



Submission regarding the Productivity Commission's Position Paper: *A case for an extended unpaid carer leave entitlement?*

Cancer Council Australia and McCabe Centre for Law and Cancer

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This submission has been prepared by Cancer Council Australia and the McCabe Centre for Law and Cancer.

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.

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 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.

Cancer Council Australia and the McCabe Centre welcome the opportunity to provide feedback on the Productivity Commission's Position Paper: *A care for an extended unpaid carer leave entitlement?* Our submission focuses on the need to support carers of people affected by cancer. The submission responds to the following information requests:

- Information request 1 – feedback on the Productivity Commission's provisions model for an entitlement to extended unpaid carer leave
- Information request 2 – additional ways to support informal carers, beyond those discussed in the Position Paper

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This submission may be published. There is no need to anonymise this submission.

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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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Executive Summary

Care work is at the heart of our society, as all human beings are dependent on care to survive and thrive.¹ Anyone can become an informal carer during their life. Cancer is one of the 10 most common health conditions in receipt of informal care giving.² Almost all (>90%) of people with cancer have at least one informal carer ('carer'): a family member or friend supporting them with care over the course of their illness, treatment, and through to end of life.³

This is because cancer is the leading cause of disease burden in Australia.⁴ 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.⁵ A cancer diagnosis is a devastating and often 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.⁶

Carers are fundamental to healthcare in Australia, with a replacement value of approximately \$77.9 billion.⁷ Carers provide critical practical, medical, emotional, legal and financial support to people living with cancer; a vital but demanding role which can exceed 40 hours of direct care per week.⁸ Carers are also critical in that they enable people with cancer to remain and home and out of hospitals for longer than would have otherwise been possible.⁹

"I think that as a carer, we take a lot of the burden away from the government, financially. Because then patients are not being put into hospital to be cared for. We don't have any hospices or anything like that in our local area, but nursing homes and places like that are not being taken up with people who may need short term care and that's a cost to the government." — Tracey, carer

"The first appointment we had with the oncologist, she very rightly said to mum 'you've got stage 4 cancer, you need to get your affairs in order'. And my mum didn't understand what that meant. So, besides dealing with the cancer, I had to engage a lawyer to prepare her Will and Advance Care Directive – she could not have done that on her own. There's absolutely no way that would have happened on her own. Just reading and comprehending information was hard for her. She was completely floored at being told 'you've got cancer'. She really did need someone to help her through the challenges, the paperwork, the treatment options — Jenna, carer (note name has been changed for privacy)*

Caring for someone with cancer can be all-encompassing and affects the physical, emotional and financial wellbeing of carers.¹⁰ Carers for people with cancer report high levels of anxiety, distress and burden.¹¹ Many carers report higher levels of distress than people receiving treatment for cancer.¹²

The emotional burden is huge, especially early on because you're coming to terms not only with the diagnosis, but understanding how the cancer network works, what treatment options are available, how to access them? — Jenna, carer (note name has been changed for privacy)*

Like people diagnosed with cancer, many carers face disruptions to their ability to work — they may be unable to work or must work fewer hours or in a lower paid job to meet their caring commitments.¹³ "Financial toxicity"* is a common experience for many Australians diagnosed with cancer, their carers, and their family.¹⁴

Indeed, carers of people living with cancer are especially vulnerable in the context of work and the need for paid and unpaid carer's leave; cancer experiences are unique to each person and can fluctuate depending on the type of cancer and treatments involved. Care requirements can be urgent and

* Financial toxicity is '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: COSA Financial Toxicity Working Group, *Financial Toxicity in Cancer Care* (Clinical Oncology Society of Australia, 2022). Accessed from <https://www.cosa.org.au/media/q3ohepgs/financial-toxicity-in-cancer-care-7.pdf>

unpredictable, due to variability in both the progression of the disease and responses to treatment and can be over a short term or over months or years given the complex and chronic nature of the disease.¹⁵

Accordingly, the needs of carers of people with complex and chronic illnesses such as cancer should be considered in contemplating the introduction of additional leave entitlements and other additional supports.

“Once my mum was on treatment, she had recovered from her surgery, and she was OK and I wasn't living with her anymore to care for her. But even then, she has side effects. She has bad days. She has days where I need to be there.” — Jenna, carer (note name has been changed for privacy)*

Paid and unpaid care leave recognises the critical role of carers, the impacts of caring, and the periods throughout our lives in which we all experience a need for support.¹⁶ They are essential measures that give carers choices about the extent of care they can undertake, while providing job protection to facilitate re-entry to the workforce after a period of caregiving.¹⁷ They are also measures capable of realising a range of interrelated human rights articulated in several international human rights instruments including rights to gender equality, non-discrimination, an adequate standard of living, the highest attainable standard of physical health and mental health, social security, and decent work that accommodates family and caring responsibilities.¹⁸ Better support for carers will likely have immediate and long-term benefits for people, societies, and economies.¹⁹

While extended unpaid leave may only be used by a small proportion of working people, it can secure employment for a particularly vulnerable population (including carers of people with cancer) who may be unable to ‘choose’ to utilise flexible working arrangement entitlements due to the unpredictable and intense time commitment of caring responsibilities and the inability to meet the competing demands of the workplace. Valuing unpaid carers requires attention to the full spectrum and diversity of unpaid caring work and affording equal recognition and worth to all unpaid carers.²⁰

“With cancer things are unpredictable....from an employee perspective, I think that it is essential that people in this position, and it's not just carers of people with cancer, it's any carer role, have access to paid and unpaid leave.” — Jenna, carer (note name has been changed for privacy)*

It is therefore crucial that the Productivity Commission (‘Commission’) consider the case for extended unpaid carer’s leave from an equity perspective to ensure that carers with the greatest needs receive the greatest protections and support.

