BODYWHYS
The Eating Disorders Association of Ireland

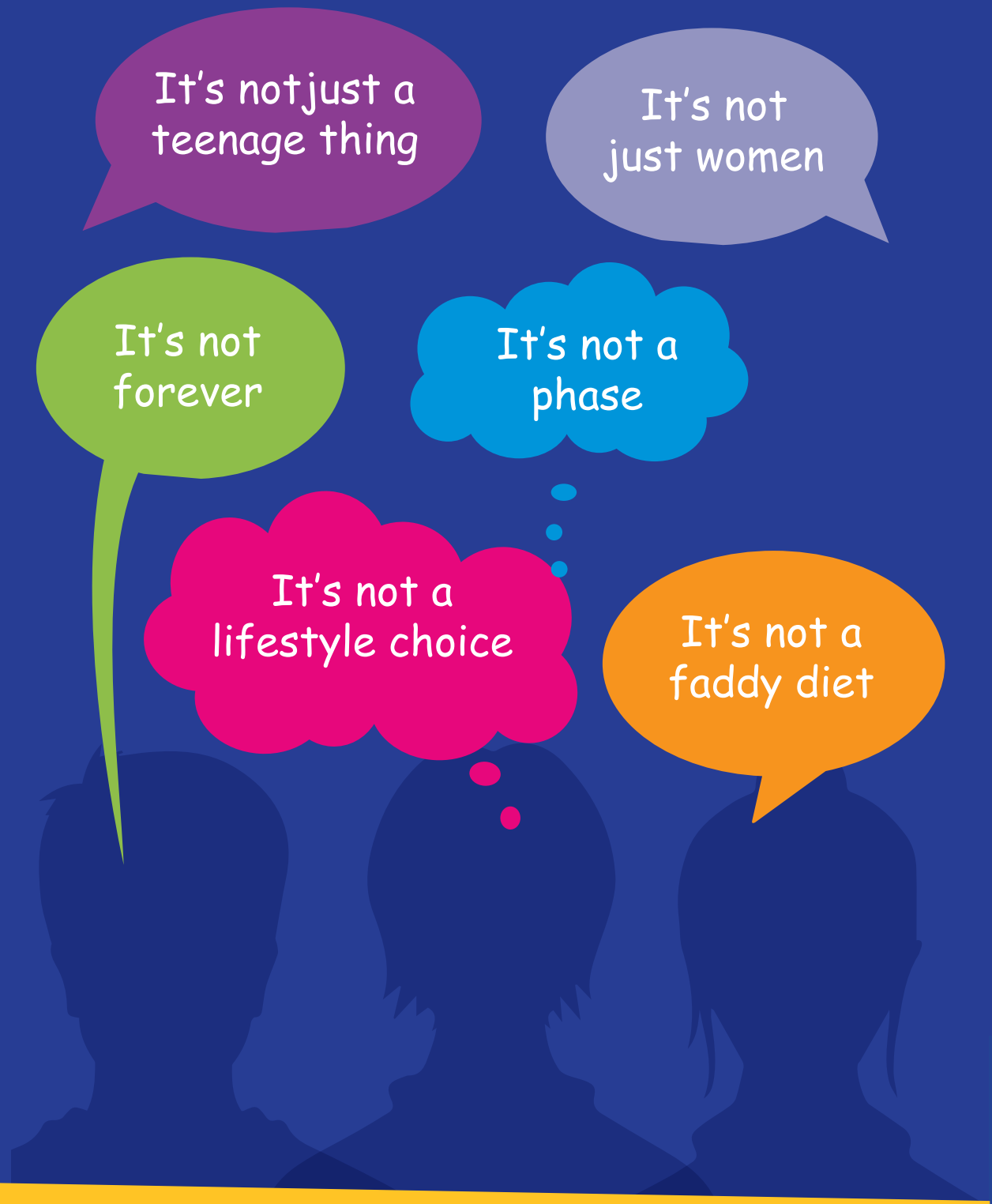
EATING DISORDERS

A Guide for Families

Supporting, coping, understanding treatment and recovery

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Contents



People **CAN** and **DO** recover from eating disorders

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Introduction

We have written this resource based on our experience of supporting and listening to families caring for someone with an eating disorder.

For those without close or personal experience of eating disorders it can be hard to understand why a person's relationship with food becomes disordered, controlled and inflexible to the point that it affects their personal and family relationships, along with school, college, work life and their health.

While an eating disorder may appear to be "all about food, weight and shape", the reality is that it is about so much more. Anyone at any weight can have an eating disorder. An eating disorder affects how a person feeds themselves, their physical health, how they think and how they feel. Ultimately, it affects a person's sense of self. **Eating disorders are serious and complex.**

Often, carers feel they have to become an expert at eating disorders to be able to support their family member. This can feel like a mammoth task and can exacerbate feelings of helplessness. As you read this resource, try to keep in mind the idea that to support your family member, it is not necessarily about becoming an expert on the subject of eating disorders, but rather it helps to focus on becoming an expert on your family member's eating disorder. Use this guide to think about your family member and how the eating disorder is influencing how they think, behave and feel.

When we use the term 'eating disorder', we are referring to any eating disorder: anorexia nervosa, bulimia nervosa, binge eating disorder, other specified feeding or eating disorder (OSFED) or avoidant/restrictive intake disorder (ARFID).

When we talk about eating disorders, it is not just girls or women. Eating disorders affect boys and men too. Eating disorders are not particular to any gender.

Types of Eating Disorders

The following information reflects a range of eating disorders, as recognised and categorised [1-2] by, the World Health Organisation (WHO) and American Psychiatric Association (APA).

Anorexia Nervosa (AN)

A person experiencing anorexia nervosa restricts their food intake, which usually causes them to lose weight and become underweight. The person experiences an intense fear of gaining weight, which can include being at what is considered a healthy weight. The idea of eating causes them to become really anxious and frightened of putting on weight. They may do something persistently that ensures they never put on any weight, for example, over-exercising. There is a compulsive element to the person's behaviours and thinking – they feel as if they have to do what the 'anorexia nervosa' side of their head is telling them to do, that they have no choice. A distorted body image is also part of anorexia nervosa.

- A commonly used threshold is body mass index (BMI) less than 18.5 kg/m2 in adults and BMI-for-age under 5th percentile in children and adolescents
- Rapid weight loss (e.g. more than 20% of total body weight within 6 months) may replace the low body weight guideline as long as other diagnostic requirements are met
- Children and adolescents may exhibit failure to gain weight as expected based on the individual developmental trajectory rather than weight loss
- Low body weight is accompanied by a persistent pattern of behaviours to prevent restoration of normal weight, which may include behaviours aimed at reducing energy intake (restricted eating), purging behaviours (e.g. self-induced vomiting, misuse of laxatives), and behaviours aimed at increasing energy expenditure (e.g. excessive exercise), typically associated with a fear of weight gain
- Low body weight or shape is central to the person's self-evaluation or is inaccurately perceived to be normal or even excessive.

Bulimia Nervosa (BN)

In bulimia nervosa, a person is driven by an intense fear of gaining weight, and they engage in and become trapped within a cycle of restriction, bingeing and purging. Sometimes, bulimia nervosa may begin with a diet but the preoccupation with food and weight becomes obsessive and can take over the person's life. Eventually, they will become locked into a compulsive cycle of bingeing and purging (getting rid of the food) or resorting to other ways of preventing weight gain. Attempts to break the cycle often fail. The person begins to feel more and more out of control.

- Frequent, recurrent episodes of binge eating (e.g. once a week or more over a period of at least one month)
- A binge eating episode is a distinct period of time during which the individual experiences a subjective loss of control over eating, eating notably more or differently than usual, and feels unable to stop eating or limit the type or amount of food eaten
- Binge eating is accompanied by repeated inappropriate compensatory behaviours aimed at preventing weight gain (e.g. self-induced vomiting, misuse of laxatives or enemas, strenuous exercise)
- The individual is preoccupied with body shape or weight, which strongly influences self-evaluation. There is marked distress about the pattern of binge eating and inappropriate compensatory behaviour or significant impairment in personal, family, social, educational, occupational or other important areas of functioning
- The individual does not meet the diagnostic requirements of anorexia nervosa.

Binge Eating Disorder (BED)

Binge eating disorder is a recognised eating disorder in which a person, due to underlying issues and other risk factors, develops a pattern of binge eating as a way of coping. A person with binge eating disorder feels compelled to continue with the disordered eating, i.e. binge eating, as a way of coping with emotional turmoil. It must be recognised that, as with the other eating disorders, a person diagnosed with binge eating disorder cannot be treated by diet alone.

- Binge eating disorder is characterised by frequent, recurrent episodes of binge eating (e.g. once a week or more over a period of several months)
- A binge eating episode is a distinct period of time during which the individual experiences a subjective loss of control over eating, eating notably more or differently than usual, and feels unable to stop eating or limit the type or amount of food eaten
- Binge eating is experienced as very distressing, and is often accompanied by negative emotions such as guilt or disgust. However, unlike in bulimia nervosa, binge eating episodes are not regularly followed by inappropriate compensatory behaviours aimed at preventing weight gain (e.g. self-induced vomiting, misuse of laxatives or enemas, strenuous exercise)
- There is marked distress about the pattern of binge eating or significant impairment in personal, family, social, educational, occupational or other important areas of functioning.

Other Specified Feeding or Eating Disorder (OSFED)

In OSFED, people experience distress and impairment in areas of functioning, but they do not meet full criteria for any of the other feeding and eating disorders. A diagnosis might be given that specifies a reason why the presentation does not meet the specifics of another disorder (e.g. bulimia nervosa - low frequency).

The following are examples of OSFED:

- **Atypical Anorexia Nervosa:** all criteria are met for AN, but despite significant weight loss, the individual's weight is in normal range (or above)
- **Bulimia Nervosa of low frequency/limited duration:** All of the criteria for BN are met, except the binge eating/inappropriate compensatory behaviour occur at lower frequency and/or for less than three months
- **Binge Eating Disorder of low frequency/limited duration:** All of the criteria for BED are met, except they occur at lower frequency and/or for less than three months
- **Purging Disorder:** Recurrent purging behaviour to influence weight or shape in the absence of binge eating
- **Night Eating Syndrome:** Recurrent episodes of night eating, eating after awakening from sleep or excessive food consumption after the evening meal. The behaviour is not better explained by influences/social norms. The behaviour causes distress/impairment and is not better explained by another mental health disorder (e.g. BED).

