



Australian Cancer
Survivorship Centre

Steps toward more effective management of late effects in cancer survivors

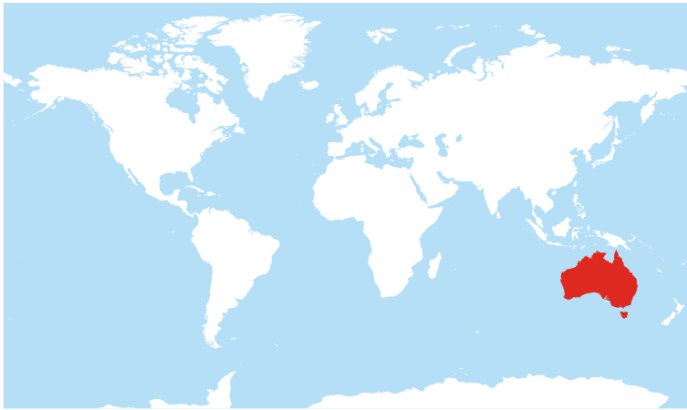
Danish Cancer Research Days
Friday August 29 2025

Prof Michael Jefford

Senior Medical Oncologist / Director, Australian Cancer Survivorship Centre
Research Lead, Centre for Health Services Research, Peter MacCallum Cancer Centre

Professor, University of Melbourne





Peter Mac

Peter Mac is...



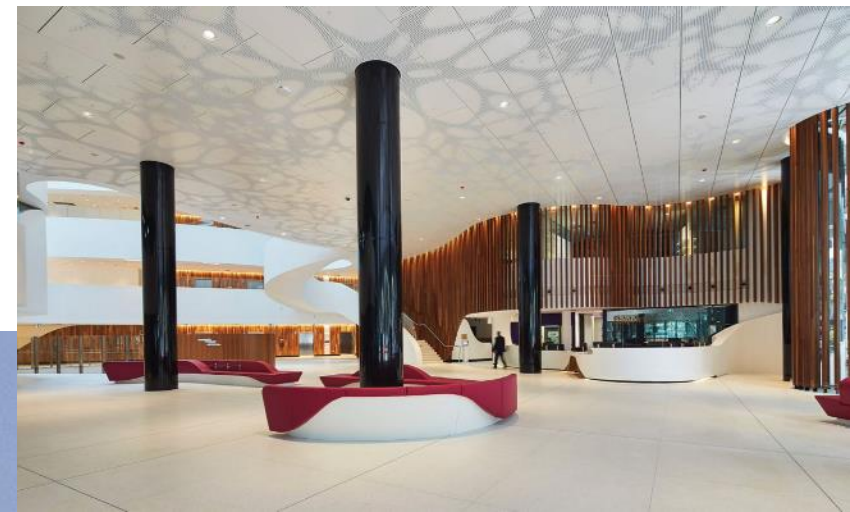
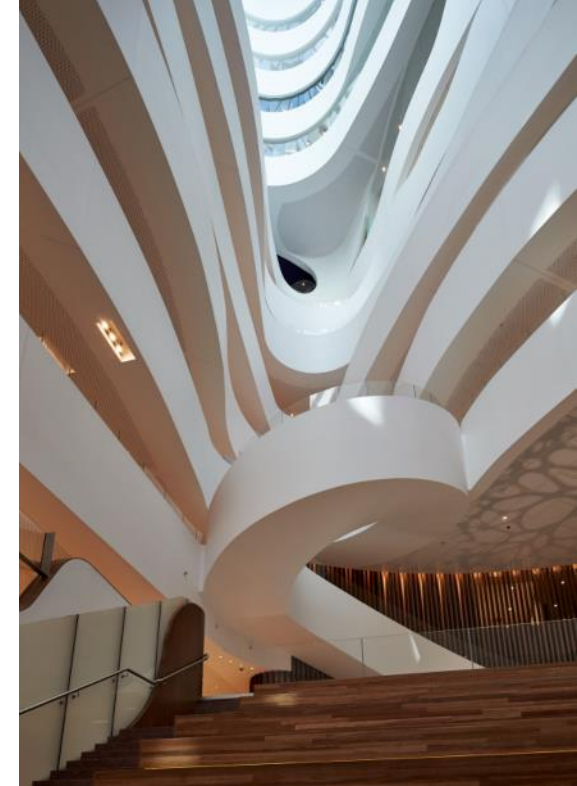
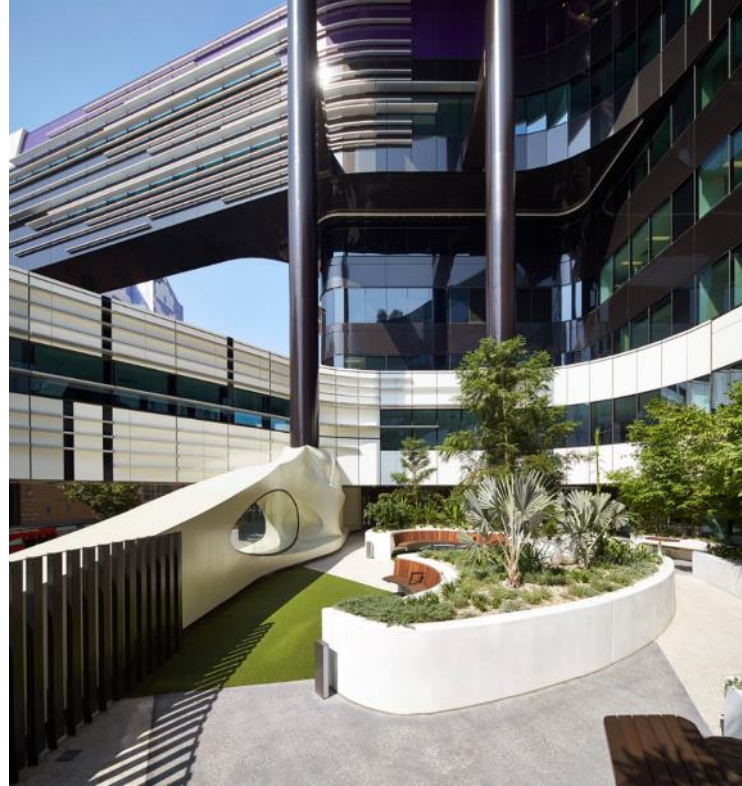
A world leading cancer research, education and treatment centre



Australia's **only public health service** solely dedicated to caring for people affected by cancer



Australian Cancer
Survivorship Centre



Outline

- Cancer survivors – definitions, numbers, common issues
- The need to improve care for cancer survivors
- Improving management of late effects
- Regional late effects clinics in Denmark
- Experience from Australia that might be relevant
- Ongoing challenges

