

4th EDITION



EATING DISORDERS in CHILDHOOD and ADOLESCENCE

EDITED by **BRYAN LASK** and
RACHEL BRYANT-WAUGH


Routledge

Eating Disorders in Childhood and Adolescence

In the fourth edition of this accessible and comprehensive book, Bryan Lask and Rachel Bryant-Waugh build on the research and expertise of the previous three editions. First published in 1993, this was the first book of its kind to explore eating disorders in children and young adolescents, a population that is very different from those in their late teens and adulthood.

The contributors' experience and knowledge have increased and the field has moved forward over the past 20 years. This fully revised edition offers a distillation of current information in the younger population, and contains brand new chapters on areas of experience, research and practice including:

- the perspective of a young person going through an eating disorder
- experiences of a parent
- updated information regarding advances from neuroscience
- therapeutic engagement
- cognitive remediation therapy.

Eating Disorders in Childhood and Adolescence offers the reader knowledge, insight and understanding into this fascinating but challenging patient group. It has both a clinical and research focus and will be an essential text for a wide range of professionals, as well as being readable for parents of children suffering from eating disorders.

Bryan Lask trained at the University of London and was a consultant in child and adolescent psychiatry at Great Ormond Street Hospital for 25 years. There, with Rachel Bryant-Waugh, he initiated the first early onset eating disorders programme in the UK. Subsequently he has written 11 books and over 200 papers. He is Past-President of the Eating Disorders Research Society and recipient of a Lifetime Achievement Award from the Academy for Eating Disorders.

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Eating Disorders in Childhood and Adolescence

Fourth edition

Edited by Bryan Lask and
Rachel Bryant-Waugh

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**Bryan dedicates this book to Renee and
Gordon Carlton for a lifetime of love and
support.**

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Preface

In the prologue to the first edition of this book we raised the question of why there should be yet another book on eating disorders. We justified the first edition on the basis that it was the first book to deal with early onset eating disorders, i.e. eating disorders occurring in people below the age of 15. This is a distinct population, quite different in many ways from those who develop eating disorders in their late teens or adult life. Obviously some of the issues are similar, but many are different. In various important respects the aetiology, clinical presentation, phenomenology and treatment all differ. Further there is a wider range of eating disorders in the younger age group. The second edition was written at the end of the twentieth century, when eating disorders, including those of early onset, had become a major public health issue. Referral rates had continued to increase and the need for more and improved services was manifested by the expansion in specialist services for this population. The third edition published in 2007 attempted to keep abreast of all the exciting developments in the field. If anything the rising trajectory of knowledge has been even sharper since then.

Our own experience and knowledge have been greatly enhanced by the passage of time, concerted research endeavours, advances in understanding of aetiology and the development of innovative treatments. We believe that the time is ripe for this fourth edition in which we offer a distillation of current information about eating disorders in this younger population. The contributors to this book are all people at the forefront of work with this fascinating but challenging patient group. Between us we have tried to convey our knowledge, perception and understanding of these problems, and to share our clinical experience of assessment and treatment. The chapters in this fourth edition are completely new or have been thoroughly revised.

Part I of the book, provides three different perspectives. It opens with a contribution from Ken Nunn which considers the concept of sensitivity, so central to those with eating disorders. With his own empathic sensitivity he conveys the pain, the shame, the fear, the self-loathing, the isolation and the many other emotions that engulf those with anorexia nervosa. He then moves on to show how sensitivity can be utilized to enhance the recovery process. Chapter 2 offers the child's perspective written by Caroline Sebastian, now a young adult but many

years ago a patient. She vividly describes her childhood experience of anorexia nervosa, her torment and suffering. Caroline clearly demonstrates that anorexia nervosa is only superficially about weight, and far more about inner distress. Chapter 3, by the mother of a teenager who had anorexia nervosa, provides the parent's perspective. She conveys only too vividly the bewilderment and torment of seeing her daughter so ill, the frustrations of negotiating the health care system, the loneliness and anxiety and the ups and downs of the difficult and lengthy process of treatment. She provides helpful tips for clinicians working with young people with eating disorders and their families and provides hope for all concerned.

Part II deals with assessment and course. It starts with an overview of eating disorders in this younger population followed by a detailed examination of what is known about aetiology. Subsequent chapters deal with physical and psychological assessment, followed by an overview of the very latest knowledge on the neuroscience of eating disorders. This section finishes with a chapter on outcome.

Part III is determinedly practical and devoted to clinical issues. The first chapter provides an overview of treatment, with succeeding chapters dealing with therapeutic engagement, nutrition and refeeding, family approaches, cognitive-behavioural therapy, individual psychotherapy, cognitive remediation therapy, and legal and ethical issues.

Here are a few technical points:

- 1 Where we made use of case illustrations, for obvious reasons we have changed the children's names to preserve their anonymity.
- 2 For ease of reading, and because far more girls than boys experience eating disorders, we have referred to the children as girls unless we are specifically discussing boys.
- 3 The age group represented in this book ranges from about 7 to 16. There is no totally satisfactory term to cover this group. In consequence we have used various terms such as 'children', 'young person', and when appropriate 'adolescent'. In a number of places we have used the word 'patient' to describe the young people we see. It seems difficult to get it right and we hope that we will be forgiven if we have appeared condescending or inappropriate in our terminology.

We hope that readers will find what follows of interest and value. Although we do not expect agreement with all we say, we trust that we have conveyed some of the fascination and challenges we have experienced in working with these children and their families.

Bryan Lask and Rachel Bryant-Waugh
March 2012

Perspectives

The sensitivities that hinder and the sensitivities that heal

Kenneth Nunn

The pain of shame and self-loathing

If you have ever been embarrassed about people seeing you naked; if you have ever felt uncomfortable about being overweight; if you have ever wished you looked different in some way or other; if you have ever experienced pain at the way others viewed you and your body; if you have ever felt your life was not really yours to control – then you may have some capacity to empathise with children and young people who suffer from anorexia nervosa.

The pain they live with day after day is the deep conviction that they are ugly, loathsome, bloated and distended. To be sure, in some this is mild and creates background noise only in their emotional life. But in malignant anorexia nervosa it is an intense, unrelenting, tortured self-concern that renders life unliveable without the most intensive support from those around. For these, starvation is extreme, self-injury is common and death is never far away with casualties at around five per cent per decade of the illness. Seriously delayed growth, brain blood-flow shutdown, osteoporosis (sometimes permanently damaged bones), infertility and unstable heart rhythms are commonplace. Many of these complications are normally only encountered in the Third World or the very elderly. The sort of medications that are usually only needed to settle the overwhelming distress of psychosis are increasingly required to quell the distress and psychiatric complications of anorexia nervosa that are unresponsive to any other intervention.

