

Therapy for Eating Disorders

Sara Gilbert



3rd
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Therapy for Eating Disorders

Therapy in Practice

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Therapy for Eating Disorders

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Third Edition

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About the Author

Sara Gilbert is a chartered clinical psychologist with over 30 years of experience. Her interest in problems with over- and under-eating developed out of a research project into the psychology of obesity in a hospital clinic in 1978–81. For the past 20 years she has specialized in the treatment of eating disorders, with people whose difficulties are expressed through eating too little or through problems with controlling what they eat. She recently retired from her NHS post as joint service lead of the community eating disorders service in Bedfordshire (South Essex Partnership Trust) and now works in private practice in London.

Sara's approach to therapy is broadly cognitive behavioural but she sees herself as an integrative therapist in that she draws on a combination of several other approaches to inform her work. She believes that the role of the therapist is to work with clients to build a joint understanding of their current difficulties in order to develop a treatment plan which fits best with evidenced based ideas and the client's own objectives and aspirations. Her aim in therapy is to help clients to learn ways to make changes for themselves, so that they can work towards becoming their own therapist or coach.

Sara's other publications include *Pathology of Eating: Psychology and Treatment* (Routledge, 1986 and 2014), the first systematic and comprehensive coverage of the psychological aspects of eating disorders and their treatment; and *Tomorrow I'll Be Slim: The Psychology of Dieting* (Routledge, 1989 and 2014).

Preface

I first became interested in exploring the nature of eating disorders when working in an obesity clinic in the late 1970s. At that time, the only eating disorder truly recognized was anorexia nervosa. People who were overweight or of normal weight, and who could not control their eating, fell sadly between two stools. Either they were forced to fit into medically oriented dietetic or nutrition clinics, where their apparent lack of motivation to do as they were advised was viewed askance by the people who tried to treat them; or they were assumed to be depressed, or even to be suffering with a personality disorder, and offered temporary shelter under a psychiatric umbrella, which was just as inappropriate. It became increasingly clear that what these people needed was something different, something which addressed the specific problems of their disorders, and which did not force them to pursue an answer which relied on their problems having an entirely physical origin or to be labelled as suffering from some form of insanity.

While the origin of eating disorders remained poorly understood, it made increasing sense to treat them with a cognitive behavioural approach, encompassing as it does a collaborative therapeutic style, the teaching of self-control to clients, and a way of exploring the meaning of their difficulties together with clients. Since the publication of the first edition of this book 12 years ago, cognitive behaviour therapy has become more firmly established as a treatment of choice for the eating disorders with a strong evidence base, and I have updated the literature and references cited in the book to take account of new developments in theory and practice. Some of the more recent developments in cognitive therapy that may also lend themselves to working with people with eating disorders, and in particular in relation to helping people to tolerate emotional distress, include methods often referred to as 'third-wave' cognitive therapies: with ideas from the work of Marcia Linehan (1993a, b) in relation to dialectical behaviour therapy in the treatment of borderline personality disorder; Hayes and others (1999) in relation to acceptance and commitment therapy; and Segal,

Williams and Teasdale (2013) in the development of mindfulness-based cognitive therapy.

In this book, I have attempted to describe how to offer therapy to people with eating disorders from a cognitive behavioural point of view. In doing so, I must acknowledge that the origin of many of these ideas is influenced by a combination of many sources, including my reading of the works of Aaron Beck and his colleagues, of Christine Padesky in relation to cognitive therapy for depression and other disorders, and of Hilde Bruch, Christopher Fairburn, David Garner, Paul Garfinkel and Kelly Bemis Vitousek, among others, in relation to eating disorders.

In updating a book of this nature and scope, it has not been possible to give detailed coverage of all aspects of eating disorders, but I have referenced the work with a large number of relevant contemporary sources so that the reader can pursue individual topic areas in further detail. In describing a broadly cognitive behavioural approach, I have assumed a basic knowledge of cognitive behavioural and generic therapy techniques. (For more details of how to use cognitive behavioural techniques to elicit and answer, for example, negative automatic thoughts and to arrive at underlying assumptions, I would refer readers to Judith Beck's [1995] excellent manual.)

