

Do you **live** with,  
or provide **support** to,  
someone with  
**mental ill-health?**

**INFORMATION BOOKLET**  
for Families and other Carers



# ACKNOWLEDGEMENTS

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## Disclaimer

Neither LEA, Healthscope or DoH will be liable for any loss or damage suffered by any person reading this Information Booklet for Families and Carers.

This guide is for informational purposes only. It is not meant to be used as a diagnostic tool. It is very important that you seek a professional evaluation if you have concerns about yourself or another person.

If you are concerned about a family member or friend you should contact your GP, local mental health service, lifeline 13 11 14, emergency 000 or the police.

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# INTRODUCTION

You have been given this information pack because you live with, or provide support to, someone with mental ill-health or a mental illness

This could mean you:

- Provide emotional support, sometimes for long periods each day
- Need to encourage the person you care for to take their medication, and watching for side effects
- Provide assistance with bill paying, filling in Medicare claims and other similar tasks
- Need to remind the person you care for when they have appointments and make sure they get to them
- Help the person you care for to understand what the doctor has said and what the treatment will be
- Check to see if there is food in the fridge, and you might make some meals
- Help with household chores such as cleaning, grocery shopping, gardening
- Make regular phone calls to the person you care for to “check in” on them
- Assist the person you care for to be involved in some social activities

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If so, this means you could be described as a ‘Carer’. Carers of people with mental ill-health or a diagnosis of a mental illness are entitled to be recognised, respected, and provided with information and support.

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‘Carer’ is a term that is used by services and governments to describe people that provide support to someone with mental ill-health or a diagnosis of mental illness that needs help. You may be, and will continue to be, primarily the persons wife, husband, partner, son, daughter, sister, brother, parent, other relative, neighbour or friend.

It doesn’t matter how many hours per week are spent providing support. Carers may live with the person they are caring for, providing assistance with daily needs, or may visit the person weekly or call regularly. Being a carer involves an investment in time, energy, and support.

We know that carers are often ‘hidden’ looking after a family member or helping a friend or neighbour with day-to-day tasks and may not see themselves as a carer. This is particularly true in situations where children may be the carers in the family.

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We see carers as our partners in the provision of healthcare. We need to work with



# LEARNING A NEW LANGUAGE

you to make sure that your family member or friend receives the best possible care.

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## Nurses

Nurses are educated to promote good health, prevent illness and care for people when they are ill. They work in a broad range of health settings including in hospitals and GP clinics. Some have received specialist training in mental health. When your family member or friend is in hospital it is the nurses who will provide 24-hour care.

## Occupational Therapists

A person specifically trained to assess the practical skills that a person has and to develop programs to support the person to learn new skills in managing day to day living that builds their independence.

## Psychiatrists

A doctor who has undertaken additional specialised training that qualifies him or her to diagnose and treat mental illnesses. Psychiatrists can prescribe medication. They work in both the public mental health service for which there is no charge and private practice which you pay for and claim back from Medicare or private health fund.

## Social Workers

A person specifically trained to work with people to change the way in which they live. This may involve assisting them with their finances or accommodation and helping them to navigate community welfare services that may offer support. This may include talking to you as a family group or support you all.

## Psychologists

A person who has completed a postgraduate degree in psychology. Psychologists are people who have undertaken specialist training in the assessment of behaviour and mental functioning, and ways of helping people change how they may think, feel, and act towards themselves and other people. Psychologists are not trained in general medicine and are unable to prescribe medication.

## Art Therapist

An allied health professional who utilises arts processes, counselling and psychotherapeutic approaches within an individual or group setting to support the goals of Recovery. Art Therapists have undertaken specialised training within a master of art therapy program and are registered in Australia with ANZACATA (Australia, New Zealand and Asia Creative Arts Therapies Association). Art therapists working within the Recovery framework will often draw on a person centred approach to their work, among other approaches, placing the consumer at the centre of their care plans. Art making may foster insight, confidence, acceptance of self, enjoyment, future focus, hope and resilience whilst offering new experiences, fostering curiosity and flexibility and a sense of pride and achievement. Art therapy in a group setting fosters connectedness and the chance to share lived experience with others in an understanding space.

## Consumer Consultant/Lived Experience/Peer Support worker

Using their lived experience of mental ill health, this team provide their support and expertise to patients and staff. They may facilitate groups, offer 1:1 advocacy and support sessions, help you settle in and understand the hospital. Consumer Consultants also advise the hospital in improving patient care and offer Consumer Centred Care training to



# COMMUNICATING WITH OUR STAFF

staff.

