

# CARING FOR A LOVED ONE WITH AN EATING DISORDER

**A Carer's Guide to Understanding the Illness and Keeping Well**

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## Authors' Note

Sections of the material in this booklet have been borrowed from the 'Anorexia Nervosa Workbook'. The workbook was developed at the Body Image & Eating Disorders Treatment & Recovery Service (BETRS) by Dr Suzy Redston.

In addition, some of the materials in this booklet are adapted from the Optimal Health Program (OHP), a self-management program which promotes hope, growth and partnership. Frameworks for Health (FFH), St Vincent's Hospital Melbourne (SVHM), has been dedicated to translating the OHP into everyday clinical practice through program development, research and training. The team was formerly known as the Collaborative Therapy Unit (CTU), based at the Mental Health Research Institute.

There are points throughout this booklet where statements or stories from our contributors have been included. The names of all individuals have been changed to protect the identity and respect the privacy of those who have shared so thoughtfully.

## Cover Art: "Untitled" Artist: Helen Wilding

Helen Wilding is an artist and Research Librarian at St Vincent's Hospital in Melbourne. This artwork contributes to the Caring Together Art Journal Project, a project that aims to help carers, consumers and practitioners to work together by starting a conversation, sharing different viewpoints, promoting mutual respect and understanding, and brainstorming how we can work together to support recovery.

## DISCLAIMER

The information contained in this booklet is not intended to be a substitute for medical care. Decisions regarding treatment are complex medical decisions requiring the independent, informed decision of an appropriate health care professional. Reference to any medication or substance does not imply recommendation by the authors who accept no responsibility for any clinical untoward event that may arise from following the recommendations contained herein.

## Acknowledgments

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The names of individual contributors have been changed to protect the identity and respect the privacy of those who have shared so thoughtfully.

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## Who is This Booklet For?

This booklet was written to support people with a loved one who have been diagnosed with an eating disorder. It aims to share practical information about the diagnosis, and offer advice about handling common experiences that can go along with it.

When caring for a loved one who is diagnosed with an eating disorder it can sometimes be difficult to focus on your own physical and emotional wellbeing. This may lead to you feeling stressed or overwhelmed, and can start to impact on your relationships with others. This booklet also shares some strategies for noticing and managing times that you are feeling stressed, so that you can help to maintain the good health of both you and your loved one.

*If you don't look after yourself, you won't be able to look after anyone else.*

Some parts of the booklet encourage you to reflect on your own experience and write down information relating to your own, or your loved one's, health. You might like to photocopy these sections as your thoughts and strategies might change over time.

Throughout these pages, you'll also find information that is highlighted and put in boxes like this one. These are the take-home messages that are particularly important to remember. When lives are busy and reading time is limited, these messages may be the easiest to flick to and use as quick reminders.

The information in this booklet might lead to you wanting to know more about eating disorders or clarify information that you already know. We strongly encourage you to approach a member of your loved one's health team with any questions or thoughts that you might have. This can often help you to understand more about your loved one's illness and can help everyone to tailor care to their needs.

## Being a Carer

Caring for a loved one with an eating disorder can be a very stressful and overwhelming experience. Families and carers often have very intense emotional responses to the situation in which the person they care for is putting their life and health at risk through self-starvation, over exercise or disordered eating behaviours. You might feel a range of different emotions such as worry, anger, guilt, grief, helplessness, resentment, powerlessness, frustration, exhaustion, shame or fear at various points in time. These emotions are very normal; however, managing these emotions will be difficult and may impact on your emotional well-being.

Research has found that carers of a person with an eating disorder face a number of distinct pressures and issues as a result of the illness, such as:

- *Family unification or disintegration.* Family units can change as a result of the stress that their loved one's illness has brought to bear on it. At times families may feel closer, at other times the family unit may feel pulled apart or fractured.

*'I ended up being 'bad cop' and my husband 'good cop.'* (Rosie, carer)

*'Trips overseas were almost cancelled because my daughter was so unwell and at risk. It's not fair on the siblings that they miss out because of the eating disorder'* (Jil, carer)

- *Inability to cope.* The emotional pressures experienced by carers sometimes lead to feelings of an inability to cope, or conversely, the burden of a loved one's illness can damage coping mechanisms.
- *Inconsiderate comments from significant others.* Unhelpful comments made by extended family members or friends can intensify the pressure upon carers and increase carer anxiety. Carers have identified that significant others did not understand the problem they were dealing with. This can lead to the 'problem' being kept within the family and result in social isolation.

*'My brother once said "why doesn't she just eat more?"'* (Anne, carer)

- *Social Isolation.* Carers may isolate themselves from friends, family and health professionals in an attempt to 'manage' the situation. Seclusion from others can limit coping resources and deprive parents from sharing the burden.
- *Financial impacts.* Health insurance, hospitalisation and therapy can be financially draining. Such financial concerns can be an additional source of stress. There can also be hidden costs of illness, such as transport costs, time missed at work etc.

It is crucial that you are able to talk about your feelings and experiences. Refer to page 55 of this booklet for more information about caring for yourself, and refer to page 65 for a list of support contacts.

*Try to remember you are not alone. There is help available for you and your loved one.*

### *Your experience...*

Have you and your family experienced any of the issues listed on the previous page as a result of your loved one's eating disorder? What emotions have you felt?

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When caring for a loved one with an eating disorder try to:

- *Get help from others.* Seek professional assistance and call on family and friends for help if you need it. Don't isolate yourself from others.
- *Take a break.* In order to continue to provide help and support to your loved one you are going to need to take some time out for yourself every now and then.
- *Get enough sleep.* Sleep is so important. If you are not getting enough sleep you are less likely to cope.
- *Join a support group.* Talking to other carers who have had similar experiences will help you feel understood and supported.
- *Be patient.* Recovery is absolutely possible but the process can be very slow. The journey to recovery can have many ups and downs. Try to be as calm and patient as possible.
- *Be compassionate.* The best medicine you can give your loved one is showing them that you care.

It's very normal to feel stressed or run down in your caring relationship from time to time. If there are times where you feel overwhelmed or experience symptoms of depression or anxiety, let your own doctor know. They may recommend a short course of individual psychological therapy or medication to help support you through a rough patch. You may also find value in regularly attending a Carer Support Group.



## Carer Rights

Carers are defined as people who provide support and assistance and/or personal care to people with a disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age. Carers include family members, friends, relatives, siblings, grandparents or neighbours.

Carers also include those situations where a person is being cared for in a foster, kinship or permanent care arrangement.

All of these people are defined as carers regardless of the amount of care, support and assistance they provide. A person may be considered as having a care relationship without having custody or guardianship.

The Victorian Government recognise the contribution family/carers make to the support and care of people with mental health problems and disorders. In 2012 the Victorian Government introduced legislation, Victorian Carers Recognition Act 2012, to ensure the rights and needs of carers were supported. This legislation together with the new Mental Health Act 2014 will direct practitioners to involve and support carers in their caring role.

As a carer you have a right to:

- Be recognised and respected as an individual, including your cultural identity and language preferences
- Be recognised and respected as part of the care relationship
- Where appropriate, have a say in decisions about care planning and care
- Receive assistance with your own difficulties which may be generated by the process of caring for a person with a mental health problem or mental disorder
- Be able to use what the '*Victorian Carers Recognition Act*' says to support their relationship and use of services
- Be provided with comprehensive information, education, training and support to assist their understanding, advocacy and care of your loved one.
- Seek further opinions regarding the diagnosis and care of their loved one
- Place limits on your availability to the person you care for
- Mechanisms of complaint and redress.

With the consent of your loved one, carers are entitled to:

- Have safe access to the person they care for
- Be consulted by service providers about measures under consideration for treatment of their loved one or for his/her welfare
- Arrange support services such as respite care, counselling and community nursing facilities
- Exchange information with those providing treatment concerning your loved one, their lifestyle and their relationships with others.

There may be circumstances where your loved one is unable to give consent or may refuse consent because of their personal choice or disturbed mental state. In such cases it may be appropriate for service providers and carers to initiate contact and involve those who may be able to assist with the diagnosis and care.

- Carers have the right to share information concerning family relationships and any matters relating to the mental state of their loved one to health service providers.
- Carers have a right to receive information which is reasonably required for the ongoing care of their loved one where the carer will be involved in providing that care.

#### References:

Victorian Carers Recognition Act 2012  
[www.dhs.vic.gov.au/carersact](http://www.dhs.vic.gov.au/carersact)

Mental Health: statement of rights and responsibilities  
<http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-m-rights2>

*For more information regarding consent and privacy issues please refer to page 49 of this booklet*

## Early Detection and Diagnoses

Early detection of an eating disorder can improve the outcome of treatment for your loved one and, in turn, can reduce the impact of the disorder on your loved one and your family. If you are at all concerned that your loved one has an eating disorder you should take them to their local doctor as soon as possible. General practitioners (GPs) play a very important role in the early recognition and ongoing management of your loved one's eating disorder.

There are a number of signs or symptoms that are common to eating disorders that you should keep an eye out for and that your loved one's doctor will want to know about. For example:

<ul style="list-style-type: none"><li>▪ Changed attitude to food and cooking</li><li>▪ Avoiding meals</li><li>▪ Slow eating/picking at food</li><li>▪ Eating in secret</li><li>▪ Eating only low calorie foods</li><li>▪ Changing food choices</li><li>▪ Weight fluctuations</li><li>▪ Low mood</li><li>▪ Mood swings</li></ul>	<ul style="list-style-type: none"><li>▪ Compulsive behaviour</li><li>▪ Suddenly developing 'allergies' to foods</li><li>▪ Medical problems</li><li>▪ Menstrual irregularities</li><li>▪ Social phobia with regards to eating</li><li>▪ Excessive work or training</li><li>▪ Poor concentration</li><li>▪ Fractures with minimal force</li><li>▪ Hypoglycaemia (e.g. 'dizzy spells')</li></ul>
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*'Looking back, an early warning sign was my daughter talking about becoming a vegetarian.'* (Rosie, carer)

### Your experience...

What are some of the signs or symptoms your loved one demonstrates? Are there any from the list on the previous page? It may be helpful to write them down before going to the GP.

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When you first visit the doctor he or she may ask your loved one a series of questions about their eating behaviour in order to open up a non-judgemental discussion about food and weight. These discussions will hopefully help the doctor to establish a therapeutic relationship with your loved one. For example, the GP may ask:

*Has your loved one:*

- Deliberately tried to limit the amount of food they have eaten to influence their shape or weight? If so, what has the result been?
- Gone long periods of time without eating anything at all to try and influence their shape or weight?
- Tried to exclude foods from their diet in order to influence their shape or weight? If so, what has the result been?

*Does your loved one:*

- Follow strict rules when it comes to eating?
- Have a desire to always have an empty stomach?
- Worry they have lost control over how much they eat?
- Make themselves sick because they feel uncomfortably full?
- Think they are fat when others say they are thin?

Your loved one may be very reluctant to go to the doctor and initially they may be unwilling to change their behaviour. This may make you feel scared, anxious or distressed. These feelings are all very normal. Make sure you talk to your doctor about how you are feeling.

If the GP suspects that your loved one does in fact have an eating disorder they will likely want to carry out a basic physical examination and monitor your loved ones weight, temperature, blood pressure and heart rate. This process will help the GP to engage with your loved one about their illness and assess how their body is responding to the disturbances in their eating behaviour.

*There is always hope for recovery; however, the earlier the intervention the higher the chance of success.*

From here your GP should request ongoing contact with your loved one and also assist with arrangements for your loved one to see a dietitian (an expert on diet and nutrition) and a psychologist or psychiatrist (for psychological treatment). Your loved one may also be given a referral to a mental health service or specialist treatment program. These services can provide ongoing support to help restore your loved ones weight, provide psychological treatment and help you and your loved one to understand why they engage in these behaviours. For more information please see the Treatment section of this booklet (p. 33).

## What is an Eating Disorder?

Eating disorders involve serious disturbances in eating behaviour and psychological issues related to food, eating and body image concerns. Eating disorders are characterised by two key sets of behaviours:

- *Disturbed eating habits:* can include restricted food intake, strict dietary rules, preoccupation with food, and altered mealtime behaviours.
- *Disturbed weight control behaviours:* may involve excessive exercise, vomiting, or the misuse of laxatives or diuretics (pills to reduce water retention).

These eating habits and behaviours become 'disturbed' when they become harmful through extreme use. For example, many people (especially girls and women) go on diets and restrict their food intake. This dieting only becomes 'disturbed' when dietary rules become so strict that daily food consumption is inadequate for health, either through being insufficient or nutritionally unbalanced.

