



**The *beyondblue* Guide for Carers –  
Supporting and caring for a person with depression,  
anxiety and/or a related disorder**



***Caring for others, caring for yourself***

This booklet has been developed by carers for carers.

Many people have shared their experiences of caring for a person with depression, anxiety or a related disorder.

Based on the personal stories of the carers, this guide offers helpful advice and tips about *Caring for others and caring for yourself*:

- how to get through the tough times
- what worked (and what didn't)
- how to overcome a range of difficulties
- how to support the person with the illness
- how to access support that's available to carers.

Although every personal experience is unique, there are aspects of the role that are common to many carers.

Throughout the booklet, there are quotes from carers which provide an insight into the many facets of their role, including thoughts, feelings and reactions.

*beyondblue* CEO Leonie Young thanks all the people who have provided valuable input into this booklet.

"I hope it will offer helpful information, support and assistance to the thousands of people caring for a person with depression, anxiety or a related disorder. Being a carer can have an enormous impact on relationships, work, education and social life, as well as the person's physical and mental health. I urge all carers to make a point of not only caring for their loved ones, but to think about how they can take care of themselves."

### **About *beyondblue***

*beyondblue: the national depression initiative* is an independent, not-for-profit organisation working to address issues associated with depression, anxiety and related disorders in Australia.

*beyondblue* works in partnership with health services, schools, workplaces, universities, media and community organisations, as well as people living with depression, anxiety and related disorders to bring together their expertise.

One of *beyondblue*'s major priorities focuses on people who have experienced depression/anxiety and related disorders (sometimes referred to as 'consumers') and their carers. People with depression/anxiety and related disorders, and carers, participate in *beyondblue* research, provide input into the development of *beyondblue* information materials (such as this booklet) and help to raise awareness by speaking about their personal experiences.

### **blueVoices**

*beyondblue* has supported the development of a national consumer and carer reference group, blueVoices, which includes people with direct personal experience of:

- depression
- anxiety
- perinatal (pre- and postnatal) depression and/or anxiety
- bipolar disorder
- co-existing substance-use and depression
- co-existing chronic physical illness and depression.

Many members of blueVoices are carers or primary support people for people experiencing one or more of the above conditions and they have contributed to the development and content of this guide.

### **Thank you**

*beyondblue* would like to thank all the carers who have contributed to the compilation of this guide by participating in focus groups, providing insight into their experiences and sharing their personal stories. The words they used to describe their experiences are quoted throughout this guide. Their contributions have been invaluable.

To find out how to become a blueVoices member go to [www.beyondblue.org.au](http://www.beyondblue.org.au) – click [Getting involved](#), then [National Reference Group blueVoices](#).

*Illustrations: Bettina Guthridge*



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# Foreword



I am delighted to see the development of this important publication which will assist the carers and families of loved ones with mental illness.

I have great confidence that this book will be extremely valuable, not only for the families of newly-diagnosed people, but also for those who have been around the mental health system for varying lengths of time.

It's more than 25 years since our family was first impacted by the challenges of mental illness. One of the glaring deficiencies in the system at that time was a lack of basic information to help educate and increase understanding of strategies to assist in daily living. We were left floundering, confused and bewildered. Now, 25 years later, it's great to see that supports of this kind are available.

I would like to express my appreciation to all of those involved in contributing to this important work. I wish to recognise the contribution of all those carers whose experiences and anecdotes have enhanced the relevance of this book. The use of real-life anecdotes will give our carers and families around Australia a real connection as they identify with the thoughts and feelings of people who have experienced the same issues.

Isolation is one of the most significant disempowering facts of life, and these stories will demonstrate that “*you are not alone*” in grappling with the challenges.

Well done to everyone involved and I commend this important publication for your reading.

A handwritten signature in black ink that reads "John McGrath".

**John McGrath AM**

**Deputy Chair**

*beyondblue: the national depression initiative*





## The purpose of this guide

No matter how long you've been supporting a person who's experiencing a mental health problem, this guide includes helpful information for all carers and family members – regardless of whether the person they're supporting has just been diagnosed, is recovering, or is in the early stages of depression/anxiety.

- Some people will be reading this guide although they are not yet certain whether the person they're supporting definitely has a mental health problem.
- Others will have recognised that something isn't right and will be taking the first steps to get a medical opinion.
- Many carers reading the guide will have been supporting a friend or loved one for some time and will be working towards recovery.
- Some carers will be looking after someone who has a mental health problem and co-existing physical health problem, disability or chronic illness (e.g. a heart condition, Parkinson's disease or a cancer diagnosis).

## What does the guide cover?

The guide is divided into two sections:

1. **Caring for others** – is about caring for and helping the person you're supporting. It covers various stages and draws on other carers' experiences including recognising that something is not right, accessing treatment, working towards recovery and managing emergency and crisis situations.
2. **Caring for yourself** – looks at understanding your feelings and the impact a mental health problem can have on you, your family and friends. It's equally important to ensure that you look after yourself physically and emotionally, and draw support, knowledge and wisdom from others, which you will find in this section.

Research shows that more than one third of carers experience severe depression and that being a carer for someone else could be one of the leading causes of their depression.<sup>1</sup>

## Who does the term 'carer' describe?

For the purpose of this guide, the term 'carer' is used to refer to the primary support person for someone with depression, anxiety or related disorders such as perinatal depression, bipolar disorder and related substance use.

- Carers may be husbands, wives, children, partners, flatmates, parents or close friends.
- Carers provide ongoing support which may be in a social, emotional, physical and/or financial capacity. Sometimes, this may be to the detriment of their own employment, relationships, social life, physical and/or mental health.

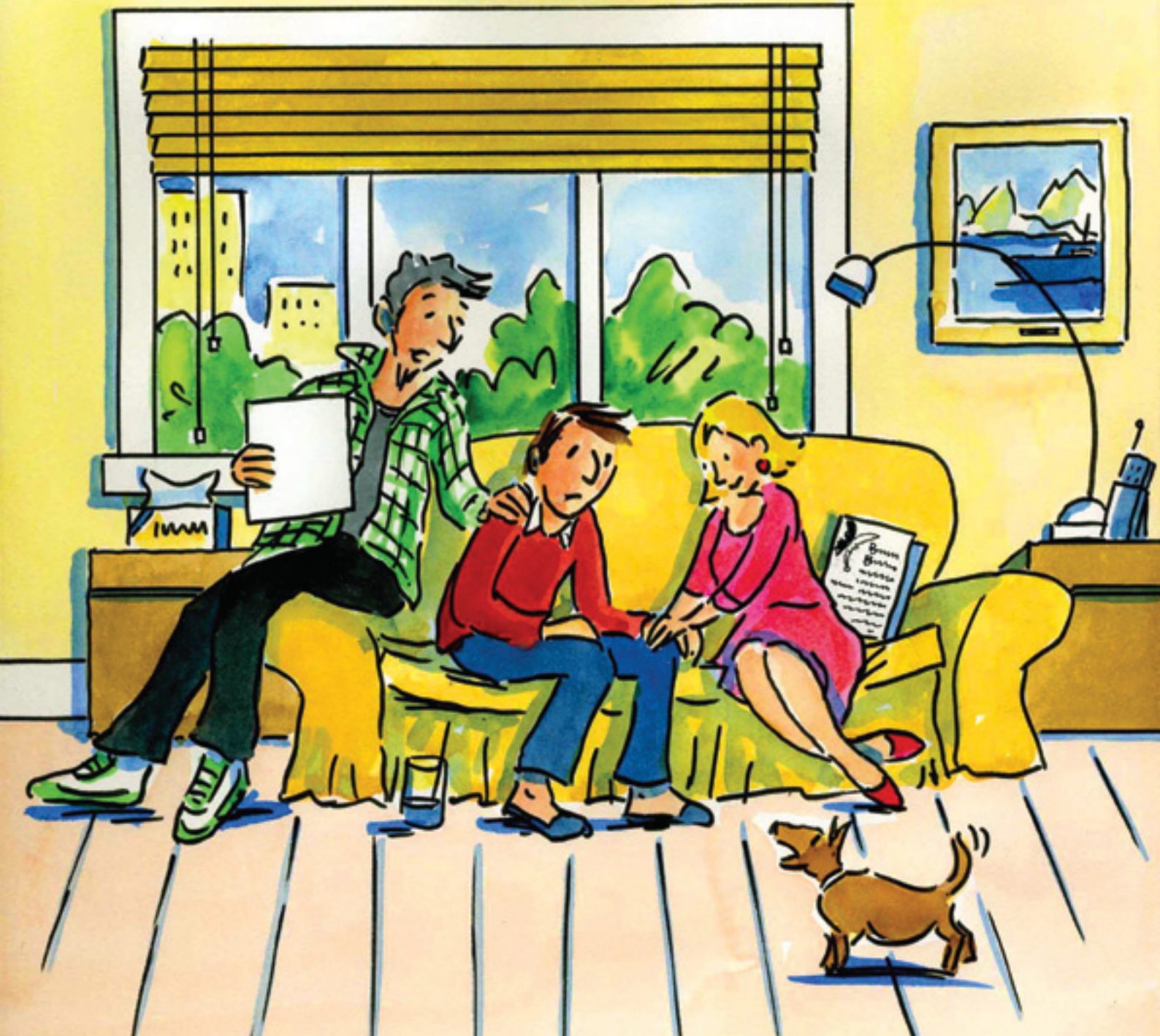
## How to use this guide

- **Section one** of the guide **Caring for others** will help you to understand the stages involved in reaching a diagnosis and getting treatment. This will be particularly helpful to people who are new to the caring role. This section covers working towards recovery, managing setbacks, and emergency and crisis situations.
- **Section two** – It's important to look after yourself, so it's recommended that you read **Caring for yourself** soon and refer to it often.
- It will be useful to read the guide in combination with *beyondblue* fact sheets which can be downloaded from the *beyondblue* website [www.beyondblue.org.au](http://www.beyondblue.org.au) or can be ordered by calling the *beyondblue* info line on **1300 22 4636** (local call cost from a landline). Fact sheets are available in more than 20 different languages.

