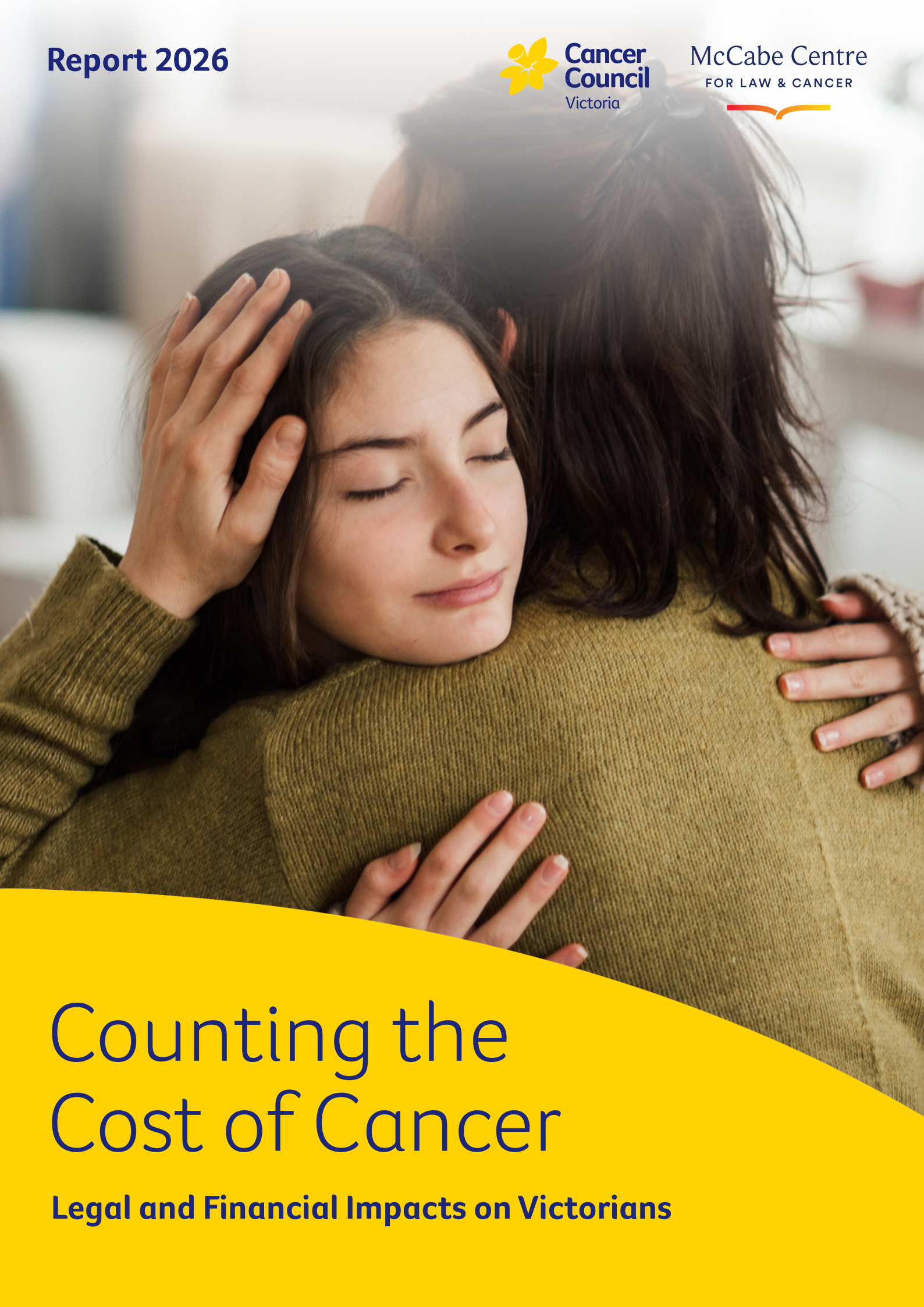


Report 2026



McCabe Centre
FOR LAW & CANCER



Counting the Cost of Cancer

Legal and Financial Impacts on Victorians

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Empowering mob and community to speak up if they need help, and to get the help they need if they are at risk of cancer.

Acknowledgement of Country

We acknowledge the Traditional Owners and Custodians of the lands and waterways on which we work and live and pay our respects to Elders past and present.

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Terminology

This report uses the following terms:

Carer	A person who gives unpaid care, support and assistance to a person with cancer.
Employee Assistance Programs (EAP)	An employer-funded program that provides confidential mental health and wellbeing support to employees of a workplace.
Health justice partnership	A service delivery model that brings together health, legal and other practitioners to deliver services to clients. A partnership might include on-site lawyers in health settings for easy warm referrals, secondary consultations to give health and social workers the right advice, or holistic wrap-around services. ⁱ
Legal services/specialist legal services	Legal bodies such as complaints and dispute resolution bodies including human rights bodies, tribunals, ombudsmen as well as community legal centres that provide legal information, advice and representation.
Medicare	Medicare is Australia's federally funded universal health insurance scheme, available to Australian and New Zealand citizens, Australian permanent residents, and some eligible overseas visitors and temporary residents. It provides access to subsidised health services and medicines, although patient co-payments may still apply. ⁱⁱ
People affected by cancer	An all-encompassing term to describe people living with or beyond cancer, their families and those providing them with unpaid care and support.
People with cancer	People living with or beyond cancer.
Supportive care	The physical, emotional and psychological, family, social and practical, information, spiritual and religious needs of people affected by cancer. ⁱⁱⁱ

ⁱ Health Justice Australia, 'Health Justice Partnership' (Web Page) <<https://healthjustice.org.au/health-justice-partnership/>>.

ⁱⁱ Australian Government Department of Health and Aged Care, About Medicare (Web Page, 20 December 2022) <<https://www.health.gov.au/topics/medicare/about?language=en>>.

ⁱⁱⁱ Cancer Council Australia, 'Support and Care' (Web Page) <<https://www.cancer.org.au/cancercareguides/support-and-care>>.

Foreword

Cancer affects most Victorians, with nearly 1 in 2 people expected to be diagnosed by the age of 85.

Cancer is relentless — but so are we.

For 90 years, Cancer Council Victoria has stood alongside those who refuse to accept the unacceptable. We have never stopped striving for better: better treatments, better outcomes, better prevention, and better care.

And the impact of cancer goes beyond health to wide-ranging legal and financial challenges, including employment security, discrimination, insurance and superannuation, income protection access, debt, housing, estate planning and decision-making.

These are barriers that the law can, and should, address.

We believe that no-one should face unnecessary legal or financial burdens while navigating a cancer journey.

And we know that these difficulties are not only experienced by the individual with cancer, but also by those who provide care and support.

As more Victorians are diagnosed, live longer with cancer, survive it, or care for someone who does, these impacts are becoming more widespread, and more urgent to address.

In this research, we heard directly from 200+ Victorians who had a cancer journey recently, either directly or as carers. The research focus was designed to strengthen the evidence base needed to improve support systems, laws, policies and practices. These findings build on insights from our Cancer Connect support line, as well as the broader body of work Cancer Council has done over many years.

The McCabe Centre for Law and Cancer is a unit of Cancer Council Victoria and is a joint initiative of Cancer Council and the Union for International Cancer Control. Founded in 2012, it is the only centre of its kind in the world focused on advancing law in cancer control.

We are committed to acting on what we have learned to drive legal and policy reforms that better protect and support people now and into the future, in Victoria and beyond, so that people affected by cancer don't have to face the burden of working out how to survive cancer's legal and financial challenges, while they are fighting to survive.



A handwritten signature in black ink that reads "Todd Harper".

Todd Harper AM
CEO
Cancer Council Victoria



A handwritten signature in black ink that reads "Hayley Jones".

Hayley Jones
Director
McCabe Centre for Law & Cancer

About Us

Cancer Council Victoria is a non-profit cancer organisation dedicated to world-leading cancer research, prevention and support. Cancer Council plays a leading role in reducing the impact of all cancers on all people. Our mission is to prevent cancer, empower people and save lives.

Established in 1936, we are independent of government and rely on the generous support from the community to carry out our work. Our singularity of purpose, a cancer-free future, drives us and will always be balanced by our deep connection with the experience of people with cancer and their families.

The McCabe Centre for Law and Cancer is a Melbourne-based joint initiative of Cancer Council Victoria, the Union for International Cancer Control and Cancer Council Australia. Established in 2012, the McCabe Centre conducts world-leading research, legal 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.

Our heritage is deeply connected with the story of Rolah McCabe, whose case against British American Tobacco Australia Services Ltd remains one of the most significant civil litigation cases in Australian legal history and has had lasting legal and policy consequences, particularly its impact on Victorian evidence and discovery laws, legal ethics, corporate conduct and access to justice. Rolah's courage in standing up to the tobacco industry before her death from smoking related lung cancer continues to inspire our work on the intersection of health, law and justice and our fight for access to justice and the rights of people with cancer, their families and those caring for them.



Executive summary

Cancer is not only a health issue. For many Victorians, it also creates significant legal and financial challenges that affect work, income, housing, care, decision-making and access to support. These challenges are widespread, often arise at times of crisis, and are shaped by systems that are complex, fragmented and poorly aligned with the realities of cancer and caring.

More people are being diagnosed, living with or surviving cancer or caring for someone with cancer. Cancer is increasingly experienced as a chronic, episodic and unpredictable condition. Treatment, recovery, side effects and ongoing surveillance may extend over months or years or be lifelong. Caring for someone with cancer follows a similarly disruptive pattern, with impacts that extend across time, roles and responsibilities.

Despite growing demand for support, there is limited contemporary evidence on the legal and financial challenges faced by people affected by cancer in Victoria and how they manage them in practice.

This report examines the legal and financial dimensions of cancer in Victoria. It draws on a mixed-methods study combining a review of existing evidence, analysis of Cancer Council Victoria data, a survey of more than 200 Victorians affected by cancer, and interviews with people living with or beyond cancer, carers and professionals supporting them.

By building a clearer picture of the legal and financial challenges of Victorians affected by cancer, we seek to identify opportunities to improve service delivery, address unmet legal and financial need, improve experiences in the workplace and to inform legal and policy reform aimed at strengthening access to justice and improving outcomes for people affected by cancer.

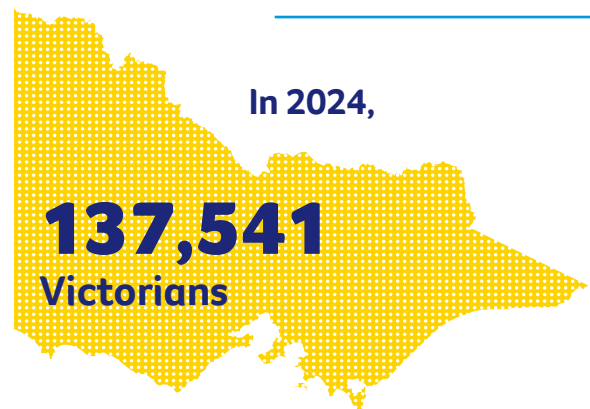
At a glance



Victorians will be diagnosed with cancer by the age of 85.

Cancer is increasingly experienced as a chronic condition with overall five-year survival at

73%



were living with a diagnosis in the past five years and 227,865 in the past 10 years.



More than 90% of people with cancer rely on unpaid carers, mostly women.

References: Victorian Cancer Registry, Cancer in Victoria 2024 (Cancer Council Victoria 2025); Anna Ugalde, Mei Krishnasamy and Penelope Schofield, 'Development of an instrument to measure self-efficacy in caregivers of people with advanced cancer' (2013) 22(6) Psychooncology 1428–34; Lan Gao et al, 'The Hidden Economic Burden of Cancer Caring' (2025) 131(14) Cancer e35970.

Our research confirms that beyond its health effects, cancer creates serious legal and financial harms. People may experience reduced capacity to work or study, loss of income, increased expenses, changing family roles, and greater reliance on informal care. Carers often face additional financial strain, reduced workforce participation, and the burden of navigating systems for others while managing their own wellbeing.

Law plays a central role in shaping these experiences. Legal frameworks governing employment, discrimination, income support, superannuation, insurance, debt, housing and decision-making influence how people and families navigate cancer. These systems are often difficult to understand and use, particularly during illness, treatment or caregiving. As a result, legal rights and entitlements are frequently unrecognised, poorly understood, or not realised in practice.

The financial costs of cancer are substantial and can continue to accumulate even after treatment ends. People face a wide range of out-of-pocket expenses for treatment, scans, travel and ongoing tests and care, often alongside reduced income or insecure employment. Financial pressures can cause significant distress and, in some cases, affect treatment decisions and access to care.

Financial pressure is widespread

What people experience

100%

of people with cancer surveyed incurred out-of-pocket costs.

~ 30%

of people with cancer and carers surveyed experienced income loss.

96%

of people surveyed who reported a worsening financial situation said it was distressing.



Costs of cancer impact health decisions.

Financial strain is widespread and unsupported, often overlapping with legal, work and caring-related challenges.



Being financially prepared for cancer and caring is a challenge.

Key findings

The research shows that legal and financial challenges are widespread, interconnected and often unrecognised within the cancer experience. These challenges can compound and can impact healthcare decisions and physical and mental health. They are shaped not only by individual circumstances, but by the design and operation of systems governing work, income support, insurance, healthcare and justice systems, as well as limited awareness of rights and inconsistent capability across the organisations and institutions responsible for delivering them.

‘Some people’s biggest fear is the financial side of things — “how on earth am I going to pay my mortgage, go to the supermarket?”, all those basic things.’

– Fiona, social worker

‘Of course I understand, the focus is so much on the patient. But the carer is incredibly important.’

– Jacinta, carer

‘Your experience at work shouldn’t depend on the compassion of your boss or the organisation. Better legislation will be a game changer for all of us.’

– Sofia, carer

‘Health/law partnerships are absolutely invaluable.’

– Lori, social worker

‘We have to ask ourselves, is Centrelink a safety net?’

– Graeme, financial counsellor

Across the findings:

- Legal and financial problems often arise unexpectedly and at moments of crisis.
- Access to support is often limited, delayed and uneven.
- Systems are fragmented, complex and difficult to navigate, especially during illness and caregiving.
- Legal and policy settings are poorly aligned with the realities of cancer and caring.
- Financial burden is substantial, cumulative and distressing.
- Carers experience distinct and compounded disadvantage.

Unmet legal need remains high

Survey snapshot

41%

of people with cancer reported legal issues.

67%

of carers reported legal issues.

Most did not access legal support despite clear need due to low awareness, system complexity, costs and limited capacity because of illness or caring responsibilities.

Taken together, the findings show that legal and financial challenges are not peripheral to the cancer experience, but embedded within it, with significant consequences for wellbeing, equity and access to care. Legal rights are often not effectively realised in practice, due to system complexity, delayed support, and limited awareness and capacity.

While this report identifies common patterns, individual experiences of cancer and caregiving are diverse and shaped by intersecting personal, social and structural factors, with legal and financial impacts varying across individuals and location.

What needs to change

Addressing these challenges requires a fundamental shift: from reactive, crisis-driven responses to systems that are proactive, integrated and accessible by design.

Legal and financial support must be recognised as core components of cancer care, not external or optional services. Earlier identification of need, better access to support, improved awareness and understanding of rights and entitlements, and stronger alignment between systems and lived experience are central to improving outcomes.

There is also a need to strengthen the capability and responsiveness of the systems and organisations with which people affected by cancer interact. This includes fostering a culture within which employers, financial institutions, government services, and complaint and dispute resolution bodies that empowers people affected by cancer to manage legal and financial distress — to ensure their experience is respected and their rights are recognised and realised in practice.

Reform priorities

The report identifies nine reform priorities:

1

Strengthen awareness of and responsiveness to the legal and financial impacts of cancer

2

Embed lived experience of cancer and caring in the design, implementation and evaluation of law and policy

3

Reduce barriers to access to justice

4

Strengthen enforceable workplace rights and protections

5

Improve uptake and usability of legal and financial planning frameworks

6

Reform insurance and superannuation

7

Protect against financial harm

8

Modernise social security to reflect lived realities

9

Recognise and support carers across all systems



Conclusion

Improving legal and financial outcomes for Victorians affected by cancer requires system-level change. Current approaches place too much responsibility on individuals and families to anticipate, understand and navigate complex systems, and to act on legal rights at times of reduced capacity. In addition, health professionals have limited training in assessing financial and legal hardship and referral options.

Reforms would help ensure that people affected by cancer — including carers — can understand, access and exercise their rights, maintain financial security, comply with complex treatment regimens, and navigate cancer with greater dignity, equity and support. Reforms would assist health professionals to connect people with the appropriate support they need.

Further, these challenges faced by people affected by cancer are often shared by those experiencing other serious illness and caring roles. Accordingly, the implications of this research extend beyond cancer, offering opportunities for reform that would benefit the broader community.

Introduction

Cancer in Victoria

Cancer affects nearly every Victorian, either directly or through someone they know, with one in two Victorians diagnosed by the age of 85.¹ In 2024, Victoria recorded its highest ever number of cancer diagnoses, reflecting population growth, population ageing, and improved detection, and reinforcing cancer as a major and ongoing challenge for the state.²

The burden of cancer is not evenly distributed. Aboriginal Victorians are twice as likely to be diagnosed with cancer and 3.4 times more likely to die from it than non-Aboriginal Victorians and have poorer outcomes and unmet needs underpinned by discrimination and a lack of culturally safe services.³ People living in regional areas experience higher rates of diagnosis and mortality than those in metropolitan Melbourne, while some culturally and linguistically diverse populations have higher rates of preventable cancers.⁴ Cancer diagnoses are also increasing among younger adults aged 25–49 — often at critical life stages involving work, family, and financial responsibility⁵ — and people with disability and/or mental ill health, LGBTIQ+ communities and other groups experience disadvantage in cancer outcomes.⁶ These inequities are often compounded where individuals hold multiple intersecting identities, leading to layered and more complex barriers to prevention, diagnosis, treatment and supportive care.

At the same time, outcomes for many Victorians have improved. Advances in early detection and treatment have increased survival, with five-year survival rates rising substantially since the 1980s. Today, 379,067 Victorians are alive after a cancer diagnosis in the past four decades.⁷ Although cancer remains the leading cause of death in Victoria, it is increasingly experienced as a long-term or chronic condition, including for people living with advanced, incurable but treatable cancer.

Unpaid carers are central to this reality. Most people (90%) with cancer rely on at least one unpaid carer — typically a family member, partner or friend — who provides support across treatment, daily living, transport, emotional, financial, legal and other practical matters.⁸ For people with cancer, having a carer is associated with better coping capabilities

and healthier lifestyle habits.⁹ Unpaid care enables people to remain at home, reduces pressure on health services, and has an estimated replacement value of \$77.9 billion.¹⁰ Approximately 3 million Australians provide unpaid care,¹¹ though this number is likely an underestimate due to a lack of self-identification as a carer.¹² Women bear the majority of caring responsibilities in Australia, making up around 70% of primary carers and outnumbering men as carers across nearly all age groups.¹³

This is mirrored in the cancer context where most carers of people with cancer are also women,¹⁴ who contribute around 30 hours of unpaid support each week.¹⁵ Caring for someone with cancer is often episodic, urgent, intense and unpredictable and may be required over days, months or years given the complex and chronic nature of the disease.¹⁶ Often, care is still required many years after a cancer diagnosis, as treatment-related effects can have a lasting impact on quality of life, with ongoing support needs extending beyond treatment and affecting both survivors and their family caregivers.¹⁷

As incidence rises and survivorship improves, more Victorians and their families are living with the longer-term impacts of cancer. These extend beyond health, affecting work, finances, caregiving roles, and future planning. People affected by cancer often navigate multiple systems — including healthcare, employment, financial services, social security, disability and legal frameworks — frequently during periods of uncertainty and reduced capacity. These impacts are shared across households, with carers balancing employment, financial pressure and their own wellbeing alongside caring responsibilities.

People diagnosed with cancer may also be living with other health conditions, and many of these challenges are experienced more broadly across the community.

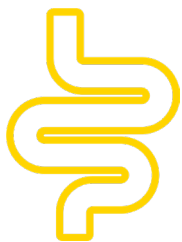
Cancer in Victoria

Cancer is the leading cause of disease burden in Victoria, with

39,641
diagnoses

and 11,969 deaths in 2024.

This equates to 109 new diagnoses per day, or one every **14 minutes.**



The most common cancers are prostate, breast, bowel, lung and melanoma (56% of all cancers).

New diagnoses are projected to increase across most cancer types over the next 15 years.



Five-year survival has increased by 43% over the past 30 years and reached 73% in 2020–2024.



In 2024, 137,541 Victorians were living with a diagnosis in the past five years and 227,865 in the past 10 years.



Most people with cancer have at least one unpaid carer, usually women.

Cancer, law and financial security

Law plays a central role in shaping the experiences of people affected by cancer. Legal frameworks underpin access to healthcare, employment protections, income support, insurance, superannuation, housing, and end-of-life decision-making. When these systems operate effectively, they support dignity, financial security, and informed decision-making; when they do not, people and families can experience significant legal, financial, and emotional harm.

Legal and financial challenges are common. Around 60% of people affected by cancer report distress related to these issues alongside their health concerns.¹⁸ Many face difficulties understanding or exercising workplace rights, such as access to leave and flexible work arrangements, and experience discrimination.¹⁹ Others encounter barriers with insurance and superannuation,²⁰ social security benefits,²² and financial institutions such as banks when seeking financial hardship support.²² Where disputes arise, navigating formal complaints bodies to enforce legal entitlements, such as the Australian Financial Complaints Authority and the Fair Work Commission, adds further complexity.

Almost all people diagnosed with cancer in Australia incur out-of-pocket costs, often alongside reduced income due to changes in work participation. Around 40% report income losses, with losses ranging from \$10,000 to over \$200,000.²³ For people with rare cancers, one in ten face expenses over \$100,000.²⁴ These pressures can be severe and can affect treatment decisions and access to care. This “financial toxicity” extends beyond direct medical costs and also affects carers, who often reduce or leave paid work while taking on additional responsibilities and

(References: Victorian Cancer Registry, Cancer in Victoria 2024. Cancer Council Victoria; 2025; Anna Ugalde, Mei Krishnasamy and Penelope Schofield, ‘Development of an instrument to measure self-efficacy in caregivers of people with advanced cancer’ (2013) 22(6) Psychooncology 1428–34; Lan Gao et al, ‘The Hidden Economic Burden of Cancer Caring’ (2025) 131(14) Cancer e35970.

expenses.²⁵ As noted above, most carers are women and many shoulder unpaid caring responsibilities — valued at over \$60,000 per annum per cancer carer²⁶ — alongside insecure or lower-paid work, driving gendered economic inequality.²⁷

These challenges are closely interconnected. For example, reduced capacity to work — whether due to illness, treatment, or caregiving — can lead to income loss, which in turn may contribute to debt, housing stress, or difficulty meeting financial obligations, impacting treatment choices, and often requiring engagement with legal and financial systems. While survival outcomes have improved, the legal and financial impacts of cancer frequently persist well beyond treatment, and gaps between system design and the realities of cancer and caring mean these challenges are often compounded rather than mitigated.

‘Some people’s biggest fear is the financial side of things — “how on earth am I going to pay my mortgage, go to the supermarket?”, all those basic things...Some people won’t even start treatment because they’re thinking “I can’t face stopping work” or “I’m a carer, I can’t stop being a carer” or “I’ve got nowhere to live, so how can I possibly come to treatment?”

— Fiona, social worker

Challenges after diagnosis: what Cancer Council Victoria data shows

Demand for legal, financial, and emotional support among Victorians affected by cancer continues to grow. In 2025, Cancer Council’s 131120 Cancer Information and Support Line service (now called Cancer Connect) responded to more than 11,000 requests in Victoria, primarily from people living with or beyond cancer, alongside a significant proportion from carers and family members.

Many enquiries relate to legal and financial challenges, including managing treatment costs, dealing with banks, and accessing government supports such as Centrelink. Employment, insurance, and advance care planning issues are also common. Reported experiences include poor treatment by banks when experiencing financial hardship, including ongoing debt recovery action despite agreed mortgage arrangements during treatment as well as workplace discrimination following diagnosis, including demotion or termination of employment.

Enquiries related to emotional and mental health support have also increased over time, with 4,291 calls relating to psychological and emotional wellbeing in 2025 alone. This reflects the considerable emotional burden that can arise from the interconnected impacts of cancer, including financial stress, and other legal and practical challenges experienced by patients and carers.

To respond to increasing legal need, Cancer Council Victoria established its Legal Support Program in July 2023, providing free, confidential assistance to eligible people with advanced cancer in partnership with Victorian law firms. To date, the Program focuses on basic wills, powers of attorney, and medical treatment decision maker documents. The Program has received 788 referrals to the end of 2025 (including 299 in 2025), representing 81% growth since inception. Demand continues to rise more rapidly than resourcing levels can accommodate.

‘This is a really nice way that we can all work together to give back to the community.’

– Gabriella, wills and estates lawyer

Demand for cancer-specific financial counselling has also increased significantly. Since 2023, Cancer Council Victoria’s Financial Counselling Program has supported over 3,100 people with issues including healthcare expenses, government benefits, insurance, and debt. In 2025 alone, more than 1,000 referrals were received across metropolitan and regional areas. Most clients were people with cancer, with additional demand from carers and families, and the majority were women—reflecting the intersection of cancer, financial security, and caring responsibilities.

‘Financial counselling is needed because finances are such a big driver in all this.’

– Naveena, breast cancer survivor

Cancer Council Victoria also partners with Berrill & Watson Lawyers to provide specialist pro bono legal support on superannuation and insurance matters. Since 2023, 234 clients have been referred for assistance with issues such as early access to superannuation, income protection, and total and permanent disability claims, underscoring both the complexity of these systems and the value of coordinated support.

‘Working with financial counsellors has really opened up to us a new cohort of people we can work with and help.’

– Tom, superannuation and insurance lawyer



In 2025, Cancer Council Victoria’s Cancer Connect support line responded to 11,335 enquiries.

64% of callers were people with cancer and **22%** were carers or family members.

20% of enquiries related to practical needs, including legal and financial issues.

Referrals to the Legal Support Program increased by 81% since 2023.

In 2025, 299 referrals were made for legal support.

Cancer Council Victoria’s Financial Counselling Program supported 1,240 people in 2025.

Why this research matters

With cancer touching the lives of more people through diagnosis, treatment, survivorship, and caregiving, legal and financial challenges can no longer be viewed as peripheral — they are central to the cancer experience. Moreover, these issues are closely connected to health, wellbeing and equity, and shape people's ability to cope with diagnosis, treatment and survivorship and their cancer caring responsibilities.

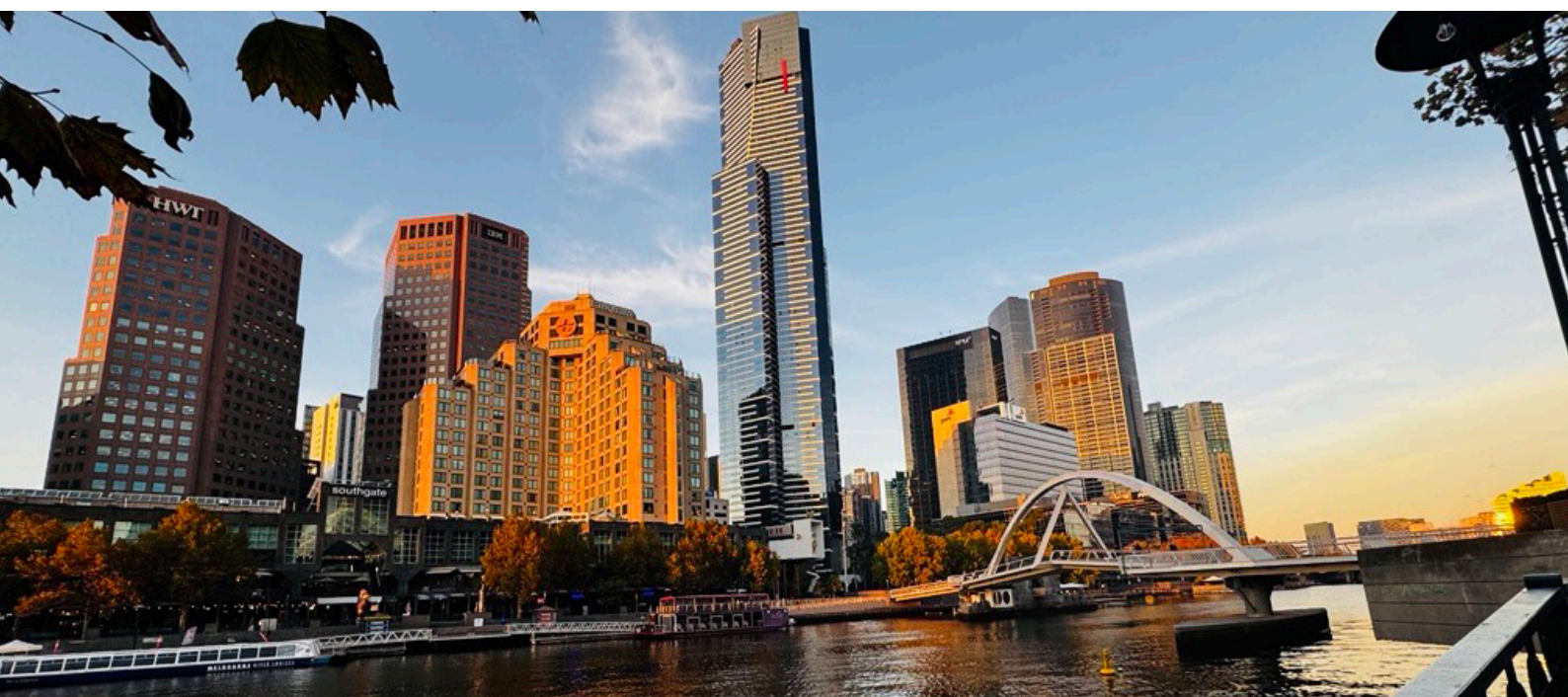
Despite growing demand for support, there is limited contemporary evidence on the legal and financial challenges faced by people affected by cancer in Victoria and how they manage them in practice. This gap is particularly significant in the context of rising living costs across all household types.²⁸ More broadly, levels of disadvantage and financial hardship and poverty are rising.²⁹

A better understanding of these issues is necessary to improve service delivery, address unmet legal and financial need, improve experiences in the workplace —given the ability to work is intertwined with legal and financial challenges — and to inform legal and policy reform aimed at strengthening access to justice and outcomes for people affected by cancer.

