

The Toowoomba Clinic

FAMILY AND CARER HANDBOOK

MAY 2018

REF: M06_V01

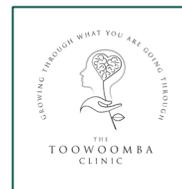
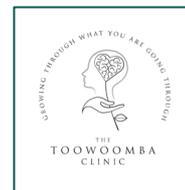


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1.0 Introduction

“Our friends are amazed how we have coped with our son’s mental illness. We just did what families do when you love someone. Our journey has been like a rollercoaster. At times it was stressful and distressing, and times when you feel isolated and lonely, but we learnt to ride the rollercoaster.

The things that helped us along the journey was getting the right information and the right help so we have been able to stay in our son’s life and support his recovery which was worth it in the end” – Carer

Living with the challenges of mental health issues can have a profound impact on both the person experiencing it, and on the family and friends who are caring for them. If someone you care for is living with mental illness, especially if it is new for you, it is likely you already feel worried and overwhelmed about the situation and what lies ahead.

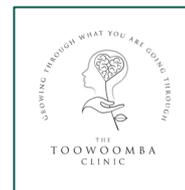
In Australia, mental illness affects around one in five people. While each person’s level of distress is different, most people fully recover or are able to have their symptoms well controlled by the many treatment options.

Family and friends play a vital role in supporting someone with lived experience. Good information, support and assistance, your caregiver support can mean a positive and life enhancing one for everyone.

2.0 Who are carers?

For the purposes of this information booklet, The Toowoomba Clinic considers carers to be the primary support person for an inpatient at the Clinic. Carers may be husbands, wives, children, partners, flatmates, workmates, parents or close friends. In this guide, the patient being cared for is referred to as “your loved one”.

After your loved one’s discharge from the Clinic, your role as a carer is to provide ongoing support, which may be physical, emotional, financial or social. At times, this role can be to the detriment of your own employment, relationships, social roles, physical and/or own mental health. Therefore, being part of a carer support group can be beneficial.



2.1 Valuing Carers

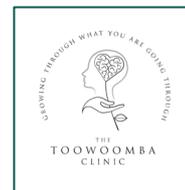
The Toowoomba Clinic recognises that carers play an invaluable role in the support for a person with mental illness. The Toowoomba Clinic also recognises that carers play an important part in the successful treatment and recovery of a loved one. We encourage working with partnership with carers to provide safe and high-quality care for your loved one. This booklet has been developed to provide useful information to carers.

2.2 Carer Rights and Responsibilities

The Toowoomba Clinic strives to provide a safe and high-quality of care for your loved one. Carers are invaluable members of the support network who can assist our staff by respecting the wishes of their loved one and complying with the rules of the Toowoomba Clinic. Carers can sometimes become frustrated when they are not provided with information about their loved one's treatment plan or progress due to privacy legislation. It is important for you to discuss with your loved one about who they would like to nominate to be provided with this information.

You and your loved ones have certain rights about the nature of care provided by The Toowoomba Clinic or any other health care provider. The Toowoomba Clinic upholds your rights as a carer which include the:

- right to respect for individual human worth, dignity, and privacy.
- right to comprehensive information, education, training, and support to facilitate their understanding, advocacy, and care for the loved one you provide care for.
- With consent of the patient, carers are entitled to:
 - Have access to your loved one whilst they are an inpatient of the Clinic.
 - Be consulted by health professionals about options under consideration for the treatment, care, and welfare of your loved one.
 - Arrange support services such as respite care, counselling and community nursing services and facilities.
 - Exchange information with those providing treatment concerning your loved one's lifestyle and their relationship with others.
 - Information concerning family relationships and any matters relating to the mental state of your loved one towards the health professional.
 - Seek further opinions regarding the diagnosis and care of your loved one.



- Place limits on their availability to your loved one.
- Access mechanisms for complaints and compliments, and redress if they have any concerns.
- Assistance with their own difficulties which may be generated by the process of caring for or acting as an advocate for the patient.

At The Toowoomba Clinic, our expectations of a carer is to:

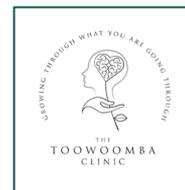
- Respect the individual human worth and dignity of your loved one with a mental illness.
- Consider the opinions of health professionals and recognise their skills in provision of treatment and care for your loved one with a mental illness or mental health disorder, and
- Cooperate as much as possible, with reasonable approaches to treatment and care aimed at the recovery of your loved one, and their optimal personal autonomy and self-actualisation.

2.3 Compliments/Complaints

The Toowoomba Clinic is committed to the provision of safe and high-quality health care. We welcome feedback relating to your experience of care as a carer. Your feedback, regardless of whether it is a compliment or complaint, assists The Toowoomba Clinic to improve services provided to our patients, carers and visitors. Feedback is anonymous unless you wish to receive a personal response to your feedback. We are happy to receive feedback in person, by phone, in writing or via our email address.

