NAVIGATING THEIR WAY TO HEALTH

A brief guide to supporting someone with the challenges, treatments and pathways to recovery from an eating disorder
This resource, *Navigating Their 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 families and friends. The quotes used throughout the resource come directly from people with a personal experience of eating disorders and the family, friends and carers who have supported them.

*Navigating Their 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 Centre for Eating and Dieting Disorders at the Boden Institute, the University of Sydney and developed by the Hunter Institute of Mental Health in collaboration with the Butterfly Foundation and stakeholders in NSW.

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

Find out more at [www.cedd.org.au](http://www.cedd.org.au) and [www.himh.org.au](http://www.himh.org.au)

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Supporting someone you care about who is experiencing an eating disorder can be challenging. You might not know what to do or what to say, but your support can make a big difference to their recovery.

Supporting someone can bring up a range of feelings for you. It is not uncommon to feel fearful, worried, angry, uncertain or sad, as you try to assist them to navigate their way through getting the right treatments and supports.

This resource can be a good starting point for working through some of the questions that may come up when you are supporting someone who is experiencing an eating disorder, or when you are concerned someone is developing an eating disorder.

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. Families and friends spoke of the stigma they experienced from those around them, the frustration they felt when trying to figure out the best way to support the person they cared about, and their concerns for the future. Where possible, their words and stories have been used throughout this resource.

Recovery from an eating disorder is possible and people do go on to lead full and contributing lives.

But supporting someone through that journey can come with its challenges. By learning more you will be better able to look after yourself and more equipped to support the person you care about.

You may find it useful to access other sources of information and support. See the section ‘Finding information and services’ on page 44.

A complementary resource has been developed for people who are experiencing an eating disorder, called Navigating Your Way to Health and can be accessed online at www.cedd.org.au or www.himh.org.au
NAVIGATING EATING DISORDERS

Brief 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, personality traits (e.g. perfectionism), and genetics.

Many people who have eating disorders may also experience depression, anxiety, and alcohol or other substance-use problems.

A person living with an eating disorder may experience long-term impairment, including emotional and behavioural effects, medical complications, social isolation, disability and an increased risk of death.

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.

Types of eating disorders

Anorexia Nervosa is characterised by extreme food restriction, low body weight and an intense fear of gaining weight. As the person becomes more unwell, people living with anorexia nervosa develop more obsessive or rigid ways of thinking and behaving, and become more committed to extreme dieting.

Bulimia Nervosa is characterised by repeated episodes of binge eating, followed by behaviours that the person believes will compensate for the food they have eaten (for example self-induced vomiting or excessive exercise) called ‘compensatory behaviours’. 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; and (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.

Common misconceptions

There are a range of myths about eating disorders that can impact on early detection and treatment. These myths can also contribute to the stigma that those living with an eating disorder, and their family and friends, can experience. The following myths have been adapted from information developed by the National Eating Disorders Collaboration and are available at www.nedc.com.au/myths

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

FACT: Eating disorders are serious and potentially life threatening mental illnesses; they are not a lifestyle choice or a diet gone ‘too far’. A person living with an eating disorder may experience severe disturbances in their behaviour around eating, exercising and related self-harm because of the difficulties with their thoughts and emotions. Eating disorders involve considerable psychological distress as well as serious medical complications.
FACT: Eating disorders can affect anyone. They occur in people across all cultural and socio-economic backgrounds; in people of all ages, from children (as young as six years) to older people (70 years); and in both men and women.

MYTH: Eating disorders only affect females, particularly adolescent girls. 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 key group with a high risk of eating disorders is women, particularly those going through key transition periods (e.g. from school to adult life). But this high risk has led to a misconception that eating disorders only happen in this population.

FACT: Eating disorders can affect anyone. They occur in people across all cultural and socio-economic backgrounds; in people of all ages, from children (as young as six years) to older people (70 years); and in both men and women.

MYTH: Eating disorders are a cry for attention or a person ‘going through a phase’. Beliefs that eating disorders are something people can ‘snap out of’ still persist in Australia and can be very harmful.

FACT: People with eating disorders are not seeking attention. In fact, due to the nature of eating disorders a person may go to great lengths to hide or deny their behaviour, or may not recognise that there is anything wrong. An eating disorder is not a phase someone is going through, it is a serious mental illness that requires appropriate treatment and support.

