a good opportunity to take time out for yourself, to rest and recharge your batteries. But, for us, we were working all day, sorting out our other daughter and spending up to four hours travelling through busy traffic - and then spending around three hours every evening with Amber. On the rare days when we didn't visit we would be on the phone with her all evening because she was lonely. It was very, very hard. But we did it, because that's what parents do. And we were desperate for Amber to get well.

Another thing that cut me to the core was the fact that this was one of the first times that Amber had ever been away from home on her own for any length of time, apart from school trips and sleepovers. I didn't want this for my daughter. It was devastating for us, especially for me, to take her and leave her there. It was the

hardest thing I've ever done.

Every single night I'd arrive home with a broken heart. Because it's not as if we'd left her in a unit around the corner; we'd taken her 70 miles away and left her in the care of others. The guilt was immense. I felt as if I couldn't care for her; as if I'd failed to make her well on my own and that I had to leave her with other people to do this. But the other part of me understood that she was in the best place because, from that point on, she started to eat by herself.

In fact she'd actually started to feed herself the day before we took her there. I think she felt that she had to prove to us that if she could do it, then she wouldn't have to go to the unit. Suddenly she'd say: "I can do it, mum! Look, I'm eating for myself! So I don't need to go there!" And we'd reply with, "Well, you do need to go there, but we'll come and see you every day," which is what we did.

In the unit, Amber was eating. She was doing everything she could to get better. She just wanted to be at home. She graduated from 24/7 care, where she was watched around the clock, even while asleep, to visits where we could take her out for a drive or even eat a meal or a snack with just us and no carers in attendance. After a couple of weeks, she was also allowed to come home for the weekend.

Around Easter, after Amber had been there for five weeks, we went in for an assessment and they told us they felt she was getting more depressed being away from us than she would be back at home. And, because she'd put on another stone or so, they said they'd discharge her and refer her back to the hospital in south London where she continued with twice-weekly sessions which, as time went on, reduced to once a week.

Amber also went back to school. She hadn't been there since Christmas. The school was wonderful. They said they could arrange for tutors to teach her at home - or the tutors could come into school and work with her in the library. Amber preferred being in school, so this is what happened. At this time she was only doing mornings and she wasn't in classes. Everyone - from the form tutors through to the

heads of year - was totally and utterly fantastic. They were completely supportive of her right up to when she left at the end of the upper sixth form. We managed to get a “statement” from the local educational authority on medical grounds which allowed the school to pay for a Special Education Assistant to help her with catching up on lessons and taking notes. This allowed her to take her exams on a computer in the special education unit because she found it much easier to type than to hold a pen. She also had extra time in exams because her concentration levels were not as they should be for a girl of her age.

In year 11, her GCSE year, Amber began to do full days. One of us would go in at break and sit with her while she had her snack and her friends would try to make sure she ate all her lunch. Meanwhile, despite the odd month where her weight would drop slightly, she continued to gain. Also, it was around this time that, after fifteen months, her periods returned. But the minute Amber’s weight dropped below a certain point they’d switch off again. She came to judge this as her “cut off point” where she couldn’t go any lower. And she’d agree with me: “Okay I need to have an extra drink or an extra snack to bring the weight back up again.” She was truly awesome, because I was well aware of how hard this was for her. I was so very, very proud of my daughter.

It was a very long time before she stopped saying things like, “Well, I can only eat *this* for my snack” or “I can only have *that* from the meal plan”. It was also a while before she stopped insisting on low fat products, for instance low fat yoghurts as opposed to creamy Greek yoghurts, and substituting lower calorie items for the items on the meal plan which the hospital had given her.

I would never have dreamed that one day we would look back on some of the things that went on then and laugh about it - for example her indignation at being given high calorie “ready meals” instead of home cooking. Also the fact that, in her mind, a bowl of soup and a marmite sandwich constituted *two* lunches, not one. However if I took the marmite out, she would eat it!

