

Carer's Guide



Carers & friends of a loved one with a mental illness

This guide has been developed to assist carers by providing information on:

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What is mental illness?

Mental illness affects around 20 per cent of Australians at some stage of their lives. Mental illness is a broad term used to describe a range of conditions including mood, anxiety, psychosis and personality disorders. These illnesses can affect every part of your loved one's life including their work, relationships and leisure time.

Because mental illness is so common, there are many people in the community who are in a similar situation to you and your family and friends.

There are many myths about mental illness and what you have heard may not be true, so it is important to find out the facts. The prospect of caring for your loved one may be daunting; however it can also be an extremely rewarding role.

Understanding mental illness

Mental illness, like physical illness, is manageable and treatable. Learning about the mental illness affecting your loved one may ease your fears about the unknown or unfamiliar. It is important for both you and your loved one to find out about the features and symptoms of the illness and treatment options and medications.

Treatment options

Treatment options for mental illness may include medication, mental health therapies, self-help approaches and education. With each of these treatments, make sure you understand what is being offered and how it will help. Combinations of these treatments may be the best approach.

The effects of mental illness on different family members

Having a loved one with a mental illness can affect family members in different ways:

- **Parents and spouses** can have feelings of fear, guilt, anger or shame alongside deep feelings of concern for their loved one. There may also be a sense of loss of 'the person that used to be' and alternating periods of hope and disappointment depending on fluctuations in symptoms. It is important to maintain emotional support and encouragement to all family members.
- **Brothers and sisters** can feel a range of emotions including confusion, embarrassment and jealousy of the attention that is being paid to the sibling and possibly even a fear of developing the mental illness themselves.
- **Young children** can find it difficult to understand why a parent, sibling or grandparent is suffering from mental illness, so it is important for them to understand that these conditions are real, like physical illnesses and can be treated. Parents need to be aware of their child's needs, concerns, knowledge and level of experience with mental illness.
- **Teenagers** are generally capable of handling much more specific information than younger children, but they may have already been given misinformation. Teenagers respond best to an open dialogue that includes 'give and take'.



Who is a carer?

In this Guide, the term carer is used to refer to the primary support person for someone with mental illness.

A carer may be the loved one's wife, husband, partner, parent, sibling, child, friend or neighbour.

It doesn't matter how many hours are spent each week providing support.

Carers may live with the person they are caring for, providing assistance with daily needs, or may visit the person regularly.

Carers are people who invest time, energy and support, generally in an unpaid capacity.

In culturally diverse communities, responsibility for the provision of care may involve the entire community.

The steps to becoming a primary carer

At Albert Road Clinic:

Albert Road Clinic is committed to involving carers in treatment programs provided at our hospital. We want to assist your role as a carer through the provision of support, education and information, regardless of whether you are a first-time carer or have been caring for your loved one for some time.

Albert Road Clinic endeavors to identify on admission, or as soon as possible thereafter, a patient's nominated primary carer. This will then be documented on the Nominated Patient Carer form (Appendix 1) which forms part of your loved one's clinical notes and permits nursing and other staff to answer any questions you may have relating to their care.

At Albert Road Clinic a patient's primary carer is someone they feel:

- They can rely on
- Worry about them the most
- Help them the most
- Do odd jobs to assist them in their day to day life
- Comfortable asking for help

To become a primary carer for a loved one you need to ask them to nominate you as their primary carer and to be given full disclosure of any personal information such as their Treatment Recovery Care Plan and progress.

Other steps to enhance your caring role:

- Asking your loved one if you can be involved in their care-planning and discharge preparation.
- Organising a time to meet with your loved one and their doctor or nurse.
- Asking for a program timetable so you become familiar with the routine in the Unit.
- Writing down the patient phone number of the Unit where they will be staying.
- Writing down the visiting hours of the Unit so you know when you can visit.
- Attending a carer support group to learn more about mental illness. Albert Road Clinic offers support groups for parents and siblings of adolescents involved in the Adolescent Service; and family/carers of patients involved in the Addictions Service (see 'Useful resources' at the back of this Guide).
- Contacting carer organisations and asking them to send you information (see 'Useful resources' at the back of this Guide).
- Continuing to look after your own mental and physical health.

Visiting the hospital and speaking with staff can assist you to become familiar with the hospital's day-to-day routines and procedures.

Hospital routines and daily programs are clearly defined and 'free time' can be spent in various ways such as having lunch or dinner together, or giving support during visiting hours.

Going out together can also increase a sense of 'normality' and offers the opportunity for communication more readily than may be the case in the hospital environment. However, before arranging to go out you will need to check with the nursing staff.

