A better way to care

Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital

Actions for health service managers
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Safety and quality pathway for patients with cognitive impairment (dementia and delirium) in hospital

Introduction

Although cognitive impairment is not a normal part of ageing, it is common in hospitalised older people.\(^1\)\(^,\)\(^2\) Dementia and delirium are common forms of cognitive impairment seen in these patients. Around 20 per cent of people more than 70 years of age who are admitted to hospital have dementia – and the rate increases with increasing age. Another 10 per cent of older patients are admitted with delirium and a further 8 per cent will develop delirium during their hospital stay.\(^2\)

Older people with cognitive impairment have deficits in one or more of the areas of memory, and have problems with communication, attention, thinking and judgement. These deficits place a person with cognitive impairment at increased risk of harm to their health, daily functioning and future wellbeing.

Older patients with cognitive impairment admitted to hospital are at a significantly increased risk of adverse outcomes and preventable complications.\(^3\)\(^-\)\(^5\) Compared with patients without cognitive impairment, they are more likely to:

- experience a fall resulting in harm\(^6\)
- experience significant functional decline\(^7\)
- develop complications such as pressure injuries, pneumonia and urinary tract infections\(^8\)\(^-\)\(^10\)
- have increased length of stay in hospital (16.5 days versus 8.9 days)\(^11\)
- require new residential care placement following their stay\(^12\)
- die; older patients with cognitive impairment are two to three times more likely to die\(^13\) while they are in hospital.

Delirium is also of significant concern. An older person with dementia has a five-fold increased risk of developing delirium while in hospital compared with those without dementia.\(^3\) Delirium may alter the clinical course and trajectory of cognitive decline, and is associated with poorer long-term outcomes in people who already have both physical and cognitive impairments.\(^3\)\(^,\)\(^5\) Patients with delirium superimposed on dementia have been shown to have a 25 per cent short-term mortality rate, increased length of stay, poorer function at discharge and greater functional decline after one month compared with those without delirium.\(^14\)

Many of these adverse outcomes and complications are preventable, and harm could be minimised if cognitive impairment is identified early and risks acted upon.\(^3\) Unfortunately, cognitive impairment is poorly recognised in Australian hospitals.\(^15\) An estimated 50 per cent of patients who have either delirium or dementia do not have cognitive impairment identified in hospital.

There is much more we can do to improve the steps taken to provide safe and high-quality care for these patients. Many of these steps are the subject of National Safety and Quality Health Service (NSQHS) Standards, which are designed to improve patient safety.

This resource aims to improve the care of older patients with cognitive impairment by ensuring that the innovative models of care occurring in many healthcare settings are implemented across the Australian acute health system. The strategies in this resource reflect evidence-based practice and incorporate existing models of care. This resource applies these strategies to the framework of the NSQHS Standards, which health services can implement to reduce the risk of harm and improve the quality of health care for patients with, or at risk of, cognitive impairment. The Australian Commission on Safety and Quality in Health Care (the Commission) will consider the best way to further support the adoption of strategies in this resource, including the development of a Clinical Care Standard.

Key point

Identifying the presence of cognitive impairment early is essential to manage the safety and quality risks, reduce harm and improve the healthcare outcomes for older patients during and after a hospital stay.
Purpose

This resource describes a pathway to improve the early recognition of, and response to, patients with cognitive impairment to reduce harm and ensure they receive safe and high-quality care in hospital. The steps in the pathway are consistent with the intent of the NSQHS Standards.

The resource has been designed for health service managers, executives and owners of health services who are responsible for achieving strategic change, and developing programs and projects to improve safety and quality.

Implementation of the pathway will contribute to creating a safe and caring culture that is aware of the needs of patients with cognitive impairment. It supports the organisation-wide implementation of safety and quality improvements for people with cognitive impairment, by enabling health services to:

- undertake a gap analysis of existing practice compared with evidence-based practice outlined in the resource
- identify strategies for improvement
- access resources and training opportunities to support the development of a skilled and informed workforce
- demonstrate compliance with the NSQHS Standards during accreditation by
  - putting processes in place to recognise and respond to patients with cognitive impairment as a high-risk patient group
  - providing examples of evidence that can be used to show compliance with the criteria and actions of the NSQHS Standards.

Two other complementary resources have been developed that describe the actions for clinicians and for consumers.

An earlier draft of this resource was the subject of an extensive national consultation with public and private sector providers, and people with cognitive impairment and their carers. This resource incorporates the feedback from the consultation.

In addition, Literature review: Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings accompanies this resource. The literature review provides the evidence supporting the strategies described in the resource.

Scope

Dementia and delirium are common forms of cognitive impairment seen in hospitalised older patients and are the primary focus of this resource. The rationale for this focus is:

- Patients aged 65 and over account for 45% of patient-days for all hospital stays.16
- The number of people with dementia is growing rapidly as the Australian population ages.
- People with dementia have a higher rate of hospital admissions than people without dementia.15
- Advancing age and pre-existing cognitive impairment are independently associated with a higher prevalence of delirium.17 Poor outcomes associated with both dementia and delirium are well documented (see above).
- Poor outcomes can be avoided and reduced through system re-design and by the way direct care is provided.

This resource has been designed to be viewed electronically. The electronic resource provides links to external web sites and will be updated as required.
Other health conditions related to cognitive impairment

This resource focuses on older people with cognitive impairment. However, a number of groups of younger people may also have cognitive impairment. For example, although dementia is predominantly a disorder related to age, it can affect people younger than 65 years old – this is known as younger onset dementia. People with Down syndrome have a higher prevalence of Alzheimer’s disease, which occurs at a much younger age than in the general population. Dementia may also be more common in people with developmental disabilities who do not have Down syndrome.18

The Commission also recognises that cognitive impairment is present in a number of other conditions. One of these is depression, which is also common in hospitalised older patients. As some symptoms are similar across delirium, dementia and depression, there are useful charts available to compare and distinguish features – for example, in the cognition section of Best care for older people everywhere: the toolkit. In addition, people may be cognitively impaired due to drug use or mental health issues, including schizophrenia or bipolar disorder. These conditions should be considered when investigating causes of cognitive impairment and appropriate referrals made if they are detected.

Although not the focus of this resource, people with other conditions associated with cognitive impairment, such as acquired brain injury and intellectual disability, are likely to benefit from a number of the resource's actions and strategies.18 Some states and territories have specific policies and resources to assist with the provision of appropriate hospital care for these population groups.19

Integrated health care

This resource has been developed to apply across the diverse range of hospital facilities that exist in Australia, from major tertiary teaching hospitals to small rural multipurpose services. Although the resource focuses on the acute and subacute care settings, it is recognised that people with cognitive impairment are also managed in primary, community and residential care. For the best possible outcomes for patients, these services need to be seamlessly linked. The resource therefore includes strategies aimed at transitions in care. These address information exchange and communication between hospitals and general practice, primary care, aged community care and residential care.

Responding to diversity

It is intended that the actions and strategies suggested in this resource are adapted and implemented locally to reflect available resources, and in a way that is sensitive to the diversity of cultural, economic and social backgrounds of the populations that are served. Providing individualised, tailored care enables healthcare organisations to respond appropriately to both clinical and cultural needs of patients, carers and families.20 Clinicians need to be supported to develop cultural competency so that they are can work effectively in cross-cultural situations.21 It is also important that clinicians are aware of the increased risk for Aboriginal and Torres Strait Islander peoples – whose prevalence of dementia is approximately three times higher than the general Australian rate.22,23

The pathway and mechanisms

This resource describes the safety and quality pathway for patients with cognitive impairment (dementia and delirium) in hospital, and the safety and quality mechanisms needed to implement the pathway within the framework of the NSQHS Standards.

The pathway

The safety and quality pathway for patients with cognitive impairment (dementia and delirium) in hospital involves three key steps. The text below and Figure 1 provide a summary of the key actions and steps to be taken to provide safe and high-quality care.

Health service managers can reduce the risk of harm and improve the quality of care for patients with, or at risk of, cognitive impairment by introducing the steps of the pathway into their organisation.
For all patients, who, on presentation, meet one or more of the following criteria:

- age 65 and over
- known cognitive impairment/dementia
- severe illness/risk of dying
- hip fracture
- cognitive concerns raised by others

Obtain history and/or information of any recent assessments from:
- the patient, carer and family
- other informants such as general practitioners, residential care and/or community care providers

Screen for cognitive impairment using a quick, validated tool

Identify risk factors for harm from:
- falling (screen)
- pressure injury (screen)
- medicines
- under-nutrition
- dehydration
- communication difficulties
- treatment unwanted by patient

Delirium diagnosis (if uncertain, continue as delirium)

Possible other cognitive impairment (refer, if required)

Delirium not identified

Assess for delirium

Changes identified

No changes identified

Risk(s) identified

Develop an individualised, integrated prevention and management plan, including goals of care, in partnership with patient, carer and family

Communicate to healthcare team

Implement an individualised, integrated prevention and management plan, in partnership with patient, carer and family

Provide individualised care

Prevent and/or manage delirium

Prevent and/or minimise harm

Manage medical issues

Respond to behavioural changes

Modify the environment

Safe and caring culture for patients with cognitive impairment

Figure 1: Safety and quality pathway for patients with cognitive impairment (dementia and delirium) in hospital
Clinicians are alert to delirium and the risk of harm from cognitive impairment among patients who:
- are aged 65 and over
- have a known cognitive impairment or a formal diagnosis of dementia
- have a severe illness or are at risk of dying
- have a hip fracture.
Clinicians are also alert when the patient, carer, family and/or other key informants raise concerns.
A patient with cognitive impairment is supported to understand and participate in healthcare decisions. Their informed consent is obtained. If the patient is assessed as unable to provide consent, their substitute decision-maker is consulted.

Be alert to delirium and the risk of harm for patients with cognitive impairment

1 Be alert to delirium and the risk of harm for patients with cognitive impairment

- A patient identified as being at risk is screened for cognitive impairment. The patient’s history is obtained from the patient, carer, family and/or other key informants. A patient’s risk of harm from falls, pressure injuries, medicines, under-nutrition, dehydration, communication difficulties or unwanted treatment is identified.
- A patient with cognitive impairment is assessed for delirium. If delirium is present, causes are investigated and treated. If uncertain, the patient’s condition is treated as delirium.
- Any change in a patient’s behaviour, or physical or mental condition is acted upon. If changes are observed, the patient is re-assessed for delirium and other risk factors.
- A comprehensive assessment of the patient is undertaken. If dementia is suspected and a comprehensive diagnostic process is not appropriate, the patient is referred for further assessment and follow-up.
- An individualised, integrated prevention and management plan is developed in partnership with the patient, carer and family, and communicated to the healthcare team.

2 Recognise and respond to patients with cognitive impairment

- The patient’s individualised, integrated prevention and management plan is implemented as follows:
  - The patient receives individualised care in partnership with the patient, carer and family.
  - The patient’s medical issues are managed, including treating the underlying causes of delirium, presenting condition and any co-morbidities.
  - A patient with, or at risk of developing, delirium has strategies implemented to prevent delirium from occurring or to limit its duration.
  - A patient with identified safety risk factors has strategies implemented to prevent and manage the risks.
  - A patient with behavioural changes is appropriately assessed and strategies are introduced to reduce distress. Antipsychotic medication is avoided unless non-pharmacological interventions have been ineffective, the patient is severely distressed and/or the patient is at immediate risk of harm to themselves or others.
  - The hospital environment is modified to provide safe and supportive patient care.
  - The patient’s healthcare information and management plan are documented and communicated to the patient, carer and all relevant healthcare providers in a timely manner and in sufficient detail, on transition from hospital to the community.

3 Provide safe and high-quality care tailored to the patient’s needs
**Safety and quality mechanisms**

The safety and quality mechanisms describe the three essential organisational systems that are required to support the implementation of the pathway. These mechanisms support the pathway in the following way:

**Mechanism 1  Establish responsive systems.**
A responsive system is well organised, integrated and administered to achieve safe and high-quality health care for patients with cognitive impairment. Organisations can track improvements in the safety and quality of care for these patients by collecting and reporting on data coming from putting the resource’s key strategies into action.

**Mechanism 2  Ensure a skilled and informed workforce.**
Safe and high-quality care is dependent on a workforce with the right knowledge, skills and attitudes. The whole hospital workforce has a role in providing care and creating a patient-centred culture. This requires continual targeted education, information and training for all levels of staff.

**Mechanism 3  Enable partnerships between clinicians, patients, carers and families.**
Care should be respectful of, and responsive to, the preferences, needs and values of patients with cognitive impairment, and their carers and families. Where there are communication difficulties, carers are a vital resource in enabling healthcare professionals to put patient-centred care into practice. Carers can provide a patient’s history and current care needs to guide understanding, diagnosis and treatment (including putting prevention and management plans into action), and can alert clinicians to changes to the patient’s condition, if the patient is unable to do so.8
Structure and use of the resource

The resource is structured in the following way and contains information about:

- **Key steps of the pathway** (one chapter for each step):
  - overview of each strategy of the pathway and context
  - safety and quality issues, and rationale for action
  - evidence-based practice.

Throughout the resource, each step is colour coded in the following way:

- **Step 1 Be alert to delirium and the risk of harm for patients with cognitive impairment**
- **Step 2 Recognise and respond to patients with cognitive impairment**
- **Step 3 Provide safe and high-quality care tailored to the patient’s needs**

- **Mechanisms:**
  - what health service managers can do to make improvements happen
  - link to the NSQHS Standards
  - examples of evidence that could be used at accreditation
  - results of implementation for patients, carers, clinicians and health service managers
  - real patient stories describing safety and quality issues faced by patients with cognitive impairment; each patient story includes examples of what went wrong, what went well and what could have been done better.

- **Resources** to assist health service managers to achieve each mechanism, with hyperlinks to each resource. Note that resources listed in one step or mechanism can also be applicable in others. For example, resources about cognitive screening found in Step 2, Mechanism 1: ‘Establish responsive systems’, are also applicable in Mechanism 3: ‘Enable partnerships between clinicians, patients, carers and families’.

- **Appendix 1: Cognitive impairment safety and quality matrix** – The matrix summarises all of the actions that health service managers can undertake within the three mechanisms, and how these strategies and actions link to the NSQHS Standards.
## Results of implementing the pathway

### What does implementing the safety and quality pathway for patients with cognitive impairment (dementia and delirium) in hospital mean to the:

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<th>Role</th>
<th>Description</th>
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<tr>
<td><strong>Patient with cognitive impairment</strong></td>
<td>When I go to hospital, my cognitive impairment is recognised and responded to. My management plan is tailored to my needs and is delivered in a way that protects my dignity. My care is provided in a safe, supportive and culturally appropriate environment.</td>
</tr>
<tr>
<td><strong>Carer</strong></td>
<td>I am supported and recognised as an active participant when decisions are made about possible causes of cognitive impairment and the management plan for the person I care for. I am encouraged to be an active partner in care.</td>
</tr>
<tr>
<td><strong>Whole of hospital workforce</strong></td>
<td>I am aware of cognitive impairment and can respond to patients’ additional communication, orientation and support needs. I understand the safety and quality risks for patients with cognitive impairment and I know I can act to make a positive difference to patient outcomes. The system supports me to provide the right care to patients with cognitive impairment.</td>
</tr>
<tr>
<td><strong>Health service manager</strong></td>
<td>I ensure that systems and resources are in place to recognise, communicate and respond to the needs of patients with cognitive impairment, their carers and clinicians, to improve patient outcomes and their experience of care. I ensure that the facility is designed to support the needs of patients with cognitive impairment.</td>
</tr>
</tbody>
</table>
| **Health system**                   | Mechanisms are in place to:  
  - include cognitive impairment in safety and quality programs  
  - convey to clinicians and healthcare staff the importance of recognising and responding to cognitive impairment, treating patients with dignity and partnering with carers and families  
  - support the delivery of high-quality care to patients with cognitive impairment  
  - promote the use of hospital substitution and community-based services for patients with cognitive impairment, and their carers and families, where appropriate  
  - improve the safety and quality of care for patients with cognitive impairment by ongoing monitoring, evaluation and change processes  
  - use nationally consistent coding systems for patients with cognitive impairment  
  - record and monitor the incidence and prevalence of patients with cognitive impairment. |
Introduction

Step 1 of the pathway aims to create an organisation and workforce that is alert to the risk of delirium and harm for patients with cognitive impairment. Having an understanding of dementia and delirium, which patients are at risk, and what to be concerned about, is the first step in being able to effectively recognise and respond to cognitive impairment. This requires a whole-of-hospital awareness program.

Dementia and delirium

Delirium is a potent and well-recognised indicator of [poor] healthcare quality … addressing delirium provides a highly practical and effective strategy to improve outcomes, decrease costs and raise the quality of health care system wide. Inouye, 2014

Dementia and delirium are common forms of cognitive impairment seen in hospitalised older patients.

Dementia is a progressive, usually gradual and irreversible decline in cognitive functioning, with Alzheimer’s disease being the most common type. In 2011, nine per cent of Australians aged 65 and over had dementia, rising to 30 per cent among those aged 85 and over.24

Delirium is an acute disturbance of consciousness, attention, cognition and perception that tends to fluctuate during the course of the day. It is potentially preventable and reversible. It is common in vulnerable older patients exposed to hospital-related events and the prevalence increases with age.

There is a complex interplay between dementia and delirium. People with dementia are at increased risk of developing delirium (five-fold increased risk) and, conversely, delirium increases the risk of developing dementia. Delirium is often dismissed and misdiagnosed as dementia. Both conditions are important and both carry increased risk of harm.

Delirium can have lasting, serious consequences. Poor outcomes for patients with delirium include increased cognitive and functional decline, hospital-acquired complications such as falls and pressure injuries, longer length of stay, increased risk of entry into residential care, and death. Mortality rates are high, ranging from 22 per cent to 76 per cent.4 Mortality increases by 11 per cent for every additional 48 hours of active delirium17 and failure to detect delirium in the emergency department (ED) is associated with increased mortality following discharge.25

Although delirium is common in hospitalised older patients, the rate of prevalence varies across different populations. For example, rates of delirium in older people after orthopaedic surgery are reported to be up to 53 per cent26, after cardiac surgery up to 41 per cent27 and, within an intensive care environment, prevalence rates range from 16 per cent to 89 per cent28. A recent large study has confirmed that patients in medical and surgical intensive care units are at high risk of long-term cognitive impairment following their survival from a critical illness.29

Safety and quality issues and rationale for action

Cognitive impairment is associated with increased risk of complications, and adverse outcomes in hospital and following discharge.

