



**Clinical
Oncology
Society of
Australia**

Model of Survivorship Care

Critical Components of Cancer Survivorship Care in Australia

Position Statement

Version 1.0

November 2016

About COSA

The Clinical Oncology Society of Australia (COSA) is Australia's peak multidisciplinary society for health professionals working in cancer research, treatment, rehabilitation and palliative care. COSA is recognised as an activist organisation whose views are valued in all aspects of cancer care. We are allied with, and provide high-level clinical advice to Cancer Council Australia.

The overarching mission of COSA is to improve the care of Australians affected by cancer. In order to improve cancer care and control in Australia COSA seeks to:

- Understand and provide for the professional needs of its multidisciplinary membership
- Promote and facilitate research across the spectrum of cancer care
- Promote and provide multidisciplinary and interdisciplinary education
- Contribute to, and advocate for, national issues surrounding cancer care policy in Australia
- Enhance the quality of cancer care

The Model of Survivorship Care was produced by a multi-disciplinary Working Group under the COSA Survivorship Group. The primary goal of the COSA Survivorship Group is to improve the care of Australians beyond cancer diagnosis and treatment.

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Executive Summary

In 2013, COSA established a multi-disciplinary Working Group to develop a position statement for COSA and its members and stakeholder groups regarding the critical components of cancer survivorship care in Australia. While acute cancer care includes supportive care and wellness planning, the approach is distinct from that in survivorship services. Therefore, the focus of the first phase of development and implementation of this project is completion of adjuvant treatment or definitive primary treatment.

Essential components of survivorship care summarised by the US Institute of Medicine in 2006 still placed post-cancer treatment emphasis on medical care and deficits rather than optimising outcomes. COSA recommends consideration of modifiable factors associated with better cancer and quality of life outcomes amongst cancer survivors as critical to defining a wellness plan. “Wellness” in cancer incorporates many dimensions and is a patient-centred concept in which people are actively increasing their awareness and making choices which can lead to a more integrated and robust existence.

Fundamental principles underpinning all aspects of the COSA Model of Survivorship Care comprise how it is done (survivor centred, integrated care across all service levels at every time point, coordinated care), what is done (promote, prevent, manage), and availability of care (accessible and equitable).

In order to appropriately meet the needs of individuals and enable cancer survivors to be active participants in their health and treatment, a needs assessment is recommended that includes assessing health literacy early (around the time of diagnosis). During initial anti-cancer treatment and in the transition phase where intensity of treatment is reducing, it may be timely to consider intervening with education, support and referral related to survivor self-management and well-being, that addresses the acute effects of the cancer and its associated treatment. During the transition from intense, regular contact with the cancer care team to follow-up care a needs assessment should include three components: a risk assessment, a treatment summary, and a survivorship care plan.

The three pillars of survivorship care in the Model are survivors themselves, the community, and health professionals (primary care services, allied healthcare services, specialist services). Survivor needs may be best met by one of these pillars or more likely a combination of them. Integration of these pillars and their services is essential in achieving a wellness and self-management approach to healthcare.

It is envisaged that, where possible, survivors will be up-skilled to ensure that they are able to advocate for themselves as well as others in the broader community. It is also anticipated that many survivors will be able to engage in self-management activities.

In the future, models of implementation for survivorship care in Australia need to be considered.

Introduction

Preamble

There have been important failings of post-treatment care of cancer survivors recognised internationally since the early 2000's. Oncology services are finding it increasingly difficult to provide high quality follow-up care to all survivors as numbers grow and resources do not match the growth. It is also clear that the cancer survivor experience varies greatly between individuals, for some it is life as normal, while for others the disease and its treatments impact on their ability to function in daily life.

The recognition that there is a need for post-cancer care to be done better promoted the COSA Survivorship Group to develop this Model of Survivorship Care to support survivors, healthcare providers, healthcare administrators, government, and non-government organisations to consider how to deliver better care to survivors without negatively impacting cancer recurrence and survival outcomes.

Background

The **LIVESTRONG** Survivorship Centers of Excellence Network was established in 2005 to advance survivorship care and improve the health and quality of life of cancer survivors. The Network spent several years testing high-level elements of survivorship care outlined in the 2006 US Institute of Medicine report "From Cancer Patient to Cancer Survivor - Lost in Transition".¹

In 2010, **LIVESTRONG** and the Network sought to collaborate with other stakeholders in order to develop the essential elements of care delivery that would represent the expectations for what constitutes an effective cancer survivorship program. The Essential Elements

of Survivorship Care Meeting (Essential Elements Meeting) was held in Washington, DC on 15-16th September 2011. The 150 stakeholders attending the meeting were led through a series of consensus building activities to refine a list of the most important components of survivorship care that programs should provide.

Following this meeting, there was excellent support from stakeholders to develop an Australian list of essential elements of survivorship care, and consider a national approach to survivorship care planning and delivery.

In February 2013, COSA established a multi-disciplinary Working Group, including a cancer consumer, to develop a position statement on the critical components of cancer survivorship care in Australia.

Objective

The objective of this project was to develop a position statement for COSA and its members and stakeholder groups defining the critical components of cancer survivorship care. The guiding questions for the project were:

- What are the critical components of survivorship care in Australia?
- What defines quality survivorship and how can it be survivor-centred?
- How can we deliver a minimum standard of survivorship care in Australia?

A further objective was to develop an action plan to support staged implementation of cancer survivorship care across a range of Australian healthcare settings. The issues around implementation of the Model in Australia will be examined as a part of the future work of the COSA Survivorship Group.