There are now several excellent self-help books available that outline cognitive behavioural protocols, some of them evidence based, and similar to those which have been subject to much research into the treatment of bulimia nervosa in particular. However, while protocols are helpful as a starting point, in this book I have taken an integrative stance and drawn on ideas from the cognitive and behavioural fields, many of them researched in practice, which can be tailored in varying combinations to the treatment of individual clients and their idiosyncratic problems. For example, I have drawn on ideas about enhancing motivation for treatment, schemas about the self and interpersonal relationships, and eating disorder as a means of coping with negative affect. I have avoided giving exact prescriptions of when and where to introduce specific techniques as it will be up to individual therapists to decide, together with their clients, at what point in therapy each approach might be most useful.

In the following chapters, I have on many occasions used the pronoun 'she' to refer to clients, rather than the more clumsy 'she/he' or 'they', and have made this choice merely because most sufferers are female. However, the ideas may apply equally to male sufferers, who have much in common with female sufferers. The case histories I have described are not those of real people. Rather, they are composites derived from clients I have met, and with the details of their stories and their names changed so as to preserve the confidentiality of the real people on whom they are loosely based.

Finally, this book could not have been published without the work and encouragement of several people. Windy Dryden, series editor, suggested that I write the book several years ago. His constructive criticism of drafts of the first chapters helped me to set the style for the book as a whole.

Despite the many obstacles to my meeting deadlines, Windy was unfailing in his patience and in his belief that I would complete it as promised. My thanks go to Kate Williams, dietician, for her comments on an earlier draft of Chapter 7 in this edition. I am grateful to colleagues past and present for the many discussions we have had over the years which have helped to shape my ideas about the nature and treatment of eating disorders, in particular: Jay Chatterton, Jacqui Dabney, Gary Kupshik and Faith Whittle. I should also like to acknowledge the hard work of the many editorial staff of Sage who have been involved in this book in all its incarnations: Melissa Dunlop, Justin Dyer for his relentless and painstaking editing of the text, Rachel Burrows, Kate Scott, Susannah Trefgarne, Laura Walmsley, Louise Wise, and Kate Wharton, and in particular Susan Worsey for her support and encouragement over long periods when personal circumstances made it impossible for me to write.

Sara Gilbert, 2013

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1

What is an Eating Disorder?

Treatment of the eating disorders has become a major mental health issue of the twenty-first century. Until the early 1980s, most people knew of the existence of anorexia nervosa, but few mental health professionals or dietitians would have considered it necessary to have more than the ability merely to recognize the disorder so that they could pass a case on to a specialist worker or unit.

In the past thirty years, however, help has become increasingly available for people with specific diagnoses of bulimia nervosa and anorexia nervosa. Mental health professionals have also begun to address the problem of binge eating disorder in both normal weight and overweight people. Awareness of the need for specialist care has meant that someone with an eating disorder is more likely than previously to be referred for psychiatric or counselling help or may at least be able to receive advice from a self-help organization.

Yet, despite increased knowledge and interest in this area, clinicians are often reluctant and sometimes anxious or even negative about working with this group of people. A review of 20 studies between 1984 and 2010 describing reactions to patients with eating disorders listed frustration, hopelessness, lack of competence and worry as reflecting the feelings of clinicians, albeit there was an inverse relationship between the strength of these feelings and clinician experience. Negative reactions to patients with eating disorders were associated with patients' lack of improvement and personality pathology (Thompson-Brenner et al. 2012). Even among specialist mental health workers there is still some erroneous information about the nature of eating disorders and confusion about the best ways to treat them as evidenced by a recent survey of National Health Service (NHS) psychiatrists in the UK (Jones et al. 2013).

This book is an attempt to provide a practical basis for helping people with eating disorders both for therapists with a mental health or health

psychology background and for dieticians. Its aim is not only to describe ways of working with people with a specifiable eating disorder, but also to suggest ways to improve the methods by which nutritional advice and therapy are offered to obese people and to those who by virtue of psychological difficulties are unable to eat in a health-promoting way.