MYTH: Dieting is a normal part of life. Research shows that most people, particularly adolescents, are confused about eating disorders. People recognise that eating disorders are potentially harmful, however they also accept body obsession and dieting as normal parts of growing up.

FACT: While some changes in diet and exercise have been shown to be safe, significant mental and physical consequences may occur with extreme or unhealthy dieting practices, particularly if it starts when a person is a child or adolescent. Eating disorders almost invariably occur in people who have engaged in dieting or disordered eating. Dieting is also associated with other health concerns including depression, anxiety, nutritional and metabolic problems, and contrary to expectation, an increase in weight.

MYTH: Families, particularly parents, are to blame for eating disorders. There is a common, historic misconception that family members can cause eating disorders through their interactions with a person at risk.

FACT: There is no evidence that eating disorders can be 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 living with eating disorders. There is, however, evidence that eating disorders have a genetic basis and people who have family members with an eating disorder may be at higher risk of developing an eating disorder themselves. Genetics play a role in many illnesses (both mental and physical), so while a person’s genetics may predispose them to developing an eating disorder, this is certainly not the fault of their family.

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.

"I remember her talking about hearing voices inside her head saying ‘YOU CAN’T EAT THAT’... That is the scariest thing to hear come from your own child... it’s really difficult to hear that sort of stuff because you know you have seriously got a problem that you can’t handle on your own."

- Parent

"It seemed to happen at a time in their life WHEN THINGS ARE CHANGING. But I still don’t know what that trigger is."

- Parent
**FACT:** An eating disorder is not always easy to detect based on weight. For example, people with bulimia nervosa tend to be at an average, or even above average, weight. The severity and impact of an eating disorder can’t be determined by the physical appearance of the person. In the same way, achieving a normal weight when being treated for an eating disorder does not mean recovery is complete as eating disorders have a range of complex medical and psychological impacts.

**MYTH:** People who are of average weight or overweight cannot have eating disorders.

While some eating disorders (e.g. anorexia nervosa) are characterised by severe weight loss, other eating disorders (e.g. bulimia nervosa and binge eating disorder) are not.

**FINDING INFORMATION ONLINE**

There is a lot of information online about eating disorders. Look for websites from trustworthy sources such as government organisations and peak bodies (see page 46 for recommendations). These sites can be a helpful resource in addition to support from health professionals.

Be aware that some websites can get in the way of recovering from an eating disorder as they promote unhealthy thinking and behaviour, minimise the significant implications of disordered eating, and discourage seeking help.
Eating disorders are serious mental and physical illnesses. However, with good treatment and support, recovery from an eating disorder is possible.

Getting help early

If you suspect that someone in your life has an eating disorder, or is showing early signs of an eating disorder, it is important to encourage them to see a health professional as soon as possible.

It is important to note that a common symptom of an eating disorder is the feeling of uncertainty about whether or not to get treatment. Part of the treatment will be about helping the person develop other ways of feeling in control and ensuring they have the help and support that they need.

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

The type of treatment that is best suited to the person (and you as their support person) will depend on a range of factors, including their age, any medical risks, symptoms they are experiencing, severity and duration of the illness, and additional medical and mental health problems they may also be experiencing.

Taking the first step

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

The NSW Service Plan for People with Eating Disorders has been developed to ensure people of all ages can access quality treatment and support in New South Wales.

For many people, the general practitioner (GP) will be their first point of contact with the health service (or perhaps a paediatrician for a younger person). It may be helpful for you to attend this meeting with the GP (with the person’s consent), and your attendance is particularly important if the person you are supporting is a child or adolescent.

A GP can provide an initial assessment of your family member’s physical health and help with referrals to other public or private 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.

The Centre for Eating and Dieting Disorders in NSW provides a ‘Search for a Practitioner’ service on their website www.cedd.org.au. The Butterfly Foundation National Helpline can also make recommendations about specialists – 1800 33 4673.

Treatment typically involves collaboration between the person experiencing an eating disorder, their family or carer and a number of health professionals (see page 22 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 eating disorders can provide treatment locally.

Family and carer involvement in treatment is usually associated with better outcomes for the person and is therefore encouraged.

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.

1800 011 511

ACCESSING EMERGENCY SERVICES

You should access emergency services by calling 000 if the person is
- suicidal or self-harming and in immediate physical danger
- experiencing physical symptoms that may be life threatening e.g. chest pain, or changes in heart rate or body temperature
- experiencing psychological symptoms such as confusion or hallucinations.
Warning signs and symptoms

There are various physical, psychological and behavioural warning signs that can signal the onset or presence of an eating disorder.

