Committee Secretary
House of Representatives Standing Committee on Social Policy and Legal Affairs
Parliament House
Canberra ACT

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HCCA Submission: Inquiry into the recognition of unpaid carers

Thank you for the opportunity to contribute to the House if Representatives' Inquiry into the recognition of unpaid carers. The Health Care Consumers' Association is pleased to present this submission to the Inquiry. It highlights the consumer perspective on and experience of unpaid care.

Recognition and support of unpaid carers is important for the health and wellbeing of both the carer and those they care for. Unpaid carers account for a significant proportion of all care work and are increasingly essential to meet the care needs of Australians.

We hope that the Inquiry leads to change in the structure and provision of services and support to meet the needs of people providing unpaid care.

Yours sincerely

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Executive Director

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HealthCare Consumers

SUBMISSION

House of Representatives Standing Committee on Social Policy and Legal Affairs:

Inquiry into the recognition of unpaid carers

17 August 2023

About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-profits Commission.

HCCA's approach to this submission

HCCA is a member-based organisation and we draw on the views and experiences of our membership and networks to advocate for consumers. Our membership includes people caring for children with complex care needs and disability, mental health carers, people caring for older people and those caring for friends and family who have complex and chronic conditions.

In this submission we will use the terms families and carers rather than unpaid carers. Families and carers can include an unpaid family members, friends, or neighbours who provides care to an individual who has an acute or chronic condition. Their support can last for a short period of post-acute care, especially after being in hospital, and over an extended period, even decades, providing ongoing care for a person with chronic care needs.

There is no single care experience as it is diverse. There are two things that apply to carers:

- carers experience negative impacts on their physical, mental, social and financial status as a result of their caring role,
- limited understanding and support is compounding the health and wellbeing outcomes for carers.

There also needs to be respect for family involvement, for patients from other cultural backgrounds. Similarly for people who identify as LGBTIQA+, the notion of chosen family is important and health services need to respect and include their families and carers.

We have focussed our submission on four areas:

- Safety monitors in hospital
- Building spaces for families and carers in hospitals
- Changes to practice to support involvement of families and carers
- Supporting health of older people

We will leave our colleagues at Carers Australia and Carers ACT to raise other issues of significance.

Involvement of families and carers in health care

Families are vital to patient care and safety, but their contribution is often unrecognised by our health systems and service providers. The National Standards require health services to have systems in place to ensure patients, families and carers are partners in healthcare planning, design, measurement and evaluation[1]. Our experience is that there is no consistent commitment to partnering. Patients and carers can not reasonably rely on their health service or care team to partner respectfully with them on decision making and provision of care. This then requires advocacy on the part of consumers and carers, further entrenching the inequality of the application of the Standards.

In response to Covid-19, we saw the introduction of bans on visiting hospitals and residential care as infection control measures. This shut out families and other carers. These strict visitor restrictions prevented them from providing supportive care. This impacted patients, families and staff.

This eased marginally with the introduction of exemption-based visitor permissions but this exclusion was still challenging for everyone and again required patients and carers to actively advocate for inclusion (apply for an exemption)

The absence of family support had significant unintended consequences for patients and staff. Where families would attend to the physical and emotional needs of patients, these tasks shifted to already overstretched staff.

It also created greater family anxiety and a desperate need for more information about what was happening for their loved one in hospital. This led to increases in phone calls to wards and residential facilities requesting updates. We also saw an increase in use of digital technology for families and patients to connect, which often required staff support.

All this underscored the direct mutual benefits of family inclusion in health care.

We need to recognise unpaid carers as partners in care and consistently support their involvement across all care settings to realise these benefits.

Safety monitors in hospital

When in hospital, patients rely on family members for physical and emotional support. This includes personal care, help with food and hydration, providing comfort and reassurance and monitoring their progress and condition.

Families are important in giving and receiving vital information when patients are too unwell or anxious to do so.

As consumers, we know the potential of carers to partner with staff to prevent health care–associated harm. Families can and do enhance patient safety.

We have heard many stories over the years about family carers picking up on medication errors. We have also heard stories about family carers ensuring discharge plans are individualised to reflect the needs and circumstances of consumers. The involvement of carers can reduce the length of stay in hospital and also reduce the risk of post-discharge errors and readmission.

With the consent of consumers, we want to see the inclusion of carers as part of the healthcare team and carer involvement in shared decision making.

We want to see hospitals recognise the value of effectively including families and carers. This includes their role in "hospital safety system surveillance, [where] they can identify errors and adverse events that are not picked up by hospital reporting systems, providing more opportunities to avoid potential harm"[2].

This is recognised to make a difference for all consumers, but particularly people with communication disabilities, intellectual disabilities, dementia, and frailty who are at high risk of experiencing health care–associated harm[3].