Another example is exercise. Moderate exercise is a healthy behaviour. However, exercise behaviour becomes 'disturbed' when it is too frequent, obsessive, driven, or used for extreme weight control so that it interferes with other aspects of a person's life. If someone is exercising excessively, they will feel upset if they are prevented from exercising and will continue exercising despite injuries or bad weather. They may also prioritise their exercise regimen over having fun or spending time with others.

Eating disorders are more commonly found amongst women than men. Approximately 90% of those with an eating disorder are women. However, eating disorders may be under-diagnosed in men because men may be more reluctant to seek treatment for such a disorder. Whilst there are similarities between males and females with eating disorders, there are some differences. Females tend to pursue thinness, while males tend to work towards having a buff body. Men and boys often want to achieve high muscle definition and low body fat. Women and girls also want low body fat, but they tend to want smaller bodies.

*It has been estimated that approximately 15% of women in Australia will develop an eating disorder at some stage in their life.*

An eating disorder can have a serious impact on an individual's quality of life, effecting one's home, work, personal and social life. People with eating disorders also have a high chance of experiencing physical and medical complications. Thankfully, most patients can make a sustained recovery with treatment. Disordered eating becomes a full-blown eating disorder when it gets bad enough to meet the criteria for a specific diagnosis. These standards are set by expert health professionals.

## *Anorexia Nervosa*

People with Anorexia Nervosa severely restrict their food intake and become obsessed with food, eating (or not eating) and their weight. A person with Anorexia Nervosa is typically very underweight and has an extremely distorted view of their body (i.e. they see themselves as being overweight when they are in fact seriously underweight). Anorexia Nervosa can develop for males and females at any age or stage of life, although it commonly develops during adolescence.

A person who is diagnosed with Anorexia Nervosa will likely display the following symptoms:

- *A persistent restriction of food intake* resulting in an extremely low body weight (sometimes less than 85% of the weight expected for their age and height).
- *An intense fear of gaining weight or of becoming 'fat'*, despite being underweight.
- *A disturbed perception of their body weight or shape*. A person with Anorexia Nervosa does not see their body in the way that everyone else sees it. Instead, they see a body that is bigger and 'fatter' than it really is. They fail to recognise how much weight they have lost and as a result do not think that their very low weight is problematic.

It is important to understand that people with Anorexia Nervosa are not just too vain or have simply taken a diet regime too far. People with this disorder are intensely fearful of gaining weight and do not see their body the way other people see it.

Anorexia Nervosa can be broken down into two main sub-types:

- *Restricting type*: A severe restriction of food intake, with no binge eating or purging behaviours. This is the most common type of Anorexia Nervosa.
- *Binge-eating or purging type*: A restriction of food intake but also regular binge eating behaviours (eating large amounts of food in a short amount of time) and purging behaviours (self-induced vomiting or the misuse of laxative or diuretics).

*Despite weight loss, a person with Anorexia Nervosa may continue to feel overweight and aim to lose more weight, even when considered extremely thin by others.*

## *Bulimia Nervosa*

People with Bulimia Nervosa tend to binge eat repeatedly (i.e. eat large amounts of food in a short amount of time) and then attempt to compensate for this behaviour by attempting to control their weight (e.g. self-induced vomiting, fasting, laxatives, overexercising). When a person with Bulimia Nervosa binge eats they feel a loss of control which is followed by feelings of guilt and shame. These feelings lead the person to try to compensate for their behaviour by utilising weight control behaviours.

A person who is diagnosed with Bulimia Nervosa will likely display the following symptoms:

- *Repeated episodes of binge eating* involving eating large amounts of food in a relatively short amount of time (e.g. within 2 hours) and experiencing a lack of control over eating during these episodes (e.g. could not stop even if they wanted to).
- *Repeated attempts to compensate* for the binge eating episodes in order to avoid weight gain, behaviours such as self-induced vomiting, fasting, laxatives, overexercising.
- *Preoccupation with body shape.* Focusing too much on their body, shape and weight.

A person with Bulimia Nervosa usually experiences weight changes but they do not necessarily lose weight. They may maintain an average weight for their age and height or even be overweight. This can mean that family or health professionals are less likely to detect that something is wrong.

Like Anorexia Nervosa, Bulimia Nervosa can be broken down into two main sub-types:

- *Purging type:* A person regularly induces vomiting or misuses laxatives or diuretics to 'make up' for the binge eating episodes.
- *Non-Purging type:* A person regularly engages in overexercising or fasting but does not demonstrate purging behaviours.

***70% of individuals who undertake treatment for Bulimia Nervosa report significant improvement***

The symptoms of Anorexia Nervosa and Bulimia Nervosa may appear to be very similar; however, there are two key differences:

- The dominant symptom of Anorexia Nervosa is extreme thinness and this is not the same for Bulimia Nervosa.
- Cycles of binge eating and compensatory behaviour are dominant symptoms of Bulimia Nervosa, but not of Anorexia Nervosa.

## *Binge Eating Disorder*

People with a Binge Eating Disorder (BED) repeatedly eat excessive amount of food, often when they are not hungry. A person with BED often uses eating as a way to distract themselves from a problem in their life and can often experience feelings of guilt, disgust and depression after a bingeing episode. However, unlike Bulimia Nervosa, a person with a BED does not display weight control behaviours after they have binged.

A person with a BED will likely display the following symptoms:

- *Repeated episodes of binge eating* involving eating large amounts of food in a relatively short amount of time (e.g. within 2 hours), at least once a week.
- *A lack of control over eating* during these episodes (e.g. could not stop even if they wanted to).
- *Eating rapidly, alone or in secret, and when they are not hungry.*
- *Marked distress over their binge eating*, such as feelings of guilt, disgust and shame.

It is important to note that binge eating can also occur as an adverse side effect of certain medications that stimulate appetite. Such medications may also interfere with a person's ability to sense when they are full after eating a meal.

A significant number of people with eating disorders do not display symptoms that neatly fit into the categories of Anorexia Nervosa, Bulimia Nervosa, or Binge Eating Disorder. In such cases they may be diagnosed with Other Specified Feeding or Eating Disorder (OSFED) or Unspecified Feeding or Eating Disorder (UFED). If your loved one receives a diagnoses of OSFED or UFED this does not suggest that they have a less severe eating disorder. Rather, it simply means that your loved one experiences a different pattern of symptoms. Their illness is still serious and they need help.

*Outcomes for people with eating disorders can be good. Many people with Anorexia Nervosa or Bulimia Nervosa have a full recovery.*



## Insight

If your loved one has an eating disorder you may be confused as to why they can't understand that their behaviour is unhealthy. The degree to which someone understands their illness is called 'insight'. A person's insight can affect their understanding of the need for treatment and/or their ability to make decisions about their care. An individual's insight can change with time and with different stages of the illness. Unfortunately, people caring for a loved one with poor insight can sometimes feel caught in the middle between their loved one and the mental health team, particularly if they have very different ideas about what might be helpful. Lack of insight often improves with treatment.

### How can I talk to my loved one about their illness?

- Choose a time that you are both feeling calm and ready to talk
- Try to talk about only one thing at a time
- Try not to confront them with your view of what is happening to them. Remember that their experience is very real to them, even if it doesn't fit with what you think is happening
- Try to understand what the name of their illness means to them

## *Your experience...*

How does an eating disorder affect your loved one? What kind of behaviours do they engage in? It may be helpful to list them below.

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## Health Consequences of Eating Disorders

A person with an eating disorder will likely experience a number of physical, emotional and personality changes. Most of the symptoms listed below are related to malnutrition. Some of these changes can be very serious and it may upset you to read about them. Try to remember that most of them are reversible, especially in the earlier stages.

### *Physical changes*

External physical changes that occur as a result of an eating disorder include:

- Thinning of the hair
- Dry skin
- Brittle fingernails
- Bruising easily
- Frail appearance, including pale complexion and/or sunken eyes
- Increase in body hair (lanugo)

Internal problems that can occur as a result of an eating disorder include:

- Reproductive changes, such as amenorrhea (cessation of menstrual periods)
- Changes in the immune system (e.g. reduced white blood cell count, wounds take longer to heal)
- Slowed metabolism
- Slowed heart rate
- Very low blood pressure (hypotension, which can cause dizziness or fainting)
- Muscle atrophy (muscles can begin to deteriorate and lose their ability to function properly)
- Growth rate can slow down and/or puberty can be delayed
- Changes of the digestive system (constipation or diarrhoea)
- Reduction of bone density (osteoporosis)
- Tooth decay
- Hypothermia (low body temperature)
- Iron deficiency (anaemia)
- Retention of fluid (oedema)

*'My daughter was in complete denial that that her these changes had anything to do with an eating disorder' (Anne, carer)*

Make sure you talk to your loved one's health professional if you think your loved one is experiencing any of the physical changes listed above. Remember, most people with an eating disorder have good outcomes, especially if they seek treatment early.

## Psychological changes

When a person is starving themselves a number of psychological changes also occur. These psychological changes can drive the disorder, and being aware of them may help you to understand some of the behaviours that your loved one may engage in.

A person who is starving themselves has a tendency to:

- Be preoccupied with food (finding it almost impossible to think about anything else)
- Become inward looking and inflexible in their thinking
- Experience difficulty concentrating and making decisions (e.g. procrastinating)
- Experience low mood and irritability
- Be prone to mood swings and sudden flare-ups
- Withdraw from family and friends
- Narrow their interests
- Become socially isolated or unaware of what is going on around them
- Become obsessional
- Do things in a rigid or ritualistic way (e.g. cutting food into tiny pieces)
- Become very competitive
- Start hoarding things

*'The hardest thing for me was the lying and deceiving – that was not my daughter, it was the eating disorder' (Rosie, carer)*

When a person is at a very low weight these psychological changes play a role *keeping* them at that low body weight, thus creating a vicious cycle. However, there are a number of strategies that can tackle these issues which are discussed in the Treatment section of this booklet (page 33).

*These behaviours may cause you to feel upset and extremely frustrated. Try to remember that your loved one is acting like this because of the illness.*

## Your experience...

What changes have you noticed in your loved one's mood or personality?

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## What Can Accompany an Eating Disorder?

Unfortunately, an eating disorder can develop alongside other mental health issues. Negative feelings and low esteem are common symptoms for eating disorders and other mental health problems, such as depression, anxiety and personality disorders.

### Depression

A person with an eating disorder is twice as likely to struggle with depression when compared to other people in the community. We often use the word “depressed” to describe the moments that we are feeling sad or down. However, depression in the clinical setting lasts longer than just a few days and can affect our thinking, feeling and behaviour.

Generally, the word ‘depression’ describes a period of very low mood that lasts at least two weeks without relief and often goes along with:

- *A lack of enjoyment:* activities that used to be fun are no longer enjoyed, or enjoyed much less.
- *Changes in sleep:* sometimes trouble going to sleep, waking for long periods during the night, or even sleeping much more than you usually would.
- *Changes in appetite:* including going off your food or eating more than you usually would.
- *Low energy levels:* feeling as though you don’t have enough spark to do what you need to do, and tiring quickly.
- *Changes in thinking:* people with depression often describe feeling guilty, having trouble holding hope for the future, trouble concentrating and feeling low in self-confidence.
- *Suicidal ideation:* some people with depression may have thoughts about or even a preoccupation with suicide.

Treatment for depression is important as it can not only affect your loved one’s enjoyment of life, but can also affect their recovery. Importantly, experiencing depression can also put someone at higher risk of having suicidal thoughts and acting on these thoughts.

It is important to let someone know if you are worried about your loved one’s mood, as family members and carers are often well placed to notice subtle changes in how their loved one is feeling or thinking.

***Depression can make a person have negative feelings about their body and themselves – this may put them at risk of developing an eating disorder.***

## Anxiety

A person who is struggling with anxiety can find it difficult to function on a daily basis. In any one year, approximately one in 10 people will experience some type of anxiety disorder. The experience of anxiety is usually a combination of physical and psychological symptoms including: intense fear or worry, feelings of dread, a pounding heartbeat, shortness of breath, sweating, dizziness, and shaking. The fears or worries themselves may be related to going out to public places, social situations, worries about germs or contamination, generalised distress about a number of things constantly, or a personalised distress that has a particular meaning to the individual.

Anxiety disorders and eating disorders often occur simultaneously, with approximately 64% of those with an eating disorder experiencing an anxiety disorder. If a person has an anxiety disorder, a co-occurring eating disorder may make their symptoms worse and recovery more difficult.

