







# **EATING DISORDERS**PATHWAY TO CARE

A GUIDE FOR PEOPLE USING SERVICES AND THEIR FAMILY MEMBERS

**Promoting Hope, Opportunity and Personal Control** 



eating disorder association NI





## Introduction



This booklet is specifically for people experiencing an eating disorder and their family and friends. It identifies some of the signs that would indicate that you or someone you love may have an eating disorder. It gives information about how to get help. It also explains what you can expect to happen if you are referred for treatment of an eating disorder.

The booklet has been developed by the Eating Disorder Association

of Northern Ireland (EDANI) and the Eating Disorder forum with support from people who have experienced an eating disorder, family members and the Regional Eating Disorder Network Group.

This booklet is mainly concerned with:

- Anorexia Nervosa
- Bulimia Nervosa
- Atypical Eating Disorder

There are other problems with eating such as binge eating, and in children, food phobias, and selective eating which also have psychological causes. People will receive help with these problems if they are referred to mental health services, but it is likely to be from mainstream adult or child and adolescent mental health practitioners rather than a specialist eating disorder service.



## What are Eating Disorders?

An eating disorder is a serious mental health condition that results in an unhealthy relationship with food and weight. Eating disorders interfere with many areas of a person's life, and can have serious physical health consequences. While at the start it might look like a person is just dieting or exercising, people with an eating disorder begin to use food as a coping mechanism to deal with uncomfortable or painful emotions or to help them feel more in control when situations seem overwhelming.

The typical image that comes to mind when people think of Anorexia Nervosa is a severely emaciated young man or women. It is true that eating disorders tend to start between the ages of 13 and 25 years, however it is not unknown for it to start in children under 13 years, or to start in people over 25.

With Bulimia Nervosa the outward signs may be hard to spot because the person's weight and body shape may not change.

However the behaviours associated with both Bulimia Nervosa and Anorexia Nervosa can have serious consequences for people's long term mental and physical health. Getting help early means that the condition is easier to treat and some of the long term health problems can be avoided.

#### **Signs and Symptoms of Eating Disorders**

There are physical and psychological indicators of eating disorders. Depending on the type of disorder these include:

- Preoccupation with food, weight and body
- · Unrelenting fear of gaining weight
- Refusal to eat except for tiny portions
- Vomiting frequently after meals
- Dehydration
- Compulsive exercise
- Excessive fine hair on face and body
- Distorted body image
- Abnormal weight loss
- Fluctuating weight loss and gain
- Sensitivity to cold
- Absent menstruation
- Eating alone or in secret
- · Misuse of laxatives, diuretics, diet pills or emetics
- Social withdrawal

Physical symptoms include significant weight loss, general lethargy and feeling unwell, weakness and abdominal discomfort. In the longer term people may develop serious problems with their heart, bones and some body organs. Anyone who is pregnant or who has diabetes along with an eating disorder can develop even more complex health problems.

Psychologically people with an eating disorder often also experience depression, anxiety, obsessive compulsive disorders or thoughts about suicide.

If you or someone you love is referred for treatment of an eating disorder you can expect that the care and treatment you are offered will take into account all of your needs and be tailored very specifically for your individual circumstances.



# **Early Detection**

Early detection and accepting help will significantly improve the chances of recovery from an eating disorder. To assess if you or someone you know is at risk of having an eating disorder ask the following questions:

- S Do you make yourself **Sick** because you feel uncomfortably full?
- C Do you worry you have lost **Control** over how much you eat?
- Have you recently lost more than **One** stone in a three-month period?
- **F** Do you believe yourself to be **Fat** when others say you are too thin?
- F Would you say Food dominates your life?

A "yes" answer to two or more of these questions would indicate that an eating disorder may be present. It is however important to remember that eating disorders manifest differently between individuals and even if someone does not answer yes to the SCOFF questions this does not mean they do not have an eating disorder.

### Other questions to ask are:

- Do you ever eat in secret?
- Do you think you have an eating problem?
- Do you worry excessively about your weight/ body image?
- Do you ever make yourself vomit, over exercise, use laxatives and/or diuretics inappropriately?
- Are you obsessive about weighing yourself?

If you think you have a problem with eating you should seek help from your GP. At this point you might also want to talk to a local eating disorder support group, helpline or charity. Contact details for eating disorder support groups are listed at the back of this booklet.

It is important to be as open and honest as possible with your GP so that they can decide the best action to take for you. They can't read minds and need you to tell them that you think you may have an eating disorder.