Note: Across AN, BN, BED and OSFED there are body image concerns, or body dissatisfaction and self-evaluation linked to weight, which can drive a person's sense of wanting to be thin and wanting to lose weight, as part of the eating disorder.

Avoidant/Restrictive Food Intake Disorder (ARFID)

Due to the symptoms of ARFID, a person may have a very limited interaction with food. If someone has frequent sensory challenges around food this may be a sign of ARFID. They may lack interest in eating or food or they may worry about the consequences of eating (phobia affecting food intake, fear of choking). They may prefer to avoid new foods with intense textures, tastes or smells, opting instead to stay with foods they know well. This can make trying new foods challenging. ARFID is not picky eating, nor is it unique to children. Due to sensory processing issues, e.g. hypersensitivity to food texture, some autistic people may experience ARFID. Or they may prefer particular routines e.g. eating the same foods at the same time in the same order or only eating specific brands of food with specific packaging.

ARFID is characterised by avoidance or restriction of food intake that results in:

1. The intake of an insufficient quantity or variety of food to meet adequate energy or nutritional requirements that has resulted in significant weight loss, clinically significant nutritional deficiencies, dependence on oral nutritional supplements or tube feeding, or has otherwise negatively affected the physical health of the individual;

   OR

2. Significant impairment in personal, family, social, educational, occupational or other important areas of functioning (e.g. due to avoidance or distress related to participating in social experiences involving eating).

- The pattern of eating behaviour is not motivated by preoccupation with body weight or shape
- Restricted food intake and its effects on weight, other aspects of health, or functioning is not due to unavailability of food, not a manifestation of another medical condition (e.g. food allergies, hyperthyroidism) or mental disorder, and are not due to the effect of a substance or medication on the central nervous system including withdrawal effects.

Warning Signs

Physical

- A marked change in weight, regardless of what the person weighs
- Loss of menstruation
- Frequent stomach issues
- Symptoms of irritable bowel
- Unexplained gastrointestinal problems
- Lack of energy
- Feeling the cold acutely
- Tooth erosion
- Osteoporosis
- Lanugo (downy/soft hair)
- Swollen salivary glands
- Bloodshot eyes, dry eyes, blurred vision
- Dry and brittle nails
- Muscle weakness
- Poor wound healing
- Dizziness and fainting
- Difficulties concentrating
- Chest pain
- Heart palpitations

Emotional

- Little concern over weight loss
- Stressed, gets upset easily
- Finds spontaneous changes to routine difficult to cope with
- Doesn't seem to be themselves, seems down
- Mood swings
- Flat mood or lack of emotion
- Marked change in personality
- Distress about eating in public or social settings
- Inflexible thinking

Behavioural

- Skipping meals, avoiding meals with family, preoccupation with diets, what they are eating
- Frequent visits to the bathroom after meals
- Food restriction in the form of "clean eating" which seems to come out of nowhere, certain foods being "safe" or "healthy"
- Restlessness
- Avoiding social life
- Spending time alone, becoming isolated
- Exercising when ill or injured, to burn calories
- Food going missing, secretive food behaviours
- Wearing baggy clothes to hide weight loss
- Eliminating whole food groups
- Developing specific food rituals
- Avoid mealtimes or food situations, by excusing themselves
- Substance use
- Suicidal thoughts, plans or attempts

Understanding Eating Disorders

Eating disorders are serious and complex psychological disorders that affect every aspect of a person's functioning. They are not a choice and are recognised mental illnesses [1-2] that pose significant risks to a person's physical, emotional and mental health, and they lead to increased risk of mortality and suicide [3-4]. They often require medical intervention, along with psychological treatment. Treatment and interventions vary depending on the age of the person, the type and severity of eating disorder and the physical health of the person. See page 16 for information about treatment.

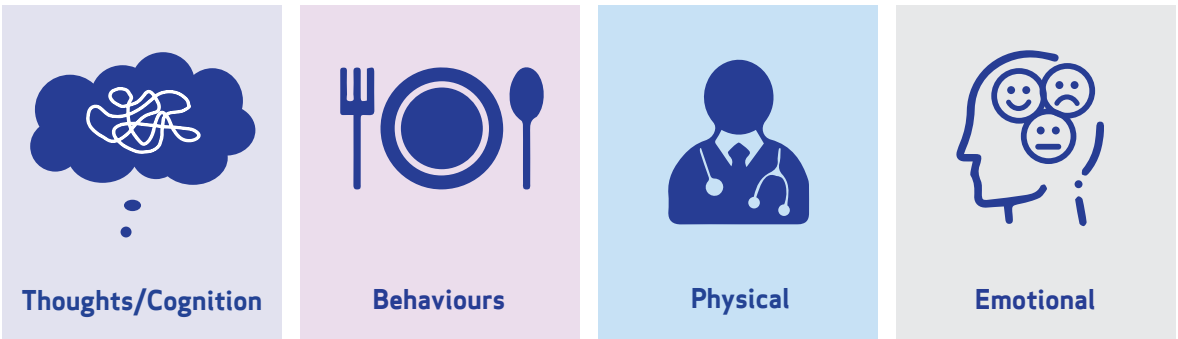
Eating disorders have a **behavioural aspect**, which means that when a person develops an eating disorder, their eating behaviours change and become disordered. A person may restrict their food and starve themselves, they may eat quite normally and then purge themselves of the food, through self-induced vomiting or over exercise, or they may binge eat. This is the aspect of the eating disorder that we can often see quite clearly.

Behind these disordered eating behaviours, there is a **cognitive aspect**. This means that what drives these behaviours are the person's distorted thoughts and thinking. Their thinking becomes more and more distorted as they get caught up in an eating disorder which in turn leads to further disordered eating, resulting in their health deteriorating.

There is the **physical aspect**, how a person feeds themselves affects their physical well-being. If a person doesn't eat enough, they will lose weight, and experience physical symptoms associated with being underweight or malnourished. If they are purging regularly there are physical effects a person can experience, and if they binge regularly, this also results in physical symptoms such as weight gain, being in the overweight or obese category of weight.

Finally, at the centre of all of this is the **emotional aspect** of the eating disorder, which is often hidden from the outside world. This means that underpinning an eating disorder, is the person's difficulty coping with their feelings, how they feel about themselves in the world, their sense of identity.

At any one time, when a person has an eating disorder, all these aspects of the eating disorder are interlinked and influencing each other.



When we see a person we care about engaging in disordered eating, and becoming physically ill, it can be hard for us to grasp the complexity of issues influencing the behaviours we see. We can think "If only they would tell us why they are doing it, we could help them to change." However, what we often don't realise is that the person themselves frequently doesn't understand why they feel compelled to do what they do.

Coping mechanism

A really helpful way of understanding an eating disorder, is to think of it as a **coping mechanism** – it is a destructive coping mechanism, but nonetheless in some way it helps your family member feel they can manage their lives on a day-to-day basis. This is why it is so difficult for them to let it go. If you can understand this, and use this idea to inform all your interactions with the person, you will support and intervene in more helpful ways that will be supportive for them.

Another way of understanding this idea is to think of an eating disorder as a physical and behavioural manifestation of your family member's difficult thoughts and feelings. Rather than confronting an emotional issue that may be affecting them, the person tries to find comfort and calm in certain behaviours around food.

This is why it is important to focus not only on what the person is doing, but to also understand how they are feeling about what they're doing, and how they are feeling about what is going on for them.

What causes an eating disorder? Why is this happening?

There is no clear-cut answer as to why someone might develop an eating disorder. Often, it is an combination of risk factors. Significant times in a person's life such as puberty, life transitions or some upheaval can heighten risk – for example, stressors such as change of school, a breakup, moving away from home, trauma or abuse. For more information on risk factors, check our website www.bodywhys.ie

Often, it is a combination of 'internal' and 'external' risk factors that can make someone more vulnerable to developing an eating disorder. For example: biological factors, a tendency towards being anxious, a perfectionist mindset, difficulties managing feelings, low self-esteem, weight-based bullying, a history of dieting, trauma, life circumstances and stressors.

Avoiding blame

Parents often feel they are to blame for their child developing an eating disorder. And the person often feels it is their fault that they have an eating disorder and are causing so much upset and worry. When everyone is feeling they are to blame this is not helpful. While everyone's feelings are understandable it is important to remember that parents don't cause eating disorders and your family member didn't choose this.

Eating Disorder Voice

Sometimes people describe their eating disorder thoughts as an 'eating disorder voice'. This is a form of distorted thinking and constant negative self-talk.

The voice may:

- Create and set certain rules in relation to food, weight, body behaviours, and how the person interacts with others
- Create a distorted logic that conflicts with a person's rational thoughts and this in turn contributes to emotional distress
- Make promises, threats and can make the person feel as though life without the eating disorder is not possible.

Managing the eating disorder voice

Living with an eating disorder voice can be a significant challenge. The voice may be present in the background, ready to jeopardise the progress a person has made. Becoming free of the voice can feel stressful as a person may have previously experienced it as a source of guidance. Moving forward may involve trying to separate out the person's individual beliefs from those that are primarily driven by the eating disorder voice.

Distinguishing between the eating disorder and your person

A natural response to your family member's eating disorder is to see it as an unwelcome invader in your family. A helpful strategy when supporting a person with an eating disorder, is to separate out the person from their eating disorder. By making the eating disorder an 'it' you are showing your loved one a number of things;

- That they are not choosing this
- That you know and have faith that they are a person who is different to who they are with their eating disorder
- If you make the eating disorder an 'it' you are making a distinction between the illness and your person and this supports or initiates the process of them separating themselves from the eating disorder
- Reducing blame towards the person
- It is the eating disorder that is making them engage in difficult and destructive behaviours, so we can feel frustrated by it, and not the person
- This allows us to align ourselves with the 'non-eating disorder' side of the person's mind, giving them the means by which they can separate and distance themselves from the illness, and set up a dynamic which can gradually facilitate change and recovery.