Cognition affects someone’s ability to remember, communicate relevant information, make decisions and function independently.30,31 Difficulties with memory, information, communication, comprehension, attention, thinking and judgement will affect a patient’s capacity to function in a hospital environment and place them at increased risk of harm.
Key point

Examples of difficulties that patients with cognitive impairment may have in hospital

A patient with cognitive impairment may have difficulties relaying information, including history of symptoms and medical history, pain or discomfort.

A patient with cognitive impairment who cannot communicate thirst and needs to be prompted to drink may become dehydrated while waiting in the ED, contributing to the development of delirium.

Patients with cognitive impairment may not be able to manage lids on containers at mealtimes and leave their food untouched.

A patient with cognitive impairment may not be able to communicate the need to go to the toilet or not be able to locate it, and become increasingly uncomfortable and distressed as a result.

The unfamiliar, noisy hospital environment can be disorientating for a patient with cognitive impairment. They may misplace their glasses or hearing aids. Any communication difficulties can add to their distress and the combination can quickly trigger behavioural disturbance.

A patient with cognitive impairment may not be able to provide informed consent and to actively participate in their own care. They may have difficulty following instructions and finding their way.

Evidence-based practice

Being aware

You must be careful not to make assumptions about behaviour and say ‘it’s just their dementia’. That stops any further investigation into a patient’s condition. Often there is an overlay of delirium and it goes unnoticed and untreated.

Despite increasing prevalence rates, cognitive impairment in older patients is poorly recognised or thought not to be clinically relevant. Cognitive impairment may be wrongly dismissed as a normal part of ageing or assumed to be a person’s usual state. This perception and lack of action affects care and increases the risk of adverse outcomes.

The hospital workforce needs to be aware that, although cognitive impairment is common in hospital settings, there is an increased risk of harm, and should always prompt further action. They also need to be aware that some patients are at greater risk of developing delirium during their hospital stay. Any changes in these patients’ condition should also prompt further action. Awareness can dispel the belief that ‘nothing can be done’ and increase the workforce’s efforts to prevent delirium from developing.

Being alert to patients at risk of delirium and of harm from existing cognitive impairment should prompt detection, assessment and action as early as possible. This enables effective strategies to be implemented before or at the same time as the cause of the cognitive impairment is being determined.

Awareness training needs to be accessible to both the clinical and relevant nonclinical workforce, such as those in hotel services and transport. The workforce needs to know that the way they provide care to patients with cognitive impairment can make a difference to patient outcomes. Increased knowledge, improved confidence and job satisfaction can improve the way clinicians communicate with patients.
Identifying risk factors for delirium

It is crucial that delirium is distinguished from dementia so that the underlying causes are investigated and treated. Often, a patient's cognitive impairment and/or behaviours are attributed to 'existing dementia' without investigating the causes. Any sudden or recent change in cognition, behaviour or health status should trigger investigation and further assessment. Delirium may be the only sign of a serious illness in an older person. When it is difficult to distinguish between dementia and delirium, guidelines suggest that clinicians should treat the patient as having delirium.

Patients at risk of delirium can be those who have predisposing factors on admission (see below) and those who have precipitating factors during hospitalisation (see ‘Preventing delirium’).

Clinicians need to be alert to all patients on presentation to hospital who:

- are aged 65 and over
- have a known cognitive impairment or a formal diagnosis of dementia
- have a severe illness or are at risk of dying
- have a hip fracture.

Other predisposing factors (or vulnerabilities) at admission include functional, visual or hearing impairment; depression; co-morbidities such as stroke or depression; and history of alcohol abuse.

Clinicians also need to be alert where concerns are raised by:

- the clinician’s own observations (e.g. the patient cannot answer questions, is easily distracted, agitated or overly sleepy)
- an informant, such as a carer, family member or friend accompanying the patient, or the ambulance driver
- documentation from the general practitioner, or residential or community care provider
- previous records that mention dementia, delirium or confusion, or previous assessments for these conditions.

Preventing delirium

Delirium is a potentially reversible condition, even when superimposed on dementia. Early detection and treatment can reduce poor outcomes and reduce the burden placed on carers when patients are discharged. Patients with persistent delirium have consistently worse outcomes than patients who recover from delirium.

Delirium is easier to prevent than treat. International research from a diverse range of settings shows that delirium is preventable in 30–40 per cent of cases, when multicomponent non-pharmacological interventions are successfully implemented. These interventions include reorientation, therapeutic activities, reduction in psychoactive drugs, early mobilisation, adequate hydration and nutrition, and provision of hearing and visual aids. These interventions also represent good patient-centred care.

Incidence rates of delirium in hospital are suggested to be an indicator of poor care management. Delirium is a multifactorial condition that results from a complex interplay between underlying risk factors in vulnerable patients and hospital-related events. For example, someone with multiple underlying risk factors such as existing dementia, taking multiple medications and with sensory impairments, may develop delirium by simply being given a sedative to assist sleep. However, although delirium is often multifactorial, it may be the only sign of a serious illness in an older person and should be urgently assessed.

Precipitating factors for delirium include:

- polypharmacy, and adding more than three medications during the hospital stay
- use of psychotropic medications
- use of physical restraint
- presence of in-dwelling catheters
- recent surgery
- under-nutrition and dehydration.

Clinicians need to be alert to the role of medicines in causing delirium directly through toxicity or indirectly through interactions, or by inducing abnormalities that precipitate delirium such as electrolyte imbalance. Older people presenting to hospital may be on anticholinergic and psychotropic medications.
Having the right attitude

Labels such as ‘acopia’, ‘social admission’, ‘bed-blocker’ are inappropriate, unprofessional and singularly unhelpful to patient care

David Oliver 2008

Feedback provided to the Commission noted concern about perceived negative attitudes towards older people, and a lack of respect and basic nursing care for patients with cognitive impairment. Patients with cognitive impairment can be perceived as:

• not fitting in with the hospital’s measured priorities
• requiring care that is too complex
• being cases for which nothing can be done.

Negative language and attitudes from healthcare staff can affect their behaviour, and lead to dismissing a patient’s cognitive impairment and not undertaking further investigations.

Understanding capacity and consent

It is a basic legal presumption that every adult can make their own healthcare decisions and/or consent to treatment. However, not all patients have that capacity. Clinicians have a legal and professional responsibility to obtain informed consent before treating any person and should satisfy themselves of their patients’ capacity to provide this consent and make healthcare decisions. Where a clinician believes that a patient’s capacity is in question, it is the clinician’s responsibility to give careful and detailed consideration to whether their patient has capacity, commensurate with the gravity of the decision to be made, to make a decision to accept or refuse treatment. Correctly identifying whether an individual has such capacity is fundamental to the protection of their human rights. An incorrect assessment raises safety and quality risks. For patients, it may adversely affect their self-esteem and dignity, deny their right to self-determination or leave them at risk of harm. For clinicians, they may have to explain their capacity assessment decision to a patient’s family or even a healthcare complaints commission.

Just because you have cognitive impairment doesn’t mean that you don’t know what is going on. A patient with cognitive impairment should not be treated for all purposes as having no decision-making capacity.

Registered nurse, regional hospital, Western Australia
Determining patients’ capacity

In most cases, patients give consent to treatment themselves. The most obvious exception to this principle is where a guardianship order or legal document exists, giving decision-making power to somebody else. If there is a question about patients’ medical decision-making capacity, health professionals should conduct or arrange a capacity assessment. In some cases, it will only become apparent on closer examination that a person’s capacity is impaired. Many people with cognitive difficulties may appear cognitively intact to people who do not know them well.

From a legal perspective, the question of capacity is a question of fact. It involves examining whether the patient can comprehend the information necessary to make an informed decision in relation to their health care. Whether a patient has capacity to make a health decision depends on the type of decision involved and the type of cognitive difficulty the patient has. The test for capacity means that a person may have the capacity to make some decisions, such as whether to make small purchases like groceries, but may lack capacity to make other decisions, such as whether to enter into complicated financial arrangements or consent to medical treatment.

Broadly speaking, when a person has capacity to make a particular decision, they are able to do all of the following:

• understand the facts involved
• understand the main choices
• weigh up the consequences of the choices
• understand how the consequences affect them
• communicate their decision.

If patients have difficulty in demonstrating this level of capacity in relation to understanding and making decisions about their medical treatment, this warrants further exploration by clinicians. Clinicians must ascertain if the difficulty is due to cognitive impairment or due to other reasons (e.g. health literacy, cultural differences, education levels or physical issues such as hearing impairment). Clinicians need to present health information in ways that overcome these barriers.

Before clinicians begin an assessment of capacity, they should inform patients about what they are doing and explain why. The aim is to get patients to participate willingly in the process. In addition, clinicians conducting assessments should be flexible and
For example, section 36 of the Guardianship Act 1987 (NSW) makes provision for substitute consent for medical treatment if an adult (over 16 years of age) is incapable of consenting to that treatment. Similarly, section 39 of the Guardianship and Administration Act 1986 (Vic) provides for substituted consent for medical treatment if a person is over 18 years in age and is incapable of consenting to that treatment.

adaptable to the individual’s needs and preferences, and understand that people are individuals, come from diverse cultural and linguistic backgrounds and have different education and skill levels.

Where the patient has not made provision for somebody else to make the health decisions on their behalf, or there is no order of a tribunal or court to the same effect, then the following principles should be followed whenever a patient’s capacity is being considered:41

- Always presume a person has capacity: Under common law, adults are presumed to have the capacity to make all their own decisions.
- Don’t make assumptions that a person lacks capacity because of their age, appearance, disability, education level or behaviour: A person’s capacity should be assessed on their decision-making abilities.
- Assess a person’s decision-making ability – not the decision they make: A person cannot be assessed as lacking capacity merely because a decision may appear to others as being unwise, reckless or wrong. However, a decision that appears to be inconsistent with the person’s best interests may indicate that further consideration needs to be given to their capacity to make that decision.
- Capacity is decision specific: Apply the presumption of capacity to every decision. If a person can make some but not all decisions, then they have a right to make as many decisions as possible.
- Capacity is fluid: A person’s capacity can fluctuate over time or in different situations, so whenever there is doubt about a person’s capacity, their capacity should be assessed for each decision.
- Respect a person’s privacy: In most cases, individuals must give their prior consent to personal information being collected about them or provided to others. Personal information should only be used for purposes relevant to the capacity assessment.
- Substitute decision-making is a last resort: Before lack of capacity is determined, everything possible should be done to support individuals to make their own decisions. When a person is assessed as not having capacity, follow the guardianship legislation in your jurisdiction to consult their substitute decision-maker or the relevant authorityb.

Helpful hint

The way in which questions are put to patients can affect their answers. Clinicians therefore need to take care to ensure their questions fully assess the patient’s ability to understand what is being discussed and how it affects them and their interests. When asking questions:

- Ask open-ended questions rather than questions that can be answered by ‘Yes’ or ‘No’, such as ‘What sort of decisions will your guardian be able to make for you?’
- Do not ask leading questions that suggest the answer, such as ‘You probably would rather have someone in your family look after this decision than a public official, wouldn’t you?’
- Frame your questions to quickly identify any areas of concern for which a person may need support or help, or require a substitute decision-maker, such as ‘Will anyone else be affected by this decision? Who? Tell me about some of the important consequences of this decision’.
- It is important to ensure it is the person being assessed who answers the questions. In some circumstances, the person may need support from a neutral person such as an advocate or an interpreter.

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a For example, section 36 of the Guardianship Act 1987 (NSW) makes provision for substitute consent for medical treatment if an adult (over 16 years of age) is incapable of consenting to that treatment. Similarly, section 39 of the Guardianship and Administration Act 1986 (Vic) provides for substituted consent for medical treatment if a person is over 18 years in age and is incapable of consenting to that treatment.

b Guardianship and Management of Property Act 1991 (ACT); Guardianship Act 1987 (NSW); Advanced Personal Planning Act 2013 (NT); Guardianship and Administration Act 2000 (Qld); Guardianship and Administration Act 1993 (SA); Guardianship and Administration Act 1995 (Tas); Guardianship and Administration Act 1986 (Vic); Guardianship and Administration Act 1990 (WA).
Step 1  Be alert to delirium and the risk of harm for patients with cognitive impairment.
Working with substitute decision-makers

Where a person has created a legal document empowering another person to make medical decisions on their behalf, such as power of attorney, or where an order exists, such as a guardianship order, a practitioner must work with the substitute decision-maker, or makers. However, this does not mean that the person about whom the document or order is made cannot make other types of decisions.

If a person lacks the capacity to make a healthcare decision and treatment is not urgent, clinicians must seek consent from a substitute decision-maker. (In an emergency, consent is not necessary if urgent treatment is required to save the person’s life or to prevent serious damage to the person’s health.)

A substitute decision-maker may be:

- chosen by a person (e.g. in a document recognised either in legislation or the common law)
- assigned to a person by the law in the absence of an appointed substitute decision-maker (e.g. family member or carer)
- appointed for a person (e.g. a guardian appointed by a tribunal or court).

Each state and territory has an Act to deal with substitute decision-making and administrators and practitioners should familiarise themselves with the relevant law. The state and territory laws, and the terminology used to describe common concepts that govern the documentation of advance care directives and the appointment of substitute decision-makers vary.

For example, substitute decision-makers can be given responsibilities under an ‘enduring power of guardianship’, an ‘enduring power of attorney for health and personal decisions’ or a ‘medical power of attorney’.

The hierarchy of substitute decision-makers also varies under the different state and territory laws. Health administrators and practitioners should familiarise themselves with the relevant hierarchy in their state or territory. The State and Territory Planning Tools tab on the Start2talk web site summarises the position in each state and territory. Generally, the hierarchy for seeking consent is:

1. the substitute decision-maker appointed by the person in writing, or by a court or tribunal
2. the spouse of the person
3. a person who has the unpaid care of the person
4. a close friend or relative of the person
5. an appropriate court or tribunal.

Applications to courts or tribunals should be pursued as a last resort when all other options have been explored. Situations in which this may be necessary include when:

- there is no-one available to make substitute decisions informally
- the person has not put legal arrangements in place to appoint someone to make decisions for them when they lack capacity
- there is a disagreement or problem preventing a decision from being made.

If a court or a tribunal finds that a person does not have the capacity to make particular decisions and appoints a substitute decision-maker for some decisions, this does not automatically mean that the person does not have the capacity to make other types of decisions.

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c States and territories have different legislation and policies dealing with this situation (e.g. see section 13 of the Consent to Medical Treatment and Palliative Care Act 1995 (SA), and the New South Wales Policy Directive. Consent to medical treatment – patient information (PD2005-406).

d See footnote b

e Advance care directives in Australian legislation in a national framework for advance care directives and the Start2Talk web site.
What can health service managers do to make improvement happen?

Implementing systems
- Establish mechanisms for alerting the workforce to patients at risk of harm due to cognitive impairment.
- Establish systems to document informed consent and substitute decision-maker.

Monitoring and reporting
- Establish a risk register to record the implementation of changes and actions to reduce harm.

System improvements
- Take action to reduce safety risks and improve the quality of care for patients at risk of harm due to cognitive impairment.
Implementing systems
✓ Establish and implement systems to enable the workforce to be alert to the risk of delirium and harm
  NSQHS Standards action: 1.8.1

Monitoring and reporting
✓ Monitor and report on the systems to enable the workforce to be alert to the risk of delirium and harm
  NSQHS Standards actions: 1.5.1, 1.6.1

System improvements
✓ Ensure ongoing improvement of the systems that support the workforce to be alert to the risk of delirium and harm
  NSQHS Standards actions: 1.5.2, 1.6.2

Examples of evidence you can use at accreditation
- Policies, procedures and protocols available to guide the workforce in being alert to patients at increased risk of harm and delirium
- Risk register that includes actions to address identified risks
- Relevant documentation from committees and meetings that details data analysis, improvement and actions taken
- Analysis of patient experience surveys and identification of organisational responses to issues
Mechanism 2
Ensure a skilled and informed workforce

What can health service managers do to make improvement happen?