## – A check list

As a carer, you should be provided with information to help you. The following checklist provides prompts that may be beneficial to you in seeking information.

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Remember, communication is a two-way process. People with mental ill-health or mental illness have the right to refuse to have personal information shared with carers however this does not over-ride your right to present your views and experience to our staff.

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If the person you support consents, our staff can provide you with general verbal and some written information about:

- The diagnosis relating to mental ill-health or mental illness
- What sorts of behaviours you might expect and how to handle them
- Medication – alternatives, benefits, and possible side effects
- Services that might be available locally for your family member/friend
- Services that might be available locally to assist you as their carer – government, private and community services
- Local and national support groups

For you to feel comfortable in talking about your concerns you need to ask us if you can have:

- Ongoing opportunities to ask questions and discuss concerns
- The opportunity to meet with staff on your own
- Assurances that the information you discuss with staff will be kept confidential
- Assurances that you are a valued member of the care team
- Practical and emotional support if needed



### Have we given you help to understand:

- The rights and responsibilities of people who have a mental illness, you, as their carers and mental health staff who work in this service?
- Any restrictions on sharing information requested by the person with the mental illness?
- What the treatment plan involves and aims to achieve?
- What a crisis plan might involve. It is a good idea to ask for this in writing?
- What a recovery plan might involve?
- Will you be included in developing a Discharge Plan?
- The roles of each staff member involved in care of your family member or friend?

### Have you made sure that you have communicated to our staff:

- Any information regarding your family member/friend that may be relevant such as changes in behaviour, use of drugs or alcohol?
- Information that may influence the choice of medication or treatment, such as allergies?
- Information regarding benefits or side effects of medication or treatment previously prescribed?
- Any problems you have in caring for your family member/friend such as them being unwilling to take medication, or to get up in the morning?
- If you need help in solving problems or handling specific situations?



# WHAT ARE MY RIGHTS AS A CARER?

Caring for someone is an important and valuable role in the community, which is often a 24-hour job that can be very demanding and may make you feel very alone. A number of pieces of Carer Recognition Legislation and Mental Health Legislation mandates that you receive appropriate support via way of access to accurate and timely information and referral where appropriate.

## Carers can expect our staff to:

- Introduce themselves and advise you of their role in caring for the person who has been admitted to our hospital
- Treat you with dignity and respect
- Explain the level of the information that can be shared and the reason for this
- Reply appropriately to any concerns or queries
- Provide you with access to interpreters if you need them
- Keep personal information you give the team about yourself as confidential and respect your privacy
- Inform you of your right to seek further opinions regarding the diagnosis and care of your family member or friend
- Let you know that you do not always have to be available to your family member or friend, i.e., you can take time for yourself
- Inform you of your right to make complaints and how you would go about doing this
- Inform you that there is information on support programs available for carers and where to go to get this information

## In addition, where your family member or friend who is unwell gives permission you can expect our staff to:

- Discuss the available treatment options with you
- Involve you in planning a program of care
- Involve you in planning for discharge and on-going care

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Relationships between people with mental ill-health or mental illness and their family or other carers are not always straight forward. They may also change frequently depending on the nature of the illness, or how unwell the person is. There may also be circumstances where the person is too unwell to give, or refuse, permission for our staff to involve you because of their disturbed mental state.

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## If this is the case, you can still expect our staff to:

- Provide you with an assurance that they will check with your family member or friend on a regular basis, the level of information to be shared
- Provide opportunities for you to give our staff information you have concerning family relationships and any matters relating to the mental state of your family member or friend to assist with diagnosis and care



# COMPLAINTS PROCESSES

## The first thing to do

If you feel that something is not right, please let our staff know. You can do this by asking to speak to a senior member of our staff. You might like to have another family member or friend to help you if this situation arises.

In most cases if you let our staff know about any concerns you may have as soon as possible, it is generally easy to deal with them.

You may also like to ask our Consumer Consultant to help you to speak with or arrange a meeting with our staff.

