



Great Ormond Street Hospital for Children NHS Trust: Information for Families

Welcome to the Eating Disorders Team

This booklet contains some information about eating problems in young people, and contains details about the Feeding and Eating Disorders Service at Great Ormond Street Hospital. As a parent or carer you play a very important part in your child's recovery, so we spend as much time thinking about how to help you help your child as we do working directly with young people themselves. This is because we see families as the main source of support for most young people – the solution, not the problem. For example, it is quite unlikely that your child would have come for help on their own, but getting to see someone who can help is a huge first step.

You may have known straightaway that something was wrong, but often parents we see say that they have found the problem creeping up on them. Parents often blame themselves for not having noticed earlier, or even worry that they have caused the problem in the first place. They sometimes have had a hard time persuading health professionals to take their concerns seriously too. This is because it is not always easy to decide when a problem becomes serious, especially something as 'everyday' as eating.

About eating disorders	1
Anorexia Nervosa	2
Bulimia Nervosa	3
Other types of eating problems	4
Selective eating	4
Food phobias	4
Food Avoidance Emotional Disorder	5
Emotional overeating	5
Family life	6
The Eating Disorders Team at GOSH	6
Referral process	7
Contacting the team	7
Further information	8
Support and further information	8

About eating disorders

Food and eating play an important part in our lives. We each have our preferences for certain foods, and the types of foods that we eat vary widely depending on age, culture, religion and appetite. It is common for children to experiment with food and eating patterns (for example, becoming vegetarian). However, some eating patterns can be damaging and some young people may develop an eating disorder. They may eat too much or refuse to eat or try to get rid of food by vomiting. These patterns of eating can cause emotional and physical harm if they continue over a prolonged period of time.



Eating disorders can affect both boys and girls, although the majority of children affected are female. It is difficult to say what makes a person vulnerable to developing an eating disorder, some contributing factors might include social and media influences about body shape, difficult life events and issues around independence and growing up, and family and peer relationships. It is unlikely that one single factor will explain why someone develops an eating disorder, as many factors are often involved. Whatever the underlying cause, eating disorders are usually a way of coping with difficult feelings and unhappiness. At first, the eating disorder can seem to provide a solution to problems, but eventually it takes over and makes the problems worse. Eating disorders are potentially life threatening and can have serious physical and psychological consequences.

Anorexia Nervosa

People who suffer from anorexia nervosa are very frightened of being a normal weight. They are afraid that if they eat normally they will become fat. Despite feeling hungry, people with anorexia nervosa go to great lengths to avoid eating. They may cut out certain foods (such as fat and carbohydrates), skip meals, exercise excessively, abuse laxatives or induce vomiting. As a result, the young person loses weight, which gives them a sense of control and achievement. They judge themselves as good or bad depending on how much they have eaten and how much they weigh. Underneath, they have very low self-esteem and are deeply afraid of not being liked by other people. As the young person continues

to lose weight, the anorexia nervosa takes over and can distort their view of themselves. They often deny that there is anything wrong with them, and continue to feel fat even when they are unhealthily thin or emaciated. They may feel that everyone around them is unnecessarily worried or upset, and they can get very angry or upset if they are pressurised to get help. Usually the young person knows deep down that they are very ill, but may feel enormous panic at the thought of giving up their eating disorder.

Anorexia nervosa can have serious physical, psychological and social consequences. The body starts to shut down as a result of starvation, leading to tiredness, poor concentration, lack of energy and feeling cold. In girls, weight loss can cause hormonal changes and menstrual periods to stop; this can also lead to the development of osteoporosis. The teenage years are an important time for growth and development. If a young person develops anorexia nervosa, this growth spurt can be missed and they may be unable to catch up with their growth and development at a later stage. Anorexia nervosa can lead to stunted growth, brittle bones and reduced fertility. At the very worst it can cause death. It is a very serious condition and it is very important that the young person gets professional help.