Cancer Survivorship

Definition of Survivorship

“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”.

<http://cancercontrol.cancer.gov/ocs/statistics/definitions.html>
Adapted from the National Coalition for Cancer Survivorship

Many alternatives have been suggested, including “thrivers” and “someone who has had cancer”.² Currently, there is no consensus beyond the term cancer survivor. Consequently, the COSA Model of Survivorship Care uses the term cancer survivor.

The broad definition of cancer survivorship is acknowledged to include the full gamut of patient experiences and the concept of cancer as a chronic illness, as well as those of caregivers, families and friends of a person diagnosed with cancer. There is a need to reflect this position in policy, practice and research. However **completion of adjuvant treatment or definitive primary treatment is the starting point for the COSA Model of Survivorship Care**, a position that is in line with the international survivorship focus and the seminal US Institute of Medicine Report. This should not be a barrier to using the Model to support wellness in people living long term with incurable cancer.

Why is a Model of Survivorship Care Needed?

Historically, the emphasis of follow-up care of cancer survivors has focused on monitoring for cancer recurrence and second primary cancers, with little attention given to the late effects of cancer and its treatment, other chronic illnesses, or modifiable risk factors. However, it is well recognised that the number of people

surviving for long periods after a cancer diagnosis have increased. Not only are the numbers increasing, so is the proportion of the population affected. Cancer survivors experience increased rates of comorbid, chronic health conditions, and while their healthcare needs are complex they are likely amenable to change.

Current models of care for cancer survivors are not survivor-centred, coordinated, or accessible. Nor do they effectively manage and minimise the burden of disease and treatment-related side effects in the post-treatment phase. Internationally there has been a substantial move towards the development of better models of cancer survivorship care to optimise survival times and quality of life. The evidence base for care in the survivorship setting is limited. To deliver healthcare effectively to those most in need we need a system with greater emphasis on integration across sectors that addresses the health needs of survivors to ensure that the level of care and intervention accessed meets their needs and potential health risks.

Any model of care must address the differing needs of three distinct stakeholders: individuals, health professionals, and the system. Care for the individual must meet their post-cancer care needs, for the health professionals it must be feasible, and for the system it should result in greater efficiency.

The US Institute of Medicine defined the essential components of survivorship care as including:

1. Prevention of recurrent and new cancers, and of other late effects;
2. Surveillance for cancer spread, recurrence, or second cancers; assessment of medical,

physical and psychosocial acute and late effects;

3. Intervention for consequences of cancer and its treatment, for example: medical problems such as lymphoedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; disabilities of function in daily living; and concerns related to social participation including employment and insurance; and
4. Coordination between specialists and primary care providers to ensure that all of

the survivor's health needs are met.

There is no doubt that care that addresses these four factors will vastly improve the post-cancer experience. However, the emphasis of post-cancer treatment continues to be placed on medical care and deficits rather than optimising outcomes. Consequently, COSA recommends consideration of modifiable factors associated with better cancer and quality of life outcomes amongst cancer survivors as critical to defining a wellness plan, particularly one that emphasises improved quality of life.

Wellness in Cancer

In 2006 the World Health Organisation (WHO) added a definition of wellness to its glossary of terms. The decision reflects an increasing emphasis on health and well-being rather than only the absence of disease or illness. As the long-term and/or late effects of living with cancer and its treatment have become increasingly recognised, so the concept of wellness in cancer survivorship has emerged as an aspirational goal for survivors and the health professionals involved in their care.

Definition of Wellness

Since 1948 WHO has defined health as *“a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”*³ Policy and guidance documents have previously emphasised the term “well-being”, more recently wellness has been defined as *“the optimal state of health of individuals and groups. There are two focal concerns: the realization of the fullest potential of an individual physically, psychologically, socially, spiritually and economically, and the fulfilment of one's role expectations in the family, community, place of worship, workplace and other settings.”*⁴

Some models of wellness have existed since the 1970's, usually in the context of complementary, alternative, and integrative medicine.⁵ The National Wellness Institute has developed the Six Dimensions of Wellness Model,⁶ which incorporates the following dimensions of wellness:

- Physical: recognising the need for regular physical activity and gaining knowledge on diet and nutrition. Benefits from this dimension often lead to psychological benefits such as enhanced self-esteem, self-control, determination and a sense of direction.
- Social: encouraging a contribution to one's environment and community that can enhance personal relationships, improve one's living space and build a better community.
- Intellectual: recognising one's creative, stimulating mental activities and exploring issues related to problem solving, creativity, and learning.
- Spiritual: recognising the search for meaning and purpose in human existence so that one's actions become more consistent with their own beliefs and values.

- Emotional: recognising awareness and acceptance of one's feelings so that feelings can be expressed freely and managed effectively.
- Occupational: recognising personal satisfaction and enrichment in one's life through work. Important components include choice of profession, job satisfaction, career ambitions, and personal performance.

Other models focus on the following five dimensions as impacting wellness:

- Physical
- Social
- Spiritual
- Lifestyle
- Mental

These factors can also affect sexuality, which is experienced and expressed through sexual behaviours and relationships, and contribute to overall sexual health and well-being.⁷

The terms wellness and well-being are commonly used interchangeably. However, as wellness models evolve and become better supported by evidence, it is likely that well-being will be considered a component of wellness.

The common underlying factor is that wellness focuses holistically on the person and ability to live the life they desire, rather than focusing on disease, its prevention or amelioration. It is a patient-centred concept in which people are actively increasing their awareness and making choices which can lead to a more integrated and robust existence.