Ways of making this distinction:

- Avoid labelling your family member as 'being anorexic/an anorexic/the anorexic'. You could say that 'have' are 'affected by' or are 'living with' an eating disorder
- Be clear that you are not assigning **blame** to them
- Encourage them to make these same distinctions

Note: Although people describe it as a 'voice', it is not an auditory hallucination.
*To learn more about the voice see **www.bodywhys.ie**, including an animation we created about it.*

Approaching Someone

It's not easy to start a conversation when you sense that someone is struggling. It can be a very emotional time. What you say, and how you say it, can be a starting point to build trusting open communication.

Acknowledging there's a problem

- An eating disorder helps a person to feel safe and secure. Accepting that it is in fact destructive requires the person acknowledging that there is a problem. It is normal and to be expected that the person will feel conflicted about doing this. Part of them may be able to, and want to, but part of them will be afraid of doing this and will feel defensive. Try not to put pressure on the person to make immediate changes to their behaviour. The idea of sudden change can feel very difficult.

Before you approach someone

- **Try to** inform yourself about eating disorders
- Have some information about resources and treatment services/options available for the person
- Seek support if you are feeling apprehensive about it.

Starting a conversation

- **Try** to focus on feelings and not food or details of weight behaviours
- **Try** not to focus on specifics any longer than you need – move the focus from specifics to ask how the person is feeling or whether there is something going on for them they would like to talk about
- **Try** to approach the person at a time and place that is **free from time pressure** or possible interruptions
- **Gently** let the person know you are concerned about them and why
- **Avoid** judging, blaming or criticising.

Moving forward

- **Ask** the person what they need from you to help. If they find it hard to identify their needs, suggest to them what you feel might be helpful, but be sure to check with them whether the suggestions are ok.

Supporting Someone

Supporting someone is generally a long process. There are many different aspects to an eating disorder and a person's experiences may often change over time.

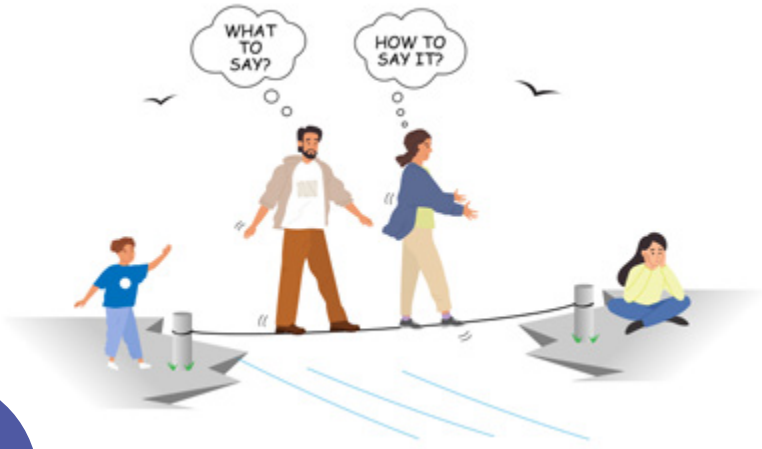
Keep in mind...

- Helpful and supportive communication focuses on encouraging the person to describe what they are thinking and feeling
- Distorted thinking can influence how the person might hear what you say
- Even the most ordinary, and in your view, helpful praise or comments about a person getting better, may be something that is difficult for the person to hear
- Do acknowledge their achievements, but leave room for the person's own thoughts, rather than just offering your opinion.

Eating disorders are often counterintuitive. Your attempt to help can be felt as an attempt to control. Your attempt to motivate, encourage and praise can be felt as a judgement and trigger panic.

If we take an authoritarian stance, this can be met with resistance because the person can feel that others are trying to take their control away, so they must protect it and not let this happen. A collaborative approach reduces this dynamic playing out, and in the long run, builds a strong and healthy foundation upon which recovery can be built.

A collaborative focus means trying to appeal to the side of the person's head that is outside the eating disorder. Family, and especially parents, often feel they are walking a fine line between being helpful and making things worse.



How can you help?

- Help them to be strong enough to not listen to the distorted eating disorder side of their heads
- Help them remember and know that this will be OK
- Help them to know that it is OK for them to be themselves in the world.

Ideas to help you do this:

- Externalising what they hear in their heads
- Visualising the eating disorder part of their head
- Imagine they are stronger than the eating disorder.

Support Resources for Your Family

Your family member's experience of an eating disorder is likely to have an impact on the family as a whole, something which you may not be prepared for. Parents and carers can feel isolated, worried and helpless.

PiLaR programme for families

The **Bodywhys** PiLaR programme is a **free**, evidence-based, 4-week psychoeducation programme and support service. The programme is open to carers, parents, family members and friends.

During the PiLaR programme we talk about:

1. Understanding eating disorders, the mindset of a person, how to manage at home
2. Communication, active listening skills
3. Dealing with meal times, routines, different behaviours and triggers
4. Dealing with rejection/shut down/anger
5. Coping with relapse
6. Treatment and recovery: what is the recovery process and how does it happen?

Parents and family members who attend the PiLaR programme often benefit from hearing from others in a similar situation and having their needs heard. To find out more or register for an upcoming programme, please email pilar@bodywhys.ie

Post-PiLaR Support Group

A support group for those who have attended a previous PiLaR programme. Please email pilar@bodywhys.ie to register.

Sibling Support Group

A support group for siblings who have attended a previous PiLaR programme. Please email pilar@bodywhys.ie to register.

New Maudsley Carer Skills Workshops

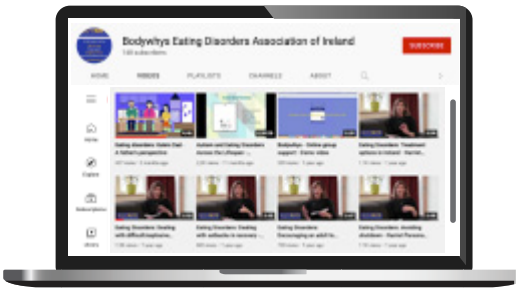
These workshops build on the knowledge that family members have gained through our PiLaR programme, by learning skills to support and motivate your family member as well as skills to cope better and build resilience. Please email pilar@bodywhys.ie to register.

Podcasts

We have created and recorded a series of podcasts focusing on New Maudsley Carer Skills, featuring interviews with Jenny Langley.

Videos

We have created a number of videos focusing on common questions. You can find them here https://www.youtube.com/user/BodywhysVideo/videos



Eating Disorders App

The HSE's app for eating disorders is regularly updated and can be accessed via https://ncped.selfcareapp.mobi/

Treatment

Figuring out treatment can feel daunting and confusing. There are two treatment pathways – the public health system and the private pathway. For our full treatment guide, please see www.bodywhys.ie

When it comes to treatment, and finding one that works, there is 'no-one-size-fits-all'.

Every person who has an eating disorder is different, and while there are elements and aspects of eating disorders that are universal, the way in which a person moves away from an eating disorder is subjective and at all times we must keep an open mind.

An open mind also allows us to try something different if what we are doing isn't working. Sometimes people say "I tried psychotherapy and it didn't work." Keeping an open mind allows us to reframe this and say: "The psychotherapy I tried didn't work for me so I need to try something different, somebody different, or a different type of therapy".

General Practitioner (GP)

Speaking to a GP/family doctor is often the first step towards recovery, and he/she can play a crucial role in the diagnosis of an eating disorder.

A GP can also make referrals directly to a hospital, to a paediatrician, or to one of the other professional services listed below.

What the GP may do

- Physically examine your family member
- Assess for the symptoms described in the Understanding Eating Disorders section of this guide
- Ask about behaviours around food, diet, exercise and weight
- Explore any potential emotional issues which may be an underlying cause
- Perform a selection of tests to determine a diagnosis
- Measure Body Mass Index (BMI)
- Blood tests to examine blood counts, liver and thyroid function, hormone levels and levels of sodium, potassium, calcium and magnesium
- Refer for a DEXA scan to test bone density
- Refer on to a specialist service.

Understanding diagnosis

If your family member has been diagnosed with an eating disorder, this means that they meet certain diagnostic criteria which define anorexia nervosa, bulimia nervosa, binge eating disorder, OSFED or ARFID.

While this may be an upsetting time, a diagnosis is in fact a positive step towards treatment and, ultimately, recovery.

The most significant implication of a diagnosis is that the eating disorder can now be seen as a concrete 'fact' – something is going on, and some action needs to be taken.

Acknowledging that there is an issue is a significant step that can be taken towards recovery, and presents an opportunity for you and your family member to speak more openly about how you are both feeling and how you can tackle this together.

Psychiatric assessment

A psychiatrist is a medical doctor specialising in mental health. They will usually work as part of a community care team, in a psychiatric hospital or unit, or in a private practice.

Sometimes a psychiatric assessment may be required in the case of an eating disorder and related or co-existing problems. This can also sometimes be necessary when a diagnosis is not straightforward. A referral may be needed, depending on the service provider.

Child and Adolescent Mental Health Services (CAMHS)

There are CAMHS teams throughout Ireland and they consist of a range of professionals who provide specialist services for people under the age of 18. Your family member may be referred to CAMHS by your family doctor once a diagnosis has been made.

Depending on your family member's physical and mental health, there may be a need for hospitalisation in which case they will be referred on from the CAMHS.

Adult Mental Health Services (AMHS)

AMHS are mental health teams who work with, treat and support adults with mental health issues in their own homes and in community settings. They may also be known as Community Mental Health Teams (CMHTs).

