

**Carers Australia Submission to
the Australian Commission on
Safety and Quality in Health Care on
the draft National Safety and Quality Health Service
Standards (third edition)**



September 2026

About Carers Australia and carers

Carers Australia is the national peak body¹ representing over 3 million carers (around 12% of the population). Carers are people who provide care and support to family members and friends who live with disability, mental illness, a chronic condition, terminal illness, an alcohol or substance issue or who are frail aged.

Our vision is an Australia that values and supports all carers, where all carers have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment, and education.

Unpaid carers, their invaluable contribution and their role in health care

Unpaid carers make an invaluable contribution to the care and lives of the people they care for, and to the community more generally. The contribution of Australia's carers was estimated to be \$78 billion in annual replacement care costs in 2020.² Today that equates to around \$94 billion.

Unpaid carers are an integral, and vital component of Australia's health care system. They often become experts in the health of the people they care for, and many carers provide most of the daily health care of the person they care for. Carers' roles can include navigating, information/record keeping and advocating for the person they care for, as well as providing hands on health care.

Based on the 2022 Survey of Disability, Ageing and Carers (SDAC):

- of the 4.4 million Australians aged 65 years and over (96% lived in households), 87% had one or more long-term health conditions (the average was 3.5 conditions), and of those requiring assistance, 38% received health care from a family or friend carer
- of the 5.3 million Australians with disability (living in households), 61% required assistance with at least one activity of daily living. Assistance with health care (30%) and with cognitive and emotional tasks (25%) were among the most needed. And among people with disability with a profound limitation (living in households), the greatest need for assistance was with mobility (83%) followed by health care (70%).³

Depending on the nature and condition of the person being cared for, carers provide a range of health-related assistance. As an example, carers may need to operate medical equipment such as enteral feeding devices, breathing apparatus and home dialysis. They may also undertake wound management and in the mental health space, provide emotional support and management of challenging behaviours. And when patients are unable to manage their own medications, unpaid carers take on that responsibility.

But while carers provide essential health care, they continue to report that they feel unrecognised, and even 'invisible' within the health care system. Carers report that health professionals rarely seek their insights on the person they care for, or listen to what they have to

¹ Our member organisations are the carer organisations in each state and territory.

² Deloitte Access Economics (2020) [The value of informal care in 2020](#).

³ [Disability, Ageing and Carers, Australia: Summary of Findings, 2022 | Australian Bureau of Statistics](#)

say, and they are often excluded from health care processes, such as care planning and hospital discharges.⁴ 44% of carers responding to the 2025 Carer Wellbeing Survey said that they did not feel recognised and valued as a carer in the health system/or education system and 48% of carers said they disagreed with the statement ‘my experience and knowledge as a carer is recognised by health professionals’.

Young carers (those aged between 15 and 24) particularly struggle with being recognised as a carer by health professionals – 48% responding to the 2025 Carer Wellbeing Survey said they felt unrecognised. As one young carer put it:

‘A lot of doctors and a lot of specialists, a lot of carers overlooked me because I was young. The feeling of it was just terrible because I’m the person, like you said, 24 hours a day.’

About our submission

Carers Australia welcomes the opportunity to provide a submission to the Australian Commission on Safety and Quality in Health Care on the initial draft of the National Safety and Quality Health Service (NSQHS) Standards (third edition). Our submission makes some general comments about the Standards before highlighting what is missing and making recommendations about what changes should be made to the Standards.

Support for the vision, direction and structure of the Standards

Carers Australia supports the vision of the NSQHS Standards of ‘high-quality care for all Australians, supported by nationally consistent and effective systems operating across the continuum of care’ and the acknowledgement that ‘engagement and partnerships with patients, families, carers, consumers and community are critical to achieving high-quality care and better patient outcomes’.⁵

Carers Australia also supports:

- the new structure of the Standards – the streamlining of the eight Standards in the second edition into three integrated standards
- the three areas of focus – Clinical Governance, Person-Centred Practice and Safe Clinical Systems
- the weaving of requirements and expectations for partnering with consumers throughout the Standards
- moving organisations from a compliance to an outcomes and learning focus.