People who experience an eating disorder may display one symptom, a combination of symptoms, or may not show any signs at all.

If you can answer yes to one or more of the following questions about someone you know or care for, it is important to encourage them to seek help as soon as possible.

› Is food dominating the person’s life?
› Is the person worried about being overweight even if they appear to be a normal weight?
› Does the person ever vomit after eating or exercise a lot more than other people?
› Is the person hiding food or eating in secret?

› Does the person’s weight affect how they feel about themselves?

Appendix A of this resource provides a list of signs and symptoms of different types of eating disorders.

Supporting the person early on

The first time a person has contact with a service about their eating disorder can be worrying for them and for you as the support person.

Regardless of whether the person has been seen in a hospital or in the community there are some things you can do to support them.

› Avoid making judgements or asking too many questions — often people just need someone to listen.
› Provide assurance that you will be there to support them, regardless of what the next steps may be.
› Where possible, speak to the treating health professionals so you get a better understanding of what is happening now and what the next steps may be.

It is especially important for you to be involved with treatment if your family member is a child or adolescent.

› Offer to assist them if they need to provide information to health professionals and advocate for their needs where appropriate.
› If the person you are supporting does not speak English, you may need to advocate for an interpreter.

Refer to page 26 for more tips on how to support someone with an eating disorder.

“I had bulimia from around age 13 years 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.”

— Personal experience

“With eating disorders — you’re in deep with it.

Life’s not going to be normal.

It really is like your child has had a diagnosis of something like cancer.”

— Parent
About confidentiality

Family members, friends and support people can help throughout the assessment, treatment and recovery phases of an eating disorder. How involved you will be, however, will depend on the age of the person you are supporting, the type of relationship you have with them and if the person has given permission for you to be involved.

All health professionals are legally required to maintain their patient’s confidentiality. However there are exceptions to this, such as when:

- the person has given their permission to share personal information
- they believe the person may hurt themselves or someone else
- they are required to talk to another health professional about the person’s 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.

If permission is not given for you to be involved you can still ask health professionals for general advice and information about the illness, treatments, and your role as a support person.

What if the person I support is a child or adolescent?

In Australia, both parents and teenagers 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.

From the age of 16 years, a person can consent to medical treatment with the same authority as an adult. However they don’t have an automatic right to refuse medical treatment, particularly life-saving treatment.

The treatment for eating disorders is complex, and denial and secrecy are common features of these illnesses and can hinder recovery if not addressed. It is best practice for the family or support people involved with children and adolescents to be actively involved throughout the treatment process.

If you are unsure how confidentiality applies in your situation, ask a health professional to explain it to you and the person you are supporting so that you both understand how it works.
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 each individual. This should be focused on an individual’s specific goals around recovery.

Different treatment options may be recommended based on the person’s age, the severity and type of eating disorder they are experiencing, and the length of time the person has been living with the eating disorder.

A treatment plan will generally involve a mix of medical, psychological and nutritional support and should recognise and address the different phases of the illness, the person’s specific symptoms, and provide ongoing support to reduce the risk of relapse.

It’s helpful if a treatment plan is holistic – taking into consideration things like social, occupational and spiritual support.

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.

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 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 often followed by community-based treatment (or outpatient treatment).

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. It is important to work with your treating team to determine which therapy will be most suitable for your child or adolescent and your family. 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.

Involving families and carers is important for maximising the effectiveness of any treatment plan. The family should generally always be included in treatment involving a child or adolescent.

Community-based treatment for Bulimia Nervosa (BN) and Binge Eating Disorder (BED)

Generally, community 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) are 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 to the person you are caring for.

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

"We really battened down the hatches as a family and surrounded him with love and support. That was our main role while the psychologist and others treated the eating disorder."

- Parent
The best treatment for people experiencing OSFED will depend on their symptoms. 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 are more like bulimia nervosa or binge eating disorder, then treatment should follow those approaches.

Choosing a Treatment Team

It’s important to have a good relationship with the health professionals that your family member is working with. This means that they understand the person’s specific experience of an eating disorder and that both you and the person being treated:

- feel comfortable to talk openly without fear of judgement
- trust the team
- are able to work with the professionals as a team.

If the person doesn’t feel comfortable with the health professionals they are seeing, it’s helpful to have a discussion about this.