<sup>1</sup> Australian Unity Wellbeing Index: The Wellbeing of Australians – Carer Health and Wellbeing, Survey 17.1, Report 17.1, 2007







## **Section 1 – *Caring for others***

How to support a person who has depression/anxiety  
or a related mental health problem









For many years, mental health problems such as depression, anxiety and related disorders were not discussed openly in the community because of fear, ignorance and stigma.

Unlike *physical* illnesses or conditions which have obvious symptoms that can be observed easily and, as a result, talked about frankly, symptoms of *mental health problems* may be deliberately hidden or unintentionally obscured. Signs and symptoms of a mental health problem like depression may remain unrecognised or attributed to being associated with certain life stages, stressful events, hormones or personality traits.

*“I put it down to just going through a life phase – I thought it would pass.”*

*“She was moody and irritable, but we just thought it was being a teenager.”*

*“My grandmother had depression for many years, but we never recognised it. We just thought she was a negative person.”*

*“I just thought it was stress from work. I never considered it to be anything more than that.”*

It's common for people not to discuss mental health problems with family members or friends. There is even more stigma around mental health problems in cultures where health issues of any type are not discussed with members of the immediate or extended family and certainly not with friends.

Negative views or stigma about mental illness are often due to misunderstandings, cultural beliefs, misconceptions and/or lack of knowledge about mental health problems and the associated signs and symptoms.

## Confirming there is a problem

*“I felt pretty terrible because I hadn't recognised it.”*

*“She was very teary and just not right.”*

*“With our son, he just had no energy... he was very tired and wasn't interested in doing things.”*

*“I attributed it all to the alcohol. It was easier for me to say, ‘He's just an alcoholic’.”*

*“He became non-communicative, withdrawn and dropped all his friends.”*

Initially, it may be difficult to confirm that someone has a mental health problem. While you may sense changes in a person's behaviour, it's understandable, when you don't have much knowledge about mental illness, that you may attribute symptoms to other causes.

Alternatively, you may not want to consider the possibility of there being a mental health problem because you're concerned or frightened about what this could mean for the person and those close to him/her.

It may also be the case that the person hides, controls or disguises many symptoms. You may no longer notice the symptoms because the associated behaviour has been going on for so long that it now seems normal.

Furthermore, symptoms may remain undetected for some time because the onset of the illness may be gradual. For these reasons, detection can be difficult and confirming whether there is a mental health problem is often complicated. The best advice is to **persevere and trust your instincts if things are not quite right.**



*"We both knew something was wrong... he didn't feel right, he didn't feel safe, but we couldn't put our finger on what it was."*

*"The key to this is that it is incremental. Every day just gets a little bit worse and that's the key. It's not a trauma injury like when you have a car accident."*

*"With my husband it was probably a gradual thing. It's very hard to pinpoint it, he just didn't fit in."*

*"It actually crept up on both of us...when you're actually there, you don't necessarily see the emergence."*

*"It wasn't until last year that she finally broke down and told me her fears and things she's been feeling. And quite frankly, I didn't even detect them."*

### What is the problem?

After confirming that there is a problem, you need to establish what that problem could be. Unlike many *physical* illnesses, there is not necessarily a one-off test which can result in a diagnosis for a mental health problem. For example, it can be difficult to know whether lack of sleep and weight loss are the result of work-related stress or whether they may be symptoms of depression, anxiety or a related disorder, or another health matter.

*"We had lots of tests done thinking it was autism or even epilepsy... and nothing came back from the doctors."*

*"I don't how many times he would have seen the GP, and just came out with sleeping tablets when there was depression there all along."*

It's important to note that there is a range of physical health conditions with symptoms similar to those of some mental health conditions which may make it difficult to diagnose the problem. For this reason, it's important to get a thorough assessment of the person's *physical* and *mental* health.

*"I've sort of seen all these little bits and pieces of the jigsaw but really hadn't put them all together."*

*"Around that time, it was a puzzle. I didn't really think about depression."*

It may be helpful to familiarise yourself with the signs and symptoms of depression and anxiety. If possible, ask the person you are concerned about to complete an online checklist which is quick, easy and anonymous and will show if the person has symptoms in common with depression or anxiety – and will indicate if the person should see a health professional. These checklists are not intended to replace a diagnosis by a health professional, but are a good starting point. Symptom checklists may be found on the *beyondblue* website [www.beyondblue.org.au](http://www.beyondblue.org.au). The depression checklist is also available in more than 20 different languages.

## Depression Checklist

To find out if you, or someone you know may have depression, complete the checklist below.

For more than **TWO WEEKS** have you:

Tick if  
Yes

1. Felt sad, down or miserable most of the time?
2. Lost interest or pleasure in most of your usual activities?

**If you answered 'YES' to either of these questions, complete the symptom checklist below. If you did not answer 'YES' to either of these questions, it is unlikely that you have a depressive illness.**

3. Lost or gained a lot of weight? OR  
Had a decrease or increase in appetite?
4. Sleep disturbance?
5. Felt slowed down, restless or excessively busy?
6. Felt tired or had no energy?
7. Felt worthless? OR  
Felt excessively guilty? OR  
Felt guilt about things you should not have been feeling guilty about?
8. Had poor concentration? OR  
Had difficulties thinking? OR  
Were very indecisive?
9. Had recurrent thoughts of death?

Add up the number of ticks for your total score: \_\_\_\_\_

### What does your score mean?

(assuming you answered 'YES' to question 1 and/or question 2)

4 or less: Unlikely to have a depressive illness

5 or more: Likely to have a depressive illness

**For further assessment, please consult a doctor or another health professional.**

References: American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 4th ed (DSM-IV). Washington, DC: APA, 1994; and, International classification of diseases and related health problems, 10th revision. Geneva, World Health Organisation, 1992-1994.

See *beyondblue* symptom checklists at [www.beyondblue.org.au](http://www.beyondblue.org.au) or by calling the *beyondblue* info line 1300 22 4636



It's important to remember, when you take the first step in dealing with depression or a related disorder, **you are not alone – help is available.**

## **Mental health problems are more common than you realise**

Mental health problems are common. In fact, one in four people experiences some form of mental health problem – the most common of these being anxiety and depression... and it's not only the person with the illness who's affected. It can also affect family members and friends.

Realising that there may be a problem and then doing something about it can be easier said than done, particularly if you feel that you're tackling the problem on your own. If you haven't dealt with a mental health problem before, it can be daunting and knowing how to help someone can be challenging. **Keep in mind that the person you're supporting can be helped if the right treatment is accessed.**

## **Beginning the conversation**

Raising the subject with the person you care about may take some planning and thought. Consider the following:

- When is the person most likely to be attentive?
- Where is she/he most comfortable and at ease?
- Where is a place you both feel safe and will not be interrupted?

It can be helpful to have this discussion as early as possible, before symptoms start dominating day-to-day life, conversations, activities and relationships. For example, a person with Generalised Anxiety Disorder may find it difficult to leave her/his home. Over time, family members may start to accommodate and support this behaviour because they're concerned and want to make life easier. In this instance, getting the person to leave the house to see a General Practitioner (GP) and access treatment may be a difficult obstacle to overcome.

It's important to let the person for whom you care know that you are concerned. Talk sensitively (in a non-accusing or non-blaming manner) about the changes you've noticed – even though you may feel tired and frustrated with the person.

Using 'I' statements may be effective, for example:

- 'I've noticed that you're not sleeping as well as you used to.'
- 'I'm worried that your appetite isn't as good as it was.'
- 'I've noticed that you don't seem to spend much time with your friends after school any more.'

The person may insist she/he doesn't have a problem. She/he may become awkward, cross, frustrated or non-communicative. In these circumstances, try to keep calm, but be firm, fair and consistent in your approach. It may be hard to raise the subject for fear of upsetting the person, but remember that you're trying to help, so it's important to try to maintain self-control. She/he may need some time to come to terms with the discussion and overcome the resulting emotions, which may include anger, shame or embarrassment.

*“He would get really defensive when I would bring it up... it was hard... I didn’t want to hurt his pride, but he didn’t want to think that he was any different from his friends.”*

You may want to tell the person that you have found some good, reliable information which will help the person to put things in perspective and to make sense of what is going on. You could leave this information for the person to read in her/his own time. You can download information from the *beyondblue* website [www.beyondblue.org.au](http://www.beyondblue.org.au) or order information material from the *beyondblue* info line **1300 22 4636**.

### **Acknowledging the impact of depression or a related disorder**

Often mental health problems lead to people becoming very introspective, making it hard for them to be aware of the impact their behaviour may be having on others. If the person is unwilling to talk about things, you could let the person know how her/his behaviour is affecting other family members. This may be a way to encourage the person to try to do something about the situation.

Encouraging the person to seek help is another key step in moving forward. Suggest that you seek help together. For example, you could make an appointment for you both to see the person’s GP for a check-up. The person may not see this as a threatening or intrusive option.

Unfortunately, sometimes the family member may be reluctant or may even refuse to get help. People may give a range of reasons as to why:

- “I’m not ready.”
- “I’m just going through a phase.”
- “It may just be stress.”

It’s common for people with depression to fail to recognise they need help or support so you may find it difficult to get your offers of help accepted. Again, it may be useful to consider highlighting the broader impact the person’s behaviour is having on others. You could also talk about the positive effects of getting help.

If the person won’t listen to you, think about asking someone else to talk to her/him. A trusted friend or family member may be able to get through to the person and raise some issues without posing a threat or creating apprehension. In more extreme circumstances, where you are very concerned, you may consider contacting your General Practitioner (GP) to see if she/he can become involved or make a home visit. **Your ultimate goal is to help the person for whom you care,** so try to keep this in mind even when she/he may be cross or agitated with you.

*“They have to admit they have a problem before you can get them any help... he’s a grown man – I can’t make him go.”*





It may be that the conversation about seeking some professional support wasn't easy and actually going to see a health professional may not be easy either... but you've taken the first step and it's important to keep up the momentum.

## Start with a General Practitioner (GP)

The best place to start is by making an appointment with the person's GP – i.e. someone with whom the person is comfortable and whom they know and trust. Alternatively, consider approaching a GP in your area who has been recommended by friends or a GP who is highly regarded.