The eating disorder that is more than an eating disorder

Anorexia nervosa is a disorder associated with difficulties of eating, together with weight and shape concerns. But it is much more. It is an illness that can cripple a young girl's ability to get through to the world around her about how she feels. She may be 'locked in' emotionally. It is also an illness that prevents young girls from understanding how those they love feel about them – others are 'locked out' emotionally. It is above all else an illness of communication between the world inside themselves and the world outside – an illness of emotional communication

in which they have difficulties expressing and receiving what matters most – their own feelings and the feelings of others.

They have no shortage of feelings, no poverty of emotion and no emptiness of real intentions or motivation. However, feelings are segregated from words, emotions remain all too often disconnected from the tears and choreography of their facial movement. An expressionless, seemingly unconcerned face may mask a tumult within. The usual desires, thoughts and driving forces in young people are utterly captured and held hostage by weight and shape. Like the delusions and hallucinations of a person trapped in the completely dominating world of psychosis, the world of anorexia nervosa is a prison tightly bound by walls of distress at every turn. In the same way, parents may be deeply concerned and this concern may not register or may be misunderstood by children with anorexia nervosa. Parents may be perplexed, bewildered and overwhelmed as to what is happening within their child; sensitive to their distress but at a loss to understand the source of the distress. It is to the sensitivities that may fuel this distress or heal this distress that I want to turn.

A needed pain

The first time I saw a child with hereditary insensitivity to pain, like probably thousands of new medical graduates before me, I was struck by the need for pain. The little two-year-old boy had already injured himself many times and there was a danger he would lose some of his toes and fingers through his injuries before he was ready to go to school. Of course, I knew that leprosy affected sensation in feet and hands and that specific nerve damage might lead to particular insensitivities, but it never occurred to me that a child might grow up largely without pain because of a rare condition and that this inability to feel pain might make the child continuously vulnerable. In the same way, the young person with anorexia nervosa may be entirely unaware of the disease that is destroying them and even of the threat this poses to parents as they are traumatised by their child's condition. This inability to personally register anorexia nervosa is one of the most perplexing aspects of the illness and increasingly appears to be medically (brain based) rather than psychologically based. It is this inability to see 'the enemy', that makes 'the enemy' all that more dangerous. The insatiable demand from within about weight, weight loss, shape, the amount and type of food eaten, is so absorbing and over-riding of all other concerns that even concerns from loved ones about survival retreat to the background.

A futile pain

At the other extreme of experience, throughout my medical career, in both general and child psychiatry, I have been involved in the treatment of pain, especially chronic pain – the long-term pain that remains unresponsive to the many forms of pain relief that have been so successful in acute medicine. Here the pain may have

gone on for months or years. The pain no longer signals acute tissue damage or threat of tissue damage but has become a problem in its own right. Sometimes it signals troubles in the life of the person, past or present. But even where this is so, the pain is yet another burden. Of course, like all my psychiatric and psychological colleagues, I will search out the possibilities that the pain is 'serving a function', 'fulfilling a meaning' hitherto unseen and of which everyone has been unaware. The reality is, however, that for many of those with longer term pain no cause is found, no meaning made and pain is just pain, quietly, inexorably grinding down its owner who searches for any relief we might offer. Sometimes the immediacy of pain obscures its own origins. We are asked to help these patients cope with pain, even when we cannot make sense of the pain, to provide support in the struggle with pain, even when we cannot eliminate the struggle, and to provide what comforts we can, even when the fundamental comfort of relief from pain is not forthcoming.

Responding sensitively to a futile pain

Strangely, anorexia nervosa is a bewildering mixture of insensitivity and sensitivity, a lack of awareness of their underlying condition that renders them vulnerable and a distress with their shape and weight that is overwhelming. Young people with anorexia nervosa can be exquisitely sensitive to an increase in weight or calorie intake and completely unaware that anything is wrong with them. Parents can be utterly overwhelmed with the distress of their child but also unaware of the medical disaster that has crept upon them by stealth.

How can we know to which distress we should respond in these young girls and their families and which distress we should see as a 'futile pain' which only distracts us from what is threatening? How can we help? How can we build treatment around their sensitivities and insensitivities so that it is likely to work more effectively? How can we understand this condition so that parents will feel confident to trust us and not find themselves 'fighting against us' and us, 'against them'? What are the sorts of sensitivities, 'the pains', from which they suffer? We may become so concerned about what this pain and distress mean that we forget that sometimes no meaning can be found, or the meanings that are found, are elaborate, ill-fitting interpretations that say more about what we are thinking, and where we are coming from than about the young person with anorexia nervosa. There is a relief that comes from acknowledging that we do not understand but we do care, that we cannot make sense of what is happening but we are not judging, and that we do not have the answer, but we will continue to be available to provide smaller answers to particular difficulties.

The varieties of sensitivity

Most children with anorexia nervosa love their pets – dogs, cats, goldfish and more recently electronic pets and babies. They are deeply distressed if anything

untoward happens to them. They feed them regularly. They do not injure them but nurture them lovingly, tenderly and sometimes tenaciously. I have sometimes asked these young people what they would think if someone starved their kitten to death and injured their tiny paws and ankles. They are distressed at even the thought. Then I have said that this is how it feels for us when we see them starving themselves as so many do when overwhelmed with the inescapable distress of anorexia. Of course, there are no clever words that can cure anorexia nervosa anymore than there are clever words to cure cancer. Treatment is a slow, hard slog with a host of obstacles on the road to recovery. But some of the girls remember these words and try to be just a little kinder to themselves as a result.

To see how ‘this might happen to me’ or to those we love, to somehow appreciate it even if we are not really aware of what the person is going through, is called *identification* in the jargon of psychiatry. It means we feel for ourselves and those we love when we see their distress – we identify with their distress. There is nothing wrong with this. It is the beginning of feeling for others but should not be confused with the feeling for others that is called sympathy or empathy. Identification is the distress that people communicate when first we tell them our bad news. Many people at funerals want to be reassured and comforted by the bereaved loved ones because they become distressed that ‘it might have been them’ or someone ‘close to them’. When we have shared bad news with others this is also the reason why many people tell us the worst story they have recently heard, of which our story reminded them. We of course do not need to hear or want to hear their worst story.

