Psychotropic Medicines in Cognitive Disability or Impairment

Clinical Care Standard

May 2024

The Australian Commission on Safety and Quality in Health Care acknowledges the traditional owners of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present.

Disclaimer

This clinical care standard was produced by the Australian Commission on Safety and Quality in Health Care to support the delivery of appropriate care for a defined condition, based on the best evidence available at the time of development. Healthcare professionals are advised to use clinical discretion and consider the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, when applying information from the clinical care standard. Consumers should use the clinical care standard as a guide to inform discussions with their healthcare professional about how it applies to their individual condition. The Commission does not accept any legal liability for any injury, loss or damage incurred by the use of, or reliance on, this document.

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The *Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard* has been endorsed by the following organisations:

Australian Government
Aged Care Quality and Safety Commission

NDIS Quality and Safeguards Commission

Australasian College for Emergency Medicine

Australasian College of Paramedicine

Australian & New Zealand Society for Geriatric Medicine

AADDM
Australian Association of Developmental Disability Medicine

AAG
Australian Association of Gerontology

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Australian College of Mental Health Nurses

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Occupational Therapy AUSTRALIA

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THERAPEUTIC GUIDELINES

Contents

Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard

Quality statements

In the statements below, person means a person of any age with cognitive disability or cognitive impairment.

1 **Person-centred care**

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.

2 **Informed consent for psychotropic medicines**

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.

3 **Assessing behaviours**

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.

4 **Non-medication strategies**

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.

5 **Behaviour support plans**

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.

6 **Appropriate reasons for prescribing psychotropic medicines**

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.

7 **Monitoring, reviewing and ceasing psychotropic medicines**

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.

8 **Information sharing and communication at transitions of care**

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.

Indicators for local monitoring

The following indicators will support healthcare services and clinicians to monitor how well they are implementing the care recommended in this clinical care standard and are intended to support local quality improvement activities.

2 Informed consent for psychotropic medicines

Indicator 2a: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for whom informed consent was obtained and documented.

3 Assessing behaviours

Indicator 3a: Evidence of local arrangements to ensure a person with cognitive disability or impairment with behaviours of concern is assessed to identify any clinical, psychosocial and environmental causes for the behaviours.

The local arrangements should specify the:

- Procedures to support reasonable adjustments for a person with cognitive disability or impairment to facilitate their involvement in the assessment process
- Process to access any existing care or behaviour support plans
- Process to involve the person's family or support people, in accordance with the person's wishes, and nominated decision-makers as appropriate
- Process to ensure any records of legal nominated decision-makers, guardianship or administration orders are accessible to staff
- Process to ensure relevant clinicians and members of the workforce receive training and education about the potential causes of behaviours in people with cognitive disability or impairment, including how to provide trauma-informed care
- Findings of assessments that should be documented in the person's healthcare record
- Process to oversee implementation of the local arrangements and evaluate their effectiveness.

4 Non-medication strategies

Indicator 4a: Evidence of local arrangements to ensure people with cognitive disability or impairment receive appropriate non-medication strategies to prevent or reduce behaviours of concern.

The arrangements should specify the process to:

- Select and implement appropriate non-medication strategies based on a person's assessment
- Monitor and document a person's response to the non-medication strategies
- Ensure clinicians and other members of the workforce who are involved in the care of people with cognitive disability or impairment receive education and training on non-medication strategies to prevent or reduce behaviours of concern, appropriate to their role and scope of practice
- Inform clinicians and other members of the workforce about the non-medication strategies that can be implemented at the service
- Oversee implementation of the local arrangements and evaluate their effectiveness.

5 Behaviour support plans

Indicator 5a: Evidence of a local policy to ensure a person's behaviour support plan is used to support their care.

The policy should specify the:

- Protocol to identify people who have an existing behaviour support plan
- Process to communicate with aged care and disability service providers to request a copy of a person's behaviour support plan if it is not available when they present to hospital
- Process to support clinicians to consider a person's behaviour support plan when providing health care to the person
- Process to support clinicians to document the person's response to the behaviour support plan and any recommendations to inform updates to the plan
- Process to assess adherence to the policy.

6 Appropriate reasons for prescribing psychotropic medicines

Indicator 6a: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for whom the reason(s) for prescribing the medicine was documented in their healthcare record.

Indicator 6b: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for behaviours of concern who had a comprehensive assessment to identify factors that might be contributing to the behaviours.

Indicator 6c: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for behaviours of concern who were also receiving non-medication strategies.

7 Monitoring, reviewing and ceasing psychotropic medicines

Indicator 7a: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for whom the timeframe to review the medicine was documented in their healthcare record.

Indicator 7b: Proportion of people with cognitive disability or impairment who were prescribed a psychotropic medicine for whom the effectiveness of the medicine on target symptoms and any adverse effects were documented at each review.

8 Information sharing and communication at transitions of care

Indicator 8a: Evidence of a locally approved policy to ensure that information about a person's behaviour support needs and their psychotropic medicines is transferred with the person between care settings.

The policy should specify the:

- Behaviour support information, including the person's behaviour support plan if they have one, that is to be transferred with the person between care settings
- Healthcare information, including a complete and accurate medicines list and key details about the use of any psychotropic medicines, that is to be transferred with the person between care settings
- Requirement to maintain and transfer up-to-date contact details of the person's family members, support people or nominated decision-maker and, as relevant, the person's disability service providers, general practitioner, Aboriginal and Torres Strait Islander Health and Medical Service, and other care and service providers
- Process to ensure the information is transferred with the person between care settings
- Process to ensure the workforce is informed and competent in the use of the policy.

Indicator 8b: Proportion of people with cognitive disability or impairment discharged with a supply or prescription for psychotropic medicine where the person or support people were provided with information about the medicine on discharge.

Indicator 8c: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine while in hospital, whose discharge information was sent to the clinician responsible for their care on discharge.

Indicator 8d: Proportion of people with cognitive disability or impairment who were prescribed a psychotropic medicine while in hospital, whose discharge information was sent to their aged care or disability service provider on discharge.

The definitions required to collect and calculate indicator data are specified online: **meteor.aihw.gov.au/content/791005**. More information about indicators and other quality improvement measures is provided in **Appendix B**.

Clinical care standards

Clinical care standards help support the delivery of evidence-based clinical care and promote shared decision-making between people, their families and carers, and clinicians. They aim to ensure people receive best-practice care for a specific clinical condition or procedure, regardless of where they are treated in Australia.

A clinical care standard contains a small number of quality statements that describe the level of clinical care expected for a specific clinical condition or procedure. Indicators are included for some quality statements to assist healthcare services monitor how well they are implementing the care recommended in the clinical care standard.

A clinical care standard differs from a clinical practice guideline. Rather than describing all the components of care for a specific clinical condition or procedure, a clinical care standard focuses on key areas of care in which the need for quality improvement is greatest.

Clinical care standards aim to improve healthcare outcomes by describing key components of appropriate care, enabling:

- People, their families and carers to understand the care that is recommended and their healthcare choices
- Clinicians to provide best-practice care
- Healthcare services to monitor quality and make improvements in the care they provide.

Clinical care standards are developed by the Australian Commission on Safety and Quality in Health Care (the Commission), an Australian Government agency that leads and coordinates national improvements in the safety and quality of health care, based on the best available evidence. By working in partnership with the Australian Government, states and territories, the private sector, clinical experts, and consumers and carers, the Commission aims to ensure that the health system is better informed, supported and organised to deliver safe and high-quality care.

About the Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard

Context

The importance of ensuring the safe and appropriate use of psychotropic medicines for people with cognitive disability or impairment was highlighted by findings of the Royal Commission into Aged Care Quality and Safety[1] and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.[2] Action on this issue is a priority for people with cognitive disability or impairment, their families and support people, as well as for healthcare, aged care and disability care service providers.

These Royal Commissions highlighted serious human rights, legal rights and safety issues relating to the use of psychotropic medicines in people with cognitive disability or impairment. The misuse and overuse of psychotropic medicines to influence a person's behaviour through their sedative effects – rather than to treat a mental health or physical condition – is common. Furthermore, psychotropic medicines are being prescribed for reasons outside their approved use and for extended periods without review.

This clinical care standard was developed following a **Joint Statement** from the Australian Commission on Safety and Quality in Health Care, the Aged Care Quality and Safety Commission and the National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission in March 2022, outlining their commitment to working together to reduce the inappropriate use of psychotropic medicines and so protect the human rights and safety of older people and people living with cognitive disability or impairment.[3]

The standard sits alongside national legislation introduced to the aged care and disability sectors that identifies use of psychotropic medicines for the primary purpose of influencing a person's behaviour as a restrictive practice (chemical restraint).[5,6] Not all state and territory mental health legislation recognises the use of medicines as a form of restrictive practice.* Where it applies, regulatory oversight distinguishes between using a medicine for a therapeutic indication – such as a diagnosed mental health or other condition – or as a restrictive practice for influencing behaviour. When the use of a psychotropic medicine falls under the definition of a restrictive practice for the person's residential or healthcare setting, relevant legislation and regulations should be applied.

Determining whether a psychotropic medicine is being used to influence a person's behaviour, and is therefore a restrictive practice, can be complex. Both the reason for prescribing and the impact of the medicine on the person should be considered. For example, when psychotropic medicines are prescribed for a diagnosed mental health or physical condition in a person with cognitive disability or impairment, some uses of the medicine could still be considered a restrictive practice if it is used to manage certain behaviours, limits a person's freedom of movement, or reduces their participation in the community through sedation. In other cases, diagnosis may be difficult to ascertain in a person with a cognitive disability or impairment. In such cases, assessing their response to a trial of psychotropic medicines may be part of the diagnostic process.

Regardless of the reason for prescribing, psychotropic medicines are high-risk medicines and have potential for harm.

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* Note: Different jurisdictions and health sectors define and regulate restraint in mental health units differently, although there is overlap. Some state and territory laws do not recognise the use of medicines as a restrictive practice. See also NSQHS Standards **Action 5.35**.

For these reasons, this standard focuses on the safe and appropriate use of psychotropic medicines for the specified group of people, rather than focusing more narrowly on the use of psychotropic medicines within a particular definition of restrictive practice.

While parts of this standard focus on the prescribing of psychotropic medicines to influence a person's behaviour, others apply whenever psychotropic medicines are prescribed. Much of the guidance is based on key principles for the safe and quality use of medicines as described in Australia's National Medicines Policy.[4] These principles apply to all medicines regardless of the reasons they are prescribed.

Goal

This clinical care standard aims to ensure the safe and appropriate use of psychotropic medicines in people with cognitive disability or impairment and to uphold their rights, dignity, health and quality of life.

Scope

This clinical care standard relates to the **health care** that people of all ages including children and adolescents with cognitive disability or impairment should receive to optimise the prescribing and use of psychotropic medicines. It is relevant to people with cognitive disability or impairment who are:

- Living independently and may have visiting support workers
- Living with family and may have visiting support workers
- Living in aged care homes
- Living in specialist disability accommodation
- Receiving care in acute healthcare facilities.

The standard relates to the care provided to people with cognitive disability or impairment when psychotropic medicines are prescribed for one or more of the following reasons:

- In response to behaviours of concern
- For treating diagnosed mental health or neurological conditions, or sleep disorders
- For treating diagnosed physical illnesses or conditions.

The standard recognises existing legislation that identifies use of psychotropic medicines for the primary purpose of influencing a person's behaviour – rather than treating a mental health condition – as a restrictive practice, and the regulatory roles of the Aged Care Quality and Safety Commission and the NDIS Quality and Safeguards Commission.[5-8] It does not replace the regulations and requirements of these two Commissions. Similarly, in healthcare services where state or territory mental health legislation applies, the standard should be considered within the requirements of the relevant mental health Act.

> This clinical care standard provides guidance that can be applied across diverse settings and to people of different ages with different types of types of cognitive impairment and disability. When implementing this clinical care standard, clinicians and those governing the provision of healthcare, aged care and disability services should consider the context in which health care is delivered and the specific relevant jurisdictional and regulatory requirements that apply to the person and healthcare setting.

What is not covered

This clinical care standard does not address the use of psychotropic medicines in:

- People who do not have cognitive disability or impairment
- The management of acute behavioural disturbance secondary to recreational drug or alcohol use
- The management of terminal delirium during the last days of life.

This clinical care standard does not provide specific guidance on the selection and choice of psychotropic medicines for any indication.

Healthcare settings

Health care is delivered in various settings. This clinical care standard applies to all settings where people living with cognitive disability or impairment receive health care. Examples of settings that are in scope for this clinical care standard include, but are not limited to:

- Hospital settings, both public and private, including subacute facilities, outpatient clinics, day procedure services and multipurpose services
- Community settings, both clinical and residence-based, including people's homes, aged care homes, hostels, boarding houses, and supported accommodation (such as specialist disability accommodation services provided through the NDIS)
- Justice or forensic healthcare services.

Implementation of this clinical care standard should consider the context in which health care is provided (such as an aged care home versus an acute care hospital); local variations that indicate a need for improvement; and the quality improvement priorities of the individual healthcare service.

In rural and remote settings, implementation of the standard may require different strategies, such as telehealth consultations and hub-and-spoke models that integrate larger and smaller healthcare services.

Implementation should comply with jurisdictional requirements relevant to the healthcare service.

Terminology

Definitions of key terms used in this clinical care standard are provided below. See the **Glossary** for a full list of terms and their definitions.

Note that some terms have different meanings for different people. It is important to be aware of these differences. For example, Aboriginal and Torres Strait Islander people may consider people other than immediate blood relatives to be next of kin. Terms used in one community may have a different meaning or no meaning in another. It is therefore important to be aware of the cultural background of the person, family or community and to seek advice from members of culturally and linguistically diverse (CALD) communities or Aboriginal and Torres Strait Islander people if possible, so that terms can be used appropriately.

Key terms used in this document

Term	How it is used in this document
behaviours of concern	Behaviours that indicate a risk to the safety or wellbeing of the person who exhibits them or the safety or wellbeing of those around them.[8–10]
Alternative terms include: changed behaviours, challenging behaviours, distressed behaviours, behaviours that cause distress, complex behaviours of concern, responsive behaviour, non-cognitive symptoms, neuropsychiatric symptoms or expression of unmet need.	Behaviours may challenge the person, their supporters and the care services they are in, but may serve a purpose for the person, such as communicating unmet needs and responses to their environment.[11–13] Behaviours that cause concern to others may not be concerning to the person who exhibits them.

While using this term, the Commission recognises that:

- Alternative terms may be more acceptable in different contexts and there is **no universally accepted** term that applies in all settings and to all groups of people across the lifespan
- The term should not be used to define a person by their symptoms or suggest that the person themselves is a concern
- The term does not represent a medical diagnosis, but a behavioural response that could have many possible causes requiring assessment to determine appropriate treatment.[14,15]

> ### People with dementia who experience behavioural and psychological symptoms
>
> In care for people with dementia, the terms 'changed behaviour' or 'expressions of unmet need' are mostly used to refer to changes in the behaviour or emotional state of the person that are commonly experienced as part of the condition. These terms are used to avoid defining a person by their symptoms, or unintentionally stigmatising the person as a challenge or a concern.[9,14,16,17] They are preferred by peak bodies that represent people with dementia, such as Dementia Support Australia.
>
> In a clinical setting, these changes are also called behavioural and psychological symptoms of dementia (BPSD). BPSD can include delusions (such as distressing beliefs), hallucinations, agitation (such as being easily upset, inappropriate screaming, crying out or making disruptive sounds, or rejection of care such as bathing or dressing), physical or verbal aggression, depression or dysphoria, apathy or indifference, or anxiety (such as worrying or shadowing the movements of others, for example, following a carer).[14]

> ### People with intellectual disability
>
> In care for people with intellectual disability, the term 'challenging behaviour' is used interchangeably with 'behaviours of concern' to refer to behaviours that can have a negative impact on the quality of life of the person or other people, cause concern, be challenging to alleviate, or put the person or others at risk.[13,15,18]
>
> Behaviours may be:
>
> - Externalised, which can involve aggression directed towards people or damage to objects, self-injury (such as head banging), and other behaviours (such as absconding, screaming or making repetitive movements)
> - Internalised, resulting in the person being withdrawn, inattentive or unresponsive, or not engaging in activities that they might otherwise do.[15]

Term	How it is used in this document
behaviour support plan	A written plan prepared with the person and their family or support people as appropriate that helps those involved in the person's daily life and care to improve the person's care to reduce or prevent behaviours of concern, and potentially eliminate the need for restrictive practices to control behaviour.
	For recipients of aged care and NDIS services, a behaviour support plan is made in accordance with the *Quality of Care Principles 2014*[8] (the Principles) and the *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018*.[6]
carer	A person who provides unpaid personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness), mental health condition, or they are frail or aged.
	An unpaid carer might be a partner, family member, friend or neighbour, and the arrangement may be temporary or permanent.[19–21]
	An individual is not a carer merely because they are a spouse, de facto partner, parent, child, other relative or guardian of an individual, or because they live with an individual who requires care.[22]
	A person is not considered a carer if they are paid, a volunteer for an organisation, or caring as part of a training or education program.[22]
cognitive disability	An umbrella term for a level of cognitive function that generally causes difficulty with things such as completing day-to-day tasks, decision-making and communication.[10,23,24] People with cognitive disability include people living with intellectual disability, dementia, acquired brain injury or feta alcohol spectrum disorder.
person, people	A person or people of any age living with cognitive disability or impairment. Other terms might include patient, resident, care recipient, consumer or participant.
family	People who are related to the person receiving care by blood, marriage (including de facto), fostering or adoption.[25,26]
	This clinical care standard primarily refers to the recipient of care as 'the person'. People have the right to involve whomever they choose in discussions and decisions about their care. This includes family members or support people of the person's choosing. Information that relates to discussions with a person about their care should be understood to include their family if their involvement is in line with the person's wishes.
	When the person receiving care is a child or adolescent under 18 years of age, the term 'parents' is used, because discussions and decisions about care will usually involve their parents or other legal guardians who hold legal authority to make decisions on the child or adolescent's behalf.
psychotropic medicines	Medicines that affect the mind, emotions and behaviour.[27] They are used to treat mental health conditions such as anxiety, depression, schizophrenia, bipolar disorder and sleep disorders, and work by adjusting levels of chemicals in the brain to improve symptoms.
	The main groups of psychotropic medicines used to treat mental health conditions and sleep disorders are antipsychotic, antidepressant and anxiolytic or hypnotic medicines. In this clinical care standard, the term 'psychotropic medicines' predominantly refers to these three classes of medicines.