National Clinical Programme for Eating Disorders (NCP-ED)

The purpose of the NCP-ED is to deliver specialised care and treatment of eating disorders in Ireland. This includes specialist eating disorder teams with specific knowledge and skills, who take referrals, carry out assessments and provide evidence-based treatment to individuals and their families. The NCP-ED addresses the complexity of eating disorders and aims to improve the lives of those affected by the illness. For up-to-date information on the NCP-ED check the HSE's website www.hse.ie

Evidence-based treatment

Evidence-based treatment specifically tailored to the treatment of eating disorders is available in Ireland, whilst support and care from a multidisciplinary team (MDT) can also be beneficial. Further information on evidence-based treatment for eating disorders can be found through the National Institute for Health and Care Excellence (NICE).

Specialist treatment

There are a number of specialist inpatient treatment centres in Ireland which may meet your family member's needs. Your GP will be able to advise you on the different options available to you if specialist treatment is deemed necessary. You may need a referral from your doctor to access these services.

Aspects of treatment

- Addressing malnourishment or the physical aspects of the illness
- Normalising food behaviours
- Addressing underlying and contributory factors and thinking patterns
- Developing self-esteem and self-worth
- Developing new coping mechanisms
- Regular health checks with a family doctor and/or medical team
- Psychotherapy – sometimes called 'talk therapies'.

Dietary advice or nutritional counselling

A dietitian is a qualified and regulated health professional who assesses, diagnoses and treats dietary and nutritional issues at an individual and wider public-health level. Using the most up-to-date scientific research, they combine knowledge of food, nutrition and other related disciplines to promote health, prevent disease and aid in the management of illness. A dietitian will usually work as part of a multidisciplinary team.

A nutritionist is a person who applies a scientific understanding of nutrition to enhance the impact of food on a person's health and well-being.

The aim of nutritional counselling is to educate both you and your family member and to allow you both to begin making choices necessary to restore healthy eating habits.

The Irish Nutrition and Dietetic Institute (INDI) is the professional body for registered dietitians in the Republic of Ireland, their website is **www.indi.ie**

Psychotherapy

Examples:

- One-to-one
- Cognitive behavioural therapy enhanced (CBT-E), tailored for eating disorders
- Group therapy
- Family therapy
- Integrative therapy
- Psychoanalysis.

Psychotherapy usually involves committing to a series of regular appointments of about an hour in length over a period of time.

The aim is to address the psychological and emotional factors that are underlying and sustaining the disorder. Family involvement in therapy can be particularly valuable in the case of younger people.

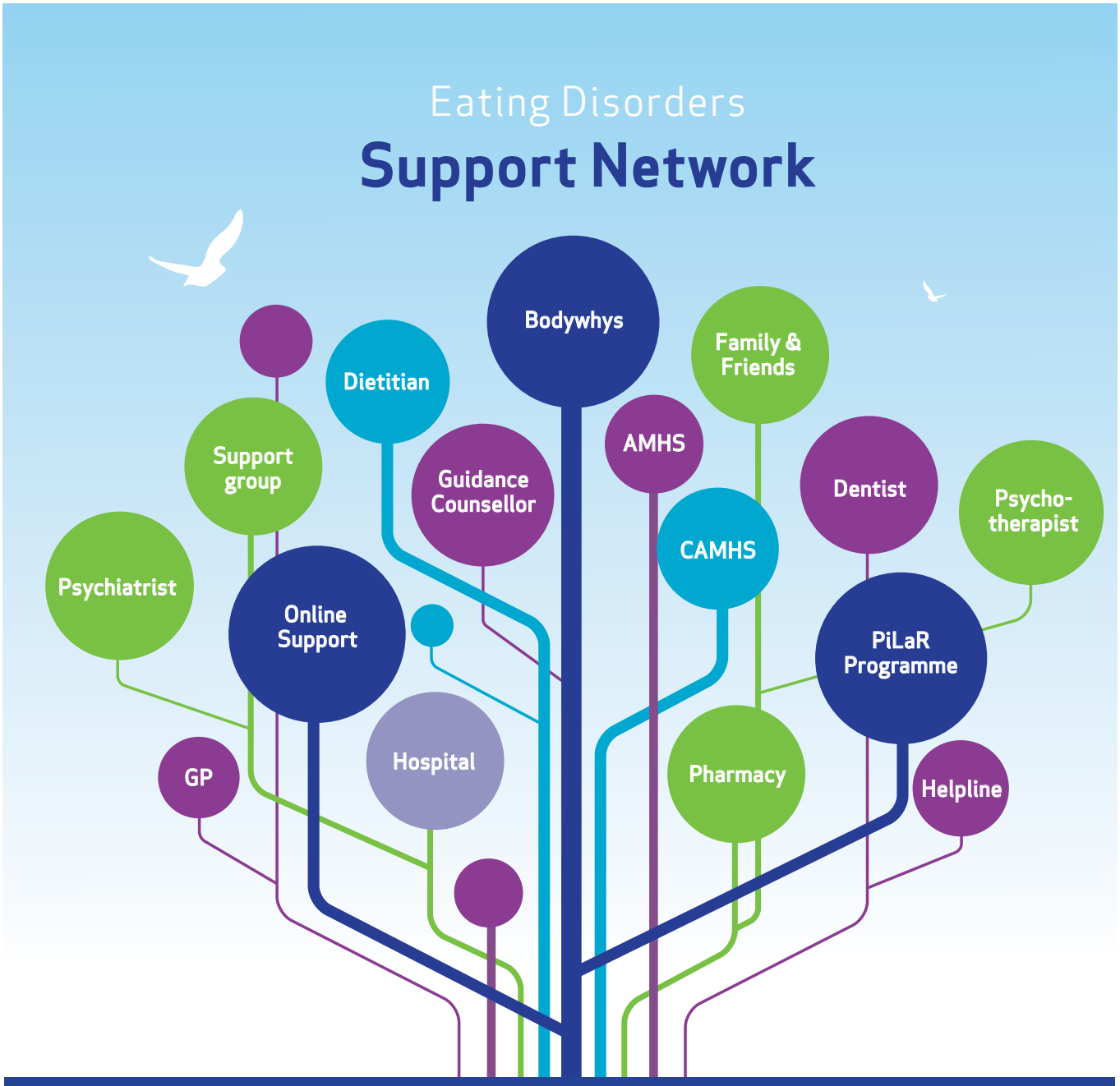
In Ireland, psychotherapy currently has no statutory regulation. It is important to ask what qualifications your chosen practitioner holds. Do also check that they are registered with an accrediting professional organisation, this ensures that they are bound by ethical and governing standards of their professional body.

Self-help and support

In conjunction with the above treatment options, it is important to maintain ongoing support for your family member within their family unit and that you continue to support yourself, so that you are better able to support your family member.

There are a wide variety of books and other resources available that you may use yourself or work on with your family member. Your local library can be a good start in exploring these options.

We have a booklist available on **www.bodywhys.ie**



The Bodywhys website contains a **'Directory of Service Providers'** with listings of the various treatment options and treatment centres available throughout Ireland.

Regional Health Authorities

As part of implementing Sláintecare, the HSE's transitioning from using Community Healthcare Organisations (CHOs) to using Regional Health Authorities (RHAs). To learn more, see www.hse.ie

Thinking About Recovery

'Recovery' is a very subjective idea, and one which is impossible to define in a concrete way which is applicable to every individual. People may say they are 'recovering', 'recovered' or 'in recovery'. There is no universal way to approach recovery, it takes time and a person's needs during recovery are about much more than weight and food. Recovery cannot be forced on a person and any recovery strategy must allow a person to feel as though they have an active role in their own recovery, and that they have a voice in it.

When we think about what recovery means or looks like, we can think of the different aspects an eating disorder affects:

- **Food behaviours** – a person starts to be able to eat normally, regularly and freely, their attitude towards food, eating and exercise changes
- **Thinking** – their thinking stops being distorted and they no longer have eating disorders thoughts / or experience the eating disorder voice
- **Physical** – their physical health is not at risk or deteriorating
- **Emotional** – self-esteem, self-worth improves and the person does not rely on controlling their food and body as a way of coping with how they are feeling
- In recovery, a person can start to express themselves, particularly in relation to issues which may have contributed to the development of the eating disorder
- A person can begin to develop a sense of freedom.

Sometimes a person may be eating normally but still may have distorted thinking and find it difficult to manage their feelings. It is helpful to show an understanding of, and compassion for, your family member's experience and an understanding that recovery from an eating disorder is not just about eating normally and being physically healthy.

Recovery at any stage should be treated with sensitivity. For someone experiencing an eating disorder, it can bring up mixed feelings about change and getting better. While on the one hand they may feel pleased and relieved to have made progress, there may also be a part of them that doesn't like change and is scared of letting the eating disorder go. Sometimes people say that in recovery they feel worse before feeling better.

As a family member you may feel a great sense of relief, however it is important to maintain an awareness of your family member's mixed feelings about getting better. While acknowledging this progress between yourselves, focusing on progress too much can be experienced as frightening for your family member.

Your family member can benefit from being given the time that he/she needs to recover at their own pace and to address any lingering issues in their own time.

Stumbling blocks and relapse

'Relapse' refers to a return to a previous state, of mind or behaviour, which a person may feel they had left behind them. This can be frustrating and disheartening both for the person experiencing relapse and for family members.

If you and your family member approach the relapse in a positive way, that it is an expected and natural part of the recovery process, it can be used as an opportunity rather than a setback.

As a supporter, it is helpful if you are able to reframe a lapse or a relapse as an opportunity to learn – the person may be acutely sensitive to the sense of failure a lapse brings, and it is helpful to be able to use the experience as a learning opportunity.

- What caused the lapse/relapse?
- What triggered it?
- What have we learned?
- How can we proceed?

Supporting an adult

When supporting an adult, you may not have any influence over how they eat, or what they eat, and other types of disordered eating behaviours. While this can add to your feelings of helplessness, do remember that people have told us that what is often of more benefit is to just be there to talk to without the pressure of having to talk about changing behaviours.

Eating disorders are often associated with younger people, but this doesn't reflect the reality that many people experience the illness as an adult, and for an extended period of time, some into mid-life or beyond. It may be particularly challenging for adults to speak about their own experiences because of the misconceptions.