If you don't know a GP in your area, you can find one on the *beyondblue* website by using the ***beyondblue* Directory of Medical and Allied Health Practitioners in Mental Health**. This is a list of practitioners (including GPs, clinical psychologists, psychologists, social workers and occupational therapists in mental health) who have a special interest in mental health, and have undertaken additional training in the treatment of depression, anxiety or related disorders. Go to the *beyondblue* website [www.beyondblue.org.au](http://www.beyondblue.org.au) and click on [Find a Doctor or other Mental Health Practitioner](#). This information can also be obtained by phoning the *beyondblue* info line **1300 22 4636** (local call cost from a landline).

When the person with depression/anxiety makes an appointment with the doctor, it's very important that he/she books a longer or double appointment, so that he/she can make the most of the consultation and not feel rushed. This also gives the doctor plenty of time to discuss the situation and avoids having to book a second appointment.

## What to expect

Another reason for booking a longer appointment is to allow time for the GP to do a thorough assessment and if necessary, to develop what is called a *Mental Health Care Plan*. This is a plan designed to enable the GP to manage and treat the mental health condition. The GP may refer the person to another health professional such as a psychologist, social worker or occupational therapist to provide psychological treatment. They would then report back to the GP on the person's progress after treatment.

Under this system, a person with a mental health problem like depression or anxiety can claim a Medicare rebate for up to 12 individual consultations (more in exceptional circumstances) and/or 12 group sessions in any one calendar year. While some health professionals will bulk bill, there may be out-of-pocket expenses with others, so it's important to ask about charges prior to commencement of treatment.

## How can you be involved in the consultation?

It's a good idea for you (the carer) and the person for whom you care to consider how you would both like to be involved in the consultation with the GP and the ongoing treatment process. It can be useful to view this as a partnership where together you both agree to seek effective treatment and work towards recovery. Your involvement at this early stage can be vital in assisting the person to get effective treatment as early as possible – as well as maintaining momentum during ongoing treatment.

*“Unless there's a family member involved somehow or there's some other back-up, things can often drift on for months.”*



It's worth discussing both your involvement in the consultations with health professionals and the overall treatment plan. You may want to discuss and agree on what information you, as the carer, are able to contribute to the session, and if you may be permitted to attend parts of the consultations. Some people have found it helpful to have the carer present at the first part of the session to help give the health professional information about how the person has been. This is particularly useful when the person with the condition finds it hard to express how they have been. Other carers, however, have talked about the importance of being involved at the end of the session, in order to find out the best way to support the person between appointments.

*“There was just so much shame and embarrassment in him about his thoughts. He couldn't even imagine telling a health professional.”*

*“One psychiatrist said he really loves involving the family because it is less work for him – and it's true. If they involve the family from the start of the treatment, giving information about the treatment, the medication... it's a lot less hard for everyone.”*

*“The best doctors will have you and the patient come in and then will turf you out of the room and talk to the patient and then turf the patient out and talk to you.”*

It's important not to undermine the person who has depression or a related disorder. While you may be eager to get treatment underway as soon as possible, remember the person with the condition needs to feel that he/she is in control and is taking responsibility for his/her own treatment as well. If the person is not actively involved in this way, he/she may feel that you are taking over and there is a risk that he/she may withdraw from you and further treatment.

## **Spend time thinking about the person's experiences and the situation**

Once you've made the appointment, spend some time together thinking about what the person for whom you care has been experiencing. It may be helpful to write down his/her experiences; add your experiences too, as well as those of family members and friends who have been affected. Having a list will be a good prompt during the appointment and an excellent way to keep things on track if either of you becomes upset or loses your way. Many people find it helpful to take along the completed symptom checklist to begin the conversation (available from the *beyondblue* website [www.beyondblue.org.au](http://www.beyondblue.org.au) or info line **1300 22 4636**).

## **Commit to the consultation**

Before the appointment, try to agree that you'll both try to make the most of it. You may discuss how you will tell the doctor about the symptoms and difficulties. It will be helpful to remember that you are both committed to helping the person become well again and that you are there to support him/her towards recovery.

## **Prepare for the consultation**

When you go to the doctor, it's helpful to take a list of things about which you're concerned including:

- what doesn't seem right
- a completed depression/anxiety symptom checklist
- a description of the behaviour
- any concerns you may have
- how the person is feeling
- any questions you both may have.

The more accurate the information you provide, the better and more precise the assessment by the doctor will be. Hiding facts, behaviour and issues because of embarrassment, fear or in defence of the person for whom you care will only delay the assessment and in turn delay the recovery. It may also be beneficial to read about depression and/or anxiety, along with available treatments so you will have some idea about what may be suggested. Also let the doctor know if you will need interpreting services.



### On the day

Some carers say that it's a good idea to be prepared for resistance or procrastination from the person with depression/ anxiety. On the day of the appointment, he/she may try to convince you that he/she is well and that there is no need to see the GP. ("See, I am okay today.") You can try to explain, that from what you have read, this may be part of depression/ anxiety – good days and bad days – and by seeing the GP today, you can all work towards having many more good days in the future.

The person for whom you care may not want to go to the appointment because of distress, apprehension, fear, worry and embarrassment. He/she may worry that he/she won't be able to 'hold it together' during the consultation with the GP. You can put the person at ease by acknowledging that those feelings are natural and may be associated with the illness – and that the GP will have seen these symptoms which are common to these disorders many times before in other people. Reassure the person that visiting the GP is an important step and you're there for support.

### If the person refuses help

Some carers say they experienced great difficulty and frustration when trying to get the person to acknowledge that help was needed. The person may deny that he/she has a problem or the person may believe that things aren't very bad and they will improve on their own, with time, and without professional help.

As with most health conditions, it's important to have the problem assessed and if necessary, get the appropriate treatment as soon as possible. If the person denies that anything is wrong, this may be because of feelings of embarrassment or shame about the possibility that he/she is experiencing a mental health problem. Alternatively, the person may dread having to discuss thoughts and feelings with the doctor.

In these instances, some carers have solved the problem by focusing on particular physical symptoms that the person is experiencing such as sleeping problems, change in appetite or lack of energy.

The person may find it easier to discuss *physical* symptoms openly with the doctor at first, and then lead onto the *emotional* symptoms being experienced.

If this doesn't work and the person is still refusing to seek help, you may have to accept that there is only so much that you can do, and that this may not yet be the right time for the person to get help. This is also true of other illnesses where people won't seek help until it gets to the stage when they can no longer tolerate the symptoms or manage from day to day.

If this is the case, while you need to continue being supportive, all you can do is make the information available and be open to discuss things when the person is ready. Meanwhile, you need to look after yourself. Be aware that there's a tendency for carers to readjust their lives around the illness and in doing so, they may inadvertently prolong the period that the person with the illness denies needing help.

### Help the person for whom you care to seek a second opinion if he/she isn't satisfied with the health professional or treatment.

While it's not always easy to talk about personal issues or feelings, sometimes the problem can be compounded if the person for whom you care feels that the health professional can't relate to his/her story – or if he/she doesn't have confidence in the health professional's ability to deal with the problem. It may take time to find the right health practitioner, but it's important to keep looking until you're satisfied the person for whom you care is getting the right help.

If you are seeking a second opinion from a GP, it's important to note that a person is eligible for only one GP Mental Health Care Plan within a 12 month period for which Medicare rebates can be claimed. It is advisable to take a copy of the previous Plan to the new GP for review, or if that isn't possible, to give the new GP your permission to obtain a copy from your previous GP.

*"You have a right to be happy with the treatment you receive."*









Obtaining information from the practitioner about the person who is receiving care can be a complex issue. There is a delicate balance between the individual's right to confidentiality, the need to ensure that the practitioner has adequate and accurate information about the person's condition, and your need to access information that is relevant to your role as the primary support person.

## Privacy and confidentiality

Privacy and confidentiality legislation means that you are not always entitled to give or receive information and you may be excluded from treatment plans and discussions because of this. However, if the person receiving treatment consents, you may be given access to information and be permitted to provide input.

Clearly, this situation has many implications. As a carer, if you live with someone with depression/anxiety or a related disorder, it can become very difficult to manage day-to-day issues if you're not fully aware of the state of the person's mental health, the treatment and any issues that would impact on the caring role.

*"As parents, we were left out of the picture as to how to relate to him."*

*"Look, I understand... there's confidentiality... but ...I think they need to take on board that you're the one he's seeing. A young man who is very proud doesn't want to really describe all the issues."*

This situation can become worse if the illness becomes more severe and you, as the carer, are unaware of important information about the individual's treatment. For example, carers often talk about the importance of understanding what treatments have been prescribed, so that they know what to expect and if the person does become particularly distressed, they will have some idea of what is happening, what to do, and who to contact.

*"They [the doctors] can't comment. Why? Because of that ridiculous privacy act. I understand the privacy act, but for crying out loud, we are married. And I'm looking to help him rather than to hinder our relationship. I'm trying to keep my own sanity... I don't go blabbing everything out to everybody about my husband; I don't have anywhere else I can go to... I'm trying to tell you how bad he is getting and I'm wondering whether he needs more medication or something. And they say we can't talk about it. It's so damn frustrating."*

*"I remember when my son had been very unwell in hospital and when he was discharged, we did not know what had happened in hospital or what medications he was now taking. Just some information would have helped us all deal with things better."*

## Communicating with health professionals

Communicating with health professionals can help ensure that you are kept informed. Find out the best way to contact them, including when to call and how to reach them in an emergency. Some health professionals may be happy for you to email your questions or to make a separate time for you to talk about your concerns. Many health professionals welcome talking to the carer.

Sometimes you may be upset when you need to contact the treating health professional, but it's helpful to remember that they're also trying to help the person for whom you care. Being angry and blaming them for what has happened will not solve the problem. Trying to work together as a team with the health professional can be more helpful and productive.