Amber's therapist at the hospital was excellent. One particular thing I remember him saying was: "You have to pick the battles, as long as she's eating and she's eating everything you're asking her to eat." By this he meant that if she was picking a 90 calorie cereal bar as opposed to 150 calorie one, then that was fine as long as she was eating everything else. Importantly, this wasn't the same thing as allowing her to actively cut back. The thinking was that the odd lower calorie item wasn't a problem as long as she was eating all the other things without a fight.

One thing that made me kick myself, however, was the fact that at Christmas we'd bought the girls a video exercise game which came with its own exercise board. The game measured height and weight and came up with a BMI level which informed my youngest daughter that she was overweight! Immediately I thought: "Oh my God, what have I done!" Especially when Amber began to say things like: "I can't go out. I can't do this or that; I've got to do my exercise." She was addicted to it from the start.

So again the therapist said: "Pick your battles. If she's doing the video exercise game and that's enough for her then at least she's not getting up at 4am and doing a thousand sit-ups that you don't know about. As long as it's not excessive. And, anyway, the endorphins will be good for her." He said that it would go, it would disappear. And it did. Gradually over time we realised that she hadn't done the video exercise that day. And then it would be a week. But before this I felt like the worst mother in the world just sitting there on the sofa watching her jumping up and down on that confounded white board.

The obsessive compulsive tendencies she had developed began to disappear, too. For example she would stand for hours rather than sit down on a sofa where the cushions weren't stacked at exactly the right angle.

Now, four years after this, Amber is fine. She is absolutely fine. Yes, she'll still beat herself up over things and there's still a certain amount of stuff going on in her head. She's still on medication, but these days we no longer weigh her. Her weight is normal, everything

is normal. She's perhaps a little shorter than she would have been if she hadn't been ill during puberty but the doctors aren't concerned about osteoporosis or any lasting damage to her bones, which is a huge relief.

I think that now she probably realises that she is no different from anyone else, from any normal girl. Everybody has days where they don't like the look of themselves or they feel down. She has these days, too.

Amber isn't as close as she once was with the childhood best friends who'd overseen her school lunches back in year 11. To be honest, I think they'd found it really hard acting as her "food police" and watching her going through the illness. I think they found it difficult to cope. They and Amber's other friends found it hard to "get" what was going on especially during the period where Amber had gained weight but was still behaving strangely. Doubtless they were thinking: "Well if she *looks* fine then why isn't she *behaving* fine?" Amber felt unable to really talk about what had happened and felt somewhat guilty about what she had put herself and her friends through. I don't think she really felt supported enough, but they were all so very young and ill-equipped to deal with such a devastating illness.

Amber was encouraged through her therapy to push herself to expand her social circle and make new friends. She flitted around for a while between different groups. But, through this, she met a couple of girls who went to a different school. They became her best friends and still are to this day. So much so that these girls actually transferred to Amber's school after the GCSE exams, so they all went through sixth form together. Seeing my beautiful, healthy, brave daughter having a laugh with her friends, just like any other young woman, means more to me than you can possibly imagine. Looking back, we've been so very fortunate. As our therapist said, Amber's eating disorder was caught early. We were also fortunate enough to have treatment at that hospital in south London.

I often look back to that terrible Christmas. I'd just given Amber

some spaghetti on toast and she was in meltdown because it wasn't a particular brand of low fat spaghetti and I had added extra butter to it. It was at that moment that the guy from CAMHS called us on the phone. He could hear everything and there I was, crying down the phone to him, "She just won't eat!" It was then that he made the immediate decision to liaise with our GP and the hospital and get her admitted direct rather than bother with the CAMHS route.

If he hadn't done that, well, I don't know if Amber would still be here.

