

CARING FOR A LOVED ONE WITH PSYCHOSIS OR SCHIZOPHRENIA

A Carer's Guide to Understanding the Illness and Keeping Well

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Authors' Note

Whilst schizophrenia and other psychotic disorders are conditions that may require long-term management, it is important to remember that with effective treatment and support the majority of individuals lead full and active lives. Enjoying meaningful relationships, caring for a family, holding down a job and contributing to the local community can all be a part of your loved one's life.

The term "patient" is used throughout this booklet to denote those who have been diagnosed with a mental illness, and the terms "psychosis" and "schizophrenia" are used to describe the mental illness that is diagnosed according to criteria found in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

There are points throughout this booklet where statements or stories from our contributors have been included. The names of all individuals have been changed to protect the identity and respect the privacy of those who have shared so thoughtfully.

Some of the materials in this booklet are adapted from the Optimal Health Program (OHP), a self-management program which promotes hope, growth and partnership. Frameworks for Health (FFH), St Vincent's Hospital Melbourne (SVHM), has been dedicated to translating the OHP into everyday clinical practice through program development, research and training. The team was formerly known as the Collaborative Therapy Unit (CTU), based at the Mental Health Research Institute.

Cover Art: "Flourish" Artist: Helen Wilding

Helen Wilding is an artist and Research Librarian at St Vincent's Hospital in Melbourne. This artwork contributes to the Caring Together Art Journal Project, a project that aims to help carers, consumers and practitioners to work together by starting a conversation, sharing different viewpoints, promoting mutual respect and understanding, and brainstorming how we can work together to support recovery.

DISCLAIMER

The information contained in this booklet is not intended to be a substitute for medical care. Decisions regarding treatment are complex medical decisions requiring the independent, informed decision of an appropriate health care professional. Reference to any medication or substance does not imply recommendation by the authors who accept no responsibility for any clinical untoward event that may arise from following the recommendations contained herein.

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The names of individual contributors have been changed to protect the identity and respect the privacy of those who have shared so thoughtfully.

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Who is This Booklet For?

This booklet was written to support people with a loved one with psychosis or schizophrenia. It aims to share practical information about the diagnosis, and offer advice about handling common experiences that can go along with it.

Whilst caring for a loved one can be incredibly rewarding, it can sometimes be difficult to focus on your own physical and emotional wellbeing. This may lead to you feeling stressed or overwhelmed, and can start to impact on your relationships with others. This booklet also shares some strategies for noticing and managing times that you are feeling stressed, so that you can help to maintain the good health of both you and your loved one.

If you don't look after yourself, you won't be able to look after anyone else.

Some parts of the booklet encourage you to reflect on your own experience and write down information relating to your own, or your loved one's, health. You might like to photocopy these sections as your thoughts and strategies might change over time.

Throughout these pages, you'll also find information that is highlighted and put in boxes like this one. These are the take-home messages that are particularly important to remember. When lives are busy and reading time is limited, these messages may be the easiest to flick to and use as quick reminders.

The information in this booklet might lead to you wanting to know more about schizophrenia or clarify information that you already know. We strongly encourage you to approach a member of your loved one's mental health team with any questions or thoughts that you might have. This can often help you to understand more about your loved one and can help everyone to tailor care to your needs.

What is Psychosis?

Around 3 in 100 people will have a 'psychotic episode' at some time in their life. A psychotic episode is a period of time that someone is experiencing psychosis.

'Psychosis' is a word used to describe changes in the way a person thinks and experiences the world, that is out of touch with reality. During a period of psychosis, a person might experience the following:

Delusions

A person is experiencing a delusion if they have a very strong belief about themselves, other people, or the world in general, that is not based in reality and not shared by other people of the same culture. For example, a person might have a delusion that they are being followed by someone who wishes them harm, even though they are not. This can sometimes be confusing or frightening as your loved one may find it hard to know what is real and what is not.

Hallucinations

A person is experiencing a hallucination if they can hear, see, taste, smell or feel something that is not really there. For example, your loved one might hear somebody talking about them, even though there is no one else in the room.

'I heard voices and recognised that other people can't hear them' (Sarah, patient)

Confused thoughts

Often a person with psychosis can feel like their thoughts are muddled. Sometimes, this might affect their ability to put their thoughts together so their speech can seem jumbled and difficult to follow.

Psychotic episodes can last from days to months and usually require treatment to get better. However, some people will experience only one episode and then recover fully.

'Sometimes it's hard to concentrate when there are voices.' (Ben, patient)

What is Schizophrenia?

Fewer than 1 in 100 people will develop schizophrenia. Schizophrenia affects people from all nationalities and affects both men and women equally. A man is most likely to develop schizophrenia from his late teens to mid-twenties, and a woman is most likely to develop schizophrenia from her mid-twenties to mid-thirties. However, schizophrenia can develop at any time in a person's life. Every person's experience of schizophrenia is different, but there are some clusters of symptoms that people with schizophrenia might experience.

Positive symptoms

Also known as psychotic symptoms, these are the same as the symptoms of "psychosis" described on the previous page (i.e. delusions, hallucinations, and confused thoughts).

Negative symptoms

As well as the symptoms of psychosis, you may notice that your loved one has trouble:

- showing their emotions
- getting motivated or starting activities
- expressing themselves
- getting enjoyment from life
- managing social situations
- thinking quickly

Sometimes, families can feel frustrated as these symptoms can look as though their loved one is simply being lazy. It is really important to remember that this is part of your loved one's illness, and that there are some treatments that can help to make these symptoms better. Try to remember it is not their fault and they can't simply "snap out of it."

Cognitive or "thinking" symptoms

A person with schizophrenia might also experience difficulty in their thinking, or "cognitive function." For example, they may have trouble:

- paying attention
- making plans
- deciding what to do first
- remembering things that have happened

A diagnosis of schizophrenia is given if a person has experienced at least six months of negative symptoms and one month of the positive symptoms of psychosis.

Your experience...

How does psychosis or schizophrenia affect your loved one? What are some of the symptoms they experience? It may be helpful to list them below so you can spot them more easily when they occur.

Insight

The level that someone understands their illness is called 'insight'. It can sometimes be difficult for people with psychosis and schizophrenia to recognise that their thinking and experience of the world has changed, and that they are experiencing psychotic symptoms. A person's insight can affect their understanding of the need for treatment and/or their ability to make decisions about their care. An individual's insight can change with time and with different stages of the illness. Unfortunately, people caring for a loved one with poor insight can sometimes feel caught in the middle between their loved one and the mental health team, particularly if they have very different ideas about what might be helpful.

How can I talk to my loved one about their illness?

- Choose a time that you are both feeling calm and ready to talk
- Try to talk about only one thing at a time
- Try not to confront them with your view of what is happening to them. Remember that their experience is very real to them, even if it doesn't fit with what you think is happening
- Try to understand what the name of their illness means to them

What isn't Schizophrenia?

Sometimes, the signs of psychosis have not been present for long enough for mental health staff to make a diagnosis of schizophrenia. In this case, your loved one might be given a diagnosis of:

- Brief Psychotic Disorder: if they have experienced positive symptoms for at least one day and less than one month, but have not had prominent negative or cognitive symptoms.
- Schizophreniform Disorder: if they have experienced the symptoms of schizophrenia for more than one month but less than six months.

Only some of the people who are diagnosed with a brief psychotic disorder or schizophreniform disorder will go on to develop schizophrenia.

There are several conditions that are similar to, but not the same as, schizophrenia. Sometimes people with these conditions can experience psychosis, but the treatment for each of the conditions can be different.

If your loved one has only experienced psychotic symptoms at times that their mood is very low or very high, they may have *depression* or *bipolar disorder* (previously known as manic depression). If they have had several episodes of low or high mood, but have also had times where they have had psychotic symptoms when their mood was stable, they may have a diagnosis of *schizoaffective disorder*.

Psychotic symptoms can be a part of many other types of mental health problems. For example, some people with *eating disorders* and some *anxiety disorders* can also experience worries that are out of touch with reality. Sometimes, people with *borderline personality disorder* can also experience psychotic symptoms; this can happen at times of high stress, or at times that they are feeling down or alone. Some people with *schizoid*, *schizotypal* or *paranoid personality* traits can appear to have psychotic symptoms such as unusual beliefs, seeming withdrawn, or believing that the world is against them. These symptoms tend to be stable from late adolescence, and treatment is usually in the form of talking therapy rather than medication.

Some people can experience psychotic symptoms or trouble with motivation and concentration when they are using *alcohol* and *other drugs*. These symptoms can sometimes continue for weeks after stopping the alcohol or other drugs. If your loved one only experiences psychosis when they are using drugs, they may not have schizophrenia.

However, using drugs such as *cannabis* can add to the risk of having a psychotic episode for people who are already at risk.

Some *medical conditions* and *medications* can cause psychotic symptoms or mimic the symptoms of schizophrenia. For example, some infections can affect the way that the brain functions. Confusion, delirium and dementia can also mimic psychosis. Some medical conditions can also make psychotic symptoms worse.

It is important that your loved one has a full medical assessment when they first experience psychotic symptoms, or if there is a change in their symptoms.

Why is Diagnosis so Important?

Unfortunately, there are no simple blood tests that can be used to diagnose psychosis or schizophrenia. Instead, a diagnosis is made by recognising patterns of thinking and behaviour over a period of time. This process involves taking a history of symptoms from an individual and their loved ones. The observations of carers, who have often known the individual for a long time, are incredibly helpful in making an accurate diagnosis.

Often, the symptoms of schizophrenia will come and go during a person's life. Some symptoms, especially the negative and cognitive symptoms, can take a long time to get better and may impact on a person's ability to do the things that they want to do. Getting the right diagnosis can help your loved one to get treatment that suits their health needs and can support them to achieve their goals.

A prompt clinical assessment is critical, as early treatment can affect the course of the illness and the recovery process. If you suspect a loved one may be suffering with the symptoms of psychosis or schizophrenia, encourage them to see their GP or a mental health specialist as soon as possible.

What Can Accompany Schizophrenia?

People with a diagnosis of psychosis or schizophrenia may also experience other mental health problems that might affect their recovery.

Depression

Around 1 in 4 people with schizophrenia will experience depression at some time in their lives. We often use the word “depressed” to describe the moments that we are feeling sad or down. However, depression in the clinical setting lasts longer than just a few days and can affect our thinking, feeling and behaviour. Generally, the word ‘depression’ describes a period of very low mood that lasts at least two weeks without relief and often goes along with:

- *A lack of enjoyment*: activities that used to be fun are no longer enjoyed, or enjoyed much less.
- *Changes in sleep*: sometimes trouble going to sleep, waking for long periods during the night, or even sleeping much more than you usually would.
- *Changes in appetite*: including going off your food or eating more than you usually would.
- *Low energy levels*: feeling as though you don’t have enough spark to do what you need to do, and tiring quickly.
- *Changes in thinking*: people with depression often describe feeling guilty, having trouble holding hope for the future, trouble concentrating and feeling low in self-confidence.
- *Suicidal ideation*: some people with depression may have thoughts about or an unusual preoccupation with suicide.