To see someone else suffering, to feel for them and with them in their distress and to register their pain is *sympathy*. It is to become aware that they are in pain and to want to relieve it. Sympathy is what we often feel when watching starving children on television and we want to relieve their starvation and distress. We feel for them even though we are clear that we will not starve and will not be in their position.

To see someone else suffering and to feel the pain as they feel it, at least in part, is *empathy*. To experience the discomfort that they are feeling in their situation, the pain in their troubles, and to wince with the embarrassment and heartache they must endure, is to understand in a different way, not merely to identify or sympathise. All of us have been children and distressed as children at some time. When we see children we can feel for them and with them.

Who owns these feelings?

There is a deeper, more difficult to put into words variety of this feeling, which often is an experience very close to empathy. It is the confusion between our own feelings and the feelings of those who are suffering. When we spend time with others, feel close to others, have things in common with others, care for others, especially when they are young and vulnerable, we may confuse our feelings, our thoughts and even our predicaments with theirs. Well-trained clinicians learn to

use these confusions in ownership of feelings creatively to help those for whom they care. But they can complicate our care and before we know where we are we can find ourselves caring for our own needs, our own problems and our own predicaments. We are taking on the problems of others as if they were our own, and acting as if their problems were no longer theirs but ours. In short, we are no longer helping troubled young people and their families. We have become troubled ourselves.

The normal tangle of feelings between children and parents

Well, all of this may sound very complicated and pathological but there is a particular type of confusion of ownership of feelings between parents and children, which is very common, very normal and very powerful. Our children may not want to talk with us about their feelings because they are worried. We might be worried but we may be reluctant to talk to our children about our feelings because we do not want to worry them. We as a family might become so worried for each other that we cannot say that we are worried for each other for fear of worrying each other. When we see each other saying 'we are all fine', we cannot feel reassurance or comfort. We are not reassured. We are not comforted. I know that I am worried but cannot talk about it. I become worried that they are not talking about their worries. Each person becomes more and more worried to the point that no one is talking. There is a danger that each person in the family may come to the conclusion that the unmentionable problem must be much bigger and more worrying because no one is discussing what is happening.

This tendency to worry about our loved ones' worries is based upon parents caring for their young children and not wanting to worry them; children caring for their parents and not wanting to worry them. It is also based on the belief as a parent that 'I feel what my child is going through'. It is based upon the understanding of children of what they believe their parent is going through. The problem is that sometimes we as parents get it wrong about our children and sometimes our children get it wrong about us as parents. Sometimes those who are close miss the very obvious things that strangers can see and become convinced of problems that are our own, not our children's. It is only with time and experiences, both good and bad, that we as parents and children can disentangle our feelings from each other. So when I talk about sensitivities it does not make sense to talk about individuals alone. We all find ourselves aware and unaware, sensitive and insensitive, to the supports and threats, nurture and pain of loved ones around us.

Young people with a problem being superficial or a superficial explanation for the problem?

In anorexia nervosa some people find it easy to identify with these children and young people. On the other hand, more than a few become convinced that this is

a self-induced, boutique disorder, in indulged upper middle class girls who are saturated with a materialistic and narcissistic culture that causes women to compete in a senseless rivalry of bodily perfection. Dealing with children and young people themselves moves us beyond this to an appreciation and sympathy that they are victims of an illness that is clearly not self-induced at all and not always middle class; they are often far from indulged or saturated with materialistic lifestyles. They are not simply vain or trying to attract boys. In fact, it would often be a real sign of progress if they were well enough even to contemplate how other people, especially young men, felt about them. They are usually so distressed and self-loathing about themselves that they are unable to consider how others might feel about them. When we see how sensitive they are to the imperfections of their own bodies we can begin to sympathise with these girls.

An emotional malignancy

Anorexia nervosa is not a trivial side effect of an over-indulged western society. It is a malignant disease of children with parents usually trying to do more than could be expected of any parent – damned if they do and damned if they don't. Some parents will sit on their hands for far too long while their daughter loses weight, not wishing to overreact, minimising the gravity of her weight loss, ignoring what is 'attention seeking' and hoping that 'she will grow out of it'. Others do become obsessed with food and preparing whatever she might eat in the hope of coaxing her back to food and normal eating. Still others, especially fathers, become angry and even violent, feeling helpless and useless in the face of their daughter's decline. When we are desperate, we do not look as normal, sensible, balanced and open to suggestion as others. If obtaining help has been difficult, if some have been thoughtless or misunderstanding toward us and if miscommunication within the medical system has led to a sense of loss of control and threat to our children, our composure is not as complete as it might be if it was someone else's daughter. When assessing parents with ill children the first question of the assessing clinician must be 'how much of the presenting picture is due to a worried parent of a troubled child?'

Of course we require experience to answer this question accurately and helpfully. However, it remains a good rule of thumb: *when in doubt, parents are best seen as normal, caring parents who are worried about their daughter.*

The sensitivity and insensitivity that save life

When dehydration sets in because drinking is restricted, we must be sensitive to vital signs and much less sensitive to pleas of distress about shape and weight. A young girl can semi-starve for years, almost unnoticed; but just a few days of not drinking and the body will deteriorate quickly. Changes to vital chemicals within the blood – potassium, sodium and phosphate – alter the basic message

systems that keep the body's systems working and the energy production that keeps each cell alive. If life is in danger, there is no kindness in listening to a distress, which will soon die along with the child who owns it. If life is in danger it is kind to replace fluids, though unwanted, restore chemical deficiencies, though unnoticed, and refeed, though food is rejected with an outpouring of distress. There is a time to be insensitive to distress in order to save life; there is a time to be cruel to be kind.

The sensitivity and insensitivity that threaten

I once attended an international meeting in London on eating disorders at which an open debate was held on the value of nasogastric tube feeding in anorexia nervosa. The debate was vigorous and the discussion slowly settled on the Dutch position which at that time was that there should be no coercive feeding of those with eating disorders with complete respect for the ill individual's wishes. The Dutch position contrasted with the British and Australian positions. Members from these countries took a strong stand on refeeding when survival is threatened and permanent damage from prolonged starvation is imminent. Of course there were professionals from each national group who did not agree with their fellow nationals' point of view. The audience sentiment was definitely swinging strongly towards the Dutch position with a concern amongst professionals and consumers alike that individual rights should not be overridden. Then someone asked the obvious question: 'What happens when the young person repeatedly and determinedly chooses not to eat or be fed?' The principal Dutch discussant then said that after much consultation and discussion euthanasia is considered, describing a 25-year-old who had opted for and was given euthanasia the previous year. Silence moved across the audience with a sense of consternation. The consensus of the meeting changed dramatically.