First-time carers

The first hospital stay for your loved one can be a time of mixed emotions for carers. Some of these may include:

- Sadness that your loved one is 'so unwell' that they need to be admitted to hospital.
- Guilt that you have not been able to meet their needs at home—perhaps feeling that you have failed them.
- Relief that somebody is going to share the burden of care—but at the same time guilt about feeling that care is a burden.
- Tiredness and perhaps even exhaustion, as your emotional and physical resources may be seriously depleted.

What you will learn from the hospital stay

Some positive things you may derive from your loved one's hospital stay could be:

- Knowing that your loved one will receive expert professional care on a full-time basis and that their needs will be recognised and met promptly.
- Being comfortable in the knowledge that the person you care for is in a safe environment.
- Having an increased understanding about the illness affecting your loved one and perhaps a more accurate diagnosis and appropriate treatment.

Letting go and allowing others to respond to the needs of your loved one can offer a tremendous sense of relief. It can also allow you to meet some of the other needs in your life that may have been neglected due to the intense focus on your loved one.

During this time, allow yourself the opportunity to replenish some of your own reserves. If you have become run down during the lead up to admission to hospital, this can be a good time to focus on regaining your strength to resume care if and when necessary.

A hospital setting can reinforce the knowledge that there are many others in a similar situation.

How hospital staff can assist carers

Albert Road Clinic aims to assist carers by providing the highest possible standard of care and services to your loved one.

Carers are recognised at Albert Road Clinic for their importance and assistance in caring for and supporting loved ones. Working together improves outcomes for loved ones; reduces family and carer anxiety; and, improves the ability and desire of family and other carers to remain supportive.

You and your loved one also have certain rights regarding the nature of the care provided by Albert Road Clinic or any other health care provider. If you feel that something is not right or you would like to make a comment about any aspect of our care and service, please speak with a member of staff/Unit Manager.

If you do not feel comfortable speaking to someone please leave a note in the Feedback box located on each Unit and at Reception. These boxes are checked weekly. You can nominate whom you would like a response from.

Carer's Rights

As a carer you have the right:

- To be recognised as a carer
- To visit during visiting hours or as otherwise arranged
- To information:
 - Information of a personal nature can only be shared with the consent of your loved one
 - Information of a general nature that can be shared is non personal and may include factual information to assist in better understanding mental illness and treatment
- To know how to contact us
- To ask questions
- To have policies and practices explained
- To ask for assistance to source support services
- To be fully engaged in your loved one's care



How carers can assist hospital staff

Albert Road Clinic invites carers to be part of their loved one's Treatment Recovery Care Plan. This plan is developed on admission and sets out the goals and key actions. These plans are routinely reviewed and updated in hospital.

To achieve the best Care Plan if there are things about your loved one, things that you believe that the staff should know (for example certain behaviours and triggers), please inform them. We understand you know your loved one well.

Carers, including family and friends, can assist our staff by respecting the wishes of loved ones and also complying with the hospital's rules affecting patient care and conduct.

Carers are our partners in care in discharge planning

Carers are often the ones that support a loved one following discharge. It is therefore important that staff involve you in planning discharge arrangements to ensure your loved one remains engaged with the health care service and transferring agency.

What to do when you know something is not right – escalating care

The Ramsay Rule for Patient Safety

The Ramsay Rule is about keeping our patients safe by partnering with you in the care of your loved one. Our commitment is to provide excellent care to our patients by focusing on their safety. The Ramsay Rule helps us to do this.

When to Activate the Ramsay Rule

If you are concerned that your loved one is looking unwell, getting worse, or their behaviour is unusual for them.

You know your loved one best. So if you are worried, follow these three simple steps to alert us of your concerns.

How to Activate the Ramsay Rule

Follow these steps to raise your concerns:

- 1. Talk to the Nurse or Doctor regarding your concerns;** and if you are not satisfied that your concerns have been addressed,
- 2. Ask to talk to the Nurse in Charge of the shift;** and if you are still concerned then you or a family member,

- 3. Activate the "Ramsay Rule" by ringing this phone number 0418 557 349.** A Ramsay Rule nurse or doctor will talk to you and arrange a review of your loved one.

What to do following discharge from hospital

Your loved one is encouraged to complete a Wellness Plan (also sometimes referred to as a Crisis Management Plan) in partnership with a member of the clinical staff and nominated carer. The intent of the Wellness Plan is to facilitate your loved one having involvement in their own care, particularly in terms of symptom management, relapse prevention and crisis planning. It serves as a recovery aid and as a prompt and reminder about what to do to support recovery if your loved one is having difficulties (Appendix 2 provides an example).