Treatment can be tough and may impact on how a person feels about the 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 the person wants to hear and they may challenge the eating disorder at times.

However, if the person doesn’t feel listened to or feels they are in the wrong hands, they can choose to seek treatment elsewhere.

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
- talk to carers or parents to help them understand what is happening.

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 medically unstable 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 the person may be experiencing alongside the eating disorder.

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
- assist in developing a healthier relationship with food and eating.
SUPPORTING SOMEONE EXPERIENCING AN EATING DISORDER

The effects of an eating disorder can impact on family and friends as well. Supporting someone experiencing an eating disorder can be challenging, but it can make a big difference to their recovery to have you involved.

**Practical tips**

There are a range of practical things you can do to support someone who is getting treatment for an eating disorder.

1. **Help the person stay connected** with you and other family and friends. A person experiencing an eating disorder can feel very isolated and alone, so it can be really important for them to participate in usual activities as much as possible while being treated for an eating disorder.

2. **Encourage the person to talk about their feelings** with open questions such as “how are you feeling today?” Then try to listen to their answer without judging or interrupting, even if you don’t agree with some of what they say.

3. **Tell the person that you care** about them and will try to support them through their recovery journey.

4. **Include the person in invitations** and usual group activities just as you would have done before the eating disorder. Don’t be discouraged if they choose not to get involved this time, keep asking.

5. **Encourage the person to talk about other parts of their life** as much as possible and not just focus all conversations on the eating disorder or the treatment plan.

6. **Be a voice of encouragement** when the person seems tired of the struggle to recover. Remind them of all the positive things about recovery – for example, things that they used to like to do and will be able to do again once they are healthy and well.

7. **Discourage negative self-talk** by distracting them with other subjects and reminding them of their achievements and progress.

8. **Stay positive** and remind the person that recovery is possible.

Try to avoid the following as much as possible:

- getting drawn into conversations about food, weight, shape or even clothes
- being critical or using negative words to describe the person or their behaviours
- trying to solve their problems for them
- giving simple solutions to overcoming problems, for example saying things like “all you need to do is eat”
- making generalisations such as “never” or “always” when talking about the person or their behaviour (e.g. “you never want to do anything”)
- talking about appearance. Even compliments about appearance (e.g. “you look so well”) can be misinterpreted by the person (e.g. “I’m fat”).

“Once I got through the fog and had some clarity and was able to realise I NEEDED TO DO SOMETHING ABOUT THIS, I was able to articulate my feelings around food to him (Dad) but when I was sick we would just scream at each other.”

- Personal experience

**IT’S HELPFUL TO SEPARATE THE PERSON FROM THE EATING DISORDER.**

It’s helpful to separate the person from the eating disorder. Doing this helps to emphasise that it’s the eating disorder that needs to be challenged and changed.

**IT IS THE EATING DISORDER THAT IS THE PROBLEM, NOT THE PERSON LIVING WITH IT.**

The eating disorder has a separate voice and thinking pattern from the person living with it, even though it can sometimes be tricky for you or your loved one to see the difference.
Tips for parents

It can be difficult to manage the dual roles of parenting and supporting a child who is experiencing an eating disorder. The experience will impact on the whole family and can be a stressful time. Below is a list of tips that may be helpful.

Communicate openly

» Involve everyone in the immediate family early, explain what is happening and maintain open communication.
» Working together as a family will provide support for the child experiencing an eating disorder and it will also keep all members included in the process.
» It’s important for adults in the child’s life to deliver consistent messages and follow the same rules.
» Consider who else in the child’s life may need to know what’s happening e.g. school staff, parents of close friends.

Get information

» Seek reliable information from health professionals and seek out other resources to equip yourself for the support role (see page 30 and 45 for suggestions).

Role model healthy behaviours

» Role model healthy behaviours and attitudes towards food, weight and body image.
» Work closely with the treatment team and support your child to follow treatment plans.

Seek support for yourself

» Access support from your social network and seek professional help if required during this stressful time. Looking after yourself will help you to be more effective in your role as a parent and as a support person for your child (see page 40 and 45 for more information).

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.

Evidence shows that the sooner a person starts treatment for an eating disorder, the shorter the recovery process will be.

“Our family attended counselling sessions to help support each other. I remember in one session my son opened up to his sister about how worried he was about her and how scared he was that she was going to die. I think that shocked her and helped her to understand how worried we actually were.”