What each society, clinician and family decide to be sensitive to and insensitive to opens up new issues with new concerns. Increasingly, anorexia nervosa is seen to be a life-threatening mental illness which is often long term but also treatable. Like other mental illnesses, anorexia nervosa requires laws for the provision of protection and treatment, even when the person who is ill does not recognise the need for treatment. We do need to be sensitive to young people's rights to freedom, but there are other rights that compete with those of personal liberty: the right to be cared for when ill; the right to be protected from harm when judgement is impaired; the right to have a future when the present threatens to take it away. Families and loved ones also have rights that compete with individual rights: the right to prevent their children from suffering where possible; the right to protect those they love who can no longer protect themselves; the right to provide needed care and to obtain expert help for loved ones. 'It's my life and I can do with it what I want' may make sense in an academic argument about individual liberty, but against the background of the solidarity of suffering that occurs in most normal families and relationships it smacks of being superficial, insensitive and naive.

Perhaps more, it indicates an impaired judgement as to the personal consequences of choosing not to eat.

Tough minds and tender hearts

Where does this leave us? Thomas Jefferson once said that what we often need in this world is a tough mind and a tender heart. We cannot afford to be weak in our appraisal of danger to those we love and for whom we care, nor can we afford to fail to respond with compassion. Physicians and surgeons in former centuries knew this all too well. Surgery without anaesthesia was agonisingly painful but so was the relentless progress of gangrene. The choices were stark and sometimes the treatment offered only a little more benefit than the illness. In the case of anorexia nervosa, we can offer much better alternatives than our forebears could and better than the Dutch solution of preserving individual liberty now does. There is pain, there is distress and there are hard decisions to be made that do not always fit with the wishes of the person in pain. Why is it so hard to find those with clear thinking and compassion? Perhaps those who are more tough minded find it hard to sustain compassion. Perhaps those who are tender-hearted have difficulty making tough decisions.

A time to hurt

There is a time to be hurtful, to allow distress, to save a life and to prevent long-term harm. There is a time to be aware of the exquisite sensitivity of these young women to their own bodies and the opinions of others. We cannot ignore fears and distress rooted in shape and weight. But we can become aware of the deeper problems: the problem of being unable to express and receive, accurately, emotional signals from others; the problem of a crippling sensitivity in girls who can nevertheless fail to see their own illness.

To be blind or partially sighted to the world around is a terrible disability. To be emotionally blind to what is going on in those around is often even more crippling than the loss of vision in blindness. The emotional blindness in those who are suffering with anorexia nervosa sits side by side with an anguish in the families that cannot be put into words. When we see the illness that these girls and young women cannot see; when we appreciate the damage that is being done that they cannot feel; when we are sensitive to the heartache of their families that they barely perceive, we are compelled to act on their behalf.

A time to heal

Healing begins as we understand the condition afflicting these girls and their families. It is not yet the healing of cure but of acceptance. However, throughout the world there is a slow recognition that anorexia is not a given of existence which must forever be with us. The sky is blue. The grass is green. But anorexia

nervosa is not immortal any more than smallpox or poliomyelitis. It is time to systematically, tenaciously and strategically seek a cure, just as our colleagues in oncology seek a cure to the malignancies they face. We must confront the reality of what we cannot do at this point in time but we must also begin to slowly but surely challenge that reality. There is much that we can do today that even a decade ago we could not have achieved. There is much more we could do if all those who suffer and have loved ones who suffer combined forces with clinicians to 'crack' this malignancy of mind and body. There is so much more suffering that could be relieved by the simple recognition of the community as a whole that those who suffer with anorexia nervosa should be accorded the same dignity as those who suffer with other malignancies. The dream of healing anorexia nervosa will only be realised at a very substantial cost; the cost of us as a community becoming aware of the pain of those who suffer from anorexia nervosa, the anguish of those who care for these young people and our responsibility to relieve their suffering and anguish.

A child's perspective

Caroline

Trapped in the darkened crowd I thought I was going to die. The noise beat away at my insides and the jostling children felt like an assault. I could see no way out and no way to make it stop. I was invisible, naked; drowning in a world that was merciless and hateful. There was no escape.

Crowds have always felt that way to me. When growing up loud music and throngs of people felt aggressive and painful. My body felt alien to me in that environment as though the outside noise was amplified inside, and the world around me had somehow infiltrated my whole being and was violating me.

I have to link that terrified little girl to the emaciated figure who stared back at me from the bathroom mirror for so many years. What I cannot combine in my head is that image with the happy little girl everyone else saw. I remember her; I know she existed once. What I cannot pinpoint is the moment when, even for her, the world became too terrifying a place in which to remain and both little girls started to disappear.

I am sure the story starts the same way for so many people. There are the doctors' visits, the psychotherapists who let me weigh myself as if I have the power to change what I did not start in the first place. There is the stay on a hospital ward when my body starts to fail me and there is the desperate rush for the specialist clinic when the weight continues to drop off. The descent is fast, devastating and rock bottom hurtles towards me before I have noticed I am falling.

I think that it is unimportant to describe my physical body as I tell my story. Of course my weight will feature but I feel very strongly that this should not be a sensationalist issue. Weight loss is not an illness. Like hair loss after chemotherapy, weight loss for me can only be described as the outward appearance that something much worse is happening inside. We all know that the most frightening things are those that we cannot see or do not understand.

My story started at Easter when I was nine years old. My sister and I sat watching films and eating our chocolate eggs. As she settled down I slipped upstairs and stuck my fingers down my throat. The relief was immense. I cannot say it was guilt that led me to do this . . . it felt like fear.

Four years later, aged 13, that fear had taken me to a small eight bed dormitory on the top floor of an old mock-Tudor style house. My mother and I drove past the

clinic when we first arrived. It was not sign posted and was down a leafy driveway tucked on the edge of a busy main road, like a secret.

