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# Schizophrenia

New Zealand  
Treatment Guide  
for Consumers  
and Carers



THE ROYAL  
AUSTRALIAN AND NEW ZEALAND  
COLLEGE OF PSYCHIATRISTS

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# Contents

## “POAUAU” ARA SCHIZOPHRENIA

1. Ko tenei mate te poauau, ara, schizophrenia, kare tonu i te ata tika te whakamarama i ona ahuatanga, tau ke atu nga taumahatanga ki runga ki te whanau, a, ki runga hoki i te turoro.
2. Ko nga tohu o tenei mate, he ngoikore, he kore e ata mararama ki te whakatakoto whakaaro, a , kei te kotiti katoa nga korero.
3. Kare e taea te ki he whaiti noaiho te mate i penei ai te tangata, engari kua kitea kei tetahi wahanga o te roro e raru ana.
4. Ka pa ohoreremai tenei mate, a hai etahi he wa roa tonu e pa haere mai ana.
5. Haere ki te kite i to rata, mana koutou e tono ki te kite i nga Tohunga wananga Hinengaro, ara psychiatrist, ki ata tirohia mena koinei te mate.
6. He pai ake nga rongoa o inaianei ki awhina turoro koianei te mate, a kei reira ano nga roopu tatotko i nga turoro tae atu hoki ki nga whanau.
7. He ahuatanga pai te noho tahi a nga Tohunga, a nga roopu awhina, a nga whanau a nga turoro ki te mahitahi. Kaore tenei mauui i te mauui ka tere ora ake te turoro, no reira te nuinga atu o nga kaiawhina, te painga atu.

## ABOUT SCHIZOPHRENIA

1. Schizophrenia is a mental illness about which there is much stigma and misinformation. This often causes patients and their family additional distress.
2. The typical symptoms of schizophrenia involve disorders of thinking, perception and motivation that distort reality. Behaviour changes commonly result from these.
3. Although it is likely that there is no single cause of schizophrenia, current evidence supports the belief that it is due to biological abnormalities of brain function.
4. Schizophrenia may develop very gradually, or it may present abruptly.
5. The diagnosis of schizophrenia is best made by a psychiatrist, and your family doctor can refer you or your family member for an assessment.
6. Modern treatments exist. New medications are possibly more effective than the older treatments, and are certainly more tolerable.
7. It is important for patients and families to establish a positive working relationship with the treatment team especially as treatment is long term. Modern treatment combines medication with education, family and social support.

## Key Points



## INTRODUCTION

### Why a Consumer and Carer Guide for Schizophrenia?

Recently, Australian and New Zealand mental health professionals have been made aware of new Clinical Practice Guidelines for the Treatment of Schizophrenia. As a person with, or a carer for someone, who has schizophrenia, you too can benefit from a guide about the best possible treatments. This guide covers early treatment, support and recovery.

This guide was developed for adults and young people with, or suspecting they have, schizophrenia, as part of a series of guides to match the one your health professionals will have. It has been written to provide you with information about schizophrenia and its treatment, based on the best research evidence to March 2003. It is intended to be read for discussion with your health professional in order to jointly plan your care.

There have been great advances in treatment recently. Research into effective therapies for schizophrenia is booming. There is already excellent knowledge about treatment but unfortunately a lot of this knowledge is not being fully utilised by professionals. It is the responsibility of health professionals to ensure that they are up to date with current best practice approaches for the illnesses their clients have.

The current treatments for schizophrenia are the most effective yet and provide much hope that a comprehensive treatment approach will reduce the suffering that schizophrenia can bring.



## What is Schizophrenia?

Schizophrenia is a poorly understood illness in the general community because there is much misinformation and stigma associated with it. Schizophrenia is not having multiple personalities. Neither are people with schizophrenia inherently violent. When in a treatment program, they are no more likely than people in the general population to commit crimes.

Schizophrenia is one of a group of mental disorders known as psychoses. A person experiencing psychosis has a loss of contact with reality. Psychosis is characterised by difficulties with thinking and can include seeing or hearing things which other people cannot see or hear; these experiences are called hallucinations.

Psychosis can also include holding beliefs that are very odd or not true. These beliefs are called delusions. People with psychosis often feel that they want to withdraw from the outside world. Their energy and emotions are affected. They may feel a loss of vitality. They may also feel depressed or irritable.

## Who Gets Schizophrenia?

Anyone can get schizophrenia. Schizophrenia affects one in 100 people across all countries, social classes and cultures. Schizophrenia usually begins when people are aged between 15 and 25, although it can also emerge later in life. Men and women are affected equally, although men tend to have an earlier onset.

## What are the First Signs Something is Wrong?

Most people experience changes in behaviour and perception. When these occur together in the early stages they are called a 'prodrome'. The prodromal symptoms include:

- Changes from normal behaviour such as worsening of usual work or school performance
- Social withdrawal
- Emerging unusual beliefs
- Changes in perception such as experiencing brief instances of hearing sounds not heard by others.

The prodromal period lasts approximately two years on average. After this time, clearer symptoms of psychosis become evident. The prodrome is best thought of as a warning and the person experiencing a prodrome is not necessarily going to develop a psychosis.

## What are the Symptoms of Schizophrenia?

Health professionals talk about two main types of symptoms in relation to schizophrenia. These are positive symptoms and negative symptoms.

**Positive symptoms** are experiences that happen in addition to normal experience. These include symptoms such as hallucinations (positive because they are additional perceptions).

**Negative symptoms** incorporate a loss or decrease in normal functioning.

They include experiences such as loss of pleasure or interest in normal activities, loss of motivation, loss of interest in socialisation.

Symptoms vary from person to person, but commonly include:

**Negative symptoms**

Feeling unmotivated

Not feeling social

Feeling apathetic

Not feeling any emotions

**Mood**

Irritability

Suicidality

Depression

Elevated mood

**Positive symptoms**

Delusions

Hallucinations

Disorganised thoughts.