- Parent
NAVIGATING THE SUPPORT ROLE

Support through different stages

Every person’s experience of an eating disorder and recovery will be different. However, there are stages that people will often go through. Knowing about these can help you to tailor your support to the person’s changing needs.

If the person has little or no awareness of the problems associated with their disordered eating:
• show compassion and understanding
• try to see the person (or child) as separate from the eating disorder
• take the focus off their eating. Instead talk about their interests and goals, at the same time, it is not helpful to pretend it isn’t happening. Instead calmly express your worries and concerns about their eating. Tell them you can and will support them and help them to access treatment

If the person has some awareness that there is a problem and is considering getting support:
• encourage the person to voice their thoughts, feelings and concerns
• demonstrate that you are listening to what they are saying. A simple way to do this is using their words in your responses e.g. “I hear you saying that part of you feels like you want to change, while another part of you feels scared of changing…”
• let them know you are pleased that they have shared their feelings with you and that you are willing to support them through the process of getting treatment and support.

If the person has made the decision to get support and treatment:
• learn as much as you can about the steps that you, and the person, need to take. Help them to navigate the treatment and support services that are available
• if the person is a child or adolescent, you may need to organise and take them to the GP and/or another health professional against their wishes. This is harder to do when the person is an adult but you still may need to be actively involved in accessing treatment for them.
• if the person is an adult, encourage them to increase their knowledge about treatment options and support them as they build their confidence in navigating the service system
• let them know that you are ready and willing to be involved in treatment if they want you to be.

If the person is actively engaged in treatment:
• acknowledge how difficult it can be for the person
• support them through challenges and let them know you believe they can recover
• be encouraging and positive. Kind comments, even repeated daily, can make a difference, e.g. “I’m so proud of you”; “How are you going today?”; “We are all behind you and know how hard you are working everyday”; “We love you and will always support you”; “You can do this”
• let the person know that you are willing to support them and that they are not alone
• ask them what you can do to help their treatment and recovery. Give them permission to ask you for help
• be a willing ear to listen to their thoughts and feelings
• if relapse occurs, explain to the person that relapse is common and doesn’t mean they can’t recover
• one of the most common reactions of family members is frustration, as the process of changing eating takes time. Try to stay patient and remain supportive.

When the person is in a phase of ongoing care:
• work together with the person to identify triggers that may impact on their longer term recovery
• help them to put strategies in place to minimise the risk of relapse
• show care, patience and compassion
• remain hopeful about their recovery.

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. “

— Personal experience
UNDERSTANDING SUICIDE AND SELF-HARM IN EATING DISORDERS

While not all people who experience an eating disorder will think about suicide, it has been identified as a major cause of death in people with eating disorders. It is important to know the facts and have some strategies you can use if you are concerned about a family member or friend.

Self-harm and eating disorders

Self-harm (or non-suicidal self-injury) is a deliberate act of self-inflicted injury intended to cause physical pain as a means of managing difficult emotions, or as a way of communicating distress to others. There is an association between eating disorders and self-harming behaviour, and some behaviour related to eating disorders can also serve as a means of self-injury (e.g. purging). While self-harm is most common in adolescents, it can occur at any age.

Any act of self-harm should be taken seriously. Talk to the person about what is going on for them without judgment or trying to ‘fix’ the problem. Encourage them to talk to a health professional about the self-harming behaviour so that they can get the treatment and support they need.

Suicide and eating disorders

Rates of suicide and suicide attempts are high among people that experience an eating disorder. While the reasons that people take their own life are complex, there are a number of factors that may increase the risk of suicide for people with an eating disorder. These include the severity and duration of the illness, substance abuse, excessive exercise and impulsive behaviour. It is important to take any thoughts of suicide seriously.

Assess the situation
What is making you worry?
Be specific – is it their behaviour, the way they are talking, how they are treating other people?

Talk to the person you are worried about in an open and honest way
Find a time to talk as soon as possible in a private space.
Tell them what you have noticed that’s causing you concern and ask if they have been feeling stressed or overwhelmed.

If you are worried they are suicidal, ask them calmly and directly.
For example: “I am worried that you are thinking about harming yourself – is this how you are feeling? Have you thought about suicide?”

Asking someone if they are suicidal may feel difficult but it shows you care and you won’t be doing any harm. It is often a relief for people to be given permission to talk about their feelings.

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If they are suicidal, ACT
Let them know it is OK to have thoughts about suicide and that they are not alone. Decide what action to take. If they have a safety plan, look at that for ideas. If you are unsure what to do, stay with the person while you ring a telephone crisis support service or a local health professional for advice (see page 44 for service information).