I had spent three weeks in a general children's ward at a local hospital on the orders of the psychiatrist I had at the time – a man whose attitude and techniques were as ineffective as they were abhorrent. I do however see his reasons for this hospital stay. My kidneys were failing me, my heart rate was low and my aorta was beating dangerously close to the surface of my skin. But hospital is not the place for an illness like anorexia nervosa for which there is no immediate medical cure; no miracle drugs or tests to be run or even as far as I could see, no need of observation. I am not making judgements as to the type of care I received – the facts can speak for themselves. Every day I was able to escape to the toilet to run vigorously on the spot for at least half an hour without being noticed. I was able to pour meals into plastic bags under my bed, having been left alone to eat and as a result I was left to continue losing weight.

During that stay I would not consider myself as being depressed, but when I hear how other people perceived me I must have retreated into some kind of trance. I would spend hours on my bed dreaming of old family holidays in France and looking forward to being back there, feeling happy and safe among the lavender and pine trees. However I was unresponsive to the world around me. To me it just felt too difficult to engage. I had no energy to communicate and would lie on the bed barely registering anything the psychiatrist was saying apart from noting that his glasses resting on my bed made my skin crawl ever so slightly.

There are many miracles that take my story to where I am now. There are many moments of luck, many extraordinary people and many moments where fate or god or just perfect timing has helped to save my life.

One such moment that did not appear significant until weeks later occurred in those numbing days of hospital and perhaps because of the psychiatrist that decided that the only care I could be given was palliative. In one of those last appointments with him as I sat in the waiting room next to my mother I saw someone walk by into another office. When I looked at her I remember a desperate urge for her to take me in her arms and tell me it was all going to go away. At that moment I was just a sick child who did not know how to ask for the love and care she needed but saw it all pass by her in the woman's face. I whispered over to my mother 'she would be able to make me better'.

Those first days in the clinic smelled like new paint and freshly sanded wood. They felt comfortable and safe. There were three of us there and it was easy and quiet and far away from the life I had escaped.

I have no way of knowing how after those first optimistic weeks the stubborn hold of illness began to envelop me. Many people think that an institution can do this to you; that those around you can condition your actions and your feelings and edge you closer to the parapet. I think for me it was all or nothing. It always is in my life, I have to be the best and when there came a point when being ill was all I was anymore I had to be the best at it. I had to push myself further and faster.

For four months I got used to a routine. I slept with a nurse watching me, I ate, I went to the toilet and I walked in furious laps around the garden. I put on weight. Little by little, every Monday and Thursday morning I watched the scales go up and I waited for the nurses to assess my meal plan for the next few days.

I started therapy sessions – endless, endless therapy. There was group therapy, art therapy, one-on-one therapy and, perhaps worst of all, family therapy where my parents and siblings would sit looking at me, all traumatised, terrified of the incomprehensible grip within which I seemed trapped.

When I met my individual therapist for the first time I saw my lifeline. It was as if fate had answered me. The woman I had seen in hospital, the women that I had known at first sight could help me was standing in front of me. She was offering me a way out.

Perhaps the refeeding process is the most traumatic time of all. It is like standing at the edge of a really high diving board, considering whether or not to jump and before I can decide I am pushed; the decision is taken from me.

The physical impact is uncomfortable and humiliating. There is the chronic diarrhoea, the distended stomach and the cold shakes that happen after a meal. But emotionally it feels as though, in feeding myself, I am fuelling the fire of illness. The more I eat the more it rages inside me. Anorexia needs to control me like a candle needs oxygen to survive. I cannot blow it out. It clings to me like an aggressive tumour.

After a few months at the clinic they allowed my parents to come and visit on Saturdays and have lunch. It is a terrifying thing to have to eat in front of the people to whom I communicated everything through the act of starvation. There were so many things that had made me feel scared and angry and hurt for so long and it was finally being recognised, even if I wasn't ready to say it out loud. To me eating meant that I was OK. Without the physical manifestation of illness what hope did I ever have of letting everyone know that whatever was broken inside me was still not fixed.

After that there were the Saturdays out. The only person I allowed to come and get me was my mother. She would drive up and more than anything I would long to run over and throw my arms around her. Instead all I could do was pull on my standard oversized black jumper and wait until we had left the clinic before grabbing the lunch bag they had provided and throwing it out the car window.

I would spend the next ten minutes screaming and raging at her to take me to the park. Overcome by a kind of panic which would start in my stomach and sting my eyes and my tongue, I would beg her to let me stop the pain just for a few minutes; just a quick walk to quiet that incessant voice in my head which reminded me of how disgusting I was and what I had allowed into my body that day.

Once we arrived at the park I would run off like an addict in search of the next fix. I would run and run in circles, my body bent like an old sparrow, my eyes fixed on nothing except the ground pounding beneath me.

One Saturday in late autumn I must have lost track of time. The park was dark. The wind sliced at my body and I could not see the path that would lead me out to

the gate. I don't remember being scared. Worse than that I was completely calm; my head was quiet. For a few minutes I hoped this was the end. Maybe I could just lie down here and sleep until the cold froze me into the earth. Maybe no one would ever find me and I could just let the world slip away from me and it would all be over without me having to do anything. The Park keeper found me and drove me back to my mother. Her red eyes and shaking hands made me want even more to die.

That winter was a dark time. Death seemed to edge closer. The whole world slipped away in a misty haze of activity. I spent my days standing staring out the window, unable to think or feel; barely existing. Maybe it sounds predictable but that winter was the first time I cut myself.

I hear a lot that people self harm because they feel in control and it takes away the pain that they are feeling. For me it was for attention. Not for people to crowd around pityingly but for someone to hear me screaming out for help. For someone to notice that I was losing myself; my soul; my life. I was dying and even in those days my survival instinct still flickered somewhere. I just wanted someone to make it better; to hear my plight and my pain and to realise that the silent figure at the window was overtaken by a force that was bigger and scarier than anyone knew. The cuts on my arm were just another form of starvation; another way of begging for help without being able to ask for it.

I was so scared. Scared of needing, of wanting more than I deserved – be that love, or food or human contact. I was scared of that basic human need for all those things because the further entrenched in illness I became, the less I believed I deserved any of it. I felt greedy.

After months of inertia there was no sign to anyone that the clouds were parting for me. If anything I was worse. It was time for a change. So I was sent home. The clinic would provide me with day care and I would sleep at home.

I think there were other sufferers in the clinic who were jealous of this – jealous that I would be able to exercise freely or run away. I was simply terrified. The clinic cocooned me safely away from a world which was too loud, too daunting, too complicated to be part of. I did not want to be home; to be in the same room where I had hidden so many meals or made myself sick or hidden for fear of having to eat. I did not want to be reminded of the time when my life was just starting to unravel and where the ghosts of all my lies and secrets on the path to illness were still languishing.

