

# Carer's Guide



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# Carers, loved ones & friends...

This guide has been developed to assist family members and friends who are caring for a loved one with a mental illness. It provides background information about mental illness and how to manage the many aspects of being a carer.

We recognise that mental illness can be associated with emotional distress and family disruption. The prospect of caring for your loved one may be daunting; however it can also be an extremely rewarding role. Carers rarely have any special qualifications or training in mental health. They are people like you, who have found themselves in a caring role for a range of different reasons.

We are committed to involving carers in the specialist treatment programs provided in our hospitals and helping you to adjust to your role as a carer; regardless of whether you are a first-time carer or have been caring for a loved one for some time.

If this is your first contact with a mental health service, you may be experiencing a range of emotions, but you do not need to feel like you are on your own. Mental illness affects around 20 per cent of Australians at some stage of their lives, so there are many people in the community who are in a similar situation to you and your family or friends.

You can provide encouragement and support to your loved one at any stage of their patient journey, including taking the first step of talking to the experienced clinicians in the admissions centre of your nearest Ramsay Mental Health hospital or unit. This step requires not only courage, but also acceptance that your loved one needs professional help from one of our inpatient or day programs.

You can also talk to the unit staff about how you can be involved as a carer and join a carer support group within the hospital or in the community.

# About Ramsay Mental Health

Ramsay Mental Health is part of Ramsay Health Care, which was established in 1964 and is now Australia's largest operator of private hospitals. We are also the country's leader in the provision of private mental health care.

We have specialist mental health units across Australia, some of which are teaching hospitals affiliated with Australian universities. Our specialist units are regarded as centres of excellence and are led by experts in the field of psychiatry who are known and published internationally.

Our specialist units have inpatient and day patient programs offering clinically sound and innovative treatments for a range of mental health disorders including: mood and anxiety disorders; psychosis, personality disorder and schizophrenia; Post Traumatic Stress Disorder (PTSD); eating disorders; and drug and alcohol addiction.

The culture and vitality that embodies the 'Ramsay Way' can be seen in our commitment to continually improving the service we provide and the team spirit that is displayed by the staff in all our units and hospitals.

## Philosophy of carer support groups

Carer support groups provide:

- Support and networking through linking carers with each other.
- Education and information on mental and physical illness as well as:
  - managing in your role as a carer
  - knowing when to step back
  - caring for yourself whilst you are caring for another.
- A link with external support agencies for both you and your loved one.

## What is a carer?

In this guide, the term 'carer' is used to refer to the primary support person for someone with mental illness who has been admitted to a Ramsay Mental Health hospital or unit.

Carers can be husbands, wives, children, partners, flatmates, workmates, parents and/or close friends. In this guide the person being cared for is referred to as your 'loved one'.

After your loved one's discharge from the unit, your role as a carer is to provide ongoing support, which may be physical, emotional, financial and/or social. Sometimes this may be to the detriment of your own employment, relationships, social life, physical and/or mental health. This is why being part of a carer support group is so important.

Adapted from: *Beyond Blue. Caring for others, caring for yourself.* Beyond Blue: the national depression initiative, 2010.

# What are a carer's rights & responsibilities?

We aim to provide the highest possible standard of care and services for your loved one. Carers, including family and friends, can assist our staff in this process by respecting the wishes of their loved one and also complying with the hospital's rules affecting patient care and conduct.

Carers can sometimes be frustrated when our staff are not able to provide them with information about their loved one's treatment plan or progress due to privacy legislation. It is therefore important for you to talk to your loved one about who they would like to nominate to be provided with this information.

You and your loved one also have certain rights regarding the nature of the care provided by Ramsay Health Care 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 contact the Nurse Unit Manager in the unit where your loved one is staying. If you prefer, you may speak to the Director of Clinical Services or write to the CEO of the unit or hospital. We welcome all feedback and will inform you of the outcome of your enquiry.

