




NAVIGATING YOUR
WAY TO HEALTH

A brief guide to approaching the
challenges, treatments and pathways to
recovery from an eating disorder



This resource, *Navigating Your Way to Health*, was developed with input from people who have a personal experience of eating disorders, their families and friends, as well as service providers and other stakeholders in New South Wales (NSW). It provides general information that has been based on a range of experiences, in the hope that this makes the journey a little easier for other people living with an eating disorder. The quotes used throughout the resource come directly from people with a personal experience of eating disorders.

Navigating Your Way to Health was developed to complement the *NSW Service Plan for People with Eating*

Disorders 2013–2018. It was funded by the NSW Ministry of Health, under the auspices of the InsideOut Institute at the Boden Institute, the University of Sydney and developed by **Everymind** in collaboration with the Butterfly Foundation and stakeholders in NSW.

The information in this resource will support your contact with health workers in NSW and supports in your local community. Do not rely on this resource alone.

Find out more at
www.insideoutinstitute.org.au and
www.everymind.org.au



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NAVIGATING THIS RESOURCE

How this information might assist you

This resource has been developed for people who have an eating disorder or who have some eating behaviours that place them at risk of developing an eating disorder. It's for people of any gender, of any age and at any stage of an eating disorder.

The resource is designed to be a starting point for working through some of the questions that can come up and offers some information and ideas that you might find useful. You can use it alongside your treatment plan and add your own notes and other useful information that you'd like to keep.

People who live with an eating disorder as well as their families, friends and carers have played an important role in the development of this resource. Through consultation, people shared their experiences which included the challenges they faced. People who had recovered from an eating disorder expressed an overwhelming feeling of gratitude and relief for the life they have now and stressed that navigating your way back to health is possible following the diagnosis of an eating disorder. Their words and stories have been used throughout this resource.

Experiencing an eating disorder and navigating your way back to health can be challenging. However, it is important to remember that with the right treatment and support, and with your personal commitment, recovery from an eating disorder is achievable. Getting help is the first step. The sooner you start treatment, the shorter the recovery process will be.

Using this resource

This resource has been developed for people in NSW and supports the *NSW Service Plan for People with Eating Disorders 2013-2018*. The general information contained in this resource, however, may be helpful to people across Australia. The information in this booklet should not be taken as medical advice and is best used alongside the support of trained health professionals, such as your GP, mental health professionals, and your own support networks.

You may find it useful to access other information and support. See the section 'Finding information and services' on page 32.

Another complementary resource has been developed for your family and friends. It is called *Navigating Their Way to Health* and can be accessed online at www.insideoutinstitute.org.au or www.everymind.org.au

" I had bulimia from around age 13, so was dealing with the new challenges of high school... For me it was a way of dealing with self-doubt and self-confidence issues and I probably didn't want to admit there was a serious problem.

**I THINK WHAT I REALLY WANTED WAS
TO KNOW I WASN'T A FREAK**

or the only one in the world who felt compelled to do such a self-destructive thing.

I'd like this resource to include stories of other people who have overcome the illness... including strategies, triggers and how good life is on the other side. Because it is an amazing feeling to be free of an eating disorder. "