I went home. I exercised every night for a week until I passed out. I went to the clinic and endured the snide comments and cruel notes that the other patients passed around me. I let the bullying happen. I let the other sufferers speak openly in group meetings about my 'attention seeking' behaviour and my selfishness. I sat head bowed, letting it seep into me, believing every word.

So I stopped going. I refused to leave the house and I refused to eat. I was cruel, manipulative, driven. I brandished a kitchen knife at my mother when offered a carton of juice and I sat in my bedroom, waiting. Those were the worst days of my life. I was ready to die. I was so tired. My bones ached, my head ached, my eyes

were blurred and I was simply too drained to fight anymore. My treat of the day was the dregs of water I sucked out of my toothbrush. That was my only sustenance. It is fascinating how quickly the body can deteriorate. Within six days my skin was white and would bruise when touched. My ears rang constantly and my eyesight was compromised. I had lost ten kilograms. I do not know why I did not die.

I do not know for sure what jolted me out of that trance between living and dying. I can believe that I lived a miracle and that whatever tiny glimmer of hope that was dormant inside me managed to flicker more brightly than before. I remember one morning, being unable to lie in the half light any longer and creeping downstairs to the kitchen. The world was still and for a minute I understood that nothing would change. The nights would turn to day, people would work and laugh. Whether I lived or died the world would carry on regardless; it did not notice my reflection in the window and it was not coming to save me. If I wanted to be part of that world I had to choose it for myself and suddenly I ached to be part of it. It was as though just for a moment I had woken before the illness and I could see what a waste it was. It was all just a pathetic, lonely waste of an existence and in that moment I was so tired of it. I have a diary entry from around that time which might help to understand the change. (I never wanted to re-visit that diary. I know it is there and it has remained untouched for ten years but I needed to remember exactly what saved my life, even if it just gives some other girl, somewhere else some hope)

‘Remember how this feels. I want you to remember that this is what death feels like; slow and painful. You are alone and bruised all over. There are disgusting scabs and scars on your arms and legs that will always be there. You can barely speak or see and your family are broken. Is it worth it? Is it worth dying to be thin or to be in control or for anything? You are fifteen; is this all you were ever meant to be? Remember this if you ever want to do it again’

It does not happen in a moment like you might expect it to. Getting well was not a one-time decision but a choice I had to make over and over again every day. The struggle back to being me was more horrendous than anything I had experienced before. I remember lying on the floor in front of the fridge sobbing, furious with myself and with an illness that would not allow me to reach inside. Perhaps that is what helped. Suddenly I was so angry that I had the strength to fight back, rather than disappearing into my former comatose state of despair and oblivion.

I went back. I started to talk to my therapist. She guided me through the tangle inside, and tiny parts of me seemed to come back. I still felt guilty and scared and like a bad person, but the more she listened the more I understood that I was being heard, and that whatever was broken inside me had been seen and might be fixed.

It would be another six months before I left the clinic, and another six years before I felt like my real self again. Rejoining life is almost worse than isolating myself from it. I had to re-learn who I was. My mind had been overtaken by something else and I no longer had a sense of who I was; what I liked, what I believed in.

I left the clinic having taken some school exams whilst there and embarked on the next step of school life. But I was different. I had missed that stage of experimentation and development that my peers had gone through between fourteen and sixteen, and I lurched blindly through a wide and often dangerous variety of sexual encounters and substance use. I had not let myself want anything for so long that suddenly I wanted everything. I was ravenous for life. I wanted to feel everything I had stifled and I wanted all the human contact I had denied myself. I wanted to ingest everything I could as a way of giving two fingers to an illness which had made me abstinent. I wanted to be the best recovery story ever.

Two years later it happened again. During the summer of my first year at university I was almost surprised at how quickly the weight dropped off and the old way of thinking came back to me. I was more amazed at how much worse it was the second time around. I was older, I had experienced life and I did not want to be different or ill or fragile. I wanted a life.

By December of that year I had battled my way back to recovery. I cannot tell what made me ill the first time or even the second. There are many schools of thought and having lived it I am no closer to choosing the most appropriate theory. I hope that one day someone will understand the connections that I felt with noise. How as a little girl noise was scary for me and how as I got older there were times when even my own thoughts screamed too loudly inside.

The only thing I am sure of is that this illness knows no cultural background and no specific trauma. It does not discriminate and it does not give up without a fight.

To win my battle I had parents, siblings, therapists and care workers on my side. I met and worked with some of the best people I have ever known but there were relationships that I had to sacrifice. I am only sad that this had to be but I get it. Anorexia must be so frightening to watch. It is inexplicable to most people how someone can starve themselves with such determination. Many friends and their parents kept away from me as if sensing the force of the illness and terrified it might be catching.

I know my family faced the same stigma. I have worked hard to feel less guilty about this and to come to terms with everything that they went through. People grieve and heal differently and I have to respect that; my brother likes to talk about it to everyone and my sister does not want to remember. I think for those that know me there were mixed reactions about me writing this article and re-living that traumatic time. For years I suffered flashbacks. I do not remember much of that time, but often moments would come back to me; a feeling of pain or fear, a memory would come crashing into my world without warning.

For me it is only now, aged 25, that I feel able to write this and able to close that chapter of my life, safe in the knowledge that it cannot hurt me again. There are still anxieties that I deal with, but mostly I just feel peaceful. I know the people around me might be scared of me getting sick again. Only time will help assuage those fears. For me I just know that the cloud has lifted. I am comfortable in my own skin. I am not frightened.

A parent's perspective

*Fiona Simons**

The big black cloud

I have heard Eating Disorders (EDs) called many things during my close acquaintance with them, but the one that sticks in my mind came from a consultant of an in-patient unit. He described EDs as ‘a big black cloud over the whole family’. What he meant, I now think, is not just that a family member is enveloped in and isolated by the cloud, but also that the family does not have and cannot find an umbrella strong enough to withstand the onslaught.

My beloved daughter, the eldest of two girls, has had a diagnosed eating disorder for some nine years. I recognised that her attitude to food was unusual when she was about 12, when I sought some help, but we all now accept that she was ill before then. She became afraid that she would die of a horrible disease, and that we would not notice, and started to ask a set of ritualised questions before eating. The set became longer, and, if interrupted, had to be repeated. She was also doing a lot of sport (that said, so were most of the family) but the advice I got was that, as long as she wasn't either losing weight or vomiting, she was not deemed to have a problem. We later learnt that the calorie counting that started at this stage was to cover up the anxiety that my daughter felt about her health, growing up, and innumerable other concerns that she was unable to discuss.