Workforce education and training

- Provide training opportunities and resources to the workforce to enable them to be alert to the risk of delirium and the risk of harm with existing cognitive impairment.
- Provide access to training opportunities and resources to the workforce to enable them to understand capacity, informed consent and substitute decision-making.
- Ensure that the workforce is aware of their roles and responsibilities.
Workforce education and training

- Provide staff education and training
  NSQHS Standards actions: 1.3.1, 1.3.3, 1.4.1, 1.4.3, 1.12.1

Examples of evidence you can use at accreditation

- Education resources and records of attendance by clinicians and other workforce at training related to cognitive impairment
- Induction checklist and orientation program for the workforce, including locum and agency, that address systems for alertness to risk of delirium and harm from existing cognitive impairment
- Feedback from the workforce regarding the training needs in this area
- Policies, procedures and protocols on training requirements for the organisation
Mechanism 3
Enable partnerships between clinicians, patients, carers and families

- Provide patients and carers with information on delirium and risks of harm from existing cognitive impairment that is easy to understand, use and apply so that they can take part in discussion and decisions about preventing harm.
- Provide patients and carers with health information that can be understood, used and applied.
- Provide patients and carers with information on informed consent and substitute decision-making.
Information for patients and carers

☑️ Enable patient and carer partnerships through the provision of information

NSQHS Standards actions: 1.17.1, 1.17.2, 1.17.3, 1.18.3

Examples of evidence you can use at accreditation

☐ Evidence that the charter of healthcare rights is displayed in areas accessible to the public

☐ A register of advocacy and support services available to the workforce, patients and carers

☐ Policies, procedures and protocols regarding the implementation and use of a charter of patient’s rights

☐ Patient clinical records that reflect assessment of need and support provided

☐ Patient information resources evaluated by consumers
## What does being alert to delirium and risk of harm for patients with cognitive impairment mean to:

| Patients with cognitive impairment | I am supported to understand my risk of developing delirium and other risks of harm, and to alert staff if I have concerns, to the extent of my cognitive ability.  
|                                  | I am supported to understand and participate in all decisions and discussions about my care to the extent that I am capable. |

| Carers | I am asked if I have any concerns about the person I am caring for in terms of their cognition and any cognitive impairment they may be experiencing.  
|        | The risk of developing delirium and/or risks of cognitive impairment are explained to me.  
|        | I am asked about the level of involvement I am comfortable with. |

| Whole of hospital workforce | I understand that cognitive impairment is not a normal part of ageing, but is common in hospitalised older patients.  
|                            | I am alert to patients at risk of delirium and of harm from cognitive impairment.  
|                            | I am aware that patients with cognitive impairment may need additional assistance. |

| Clinicians | In addition to the above, I also understand my responsibilities regarding informed consent and substitute decision-making. |

| Health service managers | I ensure that mechanisms are in place to alert the workforce to patients at risk of harm due to cognitive impairment.  
|                         | I ensure that systems are in place to document informed consent and substitute decision-makers.  
|                         | I establish a risk register to record the implementation of changes and actions to reduce harm.  
|                         | I take action to reduce safety risks and improve the quality of care for patients at risk of harm due to cognitive impairment. |
Mrs A is aged 80 years and presented unaccompanied via ambulance to the emergency department (ED) after being found in a garden with a large laceration to her forehead. Handover from the ambulance officer suggested that she had some ‘confusion’.

She informed the clinicians that she couldn’t remember the fall. She told them that she lived alone and did her own cooking, shopping and personal care. She appeared somewhat unkempt in appearance but clinicians put that down to her working in the garden. She was unable to provide clinicians with contact details of her daughter, whom she said ‘lives a long way away’. She remembered that she has a ‘normal doctor’ but could not remember the name. She informed clinicians that the doctor’s name was probably in her handbag and gave permission for them to have a look.

The ED doctor discovered that her medicines were in her handbag and included aspirin and amlodipine. The prescribing general practitioner (GP) was contacted and informed clinicians that Mrs A was a widow and appeared well except for some hypertension; however, she hadn’t seen her for many months.

The GP stated that because of Mrs A’s age, she was offered a 75-plus assessment, with a view to potentially providing her with some home-care assistance, but Mrs A refused because she didn’t want other people in her home. Mrs A’s daughter’s contact details were obtained from the GP.

On examination, Mrs A had a significant symptomatic postural hypotension and dehydration, which responded to intravenous fluids. The doctor documented that she had ‘no confusion now’. Her daughter was advised by the ED doctor that she was being admitted to the hospital to ‘keep an eye on her suspected head injury and blood pressure’.

Following suturing of her wound, Mrs A was admitted for overnight head injury and blood pressure observations. A scheduled computerised tomography (CT scan) needed to be delayed to the following evening and, therefore, she was kept in hospital another night. No cognitive assessments were undertaken.

During the following day, nurses documented that she was ‘not quite right’ and displayed some ‘confusion’. Consequently, her head injury observations were continued. On the second night, she kept calling out and couldn’t remember how to use the buzzer.

She continued to get ‘distressed’. She climbed out of bed to go to the toilet but fell over and sustained a hip fracture.
**What did not go well?**

- No cognitive screening.
- Because cognitive impairment was not recognised, the baseline history may be inaccurate. For example, her self-reported pre-admission activities of daily living (ADL) ability may have been inaccurate.
- Previous ‘confusion’ may have been an indicator of cognitive impairment (acute or longstanding) rather than a possible head injury.
- An underlying delirium may have been missed and consequently the underlying health problem not investigated and treated.
- No response to documented deterioration.
- No response to Mrs A’s increasing distress, or ‘calling out’ due to ‘not remembering how to use the buzzer’. Mrs A may have been becoming more distressed because she wanted to go to the toilet.

**What went well?**

- ED staff alerted to ‘confusion’ by ambulance officer.
- Prescribing GP contacted.
- Daughter contacted and informed of mother’s hospitalisation.
- Appropriate management of primary presenting problems.

**What could have been done better?**

- Recognising cognitive impairment earlier because policies and procedures for cognitive impairment recognition were in place and clinicians were trained and informed of their use.
- Investigating cognitive impairment further because clinicians were alert to the risk of delirium, and there were recognition and response triggers in place.
- Engaging daughter in providing a history, including medicines.
- Providing better nursing supervision of care and patient comfort.
Mechanism 1

Establish responsive systems

Note that resources in other steps and mechanisms may also be useful in achieving Step 1.

Dementia, delirium and risks of harm

- Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings: a rapid review, published by the Commission, provides a summary of 31 publications relating to the safety and quality issues faced by people with cognitive impairment in acute hospitals.
- Delirium in elderly people, published in The Lancet by Inouye SK, Westendorp RG and Saczynski JS, provides a comprehensive review of delirium, including epidemiology, predisposing and precipitating factors, diagnosis, outcomes, prevention and interventions.

Capacity, substitute decision-making and planning ahead

National

- Advance Care Planning Australia, from the Respecting Patient Choices Program, is aimed at consumers and health professionals, and includes links to each jurisdiction, as well as information about training and how to create a care plan.
- Start2talk, developed by Alzheimer's Australia and its partners, aims to help all Australians to start the conversations involved in planning ahead. It includes resources for healthcare professionals.
- Planning for the end of life for people with dementia, developed by Professor Colleen Cartwright for Alzheimer's Australia, details the current and possible future options for people with dementia planning end-of-life care.

Australian Capital Territory

- Guardianship and Management of Property Act 1991 (ACT) is the Australian Capital Territory legislation relevant to substitute decision-making.
- The Public Advocate of the ACT provides information on guardianship and the enduring power of attorney.

New South Wales

- Capacity toolkit: information for government and community workers, professionals, families and carers in New South Wales, published by the Attorney General's Department of New South Wales, is a guide to assessing a person's capacity to make legal, medical, financial and personal decisions.
- Get it in black and white: planning ahead tools, from the NSW Government, contains information, tools and resources to enable individuals to communicate their wishes and plan for the future by completing wills, powers of attorney, enduring guardianship and advance care plans. It has sections for individuals, families, carers, legal professionals, health professionals and service providers.
- A plan of care: a book to help people in New South Wales make health and personal care decisions on behalf of a person with dementia, published by the Advanced Care Directive Association, is for family members and carers who have to make decisions about the medical and personal care of people who have lost capacity.
• Capacity toolkit factsheet\textsuperscript{xi}, provided by NSW Government Lawlink, is a summary of facts and options for consumers.

• Guardianship Act 1987 (NSW)\textsuperscript{xii} is the New South Wales legislation relevant to substitute decision-making.

Northern Territory

• Advance Personal Planning Bill 2013 (NT)\textsuperscript{xiv} is the Northern Territory legislation relevant to substitute decision-making.

• The Northern Territory’s Department of the Attorney-General and Justice\textsuperscript{xv} provides information on advance personal planning, including the Advance Personal Plan and application to register.

Queensland

• Making health care decisions for others\textsuperscript{xvi}, published by the Queensland Government, provides information on how and when decisions can be made by healthcare decision-makers.

• Guide to informed decision-making in healthcare\textsuperscript{xvii}, produced by the Patient Safety and Quality Improvement Service of Queensland Health, aims to help practitioners understand the ethical and legal requirements of informed decision-making about health care.

• Guardianship and Administration Act 2000 (Qld)\textsuperscript{xviii} is the Queensland legislation relevant to substitute decision-making.

South Australia

• Office of the Public Advocate\textsuperscript{xix} has information about planning ahead and making decisions for others.

• Capacity and dementia: a guide for South Australian health care professionals\textsuperscript{xx}, produced by the Australian Centre for Capacity and Ethics, aims to prevent exploitation of people with disabilities.

• Guardianship and Administration Act 1993 (SA)\textsuperscript{xxi} is the South Australian legislation relevant to substitute decision-making.

Tasmania

• Capacity and dementia: a guide for Tasmanian health care professionals\textsuperscript{xxi}, produced by the Australian Centre for Capacity and Ethics, aims to prevent exploitation of people with disabilities.

• Guardianship and Administration Act 1995 (Tas)\textsuperscript{xxii} is the Tasmanian legislation relevant to substitute decision-making.

Victoria

• Office of the Public Advocate\textsuperscript{xxiv} has information about guardianship, medical consent, powers of attorney and supported decision-making.

• Capacity and dementia: a guide for Victorian health care professionals\textsuperscript{xxv}, produced by the Australian Centre for Capacity and Ethics, aims to prevent exploitation of people with disabilities.

• Guardianship and Administration Act 1986 (Vic)\textsuperscript{xxvi} is the Victorian legislation relevant to substitute decision-making.
Western Australia

- **Position statement: decisions about treatment**\(^{xxxvii}\) is produced by the Western Australian Department of the Attorney General, Office of the Public Advocate.

- **Consent to treatment policy for the Western Australian health system**\(^{xxxvii}\) is produced by the Office of Safety and Quality in Healthcare.

- **A guide to enduring power of guardianship in Western Australia**\(^{xxxviii}\) is produced by the Western Australian Department of the Attorney General.

- **Guardianship and Administration Act 1990 (WA)**\(^{xxx}\) is the Western Australian legislation relevant to substitute decision-making.
Dementia, delirium and risks of harm

Online courses

- **Dementia Training Study Centres** is the web site for the five dementia training study centres funded by the Australian Government, which provide development opportunities for existing and future dementia care health professionals. It includes links to e-learning, resources, education events such as guest lectures, and the *Australian Journal of Dementia Care*. It also includes online modules aimed at:
  - undergraduate students completing health-related courses
  - health and care staff wishing to undertake professional development to improve their knowledge and skills in dementia care.

The e-learning page includes links to:
  - e-learning lectures
  - ten e-learning online modules, each attracting 15 continuing nurse education points.

The web site also includes:
  - *Assessment and management of confusion in the acute care setting*, a self-directed learning package with a focus on delirium
  - *a training package to support overseas qualified nurses* as they adapt to working in the Australian dementia care setting.

- **Understanding dementia** is the University of Tasmania’s massive open online course. The free nine-week online course is divided into three themes:
  - **The brain** provides a background on basic nervous system anatomy and function, followed by a discussion of the diseases that cause dementia, current dementia research and future directions.
  - **The diseases** explores the differences between normal ageing and dementia, risk factors, symptoms of dementia, the issues surrounding diagnosis, as well as medical management.
  - **The person** addresses the difficulties in recognising symptoms, living with dementia, progression and staging, palliation, behaviours, management and alternative therapies.

Courses developed by jurisdictions

**New South Wales**

- **Health Education Training Institute dementia/delirium module** is intended for NSW Health clinical workers who are not specialised in aged care or mental health. It is an introductory module with information to assist clinicians to understand, assess and respond to patients, and accept their role in managing the issue.

- **Dementia care resource and training network** is for NSW Health participants in online dementia courses facilitated by dementia clinical nurse consultants. There are three courses:
  - **Positive approach to care of the older person** is a 12-week course aimed at registered nurses (RNs), endorsed enrolled nurses (EENs) and allied health. It is suitable for clinicians working in all settings including acute care, residential aged care and in the community. On successful completion of the course, 30 continuing professional development points are awarded.
  - **Behavioural and psychological symptoms of dementia** is a six-week course also aimed at RNs, EENs and allied health, and is suitable for those working in all settings.
  - **Person-centred care in the community** is a four-week course aimed specifically at assistants in nursing (AINs) and patient care assistants (PCAs) who work in acute care, residential aged care or the community.
The courses include discussion forums, real-time online chats, quizzes and self-directed lessons. Anyone can join to gain access to the resources on the site and to network with members. The site also provides access to dementia care competencies developed for health professionals at essential, enhanced and expert levels.

**Western Australia**

- Western Australian Centre for Health and Ageing
  - has a series of modules that include dementia and delirium. The delirium module is a case study focusing on the recognition of delirium in an older Aboriginal person in hospital.

**Educational resources**

**National**

- Alzheimer's Australia's web site has a section on understanding dementia and memory loss. It has translated information and resources for culturally and linguistically diverse groups as well as publications and resources for Aboriginal and Torres Strait Islander communities.

- Delirium in older people, available from the Australian Government Department of Health, is a booklet for health professionals on delirium.

- Delirium care pathways poster is available from the Department of Health.

**International**

- Dementia care in the emergency department: learning resource, from the National Health Service's Education for Scotland, provides practical tips and links to further resources, outlining initial contact, assessment, intervention and resolution.

- The Scottish Promoting Excellence: dementia informed practice level education framework outlines the competencies required by different levels of the workforce, and provides videos to support staff and students who require the knowledge and skills of that level.

- Dementia Gateway, developed by the Social Care Institute for Excellence, provides information and training resources on dementia.

- Portal of Geriatrics Online Education is a free collection of expert-contributed geriatrics educational materials for educators and learners.

- International Dementia Hospital Hub has a range of relevant resources and invites contributions to share knowledge about evidence-based practice.

**New South Wales**

- Care of Confused Hospitalised Older Persons (CHOPS), developed by the Aged Health Network at the Agency for Clinical Innovation, aims to improve the experiences and outcomes of confused older people in hospital.
  - Why doctors need to know about delirium: relevance, implications, screening and diagnosis, a video that focuses on the role of doctors in screening, assessment and diagnosis of delirium.
  - Overview of delirium risk assessment, prevention and management in an acute care nursing environment, a video that focuses on the perspective of patients and nurses, with the emphasis on the principles of person-centred care.
Queensland

- **Caring for a person with dementia** is a guide for hospital nursing staff that provides an overview of dementia and suggestions on how to respond to patients living with dementia.

- **Learn about delirium** is an online, independent learning resource from the Queensland University of Technology School of Nursing about delirium and delirium superimposed on dementia, with vignettes to enhance learning.

Victoria

- **Dementia care in hospitals** was a Victorian research program that sponsored four projects on dementia-friendly care in hospitals. Project outcomes provided ideas and suggestions for hospitals in:
  - culture, policy and practice change
  - education programs and resources
  - specific dementia care practice
  - engaging families and carers of patients with dementia.

  **The Dementia Care in Hospitals Program**, a dementia awareness and communication project within this program uses a bedside alert called the Cognitive Impairment Identifier (CII).

- **Best care for older people everywhere: the toolkit** is a web-based toolkit to assist clinicians to improve care and minimise the functional decline of older patients in hospital. It provides tips, clinical information and resources in a number of areas including cognition.

- **Victorian Geriatric Medicine Training Program** includes modules on delirium, dementia and the CogCard as an aid to the detection of cognitive impairment.
Resources

Mechanism 3  Enable partnerships between clinicians, patients, carers and families

Dementia and delirium

- Delirium[^1], available from the Australian Government Department of Health, is a brochure that provides information for people who have experienced delirium, and for carers and families.
- Alzheimer’s Australia[^2] has consumer help sheets about dementia.
- Care of Confused Hospitalised Older Persons[^3] (CHOPS) includes videos of carers’ experience of delirium and also has a delirium brochure in multiple languages.

[^1]: Department of Health
[^2]: Alzheimer’s Australia
[^3]: Care of Confused Hospitalised Older Persons
Introduction

Step 2 of the pathway aims to recognise cognitive impairment by undertaking cognitive screening, followed by specific delirium assessment and/or assessment of risks associated with cognitive impairment. It is essential to investigate the cause/s of delirium so that they can be identified and treated. Clinicians need to be alert to the possible development of incident delirium (delirium that develops during a hospital stay) in hospitalised older patients and, consequently, the need for assessment or re-assessment if there is any change in the patient’s behaviour, mental status or physical condition. The trigger for change and response should be incorporated into clinical handover and practice.

Safety and quality issues and rationale for action

If cognitive impairment is not recognised and acted upon, the patient can be put at risk of adverse events and the provision of safe, high-quality patient care can be threatened.7

As noted earlier, cognitive impairment influences a person’s capacity to understand, follow instructions and function in the hospital environment, and it places the person at increased risk of other complications such as falls. Cognitive impairment should always be investigated to see whether it may be delirium, because its underlying causes may be treatable.

Cognitive impairment influences medical treatment and discharge arrangements. For example, medicine safety problems can occur when patients do not recognise the generic brands used in hospital as being the same as their usual medicines, when there is inadequate monitoring of patient medicine compliance, or when there is a lack of informed consent for the use of psychotropic medicines.

Recognition of cognitive impairment should trigger an assessment of the patient’s capacity to provide informed consent to medical treatment and prompt the involvement of their family and carers in further assessment and care.

Many issues may contribute to the missed recognition of cognitive impairment, including obtaining an inadequate or incomplete patient history, because the person may be unable to communicate or understand questions and instructions. This can be exacerbated if carers are not involved in the information-gathering process.

A lack of governance systems to maintain and improve recognition of cognitive impairment, and the knowledge and skill deficits of clinicians, will significantly affect the provision of safe and high-quality patient care.
Evidence-based practice

Screening for cognitive impairment

Unlike screening in stable community-dwelling patients, there is an extremely strong case for detecting ... cognitive impairment in hospital inpatients. Shenkin 2013

Screening for cognitive impairment and identifying risks of harm should be undertaken as soon as possible after presentation, given that adverse events such as falls and pressure injuries can happen quickly. Screening patients aged 65 and over, and action within eight hours would align with NSQHS Standard 10: Preventing falls and harm from falls. The location for screening could be in an ED, a pre-admission clinic or acute assessment unit.

Although there is variation across Australia in the method used to detect cognitive impairment, the use of a cognitive screening tool is important because:

- cognitive impairment is under-recognised in current assessment practices
- tools can be a more accurate indication of cognitive impairment than clinical judgement
- people will present with existing dementia who have not been formally diagnosed and who may not raise their difficulties with clinicians as it is unlikely to be the reason for their admission
- the score provides a baseline that can be recorded and compared when any further testing is undertaken during the current and any subsequent hospital stays.

