

### This tool kit provides information about:

The impact of being a carer

Strategies for supporting and sustaining yourself as a carer

Positive ways to help and support a person living with a mental illness

Carer's rights and entitlements

Where to go for help

### What does it mean to be a carer of someone with a mental illness?

One in five Australians will experience an episode of mental illness in their lifetime.

In many of these situations their friends and relatives will care for them on a daily basis, whether this is for a brief period of recovery or over the long term.

Carers need support and information to help sustain them in this role.

When someone you know is diagnosed with a mental illness it can be confusing and distressing. Many people are disbelieving and feel deeply concerned for the future. As someone close to the person who is diagnosed, you might ask yourself: Why did this happen? Could I have helped prevent it? What should I do now? As time goes on you may struggle with conflicting feelings and concerns about how to keep providing care. It is important to know this is normal and that common emotional reactions may include:



- **Guilt:** Many people struggle to find a reason for the illness and wonder if they are in some way responsible. It is natural to ask 'why?' but remember, mental illness can happen to anyone and no one is to blame. You may also feel you do not want to be a carer, or think you are not up to the task.
- **Shame:** Mental illness is highly stigmatised so you may feel embarrassed and anxious about what other people may think.
- **Fear:** You are likely to worry about what will happen to the person if you can't cope or when you are not available to help. Fears about future or current risks are normal.
- **Anger/frustration:** You may feel frustrated or angry that this has happened; that the illness dominates your life; that others don't do more; and you sometimes feel unappreciated or taken-for-granted.
- **Grief and sadness:** You may grieve for the loss of the relationship as it was and the life you had. You may feel sad that opportunities and plans for both yourself and your friend, partner or relative have now changed. Your world has shifted and it can be hard to adjust.
- **Love:** Many carers say that their love for their friend, partner or relative deepens and they develop a closer bond over time.
- **Fulfilment:** The new relationship you form with your loved-one can bring growth and learning for you both. Sometimes the illness pushes and motivates you to find parts of yourselves you had not yet tapped into and this can be a valuable experience for self growth.

Your feelings and motivations will fluctuate over time. Along with the joy and relief that comes with supporting recovery and successful management of the illness, there can be cycles of despair and exhaustion. You may experience impacts on your own health and wellbeing or there may be financial and lifestyle implications. Being a carer is a complex and demanding role that is focused on enabling the person you love to be as independent and fulfilled as possible whilst not losing sight of your own independence and fulfilment. It is a hugely valuable and important role and you cannot do it alone.

## How can I be well equipped for my role as a carer?

A carer's job requires a number of skills, some of which include practical, emotional and intellectual skills.



The following key strategies will support the requirements of being a carer:

## 1 Share the task

Seek moral and emotional support as well as practical assistance. Don't be afraid to ask for help from friends and family and chase up professional assistance or input from other carers in a similar position. Formal support from carer's groups or professional counsellors can sometimes provide the boost you need when things feel hard. Access the resources listed in this tool kit to find out what is available to you.

## 2 Be well informed

Learn about the specific diagnosis and the system of treatment and care that is available. Mental illness is a broad term used to describe many conditions including mood and anxiety disorders, personality disorders and psychotic disorders such as bipolar disorder or schizophrenia. Each condition has specific effects and treatments.

## 3 Gain new skills

You can access programs to learn specific skills for a range of situations such as: communicating with your loved one when they are unwell; responding to crisis situations such as psychotic episodes or suicidal thoughts; asserting your own feelings and needs; negotiating and advocating with professionals. At different stages of caring there may be different tasks and skills required.

## 4 Make a regular practice of self care

To be an effective carer you need to balance the health and wellbeing of the person you are caring for, with your own sense of wellness and fulfilment. You need time and space to look after yourself. Make sure you find opportunities to relax, have fun and take time out when you need it. Exercise and sleep are also critical.

### Ask yourself:

- Do I get enough breaks from caring?
- Have I got regular times for relaxation?
- Am I getting regular exercise?
- Am I eating nutritious meals?
- Do I get enough sleep?
- Do I have someone I trust to talk to?

## 5 Be an assertive participant in the team of carers

You are a key person who is aware of your loved-one's daily experience of the illness and can understand this more than anyone else. This means that along with the person them self, you have significant knowledge and understanding of the illness and how treatments are working. As a result you are a legitimate member of the treatment and care team and you can advocate and contribute to the overall plan. Contact the mental illness specialists involved and other support services to participate in planning and sharing appropriate information.