This chapter will describe the behaviour, eating habits and physical symptoms seen in people with disorders of eating. It will define the conditions known as 'anorexia nervosa', 'bulimia nervosa' and 'binge eating disorder', and discuss some of the problems which therapists and mental health professionals may meet in people with atypical, less easily definable eating disorders, such as purging and anorexic behaviour in people of apparently normal weight, or inability to eat for reasons other than fear of becoming fat. It will also discuss the relationship between eating disorder and weight and the question of how far people at a very low weight or a very high weight in relation to height may or may not have an eating disorder.

A broad definition of eating disorder is given by Fairburn and Walsh (2002), psychiatrists who have been at the cutting edge of eating disorder research for the past 30 years. They propose: 'a persistent disturbance of eating behaviour or behaviour intended to control weight, which significantly impairs health or psychosocial functioning. This disturbance should not be secondary to any recognized general medical disorder ... or any other psychiatric disorder' (Fairburn and Walsh 2002: 171). This definition implies an understanding that the eating disorders encompass a range of difficulties. People may also be driven to overeat or under-eat for reasons which do not necessarily include the intention of controlling weight. There is increasing evidence that a disturbance in eating or purging behaviour may reflect a need for some individuals to control or escape from intolerable emotions, and the resulting change in weight is merely a side-effect of that behaviour. Eating disorders are largely defined by characteristic behaviours around food and weight control and attitudes to weight and shape. An eating disorder can never be diagnosed from weight or shape alone, although weight is an important feature of an eating disorder (see text box on the relationship between weight and eating disorder).

Recognition of the widespread nature of problems around food and eating stemmed from three areas. The first and perhaps most public of these was the feminist movement. Susie Orbach's book *Fat is a Feminist Issue* (1978) drew a great deal of attention to the movement through its novel discussion of so-called 'compulsive overeating' which talked not so much about 'fat' itself but about the fear of fat and the place held by that fear in the culture of women in the context of their relationship with men. This led to a rash of books around the area of dieting and body image, most of which carried the implication that dieting and obsession with body image have something to do with the place of women in a sexist society.

Another source of recognition was in mainstream psychiatry. Gerald Russell (1979), known for his work with anorexia nervosa, described an

anorexic-like syndrome in women of normal weight. These women had previously been anorexic and, although of normal weight on follow-up, were still obsessed with weight and shape. They binged frequently but went to great lengths to control their weight by means of vomiting, taking laxatives or starving themselves in between binges. He called this syndrome 'bulimia nervosa' as opposed to anorexia nervosa.

A third source of recognition came from epidemiological research. 'Bulimia', as it was called in the United States, or 'bulimia nervosa', as it was called in Britain, was recognized to exist on a wide scale among women who had never approached their doctors for help.

However, there is no doubt that the existence of the popular word 'binge', and the phenomenon itself, has its basis in the obsession with dieting that prevails in the Western world. Very many men and women of all ages diet habitually. In this setting, it is sometimes difficult to assess how far someone is actually suffering from an eating disorder. Dieting and a negative attitude to fat are condoned and often highly valued by people as an indicator of self-control both in themselves and in other people. Hence, it is possible for someone who is suffering intensely with an eating disorder to hide the fact not only from themselves but also from the people who might be able to help.

A note about psychiatric diagnosis

Psychological disturbances are generally classified under two parallel classification systems. These are the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM, American Psychiatric Association 2013) or the World Health Organization's *International Classification of Diseases* (WHO 1992). In this book, I have used the DSM-5 (2013) classification system as a basis for describing the disorders under discussion and the results of research into the efficacy of their treatment, although most of the research to date is, in fact, based on the DSM-IV and DSM-IV-TR classification systems which have been in use until the time of writing (American Psychiatric Association 1994, 2000).