# **Getting Referred**

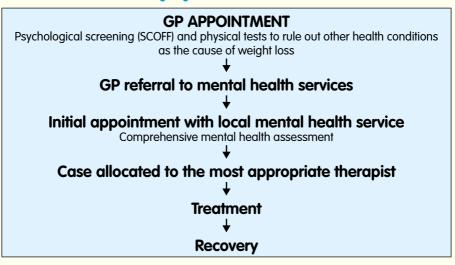
If you think you, or someone you know, has an eating disorder the first step is to visit your GP. Your GP will carry out a thorough assessment to rule out any other medical cause for your symptoms, and assess any medical risks. At this point the GP is likely to:

- Ask about your attitudes to eating and behaviours
- Measure your body mass index (BMI)
- Carry out blood tests
- Carry out an ECG

Once your GP has made an assessment and ruled out a medical cause for your symptoms they will make a referral to either adult mental health services or child and adolescent mental health services depending on your age. If a doctor or therapist treating you for another condition thinks that an eating disorder may be the cause of your health problems they too can make a referral to an eating disorder specialist.

Based on the information from the clinician making the referral mental health services will consider the nature and urgency of your case and offer an appointment for a comprehensive mental health assessment.

## What Happens Next?



## **Routine Appointment**

Most cases will be routine and you will be offered an appointment within 9 weeks of your GP making the referral.

## **Urgent Appointments**

If it is agreed that you need to be seen urgently you will be offered an appointment within 5 working days. A referral may be identified as urgent if:

- Your BMI is below 15
- You have experienced rapid weight loss
- You are experiencing significant electrolyte imbalance
- You have developed cardiac problems
- You also have diabetes
- You are pregnant

## **Emergency Appointments**

Mainstream mental health services will see anyone referred as a mental health emergency within 24 hours and can refer on to a specialist eating disorder service if this is appropriate.



# First Appointment - What Happens?

Mental health services will contact you directly to agree the time and date of your first appointment. They will try to be flexible to get a time and date that suits you. Your first appointment is likely to be with mainstream mental health practitioner. However in some circumstances your GP can refer you directly to the eating disorder service in your local Trust.

If you are under 18 years your parent or guardian will also be asked to attend. If you are over 18 years you will be invited to bring a family member or close friend with you to the appointment.

# What to expect during your Initial Assessment

The person carrying out the mental health needs assessment will have a structured conversation with you to help identify your needs and explore the options to address these with you. If you are under 18 years your parent or legal guardian will be involved in this discussion. If you are over 18 years you will be asked if you want a relative or close friend to be involved in the discussion.

The assessor will apply their professional expertise and draw on research and clinical evidence of what works for people with an eating disorder, and draw on the expertise of a range of professionals within the multi-disciplinary team, to consider the treatment options and agree the best way forward with you. The assessor will give you information and will explain any clinical terms being used. You will have opportunity and time to ask any questions that you may have.

Staff may also carry out some physical health checks. This may include taking a blood sample, and you may be referred for an ECG examination of your heart.



# **Planning Your Care**

The information gathered at your initial assessment will determine an initial treatment plan. This will include discussion and agreement about how to keep yourself safe during your treatment. You will be asked to identify family members or close friends who can help and support you throughout your treatment and, if you are an adult, asked about what information can be shared with them.

If you are under 18 years then your parents or legal guardian will be included automatically unless there is a specific reason why this should not happen. Close family members are entitled to have a carers needs assessment in their own right, even if they are not directly involved in your treatment plan.

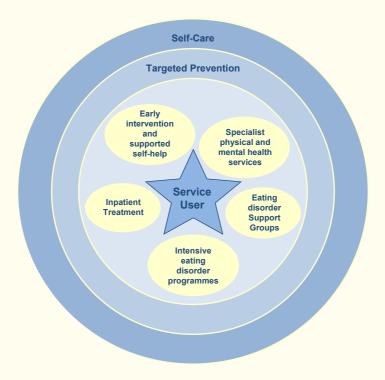
As well as mental health care you can expect to have some physical health checks as part of your treatment. This includes regularly measuring your weight and BMI to monitor if the treatment is working for you. You may also have regular blood tests and ECGs to monitor your heart.

If you are having treatment for another health condition or you are pregnant clinicians from the different services will communicate with each other frequently and share information with each other to ensure your safety and health and to make sure you get the most benefit from any treatment.

## **Treatment Plan**

Your treatment will be very specific to your particular circumstances. Based on the assessment you and your therapist will agree and then work on your treatment plan. This will be regularly reviewed with you and will change over time as your circumstances and health care needs change.