Cancer Council Australia and the McCabe Centre support the amendment of the *Fair Work Act 2009* (Cth) to provide extended unpaid carer’s leave so employees can better meet their caring responsibilities and urge the Commission to reconsider its position not to endorse the introduction of such an entitlement.

Cancer Council Australia and the McCabe Centre support the Commission’s Draft Recommendations 1 and 2.

Cancer Council Australia and the McCabe Centre make several additional recommendations:

Recommendation 1: Expand extended unpaid care leave entitlements to all employees to care for people of all ages.

Recommendation 2: Introduce flexibility into the proposed model of extended unpaid carer’s leave to cater to episodic care needs and have shorter notice periods when caring needs are urgent.

Recommendation 3: Ensure review mechanisms exist for employees to formally challenge an employer’s refusal of extended unpaid leave; and ensure consistency with other existing protections and entitlements including anti-discrimination protections and income support payments.

Recommendation 4: Adopt a health and human rights lens to the consideration of the case for extended unpaid carer’s leave and the design and implementation of such an entitlement with a view to reduce social and health inequities and to promote, respect and fulfil human rights.

Recommendation 5: Increase and improve other supports for informal carers including expanding access to paid sick and carers leave to those in working arrangements outside of formal employment, increased levels of financial support for those unable to work due to caring commitments, resourcing

education and awareness campaigns about the needs of carers, and improved awareness and access to support services and formal care, respite care and assistance in maintaining or returning to work.

Information request 1 - Feedback on the features of Productivity Commission's provisional model for an entitlement to extended unpaid carer's leave

Eligibility

Recommendation 1: Expand extended unpaid care leave entitlements to all employees to care for people of all ages

Paid and unpaid care leave recognises the essential role of carers and the impacts of caring. Anyone can become a carer at any time without warning. Over 2.6 million Australians, or close to 11% of the population, are carers.²¹

Regarding the Commission's Draft Finding 3 – Extended unpaid leave in the National Employment Standards is not the highest priority, the Commission states that few employees would use an entitlement to extended unpaid leave; that extended unpaid leave is not the highest priority for most carers; and that better access to flexible work would make a bigger difference for more carers.²² This finding seems to be based on data concerning carers of older people who are generally older than carers of younger people.

Additionally, it fails to adequately consider that expansion of unpaid care can secure the employment for a small, yet particularly vulnerable group of people — including carers of people affected by cancer (particularly those caring for people with a life-limiting cancer diagnosis, or providing palliative care, as recommended by the Australian Human Rights Commission)²³ — and those who may be unable to 'choose' to utilise flexible working arrangements due to the intense time commitment of caring responsibilities and the inability to meet competing demands of the workplace.

The Commission also states that 'upcoming changes to the flexible working arrangement provisions of the *Fair Work Act 2009* (Cth) are expected to make it easier for carers to negotiate flexible work, 'perhaps obviating the need for change.'²⁴ Cancer Council Australia and the McCabe Centre support these recent legislative changes. But these entitlements are not mutually exclusive with strengthening access to paid and unpaid carer's leave — as noted by Australian Human Rights Commission, a combination of legislative changes, flexible work arrangements, leave arrangements, carer support payments, services for carers, workplace initiatives and mechanisms within the retirement income savings system (taxation, superannuation and income support) are required to fully recognise and value informal carers.²⁵ Additionally, flexible working arrangements may not be suitable for carers experiencing significant distress and who need time off from work to manage their own health and wellbeing as well as that of the person for whom they are providing care.²⁶

Existing entitlements to 2 days paid compassionate leave and 2 days unpaid carer leave may be insufficient for carers of people living with chronic and complex conditions such as cancer. Access to extended unpaid leave for carers is valuable. Extended unpaid parental leave is considered important in enhancing labour market attachment, despite the lack of income associated with it.²⁷ In the interests of equity, an entitlement to unpaid extended carer's leave should also be made available for people with significant caring responsibilities due to illness of a family/household member.²⁸

Therefore, Cancer Council Australia and the McCabe Centre support the amendment of the *Fair Work Act 2009* (Cth) to provide extended unpaid carer's leave so employees can have more options available to them to better meet their caring responsibilities and urge the Commission to reconsider its position not to endorse the introduction of such an entitlement.