Signs and symptoms of anorexia nervosa include some of the following:

Physical

- Weight loss
- Loss of, or failure to start, menstrual periods
- Dizziness, tiredness and lethargy
- Poor circulation, resulting in cold hands and feet
- Constipation
- Difficulty sleeping
- Stomach pains
- Growth of fine, downy body hair (lanugo)

Behavioural

- Avoiding eating, or eating on low calorie or carbohydrate foods to the exclusion of other foods
- Increased interest in food, such as cooking, shopping, nutrition and calories
- Excessive exercising
- Ritualised behaviours, that is, always having to do things in a particular way and getting very upset if the routine is changed



Bulimia Nervosa

People with bulimia nervosa can appear perfectly healthy. Usually they maintain a normal body weight, but underneath they are very worried about what people think of them and are preoccupied with dieting and losing weight. Bulimia nervosa is a way of dealing with difficult feelings. When a person with bulimia nervosa feels sad, angry, unloved or depressed, they binge on large quantities of food. During a binge, they may feel panicky and unable to stop eating. Afterwards, they feel very guilty and ashamed and try to compensate by making themselves sick, taking large amounts of laxatives, or starving for a few days.

Bingeing is usually a way of fulfilling physical and psychological needs. Many people with bulimia nervosa feel trapped in a cycle of bingeing and purging, and desperately want to break this pattern and eat normally. They feel that if they could stop bingeing their problems would be over, but inside they often feel so unhappy and ashamed that they cannot go for help.

Although many people with bulimia maintain a normal body weight, the effects of bingeing and purging can cause damage to their bodies. Vomiting and taking laxatives on a regular basis can cause serious health problems. It can lead to chronic tiredness, dizziness, tooth decay, hair loss, epileptic fits, irregular heartbeat, kidney failure and bowel problems. Like anorexia nervosa, bulimia nervosa can also be fatal.

While it is true that eating disorders are serious and potentially life-threatening problems, there is no doubt that the sooner an eating disorder is recognised,



the easier it is to intervene and the chances of recovery are greatly improved. People with eating disorders often want to get help, but are afraid how others will react and what treatment will involve.

Other types of eating problems

Strictly speaking, 'eating disorders' only describe those types of eating problems associated with worries about weight and shape, although we know that there are other types of eating difficulty in which young people very tightly control their eating behaviour. This can cause just as much distress, conflict and physical ill health. There are no 'diagnoses' or agreed classification for eating problems that do not fit into those described above, which can make it very frustrating trying to find out about them. Often they are just called 'atypical eating disorders'.

Most of the information in this booklet is about anorexia nervosa and bulimia nervosa, but if your child has one of the other types of eating problem listed below we may be able to give you some information or help you find out more. Some of the books mentioned at the end also have information about these problems.



The most common ones we see are:

Selective eating

Selective eating (also called picky or fussy eating, or perseverative feeding disorder) is characterised by eating a very narrow range of foods usually for a number of years, together with a reluctance or refusal to try new foods. Developmental or anxiety factors can contribute. For example, selective eating is common in young people with autistic spectrum disorders, but most of the young people with selective eating we see do not have difficulties of this kind.

Typically a child or adolescent with selective eating will be within the normal range for both weight and height, and show no abnormality on physical examination. Sometimes selective eating can begin after a period of normal eating, but for many there may be a history of early feeding difficulties or problem with weaning. Eating a highly restricted range of foods is a common feature of toddlers – up to 20 per cent of children below the age of five years are faddy and the problem persists to the age of eight years in about a third of these. However for some young people the problem persists into middle childhood, adolescence and even adulthood. So whilst most children will grow out of it, a small number do need help to change their eating behaviour

Food phobias

Phobias are fears that lead the sufferer to avoid rigorously and relentlessly the thing they fear, as opposed to feeling afraid but still going through with it. Phobias involving food are common,



especially in school-aged children, and can occur in isolation or as part of a more general anxiety problem. The overlap with other eating problems is evident, since food avoidance is also a feature of anorexia nervosa. The difference is the nature of the fear behind the food avoidance, which is important because unlike young people with anorexia nervosa, children with food phobias are more likely to want to get better, scary though it may be.

The sorts of phobias that occur vary, but can include things like a fear of vomiting when they eat, or a fear that food is bad or contaminated in some way. This can mean that only certain family members can be entrusted to prepare foods. Another common fear is a worry about choking or not being able to swallow. This is sometimes called 'functional dysphagia', which means difficulty swallowing for psychological reasons. Depending on the severity of the phobia, the young person may lose weight, in which case most of the medical considerations are the same as for anorexia nervosa.