## What can I do to best help the person I am caring for?

Below are some general principles that will support you to be most effective in your caring role.

More detailed information on responding to people with a mental illness can be accessed via the organisations listed at the end of this tool kit.

- Understand that they need time and support to process what is happening to them. They may not have insight into their illness or information about how it can affect them. Be patient and non-judgemental while helping them learn.
- Remember the person is not defined by their illness. Help the person to notice and address the effects of the illness and encourage the expression of their individuality, separate from the illness.
- Show your appreciation of the hardship they experience as a result of the illness and respect them for the skills and capacities they have in dealing with it. Express optimism for recovery and wellbeing.
- Understand the side-effects of medications or treatments and help the person take account of these.
- Do not be afraid to talk about your own feelings and the effects on you of the person's behaviour as a result of the illness, using a calm and non-confrontational approach. A good relationship requires open, respectful communication and this is no different when mental illness is an issue.
- Notice when the intensity of your caring needs to increase or when you should take a step back to support independence. This is a hard call sometimes and seeking advice from the professionals involved, as well as talking it through with the person them self is important.
- Make sure you have regular respite despite feelings of guilt or fear. You will be a calmer more effective carer as a result.

## What are my rights and entitlements?

As a person closely involved in the care of a person with a mental illness there are a range of things you can access for support and to make sure you have a say in their treatment.

- Education and advice from mental health professionals and from carer organisations about the illness and being a carer.
- Information about the specific treatment plan being put in place in order that your care can contribute effectively to overall recovery.
- Respite – both planned and emergency respite may be available
- Peer support – there is a network of general carer support organisations as well as specific mental illness carer and peer support services
- Employment rights – if you are also in paid work your employer may provide flexible arrangements and extra carers leave under an award or agreement. There are antidiscrimination laws to prevent your employer treating you badly as a result of carer responsibilities.
- Carer allowance and other payments – you may be eligible for financial assistance through Centrelink
- Professional counselling to support your psychological wellbeing is sometimes available free or at low cost through your GP or other local networks
- Independent legal decisions about treatment, care and legal powers of attorney or guardianship can be made through the office of the Public Guardian in your state or territory.





## Places to go for help and advice about your rights:

- **Lifeline**  
[www.lifeline.org.au](http://www.lifeline.org.au)  
13 11 14 (24hrs)
- **Mental Illness Fellowship of Australia**  
[www.mifa.org.au/](http://www.mifa.org.au/)  
National helpline: 1800 985 944
- **SANE Australia**  
[www.sane.org/](http://www.sane.org/)  
1800 18 SANE (7263)
- **Carers Australia**  
[national.carersaustralia.com.au/](http://national.carersaustralia.com.au/)  
1800 242 636
- **National Carer Counselling Program**  
1800 242 636
- **Multicultural Mental Health Australia**  
[www.mmha.org.au](http://www.mmha.org.au)  
(02) 9840 3333
- **ARAFMI Australia**  
[www.arafmiaustralia.asn.au/](http://www.arafmiaustralia.asn.au/)  
  
Support and advocacy for friends and family of people with mental illness
- **Commonwealth Respite and Carelink Centres**  
[www9.health.gov.au/ccsd/](http://www9.health.gov.au/ccsd/)  
1800 052 222
- **Centrelink**  
Centrelink information for carers: 13 27 17

## Acknowledgements:



### Part of your Community

Prime Super is the proud sponsor of the Lifeline Information Service – your mental health and self-help resource.

Prime Super is Australian's only nationally operating super fund dedicated to rural and regional Australia.

For more information on Prime Super, please call 1800 675 839 or visit their website [www.primesuper.com.au](http://www.primesuper.com.au)

Lifeline and Prime Super are working in partnership to promote mental health awareness, help-seeking and suicide prevention.



For 24 hour telephone crisis support call 13 11 14  
For more information visit [www.lifeline.org.au](http://www.lifeline.org.au)  
To donate call 1800 800 768

This Tool Kit has been produced by the Lifeline Information Service as a public service. You are welcome to reproduce it without alteration and with acknowledgement of Lifeline. We invite your feedback and comments at [infoservice@lifeline.org.au](mailto:infoservice@lifeline.org.au)

The assistance of Jen Hamer in producing this tool kit is gratefully acknowledged.

*Last revised November 2010*