However, it is important that health professionals recognise that the tools must be used carefully. They need to understand that poor scoring may be due to dementia and/or delirium, or a range of other reasons such as pain, medicines, depression or sleep disturbance. In addition, a poor score could simply reflect not being able to understand questions due to language, health literacy or cultural barriers, or to hearing impairment or learning difficulties.

If there is concern about the patient’s medical decision-making capacity, a capacity assessment should be arranged.

Key point

A quick cognitive screening tool should be administered to all patients who have been identified as being at risk of delirium or harm from existing or suspected cognitive impairment.

Guidelines suggest a two-staged process, initial screening followed by more detailed assessment.

Cognitive screening needs to be undertaken respectfully by trained clinicians who know that a test score is not a diagnosis, but a trigger for further assessment.
Choosing a screening tool

A range of cognitive tools have been developed with different purposes, ranging from screening for cognitive impairment, to obtaining a differential diagnosis, rating severity or monitoring disease progression. The core domains covered vary depending on the purpose and level of detail. At a minimum, an initial screen should test orientation, recall and attention. Other cognitive tests that may be used at the comprehensive assessment stage will test other domains such as language and executive function.

The screening tool is not expected to diagnose, but to detect cognitive impairment and to trigger further investigation and action.

Assessment for validity in hospital settings should be against a gold or reference standard, such as the Diagnostic and statistical manual of mental disorders (DSM), not against other tools. A recent systematic review of screening for dementia identified the following tools that have been validated in a hospital setting:

- Abbreviated Mental Test Score (AMTS)
- Digit Span Backwards Test
- Time and Change Test
- Informant Questionnaire on Cognitive Decline in the Elderly short form (IQCODE)
- Short Portable Mental Status Questionnaire (SPMSQ)
- Ten-Item Test
- Mini Mental State Examination (MMSE).

Although the review was unable to recommend a single best instrument, the AMTS was found to be the most researched tool (it was the only one with more than one study that investigated its properties) and it:

- has good sensitivity and specificity (better than MMSE for specificity)
- did not require pen and paper, so is appropriate for people with visual or physical impairment
- was brief (3–4 minutes)
- was free (noting that the MMSE is now subject to licensing).

(Sensitivity means that the test correctly identifies that a person has the condition and specificity means that the test correctly identifies that a person does not have a condition.)

Other relevant brief screening tools include:
- 6-Item Cognitive Impairment Test (6-CIT)
- General Practitioner Assessment of Cognition (GPCOG)
- 7-Minute-Screen
- Montreal Cognitive Assessment (MoCA)
- Mini-COG
- Addenbrooke’s Cognitive Examination – revised (ACE-R)

However, these tests have not been validated in a hospital setting.

A new screening test for delirium, the 4 ‘A’s Test (4AT), incorporates two simple cognitive screening items that may mean that a test for cognition followed by a delirium test may not be necessary.

This resource does not recommend a specific tool because:

- some hospitals already have a screening tool in place that is widely used
- this is an evolving field, with increased interest in this area internationally, such as the work of the Cochrane Dementia and Cognitive Improvement Group
- although there are numerous tools in use, further validation studies of screening tools in hospital inpatients are needed and, once undertaken, will provide more choice of validated tools for use in the hospital setting.

Cognitive screening tools have been criticised for not addressing educational levels, literacy levels and English proficiency. More culturally sensitive tools have been developed such as the Mini-COG, and the Rowland Universal Dementia Assessment Scale (RUDAS) and the Kimberley Indigenous Cognitive Assessment (KICA) tool for Indigenous Australians. Because these take longer to complete, they may be more suitable for a more detailed assessment of dementia.
**History taking**

*Do not delay, defer or delegate the collateral history – a 10-minute conversation with a carer can rapidly reveal the diagnosis and direct ongoing management.*

Obtaining an accurate history is an essential component of clinical assessment. Although dementia and delirium are closely interlinked, it is necessary to distinguish between them, because each requires a different clinical pathway. Determining the onset of any change in cognition is crucial. However, a person may be unable to provide accurate information due to cognitive impairment and other factors, such as language and cultural barriers, or hearing impairment. Obtaining additional or corroborative information from carers or family members, general practitioners, and residential and community care providers then becomes a priority.

Systems need to be in place to record the information obtained so that it is available to all members of the multidisciplinary team, thus preventing unnecessary multiple requests for information.

Clinicians need to be aware that older people may present differently to younger people and may often require others to communicate their medical history, which increases the risk of missed diagnosis. During history taking, clinicians may have concerns about the patient’s capacity to make healthcare decisions and/or consent to treatment, prompting further assessment. If a patient does not have the capacity to consent to medical treatment, clinicians will need to follow the guardianship legislation in their state or territory regarding substitute decision-making. It is also important to check if a person has an existing advance care plan (see Step 1 for information on understanding capacity and informed consent).

**Key point**

The screening tool needs to be short, validated in a hospital setting, reliable and acceptable, with good sensitivity and specificity. Whatever cognitive screening tool is chosen, clinicians need to be trained in its use and interpretation, and be aware of its strengths and limitations. Tools do not replace – but rather complement – good clinical judgement and accurate history taking.

**Identifying and acting upon risk factors for harm**

Patients with cognitive impairment are at increased risk of harm from complications and adverse events, including medicine incidents, pressure injuries, falls, dehydration and under-nutrition. It is important to identify a patient’s risks for harm by undertaking appropriate screening and assessments. The identification of these risks through screens and assessments will enable the development of a comprehensive individualised management plan to manage these risks.

NSQHS Standard 4: Medication safety, NSQHS Standard 8: Preventing and managing pressure injuries, and NSQHS Standard 10: Preventing falls and harm from falls, require policies and processes to be implemented to screen and assess patients for the risk of medication safety issues, pressure injuries and falls. Policies, procedures and protocols should also be in place to screen and assess patients at risk of harm from dehydration and under-nutrition.

Any communication difficulties (including vision, hearing or speech impairment, language, cognition) should be identified so that clinicians can adapt to the patient’s needs, and engage with carers and families.

*Actions for health service managers*
Step 2 Recognise and respond to patients with cognitive impairment
Identifying and treating causes of delirium

Currently, the Confusion Assessment Method (CAM) is the most widely used tool for assessing delirium. The confusion assessment method – intensive care unit (CAM-ICU) has been developed for nonverbal, mechanically ventilated patients. A systematic review and meta-analysis found that both instruments have been validated in a variety of inpatient settings, noting a concern that their relatively low sensitivity may result in delirium being underestimated.

The 4AT is a new test for rapid screening of delirium that has been evaluated as being a sensitive and specific method of screening for delirium in hospitalised older people. The Single Question in Delirium (SQID) (‘Do you think [name of patient] has been more confused lately?’) may also be a potentially useful clinical tool.

If delirium is identified, it is essential that further investigations are undertaken to try to find and treat the cause/s. It can be difficult to distinguish between dementia and delirium, and some people will have both conditions. If clinical uncertainty exists over the diagnosis, the person should be managed initially for delirium.

It is crucial to recognise if a patient with dementia has an acute change in their mental status or behaviour, because they may have delirium superimposed on their pre-existing dementia. This assessment will be best undertaken with family and/or carers.

Hospital clinicians need to be alert to the possible development of incident delirium (delirium that develops during a hospital stay) in hospitalised older patients and, consequently, the need for assessment or re-assessment if there is any change in the patient’s behaviour or mental status. The trigger for change and response must be incorporated into clinical handover and practice.

Identification of delirium involves collating relevant history, undertaking physical examination and undertaking targeted investigations. A review of medicines is important, because they are the most frequent precipitating factor for delirium. Inouye’s recent review emphasises three key points essential to the identification of delirium:

- Delirium can be a signal of a medical emergency, so measuring vital signs such as temperature, oxygen saturation, and glucose concentration is crucial.
- Diseases can have atypical presentations in older people, so it is important not to dismiss a family member's concern that the patient is ‘just not himself’.
- Diagnostic tests should be targeted on the basis of history and examination.

Key point

Delirium, even in the presence of an underlying dementia, is a potentially reversible condition.

If cognitive impairment is identified, then an assessment for delirium needs to be undertaken. A crucial factor is determining if cognitive impairment is pre-existing, or a sudden or recent change. The most efficient and effective way to do this is to ask the carer or family member.

Re-assessment for delirium should be undertaken if there is:

- a sudden or abrupt change in the patient’s behaviour or mental status
- a deterioration in the patient’s general condition
- a sudden decline in the patient’s ability to perform activities of daily living.
Step 2  Recognise and respond to patients with cognitive impairment

Making a comprehensive assessment and/or referral for follow-up

The majority of older people presenting to EDs are likely to have multiple functional and medical problems. A large prospective observational study found that 78 per cent of people aged 75 and over presenting to EDs were dependent in activities of daily living, had cognitive difficulties or had recently fallen.\(^{48}\) Comprehensive assessment is therefore important to fully determine a patient’s needs.

A comprehensive assessment includes assessing:

- a person’s medical conditions, including presenting problem/s and co-morbidities, existing treatments, medicines and pain
- physical, cognitive, social and psychological/behavioural function
- identified risk factors, such as falls, pressure injuries, under-nutrition and communication difficulties
- support needs of carers and their preferred/available level of involvement during the hospital stay.

Cognitive assessment may be undertaken through a range of tools, including RUDAS and KICA, and others, some of which are listed in the Dementia Outcomes Measurement Suite (DOMS)\(^{lxxx}\).

A comprehensive assessment leads to improved identification of healthcare needs so that appropriate management and follow-up plans can be implemented. A comprehensive assessment may be part of an aged care assessment to determine eligibility for a home care package, a transition care program or residential aged care.

If delirium is not identified in a person with cognitive impairment, a dementia diagnostic process should be initiated. It may not be realistic for this to occur in hospital, so a referral should be made for clinical review and follow-up after discharge from hospital. Routine clinical follow-up and review should also be arranged for patients with continuing or newly-diagnosed delirium, or with suspected dementia.

Many people are not formally diagnosed with dementia and an admission can be an opportunity to start the diagnostic process. It is important to talk to the patient, carers and family if dementia is suspected or diagnosed during the hospital stay and arrange further follow-up if agreed to. Any diagnosis or concern identified in hospital should be communicated to the general practitioner.

Social circumstances and relevant relationships also need to be quickly identified. A critically ill person may also be a carer of someone at home who cannot manage on their own. Sometimes clinicians may find that a spouse who is visiting the patient may also show signs of cognitive impairment. Strategies need to be in place to support carers and, where applicable, provide support to the dependent of the patient if they are the principal carer.

Older patients with dementia are at a greater risk of forms of abuse such as neglect, and physical and financial abuse. These issues may arise during the comprehensive assessment. Clinicians need to be aware of their state or territory policies and protocols to address these issues.

Recognition of cognitive impairment is only beneficial to the patient if appropriate risk management and individualised, integrated evidence-based care strategies are then implemented. This requires a system response (see step 3).
Developing individualised, integrated prevention and management plans

The plan is a collaboration between the patient, carer and the health care team, involving identifying and prioritising needs and setting short- and long-term goals and agreeing to interventions or goals of care.

A guide for assessing older people in hospital

A comprehensive assessment enables the identification of specific needs that can then lead to the development of an individualised, integrated management plan. It is also important to identify whether patients have communicated any treatment preferences or undertaken any advance care planning so that unwanted treatments may be avoided.

An individualised plan enables the patient’s needs to be prioritised, and short- and long-term goals to be agreed to by the patient, carer and family.

An integrated plan provides a more comprehensive and holistic view of the patient’s risks and needs, and enables clinicians to minimise duplication of process and develop a coordinated response.

Systems need to be in place to clearly document and communicate the plan within the hospital and during transfer. This will support safe, high-quality care and continuity of care, and minimise the potential for harm to occur.
Mechanism 1
Establish responsive systems

Implementing systems
- Develop locally tailored clinical pathways for patients with cognitive impairment based on evidence-based clinical practice guidelines and with delineation of staff roles and responsibilities.
- Implement policies, procedures and protocols for:
  - risk assessment, delirium assessment and re-assessment
  - routine cognitive screening, including at pre-admission clinics
  - seeking and documenting informed consent
  - preparation and/or receipt, recording and transfer of advance care plans
  - communication within multidisciplinary care
  - a comprehensive assessment and/or referral system
  - inclusion of cognitive status in structured clinical handovers
  - inclusion of the patient and carer in clinical handover to report on any changes in behaviour, or in mental or physical condition
  - undertaking comprehensive medicines histories.

Information systems
- Facilitate effective professional relationships, and formalise communication protocols and information exchange systems between acute care, subacute care, general practice, residential aged care and community care.
- Provide access to an integrated patient clinical record to enable retrieval of relevant history and cognitive status, which may include electronic-based records.
- Include systems to prepare and/or receive, record and transfer advance care plans.

Monitoring and reporting
- Collect, monitor, report and evaluate organisation-wide data on screening and assessment of patients with cognitive impairment.
- Implement an organisation-wide management system to regularly review cognitive impairment policies, procedures and protocols.

Quality improvement
- Collect information through complaints, incidents and open disclosure systems to inform the review and evaluation of the recognition and response process for cognitive impairment.
- Improve practice in response to feedback from data collected regarding risk assessment, screening, delirium assessment and involvement of carers.
Implementing systems

☑ Establish and implement systems for screening for cognitive impairment, risk assessments and delirium assessment, re-assessment, investigation and treatment

NSQHS Standards actions: 1.1.1, 1.8.1, 1.8.2, 1.8.3, 8.1.1, 8.5.2, 10.1.1, 10.5.2

Information systems

☑ Develop information exchange systems

NSQHS Standards actions: 1.9.1, 6.1.1, 6.2.1, 9.8.1, 9.8.2

Monitoring and reporting

☑ Monitor and report on the systems for screening for cognitive impairment, risk assessments, delirium assessment, re-assessment, investigation and treatment

NSQHS Standards actions: 1.2.1, 1.6.1, 1.14.2, 1.15.2, 6.3.1, 8.1.2, 9.9.3, 10.1.2

System improvements

☑ Ongoing improvement of the systems that support screening for cognitive impairment, risk assessments, delirium assessment, re-assessment, investigation and treatment

NSQHS Standards actions: 1.1.2, 1.2.2, 1.6.2 and 1.8.3

Examples of evidence you can use at accreditation

☑ Risk register that includes a risk profile and risks associated with recognising and caring for patients with cognitive impairment, and includes actions to address identified risks

☑ Risk management and actions plans implemented for patients identified as being at risk of harm

☑ Policy, procedure and protocols for the recognition of patients with cognitive impairment

☑ Relevant documentation that includes the monitoring and review of the assessment of patients for cognitive impairment and strategies to reduce their risk of harm

☑ Patient clinical records showing that risk assessments and screens for cognitive impairment are completed on admission and during an episode of care

☑ Policies, procedures and protocols on structured clinical handover that include information on cognitive impairment in the minimum dataset

☑ Audit of clinician practice tools and procedures used to identify individuals who are at risk

☑ Audit of patient clinical records that demonstrates the use of screening tool and compliance with screening requirements

☑ Audit of patient clinical records shows that advance care plans and other treatment limiting orders are documented in accordance with policies and procedures

☑ A current complaints register and register of incidents, adverse events and near misses that include actions to address identified risks for patients with cognitive impairment
Mechanism 2
Ensure a skilled and informed workforce

Workforce education and training

- Clarify and communicate the roles and responsibilities for the recognition of, and response to, cognitive impairment for the clinical workforce.
- Make available training, resources and tools for relevant clinicians in the:
  - use of policies, procedures, protocols and clinical pathways
  - use, interpretation, timing and documentation of validated cognitive screening tools, risk assessment, delirium assessment and re-assessment, comprehensive assessments and management plans
  - importance of carers as informants to determine the onset of cognitive impairment and to alert clinicians to deterioration
  - assessment of capacity and informed consent.
- Support less experienced clinicians responsible for recognising and responding to a patient’s cognitive impairment through leadership, mentoring and access to clinical expertise.
Position descriptions, duty statements and employment contracts that describe the safety and quality roles and responsibilities for clinicians who care for people with cognitive impairment

Education resources and records of attendance at training on cognitive impairment by the workforce

Induction checklist and orientation program that addresses systems for screening, assessment and re-assessment of people with cognitive impairment

Mechanisms for collecting feedback from workforce on the screening, assessment and re-assessment of patients with cognitive impairment

Communication to the workforce on the screening criteria and processes

Risk management plans implemented for patients identified at increased risk of harm

Reports on the number of patients screened, assessed and re-assessed for cognitive impairment and delirium

Audit of patient records that shows that patients are screened and assessed for their risk from harm, falls, pressure injuries and delirium

Patient clinical records that demonstrate that risk assessments are completed on admission and during an episode of care

Education and training for clinicians

☑ Provide access to training opportunities, resources and tools to relevant clinicians to enable them to recognise and respond to patients with cognitive impairment

NSQHS Standards actions: 1.4.1, 1.4.2, 1.4.3, 1.4.4, 1.10.5, 1.12.1

Cognitive impairment screen and risk of harm

☑ Undertake screening for cognitive impairment and for risk of harm

NSQHS Standards actions: 1.3.3, 1.4.1, 1.4.3, 1.4.4, 4.6.1, 8.5.1, 10.5.1

Deliurium assessment, investigation and treatment

☑ Undertake delirium assessment, re-assessment, investigation and treatment for all patients with cognitive impairment

NSQHS Standards actions: 1.1.1, 1.3.1, 1.3.2, 1.7.1, 1.8.1, 1.8.2, 1.8.3

Integrated prevention and management plan

☑ Develop an individualised, integrated prevention and management plan based on the assessments undertaken

NSQHS Standards actions: 4.14.1, 8.7.1, 8.8.2, 8.10.1, 9.8.1, 10.7.1, 10.8.1, 10.10.1

Examples of evidence you can use at accreditation

☐ Position descriptions, duty statements and employment contracts that describe the safety and quality roles and responsibilities for clinicians who care for people with cognitive impairment