Cancer survivors

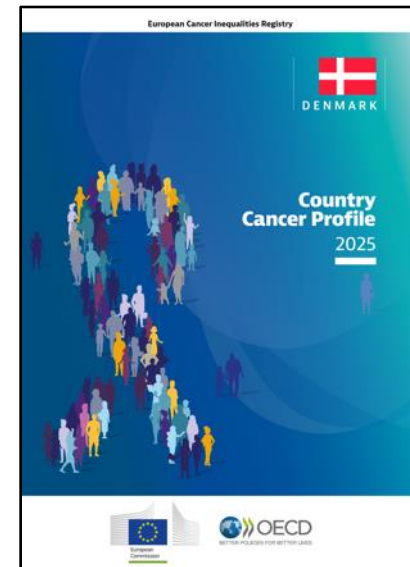
- Around 400 000 Danes have a personal history of cancer
 - 30% increase between 2010 and 2020
- Most prevalent groups are those with a history of breast cancer, prostate cancer, colorectal cancer, melanoma
- Most will have comorbid illness
 - May be a competing cause of morbidity and mortality

Issues experienced by survivors

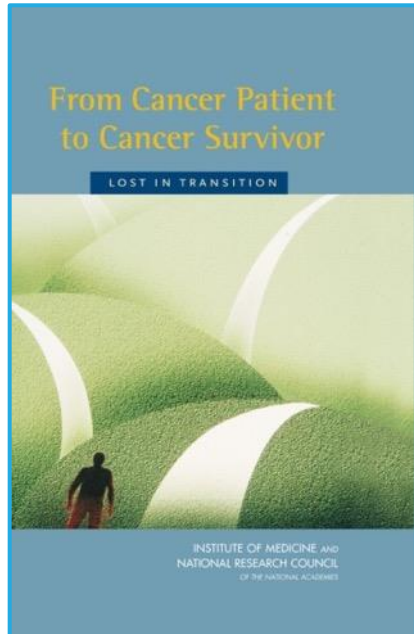
- Fear of cancer recurrence – 59% at least moderate ¹
 - Depression – 16.5% major + 14.9% minor ²
 - Anxiety – 10.3% (+ adjustment disorder 19.4%) ²
 - Cognitive problems – 30-80% ³
 - Fatigue – 49% ⁴
 - Pain – moderate to severe 38% ⁵
 - Sleep problems – 25-60% ⁶
- Any mood disorder 38.2% ²

Unmet needs in Danish cancer survivors

- Unmet information needs
 - 27% reported insufficient information on potential long-term effects
- Support
 - Relating to fatigue, sexual health, psychological issues, and home care services
 - 74% reported significant daily life challenges 4-8 months after diagnosis
 - Up to 74% reported not receiving adequate support
 - 80% had insufficient advice on economic issues



Focus on survivorship



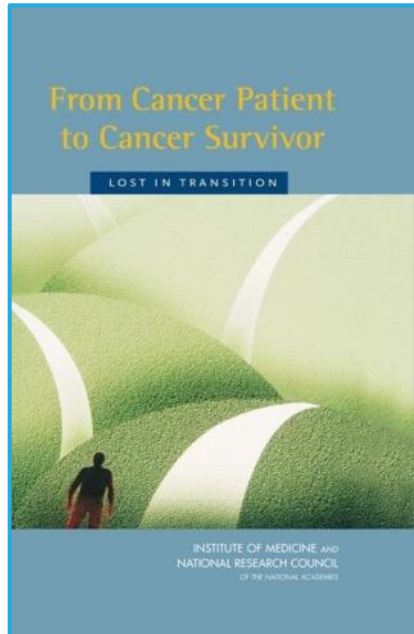
Recommendations

1. Raise awareness
2. Survivorship care plans
3. Evidence-based guidelines
4. Quality measures
5. Models of care
6. Cancer control plans
7. Educate health professionals
8. Employment
9. Access to health care
10. Research

Seminal 2006 report from the US Institute of Medicine

Free PDF book at www.nap.edu/catalog/11468/from-cancer-patient-to-cancer-survivor-lost-in-transition

Focus on survivorship



BOX ES-1 Essential Components of Survivorship Care

1. **Prevention** of recurrent and new cancers, and of other late effects;
2. **Surveillance** for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
3. **Intervention** for consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and
4. **Coordination** between specialists and primary care providers to ensure that all of the survivor's health needs are met.



Seminal 2006 report from the US Institute of Medicine

Free PDF book at www.nap.edu/catalog/11468/from-cancer-patient-to-cancer-survivor-lost-in-transition

Quality survivorship care

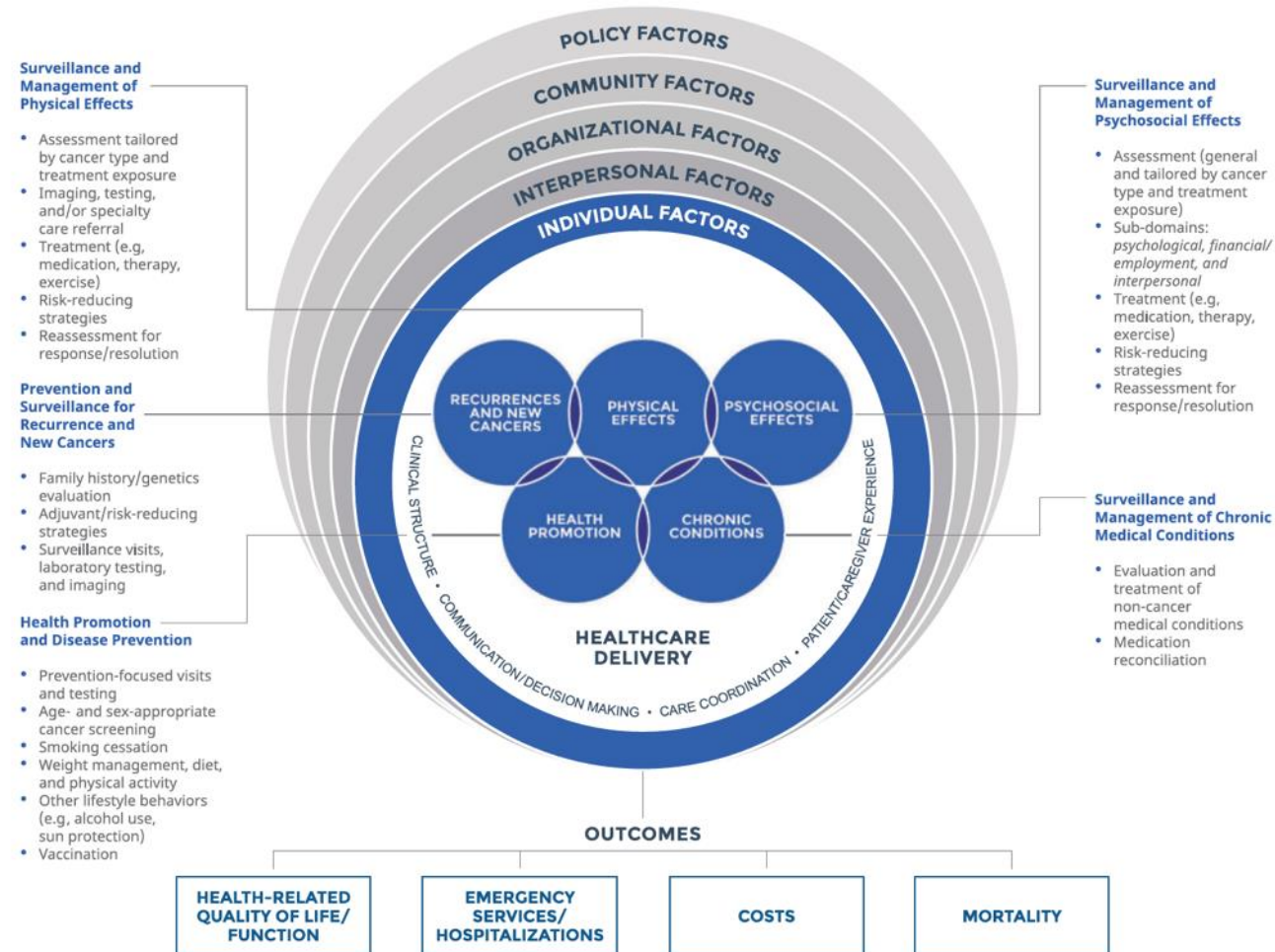
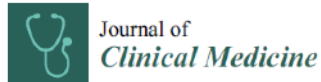