“Something like this is just going to make life that little bit easier for people who, you know, get thrust into this situation. It’s not something you choose. It’s such a horrible, horrible time. When you get that diagnosis, then you have to be worried, you know about finances and possibly a new job and you’re also disadvantaged because often the person that is diagnosed is unable to work as well.” — Tracey, carer

To be most effective to carers, eligibility criteria should include as many employees as possible so that the job security attached to the leave entitlement covers those who need it most. Guidance from the International Labour Organization is that care policies should be universal and should provide adequate and equitable benefits.²⁹

Accordingly, the provisional model for an entitlement to unpaid care leave should apply to both permanent employees (full-time and part-time) and regular casual employees. This would benefit those who already experience greater levels of job insecurity, including women who bear a greater burden of caring responsibilities during their working years,³⁰ who face losing attachment to the labour market without this protection and are also disproportionately engaged in casualised and insecure work — a situation exacerbated by the COVID-19 pandemic.³¹ Additionally, some groups disproportionately impacted by casual and insecure work also bear an unequal burden of cancer, including people living in the most socioeconomically disadvantaged areas of Australia, Aboriginal and Torres Strait Islander People, and some culturally and linguistically diverse communities.³²

The purpose of the leave should be expanded to include carer for persons of any age, not limited to those 65 years or older. Although cancer is more prevalent in older Australians,³³ 40% of people diagnosed with cancer will be of working age (25-64 years old).³⁴ Many carers will also be of working age,³⁵ and could benefit from the job security attached to the proposed extended unpaid carer leave entitlement. Accordingly, Cancer Council Australia and the McCabe Centre agree with the Commission’s Draft Finding 4 that a case for an entitlement for extended unpaid leave is similar for all carers, not just carers of older people.

Cancer Council Australia and the McCabe Centre support the Commission’s Draft Recommendation 2 that the Australian Government should review and expand the definition of carer under the National Employment Standards to extend beyond immediate family or household to other extended family members or families of choice to better reflect the diverse caring relationships of Australian families, friends and communities.³⁶

Greater flexibility for the proposed model of extended unpaid carer’s leave

Recommendation 2: Introduce flexibility into the proposed model of extended unpaid carer’s leave to better cater to care needs and have shorter notice periods when caring needs are urgent

Cancer Council Australia and the McCabe Centre recommend that some flexibility be introduced into the Commission’s model of proposed extended unpaid leave under Draft Finding 2 – A provisional model of extended unpaid carer leave, aligned to existing standards.

An entitlement of extended unpaid carer’s leave would build on the existing entitlements of paid compassionate and unpaid carer leave under the National Employment Standards and therefore needs to be flexible enough to accommodate longer term caring needs when an unexpected illness, injury, or emergency arises (such as a cancer diagnosis) to be effective.

As the Commission notes, care needs can be episodic in nature. This is particularly the case for carers of those with chronic illnesses such as cancer. Cancer Council Australia and the McCabe Centre urge the Commission to reconsider its stance that an entitlement of unpaid carer leave be taken in a single block.

Flexibility could be introduced akin to the ‘flexible parental leave’ provisions in the *Fair Work Act 2009* (Cth) that enable an employee to take up to 30 days of their 12-month unpaid parental leave flexibly within the first 24 months of the birth or placement of an adopted child and which allows employees to take flexible unpaid parental leave after taking one or more periods of continuous unpaid parental leave.³⁷ As these provisions have been in place since 2020 and have been

accommodated by employers, similar flexible unpaid leave provisions for carers of people who are ill could also be accommodated.

Similarly, in the interests of equity between carers of young children and carers of people who are ill, the Commission should consider a right to further extension of 12 months of unpaid carer leave consistent with recent amendments to the Fair Work Act to strengthen the request for an extension of unpaid parental leave³⁸ that come into effect on 6 June 2023.³⁹

Enabling carers to take periods of extended leave as required would better cater for the needs of carers of people living with cancer.

*“Making the decision of what the right treatment is so early on. I think having a good three months is really, really, important. And then being able to take, chunks of leave when you need to give them care.
—Jenna*, carer (note name has been changed for privacy)*

“The leave duration needs to be flexible to meet the needs of a person’s illness and treatment regime. Every cancer is different, and every person responds differently. So there’s no one-size-fits-all. 12 months is a really good starting point, but with flexibility...to be broken up into chunks. For instance, when my partner was on treatment (for neuroendocrine cancer) we needed to be in Melbourne, away from home for a month each cycle and I couldn’t work, but I could work in between treatment cycles.” — Tracey, carer

Cancer Council Australia, the McCabe Centre and carers acknowledge the need for notice periods for employers to effectively plan and resource their needs. However, carers of people with cancer raised significant concerns about the feasibility of the proposed 4 week notice period under Draft Finding 2, due to the unpredictable and urgent nature of a cancer diagnosis and subsequent treatment.

Accordingly,

Cancer Council Australia and the McCabe Centre recommend consideration of a shorter notice period or a 4 week notice period that allows discretion for a shorter notice period where extended unpaid leave is required urgently. While noting the preference for consistency with unpaid parental leave notice requirements, the context of sudden illness like cancer is different from pregnancy where expectant parents have several months’ notice of when they will need to take parental leave.

A reduced notice period better reflects the practical realities for working carers of people diagnosed with cancer. Furthermore, it would be consistent with existing notice requirements for compassionate leave and unpaid carer leave which require notice be given to the employer as soon as **practicable**,⁴⁰ which may be at a time after the leave has started.⁴¹

*I understand from an employer’s perspective, they need to understand their resources and apply resourcing in advance. I completely understand that they need notice. But on a practical reality level, it’s not always easy to do that as it is impossible to predict when the cancer patient will be unwell. It’s a bit of a rollercoaster as the side effects from ongoing medication can come on very suddenly.”
— Jenna*, carer (note name has been changed for privacy)*

Right to review and consistency with other existing protections and entitlements

Recommendation 3: Ensure review mechanisms exist for employees to formally challenge an employer’s refusal of extended unpaid leave; and ensure consistency with other existing protections and entitlements including anti-discrimination protections and income support payments.