☐ Education resources and records of attendance at training on cognitive impairment by the workforce

☐ Induction checklist and orientation program that addresses systems for screening, assessment and re-assessment of people with cognitive impairment

☐ Mechanisms for collecting feedback from workforce on the screening, assessment and re-assessment of patients with cognitive impairment

☐ Communication to the workforce on the screening criteria and processes

☐ Risk management plans implemented for patients identified at increased risk of harm

☐ Reports on the number of patients screened, assessed and re-assessed for cognitive impairment and delirium

☐ Audit of patient records that shows that patients are screened and assessed for their risk from harm, falls, pressure injuries and delirium

☐ Patient clinical records that demonstrate that risk assessments are completed on admission and during an episode of care
Mechanism 3
Enable partnerships between clinicians, patients, carers and families

- Treat the patient and carer/s with respect and dignity; encourage open communication and their participation; and ensure their privacy.
- Adopt or adapt a patient charter of rights that can be understood by carers and, wherever possible, patients with cognitive impairment.
- Educate clinicians on the importance of carers as informants to determine the onset of cognitive impairment and to alert clinicians to deterioration.
- Inform patients with cognitive impairment and their carers of:
  - their healthcare rights
  - the need for, and the process of, cognitive impairment recognition and response
  - informed consent and substitute decision-making
  - how they can inform clinicians of any changes in a patient’s behaviour, or mental or physical condition.
- Facilitate the participation of patients and carers in history taking, the clinical assessment process and clinical handover.
- Include the patient and carer in clinical handover to report any changes in behaviour, or in mental or physical condition.
- Ensure that informed consent processes and documentation are in place and monitored.
Information for patients and carers

☑ Enable patient and carer partnerships through the provision of information
NSQHS Standards actions: 1.18.1, 1.18.3, 4.13.2, 6.5.1, 8.9.1, 8.10.1, 10.9.1, 10.10.1

Carer informants

☑ Consult carers as key informants on patients with cognitive impairment
NSQHS Standards actions: 1.18.1, 1.18.3, 6.5.1, 8.10.1, 9.9.1, 10.10.1

Carers communicate changes

☑ Enable carers to alert clinicians to changes in condition
NSQHS Standards actions: 9.7.1, 9.9.1, 9.9.3

Advance care planning

☑ Encourage the identification of substitute decision-makers and advance care plans
NSQHS Standards action: 9.8.1

Examples of evidence you can use at accreditation

☐ Policies, procedures and protocols on communicating and including information from patients and carers in care processes
☐ Patient clinical records that reflect assessment of patient and carer needs, and support provided
☐ Information provided to patients and families on escalation processes
☐ Analysis of consumer feedback regarding healthcare rights, participation in treatment plans, and communication with workforce
☐ Results of patient and carer experience surveys and actions taken to address issues identified about participation in making decisions about their care
☐ Information for patients and carers on their roles in clinical handover
☐ Audit of clinical records shows that patients, families and carers were involved in the preparation of advance care plans
☐ Patient information packages about advance care plans
☐ Information packages or resources available for patients and carers, including on recognition and response systems
## Results of implementing Step 2

### What does recognising and responding to patients with cognitive impairment mean to:

<table>
<thead>
<tr>
<th>Patients with cognitive impairment</th>
<th>Carers</th>
<th>Clinicians</th>
<th>Health service managers</th>
</tr>
</thead>
<tbody>
<tr>
<td>My cognitive impairment is recognised, and causes are investigated and explained to me. My risks of harm are identified. My substitute decision-maker is identified and consulted if I am unable to consent to medical treatment.</td>
<td>Cognitive impairment and the risks of harm to the person I care for are explained to me. I am asked to provide information to enable risk assessments and am informed of results. I am encouraged to report changes in the behaviour, or physical or mental condition of the person I care for. The information I provide is incorporated into the development of an integrated prevention and management plan. I am asked my preferred level of involvement.</td>
<td>I have the knowledge and skills to obtain timely and sufficient information from key informants, including advance care plans. I am trained in risk assessment, cognitive screening and interpretation of results. I am alerted to a patient with cognitive impairment and I know my responsibilities. I am informed about the contribution that carers can make to my understanding of my patient and I seek their input to provide the best possible care.</td>
<td>I ensure that systems and processes are in place to access patient information (including advance care plans) on presentation and throughout the episode of care. I ensure that systems and processes are in place for the recognition, assessment and organisation-wide communication of cognitive impairment. I provide access to training for clinicians to ensure that they have the tools, resources and systems needed to effectively recognise and assess patients with cognitive impairment, and communicate plans with the healthcare team.</td>
</tr>
</tbody>
</table>
Mrs B is an 87-year-old woman with dementia, who has been a resident in an aged care facility for the past eight years. Mrs B had a fall and fractured her right femur, and was transferred to the local hospital where she had an internal fixation of her right femur performed. She subsequently suffered a minor myocardial infarction about 36 hours after surgery.

Mrs B’s daughter had raised concerns postoperatively about her mother’s bed height.

I’d been in there to attend to my mother – they had the bed up really high, which is normal nursing practice, and I had said to them before I left, ‘Will I put the bed down low because it’s up high and the cot rails are up?’ and they said, ‘No, no, no. We have to go in and attend to her’, and I said, ‘Well I’m a bit worried’, because her room was not in view of the nurses’ station. The door was just down a little bit. And they said, ‘Oh just leave her call bell over her shoulder’. I said, ‘Well that won’t do any good because she’s got dementia and she won’t remember what the call bell’s for’. Besides, she had a morphine infusion running and I said, ‘Well she’s a bit off her face’, and they said, ‘No, no, no. She’ll be fine’.

During the night, Mrs B had apparently climbed over the bed rails and fell to the floor, fracturing her left leg femur and damaging her right leg. Mrs B then required a hip replacement the following day.

Mrs B’s daughter was not informed about the fall until the anaesthetist contacted her the next morning to sign the consent form for the surgery.

The next morning the anaesthetist rang me at home and said, ‘When are you coming to sign the consent form for theatre?’ and I said, ‘Well I’ve already done that. My mum’s been to theatre’, and the anaesthetist said, ‘Well that was for the pin and plate. I’m talking about the hip replacement’. I said, ‘Well, what’s gone wrong overnight?’ and he said, ‘Didn’t the staff phone you and tell you your mum fell out of bed?’ and I said, ‘No, they didn’t’.

### What did not go well?

| ×  No falls risk assessment. |
| ×  Change in condition not acted on. |
| ×  No subsequent delirium assessment. |
| ×  Use of bedrails. |
| ×  Bed not in a low position. |
| ×  Daughter’s (carer’s) safety advice ignored. |
| ×  False reassurance. |
| ×  Clinicians not understanding care needs. |
| ×  Patient’s bed not easily visible to nursing staff. |
| ×  Daughter not informed of fall. |

### What went well?

- ✓ Daughter informed clinicians that mother had dementia.
- ✓ Daughter raised concerns about the risk of her mother falling.

### What could have been done better?

- ✓ Clinicians recognising and documenting existing dementia.
- ✓ Clinicians undertaking further assessment and developing an individualised prevention and management plan to address safety issues.
- ✓ Implementing an individualised prevention and management plan, including regular assisted toileting and environmental modification – low bed, closer to the nurses station.
- ✓ Engaging carer, and taking carer concerns seriously and acting on them.
Screening for cognitive impairment

- **Cognitive assessment in the elderly: a review of clinical methods** provides information about an array of cognitive assessment tools. It provides a comparative table that may assist you in identifying an appropriate tool to use for initial cognitive impairment identification. It includes brief tests with a reasonable sensitivity and specificity that detect the presence of cognitive impairment (but do not distinguish between causes). These include the 6-CIT, Mini-COG and Support Intensity Scale. This review is not specific to tools for hospital settings.

- **Screening for dementia in general hospital inpatients: a systemic review and meta-analysis of available instruments**, published in *Age and Ageing* by Jackson, T and Sheehan, B., is a recent review of screening tools.

- **Review of brief cognitive tests for patients with suspected dementia** reviews brief cognitive tests in primary and secondary settings. It notes that there are no instruments as yet with high sensitivity and specificity in acute care, and recommends a stepped approach of a short initial screening followed by a more detailed one.

Screening tools

- **AMTS**, from the National Ageing Research Institute, is an example of a brief screening tool and an evaluation.

- **Time and Change Test** is a screening tool based on time and money calculations.

- **Digit Span Test**, reviewed in *International Psychogeriatrics*, tests verbal working memory by seeing how many numbers the patient can remember.

- **SPMSQ** is a brief questionnaire about current events and knowledge.

- **National Institute on Aging** lists 116 tools to detect cognitive impairment in older adults.

Delirium guidelines

- **Delirium in older people: Australian and New Zealand Society for Geriatric Medicine position statement** is a position statement that provides evidence-based recommendations on the prevention, assessment, treatment and management of delirium.

- **Clinical practice guidelines for the management of delirium in older people**, designed specifically for the Australian healthcare environment for the Australian Health Ministers’ Advisory Council (AHMAC), are guidelines for the management of delirium.

- **Management of delirium in older people: quick reference guide**, from the AHMAC guidelines, is a quick reference of information.

- **Delirium care pathways** summarises the AHMAC guidelines, and provides examples of the patient journey in the community, acute care and residential care.

- **Delirium: diagnosis, prevention and management**, from the United Kingdom’s National Institute for Health and Care Excellence, is a clinical guideline that describes methods of preventing, identifying, diagnosing and treating delirium. It focuses on preventing delirium in patients identified to be at risk, using targeted, multicomponent, non-pharmacological interventions.

- **Guidelines for the prevention, diagnosis and management of delirium in older people in hospital** is part of the 2006 National Guidelines from the British Geriatrics Society.
Comprehensive assessment

- **Sharing clinical information across care settings: the birth of an integrated assessment system**[^lxxvii], developed by the InterRAI research collaborative, describes a suite of assessment tools to support assessment and care planning.

- **DSM (5th ed)**[^lxxviii], produced by the American Psychiatric Association, is a resource for clinicians, researchers, insurers, and patients. It includes information on implementation of the manual and answers frequently asked questions.

- **Advancing practice in the care of people with dementia**[^lxxix], produced by the Dementia Training Study Centres, is a resource for aged care assessment clinicians. It contains the following topics:
  - evident cognitive impairment but no formal diagnosis
  - capacity
  - behaviour or psychological symptoms of dementia
  - fitness to drive
  - hoarding and squalor
  - major neurocognitive disorder
  - comparison of the clinical features of delirium, dementia and depression.

- **DOMS**[^lxxx] provides access to a variety of cognitive identification and assessment methods, including their purpose, validation, administration time and recommended administration personnel. It provides downloads of the tools in a usable format, including:
  - Modified Mini Mental Exam (3MS)
  - Alzheimer’s Disease Assessment Scale: Cognition (ADAS-COG)
  - GPCOG
  - Psychogeriatric Assessment Scale (PAS)
  - RUDAS
  - MoCA.

- **Alzheimer’s Australia**[^lxxxi] provides access to RUDAS, which was developed to minimise the influence of language and cultural education. It provides a link to an online video, a guide to administration and scoring, as well as a scoring sheet and copies of journal articles.

- **Best care for older people everywhere: the toolkit**[^lxxxii] provides a summary and evaluation of RUDAS[^lxxxi].

Elder abuse

- **NSW Elder Abuse Helpline**[^lxxxiii] is confidential, offering information, advice and referrals for people who experience, witness or suspect the abuse of older people living in their homes in New South Wales.

- **Elder Abuse Prevention Unit**[^lxxxiv] is a statewide service to response to the abuse of older people in Queensland.


- **Elder abuse prevention and response guidelines for action 2012-14**[^lxxvi] were developed by the Victorian Department of Health as part of the Health Priorities Framework 2012-22.

- **Elder abuse protocol guidelines for action**[^lxxvii], developed by the Alliance for the Prevention of Elder Abuse, assist organisations in Western Australia working with older people to respond to elder abuse.
Mechanism 2
Ensure a skilled and informed workforce

Delirium

- **Assessing and managing delirium in older adults with dementia** provides information on assessing delirium superimposed on dementia.
- **Delirium superimposed on dementia** provides information on detecting and managing delirium superimposed on dementia, and also has links to web-videos and other sources of information.
- **Why doctors need to know about delirium – relevance, implications, screening and diagnosis** is a video available through Care of Confused Hospitalised Older Persons (CHOPS), which focuses on the role of doctors in screening, assessment and diagnosis of delirium.
- **TIME to think delirium**, developed by the National Health Service’s Education for Scotland, is a change package and provides tools.
- **Confusion Assessment Method (CAM)** provides access to the CAM training manual.
- **CAM-ICU: the complete training manual** provides information about a modified version of the CAM intended for use when the patient is only able to provide nonverbal responses.
- **Think delirium** lanyards are used by Guy’s and St Thomas hospitals to remind staff of relevant concerns and actions.

Communication

- **Best care for older people everywhere: the toolkit** is a Victorian Government online toolkit to help clinicians minimise the functional decline of older patients in hospital. It has a section on communication and how to recognise communication problems associated with vision, hearing and/or speech impairment.

Aboriginal-specific resources

- **Working with older Aboriginal and Torres Strait Islander people**, from the Benevolent Society, is a practice resource summarising the latest research and evidence.
- **Australian Indigenous HealthInfoNet – Dementia** provides information and resources about dementia in Indigenous peoples.
- **Western Australian Centre for Health and Ageing** provides access to the Kimberley Indigenous Cognitive Assessment (KICA) tool, a cognitive screening tool designed for Indigenous Australians living in rural and remote areas.
- **Strengthening aged care assessments for Aboriginal consumers: a guide for aged care assessment services in Victoria** describes best-practice principles and how to integrate these into clinical practice.
Mechanism 3  Enable partnerships between clinicians, patients, carers and families

- Working with families of hospitalized older adults with dementia provides information on involving carers in healthcare teams and describes information-gathering processes.
- My aged care, from the Australian Government Department of Human Services, explains eligibility assessments for subsidised help at home or moving into an aged care home.
- Care of Confused Hospitalised Older Persons (CHOPS) program focuses on the identification and management of patients with cognitive impairment in hospital. Through funding from the NHMRC Partnership Centre for Cognitive Decline, the NSW Agency for Clinical Innovation is supporting selected New South Wales hospitals to implement the program during 2014-15.
Step 3  Provide safe and high-quality care tailored to the patient’s needs

Introduction

Step 3 of the pathway aims to implement the individualised, integrated prevention and management plan developed in Step 2 through consideration of key components of care. It includes implementation of the plan during a hospital stay through different levels of care (e.g. acute to subacute and rehabilitation), as well as the transfer of the plan to primary, residential or community-based care.

All aspects of implementation need to be guided by the principles of patient-centred care, which require an understanding of the individual person, shared decision-making, and how to treat patients with dignity and respect.

Evidence-based practices that can minimise the impact of a hospital stay and reduce the risk of harm can be adopted. The relevant workforce needs to be supported to provide care in a way that prevents delirium from developing, or reduces its duration, and reduces the distress experienced by patients with delirium and/or dementia.

Important evidence-based actions include preventative multicomponent interventions, such as regularly mobilising patients, ensuring adequate intake of food and drink, managing pain, restoring normal sleep patterns, and involving family and carers for reassurance and orientation.51

The transfer to transition programs from hospital to home or to residential care, and arrangements for post-hospital follow-up are also important aspects of providing safe and high-quality care.

Safety and quality issues and rationale for action

Unmet care needs and preventable complications

As outlined previously, if cognitive impairment and associated risks are not recognised and assessed, then risk management strategies will not be developed to minimise the risk of harm in areas such as increased risk of falls, pressure injuries, inadequate intake of food and drink, and medicine-related problems. Poor communication and inappropriate care of patients with cognitive impairment increases the likelihood of adverse events.

Patients with cognitive impairment often have difficulty communicating their needs and may require additional supervision to provide them with safe and high-quality care. They are likely to have unidentified and, therefore, unmet care needs. They may not be able to ask for help, communicate if they are feeling worse or find their way around. Patients may require assistance with toileting, eating and drinking, and oral hygiene; they may have difficulty using the buzzer; they may be unaware of hazards; they may require assistance with mobilising; and they may not be able to communicate their sensory deficits. The person may not understand instructions – they may be frightened and/or appear uncooperative, and may try to leave the hospital. These cognitive difficulties may be further compounded for people from CALD backgrounds and people with low health literacy.

Hospitalised older patients with dementia admitted for both medical and surgical care have significantly higher rates of potentially preventable complications such as urinary tract infections, pressure injuries, pneumonia and delirium compared with patients without dementia. These conditions are sensitive to improved clinical care, such as mobilisation, hydration, hygiene, toileting, decreased use of restraints such as bed rails, and catheterisation.9

Patients may also lose functional ability and independence in the absence of an enabling approach to care. If clinicians feel frustration with additional care needs, it may lead them to take control of a patient’s decision-making and tasks of daily living to save time, leading to further functional decline.
Dealing with symptoms of dementia

There are a number of terms used to describe behavioural issues related to dementia, including behavioural and psychological symptoms of dementia (BPSD), behaviours of concern and challenging behaviours. BPSD include aggression, apathy, anxiety, agitation, psychotic symptoms, depression, disinhibited behaviours, wandering, nocturnal disruption and vocally disruptive behaviours. Nearly all people with dementia will experience some form of BPSD during the course of their illness. The severity of their BPSD can be influenced by their interaction with others, the environment and interventions.

A busy, noisy hospital environment, with unfamiliar faces and different routines, can be overwhelming for many patients, particularly those with cognitive impairment. The hospital environment can exacerbate disorientation, cause distress and agitation, and lead to aggression.

There is a risk that any behavioural disturbance exhibited by a person with cognitive impairment is attributed to the person's dementia, response to the unfamiliar environment or lack of communication. It is essential that the underlying cause is sought. Communication difficulties or delirium can lead to escalating behavioural disturbances. Behaviours such as agitation or sleep disturbance may be inappropriately managed through the use of antipsychotic or sedative medicines. These may have only modest benefit and are known to further increase the risk of adverse events. For example, there is slightly increased mortality and heightened risk of stroke in patients treated with antipsychotic medicines.

