My Healthcare Rights

A guide for people with cognitive impairment

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

Caring for Cognitive Impairment

Aboriginal and Torres Strait Islander people are warned that this publication may contain images of deceased people.

People with cognitive impairment have the right to be safe and be supported when receiving healthcare, as outlined in the Australian Charter of Healthcare Rights.

The **Australian Charter of Healthcare Rights** explains the rights that apply to all people in all healthcare settings.

The Charter describes what you, or someone you care for, can expect when receiving health care.

This guide is for people with cognitive impairment, carers, families and support people. The purpose of this fact sheet is to provide further information about keeping you safe and supported when you are in hospital and other healthcare environments.

What is cognitive impairment?

People at any age may live with cognitive impairment due to conditions such as dementia, delirium, acquired brain injury, stroke or intellectual disability.

Cognitive impairment can be permanent, as with dementia, or a temporary experience, such as delirium.

People with cognitive impairment may have difficulties with memory, emotions, thinking or communicating. There are different kinds of cognitive impairment, and this is experienced differently by each person.

A person living with an existing cognitive impairment, including dementia, is more likely to also develop delirium during their hospital stay.

What do I need to know?

Healthcare environments are required to provide high quality health care for people with cognitive impairment and keep them safe.

There are eight National Safety and Quality Health Service Standards to protect people from harm and to improve the quality of healthcare. These Standards set the level of care for patients and must be in place in healthcare environments.

There are different groups of people working together to keep people with cognitive impairment safe and supported in healthcare environments. This includes the person with cognitive impairment, carers, family members and healthcare staff.

You have the right to access **interpreters and translation services**. It is very important for healthcare staff know **if you need these services**.

Translation & Interpreter Services are available 24 hrs 7 days: Phone 131 450

What can I do?

For people with cognitive impairment including delirium

You have the right to tell your doctors, nurses and other healthcare workers:

- if you do not feel your normal self at any time
- what assistance you need
- what is important to you
- your treatment preferences
- your advance care planning
- any current medications you are taking.

You have the right to receive clear information about your condition, the possible benefits and risks of different tests and treatments, so you can give informed consent.

You have the right to participate in decision-making and be supported to do so. If you are unable to consent to treatment, staff must obtain consent from your substitute or legal decision-maker, except in emergencies.

You have the right to ask that your carer, a family member or support person be involved, if this is what you want.

You have the right to be treated in a safe, calm and respectful environment.

You have the right to be told if something has gone wrong during your care.

For family members and carers

As a family member or carer, you can contribute to safe and high-quality care and help ensure the person you care for is supported and feels safe while in a healthcare environment. Your involvement should always reflect the needs and preferences of the person you care for.

You have a responsibility to:

- Let healthcare staff know if the person you care for is not their normal self on admission or at any time in their hospital stay.
- Explain to healthcare staff the person's routine, what assistance might be helpful, and how they can be comforted in your absence.
- Provide the hospital with an up-to-date list of all prescription and non-prescription medicine and the dosages and to bring all medicines to hospital.

What can family and carers do to help?

SPEAK to healthcare staff if the person you care for is not themselves

REMIND your loved one of the day, date and situation

KEEP all glasses, hearing aids, mobility aids, and dentures close by

BRING all up-to-date medications with you

TALK about family, friends and familiar topics

See sources.

Supporting people with cognitive impairment with decision-making is a key issue when they receive healthcare.

- A person with decision-making ability has the right to make **independent** decisions about their own life.
- If a person cannot make decisions on their own, they have a right to be supported, and assisted in making decisions from a support person of their choice such as a family carer or friend – this is called **supported decision-making.**
- If and when a person does not have decision-making ability, another person can be appointed in advance by the person or by a tribunal, or assigned under State and Territory laws, if no-one has been appointed – this is called **substitute decision-making.**

Where, possible, you should obtain consent from the person you care for to participate in treatment discussions and decisions about ongoing care. Involve the person as much as possible in the discussion.