Schizophrenia appears cyclical, worsening in periods known as relapse, but improving or disappearing completely during remission. People with schizophrenia can have periods of stable emotional health. However, during the acute or psychotic phase, when delusions and hallucinations may occur or worsen, many have trouble with everyday tasks such as thinking clearly, managing their feelings, solving problems, decision making or relating to family/whanau, friends or professionals.

## What Causes Schizophrenia?

While the specifics remain to be fully clarified, it is now accepted that schizophrenia is a syndrome (cluster of symptoms) produced by a complex change in brain functioning. This change interferes with intellectual processes and produces unusual experiences and emotional changes.

The causes of schizophrenia are multiple. They involve a combination of genetic risk factors and other contributors such as complications during pregnancy and early life, and almost certainly other problems with brain development during adolescence. It is probable that a different mix of causes can occur from person to person. While in some people it is possible to show subtle structural changes in the brain using tests such as Magnetic Resonance Imaging (MRI) scans, in most people the abnormality in the brain is a reversible functional disturbance. This is why treatment with anti-psychotic drugs seems to restore normal central nervous system/brain functioning.

While much research has been carried out in recent years, a great deal still needs to be learned about this complex disorder of the central nervous system.

## What Other Problems do People with Schizophrenia Face?

People with schizophrenia may also face other problems. Anxiety and depression are very common. The rates of substance use (cigarettes, alcohol and cannabis especially) can be up to ten times higher than in the general community. Because symptoms, if left untreated, affect relationships, many people with schizophrenia are single, and unemployment can be a problem. People can also have accommodation problems and may withdraw from family/whanau and friends. Isolation and loneliness can be common.

People with schizophrenia may need assistance for several problems when seeking professional help. It is OK to ask for help for any of these problems to reduce the stress of living with schizophrenia and improve the chance of recovery.

## How is Schizophrenia Diagnosed?

There is currently no test for schizophrenia. However, your GP may want you to do some other medical tests to rule out other possible illnesses, both physical and mental, which have symptoms similar to those of schizophrenia. Getting a correct diagnosis can be difficult because psychiatric diagnoses are still based on descriptions of behaviour.

Sometimes there are difficulties in getting timely help because the person may be fearful and feel reluctant to describe their symptoms or see a General Practitioner (GP).

Your GP may be familiar with schizophrenia. However, it is advised that a psychiatrist who is more qualified and experienced in confirming the diagnosis and planning treatment is consulted.

## Is there a Cure?

There is currently no cure for schizophrenia. However, many treatments that aid recovery have been developed. Many people with schizophrenia remain vulnerable to relapse and may have sustained disability. Despite this, good quality of life is possible, and with improvements in the quality of treatment and support, many people recover to lead full lives again.

## Prevention: Can the Prodrome be Treated?

The prodrome is the period before an acute episode of psychosis. It indicates that a psychotic episode may be about to occur. People showing signs of a prodrome who have never had an episode of psychosis are encouraged to develop a relationship with a mental health professional or a GP with a knowledge of this prodromal period.

Individuals with a parent or sibling with psychosis have more risk of developing schizophrenia. If there is any change in level of functioning at school or work, or if symptoms of depression or strange thinking occur, it is a good idea for these individuals to go to their GP or a psychiatrist to be thoroughly assessed. By being monitored in this manner, if clear psychotic symptoms emerge (and there is no guarantee that they will), early specific treatment is readily available.

This can avoid the need for hospitalisation and minimise the impact of a potential psychotic episode.



See your GP for information and referral to mental health services in your area. Assessment and treatment at public mental health centres is free. There are some early intervention centres where young people can be comprehensively assessed (see Appendix 2). You can get a referral from your GP to see a private psychiatrist for an assessment and treatment.

Evidence from the PACE study in Melbourne indicates that assessment and provision of low levels of medication in the prodromal period may reduce the risk of eventual psychotic symptoms in some people.

## TREATMENT: WHAT CAN I EXPECT?

### When Should Treatment Begin?

The sooner a person with schizophrenia gets help for their symptoms the better the chance they have of receiving effective treatment. Research shows that it is important to get help early! This is important for the first and for all subsequent episodes. In many locations a specialist 'early intervention team' will provide care during the first episode and offer follow-up for the first year or two.

The first task is to undertake a thorough assessment to understand more about your life, like your accommodation, finances, symptoms and your physical health. A thorough investigation is required to make sure that there is no underlying physical condition which may better account for your symptoms. Once a medical check has been completed, a referral can be made to an appropriate mental health service or specialist. If there are significant social, cultural or religious issues that need to be considered in your treatment, you should let your healthcare workers know.

### How is My Care Organised?

It is important to understand the treatment system so that you can make it work the best way for you. Care from your GP alone in the first onset of schizophrenia is not an adequate standard of care. You need a GP who can work with you to work out when you should see a mental health professional and to help advocate

your entry to specialist care early. You can receive specialist care in the public mental health system or from a private psychiatrist.

When receiving care through a public mental health service it is usual practice to be allocated a case manager (sometimes called a key worker) and a psychiatrist. The case manager organises the assessment, treatment plan and ongoing treatment with you. This includes information and education for you and your family/whanau or partner, or carers. They also arrange links to other services such as community agencies, employment services, social security and accommodation agencies. The case manager also prepares the treatment plan that encompasses all aspects of care: medication, psychotherapy, education, support and other treatment or services required.

In rural areas, your GP may play this role and contact specialist services by telephone. In other cases, because of personal preference, or because the illness is stable, some people will have their schizophrenia managed entirely by a GP.

## How to Advocate for Improving Your Care

If you do not think that you are getting the level of care you should be, do not be silent about your dissatisfaction. Approach your case manager, or the clinic manager. If the problem is a lack of resources, approach members of parliament or become involved in a consumer or carer network. Ask to speak with the consumer consultant in your



mental health service. If there is not one, ask why not. If you are seeing a private psychiatrist, ask for a second opinion, or discuss referral to a different psychiatrist with your GP.