'Unless people have gone through [cancer] themselves, either directly or as a carer/immediate family member, you don't see all the ways cancer impacts a person's life. People think hair loss and looking skeletal, that's cancer. And they think the day the treatment finishes, you're fine, you're done...But the full horror of cancer is still not understood.'

— Naveena, breast cancer survivor

While this research focuses on the experiences of Victorians affected by cancer, we recognise that many of the issues identified are also faced by others in the community, including people living with other serious illnesses and disabilities. We also acknowledge that the experiences of people affected by cancer are not confined by geographical boundaries—insights from Victoria resonate with individuals and communities across Australia and internationally. This underscores the significance of this research and highlights the potential for the identified reform priorities to create meaningful improvements for the wider community.



About this research

Purpose of this research

This research examined the interrelated legal and financial challenges experienced by Victorians affected by cancer, including people with lived experience of cancer and unpaid carers, to address gaps in contemporary evidence. It also aimed to develop an evidence base to inform targeted service responses and evidence-based systems and law reform to improve equity, outcomes, and access to justice. This report identifies key systemic issues and high-level reform directions to guide action. Further consultation with stakeholders and more detailed recommendations will continue to be developed.

Research questions

This research sought to answer the following questions:

- What legal and financial challenges are experienced by Victorians affected by cancer, including people living with cancer and unpaid carers?
- How do people affected by cancer manage these challenges?
- To what extent are people aware of, and using, available legal and financial services?

Research methods

This study used a mixed-methods approach to examine the legal and financial experiences of people affected by cancer in Victoria.

It comprised four components:

- A targeted review of Victorian, Australian, and international research.
- Analysis of deidentified Victorian data from Cancer Council's Cancer Connect service and Cancer Council Victoria's Legal Support Program and Financial Counselling Program.
- An online survey of people with lived experience of cancer and unpaid carers.
- Semi-structured interviews with people with lived experience, carers, and professionals.

The literature review and administrative data analysis were conducted first to identify existing evidence and inform the design of the survey and interview questions. Data collection was undertaken between August 2025 and June 2026. Survey and interview data form the primary basis of the findings presented in this report.

Survey

An online survey was completed by Victorian adults with lived experience of cancer and adult carers of people with cancer. Participants were aged 18 years or over, lived in Victoria, and had experienced a cancer diagnosis or caring role within the previous ten years. People receiving terminal or end-of-life care were excluded for ethical reasons.

Postcode was used as a proxy for socioeconomic status based on ABS SEIFA (Index of Relative Socio-Economic Advantage and Disadvantage).³⁰

The survey included mainly closed-ended questions on demographics, legal (including workplace) and financial issues, impacts, and awareness and use of support services, with one optional open-ended

question. Surveys were designed for accessibility (approximately Year 9 literacy) and took 15–20 minutes to complete (see Appendix 1).

Pureprofile (I-Link Research Solutions) programmed and hosted the survey and recruited participants across Victoria. Survey respondents received a small financial incentive for their participation.

Interviews

Semi-structured interviews were conducted with people with lived experience of cancer, carers, and professionals across health, legal, social work, workplace, and financial sectors.

Participants with lived experience were recruited to reflect diverse ages, locations, and perspectives. Interviews were conducted in person or via videoconference. Participants with lived experience received a \$50 voucher in recognition of their time.

Data analysis

Survey data were analysed using descriptive statistics, with results reported as percentages. Where multiple responses were allowed, percentages do not total 100%.

For workplace-related survey items, responses were grouped into broader thematic categories reflecting key domains of challenge. Percentages represent respondents experiencing each theme, with multiple responses permitted.

Qualitative data from interviews and open-ended survey responses were analysed thematically to identify recurring themes and lived experiences. Findings from all data sources were integrated to provide a comprehensive understanding of legal and financial issues.

Ethics approval

The study received ethical approval from Cancer Council Victoria's Human Research Ethics Committee and was conducted in accordance with national ethical guidelines. Participation was voluntary, with informed consent obtained from all participants. Data were collected, stored, and reported confidentially in deidentified or in re-identifiable form.

Research participants

Data were collected from a total of **223 participants**, including:

207

Victorians who completed the online surveys:

102

people with cancer

105

unpaid carers

Of the survey respondents

40

also provided short written testimonials

16

participants took part in interviews, including:

- 4 people with lived experience of cancer
- 4 carers
- 8 professionals (including lawyers, social workers, an Aboriginal health practitioner, financial counsellor, cancer nurse, and a workplace expert (also with lived experience of cancer)).

Who we surveyed



People with cancer

- Gender: (53 women, 48 men) (*no participants identified as LGBTQA+)
- Predominantly aged 55 years and over
- 78% metropolitan; 24% regional
- 65% lived in areas of socioeconomic advantage
- 76% born in Australia; 24% overseas
- 3% identified as Aboriginal
- 97% spoke English at home
- 25% living with other conditions as well as cancer
- 62% in paid work at diagnosis
- 89% covered by Medicare

Unpaid carers

- Gender: 55 men, 50 women (*no participants identified as LGBTQA+)
- Predominantly working age (45–63 years)
- 82% metropolitan; 18% regional
- 63% lived in areas of socioeconomic advantage
- 82% born in Australia
- 91% spoke English at home
- 38% were caring for someone with cancer during the COVID-19 pandemic

Caring roles:

- Parent (30%), other relative (29%), partner (14%)
- 42% cared for more than one person
- 39% had their own health condition



Cancer profile:

- 5 most common cancers: prostate (19%), breast (13%), melanoma (13%), lymphoma (7%), non-melanoma skin cancers (6%)
- 66% diagnosed within the past 1–5 years
- 33% diagnosed 6–10 years earlier
- 32% diagnosed during the COVID-19 pandemic
- 5% living with advanced cancer

Work and responsibilities:

- 78% combined paid work and caring
 - 54% full-time, 14% part-time
- Caring roles included:
 - medical care (71%)
 - day-to-day support (78%)
 - emotional support (82%)
 - financial management (46%)
 - legal support (25%)

Study limitations

Both survey cohorts were predominantly metropolitan, English-speaking, and from relatively advantaged areas. Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse populations, regional communities, LGBTIQ+ groups, and younger adults were underrepresented. The study also did not explore the experiences of children with cancer and carers who are children.

The sample size is not representative of all Victorians affected by cancer and does not support detailed analysis by subgroup. Findings should therefore be interpreted as indicative rather than generalisable.

Although 32% of people with cancer and 38% of carers who were surveyed were diagnosed or provided care during the COVID-19 pandemic, the sample size was too small to reliably examine differences in legal and financial experiences between participants who experienced cancer during the pandemic and those who did not.

Future research would benefit from larger and more targeted samples, longitudinal designs, and national or cross-jurisdictional comparisons to better distinguish systemic from local factors.

Findings and Implications

This section presents the key findings of the research and their implications. Drawing on survey data, interviews, Cancer Council Victoria program data, and existing evidence, it examines how legal and financial challenges arise and are experienced in practice.

While the findings in this report identify common patterns, each person's experience of cancer and caregiving is unique. Legal and financial challenges are shaped by a range of intersecting factors, including age, cancer type and stage, employment circumstances, geographic location, lifestyle factors and access to support. As a result, individuals may face different combinations of issues and experience their impacts in varied and compounding ways.

'I think your kind of cancer journey very much depends on where you are in your life. Someone who might be 22 living independently out of home with minimal family support will obviously have a different experience to someone who had been working for 30 years, owned their own home and was more financially secure. So, I think that's important to note that, you know, not everyone's on that level playing field to start.'

– Michelle, living with breast cancer

Findings and interpretation are presented together to reflect the interconnected nature of these issues. Each section concludes with implications for improving access to justice and supporting more effective system responses.

Overview of Findings and Implications

Key Findings

Eight key findings emerged across the data sources. Together, they highlight interconnected legal and financial challenges across work, income support, financial systems, and decision-making, and demonstrate how system design shapes people's ability to understand, access, and exercise their rights during illness and caregiving.

People face widespread legal and financial challenges

Widespread legal need and inequity

Legal problems are common, often unexpected, and highly distressing, frequently emerging at crisis points. Legal challenges are exacerbated for those already experiencing disadvantage.

Underuse of and barriers to support services

There is a significant gap between legal and financial need and service use, driven by low awareness, cost, system complexity, resource constraints, and limited capacity to seek support during illness and caring.

Legal and financial planning underuse

Legal and financial planning is limited and typically delayed until crisis points, increasing risk and burden for individuals and families and stress on available services.

Systems are not designed for the realities of cancer and caring

Workplace protection gaps

Workplace outcomes are inconsistent and often reliant on employer discretion. Legal protections are difficult to access and do not reflect ongoing or fluctuating illness.

Insurance and superannuation vulnerability

Systems are complex and poorly understood, with gaps in coverage, challenging claims processes, and misaligned eligibility criteria.

Costs undermine the right to health

Cancer-related costs are significant, often unexpected, and include both direct and indirect expenses, contributing to financial stress and inequity.

Consequences are significant

Social security access gaps

Financial hardship is widespread, yet access to income support is constrained by restrictive eligibility and administrative burden.

Carer disadvantage (cross-cutting)

Carers experience higher legal, financial, and administrative burden across all domains, often without recognition or adequate support.

Cross-cutting implications

Across the findings, a consistent set of system-level challenges emerges. These shape whether legal rights are recognised, understood, and realised in practice, and whether people can access timely and effective support.

1. Legal and financial need is often invisible and identified too late

Legal issues are common but frequently unrecognised until crisis points, when impacts are greatest and options are more limited.

2. Access to support is constrained by systemic barriers

A persistent gap exists between need and service use, driven by low awareness, cost, complexity, limited availability and reduced capacity during illness and caregiving.

3. Systems rely too heavily on individual capacity

People are expected to navigate fragmented systems, manage administrative burden, and self-advocate at times of reduced capacity.

4. Legal and policy frameworks are misaligned with lived realities

Frameworks often assume stable and linear recovery, rather than chronic, episodic and uncertain illness.

5. Financial risk is shifted onto individuals and families

Income loss, out-of-pocket costs, and gaps in financial protection create sustained financial pressure.

6. Carers are central but insufficiently recognised

Carers carry significant legal, financial and administrative responsibility without consistent support or recognition.

7. System responses are inconsistent

Outcomes depend not only on system design, but on how organisations, institutions, services, and the people who work within them act towards people affected by cancer in practice. This relates to a lack of understanding about cancer and its impacts and knowledge of how best to respond to someone impacted by cancer.

Implications for reform

These findings point to the need for a shift from reactive and fragmented responses towards systems that are:

Proactive
identifying need earlier.

Integrated
connecting health, legal, financial and social systems.

Accessible
reducing complexity and administrative burden.

Rights-based
entitlements can be exercised in practice.

Lived experience-informed
shaped by lived insights and experience.

Reform priorities

The following reform priorities address shared structural drivers across the findings:

1. Strengthen awareness and responsiveness to the legal and financial impacts of cancer
2. Embed lived experience of cancer and caring in the design, implementation and evaluation of law and policy
3. Reduce barriers to access to justice
4. Strengthen enforceable workplace rights and protections
5. Improve uptake and usability of legal and financial planning frameworks
6. Reform insurance and superannuation
7. Protect against financial harm
8. Modernise social security to reflect lived realities
9. Recognise and support carers across all systems



Finding 1:

**Cancer and caring
give rise to significant
unmet legal need and
inequity**

'I had a family who were living in public housing with a pre-existing issue with mould and were not able to get anything done about it. Mould is a huge issue if you've got leukaemia, as you're immune compromised. So that was an instant indication to get a legal person advocating for that resolution from the Inner Melbourne Community Legal who have a health partnership with Royal Melbourne (and other) hospitals. They can respond in a very quick period and are able to call or see the patients while admitted or attending the hospitals — and at no cost. I just wanted to highlight this as the health/law partnerships are absolutely invaluable. They've had a financial counsellor linked to their service as well. So, if there's going to be debt because of no other income, I'd also make a referral for this support.'

– Lori, social worker

Legal problems are a common and often under-recognised part of the cancer experience. They are diverse, frequently distressing, and occur across multiple domains, with carers experiencing both higher prevalence and more complex responsibilities.

'I think a problem that occurs for many people is that they are not aware of legal issues or legal documents as many things are unknown until they may be needed.'

– Sofia, carer

Among survey respondents:

41%

(42/102) of people with cancer reported legal issues.

67%

(70/105) of carers reported legal issues.

Various legal problems were reported. The types and intensity of legal problems varied across both survey and interview participants, reflecting differences in individual circumstances, including stage of illness, family structure, employment status and access to support.

Types of legal problems

For people with cancer surveyed, financial challenges were the most common, including treatment-related debt, worsened pre-existing financial issues, difficulty covering housing costs, and early access to superannuation. People also faced barriers accessing government funded social security (i.e. benefits through Centrelink) and supports such as the National Disability Insurance Scheme (NDIS). Additionally, many reported difficulties with insurance claims, workplace issues (such as unfair treatment and enforcing workplace rights), and preparing legal documents.

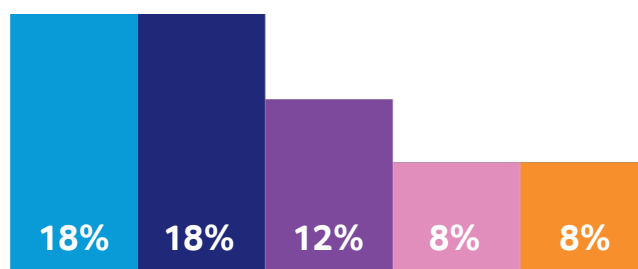
Issues including complaints about treatment and care and problems getting approved for a mortgage or rent were reported to a lesser extent, though are still significant issues, as reflected in interview findings.

Carers reported challenges across multiple areas, particularly in legal decision-making and advocacy roles, including acting as medical decision-makers (34%), legal guardians (14%), powers of attorney (12%), executors (9%), and making complaints about care (10%).

They also faced barriers accessing supports such as Centrelink, the NDIS for the person with cancer for whom they were caring and Carer Gateway, along with financial hardship and debt issues, and difficulty paying housing costs and early access to superannuation.

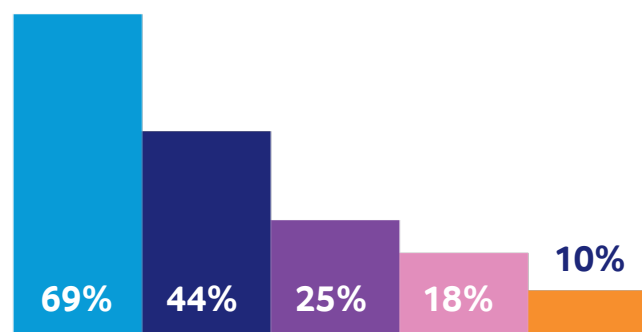
Carers more often struggled to understand their own and the patient's legal rights (12%) compared to people with cancer. Less common though not insignificant issues included those related to insurance, housing and family law matters.

Figure 1:
Most common types of legal issues experienced by surveyed Victorians with cancer



- Financial hardship and debt (18%)
- Insurance (18%)
- Workplace related legal issues (12%)
- Preparing legal documents such as wills or powers of attorney (8%)
- Difficulty accessing government support (8%)

Figure 2:
Most common types of legal issues experienced by surveyed Victorian carers of people with cancer



- Legal decision-making roles (69%)
- Workplace-related issues (44%)
- Difficulty accessing government support (25%)
- Financial hardship and debt (18%)
- Making complaints about the care and treatment of the person with cancer (10%)

Interview findings provide further insight into the types of legal issues experienced, demonstrating that legal problems are widespread, multifaceted, and closely interconnected with financial stress and system navigation. Participants described a broad range of issues affecting core areas of life, including housing, employment, insurance, decision making, estate planning and access to government systems:

Housing and financial security issues were common.

Interviews revealed difficulties maintaining mortgage repayments or rent during periods of reduced income, as well as challenges negotiating hardship arrangements with lenders and landlords. In some cases, financial strain created uncertainty about housing stability, with participants describing falling behind on payments, drawing heavily on savings, or accumulating debt.

Insurance and superannuation issues were also prominent.

Interview findings indicate widespread confusion about entitlements, including income protection, total and permanent disability (TPD) insurance, and death benefits. Participants described delayed or rejected claims, difficulty navigating processes, and limited understanding of how insurance, superannuation, and estate arrangements interact. Some reported discovering that cover had lapsed or was unavailable only after diagnosis, creating unexpected financial exposure.

Employment and workplace-related legal issues were frequently raised.

Participants described limited awareness of rights relating to workplace adjustments, leave entitlements, discrimination, and dismissal. Many relied on informal arrangements with employers rather than formal protections. Interview findings also indicate that statutory timeframes for enforcing rights were often unrealistic during periods of treatment or intensive caregiving.

For carers, these issues were compounded by a mismatch between responsibility and authority. Carers often managed workplace, financial, and administrative matters on behalf of the person with cancer, without clear legal standing or adequate employment protections.

Legal planning and decision making issues were also common.

Interview findings indicate low awareness of powers of attorney, advance care directives, and substitute decision-making arrangements. Even where documents had been completed, they were not always accessible, recognised, or used in clinical settings, limiting their effectiveness at critical moments.

Administrative and identity-related barriers further limited access to support.

Participants described challenges navigating Centrelink processes, including complex evidentiary requirements, delays, and repeated requests for medical documentation. These barriers were particularly acute for people without formal identification, stable housing, or access to banking, contributing to exclusion from services and entitlements.

Across these domains, legal problems could emerge together, interact, and compound over time. Interview findings indicate that issues were often unexpected and arose at points of crisis, creating significant distress and limiting individuals' capacity to respond effectively. Interview findings also indicate that people without immediate family or partners may face additional worries and challenges, particularly in relation to decision-making, access to information, and navigating systems without informal support.

Carers experience greater responsibility and complexity

Carers' legal needs differ in both scale and nature. They frequently act on behalf of another person — managing decision-making, finances, and system navigation — often during periods of acute illness or bereavement.

Interview findings indicate that carers often experience this as taking on multiple new responsibilities simultaneously, combining legal, financial, and administrative tasks with the practical and emotional demands of care. Many described needing to make significant decisions with limited information or authority, contributing to stress and uncertainty. For some, the experience of caring and dealing with unexpected legal consequences was traumatic:

'We have people, particularly single parents or someone in a single parent-type role, who are really worried what's going to happen to their child in the future going forward as well. And that can be a massive focus from a legal perspective.'

– Fiona, social worker

'It was very hard. My mother refused any help including from charities and insisted the "family will do it all." Unfortunately, my sister and brother refused to help her, so I was the only one doing it on my own. I was also forced to put my own health last until her passing. This has left me with diabetes that went untreated that caused heart and kidney failure. With both siblings knowing I got more in mum's will for doing all the caring, they decided to contest the will leaving me with two years of fighting them and pretty much losing every cent there was to inherit. Unless it was my husband or son, I would never help anyone with medical help again.'

– Carer survey respondent

Legal problems are highly distressing

Legal issues were associated with high levels of distress:

100%

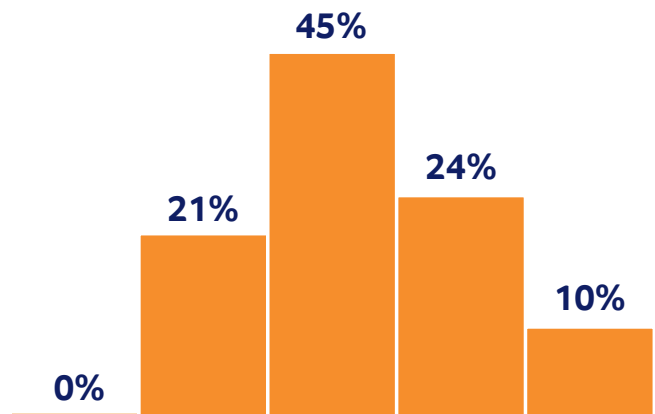
people with cancer reported distress, with 79% of people with cancer reporting moderate to extreme distress.

94%

of carers reported distress, with 64% reporting moderate to extreme distress.

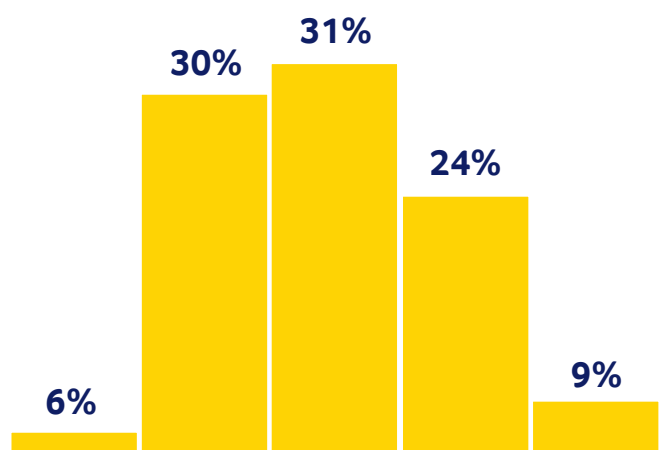
Figure 3: Distress levels associated with cancer and cancer caring legal issues.

People with cancer



- No distress (0%)
- A little distress (21%)
- Some distress (45%)
- A lot of distress (24%)
- Extreme distress (10%)

Carers



- No distress (6%)
- A little distress (30%)
- Some distress (31%)
- A lot of distress (24%)
- Extreme distress (9%)

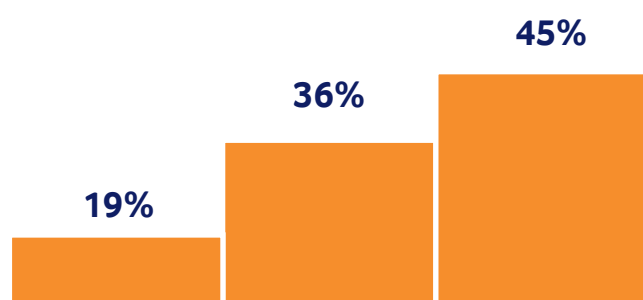
Distress was closely linked to timing, with problems often arising during treatment, complications, or end-of-life stages when capacity to respond is limited. Interview participants consistently described legal issues as adding to an already overwhelming situation, intensifying emotional and practical pressures.

Legal problems are often unexpected

Legal issues were frequently unanticipated. Only 19% of people with cancer expected legal issues to arise compared to half of carers. A sizeable proportion of both survey groups reported that legal issues were completely unexpected.

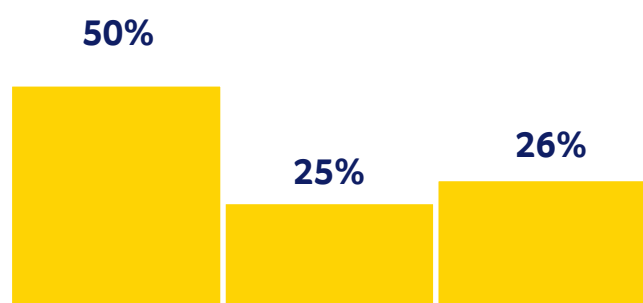
Figure 4: Anticipation of legal problems by people with cancer and carers

People with cancer



- Expected (19%)
- Somewhat expected (36%)
- Unexpected (45%)

Carers



- Expected (50%)
- Somewhat expected (24%)
- Unexpected (26%)

Interview findings reinforce this pattern, indicating that legal needs are rarely anticipated at diagnosis and are often only recognised once problems escalate. Interviewees reported that legal issues commonly emerged at crisis points—such as loss of decision-making capacity or end-of-life/bereavement—when individuals and carers were least able to respond. Interviewees emphasised that the timing of these issues often increased both their impact and the difficulty of resolving them.

System complexity exacerbates harm

Legal issues were often compounded by the complexity of legal and related administrative systems. In particular, processes such as accessing Centrelink benefits, insurance, or superannuation were described as difficult to understand, time-consuming, and burdensome. Interview participants reported repeated documentation requirements, administrative delays, and challenges navigating between services, with some indicating they disengaged from processes due to exhaustion.

'[To get the Commonwealth Seniors Health Card for my husband] we had to go through a full-on income assets assessment through Centrelink which was very, very gruelling. It was like we were interrogated and had to answer many, many questions.'

– Jacinta, carer

Challenges enforcing rights through formal dispute resolution processes, including workplace disputes and financial complaints mechanisms were also reported. These processes were often perceived as time-consuming, complex, and difficult to engage with during periods of illness or caregiving.

These challenges were more pronounced for Aboriginal people and others experiencing structural disadvantage, often requiring sustained advocacy to navigate.

‘[Superannuation] it is hugely confusing. You couldn’t possibly expect someone, particularly in the context of a life-threatening diagnosis to fully comprehend exactly what’s going on without getting advice. And how our super interacts with wills and estates is really complicated.’

– Tom, superannuation and insurance lawyer

Findings in context

These findings align with a substantial body of Australian research demonstrating that legal problems are a common, yet often under-recognised, component of serious illness.

The research is consistent with research from the Victoria Law Foundation which shows that legal problems frequently co-occur with and exacerbate challenges related to health, employment, income, and family stability.³¹ The findings align with national evidence from the Legal Australia Wide (LAW) Survey (2012) which found that people experiencing chronic illness, disability, and/or mental distress are particularly vulnerable to legal problems, an observation replicated in more recent Victorian-based research.³²

More specifically, the findings are consistent with previous research focusing on people affected by cancer. Previous research by the McCabe Centre (2013–2015) and others have shown that people affected by cancer experience a wide range of legal problems and unmet legal need across domains including employment, income support, insurance, superannuation, informed consent and decision-making.³³ Legal problems are rarely experienced in isolation and often escalate over time, particularly where early support is not accessed.

More broadly, our research highlights a bi-directional relationship between legal problems and health previously identified by the Victoria Law Foundation; with poor health status being a strong predictor of greater legal need and poor legal experience and the negative health effects of legal problems.³⁴ That same study found evidence that people with long-term illness (including having a condition which has or is likely to restrict activity for 6 months or more, such as many cancers) or disability and/or mental distress have worse outcomes, and poor access to justice.³⁵ The high-levels of distress reported in this study echo this dynamic.

The findings also extend existing research by highlighting the distinct legal burden experienced by carers. Carers not only report higher rates of legal problems, but also face more complex responsibilities, including decision-making, advocacy, and system navigation on behalf of others.

It is important to note that, for around one-third of survey participants, experiences of cancer and caring coincided with the unprecedented social and economic disruptions associated with the COVID-19 pandemic. The COVID-19 pandemic generated new legal problems and intensified existing ones across Victoria, particularly in relation to employment, housing, social security, debt and family violence, resulting in increased demand for legal assistance services.³⁶ Therefore, the experiences reported by

some participants in this study may reflect the combined effects of cancer and the wider economic and legal challenges experienced by Victorians during the pandemic.

Cancer Council Victoria's Cancer, COVID-19 + You report identified challenges experienced by both people with cancer and carers in accessing income support, understanding eligibility for government assistance, managing financial hardship and navigating available services and supports.³⁷ These challenges are closely related to areas commonly associated with legal need, suggesting that people affected by cancer require assistance to navigate complex administrative and legal processes, particularly during periods of heightened financial and legal stress.

Taken together, this evidence confirms that legal need in the context of cancer is widespread and systemic. It is shaped not only by individual circumstances, but by the accessibility and responsiveness of legal, financial, and administrative systems. Without earlier identification and more integrated responses, legal problems are likely to remain unrecognised until crisis points, increasing their impact.

Implications

Legal problems are a core component of the cancer experience rather than isolated events, emerging across multiple domains and often at crisis points when individuals and carers have the least capacity to respond. These challenges are shaped by timing, individual roles, and the design of legal and administrative systems, raising broader questions about access to justice and how effectively people are supported to protect their rights during illness and caregiving. Carers, in particular, experience a disproportionate and complex burden, with responsibilities that extend to decision-making, advocacy, and system navigation.

The findings also underscore the importance of recognising how external crises can intensify the impacts of cancer and caring for someone with cancer. Periods of significant disruption, such as public health emergencies, may exacerbate existing legal and financial vulnerabilities by affecting employment, income security, caregiving responsibilities and access to services. Building resilient support systems that can respond to both cancer-related and crisis-related legal needs will be critical to reducing hardship and legal challenges among people affected by cancer and their carers during future emergencies.

System factors play a central role in shaping outcomes. Administrative burden, delays, and fragmented or complex processes can deter engagement, escalate problems, and contribute directly to legal harm. These effects are not experienced equally: people facing disadvantage encounter greater barriers to identifying, understanding, and addressing legal issues. As such, legal need should be understood as a systemic issue, influenced not only by individual circumstances but by how accessible, responsive, and coordinated institutions and services are. Together, these findings highlight the importance of legal and financial literacy, earlier identification of legal need, clearer pathways to support, and more integrated, person-centred system responses.



Finding 2:

**Underuse of legal
and professional
support reflects
systemic access
barriers**

‘Not everyone has the resources to be able to engage a private legal firm...I’m already \$12,000 down that road. And if we go to litigation, it will be another \$75,000 to \$95,000 or even \$150,000. And I’m willing to do that. Yes, this is about me and my reputation and the loss of income and non-economic loss, but it’s about the treatment of other people as well, not only with breast cancer, but with any serious illness that impacts their life... Lucky I’m a resilient person. And I certainly think my employer did not expect me to have this level of resilience. So, there’s always this power imbalance. And if you don’t have, I think the resources behind you and the personal resilience, you just get rolled over.’

– Michelle, living with breast cancer

Legal and financial needs are common but often unrecognised in the cancer experience, resulting in a significant gap between need and use of support services. Barriers such as low awareness, cost, system complexity, and reliance on individual help-seeking mean that support is typically accessed late, often at crisis points. Access and outcomes are therefore shaped by individual capacity, contributing to inequities. Integrating legal, financial and social security support into healthcare settings significantly improve outcomes.

Low uptake of legal support despite clear need

Despite widespread legal need, engagement with legal services was low across both cohorts.

41% of people with cancer reported legal issues
but **79%** did not see a lawyer.