Carers are mentioned, but not adequately recognised or integrated into the Standards

Carers Australia is pleased to see that families and carers are referred to across the Standards and in some places their role is recognised, and clinicians are required to seek input from them. Some examples include:

⁴ [2025 National Policy Forum: Recognising Carers in Health Systems in Australia](#)

⁵ Australian Commission on Safety and Quality in Health Care. *National Safety and Quality Health Standards (Third Edition) – Initial draft*. 2026, pp. 4.-5 [nsqhs-third-edition-initial-draft_1.pdf](#)

- the section on partnering with patients in their healthcare which requires clinicians to ‘involve the patient’s family and carers in discussions about the patient’s care, investigations, treatments and care decisions’
- the section on caring for the whole person which speaks to using ‘clinical assessments, including relevant input from patients, their family and carers’ and multidisciplinary care teams documenting the plan for care and clinical decision in the healthcare record including ‘timeframes and the actions required by clinicians, the patient, their family and carers’
- the section on recognising and responding to acute deterioration which requires clinicians to ‘follow organisational systems to routinely ask patients, their family and carers to share key information and observations, including changes in condition or concerns, to support early recognition of deterioration’.
- the section on behaviours of concern which states that ‘the clinical and non-clinical workforce contribute to the safe and effective management of behaviours of concern by working in partnership with each other and with patients at risk, their family and carers to identify triggers and develop preferred deescalation approaches’.⁶

However, most references to carers do not go as far as formally recognising, engaging or integrating carers into health system processes (for example, there are no formal requirements for health services to identify carers or seek information from carers about their capacity to care). This is despite insights from international best practices that highlight the value of proactive systems that embed carer recognition into referral pathways and care planning.⁷ An example is the *NHS England Carers Toolkit* which showcases best-practice examples where carers are routinely identified, supported, and signposted via established pathways.⁸

There is also evidence to show that integrating carers into hospital processes (including from admission through to discharge planning) can improve patient and health system outcomes. For example:

- a study looking at patient experience at US Hospitals following the passage of the Caregiver Advise, Record, Enable (CARE) Act – which was designed to facilitate communication among patients, caregivers, and clinical care teams during hospitalisation – found that policies that formally incorporating carers in patient care during hospitalisation can improve patient experience and patient outcomes.⁹
- a study looking at the role of the carer in patients’ preparedness for hospital discharge pointed to the importance of engaging with carers during the hospitalisation process as a pathway linking pre-admission support to discharge preparedness. The findings of the study supported early identification of carers and health literacy at admission so

⁶ [nsqhs-third-edition-initial-draft_1.pdf](#)

⁷ Carers Australia 2025, *National Policy Forum: Recognising Carers in Health Systems in Australia*, p. 22.

⁸ [NHS England » Carers toolkit](#)

⁹ Lee, Taggart, Coe, et al (2023), *Patient Experience at US Hospitals Following the Caregiver Advise, Record, Enable (CARE) Act*, [Patient Experience at US Hospitals Following the Caregiver Advise, Record, Enable \(CARE\) Act - PMC](#)

healthcare providers can tailor communication and better engage carers in the discharge process.¹⁰

- a meta-analysis of 15 randomised controlled trials found that including carers in hospital discharge planning for older adults resulted in 25% fewer hospital readmissions at 90 days, and 24% fewer readmissions at 180 days compared with standard discharge processes. The authors concluded that the findings suggested that ‘policies that incentivise and require inclusion of caregivers may benefit the patients and payers’.^{11,12}

The Standards also fail to recognise the dual role of carers as providers of care and as individuals needing support because of their caregiving role. For example, while a carer may have extensive insights on the context, preferences and disease history of the person they care for, they could also need information about disease progression and management, how to deal with emerging issues and where to get support for themselves.

Carers are also likely to need support from health professionals and health care organisations for their own health and wellbeing so they can continue in their caring role. Only 15% of carers responding to the 2025 Carer Wellbeing Survey reported very good or excellent health which is less than half the 44% of adult Australians who reported being in very good or excellent health.¹³ When carers were asked whether they had been given advice about where to find support for the person they care for, or for themselves, just 31% said a General Practitioner had given them such advice. Other sources of reported advice to carers from within the health sector included: a specialist (19%), a nurse (10%), a pharmacist (3%), a hospital liaison officer or other hospital staff (20%), an occupational therapist (14%), a mental health professional (14%).¹⁴

Health professionals should be recognising and supporting carers, including at diagnosis and/or escalation in the health conditions of the person they care for. This should include alerting carers to what might be expected of them in the caring journey as well as making them aware of the supports available to them.