How carers can take care of themselves

When caring for a friend or relative, the carer's needs often get lost. In order to care for another, you also need to take care and take time out for yourself.

Time for yourself may include taking breaks and recognising your limits. No-one can be a carer every minute of every day. Make sure you go out and continue doing activities you enjoy.

Explore if there is a relative or friend who would be willing to share the role of carer. For a longer break, consider arranging respite care by contacting Respite Victoria for information and advice (see 'Useful resources' at the back of this Guide).

Where to start to self-care?

Developing a practical, positive attitude is always a good place to start. This involves coming to terms with the fact that someone you care for has a mental illness and that this is likely to have a serious emotional impact on you as well as your loved one.

You may be feeling anger at this happening in your family, confusion or a sense of loss and grief at how your loved one has been changed by their illness. It's important to acknowledge and talk about these feelings.

It is also important to develop a sense of balance between:

- Acknowledging the effects of the illness on your loved one and hopes for their recovery.
- Wanting to do things to help your loved one and encouraging them to be independent.
- Showing you care and not being over-involved.
- Giving your loved one your time and having time for yourself and other family members.
- Encouraging your loved one to do things and not being unrealistic and demanding.

Some tips to ease any distress you and/or family members may be feeling:

- Don't be afraid to ask our staff questions about your loved one's mental illness, treatment and our services.
- Accept that symptoms may come and go as well as vary in severity, so your level of support will most likely vary as well.
- Determine the level of care that you can realistically provide and ask our staff if you need referral to external support agencies to ensure continuity of care for your loved one once discharged.
- Talk honestly about your feelings and encourage others in the family to do the same.
- Consider the impact of mental illness on your loved one's ability to make decisions about their ongoing medical care and finances. Seek advice and discuss the options available with your loved one and family members.
- It is important to prepare yourself by learning as much as you can about the illness and its treatment. However, you cannot make your loved one behave in a certain way (i.e. taking their medication, eating properly or giving up alcohol) or solve all their problems.
- Consider what you can reasonably do to support your loved one. Discuss this with other family members and the health professionals involved in your loved one's care. It is important to remember that there is a team of people looking after your loved one and you can't be totally responsible for their welfare and wellbeing.

Maintaining good health is the best way to withstand stress. This may include:

- Taking regular exercise: walking, gardening, dancing, yoga or anything that gives you a gentle workout.
- Listening to pleasant music, meditating or reading an enjoyable book are a few ways of relaxing.
- Eating regular well-balanced meals will help maintain your energy levels and keep you physically and mentally well.
- Having a chat about what you are experiencing with a friend or someone else who is non-judgmental.
- Sharing your experience can give you comfort, strength and reduce feelings of isolation.
- Seek financial advice if needed.

In addition to taking care of yourself you may also consider the following:

- Making a plan of action in case of an emergency.
- Making a written agreement with your loved one (e.g. a Wellness Plan).
- Having a list of important phone numbers (General Practitioner, psychiatrist, case manager, hospital, crisis team, etc) on hand.
- Having an up to date list of medications on hand.
- Finding a friend or family member who is able to step in if you are suddenly unable to care for your loved one.

Self-care checklist

Please go through the following list regularly to make sure you are taking care of yourself:

- Do I have someone I trust to talk to about my experience who is non-judgemental?
- Do I get enough breaks from caring?
- Do I have regular times for relaxation?
- Am I getting enough regular exercise?
- Am I eating nutritious meals on a regular basis?
- Do I get enough sleep?
- Do I have my financial affairs in control?
- Do I need to speak to someone about my own emotions?



The Consumer and Carer Advisory Committee

Did you know that Albert Road Clinic has a committee with carer representatives? Committee members assist the hospital to consider the needs of the carer and that suitable resources for carers are provided.

The role of the Consumer and Carer Advisory Committee:

1. Generally represent the views of the consumer and carer to the Executive
2. Advise the Executive on strategies to enhance and promote consumer and carer participation at all levels within Albert Road Clinic
3. Identify and advise the Executive on priority areas and issues requiring consumer and carer participation
4. Assist in the identification of development and training needs in relation to consumer and carer participation at Albert Road Clinic
5. Assist the Executive in its communication with Albert Road Clinic's community and consumers/carers
6. Provide advice to assist the development of Albert Road Clinic's broad strategic planning and service development processes
7. Assist the Executive in the development and ongoing monitoring of key performance indicators for service quality and accessibility
8. Undertake other activities and projects as agreed with the Executive

Vacancies for carer representatives on the committee do become available from time to time. If a role on the Committee is of interest to you, an expression of interest may be addressed to:

Chair, Consumer and Carer Advisory Committee,
c/- Chief Executive Officer, Albert Road Clinic,
31 Albert Road, Melbourne 3004.