Recovery-Oriented Practice

Recovery is a concept related to wellness, emerging during the 1970s and 1980s as part of the consumer health movement. It is a concept

recognised in mental health policy and services internationally. The concepts of clinical and personal recovery are commonly used: clinical recovery, defined by mental health professionals, refers to the reduction or cessation of symptoms, a restoration of function. While personal recovery, defined by the individual, refers to ongoing holistic process of personal growth, healing, and self-determination. There are clear parallels between the concept of recovery and wellness as they relate to cancer survivorship. Recovery is one of the principles underpinning the COSA Model of Survivorship Care, encompassing the concepts of self-determination, self-management, personal growth, empowerment, and choice.

Recovery-oriented practice aims to support people in building and maintaining meaning and satisfaction in their lives and identity, regardless of their ongoing experience of symptoms of their cancer and its treatment. This is a more holistic approach to recovery and well-being that builds on individual strengths, reflecting a shift from the biomedical view of illness.

As the principles of self-determination and individualised care are key to recovery-oriented practice, the concepts of hope, inclusion, community participation, goal setting, and self-management are emphasised. To successfully build these concepts at a personal level, service provision promotes coaching or partnership relationships between individuals and their healthcare providers. Thus, individuals with lived experience are expert on their own lives, with health professionals expert on the available healthcare and lifestyle interventions in their area.

The journey for any cancer survivor is individual, and unlikely to be linear, but can promote recovery to wellness.

COSA Model of Survivorship Care

The COSA Model of Survivorship Care is shown in Appendix 1 (see Figure 1 & 2).

Principles of Care

Fundamental principles underpinning all aspects of the Model of Survivorship Care comprise how it is done (survivor centred, integrated care across all service levels at every time point and coordinated care), what is done (promote, prevent, manage) and availability of care (accessible and equitable):

- **Survivor (person) centred**⁸ in that it:
 - *Enables* individuals to participate in decision-making that will positively influence their health and well-being;
 - *Engages* individuals to motivate them to make positive health choices; and
 - *Empowers* them to seek information and support from the services most suitable to their needs at any given time.
- **Integrated care** across all service levels at all time points to ensure survivors have access to the right care, at the right intensity, at the right time (Figure 3).



Figure 3. Integration of care for cancer survivors

- **Coordinated care** across all services.
- **Promote** well-being by emphasising behaviours and actions that support wellness rather than focus on illness; **prevent** illness by supporting survivors to engage in lifestyle behaviours, self-care and preventative health checks that are appropriate to maintain health; **manage** symptoms and problems.
- Care that is **accessible and equitable**.

Needs Assessment and Care Pathways

The Model of Survivorship Care recognises that survivor-centred care is best offered from the beginning of any individual's cancer journey. Workforce and system related barriers that need to be addressed to facilitate the change from illness to wellness models of care should be considered. Inherent in this Model of Survivorship Care is the recognition that individuals come to their cancer diagnosis with a range of life and health experiences. Specific issues relating to the individual's stage of life should also be considered when providing survivorship care. For example adolescent and young adult (AYA) care may be impacted by issues such as fertility, peer-relations and disconnection with community services.⁹

Therefore in order to appropriately meet the needs of individuals a *needs assessment* that includes assessing health literacy early (around the time of diagnosis) will contribute to survivors, caregivers, and health professionals effectively establishing a partnership that enables the survivor to be an active participant in their health and treatment. During initial anti-cancer treatment and in the transition phase where intensity of treatment is reducing, it may be timely to consider intervening with education, support and referral related to

survivor self-management and well-being, that addresses the acute effects of the cancer and its treatment on the following areas:

- Physical
- Psychological
- Social
- Spiritual
- Lifestyle
- Career/work
- Environmental

During the transition from intense, regular contact with the cancer care team to follow-up care an assessment of survivor needs is recommended. This should include three components: a risk assessment, treatment summary, and survivorship care plan.

Stratified pathways of care will be influenced by:

- Assessing the level of risk for disease related comorbidity and recurrence, dependent on the tumour type;
- Short, medium and long-term treatment sequelae;
- Existing comorbidities;
- Survivor ability and motivation to engage and self-manage;
- Level of professional involvement required.

A **survivorship care plan** is a tool to facilitate care. It will deliver greatest benefit if it is used and regularly reviewed, that is it needs to be action based. A survivorship care plan can include the treatment summary and the outcomes of the risk assessment. It is a living resource document, not a static historical one.

The survivorship care plan should:

- Include recommendations, with priorities, for other education, supportive care and healthy lifestyle interventions, and referral to other health professionals;
- Be developed and disseminated in a timely manner, involving all relevant health professionals, including GPs;
- Be updated by health professionals involved with supporting the survivor;
- Include space for the individual to make notes themselves;
- Be regularly reviewed with the GP and other health professionals;
- Be communicated to all relevant parties when changes or updates are made.

Survivorship care plans, ideally, will be owned by survivors themselves and used by all health professionals to ensure seamless integration of care for the individual.

Care Coordination is a critical component of a workable model of survivorship care. Coordinated care will:

- Place the survivor and their needs at the centre of the wellness and healthcare interactions with those providing support, assistance and care;
- Facilitate communication between all health professionals including GPs and others involved in supporting survivors;
- Ensure that survivors are able to access the services that they need at the time they need them;
- Ensure regular review of the individual's needs in the context of their ongoing survivorship care plan;
- Ensure appropriate follow-up for cancer recurrence and late effects of treatment.