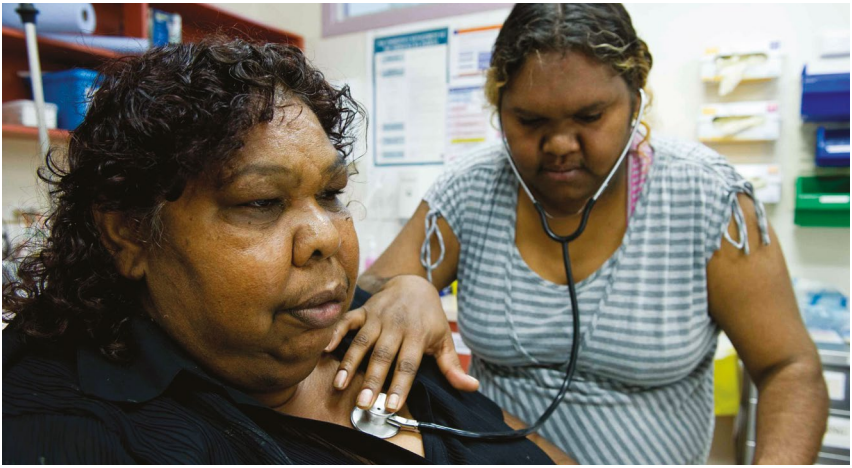
What can I expect?

From healthcare staff

All healthcare staff are required to provide safe, respectful and high quality care for people with cognitive impairment, including access to an interpreter or translation services whenever needed.

All healthcare organisations are required to recognise when a patient has cognitive impairment and to work with the person, carers and families in a safe, calm and respectful environment.

As part of the National Safety and Quality Health Service Standards, all healthcare organisations are required to screen for cognitive impairment, and respond to changes in a patient's cognition. Healthcare staff must identify people at risk of delirium and put steps in place to minimise harm as a requirement of Standard 5: Comprehensive Care Standard.



What if things don't go to plan?

Feedback and Complaints Processes

Healthcare organisations, including hospitals, value your feedback. It helps the organisation understand what they are doing well, and what might need to improve. If you have a complaint about your care or the person you care for, try to resolve it directly with the healthcare organisation. If the organisation does not respond, or you are not happy with the response you receive, you may wish to contact your state's health complaints authority.

If things don't go to plan, there is a formal process called **Open Disclosure**. Open Disclosure is the discussion between the healthcare organisation and the person, their family, carers and other support persons about incidents that happened during care which caused harm to the patient. To find out more about Open Disclosure, please see further information on the next page.

Where can I find more information?

Useful websites

- Australian Charter of Healthcare Rights: **safetyandquality.gov.au/australian-charter-healthcare-rights**
- Open Disclosure information for consumers: **safetyandquality.gov.au/our-work/clinical-governance/open-disclosure/implementing-open-disclosure-framework/open-disclosure-resources-consumers**
- Top Tips for Safe Health Care: **safetyandquality.gov.au/publications-and-resources/resource-library/top-tips-safe-health-care**
- Caring for Cognitive Impairment: **cognitivecare.gov.au**
- Dementia Australia: Helpline 8.00am and 8.00pm EST, Monday to Friday, 1800 100 500: **dementia.org.au**
- Advance Care Planning Australia: **advancecareplanning.org.au/#/**
- Cognitive Decline Partnership Centre: **cdpc.sydney.edu.au/research/planning-decision-making-and-risk**
- Australian Delirium Association: **delirium.org.au**
- Brain Injury Australia: 1800 272 461: **braininjuryaustralia.org.au**

Sources

1. Sinclair C, Field S, Williams K, Blake M, Bucks RS, Auret K, Clayton J, Kurrle S. Supporting decision-making: A guide for people living with dementia, family members and carers Sydney: CDPC; 2018.

2. Adapted from: Dementia Australia.

Acknowledgement

This resource was developed in collaboration with Dementia Australia, people living with dementia, and carers.

Caring for Cognitive Impairment

Useful Definitions:

Healthcare environments include public and private hospitals, day surgeries, outpatient services, rehabilitation and dental hospitals, and when moving in and out of these healthcare environments.

Dementia is a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia may affect thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social, emotional or working life.

Delirium is a temporary condition. A person may feel confused, disoriented and unable to pay attention. Delirium may have serious consequences if untreated, but can be reversed if causes are found and treated. Delirium can be caused by medications, infection, dehydration or constipation.

For more information visit
safetyandquality.gov.au/your-rights