

## Strengthening the NSQHS Standards to Better Recognise and Partner with Carers

### Submission to the Public Consultation on the review of the National Safety & Quality Health Service Standards

#### About Carers SA

Carers SA is the peak advocacy body for Carers in South Australia. Raising the voice and recognition of Carers, their rights, wellbeing and needs are at the heart of Carers SA's efforts. We persistently advocate across governments, health and social services and systems, business and communities to prioritise appropriate and meaningful support and services for Carers. Carers SA aims to ensure that Carers needs, wishes, values and perspectives are elevated and able to inform and influence decision-making by government, service providers, policy makers, legislators, and systems and services to improve the lives and wellbeing of Carers in South Australia.

Carers SA is both a peak body and a service provider for Carers through the Carer Gateway and other state funded programs. This provides us with a unique opportunity to understand the needs of Carers and identify and implement ways to improve the services they use. It enables us to engage with many and diverse Carers across South Australia through our broad networks and through services and supports. This positions Carers SA to raise awareness of issues facing Carers and raise the voice of Carers to inform and influence policy and decision-making about issues that impact them.

#### Carers Fill the Gaps in Health Care

Carers are critical to patient safety, quality care, and the sustainability of the health system. Supporting them reduces readmissions, improves patient outcomes, and prevents Carer burnout. The NSQHS Standards are the right mechanism to embed this partnership consistently across Australian health services.

In Australia there are **three million unpaid Carers** who provide vital support to family members, friends and loved ones every day. Their efforts alleviate pressure on formal health and aged care systems while enhancing the quality of life and independence of those they care for. It is important to recognise the critical role Carers play in society and the profound contribution they make to the lives of people they care for. **The cost of replacing unpaid Carers amounts to \$77.9 billion.**<sup>1</sup>

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<sup>1</sup> National Carer Strategy 2024-2028

Unpaid Carers are the backbone of the Australian health and social care system. They provide daily care and support to family members and friends, enabling people to remain at home, avoid unnecessary hospital stays, provide support and care needs that are not provided by health services and support safe recovery.

Despite their crucial role, **Carers remain largely invisible in health services**, in the consideration of their needs and requirements and the impact of supporting their family member or friend with changing health care needs and treatments. Carers are the silent provider of services - health care, personal care, emotional and mental health support for people with often complex needs.

When referring to the Carer's role the use of terms 'personal care, support and assistance' significantly understates the level and complexity of care and skill required by Carers. Care can include a broad range of support from household management and maintenance to complex health care tasks and at times, first aid and emergency health procedures that require training by health professionals.

This submission reviews the current Standards, highlights where Carers are already referenced, identifies gaps, and makes practical recommendations to strengthen the third edition Standards so they better align with current Carer policy, legislation, and evidence.

## **What Has Changed in The Policy and Evidence Environment That Requires Changes to Carer Recognition in The NSQHS Standards?**

Unpaid Carers provide most of the day-to-day support for people using health services in Australia. Yet Carers are too often invisible in health systems. The NSQHS Standards (2021) mention Carers but do not make their involvement systematic, measurable, or accountable. With the release of the *National Carer Strategy 2024–2034* and in line with the *Carer Recognition Act 2010* and the *Carers Charter*, there is a strong opportunity to strengthen the Standards to better partner with Carers.

Since 2021, the policy environment has shifted. The *National Carer Strategy 2024–2034* commits governments to recognising, including, and supporting Carers. The *Carer Recognition Act 2010* and the *Carers Charter* establish Carers' rights to respect, inclusion in decision making and consideration of their wellbeing.

Research and the work of advocacy peak bodies consistently show that Carers face significant barriers in health systems and services. They are not always identified and if so, they are frequently excluded from decisions about treatment due to unclear consent processes, they receive little training or preparation for home care, and they are not consistently included in transitions of care.

- [National Carer Strategy 2024 - 2034](#) and the [National Carer Strategy Action Plan 2024-2027](#)

The implementation of the National Carer Strategy 2024 - 2034 and the National Carer Strategy Action Plan 2024-2027 is a whole of government framework that commits to codesign, recognition, better information and navigation, and improved support for Carers across systems. It recognises the need for services provided across the Australian, state and territory governments to be easier to navigate. Services need to be targeted to provide the right support for Carers at the right time and right place. Alignment with the strategy is now expected across government, systems and services including health.

Aligning the Standards with the objectives and priority areas of the National Carer Strategy and Action Plan requires better recognition, information, navigation, and codesign with Carers by health services. The Standards should reference the Strategy in implementation guidance, and require

evidence of local alignment, for example partnerships with Carer Gateway providers and Carer organisations.