Term	How it is used in this document
substitute decision-maker	A person appointed or identified by law to make health, medical, residential and other personal (but not financial or legal) decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision-maker may be appointed by the person, appointed on behalf of the person, or identified as the default decision-maker by legislation, which varies by state and territory.[14,15]
supported decision making	The process of enabling a person who requires decision-making support to make and communicate decisions about their own health care. The decision-making is supported but the decision is theirs. Supported decision making upholds the human rights of people with cognitive disability or impairment and is the preferred alternative to use of a substitute decision-maker.[15,24,28]
support people	Individuals that the person chooses to involve in their care who are not family members by social definitions of family. These may include carers, friends, advocates, volunteers or people who can provide religious or spiritual support.[14,15] In this clinical care standard, support people refers to unpaid support people. The term 'support worker' is used to refer to people who are paid to provide care or support.
support worker	Anyone who is employed to provide support to people to live in the community. Examples include Aboriginal and Torres Strait Islander health workers or practitioners, personal care workers, community support workers, disability support workers, aged care workers, and home and community care workers. In this clinical care standard, 'support worker' refers to paid, formal providers of support.[21]

Evidence and other sources underpinning this clinical care standard

National and international guidelines

- Therapeutic Guidelines
  - Psychotropic[14]
  - Developmental disability[15]
- National Institute of Health and Care Excellence (NICE) Guidelines (UK)
  - *Dementia: assessment, management and support for people living with dementia and their carers* [NG97][30]
  - *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges* [NG11][13]
- NICE Quality Standards (UK)
  - *Dementia* [QS184][31]
  - *Learning disability: behaviour that challenges* [QS101][32]
- Health Quality Ontario Standard
  - *Behavioural Symptoms of Dementia Quality Standard*[29]
- World Psychiatric Association
  - *International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities*[33]

Legislation

- *Aged Care Act 1997* (Cwlth)[5]
- *Quality of Care Principles 2014*[8]
- *National Disability Insurance Scheme Act 2013*[7]
- *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018*[6]

Key national resources

- Aged Care Quality and Safety Commission
  - **Aged Care Quality Standards**[34]
  - **Charter of Aged Care Rights**[35]
- Australian Commission on Safety and Quality in Health Care
  - *National Safety and Quality Health Service Standards*[36]
  - *National Safety and Quality Primary and Community Health Care Service Standards*[37]
  - *User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium*[19]
  - **Australian Charter of Healthcare Rights**[38]

A full list of the evidence sources for this clinical care standard is available on the Commission's **website**.[39]

Supporting documents

Supporting documents for this clinical care standard are available on the Commission's **website**.[39] These include:

- Consumer guide
- Guide for clinicians
- Guide for healthcare services
- Easy Read: What you need to know about psychotropic medicines.

How to use this clinical care standard

The quality statements in this clinical care standard describe the expectations for key components of care that should be offered to people regardless of where they live.

The standard explains what each quality statement means:

- **For people**, so they know what care may be offered by their healthcare system, and can make informed treatment decisions in partnership with their clinician
- **For clinicians**, to support decisions about appropriate care
- **For healthcare services**, to inform them of the policies, procedures and organisational factors that can enable the delivery of high-quality care.

Specific considerations relating to cultural safety and equity in the provision of care have also been provided for some of the quality statements.

General principles of care

This clinical care standard should be implemented as part of an overall approach to safety and quality, incorporating the following principles that are the foundation for achieving safe and high-quality care:

- Person-centred care and shared decision-making
- Informed consent
- Cultural safety for Aboriginal and Torres Strait Islander people and other cultural groups
- Equity of care for people from diverse backgrounds.

When applying the information contained in a clinical care standard, clinicians should use their clinical judgement and consider the individual person's circumstances, in consultation with the person, their family or their support people, if in line with their preferences.

This clinical care standard supports values and principles that aim to ensure that healthcare services provide care that is equitable, safe, person-centred, informed and evidence based.

For more information and additional Commission resources, see **Appendix A**.

Measurement for quality improvement

Measurement is a key component of quality improvement processes. The Commission has developed a set of indicators to support clinicians and healthcare services to monitor how well they are implementing the care recommended in this clinical care standard. The indicators are intended to support local quality improvement activities. No benchmarks are set for these indicators.

The indicators are listed with the relevant quality statements. Further specifications for collecting and calculating indicator data are available online at **meteor.aihw.gov.au/content/791005**. More information about indicators and other quality improvement measures is provided in **Appendix B**.

Information on other quality measures, including patient-reported outcome measures and patient experience measures, is in **Appendix C**.

National standards and accreditation

Implementing this clinical care standard as part of a quality improvement activity can help healthcare services achieve actions within the NSQHS Standards[36] and the National Safety and Quality Primary and Community Healthcare Standards (Primary and Community Healthcare Standards).[37]

More information about clinical care standards, the NSQHS Standards, and the Primary and Community Healthcare Standards is included in **Appendix D**.

NSQHS Standards relevant to this clinical care standard

While all actions in the NSQHS Standards apply to people with cognitive disability or impairment, the following standards are especially important in the context of this clinical care standard[36]:

- Partnering with Consumers Standard
- Medication Safety Standard
- Comprehensive Care Standard
- Communicating for Safety Standard.

For actions in these standards that warrant specific consideration, see **Table 1**.

Table 1: Actions in NSQHS Standards for specific consideration in applying this clinical care standard[36]

NSQHS Standard	Action	Item
Partnering with Consumers Standard	2.03, 2.04, 2.05	Healthcare rights and informed consent
	2.06, 2.07	Sharing decisions and planning care
	2.08, 2.09, 2.10	Communication that supports effective partnerships
Medication Safety Standard	4.05, 4.06	Medication reconciliation
	4.10	Medication review
	4.11	Information for patients
	4.12	Provision of a medicines list
	4.13	Information and decision support tools for medicines
	4.15	High-risk medicines
Comprehensive Care Standard	5.04	Designing systems to deliver comprehensive care: b. Provide care in the setting that best meets their clinical needs c. Ensure timely referral to patients with specialist health needs to relevant services
	5.05	Collaboration and teamwork
	5.07	Planning for comprehensive care
	5.10	Screening of risk
	5.11	Clinical assessment
	5.29, 5.30	Preventing delirium and managing cognitive impairment
	5.33, 5.34	Predicting, preventing and managing aggression and violence
	5.35	Minimising restrictive practices: restraint
Communicating for Safety Standard	6.03	Partnering with consumers
	6.04	Organisational processes to support effective communication
	6.07, 6.08	Clinical handover
	6.09, 6.10	Communicating critical information
	6.11	Documentation of information

Cultural safety and equity

The Commission is committed to supporting healthcare services to deliver safe and high-quality care to the Australian community. The Commission recognises that culturally safe and responsive health care is critical to improving equitable access and outcomes.[40]

Person-centred care includes care that recognises and respects individual needs, beliefs and culture, and encompasses cultural safety. Cultural safety is about overcoming the cultural power imbalances of places, people and policies to contribute to improvements in health, especially for Aboriginal and Torres Strait Islander peoples.[41] Health consumers are safer when clinicians have considered power relations, cultural differences and patients' rights, and are providing person-centred care. Part of this process requires clinicians to review their own beliefs and attitudes.[40]

In Australia, Aboriginal and Torres Strait Islander people generally experience poorer health outcomes than the rest of the population, with systemic racism being a root cause. The considerations for improving cultural safety and equity throughout this clinical care standard focus primarily on overcoming cultural power imbalances and addressing the many barriers Aboriginal and Torres Strait Islander people face in accessing and receiving health care.[42,43]

Although it is usually applied in the context of First Nations people, the concept of cultural safety can be applied more broadly.

Cultural safety in health care is underpinned by the:

- **National Registration and Accreditation Scheme**, which aims to ensure that cultural safety is consistent within the codes of conduct for health professionals around Australia
- *National Agreement on Closing the Gap*, which is built around four priority reforms for transforming the way governments work with, and for, Aboriginal and Torres Strait Islander people to improve outcomes

- *Cultural Respect Framework 2016–2026: For Aboriginal And Torres Strait Islander Health*, which commits the Australian Government and all states and territories to embed cultural respect principles into their health systems[42]
- NSQHS Standards
  - Patient safety and quality systems – **Action 1.15**
  - Clinical performance and effectiveness – **Action 1.28**
  - Partnering with consumers – **Actions 2.11** and **2.13**
- Primary and Community Healthcare Standards
  - **Clinical Governance Standard** – Actions 1.09, 1.10, 1.16, 1.24 and 1.25
  - **Clinical Safety Standard** – Actions 3.22 and 3.23.

Embedding cultural safety in health care

Addressing inequity requires recognition that people with different levels of advantage may require different approaches and resources to achieve the same healthcare outcomes.

When implementing this clinical care standard, cultural safety can be improved by embedding an organisational approach to cultural safety.

Organisational approaches include:

- Ensuring the use of interpreter services or cultural translators when this will assist the patient and is in line with their wishes
- Ensuring the use of Aboriginal and Torres Strait Islander health workers or practitioners
- Identifying variation in healthcare provision or outcomes for specific patient populations including those based on ethnicity[44]
- Disaggregating data by Aboriginal and Torres Strait Islander status when using the indicators included in this standard to support identification of access and outcome issues so that improvements can be made
- Implementing and monitoring the six specific actions for the care of Aboriginal and Torres Strait Islander people outlined for acute care services in the NSQHS Standards, and equivalent actions in the Primary and Community Healthcare Standards.

Considerations relevant to this clinical care standard

Providing care that is culturally safe is especially relevant for people with cognitive disability or impairment given that Aboriginal and Torres Strait Islander people are more than twice as likely to experience disability compared with non-Indigenous Australians.[45]

While there are no national-level estimates, studies examining different communities of Aboriginal and Torres Strait Islander people living with dementia have consistently found that dementia prevalence rates are about three to five times as high as rates for Australia overall.[46,47]

The **National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017–2023** (the Framework)[48] aims to 'guide and inform Aboriginal and Torres Strait Islander mental health and wellbeing reforms'.

The nine guiding principles underpinning the Framework describe core cultural values relevant to health that are held by Aboriginal and Torres Strait Islander peoples and are summarised below:[49]

1. Health is holistic and includes cultural and spiritual health
2. Self-determination is critical to effective Aboriginal and Torres Strait Islander health care
3. Cultural understanding must guide health care
4. The history of trauma and loss must be recognised
5. Human rights must be recognised and respected
6. Racism and stigma are ongoing stressors
7. The centrality of kinship must be recognised
8. Cultural diversity among Aboriginal and Torres Strait Islander peoples must be recognised
9. Aboriginal and Torres Strait Islander peoples' strengths must be recognised.

Aboriginal and Torres Strait Islander peoples have a strong connection to their country and their community. Aboriginal and Torres Strait Islander people may ask for others outside of immediate family to be included as next of kin; they may need more support to communicate to others in their community who are living a long way from their supported accommodation; and they may need more support to feel connected to their culture.

People governing or leading healthcare services should ensure that cultural competency training and education is available and completed by the members of their workforce, and that Aboriginal and Torres Strait Islander people are able to access healthcare workers, family, support people and others who understand their culture.[50,51]

Good mental health for Aboriginal and Torres Strait Islander people relies on feeling physically and mentally well and feeling connected to family, culture and country. All of these need to be addressed and should be included in any care or support plans in order to maximise mental health for Aboriginal and Torres Strait Islander people.

Related resources

Resources that can help healthcare services and clinicians improve cultural safety and equity include:

- NSQHS Standards *User guide for Aboriginal and Torres Strait Islander health*[40]
- NSQHS Standards *User guide for health service organisations providing care for patients from migrant and refugee backgrounds*[52]
- NSW Health *Communicating positively: A guide to appropriate Aboriginal terminology*.[53]

Background

Psychotropic medicines is a broad term used to describe medicines that affect the mind, emotions and behaviour.[27] The main groups of psychotropic medicines used are antipsychotic, antidepressant and anxiolytic/hypnotic medicines. Each has an important place in the treatment of sleep disorders and mental health conditions such as schizophrenia, anxiety, depression and bipolar disorder.

Psychotropic medicines also have a limited role in influencing behaviour using their sedative effects, specifically for behaviours that put the person or others at risk. Careful assessment and management are required to deliver the benefits of psychotropic medicines while minimising the potential for harm.

Psychotropic medicine use, potential harms and misuse

The use of psychotropic medicines for the primary purpose of influencing behaviour is considered chemical restraint and is a restrictive practice subject to regulatory oversight in aged care and disability settings, and some Australian healthcare settings.* When prescribed to control behaviour, guidelines recommend that psychotropic medicines should only be used when non-medication strategies have been tried and found ineffective. Exceptions exist for the use of medicines as a restrictive practice in emergency situations.

Despite these recommendations, there is ongoing concern about increased use of psychotropic medicines in people with cognitive disability or impairment in the absence of a mental health condition and – in the majority of cases – at excessive doses, for long periods, often off-label, and with no clear clinical justification, adequate monitoring or review.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability[2] and the Royal Commission into Aged Care Quality and Safety[1] highlighted safety concerns relating to the use of psychotropic medicines, including their use as a restrictive practice among older people and people with intellectual disability. These safety concerns include evidence of:

- Anomalies between the rates of prescribing of psychotropic medicines and the prevalence of dementia or mental health conditions[54–58]
- High rates of psychotropic polypharmacy (use of two or more psychotropic medicines)[1,2,59]
- Use of psychotropic medicines in people with disability and behaviours of concern in lieu of non-medication strategies[2,60,61]
- Mental health diagnoses sometimes being documented to avoid legislative requirements related to use of psychotropic medicines as chemical restraint[2,60,61]
- Long-term use of psychotropic medicines as chemical restraint.[62]

Aged care homes

Use of psychotropic medicines in the community is increasing[56,63] and rises markedly on entry to aged care homes.[64] Psychotropic medicines are often prescribed in aged care homes without proper consent[65], monitoring or dose adjustment[56], and for longer than necessary.[56,66]

An Australian study of more than 150 aged care homes in 2015 found that nearly two-thirds of residents (61%) were regularly taking one or more psychotropic medicines.[57] Nearly one-quarter of residents (23%) were taking two or more psychotropic medicines concurrently. More than 30% of residents were prescribed *pro re nata* (PRN) or 'as needed' benzodiazepines and more than 11% were prescribed antipsychotic medicines.

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* Note: Different jurisdictions and health sectors define and regulate restraint in mental health units differently, although there is overlap. Some state and territory laws do not recognise the use of medicines as a restrictive practice. See also NSQHS Standards **Action 5.35**.

