Flinders University | Research Centre for Palliative Care, Death & Dying

Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry:

Carers Recognition Act 2010

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Submitted by
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ABOUT REPADD

The Research Centre for Palliative Care, Death and Dying (RePaDD), directed by Professor Jennifer Tieman, established in 2019 and is one of the research arms of the College of Nursing and Health Sciences at Flinders University. RePaDD' mission is to make a difference to care at the end of life by examining the issues and challenges experienced by people living with a life-limiting illness, their carers, and health and care professionals supporting them.

RePaDD comprises a multidisciplinary team with diverse set of skills and working in a variety of settings. The group has extensive experience in delivering successful national palliative care projects as well as high impact research relating to aged population, community experience of death and dying, carers experiences and support, innovative models of palliative care, and the contribution of palliative care to the person's end of life, health professionals and health and social care systems.

RESPONSE TO THE INQUIRY INTO 'CARER RECOGNITION ACT 2010'

RePaDD welcomes the opportunity to provide a submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs. This submission focuses upon issues relating to the recognition of carers in Australia, opportunities and challenges in accessing to support systems, and recommendations to enhance the effectiveness of the Carer Recognition Act.

Our response draws on RePaDD's strong leadership and extensive expertise in conducting and managing high quality research and large scale projects that focus on carers especially those who care for older people, patients with palliative care needs and at the end-of-life stage. The work undertaken by RePaDD provides strong evidence to inform the reform of 'Carers Recognition Act'. Examples of RePaDD's projects with a focus on carers are:

- **CarerHelp;** RePaDD (in collaboration with the University of Melbourne and Carers Australia) co-leads the CarerHelp national project funded by the Australian Government (2017-2023). The project established a website for carers to access information they need including videos, training modules, information packs and forums. Strategies to ensure the website is accessible and able to reach a diverse population of Australian carers are implemented.[1] https://www.carerhelp.com.au

- **CareSearch;** RePaDD leads the national CareSearch Knowledge Network funded by the Australian Government (2008-2026). Project website provides evidence-based online palliative care resources for health professionals and aged care sector. The website has an extensive section on information and resources for people needing palliative care and their families and carers.[2] https://www.caresearch.com

- **Review of the Literature on End-of-Life Care;** The review was commissioned by the Australian Commission on Safety and Quality in Health (2021) and revealed families and carers as an important unit of care and that systems and services should consider carers perspectives while the patient is alive, also integrating bereavement support for carers. Lack of carers knowledge on death and dying emerged from the review which highlights the importance of public education to improve death literacy.[3]

- **Bereavement Project;** RePaDD in partnership with GriefLink led a project (funded by SA Health) to develop evidence-based and user-informed resources to support grief, loss and bereavement needs of family caregivers of older people dying in residential aged care. The Bereavement Booklet[4] has been made available to residential aged care facilities in print and digitally since 2020. Additionally, GriefLink dedicated a page with information relating to grief in the context of aged care in their website.[5]

- **Digital Resources for Carers;** The project was undertaken by a RePaDD member and PhD student to understand the barriers experienced by carers in accessing and understanding digital palliative care information. The findings highlighted difficulties of information in the context of carers personal exposure to health care professionals or lived experiences. It also found challenges for carers in understanding the language and terminologies, successfully interacting with online information and software, and confidence in operating digital technologies.[6]

- **Carers Experience of Access to Information and Support Services;** The study (funded by SA Health) is being implemented collecting qualitative data through interviews and focus groups with cares of palliative patients to explore their experiences of access to information and support they need in their caring role but also for self-care. The death literacy of carers is assessed using Death Literacy Index survey. The study reconfirmed poor knowledge about support systems and the complexities of system navigation and accessing services for cares who are time pressured.[7]

- **Carers Health Assessment;** The project was led by a RePaDD member and explored the benefits and acceptability of a separate psychological assessment of carers and found that both patients and their caregivers appreciate being separated in the clinic setting to have time and privacy to reveal fears and feelings related to end-of-life care which would have an impact on carers health and wellbeing.[8,9]

- **Death preparedness and bereavement services for carers;** The project was led by a PhD student and a RePaDD member exploring death preparedness amongst carers and the purpose and value of palliative bereavement services for self-care. Carers experienced the delivery of grief information and support pathways as a safety net.[10]

- **Bereavement outcomes during Covid-10;** The project funded by the Medical Research Future Fund (2023) and aims to identify the mental health effects and support needs of carers bereaved during and following Covid-19. RePaDD's Director is a Chief Investigator on this project.

RESEARCH EVIDENCE FOR CONSIDERATION

Section below summarises key points emerged from RePaDD's research projects and recommendations for the Act reform. De-identified quotes are included where appropriate.

