

# When anorexia came to visit

*Families talk about how an eating disorder  
invaded their lives*

Bev Mattocks



First published by Creative Copy September 2013

Revised edition published December 2013

[www.creativecopy.co.uk](http://www.creativecopy.co.uk)

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ISBN 978-0-9575118-4-2

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# Dedication

This book is dedicated to the wonderful families who have allowed me to share their stories with you in order that others might find inspiration and hope. It is also dedicated to the young people themselves, individuals who have demonstrated the courage, grit and sheer determination to fight this illness and win.

# About the author

Bev Mattocks lives in the north of England with her husband and son, and works as a freelance advertising copywriter. She is a member of F.E.A.S.T. (Families Empowered And Supporting Treatment of Eating Disorders) and writes a popular blog about her experiences of supporting her teenage son through anorexia. She is the author of *Please Eat... A Mother's Struggle To Free Her Teenage Son From Anorexia* which is available from Amazon.

For more information, visit [www.anorexiaboy.co.uk](http://www.anorexiaboy.co.uk),  
[anorexiaboyrecovery.blogspot.co.uk](http://anorexiaboyrecovery.blogspot.co.uk) and  
[www.bevmattocks.co.uk](http://www.bevmattocks.co.uk)



# Foreword

By Professor Janet Treasure, OBE PhD FRCP FRCPsych,  
Director of the Eating Disorder Unit and Professor of  
Psychiatry at Kings College London

When an eating disorder comes to visit, friends and families are often the first to know. Furthermore families can play a key role in mentoring the process of recovery and moderating the isolation that causes the illness to become stuck.

However this illness is not like other illnesses. It pervades all aspects of family life. Additionally, a starved brain results in the individual being less able to manage the skills required for successful inter-personal processes. A vicious circle starts. As a result, family members need high levels of emotional intelligence and practical skills to interrupt this downward spiral and guide their child towards recovery.

*When Anorexia Came To Visit: Families Talk About How An Eating Disorder Invaded Their Lives* details the recovery stories of 20 individuals from the family perspective. These stories offer hope and resilience through their honesty and practical advice and will be an invaluable source of support for families.

*Professor Janet Treasure, OBE PhD FRCP FRCPsych*

# Preface

By Becky Henry, Founder & President of the Hope Network, LLC & Award Winning Author of “Just Tell Her To Stop: Family Stories of Eating Disorders”

Myths and misconceptions about the nature and causes of eating disorders are still endemic. Thankfully, understanding of these complex and life-threatening illnesses is increasing as new and more effective evidence-based treatments are being developed. Across the world, enlightened healthcare professionals are coming to realise that a collaborative approach between professionals and families can result in a better outcome for the patient.

As a professional certified coach, a Board Member of F.E.A.S.T. (Families Empowered And Supporting Treatment of Eating Disorders) and a parent that actively advocates for evidence-based treatment through my organization the *Hope Network, LLC*, in the USA, I look forward to the day when all healthcare professionals recognise the urgent need to update their understanding, treatment and care of people with eating disorders.

During the two years between 2000 and 2002, while I was failing to get my daughter’s eating disorder diagnosed, I had no idea that parents across the world were struggling with similar problems.

After taking my daughter to the pediatrician and two psychologists, the long path to treatment came only after I handed the pediatrician the diagnosis on a silver platter: my daughter’s friends had finally shared with me the frightening details of what was going

on. I gave the pediatrician this evidence and insisted on a referral. Unfortunately, back then, the local eating disorders treatment center was still practicing the old “parentectomy” model where we, as parents, were asked to “back off” and leave it to the health professionals to care for our daughter. As a result her eating disorder was permitted to distort her perceptions of what was being said and done and we were not included to counter this.

During my struggles I searched for connection with other parents and for more information about effective treatments. This difficult and isolating experience is what eventually drove me to interview over 40 families and write their stories for my book *Just Tell Her To Stop: Family Stories Of Eating Disorders* (January 2011) so that other families would have information and feel less isolated.

I have also made it my mission as Founder & President of the *Hope Network, LLC*, to share information on evidence-based treatment with healthcare providers so that patients can be diagnosed and treated sooner. As with any serious illness, early intervention is more effective than waiting until it is entrenched.

I am very grateful for all the wonderful reviews and feedback on my book *Just Tell Her To Stop* from both families and healthcare providers in and outside of the USA. As these are such complex and prevalent disorders, we need many similar stories to help people understand and let go of outdated information. So it was with great joy that I learned about June Alexander’s book, *My Kid Is Back: Empowering Parents to Beat Anorexia Nervosa* (February 2010) which shares stories of Australian families fighting an eating disorder. And now I am thrilled to hear of Bev Mattocks’ book *When Anorexia Came To Visit* which describes the stories of 20 families in the UK who have undergone treatment.

Of course diagnosis can be complex. As I said in my book, as much as we would wish it to be so, there is no one-size-fits-all treatment and what is important is to find the right treatment for your child. Bev Mattocks’ book - like mine - is not meant to endorse any particular treatment model; merely to describe what is available.

It is not a medical reference; it is a book of real stories describing different circumstances and treatment approaches.

As with my book, Bev Mattocks has gathered together these stories because she and the book's contributors do not want other families to go through the same nightmare. These families want to offer hope to others by showing what worked (and what was less successful) in their individual circumstances. I hope that others may be able to draw inspiration from these accounts and feel empowered when approaching treatment providers.

The other purpose of *When Anorexia Came To Visit* is to show healthcare professionals what goes on at home, beyond the confines of the consulting room. And, as parents who are living with this illness on the front line for many exhausting hours a week, I look forward to the day when it will be standard practice for parents to be recognised as a vital part of the treatment team.

