

1. What would you like to see the Australian Cancer Plan achieve?

Think ahead to the next 10 years. What do you want the Australian Cancer Plan to achieve? Think big – what transformational change(s) should we be aiming to influence?

The annual replacement value of informal carers of people living with cancer is estimated at a national income loss of AU\$3.58 billion, which is expected to increase to \$5.33 billion in 2030, an expected 49% increase over 15 years. Informal caregivers are important in the care of people with cancer, both economically and socially, with their role being complex and often lasting for years. Caregivers often assume this role under sudden and extreme circumstances, with minimal preparation and limited guidance and support from the healthcare system. With the introduction of screening programs and improvements in early diagnosis and treatment, cancer is now recognised as a chronic disease, further increasing the burden on carers.

Research shows that patient outcomes are improved when their caregivers are supported yet many carers of people diagnosed with cancer report feeling increasingly isolated and are impacted by significant levels of psychological distress, often greater than that experienced by the patient. Informal carers provide over 60% of the care needs of cancer patients. Patient outcomes improve when their caregivers feel supported, yet 43% of carers of people with cancer report significant unmet needs in balancing the care of the person with cancer and their own self-care, with higher depression associated with unmet needs.

Caring for a person living with cancer is demanding and is so overwhelming it erodes the physical and psychological health of the caregiver. A cancer diagnosis disrupts the daily rhythm of family life and the most common fears of caregivers relate to the lack of preparation to deal with patient-related problems, while almost a third of caregivers are worried about the financial effects of the disease. Despite the extensive involvement of informal caregivers in the management of people with cancer, there are a limited number of existing support services for carers of people living with cancer in general, with fewer, if any, evidence-based solutions available to support carers of people with low survival rates.

The Carer Recognition Act 2010 (the Act) states that carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

We advocate that consistent with the Act, the Australian Cancer Plan identify and include carers as central to the treatment team in caring for people living with cancer. We suggest introducing evidence-based carer services in parallel with patient treatment services from the time of diagnosis, to ensure a tailored approach in the delivery of services that supports both patients and their carers.

2. What are the opportunities with greatest potential to realise your vision?

Think about what you would like the Australian Cancer Plan to achieve. What priorities need national action? In what areas could national action drive or accelerate progress?

There are substantial economic costs to both informal carers and governments due to carers being out of the labour-force to provide informal care for people with cancer. Health and social policies supporting carers to remain in the labour force may allow governments to make substantial savings, while improving the economic situation of carers.

We propose:

1. improve evidence-based delivery of information and support services for carers, that includes a focus on First Nations Australians, Culturally and Linguistically Diverse (CALD) communities, and those living in regional and rural communities

2. create a resource, based on Optimal Care Pathways, designed to address the needs of carers across the cancer spectrum
3. develop interactive digital health platforms, comprising information, support and resources, to assist carers in their caring role and enable shared communication with clinicians across the disease trajectory
4. enable an impact assessment of caring on employment, financial, social and health burden and develop family caregiver care plans that address long-term survivorship
5. identify and assess the impact on carer risk factors associated with caregiving for people with advanced cancer and provide a practical Palliative Care Framework that supports caregivers in palliative care settings

3. What examples and learnings can we build on as we develop the Australian Cancer Plan?

Think about great examples of work within or outside the cancer sector in Australia and internationally. How can we learn from these examples and build on them to improve cancer outcomes and experience for all Australians?

The Victorian Cancer Plan 2020–2024 provides a good example of effectively recognising and supporting the important role of carers.

<https://www.health.vic.gov.au/health-strategies/victorian-cancer-plan>

Below are some international websites where information can be accessed by carers, but it does not appear that this information is readily available as part of the service for people with cancer. Provision of information and support needs to be visible and incorporated into the treatment pathway. We need to build interactive portals that can be tailored for carer needs, including exercise, nutrition, emotional support, home care services, respite etc.

<https://www.cancer.gov/about-cancer/coping/caregiver-support>

<https://cancer.ca/en/living-with-cancer/helping-someone-with-cancer/caregiving>

<https://www.macmillan.org.uk/get-involved/campaigns/carers>

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