AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

Clinical Care Standards

GUIDE
for consumers

Psychotropic Medicines in Cognitive Disability or Impairment

Clinical Care Standard

What is the Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard?

The *Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard* contains eight quality statements describing the health care that you should expect to receive to support the correct use of psychotropic medicines. You can use this information to help you and your family or other members of your support network to make informed decisions about your care together with your healthcare provider.

This guide explains each quality statement and what it means for you.

For more information or to read the full clinical care standard visit: **www.safetyandquality.gov.au/psychotropics-ccs**.

What are psychotropic medicines?

Psychotropic medicines are used mainly to treat mental health conditions like schizophrenia, anxiety, depression, and bipolar disorder. Some psychotropic medicines can also be used for health conditions such as pain or sleeping problems.

Psychotropic medicines can make people less able to move around and because of this they are sometimes used to control behaviour which is not caused by a mental health condition. If you experience behaviours where there is a high risk of harm to you or the people around you, then a psychotropic medicine could be used. Ways of managing the behaviour without medicines should be tried first, if it is safe to do so.

Psychotropic medicines should only be used when there is a good reason. When they are prescribed, their effects should be regularly monitored and reviewed to prevent harm that can occur with these medicines, with the goal of using the medicine for the least amount of time that you need.

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1 Person-centred care

What the standard says

A person receives health care that is driven by their individual preferences, needs and values, and that upholds their personal dignity, human rights and legal rights. The person is supported to be an active participant in making informed choices about their care, together with their family, support people or nominated decision-maker as appropriate.

What this means for you

You have a right to health care that is based on your preferences, needs and values, and the right to say what you think will be best for your life. You have a right to be involved in discussions and in making choices about your care. You have a right to be treated with respect. These rights are protected by laws, which must be followed by those providing your care.

Your healthcare provider will try to understand what matters to you. This includes your personal experiences, culture, religious or spiritual beliefs, and the things you like and do not like. When the person being treated is a child or adolescent under 18 years of age, this involves understanding that their needs and interests will change as they grow and develop.

When it comes to making choices about your care – including whether to have medicines – you should be asked what you want. To help you make informed choices, your healthcare provider will give you information in a way that meets your needs.

Some people can make choices independently, and some people may need support to make their own decisions. Support might be from another person – such as a family member, friend, support worker or member of an advocacy organisation – to help you understand the information and make your own choice. Support might mean giving you time to consider the choices, practical support such as having a translator or making sure you have your hearing aids, or providing information in a way that is best for you. Support does not mean that somebody else decides for you.

Some people may not be considered able to make a decision about their care, even with support. If the person is an adult, there are ways to appoint someone to make decisions on their behalf, and their views and wishes should still be sought when someone else is making decisions about their care. For children and adolescents under 18 years of age, parents usually hold legal authority to make decisions on their behalf; however, the views and wishes of a child or adolescent should still be sought and should inform final decisions.

2 Informed consent for psychotropic medicines

What the standard says

If psychotropic medicines are being considered, the person – and their family, support people or nominated decision-maker as appropriate – is informed about the reason, intended duration, and potential benefits and harms of treatment. If use of a psychotropic medicine is agreed, informed consent is documented before use. In an emergency or if the person does not have capacity to make a decision even with support, processes are followed in accordance with relevant legislation.

What this means for you

If psychotropic medicines are suggested for you, you have the right to have a say and be involved in decisions about having them.

The medicine should only be used after you have given informed consent. In an emergency where there is a risk you might seriously hurt yourself or someone else, your healthcare provider can use psychotropic medicines without your consent. Whenever possible they should still try to ask for your consent first.

To provide informed consent, you should be given information about why the medicine is being suggested, how long you might need to take it, the good and bad things about taking it, what might happen if the medicine is not taken, and possible alternatives to using the medicine. You should have the chance to ask questions and decide whether or not to have the medicine. After you have received all the information, you can choose not to consent. This information should also be provided to the people who are closely involved in your healthcare decisions, such as your family, support people or the person who makes healthcare decisions on your behalf (if you have someone with this responsibility). In the case of a child, this will often include their parents or guardians.

You can make your decision in a way that feels comfortable for you and so that you don't feel pressured by others. This might mean having a discussion in private, or it might mean having time to make the decision.

You can also involve someone to help you make your decision, for example a family member, if you need or would like. This is called supported decision making.

Even after you give your consent you can still ask more questions, request more information or change your mind.