She was so very, very poorly. I remember her smelling strange. Her skin had a yellow tinge. She was covered in dark brown hair all over her body and face. Her hair was falling out in clumps. It was as if everything was shutting down. I remember the terrifying feeling of helplessness. How could she have become that sick so quickly? That's the eye-opening thing about eating disorders; they start very gradually, almost creeping up on you unawares and then - ping! - they're off at a horrendous pace. The momentum was hideous. I am so grateful to that guy at CAMHS for calling at that moment.

Do I have any niggles about Amber's therapy? The hospital were great. They supported her for 18 months through school and through her GCSE examinations. But, because she wasn't technically in any danger at that point and her weight was well above the "danger zone", they signed her off. And that was that. It was all a bit sudden. I felt as if we'd been cast adrift and it was quite unsettling. Also, Amber missed her therapist as he had been so helpful to her.

Looking back, I am certain that she should have been signed back to CAMHS and the GP so she could have been monitored, but she wasn't. As a result we went through 18 months or so in limbo. I think we slipped through the net.

I took Amber back to our GP - a new one, because the original GP had retired - and she said she'd keep an eye on her. She was really good, but Amber wasn't getting any formal therapy. I signed her up with a local free counselling service for teens but she said that, although the counsellor was very nice, she wasn't a therapist and all

she did was listen, without treating.

Amber began to get very stressed in the sixth form with the pressure of studies. One day she came to me and told me she was worried that things were getting bad again. She was getting stressed out about her A-levels. My heart sank. So we went straight back to the GP who referred her back to CAMHS who immediately got in touch for an assessment. She was given a six month course of CBT which was really helpful. They signed her off in the August after her 18th birthday. So we had a few months where things were a bit tricky. But thankfully it didn't affect Amber's eating in any way.

These days she's so much happier. She'll come in with a takeout Chinese meal, just like anyone else. Or she'll grab a burger here and a pizza there, or sit down in front of the telly with a tub of ice cream. She is just a really happy young lady.

She laughs easily. She loves a joke with her dad and her sister. She's got a lovely disposition; she's very friendly and her confidence has come back. Also, she's becoming more and more independent, doing things that I never thought I'd see her do - like taking the train into central London where she has a part-time job which she loves. She's taking a year out before continuing her studies which I must admit is a relief because I don't think she would have been able to cope with university and living away from home.

Okay, she'll squabble with her sister, Jade, like siblings do, usually over clothes, hair products and shoes! But this is so very, very normal. The two of them have an excellent bond although my youngest seems older in so many ways. I think it's because all the trauma we've been through forced her to grow up so quickly. As for Amber, well, I think her brain is busy catching up with development as it continues to heal. It's almost like having twins instead of a five-year age gap.

But apart from that, my daughter really is just like any other girl in her late teens. It's almost as if she's picked up where she left off four years ago. It all feels so incredibly normal. But it's taken a heck of a long time to get to this normal. I am so very proud of her and the

way she refused to give in to the eating disorder.

Eating disorders don't just affect the sufferer, they affect the family too. Our youngest daughter, Jade, found it particularly hard; in fact she ended up having to have some therapy herself. When Amber first became ill, Jade was only nine years old. She thought her sister was going to die. She felt abandoned because we were constantly focusing on Amber.

In fact I carry a lot of guilt that I might have neglected Jade when she was upset and confused over her sister's illness. I don't believe I ever did neglect her but "mummy guilt" is still with me regardless. I am so proud of Jade for her understanding and her fierce protectiveness over her sister.

I often think how fortunate I was in that all my family were in a position to help. They live an hour or so away from us and were with us constantly during the dark times. My sister, who is ill with ME, set up home with us for almost six months to be there for us all but especially for Jade. Not having children of her own, she has an incredibly strong bond with both her nieces. I can't thank my family enough for their devotion to my children, especially Jade who found it so hard to come to terms with her big sister's illness.

Life goes on in our family and has its normal ups and downs. Sometimes my intuition senses that things are not right, but usually it's down to other teenage problems.

I am trying very hard to step back and let go, but it's difficult. As a parent you are hardwired to nurture and protect, and my beautiful daughter so very nearly died. So there's guilt there, too, even though I know that parents are not to blame for their child's eating disorder.