Figure 1. Cancer survivorship care quality framework.

Current survivorship care



Article

Survivorship in Colorectal Cancer: A Cohort Study of the Patterns and Documented Content of Follow-Up Visits

Victoria Garwood ^{1,2} , Karolina Lisy ^{1,3,4} and Michael Jefford ^{1,3,4,*}

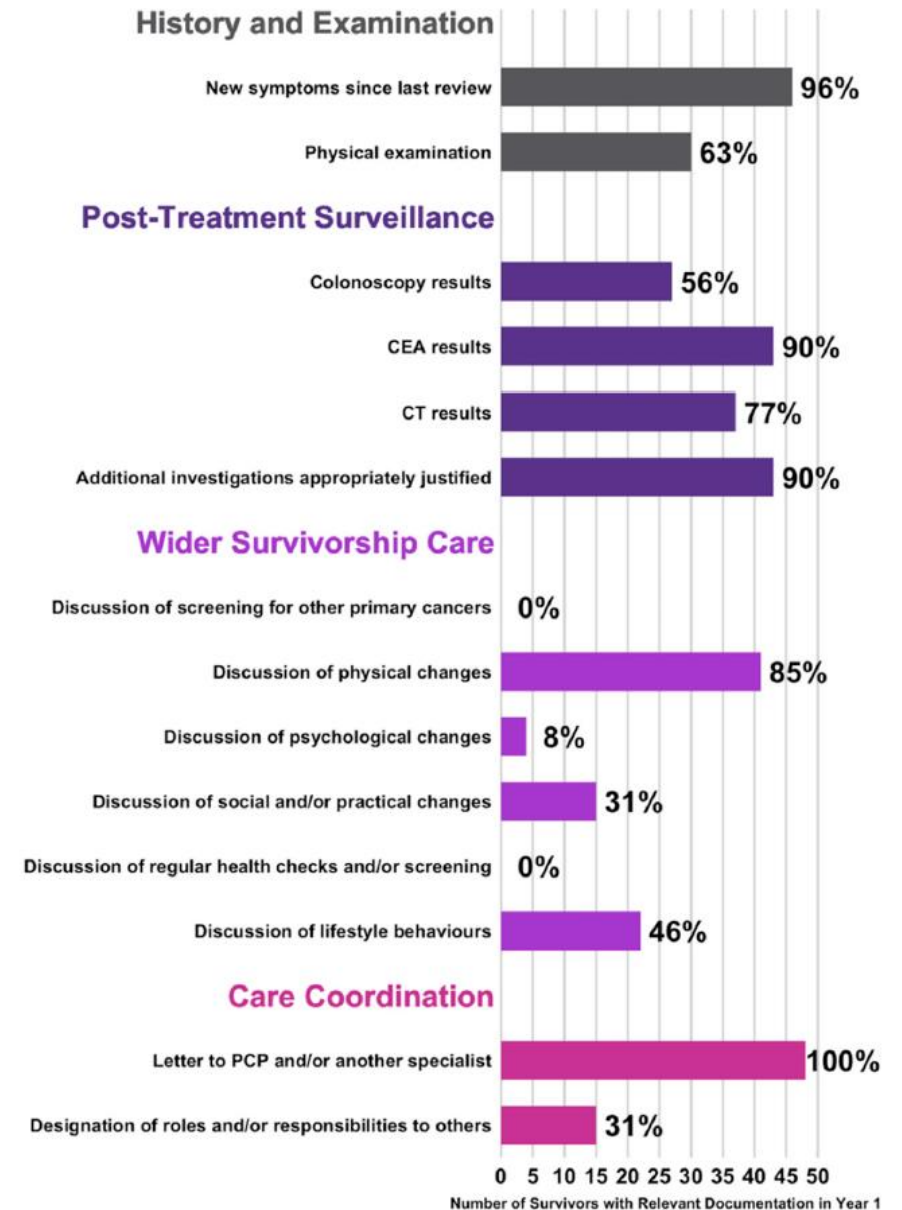
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Current survivorship care

original reports

SUPPORTIVE CARE & SYMPTOM CONTROL



Follow-Up Care for Breast and Colorectal Cancer Across the Globe: Survey Findings From 27 Countries

Michelle A. Mollica, PhD, MPH, RN, OCN¹; Deborah K. Mayer, PhD, RN²; Kevin C. Oeffinger, MD³; Youngmee Kim, PhD⁴; Susan S. Buckenmaier, MPH¹; Sudha Sivaram, DrPH¹; Catherine Muha, MSN, RN¹; Nur Aishah Taib, PhD, MSurg, MD, MBBS⁵; Elisabeth Andritsch, MSc⁶; Chioma C. Asuzu, PhD⁷; Ovidiu V. Boichis, PhD, MD⁸; Sheila Diaz, MA, MS⁹; Maria Die Trill, PhD¹⁰; Patricia J. Garcia, MD, MPH, PhD¹¹; Luigi Grassi, MD, MPH¹²; Yosuke Uchitomi, MD, PhD¹³; Asim Jamal Shaikh, MBBS¹⁴; Michael Jefford, MBBS, MPH, MHIthServMt, PhD¹⁵; Hyun Jeong Lee, MD¹⁶; Christoffer Johansen, MD, PhD, DMedSci¹⁷; Emmanuel Luyirika, MFamMed, MPA, BPA (Hons), MBChB¹⁸; Elizabeth Jane Maher, MRCP, FRCR¹⁹; Maria Madeline B. Mallillin, MD²⁰; Theoneste Maniragaba, MD²¹; Anja Mehnert-Theuerkauf, PhD²²; C. S. Pramesh, MS²³; Sabine Siesling, PhD²⁴; Orit Spira, MA, MSW²⁵; Jonathan Sussman, MD, MSc²⁶; Lili Tang, MD²⁷; Nguyen V. Hai, PhD, MD²⁸; Suayib Yalcin, MD²⁹; and Paul B. Jacobsen, PhD¹