CONTENTS
PAGE

08.
NAVIGATING
EATING DISORDERS

28.
NAVIGATING
DIFFICULT
CONVERSATIONS

30.
NAVIGATING LIFE
AFTER AN EATING
DISORDER

14.
NAVIGATING CARE:
GETTING HELP
EARLY

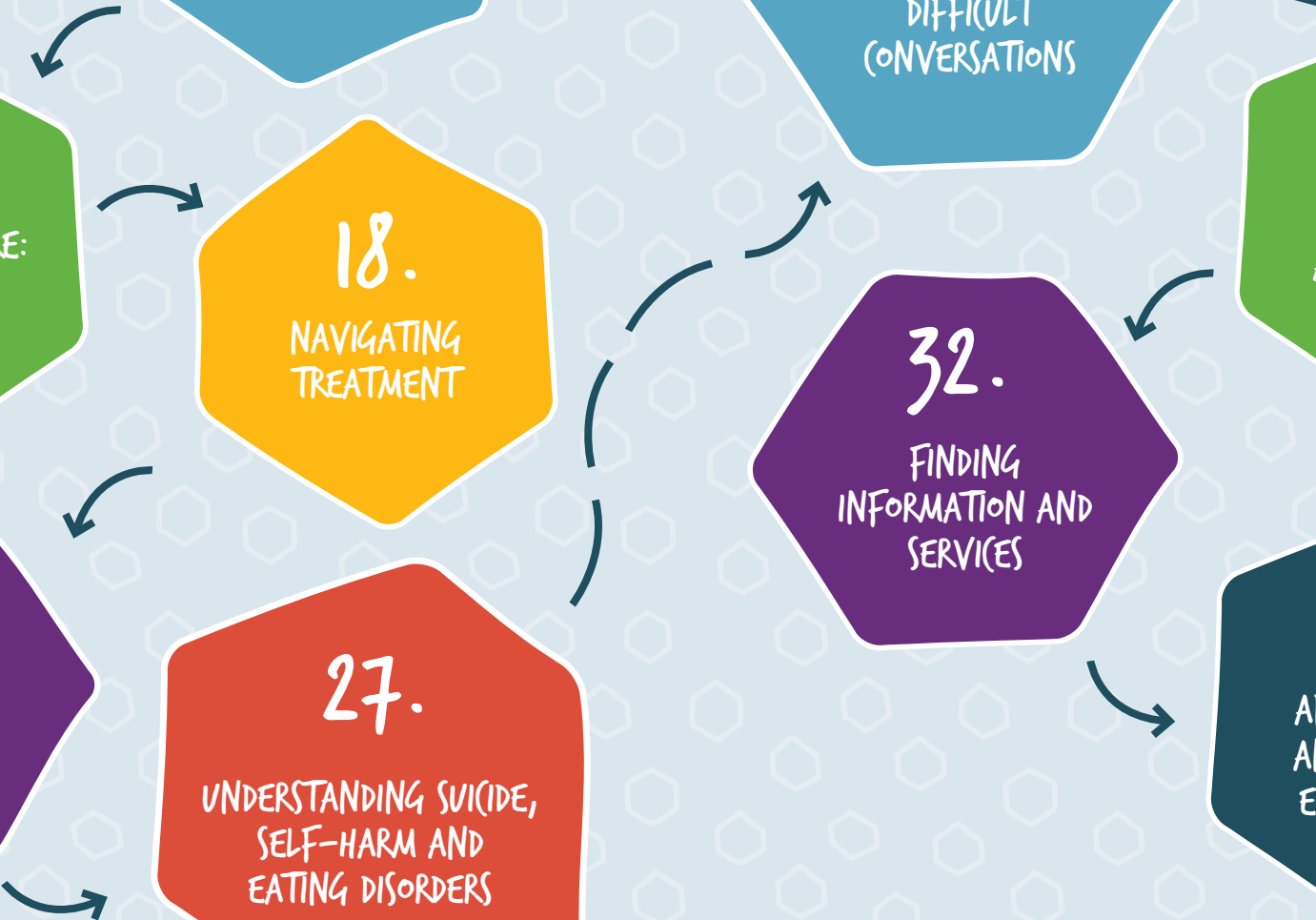
18.
NAVIGATING
TREATMENT

32.
FINDING
INFORMATION AND
SERVICES

24.
NAVIGATING
THE RECOVERY
JOURNEY

27.
UNDERSTANDING SUICIDE,
SELF-HARM AND
EATING DISORDERS

36.
APPENDIX A: SIGNS
AND SYMPTOMS OF
EATING DISORDERS



NAVIGATING EATING DISORDERS

Types of eating disorders

Even though everyone's experience of an eating disorder is different, it can be helpful to know about the broad diagnostic categories that are used within the health system for eating disorders. Eating disorders are classified into four different types, depending on what is happening for you and how often these occur. However, it is important to note that symptoms can vary and people can move from one diagnosis to another.

Anorexia Nervosa is characterised by extreme food restriction, low body weight, self-evaluation based on weight/shape, and a distorted body image. Binge eating and compensatory behaviours (for example self-induced vomiting or excessive exercise) may also occur. As people who have anorexia become more unwell they may display increased obsessive or rigid ways of thinking and behaving, including extreme dieting strategies.

Bulimia Nervosa is characterised by repeated episodes of binge eating,

followed by behaviours that the person believes will make up for the food they have eaten (for example self-induced vomiting or excessive exercise) called 'compensatory behaviours'. People who experience bulimia nervosa place an excessive emphasis on body shape and weight when evaluating themselves. The disorder can be difficult to detect as people who experience bulimia nervosa typically maintain an average weight, or slightly above or below average weight.

Binge Eating Disorder is a common eating disorder that involves two key features: (1) eating a very large amount of food within a relatively short period of time; (2) feeling a sense of loss of control while eating. Binges are generally followed by feelings of guilt, shame, disgust or depression.

Other Specified Feeding or Eating Disorder (OSFED) is a term used to describe the different types of disordered eating behaviours that are not able to be classified as one of the eating disorders described previously. That is not to say that they are less serious or less harmful to a person's health. The diagnostic category simply reflects the many different ways in which eating disorders can appear in different people.

More information about warning signs and risks associated with eating disorders are included as Appendix A in this resource. You might want to talk through these with your health professional to identify which

of these warning signs or triggers relate to your experience. This can help you look out for them again in the future, or talk to people around you about them.

WEBSITES FOR FURTHER INFORMATION ON EATING DISORDERS

InsideOut Institute
www.insideoutinstitute.org.au

The Butterfly Foundation
www.thebutterflyfoundation.org.au

**National Eating Disorders
Collaboration**
www.nedc.com.au

A full list of useful resources is
provided on page 34.

While eating disorders are often portrayed as illnesses that only affect females, IT IS ESTIMATED THAT A THIRD OF PEOPLE LIVING WITH AN EATING DISORDER ARE MALE, and many recent community-based studies have found that anorexia nervosa is more common among males than previously thought.

Common misconceptions

There are a range of myths about eating disorders that can impact on how you may feel and how others around you may react. It is important to understand some of those myths, so you know what is fact or fiction. The following myths have been adapted from information developed by the National Eating Disorders Collaboration and are available at www.nedc.com.au/myths

MYTH: Once you have an eating disorder you never get better.

FACT: It is certainly possible to recover from an eating disorder, even if you have been living with an eating disorder for many years. The path to recovery can be long and challenging, however with the right team supporting you and a high level of commitment, recovery is possible.

MYTH: Eating disorders only affect young females.

FACT: Eating disorders can affect anyone. It is true that the peak period for the onset of eating disorders is between the ages of 12 and 25 years. It is also true that one group of people with a high risk of eating disorders is females. However, eating disorders occur across all cultural and socio-economic backgrounds, in people of all ages (from children to older people), and occur in both males and females.

MYTH: Eating disorders are not serious; they are a lifestyle choice.

FACT: Eating disorders are serious and can be life threatening; they are not a lifestyle choice or a diet gone 'too far'. Eating disorders involve considerable psychological distress as well as serious medical complications.

A person with an eating disorder has a mental illness and their thoughts and emotions result in severe changes in their behaviour around eating and/or behaviours like exercising.

MYTH: Eating disorders are a cry for attention.

FACT: Although a person with an eating disorder does need attention and does need support, having an eating disorder is not about attention seeking. In fact, a person may go to great lengths to hide their behaviour, or may not recognise that there is anything wrong.

An eating disorder is not a phase someone is going through; instead it is a serious mental illness that requires appropriate treatment and support.

**" I think it's something that
VERY FEW PEOPLE
UNDERSTAND
AND KNOW WHAT
TO SAY
and what is
appropriate to try
and do to help. "**

MYTH: Dieting is a normal part of life.

FACT: Dieting is associated with a number of poor health and mental health outcomes, particularly if it starts when a person is a child or an adolescent. While some moderate and sustainable changes in diet and exercise have been shown to be safe, significant mental and physical consequences may occur with unhealthy dieting practices. Dieting is also associated with other health concerns including depression, anxiety, nutritional and metabolic problems and, contrary to expectation, an increase in weight.

MYTH: I don't deserve treatment because I don't 'look sick'.