Referral

We moved house at this stage, after a period when my husband (father of both children) worked in the new town. I thought that once the period of disruption and the move were over, things would get better: this was probably a phase. My daughter's questions increased in quantity and frequency. In hindsight, I could have dealt with them differently, but we were referred by the school nurse, to whom I had admitted my concerns, to the local Child and Adolescent Mental Health Service (CAMHS) team as a consequence of the questions and my

* The author's name is a pseudonym

increasing frustration and inability to cope with them. We were thus in the right place when, shortly after the first meeting at CAMHS, my daughter started to lose weight. Some five months later, just before Christmas 2005, she was formally diagnosed by our General Practitioner (GP) as anorexic. She was 14 years old.

Next stage

For the next year, the team involved with my daughter's care, GP, dietician, outreach workers from CAMHS, specialist nurse therapist, family therapist and family fought hard: the only person not fighting was the only person who could make a difference: my beautiful, funny, talented daughter. She was convinced there was nothing wrong with her, we were making a fuss about nothing, and anything said or done to contradict her view was simply ignored. She continued to lose weight, despite being on a regime which amounted to house arrest. She was constantly watched, given no or very little autonomy (and certainly none approaching that of her peers). By this time, she looked less than beautiful, had lost touch with her peers in every respect apart from the academic, and had lost her sense of humour and of the ridiculous. She was rude, uncooperative, disconnected from us and impossible to talk to. According to her, our only aim was to make her fat.

That Easter, she was offered an in-patient bed. She was distraught, vowed that things would change, and against my judgment, under pressure from my (mostly absent) husband and from her, we agreed to carry on at home if she could put on some weight. She rallied a bit over the summer, then at the start of the academic year in which she would take her GCSEs (academic qualifications involving examinations usually taken by students aged 15/16 years), she lost weight quickly. As she was weighed weekly by one of either our GP or practice nurse, we were aware of the scale of the problem. Despite all the persuasion, the therapy, the overseeing, she refused to eat, continued to exercise. Her lovely thick hair was mostly in her hairbrush, she was pale, with purplish hands, if she bent over her backbone was raised so she resembled a stegosaurus and every day it seemed there was some new ritual which she had to obey. She was desperate to lose weight and held a number of illogical beliefs about food and calories, including that, should she ingest one extra calorie over the daily allowance she set herself and calculated obsessively, she would gain weight as if pumped up like a balloon.

In-patient

My daughter, a shadow of herself in size and personality, was admitted as an in-patient to an adolescent unit, not a specialist facility, immediately before Christmas 2006. She was not cooperative but gained some weight so by the time she was 16 her weight was better, but her head was not. There is a legal procedure which can be used in limited circumstances by which patients can be treated and/or admitted against their will. At that stage, my daughter was well enough not to

be forced to accept treatment under that procedure. She insisted on discharge, and came home. She tried to go elsewhere, in a quest for freedom to lose weight, and we considered allowing her to do so. However, it is hard for 16-year-olds with supportive families and EDs to find emergency accommodation, and, dreadful as we expected it to be, at least if she was at home we could monitor her, encourage her to access CAHMS and make sure they were aware of her behaviour. We would also be on hand in an emergency.

She was home for eight weeks. We had thought she was ill, difficult and impossible to reach before the first admission. Now, she was completely overcome by the illness. The horror of her behaviour, of the futility of our care and of the terror we felt were and are indescribable. She was re-admitted in July 2007, saying that she wanted to recover. We were cynical and believed she was merely trying to avoid being forced to accept treatment (she was concerned that it would be a matter of record and might affect, for example, applications for jobs or university) to repeat the process. Happily, we were wrong: she cooperated with staff and us, was discharged from the unit just before Christmas and from out-patient care about a year later. She also started a new school (which she was not well enough to attend for much of the first term) where she knew no-one, yet quickly showed she was able to understand other people and forge relationships, in contrast to the years before that when the only relationship which interested her was with the ED.

Family responsibilities and emotions

During the three years in which my daughter was acutely ill, we lost the essence of her, and feared that it would never return. I understood how ancient cultures used exorcism on the mentally ill, believing them to be possessed by evil. She was truly horrid to live with, interested only in anorexia, bad tempered, rude, disobedient, untrustworthy and untruthful. It was as though she was hidden behind a thick sheet of glass: we could see her, but not reach her in any meaningful way. We were told to love the child, hate the illness, but when the illness looks and sounds like the child, they are hard to separate. She was told, as were we, how dangerous her behaviour was, to help her to understand what she was doing to herself, and to help us appreciate how important it was that she should eat, and stop exercising. The problem was that we understood all too well, but we could neither tie her to a chair, nor force feed her. We understood what we had to do, were powerless to do it, and terrified of the consequences of not doing it.

As my daughter was at home, and as we were involved in her care, it felt as if it was our responsibility that she ate, and up to us to stop her exercising. We already felt like failures as parents. Clearly this was our fault; there was no-one else whose fault it could be, after all. No-one else's child behaved like this, so it must be something we had done wrong. Had we moved at the wrong time? Had our belief that sport was a good way of meeting people eclipsed our precious daughter's needs? Why hadn't we dealt with her early anxieties more appropriately? We could have headed all this off at the pass if only we had been better

parents. Should I give up work? What more could we do? Why weren't we able to make her better? To add to all that, we compounded our failure by not imposing a food regime, and a limit on activity, on our daughter. I read the accounts of parents who just insisted that the child ate, the child did, and roses grew around the door and life was lovely again. I persuaded, cajoled, bribed, sat for hours, stayed calm, shouted, cried, insisted, but nothing worked. Clearly, I was inadequate as a parent, incapable of doing the most basic parental task of feeding my young and keeping them safe.

As a family, we felt increasingly isolated: other parents told me their woes and frankly I would gladly have swapped any of those woes for mine. If I told them what was going on (to which my daughter was opposed as many were parents of her friends) I was told that she'd eat when she was hungry (I wish) or, 'Let her come to me for a weekend, I'll get her eating in no time' (no you won't, but my goodness you know how to make me feel inadequate).