If we are to work with people and their problems, we need some way of defining the problems so that we all know that we are discussing the same phenomenon. In this regard, psychiatric diagnosis is a useful system. It also helps us to draw conclusions from research into treatment. However, the distinctions between the so-called 'disorders' are by no means firm and immutable. There is much overlap of symptoms and characteristics between disorders and there may be limited utility in producing endless classificatory systems and subsystems which describe but do little to explain or predict (see Fairburn and Cooper [2007] with regard to the utility of classification in eating disorder). It is also important to remember that the conditions to which we are referring are not necessarily illnesses or conditions which a person

can 'have' in the same way as they can 'have' multiple sclerosis or epilepsy, or which they can 'catch' in the same way that they can 'catch' pneumonia or acquire HIV; and there is growing interest in a 'dimensional' approach to the classification of eating disorders based on a model where symptoms may vary in severity on a continuum across diagnoses and with normality (see also Wildes and Marcus 2013). There is some emerging evidence of possible links with physiology and brain chemistry, but as yet there are no clear indicators of medical or genetic aetiology of eating disorder that lend themselves to the development of medical treatment approaches; and, as yet, the major treatments of choice have a psychological basis. As John Marzillier, an experienced psychotherapist and research psychologist, has pointed out:

the experiences that lead people to be diagnosed as 'mentally ill' are experiences that all of us can have in some form at some stage. This is why, despite over a century or more of research, psychiatrists are no further forward in defining and understanding – let alone successfully treating – any major psychiatric 'illness'. (Marzillier 2004: 392)

The people we meet in therapy for eating disorders may have symptoms in common, but the way they respond to therapy will be a function of the complex interaction between their symptoms and many other factors, including physiology, brain chemistry, personality, past experience and current circumstances. Therapists may experience some discomfort in trying to attach labels to the real people they meet in their consulting rooms. However, psychiatric 'diagnosis' is merely a starting point from which to explore the individual needs of clients, develop an individual formulation or 'case conceptualization', and apply the general principles and individual techniques of evidence-based psychological therapy.

The relationship between weight and eating disorder

Body mass index

Degree of overweight or underweight is commonly described by a measure known as the body mass index (BMI).

This is derived from the formula W/H^2 (weight in kilograms divided by the square of height in metres).

Weight is plotted in relation to height and the resulting graph has been reproduced in widely available table form depicting the upper and lower limits of the weight range.

Normal weight

The normal range for the BMI of adults is 20–25.

Low weight

BMI measurements below 18.5 represent increasing degrees of underweight.

The Maudsley Body Mass Index table (Janet Treasure) defines underweight as follows:

17.5–20	underweight
15–17.5	anorexia nervosa
13.5–15	severe anorexia nervosa
12–13.5	critical anorexia nervosa
> 12	life-threatening anorexia nervosa

Overweight

A BMI of 26 and above indicates increasing degrees of overweight:

26–30	grade 1 (overweight)
30–40	grade 2 (clinical obesity)
≥ 40	grade 3 (severe obesity)

Note: BMI varies through childhood and adolescence, decreasing in early childhood and then gradually increasing through adolescence. So, for children, BMI on its own is not a good measure of thinness. A chart is used to depict BMI in boys and girls aged 2 to 20, and individual BMI is expressed as a percentile.

A BMI above the 95th percentile is considered overweight, and below the 5th percentile is considered underweight (WHO 1996; Dietz and Bellizzi 1999).

Anorexia nervosa

Anorexia nervosa is a state in which the sufferer, usually female, refuses to eat enough to maintain normal body weight for her height. Usually she claims to want to lose weight to be slimmer; sometimes she says that she does not feel hungry or that it is uncomfortable to eat.

A currently accepted definition of anorexia nervosa is given in the fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual (DSM-5, 2013)* and has three criteria. The first specifies that the person takes in less energy than needed to maintain a weight that is normal for their height and age; or for a child or adolescent, their weight is less than expected. The second criterion specifies an 'intense' fear of weight gain or attempts to prevent weight gain. A third criterion specifies a disturbance in

the person's experience of their body weight or shape, or the implication that the person refuses to recognize the risks of being seriously underweight (see American Psychiatric Association 2013).