Most psychotropic medicines are prescribed in older people with dementia for BPSD despite a lack of efficacy and high rates of adverse effects.[67] Most behaviours that can occur in people with dementia are unlikely to respond to psychotropic medicines. In Australia, risperidone is the only antipsychotic medicine approved for treatment of BPSD. It has been reported that prescribing of psychotropic medicines to older people with dementia is appropriate in only 10% of cases.[68]

All aged care homes subsidised by the Australian Government have been required to report on the use of antipsychotic medicines since July 2021 as part of the National Aged Care Mandatory Quality Indicator Program.[69] These data show that 18.4% of residents of aged care homes (or around 33,000 people) received antipsychotic medicines between January and March 2023, but around half of these people did not have a diagnosis of psychosis.[69]

Older people are particularly susceptible to adverse effects from psychotropic medicines. Australian studies have reported that older people using psychotropic medicines have double the risk of being admitted to hospital for falls or confusion compared with older people not taking these medicines.[66] Use of antipsychotics to manage BPSD in older people with dementia is associated with increased risk of hospitalisation for hip fracture, pneumonia and stroke.[67,70–72]

People with intellectual disability

In adults with intellectual disability, Australian studies report considerably higher rates of psychotropic medicines prescribing compared with the general population.[73] Between 37% and 91% of adults with intellectual disability are reported to be using psychotropic medicines.[74,75] Use of psychotropic medicines in adolescents with intellectual disability is also common.[76,77]

Australian general practice data show that antipsychotics are the most common type of medicine prescribed at consultations for people with intellectual disability – at 6.1 per 100 encounters for people with intellectual disability compared with 0.6 per 100 encounters for people without intellectual disability.[73]

An Australian longitudinal study[55] found use of at least one psychotropic medicine increased from 65% of adults with an intellectual disability in 1999–2001 to 90% in 2012–2015. A population-based cohort study of 1,023 adults with intellectual disability reported that 49.5% were taking some form of psychotropic medicine, with 23.2% taking an antipsychotic despite only 4.4% having a diagnosed mental health condition.[78] High rates of prescriptions of other types of psychotropic medicines in this population have also been reported.[79]

Behaviours of concern are common in adults with intellectual disability and often lead to long-term admission to hospital and use of restrictive practices.[80,81] It is reported that 20–45% of people with intellectual disability are prescribed psychotropic medicines and, of them, 14–30% are receiving those medicines for the management of behaviours of concern.[82,83]

Long-term use of psychotropic medicines as chemical restraint is also reported in people with intellectual disability living in residential facilities, with an Australian study reporting that chemical restraint was continued beyond five years in 74% of people with an intellectual disability.[62]

People with intellectual disability are at least two-and-a-half times more likely to develop a mental health condition than the general population.[84] Often, however, atypical presentation and difficulty communicating and accessing services means that a mental health diagnosis is not made.[58,84]

Use of psychotropic medicines for behaviours of concern in the absence of a mental health condition is questionable because of the lack of high-quality evidence for efficacy and concerns about adverse effects in people with intellectual disability.[58,82,85–87] Compared with the general population, people with intellectual disability may be more vulnerable to adverse effects associated with psychotropic medicines. High levels of weight gain and obesity, extrapyramidal symptoms and other metabolic effects in this population are largely caused by these drugs and predispose the person to premature mortality.[67,88,89]

Initiatives and reforms in Australia to support appropriate psychotropic medicine use

Initiatives to optimise use of psychotropic medicines for behaviour should be a priority for healthcare, aged care and disability service providers.[13,90]

In Australia, minimising and, when possible, eliminating the use of restrictive practice has been recommended to protect the human rights and safety of people with cognitive disability or impairment.[1,2]

Initiatives and reforms aimed at supporting the appropriate use of psychotropic medicines in Australia in the past five years include government review and reform, introduction of prescribing restrictions, and quality improvement[91], education, and reporting programs.[92]

Healthcare, aged care and disability service providers are required by law to ensure that restrictive practices are used only as a last resort. Healthcare, aged care and disability service providers also require informed consent for the prescription and use of psychotropic medicines, including when used as a restrictive practice. Regulation in the aged care and disability sectors recognises that behaviour support planning and the implementation of behaviour support strategies are critical to reducing the use of restrictive practices.

Implementation

This clinical care standard emphasises the importance of supporting a person with proactive, evidence-based, non-medication strategies that are based on an understanding of the person's needs and the reasons for their behaviour, so that use of psychotropic medicines as a restrictive practice is avoided or reduced and, where possible, eliminated over time.[93–96]

Regardless of the reason for prescribing, when prescribing psychotropic medicines to people with cognitive disability or impairment, it is important to:

- Use a person-centred approach that involves family members and support people where appropriate
- Be aware of issues relating to informed consent, capacity to provide informed consent, advocacy, and the legislation that applies when a person is unable to consent
- Prescribe within a coordinated multidisciplinary team care plan after conducting a complete assessment of the person and the behaviour
- Track efficacy of medicines by defining objective behaviours and quality of life outcomes
- Strive towards using the lowest effective dose for the shortest period of time
- Conduct regular reviews of the person's response to medicines and cease use when indicated
- Evaluate prescribing through a peer or team quality review or improvement group.

The Commission is committed to working with the Aged Care Quality and Safety Commission and the NDIS Quality and Safeguards Commission to reduce the inappropriate use of psychotropic medicines, and improve the safety and quality of health care, aged care and disability supports for all Australians.

Implementing this clinical care standard and integration with other efforts to improve the use of psychotropic medicines in people with cognitive disability or impairment across the health sector is crucial to addressing some of these safety and quality issues and achieving better outcomes.

1

Quality statement 1 –
Person-centred care

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.

Purpose

To ensure a person has full and equitable access to care that is based on a holistic understanding of their individual preferences and needs, values and beliefs, and that respects their dignity and inherent right to be involved in discussions and decisions affecting their life and health care.[97–101]

What the quality statement means

■ For people

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 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 a 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.[14]

◼ **For clinicians**

Consider the individual preferences, needs and values of the person with cognitive disability or impairment and use this information to guide the health care provided.

Be aware of the person's inherent rights according to the ***United Nations Convention on the Rights of Persons with Disabilities***[100] to be included in discussions, express their wishes, and be supported to make their own decisions about their health care.

Healthcare providers should assume that people with cognitive disability or impairment **can** participate in discussions and decisions about their care. Apply principles outlined in guidelines and in accordance with regulations and legislative frameworks to assess a person's capacity to be involved in decisions, so as to not assume a person with cognitive disability or impairment is incapable of being involved.[19] If necessary, make a referral to services that can undertake an assessment of capacity.

Involve the person in all discussions and care decisions that they are able to make and to the extent that they choose.[19,28,46] Communicate with respect in a way that avoids stigmatising the person for their disability and maintains their dignity. As best as possible, determine the person's communication needs and types of assistance they may need to support their participation. Plan for and provide the necessary support, and make reasonable adjustments to enable the person's participation in decision-making to the greatest extent they are able.[28,46]

Support effective communication by tailoring and providing information to match the person's health literacy, medicines literacy and communication needs, and allow sufficient time for discussions. Consider use of augmented and alternative communication methods, visual material or other visual aids, such as material in Easy Read format. Arrange an interpreter, or support from Aboriginal and Torres Strait Islander health workers and health practitioners, if needed. Healthcare services have a responsibility to provide support for alternative communication options where they are needed.

The involvement of the person's support network, such as family members, guardians, support workers or other people the person trusts can be beneficial. Identify and involve members of the person's support network in their care, in line with the person's needs and wishes.

Ensure that information about the person's preferences for care is included in the person's healthcare record, so this can be used to guide reasonable adjustments and decision-making.

◼ **For healthcare services**

Ensure that policies and procedures are in place to support healthcare providers to deliver person-centred care to people with cognitive disability and impairment. These should ensure that:

- Information and resources, such as shared decision-making tools, are available to meet diverse health literacy, medicines literacy, communication and cultural needs
- The person's family, support people or nominated decision-maker have been identified and documented in the healthcare record
- The person and their appropriate family, support people or nominated decision-maker are provided with information about their care
- The person and their appropriate family and support people are involved in decisions about their care to the greatest extent possible or to the extent that they choose (for example, if a person does not have capacity for decision-making, they are still consulted to the greatest extent possible, by those who will make the decision)

- Reasonable adjustments are identified and implemented to facilitate the person's active participation in decision-making, including support to enable a person with capacity to make a decision, and support to increase participation by those without capacity.

Ensure adequate skills and competence in the workforce by:
- Providing rights-based training and communication skills training to relevant members of the workforce
- Providing members of the workforce with training on capacity assessments
- Providing members of the workforce with training on techniques to support participation in decision-making by people with cognitive disability or impairment.

Cultural safety and equity

Understanding the person's cultural background is essential to providing culturally inclusive, safe and responsive person-centred care.

Culture is central to the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples. Connectedness to family, community and country, the person's role within family and community, and the significant sense of loss, grief and trauma from past and current events that many Aboriginal and Torres Strait Islander people experience may affect their choices for care. They may not identify or be comfortable with an individualised approach, and instead see their identity strongly connected with family, community and country. This means that planning the care of an Aboriginal or Torres Strait Islander person with cognitive disability or impairment should consider their individual connections.[45]

Person-centred care approaches for people from CALD backgrounds should emphasise the role of cultural belonging and acknowledge potential cultural differences in beliefs about treatments, care and decision-making. Alternative approaches may be required for people from CALD communities who are experiencing isolation and loneliness, and for those who do not have extended family networks, to support them to be active participants in their care.

Consider the varying meanings of the term 'family' in different cultures. For example, family may include people who are not first- or second-degree relatives but culturally have a close tie to the person or are important in their culture and link to country.

Related resources

General

- Australian Commission on Safety and Quality in Health Care
  - **Person-centred care**
  - **Intellectual disability and inclusive health care**
  - **Cognitive impairment**
  - ***User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium***[19]

Aged care

- **The 10 principles of dignity in care**, which describes the care that people living with dementia, and their families, can expect to receive[102–104]
- **What is person-centred care?** from the Aged Care Quality and Safety Commission[105]
- *Supported Decision-Making in Aged Care: A policy development guideline for aged care providers in Australia, second edition* from the Cognitive Decline Partnership Centre[28]
- *Supporting decision-making: A guide for people living with dementia, family members and carers* from the Cognitive Decline Partnership Centre[106]
- *Supported Decision-Making: Help and assistance for decision makers and supporters* from the Cognitive Decline Partnership Centre[107]
- **Dementia and changed behaviours: supporting the person at the centre** from NPS MedicineWise[108]
- **Assessment and Management of Behaviours and Psychological Symptoms associated with Dementia (BPSD)** from NSW Health[109]

Disability care

- *Diversity, dignity, equity and best practice: A framework for supported decision-making* from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability[110]
- *Responding to Needs of People with Disability during Hospitalisation* policy directive from NSW Health[12]
- **Your right to good health care fact sheet** from the Council for Intellectual Disability
- **The Department of Developmental Disability Neuropsychiatry: A guide to resources,** developed by the Department of Developmental Disability Neuropsychiatry (3DN) to assist healthcare services with providing care to people with intellectual disability, including guidance about principles to support service delivery, suggestions for reasonable adjustments, assessing and managing behaviours of concern, and supporting responsible psychotropic prescribing in people with an intellectual disability[111]
- **Intellectual Disability Network** from the NSW Agency for Clinical Innovation[112]
- **Supported Decision Making** from Inclusion Australia[113]

Culturally safe and equitable care

- *Yarning to Make Health Decisions Together* from the NSW Agency for Clinical Innovation[114]
- *'No More Waiting': A guide for organisations to plan with Aboriginal people with disability* from the Intellectual Disability Behaviour Support Program, University of New South Wales[45]

Indicator for local monitoring

There is no indicator for this quality statement. See **Appendix C** on measuring and monitoring patient experience.

2

Quality statement 2 –
Informed consent for psychotropic medicines

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.

Purpose

To ensure that decisions about psychotropic medicines use involve the person with cognitive disability or impairment to the greatest extent possible, along with their family or other members of their support network if appropriate, and that consent is provided in a legitimate way in accordance with legislation and without coercion.

What the quality statement means

■ For people

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.

■ For clinicians

When psychotropic medicines are being considered, obtain informed consent prior to prescribing.[14,15,46] Informed consent should be obtained from the person if they have capacity to make an informed decision independently or to do so with appropriate support. In the case of a child or adolescent under 18 years of age, informed consent should be obtained from parents or guardians as they usually have legal authority to make decisions on the child or adolescent's behalf.[14,15]

Provide information about the reasons the medicine is being suggested and the intended duration of treatment. Discuss the potential benefits and risks of different treatment options with the person, together with their family, support people or nominated decision-makers as appropriate.[14,15,46]

Consider the person's specific communication and health literacy needs, as well as their decision-making capability and how it could be enhanced with the right adjustments and support. Make reasonable adjustments as necessary to support the person's understanding and facilitate their involvement in decision-making to the greatest extent possible.

If the person lacks capacity to provide informed consent to psychotropic medicines even with support, seek consent in accordance with the relevant state or territory legislation.[6,8] The person's views and wishes should still be sought to inform any decisions about their care (see **Box 1**).[14,15]

Exemptions apply in emergency situations (see **Box 2**).[6,8]

Document the outcome in the person's healthcare record as part of the informed consent process.

Box 1: Capacity to consent

Assessment of the person's capacity to consent to treatment with psychotropic medicines should be clearly documented in their healthcare record and available to others involved in their care.*

If a person is assessed to not have the capacity to provide informed consent – even with support – refer to relevant state or territory legislation for information about obtaining consent.[46,115]

Capacity is always considered with respect to the proposed treatment that requires consent at that time. A person's capacity can fluctuate. A person can be capable with respect to some proposed treatments, but incapable with respect to others. Similarly, capacity can be present for a proposed treatment at one time but absent at another time.[14,15]

Capacity to provide informed consent should be reviewed periodically and appropriate action taken to ensure that consent continues to be valid.

* Refer to Therapeutic Guidelines: Psychotropic[14] and Therapeutic Guidelines: Developmental Disability[15] for further information and guidance on assessing capacity to provide informed consent in a person with cognitive disability or impairment.

Box 2: Emergency situations

An emergency is a serious or dangerous situation that is unanticipated or unforeseen and that requires immediate action.

The requirement for obtaining informed consent is exempt when the use of psychotropic medicines as a restrictive practice is needed in an emergency. These exemptions are intended to ensure that a healthcare provider can appropriately and rapidly respond to an emergency to protect a person or others from harm. An emergency is not expected to last for an extended period and **the emergency is considered to have ended when there is no longer an immediate risk of harm or injury to the person or others.**

If psychotropic medicines are required in an emergency, as soon as practicable after their use begins, inform the person or their nominated decision-maker about use, and document their use in accordance with the provisions for emergency use outlined in legislation.[6,93]

◼ **For healthcare services**

Ensure that policies and procedures outline requirements for providing psychotropic medicines information and obtaining and documenting informed consent.

Ensure that systems are in place for healthcare providers to provide information about psychotropic medicines and discuss their use with the person, and family members, support people and nominated decision-makers as appropriate. To enable informed decision-making, these discussions should include a description of the risks and benefits of taking or not taking psychotropic medicines.

Ensure that policies and procedures enable the person, family members and support people to receive information in ways they can understand and to have an opportunity to ask questions before consent is sought. Ensure policies and procedures support a person's rights to make decisions and include the use of reasonable adjustments in line with the person's needs. These should help the person, family members and support people to participate more effectively in decision-making about their treatment, consistent with the NSQHS Partnering with Consumers Standard.

If a person needs supports and adjustments to enhance their participation in decision-making, ensure that information about the types of support required is documented and accessible in clinical communications to all relevant healthcare providers. This is especially important when care is provided by a multidisciplinary team, and when a person is transferred or referred to another healthcare setting or healthcare provider. Processes for seeking informed consent should consider that the person's capacity may fluctuate, and capacity should be reviewed periodically to ensure that consent remains valid. Ensure policies and procedures are consistent with relevant guidelines[14,15] and legislation[6,8] for assessing capacity and seeking informed consent (see **Box 1**) and for exemptions in emergency situations (see **Box 2**).

Cultural safety and equity

Policies and training should support care that is culturally sensitive and culturally safe for Aboriginal and Torres Strait Islander people with cognitive disability or impairment. When providing care to Aboriginal and Torres Strait Islander people, provide access to translators and/or cultural interpreters as necessary, particularly during assessment, diagnosis and consenting processes.[116]

Healthcare providers need to recognise and be responsive to the cultural and linguistic needs of CALD people with cognitive disability or impairment. A variety of communication tools may be required, including working with bilingual, bicultural members of the workforce or professional interpreters across the whole service pathway, but especially during assessment and consenting processes.[116]

People with cognitive impairment or disability may lose second languages such as English. In such cases:

- Healthcare interpreters should be used
- Cultural and communication protocols should be followed
- Communication boards may be important aids – these and other useful resources can be obtained from the *Centre for Cultural Diversity in Ageing*.