*"I would have to say from a carer's perspective, my experience has only been positive. Whilst I have not been invited to be part of any consultation with him, I have been able to approach and have personal contact with the psychiatrist any time I need to. This, I must say, is most comforting and reassuring for me."*

*"For me it was good... the psychiatrist said I could ring any time."*

*"We are part of the team and I don't care if I am the problem. I would rather they told me, 'Look you're doing this wrong.'... it would be better. But don't ignore me. I'm the one she comes home to."*

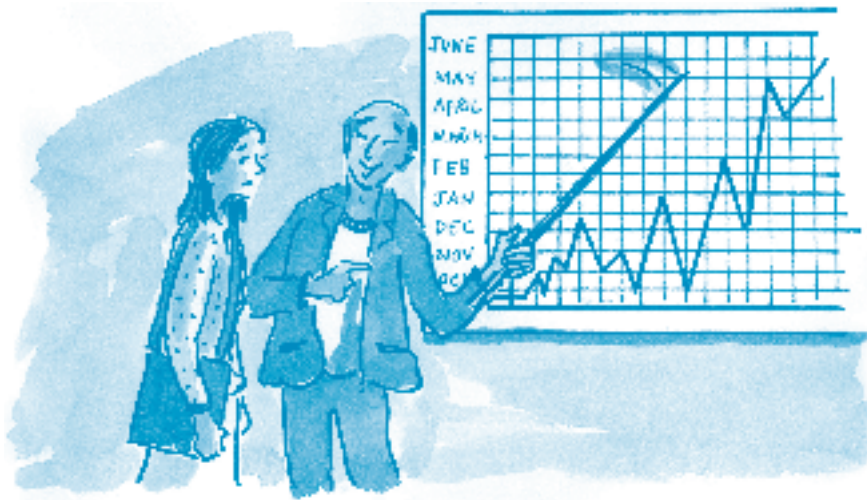
## **Be proactive**

Be persistent in trying to access information. This will benefit both of you. Be proactive about taking part in the consultation. No matter which part of the consultation you attend, it will be helpful to show your support and to make the most of the opportunity to ask questions and provide relevant information.

You have a crucial role in respecting and supporting the person for whom you care, so you need to feel confident about understanding the illness, the treatment, its impact and overall, what to expect.

*"I mean I'm not nosey... I just need to know that something's getting done."*

*"The more you understand the situation, the more it gives you strength."*



You've made it to the first appointment and sought diagnosis and treatment...however, it's important to be realistic and acknowledge this is the beginning of the recovery process, not the end.

## Educate yourself

There may be times when everything seems overwhelming and when the symptoms, behaviour and challenges seem unrelenting.

*"I must admit I tried not to think too much about the future and what was going to happen in my life. When I did, I had all these fears associated with it, so I knew I had to deal with the day-to-day living and to help him. I wasn't going to be helping if I was worrying too much about the future. So we both just took it day by day."*

One way to manage these feelings is to increase your knowledge about *what* is happening, *why* it's happening and *where* you go from here. Educate yourself with good quality, evidence-based information which is available on the *beyondblue* website [www.beyondblue.org.au](http://www.beyondblue.org.au) or by calling the *beyondblue* info line **1300 22 4636**.

*"Having a diagnosis made me feel a little bit better because at least now we know what we're dealing with. It's unfortunate that it didn't happen the year before; it would have saved a lot of suffering and heartache."*

It will benefit you to understand the illness, its progression, treatment options, medications, side-effects and the mental health system.

You may feel more informed and in control of what's happening if you know about treatment options.

It may also be useful to learn about the difference between psychologists, social workers, occupational therapists, psychiatrists, public hospitals or mental health units, specialist community services, crisis assessment teams or acute treatment teams, telephone-based and web-based services. It sounds like there is a great deal to learn and you may feel as though you have learned enough, but the information you gather along the way may prove to be helpful to you and the person for whom you care.

## Making the right decisions

Sometimes, the person may say that she/he is better. She/he may feel well and no longer in need of medication or sessions with the health professional. It's important to remind the person that it's the health professional who will help to make these decisions – and although treatment may certainly be improving the person's condition, recovering may take time. The person needs to be as stable as possible before making any changes to the treatment plan. Any adjustment to medication should be made by the GP or treating team. The person should never adjust her/his medication without consulting a doctor. If a person suddenly stops taking certain medications, it can cause withdrawal symptoms which can be unpleasant and difficult to manage.



## **Conversations and keeping a record**

An important part of your relationship may be to talk about what is happening and how the person for whom you care is progressing – also, how you're working together as a team. The person may need to know that you are confident and understand what's happening. One way to record how things are going is to write notes in a diary or exercise book every day about progress, issues and/or symptoms.

Some carers say they've used a rating system where both the carer and the person with depression/anxiety rate how she/he was on that day. It may be as simple as giving a score out of 10 – with one being a bad day and 10 being excellent.

You may devise your own rating system, but either way, it will be a useful record of improvements and a guide as to what you both see as a good or not-so-good day. You'll be able to reflect on the days when things ran smoothly and work towards having more of those days. It will also be a handy tool to have when there's a discrepancy between your ratings. You can talk about why you saw things differently.

Another constructive strategy used by many carers is to record the schedule of medications and to track, list and discuss side-effects. This will be very helpful for the doctor who may not be able to observe all of the side-effects during a consultation.

## **Broaden the focus of your conversations**

It's important to talk about other things besides the illness, so it doesn't become the focal point of your life and relationship.

Talk about things that are happening, both in your world and more broadly. The person for whom you care may not be interested or able to engage completely with this, but it's essential that she/he has some awareness of other things happening in the family or the broader community.

You may try to encourage the person to participate in a small activity each day – a short walk, helping to prepare a meal, reading or listening to music. It can be hard to persevere when the person for whom you care is not able to get much enjoyment or pleasure from anything, but it can be helpful.





**Recovery can mean different things to different people. For some, it's no longer taking medication, while for others it's managing the illness on a long-term basis.**

**It's also important to remember that when dealing with mental health problems such as depression/anxiety, the path to recovery is not always straightforward, and there are likely to be times when things seem to slip backwards.**

## **The importance of support networks**

Ongoing support will play a major role in the person's recovery and this support may come from many sources e.g. friends and family members, health professionals and perhaps support groups.

*"It's a really lonely life when you're dealing with this on your own."*

It's important to ensure that people with mental health problems develop skills to support themselves and do not become totally dependent on their carers as the sole providers of support.

## **Boundaries and goals**

At home, having structure and a routine can help set boundaries and bring some order to a life that may seem out of control. A daily or weekly plan which is visible and clear encourages positive behaviour, involvement in the household routine and looking to the future, even if only until the end of the day or week.

You can encourage the person to include the following in the plan:

- treatment plans
- medical appointments
- stress-reducing activities such as walking, meditation, music, craft.

It's a good idea to have realistic expectations about these plans and about what can be achieved. Acknowledge that some things may not get done. Don't become despondent or discouraged if some of the set tasks aren't achieved.

When working towards recovery, it's also a good idea to set goals which are small and achievable. You may help the person to recognise any achievements and acknowledge the progress he/she has made, no matter how big or small. This can instill a positive sense of accomplishment and these successes may provide an incentive for ongoing efforts.

## **Sharing the load**

Carers often describe feeling totally overwhelmed and responsible for the person. In response to this, many carers have found it helpful to enlist support from other family members and friends.

As a carer, you may wish to discuss with the person for whom you care, your need for support and together identify people who may be able to help if needed. Support from others can take many forms depending on your situation. For example, some carers talk about the importance of having a close friend with whom they can go out for a coffee and chat. Others may need more practical support such as assistance with shopping or cooking meals. Whatever support you receive, recognise that it can be very helpful especially when you feel overwhelmed.



It's important for carers and other support people to be aware of the signs that may indicate the person with the mental health problem is becoming distressed. Over time, you can learn what triggers anxiety, irritability, fear and panic in the person, just as you may recognise the warning signs of an asthma attack or migraine. Knowing what to look for helps to reduce your stress, the person's stress and can be a helpful coping strategy for everyone.

The key to managing your own role in the person's recovery is to try to incorporate the support role *into* your life and try not to let it to become your whole life.

Try to reflect on the situation sometimes. This may give you a fresh perspective on how things are going and what is working well for you and the person for whom you care.



It's common for carers and people with depression/anxiety and related disorders to say they have ups and downs, with frequent periods when they felt they were taking one step forward and two steps back. Dealing with setbacks can be frustrating and disappointing for both the carer and the person with the illness.

It may be useful to remember that life in general has its ups and downs – and while living with depression/anxiety is likely to increase your stress levels, not all problems that arise will be due to the illness itself.

## **Does a person with depression/anxiety go through various stages during the illness?**

Mental health problems such as depression and anxiety may not always run a particular course where there is a clear beginning, middle and end. This however, can occur with some physical health problems – a diagnosis, treatment such as surgery or medication and then recovery.

Following diagnosis, recovery from depression/anxiety and related disorders can involve progressing through various stages. It may include trialling different medications, treatments and health professionals. This is all part of learning what works for the person and what doesn't. This can take time, persistence and patience.

## **Medication**

In the treatment of depression, anxiety and related disorders, there are many medications which are safe, effective and non-addictive. It may take time to find the medication or combination of medications that work in the best way possible for the person with the mental health problem. It's not unusual for people to be on medication for several weeks and then have the medication adjusted or changed to suit the individual's needs. If the person is taking medication for other chronic illnesses, health professionals will be careful to monitor combinations, dosages and side-effects. It may take weeks to months to find the best treatment for the person.

Therefore, it's very important to tell the doctor if any other medication is being taken, including herbal remedies or tablets that may interact and/or interfere with the medications that have been prescribed.

Managing the side-effects of medications can be challenging. It's important to ensure that the prescribed medication is taken regularly, at the same time each day, correctly, following the prescribed dose and consistently. If the person for whom you are caring cannot tolerate the side-effects of the prescribed medication and wants to stop taking it, urge her/him to discuss this with the doctor before doing so.

The person for whom you care may feel well and consider the medication unnecessary. Again, discuss this with the doctor or encourage the person to do so.