The section below describes the range and types of services that can be beneficial for people with an eating disorder and their family members. This is sometimes called the "stepped care model".





# **Stepped Care Model for Eating Disorders**

Stepped Care means getting the right treatment, at the right time, from a service that has the knowledge and skills that you need.

#### **Self-Care**

There is a range of voluntary and community services that can help you deal with stress or emotional difficulties, or to make lifestyle changes and learn new problem-solving or coping strategies. These are available to everyone. Family members in particular can benefit from this type of service. People with an eating disorder may be signposted to some of these types of services to support their recovery and prevent relapse.

### **Targeted Prevention Programmes**

Education programmes preventing people from developing an eating disorder are delivered by some of the voluntary sector organisations working in the field of eating disorders. These are targeted mainly at groups where eating disorders are more prevalent (13 to 25 age groups) and are delivered through schools, youth clubs, further education colleges, sports groups and the

like. These programmes encourage people to ask for help if they are worried about their eating. They can also give parents, teachers, youth workers and others information and more confidence to speak up if they are worried about someone.

### **Early Intervention and Supported Self-help**

Early intervention as soon as eating disorder thinking and behaviour start is the most effective treatment.

There are specialised guided self-help and psycho-education programmes specially designed for people in the early stage of an eating disorder. These may be delivered as online programmes or through specialist voluntary or community based services. In some areas there are early intervention practitioners attached to eating disorder teams who also deliver these programmes. Some of these programmes may take place in a group setting, while others are delivered in one to one sessions. There are also programmes recommended for family and friends.

### **Physical & Mental Health**

When an eating disorder is diagnosed and /or eating behaviours are starting to have an effect on your mental and physical health you will be offered specialist services as appropriate to your specific needs.



## **Specialist Practitioners**

People in the early stages of an eating disorder and with limited complications may receive treatment from an early intervention practitioner, a member of staff in a mainstream mental health team or psychology service who has undergone additional training in eating disorders.

People with entrenched behaviours and more complex physical and mental health needs are likely to need input from the range of professionals available in a specialist multi-disciplinary team.

Some people will have physical or mental health complications that need to be addressed before they are able to get the best out of an eating disorder specific programme. For example someone who is also misusing drugs or alcohol may need support to achieve abstinence before they are able to engage in a psychological therapy. People with other mental health problems such as severe anxiety or depression may need to see a specialist in these areas first. And for some, treatment of a serious physical health condition may take priority.

If your main treatment is being delivered by another specialist they will have access to advice from an eating disorder specialist and you will be able to transfer into an eating disorder treatment programme when you are ready.

### **Multi Disciplinary Eating Disorder Teams**

Most people with an eating disorder will be seen directly by their local eating disorder service. Your treatment will be tailored to your specific needs and is likely to include psychological therapy physical health checks, re-feeding programmes, psychosocial education, body image work, and practical support (such as shopping, cooking etc) that will help you develop and sustain a more healthy relationship with eating and food.

Family therapy involving parents and siblings along with yourself might be offered, particularly to people under 18 years or if you are still living at home.

### **Hospital Treatment**

Some people may require a period of treatment in hospital. This could be for treatment of a complex medical problem, for a mental health condition, or both. For example some people need to be admitted to hospital because they need 24 hour medical supervision whilst undergoing a re-feeding programme. Most admission will be to your local hospital unless you need a treatment in a regional centre such as the Child and Adolescent mental health unit at Beechcroft or the Regional medium secure mental health unit at Shannon Clinic. A very small minority of people with specific additional needs may need to travel outside of Northern Ireland for a period of hospital treatment.

While you are in hospital clinical responsibility for your care sits with the multi-disciplinary team in the hospital, some of whom have additional training in eating disorders. Staff from the Eating Disorder team in your locality may in-reach to provide the hospital team with expert advice and to make sure there is a smooth transition back to the care of your local community based service when you are discharged from hospital.



# Support for Family Members

It can be really upsetting to suspect that your child has an eating disorder. Parents are often concerned that they may be making too much of things and hope that, if left, it will go away. However, an eating disorder will not go away by itself, so although talking about it may be extremely difficult, it is essential.

You should help encourage a healthy eating attitude and watch out to see if your child continues with disordered eating habits. Do not wait too long before seeking advice if you are worried. It can be useful to discuss this with your child's school as schools often notice the early signs of an eating disorder, or may have heard from school friends who have concerns. Schools can also be useful partners in helping young people manage their eating during treatment (e.g. supervising meals).