Carers Identification and Recognition

Self-identification as a carer is central to carers' help seeking behaviour and accessing to information and resources they need. Often, the family member in a caring relationship do not acknowledge themselves as a carer which prevents them to seek support they need.

I didn't see myself as a carer for a very long time. I was a daughter, and I was just looking after my mum. People kept saying to me, you're entitled to carers allowance and I'm going "no, that's what daughters do. (carer's interview)

There is no clear and consistent definition of 'carers' across organisations and services that are responsible to provide carers support. Carers experience confusion dealing with varied criteria for being eligible for support services provided by different organisations. Some organisations prioritise carers of patients with acute and short term conditions such as cancer rather than those who care for patients with chronic health conditions. The lack of clarify in how carers roles are defined hinders their access to support services and cause inequity for some groups of carers.

Furthermore, carers not being recognised as an integral part of the care team limits their access to patient's information, their involvement in decision making and care coordination. This is partly due to the poor knowledge and training amongst health and social care professionals.

Family Dynamic and Multiple Carers

The influence of family dynamic and its' impact on medical, end of life and other care decisions for patients is well documented. In some situations, family dynamic, relationships and conflicts hamper the ability of carers to access knowledge regarding the patient's condition, engage in effective communication with health professionals and affect access to resources and support for both the patient and carer. It is sometimes difficult to find the right balance between the patient's and carer's rights in decision making and care planning.

Mum doesn't like to feel like people talking about her or making decisions for her without her. So, it's very difficult for us…we don't necessarily feel like we can go directly to the coordinators. They're only getting Mum's perspective, not our perspective, which can be very different…what they prioritize or whatever compared to what we think should be prioritized can be very different (carer's interview)

Furthermore, it is usually presumed that there is a single carer whereas in reality, there is a network of family carers doing different aspects of the care, and thus ensuring the integrity of communication within the caring network and managing relationships is critical.

Caring relationships and responsibilities may also change when the patient moves into aged care setting. Whilst aged care staff and health professional takes responsibility of health and medical care, family carers continue to play a role in decision making and advanced care planning. This changing roles for carers require enhanced communication and relationship with health and aged care providers. There is a need for an integrated system to facilitate communication and information sharing amongst multiple carers but also between caring network and health and aged care providers.

Carers roles, relationships and support systems are particularly vague for long distance carers who are not appropriately recognised and acknowledged.

Knowledge of and Access to Support Services

In general, carers gain access to information about care assistance and other support services from websites, brochures and word of mouth. GPs and nurses play a critical role as gateways and are in a good position to proactively initiate conversations regarding the carers' role and referring them to the right service at the right time. Early referral by GPs is proven to lead to better outcomes for both the patient and the carer, timely access to equipment, information, support and financial resources.[12] Accessing resources and services is also impacted by temporal factors including time constraints. The conflict of sustaining work and other obligations and being able to provide care is an area of real social concern.[11]

System Navigation

System navigation is a major challenge for carers. Many carers are not aware of the existing support services and organisations e.g., Carers Gateway and Carers Australia. Forms and paper works are laborious which hinder access and utilisation of support services. Systems and services working in silo makes it confusing for carers. Care navigator model through one to one support and advocacy was highly recommended by carers to assist them navigating through the complex systems. Challenges in relation to system navigation persist at the later stages of caring roles when carers need to navigate systems related to death and dying as well as grief and bereavement support.

Given the growing shift towards digital technologies in providing information, care and support, an assessment of the level of digital literacy and carers' capability in using digital resources is crucial to ensure carers' needs are met. Evidence suggests difficulties for carers to understand and interact with online information which is mediated by the carer's digital capabilities and their confidence in operating digital technologies.

The whole concept of computers sends me into a panic. They give me a high anxiety rating. So the concept of actually sitting down in front of a computer and doing that online, that was very, very difficult. (carer's interview)

Self-Care Support

Caring role has a huge impact on carers physically and mentally. Self-care is a major challenge for most carers. Carers find it very difficult to consider their health and well-being while caring for a patient. The most useful self-care strategies reported carers are informal peer support, telephone or online support groups, and family support with limited access to counselling services.

The support groups, you just feel more connected to the other people, you see the similarities in the predicament and situations that we're all in. And as different as they are, there's so many similarities and you do feel like you're not alone and you just feel more connected. (carer's interview)

The current system of care has a great focus on patient-centred care. This needs to be expanded by including carers as recipients of health and care services. This is supported by evidence that separate psychosocial assessment of carers provides them time and privacy to express fears and feelings related to their caring role which will assist them to improve their own health and wellbeing.[8,9]

Grief and Bereavement Support for Carers

Grief and bereavement are integral to the caring role and present long before the death of the patient and in case of caring for patients with chronic health conditions could maintain for many years. Furthermore, bereavement after the death of the patient has a huge impact on the carer which is normally at a stage that the person is no longer recognised as a current carer and thus, might not be eligible for support services. Grief and loss are commonly experienced by families of residents in aged care setting, yet limited resources are available.