**If you are still concerned, or need more information, it is possible to telephone or meet with people who could assist you. These might include:**

### Health and Hospitals Complaints Commission

Telephone numbers vary across states and territories

### Office of the Public Advocate

Telephone numbers vary across states and territories

### Office of the Chief Psychiatrist

Telephone numbers vary across states and territories





# WHAT ABOUT YOU?

Supporting someone with a mental illness can be an extremely challenging experience that takes you along unexpected and unknown paths. Trying to make sense of your feelings, the illness, and the whole situation brings many questions with sometimes, it seems, even fewer answers. This is not an unfamiliar experience, many families and other carers often say they feel this way.

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It is important to understand 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, however it is good to find opportunities to share these feelings as you may be surprised to find how much you have in common with other people who are carers.

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When you are the carer of a person with mental ill-health or a mental illness, 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. This sometimes means you might become anxious or depressed and need to seek help for yourself.

Maybe you have had thoughts or questions like the ones below. Hopefully the stories from other carers can give you some reassurance and support to help you in your journey.

- Is what I am feeling a common experience for families and friends?
- How will the experience affect the rest of the family and my friends?
- I never expected to feel grief and loss
- How on earth am I going to cope?
- I feel like I am going to explode...I need help too...
- Something or someone's got to change. Maybe it's me...

## Is what I'm feeling a common experience for families and friends?

During the initial stage, when your family member or friend is diagnosed with mental ill-health or a mental illness, it's likely that you may also 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 feel some fear and confusion and wonder:

- Where to from here?
- Is this only the beginning?

These questions are all normal because for most people this is a new experience.



Many family members and other carers say that once the mental illness had been diagnosed, their feelings of love and protection increased. Sometimes, at the same time, you might feel a sense of helplessness because you can't control or fix the situation.

Common feelings at various stages generally include:

**Fear** **Confusion** **Blame** **Guilt** **Uncertainty** **Insecurity**

Families and friends of people with mental ill-health or a mental illness also describe other feelings such as being overwhelmed by what is required of them. It may seem just too demanding and there may be no relief in sight. The high level of responsibility that can come with caring for, and supporting, another person, particularly if this involves physical, practical, and financial support, can be exhausting and may also trigger feelings of resentment, frustration, and anger.

It is important to know that these are normal responses to a situation you did not plan. Remember, the situation in which you find yourself is beyond your control. You had no say in it. You didn't ask for this to happen – but nevertheless, here you are.

This does not mean you love or care about your family member or friend any less. However, it is likely that at some stage you might react to all these feelings – and you might not be able to predict when, or how. Again, this is a normal response because you are using all your energy and resources to take care of your family member/friend and to take care of yourself.

## How will the experience affect the rest of the family and my friends?

### Relationships

Living with or supporting a person with mental ill-health or a mental illness not only affects you. It is likely to affect the other relationships within your family and with friends.

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

Social relationships may also change. The response you get from friends and family members may be surprising or hurtful. This may be because they don't understand mental ill-health or mental illness, what it means, or what you may be going through.

In some situations, you may experience financial difficulty because of:

- Not being able to continue working full-time
- Ongoing medical expenses
- Helping to meet the financial commitments of your family member/friend

Relationships can become one-sided because people with mental ill-health or a mental illness are sometimes so focused on their own problems, they may have nothing left to share with anyone else.

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If your relationship has changed, remember this is mainly due to the person's illness. If that person gets the right treatment, then your relationship has a chance of returning to what it was, or you may move to a new stage in your relationship.

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## Finding the right balance

One of the big challenges for family and other carers is the issue of accommodating the person's illness, their behaviour and needs, and the impact this has on family life. 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 may alter, and your quality of life may be affected because you are trying to make life easier for the person with the illness.

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

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

## How on earth am I going to cope?

For many people who find themselves in a caring role, fear, concern, and worry are always present, even when they're not with the person for whom they care. They may wake up thinking about the person and even when they are busy doing other things, the person is always in the back of their mind. They wonder how they are. They hope they are okay and safe.

## I feel like I need help too

**One 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 are feeling.**

Remember that you are human and have needs of your own. Continually putting them off, or not allowing time for yourself, will only make you resentful, irritable and could eventually make you unwell.