FACT: The severity and impact of an eating disorder can't be determined by the physical appearance of a person. All people who are experiencing signs and symptoms or who are diagnosed with an eating disorder are worthy of receiving treatment and need that treatment to navigate their way to health. It makes no difference how you look, it is what you are thinking and feeling that is the indicator of what is really going on.

MYTH: If I binge eat it means I am a weak person.

FACT: Bingeing is not the result of being weak. Treatment can help you uncover and to control the factors that influence eating behaviours, but weakness is not one of them. Eating disorders are serious mental illnesses and they vary for everyone. It is important to seek help so you can work on identifying what your individual triggers might be.

MYTH: Families, particularly parents, are to blame for eating disorders.

FACT: There is no evidence that eating disorders are caused by particular parenting styles, and it is generally agreed that family and friends play a crucial role in the care, support and recovery of people with eating disorders.

MYTH: There's no point getting treatment until you are sure you want to recover.

FACT: Many people living with an eating disorder are unsure about whether or not they want to access treatment. You may be conflicted about whether you want things to change or want things to stay the same. People can be worried about what recovery might mean; and that's okay. Getting support from trained professionals will help you to manage this anxiety and navigate your way through the urges, desires and thoughts you may be experiencing.

Some other facts about eating disorders

- › Eating disorders are serious and complex mental illnesses that can have serious physical consequences.
- › About 4% of the population is affected by an eating disorder at any one time – this means almost 300,000 people in NSW alone.
- › While about two thirds of people who experience an eating disorder are female, eating disorders also affect men and boys.
- › While most common in young people, eating disorders can affect people of all ages and are particularly associated with life transitions e.g. puberty, entering high school or university, or experiencing major stress.
- › While there is no single identified cause for eating disorders, some risk factors associated with eating disorders include restrictive dieting, negative body image, a personal or family history of mental illness (especially an eating disorder), psychological factors, developmental changes and personality traits (e.g. perfectionism).
- › Many people who experience an eating disorder may also experience depression, anxiety, and alcohol/ substance-use problems.
- › A person living with an eating disorder may experience long-term impacts.
- › Treatments that have proven most effective are administered in the early years of having an eating disorder.
- › For these reasons, **it's important to identify and treat eating disorders as early as possible.**

NAVIGATING CARE: GETTING HELP EARLY

Getting help early

If you are concerned about your eating, the way you feel about your body, or you know that you have an eating disorder, it is important to get treatment and support. If you have not yet seen a health professional, it is important to do so as soon as possible. You may feel unsure about getting help; this is okay.

Eating disorders are serious, potentially life threatening, mental illnesses. **However, with appropriate treatment and support, recovery from an eating disorder is possible.**

Taking the first step of getting treatment can be hard; some days you may want to recover and other days you may not. Being in two minds about change is completely normal. You don't have to commit all at once, you can map your journey and just take one step at a time. Booking in and seeing the health professional is not the same as committing to change immediately – there is no harm in at least talking to someone.

It is important to note here that for most eating disorders a common symptom is the feeling of uncertainty about whether or not you should get treatment or even if you want treatment.

Therapists call this

AMBIVALENCE ABOUT CHANGE and it is regarded as a central feature of an eating disorder. It arises because an eating disorder often feels like it could be 'doing you good', that it is your 'friend' or it makes you feel 'in control' and effective.

It is natural to be unsure, but part of the treatment will be about

HELPING YOU LEARN OTHER WAYS OF FEELING IN CONTROL

and ensuring you have the help and support that you need.

Just as every person is unique, the pathway to recovery will be different for everyone. There is no one-size-fits-all treatment approach.

Family and carer involvement in treatment is usually associated with

BETTER OUTCOMES, so think about who you can involve to support you as you navigate your way back to health.

The type of treatment that is best suited to you will depend on a range of factors - including your age, any medical complications, the symptoms you are experiencing and any other medical and mental health issues you may also be experiencing.

Taking the first step

The first step to finding the right treatment and support is to speak with a health professional and discuss what is happening for you.

For many people, the general practitioner (GP) will be the first point of contact with the health service (or perhaps a paediatrician for a younger person). A GP can provide an initial assessment of your physical health and help with referrals to other health services and professionals. You, or your family member, can also contact mental health services in NSW through the **Mental Health Line - 1800 011 511**

ACCESSING MENTAL HEALTH SERVICES IN NSW

The Mental Health Line is a 24-hour telephone access service that acts as a state-wide single point of entry to connect people in NSW with the right type of mental health care.

The InsideOut Institute in NSW also provide a 'Search for a Practitioner' service on their website www.insideoutinstitute.org.au.

The Butterfly Foundation's National Helpline can also provide recommendations about specialists – **1800 33 4673**.

Treatment typically involves collaboration between the person with an eating disorder, their family/carer and a number of health professionals.

This might include medical doctors (GPs, psychiatrists, paediatricians), nurses, dietitians and/or mental health professionals (see page 20 for a summary).

Depending on where you live in NSW there will be a range of services available through the health service and private practitioners. In some areas, specialist treatment centres are available and in other areas of NSW, health professionals with expertise in the treatment of eating disorders can provide services locally.

The NSW Service Plan for People with Eating Disorders has been developed to ensure people of all ages can get access to quality treatment and support. While there are a range of specialist services, there is also support for a range of other services across NSW to assess, treat and support people with eating disorders and their families in their local community.

Signs and symptoms that something is not quite right

Attempting to tackle an eating disorder alone is really difficult. It is important to talk to someone you trust as soon as you recognise something isn't quite right.

This can be scary and you may feel embarrassed, guilty or ashamed. However, it is important to remember that you have not done anything wrong; that you have an illness that requires treatment, just like any other.

If you answer yes to one or more of the questions below, talk to a trusted person in your life and seek support as soon as possible.

- › Is food dominating your life?
- › Are you worried about being overweight?
- › Are you vomiting after you eat or exercising a lot more than other people?
- › Are you finding yourself hiding food or eating in secret?
- › Does your weight affect how you feel about yourself?
- › Do you feel out of control when you eat?

Appendix A of this resource provides a list of signs and symptoms of different types of eating disorders. You could use this to find things that relate to you and talk to a health professional about these.

Seeking help at the earliest possible point is much better than waiting until the illness has taken over.