Advocacy

People with mental illness and their families and carers can get help to advocate for their rights from a range of organisations, such as:

- independent mental health advocates
- the Community Visitors Program
- Victoria Legal Aid
- the Office of the Public Advocate
- the Victorian Mental Illness Awareness Council (VMIAC)
- Tandem Inc, the peak body for families and carers.

How to make a complaint

Carers who have a grievance about the care of a loved one at Albert Road Clinic can speak with a member of the Unit's staff, the Unit Manager or the hospital Complaints Officer. The hospital's Complaints Officer can be contacted by telephone (03) 9256 8380. We welcome all feedback and will inform you of the outcome of your enquiry.

If you are not satisfied with how your complaint is managed or if you feel that your complaint has not been satisfactorily resolved, you may access the Health Complaints Commissioner as below:

Health Complaints Commissioner

Complaints and Information

Telephone: 1300 582 113

Online Complaints: www.hcc.vic.gov.au

or write to:

Health Complaints Commissioner

Level 26, 570 Bourke Street

MELBOURNE VIC 3000


Thank you for being a carer

Carers are an indispensable part of our society.

They can also play an important part in the successful treatment of a loved one with a mental illness.

Your loved one may need your help to plan and set realistic goals after their stay with us. We have provided some useful resources at the end of this Guide if you need additional information about mental health organisations, carer organisations and/or respite care for your loved one.

We hope that you find the information and resources in this Carer's Guide helpful and we wish you all the best for the future.

 Albert Road Clinic Nominated Patient Carer	UR No: _____ Name: _____ Address: _____ Dr: _____ DOB: __/__/__ Gender: _____ <i>(affix Patient Identification label here, if available)</i>
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The National Mental Health Standards recommend that we maintain privacy and confidentiality for consumers and carers. However, they also recommend that we “encourage, and provide opportunities for, the patient to involve others in their care” for example, family, carer(s), or significant others.

Close family members or significant others, who may be important in the recovery from mental health conditions, can feel left out by the perceived restrictions of privacy legislation when a patient is receiving services at Albert Road Clinic.

Therefore, in order to meet your needs for privacy and confidentiality and to ensure that we facilitate your recovery, it would be helpful for us to know if there is a family member or significant other person with whom you would be happy for us to discuss your treatment plan and progress.

Please nominate the person or persons that we can include in discussions with you about your treatment plan and progress, and identify the level of information you would be happy for the staff to share with these people.

Name	Relationship	Level of Information *	Contact Details (e.g. Phone)

* 1. Full disclosure – can discuss anything with this person

* 2. General information – treatment plan & medications but not personal information disclosed in the course of therapy.

NB: Personal information about your thoughts and feelings or your history will not be discussed with anyone without your express permission.

If you would like to change the nominated carer during your treatment, please see the nursing / clinical staff.

Patient Name: _____ Date: __/__/__

Signature: _____

Witness: (print) _____ Signature: _____

Appendix 2: Wellness Plan (Example)

Name:

Things I do well / skills I have	
Things I can do to keep myself well / what helps me stay well	
Supports/ treatments / medications that have been helpful and / or I have liked	
Supports/ treatments / medications that have been unhelpful and / or I have disliked	
Things that stress me	Things I can do to reduce stress
My early warning signs are	Things that help with early warning signs

Appendix 2: Example Wellness Plan (cont.)

Name:

When I am unwell, I and / or others may notice that I....				
If I become unwell, I would like the following to happen or not to happen (e.g. care of children/ dependents/ pets, payment of bills, looking after my personal effects, contacting work or place of study, people I don't want involved in my care)				
Task / Issue	Who will do it / is responsible		When	
Contact details of my nominated support people <i>**Circle relevant response</i>				
Name	Relationship	Contact details	Input into Plan?	Copy of Plan?
	Family / Primary carer		Yes / No	Yes / No
	GP		Yes / No	Yes / No
	Psychiatrist		Yes / No	Yes / No
			Yes / No	Yes / No
REVIEW DATE:		Copy provided to consumer Yes / No		
Consumer Name:		Signature:		Date:

