EATING DISORDERS

Overview

The purpose of this section of the Framework is to deal with the Eating Disorders of Anorexia Nervosa, Bulimia Nervosa and other related eating disorders as set out in the 10th International Categories of Disease section F 50 (set out in Appendix A). Obesity and binge eating can also be associated with abnormalities in eating behaviour, thoughts and feelings similar to those found in Anorexia Nervosa and Bulimia Nervosa. While recognising areas of overlap, this section of the Framework concentrates specifically on Anorexia Nervosa and Bulimia Nervosa.

How common are Eating Disorders?

i. Based on published international estimates the incidence of Anorexia is some 8.1 new cases per 100,000 total population per year. For Bulimia Nervosa the figures are some 11.4 new cases per 100,000 total population per year.

ii. The Office for National Statistics (2000) survey found a prevalence of eating disorders in 11-15 year old girls of 4/1,000, which equates to about 500-600 in Scotland. From other published prevalence figures the most accurate (2001) estimates suggest that in Scotland some 1,200 women aged 15-24 years will be affected by symptoms suggestive of Anorexia Nervosa with upwards of 4,700 with Bulimic symptoms.

iii. While Eating Disorders are most common among females, up to 10% of sufferers are male. It is important to appreciate that for both sexes sufferers can present at any age.

iv. Nationally there is evidence of an increased incidence and prevalence of Eating Disorders. This may, in part, result from greater awareness of these conditions by both health professionals and the wider public.

Morbidity and Mortality

v. Eating Disorders may be associated with other mental health problems. For example, depression is found in around one third of people with Eating Disorders.

vi. Eating Disorders often follow a chronic relapsing course. While many patients may recover from an Eating Disorder in some 20-30% the conditions may become chronic.

vii. Anorexia Nervosa has one of the highest (earlier than normal life expectancy) death rates of all psychiatric disorders with risk of death in up to 20% of sufferers. For this reason early recognition and treatment are extremely important and may be life saving. In some cases treatment on an in-patient basis may be essential.

viii. Chronic Eating Disorders can include both medical and psychological complications. Medical complications include osteoporosis, infertility and acute electrolyte disturbances. Psychological problems such as chronic depression and repeated self harm; impaired relationships and limitations on social functioning can also feature; all of which can put severe pressure on family and carers and on the prospects of continued or fresh employment opportunities.
Services for Eating Disorders

ix. Management of patients with an Eating Disorder is complex. Mild disorders may benefit from minimal interventions such as guided self-help but established illness usually requires formal therapeutic intervention. Individual, family and group approaches are all used and require continuity of care from trained therapists, sometimes for several years. Multidisciplinary working is often required with the need to address psychological, nutritional, physical and social needs of patients and their families and carers.

x. Current (2001) provision in Scotland for those with Eating Disorders is limited and patchy. Around half the population of Scotland has no local specialist service for Eating Disorders. Much more needs to be done to create treatment protocols, clear referral pathways and a pattern of specialist in-patient provision in the NHS. Where local services are available these appear to have been developed mainly as a result of personal interest by staff and thus can lack significant managerial and funding support. Currently Scotland has no specialist NHS in-patient provision for Eating Disorders. It is also recognised that the care needs for people with Eating Disorders are not always best met in general psychiatry acute wards.

xi. For Anorexia especially, it is important to recognise that in some cases in-patient hospital care may be an essential component of the care pathway and form an integral part of the spectrum from home care and care in the community to specialist hospital services. In relation to in-patient care, upwards of 100 adults (ie age 16 and above) might be expected to be admitted to hospital care each year in Scotland. (For the in-patient care needs of younger people a review is now underway by the Scottish Needs Assessment Programme on Child and Adolescent Mental Health. This will include consideration of the feasibility of “regional” service provision.)

xii. For some areas and some services it may be that a consortia approach to the future organisation of care services and support offers the best option for both the patient and the service providers.

xiii. NHS Boards who currently commission care on a case by case basis have responsibility to oversee care arrangements, outcome and follow up. It is also important in all cases that referring clinicians retain a direct interest in the ongoing care arrangements and individual progress for all patients. The line of communication in this regard is of course two-way with an equal onus placed upon the in-patient facility and staff to advise the referring clinician on progress and care regimes. The link to the General Practitioner must also be maintained.

xiv. There is also an overall lack of information for all concerned on recognising symptoms and what help and support might be available locally. The potential for the development of self help support groups and the role of the voluntary sector also needs recognition and support locally.

xv. There is a large as yet unmet need for education and professional training about Eating Disorders at all levels from the general population to staff in specialist services.