Most survivorship care is specialist-led, hospital-based, has a major focus on screening for possible cancer recurrence, less focus on holistic, comprehensive care

Original Reports | Supportive Care & Symptom Control



International Survey of Psychosocial Care for Cancer Survivors in Low-/Middle- and High-Income Countries: Current Practices, Barriers, and Facilitators to Care

Christina Signorelli, PhD^{1,2}; Beverley Lim Høeg, PhD³; Chioma Asuzu, PhD⁴; Isabel Centeno, MEd⁵; Tania Estapé, PhD⁶; Peter Fisher, PhD⁷; Wendy Lam, PhD⁸; Inbar Levkovich, PhD⁹; Sharon Manne, PhD¹⁰; Anne Miles, PhD¹¹; Louise Mullen, MSc¹²; Larissa Nekhlyudov, MD, MPH¹³; Cristina Sade, MD¹⁴; Joanne Shaw, PhD¹⁵; Anna Singleton, PhD¹⁶; Luzia Travado, PhD¹⁷; Miyako Tsuchiya, PhD^{18,19}; Jesse Lemmen, MSc^{20,21}; Jie Li, PhD^{22,23}; and Michael Jefford, MBBS, PhD^{24,25,26}; On behalf of the International Psycho-Oncology Society Survivorship Special Interest Group

DOI <https://doi.org/10.1200/GO.23.00418>

Investigating other models of care

Journal of Cancer Survivorship
https://doi.org/10.1007/s11764-021-01128-1

REVIEW

Effectiveness and implementation of models of cancer survivorship care: an overview of systematic reviews

Raymond J. Chan^{1,2,3} · Fiona Crawford-Williams^{1,3} · Megan Crichton^{3,4} · Ria Joseph³ · Nicolas H. Hart^{1,3,5,6} · Kristi Milley^{7,8} · Paige Druce^{7,8} · Jianrong Zhang⁸ · Michael Jefford^{9,10} · Karolina Lisy^{9,10} · Jon Emery^{7,8} · Larissa Nekhlyudov^{11,12}

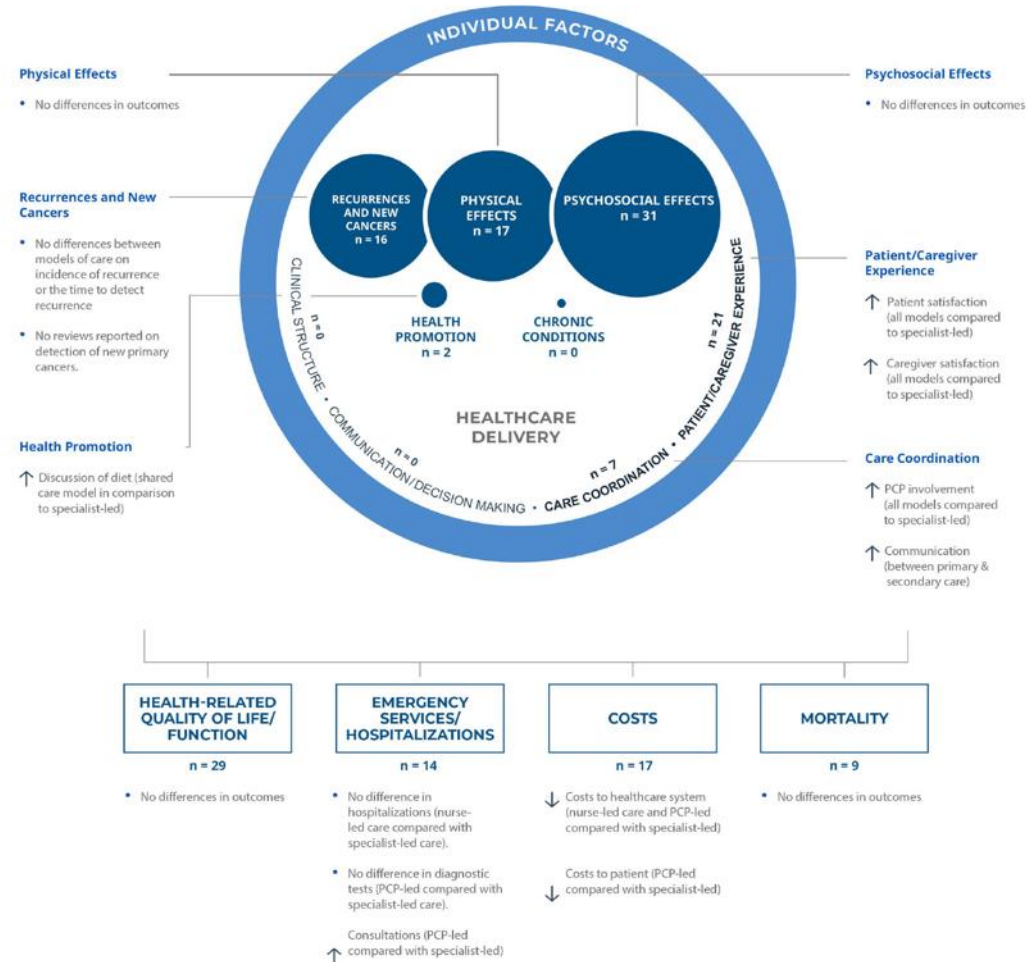


Fig. 2 Primary study numbers and findings according to the cancer survivorship care quality framework


Challenges in providing improved care

- Numbers of survivors
- Considerable unmet need
- Limited health workforce
- The dominant model of care is entrenched
- Lack of priority, will, commitment, funding



Improving management of late effects

- Prevention
- Early detection and management
 - Screening (patient reported outcomes)
- Education
- Self-management support
- Stepped care approaches



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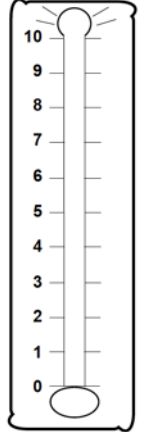
NCCN Guidelines Version 2.2025
Distress Management

[NCCN Guidelines Index](#)
[Table of Contents](#)
[Discussion](#)

NCCN DISTRESS THERMOMETER
Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.
Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress

10
9
8
7
6
5
4
3
2
1
0
No distress



PROBLEM LIST
Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical Concerns

- ☐ Pain
- ☐ Sleep
- ☐ Fatigue
- ☐ Tobacco use
- ☐ Substance use
- ☐ Memory or concentration
- ☐ Sexual health
- ☐ Changes in eating
- ☐ Loss or change of physical abilities

Emotional Concerns

- ☐ Worry or anxiety
- ☐ Sadness or depression
- ☐ Loss of interest or enjoyment
- ☐ Grief or loss
- ☐ Fear
- ☐ Loneliness
- ☐ Anger
- ☐ Changes in appearance
- ☐ Feelings of worthlessness or being a burden

Social Concerns

- ☐ Relationship with spouse or partner
- ☐ Relationship with children
- ☐ Relationship with family members
- ☐ Relationship with friends or coworkers
- ☐ Communication with health care team
- ☐ Ability to have children
- ☐ Prejudice or discrimination

