

## Position Statement

March 2015

### Cancer Survivors' Framework for Survivorship Care

**ISSUE:** Australian cancer survivors are calling for a high level framework offering best practice recommendations for survivorship for people diagnosed with cancer.

**BACKGROUND:** There are almost one million (AIHW) cancer survivors who will benefit from a clear framework. This number will increase greatly with our aging population and continuing improvements in diagnosis and treatment.

**Definition:** An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition. *Adapted from the National Coalition for Cancer Survivorship* <http://cancercontrol.cancer.gov/ocs/statistics/definitions.html>, quoted by COSA Position Statement.

A framework about evidence based best practice survivorship for people diagnosed with cancer and their carers should address **what to expect and how to navigate** the post diagnosis cancer journey and beyond. Such a framework would also help health professionals, including cancer specialists and allied health providers in service provision and delivery. This form of best practice guide is the basis for accreditation of cancer centres in some other western countries (eg USA) and a similar reference guide is urgently needed here in Australia.

Cancer consumers recognise that:

- Survivorship begins as first diagnosis and is ongoing
- Best practice service delivery must address both physical and psychosocial needs
- Best practice requires good coordination of services and communication between professionals involved in care and monitoring, and their patients

**RECOMMENDATIONS:** We recommend that a framework be developed with cancer consumer/survivor input to address the following matters:

- means of surveillance for recurrence of the primary cancer and metastases
- commencement and reviews of diagnostic details (eg stage, progression, recurrence), treatment summary and care plan for follow-up
- monitoring and managing treatment and psychosocial effects (immediate and late)
- providing follow-up recommendations for detection of second cancers
- providing information about survivorship issues, physical, practical and psychosocial) and how to find it
- promoting wellness and well-being, not just a focus on illness, including healthy lifestyle strategies, information & support
- communication with GPs and coordination of "shared care" between community care, hospital care and charity/volunteer organisations
- empowering survivors to self-manage and advocate for their own health needs
- rehabilitation around physical, practical (eg "financial toxicity", return to work) and psychological impacts of cancer & its treatment
- management of the presence and/or development of comorbidities which impact on cancer outcomes.
- collect better data about survivorship, with measures that enable national and international comparisons of survivorship outcomes across all stages and population groups