Within the pages of this book you will read many positive and inspirational stories of hope - of excellent GPs and healthcare professionals working with parents to get the child well. But you will also read about families that have battled with inadequate services and treatment, especially evident once a child reaches the age of 18 and no longer qualifies for adolescent services.

I hope that, with multiple books like this one, the tide will shift and outdated theories will finally be put to rest - and that funds will be spent on ensuring people have access to high quality treatment wherever they live.

It is thanks to pioneers like Bev Mattocks, June Alexander and others that these stories are being told which will, I hope, help to turn this tide and get these most deadly of all mental illnesses the research, recognition and understanding that is needed.

*Becky Henry, Founder & President of the Hope Network,  
LLC & Award Winning Author of "Just Tell Her To Stop:  
Family Stories of Eating Disorders"*

# Introduction

Laura Collins, Founder of F.E.A.S.T. (Families Empowered And Supporting Treatment of Eating Disorders) & Author of “Eating With Your Anorexic” explains about the F.E.A.S.T. community and its online forum Around The Dinner Table (ATDT)

The question I hear most often when a parent realizes that their child has an eating disorder is: “How do I find other families who have come through this?”

Before diagnosis, few of us will have talked with another family facing an eating disorder. So, when we discover our child is sick, we can feel isolated and frightened. We want to know there is hope; that our child will recover - and we want to meet other parents that have faced the crisis and come out the other side. Indeed talking to families that have survived an eating disorder can be one of the most encouraging and empowering comforts during difficult times.

In *When Anorexia Came To Visit*, Bev Mattocks has collected together just some of these stories, many from UK members of a very special community: Around The Dinner Table - an online forum run by parents *for* parents. I founded ATDT (as it is often known) because I envisioned a community of parents helping other parents to survive this devastating experience. When a parent is desperately searching for information and inspiration, the forum is like a lighthouse in a stormy sea, showing the way to safety. What started out in 2004 with me asking my relatives and friends to “please post

something” is now a longstanding institution with thousands of families that have come to us for support.

The generosity of the global ATDT community continues to amaze me. There are caring folks online at all hours to offer leads to information, provide inspiration or simply a friendly shoulder to cry on during stressful moments. The moderator team know our vast archives inside out and can refer a parent to relevant threads, whether current or past. British, Canadian, American, New Zealand or Australian families find one another, families facing similar symptoms find one another, and those living close enough to meet up form invaluable local support networks across the globe. By using the power of the internet, even with its drawbacks, ATDT offers support that is found nowhere else. Many practicing clinicians tell us they learned of a new technique, book or other information source from the forum. I regularly hear from parents that ATDT was an essential tool in their family’s success. Indeed many of the families in *When Anorexia Came To Visit* describe ATDT as a lifesaver during the darkest days.

The limitation of an online forum, however, is that each story is told in individual threads over time; rarely can a single thread describe a story from start to finish. This is what makes a book like *When Anorexia Came To Visit* so important. I applaud Bev Mattocks for gathering these 20 stories and giving these wonderful families a voice.

Of course, with such a complex illness and widely differing personal circumstances, each story is different. Nonetheless there will be overlaps that families will identify with. Like me and countless others, you will find yourself nodding your head and saying “Me, too!” as you read about similar experiences to your own. May these stories, and these brave families, offer you the hope and inspiration you need and deserve in the fight for full and sustained recovery.

*Laura Collins, Founder of F.E.A.S.T.  
& Author of “Eating With Your Anorexic”*

# About this book

By Bev Mattocks

One thing I remember saying over and over again to my husband - and probably still say on occasions - is this: “We should have picked up on it sooner.”

The question is: could we, or any of the families I interviewed for this book, 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 evident for some months.

The problem was that we didn’t recognise them.

Even before the signs emerged, the eating disorder was busy germinating 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 an eating disorder. You don’t expect it to happen to your ordinary, happy, close family. And, in our case, and a couple of other cases in this book, you don’t expect it to happen to your son.

Eating disorders aren’t like “normal” medical conditions 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, few of the families in *When Anorexia Came To Visit* had any idea what they were dealing with. Nor did their children. For instance it’s not as if my son sat down one day and decided to “get anorexia”. He was as ignorant as any of us. And, anyway, these days we know that anorexia is a biologically-based mental 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 have been 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 for this book 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 here lies another problem. All too often, healthcare professionals are also failing to recognise the clear warning signs of an eating disorder and take appropriate action urgently.

In the making of this book I talked to GPs, medical students, even the Royal College of General Practitioners (RCGP), and there seems to be very little formal training in eating disorders in the UK. Our local GP said she "probably had two lectures" as a medical student at Cambridge. A medical student specialising in psychiatry appeared surprised to learn from my family that males get eating disorders. And a representative from the RCGP told me that: "Currently only around 50 per cent of doctors-in-training for general practice have an opportunity to undertake specialist-led mental health or in child health training placements (e.g. based in hospitals or specialist mental health services) during their three-year GP training programme." (However I understand that proposals are in place for this to change.)

The fact is that, when you take your child to the GP, you expect them to know what is 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. After all, they're the professionals, they should know.

And, meanwhile, your child can be in complete denial that there is anything wrong. So sometimes it can be just you, the parent, puzzling over whether or not you should be worried - and then fighting a lone battle to get your child diagnosed and referred.

Thankfully, once referred, most of the families in this book saw a

service 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 from our first GP visit before we saw our local CAMHS team and only then because the assessment was expedited when Ben's pulse plummeted to 29 and he ended up wired up to machines in hospital.