If the person is in immediate physical danger, call emergency services on 000.

If you would like further information on talking about suicide, visit the Conversations Matter website at www.conversationsmatter.com.au for practical resources.
Navigating difficult conversations with someone you care about can be tricky. There is no ‘right’ or ‘wrong’ way to talk to someone with an eating disorder and different approaches will work for different people. It may also depend on your relationship with the person and where they are in their recovery journey.

Talking to the person

Sometimes people experiencing an eating disorder will find it difficult to talk about what is going on for them. They might not have the words to describe how they are feeling or may be worried that others will judge or ‘worry too much’ about them. Some people may be angry and frustrated with themselves and push others away to cope with this.

Many family and friends worry that they will say the wrong thing, or have been pushed away in the past. The important thing is to let them know you care and that you are willing to listen and you will be there for them.

You could suggest that while you don’t have all of the answers, you can work with them to find a way forward.

Early conversations:
I suspect someone may have an eating disorder

Initial conversations with a person you suspect of having an eating disorder can be challenging. Some of the following tips may be helpful.

Be prepared

The most important thing you can do when approaching someone about an eating disorder is to be prepared and educate yourself first.

The person you care about may be experiencing high levels of anxiety, embarrassment or guilt, and may not recognise that they have an eating problem.

Be prepared for a range of responses and stay calm, regardless of the response.

Avoid broaching the topic if you are around food or in situations in which either of you are angry, tired or emotional.

Listen without judgement and think about what you will say

Take into account that the person may fear revealing their behaviours or feelings. Let them know that you care about them and want to support them through whatever comes next. Some helpful tips include:

- try to use ‘I’ statements e.g. “I care about you” or “I’m worried about you”
- make the person feel comfortable and let them know it is safe to talk to you
- encourage them to express how they feel. Remember, it is important to understand how they feel, rather than just state how you are feeling
- give them time to talk about their feelings – don’t rush them through the conversation
- listen respectfully to what they have to say and let them know that you won’t judge or criticise them
- encourage them to seek help and explain that you will be there to support them. You may need to be active in helping them find the right professionals and/or making the initial appointment.

"I have at times felt anxious and fearful for my friend in regard to their eating disorder.

AT MANY TIMES I HAVE FELT HELPLESS

and that I wasn’t being the support to them that I would like to be, as I felt lost as to how to be an effective and appropriate support. My fear around ‘getting it wrong’ or ‘saying the wrong thing’ unhelpfully led me to not being as proactive in offering support as I should have been."

- Friend
General tips: talking to the person I care about

There are a range of practical tips you can try that may assist you to navigate difficult conversations over time.

› Listen without judgment. People can have intense feelings all along the recovery journey – especially if they have had a setback. While it can be hard to listen to distressing thoughts and feelings, it is important to allow the person to talk without judgement or criticism.
› Try not to start difficult conversations if you are feeling emotionally drained or tired. Wait until you are feeling prepared for anything that may come up.
› If you have very strong reactions to the behaviour of the person you care for, talk these feeling over with a health professional, counsellor or trusted friend so they don’t impact on your conversations with the person.
› Think about your body language – the person will pick up how you are feeling from the way you act, not just from the things you say.
› If you don’t know how to respond to something, be honest and say so. No-one has all of the answers.
› Be kind to yourself. Supporting someone through an eating disorder can be draining for all involved. Keep a check on your mood and seek support when you need it.

Things to avoid in conversations

When talking to someone you care about, there are also certain things you should try to avoid.

› Avoid focusing on food, exercise or body shape and weight; instead, try talking about how the person is feeling and focus on other aspects of their life.
› Avoid discussions about dieting, calories and body shape.
› Do not use language that implies blame or that the person is doing something wrong, e.g. “You are making me worried”. Instead try “I am worried about you”.
› Avoid unhelpful, blaming comments like “Just eat more food!”, “Why can’t you just eat lunch?” or “How come it is still so hard for you to stop bingeing?”.
› Try not to take on the role of a therapist. You do not need to have all the answers; it is most important to listen and create a space for the person to talk.
› Avoid statements that could be interpreted as manipulative, e.g. “Think about what you are doing to me”. This can make it more difficult for the person to be open with you about what is going on.
› Avoid threatening statements, e.g. “If you don’t eat right I will…” This can impact on the person’s emotions and may undermine trust between the two of you.