Related resources

General

- Australian Commission on Safety and Quality in Health Care
  - *User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium*[19]
  - Informed consent

Aged care

- Consent for medication in aged care from the Aged Care Quality and Safety Commission[117]
- Consent requirements for the use of restrictive practices in residential aged care from the Australian Government Department of Health and Aged Care[118]
- Medication: It's your choice from the Older Person's Advocacy Network[119]
- Supported decision-making from the Cognitive Decline Partnership Centre[28]
- Centre for Cultural Diversity in Ageing

Disability care

- My Rights Matter – Supported decision making hub from the Council for Intellectual Disability[120]
- About decision making capacity from Capacity Australia[121]
- Supported decision making from Inclusion Australia[113]
- How to make choices about taking medication Easy Read information about taking medicines by Peter Bates, from the University of Bristol[122]

Indicator for local monitoring

Indicator 2a: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for whom informed consent was obtained and documented.

METEOR link: **meteor.aihw.gov.au/content/791012**

More information about this indicator and the definitions needed to collect and calculate indicator data can be found online at the above METEOR link.

3

Quality statement 3 –
Assessing behaviours

A person with behaviours of concern is initially assessed for immediate risks to their safety and others. Further assessment is undertaken 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.

Purpose

To ensure a person is safely and appropriately assessed to identify potential underlying causes for their behaviour – taking into account the many factors that can present as behaviours of concern – to enable their care to be managed according to their needs.

What the quality statement means

■ For people

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.

■ For clinicians

When a person's behaviours cause concern to themselves or others, undertake a comprehensive assessment, including an accurate description and analysis of the behaviour, its antecedents and consequences, and its potential clinical, psychosocial and environmental causes.[14,15,31,32,123–125]

If the behaviour poses immediate or potential risks to the safety of the person or those around them, consider whether immediate action is necessary to ensure safety.[14,15,124]

Use a person-centred approach to assessing the person

Identify and make reasonable adjustments to support the person during the assessment. For example, remove distractions or arrange for one of their family members or support people to be present during the assessment if this is in line with the person's wishes. Consider their wellbeing, their ability to communicate and preferred communication methods, and the environment in which the assessment is conducted.

Consult any available care or support plans, including the person's behaviour support plan (required for recipients of aged care services and for some recipients of NDIS services).[14,15] If the person has such a plan in place, but it is not available, attempts should be made to access it.

Clinical assessment

Assess for clinical causes first:[14,15]
- Be aware of the risk of mistakenly attributing physical symptoms or altered behaviours to a person's disability or cognitive impairment, when another cause might be present
- Undertake a physical examination, including a check of vital signs, and consider medical and mental health-related causes, including **delirium**[31,125]
- Consider pain, especially in older people who are unable to verbalise and report pain
  – Undertake a suitable assessment of pain that includes non-verbal indicators of pain, such as facial expressions
  – Consider initiating a time-limited trial of analgesia, with appropriate assessment for the origin – refer to Therapeutic Guidelines: Pain and analgesia[126] for further information about assessing pain in **older people** and people with **impaired cognition**.

Psychosocial and environmental assessment

Consider psychosocial and environmental causes for the behaviour and conduct or arrange further assessment as appropriate. Consider the person's stage of psychosocial development, skills and support needs, as well as their social and environmental circumstances and the context in which the behaviour occurs.[14,15] Several tools are available to assist with assessing psychosocial and environmental factors in behaviour (see **Related resources**).

Involve others as appropriate

Consider referral to other healthcare providers, specialist services or people skilled in undertaking behavioural assessments. For example, referral could be for an assessment to accurately define and describe the behaviour, the function it serves and its consequences. This can help inform management and allow for recording of behavioural data for monitoring the type and patterns of behaviour.[15,115,124]

Involve others who know the person well, such as parents, siblings, other family members or other members of the person's support network, if possible and in accordance with the person's wishes.[13] These people can provide valuable information about the person's usual behaviour, likes and dislikes, cultural background, life experiences, needs and abilities, preferred communication methods and coping mechanisms. They may also have an important role in reducing a person's distress or de-escalating situations. They can do this by providing a familiar face, informing healthcare providers of strategies that have helped calm the person in the past, and helping healthcare providers understand what the person's behaviours may be communicating.[109]

Document the findings of the assessment in the person's healthcare record; these findings should inform the person's ongoing management plan.[19]

Refer to Therapeutic Guidelines: Psychotropic[14] and to Therapeutic Guidelines: Developmental disability[15] for further information about assessing people with cognitive disability or impairment.

For healthcare services

Ensure that systems are in place for healthcare providers to safely carry out a comprehensive assessment for people with behaviours of concern, and to document results in the person's healthcare record. Such assessment should consider the behaviour's context and its clinical, psychosocial and environmental causes. Clinical assessment should also include assessment for **delirium**. Ensure that policies and procedures support reasonable adjustments for people with cognitive disability or impairment to facilitate their assessment (see **Related resources**). This may include:

- Involving family members and support people in the assessment with the person's consent, and involving nominated decision-makers as appropriate. This may include allowing access for family, support people, and nominated decision-makers access to the health care service outside regular visiting hours
- Considering the environment in which the assessment takes place and allowing for modifications to provide safe and supportive care (for example, moving the person to a quieter room)
- Referring to any care plans that document existing behaviours and management strategies, such as advanced care plans or behaviour support plans (required for recipients of aged care services and some recipients of NDIS services).

Ensure that any records of legal nominated decision-makers, guardianship or administration orders are kept in an easily accessed place. Ensure all members of the workforce who care for the person are aware of these arrangements.

Train and educate the workforce about the potential causes of behaviours in people with cognitive disability or impairment, including in relation to trauma-informed care. Ensure that all those involved in providing care are aware of the role of care plans, including any behaviour support plans required under aged care or NDIS regulations for recipients of these services. Support referral to suitably trained providers if required to assess behaviours and contributing psychosocial or environmental factors.

Cultural safety and equity

Consider the communication needs of people with cognitive disability or impairment, including needs related to culture, during an assessment. Assess the person's level of understanding of verbal communication and English language, and their ability to communicate their needs. Consider support and make reasonable adjustments for those who have limited speech or a primary language other than English. The presence of a support person may enable better communication.

People with cognitive disability or impairment may not tolerate assessment. Consider adjustments to support assessment, such as moving the person to a separate room or using Easy Read resources or visual aids to explain what will happen.

Provide care that is culturally safe and informed to Aboriginal and Torres Strait Islander people with cognitive disability or impairment, and use translators and/or cultural interpreters when appropriate, particularly during assessment.[115]

Consider the varying meanings of the term 'family' in different cultures. For example, family may include people who are not first- or second-degree relatives but culturally have a close tie to the person or are important in their culture and link to country.

Related resources

General

- *User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium*[19] from the Australian Commission on Safety and Quality in Health Care

Aged care

- **Behavioural Assessment Form** and **Behaviour Frequency Chart** from Dementia Support Australia[127]
- **Dementia Outcomes Measurement Suite (DOMS)**, a compendium of tools to assess BPSD, from Dementia Centre for Research Collaboration[128]
- *Assessment and Management of Behaviours and Psychological Symptoms associated with Dementia (BPSD*) from NSW Health[109]
- *Behaviour Management: A Guide to Good Practice* and **resources** to support the management of behaviours and psychological symptoms associated with dementia (such as the *Clinicians Field Guide to Good Practice*, *Guide for Family Carers*, **BPSD app for clinicians** and **Care4Dementia** app for family members), from the Dementia Centre for Research Collaboration[129]

Disability care

- **Developmental Behaviour Checklist**, a suite of questionnaires completed over six months by parents, other primary carers or teachers to inform assessment of behavioural and emotional problems of children, adolescents and adults with developmental and intellectual disabilities[130]
- **Compendium of Resources for Positive Behaviour Support: A guide for behaviour support practitioners**, a comprehensive list of positive behaviour support assessment tools that can be used by behaviour support practitioners for behaviour support assessment, planning, intervention, monitoring and review, from the NDIS Quality and Safeguards Commission[131]
- ***The Department of Developmental Disability Neuropsychiatry: A guide to resources***, developed by the Department of Developmental Disability Neuropsychiatry (3DN) to assist healthcare services with providing care to people with intellectual disability, including guidance about principles to support service delivery, suggestions for reasonable adjustments, assessing and managing behaviours of concern, and supporting responsible psychotropic prescribing in people with an intellectual disability[111]

Indicator for local monitoring

Indicator 3a: Evidence of local arrangements to ensure a person with cognitive disability or impairment with behaviours of concern is assessed to identify any clinical, psychosocial and environmental causes for the behaviours.

The local arrangements should specify the:
- Procedures to support reasonable adjustments for a person with cognitive disability or impairment to facilitate their involvement in the assessment process
- Process to access any existing care or behaviour support plans
- Process to involve the person's family or support people, in accordance with the person's wishes, and nominated decision-makers as appropriate
- Process to ensure any records of legal nominated decision-makers, guardianship or administration orders are accessible to staff
- Process to ensure relevant clinicians and members of the workforce receive training and education about the potential causes of behaviours in people with cognitive disability or impairment, including how to provide trauma-informed care
- Findings of assessments that should be documented in the person's healthcare record
- Process to oversee implementation of the local arrangements and evaluate their effectiveness.

METEOR link: **meteor.aihw.gov.au/content/791014**

More information about this indicator and the definitions needed to collect and calculate indicator data can be found online at the above METEOR link.

4

Quality statement 4 –
Non-medication strategies

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.

Purpose

To maximise the use of behavioural, environmental and other non-medication strategies as the predominant approach for addressing behaviours of concern and ensure these strategies suit the person's individual needs and are non-restrictive in nature.

What the quality statement means

■ For people

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.

◼ For clinicians

Non-medication strategies that are non-restrictive in nature are considered the best-practice response to behaviours of concern. They are the primary component of initial and ongoing care and should be used by the multidisciplinary team to prevent or reduce behaviours of concern.[126] Non-medication strategies should be continued even if psychotropic medicines are trialled. Medicines should not be used on their own.[14,15,46,115,124]

Choose non-medication strategies based on precipitating and modifiable causes for the person's behaviour.[14,15] A combination of non-medication strategies may be used and is usually most effective. Document the choice of strategies in a place that can be easily accessed by all those involved in the person's care. Communicate the strategies to everyone who regularly interacts with the person. Non-medication strategies should be documented in a behaviour support plan for all people receiving aged care services, and for NDIS participants with behaviours of concern, especially if psychotropic medicines form part of their care.

People who do not have an aged care- or NDIS-required behaviour support plan will still benefit from a coordinated approach to the use of non-medication strategies: share information about effective non-medication strategies with others who support the person's care so they can be integrated consistently into the person's care.

When choosing and implementing non-medication strategies[13–15,124]:

- Use the results of the person's assessment (as described in **Quality statement 3 – Assessing behaviours**) to guide choice of non-medication strategies and ensure they are tailored to the person's preferences as much as possible
- Ensure that systems are in place for healthcare providers to safely carry out a comprehensive assessment for people with behaviours of concern, and to document results in the person's healthcare record. Such assessment should consider the behaviour's context and its clinical, psychosocial and environmental causes
- Encourage the use of non-medication strategies in the everyday care of the person, taking into account who will be using the strategies and their ability to use them.

◼ For healthcare services

Ensure that systems, processes and resources are in place for the multidisciplinary team to offer and use appropriate non-medication strategies in response to behaviours of concern both first-line and as part of ongoing care.

Establish appropriate leadership and governance for oversight of these systems.

Ensure each member of the workforce is trained and competent in the use of non-medication strategies – appropriate to their role and scope of practice – that could be implemented for a person with behaviours of concern. This may involve identifying specialist clinicians or lead clinicians at a healthcare service level to train the workforce in the use of de-escalation techniques and other non-medication strategies.

Provide systems to support documentation of the non-medication strategies that are recommended and used for the person, and to embed strategies that are effective for the person into their care. Enable members of the workforce to implement environmental changes when appropriate, such as lighting, noise, signage (for example, toilet locations), privacy or access to outdoor space.

Policies should incorporate use of the person's regulated aged care or NDIS behaviour support plan and take into account the information provided in the plan, as well as any information provided by the person's family, support people or care provider.

Cultural safety and equity

Consider causes for behaviour that may relate to a lack of cultural safety, including previous experiences of health care. Consider appropriate non-medication strategies that will meet a person's cultural needs. Be aware of the person's sense of family and connection and if a lack of contact is worsening the person's behaviours of concern.

Related resources

General

- *User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium*[19] from the Australian Commission on Safety and Quality in Health Care

Aged care

- **Dementia Support Australia**, incorporating the **Dementia Behaviour Management Advisory Services (DBMAS)**, which provides clinical support to healthcare providers, and family and support people of a person showing BPSD, including for care at home (a 24-hour helpline is available on 1800 699 799)[132]
- *A Guide for Family Carers: Dealing with behaviours in people with dementia* from the Dementia Centre for Research Collaboration[133]
- **Care of Confused Hospitalised Older Persons (CHOPs)** from NSW Health[134]

Disability care

- **Compendium of Resources for Positive Behaviour Support: A guide for behaviour support practitioners**, a comprehensive list of positive behaviour support assessment tools that can be used by behaviour support practitioners for behaviour support assessment, planning, intervention, monitoring and review, from the NDIS Quality and Safeguards Commission[131]

Indicator for local monitoring

Indicator 4a: Evidence of local arrangements to ensure people with cognitive disability or impairment receive appropriate non-medication strategies to prevent or reduce behaviours of concern.

The arrangements should specify the process to:

- Select and implement appropriate non-medication strategies based on a person's assessment
- Monitor and document a person's response to the non-medication strategies
- Ensure clinicians and other members of the workforce who are involved in the care of people with cognitive disability or impairment receive education and training on non-medication strategies to prevent or reduce behaviours of concern, appropriate to their role and scope of practice
- Inform clinicians and other members of the workforce about the non-medication strategies that can be implemented at the service
- Oversee implementation of the local arrangements and evaluate their effectiveness.

METEOR link: **meteor.aihw.gov.au/content/791016**

More information about this indicator and the definitions needed to collect and calculate indicator data can be found online at the above METEOR link.

5

Quality statement 5 –
Behaviour support plans

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.

Purpose

To ensure that if a person has a behaviour support plan it is used to support their care in all care settings, ensure consistency in their care, and reduce the need for psychotropic medicines for controlling behaviours.

What the quality statement means

■ For people

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 NDIS, 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 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.

◼ **For clinicians**

If the person has a behaviour support plan, it should be considered and integrated into the person's care. A behaviour support plan is a written document prepared in collaboration with the person with cognitive disability or impairment, their family and support people. It brings together important information about the person's background, preferences for care, and what may cause and prevent behaviours of concern.

Aged care providers are legally required to have a behaviour support plan in place for every consumer who experiences behaviours of concern or has restrictive practices used as part of their care, unless in an emergency. NDIS participants with behaviours of concern should have a behaviour support plan, although this is not a legal requirement unless restrictive practices are used.[5-8] The behaviour support plan is most often written by a behaviour support practitioner, or an authorised allied health professional, such as a psychologist, or nurse who knows the person and has assessed their behavioural needs.

A behaviour support plan developed under aged care or NDIS regulations is intended to prevent, reduce and potentially eliminate the need for restrictive practices.[9,95,135] This is most likely to be achieved when the plan is appropriate for the person and is followed by all those involved in the person's daily life and care, including those working in healthcare services.

Clinicians providing care to people who have an existing behaviour support plan can support the person's care and wellbeing by:
- Considering the following information in the behaviour support plan and integrating it into the person's care as appropriate for their clinical situation
  - Information about the person's usual behaviour and probable causes for behaviours of concern
  - Behavioural support needs and practices that are recommended, including non-medication strategies that are non-restrictive in nature
  - The person's communication needs
  - The intended use of any regular or 'when required' (PRN) psychotropic medicines, including any changes to prescribed psychotropic medicines arising during the implementation or monitoring of the plan
- Informing updates to the plan (as appropriate to the context of care) by
  - Recording behavioural data relating to the plan and the effectiveness of the strategies outlined (usually documented by support workers and others involved in the person's ongoing care)
  - Identifying and documenting behavioural responses to healthcare situations that may need to be considered in the behaviour support plan, if not already covered
  - Providing information back to the person responsible for the plan (for example, to the service provider)
  - Documenting and communicating the extent to which the behaviour support plan has been implemented as intended
  - Reviewing psychotropic medicines use described in the plan and providing information back to the service provider about their effectiveness, including any PRN use of medicines.

Any use of a restrictive practice that is not in the person's behaviour support plan should trigger an immediate review of the person and their plan.[6,8] The review should include of this will need to include members of the workforce engaged in the day-to-day care of the person and the person's behaviour support practitioner, if they have one.