Just because your child has been referred, it doesn't automatically mean they are going to receive exemplary, informed, evidence-based treatment. From my discussions with families, whether or not your child receives effective treatment appears to vary according to where you live. Additionally, some children are being referred to generalised mental health services like CAMHS whereas others are being referred to specialist eating disorders centres. In areas where there is very little available, or where a child's BMI is not considered "low enough" to qualify for treatment, families are being forced to opt for costly private care. Sometimes the NHS agrees to pay for this private treatment and sometimes it doesn't. Sometimes children are admitted into an eating disorders unit as inpatients and sometimes treatment providers prefer to keep them as outpatients. To us, as "lay" parents, there doesn't seem to be any consistent pattern, and this comes across clearly in the large cross-section of families I spoke to in the making of this book and on many other occasions - families from across the UK, including Scotland and Wales.

One of the many reasons why I decided to write this book is because I wanted to see how our own personal 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

coordinated team of clinicians using the latest evidence-based treatment focusing on full nutrition first and foremost, and recognising parents as an integral part of the recovery process.

But you will also read about families who experienced the other end of the spectrum - those mental health services that “could do better”. With these families recovery didn’t come as quickly; some are still a work in progress.

I often wonder where parents would be without the power of the internet. Would we still be ignorant of the latest evidence-based treatment? Would we still accept the outdated notion that eating disorders have to last for several years, if not for life? 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 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 F.E.A.S.T. (Families Empowered And Supporting Treatment of Eating Disorders), set up by Laura Collins, author of *Eating With Your Anorexic* (who was kind enough to write the Introduction for this book). F.E.A.S.T. and its online forum, Around The Dinner Table (ATDT), is run by parents and carers *for* parents and carers. Today F.E.A.S.T. 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 F.E.A.S.T. and other resources such as 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

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 F.E.A.S.T. and ATDT were lifesavers. It is also thanks to the people I've met through F.E.A.S.T. and Beat that I have been able to gather together these 20 powerful, insightful and inspiring stories.

Through this book, we want to show other families that they are not to blame for their child's illness. Eating disorders are biologically-based mental illnesses, not lifestyle choices. And, yes, eating disorders *are* about food - lots of it, being administered by strong, loving, dedicated families who refuse to accept that their beloved child is "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 parents are part of the solution, not the problem.

We also 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, gradually heals and returns to its pre-anorexia state.

Finally, we 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 - and the tools and coping strategies that we found most helpful.

What this book isn't, however, is a medical reference. It is not meant to be used, nor should it ever be used, to diagnose or treat an eating disorder. For diagnosis or treatment you should always consult your own physician. Nor does this book endorse any particular treatment model or approach, or any particular eating disorders clinic, hospital, unit or treatment provider. Eating disorders are notoriously complex and diverse illnesses, and a one-size-fits-all approach to

treatment is nigh impossible. Therefore everything contained within the pages of this book is for information purposes only including the tips at the end of chapters which are based on individual experiences. In other words, what worked for one family may be inappropriate for another so please be sure to consult your physician or eating disorders specialist. Also, to protect privacy, names have been changed and locations have been disguised.

Additionally, I would suggest keeping this book away from your child. As Becky Henry says in the Introduction to her book *Just Tell Her To Stop: Family Stories Of Eating Disorders*, there may be statements that could be “triggering” to the eating disorder. Becky says: “The stories in the book could ‘teach the eating disorder’ new tricks to further compromise your loved one’s health.” For this reason, in *When Anorexia Came To Visit*, I have taken care to remove references to, or disguise, specific “tricks”. However some things need to be shared in order that parents can be aware that these things happen and remain vigilant.

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 hope 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 to edit the transcript of a taped conversation or tweak a detailed written account. So, strictly, I should be calling myself *editor*,

not *author*. These 20 families and the three wonderful people who provided the *Foreword*, *Preface* and *Introduction* have written this book, not me. And I am immensely appreciative of their help, dedication and input.

Finally I must thank the young people themselves for demonstrating the courage, grit and determination to fight the eating disorder 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.

*Bev Mattocks, July 2013*

# Caroline's story

“When I look at Molly I want to show her to every desperate parent who has just discovered that their child has an eating disorder and say: ‘This is what recovery looks like!’”

You don't expect your normal, level-headed, beautiful and intelligent daughter to get anorexia. Like many people I assumed that eating disorders happened to other families. I assumed they were “caused” by traumatic events, being brought up in a dysfunctional family environment, the pressure in the media to be stick thin or a whole range of other “causes” that weren't relevant to our close, happy, normal family.

So when our university student daughter, Molly, began to show signs of an eating disorder, my first reaction was shock. How could this happen to us? My second was the realisation that I knew *nothing* about this illness that seemed to be consuming my daughter. Yes, I'd read sensational stories in newspapers and magazines and I knew of a couple of girls at Molly's old school who'd developed eating disorders, but apart from that I knew nothing.

Molly was in her second year at university in Cambridge. She'd come home for the Christmas holidays and from the moment she arrived through the front door it was clear that something was wrong. She was edgy, irritable and demanding. Molly and I had planned a night at the ballet; it was a favourite annual ritual. We'd have dinner at a favourite restaurant and then go onto the theatre. It was a real mother and daughter treat and we looked forward to it

immensely. Over dinner Molly was unusually difficult and refused to have a dessert. In the past desserts had always been a favourite. I wasn't big on home cooking, but apple pies and crumbles from Marks & Spencer were always firm favourites. But on this occasion, Molly refused to share even a small dessert.

Molly didn't speak to me in the cab we shared to Sadlers Wells. It was as if she were cross with me; as if I'd done something wrong. At the theatre I went to the bar to get a drink and when I returned I was shocked to find her sobbing in a corner. When I tried to comfort her, she told me that she was hearing "voices" in her head. She said they were telling her she shouldn't like me because I was trying to make her fat. My first reaction was shock closely followed by an intense fear as it suddenly dawned on me that something was seriously wrong.