Considerations for social media

If the person you support regularly uses social media (e.g. Facebook, Twitter, Instagram) it can be helpful for them to think about whether this is the right place to talk about what they are going through.

While it is good to talk to others and get support, it’s important to think about what might happen once this information is shared in a public forum.

It is hard to know how others reading the information that is shared may react – their response may be upsetting.

People would say “you look healthy”… I was like you’re pretty much TELLING ME I’VE PUT ON WEIGHT - don’t say that to me.”

- Personal experience

It could lead to people sharing the information with others before the person is ready to do this.
It can be harder to get the private support that the person (and you) need on public forums.
Some images and messages that other people post could get in the way of their recovery from an eating disorder.

Before you talk about your own experiences as a support person on a social media platform, be aware of the impact this may have on the person, or their ability to decide who knows about their eating disorder. Talk this through with them.
Communicating with others

Once the person is getting treatment and support, it is important to have a clear agreement about who they want to involve in their recovery and how they want them to be involved. This includes discussing what information should be shared and with whom.

You may find it helpful to identify the words you will use to let people know what is happening and how they can support you and/or the person who is living with the eating disorder.

There is a significant level of misunderstanding about and stigma associated with eating disorders in the general community. You may find yourself ‘educating’ friends, family and others about the illness and its impacts. The section ‘Common misconceptions’ on page 09 may assist you with these conversations.

When talking to others in the community:
- focus on both the physical and psychological impacts that eating disorders can have on a person
- if you feel comfortable sharing your experience, you could also talk about the impact that eating disorders can have on family and friends, as this can increase people’s understanding and let them know that you need support too.

If you are not comfortable with how those around you are responding to the news, be honest and let them know what you need from them. For example, you could say the following:
- “What I need right now is someone to listen without telling me what I need to do”.
- “I’d appreciate it if we could talk about other things at the moment”.

Language and eating disorders

The way language is used is important when talking about eating disorders. Some language can be alienating for the person experiencing an eating disorder. Below are some examples of problematic and preferred language that you may find helpful.

**Language and eating disorders**

**Preferred:**
- ‘is living with’, ‘has a diagnosis of’, or ‘is being treated for’ an eating disorder or particular disorder.

**Problematic:**

**Issue:** Labelling a person by their illness can lead to the person feeling alienated or stigmatised.

**Options to consider:**
- Preferred: language that does not focus on size or appearance specifically
- Problematic: ‘thin’, ‘skinny’, ‘fat’

**Issue:** Language that suggests a lack of quality of life for people with an eating disorder.

**Options to consider:**
- Preferred: ‘is living with’ or ‘is diagnosed with’ an eating disorder or particular disorder
- Problematic: ‘afflicted by’, ‘suffering with’ or ‘a victim of’ an eating disorder.

“**In some ways I tried to protect him. I didn’t want it out there because I knew there was a lot of stigma around and I didn’t want him being judged, any more than he already felt anyway.**”

~ Parent
Navigating self-care

Understanding your response

Caring for or supporting someone with an eating disorder is a huge responsibility and can come with considerable personal strain. You may start to fear and dread meal times, or feel like the eating disorder has taken over your life, leaving no time for the things you used to enjoy as an individual or as a family.

Research highlights that people who support or care for a person with a mental illness can be at risk of developing mental health problems themselves. The practical and emotional demands of supporting a loved one with an eating disorder can be immense at times, so it is important to think about your own wellbeing too.

If you are caring for someone with an eating disorder it is possible that at times you may feel:

- anger, distress and frustration about what is happening to the person you care for, and how this is affecting you and your family
- anxious and afraid about the physical and psychological changes in the person you care about
- worn out from the extra demands of supporting someone through treatment, as well as keeping on top of family life and work commitments
- guilty about your ‘role’ in the illness. It is very common to fear that you are in some way responsible for bringing on the disorder or that you did something wrong in relation to eating, food or habits
- confused about the best way to help, on a daily basis and in the long-term
- helpless and hopeless about your ability to provide support or whether the support you are giving is enough
- frustrated or upset because you can’t fix the problem ‘straight away’
- aggravated because you can’t access the type of help and assistance from health professionals that you think you or the person needs
- fearful that the person may get worse, self-harm or contemplate suicide

The important thing to keep in mind is that these are all valid and normal feelings experienced by families, friends and carers.