67% of carers reported legal issues
yet **69%** did not see a lawyer.

This gap indicates substantial unmet legal need.

Only **21%** of people with cancer saw a lawyer and
only **23%** of carers did.

Barriers limit engagement with legal support

Survey and interview findings identify a range of barriers to seeking legal assistance.

Among people with cancer, key barriers included:

- Lack of awareness that a lawyer could help (29%)
- Cost (17%)
- Limited time or energy due to illness (12%)
- Difficulty finding a lawyer (5%).

Among carers, barriers were similar but also reflected high levels of self-reliance:

- Belief they could manage issues themselves (39%)
- Cost (23%)
- Difficulty finding a lawyer (10%).

Use of relevant specialist legal organisations was also low.

- 83% of people with cancer did not access any specialist legal service
- Among those who did, use was limited to small proportions (e.g. Fair Work Ombudsman 7%, community legal centres 5%)
- Less than 3% of people with cancer engaged with each of the following: Australian Financial Complaints Authority, Fair Work Ombudsman, Victorian Equal Opportunity and Human Rights Commission. No people with cancer surveyed engaged with the Commonwealth Ombudsman, Victorian Health Complaints Commissioner or the National Disability Insurance Agency.

Among carers:

- 69% did not access specialist legal services
- Those who did typically engaged with bodies such as the Fair Work Commission (13%) Consumer Affairs Victoria (10%), or the Victorian Civil and Administrative Tribunal (VCAT) (9%).
- Less than 8% of carers engaged with each of the following: Fair Work Ombudsman, community legal services, Victorian Equal Opportunity and Human Rights Commission, Commonwealth Ombudsman and Victorian Health Complaints Commissioner.

Interview findings reinforce these patterns.

Participants described low awareness of available services, uncertainty about how to access them, and confusion around eligibility for free or low-cost assistance. Private lawyers were noted as being costly. As a result, legal problems were often left unresolved until they escalated.

Barriers also extended to enforcement pathways. Interview findings suggest that complaints handling mechanisms including those for workplace disputes and financial complaints, are often difficult to navigate, requiring sustained effort, documentation and persistence. Although bodies such as the Fair Work Commission and other dispute resolution bodies such as the Australian Financial Complaints Authority are intended to offer accessible processes that do not require legal representation, interviews show that in practice these systems remain complex. As a result, individuals may still need legal assistance to effectively progress their claims. For people experiencing illness or caregiving demands, this often limited their ability to pursue formal resolution, meaning rights were not always exercised in practice.

Access to legal support typically occurred late and was often facilitated by trusted intermediaries, such as social workers, nurses, financial counsellors, or Cancer Council Victoria support services, rather than through direct help-seeking. Interviewees also reported uncertainty about who was responsible for initiating referral to legal support, contributing to delays.

Limited use of financial and supportive care services

Low uptake extended beyond legal services to financial and supportive care.

87%

of people with cancer

and

77%

of carers surveyed reported accessing no professional financial assistance.

Only small proportions accessed financial counsellors, financial advisers, legal specialists (e.g. superannuation or insurance lawyers), or services such as the National Debt Helpline as well as cancer support services, though carers used these services more frequently than people with cancer. Interviewees also observed that many people affected by cancer may be experiencing financial concerns or hardship for the first time, which can discourage them from seeking financial assistance due to associated feelings of embarrassment and stigma.

Interview findings indicate that access to broader supports such as cancer support services, social work, financial counselling, and mental health services, depended heavily on awareness, referral pathways, and individual capacity to navigate systems. Participants also reported that many services are resource constrained or restricted to certain cancer types limiting their ability to respond to demand.

Interviewees also noted that some pro bono services being means-tested — resulting in individuals who earn too much to qualify for free services but who cannot afford private lawyers or financial advisors — leaves a large proportion of people, often termed the “missing middle” or “missing majority” without viable options for support.³⁸ Similarly, services may be constrained by scope (e.g. support is only available for certain types of matters).

Early and embedded support improves outcomes

Where accessed, professional support played an important role in reducing burden and improving outcomes. Comprehensive and consistent supportive care screening at multiple points can assist in identifying the need for financial and legal supports and referring to appropriate services. Hospital social workers were frequently identified as critical supports, assisting with Centrelink processes, insurance, and referrals to legal and financial services.

‘If I find someone accommodation that’s fully funded local to the hospital and we help access their income protection, they feel like they’ve won the lottery.’

— Lori, social worker

Embedded models — such as Centrelink officers located within hospitals — were associated with improved access to social supports, including faster processing of claims, more timely eligibility determinations, and a reduction in administrative burden for both patients and healthcare staff. Health justice partnerships were also identified as critical, as they integrate legal assistance into healthcare settings — as was the benefits of collaboration between community legal centres and financial counsellors — enabling early identification and resolution of legal, financial, and social issues that may impact health outcomes, and supporting more holistic, patient-centred care. Interviewees also noted the benefits of having these multidisciplinary service models available across the cancer experience as issues can arise at different times.

‘[Centrelink in-house one whole day per week in the hospital] is incredibly beneficial and means lots of people have had their claims processed far more quickly because it’s helped expedite the process.’

— Fiona, social worker

‘Community legal centres, are bringing financial counsellors in and creating an integrated practise in recognition of those skills that are actually really complementary alongside lawyers... what people generally need at that acute hospital point is that financial counselling, Centrelink guidance, what grants are available, family violence is a big point in there. And then generally where someone that comes in just a touch later than that acute setting, the primary goal is eating tomorrow and also getting that primary health care. We really come into our own and working with social workers and financial counsellors a little bit later because income protection claims [require] minimum 14, often 30, 60, 90 days no work. And TPD claims a three to six months waiting period, so the hospital setting is too acute.’

— Tom, superannuation and insurance lawyer

Interview findings also highlighted the importance of trusted, coordinated support that goes beyond information provision to active assistance. Cancer Council support services and resources were noted as critical sources of trusted information, emotional support, and referral pathways.

Access is inequitable and crisis-driven

Access to support depended heavily on individual capacity, including health, literacy, geographic location, and ability to self-advocate. This resulted in unequal access and outcomes.

Support was consistently described as crisis-driven, typically accessed only after problems had escalated — for example, following rejected insurance claims, failed Centrelink processes, workplace disputes, or deterioration in health.

Interview findings suggest that this reflects a system design issue. Services intended to prevent harm are positioned late in the care pathway, and there is limited integration across health, legal, and financial systems. As a result, opportunities for early intervention are often missed.

Findings in context

These findings are consistent with research demonstrating that legal, financial and other support needs do not consistently translate into service use.

The findings from this research showing that many people are unfamiliar with legal concepts, unaware that a lawyer could assist them and low use of legal advice and engagement with legal services observed are consistent with research by the Victoria Law Foundation showing that people do not typically see everyday legal problems as “legal” and therefore are far less likely to seek legal advice and assistance from legal services,³⁹ and that there is widespread unmet legal need across the whole of the Victorian community, that is more problematic for people with chronic physical illnesses or mental distress and other forms of disadvantage.⁴⁰ The findings also reinforce the well-known problem of the “missing middle” or “missing majority” who are unable to obtain the free or low-cost legal services (or other services) they require because they do not meet eligibility criteria — such as income, case merit, or service scope — for more comprehensive forms of assistance.⁴¹

This study is also consistent with evidence showing that Australians more broadly consider that lawyers are costly and that dispute resolution mechanisms such as courts are complex, costly, slow and difficult to understand.⁴²

Similarly, findings of this study confirm previous work by the McCabe Centre showing that many people do not pursue legal complaints or enforcement pathways due to system complexity, time demands, and the difficulty of engaging with legal processes while managing illness or caregiving responsibilities.⁴³ This research adds to existing evidence that people with cancer are often exhausted by the symptom burden associated with treatment and can feel overwhelmed due to financial distress that they are unsure how to address, may avoid seeking financial assistance due to feelings of shame or concerns about stigma.⁴⁴

Our findings also align with research showing that around 70% of people affected by cancer have at least one unmet supportive care need.⁴⁵ Interview findings in this study reinforce this experience, indicating that limited awareness, uncertainty about referral pathways, and the practical burden of navigating systems and shame and stigma about their situation can prevent people from seeking various types of assistance, even where need is significant.

Taken together, this evidence indicates that underuse of legal, financial and supportive care reflects systemic access barriers rather than low need, particularly where systems rely on individual capacity to initiate help-seeking.

However, there is also strong evidence that system-level interventions can address unmet need. Cancer Council Victoria’s ACCESS (Accessing Cancer Care Equitably using Support Services) Program (2021–2024), a Victorian Government-funded initiative delivered in collaboration with the Victorian Integrated Cancer Services, demonstrated that increasing awareness, strengthening referral pathways, and expanding service capacity can significantly lift engagement with support services, including in regional areas. The program drove substantial improvements in access, including a more than fourfold increase in health professional referrals and marked growth in uptake of financial counselling and psychological support, ensuring more people affected by cancer received timely, coordinated care alongside their treatment.⁴⁶

Interviewees for this research also pointed to the success of formal health justice partnerships as well as the benefits for people affected by cancer who engage with cancer organisations such as Cancer Council Victoria and who are then connected with financial counsellors and law firms for support and advice.

Taken together, this evidence confirms that legal need in the context of cancer is widespread and systemic. It is shaped not only by individual circumstances, but by the accessibility and responsiveness of legal, financial, and administrative systems. Without earlier identification and more integrated responses, legal problems are likely to remain unrecognised until crisis points, increasing their impact. This research adds to growing empirical evidence which make it clear that access to justice challenges and opportunities go well beyond conventional understanding and approaches.

Implications

The underuse of legal, financial, and supportive care services reflects systemic barriers to access rather than low underlying need. These issues are widespread and often complex, yet support is typically accessed late, when problems have already escalated. This pattern is shaped in part by limited recognition of legal and financial impacts within cancer care, meaning needs are rarely identified or addressed as part of routine support. The availability of social workers, health justice partnerships or financial counselling is also uneven across health services and the State more broadly. As a result, opportunities for early intervention are frequently missed, raising questions about how effectively systems enable people to anticipate, understand, and respond to emerging challenges.

System design plays a central role in reinforcing these dynamics. Access is often dependent on individual capacity to identify needs, navigate complex and fragmented pathways, and pursue support through inconsistent or informal referral routes. At the same time, constrained service capacity limits timely responses. These barriers disproportionately affect those experiencing vulnerability—including illness, caregiving responsibilities, and socioeconomic disadvantage—who face the greatest obstacles despite often having the highest need. Overall, the positioning of services later in the care pathway contributes to reactive, crisis-driven responses.

Together, these findings point to the need for more proactive, integrated, and accessible approaches that support earlier identification, clearer pathways to care, and more equitable access to services.





Finding 3:

**Legal and financial
planning and legal
decision making
frameworks are
underused**

'Most people understandably put off making a will because it's not something anyone likes to think about. But even getting started with something like power of attorney documents can make a big difference. Once it's done, it's one less thing to worry about...It's also for your family's benefit in that they don't need to worry about it. They don't need to worry about if you lose capacity, who's going to be able access bank accounts or make medical decisions for you. That is all taken care of'

– Gabriella, wills and estates lawyer

'People think that cancer happens to old people. It happens to everyone. With income protection, once you're diagnosed, it's too late. I had income protection through my super and I had my own personal policy, and I had access to income protection through my workplace. Luckily, because I had income protection insurance, that has basically kept me going. It is about 60% of what I used to get paid, but it's better than nothing.'

– Naveena, breast cancer survivor

Engagement with legal and financial planning for adverse life events is limited and often delayed until periods of crisis or end-of-life. This shifts significant decision making responsibility onto carers, frequently without clear authority or guidance, increasing stress, uncertainty, and financial risk. At the same time, low uptake of protective financial products leaves many individuals financially exposed following diagnosis. These findings point to a dual challenge: not only structural and legal barriers, but also cultural reluctance to engage with forward planning and discussions about serious illness and end-of-life care.

Low uptake of planning for incapacity and financial protection

Survey findings indicate that planning for adverse life events is underutilised among people with cancer.

While 63% of respondents with cancer reported having a will, far fewer had arrangements to support decision-making during incapacity:

- Power of attorney (31%)
- Medical treatment decision-making documents (16%)
- Advance care directives (11%).

Although 70% held superannuation, only 26% had a binding death benefit nomination.

Uptake of financial protection products was also low:

- Life insurance (16%)
- Total and permanent disability insurance (10%)
- Income protection insurance (6%)
- Trauma/critical illness cover (1%).

“[Income protection insurance] — it’s the type of product that no one knows they need until they need it.”

– Tom, superannuation and insurance lawyer

Interview findings indicate that awareness of these mechanisms is uneven. Participants described legal planning tools—such as powers of attorney and advance care directives—as unfamiliar or difficult to understand, particularly without access to clear information or support.

Legal planning is delayed and crisis-driven

Interview findings show that legal and financial planning is frequently delayed and addressed late, often during periods of acute illness, deterioration, or end of life. Wills were commonly outdated or postponed, and planning for decision-making — such as powers of attorney — was rarely prioritised early in the illness trajectory. This created time pressure and limited opportunity for informed or considered decision-making.

‘A lot of people are doing [wills] when they’re in the terminal phase. It’s distressing and it’s upsetting and it’s clunky and it’s open to challenge.’

– Rebecca, Cancer Council Cancer Connect and hospital cancer nurse

Barriers to early legal and financial planning

Multiple barriers contribute to low uptake and delayed planning, including:

- Limited awareness and understanding of legal tools and financial products.
- Cost and access to legal assistance.
- Fatigue and reduced capacity during illness or caregiving.
- Uncertainty about document validity and requirements.

Legal planning for medical decision-making was often treated as separate from clinical care, leading to unclear responsibility for initiating discussions or completing documentation. Advance care planning and medical treatment decision making was frequently perceived as relevant only at end of life, contributing to delayed engagement.

Interview findings also indicate that powers of attorney are poorly understood. Many carers assumed they had automatic authority to make decisions and did not recognise the need for formal documentation. Even where documents were completed, they were not always shared or accessible to relevant institutions, limiting their effectiveness.

‘Powers of attorney, advance care planning, appointing a medical decision-makers etc. these may appear like foreign concepts and are not easy to understand... and information alone is not enough. People need someone to actually help them and guide them to complete the forms. Raising awareness that these things are available is important.’

– Sofia, carer

Participants also highlighted the importance of early access to legal and financial advice, noting that support embedded within healthcare settings can improve coordination and enable more timely planning. Social workers identified their key role in facilitating medical treatment decision making plans.

‘The more time you have to consider your estate planning, the more beneficial it can be for you because you’re not in a rush or hurry. You can think things through and set things up in a way that’s properly managed...When we can suggest mechanisms to benefit their families, it really helps lift a weight off their shoulders and gives them a sense of peace and reassurance as they move into the next stage.’

– Gabriella, wills and estates lawyer

‘I think we have a big role in identifying a medical treatment decision maker or helping someone appoint one because that’s directly related to their medical care.’

– Lori, social worker

Lack of planning increases burden and distress for carers

The consequences of limited planning are most evident in the experiences of carers. 69% of carers reported being in roles that required them making legal decisions.

60% acted as substitute decision-makers.

Roles included:

- Medical treatment decision-maker (34%)
- Legal guardianship (14%)
- Power of attorney (12%)
- Executor of estate (9%).

When considered alongside low uptake of formal planning documents, these findings indicate that carers are frequently required to assume significant responsibilities without clear legal authority or guidance.

In the absence of formal planning, decision-making often defaulted to statutory frameworks that did not reflect caregiving relationships. Interview findings indicate that this contributed to uncertainty, stress, and risk of conflict, as well as financial and administrative burden.

Structural barriers amplify disadvantage

Barriers to legal and financial planning were more pronounced among people experiencing structural disadvantage, including those with limited identification, lower literacy, language barriers, or limited access to services.

These groups faced additional challenges navigating legal processes and financial systems, often requiring more intensive support to engage effectively.

Interview findings also highlighted gaps in financial protection for carers, including limited availability of income protection mechanisms to offset lost earnings when providing care.

Findings in context

These findings are consistent with broader evidence showing that Australians are underprepared for adverse life events and future decision-making.

Research indicates roughly half of Australians do not have a will,⁴⁷ even fewer have formal decision-making arrangements such as powers of attorney in place,⁴⁸ and a large proportion of Australians do not hold life or income protection insurance.⁴⁹ Many who do hold insurance are underinsured, leaving households exposed to income loss and long-term financial instability in the event of serious illness.⁵⁰

Advance care planning is similarly uncommon. Research by Advance Care Planning Australia shows that only around one-third (33%) of Australian adults have engaged in any form of planning, and far fewer have completed formal arrangements such as advance care directives or appointed a substitute decision-maker (both approximately 6%). Barriers include low awareness, uncertainty about processes, cost, and difficulty initiating discussions.⁵¹

In the cancer context, these challenges are amplified. Consistent with our findings, research shows that legal planning is often delayed until disease progression or crisis points, with many people preferring to defer discussions rather than engage at diagnosis. One study found that only 16% of people with cancer want to discuss advance care planning at the point of diagnosis, compared to 42% who prefer to have these discussions when their

cancer is no longer curable, while a small proportion (3.9%) do not want to engage in advance care planning at all.⁵² This is despite the fact that up to half of patients with advanced cancer will experience delirium when admitted to hospital and 90% will experience delirium in the days before death, leaving them unable to make treatment decisions.⁵³

Research also indicates a mismatch between patients and their support networks. While family members and carers tend to want to discuss advance care planning earlier than the person with cancer, around one third (32%) of people with cancer prefer to raise the topic themselves.⁵⁴ These findings align with patterns observed in this study, where legal and financial planning frequently occurs late, increasing complexity and decision making burden for people with cancer and their carers.

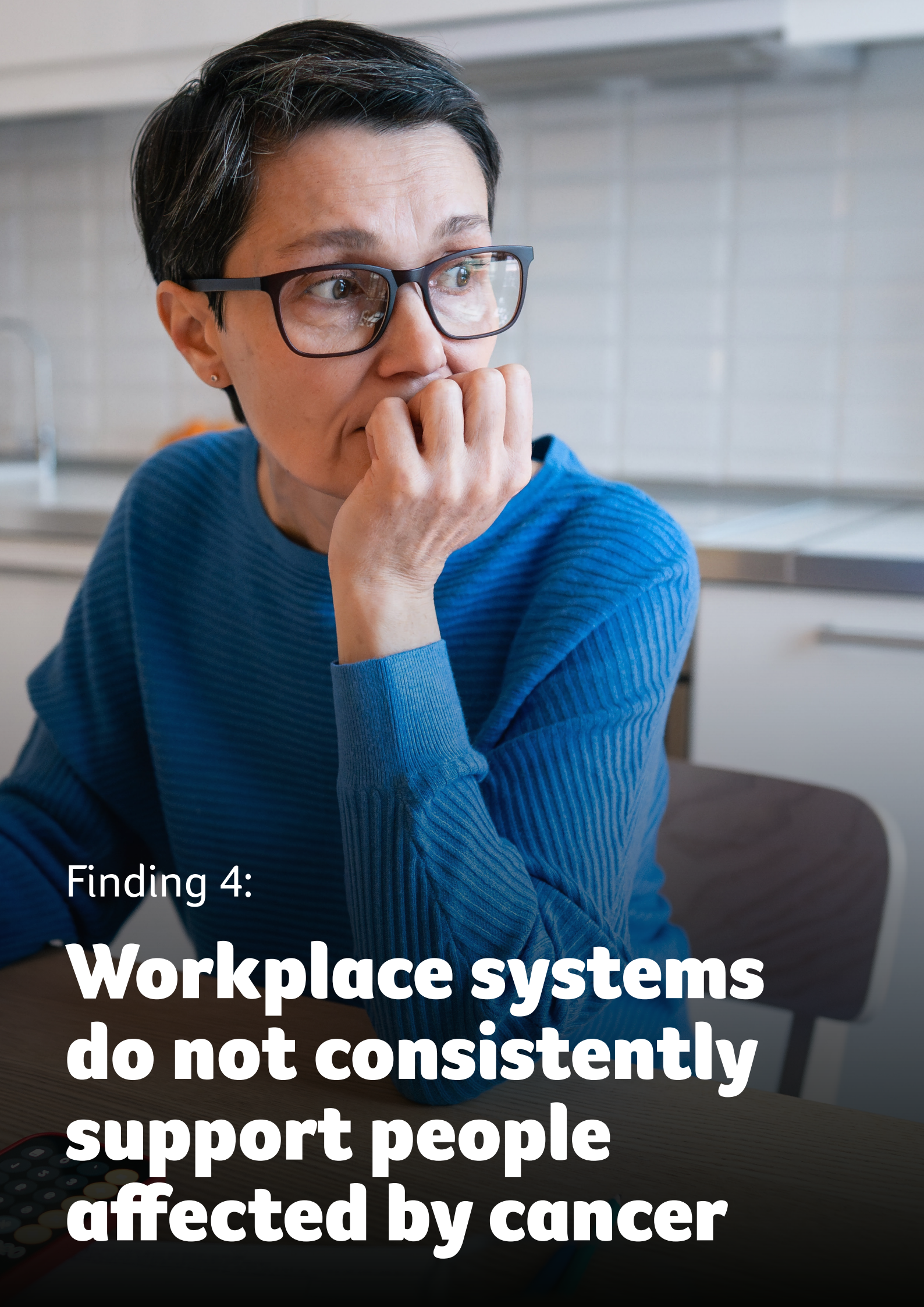
Taken together, this evidence indicates that underuse of legal and financial planning reflects not only individual behaviour, but systemic factors including accessibility, complexity, timing, limited integration within healthcare pathways and cultural averseness to engage with forward planning and discussions about serious illness and end-of-life care.

Implications

The underuse of legal and financial planning reflects a misalignment between system expectations and the realities of illness and caregiving. Planning is often delayed until crisis points, when capacity is limited and options are constrained, and remains largely peripheral to cancer care rather than embedded within it. Current approaches rely heavily on individual initiative, requiring levels of awareness, coordination, and decision-making that are often unrealistic during periods of illness, resulting in missed opportunities for early and effective planning.

System design further shapes access and outcomes. Carers frequently assume decision-making responsibilities without clear legal authority, while low uptake of financial protections increases exposure to risk. Structural barriers and disadvantage compound these challenges, limiting the ability to engage in planning and reinforcing inequities. Even where legal and financial arrangements are in place, issues with accessibility, recognition, and confidence in their use can reduce their practical impact. Together, these findings highlight the need for earlier, more accessible, and integrated approaches to legal and financial planning that reduce reliance on individual capacity and better align with the realities of cancer and caregiving.





Finding 4:

**Workplace systems
do not consistently
support people
affected by cancer**

'I do peer support through Cancer Connect for Victorian Cancer Council, so I talk to other patients diagnosed, particularly with lung cancer. There's been people I've talked to who have gone and had chemotherapy or brain radiation and they've scheduled it before work because they don't want to take the time off from work and tell their employer that they're getting a cancer treatment. And then they go and they turn up to work after that and work through those impacts because they don't want to take a sick day because you need a medical certificate to take a sick day or, you know, there's only a limited amount of non-medical certificate sick days you can take.*

It just breaks my heart to think of that person who's gone through that — the emotional impact of that treatment — and is now sitting there with the side effects of all impact, plus the side effects of the medication, sitting next to somebody else trying to type away or stand on a factory line or work on a building site or something like that next to somebody else. And pretend it's all normal.

No, that shouldn't be a reality that anyone has to face. If they want to turn up to work and do that, that should be a choice of their own. But they should be able to do that in a place where it's supported and at least their direct line manager is aware of what they've gone through and can consider it. It's a horrible scenario to think that that could be occurring to an employee next to you and no one knows.'

— Jon, living with advanced cancer

** This program is now called Peer Connect*

Workplace-related legal issues were the third most common legal issue reported by people with cancer surveyed and the second most common legal issue reported by carers. Interviews also highlighted the importance of work and the serious impacts of not being able to continue working on the lives of people affected by cancer as well as how unequal people's experiences in the workplace are.

The findings highlight that workplace experiences for people affected by cancer are shaped not only by individual circumstances, but by systemic features of the current legal and workplace framework. While formal protections exist, their operation in practice is uneven, with outcomes frequently dependent on employer discretion, workplace culture, and individuals' capacity to access and enforce their rights during periods of illness or caregiving.

Viewed through a human rights lens, these patterns point to a gap between the formal recognition of rights — including the right to work and rights at work such as non discrimination, and reasonable accommodation — and their consistent realisation in practice, particularly in the context of prolonged, episodic illness and unpaid care.

Workplace laws overview

- It is generally unlawful to discriminate against someone based on disability (including cancer) and caring responsibilities under federal and state law. This applies to hiring, promotion, workplace conditions and termination of work.
- Employers must make 'reasonable adjustments' under disability discrimination law to help a person keep working (e.g. flexible hours, reduced duties, remote work), unless this causes the employer unjustifiable hardship.
- Most employees are covered by the National Employment Standards which provide a legal minimum of:
 - 10 days personal leave (combined sick and carers leave) each year for full-time employees. Part-time employees get a pro rata amount. Casual employees have no personal leave entitlement.
 - 2 days unpaid carers leave if all paid personal leave is used on each permissible occasion. This is available to full-time, part-time and casual employees.
 - 2 days paid compassionate leave on each permissible occasion. This is available to full-time, part-time and casual employees.
- Full-time and part-time employees also get 4 weeks paid leave each year (pro rata for part-time employees).
- All types of employees may be entitled to long service leave under the National Employment Standards, an enterprise agreement or under state/territory laws. Amount and eligibility rules vary.
- After 12 months of employment, employees may have the right to make a written request for flexible working arrangements if they have a disability (including cancer) or are a carer. Employers need to follow certain rules for responding in writing within 21 days.
- All employees are protected from unfair dismissal or disadvantage because of illness, caring responsibilities, absences within lawful limits, or exercising workplace rights. However, there is a strict 21-day deadline to lodge unfair dismissal complaints.
- Employees cannot be terminated from their employment while on paid leave.
- The federal Disability Discrimination Act 1992 and the National Employment Standards under the Fair Work Act 2009 are currently under review.⁵⁵

Work matters to people affected by cancer

Survey and interview findings indicate that work is highly valued by both people with cancer and carers, not only as a source of income, but as a source of identity, structure, dignity, and social connection.

Participants described work as an important anchor during disruption, with many expressing a strong desire to remain in or return to work where possible.

'They were really good at my work. They said to me, "How can we support you?" And I said "I just want to work. I just want to do my job. I want to be normal. My COO said "Okay but be sensible. And if you need it, we're here."'

– Neroli, having cancer treatment

At the same time, the loss of work was described as deeply significant. Interviewees spoke about grief, loss of identity, and long term impacts extending beyond financial consequences. For carers, employment also

provided financial stability and connection to life beyond the caring role. However, this meant that disruptions to work had impacts extending well beyond income.

Notably, interview findings challenge common assumptions still held about cancer and work, such as cancer being incompatible with employment. Many research participants continued working during treatment or sought to do so. These findings indicate that the issue is not whether people with cancer can work, but whether workplace systems are structured to support fluctuating capacity and ongoing health needs and caring responsibilities.

'In the past with cancer, as an employee, you got diagnosed and you disappeared from the workplace pretty quickly and you went and had treatment. And then you went into the end-of-life stage. Not many people came back into the workplace from that scenario. But advances in cancer treatment and targeted therapies have enabled a real paradigm shift with younger people with families and careers that are still developing being able to work.'

– Jon, living with advanced cancer

Cancer, caring and work frequently coexist

Workplace protections are relevant to a substantial proportion of people affected by cancer, including both people with cancer and those in caring roles.

Among people with cancer surveyed, 62% were in paid work at diagnosis. Among carers, 78% were in paid work while undertaking caring responsibilities, with most engaged in full time employment.

Interview findings reinforce that cancer, caregiving, and work often occur simultaneously rather than

sequentially. Participants described continuing to work during treatment, attempting to return while still experiencing fatigue or cognitive impairment, or maintaining employment due to financial necessity, identity, or both.

This was particularly evident in cases involving prolonged treatment or advanced cancer, where both work and care were sustained over extended periods and shaped by ongoing appointments, side effects, and uncertainty. Carers similarly described managing paid work alongside intensive and often unpredictable caring responsibilities. These findings establish work as a central site of impact for both people with cancer and carers, influencing financial stability, wellbeing, and participation in everyday life.

'I'm in a workplace where I'm continually being treated [for cancer], continually suffering side effects from those treatments. And then on top of that, I have a regular scanning regime that I go to that brings a whole other level of psychological and stress and anxiety as well.'

– Jon, living with advanced cancer

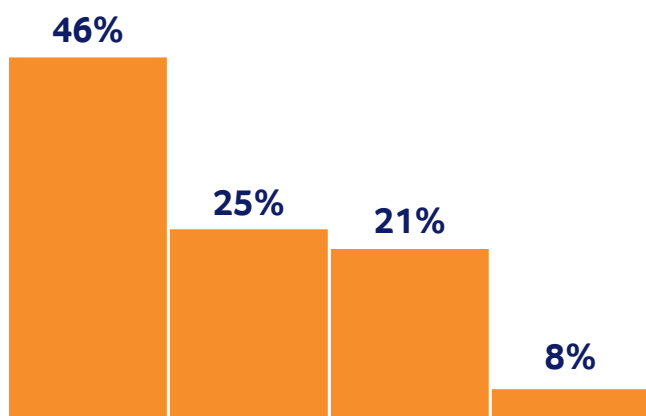
Supportive workplaces make a significant difference, but support is inconsistent

Many participants reported supportive workplaces, particularly in relation to initial responses following diagnosis. Among workers with cancer, 71% described their workplace as 'supportive' or 'very supportive'. This compared to 58% of carers reporting their workplace as 'supportive' or 'very supportive'. A small proportion of workplaces were reported as unsupportive by both cohorts.