The ballet was Cinderella. But I don't remember much about the performance. Every now and again I glanced across at Molly and she seemed absorbed in the action on the stage as though the bombshell she had just dropped had never happened. We drove home afterwards and made polite conversation about anything except the thing we most needed to talk about. Back home, Molly thanked me for a "lovely evening" and went to bed. I numbly recounted the evening to my husband, Graham, who seemed very calm about the whole thing and suggested this was maybe something many teenagers went through.

Suddenly, over the next few days, I began to notice everything I should have noticed before. Molly was extremely anxious. She was constantly cold and I became aware of a soft downy sort of hair on her face which wasn't there before. Molly was also exercising more. She'd always been interested in sport, but really only as a spectator. She was the type of child who would come last in most of the races, but would always cross the line with a huge smile on her face, glad to have been a competitor, but never competitive. But now she was swimming 100 lengths of the pool, and running most days and in all weathers. I couldn't help noticing that she didn't seem to be getting



any enjoyment out of it. Whatever the weather, she'd be out there, often carrying injuries to her ankles or shins, but driven to run regardless.

I also noticed that Molly was drinking huge amounts of water and cutting food into small pieces. Hot drinks were always black coffee and these days she never had milk. Oddly she had no problem eating fruit, but she wouldn't drink a glass of fruit juice. Requests for her to eat were met with the same responses: "I've already eaten", "I'm not hungry" or "I'll eat later".

My first reaction was guilt. Why hadn't I noticed before? Over Christmas I watched her with new eyes and started to see how anxious and unhappy she seemed. Hanging her clothes on the line after washing them, I was struck by how small her jeans were and realised that my next door neighbour's daughter's clothes looked to be about the same size, and she wasn't even 10 years old.

I frantically wanted to "fix" things, but I didn't know what to do. Oh, and I was angry with Graham who didn't seem to be as frightened as I was. Graham has always been very calm and undramatic. I didn't seem to be able to make him understand that I thought we had a really big problem on our hands.

Our GP seemed to be the first port of call. Molly agreed she needed to go because, fundamentally, she's a pleaser and she could see how worried I was. To be honest, I think she felt very ambivalent about me at this time. Part of her wanted to make me happy. But the other part of her believed I was either the problem or I had *caused* the problem. At this stage no-one had mentioned the words "eating disorder" let alone "anorexia" and in my head I still didn't put the two things together. I was absolutely in denial about what was happening. It was almost as if by giving it a name it would suddenly become real.

That first visit to the local GP left me feeling very discouraged. I had checked online to see which of the six GPs in our practice had experience of eating disorders. Naïvely I thought there would be someone that specialised in the illness. But, instead, I had to settle for

a GP who had a special interest in mental health issues.

The GP weighed Molly and agreed she was underweight. She also suggested we see a therapist to help her with her attitude to food and come back for a fortnightly weigh-in at the surgery. But I explained that it wouldn't be possible because Molly was away at university. So we agreed that Molly would visit her GP in Cambridge to seek help.

I remember feeling uneasy. Although the GP specialised in mental health, she admitted to us that she knew nothing about eating disorders. To her credit, though, she said she was willing to learn. But the thing is, when you take your child to see the GP you expect them to know what is wrong and how to deal with it. I felt as if she knew as little as me. So I hoped and prayed that the university GP would be able to help.

So, Molly returned to Cambridge where she saw one of the university's GPs. After a full psychological assessment, she was diagnosed with restrictive anorexia nervosa. I wasn't with her the day she was diagnosed, and I still hate myself for not being there. I know from talking to Molly later that the visit left her frightened and confused. The GP suggested that Molly see a CBT therapist (Cognitive Behavioural Therapy) for help with her "issues", so I found a private therapist in Cambridge and Molly started to see her once a week. During this time she continued to lose weight steadily.

It was four months before Molly was finally referred for specialist eating disorders treatment during which time she continued to lose weight. Every time I went to university to visit her or she came home she seemed to be thinner. By the time she was referred her weight was very low indeed. In fact, in my opinion, Molly was critical by this stage.

The days were punctuated with constant phone calls from Molly - always in tears, often frightened because she was trying to face the traumas presented by eating a biscuit, or more often, *not* eating a biscuit. I dreaded my phone ringing because I knew she would always be in distress. She'd complain of feeling constantly cold and permanently tired. When Graham and I visited, we dreaded leaving

her, knowing she would be crying and so very miserable with her life.

I spent hours on the computer researching anything and everything to do with eating disorders. There was just so much to learn! I thought: "Where on earth do I start?" I knew absolutely nothing about eating disorders.

Then, one day, I came across a website from a charity called F.E.A.S.T. I made contact with Laura Collins, F.E.A.S.T.'s founder in the States, who was a mine of information. I was surprised that Laura responded personally to my first desperate email. I must have sounded like a half-crazed mad woman; asking lots of questions and needing lots of answers. Laura responded calmly and with huge empathy, reassuring me that there was a way to beat the illness and encouraging me to stay calm and take control.

She gave me a reading list. I devoured *Help Your Teenager Beat an Eating Disorder* by James Lock & Daniel Le Grange and *Skills-Based Learning For Caring For A Loved One With An Eating Disorder: The New Maudsley Method* by Janet Treasure. On top of this I was on the internet every night, more often than not on F.E.A.S.T.'s online forum: Around The Dinner Table. I tortured myself reading first-hand accounts of other parents describing the hell they were going through as they sought to save their children from various manifestations of eating disorders. I was in turn comforted and reassured by all the resources on the F.E.A.S.T. website including links to academic papers that confirmed the biological nature of the illness. This was where I learned that we, as parents, didn't *cause* the eating disorder. Neither did our daughter *choose* to develop anorexia. Eating disorders are not a lifestyle choice; they are biological brain disorders in the same way that a whole range of mental health illnesses are brain disorders.