## Location

A range of treatment settings is available and the choice of which one to use is made on the basis of severity of illness. Where possible, people with schizophrenia are treated in the community to reduce the distress and disruption to their lives. The case manager should visit you at home and provide support in crisis situations.

If you are in recovery or remission you can be treated with regular outpatient appointments. However, if you are at risk of harming yourself or others, or if you are extremely distressed by your symptoms, the best option may be a short stay in hospital. Sometimes this may be necessary even though it may not be what you want at the time.

When you are well, arrangements for what will happen in the event of a relapse can be put in place in advance. This gives you more control and you will have a say in how you would like to be treated.

## HOW IS SCHIZOPHRENIA TREATED?

Treatment should include medication, psychological treatment and community support. The combination of treatments is crucial.

### Medication

Medication is essential for effective treatment of schizophrenia for most people. However, it works best when integrated with good quality psychosocial treatment.

It is necessary to find the right type and dosage of medication to treat your symptoms with the least side effects. Generally, a single medication will be used. However, in some cases it may be helpful to combine drug therapies.

The main type of medicines used to treat schizophrenia are called anti-psychotics. There are two groups of anti-psychotics. The older group, 'typical' anti-psychotics, include drugs such as chlorpromazine, haloperidol and trisluoperazine. The newer group are called 'atypical' anti-psychotics. These include olanzapine, risperidone, clozapine, and quetiapine. Older medications work, but often have more side effects, especially if used in high doses.

### Does the Medication Work?

All of the drugs used have gone through rigorous international testing, and have been shown to reduce the

Safe dose range information can be found in drug product information, or in standard manuals of medication such as MIMS or the Therapeutic Guidelines - Psychotropics (which most GPs hold). Ask your GP if you can read the section about your medications. You will be given written information on the drugs prescribed for your treatment including any side-effects which may occur.

symptoms of psychosis. They are not addictive. There are several types of medication and your psychiatrist will choose the one to best address your individual symptoms. You should ask why he/she suggested this particular medication for you. In recommended doses, anti-psychotic medication is safe. However, excessive doses can result in a range of disturbing side effects.

## What Symptoms are Helped by Medication?

The positive/active symptoms of psychosis, such as hallucinations and delusions, have been the main focus of medication treatment. Newer anti-psychotic medication may also be helpful in treating negative/deficit symptoms, particularly problems with mood, thinking and socialising. Feelings of anxiety and agitation are also helped by anti-psychotic medication.

## Does Medication Work for Everyone?

A small number of people do not respond well to initial treatment and may need to try several anti-psychotics as well as other therapies to gain control over their symptoms. The drug clozapine has been found to be effective for people whose symptoms are resistant to initial atypical anti-psychotic medications.

## Relapse Prevention and Medication

Individuals who have experienced a psychosis previously need to consult their GP or psychiatrist and case manager for strategies to prevent a further episode. This may include restarting or increasing

medication, adding a different medication in combination with psychosocial treatment and regular monitoring.

## What are the Side Effects from Medication?

As with most medications, there may be side effects when taking anti-psychotics. It is very important to communicate any changes or new symptoms to your GP as these may be side effects of your medication. Appendix 5 gives a summary guide to side effects with space for you to record your medication dosage.

### **Movement disorders**

Common side effects include movement disorders, in particular dystonia (muscle spasm), Parkinsonism (tremor, slow movements), and akathisia (restlessness). These side effects are more common with the older typical anti-psychotics.

No one should have to experience these side effects these days! Doctors can treat these effects by using low doses of anti-psychotics or prescribing medicines to reduce these movement symptoms. The newer or atypical anti-psychotics have been found in studies to be effective at treating symptoms, and to cause fewer side effects. While newer drugs in general have fewer effects on muscle tone and movement, they are more likely to cause weight gain, loss of libido, and hormonal side effects.

### **Tardive Dyskinesia**

Another effect often seen with anti-psychotic medication is Tardive Dyskinesia (TD). This involves uncontrollable muscle

You can help this by providing as much information as possible about symptoms, side effects and other problems. You have a right to expect the best treatment possible.

Take all medications as prescribed. In general, if a drug works well – stick with it. Don't chop and change – these drugs take a little while to start working. Don't stop it unless under good medical supervision.

spasms resulting in a twisting of the body or neck. TD will occur in 5% of patients who take typical anti-psychotics. Studies have found that risperidone and clozapine (two of the atypical anti-psychotics) have much lower rates of TD.

Evidence is not yet available for the newest atypical anti-psychotics (olanzapine and quetiapine), however it is expected that the risk for TD will be quite low.

## Other Side Effects

Other side effects include sedation, galactorrhea (stimulation of milk secretions), sexual dysfunction in males, and rarely, liver disorder.

Clozapine has been associated with a small chance (less than 1%) of agranulocytosis (loss of production of white blood cells which are involved in defending the body from infection). This can lead to an increased chance of experiencing life-threatening infections. To prevent this, an assessment of the white cell level is conducted weekly which aims to prevent the mortality risk.

Clozapine has been associated with seizures, sedation, drooling and increased heart rate. However, with careful monitoring, and your reporting of any difficulties or effects to your doctor, these symptoms can usually be managed.

Risperidone in low doses has very few side effects. In higher doses some movement disorder side effects have been noted. Users have also reported some gastric distress and mild sedation.

Olanzapine has few side effects, but has been associated with non-movement disorder side effects such as sexual dysfunction, weight gain, and possible mild liver dysfunction.

Quetiapine has been associated with side effects such as drowsiness, dizziness, and headaches but there is a significantly lower incidence of distressing symptoms such as movement disorder symptoms and less restlessness.

## What is the Treatment for Side Effects?

Psychiatrists often use a medication called an anti-cholinergic such as benzotropine (Cogentin) to treat movement disorders caused by older anti-psychotics.

Anti-cholinergic medications may lead to dry mouth, constipation, or impaired memory skills. Many side effects, such as sedation, improve with time, changing the dose, changing the type of anti-cholinergic, or adding another medication.

