Inquiry into the recognition of unpaid carers

McCabe Centre for Law and Cancer,

Cancer Council Victoria and

Cancer Council Australia

11 August 2023

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Cancer Council Australia and the McCabe Centre acknowledge the traditional custodians of the lands on which we live and work. We pay respect to Aboriginal and Torres Strait Islander elders past, present and emerging and extend that respect to all other Aboriginal and Torres Strait Islander people.

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About us

The McCabe Centre for Law and Cancer is working for a world free from preventable cancers and in which all people affected by cancer have equitable access to safe, effective, and affordable treatment and care. The McCabe Centre is a Melbourne-based joint initiative of Cancer Council Victoria, the Union for International Cancer Control and Cancer Council Australia. The McCabe Centre conducts world-leading legal research, policy development, and capacity building programs to promote the use of law as an essential tool in the prevention and control of cancer in Australia and overseas. The McCabe Centre is a WHO Collaborating Centre on Law and Noncommunicable Disease, and the WHO Framework Convention on Tobacco Control Knowledge Hub on Legal Challenges.

Cancer Council Victoria is a non-profit organisation that has been leading the fight against all cancers for more than 80 years in the areas of research, patient support, cancer prevention and advocacy. Its mission is to prevent cancer, empower patients and save lives.

Cancer Council Australia is Australia's peak national non-government cancer control organisation and advises the Australian Government and other bodies on evidence-based practices and policies to help prevent, detect and treat cancer.

We welcome the opportunity to contribute to the inquiry into the recognition of unpaid carers. Unpaid care is integral to cancer care and cancer outcomes in Australia. Our submission seeks to highlight the multidimensional aspects of unpaid cancer care, challenges for cancer carers, and how the *Carer Recognition Act 2010* (the Act) can better support Australians affected by cancer.

Unless specified, the term 'carers' in this submission is intended to refer to unpaid carers.

Recommendations:

1. The definition of carer in the Act is amended to recognise the complexity of care for people with cancer, and to better align with definitions in other legislation and organisations.
2. The Act should include principles and recommendations for data collection and measurement of carers' needs and their contributions to the healthcare system.
3. The Act should acknowledge Australia's human rights obligations with respect to carers, and support carers as rights holders, entitled to the full enjoyment of economic, social and cultural rights, without discrimination.
4. The Australian Government should recognise the status of unpaid carer as a protected attribute in any new National Human Rights Framework and National Human Rights Act.
5. The Australian Government should develop a new National Carer Strategy, and Action and Implementation Plan, to focus on needs and challenges for unpaid carers.
6. The Australian Government should support community education and awareness initiatives for the recognition of carers, and better facilitate carers' access to support and assistance.

Cancer Carers

Cancer is the leading cause of disease burden in Australia.[1] Over one million Australians currently live with or have cancer, and it is estimated that between 2022 and 2031, a total of 1.7 million new cases of cancer will be diagnosed.[2] A cancer diagnosis is often a life-changing experience for a person with cancer, their family and carers. People with cancer face a range of psychological, emotional, social, financial, practical, and other issues due to their cancer and its treatment.[3]

Cancer is also one of the ten most common health conditions in receipt of informal care giving.[4] Almost all (>90%) of people with cancer have at least one informal carer: a family member or friend supporting them with care over the course of their illness, treatment, and through to end of life.[5] While the focus of this submission is people with cancer and their carers, the experiences of cancer carers frequently aligns with those of carers for people with other life-limiting or chronic conditions, and engages with broader themes relating to the recognition and value of all carers in our community.

Cancer care can be urgent, intense and unpredictable, as the progression of the disease and responses to treatment can vary; and care may be required over days, months or years, given the complex and chronic nature of the disease as well as advances in treatment and care.[6] Cancer and its treatment can impact on a person's quality of life long after active treatment has ceased, and well into survivorship, and can also result in extensive and sometimes permanent care needs.[7]

Cancer experiences are unique to each person and can fluctuate depending on the type of cancer and treatments involved. Accordingly, cancer carers can have multiple and complex roles. Some, but not all, of their tasks include:

- Coordinate and facilitate communication between patients and clinicians, and sharing information and updates with family and friends;
- Make or support treatment decisions: for example, for children with cancer or for patients without decision making capacity or with limited capacity;
- Provide emotional support, at-home treatment and symptom management, and personal care;
- Provide care for children or other dependents;
- Manage a home, property, and the affairs of a patient, especially if the patient experiences functional decline;
- In survivorship, support a patient returning to life, study or work; and maintain cancer surveillance;
- At end of life, support patients' end of life choices and help them navigate legal processes, including Advance Care Planning, and take on formal legal roles as Powers of Attorney and/or substitute decision-makers[8]

Cancer carers play a significant role in helping people navigate their care in a hospital setting, supporting patient treatment decision making, coordinating access to care and services, and advocating for those in their care and their needs.[9]