I was worried about the fact that, as a legal adult, I might be excluded from Molly's treatment. By then I'd learned enough to know that, in theory, I had the right to choose where I wanted her to receive help and I thought we would agree to a referral to the local eating disorders unit to see if it was any good. If it wasn't, then I

assumed we could ask for a referral to another hospital. Our GP had recommended one particular hospital, but on closer investigation I discovered they didn't have a unit for adults with eating disorders, only children.

I had real reservations about our local eating disorders unit. Their website was shocking. It mentioned about 12 different types of talking therapies as treatment for anorexia. To me this seemed odd because, although we were looking at an eating disorders unit, nowhere on the website was there any mention of food or the importance of early intervention and restoring the patient to a healthy weight. From what I could see the idea seemed to be that you could *talk* the patient out of the eating disorder.

Within a month of being referred, Molly was sitting in front of the consultant who headed up the eating disorders unit at the local hospital, and a CBT therapist. I felt an almost instant antipathy with the consultant who conducted that first meeting with Molly without me present. He made lots of reassuring noises but maintained that Molly needed to sort out her underlying issues before she could start to eat again

In the event the treatment was pretty worthless. Molly attended around 30 CBT sessions which she said were useless. She'd sit in a warm, darkened room with a very nice lady who explored her relationships with her step-siblings and parents. How, I often wondered, was all this probing and talking supposed to help my daughter to recover from this devastating illness?

In my conversations with the consultant he gave me every indication that he thought I was an archetypal control freak. I hated myself for appearing to be so controlling. But the fact is that I wanted answers and I wanted them quickly. I didn't want to hear that "you're in this for the long haul", "the average length of time for recovery is between five and seven years" or "this may be something she never really recovers from". I refused to let this be the prognosis for my much-loved daughter and doubtless this is why I may have appeared to be "controlling".

The eating disorders unit seemed to have a culture of resignation and I wanted us to be the ones that proved it wrong. The consultant thought I was naïve; I thought he needed to educate himself about the latest evidence-based treatment for eating disorders. During one conversation I mentioned the Minnesota Experiment (a clinical study at the University of Minnesota in the 1940s to determine the physiological and psychological effects of severe and prolonged dietary restriction and the effectiveness of dietary rehabilitation strategies). The consultant smiled patronisingly and said: “Well, why am I not surprised that you’ve read about that?!”

Then all of a sudden we had another trauma to deal with. Within weeks of Molly’s treatment, my husband Graham suffered a massive heart attack and was rushed into Harefield Hospital for open heart surgery. He was there for three weeks, during which time Molly took leave from university. Those three weeks were the worst of my life. Molly seemed like a stranger. On the day of her father’s open heart surgery, she refused to come with me to visit him in Intensive Care, saying she was going for a run instead. I knew this was her way of dealing with her own stress and incredible guilt (I later found out that she believed she had caused his heart attack), but it was so uncharacteristic of her. It showed just how much the illness had changed her. My lovely girl had gone and had been replaced with a selfish, self-obsessed stranger.

When Graham came home from hospital, Molly returned to university. But within the week she was back home again. A member of F.E.A.S.T. who just happened to be her Russian tutor had asked Molly to get me to call her. This tutor had experience of dealing with anorexia as her own daughter had struggled with the illness several years before and made a full recovery.

That phone call changed everything. It empowered me to take control and stop feeling so helpless. After all, I had two people to look after now. I decided not to wait for anyone else to help us, believing that the best way to get Molly well was to feed her back to health. I wasn’t sure at that time if just restoring her to a healthy

weight would be sufficient, but I knew enough by then to know that nothing else was likely to improve until this happened.

Getting Molly to eat was going to be a hard fought battle and I needed to devote myself to it full-time. I quit my job the following day, drove to get Molly and battened down the hatches for the months to come. Luckily my job offered me a six month sabbatical to nurse Graham and Molly. We took out a bank loan to cover my lost salary for this period and, with the support of the ATDT forum and what I had learned through reading and so on, we began to re-feed Molly at home. We agreed that Molly would return to Cambridge to take her second year exams and the rest of the time she would remain at home. We left her lovely long standing boyfriend in Cambridge, with his full support and agreement that this was the best chance we had of getting Molly well.

It took seven months to get Molly back to a healthy weight - the hardest seven months of my life. In that time we treated every week as a challenge to gain at least a pound in weight. The routine was always the same. Breakfast at 8am, morning coffee and cake at 10.30am, lunch at 1pm, and dinner at 7pm. I prepared all the meals, plated them and served them - and always ate exactly the same as Molly. Sometimes meals went smoothly and sometimes they didn't.

There were some horrendous scenes, with food thrown in the bin and meals having to be cooked all over again. Sometimes Molly left the house and I was terrified that she wouldn't return. There were screaming rages and scenes in the street. I can't really describe how awful it was.

There were two occasions when I went to bed and prayed I wouldn't wake up - anything to end it all and make it go away. It was a while before I learned that my distress only fuelled Molly's anxiety and made her worse. I had to learn to stay calm and become the world's greatest actress. Nothing was an issue, everything was fine, I was so R-E-L-A-X-E-D and we were going to get through this.

Sixteen months on Molly remains at a healthy weight yet still struggles daily with the remnants of her illness. She eats well and

enjoys her food and my beautiful girl is back. She is changed by what she has been through and I am so proud of her. She describes her illness as an “evil voice” in her head, but understands now that this was something she was probably born with - a genetic predisposition towards an eating disorder and that, somewhere along the way, a failure to match the necessary intake of food with the growing she was doing in her adolescence tipped her into anorexia.