The hospital workforce frequently encounters aggression from people with cognitive impairment. However, the majority of staff do not feel confident and may lack knowledge in relation to managing these behavioural disturbances other than through the use of medicines such as antipsychotics. They may also manage behavioural disturbances through one-to-one supervision in the form of custodial care, rather than introducing behaviour-management or delirium-prevention techniques.

Lack of knowledge about how to provide appropriate care may be a consequence of limited availability of and/or access to training. In addition, policies and protocols centred on evidence-based guidelines can be in place, but not implemented or monitored.

Alternatively, evidenced-based programs may have been introduced but in a piecemeal fashion, reliant on committed individuals, rather than a systematic approach sponsored by the executive of the hospital or health service.

Advance care planning and end-of-life care

It is known that people who progressively deteriorate from conditions such as dementia do not always receive appropriate or timely end-of-life care. There may be a number of reasons, including failures to address advance care planning, and the difficulties that clinicians and carers face discussing and making end-of-life decisions. It can also be due to poor communication with carers, families, or other healthcare or aged care providers, who may be aware of existing advance care plans.

Engagement with carers

Carers are often stressed about having to leave their family member in an acute care environment where care may not be targeted to their needs. Additionally, family members may try to give advice on safety and management issues that may be ignored by clinicians, not acted on or not communicated to other members of the healthcare team.

Lack of referral for ongoing carer support can miss the opportunity to reduce carer stress and increase the risk of readmission. Carers are crucial to transfer processes and should be respected, valued and supported during these stressful periods.
Transitions

Lack of access to hospital substitution services means that patients with cognitive impairment can be admitted to, or have prolonged stays in, hospital for conditions that could be more appropriately treated at home or in residential care.

Transition programs can enable people with cognitive impairment to leave acute care earlier and return to a familiar environment with therapeutic support to aid recovery. Inadequate use of transition programs may result in patients with unresolved delirium being discharged with inappropriate support, remaining in hospital for extended periods of time or being inappropriately admitted to residential care facilities.

Clinicians may not understand the benefits and the eligibility of people with cognitive impairment for transition programs. The interpretation of eligibility for transition care programs appears to be variable,\(^{15}\) despite their potential use for people with cognitive impairment with high risk of readmission and premature entry to residential care.

Poor communication and coordination in the transition of care between acute, primary care and residential/community care can also lead to adverse outcomes and unplanned readmissions. Older people with complex care needs are at the greatest risk.\(^{56}\)

Evidenced-based practice

Providing patient-centred care

There is strong evidence that patient-centred care can lead to improvements in healthcare quality and outcomes by increasing safety, cost-effectiveness, and patient, family and workforce satisfaction.\(^{57}\) The principles of patient-centred care include:

- treating patients, consumers, carers and families with dignity and respect
- communicating and sharing information between patients, carers, families and health providers
- encouraging and supporting participation in decision-making
- fostering collaboration in program and policy development, and in health service design, delivery and evaluation.\(^{57}\)

The importance of effective communication in particular is well recognised and linked to improved outcomes and patient safety. The Commission’s Consumers in the health system and health literacy — taking action to improve safety and quality\(^{56}\) outlines strategies for effective communication and for improving health literacy.

Although many health services have adopted patient-centred care principles, the translation of these principles into the care of patients with cognitive impairment can be challenging and may require health professionals to acquire new knowledge and skills, and be supported to do so. As with any change process, committed senior leadership and change champions are critical.\(^{57}\)

Skilled clinicians are able to find the right balance between enabling a patient with cognitive impairment to contribute to their own care within their capabilities, and providing the assistance the patient needs in a way that maintains their dignity. The clinician does not assume that someone with cognitive impairment cannot make decisions and, therefore, involves the person in all decisions that they are capable of making and in discussions about their care.

When a person cannot communicate their preferences and usual routines regarding personal care and activities of daily living, having a system in place to collect personal information from family or aged care providers can help clinicians to provide care in a way that is consistent with a person’s usual preferences.\(^{58}\)
Establishing a partnership with carers

Carers are the experts in the care of the person they are caring for and should be viewed as partners in care. When a patient with cognitive impairment has difficulty communicating, obtaining history and information about the onset of change from carers can be crucial in diagnosing delirium and other forms of deterioration. Carers can also provide important information about the specific care needs and safety risks for the patient. Their concerns should always be taken seriously. Carers should be involved in transfer of care arrangements, and their own support needs should be assessed and addressed.

Partnering with carers in the provision of health care for patients with cognitive impairment is in line with national and jurisdictional responsibilities enshrined in carer legislation. If the patient does not have a carer, they may wish to nominate someone whom a clinician can contact to inform them of their admission to hospital. If the patient does not have a support person, clinicians need to arrange appropriate support while the patient is in hospital. Clinicians may also consider referral to dementia-specific community services that support people living with dementia who live on their own, when required.

Preventing and minimising harm

Prevention and minimisation of harm includes developing strategies to address the risks of falls, pressure injuries, medicine incidents, under-nutrition and dehydration. Clinicians need to be familiar with the policies, procedures and protocols that are in place in the hospital to undertake medicine reconciliation (NSQHS Standard 4: Medication safety), and develop pressure injury and falls prevention and management plans (NSQHS Standard 8: Preventing and managing pressure injuries and NSQHS Standard 10: Preventing falls and harm from falls). Clinicians also need to be familiar with the policies, procedures and protocols that are in place to screen and assess patients at risk of harm from dehydration and under-nutrition.

Strategies to address communication difficulties will enable the patient to participate in discussions and decisions about their health care as much as possible. They will also assist in preventing delirium, and reduce anxiety and distress.

Preventing and managing delirium

There is evidence that multicomponent non-pharmacological interventions to target specific delirium risk factors significantly reduce delirium incidence in older medical patients.59 These interventions include orientation activities, early mobilisation, preventing sleep deprivation, minimising the use of psychotropic medicines, assisting with the use of hearing and visual aids, and treating dehydration.

A recent systematic review concluded that there is not enough evidence to support the use of antipsychotics as a treatment for delirium in hospitalised older adults.60 Antipsychotic medicine may be appropriate if a person is severely distressed or there is an immediate risk of harm to themselves or others, but not as a first-line, routine response. Key points in prescribing antipsychotics include:

- obtain consent
- target symptoms that will potentially respond
- start low and increase slowly
- limit the time the patient is on the medicine.53

Key point

If the person agrees, carers and families should have the opportunity to be involved in decisions about treatment and care. Carers and families should also be given the information and support they need.51

Actions for health service managers
Responding to behavioural changes

There is emerging evidence regarding the benefit of non-pharmacological or psychosocial interventions as an effective alternative to antipsychotic medicines. A recent randomised clinical trial showed that effective pain management can reduce agitation and reduce the use of psychotropic medicines in residential care.

Advice should be sought from clinical experts when presentation is complex or beyond the skill level of receiving clinicians. Experts may include geriatricians, psychogeriatricians and nurse practitioners, clinical nurse consultants, and staff from Dementia Behaviour Advisory Services.

Managing medical issues

Management of medical issues includes treatment of the presenting problem and reason for admission, ongoing treatment of the underlying causes of delirium, if identified, and the optimal management of co-morbidities. Medical management also includes appropriate treatment for pain.

Helpful hint

People with dementia may not be able to communicate that they are in pain and are at high risk of under-recognised and under-treated pain. If a patient without cognitive impairment informs clinicians that they have no pain, then a clinician’s response may be to not offer pain medication. However, if a person has been recognised as having cognitive impairment and states that they have no pain, then it may alert a clinician to undertake more suitable pain assessment that includes nonverbal indicators such as patient behaviour or facial expressions.

A thorough assessment of physical health is essential. Particular attention must be paid to the assessment of potential delirium, which is a medical emergency requiring immediate treatment, and to pain and other basic physical needs such as thirst, hunger, and the need to urinate or defecate.

Older patients with delirium and/or dementia may be frail, with multiple complex health problems requiring coordination and liaison across specialties or comprehensive geriatric assessment. Two systematic reviews of comprehensive geriatric assessment have confirmed that this approach is beneficial for patients when patients are admitted to a dedicated ward area and receive care from a specialist multidisciplinary team. (This effect was not clearly seen where patients remained in a general ward and received assessment from a visiting specialist multidisciplinary team.)

Any medical treatment should be in line with a patient’s wishes to avoid unwanted treatment. Clinicians need to discuss any concerns about recovery or risk of dying with the patient, carers and families. They need to discuss the patient’s wishes and agree to goals of care, particularly if the patient’s condition deteriorates.
Making advance care and end-of-life care plans

It is important that patients, carers and clinicians have a shared understanding of a person’s prognosis, goals of care and preferences for care. Conditions such as dementia cause progressive deterioration in a person’s condition and cognition, and may limit their ability to participate in future decision-making about their treatment. Ideally, the process of advance care planning should begin as soon as possible after a person is diagnosed with a progressive disease that causes cognitive impairment.

Advance care planning should include talking with people about their values, goals of care and treatment preferences to enable future care to be provided in accordance with their wishes. Patients and carers should be involved in these discussions. In the absence of effective advance care planning, patients may receive unwarranted and burdensome treatments that delay death and cause suffering.

It is important that advance care planning and end-of-life preferences for patients with cognitive impairment are considered, documented and communicated to the healthcare team. It is also important that a substitute decision-maker is identified.

Clinicians need to understand their responsibilities with regard to respecting patients’ wishes and adhering to advance care plans.
Step 3  Provide safe and high-quality care tailored to the patient’s needs
Planning transitions

It is important that transition pathways are well planned for patient moves to and from home or residential care, and through the acute care system. For people with cognitive impairment, these transitions should include:

- Information exchange and transfer of care processes among hospitals, and all relevant healthcare and aged care providers
- Access to hospital substitution, fast-track or transition programs.

Assessment, treatment and the use of management plans on presentation, during admission and on discharge are supported by access to comprehensive information from general practice, residential care facilities and community aged care providers. Accurate information exchange is crucial for a patient’s ongoing care and appropriate management.

There are many examples of programs to triage and fast-track people with cognitive impairment to ensure that they avoid or limit the time waiting in EDs; and to provide access to comprehensive assessment, and rapid medical and pharmacological review.

There are also programs that enable people with cognitive impairment to leave acute care earlier and return to a familiar environment with therapeutic support to aid recovery. Evidence suggests that ‘hospital in the home’ programs can reduce delirium, behavioural disturbance, sleeping disorders, use of psychotropic medicines and carer stress compared with acute hospital care, with no significant difference in mortality. Good design principles include:

- Making the environment safe and secure
- Making the environment simple with good visual access
- Reducing unnecessary stimulation and highlighting helpful stimulation.

Good design principles can be applied at facility, ward or room level. Twenty-six case studies improved the physical environment of the hospital to better suit patients with cognitive impairment – for example, better lighting and signage, the removal of potential hazards, and clocks with large faces that are visible from all beds. These studies reported improvements in a number of patient outcomes, including reduced agitation and falls, reduced need for antipsychotic medication, and improved nutrition and hydration, along with improved clinician morale.

The Transition Care Program is one example that provides a short-term package of services at the end of a hospital stay, which include low-intensity therapy, nursing support and/or personal care. It is goal-oriented and time-limited, and provides support to restore functioning and time to finalise long-term arrangements.

Post-hospital review and follow-up is essential so that a person is not incorrectly labelled as having dementia.

Modifying the environment

The physical design of a hospital, ward and rooms can contribute to a patient’s disorientation, hinder appropriate care, and increase the risk for falls and other adverse events. Alternatively, design can positively contribute to reducing delirium.

Good design can reduce agitation and distress, support independence and social interaction, promote safety and enable activities of daily living. Good design principles include:

- Making the environment safe and secure
- Making the environment simple with good visual access
- Reducing unnecessary stimulation and highlighting helpful stimulation.

Good design principles can be applied at facility, ward or room level. Twenty-six case studies improved the physical environment of the hospital to better suit patients with cognitive impairment – for example, better lighting and signage, the removal of potential hazards, and clocks with large faces that are visible from all beds. These studies reported improvements in a number of patient outcomes, including reduced agitation and falls, reduced need for antipsychotic medication, and improved nutrition and hydration, along with improved clinician morale.
Evidence-based care

• Incorporate evidence-based guidelines and pathways into policies and procedures to address:
  - delirium prevention and management
  - prevention and minimisation of harm
  - appropriate response to behavioural issues
  - pain management
  - use of medicines
  - advance care planning
  - palliative and end-of-life care.

• Provide triggers in the protocols and procedures that encourage clinicians to engage patients and carers in clinical planning and delivery, including planning for transitions in care.

Models of care

• Establish evidence-based multicomponent models of care that incorporate:
  - dignity and respect
  - personal patient information provided by carers into care delivery
  - carer support mechanisms (e.g. carer support programs that offer practical support to carers, which may include access to quiet rooms, parking, tea, coffee, food, and accessible information on cognitive impairment and services available)
  - delirium management and prevention strategies into care practices
  - engagement of volunteers to support patients, carers and clinicians
  - equitable care, inclusive of and appropriate to the needs of older patients from CALD backgrounds, their families and carers, including use of a bilingual or bicultural worker, or an interpreter when indicated.

Environment

• Apply evidence-based environmental design principles at facility, ward and room level. If possible, modifying the immediate environment to encourage way-finding, reduce agitation, and promote usual routines should be considered as part of minor work upgrades.

Transitions

• Involve patients, carers and family in the planning for transitions in care.

• Facilitate access to transition programs, such as hospital in the home, transition aged care programs, day therapy or day hospital for patient transitions from hospital.

• Provide triggers for assessing the risks of night or weekend discharge transfers when there may be limited community support.

• Establish processes for organising routine clinical follow-up and review for patients with continuing or newly diagnosed delirium, or with suspected dementia.

• Facilitate effective communication protocols with practitioners and organisations receiving patients transferred from hospital care, including general practice, residential care facilities and community aged care providers.
Monitoring and reporting

- Implement policies on transition care programs that address planning, implementation and monitoring for people with cognitive impairment.
- Monitor and document training of clinicians.
- Establish systematic feedback mechanisms for patients, carers and workforce, and monitor this information.
- Collect, monitor, report and review organisation-wide data about providing safe and high-quality care. This may include data on safety and quality risks, such as use of psychotropic medicines (including after hours and weekends).
- Establish open disclosure processes that are accessible and understandable to patients with cognitive impairment and their carers.
- Record any adverse medicine event and include information on transfer.

System improvement

- Improve practice in response to feedback from data collected regarding the provision of safe and high-quality care for patients with cognitive impairment.
## Mechanism 1

### Establish responsive systems

#### Implement systems
- Establish and implement systems to enable the provision of safe and high-quality care
  - NSQHS Standards actions: 1.1.1, 1.2.2, 1.6.2, 1.9.1, 1.13.2, 1.14.4, 1.15.2, 2.2.2, 2.8.2, 2.9.2, 3.1.4, 4.5.2, 8.3.1, 9.2.4, 10.3.1

#### Evidence-based care
- Use evidence-based guidelines, pathways and protocols
  - NSQHS Standards actions: 1.3.1, 1.3.2, 1.7.1, 1.7.2, 4.6.1, 4.9.1, 8.1.1, 8.8.2, 10.1.1, 10.6.1

#### Models of care
- Apply evidence-based models of care
  - NSQHS Standards action: 1.8.1

#### Environment
- Implement evidence-based environmental design
  - NSQHS Standards actions: None related

#### Transitions
- Implement seamless transitions in care
  - NSQHS Standards action: 6.1.1

#### Monitoring and reporting
- Monitor and report on implementation
  - NSQHS Standards actions: 1.6.1, 1.7.2, 1.9.2, 1.11.2, 1.13.1, 1.14.2, 1.15.2, 1.20.1, 2.8.1, 2.9.1, 3.2.1, 3.3.2, 4.4.1, 5.1.2, 6.3.1, 8.2.1, 9.2.2, 9.9.3, 10.2.1, 10.2.2, 10.5.2, 10.6.2, 10.7.2

#### System improvements
- Ongoing improvement of the systems for providing safe and high-quality care
  - NSQHS Standards actions: 1.2.2, 1.5.2, 1.6.2, 1.13.2, 1.14.4, 1.15.2, 2.8.2, 3.1.4, 3.3.2, 4.5.2, 5.1.2, 6.1.2, 8.3.1

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**Australian Commission on Safety and Quality in Health Care**
Examples of evidence you can use at accreditation

- Policies, procedures and protocols on access and use of clinical guidelines and pathways that reflect evidence-based practice for the care of patients with cognitive impairment
- Audit of adherence to agreed evidence-based clinical guidelines and pathways using the patient clinical record
- Audit of the use of policies, procedures and protocols for the care of patients with cognitive impairment, including falls and pressure injury prevention and management
- Audit of the use of policies, procedures and protocols on patient medicines information to be provided on transfer and discharge
- Patient clinical records that show a current list of medicines, including reasons for changes provided to the clinician
- Examples of improvement activities for patients with cognitive impairment relating to care and the environment that have been implemented and evaluated
- Policies, procedures and protocols on structured clinical handover that includes information on cognitive impairment
- Discharge summary includes information on cognition for patients at risk
Mechanism 2
Ensure a skilled and informed workforce

Education and training

• Ensure that the relevant workforce is aware of their roles and responsibilities for providing safe and high-quality care.

• Identify individuals and teams to provide leadership in the provision of safe and high-quality care.

• Provide education and training for clinicians in evidenced-based strategies for providing safe and high-quality care, including:
  - individualised care, in partnership with the patient, carer and family
  - management of medical issues
  - prevention and management of delirium
  - prevention and minimisation of harm
  - response to behavioural issues
    ▪ non-pharmacological management
    ▪ risk of administering antipsychotic medicines and need for informed consent in line with guardianship legislation
  - modification of the environment.