Food Avoidance Emotional Disorder

Some young people do not know exactly why they cannot eat, and we try to keep in mind that it may be for a medical reason as well as a psychological one, such as depression or anxiety. We sometimes use the term 'food avoidance emotional disorder' or FAED where both emotional problems and food avoidance are prominent features. Unlike people with anorexia



nervosa, young people with FAED know that they are underweight, would like to be heavier, and may not know why they find this difficult to achieve. They can be just as underweight as young people with anorexia nervosa.

Emotional overeating

Worry about young people being overweight is in the news and the media at the moment, and most of these children do not need to see a mental health professional. However, a small number of children develop real concerns about weight gain, to the extent that it affects their eating behaviour and they develop periods of starving and then eating a lot, or start to show the same degree of worry about their weight or shape that we see in young people with eating disorders. Although many overweight children suffer from low self-esteem this is by no means always the case. In particular, before puberty children tend, in our experience, to have a reasonably positive self-concept. It is important to understand the psychological mechanisms underlying eating behaviour, and to recognise where eating is clearly linked to emotional arousal or upset rather than in response to environmental cues such as food availability. Our treatment programme for overweight children aims to support children change their eating habits, but a small number of young people may need extra help, particularly if they are at risk of developing an eating disorder.



Family life

Caring for a child with an eating disorder can be very difficult. Often, it is a family member or friend who first notices that there is a problem. The young person may deny that there is a problem, and reject offers of help. These reactions are signs of underlying fear, and are not meant as a show of stubbornness or rebellion. Head-to-head conflict can make the situation worse, and communication within families can become very difficult. The longer the problem remains unrecognised, the more serious it becomes and the harder it is to treat. Sometimes parents have to take the initiative in seeking help in order to safeguard the health of their child.

Parents often feel guilty and blame themselves for the eating disorder, or have developed a sense of failure while attempting to overcome their child's difficulties. This is a natural reaction but it can become paralysing and is not a good starting point to begin to tackle the problem. Try to concentrate on what you can do now and in the future, rather than what you think you should have done differently in the past.

Eating disorders can cause relationships within families to become difficult, as parents and sufferers can become paralysed by fear. It feels as if the eating disorder has taken over everyone's life, not just the sufferer's. As parents, make sure that you present a united front to your child as this will help to avoid arguments and communication problems. Other children within the family can become very upset and worried, and they too need to know what is happening.

As well as supporting the young person

to overcome the eating problem, it is important that family and friends spend some time focussing on their own needs, and build resources to cope. It is important that family life continues despite the eating disorder, and that parents and siblings are not neglected. It is important that you continue to have your own life, and you do not neglect yourself. Do not let the illness rule your life too.

The Eating Disorders Team at GOSH

Although anorexia nervosa and bulimia nervosa can cause serious and life-threatening problems, the sooner the young person gets help the greater the chance of recovery. It is very difficult for young people with anorexia or bulimia to get better on their own. There is a better chance of recovery if they have professional help and support from people who care for them. We try to ensure that children and adolescents are assessed and receive treatment at the earliest opportunity, particularly for those with (or at risk of) severe weight loss; such patients are prioritised for treatment.

The eating disorders team at Great Ormond Street Hospital (GOSH) includes medical and nursing staff, family therapists, psychotherapists, psychologists and a dietitian. The team specialises in the treatment of early-onset anorexia nervosa, meaning before or early in puberty. As well as seeing young people and families for assessment and treatment, we also consult to other professionals and offer second opinions. As a major teaching and training hospital,





the team also includes clinicians training in the treatment of eating disorders, such as psychiatrists, psychologists, nurses and therapists. During their time with the team, trainees are regular members of staff and will be involved in patient care. We live in a multi-cultural community. This is reflected in the ethnic mix of the children and parents seen in our Hospital and in the composition of our workforce. The health services we provide at GOSH aim, wherever possible, to improve upon one or more aspects of an individual's life whilst minimising any disruption to their normal living pattern. Understanding and accepting an individual's ethnic and cultural beliefs are therefore essential components of the way we work.