Some non-medication strategies may also be helpful. For example reviewing diet and exercise habits may assist with minimisation of weight gain.

## What is Depot Medication?

Depot medication can be a useful strategy for a small number of individuals, at least as a time-limited strategy. Depot medication is a form of anti-psychotic medication given by injection, which slowly releases the drug over one to four weeks (depending on which drug is given).

Currently, only the older or typical anti-psychotics are available in a depot form. A doctor or nurse will usually give the injection. Some people prefer depot medication as they



If you experience anything which may be a side effect, tell your GP as soon as possible. It may be that the symptom you are experiencing is not a side effect, but it is better to be sure.

find remembering to take pills every day difficult. However, depot medication can cause the same side effects as mentioned above for the forms of these drugs taken orally.

Sometimes people with schizophrenia are ordered to take medication under government laws such as the Mental Health Act. In this situation, depot medication is often used. An order to be treated and to take medication made under mental health legislation must be reviewed at regular intervals. There is also provision for you to appeal against any treatment order.

## Why do I Have to Take Other Medications?

Your GP or psychiatrist may consider prescribing other medications along with an anti-psychotic medication to treat the symptoms of schizophrenia or other problems you may be having. There are many medications, which may be used in conjunction with anti-psychotic medication. They include:

- Anti-anxiety agents which are used to treat distress or agitation
- Mood stabilising agents to treat mood symptoms when they occur in psychosis (Lithium, Tegretol (Carbamazepine) and Sodium Valproate)
- Sleeping tablets (hypnotics) to help insomnia
- Side effect medication (anti-cholinergics, or anti-parkinsonian drugs) used to reduce movement disorders
- Anti-depressants used to treat depression.

There are a number of points to consider. For anyone, accepting the need for regular medication is a big ask. If you think of the

challenge it can be to take a full course of anti-biotics for two weeks, it is a much bigger challenge to take anti-psychotic and side effect medication.

Taking medications long term requires some lifestyle change. Just as you would with arthritis and diabetes, having a psychotic condition also requires this approach. Making lifestyle and mindset changes is not easy. Drugs are often seen as mind altering rather than mind restoring.

This view is especially so when taking the drugs includes unpleasant experiences such as sedation, 'numbing' or slowed down thinking, movement or body problems, or sexual side effects.

Medications are a very powerful protector against a second or further breakdown. Taking medication as it is prescribed makes it five times less likely that you will experience a relapse. Sometimes it takes more than one episode for people to accept that medication is necessary.



**If you are put on an order to receive treatment, you should have been given a booklet regarding your rights. If you have not been given this booklet, it is important that you ask for it.**

## How Much do I Need?

Anti-psychotic medications are administered at the dose that proves most effective for each individual patient. For many medications, the doctor will start with a low dose and increase very slowly to reach the level where symptoms stop before side effects start to be present. Doses differ according to the potency of the medication used and cannot easily be compared against one another.

For example, 100 milligrams (mg) of chlorpromazine *is approximately equal to:*

- 2mg of Haloperidol
- 2mg of Risperidone
- 7.5-10mg of Olanzapine.

## For How Long do I Need to Take the Medication?

Some people will require anti-psychotic medication for long periods. Usually the medication is continued for one to two years after the person has achieved excellent recovery from their first episode, and is stable in life with regard to relationships, work or accommodation.

In the early years there is a high risk of relapse and if the person experiences another episode they may need anti-psychotic medication for two to five years before ceasing use. For those who have multiple episodes, they may need to use medication for much of their life.

## What if the Medications Don't Work for Me?

If you have tried one or two anti-psychotic medications and your symptoms have not improved, a thorough review is necessary. First your GP will need to check with you that you remembered to take the medication as prescribed and that the dose was correct, and that there are not other factors involved such as a medical problem or using cannabis or other drugs.

He or she may suggest that psychological therapy, described below, be offered to help you cope with the symptoms, and that other medicines be added to help. A third atypical medication may be tried. More commonly, you would be offered clozapine, a medication showing good results when other treatments are not successful. However, clozapine requires a considerable side effect monitoring scheme.

## What About Pregnancy and Breastfeeding?

Many anti-psychotic medications have not been tested on pregnant women. Unborn babies are very sensitive to drugs and it is very important to talk to your doctor about the safest choices to use during pregnancy and/or breastfeeding.

## Psychosocial Treatment

Psychosocial treatments should be tailored to your needs as an individual. Medications aim to reduce symptoms while psychosocial treatment helps you adapt to psychosis and helps you to strive for a good quality of life, despite the illness.

One important feature of all psychosocial treatment is developing a relationship with your health professional which is trusting and optimistic. Preferably, they should extend this relationship to include your family/whanau, partner or carer.

There are several kinds of psychosocial treatment that may benefit your recovery.

### **Psychoeducation**

This therapy provides education to individuals and their carers about their illness, either individually or in a group. It works by increasing your understanding of symptoms and treatment options, services available and recovery patterns. Information and education may be given via videos, pamphlets, websites, meetings, or discussions with the case manager or GP. If required, information in other languages, or interpreters will be provided to you. Materials can also be obtained from support groups as listed in Appendix 5.

### **Family/whanau therapy**

Firstly, you may not want your family/whanau involved in your care. That is your right and it should be respected, assuming you are 18 years or older. If you have a partner, you may or may not want that person involved.

However, there are reasons why you might want your family/whanau, partner or someone else involved in your care. For a majority of people, their family/whanau is the primary source of long-term support. Secondly, even if you don't want your family/whanau directly involved, they may wish to talk to a professional about their experience of your illness and how they might help. It can be very distressing to see someone you love and care

about become unwell. Thirdly, your family/whanau can be an important source of information to help in clarifying your diagnosis, and in supporting your treatment. However, the choice is yours.

Research shows that recovery is aided if treatment of schizophrenia is a collaboration between you, your family/whanau (if you choose), your doctor and case manager. The purpose of this collaboration is to work together towards recovery. Good communication exists when you, your family/whanau and your clinicians talk about the choice of treatments so that everyone receives the same information and can move towards the same goal.