Practical Concerns

- ☐ Taking care of myself
- ☐ Taking care of others
- ☐ Safety
- ☐ Work
- ☐ School
- ☐ Housing/Utilities
- ☐ Finances
- ☐ Insurance
- ☐ Transportation
- ☐ Child care
- ☐ Having enough food
- ☐ Access to medicine
- ☐ Treatment decisions

Spiritual or Religious Concerns

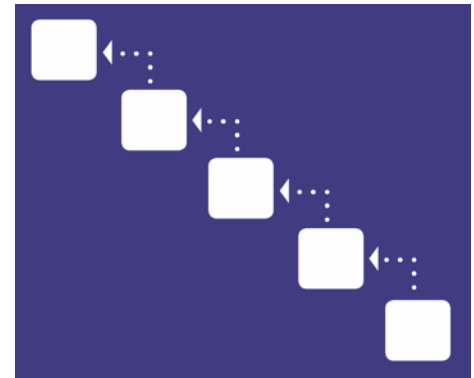
- ☐ Sense of meaning or purpose
- ☐ Changes in faith or beliefs
- ☐ Death, dying, or afterlife
- ☐ Conflict between beliefs and cancer treatments
- ☐ Relationship with the sacred
- ☐ Ritual or dietary needs

Other Concerns:

Note: All recommendations are category 2A unless otherwise indicated.

Stepped care

- Maximise the use of scarce health care resources
- Hierarchy of interventions at varying intensity levels, matched to individual needs – symptom severity, clinical response to initial treatment, risks associated with circumstance
- Progressive – all start at the lowest intensity and stepped up
- Stratified – needs assessed – matched to interventions (e.g. education materials through to clinician-administered therapies)



Stepped care, anxiety and depression

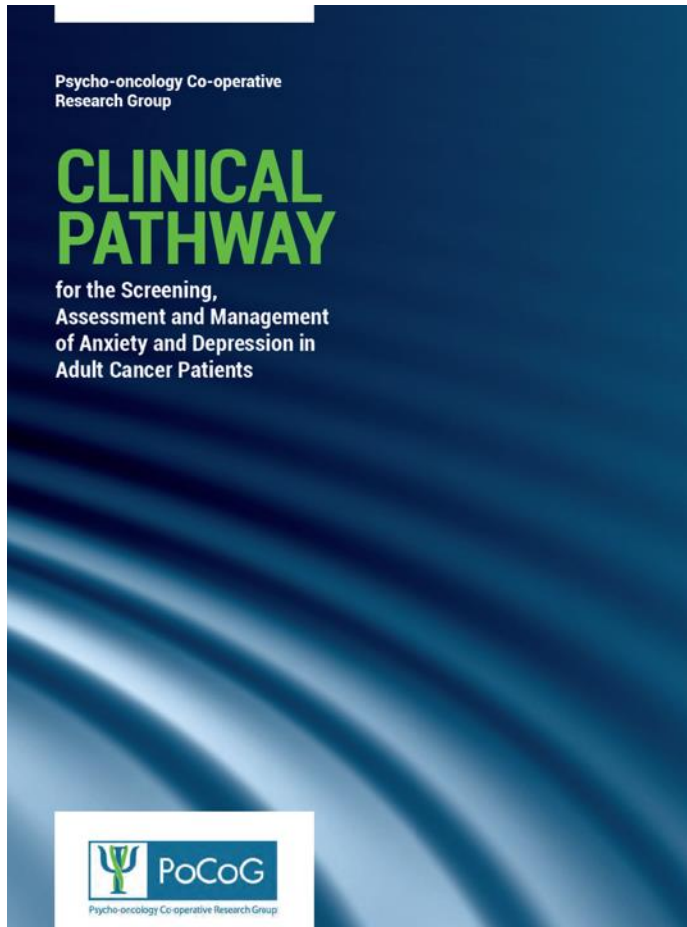
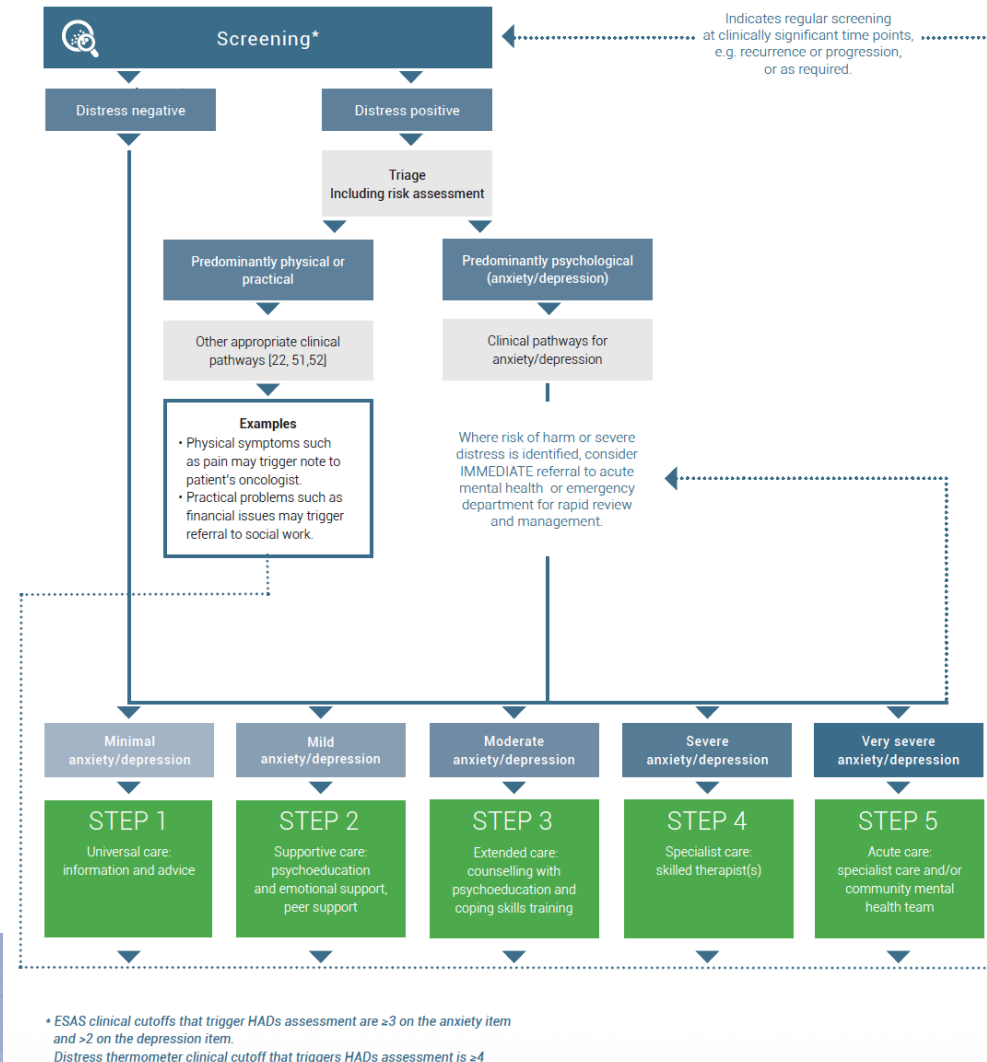
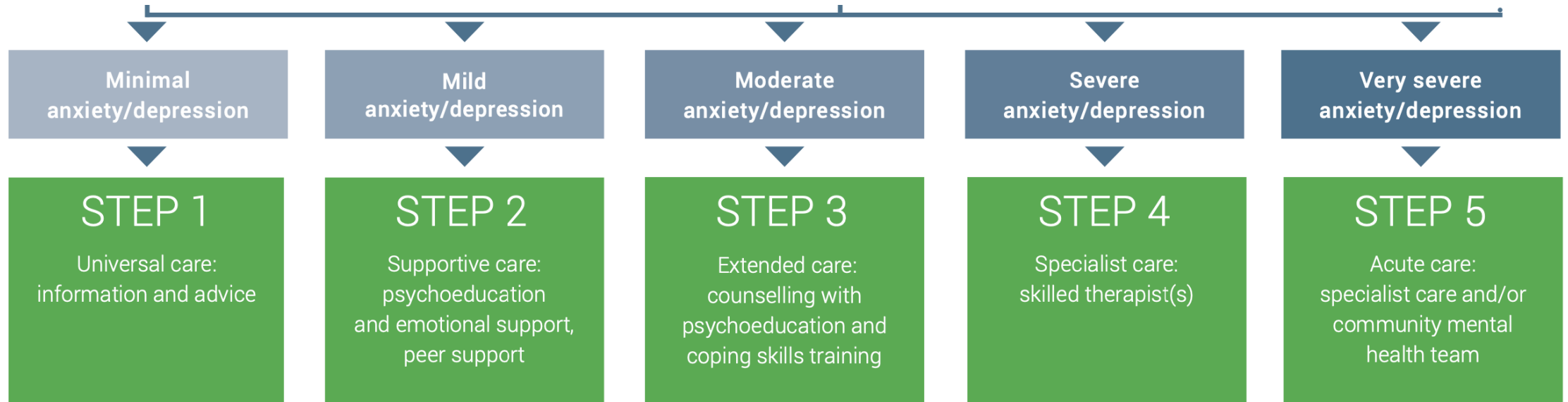