For people to fully enjoy and utilise workplace protections and entitlements such as a new entitlement to extended unpaid carer leave, other legal entitlements may need expansion and/or improvements. Within the Commission’s proposal, there should be a mechanism for employees to formally challenge an employer’s refusal. For example, employees should have 28 days within which to apply to the Fair Work Commission, if they do not agree that the employer had reasonable business grounds for refusing the unpaid carer’s leave request (or an extension).⁴²

Additionally, under international human rights law, entitlements such as paid and unpaid sick and carer's leave must be provided without discrimination.⁴³ Federal anti-discrimination and equal opportunity laws and adverse action protections under federal employment laws should be reviewed to guarantee they cover any right to extended unpaid carer leave.

Carers also expressed concern that the Commission's proposed model of leave may impact the ability to receive other carer's benefits. Specifically, that the employment security attached to the proposed leave may render them ineligible for income support payments, such as the Carer Payment. Consequently, the interaction of an entitlement to take extended unpaid leave with other existing entitlements for carers should be reviewed to ensure there are no inconsistencies across relevant laws and policies and unintended negative impacts on carers.

"Technically, if you're employed, are you going to get a Carers Payment? If you have a job, I'm wondering how that's going to fit with taking 12 months of unpaid leave? Kind of defeats the purpose if you're ineligible for Carers Payment for that 12-month period so there may need to be a change made there. I love the idea of carers being able to take that time, but we need to balance that with how they're going to survive, especially at the moment with the cost of living going through the roof." — Tracey, carer

Case study: Carer Tracey's story

Tracey's carer responsibilities began suddenly at age 40, when her partner was diagnosed with cancer at age 43.

"It happened very suddenly, and he went downhill very quickly. Unfortunately, that's the nature of what happens with cancer. It's so unpredictable."

After a car accident and a suspected cracked rib, her partner was unexpectedly diagnosed neuroendocrine cancer. Based in regional Victoria, they had to make several trips to Melbourne for treatment.

"He went to the doctors and they kind of said, oh we think it's a bit of an infection. They put him on antibiotics which didn't do anything. He was then sent for an x-ray. They found a massive lump, the size of golf ball and basically within a couple of weeks he was in Melbourne having surgery."

Tracey cared for her partner for a further 16 years before he died aged 59. During that time Tracey needed to take leave from work to focus on caring for her partner, often at short notice.

"Cancer is a disease where it's ongoing. It's chronic, it's it affects so many other aspects of your health. And it's very, very unpredictable. There's so many things that can go wrong during the cancer journey. For instance, my partner had immunotherapy and he had an allergic reaction which caused myocarditis, and he was flown to Melbourne and I had to leave work immediately. That's the unpredictability, and there has to be some discretion for employers to approve leave at short notice."

Tracey was fortunate to have employers who valued work-life balance and the importance of time spent with family. She was also fortunate to have access to paid leave and time-lieu available to her which she had accrued. Had this not been the case, access to extended unpaid leave with the security of returning to work after that time would have made real difference to Tracey:

"I could use leave that I had banked up and I was quite strategic with how I used it. But the reality is that for carers who don't have something like this, they could be changing jobs quite regularly because they don't have that safety net to say, hey, I need to take six months away from work and be told 'that's OK, your job will be here when you come back'. Sadly, not all employers are understanding and empathetic in doing that."

For Tracey, having access to extended unpaid leave that could be taken at different times rather than all at once is important:

"What also needs to be considered in all of this is that there's so many different types of cancers – some will hit suddenly and hard and it will be a very intense, short journey, whereas for others it will be longer, including periods of really good health. I think that's why it's important there be some flexibility to be able to take leave broken into different chunks rather than for a set period of time."

Adopt a health and human rights approach

Recommendation 4: Adopt a health and human rights lens to the consideration of the case for extended unpaid carer's leave and the design and implementation of such an entitlement with a view to reduce social and health inequities and to promote, respect and fulfil human rights.

To effectively address the needs of carers and existing gaps meeting those needs, and in considering impacts of adding an entitlement to extended unpaid leave to the National Employment Standards (and additional supports for informal carers), the Commission should approach this through an equity and human rights framework, not just through the lens of employment rights and the associated social and economic costs.

Such an approach would enable an intersectional lens to be applied to the realities and needs carers face, considering gender, ethnicity, age, work status, socio-economic status, disability, and the condition of the person for whom they care. This will ensure that carers falling outside the coverage of existing carer's leave employment entitlements are not left even further behind to the detriment of themselves, their families, and communities.

All aspects of cancer prevention and control are matters of human rights. Advancing human rights is imperative to addressing the underlying social determinants of health that lead to inequities we see in the unequal burden of cancer in Australia, including socio-economic disadvantage, financial distress and job insecurity discussed earlier in this submission.