- Allow time each week to do something you enjoy, something to make you feel relaxed, refreshed and that life is good
- Eat regularly and well
- Exercise as much as possible – even a short brisk walk will help
- Plan to take regular time out and/or holidays ....and take them
- Put in clear boundaries with the person you care for. Be clear about what you can and cannot do....and stick to it
- Ensure there is a least one supportive person with whom you can talk to confidentially. It is easy to lose your perspective if you feel isolated
- Remember that your GP can be a source of help. Take a friend with you if you think you may not be able to tell the doctor how you are feeling
- Knowing about the illness you are dealing with will help you to understand it and act appropriately, even if the person you care for doesn't want to know
- Joining a carers group may help relieve isolation, stress and loneliness as well as helping you to understand different types of illness
- Seek advice from our staff involved with providing care if you can – if not a Carer Consultant can help get answers for you
- Seek advice from staff involved with providing care if you can – if not a Carer Consultant or Family Liaison Worker can help get answers for you
- If you feel you should be receiving services that you're not getting, don't be too proud or too afraid to complain – don't just cope all by yourself

## Privacy

Some people like to maintain their privacy and keep to themselves when dealing with mental ill-health or mental illness. However, it is important that this does not prevent you from seeking support for yourself.

If you are struggling to support a person, don't think you are betraying a confidence because you talk to someone 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 people say they prefer to rely on family and friends for support. They know you and they know the situation. This is fine however there may be times when you may need to have your opinions and actions challenged if you are going to move forward. You may need an independent sounding board – someone with whom you can be truly honest, rather than censoring some of your thoughts.

## Counselling

Some carers find individual counselling helpful because it gives them time to off-load everything in an uninterrupted way. This could be a constructive and safe place to voice all your worries, fears, grievances, and frustrations.

It can also be a way of learning some new ways of thinking about old situations and developing some new skills.

## Support Groups

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

Talking to people who are in a similar situation may be helpful in gaining support. There are support groups just for carers. You could attend the group for as long as it meets your needs, and you find it helpful. The advantage is that people will know what you're going through because they have been there, and you won't have to keep on explaining what is happening. Even if you don't attend for long, you may meet some people whom you can continue to see outside the group.

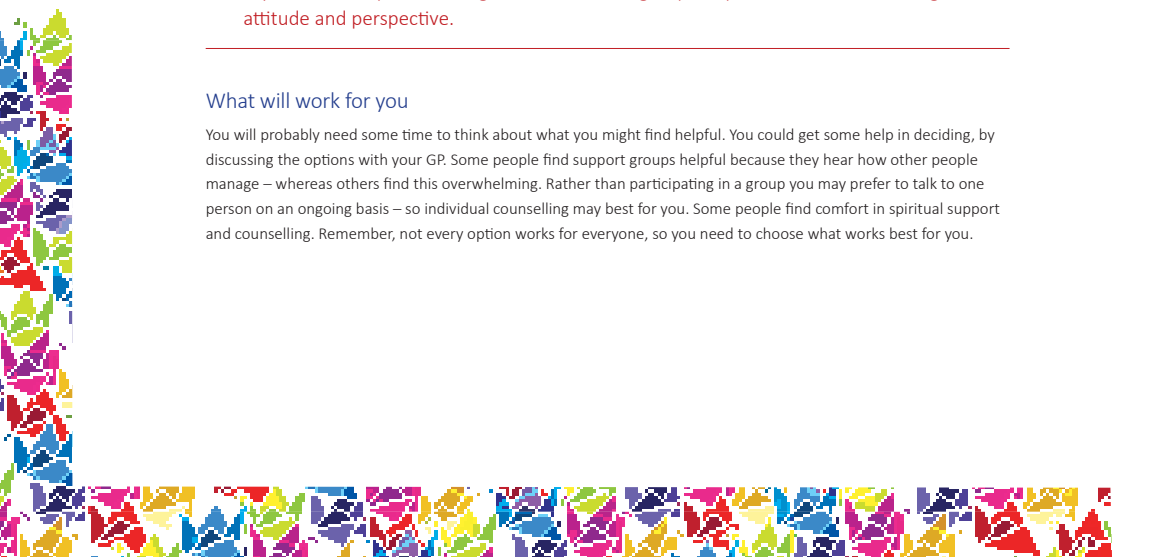
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There are a range of support groups but not all groups will suit everyone. It's important to find a group with a structure in which you feel comfortable. Some carers say the most important thing to look for in the group is a positive, forward-looking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

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## What will work for you

You will probably need some time to think about what you might find helpful. You could get some help in deciding, by discussing the options with your GP. Some people find support groups helpful because they hear how other people manage – 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 best for you. Some people find comfort in spiritual support and counselling. Remember, not every option works for everyone, so you need to choose what works best for you.



