



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

Eating disorders treatment

This leaflet gives information about the Eating Disorders Service at Great Ormond Street Hospital. It also gives details about the treatment offered to children and young people with eating disorders. For more information about eating disorders themselves, please see our accompanying leaflet.

The Eating Disorders Team at GOSH

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 with other professionals and offer second opinions.

Our Philosophy

We believe that recovering from an eating disorder involves enabling a young person to be able to eat enough to grow and develop normally by finding a way of addressing her or his emotional needs through a medium other than food and eating. Successful intervention therefore involves working towards some understanding, not just recognition, of the problem. In order to understand the eating problem we need to consider both developmental and environmental/ contextual factors.

In our view, effective long-term change is best achieved through enhancing and supporting the problem-solving and communication skills of the young person and his or her parents. The team works with a client-centred approach. We aim to work alongside the motivated part of the

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young person to find ways of resolving issues that present obstacles to their development, both as an individual and as a member of their network including family and school. Our therapeutic methods include listening to young people and their families in individual and family meetings and in small groups, hearing and bearing their distress, and finding ways of giving expression to their developmental needs.

The family is supported and helped to function as the primary agent to meet their child's emotional needs and make changes. The style of work reflects both a hope and a confidence that the alliance between the family and the team will restore the possibility of further growth for the family and the individuals within it.

Assessment

When a young person is referred to the eating disorders team at GOSH, an initial assessment is carried out by the outpatient eating disorders team. The head of the team meets all new patients and families. Other members of the multi-disciplinary team also see the young person along with their family, over two separate half days. The aim of the assessment is to get to know the young person and to determine the severity of the eating disorder so that we can offer the right kind of treatment to the individual and the family. This involves several meetings that include a combination of individual and family sessions.

Our first concern at the assessment stage is about the young person's physical health. We therefore measure weight and height at the beginning of each visit to

the clinic. A weight chart is kept for each individual that helps us to monitor any changes. Together with the young person, we work out a healthy target weight based on their age and height. Because of the potential medical problems that can occur with an eating disorder, we may also advise that the young person has some blood tests so that we can treat any physical problems that may occur.

A detailed history of the eating problem is obtained, and information is gathered on the current eating patterns, weight history, personal and developmental history, significant illnesses or events, impact on family, family tree, mental state assessment, and an eating disorders examination (EDE) is carried out. The family's expectations of treatment are clarified, together with some information about motivation and readiness to change. The young person is also routinely seen for a medical examination to establish their physical status, growth and development and weight / height. Further investigations, such as blood tests, bone scan x-ray or pelvic ultrasound may be indicated.

The aim of this process is to provide a comprehensive assessment and diagnosis, and establish the severity of the problem in order to ensure that an appropriate decision is reached regarding the immediate and long-term needs of the young person and their family. It also enables the team to assess the impact of the eating difficulty on the young person's development and general functioning. At the end of the assessment, a management plan is discussed, agreed with the young person and their family, and confirmed in writing.





Inpatient treatment

Most young people with eating disorders complete the assessment stage, and move on to outpatient treatment. However, in some cases the young person may be too ill to be treated in outpatients or things may have gone too far for the family to cope at home, and hospital treatment might be needed. Indicators for consideration of inpatient treatment include:

- Rapid weight loss or very low nutritional intake
- Findings from mental state examination that suggest risk
- Physical complications
- Impact on family too great
- Unsuccessful outpatient treatment

The National Institute for Clinical Excellence (NICE) has produced guidelines for the treatment of eating disorders (available at www.nice.org.uk/pdf/cg009niceguidance.pdf). These guidelines advise that people with anorexia nervosa requiring inpatient treatment should be admitted to a setting that can provide the skilled implementation of refeeding with careful physical monitoring (particularly in the first few days of refeeding) in combination with psychosocial interventions.

If inpatient treatment is necessary, young people between the ages of seven and fourteen years may be referred to our inpatient unit at Great Ormond Street Hospital, called the Mildred Creak Unit. Members of the eating disorders team and the inpatient team work together in planning the care of each young person. If the young person is aged 14 years or older we will discuss alternative inpatient centres with you and your local team.