Carers who have a grievance about the care of a loved one in a health care facility in NSW can contact the Healthcare Complaints Commission (HCCC) on 1800 043 159 ([www.hccc.nsw.gov.au](http://www.hccc.nsw.gov.au)) or those in other states, the Australian Health Practitioner Regulation Agency (AHPRA) on 1300 419 495 ([www.ahpra.gov.au](http://www.ahpra.gov.au)). To see the Australian Charter of Healthcare Rights, visit the Ramsay Mental Health website at: [www.ramsaymentalhealth.com.au](http://www.ramsaymentalhealth.com.au).



# Background to understanding mental illness

## What is mental illness?

Mental illness is a broad term used to describe a range of conditions including mood, anxiety and personality disorders. These illnesses can affect every part of your loved one's life including their work, relationships and leisure time.

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.

Remember that people with a mental illness are not defined by their illness. They still have likes, dislikes, opinions, talents and skills. They are still mothers, brothers, friends, colleagues etc. Their rights and individuality need to be respected.

## Understanding mental illness

A mental illness, like a 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, treatment options and medications.

Gather information from general practitioners (GPs), psychiatrists, mental health organisations and/or internet sites. Keep a diary of any problems or symptoms you need to ask about. Write down questions as you think of them and add the answers when you have them. For example, finding out the warning signs of relapse.

Treatment options may include medication, cognitive behavioural therapy (CBT), counselling, group programs, self-help approaches and/or stress management. 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.

A doctor or pharmacist will be able to give you information on medications and their side effects. Some of the things you need to know include:

- The medication's name
- What it is used for
- How long it needs to be taken
- What happens if a dose is missed
- What are its side effects and what to do if the side effects arise
- How could it interfere with other medications (including over-the-counter, supermarket and herbal preparations)
- How it could affect any other illnesses your loved one may have
- What should your loved one avoid while taking the medication (ie alcohol)
- The cheapest brand.

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 of yourself.

## The effects of mental illness on different family members

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

- **Parents and spouses** of someone with a mental illness often have feelings of fear, guilt, anger or shame alongside deep feelings of concern for the 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 strong relationships and affirm your family unit.
- **Brothers and sisters** can feel a range of emotions including confusion, embarrassment and jealousy of all 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 is suffering from a 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'.



# How to become a primary carer

Firstly you need to ask your loved one to nominate you as their primary carer and to be given full disclosure of any personal information such as their treatment plan and progress. This will then be documented in their clinical notes and permits nursing and other staff to answer any questions you may have relating to their care.

## **Other steps to becoming a carer include:**

- 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 specialist unit where they will be staying.
- Writing down the visiting hours of the specialist unit so you know when you can visit them.
- Attending a carer support group to learn more about mental illness.
- Conducting a web search for information on your loved one's mental illness.
- Contacting carer organisations and asking them to send you information (see the Resources at the back of this Guide).
- Continuing to look after your own mental and physical health.

Visiting the hospital and speaking with nursing staff can help you to become familiar with the hospital's day-to-day routines and procedures. This will help you to understand where you 'fit' in this new situation and how you can continue to support your loved one.

There is a lot of scope for spending time together, if this is what you both wish to do. Hospital routines and daily programs are clearly defined and 'free time' can be spent in various ways such as having lunch or dinner together. Going out together can also increase a sense of 'normality' and offer 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. If you have any doubt about what is appropriate, staff members will be happy to help you.

## First-time carers

The first hospital stay 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 the specialist unit, this can be a good time to focus on regaining your strength to resume care if and when necessary.

Often carers benefit from seeing that they are not alone and therefore not feeling so isolated. A hospital setting can reinforce the knowledge that there are many others in a similar situation.



# Taking care of 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 the Commonwealth Carer Respite Centre for information and advice (see Resources at the back of this Guide).

## **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.

### **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.
- Having a list of important phone numbers (GP, 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-judgmental?
- 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?

# Where to start?

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 them.

You may be feeling anger at this happening in your family, confusion or a sense of loss and grief at how the person 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 levels 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 they go home.
- 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 (ie 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.