Clinicians should offer your family/whanau members or carers frequent support when you are acutely unwell, and on an ongoing basis as needed. You should ask for printed information on your medication, therapy or group activity that you can give to your family/whanau members or partner.

Support groups are designed for patients and families where experiences with services or treatment are shared. Research shows they can be helpful. Sometimes your family/whanau may be able to help you in other ways:

- identification of early warning signs
- keeping records of the effectiveness of medication at treating your symptoms in the past, and
- in assisting you in accessing care.

They also play an important role in encouraging and supporting you to return to social, academic and vocational activities.

## **Cognitive Behavioural Therapy**

One form of psychotherapy which has been found to be effective in psychosis is called Cognitive Behavioural Therapy (CBT). It may be recommended depending on your needs and phase of illness.

Research suggests that CBT can improve coping strategies, help you learn new ways to manage stressful situations, improve thinking and memory skills, learn to socialise, reduce the level of positive symptoms, and to manage ongoing symptoms.

Research has also shown that CBT is a treatment of choice for depressive and anxiety symptoms. It may also be effective in reducing drug abuse. These are very common experiences for people going through a psychotic episode.

It is also more common for people experiencing psychosis to have suicidal thoughts and feelings. They are at a greater risk than the general community for self-harm and suicide. This risk can be reduced through supportive psychotherapy and use of expertly conducted CBT. It works by reducing depressive thoughts and severity and hopelessness which can be experienced by some people with schizophrenia.

It is important to ask your mental health professional if they have special training in CBT.

## **Vocational and social rehabilitation**

Rehabilitation focuses on social and occupational skills which may be absent or underdeveloped due to your illness. Depending on your needs, rehabilitation can be undertaken in a group or individually. It's about getting your whole life back and not just the management of symptoms.

## Group activities

People with schizophrenia may benefit from participating in groups with other people who also have schizophrenia. The focus of these groups can vary. They may provide information, teach you coping skills for dealing with mental illness, provide opportunities for formal or informal exercise, help you to develop relationships, help you to learn to become independent again, improve your confidence, enhance your study or work skills, or just be fun.

If your mental health service does not run groups, your doctor or case manager can let you know about local community agencies that do.

## Self-help groups

Self-help groups are not really considered 'treatment'. Rather, they are there for support and information. They may be beneficial because they provide support, facilitate information exchange, and provide resources.

Often self-help groups provide opportunities for new friendships. A list of self-help agencies is included in Appendix 3.

Self-help groups may also work to foster understanding of people with schizophrenia by the wider community. They can also give you the chance to help someone else who is recovering because you may benefit from hearing each other's experience.

Advocacy is important. There is much known about the optimal treatments for psychosis, however, access to these



Isolation and loneliness are related to poorer and slower recovery. Group activities counteract these problems. Get involved!

optimal treatments is not always as easy as it should be. Through self-help groups you can lobby for better services or more research.

### **Crisis support**

A system of mobile clinical support is available in most areas 24 hours a day. Public mental health Crisis Assessment Teams (CAT teams) are trained mental health professionals linked with your local service who can speak with you over the phone about your situation, current treatment and symptoms and, when necessary, visit you or arrange follow-up with your treating team. It should be part of your regular treatment plan that you know how to contact the after-hours service when you feel at risk. Ensure that you have the contact details of the service. These will also be available from your case manager or doctor. Family/whanau members can also use this service.

### **Counselling**

Talking to someone is an important part of treatment. Your case manager and doctor will provide general counselling and support during and after an episode of psychosis.

If you are feeling down, depressed, demoralised or thinking about suicide, it is VITAL that you talk to someone about it.

## **Coping With the Bad Times**

Suicidal thinking is **temporary**, but it is dangerous to try to cope with these symptoms on your own.

Suicide is one of the main causes of death for people with schizophrenia, most likely due to the depressive symptoms especially early on in people's experiences of psychosis.

Depression can be overcome. Most people have a good recovery even if things have been a bit rocky for a while. The key steps to surviving depression and suicidal thoughts in schizophrenia are:

- **Tell someone** – your GP, case manager, relatives, friends
- **Seek help** – your GP or case manager can help you manage your low feelings
- **Don't remain alone** – keep company around you and perform some positive activity.



Remember that research shows that combined treatments work best, rather than choosing only one treatment. It is important to choose both medication and psychosocial treatments together to progress your recovery.

## OTHER TREATMENTS AND TREATMENT ISSUES

### What is the Role of Hospitalisation?

A range of treatment settings should be available to people with schizophrenia. Treatment should occur in the least restrictive environment possible and hospitals used only when absolutely necessary. This may be at times when you need a place away from major stresses, or when medications need major review or other treatments are needed that can only be delivered in hospital.

Where possible, people should be treated at home. Sometimes hospitalisation is necessary for your safety even though you do not want it. Involuntary hospitalisation is governed by the Mental Health Act. Like orders to receive other forms of psychiatric treatment, it should be regularly reviewed, and you should be informed in writing of your rights in this situation.

Going to hospital can be a distressing experience. Everybody has ideas about what a psychiatric ward will be like. Most of these ideas are based on outdated stereotypes, and fiction. You have a right to be treated with respect and to have things explained to you in a way and language you understand. You can ask for family/whanau or friends to stay with you while you are admitted and get settled in.

Hospitalisation should also offer access to non-medication treatment options such as those discussed previously. Your

family/whanau or friends can visit and spend as much time with you as you wish, while you stay in hospital.

### **Electroconvulsive Therapy**

Rarely Electroconvulsive Therapy (ECT) is used if you have severe depression on top of your schizophrenia or when symptoms are very severe. ECT can be effective. It is not painful, and there are no long-term effects. If ECT is recommended as a treatment for you a brochure should be provided to you explaining how it works, how it feels and your rights.

