Caring for someone with an eating disorder
A resource for families, carers and supports
Families, carers and supports play a crucial role in the care, support and recovery of people living with an eating disorder. A carer or support can be a parent, partner, friend, sibling, grandparent, child, grandchild, relative, neighbour, colleague or any other person caring for or supporting someone living with an eating disorder. Carers and supports can contribute to an effective collaborative care approach in three key areas:

**Supporting engagement with treatment:** A characteristic of eating disorders is that the person living with an eating disorder may be reluctant to seek help, often denying the illness or concealing behaviours. People in close relationships to the person with an eating disorder play a vital role in influencing help seeking, raising awareness of eating disorder behaviours, and supporting recognition of stages in recovery.

**Supporting implementation of treatment:** The family or support network are often integral members of the care team. They may support the person to implement behavioural changes in treatment, such as sitting with the person at mealtimes and helping them cope with distress without using compensatory behaviours.

**Supporting recovery:** Recovery takes time and families and supports have a key role to play in supporting a person through their recovery journey.

The effects of an eating disorder are often felt not only by the person experiencing it, but also by their family and support network.

A carer or support can be any person involved in caring for someone living with an eating disorder. If you are caring for someone living with an eating disorder it is possible that at some time or another you might feel:

- Distressed about what is happening to you, the person you care for or support, or your family.
- Burnt out from the demands of caring for someone living with an eating disorder on top of family life, personal life and work commitments.
- Guilty about your ‘role’ in the illness. You may fear that you are in some way responsible.
- Confused about the best way to help, both daily and in the long-term goal of recovery.
- Anxious and afraid about the physical and psychological changes in the person you care for.
- A sense of hopelessness about your ability to provide support.

All of these feelings are normal. Caring for and supporting someone living with an eating disorder is a huge responsibility and can come with considerable personal strain. You may want to ‘fix’ things and feel frustrated when you can’t.

You may start to fear and dread mealtimes. You may feel like the eating disorder has taken over your life, leaving no time for the things you used to enjoy as an individual. These are all valid feelings reported by carers and supports.

To find help or learn more, visit nedc.com.au
Understanding the stages of change

The stages of change model (1) can be helpful in understanding what a person living with an eating disorder may be experiencing at different stages of illness and recovery. There are six stages of change that a person living with an eating disorder may go through. A person may go through this cycle several times or may go back and forth between these stages. The model highlights that while recovery is possible, the course of illness is not linear. Throughout each stage there may be behavioural signs which may help you identify what stage the person is in and how you can best approach them.

Pre-Contemplation

In the pre-contemplation stage, a person living with an eating disorder may deny that there is a problem. You may have noticed some of the warning signs and feel concerned about the person, but they will have little or no awareness of the problems associated with their disordered eating. Instead, they may be focused on controlling their eating patterns. In this stage, the perceived benefits (such as using an eating disorder to control or avoid strong emotions) outweigh any costs and the person may not be ready to change and may be afraid to let go of their current coping behaviours. The person may be reluctant to disclose their behaviour and may appear hostile, angry or frustrated when this topic is approached.

What you can do:

- Stay calm and try to see things from their point of view.
- Show compassion and understanding.
- Take the focus off their disordered eating. Talk about their interests, goals in life and the things they may be missing out on as a result of the eating disorder.
- Continue to support and hold hope for the person you are supporting.
- Become familiar with our tips for talking to someone you are concerned about, which you can find at NEDC What to Say and Do.
- Encourage and support access to medical treatment if their health is compromised.

Figure 1: The stages of change model
Contemplation
A person living with an eating disorder in the contemplation stage will have an awareness that something is wrong. They may be considering the benefits of changing some of their behaviours but may be unsure about taking action. As such, the person may experience internal conflict between wanting to change and wanting to maintain their disordered eating habits (known as ambivalence about recovery). This can be difficult and confusing for both you and the person you are caring for.

What you can do:
• Encourage the person to voice their thoughts, feelings and concerns.
• Demonstrate that you are listening to what the person is saying. You can even reinforce what the person is saying by reflecting it back to them (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...”)
• Show them you respect their ideas, particularly the ones in favour of change.
• Gently highlight the discrepancies in their thinking/actions and amplify the positives for change.
• Try to boost their self-esteem and confidence. This will help them believe they can change.

Preparation
In this stage, the person living with the eating disorder has decided they want to change their behaviour and is preparing to make these changes. They usually take small steps to change their behaviour and may begin to engage in conversations about change, and seek support and encouragement to take the next steps. A level of ambivalence about recovery may still be present.