Useful resources

- **Al-Anon Family Groups Australia:** 1300 ALANON (1300 252 666), www.al-anon.org.au/
- **Albert Road Clinic: Family/Carers Group (Addictions Service)**
- **Albert Road Clinic: Parents Group (Adolescent Service)**
- **Albert Road Clinic: Siblings Group (Adolescent Service)**
- **Alcohol and Drug Foundation:** Drug Info Line 1300 858 584, www.adf.org.au
- **Anglicare:** www.anglicare.asn.au
- **Anxiety Recovery Centre:** OCD & Anxiety HelpLine 1300 269 438 or (03) 9830 0533, www.arcvic.org.au
- **Beyond Blue:** 1300 224 636, www.beyondblue.org.au, www.youthbeyondblue.com
- **Black Dog Institute:** www.blackdoginstitute.org.au
- **Carer Gateway:** 1800 422 737, www.carergateway.gov.au
- **Carers Australia:** 1800 242 636, www.carersvictoria.org.au
- **Children of Parents with a Mental Illness (COPMI):** www.copmi.net.au
- **Commonwealth Respite & Carelink Centres:** 1800 052 222
- **Community Visitors Program:** 1300 309 337, www.publicadvocate.vic.gov.au
- **Dementia Australia:** National Dementia Helpline 1800 100 500, www.fightdementia.org.au
- **DirectLine:** 1800 888 236, www.directline.org.au
- **Family Drug Help:** 1300 660 068, www.familydrughelp.com.au
- **Family Drug Support Australia:** 1300 368 186, www.fds.org.au
- **Gambler's Help:** 1800 858 858, **Gambler's Help Youthline:** 1800 262 376, www.responsiblegambling.vic.gov.au
- **GROW:** 1800 558 268, www.grow.org.au
- **Health Complaints Commissioner:** 1300 582 113, www.hcc.vic.gov.au
- **Ice Advice line:** 1800 ICE ADVICE (1800 423 238), www.ice.vic.gov.au
- **Kids Helpline:** 1800 551 800, www.kidshelpline.com.au
- **Lifeline:** Crisis Line 13 11 14, www.lifeline.org.au
- **Local Council:** Many local councils have carer's groups
- **Mental Health Australia:** (02) 6285 3100, www.mhaustralia.org
- **Mental Health Complaints Commissioner:** 1800 246 054, www.mhcc.vic.gov.au
- **Mental Health in Multicultural Australia:** (02) 6285 3100, www.mhima.org.au
- **Mental Illness Fellowship Australia:** 1800 985 944, www.mifa.org.au
- **Mind Australia: Carer Helpline:** 1300 554 660, www.mindaustralia.org.au
- **National Eating Disorders Collaboration:** 1800 33 4673, www.nedc.com.au
- **NEAMI National:** (03) 8691 5300, www.neaminational.org.au
- **Office of the Chief Psychiatrist Victoria:** 1300 767 299, <https://www2.health.vic.gov.au/about/key-staff/chief-psychiatrist>
- **Office of the Public Advocate:** 1300 309 337, www.publicadvocate.vic.gov.au
- **Orygen Youth Health:** www.oyh.org.au
- **PANDA Perinatal Anxiety & Depression Australia:** 1300 726 306, www.panda.org.au
- **Parentline Victoria:** 13 22 89
- **Private Mental Health Consumer Carer Network (Australia):** www.pmhccn.com.au
- **QLife:** 1800 184 527, www.qlife.org.au
- **Relationships Australia:** 1300 364 277, www.relationships.com.au
- **Respite Victoria:** 1800 052 222, <http://www.carersouth.org.au/support-when-you-care-for/caring-for-a-person-with-a-disability/respice-victoria/>
- **Royal Australian and New Zealand College of Psychiatrists (RANZCP):** 1800 337 448, www.ranzcp.org
- **SANE Australia:** 1800 187 263, www.sane.org
- **State Trustees:** (03) 9667 6444, www.statetrustees.com.au
- **Tandem:** (03) 8803 5555, www.tandemcarers.org.au
- **The Compassionate Friends Victoria:** 24 hour grief support (03) 9888 4944 or Freecall 1800 641 091 (Country Victoria and Tasmania only), www.compassionatefriendsvictoria.org.au
- **The Schizophrenia Fellowship of Australia:** (02) 9368 0600, www.schizophrenia.org.au
- **Victoria Legal Aid:** 1300 792 387, www.legalaid.vic.gov.au
- **Victorian Mental Illness Awareness Council:** (03) 9380 3900, www.vmiac.org.au
- **Wellways:** 1300 111 400, www.wellways.org
- **WIRE Women's Support Line:** 1300 134 130, www.wire.org.au

Notes



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