Time Factors are another set of components that are critical to a workable model of survivorship care. They serve to reassure survivors and the health professionals involved in their care that:

- Survivors engage with the services (healthcare, lifestyle, professional, etc.) they need when they need them;
- The priorities and needs of the individual survivor will be addressed from most to least urgent;
- Time spent by survivors in healthcare environments is minimised to that required to improve and/or maintain their health and well-being;
- Survivors have rapid access to healthcare support when required for cancer and treatment related events;
- Survivor and health care resources are not spent on unnecessary tests, treatments, and health encounters.

A **treatment summary** will be potentially useful to survivors and all health professionals involved in supporting the survivor in the future, including general practitioners (GPs), allied health professionals, rehabilitation specialists, and cancer specialists.

Ideally the treatment summary would:

- Be automatically generated from the electronic medical record;
- Include diagnosis and disease details (date, type, location, stage);
- Include treatment details (dates, surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy, other supportive care interventions accessed).

There are a series of **tools** that may support individual survivors and the health professionals involved to deliver more efficient and effective outcomes. These include, but are not limited to:

- Needs assessment tools;
- Survivorship care plan (preferably electronic);
- Directory of services and accredited health professionals;
- Referral pathways;
- Motivational interviewing techniques and skills;
- Telehealth tools;
- Information and support services.

Three Pillars of Survivorship Care

The three pillars of survivorship care are survivors themselves, the community, and health professionals. It is essential to understand that health professionals referred to here incorporates primary care services, allied healthcare services, and specialist services (see Figure 2 in Appendix 1).

All three pillars have a role to play in surveillance, education, coordinated care, and advocacy. Contingent on a survivor's needs they may be best met by one or other of these pillars, or more likely a combination of them. Integration of these pillars and their services is essential in achieving a wellness and self-management approach to healthcare.

Survivors

It is envisaged that *survivors* will be up-skilled to ensure that they are able to advocate for themselves and their need for access to services, as well as advocating for others in the broader community. Education of themselves, their family and social group is a key role for survivors. It is also anticipated that survivors will be able to engage in self-management activities including:

- Surveillance for cancer recurrence;
- Surveillance for second primary cancers;
- Self-monitoring for signs and symptoms of cancer and side-effects;
- In the context of multi-disciplinary collaborative care encompassing the following areas:
 - Physical
 - Psychological
 - Social
 - Spiritual
 - Lifestyle
 - Career/work.

While **self-management** is being advocated in the COSA Model of Survivorship Care, it is acknowledged that some survivors may prefer not to engage in self-management activities, and that some will not have sufficient health literacy and life skills to do so.

It is critical that survivors and health professionals alike understand that patient preference must be taken into account in planning survivorship support.

Regardless of their preference, survivors should be supported in line with their values and preferences and best available evidence.

Community Services and Support

The *community services and support* (including caregivers and family) are those least integrated into models of care in the cancer setting. Community services may include primary care practices, allied healthcare services, centralised non-government organisation services, in particular Cancer Council Australia and its affiliated state bodies, consumer groups, and so on. They have distinct roles in supporting self-management by:

- Providing information about self-management and self-monitoring;
- Advising survivors when and where to seek the support most appropriate for them;
- Providing access to educational opportunities through:
 - Support groups
 - Psycho-educational programs
 - Online support tools;
- Contributing to multidisciplinary collaborative care for self-management programs; counselling and physical activity.

Community services have a substantive role to play in advocating for service provision and access to services. As they have a community-based funding stream it is important that their role in service delivery and support is fully recognised. With the increasing numbers of cancer survivors and a limited pool of resources, centralised organisations like the Cancer Councils are well-placed to deliver evidence-based and continuously improving services.

Community support groups are an excellent forum for people affected by cancer to access information from health professionals and share ideas and experiences with each other. Peer support or the lived experience, is an important part of the continuum of care for people affected by cancer. Being able to meet someone who has been through or who is going through a similar experience is empowering regardless of prognosis. It is especially valuable to meet others living well with their diagnosis, and can have a major impact on a person's ability to adjust positively to such an event. An unspoken bond exists between people who have been diagnosed with cancer and this connection in itself is therapeutic. Successful survivorship incorporating peer support appreciates there are no time lines for wellness and for dealing with issues following a cancer diagnosis.

Health Professionals

All health professionals have a distinct role in education about the goals of care and wellness more broadly. They are positioned to engage in advocacy for the wellness of individual survivors at one level and for survivorship care services at the system level.

Primary care doctors (GPs), are the central point of contact between individuals and the healthcare system. Their role is to provide

general, comprehensive healthcare and support to survivors and referral to specialist care when it is required.

Specialist care in the survivorship setting should be provided for those people with complex needs that may include severe and/or complex late effects of their anti-cancer treatment. Specialist care encompasses a range of health professional services (exercise physiology, medical, nursing, nutrition, speech therapy, occupational therapy, physiotherapy, psychology, rehabilitation services, and social work). Specialist care is likely to be provided across both the primary health and hospital-based settings. Although rehabilitation is rarely considered part of cancer survivorship care, individuals may derive substantial benefits from a comprehensive rehabilitation plan, including rehabilitation physician involvement, as an interim step between acute cancer care and wellness in survivorship.