As previously stated, of relevance to this Inquiry is that access to paid and unpaid care leave is an important measure capable of realising a range of interrelated human rights including rights to gender equality, non-discrimination, an adequate standard of living, health, social security, and decent work that accommodates family and caring responsibilities. These rights cannot be fully realised within social, economic, and political structures and approaches that value economic contributions over and above social contributions, such as caring.⁴⁴

Australia is a party to several international human rights treaties that impose obligations to progressively expand population coverage of social protections in case of sickness and the care of sick family members.⁴⁵ It has also made several other commitments to reducing the social inequalities of health— including job and income security — by advancing universal health coverage and taking measures to reduce gender inequality and to accommodate family and caring responsibilities — including through policies to recognise and value caregiving.⁴⁶ Though not automatically enforceable in Australian courts, by entering into 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.⁴⁷

Some international human rights obligations have been directly incorporated into domestic legislation, including employment entitlements to paid sick and carer's leave for some workers under the *Fair Work Act 2009* (Cth), and the *Social Security Act 1991* (Cth). Yet gaps in these protections still exist. Even when human rights law treaties have not been directly incorporated into domestic legislation, they are an indirect source of rights in that they give rise to a legitimate expectation of compliance by the state. They also provide guidance on how domestic laws and obligations should be understood.⁴⁸

Accordingly, Australia's commitments under international human rights law and other international agreements should be considered in the design and implementation of any model of extended unpaid carer leave (as well consideration of additional supports for carers). The Commission should also look to jurisprudence and treaty guidance documents, including standards and guidance from the International Labour Organization to guide the model's design and operation and supports for carers.⁴⁹

Information request 2 – Additional ways to support informal carers, beyond those discussed in the Position Paper

Better support for carers

Recommendation 5: Increase and improve other supports for informal carers including expanding access to paid sick and carers leave to those in working arrangements outside of formal employment, increased levels of financial support for those unable to work due to caring commitments, resourcing education and awareness campaigns about the needs of carers, and improved awareness and access to support services and formal care, respite care and assistance in maintaining or returning to work.

As discussed above, consideration of additional ways to support informal carers should be approached from a health and human rights perspective to reduce inequities amongst carers and to ensure the needs of carers are met — key to effective supports for informal carers is the recognition of the diversity and complexity of caring roles, and the need to support people in their caring duties across their life-course, and that of the person for whom they are providing care.

Cancer Council Australia and the McCabe Centre support the Commission’s Draft Recommendation 1.

However, based on feedback from community, Cancer Council Australia and the McCabe Centre consider that this need for better information and support on flexible work arrangements should extend to resourcing for improved education and awareness for employers and the broader community of the impact illness (particularly chronic illness such as cancer) has on carers. Such education would increase understanding amongst workplaces about the needs of working carers and help ensure that requests for flexible working arrangements and paid and unpaid leave are granted.

“I was very blessed with my employers during the cancer journey. And I was in the fortunate situation that I had access to time-in-lieu. Sadly, not all employers are understanding and empathetic in giving unpaid leave.” — Tracey, carer

*“I had to deliver my projects and I had specific deadlines. I can’t say that my employers were that receptive or understanding of my caring responsibilities. I was working on multiple projects, so I had multiple project managers and some of them were empathetic and some of them just weren’t.”
— Jenna*, carer (note name has been changed for privacy)*

Cancer Council Australia and the McCabe Centre concur with additional ways to support informal carers noted (though not necessarily formally recommended) in the Commission’s Position Paper including:⁵⁰

- Improved awareness and easier access to flexible working arrangements (noting upcoming changes to flexible working arrangements under the *Fair Work Act 2009* (Cth))
- Ensuring eligibility requirements for income support payments do not unnecessarily limit participation of carers in work, study or volunteering
- Timely and high-quality formal supports including formal care and respite care; and better navigation pathways and greater advertising of such services.

*“There needs to be better advertising about supports for carers like Carer Gateway – what it is and who can access it. Especially here in our town – I didn’t know it existed for quite some time.”
— Tracey, carer*

“The nurse at PeterMac (Peter MacCallum Cancer Centre) mentioned was that there was a Community Nurse available, which I didn't know about. So, I've only known about that quite recently. Having that Community Nurse available, or someone else that she could call, that's not me because I'm not available. It's a huge weight off my shoulders and a really, really, really reassuring for her. Because I can't go on holiday at the moment, I can't not be in Melbourne near her and having that support would be huge for me. It is necessary to have another carer available in the event that the primary carer is unwell. Luckily, I have not needed that, but as a primary carer it is very stressful knowing that I need to be available 24/7.”

— Jenna*, carer (note name has been changed for privacy)

Cancer Council Australia and the McCabe Centre recommend the following additional supports for informal carers:

- An increase in paid care leave entitlements under the National Employment Standards. This is particularly important given the gendered nature of unpaid care which disproportionately impacts women, as noted earlier in this submission. Internationally, several countries provide more than 10 days paid carer's leave additional to extended unpaid and paid leave periods,⁵¹ including for palliative care.⁵²
- Separation of paid and unpaid personal sick leave and paid carers leave. Carers reported that they have had to use up personal leave entitlements to provide care and have none left to use when they themselves are unwell:

“I was in that fortunate situation that I had access to time in lieu. So when we were working outside of hours we could bank that up. So I banked that up for my own personal wellbeing, that was my fail safe. — Tracey, carer
- Expansion of paid care leave entitlements to workers not currently eligible including some casual employees and workers in insecure forms of work such as platform or 'gig economy' work, independent contractors and sole traders, consistent with Australia's obligations to progressively expand social protection coverage under international human rights law. A scheme like the Victorian Government's Sick Pay Guarantee⁵³ is worth considering at a national level. The ILO has determined that minimum guarantees for essential social benefits such as sick leave are affordable for all countries.⁵⁴
- Increased levels of financial support are provided for carers of people with cancer who are experiencing financial hardship.
- Improvements in access for carers to income support payments. Carers suggested enhanced case management particularly for people caring for those with complex and chronic illness such as cancer.
- Improved support is provided for carers of people with cancer from culturally and linguistically diverse backgrounds, including better access to culturally safe and appropriate support services, specialised equipment and respite care and assistance in maintaining or returning to employment.
- Measures to address out-of-pocket costs associated with cancer to reduce the financial burden on carers of people living with cancer.⁵⁵
- Improvements to the NDIS as it is not yet operating adequately to support the workforce and participation rights and needs of carers.⁵⁶
- Strengthen existing legislation and policies to better acknowledge the importance of informal carers. Cultural change in our society is a crucial element of valuing unpaid care and can be shaped by laws.⁵⁷
- Address gender inequities related to caregiving, for example by reviewing the current retirement income and saving system that leaves many women who have been unpaid carers in poverty in older age.⁵⁸

Case Study, Carer Jenna's* story

Jenna was 49 years old when she became her mother's primary carer after her mother was diagnosed with stage 4 lung cancer in 2022.

Like many parents, Jenna's Mum didn't want to be a burden on her children. Knowing Jenna had a challenging job, she would avoid calling Jenna when she was working, even if she needed help. This caused Jenna stress and Jenna felt she needed to be fully available to look after her mother and support her through the daunting experience of being diagnosed with cancer.

"My mum was diagnosed with lung cancer about nine months ago. Initially she was diagnosed with stage 1 cancer, but surgery uncovered it was actually stage 4. She was living on her own and I moved in with her to help care for her. My mum wasn't in a position at all to investigate her options, she had just had surgery and was incredibly vulnerable, so it was my responsibility."

"It's a lot to take in. I needed to be at every appointment. And driving my mum to hospital. It's not easy for her to get there, to get up to the lift, doing the COVID checks you have to do online, all the little things add up. Plus, I need to be available for her because there are side effects with the treatment she's on."

For Jenna, the weight of her caring responsibilities meant she had to make the very difficult choice to stop working. Her demanding role as a contractor delivering IT projects meant flexible working arrangements were not an automatic workplace entitlement nor always practicable.

"I realised caring for my mum and working full time at the same time – it was just too hard. And working part-time wasn't really feasible either. Especially as I realised I had to research the targeted therapies and trials that the oncologist suggested to us. This was a whole new domain for me. It's really hard to get your head around the diagnosis, the treatment options and do all the research, explain it all to mum, and make treatment decisions. There's no way I could have done all that while working. It's a huge, huge, undertaking."

I gave my required two weeks' notice, and I resigned so that I could concentrate on what I needed to do for my mum."

Working as an independent contractor for most of her working life, Jenna has no access to paid sick or carer's leave. She was fortunate she ensured she had money saved aside to take a time away from working and remain financially secure if she needed to. Nonetheless, the decision to step away from work was very hard but Jenna felt was left with no other choice.

"I've always worked for the last almost 20 years. It was very, very difficult to make that decision to stop."

Access to paid and unpaid extended leave would have meant a lot to Jenna:

"They would really have been a huge weight off my shoulders. It would have made that decision a lot easier for me if I had access to that and knowing that I had a job to go back to".