Our health care system does not provide all the care that cancer patients require. With a growing ageing population, longer survival rates, moves towards greater outpatient care and patients' wishes increasingly to be cared for at home, cancer care is now largely community based.[10] A significant

amount of cancer treatment is administered in an outpatient setting, necessitating supportive care in and around treatments, often at home. Unpaid care (in addition to paid care services) is therefore essential for supporting patients through cancer treatment, survivorship and into palliative care; yet is undertaken often at great cost to the carers, and without financial compensation.[11]

For people with cancer, having an informal caregiver/s is associated with better coping capabilities and healthier lifestyle habits.[12] Many carers also report positive aspects about the rewarding experience of caring and have a higher sense of happiness compared to the general population.[13] However, carers of people with cancer also report high levels of anxiety, distress and burden[14] and often report higher levels of distress than people receiving treatment for cancer.[15]

There are numerous and sometimes hidden challenges for unpaid carers. Taking on a caring role may exacerbate or compound pre-existing risks to health and safety, including the risk of family violence or elder abuse. For culturally and linguistically diverse people a carer may be expected to act as a key communicator with clinicians and health care workers, which places them both in the position of advocate, as well as imposing responsibilities for understanding and interpreting complex, personal and sometimes distressing health information. This can create difficult ethical, cultural and emotional pressures for the carer or carers receiving information about the prognosis and effectiveness of the treatment directly.

Carers may be unable to work or must work fewer hours or in a lower paid job to meet their caring commitments[16] and many Australians diagnosed with cancer, their carers, and their family experience 'financial toxicity': 'the combined impact of direct out-of-pocket costs and indirect costs and the changing financial circumstances of an individual and their household due to cancer diagnosis, treatment, survivorship, and palliation, causing both physical and psychological harms, affecting decisions which can lead to suboptimal cancer outcomes'.[17],[18] Rural, regional and interstate carers may experience both increased time and costs burdens for caring responsibilities, due to the need to travel frequently and spend time away from home (and work).

Cancer carers perform a vital role in our society. They contend with a disease that, while all too common in Australia, impacts people and their carers in diverse ways. We need to recognise and value the contribution unpaid carers make. The Act is an important part of this process, and there is an opportunity in this inquiry and reform process to strengthen this commitment to Australia's nearly 2.8 million informal unpaid carers.

Case study: Carer recognition and the COVID 19 pandemic

During the COVID 19 pandemic, there were significant visitor restrictions for patients in Victorian hospitals and care facilities. Research undertaken by Cancer Council Victoria and the Daffodil Centre determined that visitor restrictions profoundly affected the cancer experience, with people receiving lifechanging information, treatment, and palliative care, without the support of family and friends.[19] People with cancer were denied their wish to be with their support people of choice as they reached the end of their life.[20] Carers were particularly distressed with not being able to provide support, because they were unable to help their person manage the physical and emotional challenges of cancer treatment—this distress, felt by both carers and those in their care, was exacerbated by often abrupt changes in access without proper communication.[21] This lack of communication about when carers were allowed to visit people in hospital settings created distress at end of life. The survey found examples of carers restricted to visiting the person they cared for only once they had reached end-of-life care to say their goodbyes. These experiences profoundly affected the lives of both the person with cancer, and their support networks.

"… Abrupt cancellations of access for carers to medical appointments, without any prior communication, was also extremely distressing. This was particular(ly) so as chemo brain is a real thing - the patient often doesn't hear all the detail being described, and then forgets it all within 15 minutes. This makes it even harder for carers to provide necessary or recommended support." – *Cancer Carer, captured in Cancer, COVID-19 + You research (2021)*[22]

Visitor restrictions severely limited the role of carers in helping with decision making and understanding of treatment plans for people with cancer dealing with complex information from doctors; and this was acutely experienced by people with English language barriers, for whom carers are an essential communication and comprehension support.

A 2022 Victorian Parliamentary review of the pandemic orders for visitor restrictions identified the right to equality as having potentially been limited, although in response, the Victorian Minister for Health considered that indirect discrimination against people with a disability was reasonable in this circumstance.[23] The Committee acknowledged that while hospitals are best placed to monitor and manage visitors in a health crisis, the significant impact on the welfare of patients, their families and other loved ones was a matter of serious concern. The Committee also noted the important role that friends and family play in patient care, particularly improving a patient's physical, emotional and social wellbeing and as such, restrictions to the public should be communicated more clearly, and hospitals should adopt the least restrictive options available.

This example demonstrates both the critical importance of legislation that recognises value and importance of carers, and the need to better operationalise carer recognition, including in response to health crises. We would highlight that visitor restrictions in Victoria, which deeply affected carers and the people they cared for, were all deployed notwithstanding state and federal legislation intended to recognise and preserve the vital role of carers in cancer care and other settings.