A weight criterion by which to define anorexia nervosa is given in the tenth edition of the *International Classification of Diseases* (WHO 1992), which specifies that weight is maintained at least 15 per cent below that expected or, in adults, body mass index (BMI) is below 17.5 kg/m². In younger people, instead of actual weight loss, there may be failure to gain weight as expected during puberty or childhood. According to *DSM-5*, the current level of severity of anorexia nervosa is based on current body mass index for adults and on BMI percentile for children and adolescents. Most young women with anorexia nervosa will stop menstruating; and a previous version of the *DSM*, *DSM-IV* (American Psychiatric Association 1994) stipulated the absence of at least three consecutive menstrual cycles when otherwise expected to occur. However, this stipulation has now been removed as children with an eating disorder may have not yet reached puberty; some women, including those who take the contraceptive pill, may continue to menstruate even at a low weight; and amenorrhoea can be experienced by people with all types of eating disorder (see also the review by Pinheiro et al. 2007).

People suffering with anorexia nervosa refuse food or eat very little. Some may count calories or exclude certain food groups from their diet, and many eat as little as 200–300 calories per day. They may also take strenuous exercise, apparently as a means of maintaining a low weight, but also perhaps as a means of keeping warm according to some recent evidence which showed a negative correlation between ambient temperature and physical activity in anorexics who exercise (Carrera et al. 2012). For many people, excessive exercise is maintained as a means of regulating mood. Anorexics also often appear 'faddy' with their food. Some take an immense interest in cookery and in cooking for other people, although they will themselves avoid eating the food they cook.

Individual sufferers vary widely in their presentation, and attempts to characterize types of anorexic have their limitations. For example, it has been assumed until recently that all anorexics have a 'drive for thinness' and fear weight gain, but as now reflected in the most recent version of the *DSM* (American Psychiatric Association 2013), fear of weight gain is not a prerequisite for meeting diagnostic criteria. Several authors have pointed out that up to 20 per cent of anorexics, in particular in the Far East, do not appear to be afraid to get fat: these patients are more likely to attribute fear of eating to some other phenomenon, such as stomach bloating or pain, loss of appetite or lack of hunger (see Ramacciotti et al. 2002 for a discussion). In addition, studies in children and adolescents have pointed to the fact that fear of weight gain is not always endorsed in this group, despite a clear refusal to eat (WCEDCA 2007). The authors of this latter study explain this observation in terms of 'limited verbal capacities, fewer abstracting abilities,

less awareness of emotions ... compared with adults.' (p. S117). However, the same could be said for some adult eating disorder clients too, people in whom the 'breadth and complexity of emotion regulation strategies' may be limited just as it is in individuals at an earlier stage of development.

Anorexics are also thought to have a distorted body image, in that they often appear to grossly overestimate their own size or weight. A great deal of research in the 1970s was devoted to the question of how far anorexics overestimate their body size. This is in common, however, with many other people with abnormal eating habits, and the emphasis more recently has been on sufferers' attitudes to weight and shape. Peter Cooper and Christopher Fairburn (1993) have pointed out the distinction between 'dissatisfaction with body shape', which may or may not be experienced by women with eating disorders, and 'overvalued ideas about body shape and weight', which they hold are a necessary diagnostic feature for both bulimia nervosa and anorexia nervosa.

Anorexics are specified as 'restricting types' or 'binge eating/purging types'. Some anorexics keep their weight down solely by restricting their food intake and are not currently purging or binge eating, while others also binge eat and purge themselves by vomiting or by taking laxatives, diuretics or enemas. Some patients may develop the habit of chewing and spitting out food as a means of purging or of avoiding food intake. The relative number of bingers *vis-à-vis* restrictors is on average about 50 per cent across studies, which have pointed to some consistent differences between the two groups: more of the bulimics have had heterosexual experience and are married, although their social adjustment is no better than that of the restrictors, as they also describe themselves as more anxious and depressed, more guilty about their eating habits, and more aware of difficulties in interpersonal relationships. The bulimics are significantly older when they present for treatment and have been ill for longer. More of the bulimics appear to seek help for themselves, while the restrictors often deny that they have a problem at all. However, the bulimics also appear to carry a worse prognosis, and, in addition, are more likely to exhibit impulsive behaviours, such as stealing, drug abuse, suicide attempts and self-mutilation. Garner and his colleagues (1993) have suggested an entirely different division of anorexics, between those who purge and those who do not. They have suggested that this avoids the problems of defining a binge. It also makes sense in that many anorexics purge without bingeing, and there is a strong association between purging behaviour and level of psychopathology, chronicity and length of illness (Favaro and Santonastaso 1996).