xvi. It is important to include the patient and (where appropriate) their carer and family at all stages of care planning.
### A FRAMEWORK FOR MENTAL HEALTH SERVICES IN SCOTLAND
#### SECTION 3: SERVICE PROFILES

**EATING DISORDERS**

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<tr>
<td>0. People in the Community - mental health and well-being in the local community</td>
<td>(1) Increased public knowledge and awareness of the problems of Eating Disorders. An understanding by the range of community agencies who have responsibility for, or contact with, young people that a collective approach to the benefits of sensible eating, acceptance of personal shape, maintenance of good self esteem and enhanced personal confidence by young people are important prerequisites for positive mental health.</td>
<td>(1) Accurate information is needed to better inform parents and others who may be the first to recognise signs of an Eating Disorder. Upper primary, secondary and guidance teachers, school health professionals, dentists, occupational health staff, social workers, counsellors, workers in local community services, employers, the voluntary sector and others will often be the first point of contact for someone with an Eating Disorder. Staff in all cases need appropriate educational support and ready access to fuller information and knowledge of local service provisions, and as for all specialist services attention and effort should be attached to staff training, skills upgrade and retention issues.</td>
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<td>(2) Early recognition and ease of access to information, support and services in local communities. In this context the potential role of education services and initiatives under new community schools should be explored.</td>
<td>(2) Agencies should work together and produce local directories of information/resource material, service directories and offer appropriate education programmes for staff to help with early identification of symptoms. Simple, clear guidance material is required. Advantage should be taken of the opportunities presented by the 2002 Changing Children’s Services Fund.</td>
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<td>(3) Development of “local signposts” to enable individuals to find out about the services they may require.</td>
<td>(3) There should be ready access to information systems providing guidance on how to help people with Eating Disorders and on services available locally and elsewhere. Internet based information systems could be part of this provision. In some areas the potential and role of Healthy Living Centres may be important “signposts” of local service provision. As the local services develop it is important to ensure the availability and currency of leaflets for GPs, dentists, youth clubs etc.</td>
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<td>(4) Development of accessible non-medicalised support networks. There are a few voluntary self-help/support groups scattered around Scotland but at present none have access to any mainstream funding. <em>Our National Health</em> encourages Health Boards to support voluntary organisations which can provide appropriate services. It also stresses the need for locally available advocacy services.</td>
<td>(4) NHS Boards and Local Authorities should encourage the development of local voluntary sector services and develop education and training and other support material. In doing so they may consider contacting the Health Education Board for Scotland (HEBS) and the Scottish Eating Disorder Interest Group among others. The views of users of services and their carers should also be invited, where necessary, through collective or individual advocacy.</td>
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<td><strong>1</strong> Local Services - Primary Care LHCC level</td>
<td>(1) While a significant number of people with Eating Disorders are managed by primary care services a recent Scottish study of General Practitioner opinion has highlighted a wish and need for training in the assessment and management of Eating Disorders.</td>
<td>(1) Agencies should consider the best local and other response to the agreed need for information, awareness and training in early identification, assessment and management of patients with Eating Disorders. This should address the needs of all staff in primary care and other health service settings, as well as local authority and voluntary sector staff. This could best be co-ordinated at Local Health Care Co-operative (LHCC) level.</td>
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<td>(2) Early recognition and ease of access to information and support networks is especially important for all practitioners, including not least those in dental services. Research reports have shown that around 50% of patients with Eating Disorders are not fully identified in primary care.</td>
<td>(2) Research is required in the areas of earlier identification of patients with Eating Disorders and the development of brief interventions in primary care. The short SCOFF questionnaire (See Appendix B) while not definitive has potential as a useful screening tool in the primary care setting.</td>
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<td>(3) Because these conditions often follow a chronic relapsing course, long term support for the needs of and family members should also be taken into consideration.</td>
<td>(3) NHS Boards should help create guidelines on assessment and management in primary care. To achieve this will first require the development of local Eating Disorder services. As part of joint planning for mental health services, Local Authorities will need to be involved in assessing the needs of those with a chronic condition and their carers. These needs may include supported accommodation, supported employment, special education and training opportunities which take account of chronic disability.</td>
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<td>Specialist Services (Generic locality based services)</td>
<td>(1) At present in most areas, people with Eating Disorders are currently managed by general mental health services for adults, adolescents and children reflecting that Eating Disorders cross all age and sex barriers. To manage Eating Disorders properly there is a need for development of local specialist services.</td>
<td>(1) NHS Boards with their planning and commissioning partners should undertake a review on how services are currently delivered within existing Framework mechanisms(^1). This assessment to be reviewed at regular intervals.</td>
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<td>(2) Such specialist services need to have appropriately trained staff from a range of professionals to be able to respond appropriately in providing multi-professional assessment.</td>
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<td>(3) Many people with Eating Disorders have severe and/or enduring mental disorders which must give them the priority and access to services equal to other groups with severe and or enduring mental disorder.</td>
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<td>(4) There should be local guidelines to assist generic staff in the management of mild to moderate uncomplicated cases and guidelines on who to refer to for more specialised services for Eating Disorders.</td>
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<td>(5) Patients with severe Eating Disorders suffer major physical complications some of which may be acutely life threatening. These patients require access to acute general medical specialist services with expertise in the assessment and management of severe nutritional problems. Some will present initially in General Hospital wards and will require ready access to skilled mental health liaison staff and dieticians, all trained in the assessment and management of Eating Disorders.</td>
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\(^1\) Needs Assessment for a Comprehensive, Local Mental Health Service, Scottish Executive Health Department, April 2001
## A FRAMEWORK FOR MENTAL HEALTH SERVICES IN SCOTLAND
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| Specialist Services - continued  
(Generic locality based services) | (6) Patients with possible personality disorders who may repeatedly self harm or abuse drugs and alcohol may also have Eating Disorders. These patients often present in crisis. They may benefit from input by specialist eating disorder services but they also require access to generic mental health services and specialist psychotherapy and substance misuse services. Each case will require a coordinated, cohesive response to assessed needs.  
(7) In remote and rural areas, particular attention is required to:  
- Ensure equality of access  
- Avoid stigmatisation  
- Provide local fit-for-purpose interventions. | (6) Again as local services develop in each area, the particular needs of these patients will need to be considered as part of the local mental health service planning process.  
(7) NHS Boards serving remote and rural areas should explore the full potential of telemedicine; e-mail, internet and CD-ROM based treatments. These can be delivered to remote settings from specialist centres and through liaison between specialist centres and local primary care or generic mental health services. For the out-patient, the advice locally from the voluntary sector can provide much needed and ongoing accessible support in this regard. |
## EATING DISORDERS