Whenever possible the decision to admit to hospital is planned, with the young person and family having the opportunity to find out more about admission and the treatment programme. Working collaboratively with parents during the programme is essential for a successful admission.

The treatment programme includes individual and family therapy, and additionally involves ward-based therapies that include nurse key-worker sessions to talk over treatment or other issues affecting the young person, medical and psychological monitoring, creative groups; and the young person attends the ward school.

Inpatient treatment usually lasts for four to six months. The length of outpatient psychological treatment and physical monitoring after a period of inpatient treatment should typically be at least 12 months.

Outpatient treatment

Where possible, outpatient treatment is offered which usually involves a combination of weekly family meetings and individual sessions for the young person. The NICE guidelines emphasise that "most people with anorexia nervosa should be managed on an outpatient basis with psychological treatment provided by a service that is competent in giving that treatment and assessing the physical risk of people with eating disorders". Outpatient psychological treatment for anorexia nervosa would normally be for at least six months duration.



Aims of Treatment:

Treatment addresses both the physical and psychological aspects of eating disorders, and takes into account the fact that most young people are largely dependent on their parents for physical and emotional support. Our approach to treatment has three main goals:

- To correct any medical problems which may occur as a result of the eating disorder
- To help the young person to reach a healthy weight and to develop healthy eating behaviours
- To help the young person to talk about their feelings and learn healthier ways of coping with problems

To achieve these aims, treatment needs to focus on:

- Risk management
- Enhancing motivation to recover
- Enabling parents to regain their effective parenting role
- Changing eating behaviour and restoring a healthy weight, including resuming and adapting to normal growth and development
- Developing coping/problem-solving skills
- Learning to communicate about and manage difficult feelings, within the family and with others
- Helping to develop a young person's understanding and perception of themselves
- Developing effective future relationship skills



Agreeing what treatment will involve

Our treatment programme involves a combination of therapies and medical management. We decide which combination would be most suitable in discussion with the young person and their family. Each component of treatment is intended to address one or more of the areas that are affected by the eating disorder. No part of the treatment is seen as sufficient in itself, and all parts relate to one another. The treating team therefore regularly communicate with each other about the issues facing a young person and their family.

In the early stages of treatment we try to see families once a week. We make every effort to arrange appointment times that suit family life as much as we can, but some aspects of treatment, such as the groups, only happen on one day of the week. A typical treatment programme would include a combination of the following:

Family Therapy

The aim of family therapy is to support the family in using their own ideas and strengths to help the young person to recover. We take the view that families are an essential part of treatment and of the recovery process as it is in family therapy sessions that important discussions and negotiations take place on day-to-day issues of managing the eating problem. Family therapy directly addresses the eating problem, its impact on the family and the effect of the parents' attempts to help. All family members living at home, including siblings would



normally be included in the treatment of children and adolescents with eating disorders, although in the early stages it can be helpful for some parents to meet without their children present. If one parent no longer lives at home with the young person, we would think about how that parent might be included in the meetings.

The aims of family therapy are:

- to support the family as much as possible during treatment, including during inpatient admission if it is necessary
- to help parents develop the best ways to support their child to eat
- to facilitate communication between the young person and his or her family about both eating and non-eating issues and to work with the young person and family to develop verbal communication
- to discuss aspects of effective parenting, including the management of risks such as self harm, or food refusal
- to consider the impact of the eating problem on all family members, and to facilitate families in seeking help and support from one another
- to help families develop coping/ problem-solving skills.

Sessions will normally be weekly at first for one hour, often reducing to fortnightly in agreement with the family as progress is made.



Individual Therapy

This offers the young person a private space to explore their feelings and get to know themselves better. We use a range of styles, and aim to tailor the approach to the specific needs of the young person and therapist working together. In the context of developing a trusting relationship, the young person can be helped to enhance their motivation and make changes to their behaviour that are beneficial to their health.

Individual therapy can help a young person to explore their own feelings about their eating problem, and consider the pros and cons of changing the way they have been dealing with things. This might mean thinking more broadly about what they want out of life, developing a greater understanding of themselves, and thinking about the sorts of relationships with other people, friends, families or professionals, that they both want and find helpful. Ultimately, more effective and satisfying ways of communication with family and others can be achieved.