The disorder takes a physical toll on sufferers. Long-term starvation causes muscle weakness and loss of muscle strength, which also affects the heart. Sufferers may develop cardiac abnormalities and arrhythmias which normally improve with weight regain and recovery (see Mehler et al. 2010 for a detailed description of medical complications in eating disorders). They may have dry skin and brittle hair and nails, with scalp hair loss and

excessive growth of dry brittle hair over the nape of the neck, cheeks, forearms and thighs, called 'lanugo' hair. They often have cold hands and feet, and peripheral oedema (swelling). They can suffer from constipation and often complain of feeling 'bloated'. Long-term amenorrhoea (lack of menstrual periods) may lead to premature bone loss and place sufferers at risk of osteoporosis. Indeed, there is evidence that young women with anorexia nervosa have an increased risk of fractures in later life (Lucas et al. 1999).

It is common for people with anorexia nervosa to experience mood and anxiety disorders compared with other people of the same age (Hudson et al. 2007). The experience of low mood is in part a predictable concomitant of severe food deprivation, which can subside when the person is in remission from their eating disorder, but many anorexics are diagnosed as suffering from clinical depression in addition to their eating disorder with a lifetime prevalence of between 36 and 86 per cent (Green et al. 2009). Anxiety is also common, and more prevalent in people with eating disorders than in the wider community. In a review of previous research, anorexics were described as having lifetime prevalence rates of between 23 and 75 per cent for having at least one anxiety disorder. In fact, there is some evidence that anxiety disorders predate the onset of an eating disorder in many people (Swinbourne and Touyz 2007; Pallister and Waller 2008). Up to 40 per cent of anorexics have been described as having an obsessive compulsive disorder (OCD) with compulsive symptoms which cannot be explained entirely by the need to control calorie intake and expenditure (Sallet et al. 2010).

Anorexics share many features with people who suffer with body dysmorphic disorder (BDD). BDD is a condition in which a person is preoccupied with an imagined defect in his or her appearance. The focus of the person's attention often concerns perceived flaws or blemishes which are quite small, for example of the nose, skin, face or hair, but can also centre on a more general complaint, of being 'ugly' or about weight, hips, stomach or thighs. Sufferers typically engage in repetitive and compulsive behaviours, such as mirror checking, camouflaging the defect, or excessive grooming, and may go to extreme lengths to modify the defect, such as strict dieting, or even investing, sometimes repeatedly, in plastic surgery. The diagnosis of an eating disorder, with its emphasis on body shape and weight, can obscure the presence of BDD, as it is possible for sufferers to experience both. In a study of 158 people seeking treatment for their eating disorder, 45 per cent of subjects screened positive for the presence of BDD, although their focus of complaint, like that of other people with eating disorder, was largely around weight and shape and the authors suggest that it is important to be aware of this possibility because of the greater psychopathology that may be carried by BDD and the implications for treatment (Dingemans et al. 2012).

Who develops anorexia nervosa?

Anorexia nervosa currently has a very high profile. However, it is important to bear in mind that a search throughout the world literature has shown

that it affects on average less than 0.5 per cent of young women (see Table 1.1; Hoek and van Hoeken 2003; Smink et al. 2012). Sufferers are usually in their adolescence, but the disorder can appear at any time between 12 and 44 years. It has also been reported in women over the age of 60, although it is likely that the majority of people identified had suffered with the disorder for most of their life (Scholtz et al. 2010).