- [Carer Recognition Act 2010 and Carers Charter](#)

Carer Recognition Act 2010 and the Carers Charter establish principles for how public service agencies and providers should treat Carers, including recognition, inclusion in decision making, and consideration of Carer wellbeing. Public service agencies are required under the Act to take all practicable measures to ensure that it, and its employees and agents, take action to reflect the principles of the Charter in developing, implementing, providing or evaluating care supports.

Aligning the Standards with the Carer Recognition Act would require health services to respect and include Carers in decision making, to consider Carer wellbeing, and to recognise Carers as partners. Strengthened NSQHS wording would operationalise these principles at the point of care and at governance level.

- [National Carer Survey and National Carer Wellbeing Survey](#)

Carer peak bodies across Australia document and report persistent gaps in recognition, wellbeing, and system navigation, and call for systematic partnership with Carers across health services. Common barriers in Australian healthcare include non-recognition of Carers at registration, privacy and consent uncertainty that blocks communication, variable involvement at discharge, limited training and preparation for home care, and the invisibility of Carers in governance and data. Surveys and research continue to report high burden, poor wellbeing, and navigation difficulties among Carers.

- [Australian Charter of Healthcare Rights 2<sup>nd</sup> Edition 2019](#)

Australian Charter of Healthcare Rights emphasises partnership, health literacy, and shared decision making across settings, which implies a stronger operational role for Carers.

Aligning the Standards with the Australian Charter of Healthcare Rights would require health services partnership, information, and feedback principles extend to families and Carers, so requiring identification and supported participation is consistent with the Charter.

## Where Carers Are Identified in The Current Standards

The current National Safety and Quality Health Service (NSQHS) Standards (2021) acknowledge Carers in several actions, yet these references are limited, broad, and discretionary. They stop short of embedding the Carer as a required part of the health care team as routine practice across the health system.

The current Standards identify Carers in four key standards:

- **Standard 1: Clinical Governance:**
  - References the inclusion of Carers in relation to feedback and complaints processes (ie patients, Carers, and families).
- **Standard 2: Partnering with Consumers:**
  - Acknowledges Carers in relation to the Charter of Healthcare Rights, in partnerships with clinicians and in governance roles.
- **Standard 5: Comprehensive Care:**
  - References Carers in planning, end-of-life care, cognitive impairment, suicide risk, and aggression/restraint management.

- **Standard 6: Communicating for Safety:**

- References Carers in relation to inclusion in clinical handover, structured communication, and mechanisms for raising risks.

Whilst these provisions demonstrate a level of intent for the recognition, inclusion and partnering with Carers, they do not establish consistent processes. There are no systems for identifying Carers, assessing their needs or including them as part of health care/ treatment decision-making. There is limited consideration of the impact of these decisions on the Carer and few measurable outcomes related to Carer experience.

In 2017, Australia introduced the Comprehensive Care Standard (CCS) as part of the National Safety and Quality Health Services Standards. Mandating implementation across all hospitals from 2019, these Standards are subject to accreditation assessments every three years to ensure compliance. Recognising the important role of Carers, who possess intimate knowledge of the patient and devote substantial time to their care, is critical in comprehensive care provision.

The CCS emphasises partnership with Carers in the whole process of delivering comprehensive care. Six essential elements of comprehensive care delivery include clinical assessment and diagnosis, goal identification, risk screening, comprehensive care planning, care delivery and care review and improvement, each of which requires Carer involvement.<sup>2</sup>

Carers offer unique insights into the needs and preferences of patients with chronic conditions. They provide direct assistance, offer emotional support, advocate on behalf of the patient, provide information and participate in medical decision-making.<sup>3</sup> Their role usually increases as the patient's physical and cognitive status declines. By undertaking many important caregiving tasks and activities, Carers complement the efforts of healthcare professionals in delivering comprehensive care. However, the caregiving role can adversely impact Carers' physical and mental health, especially in hospital settings, yet their needs and contributions are often overlooked by health services.<sup>4</sup>

Carers' involvement in assessment, shared decision-making and the care process are crucial factors in ensuring a positive experience for Carers of patients with chronic conditions and in providing comprehensive care for the patients. There remains however, limited quantitative data on Carers' perspective on their experience with health services even with the recognition and clear actions for engaging with Carers in the Standards.