*Note name has been changed for privacy reasons

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References

- ¹ International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work* (2018), p 5. Accessed from https://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcomm/---publ/documents/publication/wcms_633135.pdf.
- ² Palliative Care Australia, *The Hardest Thing We Have Ever Done: The Social Impact of Caring for Terminally Ill People in Australia* (Full Report of the National Inquiry into the Social Impact of Caring for Terminally Ill People, May 2004). Accessed from <https://www.yumpu.com/en/document/read/27255984/the-hardest-thing-we-have-ever-done-palliative-care-australia>.
- ³ Anna Ugalde et al, 'Effective Integration of Caregivers and Families as Part of the Care Team for People with Cancer' (2021) 50(8) *Australian Journal of General Practice* 527. Accessed from <https://www1.racgp.org.au/ajgp/2021/august/effective-integration-of-caregivers-and-families-c>.
- ⁴ Australian Institute of Health and Welfare, *Australian Burden of Disease Study 2022* (Cat no BOD 37, 13 December 2022). Accessed from <https://www.aihw.gov.au/reports/burden-of-disease/australian-burden-of-disease-study-2022/contents/about>.
- ⁵ Australian Institute of Health and Welfare, *Cancer in Australia 2021* (Cancer series no 133, Cat no CAN 144, 2021). Accessed from <https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2021/summary>.
- ⁶ National Breast Cancer Centre and National Cancer Control Initiative, *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer* (2003). Accessed from https://www.canceraustralia.gov.au/sites/default/files/publications/pca-1-clinical-practice-guidelines-for-psychosocial-care-of-adults-with-cancer_504af02682bdf.pdf.
- ⁷ Carers Australia, Deloitte Access Economics, *The Value of Informal Care in 2020* (May 2020). Accessed from <https://www2.deloitte.com/au/en/pages/economics/articles/value-of-informal-care-2020.html>.
- ⁸ Jennifer L Wolff et al, 'End-of-life care: Findings from a National Survey of Informal Caregivers' (2007) 167(1) *Archives of Internal Medicine* 40–46. Accessed from <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/411473>.
- ⁹ Anna Ugalde et al (n 3).
- ¹⁰ See, eg, Jacob J Adashek and Ishwaria M Subbiah, 'Caring for the Caregiver: A Systematic Review Characterising the Experience of Caregivers of Older Adults with Advanced Cancers' (2020) 5(5) *ESMO Open* e000862. Accessed from <https://www.sciencedirect.com/science/article/pii/S2059702920327058>.
- ¹¹ Hai-Mei Geng et al, 'Prevalence and Determinants of Depression in Caregivers of Cancer Patients: A Systematic Review and Meta-Analysis' (2018) 97(39) *Medicine (Baltimore)* e11863. Accessed from https://journals.lww.com/md-journal/Fulltext/2018/09280/Prevalence_and_determinants_of_depression_in.5.aspx.
- ¹² S K Chambers et al, 'Psychological Distress and Unmet Supportive Care Needs in Cancer Patients and Carers who Contact Cancer Helplines (2012) 21(2) *European Journal of Cancer Care* 213–23. Accessed from <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2354.2011.01288.x>.
- ¹³ Palliative Care Australia (n 2); Gaëlle Ferrant, Luca Maria Pesando and Keiko Nowacka, *Unpaid Care Work, The Missing Link in the Analysis of Gender Gaps in Labour Outcomes* (OECD Development Centre Issues Paper, 2014), p 6. Accessed from https://www.oecd.org/dev/development-gender/Unpaid_care_work.pdf.

-
- ¹⁴ Louisa G Gordon et al, 'A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay' (2017) 10(3) *The Patient - Patient-Centered Outcomes Research* 295-309. Accessed from <https://link.springer.com/article/10.1007/s40271-016-0204-x>.
- ¹⁵ Anna Ugalde et al (n 3).
- ¹⁶ Australian Human Rights Commission, *Investing in Care: Recognising and Valuing Those Who Care* (23 January 2013) Accessed from <https://humanrights.gov.au/our-work/sex-discrimination/publications/investing-care-recognising-and-valuing-those-who-care>.
- ¹⁷ Ibid.
- ¹⁸ *Universal Declaration of Human Rights*, UN Doc A/810 (10 December 1948); *International Covenant of Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976); *Convention on the Elimination of All Forms of Racial Discrimination*, opened for signature 21 December 1965, 660 UNTS 195 (entered into force 4 January 1969); *Convention on the Elimination of All Forms of Discrimination Against Women*, opened for signature 18 December 1979, 1249, UNTS 13 (entered into force 3 September 1981); *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990); *Convention on the Rights of People with a Disability*, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008); *Workers with Family Responsibilities Convention 1981* (ILO Convention No. 156, entered into force 11 August 1983).
- ¹⁹ International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work* (n 1).
- ²⁰ Australian Human Rights Commission, *Investing In Care: Recognising and Valuing Those Who Care* (n 16).
- ²¹ Australian Government Workforce Gender Equality Agency, *Gender Equality and Caring* (Webpage) <https://www.wgea.gov.au/gender-equality-and-caring>.
- ²² Productivity Commission, *A Case for an Extended Unpaid Carer Leave Entitlement?* (Position Paper, 28 February 2023). Accessed from <https://www.pc.gov.au/inquiries/current/carers-leave/position>.
- ²³ Australian Human Rights Commission, *Investing In Care: Recognising and Valuing Those Who Care* (n 16).
- ²⁴ Productivity Commission (n 22) p 13.
- ²⁵ Australian Human Rights Commission, *Investing in Care: Recognising and Valuing Those Who Care* (n 16).
- ²⁶ Winson Fu Zun Yang et al, 'Cancer Caregivers Unmet Needs and Emotional States Across Cancer Treatment Phases' (2021) 16(8) *PLoS One* e0255901. Accessed from <https://pubmed.ncbi.nlm.nih.gov/34379667/>.
- ²⁷ Australian Human Rights Commission, *Valuing Parenthood, Part C: Objectives of Paid Maternity Leave* (2002). Accessed from <https://humanrights.gov.au/our-work/publications/valuing-parenthood-part-c>.
- ²⁸ Australian Human Rights Commission, *Investing in Care: Recognising and Valuing Those Who Care* (n 16).
- ²⁹ International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work* (n 1).
- ³⁰ Australian Government Workforce Gender Equality Agency (n 21).
- ³¹ Australian Bureau of Statistics, *Characteristics of Employment, Australia* (Cat no 6330, Reference Period August 2020, Released 11 December 2020). Accessed from https://www.abs.gov.au/statistics/labour/earnings-and-workhours/characteristics-employment-australia/aug-2020/63330do001b_202008.xls; State of Victoria, Department of Premier and Cabinet,