Table 1.1 Incidence and prevalence of eating disorders

Anorexia nervosa	
Incidence	8 cases per 100,000 population per year (1 in 19 male)
Prevalence	0.3 % for young females
Bulimia nervosa	
Incidence	12 cases per 100,000 population per year
Prevalence	1 % in young women 0.1 % young men 90 % are female, 10 % male

Source: Hoek and van Hoeken (2003)

Incidence rates are highest at around 1 per cent per year for females aged 15–19 years, who constitute approximately 40 per cent of all cases, and it is relatively rare both in children under the age of 13 and in middle-aged and older women. However, given that up to one-quarter of presentations of anorexia nervosa first occurred in childhood, it is likely that its occurrence in younger children has been underestimated: there are reports of its appearance in pre-pubescent girls as young as seven (Nicholls et al. 2000) and, in one study in Australia, in children as young as five years old (Madden et al. 2009). In this study of first presentations of eating disorder, it was notable that many of the children had comorbid psychiatric disorders and medical complications, and nearly 80 per cent required immediate hospital admission. One reason for the possible under-identification of children with anorexia nervosa is that very young children are less likely than are older children or adults to be able to verbalize their distress, or to express it if they do, in terms of body shape or weight (Madden 2012). Hence, as the emphasis in the diagnostic criteria moves away from cognitive and emotional symptoms, we may see a rise in numbers of children being identified as having an eating disorder as opposed to another disorder of feeding.

There is a question with regard to all age groups as to whether or not all cases of anorexia nervosa are picked up by health care professionals and whether there are still some cases which go undiagnosed and untreated (see text box).

Are all cases of anorexia nervosa detected?

A study in the Netherlands estimated that one-year prevalence rates were higher in the community in general than in mental health care (Hoek 2006).

Researchers in Finland screened questionnaire responses of nearly 3,000 young women who had taken part in a twin cohort for the presence of eating disorder. They conducted telephone interviews with 292 women who screened positive for anorexia nervosa together with their screened negative twins (134). The authors found a lifetime prevalence of *DSM-IV* anorexia nervosa of 2.2 per cent; half of the cases had not been detected in the health care system, although detected and undetected cases showed similar symptoms and rates of recovery (Keski-Rahkonen et al. 2007).

With regard to the question of whether anorexia nervosa is on the increase, a meta-analysis of incidence in mental health care in Europe suggested that it increased up to the 1970s and then stabilized. However, long-term epidemiological studies are sensitive to changes in incidence depending on the methods used and on variations in the methods of detection over time (Smink et al. 2012). Hence, we do not yet know whether the prevalence of anorexia nervosa is really increasing or whether any reported increase in clinical referrals is simply a function of improved detection or changing demographics.

Between one in 16 and one in 19 anorexics is male, although it has recently been suggested that anorexia nervosa is more common in males than previously thought and may be even more frequently undetected in this group than in women (Hoek 2006). The presentation of anorexia nervosa in men is often described as being similar to that of women. Males, like their female counterparts, experience profound physical changes that accompany severe weight loss, including stunting of growth and decreases in libido, and psychological symptoms such as depression and obsessive compulsive behaviours. However, there are some differences. For example, some studies have pointed to more frequent physical activity, such as jogging and working out in the gym, more concern with masculine shape, and less concern with actual weight. There is also a tendency towards later detection, possibly as a result of a stronger involvement with athletics, or because men may be more inclined to hide symptoms which could be viewed as relating to a female disorder and so are more likely to escape the notice of medical practitioners (see also Lindberg and Hjern 2006). Some authors report an increased frequency of 'asexuality'; others have suggested a correlation between anorexia nervosa in boys and men and homosexuality: for example, Feldman and Meyer (2007a) have summarized findings which suggest that between 14 and 42 per cent of male anorexics in both clinical and community samples are gay or bisexual in contrast to the lack of association of eating disorders with sexual orientation in women.

Together with bulimia nervosa, anorexia nervosa has traditionally been described in both clinical and research studies as being overrepresented in the upper social classes. However, there is an increasing awareness that eating

disorders can affect people across boundaries of social class and racial groups and that the people who come to the notice of mental health specialists may not be truly representative of the social class and ethnic backgrounds from which they come (see text box). It is possible that the cultural and family difficulties engendered by immigration and change and exposure to the Western beauty ideal are more salient than are social class or culture *per se*.