■ For healthcare services

Healthcare services that provide care to people with cognitive disability or impairment who have an existing behaviour support plan should:

■ Provide guidance and protocols to ensure the behaviour support needs outlined in the person's behaviour support plan are recognised and responded to during their care, which can prevent escalation of behaviours of concern and reduce the need to use restrictive practices such as psychotropic medicines

■ Ensure that acknowledgement and use of the person's behaviour support plan and relevant feedback about the person's response are included in the person's healthcare record and correspondence, and that this is shared appropriately with other providers of care and support

■ Establish relationships with local aged care and disability coordinators or case managers who can assist in escalation of plan reviews or provide other expert advice when required.

Healthcare services that are responsible for ensuring that a behaviour support plan is developed should:

■ Ensure that behaviour support plans are clear and concise so they are easy to use by the person, their family, support people and healthcare providers

■ Ensure that behaviour support plans consider feedback provided by other healthcare providers about the person, including further behaviour support needs that may arise in healthcare settings, such as during hospitalisation

■ Refer to guidelines for developing behaviour support plans provided by the NDIS Quality and Safeguards Commission or Aged Care Quality and Safety Commission, as relevant.

Related resources

Aged care

■ **Behaviour support plans – fact sheet** from the Aged Care Quality and Safety Commission

■ Dementia Support Australia, which provides support for people living with dementia and who have behaviours of concern, including

– Help with the assessment of people living with dementia in residential aged care and recommendations on appropriate interventions

– **Behaviour support plan resources toolkit**, which assists healthcare and service providers with the changes to the requirements for residents of aged care homes to have a behaviour support plan

– For more information see the **Dementia Support Australia (DSA) website**[9]

Disability care

■ *Behaviour Support and the Use of Medication: A guide for practitioners*[18] from the Intellectual Disability Behaviour Support Program

- ■ NDIS Quality and Safeguards Commission
  - **Behaviour support introduction booklet**
  - **Participant fact sheets for behaviour support**
  - **Understanding behaviour support and restrictive practices – for providers**
  - **Fact sheets and process guides**
  - **Submitting behaviour support plans and reports** – the Interim behaviour support plan template and the Comprehensive behaviour support plan template

Legislative requirements for behaviour support plans in aged care

From 1 September 2021, under amendments to the *Aged Care Act 1997*[5] and the Quality of Care Principles 2014[8] (the Principles), residential aged care providers are required to have a behaviour support plan in place for each person who requires, or may require, the use of restrictive practices as part of their care other than in an emergency as outlined in the Principles.

The major elements of a behaviour support plan for a person living in residential aged care who requires or may require the use of restrictive practices as part of their care are set out in the Principles. Residential aged care providers are encouraged to review the Principles to ensure familiarity with the requirements of behaviour support plans.

The behaviour support plan must include evidence of informed consent from the person, if they have capacity to provide consent, or from their substitute decision-maker.

For more information, see the **Aged Care Quality and Safety Commission website**.

Legislative requirements for behaviour support plans in disability care

Requirements for behaviour support plans for people with disability are described in the *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018*[6] (the Rules).

Funding may be available for behaviour support services for people with intellectual disability. Behaviour support services funded by the NDIS are provided by an NDIS-registered behaviour support practitioner, and require referral.[15]

The behaviour support plan is developed by the behaviour support practitioner and must be reviewed at least every 12 months while the plan is in force. It must also be reviewed as soon as practicable after any change in circumstances that requires the plan to be amended.

For more information, see the **NDIS Quality and Safeguards Commission website**.

Indicator for local monitoring

Indicator 5a: Evidence of a local policy to ensure a person's behaviour support plan is used to support their care.

The policy should specify the:

- Protocol to identify people who have an existing behaviour support plan
- Process to communicate with aged care and disability service providers to request a copy of a person's behaviour support plan if it is not available when they present to hospital
- Process to support clinicians to consider a person's behaviour support plan when providing health care to the person
- Process to support clinicians to document the person's response to the behaviour support plan and any recommendations to inform updates to the plan
- Process to assess adherence to the policy.

METEOR link: **meteor.aihw.gov.au/content/791018**

More information about this indicator and the definitions needed to collect and calculate indicator data can be found online at the above METEOR link.

6

Quality statement 6 –
Appropriate reasons for prescribing psychotropic medicines

Psychotropic medicines are considered in response to behaviours of concern 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.

Purpose

To reduce inappropriate psychotropic medicine use by ensuring medicines are used only when there is a clear and appropriate need, and use is optimised to maximise the likelihood of benefit and minimise potential medicine-related harm.

What the quality statement means

■ For people

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 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.

■ For clinicians

Avoid prescribing psychotropic medicines for behaviours of concern in people with cognitive disability or impairment. They should be considered only if the behaviours pose a substantial risk to the person or others or are significantly reducing the person's quality of life.[115] Prior to prescribing, a reasonable and systematic trial of non-medication strategies should have taken place and found to have been ineffective, or to have produced an inadequate response. When there is a high risk of immediate harm, it may not be possible to implement the most appropriate non-medication strategies, but basic steps that are reasonable in the circumstances (such as verbal de-escalation and managing the environment) should still be taken.[14,15,124]

Behaviours of concern can also lead to significant risk by preventing clinical assessment or treatment of a person in distress. Short-term use of psychotropic medicines to facilitate clinical assessment of a medical problem or unmet medical need may be appropriate, especially in an emergency context (see also **Quality statement 2 – Informed consent for psychotropic medicines**).

In some people with cognitive impairment, a mental health diagnosis may be suspected but difficult to assess. Psychotropic medicine may be appropriate as a time-limited trial when a mental illness diagnosis cannot be made with certainty but is considered probable. Details of the clinical assessment and expected effect of the medicines should be documented. If possible, trial one medicine at a time, with clearly articulated and measurable outcomes, for a specific initial duration.

Consider the risks of psychotropic medicines for the specific person and indication – examples include risks of falls and risks that impact swallowing.[136]

In children, psychotropic medicines should ideally be started and managed in consultation with a clinician with expertise in this area, such as a child psychiatrist or paediatrician.[14]

Document the reason for use of any psychotropic medicine in the person's healthcare record to facilitate effective clinical communication and ongoing review. If medicine is prescribed to be taken PRN, clearly communicate the intentions for use by documenting the minimum interval between doses and the maximum dose allowed in a 24-hour period, in addition to the reason for the use.[36,137]

For guidance on prescribing psychotropic medicines in people with cognitive disability or impairment, see Therapeutic Guidelines: Psychotropic[14] and Therapeutic Guidelines: Developmental disability.[15]

■ **For healthcare services**

Ensure policies outline the safe and appropriate use of psychotropic medicines and the steps that should be followed prior to prescribing. For emergency, short-term and ongoing use, including PRN medicines, this includes assessing whether appropriate non-medication strategies have been systematically trialled for a reasonable period of time, according to the reason for use (for example, whether the medicine was used in an emergency or in a less acute context).

Ensure documentation of the reason for prescribing for any psychotropic medicine, including for medicines prescribed PRN, regardless of the indication or therapeutic use. This includes documenting the diagnosis or, in the case of a suspected mental health diagnosis in a non-verbal person, the clinical assessment conducted and the expected effect of the medicines.

Ensure that all medication charts including electronic charts include indications for use of psychotropic medicines. If medicines are used PRN, ensure documentation about use – as well as the behaviours observed when prescribed for behaviours of concern – is available to facilitate a fully informed review of the medicines' effectiveness.

Establish processes to audit the appropriateness of any psychotropic medicine prescribing, including medicines prescribed PRN.[36] Auditing processes should include evidence of the clinical assessment and rationale for prescribing. In the context of behaviours of concern, this should include auditing evidence of an inadequate response to non-medication strategies prior to prescribing psychotropic medicines.

Related resources

General

- *User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium* from the Australian Commission on Safety and Quality in Health Care[19]
- *5 Moments for Medication Safety* from the World Health Organization[139]

Aged care

- **Dementia and psychotropic medicines** from NPS MedicineWise[138]

Disability care

- *Behaviour Support and the Use of Medication: A guide for practitioners* from the Intellectual Disability Behaviour Support Program[18]
- *The Department of Developmental Disability Neuropsychiatry: A guide to resources*, developed by the Department of Developmental Disability Neuropsychiatry (3DN) to assist healthcare services with providing care to people with intellectual disability, including guidance about principles to support service delivery, suggestions for reasonable adjustments, assessing and managing behaviours of concern, and supporting responsible psychotropic prescribing in people with an intellectual disability[111]
- **Easy Read Medicine Information Leaflets** from the University of Birmingham[140]

Indicators for local monitoring

Indicator 6a: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for whom the reason(s) for prescribing the medicine was documented in their healthcare record.

METEOR link: **meteor.aihw.gov.au/content/791020**

Indicator 6b: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for behaviours of concern who had a comprehensive assessment to identify factors that might be contributing to the behaviours.

METEOR link: **meteor.aihw.gov.au/content/791022**

Indicator 6c: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for behaviours of concern who were also receiving non-medication strategies.

METEOR link: **meteor.aihw.gov.au/content/791024**

More information about these indicators and the definitions needed to collect and calculate indicator data can be found online at the above METEOR link.

7

Quality statement 7 –
Monitoring, reviewing and ceasing psychotropic medicines

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.

Purpose

To support safe and quality use of psychotropic medicines and avoid circumstances of unnecessary initiation and inappropriate prolonged use.

What the quality statement means

◼ For people

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.

■ For clinicians

Ensure regular monitoring and review of a person's response to psychotropic medicines to assess the benefits of treatment and to minimise medicine-related harm.[14,15] The goals of monitoring and frequency of review should align with the goals of treatment and the person's individual needs.

Regular monitoring and review of psychotropic medicines is important in people with cognitive disability or impairment because:[14,15]

- Polypharmacy commonly occurs, particularly with multiple psychotropic medicines (psychotropic polypharmacy)
- The person may be unable to communicate adverse effects
- Overall pill burden, or psychotropic medicines themselves, can cause or exacerbate dysphagia
- The medicine may no longer be required
- A different medicine may be appropriate
- The dose may not be appropriate (often dosages are unnecessarily high)
- Dosage forms may be inappropriately altered by the person, their family members or support people, for example, crushing tablets that should be swallowed whole.

Determine regular monitoring and review intervals appropriate for each person. The interval for reviews is determined by the person's response and should be consistent with best practice for the type of psychotropic medicine prescribed, the reason for use and the person's individual risks.[15,29]

Identify appropriate monitoring requirements, such as physical examinations, tests or investigations (for example, blood tests).

Involve the person's family, support people or support workers in monitoring the person's response – these people can provide information about medicine use and adherence, side effects, any special issues related to administration, and changes in symptoms or behaviour (as relevant).[14,15,141]

When reviewing a person's medicines, establish that there is a clear and appropriate rationale for prescribing and ensure it is documented in the person's healthcare record.

At review, assess the effectiveness of the medicine on target symptoms, and any adverse effects. Include objective assessments with input from the person. Examples of objective assessments include behavioural monitoring, reports from family, support people and support workers, and direct examination of the person's mental state. [14,15,141]

Identify, resolve and reduce the risk of medicine-related harm. Re-evaluate the dose of the medicine and the effect on the person, alongside the indication for which it was prescribed. Aim to ensure medicine is prescribed at the lowest effective dose and for the minimum duration appropriate for the person and the indication.[14,15,29]

Consider tapering and reducing the dose with a view to discontinuing the medicine (deprescribing) if treatment is ineffective, there are unacceptable adverse effects, symptoms have resolved, the person requests it, or a clear indication for use cannot be found.[14,15] When reducing psychotropic medicines, develop a deprescribing plan in collaboration with the person and their family, support people or support workers and relevant healthcare providers.[14,15] The plan should set out the approach to monitoring, a stepwise approach to dose reduction, the use of non-medication strategies (which is especially important if symptoms re-emerge) and reasons for restarting a medicine.

Ensure that family members, support people or support workers are engaged as partners in monitoring and reporting the response to each dose reduction. For advice on reducing and discontinuing psychotropic medicines, see Therapeutic Guidelines: Psychotropic[14] and Therapeutic Guidelines: Developmental disability.[15]

If the person has a behaviour support plan, request the plan and review medicines in the context of their plan alongside use of non-medication strategies. The person or clinician responsible for developing the behaviour support plan should be available to discuss problems with or any changes required to the support plan.

Document the outcome of the review, including any actions or recommendations and the timing of the next review, in the person's healthcare record. Communicate this to the person and their family or other people involved in supporting their care as appropriate.[116,142]

■ For healthcare services

Establish processes to ensure a quality use of medicines approach to the monitoring and review of psychotropic medicines.

Ensure policies and procedures are in place to outline the processes for monitoring and reviewing a person's medicines, including:

- Identifying monitoring requirements according to individual needs, and how these will be documented
- Identifying the most appropriate healthcare providers responsible for conducting a medication review
- Documenting the timing of the next review, in line with the person's individual needs and the goals of treatment
- Documenting and communicating actions and recommendations to ensure they are accessible to all those involved in a person's care (for example, the use of paper-based or electronic forms)
- Engaging with family, support people and support workers when reviewing a person's medicines and seeking feedback about changes in the person's behaviour
- Ensuring the results of a review are discussed with the person and, if appropriate, parents, family, support people, support workers and other relevant people, including the person's general practitioner or other regular prescriber
- Identifying and prioritising for review people who are most at risk of, or have experienced, medicine-related harm
- Monitoring the duration of psychotropic medicines use, the appropriateness of review intervals and trends in medicine-related harms identified during a review, which could also include harms that have been prevented.

Access Australian Government–funded medication review programs, such as Home Medicines Review (HMR) or Residential Medication Management Review (RMMR), if relevant (see **Box 3**).

Services responsible for the behaviour support plan should ensure those who developed it are regularly reviewing the person to ensure that the planned support strategies are in place and their usefulness is assessed when the dose of a psychotropic medicine is modified or being ceased, and reviewing the plan with regard to the person's needs.

Box 3: Medication management review

A medication management review (MMR) is a comprehensive and structured assessment of a person's medicines. The aim of an MMR is to help people get the maximum benefit from their medicines and to prevent medicine-related harm.

Two types of MMR services currently funded under the Medicare Benefits Schedule (MBS) and dedicated Australian Government programs are:

- Residential Medication Management Review (RMMR)* – available to people living in an eligible Australian Government–funded aged care home
- Home Medicines Review (HMR)†, also known as Domiciliary Medication Management Review – available to people living in their own home.

Community pharmacists may also conduct medication reviews outside of the RMMR and HMR arrangements. Examples include pharmacist services contracted by aged care homes and in-pharmacy MedsCheck services.

Further information about MMR programs is available from the Pharmacy Programs Administrator: Medication Management Programs.

* MBS items 903 and 249.
† MBS items 900 and 245.

Considerations when reviewing a person's medicines

Consideration should be given to potential barriers to people taking an active role in a review of their medicines. People with cognitive disability or impairment who may have difficulty communicating verbally or participating in decisions about their care may require support or a nominated decision-maker to be present.

A person's involvement in decisions about their medicines may also vary over time. Consideration should be given to adjusting the timing of a medication review to occur when a person may have the capacity to be involved. If appropriate, family members, support people or nominated decision-makers should be involved in the review.[143] Healthcare services should ensure that documentation about a person's nominated decision-maker is available to all prescribers and those involved in the person's care. This must include contact details that are up to date and easily accessible.

Cultural safety and equity

All people from all communities or groups should be supported to have their medicines reviewed, irrespective of diversity, background, age, location or personal circumstance.[142] Consider extra supports required to ensure a person's understanding and involvement in the review, including involvement of Aboriginal or Torres Strait Islander health workers or practitioners, interpreters, family or other support people.