If you are not able to make decisions about using a psychotropic medicine because of your current mental state, or in the case of a child or adolescent under 18 years of age, a decision can be made by others who are authorised to make decisions about your care for you. This person can be described as a nominated or substitute decision-maker, but other titles may be used for them too. Even if a nominated decision-maker makes a decision on your behalf, they should take into account your wishes and preferences that you have made known to them.

A record of the discussion and your decision will be kept in your healthcare record so that everyone involved in your care knows what your wishes are.

3 Assessing behaviours

What the standard says

A person with behaviours of concern is initially assessed for immediate risks to their safety and others. The person is further assessed to identify clinical, psychosocial and environmental causes of the behaviours, and to understand the context in which they occur. Assessment is carried out by suitably trained individuals, and considers existing plans to support the person's care and information from others who know the person well.

What this means for you

If you or someone else notices that your reactions or behaviour are different from usual, this could be a sign that something is wrong. A healthcare provider, such as a doctor or nurse, will assess you to try to understand what might be causing you to behave this way to see what could be done to help you.

If your behaviour is dangerous to you or other people, your healthcare providers will first need to act to keep everyone safe. This includes when you have a medical problem that needs to be treated quickly but you are too distressed to let anyone assess you. Your healthcare provider will find a way to make you and others safe before they continue. Sometimes this may mean using medicines without your consent.

Your healthcare provider will check all the different reasons that might have caused your behaviour. For example, you might be in pain, feel sick or be upset by something. They will check your physical health, your medical history, medicines you are using, circumstances in your life and how you are feeling – including asking you whether something has upset you or caused your behaviour to change. If you would like someone to be with you during the assessment, for example a family member, this can be arranged. If you prefer not, that's okay as well.

Your healthcare provider will also refer to care plans and other reports to support you if you have them in place. If you need extra support for the assessment, this should be provided – for example, if you need help understanding what is being asked or to communicate with your provider.

Your healthcare provider may want to talk to other people who know you well, such as your family, support people, or people who make decisions about your care on your behalf. People who know you well may be able to help explain the issues affecting you. They may also be able to help you say what you want to say.

If someone is speaking on your behalf, you should be asked for permission for them to be involved.

The results of your assessment will be documented in your healthcare record and used to guide your care.

4 Non-medication strategies

What the standard says

Non-medication strategies are used first-line and as the mainstay of care when responding to behaviours of concern. The choice of strategies is individualised to the person and is documented and communicated to all those involved in their care.

What this means for you

Behaviours that cause concern to you or others can often be reduced and sometimes prevented without using medicines. Ways of responding to behaviours that don't involve medicines are known as 'non-medication strategies' or 'positive behaviour support strategies'.

Your healthcare providers and any other person involved in your care should use non-medication strategies whenever possible when addressing behaviours of concern. Non-medication strategies are the best way to respond to these behaviours and to support your wellbeing. Even if medicines are used, non-medication strategies should always be used alongside them.

The non-medication strategies used will depend on what causes your behaviour. Understanding the causes of your behaviour helps identify ways to prevent it from happening. Avoiding these causes might mean adjusting your environment – for example, managing temperature, noise and lighting, and making sure you have familiar objects or people around you – or doing activities that you enjoy or are meaningful and of interest to you.

Information about non-medication strategies for you should be written down somewhere and communicated to the people looking after you or involved in your daily life so they know how to support your wellbeing. This information might be written down in your healthcare record, or your behaviour support plan if you have one. If you have a behaviour support plan, it will contain important information about the circumstances that may cause these behaviours and what can be done to help prevent or reduce them. Your healthcare providers should be informed about your behaviour support plan and use it to look after you and prevent or reduce these behaviours.

5 Behaviour support plans

What the standard says

If a person has a plan to support their behaviour, it is used to inform and support their care. The person's response to care provided under the plan – including any use of psychotropic medicines – is continually assessed, documented and communicated to inform regular updates to the plan and prescribing decisions.

What this means for you

If you sometimes experience behaviours that could cause harm or distress to yourself or others, your care providers, other providers, or someone who knows you well may have developed a plan to help you and others prevent the behaviour and support your wellbeing. This is often called a behaviour support plan. If you also receive services from aged care or have behaviours

of concern and receive services from the National Disability Insurance Scheme, then you should have a behaviour support plan.