*Encouraging your loved one to talk to their doctor about the difficulties they're experiencing with anxiety can make a big difference to their overall well-being.*

There are a number of different types of anxiety disorders:

- *Generalised Anxiety Disorder (GAD)*: feeling anxious, restless and/or worried on most days over a long period of time.
- *Obsessive Compulsive Disorder (OCD)*: ongoing unwanted and intrusive thoughts and fears that cause anxiety – often called obsessions. These obsessions make the person feel they need to carry out certain rituals in order to feel less anxious. These are known as compulsions. An example is fear of contamination leading to washing rituals.
- *Phobias*: strong fears about particular objects or situations.
- *Post Traumatic Stress Disorder (PTSD)*: bursts of anxiety that occur after a person has a major emotional shock following a stressful event (e.g. experiencing or witnessing a scenario involving death, injury, torture or abuse).
- *Panic Disorder*: frequent panic attacks (i.e. intense feelings of anxiety that seem like they cannot be brought under control).

It is vital that you look after yourself, as much as you're looking after the individual with a mental illness. There is always a risk that the pressures and demands of caring for another person with a serious illness can lead to feelings of anxiety and depression in those who are providing the care.

*Your own health needs must be tended to in order for you to be able to provide the best quality care for someone else.*

## Personality Disorders

A person with a Personality Disorder differs significantly from other people, in terms of how they think, perceive, feel or relate to other people. Symptoms of personality disorders typically get worse with stress. Research has found that there is a relationship between eating disorders and personality disorders, particularly Borderline Personality Disorder (BPD). Unfortunately, eating disorders can be associated with an increased risk of BPD, and vice versa. The biological changes and stress that is experienced by a person with an eating disorder can also predispose them to BPD.

A person affected by BPD has difficulty relating to other people and the world around them. Symptoms of BPD can include:

- *Profound feelings of insecurity.* For example, difficulty coping with fear of abandonment and loss, continually seeking reassurance, expressing inappropriate anger towards others whom they consider responsible for how they feel, a fragile sense of self and one's place in the world.
- *Persistent impulsiveness.* For example, abusing alcohol and other drugs, excessive spending, gambling or stealing, driving recklessly, having unsafe sex.
- *Confused, contradictory feelings.* For example, regularly questioning and changing of emotions or attitudes towards others, and towards aspects of life such as goals, career, living arrangements or sexual orientation.
- *Self-harm.* For example, binge eating or starving, causing deliberate pain by cutting, burning or hitting oneself, overdosing on prescription or illegal drugs, abusing alcohol and other drugs, repeatedly putting one's self in dangerous situations or attempting suicide.

The outcomes for people with BPD can be good with early diagnosis and effective treatment. However, BPD can *potentially* have an impact on treatment and outcomes for a person with an eating disorder. There are specific treatments for co-occurring eating disorders and BPD, such as exposure therapy or Dialectical Behaviour Therapy (DBT). It is extremely important to tell your loved one's doctor or treatment team if you suspect that they have a personality disorder.

If you think your loved one may have a personality disorder make sure you speak to their doctor or treatment team as soon as possible.

## *Substance abuse*

A 'substance' refers to anything that a person takes which changes their thinking or feeling. Not all substances are illegal, but those that are can carry extra risks such as getting into trouble with the police. Some medications can be considered to be a substance if they are used in ways that are not recommended by medical professionals.

Many of us use some substances on a weekly or even daily basis, particularly caffeine. Some examples of commonly used substances are:

- Caffeine (e.g. tea, coffee, energy drinks, cola drinks, chocolate etc.)
- Alcohol (e.g. beer, wine, spirits etc.)
- Nicotine (e.g. cigarettes, cigars, chews etc.)
- Cannabis (e.g. marijuana, hashish etc. Also called "pot", "hash", "weed" etc.)
- Stimulants (e.g. amphetamines, cocaine, methamphetamines etc. Also called "speed", "blow", "ice")

Research has suggested that approximately 50% of people with eating disorders abuse substances. Substance abuse can develop before, during, or after treatment for a person with an eating disorder. Individuals with an eating disorder may abuse substances as a way to suppress their appetite and/or as an avoidance-based coping strategy.

It is important that treatment for an eating disorder and treatment for substance abuse is integrated. If you think your loved one is abusing substances make sure you speak to a health professional as soon as possible.

## What Causes an Eating Disorder?

When someone you love develops an illness, it is understandable that we want to know what has caused it. However, like with most mental health issues, it is important to understand and accept that there is no single cause of eating disorders.

A person with an eating disorder tries to use eating and weight management as a way of dealing with overwhelming feelings and emotions that often have very little to do with food or weight. In other words, eating disorders do not often occur in content and emotionally stable people.

*Many people with Anorexia Nervosa see their anorexia as the best 'solution' to a number of important problems in their life*

An eating disorder can develop in someone of any age and from any socio-economic background. However, adolescents and young women are more prone to developing eating disorders. In addition, a number of psychological, interpersonal, social, genetic and biological factors can contribute to eating disorders.

### *Psychological factors*

Psychological factors that can contribute to a person developing an eating disorder include:

- Low self esteem
- Feelings of inadequacy
- Depression or anxiety
- High achievers
- Perfectionists

'Self-esteem' refers to the way we view and think about ourselves. If your loved one has low self esteem it will likely be influencing all aspects of their life, such as how they talk, handle relationships, choose career paths and create lifestyles. Low self esteem plays a very important role in the development of an eating disorder and is often related to perceptions of poor body image.

As mentioned earlier in this booklet, people with anorexia nervosa may also struggle with other psychological difficulties and mental illnesses. Depression, anxiety (e.g. obsessive compulsive disorder), substance abuse and one or more personality disorders are the most likely conditions to accompany anorexia nervosa. Refer back to page 20 of this booklet for more on these conditions.



If your loved one's self confidence is low, you may be in a position where you can help them rebuild their self-esteem. This could involve reminding them of their abilities and skills, or tasks that they have successfully completed in the past. Some ideas for improving for loved one's self esteem are listed below.

Try to encourage your loved one to:

- Forgive themselves when they make a mistake
- Celebrate their achievements, no matter how small
- Do things they enjoy and make sure these activities are a priority for them, especially at times when they are feeling down.
- Make new choices, set out goals and strategies for improving the way they think and live.
- Treat themselves with deliberate acts of kindness.
- Spend more time with people who encourage them, and less time with people who discourage them.

However, sometimes people are not looking for solutions and may just need someone to commiserate with them. Your loved one may just need you to be there for them and listen to them. Acknowledge the upsetting or difficult situation they face and let them know it's OK to experience negative feelings about it. For some people, simply knowing that someone truly understands and accepts them for who they are can improve self esteem.

### *Your experience...*

Write down the ways in which you think you could help build their self esteem. Discuss these ideas with your loved one's treating team.

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## *Interpersonal factors*

The term 'interpersonal' relates to communications, relationships or interactions between people. Interpersonal factors that can contribute to an individual developing an eating disorder include:

- Issues with family and/or other personal relationships
- Trouble with expressing emotions and feelings
- History of being bullied about size or weight
- History of physical or sexual abuse

Relationship issues, including conflict within the family, can have an indirect impact on the development of an eating disorder. In addition, individuals who have difficulty expressing their emotions and feelings, particularly negative ones, may be more at risk for the development of an eating disorder. Unfortunately it has been found that there is a high rate of reported child sexual abuse experiences amongst individuals who have been diagnosed with Anorexia Nervosa in particular.

*'My daughter had friendship issues, such as exclusion, in Year 8.'* (Anne, carer)

## *Social Factors*

Social factors that can contribute to an individual developing an eating disorder include:

- The glorification of "thinness" and the value placed on having the "perfect body"
- The tendency to value people based on their physical appearance as opposed to their inner qualities
- Unrealistic images of men and women that are portrayed in media and popular culture
- Professions that demand particular body shapes and sizes (e.g. ballet)

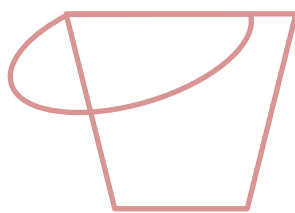
Many Westernised societies and cultures promote thinness as an ideal body form, reinforcing the message that in order for one to be happy and successful they must be thin. This message is promoted through various forms, such as magazines, newspapers, advertising, and television and can reinforce the practice of an eating disorder.

Individuals in professions where there is a pressure placed on them to maintain a particular body shape (e.g. athletes, models, dancers) are more likely to develop anorexia nervosa.



## Common Triggers of Eating Disorders

Often some kind of life crisis, such as a family death or loss, a friendship loss, moving to a new home, school or job, a personal disappointment or situations which represent a threat to self-esteem, precipitate the development of an eating disorder. However, the illness also can develop after an accumulation of circumstances or minor stressors that, in isolation, are unremarkable. These may cause the individual to feel that they cannot cope. To help you to understand this concept, imagine that your mental health is a bucket and that your stressors and vulnerabilities are like tennis balls. The vulnerabilities and stressors fill the bucket. A vulnerability is something that can increase your risk of experiencing symptoms or an episode of illness. When the bucket overflows, we can become unwell.



My mental health

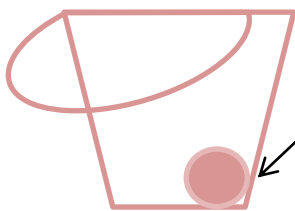


My vulnerabilities



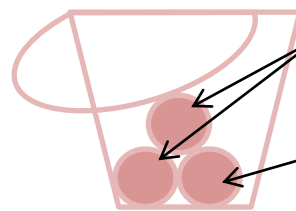
My stressors

We each start out with our own vulnerabilities. These do not tend to change over the course of our lives. Compare My-Linh and Karen as examples.



Serotonin imbalance

My-Linh has few vulnerabilities

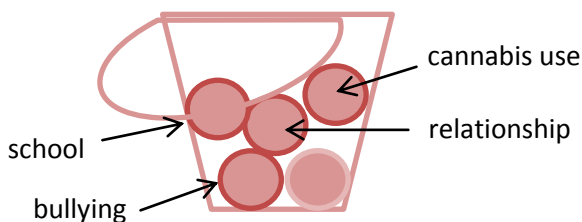


History of mental illness in the family

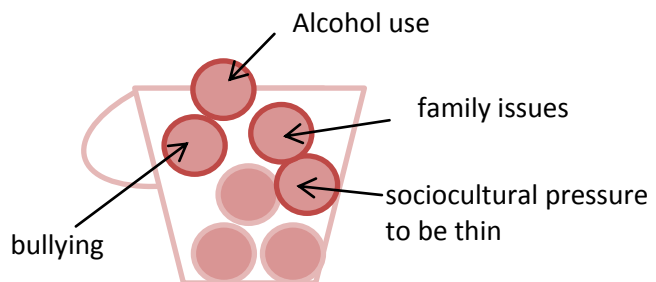
Serotonin imbalance

Karen has several vulnerabilities

My-Linh and Karen have different vulnerabilities, but their vulnerabilities alone do not make their buckets overflow. In other words, our vulnerabilities are usually not enough to cause us to become unwell. But what happens when we add stressors?



At the moment, My-Linh has four stressors



At the moment, Karen also has four stressors

Although My-Linh and Karen have the same number of stressors, Karen’s bucket is much closer to overflowing. This is because our vulnerabilities and stressors can often add together to cause us to become unwell. The impact of the psychological, interpersonal, social and biological factors mentioned earlier intensify this feeling. The person may respond to these emotions by dieting, in an effort to enhance their sense of self-control and self-worth. They may begin to see dieting as the only area in their life in which they have any form of control and may use it as a means of forming a fragile self-identity.

In anorexia nervosa, self-starvation effectively anaesthetises the individual to emotions. A person diagnosed with anorexia really has no thought for anything other than how much food they have eaten, what they weigh and what they will eat next. All of their feelings are experienced in relation to food and thus other problems may seem to disappear or become more manageable. This may seem a favourable situation to the sufferer, who feels as though they are floundering in all others areas of their life.

Listed below are some possible triggers that could predispose an individual to developing an eating disorder:

- Changes in environment (home, school, parents divorcing, moving house)
- Losses (could be relatives, pets or significant others)
- Wanting to be healthy for a special event
- Parent or grandparent being on a particular type of diet (this can make the whole family very obsessive about food and calories)
- Depression (which takes away the appetite, makes the person lose weight, everybody comments on it and then it becomes an obsession)
- Certain medications (e.g. some acne treatments) can trigger off depression which can then set off an eating disorder

*‘In year 7, my daughter experienced the death of two grandparents, started a new school and we were rebuilding our new house...’ (Jil, carer)*

### *Your experience...*

Do you think your loved one has been predisposed to any triggers?

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## What Maintains an Eating Disorder?

