

TOOL KIT Carers of people with mental illness

A self-help resource to help people living with mental illness

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. 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:** Carers may feel that their love for their friend, partner or relative deepens and they develop a closer bond over time. However, this may not always be the case. Being a carer is a complex and demanding role and there may be many conflicting feelings involved.
- **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. However, this may not always be the case. You should allow yourself to feel whatever it is you are feeling without guilt or judgement.



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?

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 have significant knowledge and understanding of your loved one's illness and how treatments are working. This makes you 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 find out how you can gain new skills (eg. you could take a Mental Health First Aid course) and to find out how to participate in planning and sharing appropriate information.

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. Prioritise nutrition, exercise and sleep and make sure you have someone to talk to.

5 Stay connected

Try not to let your concerns for the other person dominate your life. Make sure you maintain your relationships with other people and develop new social contacts. The continued involvement of family and friends is very important.

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.

- Be patient and non-judgemental while helping them process and learn about their mental illness
- 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
- Notice when the intensity of your caring needs to increase or when you should take a step back to support independence. Seek advice from professionals if needed and talk to the person themselves
- 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?

There are a range of resources 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 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 carer's 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 for 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 or 13 11 14 (24hrs)
- Mental Illness Fellowship of Australia: www.mifa.org.au/ or 1800 985 944
- SANE Australia www.sane.org/ or 1800 18 SANE (7263)
- Carers Australia: <http://www.carersaustralia.com.au/> or 1800 242 636
- Multicultural Mental Health Australia: www.mmha.org.au or (02) 6285 3100

For 24 hour telephone crisis support call 13 11 14. For more information visit www.lifeline.org.au

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