Taking medication for a mental health problem is no different from taking medication for a physical illness. For example, a person with high blood pressure takes medication to help manage the condition and would become unwell without it.

## Relapse

Some people may experience only one episode of depression/ anxiety or a related disorder during their lives where psychological treatment or medication, or a combination of treatments is effective. The episode may last for months or years, but no repeat episodes occur.

For other people, there may be recurrent episodes of depression or the symptoms related to their mental illness may re-occur for a variety of reasons:

- the occurrence of a specific event e.g. loss of job, relationship breakdown or bereavement
- biological or physiological changes in their body chemistry
- physical illness
- sleep difficulties
- employment stress
- stopping or starting medication
- no apparent reason.

*“When she started the treatment and was well again, I thought that was the end of it. I didn’t think it would come back.”*

To avoid setbacks, it may be helpful for you and the person for whom you care to think about and identify the triggers and symptoms that were present before the person was diagnosed. This may help you both to recognise these warning signs in the future. You may feel as though you always have to be vigilant, but as time goes by, you will understand that drug and alcohol use, lack of sleep and stress are common triggers leading to relapse of mental illness.

*“You have to be ever-vigilant... it’s like, you know, when a dog goes to sleep it’s always got one ear up? That’s what it’s like caring for someone with depression.”*

## Moving forward

Remember, there are ways of moving through an episode or relapse. You may have already been through this once or twice before – and you managed. Although you may fear it happening again, you’re a step ahead now because you know more about where to go, what to do and who to contact, and importantly, how to help.

Write down past achievements in the person’s recovery and focus on these. Put the notes in a prominent place, so they’ll be a positive reminder. You and the person for whom you care can refer to them when necessary.



Sometimes, when a person has severe mental health problems or the person's condition deteriorates rapidly, he/she may consider attempting suicide or harming him/herself.

This isn't necessarily the case for everyone with depression/anxiety or a related disorder, but it's important to be aware that for some people, their illness may become so severe that they may feel these actions are their only option.

It's always good to be prepared. Talk to the person about the issue of suicide when he/she isn't highly distressed and agree on a course of action that will be taken should an emergency situation arise.

## Suicide and self-harm

Hearing or reading about suicide or self-harm for the first time can be confronting and may create feelings of apprehension. These difficult subjects are not easy to discuss. Some people worry that by thinking about or raising the topic, it may happen and, therefore, they're hesitant to broach the subject. Unfortunately, in caring for someone with depression, there may be times when you face emergency or crisis situations, such as suicide attempts or incidents of self-harm and it's important to be aware and prepared.

Self-harm can occur in many ways. It's not just cutting oneself or causing physical self-harm. Self-harm may include risk-taking behaviour such as driving fast and recklessly in a motor vehicle, being careless on public transport, high rates of alcohol use, drug use and sexual promiscuity.

It's frightening and distressing when someone you care about wants to harm him/herself. It's important to remember that for many people this is part of the illness. However, learning about suicide and self-harm may help you to recognise when a person is at risk and you'll be better prepared should an emergency occur.

## Misconceptions about suicide or self-harm

Some of the misconceptions about suicide or self-harm may prevent a carer recognising when someone is actually at risk. Many people think that these actions are about 'crying wolf' or being manipulative. Instead, when people talk about suicide and their attempts, they're looking for help – they attempt suicide because they either want to stop the pain they're experiencing or they want to release the pain somehow, by harming themselves.

*"My daughter told me that she had tried to kill herself because she didn't want to go back to school. That rang alarm bells – she was suicidal!"*

*"He was saying that he wanted to commit suicide and harm himself...it's traumatic."*

Discussions about suicide or self-harm should be taken seriously so that you can comprehend what is happening to the person for whom you care and can support him/her by getting the appropriate help. Listening to the person shows your concern and can help to make him/her feel less isolated.



Asking a person if he/she is thinking about suicide or self-harm isn't an invitation for him/her to go ahead with either act, but a way for you to find out more about what the person is thinking and why, and to provide assistance.

### Warning signs

If a person is thinking about suicide, there may be some warning signs. Sometimes however, these signs may be well hidden, particularly if the person is withdrawing from you, other family members and friends.

Strong indicators are previous attempts, current or recent thoughts of suicide along with talking or joking about suicide or making a suicide plan. The person may talk about feelings of helplessness or express thoughts about death through drawings, stories, poetry or song. The following behaviour could also be warning signs that may alert you to a problem – stopping activities that he/she previously found worthwhile, giving away possessions, increasing or commencing use of alcohol or drugs and exhibiting risky or illegal behaviour.

If you have concerns, it's a good idea to check with other family members, friends and teachers. Trust your instincts if you have noticed something different and concerning in the person's behaviour.

### Contracts and agreements

Consider making a contract or agreement with the person for whom you care when he/she is well. Together, list details about what will happen if he/she starts thinking about suicide or self-harm or previous plans. Specify in the agreement that the person will let you know when he/she is feeling this way so that you can get help immediately. An agreement or contract is the best way to provide structure to what often seems like an uncontrollable situation.

*"I've found it really hard because our daughter has been suicidal...sometimes you just want to relax and be a bit more low key, but you can't because it might happen again."*

If the person is thinking about suicide or self-harm, you will need to undertake the agreed plan of action for his/her own safety, reiterating that you need to follow through because you care. You also need to assure the person that he/she can trust you.

*"There are times when action is non-negotiable."*

Remember, if the person for whom you care is feeling suicidal, he/she is not able to think clearly or rationally, so you, as the carer, need to take control of the situation.

Occasionally, the person for whom you care may need to go to hospital for treatment if his/her symptoms become more severe, if his/her medication is a problem, if he/she needs specific treatment or if he/she is at risk of self-harm or suicide. If the person is not willing to get help, then it's a good idea to talk to a health professional for advice about appropriate follow up.

### Urgent situations

If the situation is urgent and you're concerned that the person is in immediate danger, **do not leave the person alone.**

Call the person's doctor, mental health crisis service or dial **000** and say that the person's life is at risk.

If the person agrees, you could go together to the local hospital emergency department for assessment.

It is important to keep these emergency numbers handy.



## **Section 2 – *Caring for yourself***

How to look after yourself when supporting a person with depression/anxiety or a related mental health problem







When you're a carer of a person with a mental health problem, you're likely to experience a range of feelings. Sometimes, adjusting to the problems you're facing and understanding your emotional reactions can take its toll.

## Your reactions are normal

First and foremost, remember that your reactions are normal. They reflect how you feel and shouldn't be questioned or judged by other people who aren't walking in your shoes. Everyone's experience is unique, although there are many feelings and experiences that carers have in common.

During the initial stage, when the person you're supporting is diagnosed with a mental illness, it's likely that you may feel relief because:

- there is a name for the difficulties you have both been facing
- there is a reason for the behaviour
- help is available.

You may also experience some fear and confusion initially wondering:

- "Where to from here?"
- "What next?"
- "Is this only the beginning?"

However, bear in mind that these questions are normal because for most people this is a new experience.

*"I felt pretty terrible because I hadn't recognised it... so I felt shattered ...but I also felt a great relief that now we know what's wrong and it's fixable."*

Many carers say that once the mental health problem had been identified, their feelings of love and protection for the person increased. Sometimes simultaneously, carers would feel a sense of helplessness because they couldn't control or improve the situation.

Common feelings at various stages of the journey include:

- fear
- confusion
- guilt
- blame
- uncertainty
- insecurity.

*"I felt like he wasn't able to reach his full potential in a work situation and that really set him back and I felt really sad. He was an intelligent man who was so gifted in so many ways and yet he wasn't able to see that potential because of this challenge, vulnerability... I felt aggrieved for him – and for what could have been."*

*"I felt so guilty and scared at the same time. I was worried about what this would mean for us, for our family. We were reliant upon him to provide for us, and the thought that he would be unable to do this was terrifying. On top of this, I then felt totally guilty. He was suffering and there I was thinking about finances. How heartless, but then it was a frightening concept.... I was torn between fear and guilt."*

Many carers have also described experiencing what is often referred to as 'anticipatory grief'. This refers to a feeling of loss and sadness at 'what might have been' – the fear that someone may never reach his/her full potential, fulfil hopes and dreams or that the relationship may never return to what it was.

*"It's distressing; the personal powerlessness. There is no word I can say, there is nothing I can do."*

*"No mother likes to see their child's life taken away from them in a manner such as this. It's a personal sadness seeing your gorgeous son, great big strapping son, destroyed in this way. It has by far and away been the worst for me."*

*"There's this awful grief that goes on. It's not like when someone dies and the grief is there for a year or so and then it's finished. This type of grief goes on and on. You think this time it will be all right, but then you fall in a hole again. It is continual and that's what wears me down."*

*"Desperate, unhappy, sad and longing, just longing to do anything to help, but there's nothing I can do."*

*"So I felt very angry and also guilty. I felt, and still do, as a mother I should be able to make my son better. I mean I know it's impossible...but I feel very sad that I can't make his life better."*

### **There are many reactions you may experience**

People in a caring and support role have described numerous feelings such as being overwhelmed by the nature of the role because it's demanding and often unrelenting. The high level of responsibility that comes with caring for and supporting another person, particularly if this includes physical, practical and financial support, can be exhausting and may also trigger feelings of resentment, frustration and anger.

*"I wouldn't put up with it if I didn't love him."*

All of these feelings may, understandably, give rise to guilt. It's important to acknowledge these are normal responses to the situation in which you find yourself. Accept that they are part of a life experience that you didn't plan. You may ask yourself, 'How am I supposed to feel?' There is no single or short answer to this – how you feel is how you feel. **It's important to remember that help is available and you are not alone.**

Remember, the situation in which you find yourself is beyond your control. You've had no say in it. You didn't ask for this to happen – but nevertheless, here you are.

This doesn't mean that you love or care about the person you are supporting any less. However, it's likely at some stage that you will react and you may not be able to predict when and how. Again, this can be a normal response to an unusual situation because you are using all of your energy and resources to take care of the person and to take care of yourself.





Not only does living with and continually supporting someone with a mental health problem affect you and your relationship with the person, but it's likely to affect relationships with other people as well.