The factors that predispose a person or lead to the start of an eating disorder are not necessarily the same as those that maintain the condition. Factors such as the effects of starvation, changes in brain chemistry, weight loss, bingeing and vomiting, loss of social skills and friendships, loss of work skills, disruption to the family, depression and secondary gain (e.g. gaining power over others or a sense of 'specialness' derived from the disorder) may lead to a perpetuating cycle.

Maintaining factors are best understood as learned but unhelpful behaviours that are reinforced within the individual by the mechanisms of avoidance, and positive and negative reinforcement. The table on the next page provides some example of maintaining factors in anorexia nervosa. *Identification of alternative, more helpful ways of addressing each of the maintenance processes may help to break the cycle.*

Although it may be difficult to comprehend, for a person with anorexia nervosa, there are some perceived positive benefits of *not* eating. A survey of 300 women with anorexia nervosa revealed that the most common 'rewards' that are associated with the disorder were that anorexia made them feel safe, secure, in control, was a way of showing their distress and a way of helping them avoid growing up (i.e. responsibility).

Are any of these 'rewards' relevant to your loved one? If so, you need to help them to find other ways to meet these needs. For example, help them to find other ways of feeling safe, secure and in control by creating an atmosphere that is calm, consistent and compassionate. Or, you may need to help them find other ways to communicate and deal with their distress. If fear of responsibility is the issue then you need to try to make the experience of taking personal responsibility more positive.

### Your experience...

Looking at the table on the next page, what do you think your loved one's maintaining factors are?

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Type of symptom or fear	Safety or avoidance behaviour	Consequence	Outcome	Possible treatment goal
Fear of becoming obese with catastrophic consequences	Calorie restriction	No weight gain	Weight gain continues to be seen as catastrophic	Cognitive challenges Weight Gain
			Calorie restriction seen as appropriate safety behaviour	Increased energy consumption
Fear of weight gain	Avoidance of energy dense food	No weight gain	Failure to learn that energy dense foods may not cause weight	Increased consumption of energy dense foods
			Increasingly restricted range of foods consumed	Increased variety of food
Fullness after meals and abdominal discomfort	Misinterpretation as being greedy	Increased anxiety and abdominal symptoms	Further restriction in food intake	Weight restoration reversing biological symptoms of starvation with cognitive challenges
			Scanning reinforced	Techniques to reduce scanning
Worry about weight gain	Weighing, pinching of skin, checking tightness of clothes	Normal weight fluctuations noticed and interpreted as weight gain	Further weight loss behaviours	Conscious reduction in deliberate weight loss behaviours
			Relief felt when weight fluctuations downwards	Reattribution of feelings. Cognitive challenges
			Increased anxiety with weight fluctuations upwards	Mindfulness and anxiety management
			Remorseless restriction and weight loss	Restoration of normal eating. Reversal of biological symptoms of starvation
			Apparent confirmation of predictions. Belief that needs to control weight to get further mastery over this	Social exposure Cognitive challenging and normalisation of eating
Anxiety in an food or weight related situation	Symptoms experienced as intolerable and threatening	Anticipatory fear of anxiety with subsequent avoidance behaviours	Anxiety not seen as normal aspect of life	Acceptance and mindfulness
			Normal anxiety linked to weight and eating related situations	Psychoeducation
Hunger or stress	Bingeing	Short term relief	Long term sense of loss of control	Exposure work
			Self-disgust, fear of normal eating	Normalisation of eating Cognitive work including schema approach

## Anorexia and the Internet

The internet is a wonderful resource and can provide us with access to an incredible amount of information. However, some websites on the internet can be harmful for those diagnosed with an eating disorder. Unfortunately a number of “pro-anorexia” websites (also referred to as “pro-ana” or “ana”) have emerged over the years. If you type “I want to get anorexia nervosa” into to a search engine you can get up over 10 million hits. These websites contain provocative and dangerous content that promote and support anorexia nervosa.

Most commonly, pro-anorexia websites claim to offer and promote a community of support for people diagnosed with anorexia nervosa. However, they can serve to perpetuate a person’s disordered eating behaviour. For example, many of these websites contain pictures of emaciated young women which can encourage and motivate sustained weight loss in an individual diagnosed with anorexia nervosa. This is often referred to as “thinspiration”. In addition, these some of these websites include “tips and tricks” that promote fasting and/or laxative use and hiding eating habits from family. **These can be very dangerous and detrimental to people with eating disorders.**

*A large number of pro-anorexia websites deny that anorexia nervosa is an illness and refer to it as a “life-style” choice that should be respected by others.*

Many of these websites do not provide disclaimers or warning which is worrying given that this type of harmful information is available and easily accessible. Although these websites have been severely curtailed and discouraged they continue to exist. Unfortunately there is not much we can do about shutting down these sights, however; as a carer of a loved one with an eating disorder is extremely important that you know and understand that these websites exist.

If your loved one is under 18 years of age you can employ some general internet safety guidelines in an attempt to protect them from pro eating disorder sites. For example:

- Discuss with your loved one the potential dangers of the internet
- Keep the computer in a shared room of your house (e.g. the lounge room) so you can monitor your loved one’s internet activities
- Buy some monitoring software that will allow you to block certain websites and/or track the websites that have been visited
- Try to be aware of the people your loved one is chatting with online



## How is an Eating Disorder Treated?

As mentioned, a GP may refer your loved one to a specialist treatment program. In Melbourne, Australia, the Body Image & Eating Disorders Treatment & Recovery Service (BETRS) is a collaborative partnership between the mental health programs of Austin Health and St Vincent's hospital, and provides services for those situated in the Northern, Eastern and Hume regions. The treatment section of this booklet is based on the model of care that is provided at BETRS. However, there are a number of different mental health service or specialist treatment programs available. Please see the 'Further Resources' section at the back of this booklet for more information.

Remember, most people who are diagnosed with an eating disorder do recover. However, people with eating disorders require professional help. Research suggests that interventions early in the illness are likely to have more impact than interventions late in the illness.

### *Nutritional assessments*

Nutritional assessments are carried out by dietitians and are often one of the first steps of treatment for eating disorders. Dietitians provide food and nutrition information and can give advice on how to re-introduce foods in a safe manner. Dietitians also gather information such as weight, height, BMI, current exercise and activity levels, bowel movements and menstruation cycles. A dietitian will also want to know about your loved ones eating patterns and any weight management behaviours he or she may engage in. A dietitian may ask your loved one to keep a food and thought diary, perhaps listing the foods he or she may fear or food rules that they live by.

### *Workbooks*

Specialist treatment clinics often provide workbooks that have been specifically designed to strengthen skills and knowledge and to support your loved one's treatment plan. They are most beneficial if your loved one participates in the process fully. The workbooks will also provide you and your loved one with information about how to manage the eating disorder and its impact. Workbooks may include the following:

- *Reflective questions* designed to help your loved one think about the information provided and begin to apply it.
- *Activities* designed to help with recovery.
- *Information* on how to manage eating disorders and their impact.
- *Notes* pages where your loved one can write down any questions or notes that they might find interesting or helpful.

This type of treatment is also referred to as 'psycho-education'. Psycho-education is a type of learning that can help teach individuals with a mental health condition and their families to deal with their condition in the best possible way.

Psycho-education can help you and your loved one understand more about:

- Eating behaviours
- The cycle of eating disorders
- Triggers and maintaining factors
- What normal weight is
- Diets and nutritional myths
- General nutrition (e.g. food groups, serving sizes, number of serves).
- Urge management and distraction

### *Meal plans*

To help your loved one to begin eating normally again they will be given a meal plan. Meal plans can help to challenge your loved ones *thoughts, rules, and behaviours* around food and weight. They can also increase the variety of acceptable foods and help them to see that certain foods do not lead to excessive weight gain or other fears that they may have.

A meal plan will be set specifically for your loved one, considering their current weight, nutritional needs, healthy weight goals, metabolism, medical conditions, religious and wherever possible moral preferences. Meal plans might also include *guidelines* (such as only using full cream dairy products and putting butter on bread) and *challenges* (such as eating out once a week or eating take away food). This may help your loved one slowly to become more flexible and spontaneous with their food choices.

The aim of a meal plan is to improve your loved one's relationship with food and their body so that they can learn to trust them again. Often, but certainly not always, the foods that are excluded by eating disorder rules are the 'sometimes' foods that people often refer to as junk foods. They need to relearn how to eat their excluded 'feared' or 'bad' foods, which involves eating them on a regular basis. Eventually anxiety around eating these foods reduces and food choice ultimately becomes a decision based on factors such as taste, appetite, availability and social situations, rather than emotions. **Food is medicine for an eating disorder.**

*'A meal plan is very helpful as it takes the pressure off you as a parent – it is not you saying what she must eat, it's the dietitian.'* (Jil, carer)

If your loved one has followed strict food choices for some time it is very likely that they will find starting and committing to a meal plan to be very challenging. The dietitian and treatment team will be there to support them through this.

Meal plans will generally involve 3 meals and 3 snacks each day and are designed to:

- *Meet your loved one's metabolic needs.* Your loved one may need more food to meet their energy requirements while restoring their weight.
- *Allow the volume of food to be spread* throughout the day so that it is physically more comfortable.
- *Relearn hunger cues.* Once your loved one stabilises their weight, eating regularly throughout the day can help to relearn hunger and understand the feeling of being full so they can learn to trust their own body again.
- *Ensure that food is consumed regularly* during the day to prevent extended periods of time without eating. This may result in being very hungry which may trigger either binge-eating or further restriction. Learning to include a wide range of foods; including trigger foods, is one of the other ways to manage binge urges.

It is important that your loved one follows their individual meal plan closely so that they become stronger in overcoming their eating disordered thinking and rules. Having set meal times and quantities will provide your loved one with guidance on how to eat normally, restore physical health and provide the opportunity to eventually relearn hunger and fullness cues.

<b>Example Meal Plan</b>	
Breakfast	30-40 grams of cereal (e.g. muesli, weetbix, cornflakes) AND 2 x slices of toast with butter and jam
Morning snack	Small tub of full fat yogurt OR Packet of mixed fruit and nuts OR A fruit smoothie
Lunch	Tuna salad sandwich on thick bread with mayo OR Chicken breast with couscous and salad AND Dessert (e.g. Smoothie, fruit and ice-cream, slice of cake)
Afternoon snack	Small tub of full fat yogurt OR Packet of mixed fruit and nuts OR A fruit smoothie
Dinner	Fish fillet with potatoes and salad OR Tuna pasta with cheese AND Dessert (e.g. apple pie, fruit and ice-cream, slice of cake)
Evening snack	Small tub of full fat yogurt OR Packet of mixed fruit and nuts OR A fruit smoothie

### *Social eating challenge groups*

Some treatment specialist clinics also offer group activities which can involve teaching your loved one living skills such as cooking, shopping and eating out in various situations. Social Eating Challenge Groups are run by clinicians who specialise in eating disorders. Clinicians will try to engage your loved one and other group members with the processes of planning, experiencing, observation and reflection, all of which are techniques that are often used in Cognitive Behavioural Therapy.

The basic aims of the Social Eating Challenge Groups are to gradually expose your loved one to feared and avoided situations and foods and assist with their general coping skills. Your loved one will be given worksheets to help them with this process. These will include techniques regarding the practice of calming and distracting, as well as constructive and positive statement strategies.

### *Psychological therapies*

Psychological therapies, also called talking therapies, have been found to be the most successful and acceptable form of treatment for eating disorders. A psychologist or psychiatrist can provide talking therapy for the constant thoughts and behaviours that rule your loved one's disordered approach to food. Cognitive Behavioural Therapy (CBT) is one of the most common and well-studied types of psychological therapy. CBT focuses on the "here and now" rather than looking to the distant past and aims to lower distress, challenge frightening internal experiences, and help people to achieve their life goals, by looking at the relationships between thoughts, feelings and behaviours.

Enhanced Cognitive Behaviour Therapy (CBT-E) is a form of CBT that is specifically designed to treat eating disorders. CBT-E can help to minimise the negative thoughts about body image and the act of eating, and attempts to alter the negative and harmful behaviours that are involved in and perpetuate eating disorders. See the resources section at the back of this booklet for more information about accessing CBT-E for your loved one.

For treatment of anorexia nervosa specifically, family-based treatment has the best evidence support for people aged under 18 year. Family based interventions involve family members and the loved one who is experiencing a problem in their life. They are designed to benefit the patient *as well as* the family as a whole and may help to reduce the cycle of shame, guilt and recriminations that take place between a patient and their family. In addition, family interventions can significantly reduce the stigma and helplessness that is often experienced during treatment.