## **Other Issues**

### **What can I do to help myself?**

You can contribute by staying informed about schizophrenia and its treatments. Tips for good health practices include:

- Following a sensible diet
- Having regular exercise
- Avoiding all illicit drugs as they have a strong negative impact on recovery
- Not using tobacco, as for all individuals, as it acts on the liver and may mean higher doses of medication are required
- Using alcohol and caffeine moderately
- Developing good sleep habits
- Learning and using stress management techniques.

Try and build an honest and open relationship with the professionals involved in your care. It will make it easier for them to understand and help you. Pay attention to changes



**Be optimistic about your future. You can live well with, and after having had, schizophrenia!**

in your body and in your thinking, and report them as soon as practical to your treating team.

This includes collaborating with your doctor to find a medication that gives you the most benefit and use it as recommended.

It is wise to develop a plan to monitor early signs of relapse. You may want to ask close friends or family/whanau to help.

Finally, it is important to nurture all the positive relationships you have in your life to ensure you have support throughout treatment and a positive outlook for the future.

## Research Summary of Treatment Essentials

Essentials for treatment are:

- Combined drug and non-drug therapy
- Low dose atypical anti-psychotic medication is strongly recommended unless there are indications for other medication
- Adjunctive medications where required
- Psychoeducation for individuals
- Collaboration and education for families and carers
- Individual cognitive therapy and group therapy tailored to individual needs
- Case management and other agencies providing accommodation and vocational support. There should also be a focus on the future, and where you are going. Case management should be pro-active. If it is not, then you need to demand that it is
- Access to crisis support 24 hours a day.



# Appendices

# APPENDIX I

## Medication Guide

Usual therapeutic doses and intensity of common side effects of anti-psychotic medications.<sup>1</sup>

Drug	Oral Dose Range(mg)	Sedation	Postural Hypo-tension	Anti-cholo-nergic	Extrapyr-a-midial	Weight Gain
<b>Newer Agents</b>						
Clozapine	100-600	+++	+++	+++	+ <sup>2</sup>	+++
Olanzapine	5-20	++	+	+	+ <sup>2</sup>	++
Quetiapine	300-700	+	++	+	+ <sup>2</sup>	++
Risperidone	0.5-6.0	+	++(initially)	0	+ <sup>2</sup>	+
<b>Older Agents</b>						
Chlorpromazine	50-600	+++	+++	++	++	++
Droperidol	5-10 (IM)	++	+	+	+++	+
Fluphenazine	5-20	++	+	+	+++	+
Haloperidol	0.5-12	+	+	+	+++	+
Pericyazine	25-75	+++	++	+++	++	+
Pimozide	2-12	++	+	+	++	+
Thioridazine	50-600	+++	+++	+++	++	++
Thiothixene	10-40	+	+	+	+++	+
Trifluoperazine	10-50	++	+	+	+++	+
Zuclopenthixol acetate	50-150 <sup>3</sup>	+++	+	++	+++	+
Zuclopenthixol dihydrochloride	10-75	+++	+	++	+++	+

Usual therapeutic doses and intensity of common side effects of long acting traditional anti-psychotics.<sup>1</sup>

Drug	IM Dose Range(mg) <sup>4</sup>	Dosing interval (weeks)	Sedation	Postural Hypo-tension	Anti-cholo-nergic	Extrapyra-midal	Weight Gain
Flupenthixol decanoate	12-5	2-4	+	+	++	+++	+
Fluphenazine decanoate	20-40	2-4	++	+	+	+++	+
Haloperidol decanoate	50-200	4	+	+	+	+++	+
Zuclopenthixol decanoate	200-400 <sup>5</sup>	2-4	+++	+	++	+++	+

**KEY**

**0**=Negligible or absent,

**+**=Mild,

**++**=Moderate,

**+++**=Marked,

**IM**=Intramuscular (ie, injected into a muscle)

<sup>1</sup>Based on and adapted from Therapeutic Guidelines (Psychotropic) Version 4.

<sup>2</sup>Rarely a problem at usual therapeutic doses.

<sup>3</sup>Single dose, not to be repeated for two or three days

<sup>4</sup>An initial test dose is recommended for all long acting agents, especially if the person with schizophrenia has not been exposed to the type of anti-psychotic agent previously.

<sup>5</sup>Patients switched from zuclopenthixol acetate do not require a test dose of zuclopenthixol decanoate.

Dosages vary from person to person. It is recommended that you discuss this guide with your GP in relation to your prescribed dosage.

## APPENDIX 2

### Who are the Members of My Health Care Team?

**Crisis team member** – Mental health professionals from a wide range of professions who work in teams to provide assistance during periods of high stress. They are trained as a psychiatrist, psychiatrist registrar (medical doctor doing specialist training to be a psychiatrist) medical doctor, psychologist, social worker, occupational therapist or nurse.

**Case manager** – The health care provider whom you see the most for your mental health care in the public mental health system. They coordinate all your care with other members of the team. They can be medical doctors, or allied health specialist such as psychologists, social workers, occupational therapists or trained mental health nurses.

**General practitioner (GP)/ Local doctor/ Family doctor** – Registered medical practitioners who have a general training in all areas of medicine, including psychiatry, but manage your general health care.

**Psychiatric nurse** – A person especially trained to provide promotion, maintenance, and restoration of mental health, including crisis and case management. Nurses can administer medications but cannot prescribe them, whereas other allied health professionals can neither prescribe nor administer medications.

**Occupational therapist (OT)** – A person trained to provide therapy through creative or functional activities that promote recovery and rehabilitation.

**Pharmacist** – A person licensed to sell or dispense prescription drugs.

**Psychiatrist registrar** – A registered medical doctor doing specialist training to be a psychiatrist.

**Psychiatrist** – A medical doctor who specialised in psychiatry. Psychiatry is a branch of medicine that deals with the study, treatment and prevention of mental illness and the promotion of mental health.