Related resources

General

- *User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium* from the Australian Commission on Safety and Quality in Health Care[19]
- **Medication Management Programs** from The Pharmacy Programs Administrator[145]
- **Guidelines, guides, and protocols for deprescribing specific drug classes** from the Australian Deprescribing Network (ADeN)[146]
- **Deprescribing resources** from Primary Health Tasmania, outlining recommended deprescribing strategies for commonly used medicines, including psychotropic medicines, when ongoing use is not appropriate, revised and updated by geriatrician Dr David Dunbabin, GP Dr Amanda Lo and pharmacist Dr Peter Tenni[148]
- **Deprescribing algorithms** from the Canadian Medication Appropriateness and Deprescribing Network, evidence-based guidelines for deprescribing, summarised in an easy-to-use algorithm and information brochure, to help clinicians safely stop or reduce medicines for specific drug classes, developed by researchers from the Bruyère Research Institute and the Ontario Pharmacy Research Collaboration[150]

Aged care

- **Clinical practice guidelines for the appropriate use of psychotropic medications in people living with dementia and in residential aged care**[46]
- **Neuropsychiatric Inventory (NPI)**, a tool used to assess behaviours that can occur in people with dementia, and that can also be used to evaluate the effectiveness of treatment[144]
- **Dementia and psychotropic medicines** from NPS MedicineWise[138]
- **RACGP aged care clinical guide (Silver Book – Part A): Deprescribing** from the Royal Australian College of General Practitioners[125]
- **Deprescribing resources** from the NSW Therapeutic Advisory Group Inc., developed by a translational research project team led by Professor Sarah Hilmer for clinicians to support deprescribing in older persons in hospital[147]
- **Reviewing and tapering antipsychotic medicines for BPSD** review form from NPS MedicineWise[149]
- *Appropriate prescribing of antipsychotic medication in dementia* from the NHS London Clinical Network and NHS Yorkshire and the Humber Clinical Network[151]

Disability care

- *Behaviour Support and the Use of Medication: A guide for practitioners* from the Intellectual Disability Behaviour Support Program[18]
- *The Department of Developmental Disability Neuropsychiatry: A guide to resources*, developed by the Department of Developmental Disability Neuropsychiatry (3DN) to assist healthcare services with providing care to people with intellectual disability, including guidance about principles to support service delivery, suggestions for reasonable adjustments, assessing and managing behaviours of concern, and supporting responsible psychotropic prescribing in people with an intellectual disability[111]
- **Medication Management Pathway** from the Challenging Behaviour Foundation and Stopping Over-Medication in People with a Learning Disability, Autism or Both (STOMP) program[141]
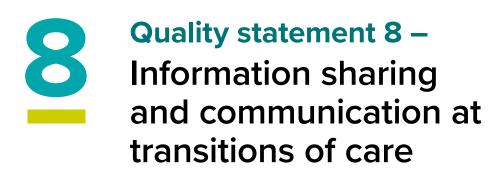
Indicators for local monitoring

Indicator 7a: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine for whom the timeframe to review the medicine was documented in their healthcare record.

METEOR link: **meteor.aihw.gov.au/content/791026**

Indicator 7b: Proportion of people with cognitive disability or impairment who were prescribed a psychotropic medicine for whom the effectiveness of the medicine on target symptoms and any adverse effects were documented at each review.

METEOR link: **meteor.aihw.gov.au/content/791028**

More information about these indicators and the definitions needed to collect and calculate indicator data can be found online at the above METEOR link.

8

Quality statement 8 –
Information sharing and communication at transitions of care

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.

Purpose

To ensure information required for ongoing care, including behaviour support needs and use of psychotropic medicines, is transferred when a person moves between care settings and providers, and is communicated to the person, their family or support people and relevant healthcare and service providers.[136]

To reduce the risk of adverse outcomes associated with transitions of care for people with cognitive disability or impairment.

What the quality statement means

■ For people

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.[36,136,143]

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.

■ For clinicians

Moving between healthcare settings can be distressing for people with cognitive disability or impairment. Unfamiliar environments, noises, routines and care arrangements may cause changes in a person's behaviour. **Transitions of care** are associated with an increased risk of adverse events such as medication errors, especially if the transition is unplanned.

Accurate and timely communication of the person's healthcare and behaviour support needs facilitates actions that can prevent the emergence of behaviour that could be distressing or harmful (and potentially lead to initiation of new psychotropic agents) and reduce the risk of delirium (see **Interventions to prevent delirium**). Identify the most effective way to share information about the person and their behaviour support needs by liaising with other healthcare or service providers.

When transferring a person to a new healthcare setting from their usual environment (such as to a hospital, a new aged care home or supported residence, or referring to a new clinician), include information about the person's individual needs and any adjustments that may help to support their care, including:

- The need for interpreters or cultural support
- Capacity to consent, need for support with decision-making, and any existing arrangements for a substitute decision-maker
- Contact details for family members, support people or a nominated decision-maker and, as relevant, the person's aged care or disability service providers, general practitioner, Aboriginal and Torres Strait Islander Health and Medical Service, other care providers, and usual pharmacy (if they have one)
- Medicines, including a complete and accurate medicines list, and any specific medication management needs, such as assistance required when taking medicines and potential adverse effects that may affect their care plan (such as risk of falls)
- Key details about the use of any psychotropic medicines the person has been prescribed (see **Box 4**)
- Clear and concise details about behaviour support needs where relevant, including the person's behaviour support plan if they have one, so that those providing ongoing care know how best to continue to support the person.

People in supported residential facilities or other care services should have this information documented by their facility and provided with the person being transferred.

When transferring a person after an episode of health care back to their usual environment or healthcare service (including an aged care home), include information about:

- Consent arrangements during the episode of care, including adjustments required to support decision-making and any arrangements for a substitute decision-maker
- Medicines administered during the episode of care, including an accurate, comprehensive and up-to-date medicines list or medication chart
- Changes to regular medicines, including medicines started or ceased or changed in dose, and any specific medication management needs, including management of potential adverse effects such as falls
- The reasons for any changes to regular medicines, including the initiation or discontinuation of psychotropic medicines.
- Psychotropic medicines that have been prescribed and key details about their use (see **Box 4**)
- Expected recommended duration of use of any psychotropic medicines that have been prescribed. Clear documentation at transfer will reduce the risk of inadvertent long-term continuation or recommencement.
- Plans for monitoring and review of psychotropic medicines, including for periodic medication review or other review process to support the person's medication management plan (see Quality statement 7 **Box 3**)
- Any behaviours of concern observed under your care, how they were managed (if applicable) and the person's response
- Recommendations about behaviour support needs and relevant non-medication strategies (including any issues not covered in an existing behaviour support plan, if they have one)
- The results of any behaviour or cognitive assessments that were carried out under your care (note that behaviour may improve after care transition, and reassessment may be needed to determine ongoing function and need for behaviour support or a change to the person's medicines)
- Contact details for questions and concerns.

Ensure that information about the person's episode of care is provided to the person, and if appropriate, and with the person's consent, their family, support people or nominated decision-maker. Information should also be provided to healthcare, aged care or disability service providers who are responsible for their ongoing care.[12,142]

Information should be transferred in one or more formats via secure routes; for example, paper-based, electronic transfer (such as uploading to the person's My Health Record) or other secure messaging system.[142] Aged care homes may need to use additional documentation to support the safe and quality use of medicines at transitions of care. Examples include the Interim Residential Medication Administration Chart or the **Aged Care Transfer-to-Hospital Envelope**.[142,152]

A person's confidentiality and wishes must always be respected when sharing information about their care – consider the person's right to privacy, confidentiality and consent requirements.[142]

Consult the ***Guiding principles to achieve continuity in medication management***[142] for more information.

Box 4: Key details about psychotropic medicines when transferring prescribing to another prescriber

- Reason for prescribing
- When the medicine was last administered
- Plans for follow-up monitoring, including monitoring the effectiveness of the medicine for the reason it was prescribed, and development of side effects
- When the next review is planned or recommended
- Intended duration of use – for instance, whether it is intended for short-term use
- Plans to reduce or cease the medicine
- Details about any changes to the person's psychotropic medicines during the episode of care

For healthcare services

Ensure that systems, policies and procedures are in place that support healthcare providers to effectively communicate comprehensive, accurate and up-to-date information about a person's ongoing care when a transition of care occurs. This communication should include any medicine-related needs and any risks to the person's behaviour that may arise with the transition of care.

Ensure policies and procedures[142]:

- Include the need to transfer documentation about strategies known to be effective in supporting a person's behaviour, which may avoid the use of psychotropic medicines; for example, the person's behaviour support plan, if they have one, or documentation in the discharge summary
- Include the requirement for a current medicines list to be transferred to enable continuity of medicines management
- Outline expectations about the timeframe in which communication should occur – emphasising that timely communication is critical to the relevance of the information – and what to do if information is not received.

If psychotropic medicines are prescribed for behaviours of concern, ensure documentation is transferred with the person, outlining:

- Behaviours that have been observed
- Causes for the behaviour observed
- Non-medication strategies that were tried or used
- Reason for prescribing the psychotropic medicine
- Effectiveness of the medicine on the target symptoms
- Potential adverse effects that may affect their care plan (such as falls risk)
- Ongoing monitoring requirements
- Plans for review or discontinuation of the medicine.

In acute healthcare services, implement the relevant NSQHS Standards and refer to the *Guiding principles to achieve continuity in medication management* to support best practice and safe and quality use of medicines at transitions of care.[142]

With the person's consent, information should be transferred securely, for example, through a secure messaging system, on paper, or by uploading to digital systems such

as the person's My Health Record.[142] This provides other clinicians with access to details about the person's care and their medicines, which can be vital for informing ongoing care in the community. Sharing information about the care provided in all care settings is especially important if the person transitions to interim care (rehabilitation or respite care) before returning to their usual residence and healthcare provider. Ensure the transfer of information takes into account consent requirements and the person's right to privacy and confidentiality.[142]

Aged care homes may need to use additional documentation to support the safe and quality use of medicines at transitions of care. Examples include the Interim Residential Medication Administration Chart or the **Aged Care Transfer-to-Hospital Envelope**.[142,152]

Related resources

General

- Australian Commission on Safety and Quality in Health Care
  - NSQHS **Medication Safety Standard**
  - NSQHS **Communicating for Safety Standard**
  - NSQHS **Communicating for Safety resource portal**
  - *User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium*.[19]
- *Guiding principles to achieve continuity in medication management* from the Australian Government Department of Health and Aged Care[142]
- **Pharmacist shared medicines list** from the Australian Digital Health Agency[154]
- **National Medication Management Plan (NMMP)**, a standardised form designed for use in Australian healthcare services to improve the accuracy and completeness of documented information to support continuity of medication management and medication reconciliation during transitions of care[155]
- Principle 4: Information sharing of the *ACCHO Medicines Management Guidelines* for Aboriginal Community Controlled Health Organisations[156]
- **Australian Medical Association position statement on general practice/hospitals transfer of care arrangements 2018** from the Australian Medical Association[157]
- Chapter 6: Facilitating Continuity of Medication Management on Transition Between Care Settings of the **Standards of Practice for Clinical Pharmacy Services** from the Society of Hospital Pharmacists of Australia[158]
- Chapter 16: My Health Record of the **Standards of Practice for Clinical Pharmacy Services** from the Society of Hospital Pharmacists of Australia[159]

Aged care

- **Aged Care Transfer-to-Hospital Envelope with Template**
- **Care of Confused Hospitalised Older Persons (CHOPs)** from NSW Health[134]
- **TOP 5,** a clinician–carer communication tool that can be used across healthcare settings to enhance the delivery of person-centred care in people living with dementia.[160]

Disability care

- **Resources for health professionals working with people with and intellectual disability** from the Monash Health Centre for Developmental Disability Health[153]
- **Practice Alert: Transitions of care between disability services and hospitals** from the NDIS Quality and Safeguards Commission[136]
- **Practice Alert: Medicines associated with swallowing problems** from the NDIS Quality and Safeguards Commission[136]

Indicators for local monitoring

Indicator 8a: Evidence of a locally approved policy to ensure that information about a person's behaviour support needs and their psychotropic medicines is transferred with the person between care settings.

The policy should specify the:

- Behaviour support information, including the person's behaviour support plan if they have one, that is to be transferred with the person between care settings
- Healthcare information, including a complete and accurate medicines list and key details about the use of any psychotropic medicines, that is to be transferred with the person between care settings
- Requirement to maintain and transfer up-to-date contact details of the person's family members, support people or nominated decision-maker and, as relevant, the person's disability service providers, general practitioner, Aboriginal and Torres Strait Islander Health and Medical Service, and other care and service providers
- Process to ensure the information is transferred with the person between care settings
- Process to ensure the workforce is informed and competent in the use of the policy.

METEOR link: **meteor.aihw.gov.au/content/791030**

Indicator 8b: Proportion of people with cognitive disability or impairment discharged with a supply or prescription for psychotropic medicine where the person or support people were provided with information about the medicine on discharge.

METEOR link: **meteor.aihw.gov.au/content/791032**

Indicator 8c: Proportion of people with cognitive disability or impairment who were prescribed psychotropic medicine while in hospital, whose discharge information was sent to the clinician responsible for their care on discharge.

METEOR link: **meteor.aihw.gov.au/content/791034**

Indicator 8d: Proportion of people with cognitive disability or impairment who were prescribed a psychotropic medicine while in hospital, whose discharge information was sent to their aged care or disability service provider on discharge.

METEOR link: **meteor.aihw.gov.au/content/791036**

More information about these indicators and the definitions needed to collect and calculate indicator data can be found online at the above METEOR link.

Appendix A: General principles of care

This clinical care standard aligns with key principles that are the foundation for achieving safe, high-quality care. When implementing this clinical care standard, healthcare services should ensure that quality improvement activities support these principles.

Person-centred care

Person-centred care is health care that is respectful of, and responsive to, the preferences, needs and values of the person receiving care.[36,161]

Clinical care standards support the key principles of person-centred care, namely:

- Treating the person with dignity and respect
- Encouraging the person's participation in shared decision-making
- Communicating with the person about their clinical condition and treatment options
- Providing the person with information in a format that they understand and encouraging them to participate in decision-making to the greatest extent that they choose.

Shared decision making

Shared decision making involves discussion and collaboration between a person and their clinician. It is about bringing together the person's values, goals and preferences with the best available evidence about benefits, risks and uncertainties of treatment, to reach the most appropriate healthcare decisions for that person.

Involving family and support people

The **Australian Charter of Healthcare Rights** (second edition)[38] describes the rights that consumers, or someone they care for, can expect when receiving health care.

People have the right to involve the people they want in planning and making decisions about their health care and treatment. This could be a family member, carer, friend, disability advocate or consumer advocate such as a social worker. Many healthcare services employ different types of liaison officers, such as Aboriginal and Torres Strait Islander liaison officers, who can provide people with advocacy, information and support.

This clinical care standard refers to family members and other people that the person chooses to support their care. Statements that refer to clinicians' discussions with people about their care should be understood to include family members and support people if this is what the person chooses, or a substitute decision-maker if the person is unable to provide their consent.

Informed consent

Informed consent is a person's voluntary and informed decision about a health care treatment, procedure or intervention that is made with adequate knowledge and understanding of the benefits and risks to them, and the alternative options available. More information is available in the Commission's **informed consent fact sheet for clinicians**.

Action 2.04 in the National Safety and Quality Health Service (NSQHS) Standards requires healthcare services to ensure that informed consent processes comply with legislation and best practice.[36]

Appendix B: Indicators to support local monitoring

The Commission has developed a set of indicators to support clinicians and healthcare services in monitoring how well they implement the care described in this clinical care standard. The indicators are a tool to support local quality improvement activities. No benchmarks are set for any indicator.

The process to develop the indicators specified in this document comprised:

- A review of existing Australian and international indicators
- Prioritisation, review and refinement of the indicators with the topic working group.

The data underlying these indicators are collected from local sources, through prospective data collection or retrospective chart audits or review of policies and protocols.

In this document, the indicator titles and hyperlinks to the specifications are included with the relevant quality statement under the heading 'Indicator(s) for local monitoring'. The definitions required to collect and calculate all data for the *Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard* indicators can be found in the Metadata Online Registry (METEOR): **meteor.aihw.gov.au/content/791005**.

METEOR is Australia's web-based repository for national metadata standards for the health, community services and housing assistance sectors. Hosted by the Australian Institute of Health and Welfare, METEOR provides users with online access to a wide range of nationally endorsed data and indicator definitions.

Other Commission-endorsed indicators to support local monitoring

The Commission recommends other quality improvement indicators listed below to support monitoring.

Hospital-acquired complications

A hospital-acquired complication (HAC) refers to a complication for which clinical risk mitigation strategies may reduce (but not necessarily eliminate) the risk of that complication occurring.[162] The HACs list comprises 16 agreed, high-priority complications for which clinicians, managers and others can work together to address and improve patient care. Each of the HACs has a number of associated diagnoses and codes, which allow further exploration of the data. Data for HACs are derived from the admitted patient data collection.

The Commission has developed several resources for clinicians, managers and executives, governing bodies and others that can help them put in place strategies that reduce the occurrence of HACs. These are available at **www.safetyandquality.gov.au/our-work/indicators/hospital-acquired-complications**.

Appendix C: Measuring and monitoring patient experiences

Systematic, routine monitoring of patients' experiences of, and outcomes from, health care is an important way to ensure that the patient's perspective drives service improvements and person-centred care. This is the case in all healthcare services.

Patient experience measures

While this clinical care standard does not include indicators specific to measuring patient experiences, the Commission strongly encourages healthcare services to use the Australian Hospital Patient Experience Question Set (AHPEQS). AHPEQS is a 12-question generic patient experience survey that has been validated in both day-only and admitted hospital patients across many clinical settings. The **AHPEQS is available for download**[163] to both private and public sector health services.

Patient-reported outcome measures

In Australia, patient-reported outcome measures (PROMs) are an emerging method of assessing the quality of health care. The Commission is leading a national work program to support the consistent and routine use of PROMs to drive quality improvement.