At the 2025 National Policy Forum on Recognising Carers in Health System in Australia convened by Carers Australia, the two most urgent areas for attention, as voted by participants were:

1. Making health care systems more proactive at referring carers to supports.

¹⁰ [Family caregiver role in care recipient preparedness for hospital discharge: A parallel mediation model | PLOS One](#)

¹¹ Rodakowski J, Rocco P, Ortiz J, Folb B, Schulz R, Morton S, Leathers S, James E. *The role of caregivers in improving outcomes: caregivers included in discharge planning reduces hospital readmissions: a meta-analysis*. Innov Aging. 2017 Jun 30;1(Suppl 1):737. doi: 10.1093/geroni/igx004.2658. PMID: PMC6248446. See: <https://pmc.ncbi.nlm.nih.gov/articles/PMC6248446/>

¹² The findings on the benefits for payers are particularly relevant for the recently formed national Hospital Discharge Joint Taskforce which is undertaking a review into the costs and impacts of older patients stranded in hospitals. The benefits are compelling: costs to taxpayers are around \$2,500 per day for a hospital stay, compared to \$220/day for Support at Home Program and \$10 for Community Home Support Program.

¹³ [CWS25 Report 300126 v2 .pdf](#)

¹⁴ 2025 Carer Wellbeing Survey, unpublished data.

2. Stronger health care system carer identification, recognition and navigation.¹⁵

Under the National Carer Strategy 2024-27 Action Plan¹⁶, the Australian Government has also committed to improving the identification and recognition of carers and ensuring they are provided with information relevant to their role and the support available to them.

- Action 2.2: Work across the Commonwealth and with states and territories to support carers to be identified and provided with information relevant to their caring role and available supports through those working in medical/health systems and education systems such as GPs, pharmacists, hospital liaison officers, educators and school counsellors.
- Action 2.3: Explore ways to improve professional training and resources for health sector professionals to better identify unpaid carers, recognise their expertise, and refer them to appropriate support services.

Changes to strengthen the Standards to support the delivery of high-quality care and better health outcomes

Referencing the Carer Recognition Act

The Standards would be strengthened by referencing the *Carer Recognition Act 2010*.

While Carers Australia is pleased to see there is a definition of the term ‘carer’ in the glossary, we recommend that the Standards reference the formal definition of carer in the *Carer Recognition Act 2010*.

Under sub-section 1.10 Patient rights underpin how health care is provided (under the Partnering with consumer section), the board, executive and leaders are required to have organisational systems to:

- ‘a. adopt and make available a charter of rights that is consistent with the *Australian Charter of Health Care Rights* to patients, their family and carers, consumers and the workforce
- b. educate the workforce on patient rights consistent with the *Australian Charter of Health Care Rights* and embed these rights in organisational culture and the provision of clinical care.’

Carers Australia recommends that the *Carer Recognition Act 2010* also be referenced (*along with the Australian Charter of Health Care Rights*). The Act stipulates that carers should be regarded as partners in care, a principle that is also in the new Aged Care Act.¹⁷ Including a reference to the Act will help emphasise carers as partners in care in the healthcare system.

¹⁵ Carers Australia, [2025 National Policy Forum: Recognising Carers in Health Systems in Australia](#), p. 5.

¹⁶ [National Carer Strategy Action Plan - English](#)

¹⁷ *Aged Care Act 2024*

Better recognition of carers, their roles, contributions and capacity to care

The Standards would also be strengthened by requirements to recognise carers and their roles and contributions as partners in delivering healthcare.

Carers Australia recommends embedding carer identification processes in health care settings, including in care plans, hospital admissions and discharge planning.

The Standards should require identification (and documentation) of carers, and their role, responsibilities, capacity to care and support needs. It is particularly important that a carer's capacity, willingness, and safety and support needs are part of care plans, including discharge and transition planning. This should include confirming what care is expected, potential warning signs, whether the carer can safely provide the care, whether additional supports are needed, and what follow-up will take place.

The Standards as currently drafted would also benefit from better recognition of carers in medication management. Medication-related harm is a significant patient safety risk, and as noted earlier, carers are often required to manage and administer medicines. They are also often the first to identify side effects or adverse reactions.

Better recognition of carers at the beginning of care journeys and hospitalisations and care transitions, will result in better outcomes for patients, carers and the health system.

While the Medicines safety and quality section of the Standards speak to clinicians using a structured approach to 'communicating medicine changes to the patient, their family and carers', it does not mention engaging with carers in medication management or seeking input from carers (or patients) about medicine effectiveness and side effects. This Standard would be strengthened by more explicit recognition of the role of carers in medicine safety and a requirement for clinicians to take into account carer input on medications, including concerns and observations. The Standards should also include carers in safety-critical communications and seek relevant input on medications administered to the person they care for.

Information, training and supports to carers to safely undertake health care caring responsibilities is also important for safety and good patient outcomes. Carers Australia recommends that the Standards more clearly state that relevant information should be provided to patients and carers where appropriate, with regards to consent, privacy, safety, and the role and capacity of the carer.