Definition of carer

The definition of carer in the Act, read together with the Statement for Australia's Carers, does not fully capture the lived realities of people caring for people with cancer described above. In describing a carer as an 'individual who provides...care...to another individual...' the definition in the Act imagines a singular and one-way caring relationship. This is not inclusive of the multidimensional aspects of caring, such as family or kinship care; carers who may require care themselves; or carers with multiple caring roles, such as 'sandwich carers'—carers, predominately women, who care for young children as well as parents with cancer,[24] or people in relationships who may already have co-dependent or co-caring roles that pre-date their partner's cancer diagnosis and impact on their capacity to act as carers. With more Australians living to older ages, the number of cancer cases diagnosed each year is increasing;[25] giving rise to situations where both parties in a relationship or multiple family members have separate cancer diagnoses, impacting both on the ability to attend treatment, as well as the psychological adjustment, especially if one person has a treatable cancer and the other may have a terminal diagnosis.

Some carers do not recognise themselves as a carer, (known as 'hidden carers') and are less likely to access support as a result. Barriers to identifying as a carer include self-comparison to stereotypical caring duties, where carers see their work as familial responsibilities rather than legitimate caring work. A definition of carer must carefully avoid narrow or stereotypical examples or limitations on the conception of a carer, to account for the many ways in which unpaid care is provided in our communities.

There are different definitions of 'carer' in state and territory carer recognitions acts, as well as differences in the way carers are defined in other legislation, and in organisations and services providing support for carers. The Research Centre for Palliative Care, Death and Dying notes that the lack of clarity in how carers roles are defined acts as a barrier to accessing support services and creates confusion for carers navigating difference support frameworks.[26]

Recommendation
The definition of carer in the Act is amended to recognise the complexity of care for people with cancer, and to better align with definitions in other legislation and organisations.

Data

Law and policy reform to improve carer recognition needs to be based on good evidence and data.

The Deeble Institute Issues Brief *Prioritising carers' health and wellbeing in the healthcare system* highlights the lack of a robust data collection framework for carers, meaning their needs are not readily identifiable, noting especially the limited data collected about carers within existing population surveys.[27] For example, while the Australian Bureau of Statistics collects characteristics on carer demographics and basic health data such as disabilities, this information is only collected every three to four years meaning that outdated evidence is used to inform decision making and delivery of services for carers.[28] Likewise, the ABS Disability, Ageing and Carers survey is conducted every four

years. These surveys could be run more frequently, to enable more recent data to be used in policy development and implementation.

As noted above, some people may not identify as a 'carer'. This is common in some communities, including First Nations peoples, and people who are culturally and linguistically diverse, and has implications for measuring the prevalence of unpaid care.[29] Additionally, people from culturally and linguistically diverse backgrounds, First Nations peoples and LGBTIQA+ are frequently excluded from data collection due to inadequate data collection design, and reporting.[30] Additionally, sampling and data collection methods must be inclusive of people who are frequently excluded from data collection, including those listed above, in order to be representative of the Australian population as a whole.

While a new National Carers Strategy (discussed further below) should include measures to address the data gaps and research needs to develop evidence-based policy and service planning, the Act is also an opportunity to recognise and emphasise the need for comprehensive data collection to facilitate improved responses to challenges for care givers and those they care for.

Recommendation
The Act should include principles and recommendations for data collection and measurement of carers' needs and their contributions to the healthcare system.

Unpaid care is a human rights issue

Carer recognition is a human rights issue. The Northern Ireland Human Rights Commission has identified the rights of informal carers protected in international human rights conventions and the duties of States party uphold them. These include the right to:

- a private and family life;
- an adequate standard of living;
- social security;
- work;
- education;
- health;
- participation,
- the rights of persons with disabilities; and
- children's rights.[31]

Gender inequality in unpaid and informal care is a persistent issue. Australia is a party to several international human rights treaties that affirm the principles of non-discrimination and equality, and impose obligations to, amongst other things, reduce gender inequality, to ensure access to decent work, and to accommodate family and caring responsibilities, including through policies to recognise and value caregiving.[32] Article 2(2) of the International Covenant on Economic, Social and Cultural Rights obliges States Party to guarantee [economic, social and cultural rights] be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.[33] Similarly, under the Convention on the

Elimination of Discrimination against Women (CEDAW) Australia has committed to take measures to ensure women's full enjoyment of human rights on an equal basis with men, including:

- Eradicating stereotyped roles for women and men
- Ensuring women's equal participation in public life
- Equality before the law
- Eliminating discrimination in employment.[34]

Globally, unpaid care work is unequally distributed between women and men. In Australia, women spend 64.4% of their average weekly working time on unpaid care work, compared to 36.1% for men.[35] The unequal gendered distribution on unpaid care work reflects discriminatory gender stereotypes, that place women in the home, and automatically assign them the role of carer, along with the inferior status and rights as a result.[36] This obstructs women's rights to autonomy, equality and non-discrimination. An additional effect of this unequal burden of unpaid care work on women is that it either prevents them from entering the job market (and exacerbates women's poverty); or, if they do work, may force them to accept low-waged, informal and insecure work.[37] This obstructs women's right to decent work under Articles 6 and 7 of the International Covenant of Economic, Social and Cultural Rights, and Article 11 of the Convention on the Elimination of Discrimination Against Women.