Figure 1 – Overview of Stepped Care



Stepped care, anxiety and depression



Stepped care, fear of cancer recurrence

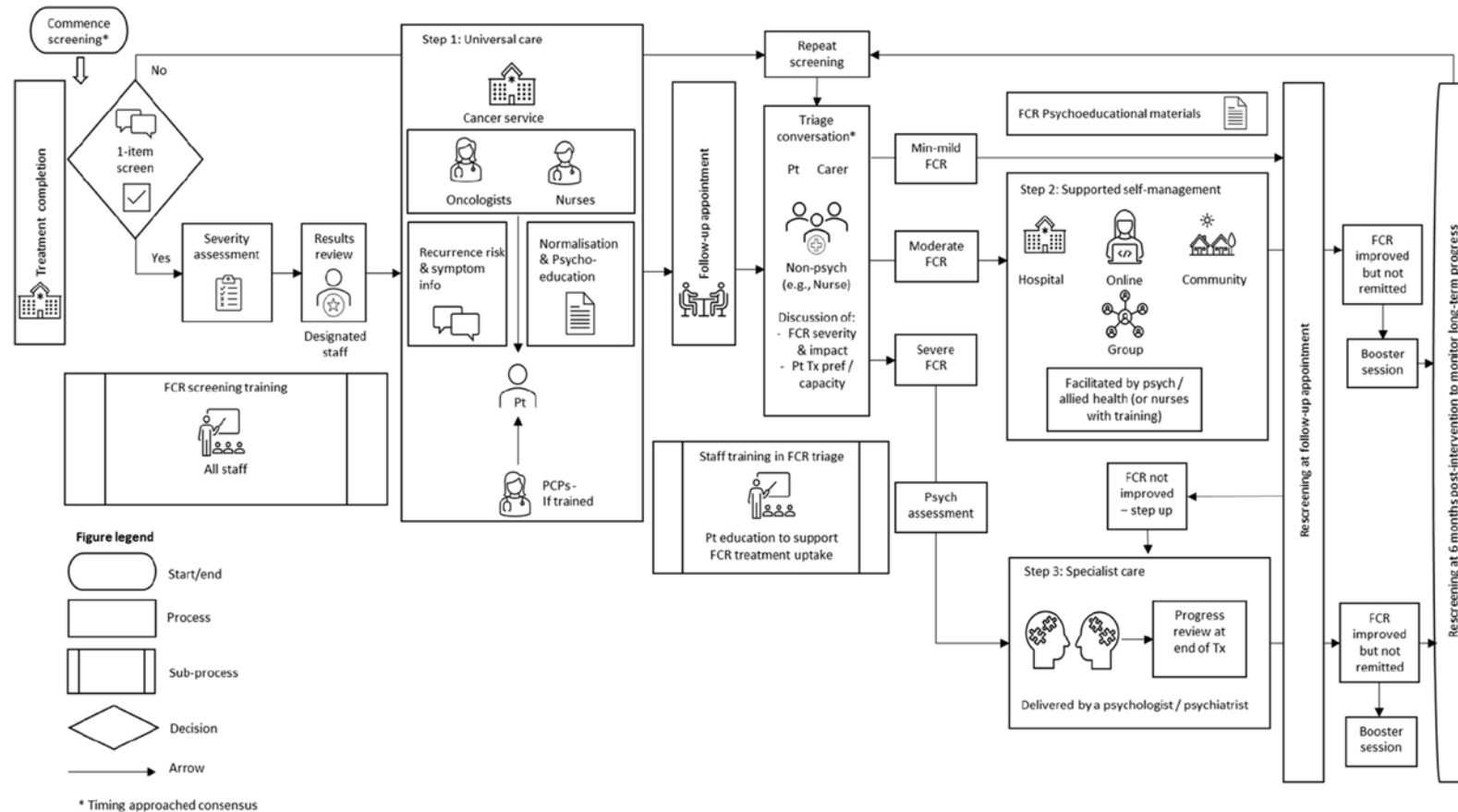


Fig. 2 Overview of the FCR clinical pathway

Stepped care models

- Systematic review, Jan 2010 – Nov 2024
- Distress (anxiety, depression), insomnia, fatigue – good supporting evidence
- Less evidence re FCR, sexual needs
- 8 studies showed clinically meaningful responses with less intense interventions
- Stepped approaches support uptake of support, referral to services
- May be cost effective
- Issues with implementation, also symptom clusters

Regeringen

Et bedre liv med og efter kræft

Kræftplan V



MAJ 2025



Australian Cancer
Survivorship Centre

Senfølgeklivnikker i hele landet

For mange markerer afslutningen på et kræftforløb starten på et nyt kapitel i livet. Men selvom man måske på papiret er erklæret rask, er det ikke ensbetydende med, at man nødvendigvis er ovenpå igen.