Dr Bronwen Merner completed a study on the role of carers as patient safety monitors[4]. She developed a way of understanding safety contributions of carers of adults with a range of support need. Dr Merner identified three roles, with different degrees of intensity of patient-safety caring:

(a) contributing without concern (low intensity),

(b) being proactive about safety (moderate intensity), and

(c) wrestling for control (high intensity).

The actions associated with each role provide insight into the ways carers can monitor patient safety in hospitals.

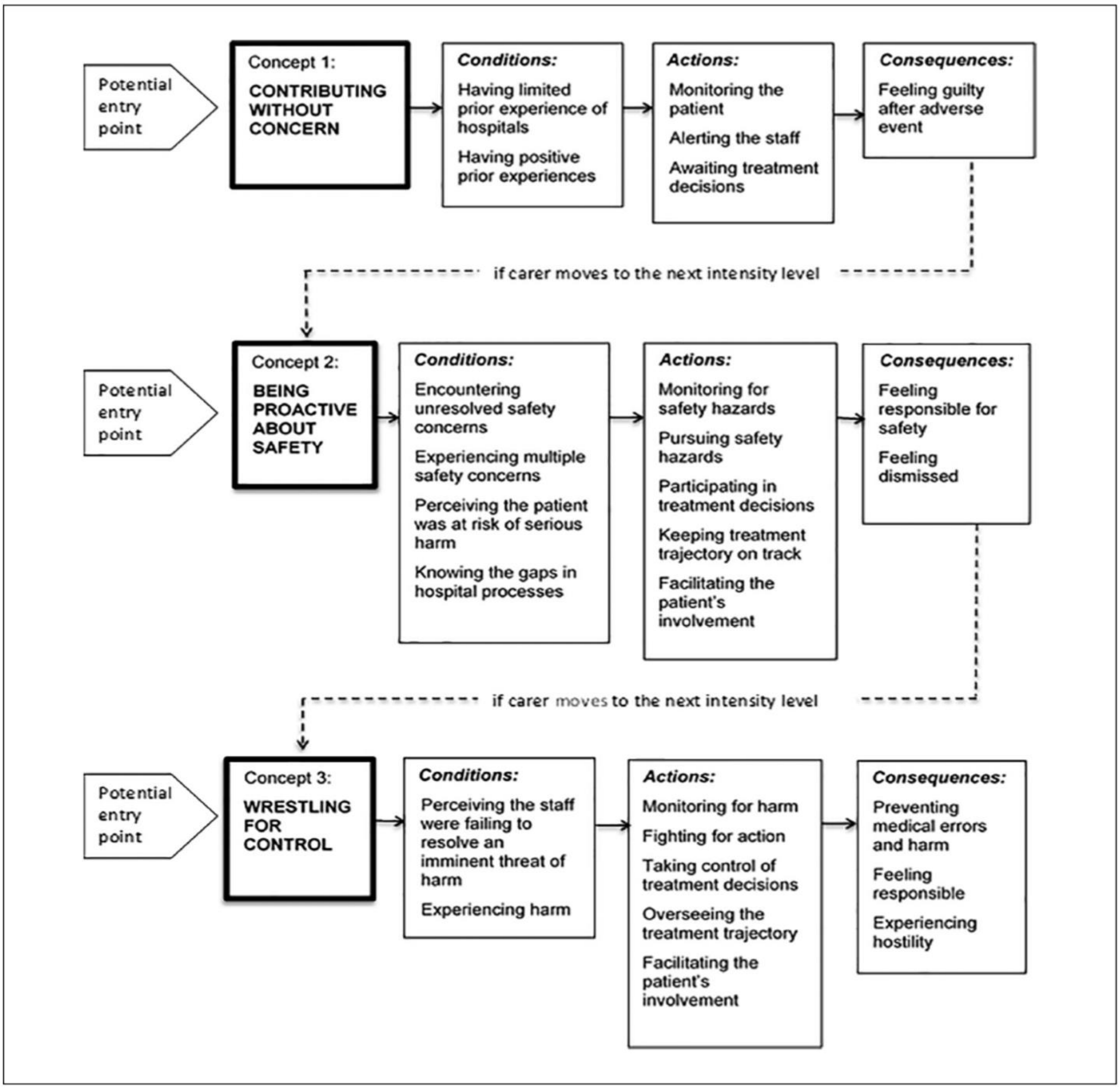

Figure 1. The process of patient-safety caring.

Dr Merner's study showed that carers perceived they worked in isolation, rather than in partnership with staff. This reflects the experience of our members and needs to be addressed by health services.

Building spaces for families and carers in hospitals

Programs such as the award-winning Carer Zones Project[5] at the Blacktown and Mt Druitt Hospital (BMDH), demonstrate the value of investing in strategies that support family members and carers to be involved in patient care. At BMDH this was done by providing a carer zone in 40 single rooms. This included a lounge that could convert to a bed. They also changed procedures regarding visitors and developed information and resources for carers.