If you are an adult with an eating disorder then support from family and friends is equally important. They can help you recognise if your eating behaviours have become worrying and support you through treatment and afterwards to prevent relapse. So staff will encourage you to involve those who love you so that they understand your behaviours and any treatment.

# Recovery & Preventing Relapse



For the best chance of recovery you will need to attend your appointments, be open and honest with your therapist, and be committed to your treatment programme. You need to pay heed to the expert advice from the professionals involved in your care, and accept help and support from your family and friends. Participating in your local peer or carer support group can keep you motivated and help you through any difficult times.

At the end of treatment your therapist will discuss and agree a relapse prevention plan with you and give you information about how to get help from the service if you have a setback.



# **Eating Disorder Support Groups**

#### **Eating Disorders Association NI**

Regional helpline; and carer and peer support groups for residents of Belfast and South Eastern Trust areas.

Helpline: 02890235959

Web: www.eatingdisordersni.co.uk

Email: edani@btconnect.com

#### 959

Web: www.adapteatingdistress.com Email: info@adapteatingdistress.com

#### Stamp-ED

On line information and resources and carer and peer support groups for residents of Northern Trust area.

Web: www.stamp-ED.co.uk

#### Defeat-ED

Support groups for residents of Western Trust grea

**Action for Eating Disorders** 

Southern Trust area.

Helpline: 02838347535

Support groups for residents of

Tel: 02871320165

#### The Laurence Trust

On line information and resources for young men experiencing an eating disorder

Web: www.thelaurencetrust.co.uk

Email: thelaurencetrust@hotmail.co.uk

#### **CARED**

Maudsley training for parents and carers. NB there is a charge for CARED training courses.

Web: www.caredni.org

Email: caringaboutrecovery@gmail.com

# Eating Disorder Treatment Teams

#### Belfast / South Eastern Trust

- Adult Eating Disorder Service: Woodstock MH Resource Centre. Tel: 02895042900
- Eating Disorder Youth Service: Beechcroft. Tel: 02895042696

#### **Northern Trust**

- Adult Eating Disorder Service: The Villa at Holywell Hospital. Tel: 02894413307
- Child & Adolescent Eating Disorder Service: Alder House Tel: 02894424600

#### **Southern Trust**

- Adult Eating Disorder Service Trasna House in Lurgan. Tel: 02838311741
- Child & Adolescent Eating Disorder Service: Ceaderwood Buildings. Tel: 02838360680

#### **Western Trust**

- Adult Eating Disorder Service: Old Bridge House, Derry. Tel: 02871320165
- Child & Adolescent Eating Disorder Service: Woodlea House, Gransha Park. Tel: 02882835990. Rivendell 02882835990



## **Helpful Resources**

Belfast HSC Trust, Mind Matters: A Young Person's Guide to Child and Adolescent Mental Health Services in Northern Ireland, www.belfasttrust.hscni.net/pdf/Mind\_Matters

Boyd, R (2014), Understanding Eating Problems, London: Mind

Bryant-Waugh, R. & Lask, B. (2013), Eating Disorders: A Parent's Guide. London: Routledge.

Centre for Clinical Intervention, Overcoming Disordered Eating, www.cci.health.wa.gov.au/resources

Eating Disorder Association NI (2016) Eating Disorders: A Resource for Parents

Fairburn, C.G. (2013) Overcoming Binge Eating 2<sup>nd</sup> Ed., New York: Gilford Press

Lock. J. & Le Grange, D. (2004) Help Your Teenager Beat an Eating Disorder, New York: Guilford Press.

Mental Health Foundation (2004) How to Talk to Your GP about Your Mental Health

Southern HSC Trust, Getting Help with Eating Disorders, www.southerntrust.hscni.net/Adult\_Eating\_Disorder\_Services.

Southern HSC Trust, Self Help Guide: Eating Disorders, www.selfhelpquides.ntw.nhs.uk/southerntrust

Tait, L & Lester, H (2005) Encouraging User Involvement in Mental Health Services, in Advances in Psychiatric Treatment April 2005, 11(3) 168-175: Royal College of Psychiatrists

The New Maudsley Approach: A Resource for Professionals and Carers of People with Eating Disorders, www.thenewmaudsleyapproach.co.uk

Treasure, J, Smith, G & Crane, A. (2007), Skills-based Learning for Carers of a Loved One with an Eating Disorder: The New Maudsley Method: London: Routledge





**Promoting Hope, Opportunity and Personal Control** 

www.hscboard.hscni.net/mentalhealth/