# ANSWERS TO SOME COMMON QUESTIONS

For many years mental ill-health and mental illness was not discussed openly in the community because of fear, ignorance, or stigma. Most people can easily recognise when someone has a physical illness or disability and is happy to seek treatment from a GP or a specialist. This is not often the case with mental ill-health or mental illness, particularly when it develops during the teenage years.

It is common for people not to discuss what may be symptoms of mental ill-health or mental illness with family or friends. Negative views, or stigma about mental illness, are often due to lack of information or experience, misunderstandings, or cultural beliefs.

## What information will our staff need to know?

Asking questions is how we find out what is happening and how we might be able to help. Being prepared for these questions will help you feel less anxious and enable us to assess the situation better. Some questions that we may ask you could include:

- Is the person talking about hurting themselves or other people?
- Has the person already been diagnosed with a mental illness?
- If yes, which one? Who diagnosed the illness? When?
- Is the person willing to accept help?
- Does the person have any medical conditions?
- Is the person on any medication? If so, what?
- Does the person misuse substances? (e.g., alcohol, illicit drugs, inhalants)
- What is happening that is worrying you and for how long has it been happening?
- What prompted you to seek help now?

## What does our hospital do?

Our hospital assesses and helps people with mental ill-health and mental illness. Our goal is to provide you and your loved one with a service that is based on each person's individual needs. We have experienced staff who have expertise in helping people with all types of mental ill-health or mental illness as well as helping parents, carers, and other family members. Our aim is to provide care that supports people on their recovery journey to return to life in the community as soon as possible. There is a lot of paperwork that needs to be completed when a person is admitted to hospital. This is also a time when you can tell our staff about your relationship with the person and what you do to support them.

Part of this process may involve asking for permission from the person you care for, so that our staff can talk with you about your experience of living with them or supporting them. Sometimes the person you care for may be so unwell that they say that they do not want our staff to talk with you. Whilst our staff must respect their wishes at that time it is important for you to understand that our staff will keep discussing this matter with the person as they become well, as their feelings about this issue are likely to change as time goes by.

Our staff recognise how important carers are in the ongoing support of a person. We will therefore be working with the person to encourage them to include you in their care and planning for their discharge.

## Being discharged from our hospital

The person you care for may only be in hospital for a short period until their illness has been stabilised. They may be referred to a less intensive level of service or back to their private psychiatrist. Discharge planning will start from the moment your family member or friend starts receiving treatment from our mental health service. Our staff will also involve you in these discussions wherever possible and appropriate.



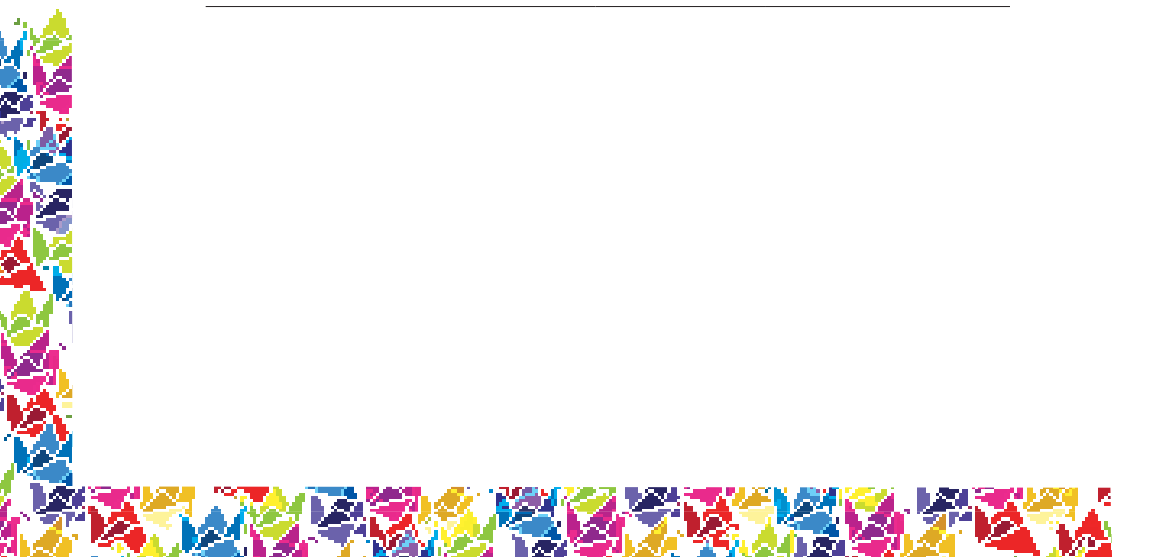
## Information regarding diagnosis, treatment, and medication

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) has developed several guidelines to assist you to gain a deeper understanding of specific diagnoses. These are available from their web site [www.ranzcp.org](http://www.ranzcp.org)

### Carer organisations

There are several organisations that support carers. There is one in most states and territories and can be accessed via the internet or via phone.