Eating disorders and social class

Anorexia nervosa and bulimia nervosa are said to be overrepresented in the upper social classes and to occur more frequently in Western and specifically white people, both in the United States and in Great Britain.

- The social class distribution of anorexia nervosa patients referred to a specialist treatment centre in London over 33 years was consistently weighted towards social classes one and two (McLelland and Crisp 2001).
- In a national survey of health registers in Sweden, where access to health services is fairly equitable, the factors most strongly associated with inpatient treatment of anorexia nervosa were having parents from northern, central or eastern Europe (as opposed to southern Europe, the Middle East or Africa) and coming from a white-collar household (Lindberg and Hjern 2003).

However, the relationship between eating disorder and class is still under debate.

- Anorexia nervosa is reported increasingly in women in all countries, including Japan (see Chisuwa and O'Dea 2010), and in all classes.
- In a study on the Caribbean island of Curaçao, Hoek found no incidence of anorexia nervosa in black women, but the incidence among the minority mixed Asian and white populations was similar to that in the Netherlands (Hoek et al. 2005).
- Anorexia nervosa has been reported to exist at a rate higher than expected in the young homeless (Freeman and Gard 1994).
- In a review of several studies dating back to 1973, Gard and Freeman (1996) noted that the belief that anorexia nervosa in particular is more prevalent in high socioeconomic groups was based on flawed evidence from small, biased samples; there were far more studies which reported either no relationship or the opposite than those which did report a relationship with high social class.
- In a meta-analysis of 119 outcome series of patients with anorexia nervosa, Steinhausen (2002) could draw no definite conclusions as to the relevance of socioeconomic status.

Does social class affect service utilization?

- An American study compared the prevalence and service utilization for eating disorders across Latinos, Asians, and African Americans living in the United States to the non-Latino white population. The prevalence of anorexia nervosa

(Continued)

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was similar across all groups examined, but lifetime prevalence of service utilization was lower for the ethnic groups (Marques et al. 2011).

- In London, referrals to a specialist eating disorder service did not reflect the ethnic composition of the local population (Waller et al. 2009).
- In Leicester, fewer than 5 per cent of female patients referred to a specialist eating disorder service were Asian, even though young Asian women comprised nearly 14 per cent of the local young female population (Abbas et al. 2010).

Some possible reasons for these discrepancies regarding ethnicity and utilization of health services in eating disorder could be:

- ethnic minority women are less trusting of medical professionals and less willing to seek help outside their immediate community;
- inequalities in health care systems;
- physicians in some settings miss the diagnosis of eating disorders in ethnic minority groups (Gilbert 2012).

What happens to people who have anorexia nervosa?

Most anorexics have just one episode of the disorder and eventually return to a normal weight. Of those who are treated in clinics and survive, between 40 and 80 per cent achieve normal weight between two and ten years after they are first seen. However, many continue to have abnormal attitudes to food and weight for a very long time, and about half of previous sufferers do not return to eating normally. Between 13 and 50 per cent of women do not get their periods back. About 60 per cent of those who continue to maintain a low weight and have problems with eating manage to live apparently normal lives, and hold down jobs.

According to Steinhausen (1999), 5 per cent of anorexics die of anorexia nervosa. About one in five deaths is due to suicide, and the standardized mortality ratio for anorexics (risk of dying compared to the general population) has been estimated at between 5.86 (Arcelus et al. 2011) and 9.6 per cent (Nielsen 2001). The difference in these estimates could be in part due to the differing length of follow-up in the studies, as the longer the follow-up period, the greater the risk of mortality in the comparison population too, or to the introduction of increasing numbers of specialist care units for people with eating disorders, or simply to differences in the reporting of anorexia nervosa as the cause of death (Smink et al. 2012). Nevertheless, the evidence is consistent with the view that anorexics have about three times the risk of dying as people with other psychiatric illnesses (NICE 2004).

Steinhausen (2002) has conducted an exhaustive study of 119 outcome series published between 1950 and 2000, comprising nearly 6,000 patients followed up for varying lengths of time. Poor outcome has been associated with