An important part of the role of health professionals is surveillance and multidisciplinary collaborative care for:

- Screening and assessment for cancer, other chronic health conditions, and physical and psychosocial issues;
- Preventative care strategies;
- Appropriate use of diagnostic procedures;
- Treatment;
- Symptom management;
- Advice about and referral to other health professionals to manage late-effects in the following areas:
 - Physical (including those who are undernourished due to disease and/or treatment)
 - Psychological
 - Social
 - Spiritual.

Health Literacy Skills

Health literacy can be defined as having the skills to “obtain, process and understand basic health information and services needed to make appropriate health decisions”.¹⁰ Cancer survivors engaging in self-management will require a sufficient level of health literacy to do so effectively. However, data suggest that up to 60% of the general Australian population lack basic health literacy skills needed to understand health-related materials,¹¹ and experience poorer health and clinical outcomes as a result.¹²⁻¹⁵ Currently available written health materials commonly require high literacy and numeracy skills. Health professionals are

known to have a low awareness of low literacy and few engage in active assessment of this skill in cancer survivors.^{16,17} Increased awareness of health literacy amongst health professionals will be essential in addressing this gap in the implementation of self-management strategies by cancer survivors. Awareness training for health professionals will be necessary to assist them to identify this silent population, as well as evidence-based interventions to overcome health literacy challenges in communication and the ability of cancer survivors to implement self-management programs and change their lifestyle.

Survivorship Care Plan for Wellness

The proportion of people living long after their initial cancer diagnosis, either disease-free or with active cancer that they manage on a daily basis, is increasing. Consequently there has been a shift in thinking towards encouraging and supporting survivors and caregivers to develop the skills to be effective self-managers of their condition. Development of resources to support self-management is a growing area; for example, the UK-based toolkits to support health professionals support survivors to

develop self-management skills (see grey box on page 14).

The COSA Model of Survivorship Care aims to incorporate the individual factors required to facilitate wellness in cancer survivors.

Existing self-management resources for long-term conditions (not cancer specific) are shown in Table 1.

Table 1. Self-management resources

Resource	Link
Expert Patient Programme	http://www.expertpatients.co.uk
Long Term Conditions Alliance Scotland	http://www.alliance-scotland.org.uk
Stanford Self Management Programmes	http://patienteducation.stanford.edu/programs/
Flinders Human Behaviour & Health Research Unit	http://www.flinders.edu.au/medicine/sites/fhbhru/

The **UK National Cancer Survivorship Initiative** recommends the following pointers for effective-self management:¹⁸

- Tailored information - increases knowledge and prepares patients for change, and should be provided to all survivors. Additional tailored support and ongoing input from health professionals will be needed to help some people use this information.
- Self-efficacy (the confidence to use self-management skills successfully). Achieved through mastery, vicarious experience, verbal persuasion, and physiological feedback.
- One size does not fit all. There is a patient 'self-management journey' and individuals need to be assessed for their understanding and confidence for self-management along the continuum of skill and confidence so that self-management support can be tailored.
- Collaborative partnerships between patients and health professionals empower patients to take on responsibility for their health and well-being. Clinicians can learn specific communication skills that foster effective partnership with patients.
- Self-management support interventions can be designed, taking account of three factors:
 - Type: adjustment focused (facilitating transition to survivorship) or problem focused (e.g. exercise for fatigue, enhancing coping skills) or a combination of both;
 - Delivery: in a group; one to one; technology-based; home-based; peer-led; professionally-led; or a combination designed for impact;
 - Techniques: goal setting; action plans; problem solving; self-monitoring; stress management; information provision; sharing experiences; counselling; coaching; motivational interviewing; feedback; peer modelling.

Implementation Plans

The COSA Model of Survivorship Care depicts the stages, factors, and processes that should be considered in planning, developing, and adapting survivorship services to support people living after the completion of adjuvant treatment or definitive primary treatment for their cancer.

It does not provide guidance on how the Model of Survivorship Care should be implemented in Australia. Implementation science is a complex and discrete area of healthcare. There are a number of important factors that are essential to address in order to successfully implement a model of care including the relationship of individuals to the evidence, the context in which the model is being introduced and facilitation of the process. While identifying

barriers and facilitators is an important step, developing strategies and tailoring them to the specific contexts and services in which the planned change will occur is critical. Iterative processes of consultation are important to ensure that local barriers are addressed and that local facilitators are not removed. Consequently, work to support the implementation of this Model of Survivorship Care requires consideration of the local, regional, state, and national contexts; without local input implementation will likely fail.

The issues around implementation of the Model of Survivorship Care in Australia will be examined as a part of the future work of the COSA Survivorship Group.

Proposed Future Work & Recommendations

- Include proposed screening tools (broad and specific) in models of survivorship care
- Develop tools to support health professional education and training, and the implementation of guidelines in practice
- Consider performance indicators of quality service delivery within this or alternative models
- Consider whether the critical components as proposed adequately address these issues, particularly for AYAs and other underserved populations e.g. CALD, indigenous Australians, and those with rare and less common cancers
- Identify ongoing Australian and international research to consider strategies and models for implementation of survivorship care
- Identify professional development resources for healthcare workers to upskill in cancer survivorship
- Identify and adapt effective interventions for the Australian environment
- Review existing resources to determine applicability to Australian context
- Tailor existing resources (with permission) for Australian context
- Make resources available to the Australian cancer community and the community more broadly
- Identify gaps in resource implementation (e.g. CALD, low health literacy, vision impaired).