We try to work with young people to find what works for them, rather than direct or try to change them. They may use the space for exploring negative feelings, such as anger or despair, self-hatred or shame, or for exploring fears such as growing up, unwelcome responsibilities or traumatic or negative experiences.

Styles of individual therapy that can be used for psychological treatment of eating disorders include cognitive behaviour therapy (CBT), psychodynamic therapy, motivational enhancement therapy (MET), and art or play therapy.



Parents' Group

This group gives an opportunity for parents to meet together to share their experiences of caring for a child with an eating disorder. The group can be helpful in reducing parents' sense of isolation and self-blame, and parents offer support to each other in caring for a young person at home. The parents' group also offers opportunities to address a variety of issues such as:

- managing challenging eating behaviour, in particular how to cope at home and not collude with the problem
- development of coping/problem-solving skills and regaining the sense of being effective parents in the face of an eating problem
- managing issues of control and responsibility
- effective communication, including when and when not to avoid conflict
- effective communication about and containment of feelings, such as bearing a child's sadness
- the importance of parents remembering to look after themselves

As parents have commented in the group "as an illness it makes you feel as if your parenting is not good enough, but also that your common sense is not common sense. It challenges you to understand something completely different and your normal responses are no longer valid." The group can be helpful in putting a new perspective on things it is not always easy to see, and is a place for sharing the highs as well as the lows on the road to recovery.



Young people's Group

This group provides a safe place to share problems arising from having an eating disorder, and to think together about ways to cope with them. The group also allows exploration together of the impact anorexia nervosa or other eating disorders have on one's life; for example, missing school and the impact on friendships, amongst others. This develops from setting up a place young people can practice expressing themselves in different ways, using colour, clay and other art materials.

As the young people become more familiar and comfortable with each other, the group can provide an opportunity to talk openly about any relevant issues. Issues around communication between young people and their family may also be explored. We aim to help enable the young people to think about appropriate ways to access help, as well as providing a space to think about aspects of growing up.

Medical monitoring

Due to the potential seriousness of the medical complications of eating disorders, it is important to monitor the young person's physical state closely. Growth and development is therefore monitored regularly, as well as the effects of any medication. This may involve some of the following tests being carried out, in addition to regular measuring of weight and height:

- *Peripheral circulation* – this is checked by feeling the hands and feet, and by measuring the pulse and blood pressure
- *Blood tests and ECG* – if the team are concerned about the young person's



physical health, blood tests or heart traces may be carried out - either here at GOSH or through your GP or local hospital.

- *Bone age assessment* – a wrist x-ray indicates bone maturity and the extent of delayed growth. Results can be used as guidance for potential growth.
- *Ultrasound* – ultrasound scans of the pelvis provide information on the reproductive organs, which shrink and change shape as a result of starvation. Ultrasound is quick, easy and painless. It just needs a full bladder, as this moves the bowel from the pelvis, giving a clearer view of the uterus and ovaries. The information from an ultrasound scan can be used to help determine a healthy target weight.
- *Bone density assessment* – this is usually carried out once a year and is a way of measuring to see whether osteoporosis has resulted from malnutrition and lack of hormones. It is very quick and uses less radiation than an x-ray.

Review meetings

A review of treatment is held about once every three months, usually with the consultant psychiatrist together with the family, young person and other team members involved in treatment. This is an opportunity to review progress and to consider whether any changes to the treatment need to be made, such as the frequency of appointments, whether to attend groups or not, further physical assessments and so on.

For families who would prefer to receive treatment with their local CAMHS team or who are unable to travel to GOSH for treatment on a weekly basis, we offer the

same reviews of progress as for someone being treated by our team. This sort of 'shared care' would need to be agreed between you, your treating team and us.

Flexibility in Treatment

The need for consistency in treatment is very important when considering how best to help young people with anorexia nervosa. Having an agreed plan avoids confusion and mismanagement and gives a clear idea about the process and expectations of treatment, which helps the young person to feel safer.