Expert support

• Seek advice and support from clinical experts when the management of cognitive impairment is complex or beyond the skill level of responsible clinicians, which may include geriatricians, old age psychiatrists, nurse practitioners, clinical nurse consultants and DBMAS.

• Engage a bilingual or bicultural clinician or worker, or an interpreter when indicated.
Education and training

✓ Provide workforce education on providing safe and high-quality care

NSQHS Standards actions: 1.3.1, 1.4.2, 1.4.3, 1.10.1, 1.10.5, 1.12.1, 2.6.1

Individualised and integrated prevention and management plan

✓ Implement an individualised, integrated prevention and management plan incorporating the following components:

- individualised care
- management of medical issues
- management and prevention of delirium
- prevention and minimisation of harm
- response to behavioural issues
- modification of the environment

NSQHS Standard actions: 1.7.2, 1.8.2, 3.19.2, 4.6.1, 4.7.2, 4.14.1, 8.7.2, 8.7.4, 8.8.4, 8.10.1, 9.8.1, 10.6.3, 10.7.1, 10.7.2, 10.7.3, 10.1.2, 10.8, 10.10.1

Examples of evidence you can use at accreditation

☐ Policies, procedures and protocols on training requirements for clinicians caring for patients with cognitive impairment

☐ Education resources and records of attendance at training by clinicians on cognitive impairment

☐ Orientation and education resources for locum and agency workforce regarding cognitive impairment

☐ Resources and materials available to clinicians to implement prevention and management plans for patients with cognitive impairment

☐ Audit of clinical record showing that risks of harm are identified in the discharge plan and included in referral documentation

☐ Training curricula that include patient-centred care

☐ Orientation and training programs that include partnerships and consumer perspectives

☐ Protocols on clinical supervision and access to expert advice and support
Mechanism 3
Enable partnerships between clinicians, patients, carers and families

Information for patients and carers
- Provide timely, relevant and understandable information to patients, carers and families on:
  - their role in handover and escalating care
  - informed consent and substitute decision-making
  - advance care planning, palliative care and end-of-life care
  - transition programs
  - community support
  - importance of keeping an up-to-date list of medicines.

Partners in decision-making
- Consult with patients and carers in clinical planning and delivery of care.

Partners in care
- Support carers to be involved in care at a level they are comfortable with.
- Encourage patients and support carers to continue activities of daily living and mobilise when appropriate.
- Assess the current and future support needs of carers, and provide information on support and referrals for care when required.
- Provide clinicians with the skills to recognise the needs of carers and mechanisms for taking action.
- Establish open disclosure processes that are accessible and understandable to patients with cognitive impairment and their carers.
- Provide triggers in the protocols and procedures that encourage clinicians to engage patients and carers in clinical planning and delivery, including planning for transitions in care.
Information for patients and carers

- Provide timely, relevant and understandable information to patients, carers and families
  
  NSQHS Standards actions: 1.18.3, 1.17.3, 2.4.1, 3.19.1, 4.5, 4.12.2, 4.15.1, 8.9.1, 10.9.1

Partners in decision-making

- Consult patient and carers in clinical decisions; involve carers in case conferencing and clinical handovers
  
  NSQHS Standards actions: 1.18.1, 1.18.3, 6.5.1, 8.10.1, 10.10.1

Partners in care

- Support patients and carers to be involved in care
  
  NSQHS Standards actions: 2.8.1, 3.19.1, 4.15.1, 8.9.1, 10.9.1

Examples of evidence you can use at accreditation

- Patient clinical records detailing information provided to patients and carers about:
  - patient and carer involvement in management of care and discharge planning
  - case conferences
  - consent forms
  - the use of patient-specific medicines information, such as consumer medicines information
  - assessment of need and support provided

- Analysis of patient and carer feedback regarding their participation in care planning

- Patient and carer information resources, including their role in handover and escalating care

- Results of patient experience surveys, and documentation of the organisational response and feedback recorded in relation to the prevention and care of patients with cognitive impairment, pressure injuries and falls

- Records of consumer medicines information being provided
Results of implementing Step 3

When safe and high-quality care tailored to a patient’s needs is provided:

| **Patients with cognitive impairment** | I am treated with respect.  
My care team is competent and caring.  
I am asked about my hospital experience to continually improve the quality of care provided.  
My healthcare information and my prevention and management plan are available to all relevant healthcare providers, my carers and me in a timely manner and in sufficient detail.  
I am encouraged to discuss my future care preferences when I have capacity to do so.  
I have the opportunity to be treated or to recover in a therapeutic environment without hospital-related risks and consequences.  
I am referred for medical follow-up if my delirium is unresolved, my diagnosis is uncertain or dementia is suspected. |
|---|---|
| **Carers** | I am recognised as part of the care team and informed about the prevention and management plan.  
I am supported when I choose to be involved in the care of the person I care for.  
I am included in ward rounds and case conferences.  
I am involved in decisions about my relative going to hospital, while they are in hospital and future transition plans. My role in transitions is valued and supported.  
I am informed of and referred to community support services, when required. |
| **Whole of hospital workforce** | I am supported by the health service systems to provide safe and high-quality care for my patients.  
I make decisions in partnership with patients and carers.  
I am alert to changes in my patient that trigger review or changes in the prevention and management plan.  
I communicate patient and treatment changes to my team. |
| **Clinicians** | I have the knowledge and skills to provide all the components of safe and high-quality care.  
I have the knowledge and skills to recognise a person approaching their end of life and to discuss goals of care.  
I understand the importance and applicability of transition programs. |
| **Health service managers** | I ensure that wards, signage, walking trails and privacy are appropriately designed to maximise quality of care.  
I ensure that training programs are in place to respond to the needs of clinicians to provide safe and high-quality care to patients with cognitive impairment.  
I ensure that systems are in place to trigger advance care planning, and to document and review goals of care, including any limitations on medical treatments.  
I institute models of care for effective care transitions. |
Mr C is an 83 year-old man who resides in a residential aged care facility. His wife died several years previously. He has moderate cardiac failure, which is well controlled, non-insulin-dependent diabetes mellitus and severe osteoarthritis of his knees, leading to very impaired mobility. He has an advance care directive (ACD) saying that he does not wish to be admitted to the intensive care unit (ICU) or have ‘extraordinary treatment’ such as assisted ventilation or intubation.

One evening he developed increasing shortness of breath in his residential aged care facility, became quite confused and was calling out. The residential aged care facility staff called an ambulance and he was taken to the emergency department (ED) of his local hospital. Here, pneumonia and an exacerbation of his cardiac failure were diagnosed, and he was started on diuretics and antibiotics.

His condition continued to deteriorate overnight and he was transferred to the ICU early the next morning. His family was not notified until later in the morning that he had been admitted to hospital and transferred to the ICU. His daughter was upset that clinicians did not observe her father’s ACD. However, the ICU clinicians were not aware that there was one in existence, although staff at the residential aged care facility were aware that Mr C had completed one. Because of Mr C’s confusion on admission, he was not asked about this.

Mr C’s condition continued to deteriorate. His condition was discussed with his family, who requested that he be returned to the ward and receive supportive management, with a view to palliative care if he continued to deteriorate. His family felt that was what he would have wanted.
**What did not go well?**

| × Clinicians in the ED did not ask the residential aged care facility if there was an ACD in existence. |
| × The residential aged care facility did not provide information about the ACD. |
| × Clinicians in the ED did not contact family despite Mr C’s obvious confusion. |

**What went well?**

| ✓ Clinicians agreed to family’s request once the existence of an ACD was known. |

**What could have been done better?**

- ✓ Contacting family to participate in information exchange and healthcare decision-making at presentation.
- ✓ Contacting the residential aged care facility at presentation to participate in information exchange regarding an ACD.
Note that resources in other steps and mechanisms may also be useful in achieving Step 3.

**Systems approaches**

- **Acute-aged care interface** provides links to the resources developed by AHMAC’s national group, the Health Care of Older Australians Standing Committee, under the national action plan 2004–08. Resources include:
  - age-friendly policies and practices – managing older people in the health service environment
  - best-practice approaches to minimise functional decline in the older person across the acute, subacute and residential aged care settings
  - a guide for assessing older people in hospitals
  - clinical practice guidelines for the management of delirium in older people
  - the ‘how to’ guide, turning knowledge into practice in the care of older people
  - delirium care pathways.

- **Dementia care in hospitals: costs and strategies** is a report from the Australian Institute of Health and Welfare that summarises a range of strategies, including those within, outside and across sectors, aimed at improving outcomes for people with dementia.

- **Dementia services pathways** provide a framework for jurisdictions in dementia service planning and delivery. The case studies illustrate the practical considerations in implementing service provision. The case studies presented are:
  - person with dementia from an Aboriginal or Torres Strait Islander community (particularly in rural or remote areas)
  - person with dementia from a CALD background
  - person with younger onset dementia (under the age of 65 years)
  - person (with undiagnosed dementia) presenting to a hospital ED or other acute setting with other co-morbidities.

- **Assessing Care of Vulnerable Elders (ACOVE)**, developed by Rand Research, details the quality indicators for the care of dementia in vulnerable elders.

- **Quality indicators for geriatric emergency care**, published in *Academic Emergency Medicine* by Terrel, K et al., details six quality indicators for cognitive assessment, six for pain management and 11 for transitions between nursing homes and EDs.

- **Acute awareness: improving hospital care for people with dementia** highlights how hospitals can improve the quality and efficiency of acute care for people with dementia, and showcases the work of National Health Service trusts and cross-agency partnerships in the United Kingdom.

- **Using the Commissioning for Quality and Innovation (CQUIN) payment framework** outlines how the National Health Service in the United Kingdom is addressing the recognition of patients with dementia and other forms of cognitive impairment. Their approach is FAIR – find, assess, investigate and refer.


- **The Health Care Complaints Commission Annual Report 2012–13 (p.33)** provides a case study that details a complaint made to the commission about the care and treatment of a man with dementia in hospital, and the investigation and resolution of the complaint.
Patient-centred care

- **Patient and consumer-centred care**[^1], by the Commission, provides access to:
  - **Partnering with consumers Newsletter**[^2], which highlights some of the national and international work being done in this area
  - **Patient-centered care: Improving quality and safety through partnerships with patients and consumers**[^3]
  - **Health literacy: taking action to improve safety and quality**[^4]
  - **National Statement on Health Literacy**[^5].

- **The South Australian Dignity in Care Program**[^6] aims to change the culture of health services by reinforcing the importance of treating patients with dignity and respect.

- **Dignity in care: the dignity factors**[^7], from the Social Care Institute for Excellence, details eight research-informed factors that contribute to a person’s sense of self-respect:
  - choice and control
  - eating and nutritional care
  - communication
  - pain management
  - personal hygiene
  - practical assistance
  - privacy
  - social inclusion.

- **National Consensus Statement: Essential Elements for Safe and High-Quality End-of-life Care in Acute Hospitals**[^8], by the Commission, guides health services in the delivery of quality end-of-life care.

- **AMBER care bundle**[^9], developed by the New South Wales Clinical Excellence Commission, is an approach for clinicians to follow for end-of-life care.

Communication

- **Consumers, the health system and health literacy: taking action to improve safety and quality**[^10] and the **Health literacy stocktake: consultation report**[^11], by the Commission, discuss health literacy and the actions health care services can take to support and improve health literacy.

- **Dementia care**[^12], developed by the Centre for Cultural Diversity in Ageing, is a practice guide to culturally appropriate communication.

Pain

- **Pain assessment in the nonverbal patient: position statement with clinical practice recommendations**[^13] was developed by a task force approved by the American Society for Pain Management Nursing.

- **Pain and dementia**[^14] is a fact sheet developed by Alzheimer’s Australia.
**Medicines**

- **American Geriatrics Society updated Beers Criteria for potentially inappropriate medication use in older adults** is a special article from the *Journal of American Geriatrics Society* published in 2012.
- **Drugs, delirium and older people** outlines medicines that precipitate delirium, and reviews those used for treatment and prevention of delirium.
- **Antipsychotic overuse in dementia – is there a problem?**, published by NPS MedicineWise, provides practice points and a summary of recommendations when using antipsychotics for people with behavioural and psychological symptoms of dementia.
- **Anticholinergics and sedatives in older people – managing the risks**, published by NPS MedicineWise, highlights the risks for older people of cumulative use of anticholinergic and sedative medicines.

**Nutrition**

- **Position Statement No 6, Under Nutrition and the Older Person**, from the Australian and New Zealand Society of General Medicine, recommends screening in all settings, including acute care, to identify older people at risk of under-nutrition and the employment of a range of non-pharmacological management strategies.
- **Best care for older people everywhere: the toolkit – nutrition** was developed by the Victorian Department of Health.
- **Nutrition and dementia: A review of available research**, published by Alzheimer’s Disease International, summarises existing research, including under-nutrition in dementia and interventions to improve the nutrition of people living with dementia.

**Partnerships with carers**

- **This is me tool**, developed by the United Kingdom’s Alzheimer’s Society, allows people with dementia let health and social care professionals know about their needs, interests, preferences, likes and dislikes.
- **Top 5**, developed by the Central Coast Local Health District, is a program that promotes communication between clinicians and the carer of a patient with cognitive impairment. It was trialled and evaluated in New South Wales by the Clinical Excellence Commission’s **Partnering with Patients** program.
- **Communication and Care Cues**, by the Northern Sydney Area Health Network, is a form used to gather information from carers.
- **1000 Lives Plus** is the Welsh national healthcare improvement program. It includes guides and implementation tools, including spreadsheets for monitoring carer involvement.
- **The triangle of care: carers included – a guide to best practice for dementia care**, by the Carers Trust and the Royal College of Nursing in the United Kingdom, has been taken from mental health services and adapted for people with dementia in acute hospitals.
- **Carers (Recognition) Act 2010 (NSW)** and the **Carers Recognition Act 2012 (Vic)** are two examples of relevant legislation about carers.

**Management and prevention of delirium**

- **Hospital Elder Life Program (HELP)**, developed by the Yale University School of Medicine, is an evidence-based delirium prevention and management strategy.
- **Delirium model of care**, developed by the Western Australian Department of Health, is a comprehensive resource for clinicians.
- **Poole’s Algorithm: nursing management of disturbed behaviour in older people** provides a decision and action tree for delirium care pathways.
Hospital substitution, fast-track and transition programs

- **Transition Care Program**\(^{cxlvii}\), by the Australian Government, is a program that provides goal-oriented, time-limited and therapy-focused care to help older people at the conclusion of a hospital stay. Older people with dementia who can benefit from the program are eligible. Families and/or carers should be involved when a person with dementia is unable to express their care goals.

- **Patient safety – handover of care between primary and acute care policy review**\(^{cxlviii}\), prepared for the National Lead Clinicians Group, is a review and analysis that assessed opportunities for improvements in transitions of care.

- **Aged Care Emergency (ACE) program**\(^{cxlix}\), based on the models previously developed at Hornsby Ku-ring-gai Hospital Geriatric Rapid Acute Care Evaluation – (GRACE)\(^{cl}\) and the Aged Care Triage model developed at Concord Hospital, supports staff in residential aged care to manage residents’ non-life-threatening acute care. The program was successfully implemented at John Hunter Hospital Emergency Department. It provides final reports from 10 New South Wales hospitals funded in 2012–13.

- **Local practices influence hospital discharge for patients with dementia**\(^{cli}\) examines the Hospital Dementia Services Project, which explores how hospital-based services influence outcomes for people with dementia who were admitted to hospital in New South Wales.

- **Aged Care Services in Emergency Teams**\(^{clii}\) play an important role in rapidly identifying and assessing patients with cognitive impairment in EDs, facilitating discharge or fast-tracking admissions where appropriate.

- **Health service framework for older people 2009–16**\(^{cliii}\) is the South Australian framework for integrated care.

- **Residential In-Reach (RIR)**\(^{cliv}\) services provide an alternative to the ED, where appropriate and safe, for people living in residential aged care services. It was successfully piloted in Victoria and evaluated\(^{clv}\), demonstrating a reduction in unnecessary admissions without compromising the quality of patient care.

- **Hospital Admission Risk Program (HARP)**\(^{clvi}\), developed by the Victorian Department of Health, provides alternative interventions for clients at risk of, or already experiencing, frequent emergency presentations or hospital admissions.

- **Friend in Need – Emergency (FINE) Program**\(^{clvii}\) in Western Australia provides older and chronically ill patients with an alternative to an ED presentation or admission to hospital through a range of programs that include:
  - **Silver Chain Home Hospital**\(^{clviii}\), which delivers non-emergency hospital-level care to patients across the Perth metropolitan area at any time
  - a residential care line that supports residential aged care facility staff to care for residents in situ rather than calling an ambulance
  - ED care coordination teams that provide patient risk screening, assessment and safe facilitation back to the community.

Environmental design

- **Developing supportive design for people with dementia**\(^{clix}\), developed by the King’s Fund in the United Kingdom, provides access to resources to enable care environments to become more dementia friendly.

- **Dementia Enabling Environment Project (DEEP)**\(^{clx}\) provides information on the built environment, interior design and gardens (not hospital specific).

- **Adapting the ward for people with dementia**\(^{clxi}\), developed by NSW Health, guides small hospitals in improving the environment, and includes design principles and an audit tool.

- **Dementia friendly environments: a guide for residential care**\(^{clxii}\) has been developed by the Victorian Department of Health.
Educational resources

- Make SPACE for good dementia care\textsuperscript{cix}, from the United Kingdom Royal College of Nursing, provides details of the five ingredients needed to support good dementia care, and includes resources and good practice examples. The ingredients are:
  - Staff who are skilled and have time to care
  - Partnership working with carers
  - Assessment and early identification of dementia
  - Care plans that are person-centred and individualised
  - Environments that are dementia friendly.

- How acute care managers can support patients with dementia\textsuperscript{clxiv} includes advice on identifying patients’ diagnosis on admission, working with carers and encouraging activity, and emphasises the importance of establishing a rapport with patients.

- Improving quality of care for people with dementia in general hospitals\textsuperscript{clxxi} is an evidence-based Royal College of Nursing guide that provides a whole-of-hospital approach to care of patients with cognitive impairment.