References

1. Institute of Medicine, National Research Council of the National Academies. From Cancer Patient to Cancer Survivor - Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine Symposium Washington, DC: National Academies Press, 2006.
2. Bell K, Ristovski-Slijepcevic S. Cancer survivorship: why labels matter. *J Clin Oncol* 2013; **31**(4): 409-11.
3. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948, 1948.
4. Smith BJ, Tang KC, Nutbeam D. WHO Health Promotion Glossary: new terms. *Health Promot Int* 2006; **21**(4): 340-5.
5. Pacific Northwest Foundation. Definitions of health/wellness. <http://www.pnf.org> (accessed July 1 2014).
6. Hettler B. Six Dimensions of Wellness Model. 1976. http://www.nationalwellness.org/?page=Six_Dimensions2014.
7. World Health Organisation. Defining sexual health: report of a technical consultation on sexual health, 28-31 January 2002, Geneva. Geneva, Switzerland: World Health Organisation, 2006.
8. Lorig K. Patient-Centered Care: Depends on the Point of View. *Health Educ Behav* 2012; **39**(5): 523-5.
9. CanTeen. Exploring survivorship care for adolescent and young adult cancer survivors in Australia. Sydney, Australia: CanTeen (unpublished), 2015.
10. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promot Int* 2000; **15**: 259- 67.
11. ABS. Adult Literacy and Life Skills Survey, Summary Results. Canberra, Australia: Australian Bureau of Statistics, Australian Government Publishing Service, 2006.
12. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011; **155**(2): 97-107.
13. Davis TC, Williams MV, Marin E, Parker RM, Glass J. Health literacy and cancer communication. *CA Cancer J Clin* 2002; **52**(3): 134-49.
14. Lillie SE, Brewer NT, O'Neill SC, et al. Retention and use of breast cancer recurrence risk information from genomic tests: the role of health literacy. *Cancer Epidemiol Biomarkers Prev* 2007; **16**(2): 249-55.
15. Schillinger D, Bindman A, Wang F, Stewart A, Piette J. Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Educ Couns* 2004; **52**(3): 315-23.
16. Kelly PA, Haidet P. Physician overestimation of patient literacy: a potential source of health care disparities. *Patient Educ Couns* 2007; **66**(1): 119-22.
17. Manning DL, Dickens C. Health literacy: more choice, but do cancer patients have the skills to decide? *Eur J Cancer Care (Engl)* 2006; **15**(5): 448-52.
18. NHS Improvement Cancer. Innovation to implementation: Stratified pathways of care for people living with or beyond cancer A 'how to guide'. United Kingdom: National Health Service; 2013.

Other Resources

Additional guidelines used to develop the COSA Model of Survivorship Care, or that may be of interest, include:

- Promoting mental health: concepts, emerging evidence, practice: World Health Organization, Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne, 2005.
- McMillan Cancer Support. Routes from diagnosis: the most detailed map of cancer survivorship yet. London, United Kingdom: McMillan Cancer Support; 2013.
- National Cancer Survivorship Resource Center. Quality of Life: Information Delivery Expert Panel Summit Workgroup Overview, 2012.
- National Cancer Survivorship Resource Center. Policy/Advocacy: Expert Panel Summit Workgroup Overview, 2012.
- National Cancer Survivorship Resource Center. Systems Policy and Practice: Clinical Survivorship Care Expert Panel Summit Workgroup Overview, 2012.
- Hacker ED, Larson J, Kujath A, Peace D, Rondelli D, Gaston L. Strength Training Following Hematopoietic Stem Cell Transplantation. *Cancer Nurs* 2011; **34**(3): 238–49.
- Denlinger CS, Carlson RW, Are M, et al. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Survivorship, 2013.
- Exercise & Sports Science Australia. Exercise is Medicine® Australia Education evaluation summary. 2014.
- Hawkes AL, Chambers SK, Pakenham KI, et al. Effects of a Telephone-Delivered Multiple Health Behavior Change Intervention (CanChange) on Health and Behavioral Outcomes in Survivors. *J Clin Oncol* 2013; **31**(18): 2313-21.
- Hudson MM, Ness KK, Gurney JG, et al. Clinical Ascertainment of Health Outcomes Among Adults Treated for Childhood Cancer. *JAMA* 2013; **309**(22): 2371-81.
- Khatcheressian JL, Hurley P, Bantug E, et al. Breast cancer follow-up and management after primary treatment: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol* 2013; **31**(7): 961-5.
- Landier W, Hawkins S, Leonard M, et al. Establishing and Enhancing Services for Childhood Cancer Survivors: Long-term follow-up program resource guide: Children's Oncology Group, 2007.
- LiveStrong. Essential Elements Ranking Tool. 2012.
- McMillan Cancer Support. Supporting your service: a best practice guide to working with volunteers in social care services. London, United Kingdom: McMillan Cancer Support; 2012.
- **LIVESTRONG** Essential Elements of Survivorship Care Meeting. Identifying the universe of elements of survivorship care, 2011.
- National Cancer Survivorship Resource Center. Policy/Advocacy: Expert Panel Summit Workgroup Overview: National Cancer Survivorship Resource Center, 2012.
- Scottish Intercollegiate Guidelines Network. Long term follow up of survivors of childhood cancer: A national clinical guideline. Edinburgh, United Kingdom: Scottish Intercollegiate Guidelines Network, 2004.
- Oeffinger KC, Argenbright KE, Levitt GA, et al. Models of Cancer Survivorship Health Care: Moving Forward. *ASCO Education Book* 2014.