Telling someone what is going on

Talking to a family or friend

Sometimes it can be difficult to see the signs and symptoms of an eating disorder in yourself.

Your friends or family may start to worry and want to talk to you about what is going on for you.

This can be quite confronting and it is natural to have a range of feelings – you might feel angry, worried, frustrated, or scared. Try to choose one or two people to be honest with about what you are thinking and feeling.

Surround yourself with people you trust and people who will listen. Eating disorders thrive on secrecy, so being open with loved ones can help take away some of the power that the eating disorder may have over you. Having friends and family who know what is going on and who can talk to you about what you need, without being overly critical, is very important. They can assist you with the journey ahead.

Talking to someone from your network

There may be somebody in your community that you feel comfortable talking to – such as a teacher, youth group leader or family friend who is a supportive figure in your life.

Some people will feel most comfortable talking to their family, but others may prefer to talk to a person outside of their immediate circle of family and friends.

Everybody's situation is unique and personal, so it is important you choose the avenue most suitable for you.

“ I relied a lot on my family when I was sick but I HAD A REALLY GOOD THERAPIST I could talk to... I didn't feel like my friends or family could understand what I was going through so for me that really helped. ”

Talking to your GP

It is important to go to your GP if you have any concerns about your health, including thoughts and behaviours that could indicate an eating disorder. Your GP will begin by asking a few questions to determine what is going on for you, and will then make recommendations about the next steps. Your GP might refer you to a mental health professional in your local area.

If you feel that your doctor does not understand what you are experiencing, seek out a health professional that does. Putting the right treatment team together takes time, and can involve navigation through the health system.

Having a good doctor who understands you and the seriousness of eating disorders is really important as they can help you access other health professionals that might be able to assist.

Talking to a service by telephone or online

If you would prefer to talk to someone on the telephone or the internet, you can

consider using a confidential service like one of the following to get some early information and advice:

- The Butterfly Foundation's National Helpline is for anyone seeking information and support around eating disorders and body image issues. Call **1800 33 4673**, access online counselling from **www.thebutterflyfoundation.org.au** or email support@thebutterflyfoundation.org.au, 8am to 9pm, Monday to Friday
- eheadspace offers support and advice from trained counsellors to help anyone 12-25 years old work through anything that is bothering them **www.eheadspace.org.au**
- You can contact mental health services directly in NSW through the Mental Health Line - **1800 011 511**.

TIP: BE CAREFUL WITH INFORMATION YOU FIND ONLINE

There's a lot of information online about eating disorders. To find accurate information look for websites from trustworthy sources such as government organisations and peak bodies (see pages 32-34 for some recommendations). These sites can be a helpful resource in addition to the support you get from health professionals.

Be aware that some websites can get in the way of recovering from an eating disorder as they promote disordered thinking and behaviour, minimise the significant health implications associated with eating disorders, and discourage people from seeking help.

NAVIGATING TREATMENT

What treatments are available?

There are many different treatments available for eating disorders. The treatment team will be able to provide guidance about the best approach for you. This should be focused on what might work best for you and the specific goals you have for your recovery.

A treatment plan will generally involve a mix of medical, nutritional and psychological support. The treatment should also recognise and address the different phases of the illness, the specific symptoms you have, and provide ongoing support to reduce the risk of relapse (or becoming unwell again). It's helpful if a treatment plan is holistic – taking into consideration things such as social, occupational and spiritual support.

You may need to be an active agent in putting your treatment team together. Don't be afraid to ask questions and keep seeking information about the things, and the people, you will need to get you well.

Treatments for Anorexia Nervosa

Different treatments are likely to be beneficial at different stages of the illness.

> For children and adolescents, Maudsley Family-Based Therapy has the strongest evidence base for treatment of anorexia nervosa. Make sure you explore your treatment options with your treatment team to determine which therapy will be most suitable to you and your family, being mindful that some treatments are not always suitable for every family.

> For adults, the best evidence for treatment of anorexia nervosa is a combination of nutritional rehabilitation and psychotherapy.

Community-based treatment usually involves a mix of psychological support, medical monitoring, dietetic support and medication if required (e.g. for depression or anxiety). This can include family-based treatments which are highly recommended for children and adolescents. The frequency of appointments will vary depending on the severity of the eating disorder.

Community-based treatment may involve regular individual consultations with health professionals (dietitians and/or psychologists), and/or it may involve a more intensive day program in which individuals attend group treatment for a number of hours on one or more days per week. A GP is usually always involved as part of the treatment team.

Hospital-based treatment may be required when a person needs medical stabilisation, nutritional rehabilitation, and intensive support to manage disordered eating behaviours or is at risk of self-harm or suicide. Hospitalisation is usually followed by community-based treatment (or outpatient treatment).

“ I have probably experienced most types of treatments – it took a long time for me to realise I had a problem but I was extremely sick.

THE THING FOR ME WAS FINDING SOMETHING THAT I COULD CONNECT WITH and once I found that and I started getting better I realised I didn't want my life to be controlled by my eating disorder. ”

Treatments for Bulimia Nervosa and Binge Eating Disorder

Generally, **community-based treatment** is appropriate with research suggesting that

a range of psychological therapies such as Cognitive Behaviour Therapy (CBT), Dialectical Behaviour Therapy (DBT) and Interpersonal Therapy (IPT) is most effective. Ongoing medical monitoring by a GP is also important and dietetic support may be useful too.

For adults, CBT has been shown to be the most effective for treatment of bulimia nervosa. For children and adolescents, both Maudsley Family-Based Therapy and CBT have research to support their use with bulimia nervosa.

Treatment may be provided individually or in groups. Some people may benefit from more intensive community-based day programs, which involve treatment for a number of hours a day, one or more days per week. It is important to work with your treatment provider to determine which therapy will be most suitable for you.

Hospital-based treatment may be required for bulimia nervosa if the symptoms are very severe, if there are any medical complications that need immediate treatment, or if there is a risk of self-harm or suicide.

Treatments for Other Specified Feeding and Eating Disorders (OSFED)

The best treatment for OSFED will depend on the symptoms you are experiencing. If the symptoms are similar to anorexia nervosa, then the treatment should be the same as for someone with anorexia nervosa. Similarly, if the symptoms overlap with bulimia nervosa or binge eating disorder, then treatment should follow these approaches.