## Relationships

Family life may be disrupted. Routines and the sense of 'normality' you once had in your home gradually change, often without you recognising it. You may find that the changes you and the family made to adjust to living with the person and her/his condition have now become the norm.

*"It restricts. I rarely see a friend or anything... I don't really invite people over that much because of it."*

*"I have very few friends because I'm frightened to invite people to our house as he might be in one of his moods on a particular day when we're having people over for dinner."*

Social relationships may also change. The response or lack of response you get from friends and family members may be surprising or hurtful. This may be because they don't understand depression/anxiety, what it means, or what you may be going through.

*"After we got married we didn't have friends because to invite people over for a meal or a barbecue or whatever was just too huge a task – too much for her to be able to cope with and they didn't understand."*

*"It was a sort of taboo area where people didn't want to talk about a mental illness and that would frustrate me endlessly because I was looking for support too to try and cope with what was happening. But they just wouldn't say anything because they just wouldn't know what to say."*

*"I just got so much flak from my workmates that I was ready to quit. They didn't understand why I would need time off at a moment's notice sometimes."*

In some situations, carers may experience financial difficulty and hardship as a result of:

- inability to maintain full-time employment
- ongoing medical expenses
- helping to meet the financial commitments of the person who is unwell.

*"I've been backing my daughter financially because she can't work and I've been paying whatever to get her by. She does budget, but I have to help her get by on a very regular basis."*

*"All our married life, the responsibility has always been on me and I've had to make all the decisions. He could never cope with money and he could never cope with the bills – that would send him into a spin. All our life, I've dealt with the financials of our life."*

Relationships may become one-sided because people with depression are sometimes so focused on their own problems that they may have nothing left to give a relationship.

*“I love my husband, we’ve been married for many years, but these things are playing havoc on our marriage.”*

If your relationship has changed, remember that this is mainly due to the person’s illness. If the person gets the right treatment and recovers, then your relationship has a chance of returning to what it was before the person became ill. You may move to a new stage of your relationship.

## Parents

Parents of children with depression or anxiety often feel responsible. They think that they may have contributed to this in some way.

*“I thought ‘oh God – what have I done?’”*

*“You do think nature/nurture. Was it their environment, how much is it nature and how much was it you?”*

This can be compounded by parents feeling blamed when they sense underlying questions from friends or other family members about their children’s behaviour, their parenting skills, or the amount of love and support they give to their child.

*“Other people can be critical of not only the way you are supporting them, but the fact that you are continually supporting them.”*

It’s important to try to work out what is *being protective* and what is *reasonable care*.

*“You always have that struggle within yourself, but then when other people are critical rather than giving helpful suggestions or support, this doesn’t make it any easier.”*

Parents often mention the challenge of balancing the need to support their children without becoming over-protective and making them totally dependent. This dependency could prevent the child from developing personal coping or management strategies which could potentially delay her/his recovery. Remember, many parents grapple with deciding when to be there and when to step away.

*“At the end of the day, you have to do what is right for you – but it is really hard. You are trying not to make them dependent, but you are trying to be empathetic, supportive and feel very protective at the same time. No matter what other people think, you just have to do what is right for your family.”*

*“You doubt yourself. On the one hand, you are thinking ‘you should be harder on her’, but then am I expecting too much?”*

*“It’s a fine balance between giving them a gentle push, without pushing them over the edge.”*

Balancing parenting and caring is further complicated when there are other children in the family. It’s difficult trying to treat all children equally and trying not to focus solely on the child with the illness. You may have to manage feelings of resentment that siblings may experience when the unwell child is seen to be given special treatment.

*“My son (not the one with the illness) said to me one day, ‘I can’t do this any longer.’ He’s fifteen. You sort of try and explain it, smooth things and make it right to keep the family sort of functioning in a dysfunctional way.”*

*“His younger brother just didn’t understand, and he was amazing with his coping skill because he tended to move away and he actually said ‘I hate my brother, I hate him, why does he do this?’ I suppose he sees him upsetting the whole family, sees him demanding ‘this has to be done this way’ and says ‘I’m not going anywhere until it’s done this way’, and that holds everybody up.”*

It can be particularly important to discuss the situation openly within the family, educating everyone about the condition and the importance of each person having a role in supporting the person with the illness (and each other) at this time.



## Children

Children of a parent with a mental illness may find they have additional responsibilities around the home or in supporting their parent in their home. They may become resentful at having to do extra things to ensure the household runs smoothly, especially when they're taking on tasks that are beyond their years.

Children may also feel embarrassed or awkward about the illness or their parent's behaviour and be unsure about how to tell others or invite them into their life or home. One of the main concerns for children is whether they too will develop the disorder, although they may not mention this, discuss it openly, or even want to acknowledge it.

*"I realised something was up with Dad – the fact that he wasn't like other people's fathers and so forth... certainly the tendency to not want to socialise – so it would really take an effort for either myself or my mother to motivate him enough to interact with other people, go out – even socialise just as friends."*

*"I wish my mum was like other mums."*

## Siblings

Siblings of children with a mental illness such as depression may worry that they too will become unwell – 'Will this happen to me too?' They may feel embarrassed and self-conscious about their sibling's situation and withdraw from the family and their sibling, particularly in school or social situations. As well, they may feel frightened of triggering behaviour in their sibling and resentful of the attention he/she receives because she/he is unwell or unhappy.

*"It's just awful, absolutely awful. You want your children to get along and you think how are they ever going to be close? And they've only got each other. They've only got one brother each, and you want them to get along."*

## Partners

Providing ongoing care and support can be particularly draining and tiring for a partner. The mental illness, increased tension, decreased communication and reduced intimacy all combine to change the relationship significantly.

In particular, carers describe a sense of loss when the level of intimacy, both emotional and physical, is reduced or has disappeared. This loss of intimacy may be attributed to a range of things. For example, the illness itself may impact on the person's self-esteem and confidence, with the person needing to withdraw from others. Alternatively, there may be side-effects from medications which impact on libido.

As a result, over time, the relationship dynamics may change significantly, and many carers say that they feel a sense of grief and loss that they no longer have the relationship with their partner that they once did.

*"I also have some grief in the sense that I missed out on a normal marriage. I'm more his mother than his wife. I'm the carer. There's affection, but there's no physical side to our marriage, it finished about three months after we got married."*

*"There are times I've said to her what was a labour of love has become just labour... So I suppose in some ways it's become more a brother/sister relationship than anything else, but I've become a carer more than a husband."*

Many people who care for a partner with a mental illness struggle most at times when the burden of care becomes overwhelming, leading some to consider leaving the relationship. This in turn leads to the carer experiencing strong feelings of guilt for considering abandoning her/his partner in her/his time of need.

*"I couldn't describe my marriage as a happy-go-lucky sort of marriage. I suppose you hear about all these people who the partner has left, they couldn't cope with it. That crossed my mind I don't know how many times. I did stay with it because of the kids in the early days, I stuck it out. And it's just gone on. One day becomes a week and another week becomes a month and a month becomes a year and the years just roll on, and that's the way it's been. And it's not been a happy time, because of all the things that have happened and you've got to go through and be put through and so forth... there's affection of course between us, always has been, I don't know. When you marry it's not a bed of roses all your life. People say you have to work at marriage, well, Jesus, I work at it."*

It's important that you try to relieve the burden by drawing on other avenues of support and give yourself some time out. This will not only provide the opportunity to relax, but you'll be able to take a step back and review the relationship and the situation. Individual and/or couples counselling may also help provide support, reassurance and strategies to cope with difficulties.

## Friends

Friends who take on a caring role may struggle to find the right balance in their relationship and they may worry about over-stepping the mark. There's a fine line between being intrusive and being supportive. It can be difficult to maintain the friendship and, at the same time, urge the person to access help/treatment. The person who's not well may resent what they see as interference and the change in the balance of the friendship.

Friends may worry about upsetting the person for whom they care, causing the person to withdraw from the friendship and isolate her/himself even further. It can also be difficult when only one person in the friendship group is aware of the problem and can't share it with others

Try to maintain an open dialogue with the person and encourage her/him to develop other supports and strategies. While you may feel privileged that your friend has opened up to you and is seeking your support, it can be difficult if she/he becomes reliant solely on you. Therefore, it's important to encourage the person to seek treatment and support elsewhere e.g. from friends, family members and/or support groups.

## Finding the right balance

One of the big challenges for carers and family members is the issue of accommodating the person's illness, her/his behaviour and needs, and the impact this has on family life.

Family dynamics may change because you're being protective and trying to reduce the stress on the person for whom you care, trying to minimise the impact on others and trying to keep things under control. Sometimes, because you adapt so much to the changes in your life, you begin to see the situation almost as a new kind of normal.

With changes at home, your behaviour alters and your quality of life is affected because you've been trying to make life easier for the person.

*"I wouldn't like to leave him unattended for too long if I can avoid it... I don't go anywhere during the week."*

Many carers describe this as 'walking on egg shells'. Remember that you also have needs and at some point, you may have to put those needs first.

Sometimes, you may need to take control of the situation – offering suggestions about options and making arrangements on the person's behalf. You may need to be assertive. The person with the illness may be self-focused and may lack the initiative or desire to connect with the outside world.

Many carers say it's important to access professional help to assist them in the caring role and to provide strategies and reassurance.

*"The only way I could get the balance right was with the direction of a psychologist who helped me learn what I needed to know, and when and how to respond to different situations."*



The impact of caring for a person with a mental health problem is, in many ways, similar to other caring or support roles, with many carers describing it as 'relentless'. The intensity of any caring role may vary depending on whether you live with the person, the extent of your experience, the severity of the condition, and access to treatment and other means of support.

*"It's hard to live like that and give up all your own life and your expectations of what you're going to do with your life to care for somebody else."*

*"I want a break from thinking about it all the time."*

## **Caring for a person with a mental health problem compared to a physical health problem**

When you care for a person with a *mental* health problem, it's different from caring for a person with a *physical* health problem. Many people simply don't understand that depression is an illness nor do they understand the intensity or the ongoing nature of the carer's role.