Many specialist clinics have a strong commitment to working in collaboration with families throughout their journey. It is well understood that eating disorders can have a big impact on families, and families play a very important role in the recovery journey. The BETRS model of care and National Institute for Health Care Excellence (NICE) guidelines for eating disorders recommend that most people with eating disorders should be managed on an out-patient basis when safe to do so. This therefore places the family in a key position of influence and often in need of support. The most common type of family intervention that is used for eating disorders is a skills-based learning model called 'The Maudsley Method'.

The Maudsley Method can help carers of people with an eating disorder to:

- Improve communication skills
- Develop problem-solving skills
- Build resilience
- Manage difficult behaviour

Eating disorders can be extremely stressful for family members. The Maudsley Method is a skills-based learning therapy that focuses on equipping carers and other family members with the skills and knowledge they need to support and encourage their loved one who is diagnosed with an eating disorder. This approach teaches carers to manage their response to the disorder in an adaptive way, thus providing an environment that encourages change, and reduces the interpersonal elements which may be maintaining the eating disorder.

*'I found the Maudsley Method to be useful as a concept and was able to reflect on my own style of dealing with the eating disorder' (Jil, carer)*

It is important to note that the Maudsley Method requires a considerable amount of commitment from carers. Although it can be very effective, it may not be for everyone and other treatment options should be sought.

There is some evidence that eating disorders can be influenced by the emotional reactions and behaviours of the people who are close to the person diagnosed with the eating disorder. Therefore, sometimes it is necessary for carers and family members to change the way they interact with the person with the eating disorder. The table on the following page describes some common reactions of people who provide care and support for people with eating disorders. These reactions can get in the way of providing help.

*Parents and carers are part of the solution, not the problem*

<b>Caring style</b>	<b>Typical carer reactions</b>	<b>Potential outcome</b>
Too much emotion and too much control	<ul style="list-style-type: none"> <li>▪ Anxiety about person with ED</li> <li>▪ Fear of death</li> <li>▪ Fear of saying the wrong thing</li> </ul>	<ul style="list-style-type: none"> <li>▪ Carer becomes overly supportive, doesn't allow personal space or responsibility</li> <li>▪ ED sufferer's feelings worsen</li> </ul>
Too much logic and too little warm emotion	<ul style="list-style-type: none"> <li>▪ Wants to take control/fix problem</li> <li>▪ Tries to talk person with ED out of it/make them see reason</li> </ul>	<ul style="list-style-type: none"> <li>▪ Sufferer feels rejected/unloved</li> <li>▪ Emotionally draining for both</li> <li>▪ ED sufferer's feelings worsen</li> </ul>
Too little emotion and too little control	<ul style="list-style-type: none"> <li>▪ Thinking about loved one with ED is too upsetting so carer ignores problem/lets clinic 'sort it out'</li> </ul>	<ul style="list-style-type: none"> <li>▪ Person with ED feels shamed and stunned.</li> <li>▪ ED problems continue</li> <li>▪ ED sufferer's feelings worsen</li> </ul>
Too much emotion and too little control	<ul style="list-style-type: none"> <li>▪ Carer feels completely overwhelmed</li> <li>▪ Strong fears ED sufferer will die</li> </ul>	<ul style="list-style-type: none"> <li>▪ Carer very emotional</li> <li>▪ Cuts self off from others</li> <li>▪ ED sufferer feels bad and avoids contact</li> <li>▪ ED sufferer's feelings worsen</li> </ul>

*Note: ED stands for 'Eating Disorder'. These carer styles and reactions are based upon Janet Treasure's work "Skills Based Learning for Caring for a Loved One with an Eating Disorder". See the references section at the back of this booklet for more details.*

As you can see, the caring styles above *may* lead the person who is diagnosed with the eating disorder to feel worse. It is suggested that carers should instead aim to respond in the following way/s:

<b>Optimal caring style</b>	<b>Optimal carer reactions</b>
Just enough caring and control	<ul style="list-style-type: none"> <li>▪ Provides subtle direction</li> <li>▪ Nudges ED sufferer to safety</li> <li>▪ Provides encouragement</li> <li>▪ Stands by their side</li> </ul>
Just enough compassion and consistency	<ul style="list-style-type: none"> <li>▪ Responds consistently</li> <li>▪ Is reliable and dependable under all circumstances</li> <li>▪ Does not panic</li> <li>▪ Is calm, warm and nurturing</li> </ul>



## Understanding Change

Changing behaviour is a complex process and often involves many steps and processes. The ability to change depends on a number of factors, such as our circumstances, the environment, other people's demands, the perceived pros and cons of the change and how confident we feel. For a person who is suffering from starvation, change can be particularly difficult because of their limited capacity to think clearly.

There are a number of stages that a person with an eating disorder will probably pass through when attempting to make changes:

- **Pre-contemplation:** In this stage the person stubbornly resists any idea of change. They see no need for change, despite the concern expressed by loved ones and health professionals.

How can you help? Remain calm and compassionate, talk to your loved one about their values, beliefs and goals, help them to step back and see the bigger picture.

- **Contemplation:** At this stage the person is aware of a problem and is considering change, but is not yet fully committed. The person may begin to juggle the pros and cons of change. This stage is often a time of confusion and distress.

How can you help? Try to improve your loved one's self esteem so that they can build confidence to make change. Show respect for their efforts and show you are listening. Direct them to information regarding eating disorders and encourage them to talk to a health professional.

- **Determination and difficulties:** In this stage the difficulties of change are recognised and the person with an eating disorder begins to develop the personal determination to at least try to change the behaviour that is causing the problem. They begin to see that the costs of maintaining the eating disorder outweigh the benefits.

How can you help? Help your loved one identify goals and develop a detailed plan of how these changes will be managed.

- **Action:** At the stage a person with the eating disorder makes some steps towards getting help and is the beginning of real change. However, this stage can be extremely difficult as a number of physical and psychological issues may arise for the individual.

How can you help? Help your loved one take the steps towards change by supporting them.

- **Maintenance:** In this stage, the person will have been making changes and be learning to live without an eating disorder. The person will consolidate and build on previous progress. Continue to encourage and support them.



## Communication Skills

Communicating with your loved one can be difficult at times, particularly if one or both of you are feeling stressed, or if your loved one is physically unwell. We can often feel overwhelmed at these times and worry that what we say or do will make our loved ones more upset or angry.

If your loved one is diagnosed with an eating disorder it is likely that communication between the two of you is difficult at times. It is not uncommon for families to break the rules of good communication, for example interrupting each other or assuming we know how the other family member will react. However, with eating disorders, communication becomes particularly important, therefore good communication rules are particularly important. Some basic rules for good communication are as follows:

- Only one person speaks at a time
- Try to work at really understanding what the other person is saying
- If talking isn't working, try writing to each other
- Create an atmosphere that is calm, compassionate, warm and respectful
- Remain positive by referring to achievements and progress

Often, our tone of voice and non-verbal communication (e.g. eye contact, touching, body-language etc) can be just as important, and sometimes more important, than the words that we use. It is important to think about the way that we can communicate, as it can help you to stay calm and show your loved one that you understand their concerns. If your emotional tone is warm and accepting, this may help promote change.

*'My daughter rarely verbalised her feelings the eating disorder but seemed to be able to express things in writing. We found writing to each other was easier sometimes.'* (Jil, carer)

If possible, you need to provide your loved one with the opportunity to express what they are thinking and feeling. If your loved one is resistant to change, the following suggestions may be helpful. This is also known as 'motivational interviewing'.

TRY TO	TRY NOT TO
<ul style="list-style-type: none"><li>▪ Focus on your loved one's concerns</li><li>▪ Emphasise that they have a choice/responsibility for future behaviour</li><li>▪ Explore/reflect upon their perception of the situation</li><li>▪ Be as warm and as loving as possible</li><li>▪ Beware of hostility and criticism</li></ul>	<ul style="list-style-type: none"><li>▪ Do all the talking</li><li>▪ Argue, lecture or try to persuade with logic</li><li>▪ Be authoritarian or the 'expert'</li><li>▪ Order, direct, warn or threaten</li><li>▪ Criticise, preach or judge</li><li>▪ Tell your loved one they have a problem</li></ul>

*This information is adapted from Janet Treasure's "Skills Based Learning for Caring for a Loved One with an Eating Disorder". See the references section at the back of this booklet for more details.*

At times, it may be difficult for you to tolerate the distress your loved one is experiencing. You may find yourself inadvertently dismissing their emotional pain (e.g. with comments like “That’s ridiculous, you are smart and beautiful, I don’t believe you think you are worthless!”). Statements like this are unhelpful as they only cause your loved one to feel as though their thoughts and feelings are discounted and rejected by you. Instead, try to validate their feelings. Remember that an eating disorder is an illness of emotions, so therefore try to listen and remain calm, consistent and compassionate.

- *Listen.* You can show that you are actively listening and understanding by summarising your loved one’s concerns in your own words and by showing your interest in your facial expressions and posture (e.g. making calm eye-contact and offering soothing responses if appropriate, for example ‘I am trying to understand why you are feeling that way’).
- *Look and feel calm.* Although it can be difficult when you are both feeling stressed, staying calm can help your loved one to feel less frightened. You can show that you are feeling calm by speaking in a soft, low and steady voice, relaxing your posture and breathing slowly and deeply. You can make the environment calmer by reducing distractions such as television, radio or the internet.
- *Ask open-ended questions to start conversations.* These questions often start with the words ‘who’, ‘what’, ‘where’ and ‘how’, and encourage your loved one to describe what they are experiencing. ‘Why’ questions can sometimes be interpreted as being accusing, so consider using a ‘what’ question instead. For example, ‘why didn’t you go to your appointment?’ might be changed to ‘what got in the way of you going to your appointment today?’
- *Stay supportive and understanding.* Your loved one might express some beliefs about themselves or the world that are difficult for you to understand. It can be helpful to focus on how they are feeling; for example ‘it must be frightening to feel like you’re so alone right now’. It is often not helpful to directly challenge your loved one’s beliefs when they are very stressed, as this can lead to them feeling misunderstood or angry. It is also unhelpful to tell them that you believe that they are exaggerating their symptoms or ask them to ‘snap out of it’.

*‘My biggest tip for families is not to argue, but to listen to the emotional content of what people are saying’ (Susan, clinician)*

## Self-Harm and Suicidal Thoughts

Unfortunately, the prevalence of self-harm in people with eating disorders is thought to be about 25%, and is particularly high among those who binge and purge. These actions can indicate that a person may be suffering and should always be taken seriously.

It is common for people to feel upset or overwhelmed when thinking about their loved ones and self-harm or suicide. It is important to remember that asking your loved one about self-harm and suicide will **not** make it more likely for them to act on their thoughts. In fact, being open about suicide can help your loved one to feel understood and get the right help.

### *Understanding self-harm*

Self-harm is any behaviour that results in a person intentionally causing themselves discomfort, pain or injury. Self-harm is common in the general population, with around 8% of adults experiencing thoughts of self-harm at some point in their life. A person is more likely to self-harm if they are going through a particularly stressful period in life, are using alcohol or other drugs or are experiencing symptoms of their illness. People usually do not self-harm with the intention of dying, but there is a risk of serious injury and accidental death.

Examples of ways that people might self-harm:

- Cutting, scratching or burning skin
- Taking too much medication
- Eating or drinking substances that are toxic
- Punching or hitting themselves
- Banging their head
- Not allowing wounds to heal

A person might self-harm to:

- Distract from strong emotions and emotional pain
- Relieve tension
- Help others to understand how they are feeling
- Punish themselves
- Feel 'something', or feel 'alive'
- Feel in control

Remember that you are not responsible for stopping your loved one from self-harming. However, you can support them to manage their self-harm by:

- *Being open to talking about it.* It is ok to be honest about your concerns, and let them know that you would like to help. Try not to appear shocked or judgemental.
- *Helping them to make a safety plan* (see page 46)
- *Encouraging them to talk to a doctor or health professional.* There are many techniques, including some talking therapies, which can help a person find more positive ways to manage their distress.
- *Calling for urgent help.* It is important to call emergency services if you are worried that your loved one might be at imminent risk of serious injury or death.

*It is important to note that people do not usually self-harm 'to get attention'. In fact, many people keep their self-harm a secret as they feel embarrassed or ashamed, and this can make it difficult to get help.*

### *Understanding suicidal thoughts*

Although suicidal thoughts are common in the general population, people with mental illness are at higher risk of having suicidal thoughts. Whilst this doesn't always mean that your loved one will act on them, they need to be taken seriously. They should alert you to the fact that the individual is still suffering and needs help.