Referral process

The team accepts referrals of young people with complex eating disturbance or an eating disorder. This can include those presenting with restricted as well as irregular, chaotic or excessive dietary intake, where there is associated psychological distress. The team sees

children and young adolescents between the ages of 7 and 16 years with a wide range of eating problems. We see a large number of children suffering from anorexia nervosa, but also treat bulimia nervosa, selective eating, specific phobias leading to eating disturbance, food avoidance emotional disorder and compulsive eating.

Referrals can be accepted from GPs, paediatricians, psychiatrists, psychologists or other child health care workers. In the case of GP referrals, the local CAMHS and/or paediatric service must be aware of, and in agreement with the referral and correspondence is required to this effect. In the case of secondary referrals (psychiatrists, paediatrician, dietician and so on) we request that the GP is made aware and agreement is sought regarding the referral. We will often seek this agreement once we have received a referral.

On receipt of a routine referral, the information is discussed at a weekly meeting. At present children and their families are seen within four to six weeks of receipt of referral. Assessment will be planned following discussion with the referrer, and on receipt of CAMHS agreement.



Contacting the team

Referrals should be addressed to Consultant Child and Adolescent Psychiatrist, Feeding and Eating Disorders Service.

Feeding and Eating Disorders Service

Child and Adolescent Mental Health Services (CAMHS)

Great Ormond Street Hospital for Children NHS Trust

Great Ormond Street

London WC1N 3JH

Tel: 020 7829 8679 Fax: 020 7829 8657

Team administrator: 020 7405 9200 Ext 5858

Website: www.ich.ucl.ac.uk/clinservi/dcamhs/fed_eds_parents.htm



Further information

If you are unable to get a copy of any of these books from your bookshop, you should be able to order them through your local library to borrow for a few weeks.

- Rachel Bryant-Waugh and Bryan Lask (2004) *Eating disorders: a parents' guide* (published by Brunner Routledge)
- Janet Treasure (1987) *Breaking free from anorexia nervosa: a survival guide for families, friends and sufferers* (published by Psychology Press)
- Ulrike Schmidt and Janet Treasure (1993) *Getting better bit(e) by bit(e): survival kit for sufferers of bulimia nervosa and binge eating disorders* (published by Lawrence Erlbaum)
- A.H. Crisp et al (1996) *Anorexia nervosa: the wish to change* (published by Psychology Press)
- Christopher G. Fairburn (1995) *Overcoming binge eating* (published by Guilford Press)
- Peter J. Cooper (1993) *Bulimia nervosa: a guide to recovery* (published by Robinson Publishing)
- Bryan Lask and Rachel Bryant-Waugh (2000) *Anorexia nervosa and related eating disorders in childhood and adolescence 2nd edition.* (published by Psychology Press)
- James E. Lock (2002) *Treatment manual for anorexia nervosa: a family-based approach* (published by Guilford Press)
- Lori Ernsperger and Tania Stegen-Hanson (2004) *Just take a bite* (published by Future Horizons)



The following two publications are available from:

Royal College of Psychiatrists Research Unit

4th Floor Standon House

21 Mansell Street, London E1 8AA

Tel: 020 7977 6655

Web: www.focusproject.org.uk/publications

- Claudine Fox and Carol Joughin (2002) *Eating problems in children: Information for parents*
- Claudine Fox and Carol Joughin (2002) *Childhood-onset eating problems: findings from research*

Support and further information

The Eating Disorders Association

103 Prince of Wales Road

Norwich NR1 1DW

Adult helpline: 0845 634 1414 (open Monday to Friday 8.30am to 8.30pm)

Adult email: helpmail@edauk.com

Youthline: 0845 634 7650 (open Monday to Friday 4pm to 6.30pm)

Youth email: talkback@edauk.com

Website: www.edauk.com

Young Minds

48-50 St John Street

London EC1M 4DG

Parents Information Service: 0800 018

2138 (open Monday and Friday 10am to 1pm; Tuesday and Thursday 1pm to 4pm ; Wednesday 1pm to 4pm and 6pm to 8pm)

Email: enquiries@youngminds.org.uk

Website: www.youngminds.org.uk/eatingproblems/



Notes



Compiled by the Feeding and Eating Disorders Service, Child and Adolescent Mental Health Service
in collaboration with the Child and Family Information Group.

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www.goshfamilies.nhs.uk www.childrenfirst.nhs.uk