Carers may feel isolated due to the lack of understanding about depression and the associated stigma, not only in their community, but often among their own families and friends.

Carers of people with a mental health problem such as depression/anxiety may face difficulties which carers of people with other health problems may not face. For example, the person with depression/anxiety may not want to get help. This may be due to denial, pride, fear or embarrassment – feelings which may not be as common with many physical illnesses. Many carers support people with both physical and mental health problems, which can be especially challenging. It's important that all health problems are recognised and treated.

Carers may also live with the person's extreme behaviour (associated with the mental health problem). This may include for example, rituals associated with Obsessive Compulsive Disorder (OCD), periods of elevated mood associated with bipolar disorder and periods of low mood and withdrawal associated with depression. This behaviour isolates the person with the illness and the carer too.

## **Hope**

For many carers, fear, concern and worry are always present, even when they're not with the person for whom they care. They may wake thinking about the person and even when their thoughts are occupied and they're busy, the person is always in the back of their minds. They wonder how he/she is. They hope he/she is OK and safe. They want the best for the person and hope he/she will be able to recover and return to his/her former self.

*"It has taken me eleven years to get hope back...it has been an evolution."*

And it is important that you do have hope.

On the not-so-good days, when hope is missing, carers should remember that in most cases depression, anxiety and related mental health problems are treatable or manageable.

Hope may be drawn from small achievements like when the person for whom you care attends a doctor's appointment, gets out of bed or sees a friend. Even though these are small achievements, nevertheless, they are achievements. You will learn to appreciate them in whatever form they come, the good days and the good moments, the hugs and the smiles – all of which happen day by day.



## Don't be too hard on yourself

Many carers are hard on themselves. They worry that they aren't doing enough and that they should be doing more for the person for whom they care. They may feel that some of the person's mental health problems are their fault:

- "It's genetics."
- "It's my parenting."
- "I haven't been a good friend or partner."

Carers may internalise these issues because they can't make sense of why there is a problem and they may blame themselves. Remember **this is not your fault**. It's nobody's fault.

Try to refocus your 'self-talk' and make it more positive. Remind yourself that you're doing the very best you can and although you may not have all the answers, it doesn't mean you're doing the wrong thing by the person for whom you care. Remember, you didn't make the person unwell or cause the person's mental health problems. You want what is best for the person, even on the days when you feel extremely frustrated. When the person is angry and resentful towards you, remember that when he/she can see more clearly, he/she will understand and appreciate that you are there.

Often, carers of people with a mental illness say it's important to set boundaries. This may mean you need to protect yourself by not looking too far forward and take each day as it comes.

*"At some point, it has got to be about you and about having a life for yourself some times."*

*"One of the hardest things to do...is to step back from being a carer and resume being what you were before this thing happened."*

*"I have to try and step back and say, I am no longer your carer, I am your husband again."*

It may mean you need to plan and take breaks. Make time for exercise, relaxation, dinner with friends and time for your interests. Continue the activities you enjoy, maintain a life of your own and look after yourself. It's important that you're not hard on yourself and that you give yourself a break.

*"I don't go away on holidays as much as I should...for the marriage it's better, and yet I've got this guilt."*

*"One of the best ways to look after somebody else is to look after yourself first."*

## Being self-aware

Another way of taking care of yourself is to recognise when you need more help and seek support. Monitor what you're thinking and how you're feeling. Be aware of self-talk, notice if you're experiencing more frequent headaches, tightness in your muscles, lack of sleep and poor concentration.

Knowing how to take care of yourself and where to get help will benefit you. Below are some suggestions:

- find out about local counsellors
- use your Employee Assistance Program in your workplace if it's available
- book in for a massage
- exercise at your local pool or leisure centre
- walk regularly in surroundings you enjoy.

To give yourself a break and relieve some tension, do whatever works best for you. It will also help to ensure that you get enough sleep, eat nutritious and well-balanced meals, exercise regularly and maintain your friendships and interests.

*"I'm fairly calm. It takes a fair bit to get me going, but there have been occasions where I've lost it I suppose... it just builds up inside of you. I suppose the only way I can cope with it is just by closing it off. Instead of exploding, I close it off."*

*"And I've kind of run out of adrenalin.... I'm not sure if I'll be able to carry on forever."*

*"In some ways, I am not allowed to be stressed or depressed or sick, because that makes him anxious...and then you get in trouble for not being well or depressed. Sometimes, you pretend...you try to cover. There's a real panic that there's something wrong with the rock."*



So much of your role as a carer is about supporting the person with the mental health problem. You've helped the person to see a GP. You've supported the person when treatment has been started – whether it's medication or a combination of treatments or another form of therapy. Your thoughts, conversations, lifestyle, worries, lack of sleep, frustrations, efforts and energy have mainly been directed towards the person for whom you care. You've tried to make sure the person has the right support to reach recovery – but what support is there for you? And what support is right for you?

## Your privacy

Many people prefer to maintain their privacy and keep to themselves when dealing with mental illness. However, it's important that this does not prevent you seeking support for yourself.

If you're struggling to support a person, don't think you're betraying a confidence because you talk to someone in order to get support for yourself. There is only so much you can do for other people if you're not physically and mentally well yourself.

## Informal support networks

Some carers say they prefer to rely on their informal support networks including family and friends. They know the carer and if he/she's been open with them, they'll know the situation. There can be problems with relying on informal support. There may be times when a carer needs constructive and challenging points of view to help move through a rough patch. Carers may need an independent sounding board – someone with whom they can be truly honest, rather than containing some of their thoughts, particularly if they are building resentment or thinking of leaving a relationship.

## Counselling

Other carers have found individual counselling to be helpful because it gives them time to debrief, uninterrupted. They see it as constructive and a safe place to voice all of their worries, fears, grievances and frustrations.

*"I needed the help as a carer, not anything to do with my husband. It was just that I needed somewhere to go for support for me."*

## Support groups

When it comes to support groups, there is a range of groups and it's not one-size-fits-all.

Talking to people who are in a similar situation may be helpful in gaining support, but it also normalises all that is happening in your life. You may like to attend a support group especially for carers. You may continue to attend the group regularly for as long as it meets your needs and you find it helpful. The advantage of support groups is that people will know what you're going through because they have been there and you won't have to explain what's happening. You are much less likely to be judged by people who understand your experiences. Even if you don't attend the group for a long time, you may meet people whom you can continue to see as an independent support-base outside the group.

You can visit your local Community Health Centre, Community Centre or Neighbourhood House to find out about support groups or activities near you.

*"I found the biggest help is to talk to somebody else and you hear them talking and you hear them say I can relate to that, or you know that someone understands what they're talking about. Someone can be sympathetic, but if someone actually knows what you're talking about, that's the big thing...because nothing else is going to change."*

There is a range of support groups but not all groups will suit everyone. It's important to find a group with a structure in which you feel comfortable. Some carers say that the most important thing to look for in a support group is a positive, forward-looking attitude and perspective.

*"I have made some of my best friends and supports through support groups. They truly understand not only what you are going through at the time, but even when things are back on track they are still with you."*

## What will work for you

It's a good idea to think about what you find helpful and what will work for you. To help you decide, talk to your GP and discuss the options. Some carers find support groups very helpful because they hear how other people manage, learn strategies and tips – whereas others find this overwhelming. Rather than participating in a group, you may prefer to talk to one person on an ongoing basis – so individual counselling may be your best option. Some people find comfort in spiritual support and counselling. Remember, not every option works for everyone, so you need to choose what is best for you.





A wide range of *beyondblue* depression-related information resources is available free of charge to print or order at the *beyondblue* website [www.beyondblue.org.au](http://www.beyondblue.org.au) (click [Get information](#), then [Downloadable beyondblue information resources](#) or [Order beyondblue resources](#)). These include:\*

## General depression information

- Understanding depression (fact sheet)
- Depression symptom checklist
- What causes depression (fact sheet 3)
- DVD – *Stories of Hope and Recovery* (interviews with *beyondblue*'s Ambassadors)
- DVD – *Don't beat about the Bush!* – Depression in rural areas

## Family and friends

- How can you help someone with depression? (fact sheet 1)
- Living with and caring for a person with depression (fact sheet 2)
- *Taking care of yourself and your family* – book by John Ashfield (reproduced with support from *beyondblue*)
- Practical ways to help someone with depression (information card)
- *Taking care of yourself and your family after retrenchment or financial loss* (booklet)
- Antidepressants for the treatment of depression in children and adolescents (fact sheet for parents and carers)
- DVD – *Carers' Stories of Hope and Recovery*

## Treatment

- Types of help available (fact sheet 4)
- Changing your thinking – Cognitive Behaviour Therapy (fact sheet 10)
- Antidepressant medication (fact sheet 11)
- Help for depression, anxiety and related disorders under Medicare (fact sheet 24)
- *What Works for Depression – A comprehensive review of all known treatments for depression, including medical, psychological, complementary and lifestyle interventions*

## Recovery

- Reducing stress (fact sheet 6)
- Sleeping well (fact sheet 7)
- Keeping active (fact sheet 8)
- Recovery (fact sheet 15)
- Healthy eating for people with depression, anxiety and related disorders (fact sheet 30)

## Related disorders

- Anxiety disorders (fact sheet 21)
  - Post-Traumatic Stress Disorder (fact sheet 31)
  - Generalised Anxiety Disorder (fact sheet 35)
  - Panic Disorder (fact sheet 36)
  - Obsessive Compulsive Disorder (fact sheet 37)
  - Specific Phobias (fact sheet 38)
  - Social Phobia (fact sheet 39)

- Bipolar disorder (fact sheet 16)
- Postnatal depression (fact sheet 22)
- Reducing alcohol and other drugs (including smoking) (fact sheet 9)
- Eating disorders and depression (fact sheet 42)

## Depression and chronic illness

- Chronic physical illness and depression (fact sheet 23)
- Depression and coronary heart disease (fact sheet 18)
- Depression and diabetes (fact sheet 19)
- Depression after stroke (fact sheet 20)
- Depression and dementia (fact sheet 25)
- Depression and asthma (fact sheet 26)
- Depression and arthritis (fact sheet 27)
- Depression and Parkinson's disease (fact sheet 32)
- Depression and breast cancer (fact sheet)
- Prostate cancer and depression/anxiety (fact sheet 34)
- Depression and incontinence (fact sheet 41)
- Anxiety disorders and depression in men with testicular cancer (fact sheet 43)