Treatment for depression is important as it can not only affect your loved one’s enjoyment of life, but can also affect their recovery following a psychotic episode. Importantly, experiencing depression can also put someone at higher risk of having suicidal thoughts and acting on these thoughts.

Depression can occur at any time, but a person with schizophrenia might be more likely to develop depression around the time of an episode of psychosis or immediately after. Some people might experience particular symptoms of depression in the days before an episode of psychosis. Others might experience depressive symptoms following an episode of acute psychosis, which is sometimes known as *post-psychotic depression*. Depression can also occur during a psychotic episode. Unfortunately, the symptoms of schizophrenia can

sometimes make it difficult to recognise depression as some symptoms are similar. Also, psychosis can also make it harder for people to express how they are feeling. It is important to let someone know if you are worried about your loved one's mood, as family members and carers are often well placed to notice subtle changes in how their loved one is feeling or thinking.

Depression can lead to suicidal thoughts. If you think your loved one is having suicidal thoughts, seek help as soon as possible from the mental health team.

Demoralisation

If a person experiences frequent disappointment, particularly about the way that their life is going, they can start to feel demoralised. People who feel demoralised can feel discouraged, can dwell on the past with few hopes for the future, and can feel as though they have little control over their lives. Sometimes, people with schizophrenia can find it difficult to put these feelings into words so careful listening and making time to talk can be helpful. People who are feeling demoralised can also often benefit from cognitive behavioural therapy and other talking therapies such as motivational interviewing.

Anxiety

More than one-third of people with a diagnosis of a psychotic illness will also experience an anxiety-related illness at some time in their life. Some people experience the feeling of anxiety as part of their schizophrenia, whereas others might develop a separate anxiety disorder. Like depression, anxiety symptoms can also be a warning sign before an episode of psychosis.

The experience of anxiety is usually a combination of physical and psychological symptoms including: intense fear or worry, feelings of dread, a pounding heartbeat, shortness of breath, sweating, dizziness, and shaking. The fears or worries themselves may be related to going out to public places, social situations, worries about germs or contamination, generalised distress about a number of things constantly, or a personalised distress that has a particular meaning to the individual.

Anxiety symptoms may be so severe that they impact on the individual's mood stability. Effective treatments are readily available. So, once again, encouraging your loved one to talk to their doctor about the difficulties they're experiencing with anxiety can make a big difference to their overall well-being.

Alcohol and Other Substances

A 'substance' refers to anything that a person takes which changes their thinking or feeling. Not all substances are illegal, but those that are can carry extra risks such as getting into trouble with the police. Some medications can be considered to be a substance if they are used in ways that are not recommended by medical professionals. Many of us use some substances on a weekly or even daily basis, particularly caffeine. Some examples of commonly used substances are:

- Caffeine (e.g. tea, coffee, energy drinks, cola drinks, chocolate etc.)
- Alcohol (e.g. beer, wine, spirits etc.)
- Nicotine (e.g. cigarettes, cigars, chews etc.)
- Cannabis (e.g. marijuana, hashish etc. Also called "*pot*", "*hash*", "*weed*" etc.)
- Stimulants (e.g. amphetamines, cocaine, methamphetamines etc. Also called "*speed*", "*blow*", "*ice*")

Unfortunately, people with psychosis or schizophrenia are more likely to use substances, to use the substances more often and in larger amounts, and experience more harm due to their use than the general population. For example, people with schizophrenia are five-times more likely to smoke than the general population and will smoke more heavily, drawing more nicotine from each cigarette.

Recognising and managing substance use in people with psychosis or schizophrenia can be challenging as the way that we use substances is often strongly linked to how we are thinking or feeling. Some symptoms of substance use and psychosis are very similar, and both can influence your loved one's behaviour and choices. However, there is now good evidence that people with psychosis or schizophrenia can stop using substances successfully and experience significant improvements in their overall wellbeing as a result.

People living with schizophrenia experience the best outcomes when the treatment for their substance use is incorporated with the treatment for their mental health.

There are effective treatments for difficulties with alcohol or substance addiction. Getting help does take a lot of motivation and courage but can make an incredible difference to the stability of an individual with psychosis or schizophrenia. Sensitively encouraging your loved one to keep an open mind about talking to their doctors about their options to reduce or quit can start the process of addressing this very common problem.

Gambling

Around 0.5-1% of Australians have problems directly relating to gambling. Recent research suggests that people with schizophrenia might be more at risk. There is also good evidence that some mood, anxiety and substance use disorders which are commonly diagnosed with schizophrenia can also make it more likely that a person will have problems related to gambling.

It can sometimes be quite difficult to know when a loved one is experiencing problems relating to gambling. Consider asking your loved one about gambling if you notice that they:

- Have become more secretive or get angry when talking about money
- Take money or possessions without asking
- Are being contacted by creditors
- Are away from home for long periods of time without an explanation

You can support your loved one to get help for problems relating to gambling by encouraging them:

- To learn more about gambling and how it might be affecting them.
- To let someone know that there might be a problem. Support your loved one to talk to their GP or mental health team if they are worried about their gambling.
- To get financial advice. It is important that you also seek professional advice about ways to protect finances.
- Not to ask for cash. Many people who have problems related to gambling believe that their luck will change, or that they will have their next big win soon. Help your loved one to limit their money supply by buying them essential items such as food rather than giving out cash.

How is Schizophrenia Treated?

There are a wide range of treatment strategies that can help to improve symptoms, and help people with schizophrenia to work towards their life goals. Unfortunately, there is no cure for schizophrenia at the moment, but many treatments can help to support your loved one to get well and stay well.

Many people with schizophrenia benefit from a combination of treatments, which might include medication, practical help, talking therapy, and lifestyle strategies.

Medications

A brief overview of possible medications will be given here, but please see the Psychiatric Medication Information Handbook published by the St Vincent's Mental Health Service for more detailed information. Copies can be obtained through St Vincent's Hospital and the contact details are provided at the end of this booklet.

Anti-psychotics

The main type of medication used for the treatment of psychosis and schizophrenia are called *antipsychotics*. These medications target the chemical messengers of the brain (especially dopamine) and can help improve psychotic symptoms. Depending on their needs, your loved one might take antipsychotics in the form of tablets, dissolvable wafers, injections, or a combination of these.

Mood Stabilisers

These medications are usually prescribed if a person is experiencing serious changes in mood as part of schizoaffective or bipolar disorder. This group includes lithium and medications which also work for epilepsy. As our bodies can process these medications differently, your loved one may need to have regular blood tests to make sure that they are taking the right amount. Some antipsychotic medications can also help to even out mood.

Anti-depressants

Antidepressants can be used for low mood and anxiety-related disorders such as generalised anxiety, social phobia, post-traumatic stress disorder, and obsessive compulsive disorder. Antidepressants are generally effective and contribute to the recovery of about two-thirds of people who take them.

Anti-anxiety medications (aka anxiolytics)

These medications include benzodiazepines and other types of medications that can also help with sleep. They can be helpful for the short-term (usually days to weeks) relief for the symptoms of anxiety, but do not treat the cause of the worries or sleep problems. Unfortunately, people taking these medications can find that they need higher and higher doses, and find it difficult to stop. Antidepressants and talking therapies are generally preferred for the long-term treatment of anxiety.

Unfortunately, there is no “one size fits all” medication, so it may take a few trials to find the right medications for your loved one. Medications can sometimes take days to weeks to start working, and you may not notice the benefit straight away.

Each medication has a range of side effects that can range from minor annoyances to serious health problems. Although we can predict the types of side effects that each medication can cause, each person may experience these side effects differently. It is important to balance the helpful effects of medications against the side effects of the medications, and how they make your loved one feel, when deciding which treatment strategy is the best fit for them.

Your sensitivity and understanding, whatever the issue, will help ease the personal difficulties they may be facing because of the medication side effects.

Most side effects last only a few weeks after starting or changing a dose, but some can persist. Some of these side effects can improve with other medications or lifestyle changes. Sometimes, the side effects of a medication can be helpful. For example, some antipsychotic medications can be helpful for sleep.

It is important that your loved one talks to their mental health team about what to expect when starting a medication. This can help you to monitor for side effects, keep your loved one motivated whilst waiting for health benefits, and plan to reduce the impact of side effects on your loved one’s health and wellbeing.

It is also important to take antipsychotic and other mental health medications as prescribed, as sometimes missing only one or two doses can contribute to a relapse.

Always remind your loved one to take their medication as it has been prescribed, and not to experiment with stopping or changing the dose.

To help your loved one remember to take their medication regularly, here are some tips that might help:

- Take the medication at a set time every day.
- Set a daily alarm to remind the person to take their medication each day.
- Link it to a regular activity, such as brushing their teeth.
- Keep a simple medication diary or mark it on a daily calendar.
- Use a dosette box or a Webster pack that can be pre-filled by the local pharmacy.

Your experience...

Make a list of the things that can affect whether your loved one takes their medication regularly. This list can help your loved one's treating team to find the right medications.

E.g. Feeling too sleepy in the morning to remember to take medications

Your experience...

Make a list of your loved one's medications and any unwanted effects that they have experienced.

Name of medication	How medication is taken	Unwanted side effects
E.g. antipsychotic "x"	1 x 10mg tablet at night	Very tired in the mornings

Where to get more information about medications

Mental Health Team. Your loved one's mental health team can provide:

- Information about types of medications and why they have been prescribed
- Alternatives to these medications and the risks and benefits of each
- Information about safely making changes to medication regimes
- Information about, and monitoring for side effects
- Practical advice about supporting your loved one to take their medication

Pharmacist. Your local pharmacist is an excellent resource and can provide:

- General information about medications, including physical health medications
- Specific information about your loved one's medications, including when and how to take it for best effects
- Interactions between medications
- Dispensing options such as blister packs, webster packs and sachet packs
- Practical advice about supporting your loved one to take their medication

Other resources:

For more detailed written information about medications and managing side effects, please read the Psychiatric Medication Information Handbook which is produced by St Vincent's Hospital, Melbourne.

Medicinewise (www.nps.org.au) is produced by the National Prescribing Service (NPS) and provides written medication information for consumers, carers and clinicians. The NPS also provides a telephone medication advice service (1300 MEDICINE or 1300 633 424) focusing on medication effects, side effects, use in pregnancy and breastfeeding, and how to take and store medications safely. They do not provide emergency assistance, specific health advice, or second opinions.

- If you are concerned that your loved one may have taken too much medication, appears unwell, or for any other emergencies, contact 000
- For less urgent information about suspected poisoning or too much medication, please contact the Poisons Information Centre (13 11 26)
- For urgent mental health advice, please contact your local area mental health service

Psychological Therapies

Psychological therapies are talking therapies that can help manage some of the symptoms of psychosis and schizophrenia. They are used as an adjunct to medication, and do not replace medications.