As with anyone with an eating disorder, if you are supporting an adult, all of the basic principles of having a conversation and taking on board the ideas in this resource may assist you. **Again, one of the most important things to remember is not to judge a person's wellness based on how they eat or how they look. Focus on how they are feeling rather than what they are doing.** This helps to keep lines of communication open.

Supporting siblings

Siblings may worry about the impact on you as their parent, whilst also feeling stressed about their sibling. They may try to make life less stressful by trying not to be an added burden to you, but at the same time often they may feel neglected and excluded. In turn, they may feel guilty at these difficult feelings towards their sibling.

- For younger siblings, allowing them to know that their sibling is unwell can reassure them that the adults in the situation are aware and in control of things
- Provide reassurance that other members of the family's own issues and day-to-day achievements and upsets are also valid, and that you are able and willing to support them too
- Education around what is happening for their sibling, and why things may have to be a certain way for now, can allow their sister or brother to understand that sometimes difficult behaviours and changes in mood can be a part of their sibling's recovery
- Include siblings in any changes that are taking place in the family, and discuss the eating disorder and related issues with them so that they feel they can participate in, and contribute to, the support network you are building
- It is important that siblings avoid 'teasing' of any kind that might inadvertently pressurise the family member affected by an eating disorder
- For mealtimes, it can be useful to speak with other family members in advance about how to ensure meal times can be as comfortable as possible for the whole family. Siblings in particular may feel anxious about what may happen at the table and about how they should respond.

I am a sibling - What can I do?

Learn about eating disorders, from a source you can trust. This will help you remember that your sibling is still the same person, but it is their eating disorder may be making them behave differently.

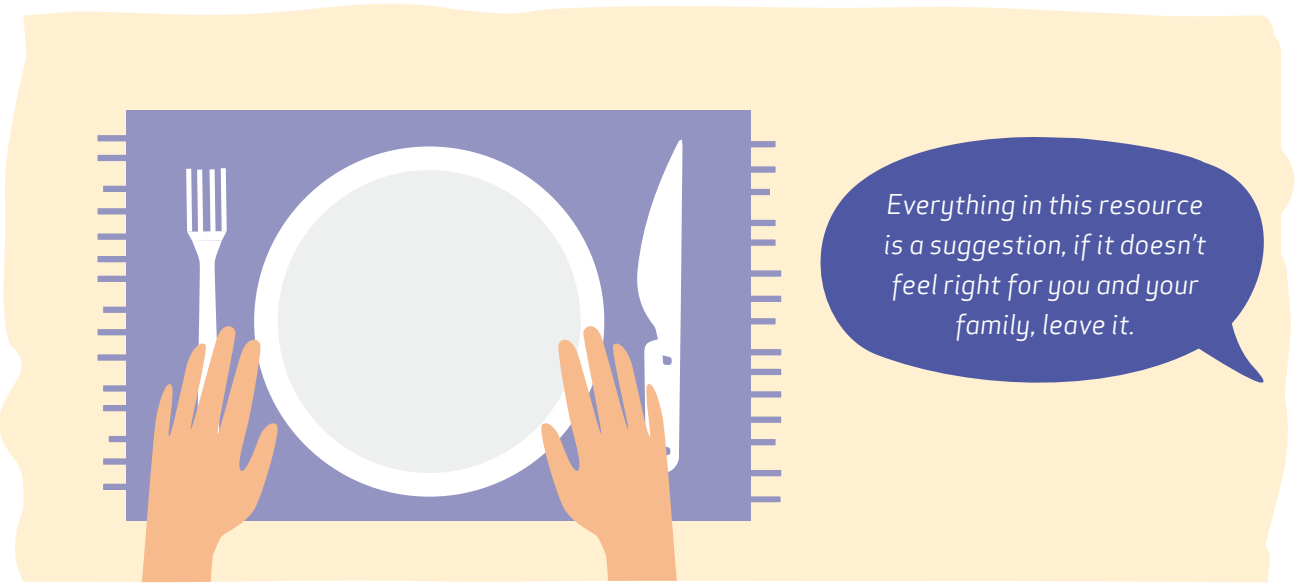
Eating disorders develop for lots of reasons and it takes time for people to get well. You are not the person whose responsibility it is to get your sibling better. Nor are you to blame.

If you are finding your own feelings difficult to manage, do try to connect with another family member, a friend, or a professional, to talk out your feelings.

If you are a sibling reading this resource, know that it is important that you live your own life and look after yourself. Like we have said for parents, it is helpful to 'role-model' living your life for your sibling with an eating disorder.

Sometimes you may be aware of behaviours that your parents are not, or your sibling who is unwell may ask you to keep something secret. If you don't feel comfortable doing this, or if you feel that ultimately it is not helpful, it is okay to want to share that with the adult / parent in your life. Eating disorders thrive in secrecy, and in this instance keeping secrets is not always in your sibling's best interest.

Managing at home



Everything in this resource is a suggestion, if it doesn't feel right for you and your family, leave it.

Dealing with mealtimes

For a person affected by an eating disorder, and for their family, daily mealtimes can be one of the most difficult aspects of the recovery process. Preparing yourselves in advance for potential difficulties can remove some of the stressors from the situation.

Getting to the table

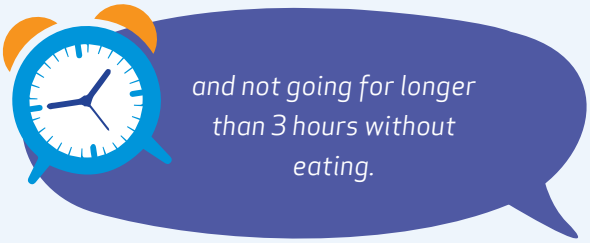
- Plan mealtimes in advance, and allow a certain amount of time per meal
- Decide if the meals should be the whole family or if your family member would be more comfortable eating separately for now. As much as you can, try to eat with your family member to show by example that eating a meal is a normal and necessary part of the day
- Try to normalise the act of sitting down to a meal. Your family member may feel very anxious about this, and this anxiety needs to be recognised, but it should not be allowed to dictate when or what your family member will be eating
- Try to get your family member to talk out loud about the thoughts and fears they are having about sitting down to the meal.

Remember to frame challenges or goals as experiments. We are focused on learning – we expect it may not work the first time. This takes the pressure off doing something new.

Planning meals

- Working with your doctor and/or dietitian to develop a **meal plan** can help to regulate mealtimes
- Establishing a meal plan in advance can also help both you and your family member to manage your expectations about what will happen during the meal
- A meal plan can also remove some of your own anxiety around ensuring your family member is receiving sufficient nutrients to aid their recovery.

Regular eating is a cornerstone of recovery.



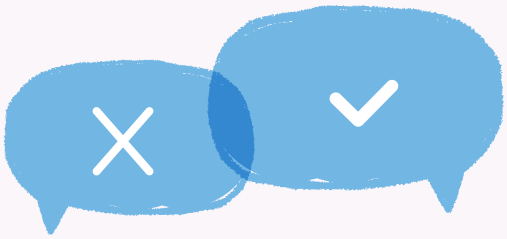
Establishing a Routine

Establishing and keeping a routine around mealtimes and meals is extremely important, especially in the early weeks of recovery. While this may seem quite rigid to begin with, the routine is important for a number of reasons:

- The regularity of eating makes things easier in the long run. If you eat three meals and three snacks one day, it is easier to do it the next day, whereas if you skip a meal or snack one day it makes it much harder for your family member to have it the next day
- Eating regularly also ensures there are no long gaps between meals. This means that your family member will not experience intense hunger, which can trigger feelings of panic and eating disorder thoughts. This helps reduce the risk of skipping meals, but also of the compulsion to binge and purge
- Establishing the routine around meals also helps your family member to see that food and their feelings can be separate. It allows a person to experience good days and bad days and, because they are eating the same way no matter what kind of day they may be having, they can begin to learn that how they are feeling is not dependent on what they are eating
- While the routine might seem rigid at first, eventually your family member will begin to be able to make small changes to their routine and the routine will become more flexible as recovery progresses.

It is important that families try to avoid putting the focus solely on the food while also maintaining a normality about mealtimes.

- Don't stop complimenting the chef, expressing joy about eating, or expressing dislikes about food
- Do avoid any comments on calorie content, weight and portion size. This will need to be agreed with family members prior to mealtimes
- Encouraging the rest of the family to act as normally as possible during the meal will help your family member to readjust to family mealtimes and can also serve as a distraction from the act of eating.



What to say, what not to say

- ✓ Do reassure your family member that you understand that full meals may be a challenge for them for some time
- ✓ Do let them know that you are there to support them
- ✓ Do allow them to speak openly about their anxiety around mealtimes
- ✗ Don't focus mealtime conversations on food and the eating disorder Especially if the family is present, try to steer the conversation around unrelated issues and activities
- ✓ Ensure as much as possible that everyone is eating the same types of food.

What to expect

- **Tears and anger.** Your family member is probably making a huge effort to try to eat normally, but this produces a conflict with the eating disorder rules and thoughts, resulting in tears and anger. Try to get your family member to talk out the thoughts in their head, and to express the conflict so that this is out in the open and can then be dealt with

- **Fear** is probably the overriding feeling your family member will have at mealtimes, and this may be what triggers all of the other behaviours you observe. It can help enormously if parents recognise and communicate with their family member that they understand that the meal is frightening for them, and that they want to make it okay for them. Getting your family member to talk out their fear, to tell you what they are afraid of, and what they feel will happen if they eat, will help your family member to deal with their fear
- **Delay tactics to avoid eating.** To deal with this in the early stages, it is important for your family member to understand that they will have to eat what has been agreed, and that they cannot negotiate about this. Patience on the part of the parent is very important to make this work in the early stages

- **'Playing' with food**, e.g. cutting food into smaller pieces, mixing around plate etc. While this is not necessarily to be stopped – it can be your family member's way of dealing with the conflict between themselves and the eating disordered thoughts - be watchful to make sure that the agreed amount of food is still eaten
- **Attempts to hide food** rather than eating it
- **Remember** to try to reframe the behaviours you are seeing – if your family member tries to hide food for example, that is telling you that they are really afraid and the eating disorder in their head is trying to avoid you making them eat. Rather than getting angry and feeling like your family member is trying to trick you, express your understanding that they are finding it difficult and ask them how you can help make it easier for them. Align yourself with your family member, supporting their attempts to disobey the eating disorder's rules.