## Depression and life stages or events

- *Emotional health during pregnancy and early parenthood* (booklet, including helpline cards for each state/territory)
- *Maintaining your well-being: Information on depression and anxiety for men with prostate cancer and their partners* (booklet produced by *beyondblue* in association with the Prostate Cancer Foundation of Australia).
- Grief, loss and depression (fact sheet 28)
- Separated parents and tough times (fact sheet 29)
- Depression in older people (fact sheet 17)
- *Men and Separation: Navigating the Future* (booklet)
- *Looking after yourself after a disaster* (booklet)

## Depression and population groups

- Depression in men (fact sheet 12)
- Depression in Women (fact sheet 13)
- Depression in people who are deaf or hard of hearing (fact sheet 33)
- Depression and anxiety in people who are gay, lesbian, bisexual, transgender or intersex (GLBTI) (fact sheet 40)
- *Older people and depression* (booklet)

## beyondblue Research

- Research Book 2001-2007 (contains information on all *beyondblue*'s completed research projects)
- Results of all *beyondblue*'s research projects are available at [www.beyondblue.org.au](http://www.beyondblue.org.au) – click [Research](#)

All *beyondblue*'s fact sheets and information resources can be ordered free of charge at [www.beyondblue.org.au](http://www.beyondblue.org.au) or by calling the *beyondblue* info line **1300 22 4636**. Fact sheets are available in more than 20 languages, as well as Braille and audio CD formats.





## **beyondblue: the national depression initiative**

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

beyondblue info line **1300 22 4636** (local call cost)

Information on depression, anxiety and related disorders, available treatments and how to help someone

[www.youthbeyondblue.com](http://www.youthbeyondblue.com)

beyondblue's website for young people – information on depression, anxiety and where to get help.

## **Lifeline**

**13 11 14**

24 hour crisis support, information and referral (local call cost)

## **Suicide Call Back Service**

**1300 659 467**

Telephone support service for those at risk of suicide, their carers and those bereaved by suicide.

## **MensLine Australia**

**1300 78 99 78** or [www.menslineaus.org.au](http://www.menslineaus.org.au)

24 hour professional counselling for men with family and relationship problems (local call cost)

## **Kids Helpline**

**1800 55 1800**

Counselling for children and young people aged between 5 and 25.

## **Post and Antenatal Depression Association (PaNDa)**

**1300 726 306**

Support and referral to anyone affected by post and antenatal depression, including partners and extended family

## **Relationships Australia**

**1300 364 277** or [www.relationships.com.au](http://www.relationships.com.au)

Relationships support and counselling

## **ORGANISATIONS FOR CARERS INCLUDE:**

### **ARAFMI**

Association for Relatives and Friends of the Mentally Ill (ARAFMI) offers a range of services for carers of people experiencing mental illness. These include support groups, information materials, a library, telephone and home-based outreach support.

- **New South Wales**

[www.arafmi.org](http://www.arafmi.org)

Sydney **02 9332 0700**

NSW country areas – Toll free **1800 655 198**

- **Northern Territory**

[www.mentalhealthcarersnt.org](http://www.mentalhealthcarersnt.org)

**08 8948 1051**

- **Tasmania**

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

Northern Branch and Head Office **03 6331 4486**

Southern Branch **03 6228 7448**

- **Queensland**

[www.arafmiqld.org](http://www.arafmiqld.org)

**07 3254 1881**

- **Victoria**

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

**03 9810 9300**

- **Western Australia**

[www.arafmi.asn.au](http://www.arafmi.asn.au)

**08 9427 7100**

Rural freecall **1800 811 747**

### **COPMI**

Children of Parents with a Mental Illness (COPMI) provides resources for workers, parents and young people.

[www.copmi.net.au](http://www.copmi.net.au)



## CARERS AUSTRALIA

[www.carersaustralia.com.au](http://www.carersaustralia.com.au)

Carers Australia is a not-for-profit organisation dedicated to improving the lives of carers. Carers Australia is the national, peak carer organisation with eight member organisations – the Carers Associations in each state and territory.

Carers Australia works to promote the important role of carers in our community and to assist them with better information and resources. Together they provide important services like carer counselling, advice, advocacy and education and training.

To find the latest information on services and events, go to [www.carersaustralia.com.au](http://www.carersaustralia.com.au) and click on your state or territory:

- Carers NSW
- Carers Victoria
- Carers Queensland
- Carers WA
- Carers SA
- Carers Tasmania
- Carers NT
- Carers ACT

### Carer Advisory and Counselling Service

For family carer support and counselling you can contact your state or territory Carers Association on **1800 242 636** (free call from landlines)

## Commonwealth Respite and Carelink Centres

Commonwealth Respite and Carelink Centres support carers to access respite or 'take a break'. The Centres can:

- provide information and advice about respite options
- help organise emergency or planned respite
- purchase or subsidise short term or emergency respite when needed.

Call **1800 052 222** to find your nearest Respite and Carelink Centre.

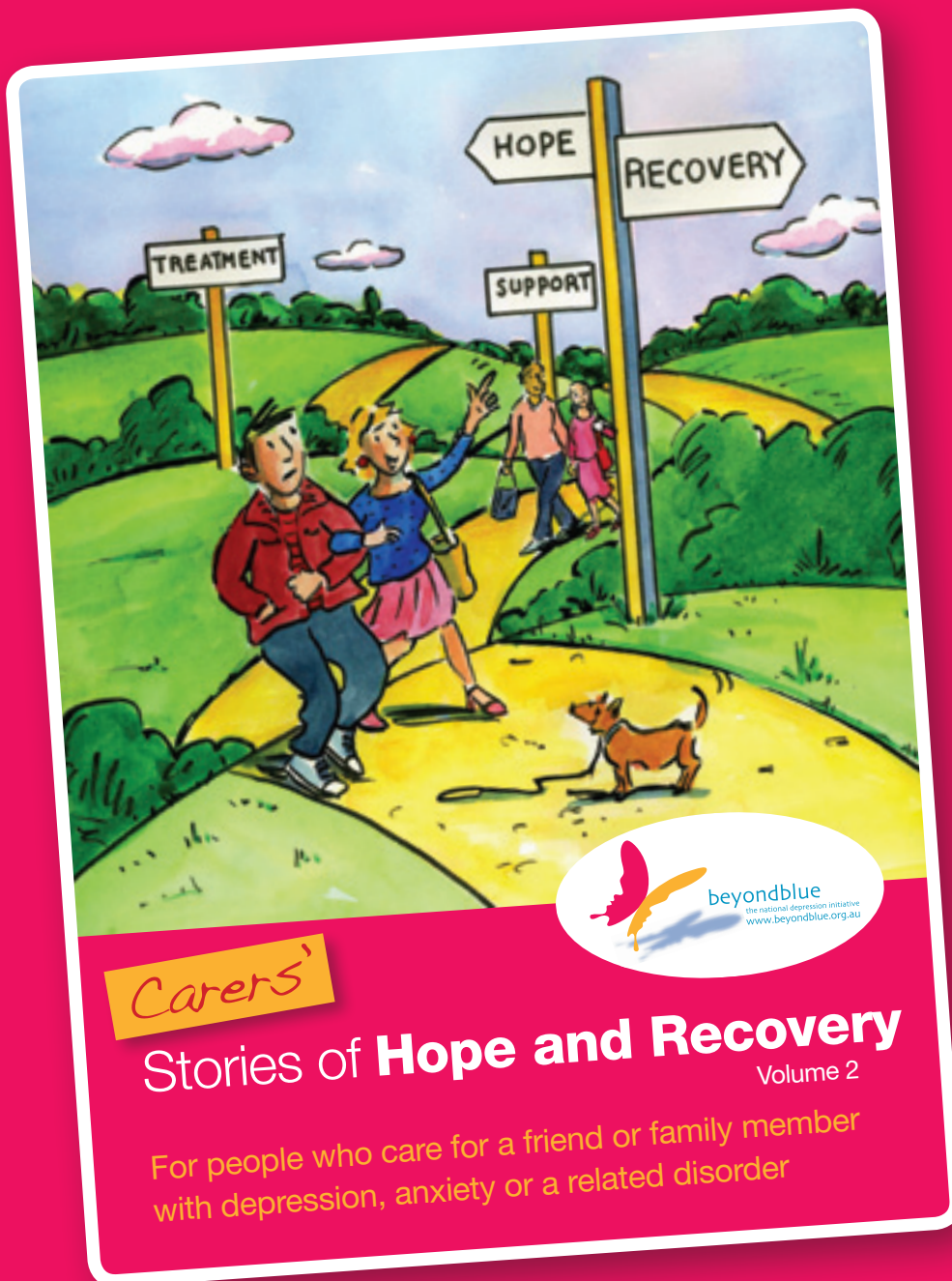
*beyondblue* acknowledges the valuable contribution made to the development of this *Guide for Carers* by Carers Victoria in particular, and carers from around Australia.



## Mental Illness Fellowship of Australia

**1800 985 944** or [www.mifellowshipaustralia.org.au](http://www.mifellowshipaustralia.org.au)

The Mental Illness Fellowship of Australia is a membership based, non-government organisation which has branches in every state and territory. All affiliates provide a range of services to carers of a person with mental illness including information, education (through programs such as Wellways), advocacy and support. All members have a telephone information and support service and some members provide telephone outreach and carer respite services.



**Carers' Stories of Hope and Recovery DVD** – personal accounts of caring for a family member or friend with depression, anxiety or a related disorder. This free DVD can be obtained from the *beyondblue* website [www.beyondblue.org.au](http://www.beyondblue.org.au) or from the *beyondblue* info line **1300 22 4636**.

For an up-to-date list of resources, please visit [www.beyondblue.org.au](http://www.beyondblue.org.au) or call the ***beyondblue* info line on 1300 22 4636**



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