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<td>3</td>
<td>Specialist Expertise (Specific for Eating Disorders)</td>
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<td>(1)</td>
<td>Currently (2001) there are established Eating Disorder Services in Edinburgh and Aberdeen. Other areas (currently few in number) have small staff groups with identified responsibilities for Eating Disorders. Teams should include staff from a range of professions including psychiatry, clinical psychology, nursing and dietetics and sometimes others such as art therapists, drama therapists and occupational therapists. Published experience from Eating Disorder services in Grampian suggests that the provision of specialist Eating Disorder services throughout Scotland would attract around 2,000 referrals per annum.</td>
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<td>(2)</td>
<td>Without appropriate planning and consideration of age and sex sensitive services, care can be disrupted as patients move through child and adolescent to adult services.</td>
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<td>(3)</td>
<td>Younger patients with Eating Disorders require specialised help and sympathetic consideration to their special age related needs. For this group especially there is added importance of support and working actively with families from the earliest stage.</td>
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<td>(1)</td>
<td>Each NHS Board should have a specialist multidisciplinary team for Eating Disorders. The team membership will depend on identified need. Some areas may consider a consortium approach for the development of multidisciplinary services.</td>
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<td>(2)</td>
<td>Specialist services should be designed to make available age appropriate expertise in eating disorders and to provide continuity of care. This may require innovative approaches for those patients who move through the child and adolescent age range to adulthood. The transition to adult services, as for all services, should be made as smooth as possible.</td>
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<td>In this regard age consideration should be considered in terms of care options. The National Service Framework (England)(^2) acknowledges that family therapy seems very effective in younger people. However adults with anorexia are more likely to respond to individual eclectic psychotherapy and those with bulimia to group or individual cognitive behavioral therapy. Antidepressants can reduce purging and bingeing whether or not the person is also depressed.</td>
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<td>(3)</td>
<td>Those responsible for children’s services should ensure appropriate age and sex sensitive provision for those with Eating Disorders and smooth transition to adult services when necessary. This could most appropriately be carried out at a consortium level (see Level 4) within a national context through discussions with the Scottish Executive.</td>
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\(^2\) National Service Framework for Mental Health, 1999 Department of Health (England)
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<td><strong>4</strong> Supra-area Specialist Services</td>
<td>(1) Specialist in-patient provision in Scotland relates mainly to advanced Anorexia Nervosa because of the severe physical as well as psychological morbidity and potential mortality. Estimated demand for in-patient care at national level is upwards of some 100 patients per year. A minimum in-patient stay can be in the region of 3 months with a possible median stay of some 4-6 months. In addition to those requiring admission, up to another 400 patients in Scotland could require intensive multidisciplinary care such as day care and intensive outreach.</td>
<td>(1) NHS Boards should consider cost effective policy and models in terms of accessing in-patient care to serve the needs of their local population. Planning and commissioning discussions may best be advanced on a consortium basis (see below) for the provision of Tier 4 services.</td>
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<td>(2) Consideration of the Report of the Royal College of Psychiatrists Special Interest Group on Eating Disorders suggests an in-patient need of 6 beds per 1 million population. However the precise and appropriate level of bed provision for each area or consortium will depend on the local assessments of need. Bed numbers are not always an accurate reflection of need (Overview x. refers) and must form part of a broader response to care provision, including out-patient and other services.</td>
<td>(2) Commissioning consortia covering East, West and North Scotland already exist. These consortia should begin to address the issue of commissioning appropriate in-patient provision. In each case, it aids the process where a lead NHS Board is agreed to take forward plans for supra-area specialist services. Consortia planning and development should involve the voluntary sector, users of services, carers and other statutory agencies.</td>
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<td>(3) Currently there are very few professional staff with specialist knowledge and skills in the diagnosis and treatment of Eating Disorders. NHS Boards and others have yet to establish training resources to rectify the deficit in the availability of trained staff.</td>
<td>(3) As part of mental health planning agencies should include the need to develop a strategy to increase and sustain the number of staff with specialist training in Eating Disorders.</td>
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3 Eating Disorders in the UK – Policies for Service Development and Training – October 2000
A FRAMEWORK FOR MENTAL HEALTH SERVICES IN SCOTLAND
SECTION 3: SERVICE PROFILES