It is essential for health care professionals to be more aware of and responsive to Carers needs including a greater understanding their unique role, their needs for psychological support, assistance with information-seeking, shared decision-making, training and skills acquisition for home care and the impact of caring and changes to health care and treatment options have on Carers. However, despite these identified needs, studies continue to identify gaps in care where Carers often feel their needs were not met, deliberately overlooked by health professionals, and their concerns disregarded, with information provided about patient needs often ignored and discounted in health care decision-making. It is vital to recognise and address Carers' needs and provide them with adequate support and resources to cope with the challenges and burden of caregiving.

Carers must be recognised, not as an appendage of the patient but as a partner in care who is directly impacted by health care decisions and that the decisions can add to the burden or their caring role to the extent that negatively contributes to their own health and wellbeing. They should also be recognised as a resource for health care practitioners as they are the person most with the patient's changing health status, their current issues and what works and doesn't work in the person's care.

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<sup>2</sup> Beibei Xiong, Christine Stirling, Daniel X. Bailey, Emmy Trinh, Ziyinyue Zeng, Melinda Martin-Khan Journal of Clinical Nursing published by John Wiley & Sons Ltd.

<sup>3</sup> ibid

<sup>4</sup> ibid

**Recommendation 1**

*Strengthening recognition of the unique role of Carers should be further embedded across all of the Standards - including the impact of caring on the Carers own health and wellbeing, and the importance of actively engaging with Carers as part of health care planning, decision making and transition.*

## Gaps that should be strengthened in the third edition

### Identification of Carers

*Carers should be formally identified and recorded in health records at admission and key transitions*

There is no requirement to formally identify and record a health consumer's nominated Carer in their health records or care planning pathway. Carers are frequently seen as the passive recipient of health decision-making, with an assumption that they will take on the caring role.

This requires particular consideration when the person is a Young Carer (between the ages of 5-25) and particularly when they are a child.

**Recommendation 2**

*Partnering with Carers require services to document each patient's nominated Carer at admission and transition of care and record their communication preferences.*

**Recommendation 3**

*Apply clear protocols for sharing information in line with consent and the Carer Recognition Act and the Carer Charter.*

**And includes actions such as**

- *Carers are partners in decisions and choices about the individual care and treatment of the person they care for.*
- *Carers are recognised and acknowledged as part of the treating team from the commencement of care and treatment to discharge and transition of care.*

### Assessment and Support

*A simple Carer needs and readiness check at admission and discharge could help ensure they are prepared for the role*

The Standards do not require health services to check whether Carers are able or supported to provide care resulting from changes in health status, new diagnosis of health conditions, undertaking health care tasks or able to provide the level of care that may arise as a result of changes in a person's health care needs. There is also no consideration of whether the person's family member or friend is willing to take on the Carer role.

This requires specific consideration and assessment where the changes in health care will have a significant impact on the Carer and should be part of planning and discharge and transition and is key to a comprehensive care model.

**Recommendation 4**

*Require a Carer needs and readiness check at admission and discharge as part of discharge planning and transition of care.*

**Recommendation 5**

Require documentation of Carer education, training and identification of Carer capacity against likely burden and mandated referral to the Carer Gateway were assessed as indicated.

**And includes actions such as**

- Carers are actively engaged with to identify their individual needs, and to develop appropriate services.
- Carers are provided with services that support their role in caring for patients in the public health system.

**Education and Training**

Carers need tailored information and practical training for tasks they will be expected to do at home, such as managing medicines or wound care

Carers are not guaranteed access to practical training or information on care tasks they are expected to perform at home which may include complex medicines administration and/or a range health care procedures. There is not consideration of the Carers capacity, willingness or ability to perform such tasks.

**Recommendation 6**

Provide Carers with practical training and Carer tailored resources for care tasks at home (e.g., wound care, mobility, end-of-life care, suicide prevention) as a part of routine patient care planning and transition.

**Recommendation 7**

Require clinicians to identify Carers responsible for medication at home and provide them with safe use of medicines education and facilitate access to resources and equipment for administration.

**And includes actions such as**

- Provide and document Carer education and skills training for the specific care tasks required at home, for example medications, wound care, mobility, delirium prevention, palliative symptoms, and cognitive impairment supports, and record referral to Carer Gateway where appropriate

**Transitions of Care**

Handover and discharge processes should include a section that confirms Carer involvement, their understanding of care instructions, and referral to support such as the Carer Gateway

Discharge and handover processes often exclude Carers or provide them with insufficient information, little transition time, lack of access to additional resources to provide safe care, no consideration of the burden of cost of such care at home (particularly when Carers experience higher levels of financial distress than non-carers).

Consideration also must be given to the translation of the health care required into hours of care at home and the impact on the Carer who may also need to work or may have to give up work to provide Carer.