- *Cognitive Behavioural Therapy (CBT)* is one of the most common and well-studied types of psychological therapy. It has been adapted to target both the psychotic and negative symptoms of schizophrenia. The therapy focuses on the “here and now” rather than looking to the distant past. CBT aims to lower distress, challenge frightening internal experiences, and help people to achieve their life goals, by looking at the relationships between our thoughts, feelings and behaviours. This sometimes includes practical exercises such as relaxation techniques, keeping a thought diary, and problem solving strategies. The effects of CBT get better with practice, so your loved one will need to complete some tasks at home between sessions.
- *Social Skills Training.* It can sometimes be difficult for people who are experiencing symptoms of schizophrenia to feel comfortable in social situations or feel like they “fit in”. For example, some psychotic symptoms such as paranoid thinking can affect the way that your loved one uses facial expression and eye contact to communicate, which can sometimes look unusual to people who are not familiar with them. Social skills training helps to problem solve differences in communication style so that your loved one can feel more confident when talking to others.
- *Family-Focused Therapy* involves working with the individual and their family together to help strengthen the existing support within the family unit. It helps resolve underlying conflicts that might be contributing to distress within the family. This therapy can offer a safe space for members of the family to voice their concerns or fears to each other with the sensitive guidance of a trained family therapist.

Psychological therapy is sometimes referred to as ‘talking therapy’ and helps individuals reframe their experiences in more helpful ways. It can improve your loved one’s quality of life and assist recovery by helping them better understand themselves and overcome the challenges they may face because of their illness.

There are many other types of psychological therapy that you may be interested in helping your loved one look into. When they're ready, encourage them to approach their doctor or mental health practitioner about finding the right sort of therapy for them.

Keep in mind that these therapies take commitment and ongoing work outside of sessions to really be effective. Try to help them integrate what they learn into their daily life.

It's very normal to feel stressed or run down in your caring relationship from time to time. If there are times where you feel overwhelmed or experience symptoms of depression or anxiety, let your own doctor know. They may recommend a short course of individual psychological therapy to help support you through a rough patch. You may also find value in regularly attending a Carer Support Group.

Electro-Convulsive Therapy

Electro-Convulsive Therapy (ECT) is sometimes recommended for people with distressing psychotic symptoms that are not responding to medications. It is often reserved for situations where a person's symptoms are significantly impacting on their health or are life-threatening, for example if they are no longer eating and drinking, or are profoundly suicidal.

ECT is also sometimes referred to as "shock therapy" and has unfortunately received a lot of bad press because of its history and inaccurate information that is sometimes circulated in the general media. ECT is generally safe and can be effective for certain conditions. However, as with any treatment it is important that the risks and benefits of ECT are discussed in detail before starting. Your mental health team can provide information about the procedure, effects, side-effects and alternatives. If ECT is suggested as a helpful treatment for your loved one, ask the prescribing doctor as many questions about it as possible. Inform yourself about aspects that are unclear.

Modern medical practice and equipment has allowed ECT to be administered in a controlled and safe hospital environment with very close monitoring for any physical stress on the body whilst the treatment is being given. A course of ECT usually involves at least six individual treatment sessions spaced over a few weeks. It is common to see a rapid improvement in your loved one's mental and physical state after the first few treatments.

Lifestyle Strategies

Lifestyle strategies are things that we can all do to balance the stressors in our lives. Lifestyle strategies can help to improve not only our mental health but also our physical health. Whilst medications and additional psychological therapies can help your loved one keep their symptoms under control, paying close attention to their lifestyle habits is also important for illness stability. Most often, it is the delicate balance of healthy lifestyle habits, regular helpful medication and beneficial psychological strategies that give your loved one the best chance of maintaining a stable mental state.

Lifestyle habits collectively refer to how individuals choose to live their lives. This involves activities and behaviours that may either have a negative or a positive impact on your loved one and their well-being. You can encourage them to adopt healthier lifestyle habits if you've identified areas that may be creating stress or more vulnerability for ongoing symptoms or clear relapse. By paying attention to the following areas, your loved one's mood can remain better controlled and relapses may be minimised in the longer-term.

- *Maintain stable sleep patterns.* This is vital for optimal mental health. Please read more about it in 'The Importance of Sleep' section on page 33.
- *Nutrition.* Eating several healthy meals regularly each day is also an important part of keeping the mind and body's natural rhythms stable. Try to help your loved one remember the importance of a healthy balanced diet, and try to discourage them from relying on high carbohydrate or fatty meals and fast food options. This will also help prevent the longer-term physical complications of unhealthy diets.

In an average day your diet should include 5-6 servings of vegetables, 6 servings of cereals or grains, 3 serves of proteins, 2-3 serves of dairy and 2 servings of fruit.

- *Exercise.* Regular exercise is great for the mind and body. It's important to help your loved one find a form of exercise that they enjoy doing, so they may keep doing it regularly over time. For example, you may decide to go for walks together every day or several times a week, as a pleasurable way of spending time together with a healthy benefit for both of you.

Try and get at least 30 minutes of exercise each day, such that you work up a bit of a sweat.

- *Substance Use.* Remind your loved one about the negative effects of alcohol, nicotine and other drugs on their mood and on the medications they are taking to keep their health stable. This will help them with their mental health and well-being, but also their physical health.
- *Quitting Smoking.* Unfortunately, people with schizophrenia are very likely to smoke, and tend to smoke heavily. Some aspects of schizophrenia such as feeling socially isolated or bored, or having trouble making decisions or getting motivated, and having friends or family who smoke can affect your loved one's decision to quit.

Having a range of supports and strategies can help your loved one to quit smoking successfully. Please note that changes in smoking can affect the potency of some medications, so encourage your loved one to speak to their mental health team if they are thinking about quitting.

'Knowing how to manage myself overall, regular sleep, having a daily routine, getting sunshine, pacing myself, managing my medications... has made all the difference.'
(Claudia, patient)

- *Minimise stressful situations* whenever this is possible. Whether the source of stress is relationships, work, money, housing or another area of their lives, help your loved one work through the difficulties they're having.
- *Remember the good things!* Help your loved one identify activities or hobbies that they enjoy doing, this can help to restore purpose and meaning to their lives. Encourage them to take time out and regularly insert these activities into their week. For example, they might enjoy playing a musical instrument, singing, watching television or movies, practising yoga, drawing, gardening etc. Depending on what it is, their chosen activity can also help improve their confidence and social skills, especially if they participate in a group setting.
- *Spirituality* may also help. If your loved one adheres to a particular faith or draws strength from a particular spiritual philosophy, encourage them to continue these connections. It is a very individual thing, but many benefit greatly from the support of a greater spiritual community.

'It's a matter of hanging in there with them.' (Nicholas, carer)

Your experience...

Keeping a food diary for a week can be a good way to get a true sense of what your loved one is eating.

FOOD MONITORING DIARY				
	Monday	Tuesday	Wednesday	Thursday
Breakfast	e.g. toast and eggs, OJ			
Lunch	Tuna salad sandwich on rye, water			
Dinner	Lasagne and green salad, water			
Snacks	2 x banana, almonds, 3 x crackers with hummus			
Alcohol	1 x glass of wine			

Your experience...

Help your loved one to plan their activity. Are there some activities you could do together?

WEEKLY EXERCISE PLANNER				
	Monday	Tuesday	Wednesday	Thursday
Week 1	e.g. Walk to the shops (20 mins)			
Week 2	Swimming at the beach (20 mins)			
Week 3	Sit-ups and lunges (15 mins)			

Vulnerabilities, Strengths, Stressors and Strategies

You may be wondering what causes schizophrenia. No one thing causes schizophrenia. Rather, schizophrenia is caused by a combination of factors relating to a person's genetics and early life, environment and stress. Understanding more about our vulnerabilities, personal strengths, strategies and the way that we experience and manage stress can help to us to feel more in control of our health, and feel understood and respected.

Vulnerabilities

Everyone has vulnerabilities. A vulnerability is something that can increase your risk of experiencing symptoms or an episode of illness. However, there are some factors, or *vulnerabilities*, that can add together to make a person more likely to develop schizophrenia. Vulnerabilities are usually ongoing and cannot be changed. These might include:

- Genetic factors. For example, having a family member with a history of mental illness.
- Environmental/non-genetic factors. For example, complications of pregnancy and birth, infections during pregnancy or heavy drug use during adolescence.
- Brain chemistry. Neurotransmitters are chemicals that help to pass messages through the brain. In people with schizophrenia, the levels of some of these chemicals (especially dopamine and serotonin) might be out of balance, or the brain might not process them properly.

It is important to note that many people with these vulnerabilities do not go on to develop schizophrenia.

Your experience...

What vulnerabilities do you think your loved one is or has been exposed to? It may be helpful to list your own vulnerabilities as well.

E.g. family history of illness, complicated pregnancy, heavy drug use in teens etc.

Strengths

What is a strength? Our personal qualities, skills and talents, interests and features in our environment all add together to form our strengths. Our strengths help to balance our vulnerabilities, and we can draw on them at times of stress. Some strengths are things that come naturally to us, whereas others are skills that can be learned.

Some examples of strengths are:

- *Personal qualities*: your personality (e.g. friendliness, sense of humour, hopefulness, honesty, kindness, empathy, generosity)
- *Environmental strengths*: resources that exist outside of your personality (e.g. friends and family community, your job, education, a pet)
- *Skills and talents*: things you are good at (e.g. playing an instrument, solving crossword puzzles, running, cooking, collecting coins)
- *Interest/aspirations*: things you are passionate about (e.g. gardening, watching old movies, becoming a musician, owning a car, going to coffee shops)

Every person's strengths and vulnerabilities are different and some can change at different times during a person's life.

Your experience...

Together with your loved one, write down a list of both of your strengths. Are they similar or different?

Stressors

Stressful life events can be called “stressors”. Stressors are the pressures and demands from the outside world. For example, money troubles, being judged by others, not having time, fear of catching a plane and isolation to name just a few. Stressors can come and go with time. “Stress” is our physical, psychological and behavioural response to stressors. Some life events can be stressful and can trigger the start of schizophrenia in someone who is already vulnerable to developing the illness. They can also contribute to relapse.

Some examples of stressors that might trigger schizophrenia are:

- drug use, especially cannabis, amphetamines and drugs like LSD
- financial hardship
- abuse
- losing something that is very important, such as the loss of a loved one, a partner or a job
- life changes such as moving house, getting married, or going on holiday

Each person experiences stress differently and might identify different life events as stressors. Understanding more about our own stressors and the way that we handle them can help us to find strategies to help balance our stress. It can also help us to plan for future stressors so that they might have less of an impact on our overall health.

Everyday positive stressors (e.g. planning a birthday party) and negative stressors (e.g. a lack of stable housing) can often add together to become cumulative. Cumulative stress can often feel overwhelming and can affect our thinking and the way that our body functions.

You or your loved one might be experiencing cumulative stress if you:

- feel tired often or tire very easily
- often get coughs, colds or infections
- have trouble problem solving and making decisions
- feel overwhelmed by everyday stressors
- notice a change in your appetite or in your sleep
- experience changes in your mood

Being aware of both everyday and cumulative stress can help us to know when to use some of our ‘strategies’ and when to get help. This is particularly important for people with psychosis and schizophrenia, as stress can affect how we experience symptoms, our ability to work with our supports, and our recovery.