Within this, however, we recognise that all young people and families are different and it is important to plan individualised care. For this reason we do not write down the instructions to follow, or give a road map to recovery. An example of this is when a young person has a physical condition that affects his or her ability to eat or tolerate certain foods. At times of pain or discomfort due to physical illness, the young person may need alterations made to his or her diet and exercise regime for a period of time and consideration given to determining at what point, if any, the original plan is put back into place.

Although individualised care and creativity in treatment is necessary, this can have an effect on others such as siblings or other people receiving the same treatment, for example, why one rule applies to one person and another to someone else. Whilst explanations can help, it is best to avoid any attempts at reasoning or negotiating. If someone does appear to be finding this particularly difficult to cope with, it may need to be discussed directly in family meetings.





Measuring weight and height for young people with anorexia nervosa

Losing weight can be dangerous. We are committed to keeping young people physically safe whilst we try to see if we can help with their eating problem. In order to ensure that the young person is medically safe we need to monitor weight regularly. This will alert us to whether any further investigation of medical risk is needed.

Each young person has his or her weight and height measured at the beginning of treatment. Weighing takes place at each clinic appointment thereafter, unless previously agreed between the young person, their parents and the team. If possible, we try to record weights at the same time of day and with an empty bladder to rule out inaccuracies. If these circumstances are different, this will be documented on the height and weight chart as weight can alter throughout the day. Height will be re-measured every two months.

Weighing takes place in light indoor clothing without shoes, and on the same scales every time. These scales are calibrated regularly. Weights are recorded on a height and weight chart. If a young person chooses not to know their weight, we will discuss the benefits and drawbacks of this with them. We need to know the young person's weight, in order to assess their safety. As parents are responsible for safety on a day-to-day basis, they also need to know the young person's weight. As treatment progresses, weighing may take place less frequently if it is agreed between the young person,



their parents and the team that weight is no longer an area of concern.

If the young person refuses to be weighed when they are attending for assessment, we will not be able to recommend outpatient treatment. If a young person attending for treatment refuses weighing, a doctor or nurse in the team will medically assess them. If we are concerned about the young person's physical health, or if we are unable to assess the medical risk, we will transfer responsibility for care of the young person to their GP or local hospital. The team is unable to continue treatment until the young person is medically stable and agrees to regular monitoring of their physical health.

The expected rate of weight gain is 0.5kgs for outpatients and between 0.5kg and 1kg per week for inpatients. If this is not achieved for two or more consecutive weeks, this will be reviewed. The reasons for this could be one of many: excessive exercise, insufficient calorific intake, purging or physical illness. Similarly, if excessive weight gain occurs for two or more consecutive weeks this will also be investigated. It is not unusual for rapid weight gain of between 1kg and 3kg to occur within the first week of treatment, followed by a degree of weight loss afterwards. This is largely due to the rehydration process at the onset of refeeding.

Setting exact 'target' weights for young people is not necessary, as these weights will be highly variable. In terms of adolescence, what may be a 'healthy' body mass index (BMI) or weight for one individual may not be so for another. The recommended way of measuring a healthy weight range is to



calculate weight for height (or %BMI). This measurement calculates the body weight of an individual in proportion to their height. A healthy weight range is between 95 and 105 per cent. As height can change over time, it may be necessary for a young person to increase their weight in proportion to this. The optimal weight range for each young person is best measured through the use of pelvic ultrasound, which tells us when the hormones that stop being produced during malnutrition start working again.

Involving school

We do not routinely copy information to schools, as this would breach your right to medical confidentiality. Instead we will work with you to think about how to involve a young person's school, as this is a crucial part of managing as an outpatient. This may involve giving them information, or even inviting key school personnel to meetings. In our experience, schools are usually very supportive and in some cases really make the difference to whether a young person can manage out of hospital.

Your GP and local team

Because eating disorders can change how a person behaves and feels on a day to day basis, we think it is helpful to know where the safety net lies if things should get worse. Knowing a safety net is there can make a difference to how confident you feel and therefore make you less likely to need to use it.