- Centers for Disease Control and Prevention. Well-being Concepts. 2013. <http://www.cdc.gov/hrqol/wellbeing.htm>.
- Roberts K, Faithful S, Robb K, et al. Improving cancer patient experience: A top tips guide: McMillan Support, 2012.
- Silver JK, Baima J. Cancer prehabilitation: an opportunity to decrease treatment-related morbidity, increase cancer treatment options, and improve physical and psychological health outcomes. *Am J Phys Med Rehabil* 2013; **92**(8): 715-27.
- Skinner R, Wallace WHB, Levitt GA. Therapy based long term follow up: Practice Statement. 2nd ed. Sheffield, United Kingdom: United Kingdom Children's Cancer Study Group; 2005.
- American Cancer Society. Cancer Treatment & Survivorship: Facts and Figure 2012-2013. Atlanta, 2012.
- McMillan Cancer Support. Improving the quality of cancer care in primary care: A practical guide for GP appraisal and revalidation. London, United Kingdom: McMillan Cancer Support; 2012.
- The Royal Australian College of General Practitioners. Guidelines for preventive activities in general practice. 9th ed. East Melbourne, Vic: RACGP; 2016.
- McMillan Cancer Support. Facing the fight alone: Isolation among cancer patients. London, United Kingdom: McMillan Cancer Support; 2013.
- McMillan Cancer Support. Providing person-centred cancer care in Wales: A guide for local health boards. London, United Kingdom: MacMillan Cancer Support; 2013.
- McMillan Cancer Support. Evaluation of Phase 1 of the One-to-One Support Implementation Project: Baseline report. London, United Kingdom: MacMillan Cancer Support; 2014.
- Swedish Working Group for Long-term Follow-up after Childhood Cancer SALUB, Hjorth L, Moëll C, et al. Follow-up after childhood cancer, 2010.
- Cancer Australia. Draft Principles of Cancer Survivorship: Living with and beyond cancer. Sydney, Australia: Cancer Australia 2016.

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Model of Survivorship Care: Appendix 1

Cancer Survivorship: Living well with and beyond a cancer diagnosis

PRINCIPLES OF CARE

- Survivor centred (enabling, engaging, empowering)
- Integrated care across all service levels at every time point
- Coordinated care
- Promote, prevent, manage
- Accessible and equitable

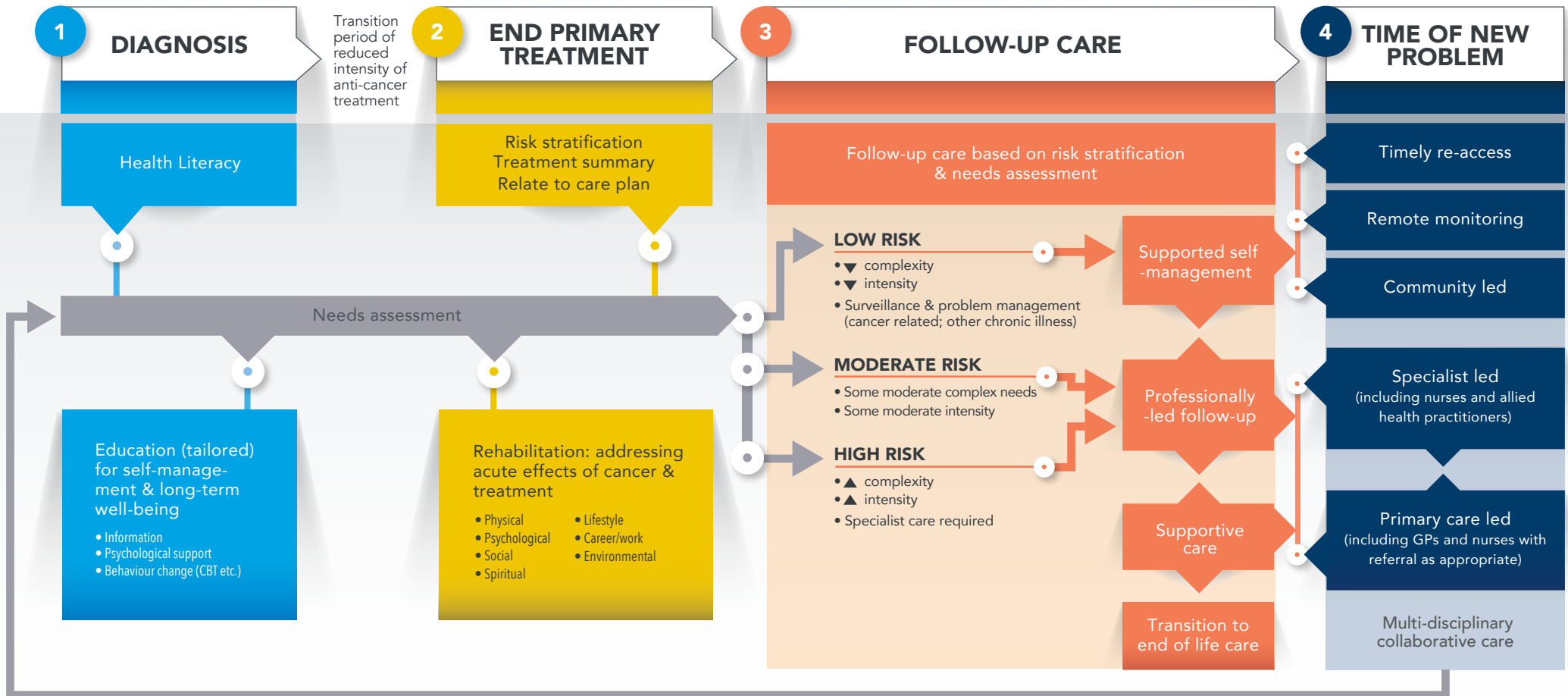


Figure 1. Model for wellness in cancer survivorship

RISK STRATIFICATION

- Level of risk associated with cancer type
- Needs assessment
- Short & long term effects of treatment
- Comorbidities
- Patient ability & motivation to self-manage
- Level of professional involvement required