Figure 5:
Levels of support from their workplace
reported by Victorians with cancer
and Victorian carers surveyed

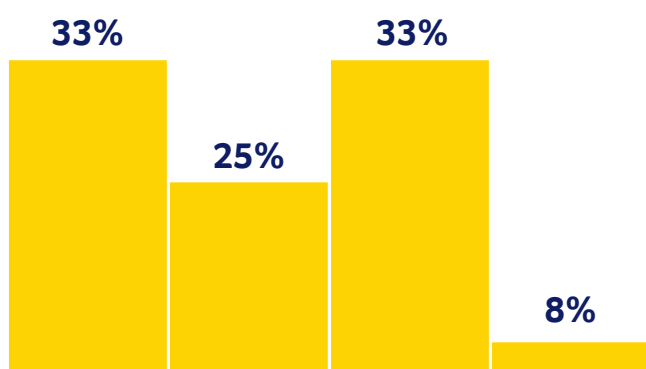
People with cancer



Support Levels

- Very supportive (46%)
- Supportive (25%)
- Somewhat supportive (21%)
- Not supportive (8%)

Carers



Support Levels

- Very supportive (33%)
- Supportive (25%)
- Somewhat supportive (33%)
- Not supportive (8%)

However, the nature of this support was often informal, partial, and highly variable.

Survey data indicates that:

- 37% of workers with cancer reported receiving none of the 25 supports they were asked about.
- Structured supports such as return to work programs, regular check-ins with managers, supervisors or Human Resources, Employee Assistance Program (EAP), mental health support, occupational therapy support and access to workplace policies and programs to manage work and cancer or work and caring were uncommon across both cohorts.
- Information about workplace rights was reported by only a small minority (3% of workers with cancer and 10% of carers).

Flexible work (hours and remote working) represented the most common form of support reported by both survey cohorts, followed by additional paid leave or unpaid leave:

- 29% of workers with cancer and 48% of carers accessed flexible work hours.
- 11% of workers with cancer and 20% of carers reported working remotely.
- 16% of workers with cancer reported receiving additional paid leave, and 16% reported access to unpaid leave.
- 18% of working carers reported access to additional paid leave and 27% reported access to unpaid leave.

More structured forms of workplace flexibility — such as part-time arrangements or job sharing — remained rare. A small proportion of people with cancer and carers surveyed had difficulty in securing flexible work arrangements (less than <10%).

'It was a very stressful time in my life made worse by toxic workplace.'

– Survey respondent with cancer

‘My employer was somewhat inflexible when I reached 67 and sought part time work all from home for three days a week. They offered four days and changed my duties. After two months I decided to retire as this wasn’t working for me.’

– Survey respondent with cancer

Interview findings were consistent with survey findings regarding the most common types of workplace supports offered. Some interview participants also had access to time off in lieu and access to leave at half-pay and paid leave intended for recreation purposes rather than illness/caring which they could use such as annual leave or long service leave.

‘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 leave.’

– Tracey, carer

Interview findings also reinforce that support was:

- Highly dependent on individual managers.
- Often based on goodwill rather than formal rights.
- Fragile and subject to change over time.

Interview participants described how supportive arrangements could diminish as illness became prolonged or withdrawn following changes in management.

‘The biggest impact on a person in terms of the efficacy of the support from the workplace is with the manager.’

– Sue, cancer survivor and Founder, LiveWorkCancer

‘The lack of engagement from the employer around my illness, I mean, I was left thinking, well, maybe having breast cancer isn’t a big thing.’

– Michelle, living with breast cancer

What worked well in supportive workplaces

Across interviews, several consistent features of supportive practice emerged:

- Flexible work arrangements, including reduced hours, remote work, and task redistribution.
- Trust based approaches focused on outcomes rather than rigid schedules.
- Manager empathy and proactive communication.
- Reduced administrative burden, including less reliance on repeated evidence of illness or caring.
- Gradual or staged return to work approaches.
- Ongoing review of capacity, rather than one off adjustments.
- Practical supports separate to work adjustments including access to employer group income protection and occupational therapy.

These practices were effective because they allowed people to manage fluctuating capacity in real time and remain connected to work where possible.

'I would often feel tired. So, I'd say to my boss, "I'm going to have a lie down" and he'd go "No worries, just take the rest of the afternoon off if you need to". And then I'd lie down for a couple of hours and go back to work.'

– Neroli, having cancer treatment

'Work was very accommodating. I was able to take leave at half-pay to extend my time off and income. They even had an occupational therapist and income protection insurance I was able to use. They were very good at communication and keeping both sides [me and the manager] supported.'

– Naveena, breast cancer survivor

'Both times my line managers were quite willing to find a way to make things easier for me and for me to not have to constantly present evidence. They just said "do you have your initial referral, for your husband? If you just give us a copy of that, that's it. That's all we need. And then you just tell us when you need to take a carer's day or you need it for a few weeks and you don't need any more evidence. That's it. We've got it already". And that was brilliant because otherwise, every time you take a carer's day, you have to show evidence. And for doctors, it must be wasting their time as well.'

– Jacinta, carer

However, such approaches were described as exceptional rather than standard and not consistently embedded in workplace systems.

Workplace challenges are widespread, cumulative and interconnected

Despite some positive experiences, participants reported a broad range of challenges that often accumulated and interacted over time:

(i) Managing health impacts while working

Workers with cancer reported significant physical, cognitive, and emotional or psychological challenges (e.g. anxiety).

Workers with cancer reported significant physical, cognitive and emotional impacts:

- 25% reported physical limitations or fatigue.
- 24% reported emotional or psychological challenges.
- 6% reported cognitive difficulties following cancer treatment.

Taken together, around 31% of workers with cancer surveyed reported physical or cognitive impacts affecting work. Similarly, interview participants described side effects including:

- Unpredictable fatigue
- “Brain fog” and reduced concentration
- Chronic pain
- Long term side effects of treatment affecting daily functioning. These can often continue for months or years after treatment has finished, known as ‘late effects’.

These effects were often unpredictable, and persisted beyond active treatment, making sustained work participation challenging. For those living with advanced cancer, treatment and side-effects are ongoing and can be a part of daily life.

‘My treatment is every day all day. And my side effects are continuous that I experience all day at work as well.’

– Jon, living with advanced cancer

Interviewees reported that often these late effects were difficult for colleagues to understand, particularly where individuals appeared outwardly well.

‘The “You look well” comment. I never begrudged anyone that. But just because your hair grows back doesn’t mean you’ve recovered. You’ve been cut, burned, poisoned, and in some cases chemically castrated with endocrine therapy that can go on for five, ten years. So, people might come back to work looking normal, but they’re still going through all these things that people are going through which are not visible on the outside. The joint pain, the lack of sleep, the hot flushes, weight gain, nausea. There are all these things that people don’t realise are part of having cancer.’

– Naveena, breast cancer survivor

Over a third (33%) of carers surveyed who were working also reported emotional or psychological challenges.

'I just kept soldiering on and trying to work through stress.'

—Jacinta, carer

(ii) Workplace culture, stigma and pressure

Survey findings indicate that amongst people with cancer:

- 10% were concerned about telling their workplace.
- 8% reported experiencing unfair treatment/discrimination or stigma.
- 12% reported experiencing difficulties with co-workers, a lack of support from managers/supervisors or Human Resources teams.
- 6% reported difficulty balancing workload and work expectations.
- 8% reported burnout or stress.

'People at work don't understand the ongoing symptoms and lack of energy from ongoing cancer treatment. They just expect that if you are working you have to pull your weight. I am so tired after each workday but need the money. I am a nurse so a physical job.'

—Survey respondent with cancer

Carers also experienced a range of significant pressures at higher rates than people with cancer:

- 24% reported difficulty balancing workload expectations.
- 21% reported concern about telling their workplace.
- 15% reported difficulty managing work and care.
- 12% reported difficulty understanding their rights at work.
- 12% reported unfair treatment/discrimination or stigma.
- 17% reported burnout or stress.

Interview participants reiterated survey findings, reporting that people affected by cancer commonly have concerns about:

- Their workplace rights.
- Disclosing their illness.
- Pressure to appear “fully recovered”.
- Fear of being perceived as unreliable or less capable.
- Challenges with workload and work expectations.

'It is kind of the expectation unsaid, that if I'm at work, I'm at work. And I am 100% capable at work the whole time, whether that is my reality or not, or whether I've got to push myself to be able to do that is not discussed in any way. And there are a whole bunch of small little supports that could make significant difference in the way I can be effective at work.'

—Jon, living with advanced cancer

Many described concealing illness or repeatedly justifying adjustments. Workplace harms also arose through peer behaviour, exclusion, and stigma.

‘Sometimes colleagues may be supportive, but not when you take time off because that means they have to absorb the work that you leave behind. So that’s a little bit tricky. And I hear it so many times in my line of work that “my colleagues are talking behind my back”. Not a lot of people, but some do. That adds to the stress and it’s kind of like bullying in a sense. It happened to me, but my employer was supportive.’

– Sofia, carer

Interviewees discussed how workplace culture relates to concerns about employers and managers being poorly equipped to have delicate and sometimes difficult conversations to support people with cancer, which they noted are skills that all managers should have, regardless of whether they are working with someone with cancer.

‘In my return to work, I was offered no return-to-work process at all... but a conversation that should have been had was “It’s wonderful to have you coming back to work. How do we make that work for you?”. I just came back to work and started working...as a manager of people, you need to have empathy and to know how to have a challenging conversation without being inappropriate...If you can enable those conversations to be held in a respectful and appropriate way, and I mean appropriately legally as well, where everyone understands what is available and what can be done and what can’t be done, then I think that’s a better outcome for both the employer and the employee as well.’

– Jon, living with advanced cancer

(iii) Inadequate leave and entitlements

As noted above, many participants exhausted available paid leave entitlements, including sick leave and annual leave (and where available, long service leave and time off in lieu) and subsequently relied on unpaid leave or informal arrangements or had to reduce their working hours.

Of people with cancer surveyed who were working:

- 16% used up all paid leave
- 17% took unpaid leave
- 16% took long periods of leave (3+ months)
- 13% reduced working hours.

For carers:

- 20% used up all paid leave
- 27% took unpaid leave
- 21% reduced working hours
- 7% took long periods of leave (3+ months).

Together, these findings indicate that around half of workers experienced leave depletion, unpaid leave, or reduced work participation. This reflects a mismatch between the duration and unpredictability of cancer and caring for someone with cancer and existing legal frameworks for paid leave, with current minimum legal entitlements under the National Employment Standards set at 10 days of combined sick and carer's leave, known as 'personal leave'.

'How the heck do you do cancer with 10-days sick leave?'

– Sue, cancer survivor and Founder, LiveWorkCancer

Interviewees noted that the bundling of paid sick and carer's leave into a single entitlement of 'personal leave' was particularly problematic for carers who would often expend their personal leave on caring responsibilities, leaving them without paid sick leave when they fell ill themselves.

'You use up all your own leave. I know after my partner passed away, and I know this has happened to a lot of people that I've spoken to, you take that step back and go "I can breathe now". And then you get sick. And that's happened to me and I was off work for two weeks. If [leave] is separated, it does allow the carer that safety net for themselves should they need to take that time off.'

– Tracey, carer

Interviewees also noted that there are workplace entitlements for paid and unpaid parental leave which provide clear job protection, connection to the employer, flexible use and integrated income support payments, and questioned why similar entitlements do not yet exist for those experiencing serious chronic illnesses such as cancer and associated caring responsibilities. Similarly, interviewees noted that there are structured processes in place in terms of return-to-work and workplace adjustments for workers injured at work under occupational health and safety laws, however, these structured processes are not yet embedded into employment laws.

(iv) Financial pressure shapes work decisions

Work decisions were often constrained by financial necessity rather than health or preference. For people with cancer:

- 17% of workers continued working or returned early due to financial need.
- 8% did so due to fear of job loss.

For carers

- 34% reported working despite wanting to stop due to financial need.
- 22% reported working due to fear of job loss.

Combined, 25% of workers with cancer and 56% of carers surveyed experienced pressure to continue working due to financial or job security concerns. This survey finding was reinforced by interview participants who described continuing to work or returning earlier than preferred due to income loss, ongoing expenses or job insecurity.

'People feel forced to work because they need the money. This is a reality, which is why income protection is so helpful.'

– Naveena, breast cancer survivor

(v) Barriers to accessing and enforcing workplace rights

While workplace protections exist, participants rarely described relying on formal legal rights to resolve issues or secure support.

Interview findings indicate that awareness of workplace rights was limited. Many participants were uncertain about their entitlements, including rights to flexible work, leave, and protection from discrimination. As a result, workplace issues were typically managed through informal negotiation rather than formal processes.

‘People sometimes don’t know they can use their personal leave as carers leave.’

– Lori, social worker

‘I think it’s essential that there is information about the basic legal rights you have with an employer.’

– Jon, living with advanced cancer

Even where participants were aware of their rights, significant barriers to enforcement were described. These included:

- Limited capacity to engage in legal processes while unwell or caregiving.
- Complexity of workplace laws and complaint pathways.
- Lack of timely access to legal advice or support.
- Costs of legal advice.
- Short statutory timeframes for pursuing unfair dismissal claims.
- Concern about damaging relationships with employers or risking job security.

Interviewees noted that many people affected by cancer do not pursue formal complaints or remedies, even where they experienced unfair treatment. Instead, they adapted their behaviour, reduced work, or exited employment altogether. Interview participants shared concerns for more junior employees who out of concerns for their career development are less likely to advocate for themselves or call out inappropriate or unlawful behaviour by employers. The costs of engaging private lawyers to resolve complaints was also noted as a barrier for people affected by cancer.

Survey findings reinforce this pattern of low engagement with formal pathways. Among people with cancer, only small proportions (less than 4%) reported seeking assistance from each of the following formal supports: workplace Human Resources team, lawyers, the Fair Work Ombudsman, unions or human rights bodies. Instead, participants were more likely to seek support from informal or health-related sources, such as doctors (16%), social workers (4%). A small proportion sought assistance from Employee Assistance Programs (4%).

Patterns were similar for carers surveyed, although slightly higher proportions reported seeking support from their workplace Human Resources team or Employee Assistance Programs (12%), lawyers (11%), Fair Work Ombudsman (8%) or human rights bodies (3%). Overall, however, formal mechanisms remained underutilised.

Insights from interviews suggested that a lack of organisational capacity to support people affected by cancer may in turn lead to overreliance on Employee Assistance Programs that may not provide people with the support they need.

‘Organisations often flick [people with cancer] over to EAP. And I haven’t spoken to anyone in my time in the last three and a half years that’s been impacted by cancer that said EAP was great. They don’t even call EAP.’

– Sue, cancer survivor and Founder, LiveWorkCancer

Interview findings also indicate that responsibility for initiating and navigating workplace adjustments often rested with the individual, whereas they would have preferred a more proactive approach from their employer upon disclosure of their illness or caring responsibilities. Some participants described needing to repeatedly explain their situation, request accommodations, and ensure ongoing arrangements remained in place, particularly where management changed.

Taken together, these findings suggest that the effectiveness of workplace protections depends not only on their legal content, but on their accessibility and usability in practice.

(vi) Carers face distinct and compounded workplace challenges

Working carers experienced significant and overlapping pressures.

‘I think caring is a job. It’s just, you’re not paid for it.’

– Jacinta, carer

Survey and interview participants described carers as having:

- Difficulty balancing work with intensive caring responsibilities.
- Exhaustion and emotional strain.
- Pressure to remain in work despite caregiving demands.

‘You’re trying to do your best, to comply with your work responsibilities as well as your care responsibilities. But it’s tricky for people providing care, when the person they care for is really sick and they are expected to pass away, and there is a sense of guilt in having to decide to “should I choose my employer because I need the money?” It’s really challenging having to deal with that.’

– Sofia, carer

‘I was working long hours to ensure there was money.’

– Carer survey respondent

Many carers reduced hours, used up leave, or left the workforce altogether. These outcomes were rarely voluntary, reflecting structural gaps in recognising and supporting caregiving within workplace systems.

Carers also relied heavily on informal arrangements and employer goodwill to stay in employment and manage their caring responsibilities with work, safeguarding their financial security.

‘I’m so grateful to that particular workplace. I ended up having about eight weeks off work, fully paid. If I didn’t have that, we would have lost our house... It should just be an absolute given that... you get the leave and the support that you need. Because my experience is not what everyone experiences as a carer and worker.’

– Jacinta, carer

(vii) People outside standard employment are especially exposed

Participants in non standard forms of work — including self employment, contract work, and casual employment and other forms of insecure work — faced additional vulnerability.

These workers often lacked access to:

- Legislated paid leave.
- Legislated job protected absence.
- Structured return to work supports.

As a result, cancer can have an immediate and destabilising impact on work and income.

‘Once carers rights are in legislation, people will feel empowered to make those decisions about work and caring without fear of losing their job.’

— Sofia, carer

‘My husband’s been self-employed most of his life, but because I work, he’s not eligible for any Centrelink support...I don’t know what’s available for self-employed people. Maybe it’s just expected that, well, you need to just set it all up yourself?’

— Jacinta, carer

Workplace impacts are significant and enduring

Workplace challenges translated into measurable changes in employment outcomes and workforce participation. Participants reported reduced hours, extended leave, job loss, and long term disengagement from work.

For people with cancer:

Full time employment declined from 62% to 54% and part-time employment fell from 27% to 17%.



13% reduced their work hours.

Of the 21% who took a long period of leave (3 or more months) or left work, retired or stopped being self-employed because of cancer, 43% did not return to work.



Carers:

Full time employment declined from 61% to 54% whereas part-time employment increased from 11% to 14%.



21% reduced their work hours.

Of the 15% who took a long period of time off work (3 months or longer) or stopped work or stopped being self-employed to care for someone with cancer, 19% did not return to work.



These impacts had lasting consequences, including reduced earning capacity, loss of superannuation accumulation, and financial insecurity. Interview findings also highlight these longer term impacts, and additionally impacts on career progression. These impacts are gendered as they disproportionately impact women. Interviewees noted therefore, the importance of income protection insurance but acknowledged difficulties people may have in accessing this, particularly through superannuation. Some interviewees noted how helpful employer group income protection policies can be for people with cancer.

‘I’ve had that recently where the employer provides the income protection for their staff...Some industries seem to be very good at making this a standard benefit. And it’s amazing the difference it makes. I remember having a bus driver once and we confirmed he had income protection provided by his employer and he just said, “I don’t know what we would have done. We’d have had to sell the house and things like that.”’

— Lori, social worker

Workplace challenges are highly distressing

Workplace issues were a significant source of distress for both people with cancer and carers.

For people with cancer:

86%

of people with cancer who experienced challenges at work reported distress, while every carer surveyed

100% who reported workplace challenges or concerns also reported distress.



These findings indicate that workplace impacts are not incidental, but a major contributor to emotional and psychological burden. Distress was driven by the interaction of health impacts, financial pressure, job insecurity, and the demands of managing workplace relationships and expectations.

Interview participants described:

- Anxiety about job security.
- Emotional strain from managing work alongside illness or caring.
- Burnout and reduced wellbeing.
- Grief associated with loss of role or identity.

Workplaces could act either as a source of stability or an additional source of stress, depending on the level and consistency of support.

'I'd spent 20 years building this career. And I thought "I am going to go back to work. Of course I am going back to work". My work was very accommodating, they did everything they could to make sure I could go back to my job. I was very lucky, I know a lot of workplaces will not do that. They were not putting pressure on me, I was putting pressure on myself. But in the end, I had to call I quits — I have cognitive impairment both from the chemotherapy and the cocktail of pain killers to manage the side effects of cancer treatment. I felt a loss of self because I thought "I don't have a job and so I don't have an identity." There was a sense of loss and grief knowing that I could not go back to doing the work I used to do.'

— Naveena, breast cancer survivor

'It's such a horrible, horrible time. When you get that diagnosis, then you have to be worried, 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

Participants identified practical changes to improve workplace support

Across interviews, a consistent theme was that effective workplace support should not depend primarily on employer goodwill or individual manager capability. Participants expressed a clear preference for more structured, transparent, and enforceable approaches, where expectations are clearer and support is consistently available. Taken together, these findings suggest that improving workplace outcomes does not require entirely new approaches, but rather the more consistent and systematic application of practices that are already known to be effective.

Interview participants consistently identified a range of practical changes that could improve workplace support for people affected by cancer and caring. These suggestions centred on the need for a better understanding about cancer and the impacts of cancer or caring for someone with cancer, greater consistency, clearer expectations, and reduced reliance on individual discretion, reflecting the broader findings of this section.

'One of the key barriers is just the awareness.'

— Sue, cancer survivor and Founder, LiveWorkCancer

‘For most people who haven’t had a personal experience of cancer, there’s a stereotype image of what somebody with cancer is — it’s generally somebody with no hair and who looks really skinny and gaunt... You’ve got to understand the stereotypical view is not the reality for a lot of cancer patients now... No one can be expected to understand the entire cancer landscape properly, but a fundamental understanding of cancer treatments and the reality of cancer would definitely help.’

— Jon, living with advanced cancer

‘Certainly a breast cancer diagnosis should trigger, in my view, some kind of education for both the person with the cancer and their employer... I don’t really think they [my employer] understood the legislation, either they didn’t understand or had a firm disregard for it. And I don’t believe that they engaged with legal advice till later. So, I think that’s one point to take out of it [my experience], that before employers make decisions, they should engage with legal. It doesn’t mean that it’s somehow kind of turning the temperature up, it’s taking advice early... Instead it was a series of kind of really poor decisions on their part.’

— Michelle, living with breast cancer

Workplace-level improvements

Participants emphasised that many workplace challenges could be reduced through relatively practical changes in employer practices. Key areas included:

- Manager training to build understanding of cancer as a chronic and variable condition and the demands of caring for someone with cancer.
- More flexible and adaptive work arrangements, including the ability to adjust hours, workload and duties in response to fluctuating capacity.
- Reduced administrative burden, particularly lower requirements for repeated medical evidence once a condition was established.
- Clearer and more consistent manager practices, including proactive check-ins and open communication about capacity and expectations.
- Structured return to work processes that extend beyond initial treatment and recognise ongoing or long-term impacts.
- Workplace cultures that normalise reduced capacity due to cancer or caring without stigma and reduce reliance on employees to initiate and justify adjustments.

Participants also highlighted the importance of continuity and predictability, noting that changes in management often required them to renegotiate arrangements repeatedly.

System and policy-level improvements

Participants also identified broader changes that would require policy or legislative reform and legal service delivery. These included:

- Expanded and more flexible leave entitlements, including access to extended or serious illness leave (paid and unpaid) akin to parental leave.
- Greater recognition and protection of carers in the workplace, including clearer rights and job protection.
- Clear, accessible information about workplace rights and entitlements, provided early and through multiple channels.
- Stronger alignment between workplace systems and the realities of cancer, including fluctuating capacity and ongoing treatment and related caring.
- Reduced reliance on individual negotiation, with more consistent, rights-based approaches across workplaces.
- Accessible legal services for people affected by cancer.

Participants also emphasised the importance of early and proactive support, noting that delays in information or assistance increased stress and limited available options.

‘Your experience at work shouldn’t depend on the compassion of your boss or the organisation. Better legislation will be a game changer for all of us.’

– Sofia, carer

‘Where is the legal service, a dedicated breast cancer legal service that is either funded by government or funded by private institutions or a charity that provides this legal support for people going through the system?’

– Michelle, living with breast cancer

‘You would like to think all workplaces, all organisations, employers would be supportive, but they’re absolutely not. Now I can talk about both times [caring] as very positive for me... But I hear people some people have had terrible experiences where they’ve not been supported at all or they’ve had leave knocked back, which is just appalling. Because [caring] is so stressful, you don’t need that stress about your income and your job. It’s great to see now that through the Fair Work Act that there is family and domestic violence leave. I think there needs to be something equivalent if you have a genuine, very serious illness or disease. It should just be an absolute given that you’re not going to be hassled, you just get the leave. You just get the support that you need because, my experience is not what everyone experiences as a carer and as a worker.’

– Jacinta, carer

Findings in context

The workplace experiences identified in this study are consistent with prior research demonstrating that cancer is not only a health issue, but also a significant employment, income and workforce participation issue affecting both people with cancer and those in caring roles.⁵⁶

The McCabe Centre and others have consistently found that many people affected by cancer seek to remain in or return to work, and that employment plays an important role in financial stability, identity, dignity and wellbeing.⁵⁷ These findings align closely with the present study, which identifies work as highly valued and central to continuity in everyday life.

Across this body of research, a consistent theme is the misalignment between workplace systems that remain structured around short term or linear absence and the lived realities of cancer.⁵⁸ Cancer is often prolonged, episodic and unpredictable. This is reflected in the present findings, including patterns of leave depletion, reliance on informal flexibility, pressure to remain in work despite ill health or caregiving demands, and difficulty sustaining employment over time.

Both Australian and international research demonstrate that the existence of legal protections does not guarantee effective outcomes in practice. Barriers such as low awareness of rights, complexity of legal frameworks, reliance on individuals to initiate processes, and limited access to timely advice all contribute to underutilisation of workplace protections.⁵⁹ These dynamics are evident in this study, where formal help seeking was low and workplace issues were typically resolved through informal negotiation. Evidence from case law further indicates that the fulfilment of workplace entitlements is inconsistent. While mechanisms such as unfair dismissal and discrimination protections are available, outcomes vary and processes can be difficult to navigate, particularly for individuals managing illness or caregiving.⁶⁰

The experiences of carers are also consistent with broader research, which shows that workplace frameworks tend to recognise caregiving only indirectly. While carers may access general leave entitlements or anti discrimination protections, these mechanisms do not adequately reflect the intensity, duration, and unpredictability of cancer-related caring.⁶¹ The findings are consistent with the 2024

National Carer Survey showing that over 20% of carers for someone with cancer experienced loss of work or income; 29.3% reduced their hours; and 31.7% stopped paid work temporarily or permanently due to caring commitments.⁶²

The findings also align with research showing that people in non standard forms of employment experience reduced access to workplace protections, including paid leave and job protected absence, increasing their vulnerability to income loss and workforce exit.⁶³ These impacts are not evenly distributed: groups disproportionately represented in insecure work and with fewer workplace protections also bear an unequal burden of cancer, including people living in the most socially disadvantaged areas of Australia, Aboriginal and Torres Strait Islander People and culturally and linguistically diverse people, with disparities compounded for people experiencing multiple forms of disadvantage or marginalisation.⁶⁴ The study also found that people often turn to health professionals for assistance with workplace matters. This is consistent with evidence that suggests that people are more likely to raise legal problems with health professionals than lawyers.⁶⁵

Taken together, this study both confirms and extends evidence. While workplace protections formally exist, they are not consistently accessible or effective in practice and are not well aligned with the realities of cancer and caregiving.

Implications

Workplace challenges experienced by people affected by cancer and caregiving reflect structural features of workplace systems and legal frameworks rather than isolated incidents. While formal protections exist, they are not consistently accessible or effective in practice, particularly during periods of illness or intensive caregiving. Current workplace models tend to assume stable, continuous employment and short-term absence, whereas cancer and caregiving are often prolonged, episodic, and unpredictable. As a result, the right to work and rights at work—including access to reasonable adjustments, fair conditions, and protection from discrimination—are not consistently realised. Workplace experiences also intersect with broader rights, including health and wellbeing, financial security, and the recognition of unpaid care.

System design and access barriers play a central role in shaping outcomes. Workplace rights are often under-recognised and underutilised, with low awareness, complexity, time constraints, and concerns about negative

consequences limiting their use. Enforcement mechanisms can be difficult to access during illness or caregiving, reducing the practical effect of legal protections, while reliance on employer discretion leads to inconsistent and inequitable outcomes. These challenges are particularly pronounced for carers and those in non-standard work arrangements, who face greater disruption and fewer formal supports. The study findings also show that people often turn to health professionals for support with legal issues. While health professionals are highly trained in clinical care, they are not typically formally trained or well versed in legal and financial issues, highlighting the importance of effective referral pathways and interdisciplinary partnerships.

Overall, workplace conditions are a key driver of financial hardship and distress, reinforcing the interconnected nature of employment, income, health, and care. Together, these findings point to the need for more consistent, accessible, and structured approaches that reduce reliance on individual negotiation and better align with the realities of cancer and caregiving.





Finding 5:

**Insurance and
superannuation
law emerge as
priority areas of
legal vulnerability**

'I remember a family saying once, "We prepared for this. We have income protection, both of us." She said, "So my husband's been able to get his income protection, but there's no such thing as income protection for being a carer". So, she lost her income because they had to relocate from regional Victoria to Melbourne, for an extended period of over 10 months. And she said, "We did everything right, we took out all this [insurance], but I could never access my income protection. So, despite everything we did, we went from two incomes to a single income at 80% of what his wage was, and we're then having to support our children at home and make sure they're fed up there and then support ourselves down here." This was a really good example of someone who got their finances in order in case something like this happened, but still struggled financially. And the only saving grace for them was that they were in accommodation with no cost... And that's not government funded accommodation; it was funded by a charity.

– Lori, social worker

Insurance and superannuation products and systems are a central source of legal vulnerability for people affected by cancer. Low awareness, loss of coverage, misalignment with chronic illness, and complex access pathways shift financial and legal risk onto individuals at the point of greatest need.

Insurance and superannuation issues are common and consequential

Survey data identified insurance-related problems as a commonly reported legal issue (14%), including:

- Travel insurance access (6%)
- Other insurance access (4%)
- Claims difficulties (4%)
- Delays in payouts (3%)
- Barriers to early superannuation access (3%)

Interview findings indicate that insurance and superannuation are not isolated issues but a central and interconnected area of legal vulnerability, with significant implications for financial security and wellbeing. In some circumstances, this extended to not only people with a cancer diagnosis, but to healthy family members as well.

Common issues include:

- Difficulty obtaining risk-rated insurance.
- Assistance to claim insurance (income protection, TPD, critical illness/death insurance benefit).
- Loss or lapse of insurance coverage.
- Challenges accessing early superannuation.
- Complex end-of-life super and insurance decisions.
- Administrative and identification barriers.

These issues often compound over time, particularly where awareness of entitlements is limited.

'I was advised to obtain life insurance (income protection, critical illness and TPD) outside of my superannuation because of a strong family history of breast and ovarian cancer and my mother testing positive for the gene change in the BRCA1 gene that increases the risk of these types of cancers. This proved very difficult even with an insurance broker. Despite being young and in good health, I was only able to secure this insurance cover by paying higher premiums until I underwent genetic testing which showed I had not inherited the gene change. Although my insurance premiums were lowered after that, but I was unable to recover the years of higher premiums I paid. It felt very unfair.'