Your GP is a key person, who coordinates all the treatment you receive in this hospital and elsewhere. He or she

therefore needs to be up to date at all times about your treatment. If you are an outpatient, your GP is also the first port of call for any medical concerns. During working hours you may want to speak to one of us first before contacting your GP, but we are not always able to be here when you might need us, such as in the evenings or at weekends.

If it is a real emergency, you might be advised to attend an accident and emergency department, where the situation will be assessed. You could then be referred to a paediatrician or a child and adolescent psychiatrist. For this reason, we also let your local child and adolescent mental health (CAMHS) team know that you are receiving treatment here, as well as any other health professionals who have been involved in your care. This way, if something happens out of hours, they know who is responsible for what.

Getting involved with research

Our team is always looking for ways of offering the best possible treatment for young people with eating disorders. We are continually updating the way that we work to be sure that we are offering the best care. To help us achieve this, research forms an important part of our work at Great Ormond Street Hospital. Together with our close neighbour, the Institute of Child Health, it is a leading centre for cutting edge research. It is possible therefore that you may be approached regarding one or more studies being carried out by members of the Eating Disorders Team. We hope that you will be





able to help us to help others with eating disorders by allowing us to follow your child's treatment and recovery in detail.

Involvement in studies is entirely voluntary, and you do not have to be involved if you choose not to. The researcher will give you written information about the study for parents and for young people. You will always have time to read the information carefully before you decide whether or not you wish to take part, and to contact the research team if you have any questions or queries.

If you decide to take part, you are still free to withdraw at any time. Your decision will not affect the treatment your child receives in any way. Any information about you and your child, which is collected during the course of the research, will be kept strictly confidential. Only members of the research team and the staff involved in your child's treatment or assessment will have access to research information. Any information about you that leaves the clinic will have your child's name and address removed so that he or she cannot be recognised.

We are continually involved in research studies, if you would like any information on recent or current studies please ask a member of the team.



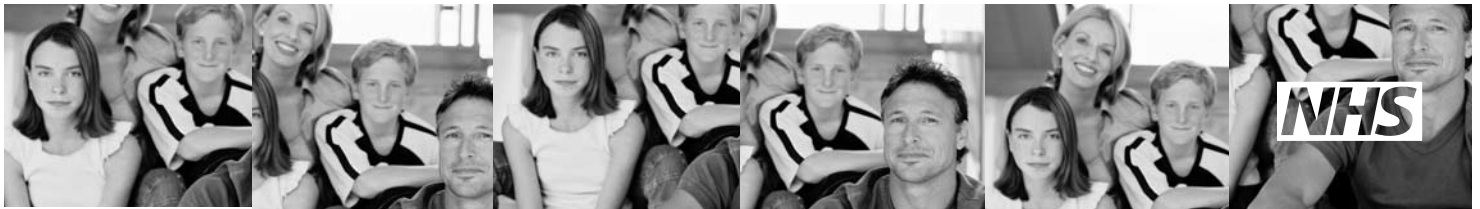
Making a complaint

At Great Ormond Street Hospital, we try to achieve a high standard in our clinical care as well as in all the services we provide for children and families. We have a complaints system that you can use when you experience a problem with any of our services.

There are various ways you can get help, support and advice about any problems that occur:

- Talk to the doctor or nurse caring for your child
- Talk to the person in charge of the ward or department
- Visit the Pals (Patient Advice and Liaison Service) office, opposite the hospital shop. You can also ring them on 020 7829 7862 or email them on pals@gosh.nhs.uk

You can ask at the department reception for a leaflet about making a complaint or if you need further help or information, please contact the office manager or the service manager for Child and Adolescent Mental Health Services (CAMHS). Their telephone numbers are in the next section.



Contacting the team

Feeding and Eating Disorders Service
Child and Adolescent Mental Health
Services (CAMHS)

Great Ormond Street Hospital for
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Great Ormond Street
London WC1N 3JH

Tel: 020 7829 8679

Fax: 020 7829 8657

GOSH switchboard: 020 7405 9200

Team administrator: Ext 5858

CAMHS officer manager: Ext 5618

CAMHS service manager: Ext 0554

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

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