Carers not having adequate and appropriate information and training can result in care being provided unsafely, and there is increased risk of patients landing back in hospital, injuries and delayed recovery. When carers are involved in discharge planning, patients are more likely to experience a safe transition from hospital to home.

As an example, Carers Australia has heard from carers about being given an instruction sheet to take home with them on how to use medical devices when the person they care for was being discharged from hospital. We suggest a requirement that carers are provided with education and training relevant to the care they provide prior to a patient being discharged from hospital.

The Medical Devices section of the Standards does not cover training in the use of medical devices. Under the US Care Act, there is a requirement for hospitals to train carers in care management prior to a patient being discharged from hospital. Carers Australia recommends that training be covered in this section, particularly for carers who are required to use medical devices (such as enteral feeding devices, breathing apparatus, home dialysis, monitoring devices).

Improved access and referrals to carer supports

Better identification and recognition of carers within health care settings (primary care and hospital settings) should support improved access and referrals to carer supports (such as respite and counselling). As noted earlier, the National Carer Strategy Action Plan commits to supporting carers to be provided with information relevant to both their caring role and available supports, including in health care settings. Where processes are in place to identify carers in health care settings, there should also be processes to offer referrals to appropriate carer supports.

Indicators that carers are being identified, included and supported

To ensure carers are being recognised and supported, the Standards should encourage services to track and report on carer-inclusive practices. The Clinical Governance Standard could require organisations to monitor and improve carer identification and engagement as part of quality and safety systems. Reporting could include:

- rates of carer identification and recording of patient records
- rates of carer involvement in care planning, including discharge and transition planning
- whether carers received adequate information and training to safely undertake their caring role
- whether discharge planning considered carer safety, capacity and support needs
- post-discharge follow-up and representation outcomes where relevant.
- rates of carer-related complaints and feedback and carer involvement in incident review where appropriate.

Digital initiatives

Carers Australia is also of the view that the Standards should reference digital initiatives aimed at improving improvements in healthcare. The Standards define what good looks like and National Digital Health Strategy describes how digital technology can help deliver it.

Carers Australia recognises the importance of the Strategy in providing a transformation framework which sets the vision and direction for the interoperability of patient records; Sparked (Fast Healthcare Interoperability Resource Accelerator) defines interoperability standards; the Single Digital Patient Record (SDPR) in NSW public hospitals formally recognises

carers. SDPR implements standards in clinical practice, and the resulting carer dataset makes carers visible and allows them to be involved across a patient's care journey. Carers Australia is of the view that the SDPR should be adopted in hospitals in all other states and territories, and that the Standards are fundamental to the success of these digital initiatives.

Concluding comments

The NSQHS Standards are a solid foundation for patient safety and quality. However, they do not adequately recognise carers as partners in care or integrate them in safety and quality systems. For high-quality care for all Australians, supported by nationally consistent and effective systems operating across the continuum of care, the Standards should require that:

- carers are identified early in the episode of care
- carers are included in shared decision-making where appropriate
- carers are engaged in medication management and discharge planning
- carers are provided with education, safety information and training (when required) and referrals to carer supports
- there is tracking and reporting of carer identification and engagement as part of quality and safety systems
- carers are recognised as partners in clinical governance, person-centred practice and safe clinical systems.

A simple principle could be: 'Nothing about the patient without the patient and, where appropriate, their carer.'

About Carers

Our definition of a carer aligns with the *Carer Recognition Act 2010*:

Section (1) For the purpose of this Act, a carer is an individual who provides personal care, support and assistance to another individual who needs it because that other individual:

- a) has a disability; or
- b) has a medical condition (including a terminal or chronic illness); or has a mental illness; or
- c) is frail and aged.

Section (2) An individual is not a carer in respect of care, support and assistance he or she provides:

- a) under a contract of service or a contract for the provision of services; or
- b) in the course of doing voluntary work for a charitable, welfare/community organisation; or
- c) as part of the requirements of a course of education or training.

Section (3) To avoid doubt, an individual is not a carer merely because he or she:

- a) is the spouse, de facto partner, parent, child or other relative of an individual, or is the guardian of an individual; or
- b) lives with an individual who requires care.

Carers Australia also recognises carers who provide unpaid care for people experiencing drug and substance issues.

Key Statistics



3 million carers across Australia *



11.9% of people in Australia are carers *



11% of carers are aged under 25 years (391,300); an increase of 60% since 2018*



30% of primary carers cared for 40 hours per week or more*



4.6% of all people in Australia (1.2 million people) are primary carers, those who provide the most informal care support to a family member or friend *



43.8% of primary carers have disability themselves*

Further information:

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