

Anorexia and Bulimia in the Family

One Parent's Practical Guide to Recovery

Gráinne Smith



John Wiley & Sons, Ltd

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To my daughter Jay with love

The mother's place now seems to be, not in the kitchen or the home, but in the wrong . . .

Unknown



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About the author

Gráinne Smith has worked for several years on the Eating Disorder Association helpline as a volunteer, putting to good use her training and experience as a former Samaritan. During that time she has spoken to hundreds of carers and sufferers as well as to many professionals.

A founder member, now chairperson, of NEEDS Scotland (North East Eating Disorder Support) and a member of the Mental Health group that developed the Scottish Executive Health Department framework document for eating disorders services in Scotland, she has also taken part in Mental Health and Wellbeing Support Group visits to health boards and presented a petition on eating disorders to the Scottish Executive. She currently works to raise awareness of how poor mental health affects whole families while good mental health underpins physical well-being.

During a long career in primary education, including nine years as head teacher of Fyvie Nursery and Primary School, Aberdeenshire, she enjoyed working with whole families and children aged from 3 to 12. As a writer, Gráinne has had short stories and poems published in magazines and anthologies; while working with Grampian Region she helped write and present courses for teachers and head teachers; she has also written many educational materials including co-ordinating and contributing to the pack “Fyvie Castle – Its Life and Legends”.



Foreword

I am delighted to be asked to write the foreword to this book by Gráinne Smith. I think it is a unique contribution, as it gives voice to a neglected group in the management of people with eating disorders (i.e., carers or family members). Gráinne not only speaks from her own personal experience, she has also been involved in running one of the telephone helplines for the Eating Disorders Association (EDA), and has heard the difficulties and frustrations of numerous other carers. This book is shot with these heart-rending accounts. This in itself is of great interest and is invaluable as a source of emotional validation, comfort and support to other carers and gives an opportunity for those involved in the management of eating disorders to see the other side of the drama, the “Noises Off”. There are also some poignant details of how professionals can wound and render carers guilty, frustrated, emotionally paralysed and helpless.

This book offers much more than a vivid description of a carer’s experience. It is perhaps Gráinne’s background, experience or part of her personality, which has meant she has not been content with experiencing and understanding alone. Rather her active problem-solving mentality has gone out searching for

answers and solutions. As such she has forged for herself a pathway into the role of an “expert carer”.

The Department of Health recommends the introduction of user-led self-management for chronic disease in all areas of the NHS by 2007 (DoH, 2001). The idea is that many patients could develop the skills to become expert in managing their own disease. Anorexia nervosa is a chronic illness, and so would fall into such a remit. However, because of its onset during adolescence or young adulthood the concept of expert carer is probably as appropriate as that of expert patient. This is particularly so because we know that people with an eating disorder themselves have mixed feelings about recovery.

The evidence on which the concept of an “expert carer” was developed in Stanford, CA. Kate Lorig led a research programme which found that training people who have chronic illnesses such as rheumatoid arthritis or diabetes in the management of their own illnesses, so that they become experts, increases the quality of life and overall outcome. Currently in the UK projects are under way in manic-depressive psychosis and diabetes. Kate Lorig’s course, which has been used across the world, has six consecutive weekly training sessions each of 2.5 hours. This training is supplemented with patient-orientated self-help books. This book by Gráinne Smith is an excellent cornerstone for the development of this concept within eating disorders, as it provides an excellent carer-led manual.

Our experience from hosting the National Carers Conferences for Eating Disorders jointly with the Eating Disorders Association is that carers are desperate for knowledge, information, skills and resources to help them manage the day-to-day problems, which arise as part of living with someone with an eating disorder.

Research has shown that the longer the delay between the onset of the illness and active treatment the less chance there is of a good outcome (Reas et al., 2000). Family members and other carers are in the prime position to ensure that early intervention is a reality rather than an optimistic fantasy. Furthermore, families and carers can maximize the effectiveness of all treatments. Thus this book will be an invaluable contribution to all treatments for eating disorders. It can serve to take the sting of guilt and blame from the diagnosis and ensure that the process of recovering from

an eating disorder takes place in the context of a collaborative effort of all those concerned.

Professionals working with people with eating disorders have recognized that specialized skills and expertise are essential for working with this client group. For example, specialized forms of psychotherapy (Dare et al., 2001) and specialized services (Nielsen et al., 1998) are associated with a better outcome. It follows that carers also need special skills.

Gráinne has succeeded in distilling the specific problems and solutions that carers face. Therefore, I hope that the book will serve as a source of inspiration for all other eating disorder carers to become “experts”. Also I hope that it can break down some of the barriers between patient, carer and professional. It is all too easy for the professional to place him or herself on a pedestal offering wisdom and expertise and superior intensive care to rescue the individual from her eating disorder. Too often this is perceived as taking over where carers have failed or even stepping in to right the supposed wrongs that parents have wrought.

After reading this account I hope that professionals will develop a sense of respect and humility. How many of us could withstand such an onslaught and rejection of nurturance, the core of care?

Professor Janet Treasure
Guy's Hospital
London
13 October 2002



Preface

In autumn 1993 when my daughter finally told me that she had been diagnosed with anorexia nervosa “with elements of bulimia”, I asked my GP what I could/should be doing to help. The reply was that I knew as much as the GP . . .