The way that a person experiences suicidal thoughts can change over time and in response to different life situations. If you have any concerns that your loved one might be having suicidal thoughts, it is important to:

- *Ask directly about suicide.* By asking directly in a calm and understanding way, it can help your loved one to feel supported and gives them an opportunity to talk about their feelings. For example, ask 'are you thinking about ending your life?' It is ok to use words like 'suicide', 'killing yourself' and 'dying'.
- *Let them know that you are worried and want to help*
- *Be open and clear about getting help.* Although your loved one may ask, it is important *not* to promise that you will keep their suicidal thoughts a secret. Not only is it too much of a burden for you to bear alone, but it is also critical that a health professional is aware of the situation as they can offer other avenues of support.

- *Ask if they have made any plans to act on their suicidal thoughts.* Having a plan makes it more likely for your loved one to suicide, so it is important to get help quickly.

If your loved one has a plan you must:

- *Call for help.* This might include the local crisis team or 000.
- *Try to remove anything that might help them to carry out their plan* from the vicinity if it is safe for you to do so. For example, ask a relative or neighbour to look after any blades, tablets or rope.

Sometimes it can be difficult for people to talk about their suicidal thoughts, even if they are asked directly. Some behaviours can act as warning signs that a person might be thinking about suicide. For example:

- Talking or writing about death or dying, sometimes in a casual or indirect way.
- Losing touch with friends, family or activities that they used to enjoy
- Often feeling angry or talking about revenge
- Showing less interest in the future.
- Using more alcohol or other drugs
- Sudden strong changes in mood.
- Feeling trapped
- Feeling depressed or hopeless
- Researching ways to kill themselves
- Feeling that there is no reason for living
- Giving away possessions

Some of these warning signs can also be features of an eating disorder, and do not always mean that your loved one is suicidal.

*If you are worried that your loved one is suicidal, ask for professional help; it is too much of a burden for you to carry alone.*

## Making a Safety Plan

Unfortunately, there may be times when your loved one needs to access other supports to remain safe. These times can be overwhelming for both you and your loved one, and can be feel especially daunting when immediate help is needed after hours or at a time that you are not able to be in touch with mental health practitioners who are more familiar to you.

Working with your loved one to create a safety plan can help you and your loved one to identify what is most helpful at times of high stress, and to have a range of supports on hand when help is needed.

*These plans should be devised in collaboration with the individual living with an eating disorder, their carer and the treating doctor or case manager.*

If you need to call the Psychiatric Triage or the local Crisis Team, you can expect to talk to a trained mental health clinician who will explore the current concerns that you have for your loved one. They will then give you advice based on the level of urgency of the situation. Sometimes, they may ask you to wait at home with your loved one until the Crisis Team arrives to speak with you both directly. At other times, they may ask you to take your loved one into the emergency department of your local hospital for a medical assessment, or will help you to call an ambulance or the police.

*After the crisis has passed, if you continue to feel traumatised or fearful – seek medical advice and consider psychological support to help you come to terms with the episode of aggression.*

Note down these details for a crisis plan on the following pages as a guide. You may never need to use the information, but it's always handy to have ready, just in case.

**SAFETY PLAN**

Date of Completion:

**Details of Patient**

Name

Date of Birth

Address

Phone Number

Carer or Next of Kin

Contact Details

(name, phone number,  
address)**Healthcare Professionals involved in the Patient's Care**

(name, phone number, place where treatment is received)

General Practitioner

Mental Health Clinic

Case Manager

Psychiatrist

Psychologist

Counsellor

Others

**Clinical Information**

Diagnosis

Current Medications and  
DosesAllergies or Serious Side  
Effects from Previous  
Medications

<b>Crisis Information</b>	
Triggers of a Crisis (eg. stopping medication, stress, sleep disturbance, drugs, alcohol)	
Frequency of a Crisis	
Safety Concerns during a Crisis (eg. serious relapse, putting self at risk, putting others at risk, suicidality, aggression, vulnerability)	
<b>Pathways of Action in Managing a Crisis</b>	
Communication Skills that may be helpful in a Crisis (eg. calm, empathic responses, active listening, non-judgmental approach)	
Who to call during business hours, 9-5 Mon- Fri (eg. case manager, clinic, GP, Psychiatrist)	
Who to call after hours or on weekends (eg. Crisis Team, Emergency Dept, Ambulance or Police)	
<b>Additional Important Contacts</b>	
Local Psychiatric Triage	
Crisis Assessment and Treatment (CAT) Team	
Emergency Department of Local Hospital	
Police or Ambulance Services	
Other	



## Consent and Privacy

Consent is an important term that is used to describe the process of making a decision that is based on correct information, including understanding the pros and cons, and is made freely without outside pressure. Our ability to consent to something, or agree after examining the important facts, can change from day-to-day and depends on the specific situation.

Wherever possible, your loved one will be supported to make decisions concerning their health. Unfortunately, there may be times when features of their illness make it difficult for them to weigh the pros and cons, or make considered choices. At these times, your loved one may be placed under the Mental Health Act (MHA), so that the medical staff can make important treatment decisions on their behalf. This is also known as being subject to a 'compulsory treatment order'. The Mental Health Act is only used at times where a person is at immediate risk of harm to themselves or others. At these times every attempt will be made to consider the individuals wishes.

*Talking to your loved one about the types of information that they would like to be shared with you can be helpful. Consider discussing this at a time that they are feeling well.*

Balancing your loved one's privacy and your need for information can be difficult to negotiate, particularly if your loved one is not able to, or is refusing to, consent to you speaking to their treating team. Unfortunately, the laws surrounding this issue are complex and difficult to understand, so it is best to check with your loved one's mental health team if you have specific concerns. In general, a mental health professional cannot disclose specific medical information without an individual's consent. However there may be times that they are able to do so, such as during an emergency, or if there are risks that you need to be aware of to keep yourself or others safe.

There may be times when your loved one would like direct access to their medical records. Under the Australian Commonwealth's Freedom of Information Act 1982, they can apply for access by making a Freedom of Information (FOI) request. If your loved one is a compulsory patient under the MHA 2014, they should be provided with access to their file prior to any scheduled Mental Health Tribunal hearing. Your loved one's mental health team can provide more information about this process.

## Pregnancy

Planning a family can be an exciting time. However, when a woman is pregnant, her wellbeing and nutrition is extremely important. An unborn baby and its mother can be adversely affected if nutrition is not sufficient.

*Risks of an eating disorder in pregnancy for the mother include:*

- High blood pressure and gestational diabetes
- Increased risk of miscarriage
- Dehydration and possible cardiac irregularities
- Depression (either during or after pregnancy)
- Taking longer to heal from a caesarean, episiotomy or tearing

*Risks of an eating disorder in pregnancy for the baby include:*

- Premature birth
- Low birth weight
- Poor development
- Feeding difficulties
- Respiratory distress

If a woman with an eating disorder is planning pregnancy, they must get their eating disorder under control prior to conception. This would involve eating balanced meals and maintaining a healthy weight for at least seven months before pregnancy. If they are able to get their eating disorder under control they are more than likely to have a normal, healthy pregnancy and baby.

If your loved one has an eating disorder and falls pregnant you must encourage and help them to seek professional support and guidance as soon as possible.



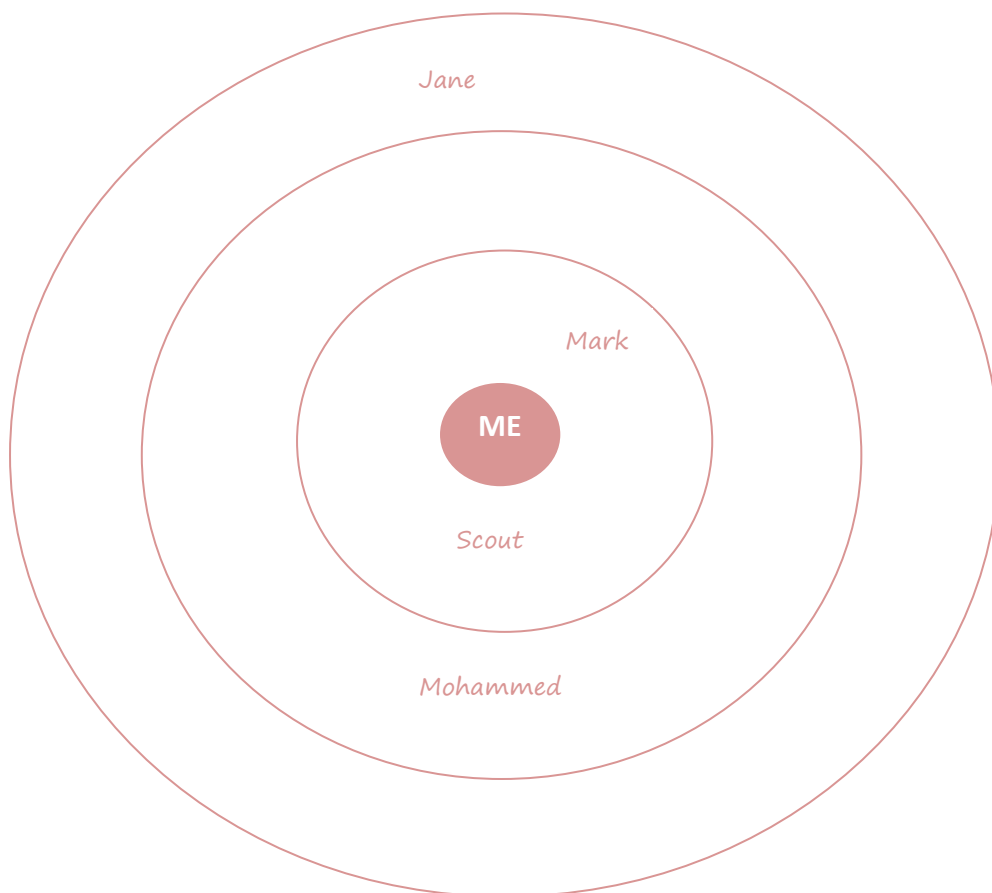
## Collaborative partners

It can be difficult to reach out to others when we are feeling stressed. Consider taking some time when you are feeling relaxed to think about the types of relationships and supports that you and your loved one have already, or would like to have in the future. We call these people 'collaborative partners'.

The diagram below is a useful way to help represent yourself and the people in your life. It can be used to help you think about who you or your loved one can work with to maintain optimal health.

You are in the centre of the circle. Write the names of the people in your life in the circles around you. Put the names of the people that are closest to you in the inner circle. In the next circle, write the names of people who are important but who you see less often. Consider writing the names of people who you see only occasionally but are still important to you, in the outer circle. Don't forget to include health professionals who you see on a regular basis.

Here is an example:



For each person, think about your *relationship*, and the type of *support* and *frequency* of their support. The relationship and type of support offered from each person in the example is as follows:

Name	Relationship	Support	Frequency
Mark	Partner	Emotional	Daily
Scout	Pet dog	Physical exercise and emotional	Every second day
Jane	Dietitian	Practical help with meal plans etc	Every week
Mohammed	Waiter at favourite coffee shop	Practical and emotional (makes me laugh)	Every week

*A collaborative partner is someone who is close to you who doesn't mind being contacted to help when you need more support.*

What does your map look like? How is it similar or different to that of your loved one? There are two maps on the following page for you and your loved one to fill out. Try not to get too worried about where the names go; the aim is not so much to have a strict ranking, but rather to map out supports. There might be times in your life when your supports change, so it can be helpful to revisit the picture from time to time. Once you have finished writing in all the circles, it may be helpful to think about which of these people play an important role achieving your health goals. Consider asking two or three of these people to become a collaborative partner.