What you can do:
• Be informed. Learn as much as you can about the steps you and the person you are caring for or supporting need to take in order to recover.
• Continue to encourage the person to voice their thoughts, feelings and concerns.
• Support the person to access treatment.
**Action**

In the action stage, a person living with an eating disorder will be taking steps towards treatment and recovery. They are engaged in treatment and have begun to change their behaviours, thoughts and environment. The person will be learning ways and strategies to cope and will be making progress to return to normal eating behaviours. A level of ambivalence about recovery may still be present.

**What you can do:**

- Acknowledge that it is challenging to change and recover from an eating disorder.
- Support the person through challenges and let them know you care for them and believe in them. This will help build their confidence.

**Maintenance**

In the maintenance stage, a person living with an eating disorder will have changed their behaviours and will be proactively implementing new behaviours into everyday life. Eating disorder thoughts and feelings may be reducing in frequency and intensity. They are working to sustain the new behaviours and navigate the pathway to ongoing recovery. Relapse may occur at this stage where old thoughts and behaviours return. While relapse can be stressful, it is normal and allows the person to develop insight and develop ongoing strategies for recovery.

**What you can do:**

- Work together with the person to identify triggers that may impact their recovery.
- Accept relapse as a part of learning and the process of recovery.
- Help them to put systems and strategies in place to help avoid relapse.
- Show care, patience and compassion.

**Termination**

Termination is the final stage of the stages of change model. It describes a sustained period with no return to eating disordered behaviours or cognitions. During this stage, no matter what situation a person who had been living with an eating disorder may face, they are confident they will continue to cope in adaptive ways and will not relapse to disordered eating behaviours. Ideally, their adaptive behaviours have become largely automatic.

Although full recovery is possible for many people, it is important to recognise that for some a more realistic expectation is ongoing management of eating disorder behaviours, thoughts and feelings.
Helpful tips for families and supports

Recovering from an eating disorder can be a slow process and can sometimes take many years. Each stage will bring its own triumphs and challenges to both the person living with the eating disorder and to those caring for and supporting them. Here are some tips to help you along the way.

1. Learn as much as you can:

Having a good understanding of eating disorders will help you to be better able to support a person. There is information available to provide you with skills and coping mechanisms to help you throughout this difficult time. To find useful resources visit NEDC Research and Resources and to find helpful tips visit NEDC Supporting Someone and Families, Carers and Lived Experience.

2. Remember who the person is:

The person you care for and support is not their illness even though it may affect their sense of identity. Remember that they are still the same person they have always been. Separating the person from the illness can be helpful for you and the person you are caring for. This is called externalisation and helps all involved to see the illness as the problem and the person you are caring for as part of the solution. This can be very empowering for everyone involved, as the target of all treatment is the problem not the person.

3. Communicate openly:

Communicate openly, without judgement or negativity, and allow the person to express how they are feeling. Avoid focusing on food and weight and instead try to talk about the feelings that may exist beneath the illness. Pay attention to the person’s non-verbal reactions and body language and encourage them to trust and speak openly with you.

4. Stay positive:

Draw attention to the person's positive attributes. Talk about the things they enjoy and are good at and the things you love about them. Reminding the person of their life outside of their illness can help them to realise there is more to them than their eating disorder.

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5. Make time for yourself:

Prioritising ‘time out’ for yourself will help restore your energy and rejuvenate your mind. Make the time to see a friend, go for a walk, do some exercise or watch a movie. The better you care for yourself, the more you will be able to help the person you are caring for.

6. Be patient:

People living with eating disorders can experience a range of different and conflicting emotions all in one day. This can be very hard for you and the person you are caring for or supporting to manage. The road to recovery is filled with emotions and setbacks and can be a long journey. It is important to be as calm and patient as possible throughout their recovery and remember that there is no quick fix. Recovery takes time and patience.

7. Seek support:

Seeking professional support from a medical or mental health professional can reduce the amount of stress you carry and improve your capacity to care for someone living with an eating disorder. Eating disorder organisations and support groups can help you through challenges by providing guidance, strategies and resources, and connect you with others going through similar experiences.

Getting help and support

Many organisations provide further advice and resources for carers and supports of people living with eating disorders. For a searchable directory of eating disorder support organisations in Australia go to NEDC Support and Services.

If you suspect someone you know is living with an eating disorder, it is important to support them to seek help immediately. The earlier someone seeks help the closer they are to recovery. While your GP may not be a specialist in eating disorders, they are a good ‘first base’ and can refer you to a practitioner with specialised knowledge in eating disorders.

To find help in your local area go to NEDC Get Help.
References

Building a safe, consistent and accessible system of care for people with eating disorders

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www.nedc.com.au