Poor access to counselling services with expertise in grief and bereavement, waiting lists and affordability issues are major barriers faced by carers.

RECOMMENDATIONS

Based on evidence generated from various projects, the following areas are recommended to be considered in the Carer Recognition Act review and reform.

- It is critical to ensure diverse groups of carers are appropriately and equally recognised to enable their access to support services. Although Schedule 1/Statement 1 emphasises *rights, choices, and opportunities for ALL carers*, it is important to acknowledge that caring for people with chronic illness, older people with frailty, co-morbidity and terminal disease comprises a significant group of carers which their value and contribution are not recognised enough. Given the diversity of pathways to an expected death, recognition of carers supporting chronic and terminal illnesses needs to be further clarified in the Act. This will lead to a recognition of diverse needs and support that various groups of carers require at different points of time i.e., the provision of the right support at the right time.

- The Act should further clarify the definition and eligibility criteria for carers support services. These criteria should be consistent across organisations, sectors, and services to prevent confusion for carers and inequity in access to services (Meaning of carer - p3 of the Act).

- Given that 7 out of 10 primary carers in Australia are female[13], a greater emphasis on gender nature of caring, and family and employment obligations of female carers is recommended. The Act should align with the national and jurisdiction gender equality

Acts and legislations including the Australian Workplace Gender Equality Act 2012 (Schedule 1/statement 1 – p9 of the Act)

- The complexity of the relationship between carers and the person for whom they care should be further clarified to include multiple carers and carers network within family context with various responsibilities, carers of people living in residential aged care, and long distance carers (Schedule 1/statement 6 – p9 of the Act)

- The Act must consider how carers are included in the priority actions and integrated into care planning team within health and social care services. A shift of focus to ensure a patient-centred care recognises families and cares within the care context and takes patients' rights as well as carers' rights into consideration is recommended. These include the right to access to information, ability to make care decisions, and a timely referral to support services (Schedule 1/statement 7 – p9 of the Act). This point aligns with the Charter for Aged Care Rights and Australian Charter of Healthcare Rights which focus on valuing and supporting the identity, culture, and diversity of both patient and carers.

- System integration and coordination is critical to facilitate ongoing access to information and support services so that the changing needs of carers are met. The act should highlight ways that such an integration may occur. Statement 10 of the Act on 'timely, responsive, appropriate, and accessible support for carer' must also include referral pathways, role of GPs and other health professionals in the provision of information and referral, ways to tackle access barriers including geographical, language, gender and economic. Diversity of carers and their needs should be acknowledged to ensure responsiveness and appropriateness of support services. (Schedule 1/statement 10 – p9 of the Act)

- The Act must include the importance of system navigation and navigator models and frameworks to support patients and carers at different settings and levels of care including primary health care, hospitals, aged care, and other social care services to navigate care and death systems. Discrete needs of the patients and carers are to be considered in system navigation models (Schedule 1/statement 10 – p9 of the Act).

- The role of digital technologies in improving carers support including the provision of online training, peer support and counselling services should be included in the Act. The Act should also acknowledge issues associated with digital health literacy and underserved population (Schedule 1/statement 10 – p9 of the Act).

- The importance of self-care is underestimated. This includes mental and physical assessment of carers (separated to the patient), improve accessibility and affordability of self-care services and respite care. Carers should be 'acknowledged' and 'supported' to maintain their own health and wellbeing beyond the caring role. (Schedule 1/statement 5 – p9 of the Act)

- Grief and bereavement support for carers is an area currently missing in the Act. Timely, accessible, and affordable grief and bereavement support before and after death is critical for carers in their caring role but also their own health and wellbeing. Grief and loss impact carers more broadly and include loss of identify, loss of social life, and loss of employment and income and should be acknowledged in the Act. The Act much include the importance of death literacy and grief and bereavement support for carers and the role that organisations, employers, and health services can play in this matter.

The current Act ‘does not create legally enforceable obligation in judicial or other proceedings’. To ensure carers support at all levels of government, employment and services, the Act needs to have an alignment with other Acts in relation to employment, health services, gender equality, and the Australian Safety and Quality Commission. A review of relevant laws and policies is required to ensure consistency across national and state/territory laws and legislations.

We hope our submission provides the Committee on Social Policy and Legal Affairs with the impetus to further integrate research evidence into the process of the Carer Recognition Act revision and reform. RePaDD welcomes collaboration with the Committee to further discuss areas highlighted in this submission to inform agenda for carers support in Australia.

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