If you are unhappy with any aspect of your loved one's care, or feel uncomfortable about directly approaching staff at The Toowoomba Clinic, can make complaints in several ways:

- Using the Feedback Form – Compliments and Complaints available in public areas or on request at The Toowoomba Clinic
- contact the Australian Health Practitioner Regulating Authority (APHRA) on 1300 419 495 or via the website at www.ahpra.gov.au.
- Contact the Office of the Health Ombudsman, Telephone: 133646, Website www.oho.qld.gov.au; Email: info@oho.qld.gov.au; Address: PO Box 13281 George Street Brisbane QLD 4003



3.0 What are the benefits from the hospital admission?

There are benefits from your loved one's hospital admission. Some positive things are:

- Peace of mind knowing that your loved one will receive expert professional care on a full-time basis and that their needs will be recognised and met properly.
- Being comfortable that your loved one 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 time 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, use this time to replenish some of your own reserves. If you have become run down in the lead up to your loved one's admission, this can be a good time to focus on regaining your strength when necessary.

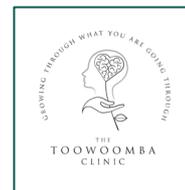
Often carers benefit from knowing they are not alone and not isolated. A hospital setting can reinforce the belief that they are not alone and there are many other carers in a similar situation.

4.0 Visiting Hours

You are welcome to visit your loved one during their admission. Parking for visitors is available free of charge on the grounds. Visitors are requested to sign in and out of the clinic using the Visitor Register. The Toowoomba Clinic insists visitors do not visit during group program session times. The visiting hours are 4.00 pm – 8.00 pm during weekdays, and 2.00 pm – 8.00 pm on weekends and public holidays. Visiting outside of these times should be arranged in consultation with nursing staff. Children must be directly supervised by visitors always.

5.0 Smoking

The Toowoomba Clinic is a smoke-free facility. Smoking in buildings and on the grounds of The Toowoomba Clinic is strictly prohibited.



6.0 Infection Prevention

The Toowoomba Clinic undertakes strict infection prevention measures to minimise the risks of transmission of infection to a patient, carer or visitor. Staff continually undertake precautions and monitoring in the clinic.

Hand hygiene is important in preventing transmission of infection. You are encouraged to wash your hands after using the bathroom, before eating. Antiseptic hand gel is available at various locations throughout the Clinic.

Any visitor can bring an infection into the clinic. The Toowoomba Clinic recommend that visitors with symptoms of illness such as influenza or gastroenteritis or other transmissible illness refrain from visiting until they are symptoms free for at least 48 hours. More information on specific illnesses can be obtained from nursing staff.

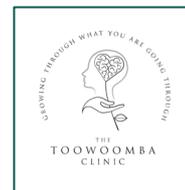
7.0 Escalation of Care

Carers know their loved one better than the treating team. Sometimes, they are the first to notice a deterioration in either mental or physical condition, (e.g. such as the person is getting worse or not as good as they were). The Toowoomba Clinic encourages carers to raise any concerns that may represent a deterioration in mental or physical conditions by reporting their concerns to nursing staff or using the emergency buzzer.

Nursing staff will respond by making a thorough assessment of your loved one including an assessment of their physical observations or mental state and clinical risk. Nursing staff will notify your loved one's treating psychiatrist of the assessment, so your loved one's treatment and care can be modified accordingly.

8.0 Zero-tolerance of Aggression

The Toowoomba Clinic strives to provide a safe and comfortable environment for a wide range of people. The Toowoomba Clinic has a zero-tolerance for aggression. Verbal and physical aggression will not be tolerated. Visitors who engage in aggressive behaviour will be asked to leave the premises.



9.0 What is mental illness?

Mental health issues are common. Almost one in five adult Australians are affected by some form of mental illness. A mental illness or disorder is a diagnosable illness that can affect a person's thoughts, feelings and behaviour and it can significantly impact on a person's ability to take part in everyday activities, such as work, maintaining relationships and looking after yourself.

Most people with a lived experience recover well with appropriate ongoing treatment and support. There are many different types of mental health issues and it is important to remember that this can affect people in different ways. Sometimes people with a lived experience can behave in ways that are confronting, confusing or even frightening. Very often, this behaviour is misunderstood. Knowing how mental health challenges affect your loved one is perhaps one of the most important aspects of a caring role, and a valuable tool in supporting their recovery journey. Your loved one should not be defined by their mental illness. They continue to be mothers, fathers, sisters, brothers, sons, daughter, grandsons, granddaughters, aunts and uncles. They continue to have opinions, strengths, talents, skills, likes and dislikes. Their rights for individuality need to be respected, regardless of their mental illness.

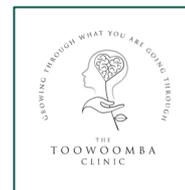
9.1 Understanding mental illness

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 and unfamiliar. It is important that both you and your loved one understand the symptoms of mental illness, treatment options and medications. Information about mental illness can be obtained from a range of sources including the treating doctor, health professionals, mental health organisations and internet sites. We encourage carers to write down their concerns especially about symptoms or other problems that you may wish to clarify with the treating staff.