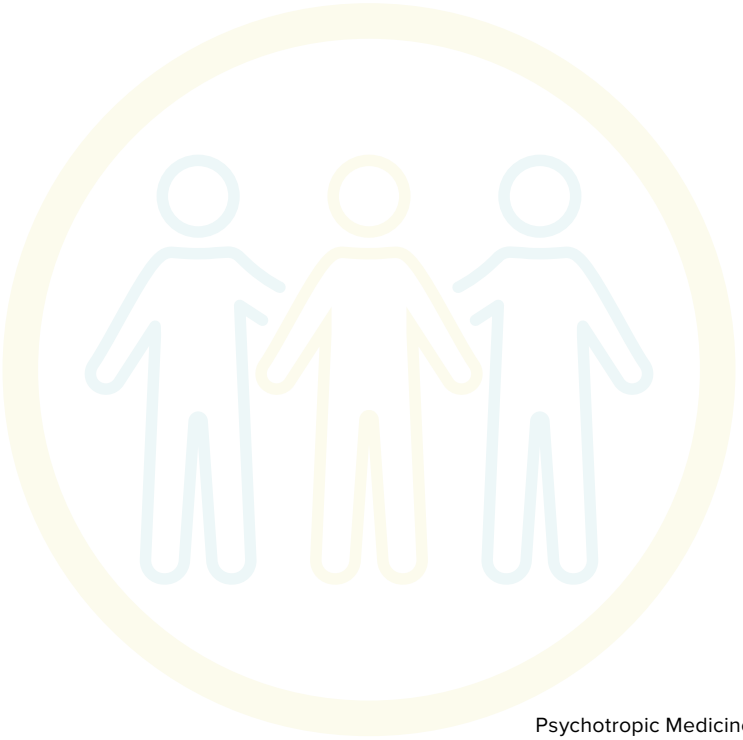
If you have a behaviour support plan, it is important that it is used by the people who provide you with care. The plan helps everyone to have a shared understanding about how to best support your wellbeing.

The plan is developed by someone who works with you to understand what can cause your behaviour. It describes why your behaviour happens, and things that you and other people can do to help prevent the behaviour from happening. This might include doing activities that you like, or learning new ways to cope when things get difficult. The plan explains what other people can do to and helps them to see when you may need extra support and how to communicate with you better.

Sometimes, a behaviour support plan might include use of medicines to help you change or stop a behaviour, for example, to stop you from hurting yourself or others. When a medicine is used this way, it is referred to as a restrictive practice. Having a behaviour support plan should help to reduce the use of medicines to influence your behaviour.

Your plan will probably change over time as you and your care team learn what causes your behaviour and what works and doesn't work.

It is important to check that the plan is helping and things are getting better over time. If the plan is not helping, something may need to change.



6 Appropriate reasons for prescribing psychotropic medicines

What the standard says

Psychotropic medicines are considered in response to behaviours only when there is a significant risk of harm to the person or others, or when the behaviours have a major impact on the person's quality of life and a reasonable trial of non-medication strategies has been ineffective. Psychotropic medicines are also considered when a mental health condition has been diagnosed or is reasonably suspected following a documented clinical assessment. The reason for use is clearly documented in the person's healthcare record at the time of prescribing.

What this means for you

Psychotropic medicines are a group of medicines that affect how the brain works. There are several different types. Most often, psychotropic medicines are used as important treatments for mental health conditions such as depression, anxiety and schizophrenia. However, sometimes they are used to control the way a person is behaving, not for treating a mental health condition as such.

Psychotropic medicines should only be used to control behaviour when there is a good reason for doing so, for example, if the behaviour is likely to harm you, harm others or is seriously reducing your ability to function and participate in everyday activities. Whenever possible, other ways of managing the behaviour should be tried first before using psychotropic medicines. However, this might not be possible if the behaviour needs to be controlled quickly, to prevent someone being hurt. In the same way, if you need urgent medical treatment, but it's not possible due to your behaviour, then psychotropic medicines may be used to help reduce your distress so that you can be examined and treated.

The reason for prescribing a psychotropic medicine and which medicine is prescribed will depend on your individual circumstances. Your healthcare provider will assess you thoroughly to see whether a psychotropic medicine may help you. If this is the case, a trial of the medicine will be discussed with you, and your family, support people or nominated decision-maker as appropriate.

In some people with cognitive disability or impairment, it may be difficult to be sure whether the behaviour is caused by a mental health condition. In such cases, the medicine might be tried for a short time to see if it helps.