CHOOSING YOUR TREATMENT TEAM

It's important to have a good relationship with the health professionals that you are working with. This means that they understand your experience of the eating disorder and that you:

- feel comfortable to talk openly without fear of judgement
 - trust each other
 - work as a team.

If you don't feel comfortable with the health professional/s you are seeing, talk to them about how you are feeling.

Treatment can be tough and may impact how you feel about your treatment team so it's good to separate out the challenges of treatment from any tensions in these relationships.

A good therapist won't always say what you want to hear and they may challenge the eating disorder at times. However if you don't feel listened to or feel you are in the wrong hands, you can choose to seek treatment elsewhere.

Treatment approaches

Psychotherapy

Psychotherapy utilises a variety of techniques to manage and treat someone with an eating disorder. Emphasis during psychotherapy is placed on thoughts, emotions, behaviours, patterns of thinking, motivations and relationships. Psychotherapy can be provided individually or in a group with other people living with an eating disorder.

Family approaches

Family approaches are most commonly used when children, adolescents, and young adults are experiencing an eating disorder, but they can also be recommended for adults. Family approaches will involve the whole family or support network in treatment, with the aim of supporting and educating the family about how to care for the person with the eating disorder while also providing treatment to the person. Focus is also placed on strengthening family relationships, and in the case of children and adolescents, empowering the parents under the guidance of a specialist to restore nutrition in the child or help the child tackle the symptoms of the eating disorder.

Nutritional management

Nutritional management is provided by a dietitian and involves education and therapeutic support to encourage healthy nutritional intake and eating behaviours as well as achieving and maintaining a healthy weight.

Medication

Medication-based approaches are often used if a person also has another type of mental health problem, such as depression, anxiety, insomnia or psychosis. This is sometimes talked about by professionals as a co-morbid disorder. Medications can be prescribed by your GP or another doctor (such as a psychiatrist) and should only be used in conjunction with other treatment approaches.

A NOTE ABOUT MEDICATIONS

Unlike antibiotics, medications to help with your mental health can take up to four weeks and in some cases longer to take effect. Sometimes medications can make you feel worse until they start to work.

Make sure you have regular reviews with your doctor if you are starting a new medication and talk to your support network about how you are feeling.

What professionals may be involved?

Medical practitioners

General Practitioner

A general practitioner (GP) is a doctor who has general medical expertise. A GP will be able to:

- conduct a physical health assessment
- provide information about eating disorders
- make a referral to a mental health

professional for a more detailed assessment and treatment

- make a referral to a dietitian for specialist dietary support and treatment
- provide information about other support services
- make arrangements for a hospital admission to restore physical health if it is required.

Paediatrician

A paediatrician is a doctor who has medical expertise with infants, children and adolescents. Paediatricians can:

- conduct an initial assessment
- talk to carers or parents to help them understand what is happening
- provide information about treatment options
- make referrals to other specialist services
- admit patients to hospital and develop treatment plans for children and adolescents
- specialise in the medical management of younger patients with eating disorders.

Physician

A physician is a doctor who has undertaken further training in a medical specialty to diagnose and manage complex problems. This may include:

- an **endocrinologist**, who will look into hormonal imbalances, particularly the absence of normal menstruation in females
- a **gastroenterologist**, who will look into issues regarding the gastrointestinal tract, particularly in relation to pain, constipation and vomiting caused by restricting and purging behaviours.

Psychiatrist

A psychiatrist is a medical practitioner who specialises in the diagnosis and treatment of mental, emotional and behavioural disorders. Psychiatrists can:

- provide a thorough assessment and develop treatment plans
- provide ongoing therapy
- prescribe medication and monitor how the medication is working.

Mental health professionals

Mental health professionals have similar roles in providing evidence-based care for individuals with an eating disorder.

Psychologist

Psychologists are commonly involved in the treatment of eating disorders. They will:

- use a variety of therapeutic approaches to address the psychological issues associated with the eating disorder as well as other problems that people may experience alongside the eating disorder.

“ I found it difficult at first because I didn't see I had a problem but I EVENTUALLY FOUND A GOOD PSYCHOLOGIST when I lived in Sydney. Then when I moved back home so my parents could look after me I was Skyping my psychologist because I was four hours away... I'm glad we have that kind of technology now.”

Social Workers

A social worker is often involved with treatment if the person presents with behavioural, social or mental health problems in addition to an eating disorder. Social workers can provide individual, couple and family counselling for the person and their carers or family. They can also provide evidence-based treatment for eating disorders and facilitate other supports that may be needed.

Occupational Therapists

Occupational therapists and rehabilitation therapists help someone experiencing an eating disorder to develop, practice and implement the life skills they require to address disordered eating behaviours. They can also provide evidence-based treatment for eating disorders.

Nurses and Mental Health Nurses

Nurses and mental health nurses form a part of the multidisciplinary treatment team. Their role is to provide practical medical and mental health care for someone experiencing an eating disorder while that person is hospitalised or gaining treatment via the health system.

Family Therapists

For children and adolescents the treatment with the most evidence is family-based treatment. This therapy can be delivered by different types of health practitioners (e.g. psychologists, social workers, counsellors), not just those called family therapists. This type of therapy will not suit all families, so work with your health practitioners to determine if it is likely to work for you.

Nutritional management

Dietitians

A dietitian is a health professional qualified in nutrition and dietetics. A dietitian can:

- provide practical advice about food and healthy eating
- dispel food myths held by individuals and family members
- establish an eating plan to help support recovery and improve understanding of the food-body relationship.

About confidentiality

Family members, friends and support people can help throughout the assessment, treatment and recovery phases, but how involved they are may depend on your age, the type of relationship you have with them and whether you give permission for them to be involved.

All health professionals are legally required to maintain their patient's confidentiality but there are exceptions, if:

- you have given permission to share personal information with them
- they believe you may hurt yourself or someone else
- they are required to talk to another health professional about your treatment
- they are legally required to share confidential information.

A person's status under the NSW Mental Health Act can mean that the primary person responsible for their care is entitled to certain information regardless of the person's consent e.g. if the person is an involuntary patient or under a Community Treatment Order.