– Priya, carer

Legal complexity, low awareness, and loss of cover create unexpected vulnerability

Insurance and superannuation frameworks were consistently described as complex and difficult to navigate.

Interview findings indicate low awareness of entitlements held through superannuation, including income protection, total and permanent disability (TPD), and death benefits. Many individuals only became aware of these after diagnosis or deterioration, while others discovered their cover had lapsed or was never in place.

This creates unexpected financial vulnerability, often revealed only at the point of illness when options are limited.

Structural changes have compounded this. The 2019 Protecting Your Super reforms restricted default insurance for:

- Members under 25;
- Low-balance accounts (<\$6,000); and
- Inactive accounts.

These changes resulted in the loss of default cover for millions of Australians,⁶⁶ particularly affecting younger people, many of whom may later face serious illness without insurance protection.

Laws and products are misaligned with the realities of cancer

A key source of vulnerability is the misalignment between insurance frameworks and the lived experience of cancer.

Insurance eligibility criteria often require total or permanent incapacity. This can exclude individuals who retain partial work capacity or who move between work and treatment.

'What we see is that a cancer diagnosis is no longer necessarily TPD. It's a chronic disease which is managed and requires a substantial disruption to work, no doubt, and perhaps a fluctuating work capacity. But what we don't have is flexibility in our TPD product to accommodate that.'

– Tom, superannuation and insurance lawyer

Income protection insurance attached to superannuation was repeatedly highlighted as an important financial product for people to have, despite limitations with how it operates.

[Income protection] can take 30, 60 to 90 days after you stop work due to illness. I've got a patient at the moment, he's got it and while it's been approved, they pay at the end of the month of the 60-day period. So, it's effectively three months until he's got income. That's a really long time.'

– Lori, social worker

Nonetheless, several interviewees stated that income protection insurance should be offered by all superannuation funds and should be an opt-out rather than opt-in product.

'Default cover is really important because for someone who is diagnosed with cancer, it will often be the only source of financial support that they have outside of the Disability Support Pension, which can be very difficult for people with cancer to obtain.'

– Tom, superannuation and insurance lawyer

'I don't know why [income protection insurance] is an opt out. It should be automatically attached to everyone's super, like the TPD and the life [insurance] is.'

– Lori, social worker

Interview findings also indicate gaps in support for carers. Income protection products are generally limited to the insured individual in the case of illness, meaning people who leave work to provide unpaid care often experience significant income loss as they are unable to rely on income protection insurance, even if they have it. Discussions with interviewees suggest that this is not well understood by the public.

The entitlements that are on offer through super and insurance are really geared towards people who have a diagnosis, and predominantly around their work being impacted or their life expectancy being impacted... There are some entitlements, for example, early access to super for people who are carers, but they aren't so much income based, but rather there's a capacity to access super early to fund palliative care for a dependent, for example, or pay for funerals. Often times carers aren't able to access super early.'

– Tom, superannuation and insurance lawyer

Superannuation law also reflects narrow assumptions about family and dependency. Death benefit rules rely on restrictive statutory definitions of “dependant”, limiting distributions to spouses, children, interdependent relationships or legal representatives. This can exclude non-traditional family structures, including blended families, chosen family networks, and culturally diverse kinship systems and is a rule that disproportionately disadvantages single people.

Where binding death benefit nominations are absent, lapsed, revoked or invalid, trustees retain discretion over distribution, which may not reflect an individual's intentions and preferences. Interview findings indicate that many people are unaware of

these rules or do not maintain valid nominations (particularly those that are lapsing and must be renewed), increasing the likelihood of outcomes that differ from their wishes and that could create conflict amongst surviving loved ones.

Claims processes are complex and depend on support

Claims processes for insurance and superannuation were described as administratively complex, time-consuming, and poorly aligned with illness, with one participant describing the process as “soul destroying”.

Interview participants reported:

- Not knowing what to expect when making claims.
- Repeated requests for documentation.
- Long delays.
- A lack of transparency.
- Difficulty managing processes alongside treatment or caregiving.

Access to entitlements often depended on specialist support. Individuals who successfully navigated claims frequently did so with assistance from lawyers, financial counsellors, or integrated services within health settings. Those without such support were more likely to experience delays, unsuccessful claims, or missed entitlements.

This reflects a system that relies on persistence and external support rather than being accessible by design.

Gaps in accountability increase inconsistency

Interview findings highlight inconsistencies in regulatory and accountability frameworks.

While insurers operate under formal codes of practice, no equivalent framework governs superannuation trustees. This creates variability amongst superannuation funds in:

- Decision-making
- Communication
- Timeframes
- Transparency.

‘Some super companies are lovely and really helpful, but then others say, well, if you want early release of your super, you’ve got to go to the ATO [Australian Tax Office].’

– Fiona, social worker

The interaction between insurance and superannuation systems further contributes to complexity, particularly for people navigating both simultaneously.

‘Let’s say you do a TPD claim, the insurer’s got to assess the claim, they’ve got the Life Insurance Code time frames, they’ve got a structure that they have to work within. It’s not binding, but it means something, the reporting of them against it. But then there’s still an involvement of a super fund before the insurer gets the claim and after, particularly for death claims where the insurance benefit might be paid. And then we’ve got to work out which of my dependents, for example, get paid the benefit. And so [at the moment] super funds have no time frames, no structure, no code of conduct when dealing with those or other similar claims. Lots of super funds could do a lot better.’

– Tom, superannuation and insurance lawyer

System design produces inequity and distress

These combined features — limited coverage, complex rules, and reliance on individual navigation and poor governance — produce unequal outcomes. Access to benefits depends heavily on coverage, prior knowledge and access to professional support.

As a result, younger people, carers, casual workers, and those with lower financial or legal capability are disproportionately affected.

Interview findings also indicate that navigating these systems is highly distressing. Participants reported fatigue, anxiety, and disengagement, with some abandoning claims processes due to administrative and emotional burden.

Findings in context

These findings align with a substantial body of research demonstrating persistent barriers in access to insurance and superannuation for people affected by cancer.

Research by the McCabe Centre and Cancer Council Australia has shown that people with cancer frequently face difficulties obtaining risk-rated insurance, including life and travel insurance, even after treatment or during remission. While anti-discrimination laws apply, the Disability Discrimination Act 1992 (Cth) contains an exception allowing insurers to rely on actuarial or statistical data to justify exclusions or refusal of cover, which can result in limited access in practice⁶⁷

Recent reforms have begun to address some forms of this discrimination. The Treasury Laws Amendment (Genetic Testing Protections in Life Insurance and Other Measures Act) 2025 (Cth) prohibits life insurers from using adverse genetic test results in underwriting from October 2026, reducing barriers to genetic testing and early detection. However, these protections do not extend to all insurance products, including travel insurance.

More broadly, research highlights that access to insurance and superannuation is shaped by structural factors including insurance underwriting practices, regulatory settings, and system complexity. Individuals affected by cancer often experience higher insurance premiums, exclusions, or denial of insurance coverage, alongside complex claims processes and low awareness of entitlements.⁶⁸

Numerous Australian Financial Complaints Authority (AFCA) determinations involving people with cancer reveal concerns with financial products—particularly insurance claims—and how financial institutions respond to serious illness.⁶⁹ For example AFCA has determined that:⁷⁰

- A major bank failed to meet its hardship and vulnerability obligations, caused extreme stress, inconvenience and disappointment to the complainant couple — one of whom was off work for six months without income due to cancer requiring urgent treatment — and inaccurately reporting adverse home loan repayment history information on the complainants' credit files.
- An insurer failed to properly investigate whether the complainant's melanoma met their policy's cancer definition by choosing to rely on the informal opinions of its in-house doctors rather than asking relevant questions of the complainant's treating doctors.
- An insurer misled a complainant by cancelling a life and repayment cover policy connected to a closed home loan account after repeatedly assuring them that the cover would remain in force, continuing to deduct premiums and issue renewal notices, leaving the complainant financially exposed when subsequently diagnosed with cancer and unable to obtain alternative insurance.

Collectively, these matters point to systemic challenges in accessing financial support, navigating complex policy terms, and effectively engaging with financial providers such as banks and insurers.

These determinations show that people with cancer often experience significant financial hardship, as insurance claims are frequently denied due to strict requirements around disclosure, pre existing conditions, and timing of diagnosis — even where the illness was unforeseen. They also highlight how narrow and technical definitions of “cancer” in insurance policies can exclude individuals with genuine illness, particularly where diagnosis timing, staging, or clinical criteria are not met.⁷¹ As a result, many face sudden loss of income and inadequate financial support and broader financial vulnerability despite the severity of their condition.

The dispute resolution pathway offered by AFCA itself also present challenges. Interview findings and Cancer Council Victoria service data indicate that the process can be stressful and difficult to navigate, despite being intended to be an accessible dispute resolution system. Outcomes are often determined by technical policy interpretation and evidentiary requirements, and the process is frequently engaged only after significant harm has occurred. Participants reported difficulty sustaining engagement with complaints processes while managing illness.

Taken together, this evidence indicates that insurance and superannuation systems are shaped by legal, regulatory, and structural factors that limit accessibility and responsiveness to illness, contributing to the vulnerabilities identified in this study.

Implications

Insurance and superannuation systems are not functioning as effective safety nets for people affected by cancer but instead operate as significant sites of legal and financial vulnerability. Risk is frequently shifted onto individuals through complex rules, eligibility criteria, and administrative burden at the point of illness, while gaps in coverage—often driven by loss of default insurance and low awareness of entitlements—leave many without protection when it is most needed. Existing legal and product frameworks are not well aligned with the realities of cancer and caregiving, particularly in relation to fluctuating capacity and the roles of carers, while superannuation rules do not always reflect contemporary relationships or individual preferences. Changes to superannuation laws that removed default insurance coverage which have disproportionately impacted younger people is a concern given the rise of early onset cancers.

System design further limits accessibility and fairness. Access to benefits often depends on the availability of specialist support rather than being embedded in the system itself, and inconsistencies in accountability and oversight contribute to variability and reduced transparency. These challenges disproportionately affect younger people, carers, and those with fewer resources, reinforcing inequities in who can successfully access support. Together, these findings highlight the need for more accessible, transparent, and responsive insurance and superannuation systems that better align with the realities of cancer and caregiving.



Finding 6:

**Cancer-related costs
undermine the right
to health**



‘So, from a financial perspective, and this feels like it’s growing because of the cost of living and the cost of petrol, we’ve got a lot of people who are saying, “Well, I can’t afford to get to treatment. How can you help us financially?” And there’s really very few pools of money we can tap into. For some tumour stream specific areas, there are options that we can try, but for others there is nothing at all. And it’s quite surprising when there’s a lot of funds going into certain streams of cancer that there isn’t a little bit of money put aside to actually help you with finances.’

– Fiona, social worker

Cancer and caring impose significant direct and indirect costs, often without clear or timely financial information. These costs are widespread, difficult to anticipate, and extend beyond medical care to include income disruption, household expenditure, and long-term impacts. As a result, financial pressures can influence treatment decisions and access to care, raising important questions about equity and the realisation of the right to health.

Financial costs are widespread and substantial

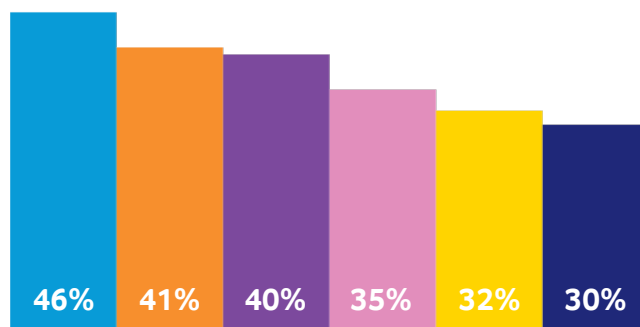
All people with cancer surveyed reported incurring out-of-pocket costs despite high levels of Medicare coverage (89%) and significant use of the public system (46% were treated in the public health system, 37% in the private system and 17% in both the public and private system).

‘Specialists charge whatever they want and a lot of this cannot be claimed back using private health insurance.’

– Survey respondent with cancer

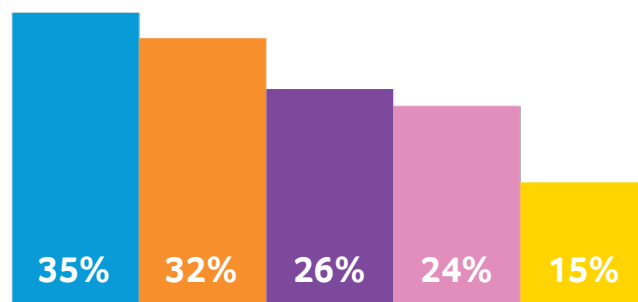
Common costs for people with cancer surveyed are shown in Figure 6. Additional costs included allied health, food, specialised items, and complementary therapies.

Figure 6:
Common costs reported by Victorians with cancer surveyed



- Travel to appointments (46%)
- Treatment and reconstructive surgery (41%)
- Hospital parking (40%)
- Diagnostics (35%)
- Medication (32%)
- Loss of income (30%)

Figure 7:
Common costs reported by Victorian carer of people with cancer surveyed



- Increased household costs (35%)
- Loss of income (32%)
- Additional caring-related expenses (26%)
- Travel and accommodation (24%)
- Workforce exit (15%)

Interview findings reinforce that these costs extend well beyond clinical care. Participants described a wide range of direct and indirect expenses, as well as ongoing costs associated with long-term side effects and survivorship, including dental care, chronic pain, and specialist follow-up.

‘The unexpected and biggest ongoing side effects [of his throat cancer] amongst many and what is a huge cost that has been going on since 2010, is that his gums and teeth are basically wrecked. We don’t have private health insurance, we can’t afford it. We can’t afford dentures either. And he’s just really lucky that he’s got a good dentist, she’s so kind, she doesn’t charge him. It’s so sad and disappointing that they shut down the Chronic Disease Dental Scheme because he did have that for a couple of years. And it was exactly designed for someone like him, which really helped. And there’s nothing now. There’s nothing for me. And it’s a human right, isn’t it, to be able to eat?’

– Jacinta, carer

These findings indicate that financial costs are not incidental, but a routine and significant feature of the cancer experience that profoundly impacts people’s lives and the quality of their lives.

Costs are cumulative, long-term, and shaped by many factors

Financial burden accumulates across the cancer pathway, from diagnosis through treatment which involves several hospital visits, survivorship, and in some cases, end-of-life bereavement.

‘My expenses have been at least \$10,300 in just over two years.’

– Neroli, having cancer treatment

‘Parking at most hospitals, it’s very pricey’

– Jacinta, carer

‘I do think that there’s a lot of appointments that people probably change or miss because they can’t miss another day of work or they just don’t have the funds to get in a taxi, they don’t have the capacity to drive their own car, that type of thing.’

– Aboriginal Health Practitioner

Loss of income emerged as a major driver of financial impact. Participants described reduced work hours, extended leave, and workforce exit, with long-term consequences for financial stability, career progression, and superannuation. Interview findings also indicate that costs are unevenly distributed. Greater burden was reported among those experiencing one or more of the following factors, with impacts often compounded where multiple factors intersected:

- Advanced or rare cancers
- Caring responsibilities (particularly women)
- Living in regional areas
- Lack of access to Medicare
- Aboriginal and Torres Strait Islander identity
- Housing instability.

‘You either have a family where the entire family relocate to Melbourne, or the children will stay home to be looked after by grandparents or other family. And then they’re having to service two pantries, so to speak, as well as facilitate the travel to visit home in between cycles.’

– Lori, social worker

‘We get a lot of questions about clinical trials for treatments that are not on the [Pharmaceutical Benefits Scheme] (PBS) for a person’s tumour stage or diagnosis. That’s always a really difficult conversation because they’ve been told by medical oncologists that there is a treatment out there that may potentially help them, they’ve seen results, however, it hasn’t hit the PBS yet. It’s really hard for them to reconcile that there is a treatment that may help, but they have to pay for it. It varies, but it’s thousands per cycle but there is no financial assistance in that situation... There’s a large number of Medicare ineligible patients that will call up as well, families of patients who live overseas wondering how they can access funds to pay for people to have treatment here, which we usually refer to PeterMac, they have a specific Medicare ineligible service. It’s still a paid service.’

– Rebecca, Cancer Council Cancer Connect and hospital cancer nurse

For regional participants, repeated travel, accommodation costs, and time away from work and family added substantial burden, with some describing the health system as “city-centric”. These pressures, in some cases, influenced decisions about treatment.

'Because my partner had a rare cancer, we literally couldn't have any treatment locally, so that required us to travel. So obviously, there was the impact of having to be away from work and organising after-school care for the kids if we weren't going to be back in time. When he had treatment, we were gone for four days and three nights, so we had to fund the motel. You're away from home so you're paying for meals and you've got to eat three meals a day. If there weren't laundry facilities, then you start incurring the cost of laundry... And I had several trips down to Melbourne to PeterMac to collect medications that they wanted him to take that I could not get in my local community. So, there were all these additional costs because that we had to incur because he couldn't be treated locally. And now I'm seeing the impacts longer term, even though he's been gone five years. Obviously, you have a percentage of your wages going into superannuation and that adds up [that you lose when not working]. That's a long-term impact that most people don't think about.'

– Tracey, carer

Cost information is unclear and informed financial consent is limited

Out-of-pocket costs were often unexpected or poorly understood among people with cancer and carers.

Overall,

55%

of both groups surveyed reported that costs were either different from what they had anticipated or that they did not know what to expect.

30%

of people with cancer reported higher than expected out-of-pocket costs, while 18% said they had no knowledge of what costs to expect.

20%

of carers reported higher than expected out-of-pocket costs and 29% indicated they did not know what out-of-pocket costs to expect.

'You either have a family where the entire family relocate to Melbourne, or the children will stay home to be looked after by grandparents or other family. And then they're having to service two pantries, so to speak, as well as facilitate the travel to visit home in between cycles.'

– Lori, social worker

Interview findings consistently highlight limited transparency around costs at the point of treatment decision-making. Confusion about what expenses are covered under the public and private health systems is common. Even where care was described as “covered”, this often excluded significant out-of-pocket expenses.

Collectively, participants described:

- Unclear explanations of downstream costs.
- Limited ability to anticipate total expenditure.
- Being required to make decisions under time pressure and emotional distress.
- A clearer understanding of costs well after treatment instead of before it.

‘My wish is for patients to be informed. Nobody explained anything. Nobody told us about costs. Nobody advertises their costs. But everything else in life, you get a quote. The whole process has fear built into it and has quite a lot of complexity built into it, even though it is one of the better systems in the world.’

– Naveena, breast cancer survivor

‘When you sign a form, when you’ve got all these things going through your head, it says there could be other costs incurred during this procedure. You just don’t expect to get a nearly \$2,000 bill for a pathology. So, I guess whilst there was that little clause, you don’t feel like it was explained to you in advance, the kind of costs that would flow. And what sort of costs they were and what was needed, not at all. So, you weren’t made aware of what was needed.’

– Neroli, having cancer treatment

This environment of poor cost transparency reduced capacity to ask questions or consider financial implications. Some participants reported they would have made different treatment decisions had costs been clearly explained earlier. These findings indicate that meaningful informed financial consent is often absent or incomplete, with cost implications emerging only after decisions have been made.

‘I used private health insurance. I thought this is why you have it. And I knew it would be quicker. The surgeon said to me ‘I work both private and public. But I can get in next week for private’. He said, ‘I need to do this soon’ and ‘the costings, it will be messy’. But he didn’t give a dollar figure or estimate. And I thought ‘okay, let’s just do it’. And in hindsight, I could have had a breath. I could have waited a couple of weeks. You know, it doesn’t have to happen straight away. And I found this all out afterwards. I could have had a breath. I could have spoken to a breast care nurse and really had an in-depth conversation... but I felt really rushed and it didn’t need to be.’

– Neroli, having cancer treatment

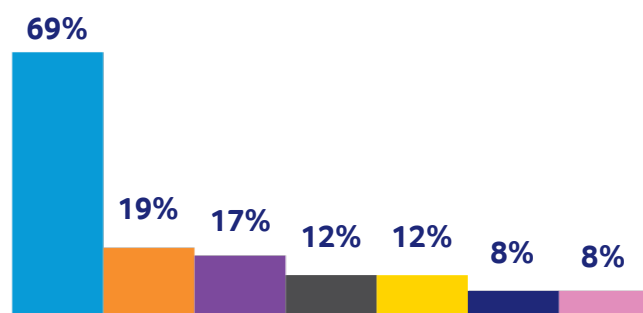
'I realised later that if my radiation oncologist had kept me in the private system, I would have paid for radiation, and it is not covered by health insurance. I found that out after I finished all my treatment and went to a focus group a couple of years later and these women around the table were telling me they're getting \$20,000 bills because radiation was through the private system.'

– Naveena, breast cancer survivor

People rely on personal sacrifice to manage costs

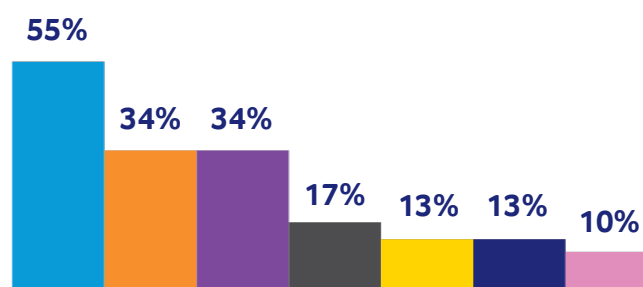
Costs were primarily managed through personal financial sacrifice. Both people with cancer and carers surveyed relied heavily on savings, staying in work or returning to work earlier than preferred and cutting back on spending (including on essential items) and selling assets such as cars, clothes and other items. Some surveyed carers reported delaying healthcare or not buying or reducing medication that they or someone else in their household needed as a cost saving measure.

Figure 8:
Main ways in which Victorians with cancer manage cancer-related costs



- Using savings (69%)
- Spending less on non-essential items (19%)
- Working during treatment or returning to work earlier than preferred (17%)
- Buying less food and groceries (12%)
- Centrelink payments (12%)
- Someone else in the household worked more (8%)
- Selling assets (8%)

Figure 9:
Main ways in which Victorians caring for someone with cancer manage costs associated with unpaid cancer caring



- Using savings (55%)
- Spending less on non-essential items (34%)
- Working when they would have preferred to focus on caring because of costs (34%)
- Buying less food and groceries (17%)
- Having someone in their household work more (13%)
- Delayed/foregone treatment or reduced medication that they or someone else in their household needed due to cost (13%)
- Selling assets (10%)

Use of formal supports — such as financial assistance, hardship arrangements, or external support services such as charities—was limited across both survey groups but important. In interviews, charities that assist in funding accommodation for certain cancer types were reported as invaluable in ensuring people undergo treatment, despite some limitations in the support such charities could offer — for example, a lack of options for those needing short-term stays.

‘We’re very fortunate that we have places like Leukaemia Foundation that will provide fully funded accommodation.’

— Lori, social worker

Interview findings indicate that coping strategies were often fragile and dependent on existing resources such as savings, stable employment, or support networks. Individuals with higher financial literacy or advocacy capacity and access to professionals such as social workers were better able to access support early.

‘I’m just lucky, lucky that all I had to forego was a holiday, not a gas bill or an electricity bill.’

— Neroli, having cancer treatment

‘We’ve been lucky that we’ve had enough saved to have some of my husband’s treatment privately’

— Carer survey respondent

‘I had to rely on community service organisations to help me with funds and bills.’

— Survey respondent with cancer

Where these resources were absent, financial distress intensified, leading to delayed care, avoided services, or worsening hardship.

Costs create inequity and can affect care

The financial burden of cancer and caring was unevenly distributed. Interview participants identified key factors shaping impact:

- Cancer type and stage
- Income and savings
- Employment security
- Geographic location
- Access to support networks
- Life stage.

Interview findings indicate that costs can directly influence care, with some participants reporting:

- Delaying or avoiding appointments.
- Foregoing supportive care.
- Making treatment decisions based on cost or travel burden.

For regional participants, travel requirements and associated costs were a significant barrier to ongoing treatment. The financial impact of cancer also differs for people who are single or living alone. Without access to a partner’s income or shared household resources, single people may be less able to absorb income loss and unexpected expenses, increasing their exposure to financial risk.

‘Towards the end, my partner was so unwell that just the thought of a two-and-a-half-hour trip to Melbourne was the deciding factor in stopping all treatment. The sad thing is when we live in regions, we have to make life altering decisions based around our eligibility to get treatments and it then becomes a financial, physical and emotional burden on people...Health and finances would be improved by having more treatment options closer to home.’

– Tracey, carer

‘The doctor said, there is a treatment, but every treatment cycle costs \$2000 and so that was out of reach because my father was a public patient...ultimately it was his decision to go with palliative care...but I thought about privilege and non-privilege, equity and inequity. And it’s just really unfair that the ones that can basically buy time and buy life can, because they have money.’

– Sofia, carer

These findings indicate that cancer-related costs are not only a financial issue but an equity issue. Where access to care is influenced by financial capacity, there is a risk that treatment decisions are shaped by cost rather than clinical need.

System design contributes to avoidable financial harm

Interview findings indicate that financial burden is shaped not only by illness, but by system design. Participants described:

- Fragmented care pathways
- Limited cost transparency
- Difficulty identifying available supports
- Heavy reliance on individual navigation and advocacy.

Many described moving through treatment without a clear understanding of future costs, with financial consequences emerging retrospectively.

Interview participants identified several areas for reform, including:

- Reducing medicine costs and improving PBS access.
- Reducing other direct costs such as specialist fees, pathology, scans etc.
- Addressing travel and accommodation burdens.
- Redesigning support schemes to reduce upfront costs.
- Improving access to survivorship and long-term care.

There was also a strong emphasis on the need for:

- Earlier and clearer cost discussions.
- Repeated conversations over time.
- Embedded financial navigation support within cancer care.

Interview findings indicate that information alone is insufficient. Participants highlighted the importance of integrated support, including social workers, financial counsellors, and services such as Centrelink within healthcare settings, to assist with navigating complex systems.

Findings in context

These findings align with a growing body of Australian evidence identifying “financial toxicity” as a significant and increasingly recognised impact of cancer,⁷² and an experience that is worse for some, including those who live in regional and remote areas.⁷³

This research is consistent with 2025 data from Cancer Council Australia showing that out-of-pocket costs are a near universal experience for people with cancer, alongside substantial income loss.⁷⁴ It affirms previous research showing that costs of cancer and financial toxicity can shape treatment and care decisions,⁷⁵ vary depending on cancer type and stage,⁷⁶ and have lasting impacts on financial wellbeing, as individuals draw on savings, take on additional debt, or access superannuation to cover medical and everyday expenses — leaving them in a worse financial position even after treatment has ended.⁷⁷

These findings add to existing research by providing detailed insight into how financial harm occurs in practice, including the role of limited cost transparency, weak informed financial consent, and fragmented support systems in shaping financial outcomes. Consistent with previous research, the poor obtaining of informed financial consent observed in this study suggests that greater workforce capability is needed to support discussions about the costs of cancer and financial concerns. Research has found that while healthcare professionals often recognise the importance of discussing costs with patients, they may be constrained by limited training, confidence and available support services, highlighting the need for cancer-specific financial counselling, advocacy and workforce development.⁷⁸

These research insights confirm prior research indicating that people with cancer often feel they have little control over where they receive care and the costs associated with that care. They also suggest that many people mistakenly believe that all expenses related to their cancer treatment and care will be covered by their private health insurance or the public healthcare system.⁷⁹ When this is not the case it can result in significant financial burden and stress, heightening the emotional, physical, and practical challenges of cancer treatment.⁸⁰

More broadly, research demonstrates that health system design plays a critical role in shaping affordability. Where costs are unclear, where support is difficult to access, and where individuals must navigate complex pathways during periods of illness, financial harm becomes a predictable outcome rather than an isolated risk.

As noted earlier in the report, for many survey respondents, cancer and caring was experienced alongside unprecedented social and economic disruptions associated with the COVID-19 pandemic. Financial hardship increased substantially among Victorian adults during and following the COVID-19 pandemic, with the proportion experiencing at least one form of financial hardship rising from 23.5% in 2020 to 38.5% in 2022.⁸¹ Cancer Council Victoria’s Cancer, COVID-19 and You report found that the pandemic compounded existing financial distress among people affected by cancer, with 36% of people with cancer reporting changes to their income, almost half reporting higher-than-expected out-of-pocket costs, and around one-third experiencing difficulty paying for cancer-related medicines, services and transport. Financial distress was reported to be highest during lockdown periods. Carers also experienced income disruption, reduced workforce participation, uncertainty regarding eligibility for government supports and difficulties accessing information about available assistance.⁸² Consequently, the financial hardship reported by some participants may reflect the combined effects of cancer-related costs and broader pandemic-related economic challenges, including employment instability, income loss, reduced working hours and increased household financial pressures.

Nonetheless, taken together, this evidence indicates that cancer-related financial burden reflects both the cost of illness and the way health and associated systems are structured. In this context, affordability is not only a matter of individual capacity, but a core component of equitable access to care.

Implications

Cancer-related costs represent a systemic challenge that extends beyond financial burden to affect equity, access to care, and the realisation of the right to health. Although often described as “financial toxicity,” these impacts also reflect gaps in achieving equitable and affordable healthcare in practice. The findings indicate that costs are frequently opaque and unpredictable, limiting informed decision-making, while the financial burden extends beyond treatment to include income loss, household expenses, and long-term impacts across the cancer pathway. As a result, individuals and families often bear primary responsibility for managing costs. This highlights that universal health coverage — that all people have access to the quality health services they need, when and where they need them, without financial hardship⁸³ — is far from being achieved, despite being a goal that Australia has repeatedly committed to realising and the practical realisation of the right to health.⁸⁴

Health system design plays a significant role in shaping these outcomes. Financial pressures can influence treatment decisions, delay care, and reduce engagement with services, while fragmented pathways and limited navigation support increase overall burden. These impacts are not evenly distributed: people with fewer financial resources, those in regional areas, and carers face greater challenges, with costs often extending across households and over time. Where affordability constrains access to care, broader human rights considerations arise, particularly in relation to the right to health.