7 Monitoring, reviewing and ceasing psychotropic medicines

What the standard says

A person's response to psychotropic medicines is regularly monitored and reviewed according to the person's individual needs and goals of treatment. The benefits and harms of treatment and the potential for dose adjustment or cessation are considered at each review. The outcome is documented and communicated, along with the timing of the next review.

What this means for you

If you have been prescribed a psychotropic medicine for any reason, it is important to regularly check whether it is helping you and that it is still the best option.

Your first check-up should occur soon after starting the medicine. How soon the check-up occurs will depend on what medicine you are taking and the reason it was started.

You and your healthcare provider should have a way of checking whether the medicine is helping you. For example, if the medicine is expected to help you avoid a particular behaviour, keeping a record of how often the behaviour occurs after starting the medicine can build a picture of whether the medicine is helping.

When you have a check-up, information may also be sought from people who know you well such as your family, support people or other people who are involved in your care.

This check-up is to help to understand how well the medicine is working and whether you are experiencing any unwanted effects. If you are experiencing unwanted effects from the medicine, talk to your healthcare provider.

If the medicine is helping you and you need to continue to take it, you should keep having regular check-ups with your healthcare provider. Sometimes your dose may need to change. If the medicine is not helping you, it should be stopped. It may also need to be stopped because of unwanted effects. If you need to stop taking a psychotropic medicine, it is important to talk with your healthcare provider to find out the best way to do this.

If you have a behaviour support plan, information about how well your medicines are working should be given to the person who developed and looks after your behaviour support plan. This is so they can make sure that your behaviour support plan is working and update it if necessary.

The results of your check-up and any changes made will be explained to you and, if appropriate, other people who are involved in your care. This information will be written in your healthcare record, along with the date for your next check-up. It is important to know when your medicine will next be checked. You can always ask for a check-up sooner if you have questions or concerns about your medicines.

8 Information sharing and communication at transitions of care

What the standard says

When the health care of a person is transferred, information about their ongoing needs is shared with the person, their family or support people and the healthcare and service providers continuing their care. This includes information about behaviour support plans or other strategies. If psychotropic medicines are prescribed, the reason for use, intended duration, timing of last administration, and plans for monitoring and review are documented and communicated to support the person's ongoing care.

What this means for you

When you move between different healthcare services, it is important that information about your care is shared between providers so they can care for you well – for example, when you enter or leave hospital, see different doctors, or move from one residential care or supported accommodation setting to another. This information should also be shared with you and, with your consent, your family, support people and other people who are involved in your care. It can be unsettling to go to hospital or a new place, have changes to your normal routine, or be with a lot of new people. Understanding how to make you feel more comfortable is important. It is also important that your healthcare needs are understood. Good communication about your care, your treatments and any support that you need helps to keep you safe and well.

For example, if you go into hospital, information about your ongoing care needs and any medicines that you take should be given to the hospital. If you have any plans to support your behaviour, they should also be given to the hospital.

When you leave hospital, information about your hospital care should be given to you, your family or support people, and other healthcare or service providers you use, including a copy of the information for your doctor. This should include information about the care you received while in hospital, such as changes to your regular medicines, and information about your behaviour support needs while you were in hospital.

If you are prescribed a psychotropic medicine and need to continue it after you leave the healthcare service you should be given information about:

- Why the medicine has been prescribed
- When it was last given to you
- How long you should take it for
- The possible side effects
- When to have a check-up to see how well the medicine is working.

It is also important for your doctors and other healthcare providers to share this information with each other and with others involved in your care.

Questions?

Further information about the clinical care standard is available from: **www.safetyandquality.gov.au/psychotropics-ccs**.

Further information about the Australian Charter of Healthcare Rights is available from: **www.safetyandquality.gov.au/our-work/partnering-consumers/australian-charter-healthcare-rights**.

You can contact the Clinical Care Standards program team at: **ccs@safetyandquality.gov.au**.

The Australian Commission on Safety and Quality in Health Care has produced this clinical care standard to support the delivery of appropriate care for a defined condition. The clinical care standard is based on the best evidence available at the time of development. Healthcare professionals are advised to use clinical discretion and consideration of the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, when applying information contained within the clinical care standard. Consumers should use the information in the clinical care standard as a guide to inform discussions with their healthcare professional about the applicability of the clinical care standard to their individual condition.