-
- Victorian Government Submission 16 to the Senate Select Committee on Job Security, *Inquiry into the Impact of Insecure or Precarious Employment* (31 March 2021). Accessed from https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Job_Security/JobSecurity/Submissions.
- ³² Australian Institute of Health and Welfare, *Cancer in Australia 2019* (Cancer Series No 119, Cat no CAN 123, 2019). Accessed from <https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2019/summary>.
- ³³ Australian Institute of Health and Welfare, *Cancer in Australia 2021* (n 5).
- ³⁴ Nicole Bates et al, 'Labour force participation and the cost of lost productivity due to cancer in Australia' (2018) 18 *BMC Public Health* 375. Accessed from <https://bmcpublikealth.biomedcentral.com/articles/10.1186/s12889-018-5297-9>.
- ³⁵ Australian Government Workforce Gender Equality Agency (n 21).
- ³⁶ Productivity Commission (n 22) p 62.
- ³⁷ *Fair Work Act 2009* (Cth) s 72A. Accessed from: <https://www.legislation.gov.au/Details/C2017C00323>
- ³⁸ *Fair Work Act 2009* (Cth) s 76.
- ³⁹ *Fair Work Legislation Amendment (Secure Jobs, Better Pay) Act 2022*, s 659G. Accessed from: <https://www.legislation.gov.au/Details/C2022A00079>.
- ⁴⁰ *Fair Work Act 2009* (Cth) s 107.
- ⁴¹ Fair Work Ombudsman, *Sick and Carer's Leave and Compassionate Leave* (Factsheet, February 2023) <https://www.fairwork.gov.au/tools-and-resources/fact-sheets/minimum-workplace-entitlements/sick-and-carers-leave-and-compassionate-leave>.
- ⁴² JobWatch, Submission Number 17 to Productivity Commission, Carer Leave Inquiry (26 August 2022). Accessed from https://www.pc.gov.au/_data/assets/pdf_file/0014/345200/sub017-carer-leave.pdf.
- ⁴³ Committee on Economic, Social and Cultural Rights, *General Comment No. 19: The Right to Social Security*, UN Doc E/C.12/GC/19 (4 February 2008). Accessed from: <https://www.refworld.org/docid/47b17b5b39c.html>; Committee on Economic, Social and Cultural Rights, *General Comment No. 23 The Right to just and favourable conditions of work*, UN Doc E/C.12/GC/23 (7 April 2016). Accessed from <https://www.refworld.org/docid/5550a0b14.html>.
- ⁴⁴ Australian Human Rights Commission, *Investing In Care: Recognising and Valuing Those Who Care* (n 16).
- ⁴⁵ *Universal Declaration of Human Rights*, UN Doc A/810 (10 December 1948) arts 22, 25; *International Covenant of Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976) art 9; Committee on Economic, Social and Cultural Rights, *General Comment 19* (n 43); *Workers with Family Responsibilities Convention 1981* (ILO Convention No. 156, entered into force 11 August 1983)
- ⁴⁶ *Political Declaration of the high-level meeting on universal health coverage: Universal health coverage: Moving together to build a healthier world*, UNGA A/Res/74/2 (18 October 2019); *Transforming Our World: The 2030 Agenda for Sustainable Development*, UNGA Res 70/1, UN Doc A/RES/70/1 (21 October 2015).
- ⁴⁷ *Vienna Convention on the Law of the Treaties*, 23 May 1969, 1155 UNTS 331 art 26.
- ⁴⁸ *Minister for Immigration and Ethnic Affairs v Ah Hin Teoh* (1995) 183 CLR 273.

-
- ⁴⁹ *Social Security (Minimum Standards) Convention, 1952* (ILO Convention No. 102, entered into force 27 April 1955), *Workers with Family Responsibilities Convention 1981* (ILO Convention No. 156, entered into force 11 August 1983); *Medical Care and Sickness Benefits Recommendation 1969* (ILO Recommendation 134, adopted 25 June 1969); *Social Protection Floors Recommendation 2012* (ILO Recommendation No. 202, adopted 14 June 2012).
- ⁵⁰ Productivity Commission (n 22).
- ⁵¹ Ibid pp 29-30.
- ⁵² Australian Human Rights Commission, *Investing In Care: Recognising and Valuing Those Who Care* (n 16).
- ⁵³ 'Victorian Sick Pay Guarantee', Victorian Government (Web Page, Reviewed 20 January 2023) Accessed from <https://www.vic.gov.au/sick-pay-guarantee>.
- ⁵⁴ 'Paid sick leave pays off in times of crisis', *International Labour Organization* (Web Page, 24 June 2010). Accessed from https://www.ilo.org/global/about-the-ilo/mission-and-objectives/features/WCMS_142245/lang--en/index.htm.
- ⁵⁵ Cancer Council Australia, Submission 58 to The Senate Community Affairs Reference Committee, *Inquiry on the Extent and Nature of Poverty in Australia* (3 February 2023). Accessed from https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/PovertyinAustralia/Submissions.
- ⁵⁶ Darwin Community Legal Service, Submission Number 33 to Productivity Commission, *Carer Leave Inquiry* (2 September 2022) p 4. Accessed from https://www.pc.gov.au/data/assets/pdf_file/0004/345577/sub033-carer-leave.pdf.
- ⁵⁷ Australian Human Rights Commission, *Investing In Care: Recognising and Valuing Those Who Care* (n 16); Gaëlle Ferrant, Luca Maria Pesando and Keiko Nowacka (n 13) p 7.
- ⁵⁸ Australian Human Rights Commission, *Investing In Care: Recognising and Valuing Those Who Care* (n 16).