I would like to be able to say that we are completely out the other side of this dreadful illness, but I can't say we are truly there yet. I don't think we will ever be able to leave it totally behind. I will always be worried. My radar is on constant alert.

I was rocked recently with a revelation from Amber about vomiting. She was ill a few weekends ago, following a boozy night out and decided that if she made herself sick, she might feel better.

She told me in the morning that she had used her bulimic tricks to make herself vomit. When I responded that she'd told me she'd never done that during her illness, she looked at me and simply said... "I lied, I used to do it all the time".

I was shocked because for the last four years I had been taken in and totally believed that lie. I now find myself watching and wondering again, and racking my brains to see if I can remember when she could have possibly done this over the last four years without me noticing. I find myself making excuses to check on her and hover near the bathroom once more. I believe in my heart that she did this when she was early in recovery, probably when she went back to school and was eating on her own. I am certain that she did this out of the house as I would have known and certainly would have found and smelt the evidence, but there was nothing.

I hope and pray that Amber won't ever suffer a relapse. She remains on antidepressants and when she says she is fine, I have to believe her.

Anorexia changed her and changed me. It totally devastated us at the time. We were lucky we had never had to face such trauma in our family before, but it has taught me that we are a strong family, stronger than I ever thought possible. We faced one of the most awful illnesses imaginable and hopefully kicked it out of her life and our lives forever. A telling time will be when Amber eventually leaves home, but thankfully that is still a few years away as the college she hopes to attend is in London. Her healing can carry on at home for now.

I think it is so important for other families facing what we went through to know that it's possible to be a happy family again. You can beat this, just as we did. It will be a long, hard, uphill struggle at times, but you can get there like we did. It just takes endless food, love and patience. And we parents have limitless supplies of that!

Amanda's story

“‘Just how far will you go?’ I asked my daughter. ‘There is no end,’ she said. Terrified, I promised her there and then that, whether she hated me for the rest of her life, I was fighting for her very survival.”

It's odd how you remember conversations you had with your children that meant “nothing” at the time but, in hindsight, you realise how important they were. Those moments when they ask: “Is it you?” meaning are we Father Christmas? And those moments when your beautiful, perfect and, to all intents and purposes, normal daughter begins to talk about body shape and pointing out how some jeans are made for different shapes than others.

The first time my - then - 15-year old daughter, Ellie, and I had one of these conversations I remember thinking: “That was weirdly out of proportion.” It was during the Easter holiday of 2009 and Ellie was talking about the prospect of a summer holiday with some friends. These friends have three daughters who grew like beanpoles. At the time Ellie was about a foot shorter than the eldest. Her reaction was really extreme. It went something along the lines of: “Well, I won't go on holiday with them. There's no way I could lie next to T--- by the pool 'cause I'm just so huge!”

I was horrified that she thought this way about herself, but brushed it over with a loving response of somewhere between “there, there” and “don't be so silly”. In the event, and for reasons totally unrelated to that, the holiday never took place.

A couple of months later, Ellie took four of her GCSE

examinations early; she was one of the brighter pupils in her year group. It was then that I noticed she was self-harming - nothing too dramatic, just scratching herself and not allowing it to heal. But it was enough to make me notice and assume the exams must be causing her stress. Then in August when the results came out, one of them was a B. Forget about the fact that the other three were As; Ellie saw the B as “failure”, so much so that she couldn’t celebrate the success.

During that summer Ellie made an attempt to diet, just to shift a couple of pounds. To me this was normal teenage behaviour, so I wasn’t unduly concerned. The diet didn’t work, so she stopped. It didn’t really cross my radar. Perhaps it should have done. In the autumn I remember asking a friend (with older daughters) how one talks about these things with teenage girls. By then something must have worried me enough to ask a question like this. Then I went away for a week. Meanwhile Ellie developed a virus which meant she couldn’t eat.