Op mod 60 pct. af alle, der har haft kræft, oplever senfølger. Det kan eksempelvis være kroniske smerter, mave-tarmproblemer, tandproblemer, søvnbesvær eller depression. Listen er lang. Men fælles for senfølgerne er, at der er tale om udfordringer, som kan påvirke den enkeltes livskvalitet og hverdag.

I dag er der imidlertid alt for stor forskel på senfølgetilbuddene på tværs af landet. I nogle regioner er der kun senfølgetilbud til patienter med bestemte senfølger efter kræft, såsom senfølger efter tarmkræft. I andre regioner er der etableret senfølgeklivnikker, hvor patienter kan få hjælp til flere typer af senfølger efter forskellige kræftsygdomme. Det er ikke godt nok. Ens bopæl skal ikke være afgørende for den hjælp, man kan få.

Derfor vil regeringen sikre, at der er senfølgeklivnikker med ensartede tilbud til patienter med senfølger efter kræft i alle regioner.

Konkret vil regeringen etablere ensartede senfølgetilbud, eksempelvis senfølgeklivnikker, i alle regioner, der skal kunne hjælpe patienter med senfølger efter kræft af mere generel og kompleks karakter. Det kan være patienter, der har kroniske smerter som følge af deres kræftbehandling. Eller patienter, der har flere senfølger på samme tid, såsom træthed, fysiske eller seksuelle udfordringer.

Senfølgeklivnikkerne skal samtidig være videns-| centre og kunne rådgive det almenmedicinske tilbud og relevant sundhedspersonale i regioner og kommuner om senfølger efter kræft. Det skal sikre mere opmærksomhed og viden om, hvordan patienter med senfølger hjælpes på bedst mulig vis.



Regional late effects clinics

- Dealing with issues such as (and new national guidance regarding)
 - Fatigue
 - Pain
 - Sleep problems
 - Anxiety
 - Depression
 - Fear of cancer recurrence
 - Cognitive difficulties

Structuring for success

1. Policy imperative ✓
2. Funding, resources ✓
3. Guidance ✓ (and standards)
4. Workforce, training
5. Process, pathways, resources
6. Measurement
7. Accountability

Some of what's been helpful in Australia

- Policy, guidance
- Resources for survivors and health professionals
- Education for health professionals
- Community of practice
- Australian cancer survivorship research priorities
- Leveraging international community

Policy – the Australian Cancer Plan



Most of cancer care is not funded by federal government

No published implementation strategy

Not budgeted

No clear targets

Australian Cancer Plan

Developed by Cancer Australia, the ten-year **Australian Cancer Plan (the Plan)** is a future-focused plan designed to improve cancer outcomes, particularly for those groups whose health outcomes are poorer. The ground-breaking national strategy sets out strategic objectives, ambitions, goals and priority actions for cancer control.

The Plan was developed through extensive engagement and consultation across the cancer sector, with input from people affected by cancer, consumer organisations, peak bodies, Aboriginal and Torres Strait Islander people, researchers, health professionals, non-government organisations, and policy makers.

To view the Australian Cancer Plan and learn more about how we can help achieve world-class cancer outcomes and experiences for all Australians, visit www.australiancancerplan.gov.au



COSA model of survivorship care



Model of Survivorship Care

Critical Components of Cancer Survivorship Care in Australia

Position Statement

Version 1.0

November 2016

Clinical Oncology
Society of Australia
position statement on
cancer survivorship care

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Optimal Care Pathways

The best cancer journey for specific cancer types

The Optimal Care Pathways are a framework for the delivery of consistent, safe, high-quality, and evidence-based care for people with cancer. They aim to improve patient outcomes through promoting quality cancer care and ensuring that all people diagnosed with cancer receive the best care, irrespective of where they live or receive cancer treatment. The Optimal Care Pathways can guide, support and inform increased collaboration, more effective care, improved healthcare provider–patient communication and patient experience.

Cancer Council Victoria, supported by the Victorian Government, has undertaken work to refresh the Optimal Care Pathways, Quick Reference Guides and Guides to Best Cancer Care (formerly named the What to Expect Guides) for 15 cancer types (2nd edition).

The 2nd edition of the Optimal Care Pathways for cancer of unknown primary, cervical cancer and sarcoma are currently in progress.

The Optimal Care Pathways are endorsed by Cancer Australia, the former National Cancer Expert Reference Group (a committee that reported to the former Australian Health Ministers Advisory Committee (AHMAC) and through this committee, to the former Council of Australian Governments Health Council) and all states and territories. The former AHMAC has become the Health Chief Executives Forum, and Optimal Care Pathways are currently nationally endorsed by this forum. The Optimal Care Pathways have Australia-wide acceptance and



The Optimal Care Pathways web application



Access the Optimal Care Pathways in an interactive web app on your mobile or your desktop.

QUICKLINKS

[CLINICAL PRACTICE GUIDELINES](#)[CLINICAL GUIDELINES NETWORK](#)[CANCER COUNCIL RESEARCH PROGRAMS](#)[Feedback](#)