Addressing unequal care responsibilities is an essential component of Australia's commitments under international human rights law and the international human rights treaties to which Australia is a party. Though not automatically enforceable in Australian courts, by entering these treaties, Australia has voluntarily committed to comply with their provisions in good faith and to take the necessary steps to give effect to those treaties under domestic law.[38]

Despite this commitment, there is a general lack of federal constitutional protection of human rights in Australia.[39] Currently, human rights are protected in a patchy, complex, and piecemeal way and across various pieces of legislation resulting in an incomplete national human rights framework, which especially disadvantages the most vulnerable people in our society, including carers and the people they care for who may also experience other difficulties, marginalisation and discrimination. For carers, this fragmented approach to human rights—including different conceptions of what a carer is—manifests in gaps in coverage for carer responsibilities under current federal discrimination laws[40] (the *Sex Discrimination Act 1984* (Cth) and *Disability Discrimination Act 1992* (Cth)), and inconsistencies with the *Fair Work Act 2009* (Cth) and state/territory discrimination and equal opportunity acts, some of which provide a broader and different definition of 'carers' to address varied domestic relationships and cultural understandings of kinship.[41]

The current Parliamentary Joint Committee on Human Rights' Inquiry into Australia's human rights framework represents an opportunity to apply the principles of carers recognition, as articulated in the Act, in a meaningful way by recognising status as an unpaid carer as a protected attribute in any new National Human Rights Framework and National Human Rights Act. This would provide important protections for unpaid carers from discrimination in public life and signal a commitment to recognising and upholding the human rights of carers. Enhanced recognition of carers via a National Human Rights Framework and Act may also address some of the inconsistencies in the way carers are defined and the application of discrimination protections in related laws.

Recommendations
All aspects of cancer prevention and control are matters of human rights, including the provision of care for people affected by cancer.

The Act should acknowledge Australia's human rights obligations with respect to carers, and support carers as rights holders, entitled to the full enjoyment of economic, social and cultural rights, without discrimination.

The Australian Government should recognise the status of unpaid carer as a protected attribute in any new National Human Rights Framework and National Human Rights Act.

National Strategy for Carers

The *National Carers Strategy 2011, Action Plan 2011-2014* and *Implementation Plan* lapsed in 2014, and the Albanese Government made a pre-election commitment to develop a National Carer Strategy within its first term of government and.[42] While the Act is valuable for acknowledging the role of carers, its scope is limited.

A new National Carer Strategy, and Action and Implementation plan should be developed as part of a broader approach to recognising the role of unpaid carers, which includes the need for improved data and research into carer roles and needs, and their economic and social contribute to our community. A new Strategy would provide a carer-specific focal point for policy development and reform for addressing carers rights and needs, in step with developments in paid care and support services as outlined in the draft National Care and Support Economy Strategy. Development of a new National Strategy should also complement and align with policy development and reform in the Australian Cancer Plan (forthcoming), as well as related strategies such as Australia's Primary Health Care 10 Year Plan 2022-2023, Australia's Disability Strategy 2021-2031 and the National Aboriginal and Torres Strait Islander Health Plan 2021-2031, and support implementation of recommendations from previous inquiries and reports, including the Royal Commission into Aged Care Quality and Safety and the the 2013 Investing in Care report by the AHRC.

Recommendation
The Australian Government should develop a new National Carer Strategy, and Action and Implementation Plan, to focus on needs and challenges for unpaid carers.

Community Education and Awareness Campaigns

The Act formally acknowledges the role and value of unpaid carers; community education and awareness campaigns connect the intent and content of legislation with the individuals and communities the laws are intended to support.

A reformed Act (and any new National Carer Strategy) should be accompanied by community education and awareness campaigns that:

- Ensure the carers and the community are well-informed about support and assistance available for carers; and

- Increase the awareness of the social and economic value, and contribution of, all forms of unpaid care, and the challenges faced by parents and carers, as recommended by the Australian Human Rights Commission's 2013 research report *Investing in care: Recognising and valuing those who care*[43]

Recommendation
The Australian Government should support community education and awareness initiatives for the recognition of carers, and better facilitate carers' access to support and assistance.

The McCabe Centre for Law and Cancer, Cancer Council Australia, and Cancer Council Victoria thank you for consideration of this submission.

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