The difference is that, these days, Molly recognises the illness for what it is. She never wants to get sick again and knows what she needs to do to stay well. Indeed she's told me how terrified she is of the anorexia coming back and I believe it's this fear that keeps her eating. When she's stressed, for example when studying becomes too much, I can almost see it creep up on her, like an Achilles heel that the eating disorder takes advantage of. Often I have to sit down with her and point out all the positives, talk to her about the future she deserves to have, the family she deserves to have, and all the little things that have changed in order to show her just how far she has come.

Molly is bright and sensitive. She gets it. She knows she has been to hell and back and never wants to go there again. She says she feels embarrassed now when she thinks about how she behaved when she was so sick, so she tries not to think about it. I tell her it wasn't really her. That person was the one who had been hijacked by anorexia. Molly was buried in there all the time, desperate to get out.

Molly returned to university in September 2012 after a gap of 17 months. Graham or I visit her at least once a week for a meal. We talk openly to her about managing the risks that the illness exposes her to. We agree that it would not be wise for her to resume exercising again. She does a lot of walking and enjoys cycling with her boyfriend, but solitary running and swimming would not be good for her. She understands that she needs to make time for herself and have a good balance between work and play. It has been a joy in the last six months to hear her recount stories of dances she has been to, having one glass of wine too many, buying a new dress in an

acceptable size - all normal student things.

Going back to those early months it's clear that our GP had limited awareness of eating disorders. I felt as if I knew more about the illness than she did, and, at the time, my own knowledge was pretty patchy. But, once I'd done the research, I actually felt I knew more about the latest evidence-based approaches than the consultant at the eating disorder unit. The health professionals we interacted with throughout Molly's illness all seemed to share the same view that Molly had an eating disorder that needed intensive psychological therapy, and this was best accomplished with Molly on her own.

I remember being reduced to tears on several occasions.

On one occasion when Molly was being interviewed while I sat in the waiting room outside, the therapist asked her why she felt *I wanted her to gain weight*. Molly replied that she thought it was because I wanted her to get well. His response was: "What *other* reason do you think your mother could have for wanting you to gain weight?" To be honest, it's the closest I came to hitting him. I felt as if he were implying that our mother/daughter relationship was dysfunctional and that somehow I was the cause of her illness.

We were offered "family therapy" to help us work through our "communication issues" and to help me "separate" myself from Molly so that she could function independently. I was so angry and confused by this needless and almost ridiculous emphasis on "family problems". So much so that I'd find myself waking up in the small hours of the night, asking myself if really there was something wrong with the way we had brought Molly up. Had we loved her too much? Was that even possible? In retrospect, I think it was all complete nonsense. We were close and loving before and we are close and loving now. I'm still angry that people made me doubt myself, doubt my husband and doubt us as a couple and as parents.

I am relieved to say that Graham has made a good recovery and is immensely grateful that we lived so close to such a great hospital as Harefield. I think it's ironic that on the one hand we were able to benefit from amazing clinicians who saved my husband's life while



with Molly we were very much on our own. I'd love it to be mandatory that in every GP practice there is *at least* one person who understands eating disorders and is up to date with the latest thinking on treating these illnesses. If it's not possible to have one person in every practice, then at least be able to make a swift and informed referral to someone else locally who can help.

Molly has been able to make such an amazing recovery because we were fortunate enough to come across an online resource in F.E.A.S.T. that educated, informed and supported us in making choices that saved her life. At times it felt like a bit of a gamble because we had so little faith in the options being presented by the GP and the local hospital. But, ultimately, we had to trust that, as her parents, we knew best. I certainly wouldn't advocate our approach for everyone, though. If you can work with a team of experienced clinicians who are supportive of Family-Based Treatment, and who see you as part of the solution rather than part of the problem, you are very fortunate and have a huge advantage.

Today, Molly looks and feels beautiful. She has bright eyes, shiny hair and lovely curves. She laughs all the time. She is very much loved and she knows that. Most importantly, she has a future which will be happy and healthy. Her experience has changed her, certainly, but probably for the better. She has huge levels of empathy for other people and I believe she knows just how fortunate she is to have survived the hell of anorexia.

## MY TIPS:

*Take control* - and don't be afraid of what your child is afraid of.

*Trust your intuition.* The experts don't always know as much as you assume they do.

*Look after yourself.* Once Molly was at a healthy weight, I had a complete breakdown. At Christmas 2011 I visited the doctor and

sobbed uncontrollably for a full half hour. I felt as though my life had irreparably changed and all the certainty that had given me such security and confidence before had vanished. I was fearful all the time that something awful was about to happen. I'm not sure how I could have avoided this. People talk about self-care being so important and it really is, but in my case I think I was just too pig-headed to do anything about it. I've always been a very driven person and I was determined to get my family through a very challenging situation. I didn't stop to think about what would happen to me if we got through it

*No-one will love or know your child better than you.* Don't let anyone knock your confidence or tell you to step back and "leave this to the experts".

*Recovery is possible.* Don't ever give up and when setbacks occur (and, believe me, they will occur), face them and move on.

*Join the ATDT forum.* Don't be afraid of the internet or think it's "weird" to form relationships with a group of individuals you've never met before but end up speaking to online at all hours of the day and night. Places like the ATDT forum can provide life-saving support and comfort during what can be a very bleak time. (See list of resources at the end of the book.)

*Look after your marriage or relationship.* I was totally focused on my daughter, even when my husband was recovering from his heart attack. I rationalised that I knew his life was saved, but I didn't know if we could save Molly, so in my mind this justified cutting Graham out of a lot of things.