**Psychologist** – A person usually trained at a post-graduate level who works to apply psychological principles to the assessment, diagnosis, prevention, reduction, and rehabilitation of mental distress, disability, dysfunctional behaviour, and to improve mental and physical well-being.

**Social worker** – A person with specialised training in individual and community work, group therapies, family/whanau and case work, advocacy and the social consequences of disadvantage and disability, including mental disorders. They can provide psychosocial treatments for mental disorders and assist with welfare needs such as finance, or accommodation.

## APPENDIX 3

### Can You Explain That Term?

**Anti-psychotic medication** – A group of medications used to treat psychotic illnesses.

**Delusion** – A symptom of psychosis. A delusion is an illogical belief that is held strongly, even in the face of evidence that it is false.

**Depression** – A mood disorder ranging from passing sad moods to a serious disabling illness requiring medical and psychological treatment. Major depression is a 'whole body' disorder impacting on the patient's emotions (feelings of guilt and hopelessness or loss of pleasure in once enjoyed activities), thinking (persistent thoughts of death or suicide, difficulty concentrating or making decisions), behaviour (changes in sleep patterns, appetite, or weight), and even physical well being (persistent symptoms such as headaches or digestive disorders that do not respond to treatment).

**Hallucination** – A false or distorted perception of objects or events, including sensations of sight, sound, taste, touch and smell, typically with a powerful sense of their reality.

**Mental illness** – A general term for a wide range of disorders involving the brain where both psychological and behavioural symptoms may be exhibited.

**Mental disorder** – A diagnosable mental illness under agreed international criteria such as 'schizophrenia'.

**Negative symptoms** – Symptoms where a normal behaviour or emotion, such as motivation, socialisation, or interest is lacking. They are called negative symptoms because the behaviour or emotion has been removed from the normal range of behaviours.

**Neuroleptics** – Another name for anti-psychotic medication.

**Paranoia** – An insidiously developing pattern of unfounded thoughts and fears, often based on misinterpretation of actual events. People with paranoia may consider themselves endowed with unique and superior abilities or may have the delusion that others are conspiring to do them harm.

**Positive symptoms** – Symptoms such as delusions, hallucinations, disorganised thinking and agitation (called positive because the behaviour adds to what is considered normal).

**Prodrome** – A period of change in behaviour and low-grade symptoms experienced before an episode of psychosis.

**Psychosis** – This is central to a group of mental disorders that includes loss of contact with reality eg, hallucinations or delusions and breakdown of normal social functioning and extreme personality changes. A psychotic episode may be short lived or chronic.

**Psychotherapy/Psychological intervention** – A form of treatment for mental disorders based primarily on verbal communication between the patient and a mental health professional, often combined with prescribed medications. Psychotherapy can be conducted in individual sessions or in a group.

**Symptom** – A feeling or specific sign of discomfort or indication of illness.

## What do these Acronyms Stand for?

**CAT team** Crisis Assessment Teams

**CBT** Cognitive Behavioural Therapy

**ECT** Electroconvulsive Therapy

**GP** General Practitioner

**MRI** Magnetic Resonance Imaging

**OT** Occupational therapist

**TD** Tardive Dyskinesia

## APPENDIX 4

### Troubleshooting: Strategies for Getting the Most out of Treatment and for Solving Common Problems

Sometimes in an appointment people forget the questions they want to ask, or remember what the answers were, so it is a good idea to prepare specific questions by writing them down for discussion. Other strategies include writing a letter containing your queries to your clinicians requesting a written response, or to take a friend or family member with you to appointments.

Ask your health professional to explain any terms that they use which you don't understand.

### A Table of Common Scenarios and Possible Solutions

SCENARIO	POSSIBLE SOLUTIONS
<b>A</b> Excess medication leading to side effects such as movement disorder.	Inform nurse or doctor of side effects. Dosage may be reduced, medication changed to a different anti-psychotic or another medication added to counter side effects.
<b>B</b> Traumatic admission – eg, you were brought to hospital by police and/or restrained by hospital staff.	Provision of counselling by mental health service, preferably with a staff member not associated with the trauma. Also similar service provided to relatives who may have been traumatised by your admission.
<b>C</b> Scary inpatient experience.	You have a right to feel safe in hospital. If you do not, you should speak to staff about your concerns. You may be placed in a locked ward as a safety precaution. This situation has to be reviewed regularly, and you should be informed of why you are still in a locked ward.

SCENARIO	POSSIBLE SOLUTIONS
<p><b>D</b> Negative attitudes to schizophrenia?</p> <p><b>i.</b> Mental health staff and other health staff</p>	<p>If you perceive poor attitudes from a member of the mental health services, in the first instance speak to that person's manager (eg, shift leader, charge nurse, clinic manager) or to a member of your treatment team you feel you can talk to. Or speak to the consumer consultant in your service who is there to advocate for you.</p>
<p><b>ii.</b> Public</p>	<p>The general public is typically uneducated about mental illness. Where possible, try to use opportunities to educate people about mental illness. Speak to a clinician about the way you feel. If you experience attitudes that seem like discrimination or harassment eg, at your accommodation, or workplace, then there are generally actions you can take. It is illegal to discriminate against someone because of mental illness.</p>
<p><b>E</b> Low skill care</p>	<p>You should receive care from professionals who are up to date in their knowledge of psychosis and schizophrenia. Check out their qualifications. Membership of a professional association may indicate that they are required to keep up to date. Ask questions such as: What are the qualifications of the clinician? What is their experience in working with people with psychosis? How do they keep their knowledge up to date (answers you will want are reading journals, attending conferences, and attending courses)? Are they a member of a professional association such as the Royal Australian and New Zealand College of Psychiatrists, the New Zealand College of Clinical Psychologists, Aotearoa New Zealand Association of Social Workers.</p>