Family and carer involvement in treatment is usually associated with better outcomes. Think about how your family/carer can best support you in your recovery.

Confidentiality for children and adolescents

In Australia, parents and teenagers both have rights to consent to a teenager's treatment. A young person can consent to simple health care treatments without a parent at around 14 years old.

However, the treatment for eating disorders is complex. Denial and secrecy are common features of these illnesses and can hinder recovery if they are not addressed.

It is best practice for the family and/or support people of children and adolescents to be actively involved throughout the treatment process.

If you are unsure how confidentiality applies in your situation, ask the health professional to explain it to you and your support person, so that you both understand how it works.

NAVIGATING THE RECOVERY JOURNEY

Recovery is different for everyone

Recovery from an eating disorder will be different for everyone, but it generally involves challenging and overcoming the beliefs and behaviours associated with the illness as well as developing healthier ways of eating, thinking and behaving.

Recovery often means a person will have a healthier self-esteem, can return to social activities and interests they may have stopped, and integrate back into daily life.

There is no set time for how long recovery will take as this will depend on a number of factors including the treatment and support received.

Sometimes it may feel that recovery is slow or even an impossible task. However, with the appropriate treatment and a high level of personal commitment, recovery from an eating disorder is definitely possible.

“ I don't know what it was for me but something clicked –

**I DIDN'T WANT TO DIE
AND WANTED TO BE ABLE
TO HAVE A FAMILY OF
MY OWN SOMEDAY.**

That's probably when I really started to get better... I've had ups and downs throughout it all but I'm in a much better space now where I'm actually living – I definitely wasn't before. “

Evidence shows that the sooner you start treatment for an eating disorder, the shorter the recovery process will be.

Who to involve in your recovery

Your treatment team will be vital to your recovery. They can help you work through the different aspects of your eating disorder, explore what your triggers are and work with you to overcome these. It is also important to surround yourself with people who are supportive and

understanding of your eating disorder and recovery journey.

Your family is usually one of your biggest supports when going through treatment and recovery from an eating disorder, but there may be other friends or community networks you want to involve as well.

Recovery can be hard, and at times you may want to give up, but having friends and family around you that you trust and who will listen to you without fear of judgement can make a real difference. It is also important to have people who will tell you the truth in a supportive way, to help you challenge thoughts and behaviours.

Different people in your life may have different roles throughout your recovery journey. This can include providing ongoing support as well as active involvement in managing eating disorder behaviours.

- > **A parent or family member** can help you through the treatment process.
- > **A friend** may be great if you are feeling down and want to do something socially that is not about your eating disorder.
- > **A school teacher or counsellor** may be a good person to talk to and help you to feel included at school and in class activities.
- > **A neighbour or work colleague** might be a good person to talk to about other things other than the eating disorder (e.g. sports, current affairs).
- > **A religious or community leader** may help you to connect with spiritual beliefs or community activities.

- > **A health professional** may help with strategies to assist with managing stress.
- > **A telephone or online counselling service** may provide non-judgemental support if things get tough.

The Butterfly Foundation has a telephone and online support service as well as online and face-to-face support groups for people who are recovering from an eating disorder, carers and siblings.
Visit The Butterfly Foundation's website
www.thebutterflyfoundation.org.au
call 1800 33 4673
or email support@thebutterflyfoundation.org.au
8am to 9pm, Monday to Friday.

Useful complementary activities

In addition to the various treatments available for eating disorders, there are complementary activities that people with eating disorders have found useful when navigating their way back to health. Some of these are listed below, but there may be other things that work for you. Talk through options with your health professional and your support network.

Yoga can reduce stress levels, which can lead to improved health and clearer thinking.

Meditation can help with managing negative thoughts and stress. It can also increase self-acceptance and promote awareness of the body.

Remedial massage can increase feelings of wellbeing and assist with reducing stress levels.

Mindfulness teaches people to respond to their thoughts without judgment and to be present in their thoughts, feelings and body. It can assist in teaching someone to regulate their emotions and manage distress.

What if I relapse?

While some people may experience a relapse as they are recovering from an eating disorder there are some things you can do to try and prevent this from occurring:

- make sure you have a solid support network
- stick with your treatment plan, and talk to your treatment team about any challenges you are having
- participate in activities that make you feel positive about yourself
- avoid media and social media channels that promote being thin, or make you feel bad about yourself
- talk to your friends and family about your concerns and what they can do to support you.

A relapse does not signify a failure to recover; instead it is simply a part of the recovery journey.

Relapses offer an opportunity to consolidate what works for you as an individual, help to further identify your triggers for relapse, and can provide an opportunity to learn new coping techniques. This can help you to recover more quickly or easily next time.

If a relapse does occur:

- focus on navigating your way back to health
- seek help from your treatment team and support network
- use the coping skills and techniques you have learned
- try to identify the triggers that led to the relapse and consider how you could manage these triggers next time
- boost your self-esteem by spending time with your support network and engaging in activities that you enjoy.

UNDERSTANDING SUICIDE, SELF-HARM AND EATING DISORDERS

It is not uncommon for people who experience an eating disorder to also harm themselves or have thoughts about suicide.

Some people can experience intense psychological pain along with negative feelings that seem difficult to get relief from. These feelings can come about because of the way the eating disorder is impacting on their life, but it may also be because of other stressful life events.

It is important to talk to someone you trust and your health professional if you are having thoughts of self-harm or suicide.

A health professional can:

- help you to develop strategies that reduce uncomfortable feelings
- provide a different perspective in what is happening
- link you with other doctors, health professionals or services if they are needed
- help you to think about new coping strategies
- help you to stay safe.

NATIONAL 24/7 COUNSELLING SERVICES

Lifeline

13 11 14

www.lifeline.org.au

Suicide Call Back Service

1300 659 467

www.suicidecallbackservice.org.au

beyondblue

1300 22 4636

[www.beyondblue.org.au/
get-support/get-immediate-support](http://www.beyondblue.org.au/get-support/get-immediate-support)

Kids Helpline

1800 55 1800

www.kidshelpline.com.au

NAVIGATING DIFFICULT CONVERSATIONS

Family and friends of people living with an eating disorder have talked about feeling:

- confused - not knowing what to say or do
- guilty - feeling responsible
- fearful - worrying about what the future may hold.