The findings also highlight that financial challenges experienced by people affected by cancer do not occur in isolation. These challenges may be amplified during periods of broader social and economic disruption, such as public health emergencies. The COVID-19 pandemic demonstrates how external crises can exacerbate existing vulnerabilities, increasing the risk of financial hardship and related legal problems and barriers to accessing support for people living with cancer and their carers.

Together, these findings point to the need for reform to drive down the out-of-pocket costs of cancer as well as more transparent and meaningful cost discussions, coordinated, and accessible approaches to managing cancer-related costs, including stronger integration of financial support within healthcare systems. Achieving this will require investment in cancer-specific financial counselling and navigation services, alongside training and capability-building for healthcare professionals to support informed financial consent and conversations about the costs of care.



Finding 7:

**Financial hardship
is widespread and
reflects under access
to social security
protections**

'I spoke to a gentleman who had a prostate cancer. He is self-employed. He is right about 60, has never applied for Centrelink in his life. He's going to be out of work for six to eight weeks. He has no insurance, no super, so he can't fall back on any of those. He now needs to apply for Centrelink because he's a self-employed tradie-type person. He has to apply and then provide evidence of his business as well, in terms of the financial assessment to apply for services. He's behind with his taxes for three years, so he needs to get those up to date before he can even really apply. And by the time he's done all of that, he'll probably have had his surgery and then be back at work. So, he has no way of paying his mortgage, no way of paying his bills other than the tiny little bit of savings he's got. So, we've had to kind of work with him to decrease his outgoings where we can. And then I've referred him to the Cancer Council Victoria Financial Counselling service. He's going to our Centrelink clinic next Wednesday. So, he's going through all the processes, but I don't think that's going to be fast enough for him. So, sometimes the consideration is: Is there any way of expediting people's claims? And same with the Disability Support Pension — is there any way people could be put on that as a short-term measure rather than having to wait until they're fully treated?'

— Fiona, social worker

Survey and interview findings show that financial hardship is a common and distressing consequence of cancer and caregiving. Despite significant financial need, access to income support and related protections is limited and often difficult to obtain. This indicates that financial hardship reflects not only the impacts of illness but also gaps in the design and accessibility of social security systems.

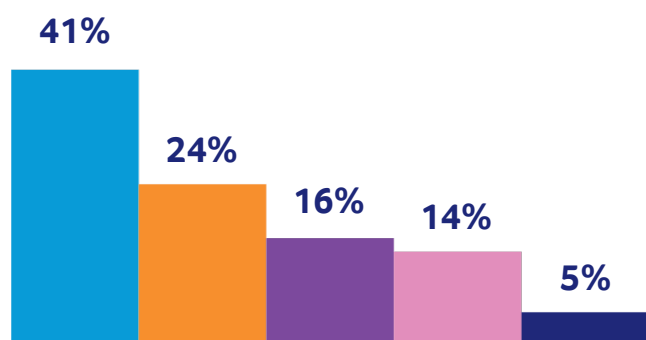
Financial hardship is common and highly distressing

36% of people with cancer and **30%** of carers surveyed reported that their financial circumstances had worsened following a cancer diagnosis or their caring responsibilities.

Among those affected, levels of distress were extremely high, with

95% of people with cancer and **97%** of carers reporting distress.

Figure 10:
Distress reported by Victorians with cancer who experienced a worsening financial situation after diagnosis

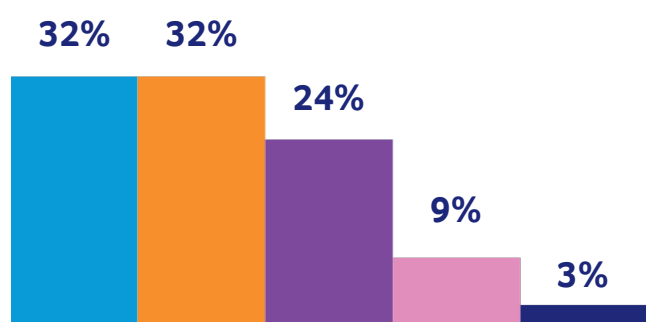


- A little distress (41%)
- Some distress (24%)
- A lot of distress (16%)
- Extreme distress (14%)
- No distress (5%)

Interview findings reinforce that financial strain compounds the broader burden of illness and caregiving. Participants described financial hardship as cumulative and interwoven with emotional, physical, and practical pressures. These impacts also vary depending on household structure. People who are single or living alone may have no access to shared income or informal financial support, increasing their vulnerability to financial hardship when income is disrupted. In contrast to assumptions embedded in some policy settings, financial resilience cannot be assumed in the absence of a partner or broader support network.

These findings indicate that financial hardship is not only an economic issue, but a significant contributor to distress within the cancer experience.

Figure 11:
Distress reported by Victorian carers who experienced a worsening financial situation due to caring responsibilities



- A little distress (32%)
- Some distress (32%)
- A lot of distress (24%)
- Extreme distress (9%)
- No distress (3%)

Government financial support is limited and difficult to access

Social security options for people affected by cancer (benefits, pensions and other payments)

- Centrelink provides a range of payments relevant to people affected by cancer, including the Disability Support Pension, JobSeeker, Carer Payment and Carer Allowance etc.
- The Disability Support Pension is an income support payment for individuals who are unable to work due to an illness, injury or disability that is long-term (more than 2 years) that stops you from working. It has strict medical and non-medical eligibility criteria.
- JobSeeker is an income support payment if you are sick or injured and unable to do your usual work for a short time. It pays less than the Disability Support Pension (DSP).
- The rules for Centrelink payments are very complicated and there are different tests for different types of payments.
- If eligible, the type of payment and how much you get depends on your circumstances.
- Centrelink uses two tests to decide if you can get a payment, and how much that payment will be. The tests include an income test (how much you earn) and an asset test (how much you own). If you have a partner, Centrelink also looks at your partner's income and assets.
- If you receive a benefit or pension, you may also be able to get Rent Assistance.
- The DSP, JobSeeker payment, Carer Payment, Carer Allowance and Rent Assistance have been criticised for being too low to meet basic needs and leave many people in poverty.⁸⁵

Despite widespread need, uptake of government support was low:

64%

of people with cancer

78%

of carers

surveyed reported no government financial support.

Few survey respondents accessed specific payments or concessions, and no single payment was reported by more than a small proportion of participants:

Fewer than 15% of people with cancer reported receiving any specific form of Commonwealth support, with the most reported being the Commonwealth Health Care Card (14%), Age Pension (8%) and Disability Support Pension (8%). Access to JobKeeper was lower again at 4%.

No single payment, allowance or concession was reported by more than 10% of carer respondents, with the most common being the Low-Income Health Care Card (10%), Carer Allowance (8%) and Carer Payment (7%). No survey respondents reported accessing Victorian Government supports such as the Private Rental Assistance Program or the Victorian Patient Transport Assistance Scheme (VPTAS).

Where support was accessed, it was often difficult to obtain.

33%

of people with cancer

43%

of carers

surveyed reported difficulty accessing government support.

Interviewees reported that many people affected by cancer are unaware of available support programs.

‘Many people don’t know that they can apply for Carers Allowance and Carer Payment. But the forms are not easy to complete. And it also means talking to a GP and the GP completing a Centrelink form. Sometimes the GPs don’t know exactly how the forms work and the application may be rejected, and you may need to go back to the GP to complete a whole new report. It can get really complicated and you don’t need that additional stress.’

– Sofia, carer

Some people affected by cancer acknowledged that their own awareness of these supports was due to their professional roles within the health and community services sectors. Interviewees highlighted the importance of financial counsellors and social workers in helping people identify available government supports.

‘You’re advocating to make sure people get the best sort of financial payment because otherwise they’re going to be really in dire straits’

– Lori, social worker

Eligibility settings are poorly aligned with illness and caring realities

Interview findings indicate that eligibility criteria and payment structures are not well aligned with cancer and caregiving.

Participants described:

- Restrictive eligibility thresholds.
- Requirements that do not reflect fluctuating illness.
- High thresholds of need required by the person with cancer for carers to be eligible for benefits.
- Significant gaps between income support and actual income loss.

‘I don’t really feel like government payments consider cultural kinship, anything like that...Centrelink don’t have any type of Aboriginal support. It actually says it does, but it really doesn’t. The amount of times that I have contacted Centrelink on behalf of patients and they just sit there on the line for I don’t even know how long. And they say they offer all this support. And it’s really just a tick box. It’s a tokenistic thing that isn’t really supportive.’

– Aboriginal Health Practitioner

'I feel like with cancer, it falls through the cracks. A lot of people think even if they're going to be pretty incapacitated for a couple of years, which is what the time frame is for Disability Support Pension, they'll be able to get it. But because they're still under treatment, they're not eligible. I just feel with cancer, they need to look at it differently, with all the impacts of treatment and ongoing or permanent effects. Some kind of cancer payment would be really good.'

—Jacinta, carer

The Disability Support Pension, commonly referred to as the DSP, was identified as a key area of concern. While it is intended to provide greater financial security for people unable to work due to disability, its eligibility framework does not align well with cancer. Access requires applicants to meet specific impairment thresholds and demonstrate that their condition is “diagnosed, reasonably treated and stabilised”. Interview findings indicate that this requirement remains difficult to satisfy in the context of cancer, which often involves ongoing treatment, fluctuating functional impacts, and uncertain prognosis.

As a result, many people with cancer who are unable to work do not meet DSP criteria and are instead directed to lower-rate payments such as JobSeeker. Participants and professionals described this as a significant gap, noting that these payments provide substantially less financial support and may include requirements — such as mutual obligations — with exemption processes to meet during treatment or recovery. Even where people are successful in obtaining JobSeeker payment, it was described as “not even close to a liveable wage”.

Participants also highlighted broader challenges with income and asset tests. In practice, eligibility settings often assume that financial need can be met within households — for example, where a partner remains in paid work — even where combined income is insufficient to absorb treatment costs and loss of earnings. Interview findings indicate that this can create what participants described as “perverse incentives”, requiring households to exhaust leave, reduce work, or experience significant hardship before qualifying for support.

'At the time of my husband's first diagnosis, he was not at age pension age. He was self-employed, he didn't have income protection or anything like that. He was not eligible for any sickness allowance or anything like that. He couldn't walk very far but wasn't even eligible for disabled parking. He wasn't eligible for anything, really. It was so disappointing. And then this time around, he is nearly 70 now. And again, he's not eligible for the Age Pension because I'm a full-time employee. So basically, he can't really work now because he has ongoing and permanent side effects from both the cancers. And in the end, all that he's been eligible for is the Commonwealth Seniors [Health] Concession Card. It'd be great if there was some sort of a temporary Centrelink payment or even just a small allowance. And thankfully, because both times we went to PeterMac [as a public patient], we didn't have to pay for treatment.'

—Jacinta, carer

Income support settings were also described as poorly aligned with the realities of caregiving. Many carers reported that available payments, such as the Carer Payment and Carer Allowance, require a high threshold of care and Carer Payment may require carers to reduce participation in paid work. In practice, this all creates a gap for those providing substantial care while attempting to maintain employment, or where caring responsibilities fluctuate over time.

Participants also described the “all or nothing” nature of support, where carers may not qualify for meaningful assistance until they have already reduced work or experienced significant financial strain. This creates difficult trade offs, requiring carers to choose between maintaining income and meeting caring responsibilities. In many cases, support was seen as both insufficient in amount and too restrictive in eligibility to provide effective financial protection.

Social workers and financial counsellors also observed that many people are surprised to learn that social security functions as income support rather than income replacement, leaving households exposed to a sharp and often unexpected drop in living standards.

‘Centrelink benefits, we need to be more honest about what they are...We have to ask ourselves, is Centrelink a safety net? And for some people it can be. But it’s so complicated now. The cost of housing is such a huge issue in society that if you’re on Centrelink and, say you get Rent Assistance, Rent Assistance doesn’t cover rent. It doesn’t even purport to cover rent.’

– Graeme, Cancer Council Victoria financial counsellor

‘A lot of people have an expectation that Centrelink is like an income replacement. And I explain it’s more like a welfare net. And your outgoings; your costs, your mortgage, and other expenses are completely irrelevant. It’s only assessed on what your incoming [income] is. So that can be a big shock to a lot of people.’

– Lori, social worker

Taken together, these findings suggest that current eligibility and assessment frameworks are not well adapted to the episodic, non-linear, and financially disruptive nature of cancer and caregiving, and the realities of fluctuating work and income. Nor are the adequacy of social security benefits.

‘No one should have to choose in this country to die so that they can leave their family financially secure. That should not happen here in Australia, but it is, and that’s the sad fact of it. And the government needs to start looking after our sick people.’

– Tracey, carer

Administrative burden prevents access to support

Even where eligibility exists, administrative complexity limits access.

Participants described:

- Extensive paperwork
- Forms that are unclear and confusing
- Repeated medical evidence requirements
- Long delays and difficulty contacting services
- Processes that are difficult to navigate during illness or caring.

Interview findings indicate that these demands often result in:

- Delayed applications
- Disengagement
- Abandoned claims.

This suggests that administrative burden is not incidental, but a key driver of unmet need.

‘Giving Centrelink a call is obviously very difficult, because you’re on hold for ages—which is fine if you’re well enough to do it. But if you’re a sick patient in hospital and getting interrupted all the time, it’s near impossible.’

—Lori, social worker

Innovative tools were identified as valuable resources for trying to reduce the administrative burden associated with the DSP, although awareness of these may be limited. DSP Help, developed by Social Security Rights Victoria (SSRV), is a free online resource for DSP applicants and their support workers that includes a chatbot to help users gather the medical evidence

needed to support their application.⁸⁶ The DSP Toolkit, developed by SSRV in collaboration with Berrill & Watson Lawyers, is an online resource intended to be used alongside training provided by SSRV staff and assists medical practitioners, social workers and community workers to help clients obtain the evidence required for DSP applications.⁸⁷

Barriers are amplified for people experiencing structural disadvantage

Interview participants highlighted that individuals affected by cancer often face two unfamiliar and demanding challenges simultaneously: managing their cancer journey and navigating a complex social security system—both of which they may have little or no prior experience with.

But barriers to accessing support were more pronounced for people experiencing structural and/or intersectional disadvantage, including:

- Aboriginal people
- People without identification or stable housing
- People already experiencing financial hardship or poverty
- People with limited English, literacy, or digital access.

‘Our role is to absolutely make an issue of those who are left behind, structurally, for whom the \$12 a day parking fee becomes a huge issue.’

—Graeme, Cancer Council Victoria Financial Counsellor

Interview findings indicate that digital systems and identification requirements are exclusionary, requiring intensive advocacy from support professionals to navigate.

‘We’ve turned everything electronic and we don’t consider people who don’t have phones, don’t have ID, don’t have bank accounts — and then we wonder they disengage... Trying to get a bank account for a person who has no ID, who is homeless. It doesn’t exist. There is no way to get somebody a bank account. I don’t think it would be a massive endeavour to have these types of things in place for people who are homeless.’

– Aboriginal Health Practitioner

In many cases, carers were required to assume responsibility for navigating systems on behalf of others, increasing their own burden and the risk that people would not access support at all.

Travel and accommodation support are inadequate

Government travel and accommodation assistance schemes were described as important but insufficient.

Interview findings indicate that:

- Reimbursement models require people to pay costs upfront.
- Payments often do not reflect actual travel and accommodation expenses.
- Delays and rejected claims create additional stress.
- Eligibility criteria are problematic.

These features were particularly challenging for people already experiencing financial strain, and for those in regional areas requiring repeated travel for treatment and those living in peri-urban areas of Melbourne who have long distances to travel but fall outside eligibility criteria.

‘We’re not eligible for assistance because we’re peri-urban... We’re far enough that it’s an impost on us, but not far enough that we can get any help.’

– Jacinta, carer

‘One of the biggest things we hear [from Aboriginal people with cancer and their carers] is transport and accommodation, and this isn’t just siloed to those who live rurally. People who, for example, live in Geelong, they can’t access VPTAS. Apparently, VPTAS is one of the most difficult programmes out of all the patient travel support schemes in Australia. Not only do you have to fork out the money prior, then you have to wait, I think it’s about 30 days before you can get any of that money back.’

– Aboriginal Health Practitioner

‘There are people who have intensive haematology treatments who live just under the 100-kilometre mark, who don’t quite meet the criteria or people who live in the Mornington Peninsula who are travelling extensively for treatment, but they’re counted as metro and it’s the same for some areas near Geelong as well. So those metro categories don’t help for some patients.’

– Fiona, social worker

‘Many programmes that help with some reimbursement for [accommodation] are retrospective. So, you have to apply for this partial reimbursement. And they’re certainly not covering close to the cost of what a hotel is in CBD Melbourne for the night. There is significant disparity in how much can be accessed depending on which state you come from’

– Lori, social worker

Interview findings also highlighted that, in some cases, Aboriginal Community Controlled Organisations (ACCOs) and Aboriginal Community Controlled Health Organisations (ACCHOs) absorb these upfront costs or manage claims on behalf of patients so that individuals are not required to pay out-of-pocket. While this reduces immediate financial pressure for patients, it effectively shifts the burden onto community organisations rather than addressing underlying gaps in scheme design.

Support is often identified too late

Support was frequently identified only after financial hardship had escalated.

Interview findings indicate that:

- Awareness of support often depended on prior experience.
- Information was rarely provided proactively.
- Support was less effective once financial stress was entrenched.

This suggests that timing is critical to the effectiveness of support systems.

‘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

Embedded support improves access and outcomes

A consistent finding was that access improves when support is embedded within healthcare settings.

Participants described positive experiences where:

- Centrelink or other services were integrated into care.
- Professionals assisted with navigating systems.
- Administrative burden was reduced.

Interview findings indicate that embedded, coordinated support is more accessible and effective than relying on individual navigation.

Findings in context

These findings align with broader evidence that people affected by cancer experience both significant financial hardship and limited awareness and access to social security protections.

The findings affirm Cancer Council Australia and Oncology Social Workers Australia and New Zealand (OSWANZ) calls that existing income is not well suited to the realities of cancer, particularly where illness is prolonged, episodic, or disrupts work in non-linear ways.⁸⁸ It also supports other evidence highlighting that many people affected by cancer are unaware of social security programs,⁸⁹ have difficulty navigating and accessing Services Australia programs due to

complex application processes,⁹⁰ and the challenges with household and dual income assets tests that do not account for the broader financial impact of cancer and burden of financial toxicity on the household.⁹¹ The findings also support research showing that the barriers in accessing social security leave people feeling discouraged and in worse financial situations due to delays in accessing support.⁹²

The present findings extend this evidence by showing how eligibility settings, administrative processes, and timing of support interact to limit access in practice. In this context, financial hardship reflects not only the cost of cancer, but the accessibility and responsiveness of social protection systems.

Implications

Financial hardship in the cancer context reflects both the economic impacts of illness and the limited accessibility of social security protections, raising significant human rights considerations. The right to social security and an adequate standard of living requires access to timely and sufficient financial support during periods of illness, disability, and caregiving, yet the findings indicate these protections are not consistently realised in practice. Support systems are often not well aligned with the fluctuating and unpredictable nature of illness or the demands of caregiving, while access is constrained by administrative burden, delays, and complex evidentiary requirements. As a result, low uptake of available payments reflects barriers to access rather than low need, and support is frequently accessed too late to prevent financial strain from escalating.

System design plays a central role in reinforcing these challenges. Responsibility is effectively shifted onto individuals and families to identify, access, and sustain engagement with complex systems, with carers carrying a substantial and under-recognised share of this burden. These barriers disproportionately affect those already experiencing disadvantage — including Aboriginal people, regional communities, and individuals with limited access to identification, digital resources, or support — compounding inequity. Where access to adequate and timely income support is limited, individuals and

households are left to absorb financial shocks that social protection systems are intended to mitigate.

In this context, practical, user-centred tools may help reduce some of the administrative barriers that limit access to government support. Resources such as DSP Help and the DSP Toolkit support people affected by cancer, as well as the health and community professionals assisting them, to navigate complex eligibility requirements, gather evidence and complete applications. The substantial uptake of DSP Help — including more than 30,000 website users, almost 3,500 chatbot users, and over 2,000 personalised Medical Evidence Kits generated during its first two years — suggests there is demand for initiatives that simplify access to support.⁹³ Increasing awareness, uptake and evaluation of such tools may therefore complement broader policy and system reforms aimed at improving access to the DSP and other income support payments.

Together, these findings indicate that financial hardship should be understood as both a socioeconomic and systemic issue. Addressing it will require more accessible, responsive and integrated approaches that improve both the design of support systems and people's ability to access them. This includes embedding financial support within healthcare settings, reducing administrative burden, strengthening access to timely assistance, and increasing awareness of practical tools and resources that help people affected by cancer navigate government income support and other financial assistance.



Finding 8:

**Carers experience
distinct and
compounded
legal and financial
disadvantage and
distress**

‘Caring makes a massive difference for the person with cancer and how they get through the treatment because no cancer treatment is nice, and their survival too. You have such an incredibly important part to play. So, you’ve got to really look after yourself...It’s really hard at times because you’re so emotional and full to the brim dealing with everything. But sometimes you have got to really advocate for yourself and the person you’re caring for. If you haven’t been through it, you don’t know how traumatic it is....To see someone that you love suffering so much is really, really hard. But you’ve got to keep it together for them. Because you want to support them, and to show care and show empathy. But you can’t fall apart either. So, it’s a bit of a delicate balance...Don’t try to do it all yourself. Ask for help...It’s really challenging, and you’ve got to look after yourself equally as much as the person you’re caring for.’

– Jacinta, carer

This section draws together findings across all domains to highlight the distinct and cumulative impact of legal and financial challenges on carers.

Care work is at the heart of our society, as all human beings are dependent on care to survive and thrive.⁹⁴ Carers are also critical in that they enable people with cancer to remain at home and out of hospitals for longer than would have otherwise been possible⁹⁵ Carers play a central role in helping people with cancer navigate employment, legal, financial, and care systems, yet their contributions, needs and rights remain insufficiently recognised across legal and policy frameworks.⁹⁶

‘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.’

– Tracey, carer

‘Of course I understand, the focus is so much on the patient. But the carer is incredibly important.’

– Jacinta, carer

While carers’ experiences are reflected throughout the report, the findings show that these challenges intersect and compound, resulting in a more complex and intensive impact than that experienced by people with cancer alone. Among survey respondents, carers reported higher rates of foregoing sport, exercise and other social or leisure activities than people with cancer, reflecting the wider social and personal impacts associated with caregiving responsibilities.

Many survey respondents and interviewees reported mixed feelings associated with caring — several said that caring for someone with cancer was a privilege and a rewarding experience which they would do again. However, many others reported how challenging and potentially isolating the experience is. Some

people reported that caring was a duty or obligation. Several respondents and interviewees noted the physical, emotional and mental toll of caring and the challenges of accessing mental health support for carers.

'It was a difficult time. I have anxiety and health anxiety so spending time with my friend/neighbour almost daily was hard. I did my best to make sure she had the little things that made her happy. Her family worked so weren't there most days. Seeing her slowly deteriorate over the months was heartbreaking and left a lasting mark on me.'

– Carer survey respondent

'Caring for a cancer patient is physically and mentally challenging'.

– Carer survey respondent

'I half joke that I could be a nurse now...I realised after attending vicarious trauma training that I had trauma from being a carer.'

– Jacinta, carer



'I have seen movies about zombies and that's exactly how I felt...I kind of felt that I was so numb and just walking like on autopilot, I actually felt like a robot...Carers are just so busy caring that it leads to isolation because you're too busy.'

– Sofia, carer

'It all compounds. When we think of the cost of cancer, we need to take a holistic view of it. It's not just the financial burden, it's also then the physical and emotional burden on people...You try getting mental health support because you are suffering from cancer or you're supporting someone who's suffering from cancer and you are down the bottom of the list. The only supports available to me was through my work EAP and that's only a limited amount. Other than it was only if we linked in with the social services at PeterMac but we had to be prepared to go to Melbourne for that. It's not a viable option for people that live in rural areas.'

– Tracey, carer

Key Findings

Across the study, carers consistently reported:

- Higher and more complex legal need, often spanning multiple domains simultaneously.
- Responsibility for navigating systems for both themselves and another person.
- Significant decision-making roles, frequently without clear legal authority.
- Challenges juggling work and caring.
- Reduced workforce participation and income loss, alongside increased costs.
- Limited access to financial protections, including insurance and income support.
- Barriers to accessing support due to time constraints, fatigue, and system complexity.
- Higher rates of distress, including poor mental health.

These challenges are cumulative and often occur concurrently, intensifying over time. Interview findings indicate that carers frequently defer their own needs and delay seeking support, shaped by both limited capacity and strong social expectations that prioritise caregiving responsibilities.

Findings in context

Our findings confirm that carers provide critical practical, medical, emotional, legal and financial support to people living with cancer.⁹⁷ Our data is also consistent with research on the experience of cancer carers, including the impacts on work and income and financial security,⁹⁸ and that caring for someone with cancer can be all-encompassing and affects the physical, emotional and financial wellbeing of carers.⁹⁹ Our research reiterates existing evidence that carers for people with cancer report high levels of distress and burden,¹⁰⁰ and previous findings that show that carers report higher levels of distress than people receiving treatment for cancer.¹⁰¹

While our survey respondents were fairly equally split in terms of gender, research consistently demonstrates that women bear a disproportionate caring burden.¹⁰² Gender stereotypes and expectations contribute to the imbalance in caring responsibilities in families. Men who want to take on more care may face difficulty or discrimination accessing leave or flexible work, as identified in previous research by the McCabe Centre.¹⁰³ Some women have greater caring responsibilities that stem from cultural, religious or community expectations.¹⁰⁴ 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 or higher rates of part-time work,¹⁰⁵ as was seen in our study. This can have long term impacts of women's economic security, and that of their households.¹⁰⁶

Implications

Carers' experiences reflect a structurally produced form of disadvantage arising from the interaction of multiple systems, the allocation of responsibility without equivalent support, and a reliance on individual capacity to navigate complex processes. Some carers do not identify with the role, which may limit awareness and uptake of available supports and legal entitlements. From a rights-based perspective, these patterns engage principles of equality and non-discrimination, recognition of unpaid care, and access to social security and an adequate standard of living. However, the findings indicate that these protections are not consistently realised in practice.

System design plays a central role in shaping these outcomes. Carers' needs are not consistently recognised across legal, financial, and policy frameworks, and significant responsibilities are often assumed without corresponding authority or support. Impacts are cumulative and cross-cutting, spanning employment, income support, legal and financial systems, and healthcare, while reliance on individual capacity during periods of stress drives inequitable outcomes. Existing supports are fragmented and insufficient, contributing to delayed or unmet need. Together, these findings indicate that carers' disadvantage is embedded in system design, with carers frequently left to absorb substantial legal, financial, and emotional impacts.

'Carers need a combination of supports. Unpaid leave, paid carers leave, an allowance for everyone, no matter what job they do. And most of all, work flexibility.'

– Sofia, carer

Conclusion on Carers

Carers emerge as a group experiencing heightened and compounded legal and financial vulnerability, reflecting their central but under-recognised role across systems.

Addressing these challenges requires reform that explicitly recognises carers within legal and policy frameworks, strengthens financial and legal protections, reduces reliance on individual system navigation, and embeds carer-centred approaches across services.

These findings underscore the importance of recognising unpaid care as a critical social and economic function. Ensuring that carers can access adequate financial support, legal protections, and practical assistance is essential to sustaining their wellbeing and participation in society. Strengthening support for carers will likely have immediate and long-term benefits for people, societies, and economies.¹⁰⁷

Summary of all findings and implications

Taken together, the findings across this report demonstrate that legal and financial challenges are a central and systemic dimension of the cancer and caregiving experience, rather than isolated or incidental issues. Across multiple domains — including employment, social security, legal planning, insurance, and access to care — outcomes are shaped not only by individual circumstances, but by the design, accessibility, and interaction of legal, financial, and service systems. Carers experience particularly pronounced and cumulative impacts, reflecting their cross-cutting role within and across these systems.

While legal protections and supports exist, their accessibility and effectiveness in practice are uneven, often relying on individual capacity, awareness, and access to support during periods of significant vulnerability. These findings highlight consistent system-level challenges across domains and point to the need for more accessible, coordinated, and responsive approaches. They provide a clear, evidence-based foundation for reform.



Reform Priorities

The following reform priorities are informed by the findings of this research. They address the structural drivers of legal and financial vulnerability experienced by people affected by cancer and those who support them.

These reform priorities are interconnected and mutually reinforcing, and improving outcomes requires coordinated change across law, policy, service delivery, and professional practice. Addressing the legal and financial impacts of cancer cannot be achieved by any single entity or sector alone. It requires an all-of-society response, including involving governments, healthcare systems, legal and financial services, employers, and cancer organisations working together to deliver more integrated, accessible and responsive support. While law is a necessary tool to improve the lives of people affected by cancer, it is most effectively employed in coordination with other interventions including policy initiatives, service delivery, education and advocacy campaigns or standards set by professional bodies.

Many of the issues identified are shaped by the design and operation of national systems — including social security, employment law, insurance, and superannuation — and will require leadership and reform at the Australian Government level. At the same time, there is a critical role for state government, services and institutions in improving access to justice, embedding legal and financial support within healthcare and community settings, strengthening service integration, and ensuring that systems respond effectively in practice. The reform priorities therefore identify areas for joint action, including opportunities for immediate, practical change alongside longer-term legal and policy reform.

They build on an established body of policy and law reform work, including submissions and proposals developed by the McCabe Centre and Cancer Council. Further detailed and implementation-focused measures will continue to be refined through ongoing consultation with stakeholders.

Across all domains, the findings demonstrate consistent system-level challenges: awareness of the legal and financial impacts of cancer is limited; legal and financial issues are often identified too late; access to support is fragmented and reliant on individual capacity; system settings are not well aligned with the realities of illness and caregiving; and financial and administrative burden is frequently shifted onto individuals and families, with carers playing a central but insufficiently recognised role.

Addressing these challenges requires a shift from reactive, individualised responses toward systems that are proactive, integrated, accessible, and rights-based.