SCENARIO	POSSIBLE SOLUTIONS
<p><b>F</b> No psychosocial recovery program</p>	<p>The aim of a mental health service should be to provide a comprehensive, best practice service. It is known that a psychosocial recovery program is an integral part of an optimal rehabilitation. Ask for the types of programs or activities that have been mentioned in this guide. Again, advocate for improvement.</p>
<p><b>G</b> Barriers to early access:</p> <p><b>i.</b> First episode</p>	<p>Problems in getting access to quality services for a first episode are beginning to be addressed by the development of specialist early intervention centres or teams within existing services. Ask what special approaches are available in your area. Sometimes there are barriers when you want help but you are told that you are not unwell enough. In this case, talk to your GP and try together to get access. It is important to reduce the delay in receiving care as the earlier treatment is started, the better the outcome. A private psychiatrist or self help group can also be an advocate.</p>
<p><b>ii.</b> Multiple episode</p>	<p>People experiencing a relapse may also experience difficulties accessing mental health services. The difficulty can be minimised by having a plan worked out in advance with your clinicians and carers.</p>
<p><b>iii.</b> Declining treatment</p>	<p>Sometimes people who are unwell with schizophrenia feel that they don't need or want treatment. This is another barrier to receiving services. Often mental health services will say that they are not able to force treatment on someone who is not 'at risk' (ie, imminently suicidal/homicidal). However, this is not absolutely true. If you are a carer, a good suggestion would be to become familiar with the mental health act in your area. This will help you to advocate for care when it is needed.</p>

## APPENDIX 5

### Where Can I Find More Information and Support in New Zealand?

For further information on this guideline and other Clinical Practice Guidelines see [www.ranzcp.org](http://www.ranzcp.org)

#### **Schizophrenia Fellowship New Zealand**

National Office

PO Box 593, Christchurch

Phone: 03 366 1909

Freephone: 0800 500 363

Fax: 03 379 2322

Email: [sfnatoff@xtra.co.nz](mailto:sfnatoff@xtra.co.nz)

Website: [www.sfnat.org.nz](http://www.sfnat.org.nz)

#### **Q-nique**

PO Box 31 187, Lower Hutt, Wellington

Phone: 04 570 2320

Fax: 04 570 2321

#### **Richmond Fellowship New Zealand**

National Office

Level 3, 249 Madras Street

PO Box 2322, Christchurch

Phone: 03 365 3211

Fax: 03 365 3905

Email: [national@richmond.org.nz](mailto:national@richmond.org.nz)

Website: [www.richmondnz.org](http://www.richmondnz.org)

## Information and Support in Australia

Many of these organisations are community-managed non-profit associations. They provide mutual support, information, housing, rehabilitation, employment or advocacy services to people with or having had schizophrenia, their relatives and friends.

### **Mental Illness Fellowship of Australia**

Website: [www.mifellowshipaustralia.org.au](http://www.mifellowshipaustralia.org.au)

### **Mental Illness Fellowship of South Australia**

Phone: +61 8 8948 1051

Email: [mifsa@mifsa.org.au](mailto:mifsa@mifsa.org.au)

Website: [www.mifsa.org.au](http://www.mifsa.org.au)

### **Mental Illness Fellowship of Western Australia**

Phone: +61 8 9228 0200

Website: [www.mifwa.com](http://www.mifwa.com)

### **Schizophrenia Fellowship of Queensland**

Phone: +61 7 4725 3664

### **Mental Illness Fellowship of Victoria**

Phone: +61 3 9482 7832

Email: [enquiries@mifellowship.org](mailto:enquiries@mifellowship.org)

Website: [www.mifellowship.org](http://www.mifellowship.org)

### **Canberra Schizophrenia Fellowship**

Phone: +61 2 6205 1349

### **Schizophrenia Fellowship of NSW**

Phone: +61 2 9879 2600

Email: [info@sfnsw.org.au](mailto:info@sfnsw.org.au)

Website: [www.sfnsw.org.au](http://www.sfnsw.org.au)

### **Schizophrenia Fellowship of South Queensland**

Phone: +61 7 3358 4424

Email: [sfsq@sfsq.org.au](mailto:sfsq@sfsq.org.au)

Website: [www.sfsq.org.au](http://www.sfsq.org.au)

### **SANE Australia**

Phone: +61 3 9682 5933

Website: [www.sane.org](http://www.sane.org)

### **Carers Australia**

Phone: +61 2 6122 9900

Email: [caa@carersaustralia.com.au](mailto:caa@carersaustralia.com.au)

Website: [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

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

### **ARAFMI New South Wales**

Phone: +61 2 9887 5897

Helpline: +61 2 9805 1883

Email: [arafmi@webtime.com.au](mailto:arafmi@webtime.com.au)

Website: [www.arafmi.org.au](http://www.arafmi.org.au)

### **ARAFMI Queensland**

Phone: +61 7 3254 1881

Email: [arafini@irvnet.org.au](mailto:arafini@irvnet.org.au)

### **ARAFMI Western Australia**

Phone: +61 8 9228 0577

### **ARAFMI South Australia**

Phone: +61 8 8221 5166

**ARAFMI Tasmania**

Phone: +61 3 6326 9251

**ARAFMI Northern Territory**

Phone: +61 8 8942 2811

**ARAFEMI (VIC) Inc**

Phone: +61 3 9889 3733

Email: *admin@arafemi.org.au*

**The Network for Carers of People with Mental Illness**

Website: *www.carersnetwork.org*

**Other Useful Web Sites about  
Schizophrenia**

Australian Department of Health and Aging	<i>www.health.gov.au</i>
Commonwealth Rehabilitation Service (CRS)	<i>www.crsrehab.gov.au</i>
EPPIC	<i>www.eppic.org.au</i>
Mental Help Net	<i>www.mentalhelp.net</i>
Reach Out	<i>www.reachout.com.au</i>
World Fellowship for Schizophrenia and Allied Disorders	<i>www.schizophrenia.com</i>

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## Quality Statement

This guide has been consulted upon bi-nationally and drafts were available for comment on [www.ranzcp.org](http://www.ranzcp.org). It has been appraised using DISCERN by a national workshop consumer consultants and meets NHMRC criteria for presenting information on treatments for consumers.