9.2 Treatment options for mental illness

Treatment options for mental illness include:

- Medications which target symptom management and prevent relapse
- Cognitive behavioural therapy (CBT)
- Counselling
- Group therapy
- Individual therapy
- Self-help and stress management



Combinations of these treatments are often the best approach. It is important that you understand what treatment is being proposed and how it can help. Your loved one's treating doctor is able to provide you with information on your loved one's prescribed medications including its use, the usual dose ranges, possible side effects and what to do if side effects are experienced, the length of time it needs to be taken, what happens if doses are missed, how medications can interact with other medications (prescribed and over the counter medicines), effects on other illnesses your loved one lives with, precautions needed while taking the particular medication (e.g. avoiding alcohol).

Information sheets on specific treatment options and medications can be obtained from the nursing staff.

9.3 The effects of mental illness on different family members

When caring for a friend or relative, the carer's needs often get lost. To care for another, you also need to care for yourself. Having a loved one with a mental illness can affect family members in different ways:

Parents and spouses of someone with a mental illness often experience feelings of fear, guilt and anger or shame along with deep feelings of concern for their loved one. There may also be a sense of loss of the person who 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.

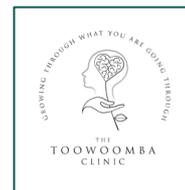
Brothers and sisters can experience a range of emotions including confusion, embarrassment, jealousy of all the attention that is being paid to the sibling, and even a fear of developing a mental illness themselves.

Young children can find it difficult to understand why a parent is suffering from a mental illness. It is important for them to understand that these conditions are real and like physical illnesses 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. However, they may have already been given misinformation. Teenagers respond best to an open dialogue that includes give and take.

9.4 Taking care of yourself

Caring for yourself may mean taking time out to recognise your limits. No-one can be a carer every hour of the day. Caring for yourself means taking time to do activities you enjoy. Explore if there is another relative or friend who is willing to



share the role of carer. For a longer break, consider arranging respite care by contacting The Commonwealth Carer Respite Centre, on 1800 200 422.

Manage your own stress by:

- Having a positive attitude
- Taking regular exercise such as walking, gardening, dancing, yoga or anything that gives you a gentle workout
- Listening to pleasant music
- Reading an enjoyable book
- Meditating
- Eating a regular healthy diet
- Talking to someone about your stress
- Sharing your experience can reduce feelings of isolation and provide a source of comfort

A checklist for self-care may include:

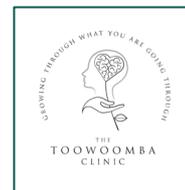
- Do I have someone I trust to talk to about my experience; someone who is non-judgemental?
- Do I take enough breaks from my carer role?
- Do I have regular times for relaxation?
- Am I getting enough regular exercise?
- Am I eating healthy meals on a regular basis?
- Do I get enough sleep?

It is also useful to consider the following:

- Developing a plan of action in case of an emergency
- Making a written agreement with your loved one
- Understanding the early warning signs of relapse
- Having a list of important phone numbers and crisis contacts available (GP, psychiatrist, Acute Care Team, hospital etc)
- Having a list of current medications on hand
- Having someone else who can easily step in if you are unable to care for your loved one.
- Acknowledging and talking about your feelings about the impact of your loved one's mental illness.

Some tips for easing distress that you or your family may be experiencing

- 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 may vary as well.
- Determine the level of care you can realistically provide and ask our staff if you would like referral to external agencies to ensure continuity of care for your loved one once they return home.
- Talk honestly and openly 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, giving up alcohol, eating properly etc) or solve all their problems.

Consider what you can reasonably do to support your loved one. Discuss this information with other family members and the health professionals involved in your loved one's care. It is important to remember there is a team of people looking after your loved one and you can't be totally responsible for their welfare and wellbeing.

10.0 Where to get help

10.1 Carer Consultant

The Toowoomba Clinic has established a Carer Consultant position. The carer consultant will work closely with patients, families and carers, and service providers to ensure the carer's perspective is incorporated at all levels of service provision. The Carer Consultant is available to provide you with support and assistance in addition to their role in improving the safety and quality of services at the Clinic. You can participate in activities coordinated by the Carer Consultant by discussing your interest with nursing staff.

10.2 Information and resources

Beyond Blue	Tel: 1300 224 636 www.beyondblue.org.aum
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Black Dog Institute	www.blackdoginstitute.org.au
Children of Parents with a Mental Illness (COPMI)	www.copmi.net.au
Family Drug Support	Tel: 1300 368 186 www.fds.org.au
Headspace	www.headspace.org.au
Reachout	www.au.reachout.com
Relationships Australia	www.relationships.org.au
Sane Australia	Tel: 1800 187 263 www.sane.org
Siblings Australia	www.siblingsaustralia.org.au
Transcultural Mental Health Centre	Tel: 1800 648 911
Al-Anon Family Groups Australia	www.al-anon.org/Australia
Kids Helpline	Tel: 1800 55 1800
Family Drug Support	1300 368 277
Mental Illness Fellowship Australia	Tel: 08 8272 1018 www.mifellowshipaustralia.org.au