How do you feel?

Caring for someone with a mental illness is a complex and demanding role, and it is normal for carers to experience a range of feelings about it. Initially, you may experience disbelief (“This can’t be happening”). Later, you may develop seemingly conflicting feelings of anger, shame and love. It’s important to know this is normal, and that no feelings are right or wrong. Typical emotions include:

- **Guilt** – You may feel responsible for the illness but no one is to blame. You may feel guilty about not wanting to be a carer, or perhaps think, “I’m not doing enough.”
- **Shame** – The stigma around mental illness can cause embarrassment. You may worry about what others think.
- **Fear** – It is normal to fear for the person’s future or to worry about what will happen to him or her if you can’t cope.
- **Anger/frustration** – You may feel frustrated with being a carer, or angry that others don’t pitch in. You may think, “My friend/relative doesn’t appreciate what I do or what I have sacrificed for them.”
- **Sadness** – You may grieve for the loss of the relationship as it was, and the life you once knew. You may feel sad about the loss of opportunities and plans for both yourself and your friend/relative.
- **Love** – Your love for your friend/relative may deepen and you may feel very motivated to help.

Your feelings and motivation may change over time. In the early stages of caring for someone people often focus on gathering information and finding their way through the mental health system. As acceptance and understanding grow, many long-term carers find that their attention turns to a more political focus such as lobbying and advocacy.

How do I understand what is happening?

Mental illness is a broad term used to describe many conditions including mood and anxiety disorders, personality disorders and psychotic disorders such as schizophrenia. These illnesses can affect every part of a person’s life including work, relationships and leisure.
There are many myths about mental illness. What you have heard may not be true so it is best to find out the facts.

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

a) Understanding the illness
A mental illness, like a physical illness, is treatable. Learning about the mental illness may ease fears about the unknown or unfamiliar. It is important to find out about:

• The features of the illness
Gather information from GPs, psychiatrists, mental health organisations and internet sites. Keep a diary of any problems or symptoms you need to ask about. Find out the warning signs of relapse.

• Treatment options
These may include medication, cognitive behavioural therapy, counselling, group programs, self-help approaches, stress management etc. With each of these, make sure you understand what is being offered and how it will help. Think about combining treatments. Keep a diary and write down questions as you think of them and add the answers when you have them.

• Medications and their side effects
A doctor or pharmacist will be able to help. You need to know the medicine’s name; what it is used for; how long it needs to be taken for; what happens if a dose is missed; what to do if side effects arise; how it could interfere with other medications including over-the-counter, supermarket and herbal medications; how it could affect any other illnesses the person may have; what should be avoided while taking the medication; and the cheapest brand.

b) Understanding the mental health system
• The first step is to see a GP. To see a psychiatrist you will need a referral from a GP.
• Find out the structure of your local mental health service. Keep handy a list of important phone numbers including the number of the crisis/assessment team, doctor/psychiatrist, hospital, support groups etc.
• Investigate other treatment services including private psychiatrists, psychologists and your community health centre. Your GP may direct you to Commonwealth subsidised allied health services.
• Look into local professional and community support services for carers and people with mental illnesses. Contact Lifeline on 13 11 14 for information.

3 Communication:
"Everything I say and do is wrong"
Good communication is difficult at the best of times. When situations become really difficult, it is even more important to share feelings and thoughts in a way that avoids unwelcome responses.
**a) Non-verbal communication**

Communication is more than what we say. We also communicate in ways that are non-verbal. You may have heard the phrase, “Actions speak louder than words.” That means non-verbal communication can be more powerful than words. It is thought that up to 70% of communication is non-verbal.

- **Posture and gestures**
  Maintain an open posture, which means not crossing your arms which can be taken as unwillingness to listen. Try to avoid exaggerated movements such as pointing, waving your arms or putting your hands on your hips, which may appear aggressive or confrontational.

- **Facial expressions and eye contact**
  Faces express feelings but sometimes when we speak, our facial expressions don’t match the meaning of what we are saying. It is important to be honest and learn to share in a non-confrontational way what you are feeling and thinking. Maintain a comfortable level of eye contact: looking someone in the eye shows you are listening to them and not bored or frightened, although staring can cause the person to become uncomfortable or feel threatened.

- **Personal space**
  We all feel the need to keep some personal space between another and ourselves. Standing too close can cause the other person to feel uncomfortable. If a person is feeling vulnerable or disturbed, standing too close can increase discomfort.

**b) Discovering new ways of communicating**

Learning new ways of communicating with the person you care for can reduce misunderstandings. Pay attention to the words you use. Be specific and concrete: however avoid oversimplifying, as it can seem patronising.

Carers may be accused of not understanding or listening. It is natural to defend yourself although arguments are not helpful. The symptoms of some mental illnesses can make communication difficult.

It is useful to think about how you communicate. The three aspects of communication listed below may provide some pointers and the techniques described can be used very effectively.

- **Listening skills** – Listening to what a person is saying without interrupting can be difficult, especially when you disagree with what is said, but if you do this, you are more likely to be heard too.
  Acknowledgement is another aspect of listening. Acknowledgement is done by making sounds like “uh huh” or “Mmmm”. This does not mean that you agree but shows you are paying attention.
  Encouraging your friend or relative to fully explain what they are thinking and feeling helps you understand what he or she is going through. Use phrases such as: “Tell me more”, “What happened then?”, “When did the problem start?”

- **Reflecting meaning** – You can show you understand someone by reflecting his or her feelings and the reasons for them. It is important to reflect the correct intensity of feeling. If a person is terrified, say, “You’re really terrified,” not “So you feel a little bit scared”. You might say, “You’re feeling really terrified because the voices are saying that people are spreading lies about you”. Reflecting meaning is also a good way to clarify exactly what the person is saying.