Talking to others

Generally it's helpful to talk to people you trust about what you are going through. Having direct conversations about what's happening for you and the support you require can assist them to understand your experience and what they can do to help.

These conversations can be challenging, so you may want to plan and talk through this process with your health professional. Striking the balance between getting the support you need and maintaining good boundaries is important.

You have the right to receive help from those around you as well as having the right to privacy if that is what you need. You may be concerned that the people you confide in will judge you, or try to 'fix things'. Remember that when people try to help, it's often because they care about you and want you to be healthy and happy.

Having open conversations can ease some of their fears while also assisting you to receive the support you need. Sometimes you need to tell someone exactly what they can do to help, even when it feels hard or awkward to do so.

Getting back to school, work, study and other activities

If you have been away from school, work or study, returning to these activities can signal that you are getting back on track, but it can be difficult to explain to others why you have been away.

What you decide to tell people will probably depend on the relationships you have with them. It is okay not to talk to people about what has happened and keep your school/work/study/sport life separate from your personal life. However, by letting someone in that setting know (such as a teacher, manager, supervisor, study coordinator, coach) you can create opportunities to get additional support.

If you are returning to work or study, it may be useful to discuss the possibility of:

- flexible days or hours, for the initial period after your return
- the potential need to have time off to attend appointments
- initial reduced work or study loads while you are still recovering, or getting used to the treatment/s
- flexible deadlines
- additional support.

Considerations for social media

If you are a regular user of social media sites (e.g. Facebook, Twitter, Instagram) think carefully about whether it is the right place to talk about what you are going through.

While it is good to talk to others and get support, everyone is different and you might want to think about the following first:

- **it is hard to know how others reading the message may react – their response may bring up feelings you were not expecting**

- **people may start talking about what you are going through with other people before you are ready to tell them**
- **it can be harder to get the private support you need on public forums**
- **some images and messages that people post could hinder your recovery.**

NAVIGATING LIFE AFTER AN EATING DISORDER

People who have recovered from an eating disorder have spoken about how much stronger their relationships with their parents or partners were after working through the treatment together. However some relationships and friendships can also change.

" My three best friends and I had gone from Kindergarten to Year 12 and I'VE HAD NO CONTACT WITH THEM SINCE TWO YEARS INTO MY ILLNESS.

I think they just went 'too hard basket'... I have made some really great friends now who are really understanding and value me as a person... it took me a while to realise that's what really matters."

Recovering from an eating disorder is like opening a new chapter to your life. One where you can hopefully now find joy and peace and look forward to life - whether that means finishing school, going to university, embarking on a new career, fostering a new positive relationship or becoming a parent.

This resource was developed by bringing together the collective wisdom of people who have recovered from an eating disorder, the family members and friends who have supported someone with an eating disorder, as well as eating disorder experts. Hopefully the information will assist you as you navigate your way through treatment and recovery.

The people we spoke to who had recovered from an eating disorder talked about not wanting the illness to define their future. We wish the same for you.

" My parents and I are much closer now; I really leaned on them and needed their help.

I WOULDN'T HAVE GOTTEN THROUGH IT WITHOUT THEIR HELP AND SUPPORT. "

" I feel like I've grown up a lot, very quickly. I KNOW NOW I'M A STRONG PERSON from being able to overcome this."

" I struggled along for so long that I was only partially functioning.

I NOW MANAGE MY EMOTIONS A LOT BETTER AND DON'T GO TO RESTRICTING AND BINGING ANYMORE...

I've finished university and have a great job...

I'M PROUD OF WHAT I'VE BEEN ABLE TO ACHIEVE NOW."

FINDING INFORMATION AND SERVICES

Emergency support

If you are seeking help for a medical emergency or crisis contact **emergency services on 000**.

Helpful 24-hour crisis support can be accessed via:

Lifeline

Phone: 13 11 14
www.lifeline.org.au

Free, confidential 24-hour telephone counselling service. The website also provides a range of information for people who are suicidal and concerned family members and friends.

Suicide Call Back Service

Phone: 1300 659 467
www.suicidecallbackservice.org.au

Free, confidential 24-hour telephone and online counselling service for people who are suicidal, and concerned family members and friends. The website also provides a range of information.

beyondblue

Phone: 1300 22 4636
www.beyondblue.org.au/get-support/get-immediate-support

Free, immediate 24-hour telephone and email support from a trained professional. Online web chat is also available from 4pm-10pm, 7 days.

For children and young people

Kids Helpline

Phone: 1800 55 1800
www.kidshelpline.com.au

Free, confidential 24-hour telephone counselling for people aged 25 and under.

headspace

Phone: 1800 650 890
www.headspace.org.au

Free online chat, counselling, forums and information about youth mental health issues, as well as mental health services for young people and their families and friends across Australia.

ReachOut.com

www.reachout.com.au

Online forums and chat, fact sheets and videos about youth mental health issues.

Support for Eating Disorders

Eating Disorder Coordinators are located in every local health district in NSW. Initial contact with mental health services in NSW can be made via:

Mental Health Line (NSW)

Phone: 1800 011 511

For information about eating disorders and services in NSW, visit

InsideOut Institute

www.insideoutinstitute.org.au

The **Butterfly Foundation** National Helpline and online counselling service
Phone 1800 ED HOPE / 1800 33 4673

Online Support

The Butterfly Foundation's National Helpline **Call 1800 33 4673**, access online counselling from **www.thebutterflyfoundation.org.au** or email support@thebutterflyfoundation.org.au, 8am to 9pm, Monday to Friday.

SANE Lived Experience Forum

SANE Lived Experience Forum is an Australian service for people experiencing mental health issues. This is an online forum that provides a safe and anonymous place to share your story and help others experiencing similar issues. Visit **www.saneforums.org**

eheadspace

eheadspace offers support and advice from trained counsellors to young people and their families going through a tough time. Visit **www.eheadspace.org.au**

Apps and Tools

Using apps can be a handy way of helping you in your journey to recovery. We've listed some FREE apps here that might be useful.

The following apps have been designed to help people with eating disorders to empower you to be in control of your recovery.