CARE PLAN

- Aims to document main concerns of survivor & health professional & agreed actions for:
 - Surveillance
 - Management
 - Discussion
 - Patient action
 - Rehabilitation
 - Clinical team follow-up, sign posting on referral

CARE COORDINATION

- Places survivor & their needs at centre of healthcare & wellness interactions
- Facilitates communication between all health professionals
- Gets survivors to the right services at the right time
- Ensures regular review of survivorship care plan and survivor needs
- Ensures appropriate follow-up for cancer recurrence and late effects of treatment

TIME FACTORS

- Survivors engage with services they need when they need them
- Survivor priorities & needs are addressed from most to least urgent
- Survivor time in healthcare environments is minimised to that required to maintain health & well-being
- Survivors have rapid access to healthcare support when required for cancer & treatment related events
- Resource use is minimised to the level that is effective and meaningful

TOOLS

- Needs assessment tools
- Care plan (electronic)
- Directory of services
- Referral pathways
- Motivational interviewing
- Telehealth tools
- Information & support services

Model of Survivorship Care: Appendix 1

Cancer Survivorship: Living well with and beyond a cancer diagnosis

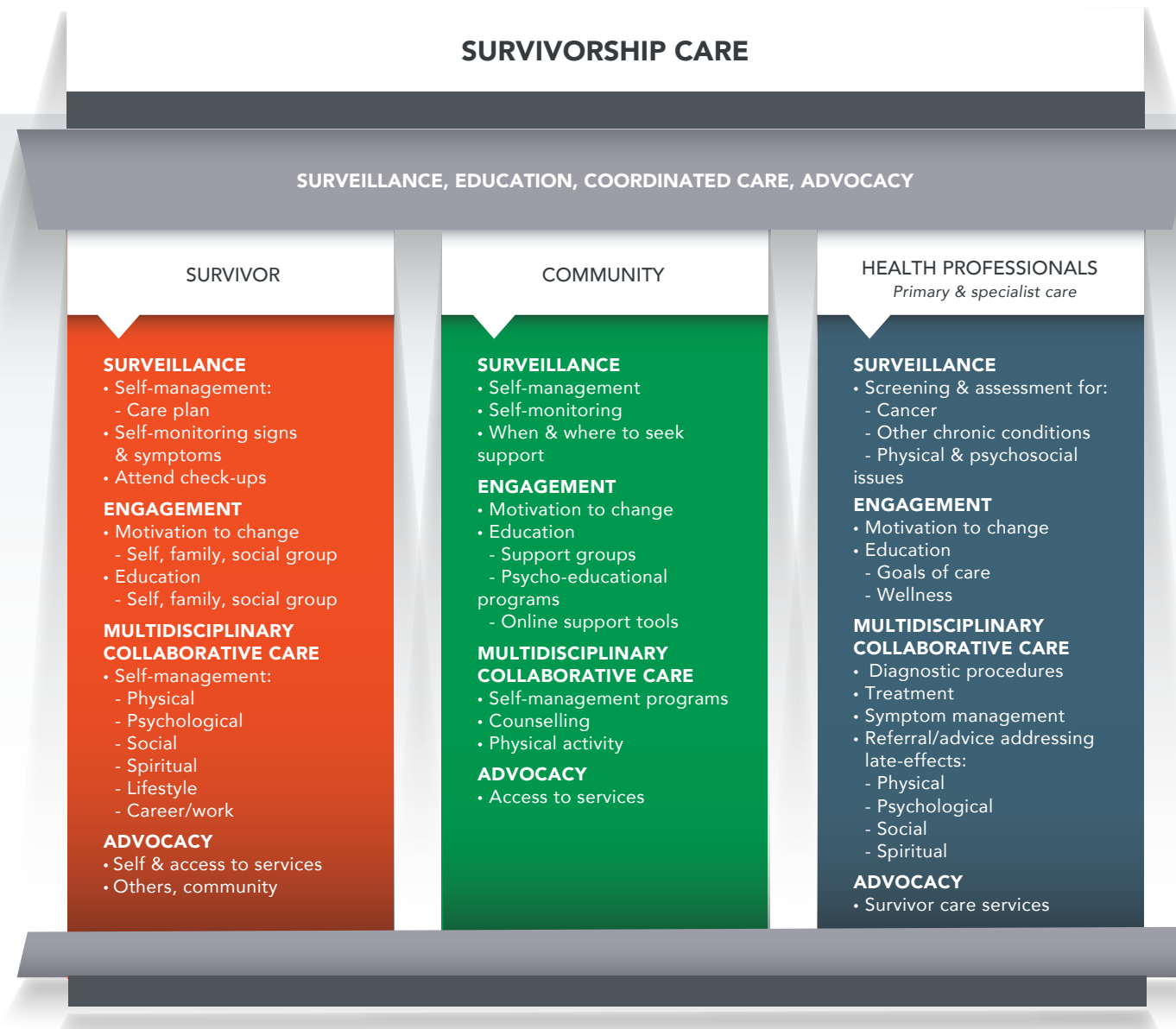


Figure 2. Three pillars of survivorship care