For me I continued to make sure I had a daily walk, any way I could... just trying to get out of the house...

It was often the only time I got to myself, to process everything and enjoy the environment and start the day positively.

I know I would’ve been no good to anyone without those walks. They were purely for me, for my own sanity.”

- Parent

“I remember saying very early on to my husband “This is terribly stressful, we’ll need to take care of our relationship and take care of each other…”

It’s an enormously stressful thing to have in a family and on a relationship, taking care and taking time out from it whenever you can is very important.”

- Parent
Manage stress

The most important thing you can do for the person you are supporting is to look after yourself. As with any other stressful time it is essential you look after your emotional and physical health.

When there are a lot of demands on your time, it can be important to find the right balance between how much you can offer to others and how much you need to look after yourself.

- Take regular breaks throughout the day and planned times just for you.
- Ask other people to help out – many will welcome the opportunity to be useful.
- Consider speaking to your employer about assistance the workplace may be able to provide e.g. access to Employee Assistance Programs (EAP); flexible work hours.
- Be prepared to say “no” to additional requests for your time.

Make time for yourself

It is important to take regular short breaks as well as scheduling time just for yourself. Make a list of activities you enjoy (e.g. watching a movie, playing sport, gardening, catching up with a friend) and make time for them.

Keep healthy

It can be difficult to manage extra demands if you are not paying attention to your own health. Looking after your physical and mental health will have positive impacts on how you think and feel.

- Eat a balanced and healthy diet.
- Reduce alcohol and other drugs.
- Exercise regularly.
- Make sure you get enough sleep and rest.
- Build in relaxation or mindfulness.

Build a support network

Just as the person you care for will need a strong support network, so will you. Some people find it helpful to link with others who have had similar experiences.

- Think about people in your life who are good listeners and understand you, and make sure you schedule time with them.
- Consider joining a face-to-face or online support network to share experiences with others (see page 45).

Seek support

You may find times when you are completely overwhelmed. It may be helpful to seek professional help for your own emotional and psychological wellbeing. This will help you work through any issues you are experiencing in your role supporting someone with an eating disorder, which will in turn help you support the person more effectively.

“Having a child going through an eating disorder can be so isolating. Often people don’t know what to say so they don’t say anything at all which can make you feel very much alone.”

- Parent
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.

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 Centre for Eating and Dieting Disorders
www.cedd.org.au

The Butterfly Foundation
The Butterfly Foundation’s National Helpline is for anyone seeking information and support around eating disorders and body image issues, including carers and health professionals.
Call 1800 33 4673, or access their online counselling from www.thebutterflyfoundation.org.au or email support@thebutterflyfoundation.org.au
8am to 9pm, Monday to Friday.

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 family and carers

The Butterfly Foundation
Online and face-to-face support groups for parents, adult carers, siblings and young carers who support someone with an eating disorder. Available online at set times to enable people to share experiences with others in similar situations. Visit www.thebutterflyfoundation.org.au or email support@thebutterflyfoundation.org.au

SANE Carers Forum
SANE Carers Forum is an Australian service for families, friends and other carers of someone living with mental illness. This is an online forum for carers, where stories are shared and help is provided by other carers.
www.saneforums.org

Families Empowered and Supporting Treatment of Eating Disorders
Families Empowered and Supporting Treatment of Eating Disorders (F.E.A.S.T.) is an international organisation of and for caregivers of people with eating disorders. F.E.A.S.T. information and online forums available via www.feast-ed.org
Websites

Centre for Eating and Dieting Disorders
www.cedd.org.au

National Eating Disorders Collaboration
www.nedc.com.au

The Butterfly Foundation
www.thebutterflyfoundation.org.au

Eating Disorders Info (for young people)
www.eatingdisordersinfo.org.au

Feed Your Instinct (for parents)
www.feedyourinstinct.com.au

Books

Skills-Based Learning for Caring for a Loved One with an Eating Disorder.
Authors: Janet Treasure, Gráinne Smith, Anna Crane

Talking to Eating Disorders: Simple Ways to Support Someone who has Anorexia, Bulimia, Binge Eating or Other Eating Disorders.
Authors: Jeanne Heaton and Claudia Strauss

Author: Sue Cooper

If your adolescent has an eating disorder: an essential resource for parents.
Author: Timothy Walsh

Surviving an eating disorder: strategies for family and friends.
Author: Michelle Siegel

List your own key contacts or useful resources:
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
- 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
- Secrecy 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