That’s when I believe “it” got in.

On my return, Ellie talked of having lost four pounds. She also said her periods were a “bit weird”. I remember brushing it off with a “don’t worry you’ll soon be back to normal” comment.

Meal times started to get fraught. She’d leave food untouched and refuse some food types. I remember getting very angry over a baked potato and some gammon. Actually I was so cross that I mentally took a step back from the situation and thought “this line of attack isn’t working; I need to think how to get round this in a better way”. I tried cajoling and cooking her favourite foods. I asked what she had eaten at lunch thinking that if she’d eaten a good school lunch then I needn’t be so worried about what she wasn’t eating at home.

I was beginning to lose sleep over it. Ellie was beginning to lie about what she was eating at school. I knew this because she talked about eating cottage pie and she never ate cottage pie at school! Her breakfast became a pint of black coffee and an apple. When her younger brother reported that she was having the same for school lunch, I knew something was wrong. The tension in the house was

beginning to rise around meal times. I began to be thrilled if I saw anything edible pass her lips. But more than once I thought: “It can’t be anorexia because anorexics don’t eat anything at all.”

I noticed that Ellie was finding it hard to keep warm. Chilblains set in that actually made her cry. She said she thought her toes were going to fall off. Worried, I had a chat with one of her friends who told me how concerned she was about Ellie. I’m a nurse by profession and immediately I put on my nurse’s hat, so to speak, and began to think about anorexia. That afternoon I confronted my daughter. It didn’t go well and the shutters came down. But the gloves were off. I had thrown the “anorexia word” into the conversation and told her how fearful and worried we all were. I asked where the money I gave her for school lunches was. Two hours later a shoe box with two months’ worth of school dinner money was handed to me.

Initially I thought: “This can’t be happening to us.” Ellie was always such a good girl. She was always highly thought of and had always been taught not to lie. She was well behaved at school, was very popular and had boyfriends. We were hugely proud of her in every way.

We are just a normal, close, “functioning” family; there is nothing unusual about us. If anything, we’re the kind of family that, to others, might appear to “have it all”. But, as time went on, that couldn’t have been less true. With the arrival of an “unwanted extra” in our midst, we became a dysfunctional family. We didn’t change immediately; we were still the five of us, going about our daily lives. But, to the professionals, we became dysfunctional.

I rang the GP. She rang me back right away and I sobbed Ellie’s story to her down the phone while she listened patiently. The GP acted fast and told me to bring Ellie in under the pretext of the chilblains and let her do the rest.

We arrived and I was allowed into the consultation where the GP asked Ellie some gentle, quiet and insightful questions. Was she feeling okay? Was she a bit stressed? Had she noticed losing weight?

Ellie admitted to losing a stone so far, but she insisted she was okay and that there was nothing to worry about. But the GP *was* worried. She asked us to return in two weeks for another weigh-in and chat. If she saw deterioration then Ellie would be referred to CAMHS. It was Christmas 2009.

Two weeks later and another four pounds lighter, Ellie begged for more time so she could stop losing weight. The GP gave her a week. I started to leak (cry) a lot. Surely the 500 calories a day she was eating wasn't enough to stop the weight loss?

Back at school, the horror texts started with messages about how she couldn't cope with everyone looking at her, how she wasn't good enough to be liked or loved. She lost another four pounds.

Thankfully the CAMHS referral came very quickly. Our first appointment was with a nurse at the local child and family mental health unit. Ellie was furious. She refused to talk. The nurse asked patronising questions like: "Is this your mum? What's her name?" I was sitting right there! And "Is this your dad? What's his name?" Ellie sat tight lipped while I fumed. I mean, Ellie was an intelligent articulate 15-year old girl, not a four year old child in need of cajoling. So, to be honest, I wasn't surprised when Ellie refused to go back. However, we persisted for a while. The patronising tone continued and Ellie continued to not eat. She was two stone down by now. An emergency psychiatrist was called in for an assessment; we needed a diagnosis for our skiing holiday insurance. Well, we just needed a diagnosis, full stop. The usual psychiatrist was on holiday.