Reform Priority 1: Strengthen awareness of the responsiveness to the legal and financial impacts of cancer

Why this matters

Legal and financial challenges are a common part of the cancer experience and will inevitably be faced by many. Yet awareness of potential legal and financial issues, legal rights, financial risks, and available supports is limited, particularly during periods of intense illness or caregiving when capacity to engage is reduced. At the same time, organisations, services and systems that people interact with, including employers, government agencies, financial institutions and legal services and bodies vary significantly in their understanding of cancer and its impact. This contributes to inconsistent responses and places responsibility on individuals to navigate complex issues at times of reduced capacity.

What needs to change

Awareness of the legal and financial dimensions of cancer must be strengthened for people affected by cancer, alongside improved recognition of these issues across the systems they rely on. Legal and financial challenges should be identified early and addressed as a core part of cancer care and support. Systems must also be better equipped to recognise and respond to these needs in practice, and ensuring that responses are timely, consistent and person-centred.

System-level priorities

- Improve awareness of legal issues, financial risks associated with cancer and caring as well as legal rights and available supports among people affected by cancer.
- Improve legal and financial literacy across the community, including people affected by cancer.
- Strengthen capability across systems to identify, recognise and respond to legal and financial issues.
- Support earlier identification of need through proactive, integrated approaches rather than reliance on individual help-seeking.
- Build capability of frontline staff through training, guidance and clear referral pathways across health, legal and financial services.

Translating priorities into action – next steps

- Governments should prioritise improving awareness of legal and financial impacts of cancer through clear, accessible information delivered across multiple points of contact, including healthcare settings, government services and community organisations. In parallel, investment is needed to strengthen capability across systems — including through training for frontline staff such as Centrelink and other Services Australia employees, development of practical guidance, and clearer referral pathways to legal and financial support. Investment in strengthening and expanding integrated service models that embed legal and financial support within healthcare and community settings is also needed. Investments in improving legal and financial literacy amongst the public is also needed.
- Healthcare services can support the identification of legal and financial needs by embedding supportive care screening into care pathways at multiple points, improving staff capacity to recognise the legal and financial impacts of cancer, strengthening understanding of when legal problems may be affecting health and wellbeing, and establishing clear referral pathways to legal, financial counselling and social support services.
- Employers, government agencies and financial institutions should improve their understanding of cancer and its impacts and implement consistent, supportive responses. Employers should utilise the services of cancer organisations for cancer information and support.
- Cancer organisations have a critical role in strengthening awareness of the legal and financial impacts of cancer in the community and across society and can work with government agencies, financial institutions and employers to improve their understanding of and responses to people affected by cancer. Integrating responses to these issues within their own supportive care services is necessary to facilitate timely access to support.

Reform Priority 2: Embed lived experience of cancer and caring in the design, implementation and evaluation of law and policy

Why this matters

Cancer affects far more than health. It disrupts work, income, decision-making, caregiving roles, and access to support. Yet these impacts are not consistently recognised within legal and policy frameworks, meaning legal and financial challenges often remain invisible until they escalate. This contributes to unmet need, delayed support, greater distress, and inequitable outcomes.

What needs to change

Legal and policy frameworks must explicitly recognise that cancer is a whole-of-life issue, with impacts extending beyond health. This includes embedding recognition of cancer as a chronic and episodic condition and acknowledging the central role of carers. Systems must also support individuals to understand and act on their rights in practice, particularly during periods of illness and reduced capacity.

System-level priorities

- Embed lived experience of cancer and caregiving across legal and policy frameworks.
- Redesign systems to respond proactively with hands-on support.
- Integrate legal, financial, and social support into healthcare pathways.

Translating priorities into action – next steps

- Governments must recognise that addressing the burden of cancer goes beyond investing in medical treatments for it. This should be reflected in policy guidance including cancer plans, service standards and program design. The wide-ranging effects of cancer, including the legal and financial impacts of cancer must be acknowledged and acted upon. Without this, too many people will continue to fall through systemic gaps. Laws can help address many of these issues but must be reformed or developed with the lived experiences of people with cancer in mind and should involve meaningful engagement of people affected by cancer. Governments should strengthen the legal rights of people with cancer and those caring for them, including at both state and national levels.
- Cancer organisations play a central role in elevating lived experience and supporting integrated, person-centred responses across systems. They can engage in legal and policy development and reform activities and engage with law and policy-makers with people affected by cancer to ensure the needs of people affected by cancer are addressed.

Reform Priority 3: Reduce barriers to access to justice

Why this matters

Despite widespread legal need, many people affected by cancer do not access legal or financial support. Complex processes, cost barriers, low awareness that legal issues may arise and where to seek assistance, and reduced capacity during illness and caregiving mean that legal problems often go unresolved or are addressed too late.

What needs to change

Access to justice systems must be redesigned to be accessible by default and made responsive to the realities of illness and caregiving. This includes simplifying processes, reducing reliance on individual help seeking, and ensuring legal support is available early and that people can understand, access, and act on their rights.

System-level priorities

- Redesign access to justice systems to be accessible by default.
- Reduce complexity, duplication, and reliance on individual help-seeking.
- Expand availability of timely, accessible and affordable legal information and support.
- Reform complaint and dispute resolution processes to improve accessibility.

Translating priorities into action – next steps

- Governments have a critical role in reducing barriers to justice by improving legal literacy, improving plain language guidance, simplifying complaint and dispute resolution processes, and expanding resourcing for community legal services and encouraging the legal sector, including private lawyers to help meet demand, including people who fall outside eligibility for free or low-cost legal support.
- There is a need for accessible, plain-language legal information, delivered in stages that reflect how people experience legal issues over time, rather than assuming a single point of need. Governments can also strengthen and scale up integrated models such as health justice partnerships in hospitals and other partnerships between legal services, financial counselling and cancer organisations. Improving access to justice also involves strengthening human rights laws to promote prevention of rights violations and appropriate remedies.
- Healthcare providers and community organisations such as community legal centres and cancer organisations should embed models of care that support early identification of legal need and establish clear referral pathways and connect people to legal support early.
- Employers can also help by providing information about rights at work and having information available to employees on legal and financial supports available such as those available through Cancer Council.
- Cancer organisations can connect people affected by cancer experiencing legal and financial challenges with appropriate support services, as well as developing partnerships with the legal sector and financial counselling sectors as part of their service offerings.

Reform Priority 4: Strengthen enforceable workplace rights and protections

Why this matters

Despite the critical nature of workplace experiences and workforce participation for people with cancer, protections are inconsistently applied and often difficult to access or enforce. Outcomes frequently depend on employer discretion rather than clear, enforceable rights, leaving people exposed to income loss and workforce exit.

What needs to change

Workplace laws must provide clear, enforceable, and accessible protections that reflect the realities of cancer and caregiving, including fluctuating capacity and long-term impacts. Employers and other workplaces and workplace regulators must be better equipped to understand and respond to the needs of people affected by cancer. Broader coverage of existing workplace protections to those outside of formal employment and insecure work would especially benefit groups already facing greater job insecurity.

System-level priorities

- Align workplace laws and entitlements with chronic, episodic illness and caregiving realities.
- Shift from discretionary support to enforceable, accessible rights.
- Improve usability and accessibility of enforcement mechanisms.
- Broaden coverage of workplace protections during illness and caring to more types of workers.

Translating priorities into action – next steps

- Governments can clarify existing workplace rights through updated guidance, simplify access to enforcement mechanisms, and strengthen workplace rights to better align them with the lived realities of cancer and caring for all types of workers. We acknowledge current reviews are underway into the federal legislation impacting the workplace including reform of the *Disability Discrimination Act 1992* and the Inquiry into the National Employment Standards to which the McCabe Centre and Cancer Council have made detailed recommendations.
- Regulators, tribunals and courts should prioritise streamlined processes, extended timeframes, and flexible participation options to ensure rights can be meaningfully exercised during illness and caregiving.
- Employers need not wait for legislative reform to improve experiences at work, noting that the National Employment Standards act as a floor, not a ceiling of workplace entitlements and protections. They can act now to improve accessibility of flexible work arrangements, implement return-to-work processes, clearly communicate supports, train managers to respond appropriately to the impacts of cancer and caregiving and take steps to foster supportive workplace cultures that enable disclosure and access to support.
- Employers can strengthen financial protections and supports available to employees, such as group income protection policies.
- Cancer organisations can support workplace change by providing practical resources, advice and training for employers, managers and HR professionals to help them respond appropriately to the impacts of cancer and caregiving. They can also promote cancer-inclusive workplace practices, support effective return-to-work processes, refer individuals to employment and discrimination law advice where appropriate, and contribute evidence and lived experience to inform workplace policy and reform.

Reform Priority 5: Improve uptake and usability of legal and financial planning frameworks

Why this matters

Legal planning and decision-making tools such as those for estate planning and medical-treatment decision-making are underused and often delayed until crisis points. Similarly, financial planning and risk management for adverse life events, for example through income protection insurance coverage amongst the community needs improvement. Low awareness, complexity, cost, and discomfort with planning for illness, incapacity and death mean many people do not have arrangements in place, increasing burden and uncertainty for individuals and carers.

What needs to change

Planning frameworks must be simplified, more accessible, and better aligned with how people engage with planning in practice. They must also be supported by measures that normalise and encourage earlier engagement.

System-level priorities

- Simplify legal planning requirements and reduce cost and access barriers.
- Embed legal planning within healthcare and service systems.
- Improve community understanding of legal planning and decision-making tools and financial protection mechanisms, including insurance and superannuation.
- Simplify and normalise planning for decision-making and future adverse life events.

Translating priorities into action – next steps

- Governments can simplify legal planning by streamlining documentation requirements, providing clear, plain-language templates, and expanding access to low-cost or free support. It can also fund campaigns to improve uptake of legal-planning tools. Governments can fund financial literacy programs and ensure that the insurance and financial advisory services are well regulated to ensure people have access to quality information and advice.
- Governments, regulators and industry can deliver co-ordinated, plain language education campaigns that explain the role of insurance products and superannuation. They can work to simply product information, improve transparency and ensure communications are accessible and sensitive to the needs of people facing serious illness.
- Healthcare and community services should routinely prompt and support legal and financial planning discussions at key points in the care pathway, rather than waiting for crisis. Targeted awareness efforts can also normalise planning for illness and incapacity as a standard part of care and life planning.
- Legal services, healthcare providers and community organisations, including cancer organisations, should work together to provide coordinated, hands-on support that enables early completion of planning documents. These practical actions can be implemented without delay to ensure legal planning frameworks are not only available but actively used—reducing uncertainty and easing the burden on individuals and carers.
- Cancer organisations can help normalise legal and financial planning and support early engagement through information, assistance and referral pathways to financial counselling and other relevant specialist services.

Reform Priority 6: Reform insurance and superannuation

Why this matters

Insurance and superannuation systems are complex, poorly understood, and often fail to provide accessible and timely financial protection. Gaps in coverage, restrictive eligibility criteria, and difficult claims processes create significant vulnerability at the point of illness. A lack of industry standards for superannuation funds contributing to inequitable outcomes must also be addressed.

What needs to change

Legal and regulatory frameworks must ensure insurance and superannuation systems operate fairly, transparently, and in ways that reflect the realities of cancer and caregiving.

System-level priorities

- Align insurance and superannuation frameworks with chronic illness realities.
- Improve adequacy of financial protection.
- Strengthen transparency, fairness, and accountability.

Translating priorities into action – next steps

- Governments can strengthen regulatory guidance on fair claims handling, requiring clearer disclosure of coverage and entitlements, and working with industry to simplify claims processes and documentation. Practical measures such as standardised forms, clearer timeframes, and streamlined pathways to access to benefits can be implemented quickly to improve usability. Inquiries should be conducted to ensure that regulators have appropriate powers and remedies. Superannuation and insurance frameworks should be strengthened to improve access to adequate and reliable financial protection.
- Regulators should increase oversight and accountability through internal reviews of processes and clearer expectations on responsiveness to serious illness.
- Employers can support this by improving communication with employees about available insurance cover, particularly through superannuation, and ensuring that any workplace-based cover—such as group income protection—is accessible and clearly understood.
- Industry standards and accountability mechanisms should be strengthened, particularly for superannuation funds, including through sector-led codes of conduct and consideration of co-regulatory or regulatory approaches.
- Cancer organisations can assist individuals to understand insurance and superannuation and help connect them to specialist support.

Reform Priority 7: Protect against financial harm

Why this matters

Cancer-related costs are substantial, cumulative, and often unpredictable. Limited cost transparency and weak consumer protections mean financial pressure is widespread and can affect treatment decisions, undermining equitable access to care and the right to health.

What needs to change

Stronger legal protections are required to ensure cost transparency, prevent financial harm, and reduce reliance on personal financial sacrifice to manage care-related costs and ensure that affordability does not limit access to treatment. Legal and policy reform is required to address the underlying drivers of the direct and indirect costs of cancer for people with cancer and their carers. This should be accompanied by investment in workforce capability and financial support services to strengthen informed financial consent and cost discussions. Ongoing investment in health systems strengthening and addressing the social determinants of health is required to achieve universal health coverage.

System-level priorities

- Reduce the overall financial burden associated with cancer.
- Strengthen transparency and informed financial consent.
- Build workforce capacity to identify and respond to financial concerns.
- Embed financial support within care pathways.

Translating priorities into action – next steps

- Governments must take measures to reduce both direct medical costs and broader out-of-pocket and indirect costs and improve how both the public and

private health systems operate and interact. Financial harm can be reduced by strengthening requirements for clear, upfront cost information and consistent financial consent processes, including standardised estimates of likely costs at key decision points. Governments should invest in equipping healthcare professionals with the skills, confidence and resources needed to support informed financial consent and cost discussions, expand access to dedicated financial counselling, navigation and advocacy services, and improve coordination between healthcare providers and support services. The emotional and psychological distress related to the financial costs of cancer must also be addressed through improved mental health support for people with cancer and their carers. Governments must continue to invest in realising universal health coverage so people with cancer and their carers can access the quality health services they need without experiencing financial hardship. Health services, universities and other health professional education providers should strengthen workforce capability by equipping healthcare professionals with the skills, confidence and tools needed to support informed financial consent, have meaningful discussions about the cost of care, and identify and connect patients to appropriate financial assistance through clear referral pathways to counselling, navigation and advocacy services.

- Financial institutions can educate themselves on how they can better support people affected by cancer and strengthen hardship responses by offering flexible, accessible support and proactive options for customers experiencing financial strain.
- Employers can also act now by recognising the financial pressures associated with cancer, offering flexible work and offering leave arrangements above that of the National Employment Standards and group income protection policies (if resources permit), and connecting employees to financial and support services.
- Cancer organisations can provide information to individuals and help connect them to specialist support and continue to advocate to address the underlying drivers of costs.

Reform Priority 8: Modernise social security to reflect lived realities

Why this matters

Financial hardship is widespread, yet social security systems are difficult to access and poorly aligned with the realities of cancer and caregiving. Restrictive eligibility criteria, inadequate payments, and administrative burden limit their effectiveness as safety nets.

What needs to change

Social security law must be modernised to reflect fluctuating capacity, episodic illness, and caregiving responsibilities, and to provide accessible and adequate income support.

System-level priorities

- Align eligibility criteria with illness trajectories and fluctuating work capacity.
- Improve adequacy, accessibility and responsiveness of payments to better shield people affected by cancer from financial hardship.
- Reduce administrative burden and introduce flexible, health-sensitive processes including embedded support within healthcare settings.

Translating priorities into action – next steps

- Governments should simplify social security access by reducing evidentiary requirements, streamlining applications and introducing more flexible eligibility assessments that address fluctuating work capacity and ongoing treatment. Practical actions such as embedding Centrelink within healthcare settings for people affected by cancer, fast tracking claims for people with serious illness and their carers, and improving access to clear, plain language information should be implemented. Governments should also invest in and support the development, promotion, evaluation and scaling of practical, user-centred navigation supports that help people affected by cancer, carers, and the professionals supporting them to understand eligibility requirements, gather evidence, and access and maintain social security entitlements. Such initiatives should complement broader reforms to improve the adequacy, accessibility and responsiveness of income support systems. Law and policy-makers should support this through regular reviews of the operation and adequacy of social security benefits, allowances and concession cards at both state and federal levels to ensure they remain fit for purpose and responsive to the needs of people affected by cancer and their carers.
- Employers can support these efforts by providing employees with timely information about leave and income support options.
- Integrated models such as health justice partnerships and legal-financial counselling collaborations can support navigation of the social security system through co-ordinated assistance.
- Cancer organisations can provide advocacy and referral to appropriate services.

Reform Priority 9: Recognise and support carers across all systems

Why this matters

Carers are central to the cancer experience but experience compounded disadvantage. They frequently assume significant legal, financial, and administrative responsibilities without adequate recognition, authority, or support.

What needs to change

Carers must be recognised as rights-holders across legal and policy frameworks, with clear entitlements, protections, and access to support across systems.

System-level priorities

- Recognise carers as rights-holders across legal and policy frameworks.
- Align supports including eligibility and payment structures with episodic illness and the scale and complexity of caregiving.
- Reduce administrative burden and delays.

Translating priorities into action – next steps

- Governments can strengthen support for carers by updating eligibility rules and program guidance to explicitly reflect caregiving alongside illness, and by expanding access to existing payments and supports. Practical actions such as streamlining application processes, improving clarity of eligibility, and embedding carer support services within healthcare settings is needed. Strengthening the rights of carers and investing in campaigns to ensure carers are recognised and valued in society is necessary. This includes laws and policies (including those related to work) that help shift the burden of caring from women and by facilitating and encouraging men to take on caring duties.
- Legal and financial services can assist carers to establish appropriate decision-making authority and navigate complex systems.
- Employers can support this by recognising caregiving in workplace policies, offering flexible work and leave arrangements, and proactively connecting carers to available supports.
- Cancer organisations should ensure that carers are a focus of their efforts by recognising their needs, providing targeted information, connecting them to legal, financial and emotional support and advocating for carers.

Conclusion

This report demonstrates that the legal and financial challenges associated with cancer are neither incidental nor peripheral to the illness experience. Rather, they are widespread, interconnected, and embedded in how people navigate diagnosis, treatment, survivorship, and caring. These challenges extend beyond individuals to affect families and households, and are shaped not only by personal circumstances, but by the design and operation of legal, financial, and service systems. To fully address the burden of cancer, its legal and financial impacts must be addressed.

The findings show that legal and financial problems often arise unexpectedly and at the most difficult points in the cancer trajectory, when individuals and carers have the least capacity to respond. Despite their prevalence and impact, access to support remains limited, fragmented, and heavily dependent on individual awareness, resources, and ability to navigate complex systems. As a result, legal needs frequently go unrecognised, rights and entitlements are not understood or realised in practice, and financial hardship and distress are common.

At a structural level, the report highlights a consistent misalignment between system design and lived experience. Legal frameworks, financial systems, and support pathways are often built around assumptions of stability, predictability, and individual capacity. In contrast, cancer is increasingly experienced as a chronic, episodic, and uncertain condition, while caring is intensive, relational, and often prolonged. Where systems fail to reflect these realities, the burden is shifted onto individuals and families, contributing to avoidable hardship, inequity, and reduced access to care and support. These challenges are compounded by limited awareness of legal and financial rights and variable capability among the professionals and institutions responsible for administering, advising on, and enforcing them.

Importantly, these challenges are not evenly distributed. The evidence points to clear inequities in both exposure to legal and financial problems and the ability to resolve them. Outcomes are shaped by intersecting factors such as income, employment security, geographic location, health literacy, and access to support, with these impacts often compounded for people experiencing multiple forms of disadvantage or marginalisation. Carers, who play a central and often invisible role across all stages of the cancer experience, face particular and compounded disadvantage, frequently without adequate recognition or protection.

The experiences captured in this report also underscore the importance of viewing cancer-related hardship within its broader social and economic context. External shocks, including public health emergencies such as pandemics, can magnify existing legal and financial pressures, particularly for those already experiencing illness, caregiving responsibilities or socioeconomic disadvantage. Future planning should ensure that legal frameworks and support systems are sufficiently adaptable and responsive to protect people affected by cancer during times of crisis.

These findings point to the need for a fundamental shift in how legal and financial needs are understood and addressed within the cancer context. Legal and financial support must be recognised as core components of cancer care, rather than external or optional services. This requires moving beyond reactive, crisis-driven approaches toward systems that are proactive, integrated, and accessible by design. Early identification of need, coordinated service delivery, simplification of processes, improved awareness and understanding of rights and entitlements, and embedded navigation support are central to this shift.

At the same time, legal and policy reform is required to ensure that frameworks governing work, income support, insurance, and decision-making reflect contemporary realities. Rights must be not only formally recognised, but also clearly understood and practically accessible, supported by systems and institutions capable of responding effectively to illness and caregiving contexts. Systems intended to provide financial protection—such as social security, insurance, and superannuation—must function as genuine safety nets, rather than creating additional barriers at times of greatest need.

The priority reforms set out in this report provide a clear, evidence-based pathway for meaningful change. They focus on addressing the structural drivers of unmet need, strengthening access to justice, and improving financial security for people affected by cancer and those who support them. While grounded in the Victorian context, the issues identified have broader relevance, reflecting challenges present across jurisdictions and other serious illnesses.

Ultimately, improving legal and financial outcomes for people affected by cancer is not only a matter of service delivery or policy design. It is central to equity, dignity, and the realisation of fundamental rights, including the rights to health, work, social security, and non-discrimination. Ensuring that these rights can be understood, exercised, and upheld in practice—and that the systems and professionals responsible for them are equipped to respond appropriately—is essential to reducing harm, supporting wellbeing, and enabling people to navigate cancer with greater security and confidence.

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Appendix 1 - Online surveys

The following online surveys were administered to participants who satisfied the eligibility criteria through screening questions.

Survey questions – People with a lived experience of cancer

Section 1: About You

In this section, we want to know more about you.

1. How old are you?

- ☐ 18-24 years
- ☐ 25-34 years
- ☐ 35-44 years
- ☐ 45-54 years
- ☐ 55-64 years
- ☐ 65 years and over

2. What is your gender?

- ☐ Man or male
- ☐ Woman or female
- ☐ Non-binary
- ☐ [I/They] use a different term (please describe):

- ☐ I prefer not to say

3. What is your postcode? (Please state): _____

4. Are you of Aboriginal or Torres Strait Islander origin?

- ☐ No
- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, both
- ☐ Prefer not to say

5. What is the main language you speak at home?

[insert drop down list of languages that includes 'prefer not to say' option]

6. What is your country of birth? [insert drop down list of languages that includes 'prefer not to say' option]

7. When were you last diagnosed with cancer? (If you have been diagnosed with cancer more than once, please select the year of your latest diagnosis)'prefer not to say' option]

8. At what stage are you at in your cancer treatment?

- ☐ I am about to start cancer treatment
- ☐ I am having cancer treatment
- ☐ I have finished cancer treatment
- ☐ I am having treatment and palliative care (care that helps to relieve symptoms of cancer and effects of cancer treatment such as nausea and pain. Palliative care can also include emotional and spiritual support to improve quality of life for people with cancer)
- ☐ I am having palliative care only
- ☐ I am not having treatment but being closely monitored
- ☐ I think of myself as being in remission or a cancer survivor
- ☐ Not sure
- ☐ Other (please describe): _____

9. Was your cancer diagnosis or treatment and care affected by the COVID-19 pandemic?

- ☐ Yes – I was diagnosed and/or was having treatment/care for cancer during the pandemic
- ☐ No – I did not have cancer during the pandemic

**10. What type(s) of cancer do you, or did you, have?
(Choose all that apply)**

- ☐ Bladder
- ☐ Blood cancer (e.g. Leukaemia, myeloma)
- ☐ Bone
- ☐ Breast
- ☐ Bowel
- ☐ Cervical
- ☐ Colorectal
- ☐ Endocrine
- ☐ Kidney
- ☐ Liver
- ☐ Lung
- ☐ Lymphoma
- ☐ Melanoma
- ☐ Mouth, nose or throat
- ☐ Non-melanoma skin cancers
- ☐ Ovarian
- ☐ Pancreatic
- ☐ Prostate
- ☐ Sarcoma
- ☐ Stomach or oesophageal
- ☐ Testicular
- ☐ Thyroid
- ☐ Uterine
- ☐ Other (please describe): _____

11. Are you living with advanced cancer (the cancer has spread or has returned and is unlikely to be cured)?

- ☐ Yes
- ☐ No

12. At the time you were diagnosed with cancer, were you also living with any other health conditions (including mental health conditions) or disabilities?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

Section 2: Cancer and legal issues

Cancer can impact people in many ways. In this section we want to know more about your experience.

13. Have you experienced any of these issues since your cancer diagnosis, either because of having cancer or related to it? (Choose all that apply)

- ☐ Workplace issues (e.g. being treated unfairly or losing your job because of cancer, difficulty changing your work hours so you could keep working while having cancer)
- ☐ Difficulty understanding your rights as someone with cancer (e.g. at work or in getting medical care)
- ☐ Problems getting travel insurance
- ☐ Problems getting other types of insurance (including mortgage, life or income protection insurance)
- ☐ Trouble making an insurance claim
- ☐ Rejected insurance claims
- ☐ Delays in insurance claim payouts
- ☐ Trouble using your superannuation early to help pay for the costs of cancer
- ☐ Trouble with Centrelink to get government support (e.g. pensions and allowances)
- ☐ Problems getting approved for a mortgage or rental property
- ☐ Having to make legal documents (including wills, power of attorney documents, making an advance care directive)
- ☐ Trouble accessing the National Disability Insurance Scheme (NDIS)
- ☐ Trouble paying your mortgage or rent
- ☐ Cancer treatment-related debt problems because of high treatment costs
- ☐ Problems with debt before having cancer that got worse after having cancer
- ☐ Family law issues (e.g. divorce, child custody)
- ☐ Making complaints about your cancer care and treatment and/or delayed diagnosis
- ☐ Workers' compensation claims for cancers related to work (e.g. due to asbestos, silica, firefighting)
- ☐ Other (please describe): _____
- ☐ Not Applicable – I have not had these issues

If response is 'not applicable – I have not had these issues', then skip Q14–18. Go to Q19.

14. Were these issues expected?

- ☐ Yes
- ☐ No
- ☐ Somewhat

**15. How much distress did these issues cause you?
(Select one)**

- ☐ No distress
- ☐ A little distress
- ☐ Some distress
- ☐ A lot of distress
- ☐ Extreme distress

**16. Did you get help from a lawyer for any or
all these issues?**

- ☐ Yes – the lawyer was helpful
- ☐ Yes – the lawyer was helpful for some but not all issues
- ☐ Yes – the lawyer was not helpful
- ☐ No – I did not know a lawyer could help me
- ☐ No – I did not know how to find a lawyer
- ☐ No – I could not afford to get help from a lawyer
- ☐ No – I did not have the energy or time to get a lawyer because of having cancer
- ☐ No – other reasons (please explain):

- ☐ I prefer not to say

**17. Did you ask for help from any of these
organisations? (Choose all that apply)**

- ☐ Australian Financial Complaints Authority
- ☐ Victorian Civil and Administrative Tribunal
- ☐ Consumer Affairs Victoria
- ☐ Fair Work Commission
- ☐ Fair Work Ombudsman
- ☐ Community Legal Centres
- ☐ Victorian Equal Opportunity and Human Rights Commission
- ☐ Commonwealth Ombudsman
(e.g. for complaints about Centrelink)
- ☐ Victorian Health Complaints Commissioner
- ☐ National Disability Insurance Agency
- ☐ Other (please describe):

- ☐ No – I did not ask for help from them

18. Are any of these issues ongoing?

- ☐ Yes – I am still having these issues
- ☐ Yes – some issues were sorted out, but some are still ongoing
- ☐ No – all these issues were sorted out

Section 3: Cancer and money

In this section we want to know more about how the costs of cancer have impacted you.

19. Did you have a loss of income because of having cancer?

- ☐ Yes
- ☐ No
- ☐ I am not sure

20. Because of having cancer, how has your financial situation changed?

- ☐ Much worse
- ☐ Worse
- ☐ No change
- ☐ Better
- ☐ Much better

If response is 'No change', then skip Q21. Go to Q23.

21. How much distress did the change in your financial situation because of cancer, cause you?

- ☐ No distress
- ☐ A little distress
- ☐ Some distress
- ☐ A lot of distress
- ☐ Extreme distress

22. Are you covered by Medicare?

- ☐ Yes
- ☐ No

23. Which health system did you use for your cancer treatment and any reconstructive surgery? (cancer treatment can include surgery, chemotherapy, radiotherapy, immunotherapy, clinical trial treatment)

- ☐ Public (I am/was covered by Medicare)
- ☐ Private (I use/used private health insurance for treatment)
- ☐ Both public and private

24. What are the main costs of having cancer that you had to pay that were not fully covered by Medicare or by private health insurance (called out-of-pocket costs)? (Choose all that apply)

- ☐ Cancer diagnostics
(scans, blood tests, other medical tests)
- ☐ Cancer treatment
(surgery, chemotherapy, radiotherapy, immunotherapy, hormone therapy, clinical trial treatment)
- ☐ Reconstructive surgery
- ☐ Medication
(prescription and non-prescription)
- ☐ Allied health appointments because of cancer treatment
(including physiotherapy, speech therapy, psychology, occupational therapy, exercise physiology, dietician)
- ☐ Complementary therapies to manage side effects of cancer treatment
(including art and music therapy, yoga, acupuncture, aromatherapy, naturopathy, reiki, bush remedies, herbal medicine)
- ☐ Travel to cancer related appointments treatment
(petrol, bus, train fare)
- ☐ Hospital parking costs for cancer related appointments
- ☐ Accommodation costs
(if you had to have treatment away from home or were asked to stay close to the hospital)
- ☐ Meals
(e.g. takeaway meals)
- ☐ Home and self-care assistance
(cooking, cleaning, personal care services, home care services, changes to the home or special equipment to use in the home)
- ☐ Other costs
(special clothing, wigs, scarves, prostheses)
- ☐ Special foods and supplements
- ☐ Childcare costs
- ☐ Insurance costs – increase in insurance premiums
- ☐ Other (please describe)

25. Were the out-of-pocket costs of cancer what you expected?

- ☐ Yes – costs were as expected
- ☐ No – costs were more than expected
- ☐ No – costs were less than expected
- ☐ I am not sure – I did not know what out-of-pocket costs to expect

26. How have you (and your household) managed the out-of-pocket costs of cancer and/or a loss of income because of cancer that you may have experienced?