As a lifelong reader, I then set out to find a helpful book by someone who had experienced the illness. I searched the local library and bookshops and those within driving distance, but was handicapped by not ever having heard the phrase “an eating disorder”, and therefore did not connect it with my daughter’s illness, the dramatic weight loss and personality changes. It took me two years to find Eating Disorder Association (EDA) and link up what had started as a local information helpline with EDA.

For several years I continued my search, coming across all sorts of interesting, sometimes devastating, information and opinions. I found books by professionals whose writing was about patients whom they saw only in clinic and hospital settings; some of them wrote about families. I found one or two books by carers which told their own personal story, but were of little practical help beyond reassuring me that other people had been through similar situations.

In 2000 I attended the first-ever EDA Carers' Conference in London, which turned out to be a major turning point. Six months later I visited friends in Boston and spent some time in bookshops again searching for that elusive book. I wondered what was available for families coping with other life-affecting problems. It was there in Boston I found a book on how to help an alcoholic without hurting yourself (a revelation!), books on living with all sorts of other serious and chronic illnesses and disorders. But not what I was looking for . . . And at last I realized that I was not going to find what I was looking for – a practical book by someone who had experience of living with all aspects of the illness.

Over the last three years I have collected together all I have learned: from reading widely in any and all areas, plus personal and work experiences that I thought just might be relevant and useful; from listening to many other family members talking about common problems in eating disorders and difficulties in coping; and from listening to and discussions with professionals who feel that families can play an important part in either supporting and maintaining the illness – or helping motivate sufferers toward the long road to fighting against eating disorders.

I hope what I have learned will be of practical use to families and other carers.

February 2003



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I would like to say thank you to all the many carers I have talked to over the last few years, who have allowed me to share in their lives and stories; to the Aberdeen Eating Disorder Service, who do wonders on small resources and in difficult circumstances; to the Macduff Medical Practice; to all my many friends, who have walked alongside on the long road.

Special thanks go to Jan, Edith and Douglas for unfailing, unquestioning support in the darkest days; to Janice, who answered questions, gave me information and listened; to Margaret, who gave me hope; to Vivien Ward and Lesley Valerio at Wiley, who had faith; to Janet Treasure and Ulrike Schmidt for their interest and encouragement; and to Ian McIlwain, who said, "Get a life!" And I did.



Part I

Healing is a matter of time, but it is sometimes also a matter of opportunity.

Hippocrates (460–400 BC)

Introductions

Beginning . . .

My life was opening up, I had lots of friends and an improving social life, a job that gave a lot of satisfaction as well as hard work, and I began to plan for my own future . . . Work abroad for a children's charity? Write full-time? Move house?

I felt I'd come through some very tough times (some day if you have a spare week or so, I'll tell you my life story!), but my horizons were expanding, growing and I was looking forward . . . then Anorexia came, uninvited, to visit my home.

Just a few years ago in 1993 I was living alone – my daughter married, my son working in Glasgow. At 48, I was working full time at a high-profile, high-energy, high-stress job (primary head teacher). Having brought up my kids from an early age on one teacher's salary, for the first time in my life I was enjoying having some money at the end of a month and had bought one or two luxuries, total unnecessarys, trying hard to get over the Scots prudence that says *Save*.

Having survived various teenage traumas, both my children seemed happy with their respective life choices. I felt I'd put into practice my strong belief in teaching a mixture of rights, responsibilities and respect for others. From an early age they were both

expected to take responsibility in keeping our home, and their own rooms in particular, reasonably clean and tidy (our views of “reasonably clean and tidy” often differed – which led to me keeping their bedroom doors shut rather than look at the clutter!!). Each week I listed the chores that had to be done and asked which they’d prefer to do . . . in their rush to avoid the ones they hated, they volunteered for the ones they regarded a bit more favourably, at least taking a couple of chores off my shoulders. Despite a few grumbles, they saw the fairness of helping around the house, which made the environment better for all of us. From the time they could count, they helped set the table for meals and from 12 years onward they cooked a weekday meal once a week. As they also got to choose what that meal was, they seemed happy to learn to cook at the same time as making a valuable contribution to the running of the house. (Especially at the beginning, it did mean that sometimes we ate sausages and beans rather more often than I would have preferred . . .)

Training our children to be able to cope in the Big Bad World out there is an important part of being a parent as well as loving them, and I thought I’d done an OK job in bringing up my children. OK. Not brilliant – I could think of several things I felt had been mistakes along the way, but I’d always loved them, demonstrated that love often with hugs and cuddles as well as bedtime stories, games and so on, encouraged them in their individual strengths, tried to help them with things they weren’t so good at. If they did their best that was good enough.

My son seemed to grow through the teenage years as he had done everything else, with good humour (and an increase in his accustomed untidiness and lack of organization), but major rows with my daughter had been part of the picture at that stage, as she stayed out until 3 or 4 in the morning and refused to even look at homework, let alone do it. But those days were now past and she appeared happy in her marriage at 19 to the boy she’d gone out with since she was 13 (the reason she had wanted to stay out at night). Unfortunately, that marriage, so much looked forward to, was a very unhappy experience and two years later Jay asked to return home. Unknown to me, Anorexia and Bulimia also came to stay.

At that time, they were just words on the edge of my vocabu-