The GP and the emergency psychiatrist were exemplary in their thoughtful, insightful and trust-inducing help in a situation that was fast spinning out of control with no apparent brakes in sight.

The emergency psychiatrist talked about how we shouldn't trust anything Ellie might say to us about food and that she couldn't be relied on to be telling the truth. She talked about food being Ellie's medicine and insisted we increase her calories and give her six meals a day - three main meals and three snacks. We were to go home and feed her on hot buttered toast and hot chocolate. At last I had

instructions. I naïvely thought to myself, yes, I can feed my child with this kind of stuff. After all, how hard could it be?

We were in a town a couple of hours from home. The café was crowded. I placed the toast and hot chocolate in front of Ellie while she stared at it as if I'd offered her poison. She picked at it, eating the tiniest mouthfuls and cried. She didn't finish it. From what she told me years later she kept it in her mouth and spat it out in the car. But at the time I had no idea that this kind of thing could happen. I was just so horrified at how, when I fed my daughter food, the "monster" reared its ugly head and fought back. I am grateful that no-one in that café knew us.

I went from being the happy, chatty mother at mealtimes to being my daughter's gaoler. Or at least that's how it felt. I became savvy at watching as surreptitiously as possible at mealtimes, open-mouthed at the "monster's" wily tricks of stashing food up sleeves, throwing things around, smashing stuff and running out of the room.

Desperate to find out more about what was consuming my daughter, I began to read. Book after book after book. I equipped myself with Lock and Le Grange's *Help Your Teenager Beat An Eating Disorder* (another nugget from the emergency psychiatrist). I also became familiar with Janet Treasure's *Skills-Based Learning for Caring for a Loved One with an Eating Disorder* and learned about her animal metaphors for different types of carer.

I was very quickly realising that Ellie needed me to fight for her survival. Yet at the same time I was falling apart, silently weeping and mourning the loss of my dear daughter who had changed beyond recognition, mentally and physically. The "real" Ellie had completely disappeared, just like her weight. Of course our, then, eight year old youngest son didn't understand what was happening. "I just want my Ellie back," he whispered to me one morning.

Meanwhile, we saw CAMHS weekly. Ellie was also weighed at the GPs' surgery. By now we were seeing the regular psychiatrist again. At the very first meeting she told us that Ellie wasn't thin enough to be diagnosed with anorexia. Now, I am not a swearing woman, but -

boy - did I swear then! “I’m not bl***y standing around waiting for her to get thin enough!” I shouted at her.

Of course Ellie - or rather the “monster” that had replaced Ellie - saw this as a triumph and “official permission” to carry on losing weight... three stone in as many months by this time.

Every week the psychiatrist would ask her how she was feeling. On those weeks when the GP couldn’t see her, I remember the psychiatrist telling Ellie that she “looked like she was gaining weight”. The result of these less-than-artful comments? Hours of self-harming, berating and loathing once we got home.

Ellie couldn’t sleep. I didn’t sleep. I would sit on her bed, stroking her back for hours on end, willing her to realise that she was loved and willing her to eat. I’d tell her stories of her childhood, remembering happier times. Praying. Hoping. Losing hope and losing time.

Gradually I realised that I had to be strong. I had to fight on Ellie’s behalf against the eating disorder. I couldn’t just sit there, go to pieces and leak my way through umpteen boxes of Kleenex tissues. I’d always been the strong one. I’d always known what to do. Now I had to be strong. I had to fight. I had no choice.

By this time Ellie couldn’t face school. One day she begged me to pick her up. She couldn’t face lunchtimes. She couldn’t face her friends seeing how “hideously fat” she was. All I was seeing was a girl who was losing weight fast, who was developing the tell-tale peardrops smell on her breath, had a vacant look in her eyes and a dreadful pallor that made her skin almost translucent. Her frozen fingers, toes and expression... All were lost to the illness that consumed her mind and thoughts.