After the meal

- It can be helpful to sit down with your family member after the meal, in a different room, and spend some time together after the stressful encounter
- This can simply be used as 'downtime' or as an opportunity to encourage your family member and acknowledge their progress
- This can also serve as a distraction to ensure that your family member is not purging after the meal.

Meals outside the home

- Family events and other meals outside the home may be particularly stressful for your family member. Consuming any food in the early stages of recovery may be overwhelming, so large portions and pressure at outside events may add to the stress
- If your family member has recovered sufficiently to be comfortable in this environment, try to prepare for stumbling blocks
- If your family is going out to eat at a restaurant, be mindful of the type of restaurant you choose. While it may be okay to try a fast food restaurant, it also may not be, so parents need to think about the types of food that their family member can handle ordering
- In the early stages of recovery, if you do plan to eat out, try to give your family member some notice of this, and also reassure them that it will be okay and that you will try to ensure that they will have something that they consider a 'safe' food
- Try to be near your family member when you are ordering and allow your family member enough time to decide what they want. Sometimes it can help to look at the menu beforehand and decide what your family member will order. This will help with indecision in the moment
- Be prepared to ask staff how food is prepared, and how it is served, and try not to make this a big issue. Reassure your family member that you will do this for them and reassure them that this is okay to do
- Be prepared to ask for slight changes in the menu and try to be okay doing this. While this may seem to be giving in to the eating disorder, it is important that these events are experienced as safe, so in the beginning making it as safe as possible is more important than insisting your family member eats foods that they are uncomfortable with.

Building self-esteem

Working with your family member to build their self-esteem can be a positive step towards recovery from the eating disorder, while at the same time encouraging your family member's overall sense of self.

Some tips:

- Spend time with your family member, doing things they enjoy
- Listen to your family member when they are speaking, and show that you value their opinions
- Ask your family member for input or advice on how they think you could deal with an issue and then take their advice and act on it. This helps your family member to feel that they can manage issues and that their opinion is valued by you
- Acknowledge skills and talents your family member has, particularly ones that aren't 'physical'
- Get your family member to make a list of activities they enjoy and that make them feel good about themselves
- Focus praise on your family member's personality and individuality rather than on appearance
- Teach your family member to understand and admire difference – explain that all family members are born unique
- Work with your family member to identify their friends who support and respect them. Encourage your family member to spend time with these friends
- Discuss bodily changes with your family member, particularly around the age of puberty, and keep lines of communication as open as possible
- Examine your own attitudes to body image, and to yourself: your family member will pick up on these

Frequently Asked Questions (FAQs)

Frequently Asked Questions - FAQs

Who else do we need to tell?

You may feel that telling other people in your family member's life is an important part of tackling your family member's eating disorder.

If your family member is of school-going age, their teacher(s) will see them for a considerable portion of their day. They may observe behaviours that you are not aware of. They may also be the person that your family member confides in about their eating disorder. If you feel it is necessary, and it often is, let their teacher know what is going on.

The question of who to tell or who not to tell is one that you must address with your family member so that they feel part of any decision to discuss their eating disorder with others. Equally, it's important that your family member doesn't feel that people are talking about them behind their back.

If your family member feels that letting others know will help them towards recovery, then it may be appropriate to let people know as much as you are comfortable sharing.

Is eating disorder treatment covered by my health insurance?

Most health insurance policies do make provision for mental health issues, including treatment for eating disorders. Cover for inpatient or outpatient treatment and for individual psychotherapy sessions can vary depending on your individual policy and the practitioner in question.

Always ask for, and keep, receipts when you are paying for treatment – these may be needed for insurance purposes or to claim tax relief.

If you have any queries you should raise them with your health insurance provider and see what your specific policy covers.

What treatment options are available if you don't have insurance and can't afford to pay for private treatment?

For most people the first port of call is a GP. A GP can then advise or make a referral to:

- Psychiatrist
- Psychologist e.g. Clinical or Counselling
- The local Child and Adolescent Mental Health Service (CAMHS) or Adult Mental Health Service (AMHS)
- Psychotherapist
- Dietitian.

In the public health system, a GP may refer a person to a specific treatment programme or CAMHS/AMHS.

- For example, hospital admission for an eating disorder by going to an accident and emergency department
- If there is no public service available, the HSE may apply for funding for a private treatment programme
- If you're ordinarily resident in Ireland, and require inpatient treatment that's necessary, and is not available in Ireland, the HSE may authorise the provision of this treatment outside of the State, if certain conditions are met
- Generally, there is a fee for attending a psychotherapist in a private capacity. This fee is determined by the practitioner themselves so fees can range from being minimal to more costly

- Some psychotherapists may specify that they have a 'sliding scale', which means that people pay based on their income or what they can afford to pay
- It is recommended that when you contact a therapist you should ask about their fee structure.

I think my family member has been visiting pro-ana sites, what can I do?

Harmful online content about eating disorders has been around since the early days of the internet, including tips on how to engage in eating disorder behaviours. The potential effects of accessing 'pro-ana' (pro-anorexia) or 'pro-mia' (pro-bulimia) material include: an impact on a person's thoughts, feelings and eating and weight behaviours and feeling under pressure. If you discover that your family member has been visiting pro-ana or pro-mia websites or social media, it is important not to judge or criticise this behaviour. Part of the appeal of these sites is that they allow people experiencing an eating disorder to feel accepted as they are. Sometimes people use both pro-recovery and pro-anorexia websites simultaneously - this reflects the confusing nature of eating disorders.

Do try to open a dialogue with your family member about the sites, and about why they were looking at them. It may be mere curiosity, but it could be something more serious. Be sure to listen to their responses, and try to accept their reasons without judgement.

If you can, guide your family member towards healthier, more constructive alternatives (e.g. online support meetings, message boards, etc. offered by reputable support organisations).

My son/daughter is starting college this year, what can I do to make sure s/he will be okay?

Starting college can be a particular challenge for a person with an eating disorder, or a person in recovery, and also for their family.

It is important to give your son/daughter the freedom to explore the new world they are entering, but at the same time maintain regular contact to ensure that they do not feel isolated.

Before the college year starts, it may be useful for you to explore what support services are available both on campus and in the surrounding area. This will allow you both to establish a new support network for your son/daughter which can help you both with the transition.

Why are the doctors insisting on re-feeding first?

If your family member is particularly underweight, it may be necessary for them to return to a healthier weight level before other forms of treatment can commence.

This is because the body requires a certain level of nourishment in order to sustain itself and in order to function at the level required to complete treatment in other forms.

Your support will be particularly important at this time as this can be quite a traumatic experience for your family member.

My family member is self-harming, what should I do?

Self-harm refers to the various methods in which people may harm themselves, including self-cutting and taking overdoses. Self-harm is extremely serious and potentially very dangerous.

Self-harm may be seen as a way of coping with overwhelming feelings, and can often co-exist with an eating disorder.

If your family member is engaging in actively self-destructive behaviour which is harming themselves it is vital that this is addressed urgently.

If you're particularly concerned, bring your family member to a GP or a hospital accident and emergency unit/emergency department for immediate medical treatment.

Will my family member ever be the same again?

Every life experience changes a person, and the process of recovering from an eating disorder is likely to have some impact on your family member; however recovery is a very positive process, and one which often allows the person to emerge as a more self-confident person with a clearer idea of who they are and a better grasp of the mechanisms required to cope with future hurdles.

My son/daughter wants to go on a school trip. What should I do?

If your family member wishes to go away on a school trip, it is likely that the teacher accompanying the class group will have to be informed about your family member's eating disorder. You may need to discuss this with your family member as a pre-condition of their participation.

If your family member wishes to go away without your supervision, it is important that you assess whether or not you feel they are ready. The advantages for them of having a trip away should be weighed against the potential risk of relapse or other difficulties.

Ultimately, if you feel that your family member is not ready for such a trip, you should be honest with them. If you decide they are ready to go, it may be useful to discuss potential stumbling blocks with your family member in advance to ensure that both you and your family member can feel confident about their ability to cope with any issues that may arise. Also, if they are in treatment, it is always important to discuss any trips with the treatment team.

How should I handle people (such as strangers) making comments about my family member's appearance?

When a person has an eating disorder, or is in recovery from an eating disorder, they can be extremely sensitive to comments made about their weight and appearance.

As a general rule, when a person is trying to recover it is best to avoid making any comments about their appearance in any way.

A seemingly innocent comment (for example: "You look well") can be perceived by a person with an eating disorder as having any number of alternative meanings – for example: that they have put on, or lost, weight. They may simply not be ready to appreciate this comment as it was intended.

While it may be possible to ensure that people known to the person recognise this, it is not always possible to ensure that strangers do not make comments about the person's appearance, especially if the person is visibly under/overweight.

A more difficult scenario may be that a comment intended as a concern (for example: "That person is far too thin") may be interpreted by your family member as a positive affirmation.

If this situation arises it is important to address it with your family member as soon as is appropriate. Try to be prepared to counter any distorted thinking.

If the physical effects of the eating disorder are visible, be aware of this reality. Keep in mind that this does not make it any easier for the person to hear comments about their appearance or assumptions about their health.

Talking with your family member about the comment and being realistic and reassuring about it by putting it in a context and by supporting the feelings your family member has around it.

To ignore a comment that the person has heard, runs the risk of allowing it to establish itself in the person's mind, which in turns runs the risk of sabotaging progress that has been made.

Our family member is about to come out of an inpatient programme - how should we prepare for her/his return, and what can we do to make the transition easier?

Before your family member returns home, ensure that you have had a full and extensive handover and information session with the staff who have been caring for them. Ask them what issues you need to be aware of and what practical aspects you need to put in place.