State Based Carer Organisations	Phone	Web site
<b>Arafmi Queensland</b>	(07) 3254 1881  1800 35 1881 (regional Qld)  Or 1300 554 660	<a href="http://www.arafmi.com.au">www.arafmi.com.au</a>
<b>Mental Health Carers NSW</b>	(02) 9332 0777	<a href="http://www.mentalhealthcarersnsw.org">www.mentalhealthcarersnsw.org</a>
<b>Carers Australia ACT</b>	(02) 6296 9900	<a href="http://www.carersact.org.au">www.carersact.org.au</a>
<b>HelpingMinds – WA</b>	(08) 9427 7100	<a href="http://www.helpingminds.org.au">www.helpingminds.org.au</a>
<b>Mental Health Family and Friends Tas</b>	(03) 6228 7448	<a href="http://www.mhfamiliesfriendstas.org.au">www.mhfamiliesfriendstas.org.au</a>
<b>Carers Australia NT</b>	(08) 8944 4888	<a href="http://www.carersnt.asn.au">www.carersnt.asn.au</a>
<b>Tandem – Victoria</b>	(03) 8803 5555	<a href="http://www.tandemcarers.org.au">www.tandemcarers.org.au</a>
<b>Carers Australia – SA</b>	(08) 8291 5600	<a href="http://www.carerssa.com.au">www.carerssa.com.au</a>



Other Organisations	Phone	Website
<b>Carers Australia (National)</b> For family carer support and counselling you can contact your state or territory Carers Association on the same telephone number	1800 242 636	<a href="http://www.carers.australia.com.au">www.carers.australia.com.au</a>
<b>SANE</b>	1800 187 263	<a href="http://www.sane.org">www.sane.org</a>
<b>Beyond Blue</b> The national depression initiative	1300 224 636	<a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a>
<b>Mental Illness Fellowship Australia</b>	(08) 8272 1018	<a href="http://www.mifa.org.au">www.mifa.org.au</a>
<b>Multi Cultural Mental Health Australia</b>	(02) 9840 3333	<a href="http://www.mmha.org.au">www.mmha.org.au</a>
<b>Orygen Youth Health</b>	(03) 9342 2800	<a href="http://www.oyh.org.au">www.oyh.org.au</a>
<b>Headspace – Kids Help Line</b> A 24-hour telephone and online counselling service for 5- to 25-year-olds in Australia	1800 551 800	<a href="http://www.headspace.org.au">www.headspace.org.au</a>
<b>CounsellingOnline</b> Free alcohol and drug counselling online 24 hours a day, 7 days a week	1800 888 236	<a href="http://www.counsellingonline.org.au">www.counsellingonline.org.au</a>
<b>Family Drug and Alcohol Support Australia</b>	1300 368 186	<a href="http://www.fds.org.au">www.fds.org.au</a>
<b>Qlife</b> Providing LGBTI peer support and referral	1800 184 527	<a href="http://www qlife.org.au">www.qlife.org.au</a>
<b>Grow</b>		<a href="http://www.grow.net.au">www.grow.net.au</a>
<b>Anglicare</b>		<a href="http://www.anglicare.org.au">www.anglicare.org.au</a>
<b>Centacare</b>		<a href="http://www.centacare.org.au">www.centacare.org.au</a>
<b>Relationships Australia</b>		<a href="http://www.relationships.com.au">www.relationships.com.au</a>
<b>YWCA</b>		<a href="http://www.ywca.org.au">www.ywca.org.au</a>

### Where to go for help

- Your general practitioner.
- Your community health centre.
- Your community mental health centre.

For immediate counselling assistance, contact Lifeline on 13 11 14

24 hour confidential telephone counselling to anyone within Australia

For information on services, check the Community Help and Welfare Services and 24-hour emergency numbers in your local telephone directory.



**Lived  
Experience**  
AUSTRALIA



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