We removed Ellie from school. She didn’t return for nine months. Her GCSEs became unimportant, unattainable. They could wait.

I realised that, although I was never “pushy” (having failed all my school exams I never expected my kids to be brilliant), I did have dreams for my kids’ futures. Who doesn’t? But, at this time, I began to reassess these dreams. I wondered if Ellie would ever have

relationships again. Her friends had stopped visiting and she hated herself. I wondered if she'd ever go out again. She was just too scared to be seen in public.

I grieved. Yes, that's what I did in those months... I grieved and I fought. But I fought the illness, not Ellie. I fought for her existence. I even rang the Government demanding a specialist dietician for our area. It was provided but only for Adult Services.

I rang various advocacy groups. Surely my daughter needed specialist help? Going to CAMHS didn't seem to be doing anything. It was a bit like taking your child to see the GP over and over again with a broken leg when really she needed to see an orthopaedic surgeon. CAMHS didn't seem to "get it". And I felt judged not supported. Meanwhile I continued to read anything I could get my hands on about eating disorders. I read avidly morning, noon and night. Well, mostly during the night as sleeping became impossible.

Our happy, close, normal family because a statistic: a dysfunctional family. Our marriage was crumbling, our daughter was dying and our two sons were floundering around without the normality of our "old" life.

By the summer of 2010 Ellie's weight had stabilised. She wasn't losing as fast and we had worked so hard on trust. She was now managing to eat what I put in front of her. Okay, it still wasn't enough and there was still a lot of food that she wouldn't touch. But at least she wasn't running out of the house into the snow with only her pjs on, getting lost for hours while friends and family combed the fields looking for her. She was able to eat in front of the TV and, occasionally, at the table with the family. I saw all of these things as small steps in the right direction.

By now I'd found a superb online resource called F.E.A.S.T. and its forum, Around The Dinner Table, for parents of young people with eating disorders. Through these two resources I learned an enormous amount. I also continued to read. And you know what? Everything I was discovering pointed towards the fact that my child must eat to recover. Now, to the uninitiated, that might sound

obvious. Starving people need to eat. But, strangely, not once had CAMHS (bar the emergency psychiatrist at the beginning) mentioned that Ellie needed to eat to get well.

So, as a family, we made a radical decision. We quit CAHMS and moved Ellie's treatment to a specialist private eating disorder unit two hours' drive from our home. Initially we attended twice a week. The first time Ellie went there she came out smiling, exclaiming: "They understand, mum!"

They had talked to her about the fine hair on her body, her lack of periods and the need to eat. They had congratulated her on her triumphs thus far in halting the tumble downwards and they began to work with her. In just two hours they had gained her trust - and ours. They also cost my parents and in-laws a small fortune...

My husband and I were kept out of the loop apart from a few ten-minute sessions at the end to ask how things were going from our perspective. I found myself between a rock and a hard place. If I told them how it *really* was I'd have two hours of sulking and trying to jump from the car on the journey home. (No, not me, Ellie...) If I pretended everything was okay, then it wasn't so traumatic. So some days I pretended, other days I went greyer!

That September Ellie returned to school for the sixth form, initially part-time then gradually full-time. Bit by bit I began to see a blossoming of hope and signs of recovery. Her therapists had given her the tools to handle the stresses thrown at her. She was discharged after 18 months of treatment and, at first, I was delighted.

Sadly, though, unbeknown to me she had been discharged at a sub-optimal weight. Also, she wasn't given any follow-up with the result that she relapsed quite significantly while studying for her A-level examinations. I remember weeping to my mother on the phone: "I just can't go through this again, mum!"

"Yes you can," came the reply. So we did, but this time Ellie had the tools to see that real life was far more important and that the recovery she'd already glimpsed wasn't as far away as before. Gradually she cottoned on that, yes, life is worth living and that, with

help and encouragement, she would make it back.