Things to be mindful of are:

- Has a routine around food been agreed and negotiated with your family member?
- Has a daily routine been agreed with your family member and yourselves?
- What are the difficult times of day for your family member and what supports can you put in place to help her or him through these?
- What freedoms should you give your family member and what do they expect from you when at home?
- Has your family member thought about what their expectations are of going home?
- Have you discussed your own fears about coping at home with the healthcare team?
- Have you, as a family, including siblings and other important family members, discussed and agreed on what will happen when your family member goes home?
- What supports do you have for yourself over the coming weeks?
- How do you deal with possible relapse?
- How do you deal with feeling frustrated by slow progress?
- Most importantly, have you talked with your family member about what you can do, and how you can make coming home easier for them to cope with?
- Do you have contact details for someone from the programme in case you have questions or need assistance?

Questions for your healthcare practitioner, treatment service provider

These are some suggested questions that may serve as a useful starting point in developing a good working relationship with your healthcare practitioner, while ensuring that both you and your family member feel comfortable with the treatment plan you are following.

Background

- Have you worked with eating disorders before?
- What's your training?

About treatment

- What treatment would you recommend?
- How involved will you be with the treatment process?
- What are the goals of treatment?
- How and when do you review whether the treatment is working?
- How frequently do you need to see my son/daughter?
- What happens if my family member doesn't respond to treatment?
- Do you have a sliding scale?

Family

- What role can I play?
- How involved will I be in my family member's treatment?
- How will we learn about our family member's progress?
- How does confidentiality work?

Appendix 1:

Additional issues

Autism and neurodivergence

Over the past number of years research has increasingly shown that there is a strong connection between autism and eating disorders. Estimates suggest that 20-30% of people with an eating disorder may also be autistic. To learn more about this see www.bodywhys.ie Other neurodivergencies such as ADHD may also overlap with eating disorders.

Body image

Body image describes how a person feels about their own body and appearance. It includes how you see yourself, how you think and feel about how you look and how you think others see you. Our body image often affects the way we treat our body. We all have negative thoughts and feelings about our body sometimes. However, persistent concerns in relation to body image can hold someone back from engaging fully with other aspects of their life. How we feel about our body is strongly linked to our overall well-being.

Being unable to see oneself as one actually is, and instead having a distorted image of what one looks like, is a core feature of an eating disorder. The person with an eating disorder is often unable to see themselves as others do, and do not see aspects of physical deterioration for example significant weight loss.

Visit our dedicated body image resource website www.bodywhysbodyimage.ie

Boys and men

Men may be reluctant to seek help in part due to the perception of eating disorders as being seen as a 'female issue'. They may feel they act as though they need to appear strong and that they do not require support from a general practitioner (GP). Illness may be seen as weakness and some men may ignore problems in the hope that they can get better without help [5-6].

Specific issues for men include [7-9]:

- Depression and shame
- Excessive exercise to compensate for caloric intake
- Excessive weight and exercise training
- Muscle dysmorphia
- Use of steroids and growth hormones
- Substance use
- Self-harm
- Isolation
- Uncertainty about how to seek help
- Protein overconsumption
- 'Cheat' meals
- Dietary restriction.

LGBTQ community

People from the lesbian, gay, bisexual and transgender and queer (LGBTQ) community may be more likely to develop an eating disorder or disordered eating behaviours [10-11]. For those who are transgender, pressure to conform to a gender, which is not in harmony with their body, may contribute to body dissatisfaction for both genders and subsequently an eating disorder. For gay men, trying to comply with specific roles, and the effect of the media, may also influence body dissatisfaction. Mental health problems, such as depression, low self-esteem and interpersonal difficulties, in LGBTQ people may heighten vulnerability to developing eating disorders [12]. The stress of being a minority, and discrimination, can also be risk factors for body dissatisfaction and disordered eating behaviours [13-15].

Appendix 2:

Terms you may hear about

Alexithymia
Alexithymia is when someone has difficulty recognising, identifying and describing emotions and feelings.

Amenorrhoea
The absence of normal menstrual flow. Diagnosis requires missing at least three consecutive menstrual cycles without being pregnant.

Anaemia
Anaemia is a deficiency of haemoglobin or red blood cells, caused by lack of vitamins and minerals in the diet. This condition is common amongst those affected by anorexia nervosa. Anaemia can cause weakness, fatigue, shortness of breath and heart palpitations.

Anorexia Athletica or Athletica Nervosa
The practice of exercising to excess in order to reach and/or maintain a low body weight. Though not a medically defined condition, this form of over-exercising is becoming increasingly common, particularly amongst athletes, dancers and others engaged in weight-focused activities.

Arrhythmia
Any irregularity in the rhythm of the heart; can lead to a heart attack and other heart problems.

Bibliotherapy
Bibliotherapy means reading as a healing activity – books, self-help material

Bingeing
'Bingeing', or binge eating, is defined as eating larger than normal quantities of food in a short space of time.

Body Dysmorphic Disorder (BDD)
Body Dysmorphic Disorder or body dysmorphia is an anxiety disorder that is linked to Obsessive Compulsive Disorder (OCD). In BDD, a person experiences intense preoccupation and engages in frequent checking behaviour such as mirror checking or skin picking due to a perceived physical defect in their appearance. The preoccupation causes severe emotional distress and significant impairment in the individual's life, including risk of suicide. The obsessive concern can relate to facial features, other parts of the body, hair or even odour. BDD shares some similarities to eating disorders in that involves compulsion, repetitive behaviours and distorted beliefs.

Body Mass Index (BMI)
Body Mass Index is a measurement of the relative percentages of fat and muscle in the body. The 'normal' BMI range is from 18.5 to 25, although this depends on the age and height of the person. A BMI of less than 18.5 is associated with the diagnosis of anorexia nervosa.

Calluses
Areas of toughened or hardened skin; calluses are often visible on the fingers of a person who has been engaging in self-induced vomiting.

Cognitive Behavioural Therapy (CBT)
CBT is a specific form of therapy which focuses on behaviours and thought processes. CBT is common in the treatment of eating disorders e.g. CBT-E.

CBT-AR
CBT for ARFID.

Cognitive Behavioural Therapy Enhanced (CBT-E)
Provided as part of the HSE's NCP-ED, CBT-E was originally developed for use for those attending outpatient treatment, but it has also been adapted for those who are treated as inpatients. CBT-E involves an initial assessment, followed by 20 sessions over 20 weeks. CBT-E is highly individualised and is also divided into four stages.

Community Mental Health Teams (CMHTs)
CMHTs treat and support people in their own homes and local community as much as possible and use therapies and group programmes. Services are provided in out-patient clinics, day hospitals and day centres.

Compulsive Exercise
Compulsive exercise doesn't have a set definition and may also be described as excessive exercise or exercise dependence. Possible signs of compulsive exercise are that it's rule driven, applied rigidly, it is time consuming and interferes with routine, that it continues despite illness or injury and the person feels the exercise will prevent some dreaded consequence or will reduce distress.

CORU (Health & Social Care Professionals Council)
CORU's role is to protect the public by promoting high standards of professional conduct, education, training and competence through statutory registration of health and social care professionals in Ireland. CORU was set up under the Health and Social Care Professionals Act 2005 (as amended).

Dehydration
A condition caused by excess loss of water from the body. Dehydration can be caused by sweating, vomiting or diarrhoea and is usually accompanied by deficiency of electrolytes. If untreated, severe dehydration can lead to shock.

Depression
A mood disorder characterised by feelings of hopelessness, impaired concentration, and a lack of energy or interest in usual activities. Depression can vary from mild to severe, affecting every aspect of a person's life, their relationships, family and work life.

DEXA Scan - (dual energy X-ray absorptiometry)
A DEXA scan is a form of x-ray that analyses the strength of bones. It is used to diagnose the potential onset of bone density problems which may lead to the development of osteoporosis.

Diuretic
A substance or drug that tends to increase the discharge of urine; may be used as a form of purging.

DSM Diagnostic Criteria
The Diagnostic and Statistical Manual of Mental Disorders (DSM) is published by the American Psychiatric Association and provides diagnostic criteria for psychiatric disorders.

Eating Disorder Not Otherwise Specified (EDNOS)
A diagnostic term used from 1987-2013. It applied to those who met some, but not all of the diagnostic criteria of one of the defined eating disorders. It was replaced with OSFED (see page 8).

Electrolyte (imbalance)
Electrolytes are body salts that conduct electricity in body fluids, blood and tissue. Electrolyte balance is essential so that the heart and muscles can function correctly. Inadequate intake of food or regular vomiting can cause an electrolyte imbalance which can be very dangerous.

Family Based Treatment (FBT)
Provided as part of NCP-ED in Ireland, FBT is a structured form of treatment where the involvement of parents/family is key.

Hematemesis
Vomiting of blood, which occurs after bleeding into the upper gastrointestinal tract. This can occur as a side-effect of ongoing purging behaviours associated with, in particular, bulimia nervosa.

Hypoglycaemia
An abnormally low level of glucose in the blood, which can cause weakness, dizziness and disorientation. Hypoglycaemia may occur as a side-effect of a very restricted diet.

ICD
ICD refers to the International Classification of Diseases published by the World Health Organisation (WHO). Each health condition is given a unique category and a list of symptoms for that condition is provided.

Ketosis
Ketosis is the accumulation of excess ketones (acids) in the blood and urine. This can happen when the body begins digesting its fat stores as a sole source of energy. Ketosis can lead to dehydration, kidney damage and heart arrhythmia.

Lanugo
Lanugo is a fine, downy hair that may grow on the face, back and arms of a person who is experiencing starvation or malnutrition. The hair is the body's mechanism for insulating itself when body fat is lost. Lanugo is a common physical sign of anorexia nervosa.

Laxative
A food or drug intended for relieving constipation; because laxatives can stimulate evacuation of the bowels, they are sometimes used as a form of purging.

Longstanding eating disorders
Longstanding eating disorders is a term used to describe when a person has had an eating disorder for a considerable period of time, or when a person's eating disorder might be considered more chronic in nature. They may also be referred to as severe and enduring eating disorders (SE-ED) and severe and enduring anorexia nervosa (SE-AN). There is no agreed definition on terminology at present.