Your experience...

We are able to notice stress by identifying the physical, psychological and behavioural signs. Think of an example recently when you experienced feeling 'stressed out'. *This is a great activity to do with your loved one.*

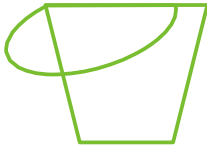
What physical changes did you notice in your body? E.g. sweating, increased breathing, shaking, muscle tension, churning stomach etc.

What kind of thoughts and feelings did you have? E.g. became easily frustrated, felt more/less motivated, felt overwhelmed, became oversensitive to remarks made by others.

What did you do after that situation? E.g. spent more time at home, drank alcohol, procrastinated, avoided communication with friends etc.

How do strengths, vulnerabilities and stressors affect each other?

Imagine that your mental health is a bucket and that your stressors and vulnerabilities are like tennis balls. The vulnerabilities and stressors fill the bucket. When the bucket overflows, we can become unwell.



My mental health

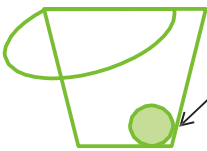


My vulnerabilities



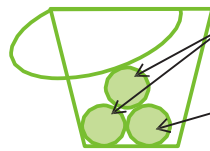
My stressors

We each start out with our own vulnerabilities. These do not tend to change over the course of our lives. Compare My-Linh and Karen as examples.



Low oxygen when born

My-Linh has few vulnerabilities

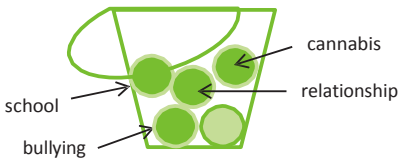


Uncle and grandmother with schizophrenia

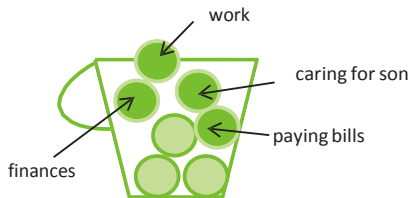
Different brain chemistry

Karen has several vulnerabilities

My-Linh and Karen have different vulnerabilities, but their vulnerabilities alone do not make their buckets overflow. In other words, our vulnerabilities are usually not enough to cause us to become unwell. But what happens when we add stressors?



At the moment, My-Linh has four stressors



At the moment, Karen also has four stressors

Although My-Linh and Karen have the same number of stressors, Karen's bucket is much closer to overflowing. This is because our vulnerabilities and stressors can often add together to cause us to become unwell. Our strengths help to build resilience, or help us to make our bucket bigger so it less likely to overflow.

Early warning signs

Early warning signs are the things that we notice about our thinking, feeling or behaviour that indicate that we might be becoming unwell or are having difficulty coping. Noticing early warning signs does not necessarily mean that an episode of illness is on the horizon, but they can let us know that we are feeling very stressed or overwhelmed.

Some examples of early warning signs might be:

- Feeling less social
- Feeling more suspicious
- Having trouble sleeping
- Using substances more often, in larger amounts, or in ways that are particularly risky
- Being sensitive to bright lights/loud sounds
- Being more sensitive to criticism
- Feeling angry, sad, overwhelmed
- Thinking about suicide

Identifying what you and your loved ones early warning signs are might help to prompt you to put your strategies into action, or ask others for support.

Strategies

‘Strategies’ are the skills, activities and behaviours that we use to respond to stressful situations. We are not always aware of our strategies, and some may be more helpful than others in the long term. Understanding more about the way we respond to stress can help us to harness the helpful strategies that we already use and find new strategies to lower the impact of stressful situations. It is important to use a range of strategies, as they can sometimes become stale or less effective if we use the same ones all of the time. Effective strategies can also help to stop stress from building up over time, or becoming cumulative.

Some examples of strategies that people might use:

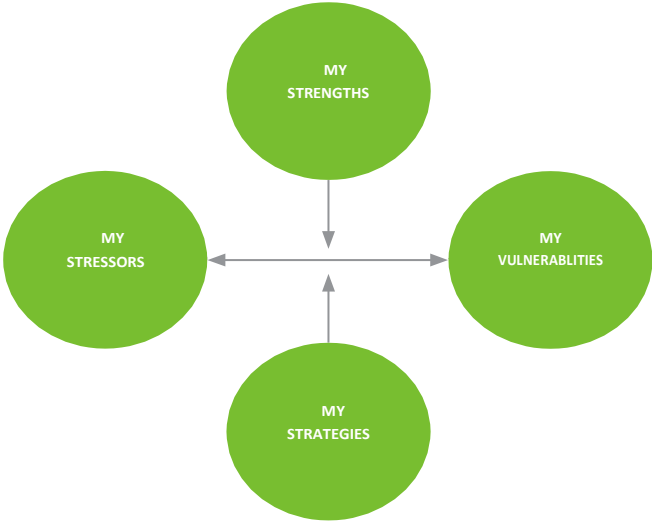
- Smoking
- Listening to music
- Painting, drawing, writing
- Going for a walk
- Meditating
- Deep breathing
- Drinking
- Praying
- Eating healthy food
- Using humour
- Ignoring the problem
- Eating lots of sweets

Notice that some strategies that might be helpful in the short-term may *not* be so helpful in reducing your stress in the longer-term. A good example might be smoking cigarettes. Although smokers report that they smoke to reduce stress, evidence shows that smoking can actually make stress worse over time. Some examples of helpful strategies might be:

- Getting organised
- Eating more fruit and vegetables
- Walking more
- Smoking less
- Having an alcohol-free week
- Having a bath
- Breathing deeply
- Talking to a close friend
- Attending a community centre
- Eating less sugar

Consider working together with your loved one to understand more about the kinds of strategies and supports that are helpful for each of you. Notice where these are similar and where they are different. This can also help your loved one to recognise times that you might be feeling stressed and overwhelmed, and empower them to find ways to support you at these times.

The ‘I-Can-Do’ model below illustrates how all of the factors previously discussed can influence a person’s health and well-being.



Your experience...

Let's explore what your current strategies are. Make a list of the ones you currently use to reduce your levels of stress. Then try to rate how effective you think they are. Can you improve them? There is one table for you and one table for your loved one to complete.

MY STRESSORS (Things that stress me out)	MY CURRENT STRATEGIES (What I currently do)	HOW EFFECTIVE IS IT? (1-10)

MY STRESSORS (Things that stress me out)	MY CURRENT STRATEGIES (What I currently do)	HOW EFFECTIVE IS IT? (1-10)

Well-Being Considerations

The Importance of Sleep

Maintaining a *regular sleep-wake cycle* is important for everyone's general health and well-being. Sleep is critical to survival, just like oxygen, water and nutrition. Unfortunately, it's not usually until sleep patterns becomes terribly disturbed that we realise how much they impact on our physical, mental and emotional health.

It can be difficult for some people with psychosis and schizophrenia to get regular sleep, particularly if they are taking medications that make them drowsy. However, regular exercise and healthy food choices can help with getting good quality sleep.

'Sleep's the most important aspect' (Jane, carer)

You can support your loved one to sleep well by:

- *Finding a routine.* Our bodies have a natural "clock" that tells us when to go to sleep. For some people with schizophrenia, their clock tells them to sleep during the day and stay awake at night. Having a regular wake-up time can help our body clock to get back on track, and eventually you will start to go to bed at a regular time. You might need to set an alarm to get up in the morning, especially in the first few weeks.
- *Getting the right set-up.* Making even small changes to your bedroom can help make big improvements in your quality of sleep. Aim to have your room as dark and quiet as possible, and free of distractions such as televisions, computers and gaming devices. It can be helpful to use earplugs, block-out blinds or eye masks if you are sensitive to noise and light. Watching the clock at night can make us feel more anxious and does not help us to get to sleep, so move bedside clocks so that they can't be seen from the bed.
- *Going outside.* The sun acts as a natural pick-me-up, so going out for a short time in the morning can help get our body clock back on track. Early morning light is particularly good for you. Be careful not to get burnt in summer!
- *Avoiding naps.* Sometimes we need naps, but try to keep them to less than 30 minutes and avoid napping after 2pm.
- *Only going to bed when you're tired.* Lying awake in bed can be stressful and frustrating, so only get into bed when your body is ready to go to sleep (e.g. heavy eye lids, yawning).

If your body isn't ready, try sitting out of bed and reading or taking a warm bath or shower. Some foods such as milk, yoghurt, oats, bananas and honey trigger natural brain chemicals that help with sleep.

- *Relaxing.* Some people find it helpful to use techniques such as deep breathing, muscle relaxation, and mindfulness to help them to prepare for sleep.
- *Cutting back on caffeine.* Cola drinks, coffee, black tea, green tea and chocolate all contain caffeine, a chemical that can upset our natural sleep patterns. Try to cut down the amount of caffeine that you take in after lunchtime by drinking fruit and herbals teas, non-Cola drinks such as soda water or water, and avoiding chocolate in the afternoon.
- *Cutting back on nicotine.* Nicotine is a chemical in cigarettes that can make it difficult to wind down. Try cutting back in the hours before bed or stopping all together.
- *Cutting back on drugs and alcohol.* People can sometimes use alcohol and other drugs to help to get to sleep. Unfortunately, these substances give us poor quality sleep so that we are still tired the next day. Encourage your loved one to make a list of other strategies that might help with sleep and try them instead of using alcohol or other drugs.
- *Getting medications right.* Help your loved one let their doctor or mental health supports know if they are feeling drowsy during the day or having trouble getting to sleep at night, so that they can adjust their medication to help.
- *Making a list of strategies to keep by the bed.* When we get worried about our sleep, it can be hard to remember what has helped in the past. Help your loved one to write a list of strategies that work for them, a perhaps some new ones from this booklet, so that they can tick them off when they are next trying to get to sleep.

Of course, every now and then, there may be nights when it might take a long time to get to sleep or it might be difficult to fall back asleep after waking up in the middle of the night. The most important thing is to try and regulate sleep for the next few nights as strictly as possible, to prevent it from snowballing and becoming an ongoing problem. If sleep patterns become recurrently disturbed, alert your loved one's doctor to the problem so that action can be taken quickly.

Planning for a family

Planning a family can be an exciting time. However for many new parents with psychosis or schizophrenia, pregnancy may be unexpected or unplanned. A person with schizophrenia has the same chance of becoming pregnant as the general population, as psychosis and schizophrenia do not affect fertility. However, living with schizophrenia may make it more difficult to plan for pregnancy, particularly in the setting of some of the other difficulties that can go along with schizophrenia such as substance use, poverty, poor nutrition, limited social support and homelessness.

There are many options for treatment and support during pregnancy, however it is important to know that some medications can affect the way that a baby develops in the womb. Pregnancy can also be a stressful time, and some people might be more at risk of an episode of illness in the time during pregnancy or following birth. This can impact on the parents' enjoyment of their baby, their ability to build emotional bonds with their child, and their ability to meet all of their baby's needs.