It is now April 2013 and Ellie is in a gap year before going to university. She is spending the year living away from home. Yes, she is thin. But I guess she might always be this way. She knows she can't ever "diet" again or even miss meals. She is well aware that the "ED voice" comes back if she doesn't have her snacks. She knows that it's still a bit of a knife-edge existence, but she also knows how to pull it back if the eating disorder comes knocking.

The professionals talk about independence with eating. They talk about families pulling back from treatment, not being so involved, especially with adult sufferers. My reply has always been that, although most good parents encourage their children to be independent, there are times when - if they fall, through illness or otherwise - it is still our responsibility to step in. And if that means "nursing" them back to a place where they can take that independence back, then that's what we'll do, regardless of their age.

I'll never forget the day I stood next to my, then, 15-year old daughter whilst she hugged the radiator through sheer cold because she just couldn't warm up - her fingers blue with cold, her skin pale and her breath smelling of peardrops, a vacant look in her eyes.

"Just how far will you go?" I asked her. "There is no end," she said. At that moment the fight for life took over and I promised her there and then that I would fight the illness that was "consuming" her every thought. I promised that, whether she hated me for the rest of her life, I was fighting for her very survival. I would know that as her mother I had and was doing the right thing, and hopefully one day she would thank me.

I couldn't stand by and watch my wonderful, gorgeous and in my eyes perfect daughter be killed by something too big for her to fight herself. As a family we encouraged and rooted for her, cheering her bravery and quietly loving the fact that she was on the road to health again, singing daily and able to go to parties, shop with friends and eat at the table with us. Now she is in recovery. At last we have a teenager who does teenager stuff. We so nearly didn't.

MY TIPS:

Get reading. Order these books: *Skills-Based Learning For Caring For A Loved One With An Eating Disorder: The New Maudsley Method* by Janet Treasure and *Help Your Teenager Beat an Eating Disorder* by James Lock & Daniel Le Grange. (See list of resources at the end of the book.)

Put yourself in your child's shoes. I was told to imagine that having an eating disorder (anorexia in our case) made food and the fear of getting fat the scariest thing ever, like being in a room full of spiders or snakes.

There is hope. Eating disorders, although extremely dangerous, are treatable through patience, persistence and love.

Food is medicine. I firmly believe that recovery starts at home. We are with our children most. We are the food providers. Food is their medicine.

Never go by look. It is a myth to believe that someone with an eating disorder needs to look emaciated.

Separate your child from the eating disorder. By separating the eating disordered thoughts and actions from your child, it gives strength to the “real” person that they are rather than the eating disorder.

Don't blame yourself. Your child's eating disorder is not your fault; it is a mental illness.

Take charge. Your child needs help and the security of knowing that adults who care and love them are there to fight on their behalf. Taking charge of eating when your child is unable to do so is imperative. Do not be afraid to do this. Get them to eat six times a

day: three meals and three snacks i.e. breakfast, snack, lunch, snack, supper, snack.

Be patient, be consistent and be encouraging. It's tiring, it's difficult, it's lonely and it's tough but it's worth it!

Be vigilant. If there is a binge/purge element to the eating disorder (e.g. bulimia nervosa) take time following a meal to distract (games, TV, following them around the house and allowing no time alone) for at least an hour - to avoid purging.

Sadly an element of trust is lost to the disorder. It's hard to learn never to leave food and the eating disordered person alone. However, they will try to hide food or not eat. Be aware of this and always stay with them when they are eating. Unfortunately you can no longer believe that what they claim to have eaten has been eaten - unless you have seen it going in. Sadly this is a very deceptive illness, regardless of how honest and truthful the child was beforehand.

Find what works for you and your child. You have to decide what this is. Some people find that hiding calories (adding cream, butter, etc) works. Others find that trust, making a contract that nothing will be hidden, but that what is given must be eaten is another way of food introduction.

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