Elements of longstanding eating disorders may include:

- Difficulty in maintaining regular functioning
- That the eating disorder experience is chronic in nature
- Behaviours aimed at weight loss: restriction, over-activity, purging
- Social isolation, ambivalence about change
- Treatment has been unsuccessful
- Multiple medical complications, repeat hospital admissions
- A lack of flexible thinking
- A strong feeling from the person that they can manage alone
- Extreme apprehension about loss of control
- Mistrust of interpersonal relationships
- Impaired decision making
- The illness is persistent
- High unemployment.

MANTRA
Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA).

MARSIPAN/Junior MARSIPAN
Management of Really Sick Patients with Anorexia Nervosa. Junior MARSIPAN is for under 18s. The MARSIPAN guidelines were replaced by the MEED guidelines.

MEED Guidance
Guidance on Recognising and Managing Medical Emergencies in Eating Disorders (MEED) were developed and published by the Royal College of Psychiatrists in the United Kingdom in May 2022.

Muscle Dysmorphia
Muscle dysmorphia, also sometimes referred to as reverse anorexia or bigorexia, is a condition in which a person becomes obsessively focused on feeling that they are too small and not muscular enough.

People with muscle dysmorphia resort to a variety of measures to try to increase muscle mass. These measures may include excessive exercise, including weight lifting and other body building exercises, excessive attention to diet, misuse of a high protein diet, misuse of steroids and other muscle-building drugs, training through injury, excessive attention to diet and protein. People with muscle dysmorphia may feel shame, anxiety, guilt and embarrassment linked to their experiences. Muscle failure, osteoporosis,

heart and kidney failure are among some of the risks associated with muscle dysmorphia. Depression is often co-existent with the condition.

Nasogastric (NG) feeding
If a person is hospitalised at a very low weight and are unwilling or unable to eat, it may be necessary to feed them through a tube to ensure they can gain sufficient weight to allow for other treatments. If this is the case, a plastic tube will be inserted through the nose and past the throat into the stomach.

New Maudsley Method
The New Maudsley Method equips carers and parents with the skills and communication tools to support their family member. It may be used in conjunction with treatment, but is not a treatment in itself.

National Institute for Health and Care Excellence (NICE)
NICE publish guidelines for a range of health conditions, including eating disorders.

Obsessive Compulsive Disorder (OCD)
OCD is an anxiety disorder where a person experiences intrusive, upsetting and repetitive thoughts and behaviours. Fear of dirt, germs and contamination are common. A person may feel unsafe. Compulsions can include excessive handwashing, cleaning and counting and repeating things to live by certain 'rules'. Obsessions can bring up feelings of disgust and fear. OCD overlaps with eating disorders in terms of obsessive and/or compulsive behaviours or tendencies.

Orthorexia Nervosa (ON)
ON was first identified by Dr Steven Bratman in 1997, however it is not currently a diagnosable eating disorder. In ON, a person focuses on the purity of food and its origin and this becomes how a person copes. He/she may develop rules in relation to food, lack flexibility and engage in strict diet behaviours and experience feelings of shame and guilt. Over time the rules increase and ON negatively affects a person's health.

Osteoporosis
Osteoporosis is the loss of bone density leading to porous, brittle bones which can cause bone fractures and skeletal deformities. Causes include lack of calcium and lower oestrogen levels.

Pica
In Pica, a person may eat non-food substances such as clay, chalk, string or hair. Pica can lead to serious medical complications such as poisoning, bowel and other problems.

Purging
Any behaviour driven by the motivation to rid the body of what has been ingested.

Relative Energy Deficiency in Sport (RED-S)
Previously, athletes experiencing difficulties were thought to have what was described as the female athlete triad (Triad), which referred to issues with bone mineral density, menstruation and low energy availability (with or without an eating disorder). Research and science has since evolved to highlight RED-S which can occur in athletes across a range of sports. Low energy availability or an energy deficit occurs because an athlete does not take in enough food (fuel) to meet the demands of their training, daily living, health and functioning. The consequences of RED-S are very serious and can damage a person's health, ranging from impairments of metabolic rate, menstrual function, bone health, immunity, and cardiovascular health. Psychological problems can be both, the result of and the cause of, RED-S. The screening and diagnosis of RED-S requires a good knowledge base of issues affecting athletes. Symptomatology can be subtle as athletes may find it hard to disclose their difficulties. When RED-S is addressed appropriately, athletes can return to good health and in turn, training, performance and sport.

Telehealth
Treatment, support psychotherapy or assessments delivered through web-based or technological devices and applications.

Trigger
The term 'trigger' has been used in the mental health field for a long period of time. Another way of thinking of trigger is 'activate', so when a person is triggered or talks about triggers they are describing things and circumstances that can make them stressed, anxious, worried or feeling unable to cope. Their negative feelings are linked to, or sparked by, triggers.

Tooth erosion
The erosion of tooth enamel is a common side-effect of frequent vomiting. Stomach acid that comes into contact with the teeth can wear down the enamel, which over time can cause a marked increase in tooth decay and related problems.

Particularly in the case of a person with bulimia nervosa, the person's dentist may be the first person to recognise the eating disorder if they can identify ongoing erosion of the enamel.

Thinspiration
Meaning 'inspiration towards thinness', thinspiration (or 'thinspo') is a culture of striving for extreme thinness and encouraging others, generally found online. This may be through images, messages, mantras, exercise routines, commentary and suggestions based around thin body ideals and aesthetics. Typically, this is to inspire fellow users and viewers to be thin and to admire the body depicted, with certain poses and a particular look. In most instances, the imagery depicts women. The nature of thinspiration content may be associated with the encouragement of and motivation to support, endorse and sustain eating disorder behaviours.

Bodywhys Services

The Bodywhys **Helpline 01-2107906** is a listening, information / signposting service for people with an eating disorder, as well as family and friends. For times of operation, see our website www.bodywhys.ie

Bodywhys provides **Online Support Groups**, **BodywhysConnect** (19+) and **YouthConnect** (13-18), for people with eating disorders only, which are particularly popular with those who wish to maintain anonymity or are living in an isolated area. The online groups operate 4-5 evenings per month and are based on our website at www.bodywhys.ie Simply create a username and log in at the times the groups are operating at. For adults, through BodywhysConnect, we also have specific online groups for men and third level/college students.

We have recently developed **Virtual Support Groups (18+)** for adults which are facilitated over video call software. You can find out more about these on our website or by contacting virtualgroups@bodywhys.ie

"Like a helpline call in an email", the Bodywhys **Email Support Service**, alex@bodywhys.ie People email for support, a listening ear, information and signposting.

An eating disorder diagnosis is not required to access support services provided by Bodywhys.

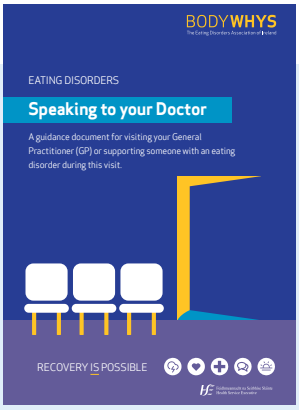
The Bodywhys **PiLaR Programme** is a free, 4-week, evidence-based psychoeducation and skills programme for family members supporting a person with an eating disorder.

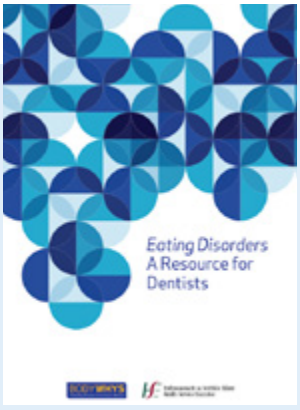
Please email pilar@bodywhys.ie to register and you will be contacted when a programme is starting. You can find out more about PiLaR on www.bodywhys.ie

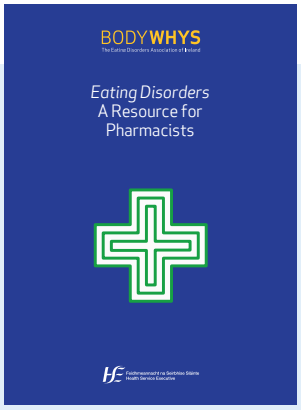
The Bodywhys website www.bodywhys.ie provides a wide variety of information on eating disorders, treatment options and support services.

Also accessible from the site:

- Links to other relevant eating disorder and mental health websites
- Directory of service providers, searchable by location
- Reading list
- SeeMySelf - a free online psychoeducation programme for those aged 15-24
- Body image resource www.bodywhysbodyimage.ie
- Podcasts and webinars.



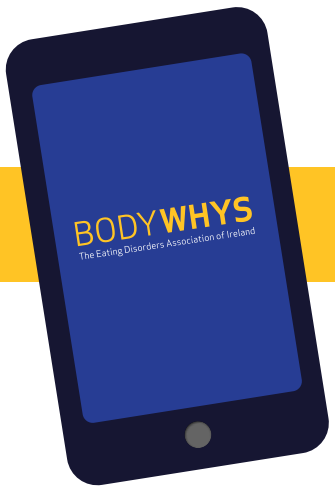




Free Information and Resources

Bodywhys offers a range of leaflets and resources including, but not limited to the following:

- Eating Disorders - A Guide for **Families**
- Eating Disorders - Speaking to your **Doctor**
- Eating Disorders - A Resource for **Dentists**
- Eating Disorders - A Resource for **Pharmacists**
- Eating Disorders - A **Treatment Guide**
- Binge Eating: Breaking the Cycle. A **self-help guide** towards recovery.



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Notes

Founded in 1995, Bodywhys – The Eating Disorders Association of Ireland - is the national voluntary organisation supporting people affected by eating disorders and their families. We provide a range of non-judgemental listening, information and support services, as well as school talks, training, literature, webinars. Bodywhys is the support partner to the HSE's National Clinical Programme for Eating Disorders (NCP-ED).

BODYWHYS
The Eating Disorders Association of Ireland

If you have used this guide either as a source of information or as a recovery tool, we would be very happy to hear your feedback. You can send this to **info@bodywhys.ie**

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EATING DISORDERS

A Guide for Families

Supporting, coping, understanding treatment and recovery

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Connecting for Life