Planning for pregnancy allows new parents to feel more prepared and supported. This might include:

- *A pre-pregnancy assessment.* Seeing a GP or an obstetrician for advice about diet, fertility and information about pregnancy and birth. Some hospitals provide free pre-pregnancy clinics.
- *Talking to your mental health team* to discuss the options for medication and monitoring.
- *Getting the right information* about the potential effects of medications or substance use on fertility and pregnancy.
- *Sorting out practical supports.* This might include making decisions about housing, financial support through work or government payments, or joining local parent or support groups.

It is important that any women of child-bearing age talk to their mental health team and GP about their options, even if they are not thinking about becoming pregnant, so that they can make choices that are informed and supported.

If your loved one is unexpectedly pregnant, strongly encourage them to talk to their mental health team and GP as soon as possible as there are many positive steps that can be taken to optimise your loved ones and baby's health even late in the pregnancy.

Employment and taking time off work

If your loved one becomes unwell when they are employed, they may need to take some time off work until they are feeling better in themselves again. You may also find yourself needing to take time off work to provide extra care and support during these periods. This might be to spend more time with your loved one, or to help them to get to extra medical appointments or sessions that will help their recovery.

'Learn to reprioritise your expectations and be realistic about what to let go.' (Helen, carer)

Consider talking to your loved one's mental health team, who may be able to link with you with information and practical supports. Many employers offer carer's leave, which allows you to take time off work to care for your loved one. Some employers also offer flexible working hours. Medical staff can also provide you with a certificate of attendance for medical appointments that you attend with your loved one.

Finding work after being unemployed for a period, particularly during an episode of illness, can be daunting, however there are many services and supports that can help. This might include assistance in finding a job that meets your loved one's needs, supporting your loved one during work, or advocating for your loved one if issues arise in the workplace. Encourage your loved one to speak to their mental health team about their goals for their occupation or employment.

'I had one professional at one point say to me, 'You may not be able to continue your employment right now. You may have to drop your job and put all of your focus over there, and that's your reality.' Something's gotta ease off, and that's okay. That is okay to say that and admit it to everyone. Instead of beating yourself up over the fact of 'Oh my gosh, I can't maintain the whole family, and my work, and this crisis.' Otherwise everyone walks around going 'Why can't I manage all of this? I should be able to manage all of this.' (Natalie, carer)

Optimal Health

‘Optimal Health’ is a broad approach to health. It considers the balance of your mental, emotional, social, occupational, physical and spiritual needs. It means working towards the best possible condition that a person can achieve. By considering the Optimal Health Wheel on the next page you can begin to look at different areas of your life in an attempt to understand where you may feel satisfied or unsatisfied. This activity may also identify changes you may want to make. This is a wonderful activity for your loved one to do as well.

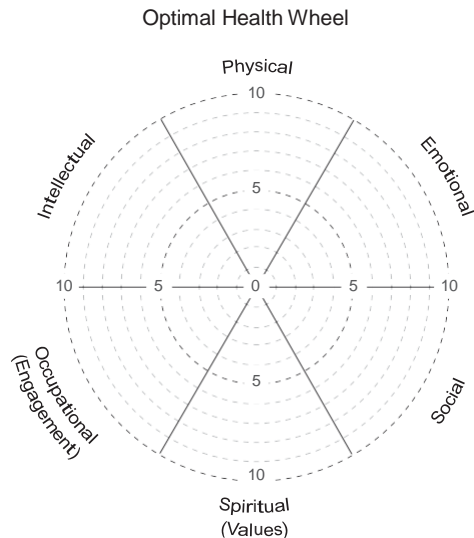
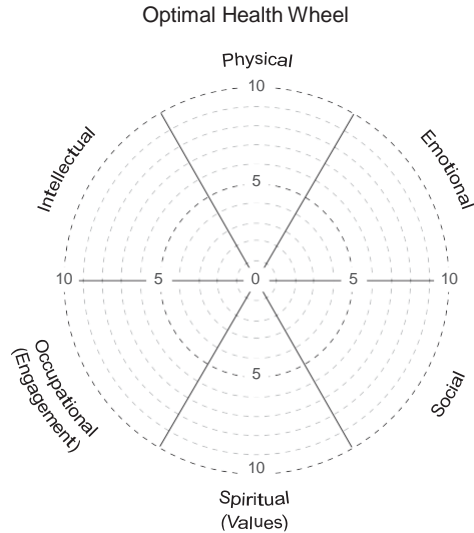
The six areas of optimal health are:

- *Physical*: this involves taking an active role in maintaining our physical health and choosing behaviours that promotes health. It involves being aware of what physical illnesses we are vulnerable to and looking for early warning signs that indicate we might become unwell.
- *Emotional*: this area recognises awareness and acceptance of our feelings. It involves the capacity to manage our feelings and related behaviours including the ability to manage stress.
- *Social*: this involves relationships with family, friends and people in the wider community we interact with. This area considers our level of comfort and ability to access resources in the community.
- *Spiritual (values)*: This area considers the meaning and purpose of our lives and how consistent our actions are with our beliefs and values. It may or may not include identification with a common belief system or faith.
- *Occupational (engagement)*: This area not only includes work (paid or voluntary) but involves all the things we do to occupy our time including looking after ourselves, family, home and participating in leisure activities/hobbies or study.
- *Intellectual*: this area relates to our ability to think, concentrate, learn and solves problems. It recognises the need for mental health stimulation and challenge in daily life and develop our understanding of ourselves and the world we live in.

‘People need to understand that mental illness is a lifelong illness, but that you can still have a life.’ (Elizabeth, patient)

Your experience...

Colour in a section on your Health Wheel between 0 and 10 according to your satisfaction with your health in each of the optimal health areas. 0 = very dissatisfied and 10 = very satisfied. There is one wheel for you and one for your loved one to complete.



Your experience...

After you have filled in the Optimal Health Wheel have a go at completing the table below. Think about what areas of your health you would like to improve.

Area of health	Things I do that I'm satisfied with	Things I do that I'm dissatisfied with	Things I want to improve
Physical			
Emotional			
Social			
Spiritual (values)			
Occupational (engagement)			
Intellectual			

Making Changes

The Optimal Health activity above may have made you think about some changes in your life you would like to make. It is now important to:

1. Define it

The change I would like to make is: _____

How important is it to you (0 – 100%)? _____

How confident do you feel (0 – 100%)? _____

What would it take to make you more confident and what needs to happen to achieve this?

2. Prepare

Now it's time to gather relevant information about yourself and the problem. Go back to your Optimal Health Wheel (page 38) and the strengths you listed on page 26.

What are some of your strengths and values that can assist you in achieving the changes you want to make?

What could be holding you back? For example, obstacles or fears that you are facing or vulnerabilities that might stand your way.

How could you overcome this obstacle? Try to brainstorm and generate some ideas and options.

3. Anticipate the future

Now imagine you wake up one morning and you have achieved this goal. What is the first thing you would notice? Imagine how you would feel. If you can, write down what this would look or feel like:

4. Set goals

Setting goals is a means of choosing what, where and how in order to:

- Make sure you create regular planned opportunities.
- Turn your reasons for wanting to have better well-being into something tangible that you can guide and monitor.

Break your goals into smaller steps and write in your diary or calendar when you will achieve each step. Set an achievable time frame. Think about who can assist you and don't be afraid to ask for help.

Try to make your goals:

- *Specific*: Focus on one topic and use clear, simple language.
- *Measureable*: Set defined targets to assess how things are tracking.
- *Attainable*: Something that you can achieve.
- *Relevant*: They should be important enough.
- *Time bound*: You should set a realistic time limit.
- *Enjoyable*: Provide enough satisfaction to make the hard work satisfying.
- *Rewarding*: Offer enough challenge to provide fulfilment and reward.

The goals I am working towards are:

I will review these goals on this date: _____

5. *Reflect and Celebrate*

At the review date assess how successful you were with your achievement. **If you succeeded, then celebrate!** If it didn't work, think about what could work instead. Write that to your list as the next step to reach your goal and try again.

What were the steps taken to reach your goal?

What did you learn and what are the next steps?

What did you celebrate?

Relationships

Staying Connected

It is important to stay connected with the parts of our lives that help to give us meaning and purpose. These might be people, culture, activities, beliefs, or knowledge and talents, and are different for everybody.

You can support your loved one to stay in touch by encouraging them to:

- *Stay connected with family and friends.* It can sometimes be difficult for your loved one to feel involved in social situations, particularly if they have been unwell or in hospital for a period of time. Socialising in large groups can sometimes feel overwhelming, so consider helping your loved one to organise smaller get-togethers with close friends or family.
- *Get involved in local cultural or spiritual groups.*
- *Try working or volunteering*
- *Do things that are fun*
- *Do things that give meaning and purpose.* We can find meaning by caring for others, working towards our goals, and doing activities that give us a sense of achievement.

Your experience...

Make a list of some activities that could help keep you and your loved one connected.

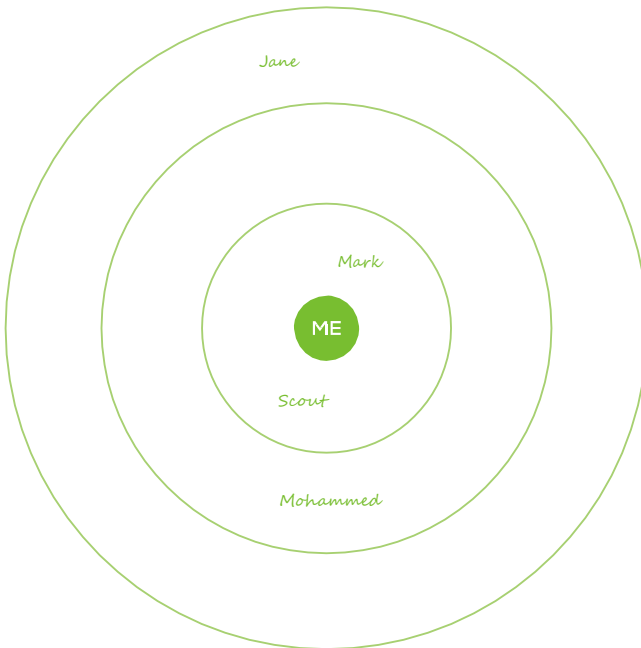
Collaborative Partners

It can be difficult to reach out to others when we are feeling stressed. Consider taking some time when you are feeling relaxed to think about the types of relationships and supports that you and your loved one have already, or would like to have in the future. We call these people 'collaborative partners'.

The diagram below is a useful way to help represent yourself and the people in your life. It can be used to help you think about who you or your loved one can work with to maintain optimal health.

You are in the centre of the circle. Write the names of the people in your life in the circles around you. Put the names of the people that are closest to you in the inner circle. In the next circle, write the names of people who are important but you see less often. Consider writing the names of people who you see only occasionally but are still important to you in the outer circle. Don't forget to include health professionals who you see on a regular basis.