*My collaborative strategies:*

When I experience a stressful situation, for example:

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and I notice my early warning signs such as:

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I will contact:

Name \_\_\_\_\_

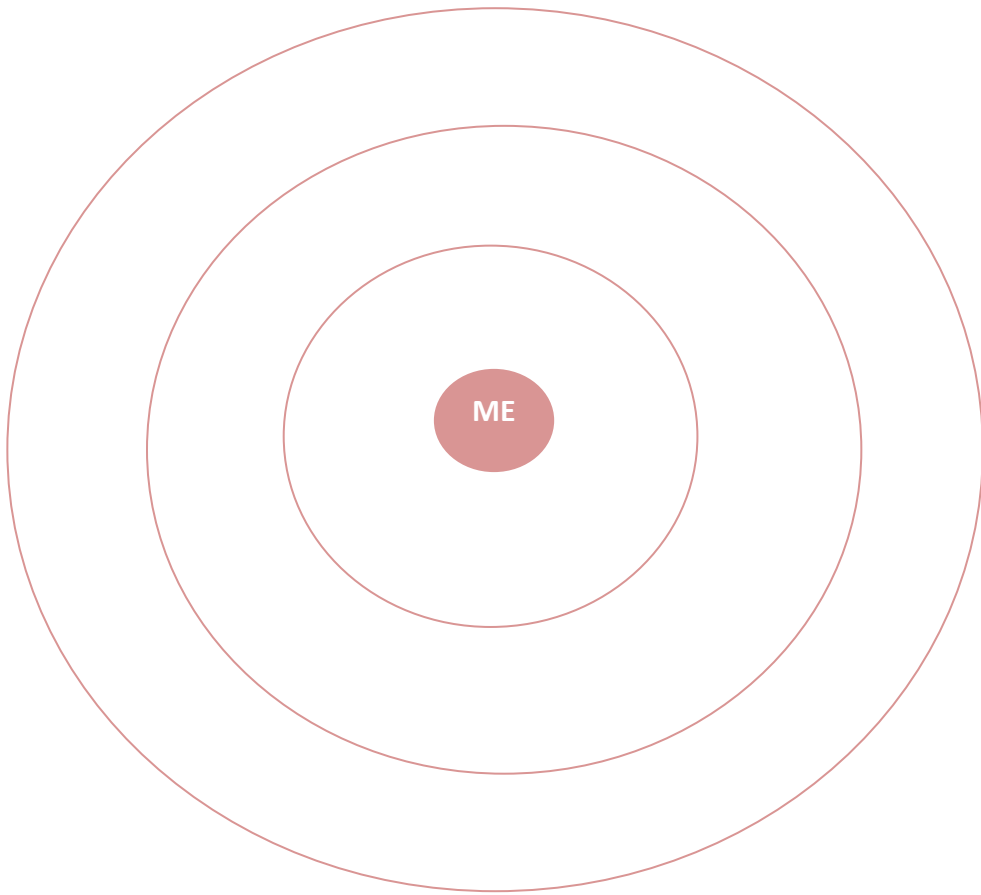
Address \_\_\_\_\_

Relationship \_\_\_\_\_

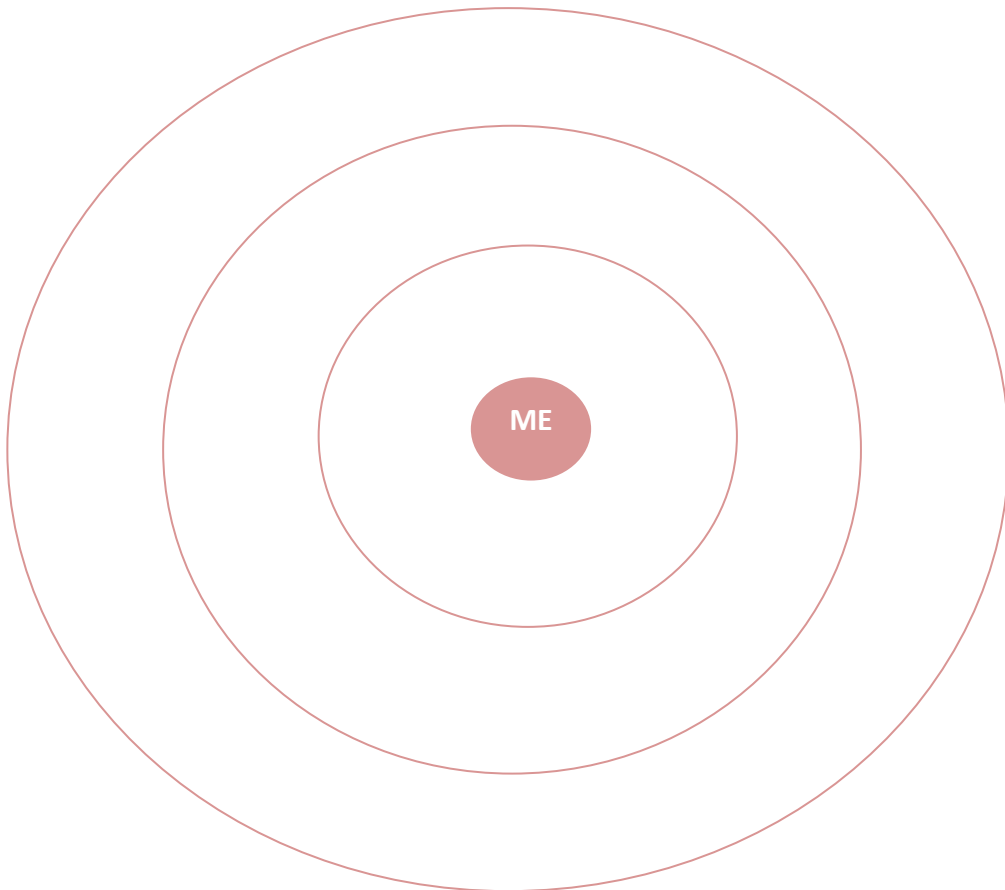
Phone: \_\_\_\_\_

They can be involved by \_\_\_\_\_

*The people in my life....*



*The people in my loved ones life...*



## Caring for Yourself

It might be useful to keep some practical strategies in mind:

- *Educate yourself* generally. Learn about eating disorders, so you can understand and help others understand what it is and why someone with this illness might react in a certain way.

*'The first step is to get educated about what it is and what's going on. Get savvy with the area of mental illness and this will reduce fears, prejudice and stigma.'* (Rosie, carer)

- Be *open* and *inquisitive*. Knowing what your loved one needs from you when their illness does relapse will help you provide them with the care they have identified as most valuable during these difficult times.

*'Informing yourself is empowering yourself.'* (Jil, carer)

- *Make your own health a priority*. Eat nutritiously, exercise regularly and try to sleep well. Develop balanced routines that support you in maintaining a healthy lifestyle. See page 55 of this booklet for some sleep strategies.
- Have *your own GP*. Make sure you are linked in with a general practitioner for your own physical and mental health needs. It is not uncommon to be so focussed on your loved one that you forget about the importance of addressing your own health. This might mean routine check-ups or a doctor to see when you are beginning to feel persistently stressed.

*'I found out by accident that I had developed high blood pressure. It was suggested that it was a result of the stress of managing my daughter's eating disorder. Once I became aware of this I was able to bring it back under control.'* (Jil, carer)

- *Learn to receive support* from the person you care for. Be open to their efforts to repay your kindness or express gratitude. Acknowledge the incredible support and care you provide on a daily basis. Thank yourself, and allow yourself to be thanked.
- *Maintain hope*. It's important that you maintain optimism and hope. That you continue to believe the person will get better, and you will see better days together.

*'Remaining optimistic is so important, you have to see the glass as half full. You have to believe there will be better days.'* (Anne, carer)

- *Keep healthy boundaries.* This can help ease the tension in your relationship with the person you are caring for, and prevent cycles of anger, frustration or resentment from repeating.

*'Carers need to look after themselves, take time out, and have respite. They need to hold onto their identity outside of the caring relationship.'* (Elizabeth, patient)

Consider strategies such as:

- *Delegating* certain duties of care to other family members or friends.
- *Arranging your own* time out so you continue to maintain your interests and relationships outside of your relationship of care.
- Stick to a general *daily routine* as best as possible.
- Find *someone you can talk to* about your feelings.
- Join a *carer support group* to share experiences and tips with others who are in the same position as you.

Remember:

- *You can't fix everything for your loved one.* Try to remain realistic about the influence of your support, which may, at times, be in conflict with the influence of the illness.
- *Allow yourself to have a 'down day'.* You don't have to be strong all of the time. Give yourself permission to have days where you accept that you are not coping.



## *The importance of sleep*

Maintaining a *regular sleep-wake cycle* is important for everyone's general health and well-being. Sleep is critical to survival, just like oxygen, water and nutrition. When caring for a loved one with an eating disorder you may find it difficult to sleep because you are worried. Unfortunately, it's not usually until sleep patterns becomes terribly disturbed that we realise how much they impact on our physical, mental and emotional health.

Some strategies to help you sleep are as follows:

- *Develop a routine.* Our bodies have a natural "clock" that tells us when to go to sleep. Having a regular wake-up time and sleep time in the evenings can help our body clock to get into a good routine and promote sleep.
- *Getting the right set-up.* Making even small changes to your bedroom can help make big improvements in your quality of sleep. Aim to have your room as dark and quiet as possible, and free of distractions such as televisions, computers and gaming devices. It can be helpful to use earplugs, block-out blinds or eye masks if you are sensitive to noise and light. Watching the clock at night can make us feel more anxious and does not help us to get to sleep, so move bedside clocks so that they can't be seen from your bed.
- *Going outside.* The sun acts as a natural pick-me-up, so going out for a short time in the morning can help get our body clock back on track. Early morning light is particularly good for you.
- *Avoiding naps.* Sometimes we need naps, but try to keep them to less than 30 minutes and avoid napping after 2pm.
- *Only going to bed when you're tired.* Lying awake in bed can be stressful and frustrating, so only get into bed when your body is ready to go to sleep (heavy eye lids, yawning). If your body isn't ready, try sitting out of bed and reading or taking a warm bath or shower. Some foods such as milk, yoghurt, oats, bananas and honey trigger natural brain chemicals that help with sleep.
- *Relaxing.* Some people find it helpful to use techniques such as deep breathing, muscle relaxation, and mindfulness to help them to prepare for sleep.
- *Cutting back on caffeine.* Cola drinks, coffee, black tea, green tea and chocolate all contain caffeine, a chemical that can upset our natural sleep patterns. Try to cut down the amount of caffeine that you take in after lunchtime by drinking fruit and herbals teas, non-Cola drinks such as soda water or water, and avoiding chocolate in the afternoon.

- *Cutting back on nicotine.* Nicotine is a chemical in cigarettes that can make it difficult to wind down. Try cutting back in the hours before bed or stopping all together.
- *Cutting back on drugs and alcohol.* People can sometimes use alcohol and other drugs to help to get to sleep. Unfortunately, these substances give us poor quality sleep so that we are still tired the next day.
- *Making a list of strategies to keep by the bed.* When we get worried about our sleep, it can be hard to remember what has helped in the past. Try to write a list of strategies that work for you, perhaps some new ones from this booklet, so that you can tick them off when you are next trying to get to sleep.

Of course, every now and then, there may be nights when it might take a long time to get to sleep or it might be difficult to fall back asleep after waking up in the middle of the night. The most important thing is to try and regulate sleep for the next few nights as strictly as possible, to prevent it from snowballing and becoming an ongoing problem. If sleep patterns become recurrently disturbed, alert your doctor to the problem so that action can be taken quickly.

## Managing Stress

### Stressors

Stressful life events can be called “stressors”. Stressors are the pressures and demands from the outside world. For example, caring for a loved one who is unwell, money troubles, being judged by others and isolation, to name just a few. Stressors can come and go with time. “Stress” is our physical, psychological and behavioural response to stressors.

Each person experiences stress differently and each individual might identify different life events as stressors. Understanding more about our own stressors and the way that we handle them can help us to find helpful strategies to help balance our stress. It can also help us to plan for future stressors so that they might have less of an impact on our overall health.

Everyday positive stressors (e.g. planning a birthday party) and negative stressors (e.g. a lack of stable housing) can often add together to become cumulative. Cumulative stress can often feel overwhelming and can affect our thinking and the way that our body functions.

You might be experiencing cumulative stress if you:

- feel tired often or tire very easily
- often get coughs, colds or infections
- have trouble problem solving and making decisions
- notice a change in your appetite or in your sleep
- experience changes in your mood

Being aware of both everyday and cumulative stress can help us to know when to use some of our strategies and when to get help.

### Early warning signs

Early warning signs are the things that we notice about our thinking, feeling or behaviour that indicate that we might be becoming unwell or are having difficulty coping. Noticing early warning signs does not necessarily mean that an episode of illness is on the horizon, but they can let us know that we are feeling very stressed or overwhelmed. Identifying what your early warning signs are might help to prompt you to put your strategies into action, or ask others for support. Some examples of early warning signs might be:

- Feeling less social
- Having trouble sleeping
- Drinking alcohol or smoking more often
- Being more sensitive to criticism
- Feeling angry, sad, overwhelmed
- Being sensitive to bright lights/loud sounds

## *Your experience...*

We are able to notice stress by identifying the physical, psychological and behavioural signs. Think of an example recently when you experienced feeling 'stressed out'.

What physical changes did you notice in your body? E.g. sweating, increased breathing, shaking, muscle tension, churning stomach etc.

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What kind of thoughts and feelings did you have? E.g. became easily frustrated, felt more/less motivated, felt overwhelmed, became oversensitive to remarks made by others.

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What did you do after that situation? E.g. spent more time at home, drank alcohol, procrastinated, avoided communication with friends etc.