Our feelings, of anger, helplessness, worry, fear, isolation, did not improve our equilibrium as a family. My husband buried himself in his work and often was away from home, leaving me to manage at home, and work. I worked because I felt more competent there than I did at home, and for at least some of the time, EDs were not at the forefront of my mind, which amounted to a bit of respite. Our younger daughter became anxious and disconnected at school, and resentful of the time spent on and with her sister. I should have been keeping my younger daughter's nose to the grindstone, but after every day of appointments, telephone conversations, trying to get advice on days we had no appointments, dealing with endless questions, trying not to scream at my elder daughter that she just needed to bloody eat (and worse), spending hours in supermarkets watching my elder daughter examine plain fat free yogurt pots for calorie values, frankly as long as my younger daughter was undemanding, so was I of her. My worries about my elder daughter were much more pressing.

Looking back, we were helped by a sympathetic, knowledgeable GP, by CAMHS (in particular one man who first assessed us, gave me support and became our family therapist, seeing us regularly over five years) and then the in-patient unit. I would not have coped without friends, virtual and real, who understood what I was going through and empathised. There are things that might have helped us (and others) but there are also some things that those dealing with us appeared not to understand. It is both those things that I hope to highlight here.

What parents feel

Not that long ago, the cause of eating disorders was said to be parents. There are no doubt cases to which families contribute, but current thinking is that parental influence is not solely responsible for a child developing an ED. Certainly, it is hard to accept one element alone as the cause when there are so many contributing factors, one of which seems to be underlying genetic traits. Current research suggests that, if support is given to carers, they in turn can offer more support to

sufferers, and outcomes will improve, showing that families have an important role to play. There is a difference, however, between logic, research, and how a parent feels. I have not yet come across a parent who does not blame him/herself at some point in the illness. In my case, I felt that if I was responsible for the illness, then surely there was something I could do (or stop doing) and everything would be alright. If I had no responsibility, I had also to accept that I could not change things, and in the early days, that felt like giving my child up to the illness. My child was not fighting so I had to, however futile it was. I knew in my head that the illness (it is an illness, after all) was not my fault, but it took a long time, and therapy, to accept that in my heart. Helping all parents to reach that point, and offering them therapy to help, should be part of the work of the professional team.

It is hard for us to be open with you, because we do not necessarily know what you do, or what you offer: we are referred to some mysterious place called CAMHS, and as we blame ourselves for the predicament we are in, we assume others, including you, will too. Whilst often you offer the first real expert help we have encountered, and seeing you is therefore A Good Thing, it takes us into unknown territory. Some of what you talk about, for example family therapy, sounds threatening to us.

In addition, when we first meet you, we have either been watching our child commit slow suicide in front of us and felt helpless, or have just discovered the magnitude of a problem our child had hidden, and feel neglectful. We may know an eating disorder has been diagnosed, but we may need time to come to terms with the fact that life is not as we expected it to be. Unless we have encountered an ED before, we are unlikely to understand the implications of the diagnosis. I thought that, once diagnosed, there would be a cure. We would see you, my daughter would get better. In my defence, that had been the context of my encounters with the medical profession until that point, as I guess it is for many. It later became apparent that things might not be that simple, and we might be in this for the long haul, which was profoundly depressing. I did not truly understand that an ED is a mental illness, and as I had had no real experience of mental illness, I did not know what to expect. Our team was careful to manage our expectations, not to give us false hope, and to avoid speculation as to what the time scale might be at any stage, which was frustrating at the time, but in retrospect I am glad that I did not know how long the long haul might be.

Hope, too, is a difficult issue. For me, the worst times were not the times I knew things were bad and expected them to stay that way or deteriorate. The worst times were when I began to hope that there was some progress in the right direction, only for those hopes to be dashed (as, after all, is the nature of the illness and of recovery). Losing hope is a desperate feeling, with which I learnt to cope by trying not to hope in the first place. I know I was seen as negative, and pessimistic, by the professional team, but I was the main carer, and my feelings needed to be accommodated too. I have heard carers tell each other that they need to look after themselves in order to have the strength to care for their loved one (as the airline advice goes, put your oxygen mask on before helping others with theirs) and

professional teams need to understand that need, and do what they can to meet it. Is it possible for you to offer to supervise one meal a day, or even a week, for the parents? Can you give them time to get out and breathe air uncontaminated by the ED? This might be especially important for a single parent.

Walking on eggshells

One of the more pernicious aspects of an ED which is difficult to explain to those with no experience of it is the way in which the ED can control the entire family, as well as being a black cloud over and around it. The ED affects what one does and says, to the extent that it can control the vocabulary used by the family. 'Well' to a person with an ED, in terms of their looks, is synonymous with 'fat' and should be avoided. However, others do not understand that, and when they meet a sufferer, they think it rude to remark on how dreadful the sufferer looks. Families and professionals have learnt to comment on clothes, hairclips or makeup, but others say, untruthfully, 'You look well'. For some reason, what I or the professionals said a hundred times to my daughter was clearly wrong when compared to what a comparative stranger said once in a moment of awkwardness.

My daughter could not bear the thought that she was fat. She seemed pathologically afraid that she was or would become so (in passing, whilst I agree that the messages given out by the media are at best inconsistent so far as size and weight are concerned, my daughter did not want to look like a supermodel, or be a particular size). To be lazy, in her eyes, was the same as fat. Anything that could possibly infer that she was lazy therefore carried the implication that she was fat. So far, so logical, but carried to an ED driven conclusion, I could not ask her to help in the house. If, for example, she was asked to empty the dishwasher, she had not done it already, so I was accusing her of being lazy. I soon learnt that it was simpler, and quicker, to do the chore myself. In fact my daughter never did a chore without being asked, which confirmed in some people's minds the attention seeking nature of the illness, although I think she had so much ED noise in her head that there was no spare space for noticing the needs (or even sometimes the existence) of others.

The solution to an accusation of laziness was to exercise manically. The solution to a comment made thoughtlessly by me or by someone who did not know she was unwell/did not understand the effects of the illness was hours of ritualised questions. I remember one particular incident when I said to both girls in the midst of feeling that I was responsible for all things domestic, 'I am fed up with doing everything around here, you need to pull your weight'. What did I mean by that? What sort of weight was I referring to? I must mean she was heavy. If I thought she was heavy, why did I keep saying she was too thin? Why did I lie to her?

The whole family learned to think before they said anything, to examine every phrase for an ED interpretation, to treat every conversation as a game of chess and look two moves further on. It affected our spontaneity in words and deed, and in fact still does.