*You will get your child back.* Your relationship with your child may feel terrible for a long time and you may think you won't ever regain their love and trust. But you will. Anorexia makes demons of them. When

it's gone, they come back. Molly had a job interview recently and the interviewer asked her to talk about someone she felt was "inspirational". She said "My mum". Every time I think of that comment I feel so grateful and blessed. We love one another so much and, in a way, I'm glad to have been given the opportunity to show her how far I would go and what I would do to keep her safe. This sounds odd I know, but Molly will never be able to doubt the depth and intensity of a parent's love.

*Ultimately, I believe food is the answer.* Not the whole answer in that there may be underlying co-morbid conditions that need addressing. Low self-esteem needs to be dealt with and often other things too. But food is so important. It is also vital to learn to externalise the illness - in other words to separate the illness from your child, almost as if they were two "beings". Looking back I can see how important it was, too, to deal with the rages and horrible behaviours in a calm, supportive and consistent way. This is definitely easier said than done. In the early days of Molly's illness when I was caring for her full-time at home, I attended four carers' workshops at a big hospital in South London in an effort to upskill myself. They reinforced the idea that I needed to remain calm, consistent and supportive at all times. Even when I felt like screaming. Even when I was being screamed at. This persona was presented as a calm dolphin-like personality who nudges their child along, guiding from the side, always supportive, well balanced and calm.

*Don't give up.* I haven't yet met a parent that would entertain the idea that their child could have an eating disorder for life. Giving up on your child is never an option because there are so many grounds for optimism. Be frightened by all means; indeed a sense that you are standing on a burning platform can actually spur you into action and give you a reason to be decisive. Be prepared to make a nuisance of yourself, but don't ever give up. Read stories of other people who have made a full recovery and believe completely that it is possible.

Prepare for setbacks and don't be surprised by them. They do happen and they can be hugely discouraging, but they are steps along the way. Every day remind yourself of how much easier things are becoming and look back to when things were at their worst to remind yourself of how far you have come. Every mouthful, every meal completed, every pound gained is a victory. Nowadays when I look at Molly I want to be able to show her to every desperate mum or dad who has just discovered that their child has an eating disorder and say: "This is what recovery looks like!" It may be fragile, but it's real and we are determined to make sure it lasts.

# Marianne's story

“‘Can you try and eat an apple?’ the GP asked. I sat there open-mouthed. Lindy had almost stopped eating by this point. And, anyway, what difference would an extra 40 or 50 calories make?”

Oh my goodness, do I remember the GP's face when I told her I thought my daughter, Lindy, was developing an eating disorder? The GP just seemed to freeze. Then she went all quiet and starting typing rapidly on the computer. Lindy burst into tears and I did all the talking. It was quite bizarre, it really was. No, it wasn't bizarre; it was terrifying because, by this stage, Lindy had virtually stopped eating. Just a little bit of potato each day, no more than a few hundred calories. And the weight was falling off her.

As a child Lindy had never been fussy about food. She'd been a bit underweight as a toddler, but then she'd put on weight. By her teens she was just normal. In fact we were all so very normal - a normal family with a normal background. We ate normally; indeed we ate very healthily. Lindy had a good appetite. She wasn't fussy like a lot of children; she'd eat everything that was put in front of her.

Then in the lower sixth form, aged 17, she developed a Streptococcal throat infection which made her very poorly and made swallowing difficult. She was put on a fluids-only diet for several days. As a result she lost quite a bit of weight. When she recovered she seemed pleased with her new slimmer appearance.

The following spring, she had appendicitis and lost more weight. Afterwards, her weight continued to drop very slightly. I remember

telling her that she didn't need to lose weight; she was fine as she was. But she was gradually restricting and cutting things out of her diet. She decided to go vegetarian, but this didn't trigger any alarm bells because she'd gone veggie on and off before. Meanwhile she'd go out running early in the morning and began exercising with a video exercise game. At first I thought it was just to get fit after the illness, so - again - I wasn't too concerned.

It was the January of her upper sixth form year that she began to look even closer at what she was eating. She cut out bread, for instance. But, again, I didn't really notice anything because it was so very gradual. Her boyfriend would try to take her out for meals but she either wouldn't eat or she'd eat very little. Her friends began to pick up on this, although I only found this out recently. "Why didn't you tell me?" I asked them. "We thought you knew!" they said. Her boyfriend was worried, too. But he didn't say anything either.

Looking back, I really wish people had said something to me because it would have reinforced my own concerns and probably made me act sooner. In fact I feel incredibly guilty about not acting sooner. Why didn't it dawn on me what we were dealing with? The thing is you simply don't expect your healthy, happy, food-loving child to get an eating disorder. I guess I hoped it was just a teenage phase that she would grow out of. But she didn't grow out of it.

I'll never forget the night of the school prom. Lindy didn't want to go; she couldn't face the idea of sitting down to a three-course meal. Already she was down to a very small UK dress size, but when she tried on her dress, it just hung off her. She was freezing cold and I noticed how painfully thin her arms and legs were. We had to call my mum round to take in the dress. My mum was very worried too. In the end, Lindy went to the prom, but she texted me all through the evening for reassurance and support, and she came home early.

We began to notice that she was getting pale. She'd claim to have eaten when she hadn't. Lindy had a part-time evening job in a restaurant and she'd have her evening meal there - just half a jacket potato and some beans because she'd "had a big lunch at school".

Then the beans went and it was just the half potato with some salad. I was desperate to understand why she was doing this; I felt she was slim enough. Too slim... But I was scared to say anything in case it made things worse. It's difficult to explain unless you've been through this, but I really felt that by keeping quiet things would eventually change and Lindy would get back to normal.