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## Strategies

'Strategies' are the skills, activities and behaviours that we use to respond to stressful situations. We are not always aware of our strategies, and some may be more helpful than others in the long term. Understanding more about the way we respond to stress can help us to harness the helpful strategies that we already use and find new strategies to lower the impact of stressful situations. It is important to use a range of strategies, as they can sometimes become stale or less effective if we use the same ones all of the time. Effective strategies can also help to stop stress from building up over time, or becoming cumulative.

Some examples of strategies that people might use:

- Smoking
- Listening to music
- Painting, drawing, writing
- Going for a walk
- Meditating
- Deep breathing
- Drinking
- Praying
- Eating healthy food
- Using humour
- Ignoring the problem
- Eating lots of sweets

Notice that some strategies that might be helpful in the short-term may not be so helpful in reducing your stress in the longer-term. A good example might be smoking cigarettes. Although smokers report that they smoke to reduce stress, evidence shows that smoking can actually make stress worse over time. Some examples of helpful strategies might be:

- Get organised
- Eat more fruit and vegetables
- Walk more
- Smoke less
- Have an alcohol-free week
- Have a bath
- Breathe deeply
- Talk to a close friend
- Attend a community centre
- Eat less sugar

*'There were times when I found hitting a tennis ball REALLY HARD and swimming and screaming under water to be really therapeutic!' (Jil, carer)*

## Your experience...

Let's explore what your current strategies are. Make a list of the ones you currently use to reduce your levels of stress. Then try to rate how effective you think they are. Can you improve them?

MY STRESSORS (Things that stress me out)	MY CURRENT STRATEGIES (What I currently do)	HOW EFFECTIVE IS IT? (1-10)

## Time for yourself

Create times in your week that are just for you, where you can relax and rejuvenate your own emotional strength. This may mean spending time with friends, spending thoughtful time alone or participating in regular activities that add meaning to your life. It's different for different people, but pursuing what you need will benefit you, your care and your ability to cope in difficult times.

*'If you can't reclaim some joy in your own life along the way, then you're going to be sunk.'* (Natalie, carer)

*'It's important to be conscious of your limitations as a carer.'* (Elizabeth, patient)

An example of a *weekly planner* has been included on the following page. Use it as a guide to think about how much time in the week you spend actively caring for your loved one, and how much time in the week you spend actively caring for *you*.

Is there a big difference? Are there any opportunities to create some more time and space for yourself? To enjoy an activity alone, or with others who are also important to you?

**WEEKLY ACTIVITY SCHEDULE**

	<b>MON</b>	<b>TUES</b>	<b>WED</b>	<b>THURS</b>	<b>FRI</b>	<b>SAT</b>	<b>SUN</b>
<b>MORNING</b>							
<b>AFTERNOON</b>							
<b>EVENING</b>							

## *Grief*

Grief is the name given to our natural response to major changes or losses in our life. We often experience grief in response to the death of a loved one; however we can also experience grief after losing a job, breaking up with a partner, or other serious life events.

Many people with a loved one with an eating disorder experience a sense of loss or sadness at some time during their loved one's illness. These feelings may come and go, but often arise at the time of diagnosis or at other important times in their or their loved one's life. People may also feel a sense of loss when thinking about their relationship with their loved one, their hopes for the future, or their own relationships and aspirations which may have been affected by their loved one's mental health.

*'I still feel like I'm sort of in shock and grieving it.'* (Rosie, carer)

### *Managing grief*

When coming to terms with the person's illness or a new diagnosis, give yourself time to grieve. You might experience sadness about the changes and losses you perceive for the person you are caring for. This is natural, and will come to pass. Often, sharing your experience with others can help to lessen the burden of grief. You might choose to talk to a close friend or relative, your own GP, a mental health professional or a peer support group.

We all experience grief differently. It is common to experience strong emotions such as anger, sadness, frustration and loneliness as part of grief. Some people may also experience changes in their body including feeling tight in the chest, crying a lot, or sleep problems. Some of these experiences are similar to what you might experience if you were depressed or anxious, so it can be helpful to talk to your GP if you are feeling overwhelmed or unable to do the things that help you to feel well.

*'I think that grief is something that is a very important part of the process.'* (Lisa, carer)



## *Carer support groups*

The demands of caring for your loved one may leave you feeling *emotionally drained* and *socially isolated* at times. The difficult feelings that can accompany different points in your caring relationship might feel less understood by those who have not had similar experiences. *Carer Support Groups* are regular gatherings of people who are interested in hearing and sharing mutual experiences to help with feelings of connectedness and support. These groups are typically run by a mental health professional, who will guide discussions and help group members share experiences and knowledge, to give and receive support. They are usually arranged through local community organisations.

*‘You just feel like you’re so out on a limb and on your own, and no one else is going through this... You need support and people that can understand a little bit of what you’re going through.’ (Mary, carer)*

Many carers experience relief through sharing their stories, feelings and information on caring for their loved one. A lot of strength and hope can be gained from *sharing experiences* with others who are in familiar situations.

*‘The stories that are shared are educational. And they do give you that sense of, okay, you’re not like Robinson Crusoe, you’re not on your own. Some of the simplest little tales that are told, and stories that are passed on can be enormously helpful, in a practical way.’ (Nicholas, carer)*

Along with carer support groups, you may like to consider seeking support in the form of *individual counselling sessions*. There may be times when you’re seeking a private outlet to talk through the feelings and impact that your caring relationship is having on your life. There are a range of services available through various carer organisations which can be explored as needed. See ‘Further Resources’ for the details.

*‘You’re so consumed by it all that you put your whole life on hold.’ (Mary, carer)*

*Carer respite* is another area of support that may be able to provide you with opportunities to make your own health and well-being a priority and be assured that your loved one is in safe and professional hands. This might involve having a community-employed carer come to your home and provide care for your loved one whilst you attend to your own personal obligations. Or it might involve your loved one attending a community day program outside of the home, or staying short-term in supported residential accommodation, to help improve their skills of independence and provide you with a short break from your caring responsibilities.

## Further Resources

*Body Image Eating Disorders Treatment & Recovery Service (BETRS)* is a collaborative partnership between the mental health programs of Austin Health and St Vincent's Melbourne, and provides services for those situated in the Northern, Eastern and Hume regions. BETRS outpatient campus in Kew is a community-based service for people with eating disorders, their families and carers. The BETRS service contributes to a continuum of care between primary, tertiary, inpatient and community based services.

Anyone, over the age of 18, who thinks they may have an eating or body image problem is encouraged to contact BETRS following a discussion with their doctor and/or health professional. Concerned family members can contact BETRS for information or advice and assistance with the referral process.

Address: Rear 104 Studley Park Rd, Kew VIC 3101. Australia

The BETRS Clinical Intake Service operates from Monday to Friday between 9.30 and 11.30am, and is the first point of contact for anyone wanting to refer themselves or others to the service - **9231 5718**. For general inquiries: **9231 5700**

[betrs@svha.org.au](mailto:betrs@svha.org.au)

*Eating Disorders Victoria* run support groups for those whose lives are affected by an eating disorder, including people with eating disorders (18 years and over) and their family and friends. All EDV support groups are run by trained volunteers with knowledge and/or experience relevant to running groups and/or a personal experience with eating disorders. To view support group locations and dates visit the EDV website:

<http://www.eatingdisorders.org.au/quick-links/support-groups>

Eating Disorders Victoria also has a Helpline number which provides information, guidance and support to anyone whose life is affected by an eating disorder, body image issues or disordered eating. The Eating Disorders Helpline is the first point of contact with support, guidance, information and referrals for thousands of people with an eating disorder and their families, partners and friends. This number is: **1300 550 236**.

If you are not comfortable speaking over the phone or can't get to a phone in working hours, our Helpline advisors will attend to any questions or concerns you may have by email. To access this service, please email your questions to:

[help@eatingdisorders.org.au](mailto:help@eatingdisorders.org.au)

*Carers Australia* is the national peak body representing carers in Australia. *Carers Australia* works with the Carers Associations in each of the state and territories to deliver carer programs and services and advocate on behalf of all carers. The services provided will vary according to where you and your loved one are living, but can all be accessed and explored via the national website at: [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

Information is also available via a free call to the *Carer Advisory and Counselling Service* on **1800 242 636**.

*Mind Australia* is a leading provider of community mental health services in Victoria and South Australia. They provide personalised support services, residential and prevention and recovery care (PARC) services, family and carer services, group support services and care coordination services and the Mind Recovery College. Mind recognises the importance of families and carers in the lives of those on their journey of mental health recovery. They offer a variety of carer services including a Carer Helpline, counselling, respite, peer support and support groups.

Please visit their website for more information: <http://www.mindaustralia.org.au/need-help/mind-services-in-victoria/mind-victoria/family-and-carer-services.html>

The Mind Carer Helpline number is **1300 550 265**.

*MIFA* (Mental Illness Fellowship of Australia) is a non-government, not-for-profit organization aimed at supporting and advocating for people with serious mental illnesses and their families. They offer many different services, including *Well Ways* a family educational program that provides information on mental illness, helpful ways to cope and practical ways to take care of yourself. Information on this program and other services provided by MIFA can be accessed at: [www.mifa.org.au](http://www.mifa.org.au)

Or contact the *National Helpline* to be directed to the right service on **1800 985 944**.

*SANE Australia* is a national charity that conducts innovative programs and campaigns to improve the lives of people living with mental illness, their family and friends. They offer useful resources and guides to help you and your loved one with their mental health needs. The section entitled '*Snapshots*' on the website contains inspiring personal accounts of what it means to live, and live well, with a mental illness. The importance of sharing, recovering and connecting is highlighted through meaningful real-life stories.

Access this information at: [www.sane.org](http://www.sane.org)

The *SANE Helpline* can also offer information and advice on **1800 18 SANE (7263)**.

Information obtained via the internet can sometimes be inaccurate or misleading. Keep an open mind about what you are reading, particularly if you are unsure about the credibility of the source. Try to check what you've read with your loved one's doctor or mental health practitioner to ensure you are getting the correct information.

Listed below are some additional websites that provide accurate information and might be of further help:

<http://www.eatingdisorders.org.au>

<http://www.b-eat.co.uk/>

[http://www.cci.health.wa.gov.au/resources/infopax.cfm?Info\\_ID=48](http://www.cci.health.wa.gov.au/resources/infopax.cfm?Info_ID=48)

[www.beyondblue.org.au](http://www.beyondblue.org.au)

<http://thebutterflyfoundation.org.au/>

Most community mental health clinics will have a Carer Consultant who can provide specific advice and pathways to assistance if you're experiencing any difficulties in your caring role. Check with your loved one's mental health practitioner to find out more about this service.

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*'While there is life, there is hope.'* (Samantha, carer)

*'It's a matter of hanging in there with them.'* (Nicholas, carer)

*'Don't try to fix it, just get through it. Persevere.'* (Natalie, carer)

*'To be able to move forward in their lives - that's all you want for them.'*  
(Mary, carer)

*Remaining optimistic is so important, you have to see the glass as half full. You have to believe there will be better days.'* (Helen, carer)

*'And how lucky are our loved ones, in one way, that they have us?'*  
(Samantha, carer)

## ORDER INFORMATION

St. Vincent’s Mental Health Service has developed a range of educational materials for carers and patients.

Please see list below for our materials and their pricing.

Service/Company: \_\_\_\_\_

Contact Name: \_\_\_\_\_

Delivery Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Postcode: \_\_\_\_\_ Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

**COSTS** – Medication Booklets \$2.50 + GST per booklet + P&H

“Caring for a loved one with..... “ \$8.00 + GST per booklet + P&H

Quantity		Quantity		Quantity	
<b>English Medication Booklet</b> 3rd Ed. Jan 15		<b>Vietnamese Medication Booklet</b> Jun 08		<b>Chinese Medication Booklet</b> Jun 08	
<b>Greek Medication Booklet</b> Jun 08		<b>Italian Medication Booklet</b> Jun 08		<b>Arabic Medication Booklet</b> Jun 09	
<b>Caring for a loved one with bipolar</b> Feb 2012		<b>Caring for a loved one with psychosis or schizophrenia</b> Sep 2014		<b>Caring for a loved one with an eating disorder</b> Jan 2015	

**All booklet orders & inquiries to Mary Veljanovska**

**St. Vincent’s Mental Health**

**PO Box 2900 Fitzroy Vic 3065**

**Email: [mary.veljanovska@svha.org.au](mailto:mary.veljanovska@svha.org.au)**

**Tel: (03) 9231 4751 or Fax: (03) 9231 4802**

Copies of this booklet can be requested through:

**St Vincent's Mental Health Services**  
**ISBN 978-0-9971537-2-2**

**Level 2, 46 Nicholson Street**  
**Fitzroy VIC 3065**  
**Ph: 03 9288 4751 Fax: 03 9288 4802**

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