- > Rise Up + Recover
- > Recovery Record – RR
- > recoveryBox
- > MindShift

Other helpful apps

- > Positive Thinking – The Key to Happiness
- > Cognitive Diary
- > Breathe2relax

Websites with online self-help tools

MoodGYM – Online cognitive behaviour therapy skills **www.moodgym.anu.edu.au**

myCompass – Online personalised self-help program **www.mycompass.org.au**

This Way Up – Online courses to help with depression, anxiety and other social anxiety illnesses. Mental health online – **www.thiswayup.org.au**

Websites for information on eating disorders

The Butterfly Foundation

www.thebutterflyfoundation.org.au

Centre for Eating and Dieting Disorders

www.cedd.org.au

National Eating Disorders Collaboration

www.nedc.com.au

Eating Disorders Info (for young people)

www.eatingdisordersinfo.org.au

Men Get Eating Disorders Too

www.mengetedstoo.co.uk

Beating Eating Disorders

www.b-eat.co.uk

Eating Disorders Victoria

www.eatingdisorders.org.au

ED Hope

www.eatingdisorderhope.com

Feed Your Instinct (for parents)

www.feedyourinstinct.com.au

Books

There are a number of books and readings available on all the different aspects of eating disorders. Below is a list of some from different areas that you may wish to start with.

Beating Your Eating Disorder.

Authors: Glenn Waller, Victoria Mountford, Rachel Lawson, Emma Gray, Helen Cordery, Hendrik Hinrichsen.

GAINING: The Truth About Life After Eating Disorders.

Author: Aimee Liu.

8 keys to recovery from an eating disorder.

Authors: Carolyn Costin, Gwen Schubert Grabb.

The beginner's guide to eating disorders recovery.

Author: Nancy J Kolodny.

Eating disorders: the path to recovery.

Author: Dr Kate Middleton.

Bulimia: a guide to recovery.

Authors: Lindsey Hall, Leigh Cohn.

The invisible man: a self-help guide for men with eating disorders, compulsive exercise and bigorexia.

Author: John F Morgan.

Overcoming binge eating.

Author: Christopher Fairburn.

Regaining yourself.

Author: Ira M Sacker.

LIST YOUR OWN KEY CONTACTS
OR USEFUL RESOURCES:

APPENDIX A

SIGNS AND SYMPTOMS OF EATING DISORDERS

Note: Not all of these symptoms will be indicative of an eating disorder, and someone experiencing an eating disorder may not display all of these signs.

Anorexia Nervosa

Physical signs

- › Rapid weight loss, persistent low weight, failure to gain expected growth, or frequent weight changes
- › Loss or disturbance of menstruation in girls and women and decreased libido in men
- › Fainting or dizziness
- › Feeling cold most of the time, even in warm weather
- › Feeling bloated, constipated
- › Feeling tired and not sleeping well
- › Lethargy and low energy
- › Fine hair appearing on face and body

Psychological signs

- › Denial of any issues
- › Preoccupation with eating, food, body shape and weight
- › Feeling anxious and/or irritable around meal times
- › Intense fear of gaining weight
- › Low self-esteem and feelings of shame, self-loathing or guilt, particularly after eating
- › Depression and anxiety
- › Reduced capacity for thinking and increased difficulty concentrating
- › 'Black and white' thinking
- › Having a distorted body image
- › Low self-esteem and feelings of shame, self-loathing or guilt, particularly after eating, and perfectionism
- › Increased sensitivity to comments relating to food, weight, body shape, exercise
- › Body image dissatisfaction

Behavioural signs

- › Dieting behaviour
- › Deliberate misuse of laxatives, appetite suppressants, enemas and diuretics*
- › Repetitive or obsessive behaviours relating to body shape and weight
- › Evidence of binge eating
- › Eating in private and avoiding meals with other people
- › Anti-social behaviour
- › Secrecy around eating
- › Compulsive or excessive exercising
- › Radical changes in food preferences
- › Obsessive rituals around food preparation and eating
- › Preoccupation with preparing food for others, recipes and nutrition

Bulimia Nervosa

Physical signs

- › Frequent changes in weight (loss or gains)
- › Signs of damage due to vomiting including swelling around the cheeks or jaw, calluses on knuckles, damage to teeth and bad breath
- › Feeling bloated, constipated
- › Disturbance of menstrual periods in girls and women
- › Fainting or dizziness
- › Feeling tired and not sleeping well

Psychological signs

- › Preoccupation with eating, food, body shape and weight

- › Sensitivity to comments relating to food, weight, body shape or exercise
- › Low self-esteem and feelings of shame, self-loathing or guilt, particularly after eating
- › Having a distorted body image
- › Obsession with food and need for control
- › Depression, anxiety or irritability
- › Body dissatisfaction

Behavioural signs

- › Evidence of binge eating
- › Vomiting or using laxatives, enemas, appetite suppressants or diuretics*
- › Eating in private and avoiding meals with other people
- › Anti-social behaviour, spending more and more time alone
- › Repetitive or obsessive behaviours relating to body shape and weight
- › Secretive behaviour around food
- › Compulsive or excessive exercising
- › Dieting behaviour
- › Erratic behaviour
- › Self-harm, substance abuse or suicide attempts

Binge eating disorder

Physical signs

- › Changes in weight
- › Feeling tired and not sleeping well
- › Feeling bloated or constipated

Psychological signs

- › Preoccupation with eating, food, body shape and weight
- › Extreme body dissatisfaction and shame about their appearance
- › Feelings of extreme distress, sadness, anxiety and guilt during and after a binge episode
- › Low self-esteem
- › Increased sensitivity to comments relating to food, weight, body shape, exercise
- › Depression, anxiety or irritability

Behavioural signs

- › Evidence of binge eating
- › Secretive behaviour relating to food
- › Evading questions about eating and weight
- › Increased isolation and withdrawal from activities previously enjoyed
- › Erratic behaviour (e.g. shoplifting food or spending large amounts of money on food)

If you have recognised one or more of the above signs or symptoms in someone you care about, you should seek help immediately.

*Note these are not effective weight loss strategies

YOUR CONTACTS

Local Doctor/GP

Local Hospital Emergency Department

Local Health Service

Other contacts

Local Mental Health Service



EVERYMIND

INSIDEOUT
Institute for Eating Disorders



NSW
GOVERNMENT

Health