Here is an example:



For each person, think about your *relationship*, and the type of *support* and *frequency* of their support. The relationship and type of support offered from each person in the example is as follows:

Name	Relationship	Support	Frequency
Mark	Partner	Emotional	Daily
Scout	Pet dog	Physical exercise and emotional	Daily
Mohammed	Waiter at favourite coffee shop	Practical and emotional (makes me laugh)	Every week
Jane	Pharmacist	Practical help with medications	Every month

What does your map look like? How is it similar or different to your loved ones? There are two maps on the following page for you and your loved one to fill out. Try not to get too worried about where the names go; the aim is not to have a strict ranking but rather to map out supports. There might be times in your life when your supports change, so it can be helpful to revisit the picture from time to time. Once you have finished writing in all the circles, it may be helpful to think about which of these people play an important role achieving your health goals. Consider asking two or three of these people to become a collaborative partner.

A collaborative partner is someone who is close to you who doesn't mind being contacted to help when you need more support.

My collaborative strategies:

When I experience a stressful situation, for example:

and I notice my early warning signs such as:

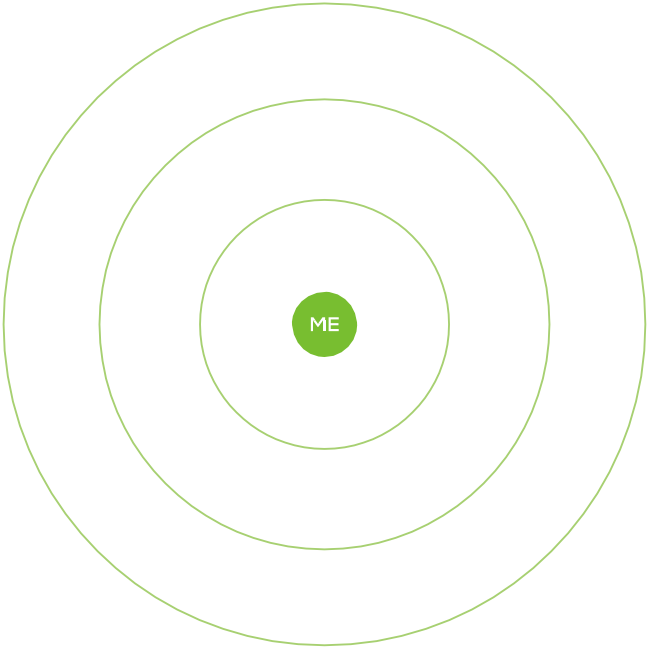
I will contact:

Name _____ Address _____

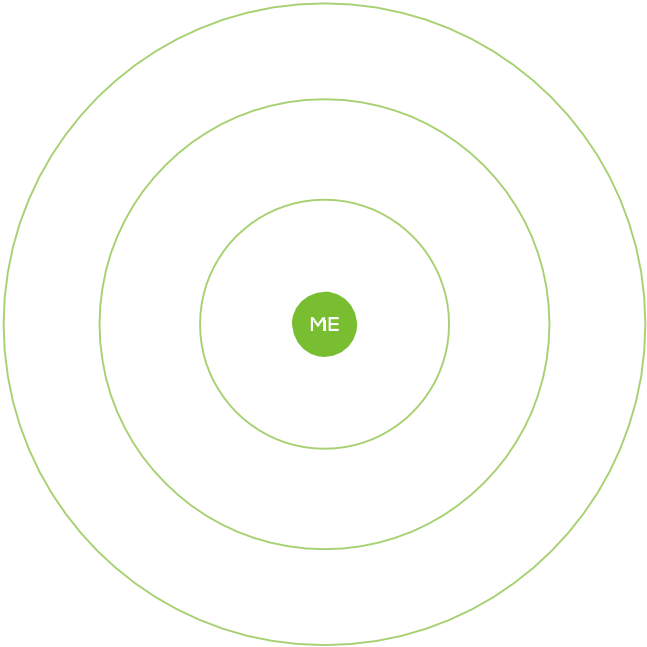
Relationship _____ Phone: _____

They can be involved by _____

The people in my life...



The people in my loved ones life...



Case Management

Case Management is an important part of the overall care of your loved one. There are many models of Case Management, however most involve at least one clinician working with a person with a mental health problem to achieve their health and wellbeing goals.

Case Managers come from a range of disciplines including social work, occupational therapy, nursing and psychology, and bring their own expertise to the role. The roles of case management include:

- *Building a good working relationship with your loved one.* Research shows that the success of case management as a treatment relies on a good working bond between the clinician and the person living with a mental health problem.
- *Assessment.* This process helps to determine your loved one's case management needs and matches them with the appropriate type of case management.
- *Monitoring mental and physical health* to ensure that early warning signs or an episode of illness is managed promptly.
- *Working with your loved one to better understand their goals* and helping them to achieve them.
- *Providing education* about a diagnosis, treatment options, and symptoms.
- *Providing psychological therapies* or assisting with referral if specialist support is needed.
- *Advocating* on you loved one's behalf, particularly for social and economic support.
- *Linking your loved one with other types of community supports*, such as employment and housing.
- *Monitoring for changes in risk* and helping to link your loved one with more intensive support when needed.

Case managers can be important collaborative partners for you and your loved one. Take this booklet to them and ask whether and how they can be involved.

Communication Skills

Communicating with your loved one can be difficult at times, particularly if one or both of you are feeling stressed, or if your loved one is unwell. We can often feel overwhelmed at these times and worry that what we say or do will make our loved ones more upset or angry.

Often, our tone of voice and non-verbal communication (e.g. eye contact, touching, body-language etc) can be just as important, and sometimes more important, than the words that we use. It is important to think about the way that we can communicate, as it can help you to stay calm and show your loved one that you understand their concerns.

'Communication is so important.' (Angela, carer)

Feeling stressed can also affect our sense of 'personal space'. Personal space is the area around us that we feel is our own. It can be different for everybody and is influenced by culture, our emotions and the situation. For example, we might feel very comfortable standing side-by-side with a partner, but could feel very uncomfortable standing close to a stranger on the bus. Often, a person's personal space will get bigger when they are feeling stressed, angry or frightened. It is common for people to feel this way when they are psychotic, so you may need to position yourself further away at these times to avoid your loved one feeling trapped or unsafe.

When communicating with your loved one, it can help to try to:

- *Look and feel calm.* Although it can be difficult when you are both feeling stressed, staying calm can help your loved one to feel less frightened. You can show your loved one that you are feeling calm by speaking in a soft, low and steady voice, relaxing your posture and breathing slowly and deeply. You can make the environment calmer by reducing distractions such as television, radio or the internet.
- *Listen.* It can sometimes be helpful to listen more than talk when your loved one is stressed. However, people can sometimes interpret silence as not being heard properly and can feel hurt or angry. You can show your loved one that you are actively listening and understanding by summarising their concerns in your own words and by showing your interest in your facial expressions and posture (e.g. making calm eye-contact and offering soothing responses if appropriate, for example 'I can understand why you are feeling that way').

- *Ask open-ended questions to start conversations.* These questions often start with the words ‘who’, ‘what’, ‘where’ and ‘how’, and encourage your loved one to describe what they are experiencing. ‘Why’ questions can sometimes be interpreted as being accusing, so consider using a ‘what’ question instead. For example, ‘why didn’t you go to your appointment?’ might be changed to ‘what got in the way of you going to your appointment today?’
- *Stay supportive and understanding.* Your loved one might express some beliefs about themselves or the world that are difficult to understand when they are unwell. It can be helpful to focus on how your loved one is feeling, for example ‘it must be frightening to feel like you’re so alone right now’. It is often not helpful to directly challenge your loved one’s beliefs when they are very stressed, as this can lead to them feeling misunderstood or angry. It is also unhelpful to tell your loved one that you believe that they are exaggerating their symptoms or ask them to ‘snap out of it’.
- *Let go of hurtful comments.* We sometimes say things that we do not mean when we are angry or stressed, and this is particularly true for people who are experiencing psychosis. Try not to take hurtful comments too personally and remember that your loved one’s thoughts and beliefs may be affected by their illness.

‘My biggest tip for families is not to argue, but to listen to the emotional content of what people are saying’ (Susan, clinician)

Safety

Unfortunately, there may be times when you feel unsafe or frightened by your loved one's behaviour. People experiencing psychosis are at a slightly higher risk of aggression, often in response to their positive symptoms which can be frightening. A person with psychosis is also more likely to respond in a way that is aggressive or violent if they have been using alcohol or other drugs.

If you are concerned that your loved one is becoming aggressive, try to:

- *Be alert and stay calm.* Pay attention to your 'gut feelings' or instinct which will help you to assess whether a situation is unsafe.
- *Listen.* It is sometimes unhelpful to continue to try to reason with your loved one when they are agitated, as features of their illness may limit their ability to respond rationally.
- *Look for early warning signs of aggression including:*
 - Pacing
 - Clenched fists or teeth
 - Swearing
 - Speaking more quickly or loudly
 - Moving quickly or suddenly in unexpected ways
 - Slamming doors or damaging property
 - Invading your personal space

'Always be aware that you may be talking to a person who is affected by an illness – not the 'real person' who is being aggressive or abusive.' (Roger, carer)

- *Have an action plan for staying safe.* This might include removing items that could be used as weapons or having an escape route.
- *Remove yourself from the area.* If you are unable to leave, stay close to a door or exit.

- *Call for help.* It is important to contact the local crisis service or 000 if you or others are at risk. People caring for a loved one with psychosis can sometimes feel hesitant to call police due to concern about what will happen to their loved one. In fact, police can help your loved one to get urgent mental health assistance and may prevent harm that could have serious consequences for both you and your loved one.

Certain ways of responding when your loved one is unwell may be more *harmful to their mental health, as well as your relationship with them.* For example, try to avoid:

- Insisting that they “snap out of it.”
- Accusing them of exaggerating their reactions or not being genuinely unwell.
- Reacting to them in an aggressive or frightening manner.
- Providing all the answers for them or feeling like you can save them.

‘Accept that there will be anger, rejection’ (Ben, patient)

Self-Harm and Suicidal Thoughts

Unfortunately, many people living with psychosis or schizophrenia will experience thoughts about self-harm and suicide at some time in their lifetime. These thoughts can indicate that a person may be suffering and should always be taken seriously.

It is common for people to feel upset or overwhelmed when thinking about their loved ones and self-harm or suicide. It is important to remember that asking your loved one about self-harm and suicide will **not** make it more likely for them to act on their thoughts. In fact, being open about suicide can help your loved one to feel understood and get the right help.

Understanding self-harm

Self-harm is any behaviour that results in a person intentionally causing themselves discomfort, pain or injury. Self-harm is common in the general population, with around 8% of adults experiencing thoughts of self-harm at some point in their life. A person is more likely to self-harm if they are going through a particularly stressful period in life, are using alcohol or other drugs or are experiencing symptoms of their illness. People usually do not self-harm with the intention of dying, however there is a risk of serious injury and accidental death.

