

COMMUNITY SUPPORT
ORGANISATIONS'

Cancer Survivorship Care Consensus Statement

DECEMBER 2019

PURPOSE

To articulate the vital role of community support organisations in the provision of survivorship care to Australians of all ages who have been diagnosed with cancer.

AUDIENCE

- primary care providers
- hospital-based providers
- community support organisation providers and patient organisations
- funders
- policy makers (State and Federal Government)
- researchers
- cancer survivors and those affected by cancer

INTENDED USE

To communicate the role of community support organisations in providing survivorship care in order to: promote better understanding amongst audience groups, to consider how community providers can be best incorporated as part of the continuum of care, to improve integrated referral pathways, to support advocacy and collaboration within the sector (including collaborative funding opportunities) and to improve understanding across the health sector more broadly.

Definitions

Community support organisation:

Non-Government Organisation (NGO; also called not-for-profit, charity). This includes cancer-specific organisations and non-cancer specific organisations that provide services to cancer survivors. These may have local, community, state or national remit.

Cancer survivor:

A person who has been diagnosed with cancer, from time of diagnosis through their life. Some people prefer the term 'living with or beyond cancer' or similar. While completion of adjuvant treatment or definitive primary treatment is the starting point for the COSA Model of Survivorship Care,^{1,2} 'cancer survivor' may include people on first-line treatment, or living long term with incurable cancer. This is often called the survivorship phase.

Those affected by cancer:

Cancer can have a lasting impact on family members, friends, colleagues and caregivers. Includes anyone affected by a person's cancer diagnosis.

Preamble

Australian Institute of Health and Welfare data suggests that at the end of 2014, 1,082, 511 people living in Australia had been diagnosed with cancer. With an estimated 144, 713 new cancer diagnoses expected in 2019 and almost 70% of these Australians expected to survive for five years or more, the population living with the chronic health impacts of their cancer and treatment will continue to increase³. By 2040, Cancer Council Australia estimate that almost 1.9 million people will be living with or beyond a cancer diagnosis⁴. The responsibility to provide high quality, evidence-based, comprehensive survivorship care to this population cannot reasonably be expected to fall to any one sector of the Australian health system.

A key challenge for the Australian health system is ensuring the optimal utilisation of all sectors and services. The acute and primary care sectors are overburdened and not consistently able to address the needs of cancer survivors, particularly those with complex or chronic illnesses.

Cancer follow-up approaches predominantly emphasise the monitoring of cancer recurrence and second primaries while paying insufficient attention to psychosocial needs, late effects of cancer and treatment, financial impacts, emergence and management of other chronic illnesses as well as attention to modifiable risk factors such as diet, exercise or smoking.

In 2016, the Clinical Oncology Society of Australia published its Model of Survivorship Care specifying three pillars of survivorship care - survivors themselves, the community, and health professionals¹. The model highlights that the integration of these pillars and their services is essential in achieving a wellness and self-management approach to healthcare. A further article about the model of care was published in late 2019.²

The role of community support organisations in survivorship care

The community sector is broad and diverse, and its role in survivorship care is not always well understood. There are many benefits for cancer survivors and those affected by cancer in strengthening referral pathways from hospital to community support organisations.

Collectively, community support organisations:

1. Are a critical third sector of the Australian health system, targeting a multitude of health conditions, delivering essential services, support, resources and research contributions that relieve considerable burden on the primary and acute care sectors
2. Address many of the care-navigation, psychosocial and information needs of cancer survivors and those affected by cancer
3. Have flexible offerings allowing a person-centred approach to service delivery that is responsive to individual needs
4. Have a focus on health advocacy, through work with government and health service policy makers to ensure equitable and affordable access to best practice survivorship care
5. Take a substantial leadership role in development and delivery of health promotion interventions to address cancer risk behaviours
6. Address equitable access issues by typically providing their services and support at low or no cost to service users, often in non-hospital settings close to where cancer survivors live

What community support organisations offer

The services community support organisations offer cancer survivors and those affected by cancer may include:



The following community support organisations endorse this statement



The Australian Cancer Survivorship Centre (ACSC), based at Peter MacCallum Cancer Centre, convened a number of meetings of Community Support Organisations to discuss work around cancer survivorship. A major recommendation from these forums was the development of a consensus statement. ACSC has facilitated that process. We see this document as a foundational document for future work.

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REFERENCES

- 1 Clinical Oncology Society of Australia Model of Survivorship Care Working Group. Model of Survivorship Care: Critical Components of Cancer Survivorship Care in Australia Position Statement. Clinical Oncology Society of Australia. 2016. <https://www.cosa.org.au/media/332340/cosa-model-of-survivorship-care-full-version-final-20161107.pdf> (accessed 4 September 2019)
- 2 Clinical Oncology Society of Australia position statement on cancer survivorship care. Vardy, J., Chan, R., Koczwara, B., Lisy, K., Cohn, R., Joske, D., Dhillon, H., Jefford, M. *Australian Journal of General Practice*, 48(12), 833-836. <https://www1.racgp.org.au/ajgp/2019/december/clinical-oncology-society-of-australia-position-st> (accessed 2 December 2019)
- 3 Australian Institute of Health and Welfare 2019. Cancer in Australia 2019. Cancer series no.119. Cat. no. CAN 123. Canberra: AIHW. <https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2019/data> (accessed 26 August 2019).
- 4 Cancer Council Australia, Australians living with and beyond cancer in 2040. 2018. February 2018. https://www.cancer.org.au/.../Prevalence%20in%202040_FINAL.PDF (accessed 26 August 2019).