This project found that supporting carers to stay overnight in hospital with the patient led to:

- improved patient and carer experience. Patients with carers staying overnight reported reduced anxiety and improved satisfaction while carers also reported very favourably on their experience,
- improved opportunity for staff-carer communication,
- a positive impact on nurse workload with a reduced frequency of nurse calls being reported,
- a reduction in the number of patient falls within the Stroke and Rehabilitation wards,
- increased opportunity for clinicians to communicate with carers leading to better discharge planning, education opportunities and the exchange of relevant information.

We also advocate for spaces that are:

- culturally appropriate, safe and welcoming to all people, including Aboriginal and Torres Strait Islanders and people from culturally and linguistically diverse communities.
- a Dementia Enabling Environment[6] to maximise enablement and wellbeing for people living with dementia. By implementing the principles of a Dementia enabling environment, it is possible to create a calm, inclusive and functional area for all people.

Changes to practice to support involvement of families and carers

Supporting someone admitted to hospital is usually a stressful time for family members and carers. They often experience heightened levels of anxiety, fear, emotion and sometimes grief. There are practical, service-wide measures that can be put in place to partner with families. In addition to the design of the facilities, there are other practices that can improve the experience of care. For example,

- when patients are admitted to hospital, family orientation can help to inform patients and their families about the services and health care.
- tell families and carers what action they take if they are concerned that the needs are not being met or if there are signs of clinical deterioration.
- standardising ward rounds times is another measure that makes a difference. It means families and carers can be present when information is shared and decisions need to be made.

Health of older people

With an ageing population, we need to do better at involving families and carers in hospitals and residential care settings. We need innovative, co-designed strategies to support the integration of families and carers in hospitals and residential care.

Delirium is an area of particular interest to HCCA's members. The Delirium Clinical Care Standard[7] states that about 10–18% of Australians aged 65 years or older have delirium at the time of admission to hospital, and a further 2–8% develop delirium during their hospital stay.

Older people with delirium may be confused and disorientated, fearful and anxious, and may not recognise their carers or families. They may try and leave the hospital because they feel unsafe. They can also be agitated and suffer from hallucinations. They can be disruptive or aggressive. We also know that delirium may present as being drowsy or as incontinence when usually they have control. It is distressing and it affects their experience of care and the trajectory of their recovery. It also impacts their family and carers, as well as staff.

Delirium is associated with increased risks of medical and surgical complications, falls, increased length of hospital stay, increased readmission rates, and functional decline leading to older people losing independence and moving to residential care.

The NSQHS Comprehensive Care Standard (Action 5.29)[8] requires health service organisations to incorporate best-practice strategies for the early recognition, prevention, treatment, and management of cognitive impairment in their systems of care, including the Delirium Clinical Care Standard.

Early identification of confusion, treatment of the underlying cause and management of symptoms can prevent these adverse effects and minimise their duration and severity. One example of this is the Delirium toolbox[9]. It was developed with carers to support their integration as partners in the care of hospitalised older adults at risk of delirium. This toolbox is now being trialled in hospitals. It holds promise and we look forward to seeing this tool finalised and rolled out across health services.

This is just one way of actively and formally supporting and utilising unpaid carers in health care. Carers have the potential to contribute in this way throughout the health system and we would like to see this potential formalised to ensure they are not excluded from participating in care in the future.

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[1] Australian Commission on Safety and Quality in Health Care. The National Safety and Quality Health Service (NSQHS) Standards. https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard

[2] Miles Sibley, Laila Hallam, Sue Robins (2023). Invisible no more: unpaid care giving in the shadow of covid-19 BMJ 2023; 382 doi: https://doi.org/10.1136/bmj-2022-073053

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[3] Bronwen Merner, Sophie Hill, and Michael Taylor(2019). "I'm Trying to Stop Things Before They Happen": Carers' Contributions to Patient Safety in Hospitals. https://doi.org/10.1177/104973231984102

[4] Bronwen Merner, Sophie Hill, and Michael Taylor(2019). "I'm Trying to Stop Things Before They Happen": Carers' Contributions to Patient Safety in Hospitals. https://doi.org/10.1177/104973231984102

[5] http://www.bmdhproject.health.nsw.gov.au/projects/carer-zones

[6] Dementia Enabling Environment Design Principles developed by Professor Richard Fleming, Wollongong University. See also https://www.enablingenvironments.com.au/hospitals.html

[7] Australian Commission on Safety and Quality in Health Care. Delirium Clinical Care Standard | Australian Commission on Safety and Quality in Health Care

[8] Comprehensive Care Standard | Australian Commission on Safety and Quality in Health Care

[9] Christina Aggar, Alison Craswell, Kasia Bail, Roslyn Compton, Mark Hughes(2022) A co-designed web-based Delirium Toolkit for carers: An eDelphi evaluation of usability and quality – Collegian https://www.collegianjournal.com/article/S1322-7696(22)00164-0/fulltext