(Choose all that apply)

- ☐ Using savings
- ☐ Changed work situation (me or someone in my household is working longer hours or working more than one job or working from home to save on work travel costs)
- ☐ Got Centrelink payments
- ☐ Mortgage relief (changes to home loan repayments as agreed with lender)
- ☐ Rent relief (changes to rent agreed with landlord)
- ☐ Financial hardship payment plans (for phone, internet, electricity, gas, water, council rates)
- ☐ Loan from the bank
- ☐ Crowdfunding (e.g. set up a GoFundMe page online)
- ☐ Buying less food and groceries
- ☐ Spending less on non-essential items
- ☐ Selling things (e.g. clothes, car, other items)
- ☐ Selling shares
- ☐ Sold my business
- ☐ Financial or other support from family or friends
- ☐ Financial or other support from charities (including religious organisations)
- ☐ Not going to my health appointments
- ☐ Not buying or buying less of my medication
- ☐ Delaying or saying no to my treatment because it costs too much
- ☐ Other (please describe)

- ☐ Not applicable
- ☐ Prefer not to say

27. Have you got, or did you get, any financial support to manage the costs of cancer and/or loss of income because of cancer? (Choose all that apply)

- ☐ Health Care Card
- ☐ Low Income Health Care Card
- ☐ Veteran Card
- ☐ Commonwealth Seniors Health Card
- ☐ Age Pension
- ☐ Service Pension
- ☐ Disability Support Pension
- ☐ JobSeeker payment
- ☐ Commonwealth Rent Assistance payment
- ☐ Victorian Government Private Rental Assistance
- ☐ Victorian Patient Transport Assistance Scheme
- ☐ Income protection insurance payout
- ☐ Life insurance payout
- ☐ Superannuation payout
- ☐ Other (please describe)

- ☐ Prefer not to say
- ☐ Not Applicable –
I did not receive this financial support

If response is 'Not applicable', then skip Q28. Go to Q29.

28. Generally, how easy was it to get this financial support?

- ☐ Very easy
- ☐ Easy
- ☐ Neutral
- ☐ Hard
- ☐ Very hard

29. Did you get financial counselling or other professional support to manage the out-of-pocket costs of cancer and/or loss of income because of cancer? (Choose all that apply)

- ☐ Yes – financial counsellor
- ☐ Yes – accountant
- ☐ Yes – bank advice
- ☐ Yes – financial planner or financial advisor
- ☐ Yes – social worker
- ☐ Yes – superannuation and insurance lawyer
- ☐ Yes – National Debt Helpline
- ☐ Yes – Centrelink
- ☐ No – no professional support
- ☐ Other (please describe)

30. Do you have any of these? (Choose all that apply)

- ☐ Superannuation
- ☐ Life insurance
- ☐ Total and permanent disability insurance
- ☐ Income protection insurance
- ☐ Trauma or critical illness insurance
- ☐ Will
- ☐ Superannuation binding death benefit nomination
- ☐ Advance care directive
- ☐ Powers of Attorney
- ☐ Medical Treatment Decision-Maker
- ☐ I prefer not to say

Section 4: Cancer and work

In this section, we want to know about how cancer has changed your work and your experiences at work.

If you have had more than one employer since being diagnosed with cancer, think about your main employer when answering these questions.

31. Were you doing paid work when you were diagnosed with cancer?

- ☐ Yes
- ☐ No

If response is 'Yes', then go to Q32.

If response is 'No', then skip Q32. Go to Q42.

32. What was your paid work status when you were diagnosed? (Choose all that apply)

- ☐ Full-time work
- ☐ Part-time work
- ☐ Casual work
- ☐ Self-employed/sole trader
- ☐ Independent contractor
- ☐ 'Gig economy' worker
(e.g. for Uber, Airtasker, Deliveroo etc.)
- ☐ I was looking for paid work
- ☐ Other (please describe):

33. How supportive was your workplace during your cancer diagnosis, treatment and after treatment (if you have finished treatment)?

- ☐ Very supportive
- ☐ Supportive
- ☐ Somewhat supportive
- ☐ Not supportive

34. Due to cancer did your workplace offer you any of these after you were diagnosed with cancer? (Choose all that apply)

- ☐ Information about your rights at work as someone with cancer
- ☐ Access to policies and programs to manage work and cancer
- ☐ Extra paid leave
- ☐ Unpaid leave
- ☐ A long period of time off work (3 months or more)
- ☐ Reduced workload and expectations
- ☐ Change in work duties or tasks
- ☐ Changing the work environment (e.g. different workstation or equipment)
- ☐ More time to complete work tasks
- ☐ Flexible work hours
- ☐ Working from home or other remote work options
- ☐ Part-time schedules
- ☐ Job sharing options
- ☐ Regular check-ins with Human Resources manager, other managers or your supervisor
- ☐ Rest breaks
- ☐ Cognitive workplace adjustments (e.g. quiet workspace, more written guidance and less multitasking and distractions)
- ☐ Mental health support
- ☐ Occupational therapies and support
- ☐ Return-to-work program
- ☐ A coach or buddy to help you
- ☐ Retraining
- ☐ Employee Assistance Program
- ☐ Other (please describe):

- ☐ Not applicable (e.g. self-employed, insecure work)

35. Did you, or are you, experiencing any of these issues at work because of having cancer? (Choose all that apply)

- ☐ Concern about telling your workplace about your cancer
- ☐ Treated differently or unfairly at work because of your cancer (e.g. being demoted, not promoted, losing your job because of your cancer, being discriminated against)
- ☐ Feeling stigma in the workplace because of your cancer
- ☐ Difficulty getting the workplace to make changes to your work such as flexible work (e.g. part-time work, job sharing, remote work options, rest breaks etc) or changes to equipment to help you manage work and cancer
- ☐ Difficulty with co-workers
- ☐ Lack of support from manager, supervisor, and/or Human Resources
- ☐ No return-to-work policies or return to work program
- ☐ No paid leave
- ☐ Having to keep working during cancer treatment or going back to work earlier than I wanted for fear of losing my job or being treated negatively in another way
- ☐ Having to keep working during cancer treatment or going back to work earlier than I wanted to because I needed the money
- ☐ Physical limitations and fatigue since cancer diagnosis
- ☐ Emotional and psychological challenges (e.g. anxiety)
- ☐ Difficulty balancing workload and work expectations
- ☐ Difficulty thinking, making decisions and problems with my memory because of cancer treatment
- ☐ Burnout or stress
- ☐ Other (please describe):

- ☐ Not applicable – I did not experience these issues

**36. Due to cancer, did your work status change in any of the following ways?
(Choose all that apply)**

- ☐ Job loss
- ☐ Resigned
- ☐ Changed job
- ☐ Retired
- ☐ Stopped being self-employed/independent contractor/closed my business
- ☐ Reduced working hours
- ☐ Used up all paid leave
- ☐ Took unpaid leave
- ☐ Took a long period of leave (3 months or more)

If response to both Q35 and Q36 is 'Not applicable', then skip Q37–Q41. Go to Q42.

If response to Q36 does not include 'Job loss', 'Resigned', 'Retired', or 'Took a long period of leave', 'Stopped being self-employed/independent contractor/closed my business', then skip Q40 and Q41.

37. How much distress did all these work issues cause you?

- ☐ No distress
- ☐ A little distress
- ☐ Some distress
- ☐ A lot of distress
- ☐ Extreme distress

38. Did these difficulties at work get sorted out?

- ☐ No – I am still experiencing these issues
- ☐ Some of these issues were sorted out but some are still ongoing
- ☐ Yes – all these issues were sorted out

**39. Did you ask for help for any difficulties at work?
(Choose all that apply)**

- ☐ Human Resources manager at work
- ☐ Lawyer (paid a solicitor)
- ☐ Lawyer (lawyer at a community legal centre)
- ☐ Employee Assistance Program
- ☐ Fair Work Ombudsman
- ☐ Union
- ☐ Victorian Equality Opportunity and Human Rights Commission
- ☐ Australian Human Rights Commission
- ☐ Cancer Council Victoria resources and support services
- ☐ Social worker
- ☐ Doctor
- ☐ Other (please describe):

- ☐ Not applicable – I did not ask for any help

40. If you took a long period of leave (3 months or more), or left a job, retired, or stopped being self-employed

- ☐ Yes – same workplace and same role and hours
- ☐ Yes – same workplace and same role but different hours
- ☐ Yes – same workplace but different role
- ☐ Yes – different workplace/type of work
- ☐ Yes – started my own business/became self-employed
- ☐ No – I am still on leave and planning to go back to work
- ☐ No – I did not go back to work

If response is 'No', then skip Q41. Go to Q42.

41. On returning to work, how supportive have you found your workplace to be?

- ☐ Very supportive
- ☐ Supportive
- ☐ Somewhat supportive
- ☐ Not supportive

**42. What is your current paid work status?
(Choose all that apply)**

- ☐ Not working
- ☐ I am looking for paid work
- ☐ Full-time employee
- ☐ Part-time employee
- ☐ Casual employee
- ☐ Self-employed/sole trader
- ☐ Independent contractor
- ☐ 'Gig economy' worker (for example working for Uber Eats, Deliveroo, DoorDash etc)
- ☐ Retired
- ☐ Other (please describe):

Section 5: Impact and resources

43. Has having cancer stopped you from doing any of these things?

- ☐ Studying
- ☐ Volunteer work
- ☐ Playing sport or doing exercise
- ☐ Other social or leisure activities
- ☐ Other (please describe):

**44. How often do you use the Cancer Council Victoria website for information and support for people with cancer
(<https://www.cancervic.org.au/get-support?>)?**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Very often

45. How often do you use Cancer Council Victoria support services (13 11 20 Information and Support service, Counselling service, Financial Counselling Program, Legal Support Program)?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Very often

46. How often do you use other support services (for example, from other cancer organisations)

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Very often

47. If you would like to, please share any other comments about your cancer experience:

That ends our survey. Thank you for your time today!

If the questions have caused you some distress or uncomfortable feelings, and if you need someone to talk to you can call Cancer Council's free, confidential information and support service on 13 11 20.

If you need help with legal, workplace or financial concerns, you can:

- Call Cancer Council Victoria's information and support service on 13 11 20
- Visit cancervic.org.au for free information and resources on cancer as well as dealing with legal, financial and workplace issues when living with cancer
- Contact the Federation of Community Legal Centres to help find free legal support and advice: <https://www.fclc.org.au/> or call (03) 9652 1501
- Contact the National Debt Helpline for free financial counselling: <https://ndh.org.au/> or call 1800 007 007
- Carers Victoria Carer Advisory Service 1800 514 845

If you have any questions about this survey, please contact Tarishi Desai at Tarishi.Desai@mccabecentre.org.

If you would like to share more about your experiences for our research project and potentially be a case study for the project, please email info@mccabecentre.org and we will be in touch with you. Thank you.

Please note that if you email the Research Team, your email address will not be reflected in the survey analysis. Your email address and personal information will be handled in accordance with Cancer Council Victoria's Privacy Policy.

If you have any concerns about this survey, you can also contact the Cancer Council Victoria Human Research Ethics Committee at:

Attention: Research Governance Unit (Strategy & Support Division)

Postal address: Cancer Council Victoria

Level 8, 200 Victoria Parade

East Melbourne, VIC 3002

Email: RGU@cancervic.org.au.

Phone: +61 3 9514 6100 (Cancer Council Victoria general number)

Survey questions – cancer carers

Section 1: About You

In this section, we want to know more about you.

1. How old are you?

- ☐ 18-24 years
- ☐ 25-34 years
- ☐ 35-44 years
- ☐ 45-54 years
- ☐ 55-64 years
- ☐ 65 years and over

2. What is your gender?

- ☐ Man or male
- ☐ Woman or female
- ☐ Non-binary
- ☐ [I/They] use a different term (please describe):

- ☐ I prefer not to say

3. What is your postcode? (Please state): _____

4. Are you of Aboriginal or Torres Strait Islander origin?

- ☐ No
- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, both
- ☐ Prefer not to say

5. What is the main language you speak at home?

[insert drop down list of languages that includes 'prefer not to say' option]

6. What is your country of birth? [insert drop down list of languages that includes 'prefer not to say' option]

7. Are you caring for someone or more than one person living with cancer now?

- ☐ Yes
- ☐ No – I cared for a person(s) with cancer in the past?
Please tell us in what year(s): _____

8. How are you related to the to the person(s) with cancer? (Choose all that apply)

- ☐ Spouse or partner
- ☐ Child
- ☐ Parent
- ☐ Brother or sister
- ☐ Other relative
- ☐ Friend
- ☐ Neighbour
- ☐ Other (please describe):

9. When caring for the person(s) with cancer did you also have to care for someone else?

- ☐ Yes – parent
- ☐ Yes – child
- ☐ Yes – another adult
- ☐ Yes – more than one child
- ☐ Yes – more than one adult
- ☐ No

10. When caring for someone with cancer, have you also had health concerns of your own to manage?

- ☐ Yes
- ☐ No
- ☐ I prefer not to say

**11. What activities did you, or are you doing, to care for someone with cancer?
(Choose all that apply)**

- ☐ Helping with medical care
(such as attending medical appointments with the person, helping the person when they feel unwell, getting their prescriptions and medicines, looking after their paperwork, speaking with their doctors and nurses)
- ☐ Giving practical support
(such as taking the person to their medical appointments, making them meals, doing their shopping, looking after their home, caring for their children, parents or pets, helping them with showering, dressing and going to the toilet, getting them aides and mobility equipment, taking them to visit family or friends, helping them go to leisure activities or events, helping them out online)
- ☐ Giving emotional support
(such as giving comfort, getting them professional support if needed, talking with them about things other than cancer, keeping their family and friends updated)
- ☐ Helping with legal matters
(such as helping the person to understand their rights (e.g. at work), getting them professional legal advice, helping them to organise legal documents, talking to them about end-of-life plans and wishes, being their legal power of attorney, medical treatment decision-maker or executor of their will)
- ☐ Helping with financial matters
(such as paying their bills, dealing with their banks, electricity and internet companies, helping the person sign up for insurance, finding the person sources of financial support, helping the person to sign up for financial support, helping the person plan the future, getting them professional financial advice)

12. Were your carer duties affected by the COVID-19 pandemic?

- ☐ Yes – I was caring for someone with cancer during the pandemic
- ☐ No – I was not caring for someone with cancer during the pandemic

Section 2: Cancer caring and legal issues

Being a carer for someone who has cancer can change your life in many ways. In this section we want to know about your experience.

**13. Have you experienced any of these issues, either because of caring for someone with cancer, or related to caring for someone with cancer?
(Choose all that apply):**

- ☐ Concern about telling your workplace that you care for someone with cancer
- ☐ Unfair treatment (e.g. being treated unfairly at work or losing your job because of your caring responsibilities, discrimination or unfair treatment in accessing goods and services)
- ☐ Difficulty understanding your rights or the rights of the person with cancer (e.g. at work or when receiving medical care)
- ☐ Difficulty with Centrelink to get income support as a carer (e.g. Government Carer Payment or Carer Allowance)
- ☐ Trouble getting a mortgage or a rental property
- ☐ Trouble getting support from the NDIS for the person with cancer
- ☐ Trouble getting support from Carer Gateway
- ☐ Trouble paying your mortgage or rent
- ☐ Problems with debt
- ☐ Making decisions as a power of attorney for the person with cancer
- ☐ Making decisions as the medical treatment decision-maker for the person with cancer
- ☐ Making decisions as legal guardian of the person with cancer
- ☐ Making complaints about the care and treatment the person with cancer had, or that you experienced as their carer
- ☐ Having to carry out duties as executor of their will
- ☐ Trouble getting insurance
- ☐ Trouble using your superannuation early (e.g. to help pay for cancer treatment, or because of financial hardship due to caring for someone with cancer)
- ☐ Difficulty getting insurance claims paid out on the person with cancer's insurance
- ☐ Family law matters (e.g. divorce, child custody)
- ☐ Other (please describe): _____
- ☐ Not Applicable – I have not had these issues

If response is 'Not applicable', then skip Q14–17. Go to Q18.

14. Were these issues expected?

- ☐ Yes
- ☐ No
- ☐ Somewhat

15. How much distress did these issues cause you? (Select one)

- ☐ No distress
- ☐ A little distress
- ☐ Some distress
- ☐ A lot of distress
- ☐ Extreme distress

16. Did you ask for help from a lawyer for any or all these issues?

- ☐ Yes – the lawyer was helpful
- ☐ Yes – the lawyer was helpful for some but not all issues
- ☐ Yes – but the lawyer was not helpful
- ☐ No – I was able to sort out the issues by myself
- ☐ No – I did not know how to find a lawyer
- ☐ No – I could not afford a lawyer
- ☐ No – other reasons (please explain): _____
- ☐ I prefer not to say

17. Did you ask for help from any of these organisations? (Choose all that apply)

- ☐ Australian Financial Complaints Authority
- ☐ Victorian Civil and Administrative Tribunal
- ☐ Consumer Affairs Victoria
- ☐ Fair Work Commission
- ☐ Fair Work Ombudsman
- ☐ Community Legal Centres
- ☐ Victorian Equal Opportunity and Human Rights Commission
- ☐ Commonwealth Ombudsman (e.g. for complaints about Centrelink)
- ☐ Victorian Health Complaints Commissioner
- ☐ Other (please describe) _____
- ☐ No – I did not ask for help from them

Section 3: Cancer caring and the costs of cancer

In this section we want to understand how being a carer for someone with cancer has changed your life and your financial circumstances.

18. Did you have a loss of income after becoming a carer for someone with cancer?

- ☐ Yes
- ☐ No
- ☐ I am not sure

19. How has your financial situation changed since you started caring for someone with cancer?

- ☐ Much worse
- ☐ Worse
- ☐ No change
- ☐ Better
- ☐ Much better

If response is 'No change' then skip Q20–Q21. Go to Q22.

20. How much distress did the change in your financial situation cause you?

- ☐ No distress
- ☐ A little distress
- ☐ Some distress
- ☐ A lot of distress
- ☐ Extreme distress

21. What has contributed to your changed financial circumstances due to caring for someone with cancer? (Choose all that apply)

- ☐ Less pay/income because of fewer hours at work due to caring responsibilities
- ☐ Resigned or retired from work because of caring responsibilities
- ☐ Lost work/was fired because of caring responsibilities
- ☐ Unable to access government income support for carers
- ☐ Travel to take person with cancer to medical appointments and accommodation costs (including petrol, train, bus fares)
- ☐ More household costs (cleaning, in-home paid carers or aides)
- ☐ Other extra costs (extra childcare costs, parking costs, helping the person to pay for treatment, food and meals, paying for meals away from home, changes to the home or new equipment for the person with cancer to use at home)
- ☐ Increase in income due to government financial support (e.g. Carer Allowance)
- ☐ Other (please describe): _____

22. Were the costs due to caring for someone with cancer expected?

- ☐ Yes – costs were as expected
- ☐ No – more costs were more than expected
- ☐ No – costs were lower than expected
- ☐ I am not sure – I did not know what costs to expect

23. How have you (and your household) managed the costs of caring for someone with cancer and or the loss of income due to caring duties? (Choose all that apply)

- ☐ Used savings
- ☐ Changed work situation (me or someone in my household is working longer hours or working more than one job)
- ☐ Got Centrelink payments
- ☐ Mortgage relief (changes to home loan repayments as agreed with lender)
- ☐ Rent relief (changes to rent as agreed with landlord)
- ☐ Financial hardship payment plans (for phone, internet, electricity, gas, water, council rates)
- ☐ Loan from the bank
- ☐ Crowdfunding (e.g. set up a GoFundMe page online)
- ☐ Accessed superannuation
- ☐ Selling shares
- ☐ Sold my business
- ☐ Buying less food and groceries
- ☐ Spending less on non-essential items
- ☐ Selling things (e.g. clothes, car, other items)
- ☐ Financial or other support (e.g. food, clothes) from family or friends
- ☐ Financial or other support (e.g. food, clothes) from charities (including religious organisations)
- ☐ Not going to health appointments for myself or others
- ☐ Not buying or buying less medication for myself or others
- ☐ Delaying or saying no to treatment I need or that my household needs because it costs too much
- ☐ Other (please describe): _____

24. Have you got, or did you get, any financial support? (Choose all that apply)

- ☐ Government Carer Allowance
- ☐ Government Carer Payment
- ☐ Government Carer Supplement
- ☐ Government Carer Adjustment Payment
- ☐ Low Income Health Care Card
- ☐ Carer Gateway financial support
- ☐ Child Disability Assistance Payment
- ☐ Victorian Carer Card
- ☐ Other (please describe): _____
- ☐ No – I have not received financial support

If response is 'No' then skip Q25. Go to Q26.

25. Generally, how easy or difficult was it to access financial support?

- ☐ Very easy
- ☐ Easy
- ☐ Neutral
- ☐ Hard
- ☐ Very hard

26. Did you receive financial counselling or other professional support to manage unexpected costs and or loss of income due to caring for someone with cancer?

- ☐ Yes – financial counsellor
- ☐ Yes – accountant
- ☐ Yes – bank advice
- ☐ Yes – lawyer
- ☐ Yes – financial planner or financial advisor
- ☐ Yes – social worker
- ☐ Yes – National Debt Helpline
- ☐ Yes – Carer Gateway
- ☐ Other (please describe): _____
- ☐ No – no professional support

Section 4: Cancer caring and work

In this section, we want to know how being a carer for someone with cancer has changed how you work and your experience at work.

If you have had more than one employer since being diagnosed with cancer, think about your main employer when answering these questions.

27. What was your paid work status before you started caring for someone with cancer?

- ☐ Not working
- ☐ Not working – full-time parent or carer
- ☐ Full-time work
- ☐ Part-time work
- ☐ Casual work
- ☐ Self-employed/sole trader
- ☐ Independent contractor
- ☐ 'Gig economy' worker (e.g. for Uber, Airtasker, Deliveroo etc.)
- ☐ Looking for paid work
- ☐ Full-time carer for other people (e.g. full-time parent)
- ☐ Retired
- ☐ Other (please describe): _____

28. Are you, or were you, doing paid work while caring for someone with cancer?

- ☐ Yes
- ☐ No

If response is 'No' then skip Q29-37. Go to Q38..

29. How supportive is or was your workplace while you are or were working and caring for someone with cancer? (Select one)

- ☐ Very supportive
- ☐ Supportive
- ☐ Somewhat supportive
- ☐ Not supportive
- ☐ A little distress
- ☐ Some distress
- ☐ A lot of distress
- ☐ Extreme distress

30. Did your workplace offer you any of these things while you were working and caring for someone with cancer? (Choose all that apply)

- ☐ Information about your rights at work as a carer
- ☐ Access to policies or programs to manage working and caring
- ☐ Reduced workload and expectations
- ☐ More time to complete work tasks
- ☐ Flexible work hours
- ☐ Remote work options
- ☐ Part-time schedules
- ☐ Job sharing options
- ☐ Using annual leave for caring
- ☐ Extra paid leave
- ☐ Unpaid leave
- ☐ Taking a long period leave (3 months or more)
- ☐ Regular check-ins with Human Resources manager, other managers or your supervisor
- ☐ Cognitive workplace adjustments (e.g. quiet work environment, more written guidance and less multitasking and distractions)
- ☐ Mental health support
- ☐ Employee Assistance Program
- ☐ A coach or buddy to help you
- ☐ Other (please describe): _____
- ☐ Not applicable (e.g. self-employed)

31. While you were working and caring for someone with cancer, did you experience any of these because of your caring responsibilities? (Choose all that apply)

- ☐ Job loss
- ☐ Resigned
- ☐ Changed job
- ☐ Retired
- ☐ Reduced working hours
- ☐ Stopped being self-employed/independent contractor/closed my business
- ☐ Used up all paid leave
- ☐ Had no paid leave
- ☐ Took a long period of leave (3 months or more)
- ☐ Treated unfairly because of your caring responsibilities (e.g. being demoted, not being promoted, losing your job, being discriminated against)
- ☐ Treated differently by co-workers
- ☐ Feeling stigma in the workplace because of your caring responsibilities
- ☐ Difficulty managing work and caring responsibilities
- ☐ Difficulty getting workplace to agree to flexible work (e.g. part time work, job sharing, remote work options, time off for caring responsibilities etc.)
- ☐ Lack of support from manager, supervisor, and/or Human Resources
- ☐ Not applicable – I had no issues

If response to Q31 does not include 'Job loss', 'Resigned', 'Retired', or 'Took a long period of leave', 'Stopped being self-employed/independent contractor/closed my business', then skip Q36 and Q37.

**32. Did you also experience any of these issues?
(Choose all that apply)**

- ☐ Having to keep working and caring because I feared I would lose my job
- ☐ Having to keep working because I needed the money. But I wanted to stop work to focus on caring for the person with cancer
- ☐ Emotional or psychological challenges (e.g. anxiety)
- ☐ Difficulty balancing workload and productivity expectations
- ☐ Burnout or stress
- ☐ Not applicable – I did not experience these issues

If response to both Q31 and Q32 is 'Not applicable', then skip Q33–35

33. How much distress did all these work issues cause you? (Select one)

- ☐ No distress
- ☐ A little distress
- ☐ Some distress
- ☐ A lot of distress
- ☐ Extreme distress

34. Did these difficulties at work get sorted out?

- ☐ No – I am still experiencing these issues
- ☐ Some of these issues were sorted out but some are still ongoing
- ☐ Yes – all these issues were sorted out

**35. Did you ask for help for any problems at work that you had as a carer?
(Choose all that apply)**

- ☐ Human Resources Manager at work
- ☐ Lawyer (paid a solicitor)
- ☐ Lawyer (lawyer at a community legal centre)
- ☐ Employee Assistance Program
- ☐ Fair Work Ombudsman
- ☐ Union
- ☐ Victorian Equality Opportunity and Human Rights Commission
- ☐ Australian Human Rights Commission
- ☐ Cancer Council Victoria resources and support services
- ☐ Social worker
- ☐ Doctor
- ☐ Other (please describe): _____
- ☐ No – I did not ask for any help

36. If you took a long period of leave (3 months or more) or stopped work or stopped being self-employed to care for someone with cancer, have you gone back to work?

- ☐ Yes – same workplace and same role and hours
- ☐ Yes – same workplace and same role but different hours
- ☐ Yes – same workplace but different role
- ☐ Yes – different workplace/type of work
- ☐ Yes – started my own business/became self-employed
- ☐ No – I am still on leave and planning to go back to work
- ☐ No

If response is 'No', then skip Q37. Go to Q38.

37. How supportive was your workplace when you went back to work after caring for someone with cancer?

- ☐ Very supportive
- ☐ Supportive
- ☐ Somewhat supportive
- ☐ Not supportive

**38. What is your current work status?
(Choose all that apply)**

- ☐ Not working
- ☐ I am looking for paid work
- ☐ Full-time employee
- ☐ Part-time employee
- ☐ Casual employee
- ☐ Self-employed/sole trader
- ☐ Independent contractor
- ☐ 'Gig economy' worker
(for example working for Uber Eats, Deliveroo,
DoorDash etc)
- ☐ Retired
- ☐ Other (please describe): _____

If response is 'Not working' or 'retired', then skip Q39

**39. Does your current workplace have policies to
help staff who have taken time off for caring
to go back to work?**

- ☐ Yes
- ☐ No
- ☐ I do not know
- ☐ Not applicable

Section 5: Impact and resources

**40. Has caring for someone with cancer stopped
you from doing any of these things?**

- ☐ Studying
- ☐ Volunteer work
- ☐ Playing sport or doing exercise
- ☐ Other social or leisure activities
- ☐ Other (please describe): _____

**41. How often do you use the Cancer Council Victoria
website for information and support for cancer
carers ([https://www.cancervic.org.au/get-
support/caring-for-someone-with-cancer/
overview](https://www.cancervic.org.au/get-support/caring-for-someone-with-cancer/overview))?**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Very often

**42. How often do you use Cancer Council Victoria
support services (13 11 20 Information and
Support service, Counselling service, Financial
Counselling Program, Legal Support Program)?**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Very often

**43. How often do you use other support services
(e.g. Carer Gateway, Carers Victoria Carer
Advisory Service, other cancer organisations)?**

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Very often

**44. If you would like to, please share any other
comments about your experience as carer looking
after someone with cancer: _____**

That ends our survey. Thank you for your time today!

If the questions have caused you some distress or uncomfortable feelings, and if you need someone to talk to you can call Cancer Council's free, confidential information and support service on 13 11 20.

If you need help with legal, workplace or financial concerns, you can:

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- Visit cancervic.org.au for free information and resources on cancer as well as dealing with legal, financial and workplace issues when living with cancer
- Contact the Federation of Community Legal Centres to help find free legal support and advice: <https://www.fclc.org.au/> or call (03) 9652 1501
- Contact the National Debt Helpline for free financial counselling: <https://ndh.org.au/> or call 1800 007 007
- Carers Victoria Carer Advisory Service 1800 514 845

If you have any questions about this survey, please contact Tarishi Desai at Tarishi.Desai@mccabecentre.org.

If you would like to share more about your experiences for our research project and potentially be a case study for the project, please email info@mccabecentre.org and we will be in touch with you.
Thank you.

Please note that if you email the Research Team, your email address will not be reflected in the survey analysis. Your email address and personal information will be handled in accordance with Cancer Council Victoria's Privacy Policy.

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Attention: Research Governance Unit (Strategy & Support Division)

Postal address: Cancer Council Victoria

Level 8, 200 Victoria Parade

East Melbourne, VIC 3002

Email: RGU@cancervic.org.au.

Phone: +61 3 9514 6100 (Cancer Council Victoria general number)



Cancer is hard, but finding support shouldn't be. Knowing where to go and when to get support can be overwhelming.

Cancer Council is a key place that you, and the people you care for, can turn to for trusted support.

We're here to support you, now and into the future.

Call **13 11 20** to get confidential information and support today

or visit <https://www.cancer.org.au/support-and-services/cancer-council-13-11-20>

The McCabe Centre for Law and Cancer is located at the Cancer Council Victoria office:

 Level 8, 200 Victoria Parade, East Melbourne Vic 3002

 info@mccabecentre.org

 mccabecentre.org

 [mccabe-centre](https://www.linkedin.com/company/mccabe-centre)