PROMs are standardised, validated questionnaires that patients complete, without any input from healthcare providers. They are often administered at least twice to an individual patient – at baseline and again after an intervention, or at regular intervals during a chronic illness. The information contributed by patients filling out PROMs questionnaires can be used to support and monitor the movement of health systems towards person-centred, value-based health care.

PROMs are being used to evaluate healthcare effectiveness at different levels of the health system, from the individual level to service and system levels. There is growing interest across Australia and internationally in the routine interrogation of patient-reported outcome information for evaluation and decision-making activities at levels of the health system beyond the clinical consultation.

Appendix D: Integration with national safety and quality standards

The National Safety and Quality Health Service (NSQHS) Standards and the National Safety and Quality Primary and Community Healthcare (Primary and Community Healthcare) Standards aim to protect the public from harm and improve the quality of health service provision. They provide a quality assurance mechanism that tests whether relevant systems are in place to ensure that expected standards of safety and quality are met.

Within both the NSQHS Standards and the Primary and Community Healthcare Standards, the Clinical Governance Standard and the Partnering with Consumers Standard set the overarching requirements, or clinical governance framework, for the effective implementation of other standards.

National Safety and Quality Health Service Standards

Implementation of this clinical care standard will help healthcare services to achieve some of the actions within the NSQHS Standards.[36]

Relevant actions

Under the Clinical Governance Standard, healthcare services are expected to:

- Support clinicians to use the best available evidence, including clinical care standards (Action 1.27b)
- Monitor and respond to unwarranted clinical variation (Action 1.28).

For more information about:

- Assessment to the NSQHS Standards and applicability of clinical care standards, visit the **NSQHS Standards webpage** outlining requirements
- Monitoring and responding to unwarranted clinical variation, see the ***NSQHS Standards User Guide for the Review of Clinical Variation in Health Care***
- Other relevant actions in the NSQHS Standards, see the **NSQHS Standards**.

National Safety and Quality Primary and Community Healthcare Standards

The Primary and Community Healthcare Standards are aligned to the NSQHS Standards.[37]

Relevant actions

Under the Clinical Governance Standard, healthcare services are expected to:

- Support healthcare providers to use best-practice guidelines and available evidence, including clinical care standards, where relevant (Action 1.20b)
- Monitor and respond to unwarranted clinical variation (Action 1.21).

Application of the Primary and Community Healthcare Standards is voluntary. They should only be applied where services are involved in the direct care of patients. The way in which an individual primary and/ or community healthcare service implements the Primary and Community Healthcare Standards will be dependent on the size of the healthcare service, as well as the risks and complexity associated with the services it delivers.

Further information about the Primary and Community Healthcare Standards is available at the **Primary and Community Health Service Standards webpage**.

Glossary

Term	Definition
adverse drug reaction	A response to a medicine that is noxious and unintended and occurs at doses normally used or tested in humans for the prophylaxis, diagnosis or therapy of disease, or for the modification of physiological function. An allergy is a type of adverse drug reaction.[36,164]
adverse event	An incident that results, or could have resulted, in harm to a person or consumer. A near miss is a type of adverse event.[36,164]
aged care home	A special-purpose facility that provides accommodation and personal care 24 hours a day, as well as access to nursing and general health services, and assistance towards independent living, for senior Australians who can no longer live in their own home. All government-funded aged care homes must be approved providers and meet the Aged Care Quality Standards.[164]
assessment	A clinician's evaluation of a disease or condition based on the person's subjective report of the symptoms and course of the illness or condition, and the clinician's objective findings. These findings include data obtained through laboratory tests, physical examination and medical history; and information reported by carers, family members and other members of the healthcare team. The assessment is an essential element of a comprehensive care plan.[36,164]
augmented and alternative communication	Methods of communication personalised to enable the participation of a person who may experience barriers to spoken communication. They include unaided forms, such as eye contact, gestures, facial expression, vocalisations and sign language, and aided forms that use devices, such as a speech generating device, to communicate.[24]
Australian Charter of Healthcare Rights	Specifies the key rights of people when seeking or receiving healthcare services. It was updated in 2020 and reflects an increased focus on person-centred care and empowers people to take an active role in their health care.[164]
behavioural and psychological symptoms of dementia (BPSD)	Symptoms of disturbed perception, thought content, mood, or behaviour that occur commonly in people living with dementia. BPSD include calling out, screaming, verbal and physical aggression, hypersexuality, resistiveness, wandering, intrusiveness, repetitive behaviour, hoarding, nocturnal restlessness, emotionality, delusions and paranoid or reckless behaviours. Overall, prevalence increases with the severity of dementia. However, BPSD can occur at any stage of, and vary between types of, dementia. In frontotemporal dementia, disinhibition often results in early behavioural symptoms, while in Lewy body dementia, visual hallucinations are prominent. See also **dementia** and **responsive behaviour**.[164]

Term	Definition
behaviours of concern	Behaviours that indicate a risk to the safety or wellbeing of the person who exhibits them or those around them.[8–10] Behaviours may challenge the person, their supporters and the care services they are in, but may serve a purpose for the person, such as communicating unmet needs and responses to their environment.[11–13] Behaviours that cause concern to others may not be concerning to the person who exhibits them. While using this term, the Commission recognises that: ■ Other terms may be more acceptable in different contexts, but there is no universally accepted term that applies in all settings and to all groups of people across the lifespan (see below) ■ The term should not be used to define a person by their symptoms or suggest that the person themselves is a concern ■ The term does not represent a medical diagnosis, but a behavioural response that could have many possible causes, requiring assessment to determine appropriate treatment.[14,15] Other terms include: 'changed behaviours', 'challenging behaviours', 'distressed behaviours', 'behaviours that cause distress', 'complex behaviours of concern', 'responsive behaviour, 'non-cognitive symptoms', 'neuropsychiatric symptoms' or 'expression of unmet need'.
behaviour support	Individualised strategies that address the needs of the person and the underlying causes of behaviours of concern, while safeguarding the dignity and quality of life of people who require behaviour support.[131]
behaviour support needs	This term is used to relate how the needs of a person that are expressed as behaviours of concern can be addressed through behaviour support.
behaviour support plan	A written plan prepared with the person – and their family or support people as appropriate – that helps those involved in the person's daily life and care to improve the person's care to reduce or prevent behaviours of concern, and potentially eliminate the need for restrictive practices to control behaviour. For recipients of aged care and NDIS services, a behaviour support plan is made in accordance with the ***Quality of Care Principles 2014***[8] (the Principles) and the ***National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018***.[6]
behaviour support practitioner	A practitioner who is registered with the NDIS to provide specialist behaviour support.[165]
best interests	Decisions made by others that are motivated by what they think is best for the person.[28]
best practice	When the diagnosis, treatment or care provided is based on the best available evidence, which is used to achieve the best possible outcomes for patients.[36,164]
best-practice guidelines	A set of recommended actions that are developed using the best available evidence. They provide clinicians with evidence-informed recommendations that support clinical practice, and guide clinician and patient decisions about appropriate health care in specific clinical practice settings and circumstances.[36,164]

Term	Definition
carer	A person who provides unpaid personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness), mental health condition, or they are frail or aged.
	An unpaid carer might be a partner, family member, friend or neighbour, and the arrangement may be temporary or permanent.[19–21]
	An individual is not a carer merely because they are a spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care.[22]
	A person is not considered a carer if they are paid, a volunteer for an organisation, or caring as part of a training or education program.[22]
care and services plan	The plan required for people living in residential aged care under the Aged Care Quality Standards.[94]
chemical restraint	Chemical restraint is a form of restrictive practice that involves the use of medicine or a chemical substance for the primary purpose of influencing a person's behaviour, but does not include the use of medicine primarily prescribed for the treatment of, or to enable treatment of, a diagnosed mental health disorder, a physical illness, or a physical condition, or for end-of-life care.[6,8]
clinical care standards	Nationally relevant standards developed by the Australian Commission on Safety and Quality in Health Care, and agreed by health ministers, that identify and define the care people should expect to be offered or receive for specific conditions.[36]
clinical communication	The exchange of information about a person's care that occurs between treating clinicians, people, families and carers, and other members of a multidisciplinary team. Communication can be through several different channels, including face-to-face meetings, telephone, written notes or other documentation, and electronic means. See also **effective clinical communication**.[36]
clinical practice guidelines	Statements that include recommendations intended to optimise patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.[166]
clinician	A trained health professional, including registered and non-registered practitioners, who provides direct clinical care to people. Clinicians may provide care within a healthcare service as an employee, a contractor or a credentialed healthcare provider, or under other working arrangements. They include Aboriginal and Torres Strait Islander health workers and practitioners, allied health professionals such as hospital and community pharmacists, psychologists, or social workers, technicians, scientists, medical practitioners, midwives, nurses, paramedics, other professionals who provide health care, and students who provide health care under supervision.[36]
cognitive disability	An umbrella term for a level of cognitive function that generally causes difficulty with things such as completing day-to-day tasks, decision-making and communication.[10,23] People with cognitive disability include people living with intellectual disability, dementia, acquired brain injury or feta alcohol spectrum disorder.
cognitive function or ability	Brain-based skills and abilities that relate to carrying out tasks, memory and thinking processes, such as attention, language, decision-making and learning.[167]

Term	Definition
cognitive impairment	Deficits in one or more of the areas of memory, communication, attention, thinking, problem-solving and judgement. This can be temporary or permanent. It can affect a person's understanding, their ability to carry out tasks or follow instructions, their recognition of people or objects, how they relate to others and how they interpret the environment. Dementia and delirium are common forms of cognitive impairment seen in older people in all healthcare settings. Cognitive impairment can also be a result of several other conditions, such as acquired brain injury, a stroke, intellectual disability, licit or illicit drug use, or medicines.[164] A person with cognitive impairment can also find it difficult to learn new things, concentrate or make decisions.[167]
community care or service provider	A provider of a health and community care service in the community.[164]
consultation	Occurs when people seek information or advice and take into consideration the feelings and interests of all of the members of the medication management team.[164]
cultural safety	An environment that is spiritually, socially, emotionally and physically safe and respectful, as determined by a person or their family. Cultural safety is a key principle in improving health outcomes.[167]
culturally safe care	Care and services that are planned and delivered in a way that is spiritually, socially, emotionally and physically safe and respectful for consumers. Culturally safe care and services also ensure that a person's identity is respected so that who they are and what they need are not questioned or denied.[167]
decision support tools	Tools that can help clinicians and consumers to draw on available evidence when making clinical decisions. Some tools are explicitly designed to enable shared decision making (for example, decision aids). Others provide some of the information needed for some components of the shared decision-making process (for example, risk calculators and evidence summaries) or provide ways of initiating and structuring conversations about health decisions (for example, communication frameworks and question prompt lists). See also **shared decision making**.[36,164]
de-escalation strategies	Psychosocial techniques that aim to reduce violent or disruptive behaviour. They are intended to reduce or eliminate the risk of violence during the escalation phase, using verbal and non-verbal communication skills. De-escalation is about establishing rapport to gain the person's trust, minimising restriction to protect their self-esteem, appearing externally calm and self-aware in the face of aggressive behaviour, and intuitively identifying creative and flexible interventions that will reduce the tendency for aggression.[36]
delirium	An acute disturbance of consciousness, attention, cognition and perception that tends to fluctuate during the day. It is a serious condition that can be prevented in 30–40% of cases and should be treated promptly and appropriately. Hospitalised older people with existing dementia are at the greatest risk of developing delirium. Delirium can be hyperactive (the person has heightened arousal, or can be restless, agitated and aggressive) or hypoactive (the person is withdrawn, quiet and sleepy).[36,164]

Term	Definition
deprescribing	The planned and supervised process of tapering or discontinuing medicines that may no longer be of benefit or may be causing harm, with the ultimate goal of reducing medicine burden and improving quality of life.[168–170] Deprescribing is part of the good prescribing continuum, which spans therapy initiation, dose titration, changing or adding medicines, and switching or ceasing medicines.[171,172] It should be done in partnership with the person, with close, consistent monitoring to ensure tapering or discontinuation is safe and effective.[147,168,172]
dementia	Progressive cognitive impairment, affecting memory, judgement, language and the ability to perform everyday tasks. Alzheimer's disease is the most common type of dementia. Dementia is predominately a disorder related to age but can affect people aged under 65 years. This is known as younger onset dementia.[164]
developmental disability	Disabilities that relate to 'differences in neurologically based functions that have their onset before birth or during childhood and are associated with significant long-term difficulties'. All intellectual disabilities are developmental disabilities, but not all developmental disabilities are associated with an intellectual disability. For example, cerebral palsy is a developmental disability which may or may not be associated with intellectual disability.[173]
disability advocate	A person who is independent of any NDIS providers providing supports or services to the person with disability; provides independent advocacy for the person with disability, to assist the person with disability to exercise choice and control and to have their voice heard in matters that affect them; acts at the direction of the person with disability, reflecting the person with disability's expressed wishes, will, preferences and rights; and is free of relevant conflicts of interest.[165]
disability services	Services and supports for people with disability provided by government and other agencies, to enable and assist people with disability to fully participate in society and community life.[173]
Easy Read	Easy Read uses clear, everyday language matched with images to make sure everyone understands. Easy Read documents help to reach people with disability, including people with intellectual disability; people with English as a second language; and people with lower literacy levels.[101]
effective clinical communication	Two-way, coordinated and continuous communication that results in the timely, accurate and appropriate transfer of information. Effective communication is critical to, and supports, the delivery of safe patient care. See also clinical communication and clinical communication process.[36,164]
environment	The physical surroundings in which health care is delivered, including the building, fixtures, fittings, and services such as air and water supply. Environment can also include other patients, consumers, visitors and the workforce.[36,164]
episode of care	A phase of treatment. There may be more than one episode of care within the one hospital stay. An episode of care ends when the principal clinical intent changes or when the person is formally separated from the facility.[36] A health problem from its first encounter with a healthcare provider through to the completion of the last encounter.[37]

Term	Definition
functional behaviour assessment	A requirement under section 20(5) of the National Disability Insurance Scheme (Restrictive Practice and Behaviour Support) Rules 2018, and is a key component in the development of a comprehensive behaviour support plan.[95]
goals of care	Clinical and other goals for a patient's episode of care that are determined in the context of a shared decision-making process.[36]
health care	The prevention, treatment and management of illness and injury, and the preservation of mental and physical wellbeing through the services offered by clinicians, such as medical, nursing and allied health professionals.[36,164]
healthcare record	Includes a record of the patient's medical history, treatment notes, observations, correspondence, investigations, test results, photographs, prescription records and medication charts for an episode of care.[36]
health literacy	The Australian Commission on Safety and Quality in Health Care separates health literacy into two components: individual health literacy and the health literacy environment. Individual health literacy is the skills, knowledge, motivation and capacity of a consumer to access, understand, assess and apply information to make effective decisions about health and health care, and take appropriate action. The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the healthcare system, which affect the ways consumers access, understand, assess and apply health-related information and services.[36,164]
healthcare service	A separately constituted organisation, which can vary in size and organisational structure from single healthcare providers to complex organisations, with a governing body that is responsible for implementing clinical governance, administration and financial management of a service unit or service units providing health care. A service unit involves a clinician or a group of clinicians and others working in a systematic way to deliver health care to patients. Health care can be in any location or setting, including pharmacies, clinics, outpatient facilities, hospitals, patients' homes, community settings, practices and clinicians' rooms.[36] Where the meaning of a quality statement is explained for healthcare services in this clinical care standard, it is intended for those responsible for leading and governing the service.
Home Medicines Review (HMR)	An Australian Government–funded service in which the medical practitioner and the accredited pharmacist both participate in the medication review process, consistent with the business rules for items 900 and 245 of the MBS. See also **medication review**.[164]
hospital	A licensed facility providing health care to patients for short periods of acute illness, injury or recovery.[36]