EATING DISORDERS

Service Standards

- As defined by the Clinical Standards Board for Scotland, a system of quality assurance should *promote public confidence that the services provided...are safe and that they meet nationally agreed standards and to demonstrate that, within the resources available [organisations are] delivering the highest possible standards of care*;

- In a health context, each NHS body has a duty to monitor and improve the quality of healthcare which it provides to individuals as part of the clinical governance process. Thus **quality assurance** is *improving performance and preventing problems through planned and systematic activities including documentation, training and review*. **Accreditation** is a process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.

- A system of quality assurance and accreditation would comprise:
  - Setting standards – in an open collaborative way between the service providers, the users of the services, those who care for them and a public view;
  - Self-assessment of performance locally in relation to the standards derived;
  - Undertaking external peer review of performance against those standards;
  - Reporting findings, regularly, publicly and transparently.

- Standards should:
  - Focus on those care issues which impact on the quality of care;
  - Be written in simple language;
  - Be based on evidence;
  - Take account of other recognised standards and clinical guidelines;
  - Be clear and measurable;
  - Focus on improving the outcomes of care;
  - Be published and widely available;
  - Be regularly evaluated and revised to make sure they remain relevant and up to date.

- Standards for service provision to people with eating disorders are still in development. As people with an eating disorder are treated with a psychological intervention the *psychological interventions* standards could apply. Also, the Clinical Standards Board for Scotland core standards, which apply to all patients and those who care for them, are relevant.
A FRAMEWORK FOR MENTAL HEALTH SERVICES IN SCOTLAND
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EATING DISORDERS

CLASSIFICATION OF MENTAL AND BEHAVIOURAL DISORDERS
CLINICAL DESCRIPTIONS AND DIAGNOSTIC GUIDELINE

Diagnostic Criteria for Research

For a definite diagnosis, all the following are required:

a. Body weight is maintained at least 15% below that expected (either lost or never achieved), or Quetelet's body mass index$^4$ is 17.5 or less. Prepubertal patients may show failure to make the expected weight gain during the period of growth.

b. The weight loss is self-induced by avoidance of "fattening foods". One or more of the following may also be present: self-induced vomiting; self-induced purging; excessive exercise; use of appetite suppressants and/or diuretics.

c. There is body image distortion in the form of a specific psychopathology whereby a dread of fatness persists as an intrusive, over-valued idea and the patient imposes a low weight threshold on himself or herself.

d. A widespread endocrine disorder involving the hypothalamic - pituitary - gonadal axis is manifest in women as amenorrhoea and in men as a loss of sexual interest and potency. (An apparent exception is the persistence of vaginal bleeds in anorexic women who are receiving replacement hormonal therapy, most commonly taken as a contraceptive pill.) There may also be elevated levels of growth hormone, raised levels of cortisol, changes in the peripheral metabolism of the thyroid hormone, and abnormalities of insulin secretion.

e. If onset is prepubertal, the sequence of pubertal events is delayed or even arrested (growth ceases; in girls the breasts do not develop and there is a primary amenorrhoea; in boys the genitals remain juvenile). With recovery, puberty is often completed normally, but the menarche is late.