**Recommendation 8**

Add a mandatory Carer section in structured handover and discharge summaries care planning, confirming Carer involvement in decision-making and care responsibilities.

### **Recommendation 9**

*Build routine referral pathways to the Carer Gateway and other local supports.*

#### **And includes actions such as**

- *Implement a brief, validated Carer needs and readiness screening at admission and before discharge, with documentation and escalation pathways and record referral to Carer Gateway Services where indicated*

## **Communication, Care Planning and Consent**

**Clear processes are needed to involve Carers in communication, respecting patient wishes and privacy**

Ambiguity and health service hesitance around consent and privacy can leave Carers excluded from essential conversations. This is exacerbated when the Carer is not a direct family member but may be a friend; neighbour, extended family member (such as a grandparent) or kinship Carer and the nature of their 'informal' care relationship exists in their familial/kinship connection and not legalised through guardianship or licensing arrangements. Health service standards must recognise these informal caring roles to ensure that such Carers are recognised in partnering in care and person-centred health care.

It can leave Carers unprepared and under informed about requirements ongoing provision of care at home and issues relating to safety and signs of deterioration, community services to access, resources/equipment required etc. Carers are often the first to notice deterioration but are not given clear escalation pathways.

Consent remains ambiguous where Carers do not have legal guardianship or consent powers which often means health services fail to communicate with them fully, fail to seek their consent where indicated and fail to consider the Carer's consent to taking on the caring role. This means Carers are often not consulted on health care decisions but assumed to be responsible for providing the care.

### **Recommendation 10**

*Communicating for Carer safety through requirement for Carer reporting in handover and discharge summaries and care pathways confirming the Carer's involvement, understanding of risks, training and resources needs, burden of care.*

#### **And includes actions such as**

- *At admission and at key transitions, document the patient's nominated primary Carer and their communication preferences*
- *Require a standard consent and information sharing protocol that includes Carers consistent with the Charter and law*
- *Provide tailored health literacy resources for Carers*

## **Governance and Measurement**

**Governance structures should receive reports on how well Carers are being identified, engaged, and supported, and Carers should be part of governance and codesign processes.**

Whilst the health sector increasing uses inclusive language such as "health consumers, carers and community engagement" and "patients, carers and their families", there is little actual change in how Carers are received, acknowledged or actively partnered with in health care. This language tends more to meld these terms together, rather than recognise the distinct and unique roles and responsibilities of each of these people and the unique experiences they have with health care.

There is no requirement in the standards for boards or executive teams to monitor discreet data about Carer engagement, Carer reported experience or Carer reported outcomes and few health services outside of mental health specifically include Carers as a unique group, in governance.

**Recommendation 11**

*Clinical governance to recognise and measure partnering with Carers. Require governing bodies to set indicators for Carer engagement, track Carer experience and include Carers in advisory structures and in codesign, planning, and governance structures at all levels.*

**And includes actions such as**

- *The governing body sets targets and monitors indicators for Carer identification, engagement, experience and satisfaction*
- *The experience and contribution of Carers is captured and evaluated through existing systems*
- *Carer representatives are specifically recruited as part of consumer engagement and partnering practices*
- *require trend reporting on Carer related incidents, complaints, and compliments*
- *The governing body sets targets and monitors indicators for Carer identification, engagement, and satisfaction*
- *The experience and contribution of Carers is captured and evaluated through existing systems*
- *Establish a Carer advisory function and ensure Carer Representatives are specifically recruited as part of consumer engagement and partnering practices*

These changes would bring the NSQHS Standards into line with the *National Carer Strategy 2024–2034*, the *Carer Recognition Act 2010*, and the *Carers Charter*. They would provide evidence shows that Carer involvement reduces adverse events, improves safety at transitions, and supports better patient outcomes. The Standards would recognise that Carers provide the balance of care in the community. Recognising Carers acknowledges their unpaid contribution and addresses systemic barriers that leave them unseen and unsupported.

The NSQHS Standards provide an essential framework for quality and safety across Australian health services. Strengthening the Standards to better recognise, value, and partner with unpaid Carers is not only consistent with legislation and national strategy, but also vital for safe, effective, and sustainable health care. These recommended changes would improve patient outcomes and safer care transitions, reduced readmissions and health system costs, ensure stronger alignment with national policy and legislation and ensure appropriate and necessary recognition, in health care systems, services and practice the role and burden of unpaid Carers and act to reduce this burden of care and burnout.

Carers are partners, not bystanders, in health care. The next iteration of the NSQHS Standards must actively reflect this reality.

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