Examples of ways that people might self-harm include:

- Cutting, scratching or burning skin
- Taking too much medication
- Eating or drinking substances that are toxic
- Punching or hitting themselves
- Banging their head
- Not allowing wounds to heal

A person might self-harm to:

- distract from strong emotions and emotional pain
- relieve tension
- help others to understand how they are feeling
- punish themselves
- feel 'something', or feel 'alive'
- Feel in control

It is important to note that people do not usually self-harm 'to get attention'. In fact, many people keep their self-harm a secret as they feel embarrassed or ashamed, and this can make it difficult to get help.

Remember that you are not responsible for stopping your loved one from self-harming. However, you can support your loved one to manage their self-harm by:

- *Being open to talking about it.* It is ok to be honest about your concern, and let them know that you would like to help. Try not to appear shocked or judgemental.
- *Helping them to make a safety plan* (see next section)
- *Encouraging them to talk to a doctor or health professional.* There are many techniques, including some talking therapies, which can help a person to find more positive ways to manage their distress.
- *Calling for urgent help.* It is important to call emergency services if you are worried that your loved one might be at imminent risk of serious injury or death.

Understanding suicidal thoughts

Although suicidal thoughts are common in the general population, people with mental illness are at higher risk of having suicidal thoughts. Whilst this doesn't always mean that your loved one will act on them, they need to be taken seriously. They should alert you to the fact that the individual is still suffering and needs help.

The way that a person experiences suicidal thoughts can change over time and in response to different life situations. If you have any concerns that your loved one might be having suicidal thoughts, it is important to:

- *Ask directly about suicide.* By asking directly in a calm and understanding way, it can help your loved one to feel supported and gives them an opportunity to talk about their feelings. For example, ask 'are you thinking about ending your life?' It is ok to use words like 'suicide', 'killing yourself' and 'dying'.
- *Let them know that you are worried and want to help*

- *Be open and clear about getting help.* Although your loved one may ask, it is important *not* to promise that you will keep their suicidal thoughts a secret. Not only is it too much of a burden for you to bear alone, but it is also critical that a health professional is aware of the situation as they can offer other avenues of support.
- *Ask if they have made any plans to act on their suicidal thoughts.* Having a plan makes it more likely for your loved one to suicide, so it is important to get help quickly.

If your loved one has a plan you must:

- *Call for help.* This might include the local crisis team or 000.
- *Try to remove anything that might help them to carry out their plan* from the vicinity if it is safe for you to do so. For example, ask a relative or neighbour to look after any blades, tablets or rope.

Sometimes it can be difficult for people to talk about their suicidal thoughts, even if they are asked directly. Some behaviours can act as warning signs that a person might be thinking about suicide. For example:

- Talking or writing about death or dying, sometimes in a casual or indirect way.
- Losing touch with friends, family or activities that they used to enjoy
- Often feeling angry or talking about revenge
- Showing less interest in the future.
- Using more alcohol or other drugs
- Sudden strong changes in mood.
- Feeling trapped
- Feeling depressed or hopeless
- Researching ways to kill themselves
- Feeling that there is no reason for living
- Giving away possessions

Some of these warning signs can also be features of psychosis and schizophrenia, and do not always mean that your loved one is suicidal.

If you are worried that your loved one is suicidal, ask for professional help; it is too much of a burden for you to carry alone.

Making a Crisis Plan

There may be times when your loved one needs to access other supports to remain safe. These times can be overwhelming for both you and your loved one, and can be feel especially daunting when immediate help is needed after hours or at a time that you are not able to be in touch with mental health practitioners who are more familiar to you.

Working with your loved one to create a crisis plan can help you and your loved one to identify what is most helpful at times of high stress, and to have a range of supports on hand when help is needed. Your loved one's crisis plan can form part of their overall health plan (page 58), which contains more specific information about recognising triggers and their preferences for the types of care that they might receive during an episode of illness.

These plans should be devised in collaboration with the individual living with psychosis or schizophrenia, their carer and the treating doctor or case manager.

If you need to call the Psychiatric Triage or the local Crisis Team, you can expect to talk to a trained mental health clinician who will explore the current concerns that you have for your loved one. They will then give you advice based on the level of urgency of the situation. Sometimes, they may ask you to wait at home with your loved one until the Crisis Team arrives to speak with you both directly. At other times, they may ask you to take your loved one into the emergency department of your local hospital for a medical assessment, or will help you to call an ambulance or the police.

After the crisis has passed, if you continue to feel traumatised or fearful – seek medical advice and consider psychological support to help you come to terms with the episode of aggression.

Use the details for a crisis plan on the following pages as a guide. You may never need to use the information, but it's always handy to have ready, just in case.

CRISIS PLAN

Date of Completion:

Details of Patient	
Name	
Date of Birth	
Address	
Phone Number	
Carer or Next of Kin Contact Details (name, phone number, address)	
Healthcare Professionals involved in the Patient's Care (name, phone number, place where treatment is received)	
General Practitioner	
Mental Health Clinic	
Case Manager	
Psychiatrist	
Psychologist	
Counsellor	
Others	
Clinical Information	
Diagnosis	
Current Medications and Doses	
Allergies or Serious Side Effects from Previous Medications	

Crisis Information	
Triggers of a Crisis (e.g. stopping medication, stress, sleep disturbance, drugs, alcohol)	
Frequency of a Crisis	
Safety Concerns during a Crisis (e.g. serious relapse, putting self at risk, putting others at risk, suicidality, aggression, vulnerability)	
Pathways of Action in Managing a Crisis	
Communication Skills that may be helpful in a Crisis (e.g. calm, empathic responses, active listening, non-judgmental approach)	
Who to call during business hours, 9-5 Mon- Fri (e.g. case manager, clinic, GP, Psychiatrist)	
Who to call after hours or on weekends (e.g. Crisis Team, Emergency Dept, Ambulance or Police)	
Additional Important Contacts	
Local Psychiatric Triage	
Crisis Assessment and Treatment (CAT) Team	
Emergency Department of Local Hospital	
Police or Ambulance Services	
Other	

Consent and Privacy

Consent is an important term that is used to describe the process of making a decision that is based on correct information, including understanding the pros and cons, and is made freely without outside pressure. Our ability to *consent* to something, or agree after examining the important facts, can change from day-to-day and depends on the task.

Wherever possible, your loved one will be supported to make decisions concerning their health. Unfortunately, there may be times when features of your loved one's illness make it difficult for them to weigh the pros and cons, or make considered choices. At these times, your loved one may be placed under the Mental Health Act, so that the medical staff can make important treatment decisions on their behalf. This is also known as being subject to an 'involuntary treatment order'. The Mental Health Act is only used at times where your loved one is at immediate risk of harm to themselves or others. At these times every attempt will be made to consider your loved one's wishes.

Balancing your loved one's *privacy* and your need for information can be difficult to negotiate, particularly if your loved one is not able to, or is refusing to, consent to you speaking to their treating team. Unfortunately, the laws surrounding this issue are complex and difficult to understand, so it is best to check with your loved one's mental health team if you have specific concerns. In general, a mental health professional cannot disclose specific medical information without your loved one's consent. However there may be times that they are able to do so, such as during an emergency, or if there are risks that you need to be aware of to keep yourself or others safe.

Talking to your loved one about the types of information that they would like to be shared with you can be helpful. Consider discussing this at a time that they are feeling well, or discuss it as part of making a Health plan (page 58).

There may be times when your loved one would like direct access to their medical records. Under the Australian Commonwealth's Freedom of Information Act 1982, they can apply for access by making a Freedom of Information (FOI) request. This process may take days to weeks, and will involve a clinician sitting with your loved one and reviewing their medical information with them. Your loved one's mental health team can provide more information about this process.

Making a Health Plan

We can all experience ‘ups and downs’ as a regular part of daily life. It can be helpful to take stock of the kinds of strategies that are helpful on both the good and not-so-good days, as sometimes these can be different. It can help to have a record of these strategies to remind ourselves and others of what we kind of strategies we find helpful. This is called a *Health Plan*.

A Health Plan can be broken in to three parts:

- *Health Plan 1* is used when your health is the best that it can be, or ‘optimal’. This plan helps us to keep things running smoothly.
- *Health Plan 2* is used at times that are more stressful or you have noticed warning signs that your health is not at its best. This plan helps us to get ‘back on track’.
- *Health Plan 3* is used during an episode of illness. Many people can feel overwhelmed and disempowered when thinking about their health during experiencing an episode of illness. This plan helps us to have a say about the types of help that are most helpful and feel more in control of what happens during an episode of illness.

If your health was a car, *Health Plan 1* would be like everyday maintenance of your car (e.g. being aware of the speed, making sure you stay on the road, checking the rear view mirror). *Health Plan 2* is useful when you end up on a windy road, your car starts skidding and you need to use your brakes. Fortunately your car has anti-skid brakes to assist you. However, sometimes your car breaks down. In this case *Health Plan 3* helps you with road side assistance.

The process of making our own health plans can help us to feel more in control of our health and wellbeing, and can help others to understand how to help at times when it is hard for us to communicate because we are feeling stressed or unwell. Helping your loved one to make a health plan can also be a good prompt to talk about their health and wellbeing and can help your loved one to be respected and understood. What would your own health plan look like? How would it be similar or different to your loved one’s health plan?

Health Plan 1

Think about your strengths and strategies that you identified earlier in this booklet (pages 26-32), and also review your Optimal Health Wheel (page 38). Consider what could help you improve your overall well-being.

The things that I need to do every day to maintain my Optimal Health are:

Health Plan 2

Think about your early warning signs (page 30) and the strategies that have helped when stressful things happen. Getting in touch with your collaborative partners (page 43) can also be helpful.

The things that I need to do when I notice early warning signs are:

Health Plan 3

Building a safety plan can help others to know what is most important to us if we are feeling overwhelmed or becoming unwell, and can remind us of the strategies that we can use to feel more in control at these times. Experiencing an episode of illness can have different meanings for everyone. Some people might notice changes in their thinking, beliefs or feelings, whereas others might notice differences in our social interactions, work, or the way that other people communicate with us.

The idea behind building *Health Plan 3* is to create soothing and calming strategies that work for you *before* a crisis occurs.

People who can help me if I experience an episode of illness:

E.g. your collaborative partners, a mental health team, emergency helplines.

My triggers that might cause me to feel upset, angry, or go into crisis are:

E.g. An anniversary of a stressful event, being touched, loud noises, yelling.

My strategies for calming myself are:

E.g. going for a walk, taking slow deep breaths, having a bath, watching TV, doing artwork.

I sometimes show my stress by:

E.g. sweating, crying, yelling, pacing, throwing objects, swearing, not rude, clenching fists.

If I am admitted to a hospital, these are some things that I suggest:

E.g. alternative physical spaces like a quiet room, medication taken by mouth.

Other information that might help staff is as follows:

Medical conditions:

List any physical health concerns that may be helpful for staff to know about in an emergency situation. For example asthma, diabetes, back pain, or pregnancy.

Medications:

If other calming strategies have not worked in calming you down, what medications are helpful to you?

What medications are not helpful and why?

Caring for Yourself

During your care for someone with psychosis or schizophrenia, you might feel a range of different emotions. Some of these will be difficult and may impact on *your* emotional well-being. It isn't unusual to experience anger, guilt, grief or fear at various points in time.