- Southern NSW rural volunteer program\textsuperscript{c} trained volunteers in person-centred dementia and delirium care in two rural hospitals with high level of staff and volunteer acceptance.

- Ideas for managers on education\textsuperscript{clxvii}, by the Victorian Department of Health, is a fact sheet with education principles, such as:
  - base your education program on assessed local need and priorities
  - plan education in consultation with staff and consumers
  - draw on existing expertise and resources
  - encourage whole-of-facility training
  - provide resources and other post-training support and reinforcement
  - seek qualified and experienced trainers.

- Dementia: Osborne Park Hospital guide for occupational therapists in clinical practice\textsuperscript{clxvii} provides an overview of dementia, occupational therapy assessment processes and evidence-based strategies to address common issues related to the environment and activities of daily living.

- Acute hospitalization and Alzheimer’s disease: a special kind of care\textsuperscript{clxix}, by the United States National Institute on Ageing, provides communication and environmental tips to meet the needs of a patient with dementia.

Response to behavioural issues

- Dementia Behaviour Management Advisory Services (DBMAS)\textsuperscript{clxxi} provide clinical support for clinicians and family members caring for persons living with dementia, who present with behavioural and psychological symptoms of dementia. These services have expanded to hospitals.

- Behaviour management: a guide to good practice\textsuperscript{clxxi} was designed for clinicians of DBMAS. It outlines psychological, environmental and biological management strategies, backed by supporting evidence and an assessment of the quality of evidence. It also includes a comprehensive description of cultural competency and cultural consideration in working with Aboriginal and Torres Strait Islander people and people with CALD backgrounds. The guide has been condensed into a mobile ‘app’, A Clinician’s Field Guide to Good Practice and A Guide for Family Carers.
• Assessment and management of people with behavioural and psychological symptoms of dementia: a handbook for NSW health clinicians was developed by the NSW Ministry of Health and the Royal Australian and New Zealand College of Psychiatrists for clinicians in EDs, inpatient units and community settings. It promotes three key principles of care:
  - Ensure person-centred care.
  - Have a multidisciplinary and multiteam approach.
  - Meet legal and ethical responsibilities.
• Recognition and Management of Challenging Behaviour Program, by SA Health, is designed to identify priorities relevant to the prevention and management of challenging behaviours during health care, so as to minimise harm to workers and patients.
• Regional Dementia Management Strategy, developed by Bendigo Health, includes ‘ABCs’ of behaviour management.
Resources for carers

- **My aged care** provides information on aged care services, including caring for someone with dementia, on the National Respite for Carers Program and on the Transition Care Program. Information is also available on and through a national contact centre (phone 1800 200 422).
- **Alzheimer’s Australia** provides information on changed behaviours and dementia for carers and family.
- **Eastern Health** provides cue cards in community languages to aid in communication.
- **The National Prescribing Service** urges families of people with dementia to participate in monitoring treatment in a 2014 press release.
- **Pain and dementia** is a help sheet developed by Alzheimer’s Australia.
- **Carers Australia** is the national advocacy organisation for carers, which also provides national support programs for carers.

Attitude

- **The Essentials of Care (EOC) Program** is a New South Wales change management program aimed to at changing care and culture to provide dignified, safe and compassionate care. The program is underpinned by the methodology and principles of practice development, and the principles of collaboration, inclusiveness and participation.
- **Cultures of Care newsletter** is the newsletter for the EOC program.
Terminology

**Advance care directive:** A type of written advance care plan recognised by common law or authorised by legislation that is completed and signed by a competent adult. It records a person’s preferences for future care and appoints a substitute decision-maker to make decisions about health care and personal life management.67

**Advance care plan:** A plan that states preferences about health and personal care, and preferred health outcomes. An advance care planning discussion will often result in an advance care plan. Plans may be made on the person’s behalf, and should be prepared from the person’s perspective to guide decisions about care.67

**Advance care planning:** A process of planning for future health and personal care whereby a person’s values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate their decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed. Planning frequently involves the assistance of trained professionals, but people can choose to discuss their advance care plans in an informal family setting.67

**Alert:** A warning call, alarm or message that addresses concerns where urgent action may be needed to be provided about an actual or potential threat to patient safety.68

**Anticholinergic load:** The cumulative effect of taking one or more medicines with anticholinergic properties. Older people with dementia may be particularly susceptible to cognitive impairment associated with anticholinergic and sedative medicines. This impairment may be misattributed to the disease process itself. Even medicines with minor anticholinergic properties may contribute to unwanted central and peripheral adverse events if used in combination with other agents with anticholinergic effects. Clinically significant adverse events range from mild cognitive impairment to delirium.69

**Assessment:** A clinician’s evaluation of the disease or condition based on the patient’s subjective report of the symptoms and course of the illness or condition and the clinician’s objective findings, including data obtained through laboratory tests, physical examination, medical history, and information reported by family members and other healthcare team members.58

**BPSD:** Behavioural and psychological symptoms of dementia, which may include aggression, apathy, anxiety, agitation, psychotic symptoms, depression, disinhibited behaviours, wandering, nocturnal disruption and vocally disruptive behaviours.53

**CALD:** Culturally and linguistically diverse. A similar term is NESB, or non-English speaking background.

**Carers:** People who provide unpaid care and support to family members or friends who have a disability, mental illness, chronic condition, terminal illness, or alcohol or other drug issue, or who are frail or aged.70

**Caring culture:** The consistent, observable patterns of behaviour in an organisation that encourage interpersonal helping and influence people to go beyond the call of duty in watching over, attending to and providing for the needs of others.71,72

**Clinical handover:** The transfer of professional responsibility and accountability for some or all aspects of care for a patient, or group of patients, to another person or professional group on a temporary or permanent basis.73

**Clinical practice guidelines:** Systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific circumstances.74

**Clinical workforce:** Nursing, medical and allied health professionals who provide patient care, including students and other clinical trainees working under supervision. This may include laboratory scientists.74

**Clinician:** A healthcare provider, trained as a health professional. Clinicians include registered and nonregistered practitioners, or a team of health professionals providing health care who spend the majority of their time providing direct clinical care.74

**Cognitive impairment:** Deficits in one or more of the areas of memory, communication, attention, thinking and judgement. Dementia and delirium are common forms of cognitive impairment seen in hospitalised older patients and the focus of this resource.

**Competency-based training:** An approach to training that places emphasis on what a person can do in the workplace as a result of training completion.74
Cultural competency: A set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals that enables effective work in cross-cultural situations. ‘Culture’ refers to integrated patterns of human behaviour that include the language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups. ‘Competence’ implies having the capacity to function effectively as an individual and an organisation within the context of the cultural beliefs, behaviours and needs presented by consumers and their communities.75

Dementia Behaviour Management Advisory Service: An Australian Government–funded initiative that provides clinical support for people caring for someone with dementia who is demonstrating behavioural and psychological symptoms of dementia that are impacting on their care.76

Dementia: The progressive decline in cognitive function that affects memory, judgement, attention, language and problem solving.77 It is usually gradual, progressive and irreversible, leading to impaired functioning. The most common types are Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia or a combination of these.24

Delirium: An acute disturbance of consciousness, attention, cognition and perception that tends to fluctuate during the course of the day.77 It is a serious condition that is able to be prevented in 30–40 per cent of cases, and should be treated promptly and appropriately.51 Hospitalised older people with existing dementia are at the greatest risk of developing delirium. Delirium can be hyperactive (person can have heightened arousal, or can be restless, agitated and aggressive) or hypoactive (person can be withdrawn, quiet and sleepy).51

Diagnosis: The act or process of identifying or determining the nature and cause of a disease or injury through evaluation of patient history, examination and review of laboratory data, and the opinion derived from such an evaluation.78

Environment: The overall surroundings where health care is being delivered, including the building, fixtures, fittings and services such as air and water supply. Environment can also include other patients, visitors and the workforce.74

Evidence-based practice: Care where experience, judgement and expertise are integrated with knowledge about effectiveness gained from a systematic overview of all relevant high-quality research evidence.79

Goals of care: The aims for a patient’s medical treatment as agreed between the patient, family, carers and healthcare team. Goals of care may also include nonmedical goals such as returning home or reaching a particular milestone, such as participating in a family event. Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms or the primary aim of ensuring comfort for a dying patient.86

Hospital: A healthcare facility licensed by the respective regulator as a hospital or declared as a hospital.74

Hospital substitution services: The delivery of acute and post-acute care in settings other than an inpatient bed as a substitute for in-hospital care, also known as ‘hospital in the home’ services. They are provided across a range of specialties, diagnostic groups and treatments for patients with chronic or complex care, acute episodes or conditions requiring close monitoring or coordination.

Informed consent: A process of communication between a patient and their healthcare provider that results in the patient’s agreement to undergo treatment. This process should ensure that the patient understands all the available options and the expected outcomes, such as the success rates and/or risk of side effects for each option.80,81

Medication: The use of medicine for therapy or for diagnosis, its interaction with the patient and its effect.74

Medication error: Any preventable event that may cause or lead to inappropriate medication or patient harm while the medicine is in the control of the healthcare professional, patient or consumer.74

Nonclinical workforce: The workforce engaged in a health service organisation that does not provide direct clinical care but supports the business of health service delivery through administration, hotel service, transport and corporate record management, management support or volunteering.82
**Palliative care:** An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care interventions may be provided by a patient’s treating team or by specialist palliative care clinicians. All clinicians should be able to provide care consistent with a palliative approach, but specialist palliative care from providers with advanced training and expertise may be required for patients and families with complex care needs at the end of life.

**Patient-centred care:** Health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Different definitions and terminology have been used to describe the concepts in this area, but key principles of patient-centred approaches include:

- treating patients, consumers, carers and families with dignity and respect
- encouraging and supporting participation in decision-making by patients, consumers, carers and families
- communicating and sharing information with patients, consumers, carers and families
- fostering collaboration with patients, consumers, carers, families and health professionals in program and policy development, and in health service design, delivery and evaluation.

**Policy:** A set of principles that reflects the organisation’s mission and direction. All procedures and protocols are linked to a policy statement.

**Procedure:** The set of instructions to make policies and protocols operational, specific to an organisation or system.

**Protocol:** An established set of rules used for the completion of tasks or a set of tasks.

**Recognition:** The confirmation or acknowledgement of the existence of a condition.

**Risk:** The chance of something happening that will have a negative impact. It is measured by consequences and likelihood.

**Risk management:** The design and implementation of a program to identify, and avoid or minimise risks to patients, employees, volunteers, visitors and the institution.

**Screening:** A process of identifying patients who are at risk or already have a disease or injury. Screening requires sufficient knowledge to make a clinical judgement.

**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 for (on behalf of) the person, or identified as the default decision-maker by legislation that varies from state to state.

**System:** The resources, policies, processes and procedures that are organised, integrated, regulated and administered to accomplish the objective of a standard.

**Training:** The development of knowledge and skills through formal or informal courses and workshops.
**Transition of care:** A set of actions designed to ensure coordination and continuity of care as patients transfer between services. Transitions of care occur in real time, during weekends and overnight, are usually short lived and often involve clinicians who do not have an ongoing relationship with the patient. They occur when a patient is leaving a health service, or being transferred to a different institution or level of care, and generally consist of one or more clinical handovers. The process ends only when the patient is received into the next clinical setting. Transition of care is heavily involved in the processes of admission, referral and discharge, and is considered a unique and distinguishable process from any other healthcare setting.55

**Workforce:** All those people working in a health service organisation.
References


Resource links

Step 1 Be alert to delirium and the risk of harm for patients with cognitive impairment

Mechanism 1: Establish responsive systems
don't/capacity_tool.html
xliv. www.pogoe.org/

Mechanism 2: Ensure a skilled and informed workforce
xlix. www.internationaldementiahospitalhub.com/
Mechanism 1:
Establish responsive systems

Mechanism 2:
Ensure a skilled and informed workforce

Step 2 Recognise and respond to patients with cognitive impairment

Mechanism 3:
Enable partnerships between clinicians, patients, carers and families

v. www.bhs.org.au/node/130

Mechanism 1:
Establish responsive systems

bxii. http://ageing.oxfordjournals.org/content/42/6/689.long
bxviii. www.dsm5.org/
boxxx. www.nice.org.uk/guidance/cg103/delirium-full-guideline3
boxxxi. www.nice.org.uk/guidance/cg103/resources/cg103-delirium-full-guideline3
boxxxii. www.nice.org.uk/guidance/cg103/resources/cg103-delirium-full-guideline3
Mechanism 3:
Enable partnerships between clinicians, patients, carers and families

Mechanism 1:
Establish responsive systems

Resource links

Step 3
Provide safe and high-quality care tailored to the patient’s needs
Mechanism 2:
Ensure a skilled and informed workforce

Mechanism 3:
Enable partnerships between clinicians, patients, carers and families

Additional resources
Appendix 1 Cognitive impairment safety and quality matrix

Cognitive impairment safety and quality matrix

Responsive system  Skilled and informed workforce  Partnerships with patients, carers and families

**Implementing systems**
- Establish and implement systems to enable workforce to be alert to the risk of delirium and harm.
  NSQHS Standards actions: 1.6.1

**Monitoring and reporting**
- Monitor and report on the systems to enable workforce to be alert to the risk of delirium and harm.
  NSQHS Standards actions: 1.5.1, 1.6.1

**System improvements**
- Ongoing improvement of the systems that support workforce to be alert to the risk of delirium and harm.
  NSQHS Standards actions: 1.5.2, 1.6.2

**Information systems**
- Develop information exchange systems.
  NSQHS Standards actions: 1.9.1, 6.1.1, 6.2.1, 9.8.1, 9.8.2

**Monitoring and reporting**
  NSQHS Standards actions: 1.2.1, 1.4.1, 1.5.2, 1.5.3, 1.6.1, 1.14.2, 1.15.2, 6.3.1, 8.9.3, 10.1.2

**System improvements**
- Ongoing improvement of the systems that support screening for cognitive impairment, risk assessments, delirium assessment, re-assessment, investigation and treatment.
  NSQHS Standards actions: 1.1.2, 1.2.2, 1.6.2, 1.8.3

**Information for patients and carers**
- Enable patient and carer partnerships through the provision of information.
  NSQHS Standards actions: 1.17.1, 1.17.2, 1.17.3, 1.18.3

**Recognition and respond**

**Safety and quality pathway**

**Safety and quality pathway**

**Responsive system**

**Implementing systems**
- Establish and implement systems for screening for cognitive impairment, risk assessments and delirium assessment, re-assessment, investigation and treatment.
  NSQHS Standards actions: 1.1.1, 1.8.1, 1.8.2, 1.8.3, 8.1.1, 8.5.2, 10.1.1, 10.6.2

**Information systems**
- Develop information exchange systems.
  NSQHS Standards actions: 1.9.1, 6.1.1, 6.2.1

**Monitoring and reporting**
  NSQHS Standards actions: 1.2.1, 1.4.1, 1.5.2, 1.5.3, 1.6.1, 1.14.2, 1.15.2, 6.3.1, 8.9.3, 10.1.2

**System improvements**
- Ongoing improvement of the systems that support screening for cognitive impairment, risk assessments, delirium assessment, re-assessment, investigation and treatment.
  NSQHS Standards actions: 1.1.2, 1.3.2, 1.6.2, 1.8.3

**Information for patients and carers**
- Enable patient and carer partnerships through the provision of information.
  NSQHS Standards actions: 1.18.1, 1.18.3, 6.5.1, 4.13.2, 6.8.1, 6.8.10, 10.8.1, 10.10.1

**Education and training for clinicians**
- Provide access to training opportunities, resources and tools to relevant clinicians to enable them to recognise and respond to patients with cognitive impairment.
  NSQHS Standards actions: 1.4.1, 1.4.2, 1.4.3, 1.4.4, 1.10.5, 1.12.1

**Cognitive impairment screen and risk of harm**
- Undertake screening for cognitive impairment and the risk of harm.
  NSQHS Standards actions: 1.3.3, 1.4.1, 1.4.3, 1.4.4, 4.6.1, 8.5.1, 10.5.1

**Delirium assessment, investigation and treatment**
- Undertake delirium assessment, re-assessment, investigation and treatment for all patients with cognitive impairment.
  NSQHS Standards actions: 1.1.1, 1.3.1, 1.3.2, 1.7.1, 1.8.1, 1.8.2, 1.8.3

**Integrated prevention and management plan**
- Develop an individualised, integrated prevention and management plan based on the assessments undertaken.
  NSQHS Standards actions: 4.14.1, 8.7.1, 8.8.2, 8.10.1, 9.8.1, 10.7.1, 10.8.1, 10.10.1

**Education and training**
- Provide workforce education on providing safe and high-quality care.
  NSQHS Standards actions: 1.3.1, 1.4.2, 1.4.3, 1.10.1, 1.10.5, 1.12.1, 2.8.1

**Individualised and integrated prevention and management plan**
- Implement an individualised, integrated prevention and management plan incorporating the following components:
  - individualised care
  - management of medical issues
  - management and prevention of delirium
  - prevention and minimisation of harm
  - response to behavioural issues
  - modification of the environment
  NSQHS Standards actions: 1.7.2, 1.8.2, 3.19.2, 4.6.1, 4.7.2, 4.14.1, 8.7.2, 8.7.4, 8.8.4, 8.10.1, 9.8.1, 10.6.3, 10.7.1, 10.7.2, 10.7.3, 10.1.2, 10.8, 10.10.1

**Information for patients and carers**
- Enable patient and carer partnerships through the provision of information.
  NSQHS Standards actions: 1.18.1, 1.18.3, 6.5.1, 4.13.2, 6.8.1, 6.8.10, 10.8.1, 10.10.1

**Partners in decision-making**
- Consult patient and carers in clinical decisions: involve carers in case conferencing and clinical handovers.
  NSQHS Standards actions: 1.18.1, 1.18.3, 6.5.1, 8.10.1, 10.10.1

**Partners in care**
- Support patients and carers to be involved in care.
  NSQHS Standards actions: 2.8.1, 3.19.1, 4.15.1, 8.9.1, 10.10.1
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