Having said this, deep down I had a hunch that it was an eating disorder. One day I approached her with: "I think there might be a problem." She just looked at me and said: "I haven't got anorexia."

But over the next few weeks she began to get stomach aches. She'd claim to feel bloated. One evening I remember her lying on the sofa. My husband and I had planned to challenge her about things. She got upset, saying she was in pain. She was crying: "Mum, I think I've got a problem!"

"Oh, Lindy, I am so pleased you've told me!" I told her we'd been going to say something. I said we must go and see the GP and get her checked over. She didn't want to go. "I've noticed you're a bit pale," I said in a bid to get a pretext for going. "You might be anaemic. You might need some iron pills." Her periods had also stopped; so I told her she really needed to get that checked out, too. Thankfully, Lindy agreed to come along. By this time she'd lost over a stone and you could tell. She looked ill. Her face was ice cold. The skin on her cold hands was red and dry. Worse, she was developing fine hair on her face.

So we went to the GP and, as described above, the GP froze. But she did arrange for Lindy to have an ECG and some blood tests. I explained that Lindy was just eating half a jacket potato a day, and that was all. "Can you try and eat an apple as well?" the GP asked her. I sat there open mouthed. I mean, Lindy had almost stopped eating by this point, certainly eating no more than 300 calories a day. Getting her to eat an apple would have been nigh impossible. And, anyway, what difference would an extra 40 or 50 calories make? I remember thinking "The GP has no idea what we're dealing with!" and I panicked. Actually I did more than panic; I began to lose hope.

I think it's because when you go to the GP you expect them to know what the problem is, to scoop you up and winch you to safety. I wanted to hand it over to the GP knowing that she'd sort it out. But she didn't. Don't get me wrong, she was really sympathetic and obviously wanted to help. It's just that she didn't have a great deal of knowledge about eating disorders.

Anyhow, the GP said she'd be away on holiday for the next two weeks but we could come back when she returned. "No, that's too long!" I said, aware that Lindy was losing weight fast. I asked if there was someone else we could see in the meantime.

This time Lindy went alone, with her boyfriend. The GP checked her blood and did an ECG. Everything was normal on that count. Lindy was also weighed, but at this point her weight wasn't dramatically low so the GP didn't appear overly concerned. It also meant that she didn't qualify for Adult Mental Health Services - at 18 she was too old for CAMHS.

Thankfully, through a colleague at work, I'd come across an eating disorders service which was located about 20 miles away, part-funded by the NHS and part-funded by charity. Lindy could either self-refer or get a GP referral. We did both!

Amazingly we only had to wait two weeks before seeing the service - right on top of Lindy's A-level examinations. Also, by this time I knew more about eating disorders. I'd read Janet Treasure's book *Skills-Based Learning For Caring For A Loved One With An Eating Disorder: The New Maudsley Method* and I'd talked to the UK eating disorders charity, Beat.

The eating disorders service was wonderful. Lindy was given a thorough assessment. I was offered support, too, right away. We saw them three times a week. Each time we were there for three or four hours. We'd spend an hour with the dietician, an hour in psychotherapy followed by complementary therapies like reflexology to help Lindy relax after the counselling session. Yes, it was a 40-mile round trip every time we went and it ate up all my days off work, but it was worth it. And to think I would never have heard of this service



if it hadn't been for that colleague who mentioned it in passing; the GP never said anything.

I was aware of another, more local eating disorders support service, but Lindy wasn't considered sufficiently sick to be seen by them; her BMI wasn't low enough. If we'd never discovered the other service, what would we have been supposed to do? Wait until she deteriorated sufficiently to get admitted to the local service? It doesn't bear thinking about - especially as, when Lindy began treatment, she'd completely stopped eating. She wasn't eating a thing, just drinking diet coke and black coffee. As you can imagine, I was petrified as to where this was heading. She'd already lost a considerable amount of weight when she was "eating"; now that she'd stopped altogether... well... But even then her BMI wasn't low enough to be referred to the local service, so thank God I'd managed to get her in at the other one.

I remember the day Lindy was officially diagnosed with an eating disorder. We all sat down as a family. Lindy's boyfriend was there as well. He said: "I am so relieved - thank you for doing this for her." I thought, well I haven't done anything! But it was an immense relief to all of us.

At our first session with the dietician, I explained that Lindy had stopped eating. Together we put together an eating plan. We'd start gradually; initially we wanted Lindy to have a smoothie and an *Actimel* each day. It doesn't sound much, but it was a step in the right direction. Of course this wasn't sufficient and she continued to lose weight. Meanwhile we continued to work with the dietician on a workable re-feeding plan. The dietician would gradually add things and I did a lot of work on it at home.

I remember the time we tried to get Lindy to drink a smoothie one evening. Her dad sat on one side of her while I sat on the other. She cried all the way through. We were still sitting there at 11 o'clock at night, me holding the straw, gently persuading her to take small sips. To her credit she eventually managed it. Then, afterwards, her dad took her out for a walk. The idea was to have a chat; to try and

calm her down and distract her. But off she went... striding away down the road, intent on burning off the calories she'd just consumed...

This was a very bleak time when she would only have fluids. On one occasion she lost five pounds in just four days. I was very scared. Eventually we managed to get her to move onto solid foods. However, even then, the obsessive behaviours that seemed to be part and parcel of Lindy's eating disorder meant that the foods weren't "allowed" to touch each other. If they did, she'd have a complete meltdown.

**End of excerpt.** You can read the rest of this chapter and a further 18 chapters by purchasing *When Anorexia Came To Visit* by Bev Mattocks from Amazon. Many thanks.