It is vital that you look after yourself, as much as you're looking after the individual with a mental illness. There is always a risk that the pressures and demands of caring for another with a serious illness can lead to feelings of anxiety and depression in those who are providing the care.

Your own mental health needs must be tended to in order for you to be able to provide the best quality care for someone else's.

'Carers need to look after themselves, take time out, and have respite. They need to hold onto their identity outside of the caring relationship.' (Elizabeth, patient)

It might be useful to keep some practical strategies in mind:

- *Educate yourself* generally. Learn about psychosis and schizophrenia, so you can understand and help others understand what it is and why someone with this illness might react in a certain way.

'The first step is to get educated about what it is and what's going on. Get savvy with the area of mental illness and this will reduce fears, prejudice and stigma.' (Elizabeth, patient)

- Be *open* and *inquisitive*. Getting to know what a person with psychosis or schizophrenia needs requires an open conversation with them. Between the two of you, you are the experts in that individual's illness. Knowing what your loved one needs from you when their illness does relapse will help you provide them with the care they have identified as most valuable during these difficult times.

'Informing yourself is empowering yourself.' (Elizabeth, patient)

- *Make your own health a priority*. Eat nutritiously, exercise regularly and sleep soundly. Develop balanced routines that support you in maintaining a healthy lifestyle.
- *Have your own GP*. Make sure you are linked in with a general practitioner for your own physical and mental health needs. It is not uncommon to be so focussed on your loved that you forget about the importance of addressing your own health. This might mean routine check-ups or appointments when you are beginning to feel persistently stressed.

- *Learn to receive support* from the person you care for. Be open to their efforts to repay your kindness or express gratitude. Acknowledge the incredible support and care you provide on a daily basis. Thank yourself, and allow yourself to be thanked.

‘The patient needs to give something back - be generous to their carer after episodes and replenish their relationship.’ (Laura, patient)

- *Maintain hope.* It’s important that you maintain optimism and hope. That you continue to believe the person will get better, and you will see better days together. Each episode of illness may continue for different lengths of time, so bear in mind that you may not experience the same course as the last one.

‘Remaining optimistic is so important, you have to see the glass as half full. You have to believe there will be better days.’ (Helen, carer)

Consider strategies such as:

- *Delegating* certain duties of care to other family members or friends.
- *Arranging your own* time out so you continue to maintain your interests and relationships outside of your relationship of care.
- Stick to a general *daily routine* as best as possible.
- Find *someone you can talk to* about your feelings.
- Join a *carer support group* to share experiences and tips with others who are in the same position as you.
- Be clear on the *limits of your care* and communicate these sensitively to the individual with schizophrenia or psychosis during times of wellness. Be comfortable with saying ‘No’ sometimes.
- *Don’t expect that you can fix everything* for your loved one. Try to remain realistic about the influence of your support, which may, at times, be in conflict with the influence of the illness.

- *Keep healthy boundaries.* This can help ease the tension in your relationship with the person you are caring for, and prevent cycles of anger, frustration or resentment from repeating.

'It's important to be conscious of your limitations as a carer.' (Elizabeth, patient)

Time for yourself

Create times in your week that are just for you, where you can relax and rejuvenate your own emotional strength. This may mean spending time with friends, spending thoughtful time alone or participating in regular activities that add meaning to your life. It's different for different people, but pursuing what you need will benefit you, your care and your ability to cope in difficult times.

'If you can't reclaim some joy in your own life along the way, then you're going to be sunk.' (Natalie, carer)

An example of a *weekly planner* has been included on the following page. Use it as a guide to think about how much time in the week you spend actively caring for your loved one, and how much time in the week you spend actively caring for *you*.

Is there a big difference? Are there any opportunities to create some more time and space for yourself? To enjoy an activity alone, or with others who are also important to you?

WEEKLY ACTIVITY SCHEDULE

	MON	TUES	WED	THURS	FRI	SAT	SUN
MORNING							
AFTERNOON							
EVENING							

Grief

Grief is the name given to our natural response to major changes or losses in our life. We often experience grief in response to the death of a loved one; however we can also experience grief after losing a job, breaking up with a partner, or other serious life events.

Many people with a loved one with psychosis or schizophrenia experience a sense of loss or sadness at some time during their loved one's illness. These feelings may come and go, but often arise at the time of diagnosis or at other important times in their or their loved one's life. People may also feel a sense of loss when thinking about their relationship with their loved one, their hopes for the future, or their own relationships and aspirations which may have been affected by their loved one's mental health.

'I still feel like I'm sort of in shock and grieving it.' (Jane, carer)

Managing grief

When coming to terms with the person's illness or a new diagnosis, give yourself time to grieve. You might experience sadness about the changes and losses you perceive for the person you are caring for. This is natural, and will come to pass. Often, sharing your experience with others can help to lessen the burden of grief. You might choose to talk to a close friend or relative, your own GP, a mental health professional or a peer support group.

'That's the sad part, mourning the loss of what you hoped they could be.'
(Mary, carer)

We all experience grief differently. It is common to experience strong emotions such as anger, sadness, frustration and loneliness as part of grief. Some people may also experience changes in their body including feeling tight in the chest, crying a lot, or sleep problems. Some of these experiences are similar to what you might experience if you were depressed or anxious, so it can be helpful to talk to your GP if you are feeling overwhelmed or unable to do the things that help you to feel well.

'I think that grief is something that is a very important part of the process.' (Lisa, carer)

Carer Support Groups and Respite Services

The demands of caring for your loved one may leave you feeling *emotionally drained* and *socially isolated* at times. The difficult feelings that can accompany different points in your caring relationship might feel less understood by those who have not had similar experiences. *Carer Support Groups* are regular gatherings of people who are interested in hearing and sharing mutual experiences to help with feelings of connectedness and support. These groups are typically run by a mental health professional, who will guide discussions and help group members share experiences and knowledge, to give and receive support. They are usually arranged through local community organisations.

'You just feel like you're so out on a limb and on your own, and no one else is going through this... You need support and people that can understand a little bit of what you're going through.' (Mary, carer)

Many carers experience relief through sharing their stories, feelings and information on caring for their loved one. A lot of strength and hope can be gained from *sharing experiences* with others who are in familiar situations.

'The stories that are shared are educational. And they do give you that sense of, okay, you're not like Robinson Crusoe, you're not on your own. Some of the simplest little tales that are told, and stories that are passed on can be enormously helpful, in a practical way.' (Nicholas, carer)

Along with carer support groups, you may like to consider seeking support in the form of *individual counselling sessions*. There may be times when you're seeking a private outlet to talk through the feelings and impact that your caring relationship is having on your life. There are a range of services available through various carer organisations which can be explored as needed. See 'Further Resources' for the details.

'You're so consumed by it all that you put your whole life on hold.' (Mary, carer)

Carer respite is another area of support that may be able to provide you with opportunities to make your own health and well-being a priority and be assured that your loved one is in safe and professional hands. This might involve having a community-employed carer come to your home and provide care for your loved one whilst you attend to your own personal obligations. Or it might involve your loved one attending a community day program outside of the home, or staying short-term in supported residential accommodation, to help improve their skills of independence and provide you with a short break from your caring responsibilities.

Further Resources

Carers Australia is the national peak body representing carers in Australia. *Carers Australia* works with the Carers Associations in each of the state and territories to deliver carer programs and services and advocate on behalf of all carers. The services provided will vary according to where you and your loved one are living, but can all be accessed and explored via the national website at: www.carersaustralia.com.au

Information is also available via a free call to the *Carer Advisory and Counselling Service* on **1800 242 636**.

ARAFEMI (Association for the Relatives and Friends of the Mentally Ill) is a non-profit community based organization dedicated to supporting and advocating for family members and carers of people with a mental illness. They organize many groups and services that can be helpful for both you and your loved one. They have branches in most states and territories throughout Australia and also offer a valuable Carer Helpline service. Get more information on the Victorian ARAFEMI organization at: www.arafemi.org.au or phone **+61 3 9810 9300**.

The *Carer Helpline* service is available on **1300 550 265**.

MIFA (Mental Illness Fellowship of Australia) is a non-government, not-for-profit organization aimed at supporting and advocating for people with serious mental illnesses and their families. They offer many different services, including *Well Ways* a family educational program that provides information on mental illness, helpful ways to cope and practical ways to take care of yourself. Information on this program and other services provided by MIFA can be accessed at: www.mifa.org.au

Or contact the *National Helpline* to be directed to the right service on **1800 985 944**.

SANE Australia is a national charity that conducts innovative programs and campaigns to improve the lives of people living with mental illness, their family and friends. They offer useful resources and guides to help you and your loved one with their mental health needs. The section entitled '*Snapshots*' on the website contains inspiring personal accounts of what it means to live, and live well, with a mental illness. The importance of sharing, recovering and connecting is highlighted through meaningful real-life stories. Access this information at: www.sane.org

The *SANE Helpline* can also offer information and advice on **1800 18 SANE (7263)**.

Information obtained via the internet can sometimes be inaccurate or misleading. Keep an open mind about what you are reading, particularly if you are unsure about the credibility of the source. Try to check what you've read with your loved one's doctor or mental health practitioner to ensure you are getting the correct information.

Listed below are some additional websites that provide accurate information and might be of further help:

<http://eppic.org.au/>

<http://www.neaminational.org.au/>

<http://www.schizophreniaresearch.org.au/>

<http://iepa.org.au/resources/for-families/>

www.beyondblue.org.au

www.blackdoginstitute.org.au

Most community mental health clinics will have a Carer Consultant who can provide specific advice and pathways to assistance if you're experiencing any difficulties in your caring role. Check with your loved one's mental health practitioner to find out more about this service.

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Castle, D. & Tran, N. (2008). *Psychiatric Medication Information: A guide for patients and carers*. St Vincent's Mental Health. The University of Melbourne. Fitzroy, Australia.

Yaka, D. & Castle, D. J. 'Caring for a Loved One with Bipolar: A Carer's Guide to Understanding the Illness and Keeping Well,' 1st Edition, February 2012.

'While there is life, there is hope.' (Samantha, carer)

'It's a matter of hanging in there with them.' (Nicholas, carer)

'Don't try to fix it, just get through it. Persevere.' (Natalie, carer)

'To be able to move forward in their lives - that's all you want for them.'
(Mary, carer)

*'Remaining optimistic is so important, you have to see the glass as half full.
You have to believe there will be better days.'* (Helen, carer)

'And how lucky are our loved ones, in one way, that they have us?'
(Samantha, carer)

ORDER INFORMATION

St. Vincent’s Mental Health Service has developed a range of educational materials for carers and patients.

Please see list below for our materials and their pricing.

Coming Soon – Caring for a Loved One With an Eating Disorder

Service/Company: _____

Contact Name: _____

Delivery Address: _____

Postcode: _____ Telephone: _____

Email: _____

COSTS – Medication Booklets \$2.50 + GST per booklet + P&H

“Caring for a loved one with.....” \$8.00 + GST per booklet + P&H

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