# 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 as they plan and set realistic goals after their stay with us. We have provided some helpful resources at the end of this guide for when you go home and need additional information about mental health organisations, carer organisations and/or respite care for your loved one.

For information about our hospitals and units, go to the Ramsay Mental Health website at: **[www.ramsaymentalhealth.com.au](http://www.ramsaymentalhealth.com.au)**.

**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.**



# Useful resources

## General resources

<b>Lifeline:</b>	<b>02 6215 9400</b> 13 11 14 (Crisis Line) <a href="http://www.lifeline.org.au">www.lifeline.org.au</a>
<b>SANE Australia:</b>	<b>1800 187 263</b> <a href="http://www.sane.org">www.sane.org</a>
<b>Beyond Blue:</b>	<b>1300 224 636</b> <a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a> <a href="http://www.youthbeyondblue.com">www.youthbeyondblue.com</a>
<b>Black Dog Institute:</b>	<b>02 9382 4523</b> <a href="http://www.blackdoginstitute.org.au">www.blackdoginstitute.org.au</a>
<b>Schizophrenia Fellowship of NSW:</b>	<b>02 9879 2600</b> <a href="http://www.sfnsw.org.nsw">www.sfnsw.org.nsw</a>
<b>Mental Illness Fellowship of Australia (MIFA):</b>	<b>08 8272 1018</b> <a href="http://www.mifellowshipaustralia.org.au">www.mifellowshipaustralia.org.au</a>
<b>Mental Health Information Service:</b>	<b>1300 794 991</b> <a href="http://www.mentalhealth.asn.au">www.mentalhealth.asn.au</a>
<b>Mental Health in Multicultural Australia:</b>	<b>02 9840 3333</b> <a href="http://www.mmha.org.au">www.mmha.org.au</a>
<b>National Eating Disorders Collaboration:</b>	<a href="http://www.nedc.com.au">www.nedc.com.au</a>
<b>Relationships Australia:</b>	<b>1300 364 277</b> <a href="http://www.relationships.com.au">www.relationships.com.au</a>
<b>Family Drug Support:</b>	<b>1300 368 186</b> 1300 858 584 (Drug Info Line)
<b>Al-Anon Family Groups Australia:</b>	<a href="http://www.al-anon.org/australia">www.al-anon.org/australia</a>
<b>Kids Helpline:</b>	<b>1800 551 800</b>

## Carer organisations

**Commonwealth Carer Resource Centre:** **1800 200 422 (Freecall)**  
[www.nscchealth.nsw.gov.au/carersupport](http://www.nscchealth.nsw.gov.au/carersupport)

**Carers Australia:** **1800 242 636 (Freecall)**  
[www.carersaustralia.com.au](http://www.carersaustralia.com.au)

**Commonwealth Respite & Carelink Centres:** **1800 052 222 (Freecall)**

**Children of Parents with a Mental Illness (COPMI):** **[www.copmi.net.au](http://www.copmi.net.au)**

### **Association for Relatives and Friends of the Mentally Ill (ARAFMI):**

#### **New South Wales**

Phone: 02 9332 0700  
1800 655 198 (Freecall)  
[www.arafmi.org](http://www.arafmi.org)

#### **Victoria**

Phone: 03 9810 9300  
[www.arafemi.org.au](http://www.arafemi.org.au)

#### **Queensland**

Phone: 07 3254 1881  
1800 351 881 (Freecall)  
[www.arafmiqlld.org](http://www.arafmiqlld.org)

#### **Western Australia**

Phone: 08 9427 7100  
1800 811 747 (Freecall)  
[www.arafmi.asn.au](http://www.arafmi.asn.au)

#### **Northern Territory**

Phone: 08 8948 1051  
[www.arafmiaustralia.asn.au](http://www.arafmiaustralia.asn.au)

#### **Tasmania**

Northern branch: 03 6331 4486  
Southern branch: 03 6228 7448  
[www.arafmitas.org.au](http://www.arafmitas.org.au)

# Notes

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