- **Sharing your feelings in a non-confrontational way** – Carers often feel that everything revolves around the person with the illness. But carers have a right to express their feelings too.
  To share your feelings in a non-confrontational way use ‘I’ statements (“I feel upset and worried when you…”) rather than ‘You’ statements (“You make me so angry when you…”). ‘I’ statements show you are taking responsibility for your feelings, not blaming others.
These responses may help.

“I didn’t realise that what I said affected you that way. Now that I know, how about we sit down and talk about it calmly.”

“Tell me how you would like me to respond.”

Remember that when you feel angry or stressed it is easy to explode with sweeping, broad generalisations and criticisms, but these only block effective communication.

Learning any new skill can take time, so don’t be too hard on yourself. It may take time for others to adjust to a new way of communicating, but keep trying.

4 Looking at problem behaviours

A person with a mental illness is still responsible for his or her actions. You might need to agree on what is and is not acceptable behaviour, for example, you may agree that your friend/relative can smoke cigarettes in the home, but not use illegal drugs. It may help to discuss with a mental health professional what possible behaviours to expect and which need to be accepted as part of the illness. Some behaviour can be harmful or distressing either to the person, your relationship, or others. For example

• If your partner empties the bank account on a spending spree

You may need to decide how to approach these issues. Be aware of your own personal boundaries and discuss the situation with your friend or relative. Work together on a solution. If the agreed solution is not working, talk to a doctor, case manager, or Lifeline telephone counsellor about what you can do.

5 Empowering the person

It is important to relate to your friend or relative as an individual, not just in terms of his or her illness. He or she has the right to make decisions, including decisions about treatments. Imagine how you would feel if decisions were always made for you and not by you. Remember what the person was like before the onset of mental illness – he or she is more than likely still that person.

Recognise the difficulty of your friend’s/relative’s situation. Acknowledging the person’s strength and ability to face such situations can help minimise his or her sense of powerlessness.

6 “…But I don't have time for myself…”

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.

Self-care checklist

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

How to take care of yourself

• Taking breaks – Recognise your limits – no one can be a carer every minute of every day. Make sure you go out and continue doing activities you enjoy. Is there a relative or friend who would be willing to share the role of carer? For a longer break, consider arranging respite care. Contact the Commonwealth Carer Respite Centre (see resource list) for information and advice.

• Health – Maintaining good health is the best way to withstand stress.
  Regular exercise – Exercise can be as simple as walking, gardening, dancing, yoga, or anything that gives you a gentle workout.
  Relaxation – Listening to pleasant music, meditating or reading an enjoyable book are a few ways of relaxing.
  Diet – Regular well-balanced meals will help maintain your energy levels and keep you physically and mentally well.

• Support – Having a friend or someone you can talk to about what you are experiencing, without judgement, is important. Sharing your experience can give you comfort, strength, and reduce feelings of isolation. Talk to a Lifeline telephone counsellor 13 11 14 or contact your local ARAFMI who can give you information and support (see resource list).

• Planning – Planning ahead can make things more manageable. Include the person you care for in the planning process. You may need to plan:
  A day-to-day routine. It helps to have some structure in the day, such as regular meal times. Introduce gradual change to prevent boredom.
  Time for yourself.
  A plan of action in case of an emergency. Make a written agreement with the person you are caring for. Have a list of important phone numbers (GP, psychiatrist, case manager, hospital, crisis team etc) on hand.

Have an up-to-date list of medications on hand, and find a friend or family member who is able to step in if you are suddenly unable to care. It may be helpful to check with Centrelink about financial assistance.

What if things are getting worse?

As a carer you are in a good position to notice changes in the person’s condition. If his or her health or behaviour deteriorates, get help as soon as possible. Symptoms to watch for include hallucinations, withdrawal, severe mood swings, religious obsessions, delusions and excessive alcohol and drug use.

At times your friend or relative may feel suicidal. Be aware of the warning signs of suicide which include talking about suicide, feeling hopeless and/or
worthless, giving away personal belongings, risk taking, withdrawing, tying up affairs and saying goodbye, or suddenly feeling happy or at peace. Take suicide thoughts and behaviour seriously: ask the person directly if he or she is suicidal. Explain that you want to help. Get help for yourself. You can discuss your concerns with a Lifeline telephone counsellor 13 11 14. In an emergency, contact the local crisis team or ring 000.

Caring for someone with a mental illness may be difficult and frustrating but may also be rewarding. Don’t get discouraged. Try these tips and don’t forget to care for yourself. Use all the resources available to you.

Useful resources
ARAFMI (Association of Relatives and Friends of the Mentally Ill) – call the Lifeline Information Service for your state association.

Commonwealth Carer Resource Centre
Free call 1800 242 636 Free call except from mobile phones. Calls from mobiles are charged at mobile rates.

Commonwealth Carer Respite Centre
Free call 1800 059 059 Free call except from mobile phones. Calls from mobiles are charged at mobile rates.

Commonwealth Carelink Centres
Free call 1800 052 222

Carer payments
Centrelink, information and applications 13 27 17

Guardianship Board/Mental Health Tribunal
Call the Lifeline Information Service for state contact numbers

SANE Australia Helpline
Free call 1800 187 263

Lifeline 13 11 14: 24-hour telephone counselling and referral to other support services

Useful web sites
Carers Australia

Multicultural Mental Health Australia
http://www.mmha.org.au

SANE Australia
http://www.sane.org

This Tool Kit has been produced by the Lifeline Information Service as a public service. You are welcome to reproduce it without alteration.

We invite your feedback and comments at infoservice@lifeline.org.au