Differential diagnosis. There may be associated depressive or obsessional symptoms, as well as features of a personality disorder, which may make differentiation difficult and/or require the use of more than one diagnostic code. Somatic causes of weight loss in young patients that must be distinguished include chronic debilitating diseases, brain tumours, and intestinal disorders such as Crohn's disease or a malabsorption syndrome.

Excludes: loss of appetite (R63.0)
Psychogenic loss of appetite (F50.8)

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$^4$ Quetelet's body-mass index = weight (kg) to be used for age 16 or over $\frac{\text{weight (kg)}}{[\text{height (m)}]^2}$
F50.1 Atypical anorexia nervosa

This term should be used for those individuals in whom one or more of the key features of anorexia nervosa (F50.0), such as amenorrhea or significant weight loss, is absent, but who otherwise present a fairly typical clinical picture. Such people are usually encountered in psychiatric liaison services in general hospitals or in primary care. Patients who have all the key symptoms but to only a mild degree may also be best described by this term. This term should not be used for eating disorders that resemble anorexia nervosa but that are due to known physical illness.

F50.2 Bulimia nervosa

Bulimia nervosa is a syndrome characterised by repeated bouts of over-eating and an excessive preoccupation with the control of body weight, leading the patient to adopt extreme measures so as to mitigate the "fattening" effects of ingested food. The term should be restricted to the form of the disorder that is related to anorexia nervosa by virtue of sharing the same psychopathology. The age and sex distribution is similar to that of anorexia nervosa, but the age of presentation tends to be slightly later. The disorder may be viewed as a sequel to persistent anorexia nervosa (although the reverse sequence may also occur). A previously anorexic patient may first appear to improve as a result of weight gain and possibly a return of menstruation, but a pernicious pattern of over-eating and vomiting then becomes established. Repeated vomiting is likely to give rise to disturbances of body electrolytes, physical complications (tetany, epileptic seizures, cardiac arrhythmias, muscular weakness), and further severe loss of weight.

Diagnostic Guidelines

For a definite diagnosis, all the following are required:

a. There is a persistent preoccupation with eating, and an irresistible craving for food; the patient succumbs to episodes of over-eating in which large amounts of food are consumed in short periods of time.

b. The patient attempts to counteract the "fattening" effects of food by one or more of the following: self-induced vomiting; purgative abuse; alternating periods of starvation; use of drugs such as appetite suppressants, thyroid preparations or diuretics. When bulimia occurs in diabetic patients they may choose to neglect their insulin treatment.

c. The psychopathology consists of a morbid dread of fatness and the patient sets herself or himself a sharply defined weight threshold, well below the pre-morbid weight that constitutes the optimum or healthy weight in the opinion of the physician. There is often, but not always, a history of an earlier episode of anorexia nervosa, the interval between the 2 disorders ranging from a few months to several years. This earlier episode may have been fully expressed, or may have assumed a minor cryptic form with a moderate loss of weight and/or a transient phase of amenorrhea.

Includes: bulimia NOS
Hyperorexia nervosa
EATING DISORDERS

Differential diagnosis. Bulimia must be differentiated from:

a. upper gastrointestinal disorders leading to repeated vomiting (the characteristic psychopathology is absent);
b. a more general abnormality of personality (the eating disorder may co-exist with alcohol dependence and petty offences such as shoplifting);
c. depressive disorder (bulimic patients often experience depressive symptoms).

F50.3 Atypical bulimia nervosa

This term should be used for those individuals in whom one or more of the key features listed for bulimia nervosa (F50.2) is absent, but who otherwise present a fairly typical clinical picture. Most commonly this applies to people with normal or even excessive weight but with typical periods of over-eating followed by vomiting or purging. Partial syndromes together with depressive symptoms are also not uncommon, but if the depressive symptoms justify a separate diagnosis of a depressive disorder, 2 separate diagnoses should be made.

Includes: normal weight bulimia
THE SCOFF QUESTIONNAIRE

Source: Extract from BMJ 1999;319:1467-8 (John F Morgan, Fiona Reid, J Hubert Lacey)

The SCOFF Questions*

1. Do you make yourself Sick because you feel uncomfortably full?
2. Do you worry you have lost Control over how much you eat?
3. Have you recently lost more than One stone in a 3 month period?
4. Do you believe yourself to be Fat when others say you are too thin?
5. Would you say that Food dominates your life?

*One point for every "yes"; a score of ≥ 2 indicates a likely case of anorexia nervosa or bulimia.