Term	Definition
informed consent	An outcome of a process of communication between a person and clinician about options for treatment, care processes or potential outcomes. The communication should ensure that the person understands the care they will receive, all the available options and the expected outcomes, including success rates and side effects for each option. Informed consent exists when this communication results in the patient's authorisation or agreement to undergo a specific intervention or participate in planned care.[36,164] See also the **Consent for medication in aged care**.[94]
intellectual disability (intellectual developmental disorder)	Permanent impairment of general mental abilities that have an impact on domains of adaptive functioning. An intellectual disability exists only if an individual's cognitive impairment began during the developmental period (before the age of 18 years). Intellectual disability is diagnosed based on the severity of deficits in adaptive functioning. Intellectual disability may co-occur with other developmental disorders and other mental disorders.[173]
interdisciplinary care	An approach to care that involves team members from different disciplines working collaboratively, with a common purpose, to set goals, make decisions and share resources and responsibilities. A team of clinicians from different disciplines, together with the patient, undertake assessment, diagnosis, intervention, goal-setting and the creation of a care plan. The patient, their family and carers are involved in any discussions about their condition, prognosis and care plan. See also **multidisciplinary care** and **multidisciplinary team**.[164]
jurisdictional requirements	Systematically developed statements from state and territory governments about appropriate healthcare or service delivery for specific circumstances. Jurisdictional requirements encompass a number of types of documents from state and territory governments, including legislation, regulations, guidelines, policies, directives and circulars. Terms used for each document may vary by state and territory.[36]
medical practitioner	A medically qualified person whose primary role is the diagnosis and treatment of physical and mental illnesses, disorders and injuries. They include general practitioners, medical specialists, interns and residents.
medication management	Practices used to manage the provision of medicines, including: ■ How medicines are selected, ordered and supplied ■ How people take medicines or are assisted to take them ■ How medicines use is recorded and reviewed ■ How medicines are stored and disposed of safely ■ How medicines use is supported, monitored and evaluated. Medication management occurs at both the individual and the healthcare service levels. Medication management has also been described as a cycle, pathway or system, which is complex and involves a number of different clinicians. The person is the central focus. The system includes manufacturing, compounding, procuring, dispensing, prescribing, storing, administering, supplying and monitoring the effects of medicines. It also includes decision-making, and rules, guidelines, support tools, policies and procedures that are in place to direct the use of medicines.[164]

Term	Definition
medication management plan (MMP)	A continuing plan for the use and management of medicines developed in collaboration with the patient. The MMP records medicines taken before admission and aids medication reconciliation throughout the patient's episode of care. It is a record of patient-specific medicine-related issues, actions taken to resolve issues and medication management goals developed during the episode of care. All health professionals are responsible for documenting on the MMP regardless of the setting. The MMP may be used in inpatient, outpatient or non-admitted areas, emergency departments, subacute or primary care.[164] See also **National Medication Management Plan**, which is a standardised form.
medication reconciliation	A formal process of obtaining and verifying a complete and accurate list of each person's current medicines (including prescription, over-the-counter and complementary medicines), and matching the medicines the person should be prescribed to those they are prescribed. Any discrepancies are discussed with the prescriber, and reasons for changes to therapy are documented and communicated to the next care provider (as well as the person or their carer) when care is transferred. Medication review may form part of the medication reconciliation process.[36,164]
medication review	A systematic, comprehensive and collaborative assessment of medication management for an individual person that aims to optimise the patient's medicines and outcomes of therapy by providing a recommendation or making a change. It includes the objective of reaching an agreement with the person about treatment, optimising the effect of medicines, minimising the number of medicine-related problems and reducing waste. Medication review may be part of medication reconciliation. See also Home Medicines Review (HMR) and Residential Medication Management Review (RMMR).[36,164]
medicine	A chemical substance given with the intention of preventing, diagnosing, curing, controlling or alleviating disease, or otherwise improving the physical or mental wellbeing of people. These include prescription, non-prescription, investigational, clinical trial and complementary medicines, regardless of how they are administered.[36,164]
medicine-related problem	Any event involving treatment with a medicine that has a negative effect on a patient's health or prevents a positive outcome. Consideration should be given to disease-specific, laboratory test–specific and patient-specific information. Medicine-related problems include issues with medicines such as: ■ Underuse ■ Overuse ■ Use of inappropriate medicines (including therapeutic duplication) ■ Adverse drug reactions, including interactions (medicine–medicine, medicine–disease, medicine–nutrient, medicine–laboratory test) ■ Noncompliance.[36,164]

Term	Definition
medicines list	Prepared by a clinician, a medicines list contains, at a minimum:
	▪ All medicines a person is taking, including over-the-counter, complementary, prescription and non-prescription medicines; for each medicine, the medicine name, form, strength and directions for use must be included
	▪ Any medicines that should not be taken by the person, including those causing allergies and adverse drug reactions; for each allergy or adverse drug reaction, the medicine name, the reaction type and the date on which the reaction was experienced should be included.
	Ideally, a medicines list also includes the intended use (indication) for each medicine.
	It is expected that the medicines list is updated and correct at the time of transfer (including clinical handover) or when services cease, and that it is tailored to the audience for whom it is intended (that is, the person or the clinician).[36,164]
medicines or medication literacy	The degree to which individuals can obtain, comprehend, communicate, calculate and process patient-specific information about their medicines to make informed medicines and health-related decisions in order to safely and effectively use their medicines, regardless of the mode by which the content is delivered (for example, written, oral and visual).[164]
multidisciplinary care	An approach to care that involves team members working independently to create discipline-specific care plans that are implemented simultaneously, but without explicit regard to their interaction. See also **interdisciplinary care**. Depending on the resources of the health service, a combination of the two approaches may be used when caring for older people.[164]
multidisciplinary team	A team comprising clinicians from multiple disciplines (branches of knowledge within the health system) who work together to deliver comprehensive care that deals with as many of the person's health and other needs as possible. The team may operate under one organisational umbrella or may be from several organisations brought together as a unique team. As a person's condition changes, the composition of the team may change to reflect the changing clinical and psychosocial needs of the person. Multidisciplinary care includes interdisciplinary care. See also **interdisciplinary care**. (A discipline is a branch of knowledge within the health system).[36] Five principles that may help enhance team effectiveness include:
	▪ Shared purpose and goals
	▪ Clear roles and responsibility
	▪ Mutual trust
	▪ Effective communication
	▪ Measuring process and outcomes of team function.[164]
My Health Record (formerly known as a personally controlled electronic health record)	The secure online summary of a consumer's health information, managed by the System Operator of the My Health Record system (the Australian Digital Health Agency). Clinicians are able to share clinical documents to a consumer's My Health Record, according to the consumer's access controls. These may include information on medical history and treatments, diagnoses, medicines and allergies.[36,164]

Term	Definition
National Disability Insurance Agency (NDIA)	The **independent statutory agency** that implements the **National Disability Insurance Scheme**[167], under the auspices of the *National Disability Insurance Scheme Act 2013*.[7]
National Disability Insurance Scheme (NDIS)	A scheme launched in 2013 that offers a way of providing community linking and individualised support for people with permanent and significant disability, their families and carers. The NDIS supports people with permanent and significant disability that may affect their ability to participate in everyday activities. The **scheme** provides funding directly to individuals.[167] The scheme is administered by the National Disability Insurance Agency.
NDIS Quality and Safeguards Commission	An **independent agency** established to improve the quality and safety of NDIS supports and services.[167]
National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018	A *legislative instrument* made under section 209 of the *National Disability Insurance Scheme Act 2013*[7] that outlines the requirements for the development and review of behaviour support plans.
National Medication Management Plan (NMMP)	A standardised form to improve the accuracy and completeness of documented information to support continuity of medication management and medication reconciliation during transitions of care. It is used on admission to hospital and also includes a discharge and transfer medication plan section that needs to be completed during the discharge planning phase of a patient's hospital stay.[164]
non-prescription medicine	Medicines available without prescription. Examples are cough mixtures, simple analgesics and antacids. Some can be sold only by pharmacists ('Pharmacist Only Medicine') or in a pharmacy ('Pharmacy Only Medicine'); others can be sold through non-pharmacy outlets such as supermarkets. Also known as 'over-the-counter' medicines.[164]
outcomes	Describes the effect or result of a service or support, such as an improvement in an individual's wellbeing. Can be short-term (such as a consumer being involved in service planning) through to long-term (such as a person being able to manage daily activities on their own after support and reablement).[167]
partnership	When people and their families or carers are treated with dignity and respect, information is shared with them, and participation and collaboration in healthcare processes are encouraged and supported to the extent that the person chooses. Partnerships can exist in different ways in a healthcare service, including at the level of individual interactions; at the level of a service, department or program; and at the level of the healthcare service. They can also exist with consumers and groups in the community. Generally, partnerships at all levels are necessary to ensure that the healthcare service is responsive to patient and consumer input and needs, although the nature of the activities for these different types of partnerships will depend on the context of the healthcare service.[36,164]
patient	A person who is receiving care in a healthcare service.[36]
personal care	Activities such as bathing, showering, dressing, feeding and toileting.

Term	Definition
person-centred care	An approach to the planning, delivery and evaluation of health care that is founded on mutually helpful partnerships among clinicians and people. Person-centred care is respectful of, and responsive to, the preferences, needs and values of consumers. Key dimensions of person-centred care include: ■ Respect ■ Emotional support ■ Physical comfort ■ Information and communication ■ Continuity and transition ■ Care coordination ■ Involvement of family and support people ■ Access to care.[164] Also known as patient-centred care or consumer-centred care.[36] See also **partnership**. Care and services designed around an individual's needs, preferences and background. It includes a partnership between consumers and providers.[167]
policy	A set of principles that reflect the organisation's mission and direction. All procedures and protocols are linked to a policy statement.[36,164]
polypharmacy	The use of multiple medicines to prevent or treat medical conditions. It is commonly defined as the concurrent use of five of more medicines by the same person. Medicines include prescription, complementary and non-prescription medicines.[164]
preference	Refers to the will and wishes of the person, which are informed by their established values, as well as their more current interests and desires. These can be either expressed (verbal or written) or implied.[28]
prescriber	A clinician who is authorised by legislation to issue a prescription for the supply of medicines. Pharmaceutical Benefits Scheme (PBS) prescribers include doctors, dentists, optometrists, midwives and nurse practitioners who are approved to prescribe PBS medicines under the ***National Health Act 1953***.[164]
primary care	Clinical service that is provided at the entry level to the health system and, as such, is usually a person's first encounter with the health system.[164]
procedure	The set of instructions to make policies and protocols operational. Procedures are specific to an organisation.[36,164]
process	A series of actions or steps taken to achieve a particular goal.[36,164]
protocol	An official set of procedures for what actions to take in a certain situation.[164]
psychologist	Psychologists are mental health professionals who complete at least six years of approved university study and supervised experience and are registered with the Australian Health Practitioner Regulation Agency.
psychosocial	Social factors that have the potential to affect a person's emotional wellbeing.

Term	Definition
psychotropic medicines	The broad term used to describe medicines that affect the mind, emotions and behaviour.[27] They are used to treat mental health conditions such as anxiety, depression, schizophrenia, bipolar disorder and sleep disorders, and work by adjusting levels of chemicals in the brain to improve symptoms.
	The main groups of psychotropic medicines used to treat mental health conditions and sleep disorders are antipsychotic, antidepressant, and anxiolytic/hypnotic medicines. In this clinical care standard, the term psychotropic medicines predominantly refers to these three classes of medicines.
psychotropic polypharmacy	The use of two or more psychotropic medicines by the same person.[14]
Quality of Care Principles	The *Quality of Care Principles 2014*.[8] These principles are made under section 96-1 of the *Aged Care Act 1997*.[5]
quality improvement	The combined efforts of the healthcare workforce and others – including consumers, patients and their families, researchers, planners and educators – to make changes that will lead to better patient outcomes (health), better system performance (care) and better professional development.[174] Quality improvement activities may be sequential, intermittent or continuous.[36,164]
reasonable adjustments	Changes or adjustments made in the delivery of health care or services to remove barriers that may be experienced by people with disability, such as changing the way services are delivered, altering policies or procedures as appropriate, and providing the workforce with the proper training to help a person with cognitive disability or impairment to take part in decisions about their care on the same basis as others. Adjustments are informed by an understanding of the person's cognitive, physical and communication abilities and other biopsychosocial factors.[12,14,175]
regularly	At recurring intervals. The specific interval for regular review, evaluation, audit or monitoring needs to be determined for each case. The interval should be consistent with best practice, risk based, and determined by the subject and nature of the activity.[36,164]
Residential Medication Management Review (RMMR)	A collaborative medication review provided by an accredited pharmacist in accordance with a program funded by the Australian Government for eligible people receiving care within a government-funded aged care home, consistent with the business rules for items 903 and 249 of the MBS. See also **medication review**.[164]
respectful	Understanding a person's culture, acknowledging differences and being actively aware of these differences. It is about understanding that each person is unique and has a right to be treated in an inclusive and respectful way.[167]
responsibility	Being entrusted with or assigned a duty or charge. In many instances, responsibility is assumed, appropriate with one's duties. Responsibility can be delegated as long as it is delegated to someone who has the ability to carry out the task or function. The person who delegated the responsibility remains accountable, along with the person accepting the task or function. Responsibility is about accepting the tasks/functions inherent in one's role.[164]

Term	Definition
responsive behaviour	Also referred to as reactive behaviour. Responsive behaviour is a term originating from, and preferred by, people with dementia that represents how their actions, words and gestures are a response to something important to them, for example, as a way of responding to something negative, frustrating or confusing, and to express something important about their personal, social or physical environment. The response from the person can impede the provision of care or service or their daily activities and may create a risk of harm to the person or others.[164]
restrictive practice	Any practice or intervention that has the effect of restricting the rights or freedom of movement of a person.[5,7] Under the *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018*[6], and the updated *Aged Care Act 1997*[5] and the *Quality of Care Principles 2014*[8], there are five restrictive practices that are subject to regulation and oversight. These are chemical restraint, mechanical restraint, physical restraint, environmental restraint and seclusion. The use of psychotropics medicines for their sedative effects with the primary purpose of influencing behaviour is considered chemical restraint and is a restrictive practice. Governance for administering and monitoring the use of restrictive practices in Australia falls under state and territory jurisdictions. More information is available from the **Aged Care Quality and Safety Commission** and the **NDIS Quality and Safeguards Commission**, which have produced guidance in relation to the use of restrictive practices.[93–95,131,176]
risk	The chance of something happening that will have a negative outcome. Risk is measured by the consequences of an event and its likelihood.[36,164]
risk assessment	Assessment, analysis and management of risks. It involves recognising which events may lead to harm in the future, and minimising their likelihood and consequence.[36,164]
risk factor	A characteristic, condition or behaviour that increases the possibility of disease, injury or loss of wellbeing.
service providers	'Providers' refers to an entity which has been approved to provide aged care services or is an NDIS or other disability support provider. Approved aged care providers receive government subsidies for the delivery of care to people. NDIS providers are those who receive funding through a participant's NDIS plan to deliver supports. They may be registered or unregistered depending on the participant's plan management type and choice of provider. Providers may also be privately engaged by a person. A provider might also be referred to as: ■ An approved provider ■ A service provider ■ A registered NDIS provider ■ An organisation.
shared decision making	A consultation process in which a clinician and the person jointly participate in making a healthcare decision, having discussed the options and their benefits and harms, and having considered the person's values, preferences and circumstances.[36,164,177]

Term	Definition
side effects	Unintended effects from a medicine, treatment or device.
standard	Agreed attributes and processes designed to ensure that a product, service or method will perform consistently at a designated level.[36,164]
substitute decision-maker	A person appointed or identified by law to make health, medical, residential and other personal (but not financial or legal) decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision-maker may be appointed by the person, appointed on behalf of the person, or identified as the default decision-maker by legislation, which varies by state and territory.[14,15]
supported decision making	The process of enabling a person who requires decision-making support to make and/or communicate decisions about their own health care. The decision-making is supported, but the decision is theirs. Supported decision making upholds the human rights of people with cognitive disability or impairment and is the preferred alternative to use of a substitute decision-maker.[28]
support people	Individuals who are not family members by social definitions of family that the person receiving care chooses to involve in their care. This may include carers, friends, advocates, volunteers or people who can provide religious or spiritual support.[14,15] In this clinical care standard, 'support people' refers to unpaid support people. The term 'support worker' is used to refer to people who are paid to provide care or support.
support worker	Anyone who is employed to provide support to people to live in the community. Examples include Aboriginal and Torres Strait Islander health workers or practitioners, personal care workers, community support workers, disability support workers, aged care workers, and home and community care workers. In this clinical care standard, support worker refers to paid formal supports.[21]
system	The resources, policies, processes and procedures that are organised, integrated, regulated and administered to accomplish a stated goal. A system: ■ Brings together risk management, governance, and operational processes and procedures, including education, training and orientation ■ Deploys an active implementation plan; feedback mechanisms include agreed protocols and guidelines, decision support tools and other resource materials ■ Uses several incentives and sanctions to influence behaviour and encourage compliance with policy, protocol, regulation and procedures. The workforce is both a resource in the system and involved in all elements of systems development, implementation, monitoring, improvement and evaluation.[36,164]
terminal delirium	Delirium that occurs in the last days of life and for which treatment is not practicable or within the goals of a person's care.
timely communication	Communication of information within a reasonable time frame. This will depend on how important or time critical the information is to a person's ongoing care or wellbeing, the context in which the service is provided and the clinical acuity of the person.[36,164]

Term	Definition
training	The development of knowledge and skills.[36,164]
transitions of care	When all or part of a person's care is transferred between healthcare locations, providers, or levels of care within the same location, or as the person's condition and care needs change.[36,164]
trauma-informed care	An approach to care based on an understanding of how trauma affects people's lives, their needs and how they use services.[178]

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