Optimal care pathway for people with colorectal cancer

SECOND EDITION



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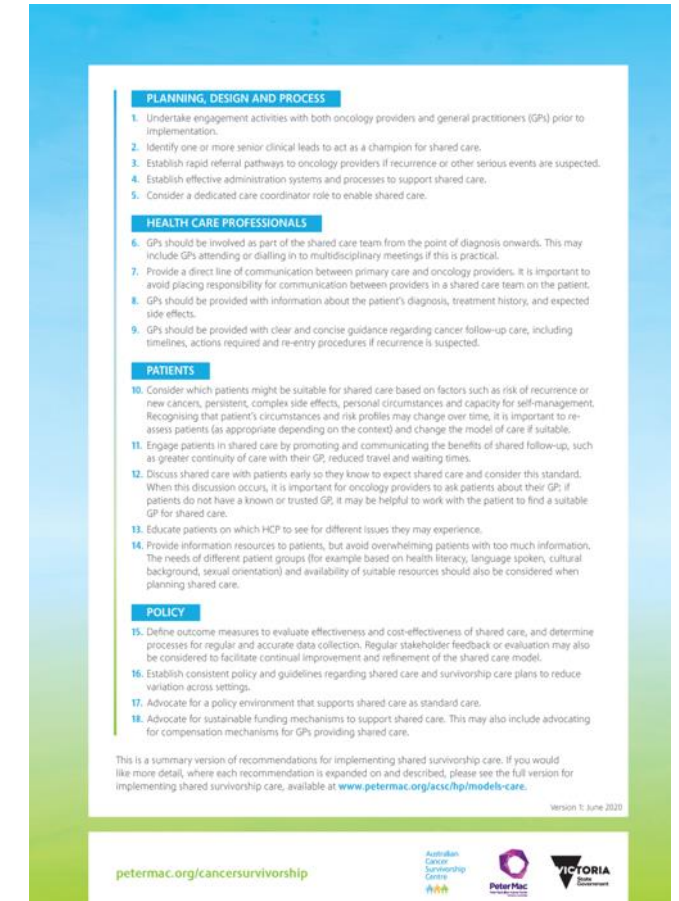
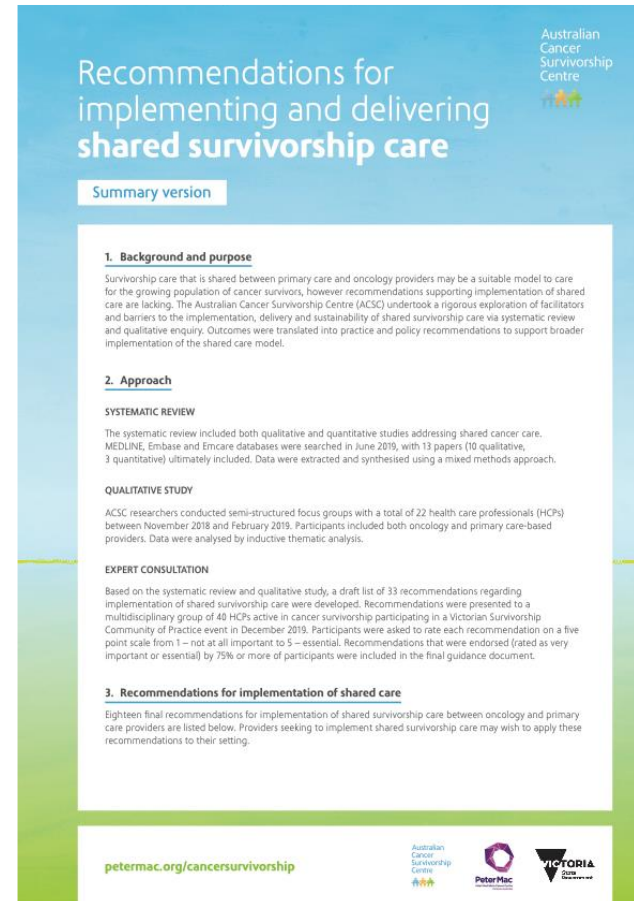
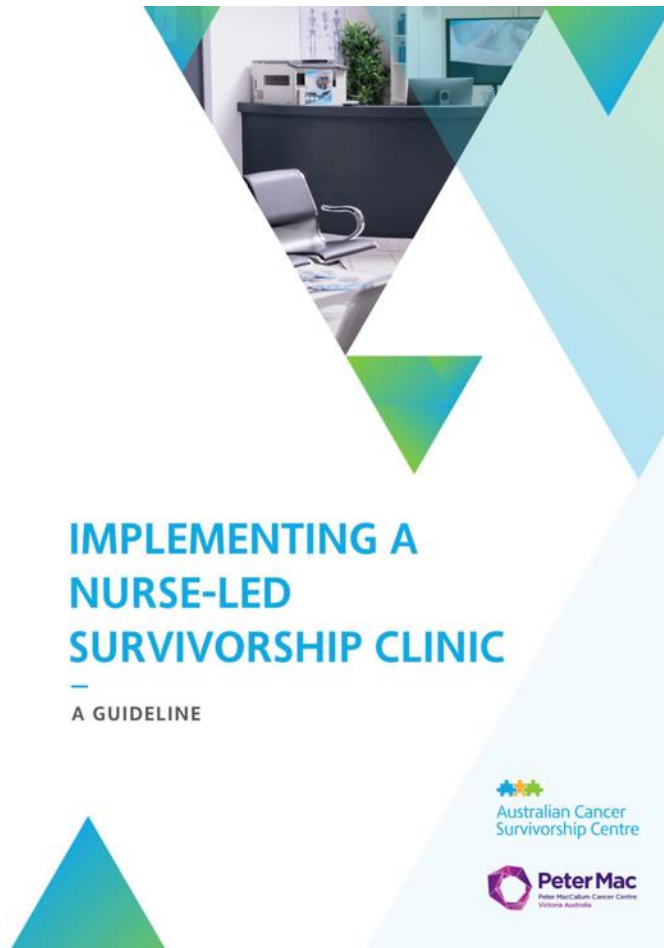
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State and territory cancer plans

Most state and territory cancer plans include objectives relating to the 10 recommendations from the US IOM report 'From cancer patient to cancer survivor, lost in transition'

	1. Raise awareness of cancer survivorship	2. Development of survivorship care plan	3. Evidence based clinical practice guidelines	4. Development and implementation of quality measures for survivorship care	5. Coordinated care; models of survivorship care	6. Development of comprehensive cancer control plans	7. Health care/workforce expansion and education	8. Employment related concerns	9. Adequate and affordable health insurance	10. Investing in survivorship research
Victoria										
New South Wales										
Australian Capital Territory										
Queensland										
Northern Territory										
Western Australia										
South Australia										**only in the Aboriginal Cancer Control Plan
Tasmania										

Guidance – nurse-led clinics, shared care



Resources

Cancer survivorship information for survivors and carers

Dealing with cancer-related fatigue

Fatigue is common among people who have completed cancer treatment and people receiving ongoing therapy.

This fact sheet explains ways to cope with cancer-related fatigue.

What is cancer-related fatigue?

Cancer-related fatigue is 'a distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning'. It is different from normal tiredness, such as the tiredness you feel after a long day of work. It is usually not relieved by rest.

Most patients who have had cancer treatment have fatigue, either for a short while or for months or even years after treatment has ended.

Fatigue touches people's personal, social and working lives. It affects your quality of life. Survivors who have cancer-related fatigue often describe it as one of the most distressing side effects of cancer treatment.

Fatigue can be a result of cancer treatment. It can also result from pain, anxiety, disturbed sleep, depression, anaemia (low blood cells), medications and other illnesses and conditions. Medications such as beta-blockers (used for heart conditions and high blood pressure), narcotics (for pain relief), anti-depressants and other drugs may add to fatigue. Heart, lung and kidney disease and other conditions can also cause fatigue.

Using alcohol and drugs like marijuana may make cancer-related fatigue worse.

Fatigue can be managed.

What your doctor can do about cancer-related fatigue

- First, fatigue needs to be identified and treated.
- Your doctor may suggest using a questionnaire to assess how bad your fatigue is and how it is affecting you in your everyday life.
- Your doctor will consider different factors that may be causing your fatigue, such as some medications, diseases or conditions. Your doctor may change the dose of some

medications to see if this reduces your fatigue.

- Your doctor may refer you to a health professional who has experience in caring for people with cancer-related fatigue.

Key messages in dealing with cancer-related fatigue

- Fatigue needs to be identified and treated.
- Speak with your doctor or healthcare team if fatigue is concerning you.
- There is evidence that moderate-intensity exercise can help reduce cancer-related fatigue.
- Eating a balanced diet will help.
- Manage your energy levels: use the '3Ps': 'plan, prioritise and pace'.
- Healthcare professionals can offer specialist support.
- There are community and hospital-based forums that can give you more information about exercise, managing fatigue and improving nutrition.

Cancer survivorship information for survivors and carers

Coping with the fear of cancer coming back (fear of cancer recurrence)

Fear about cancer coming back or worry about the future is common for people who have completed treatment and for people who are receiving ongoing therapy. More than 70% of people who have had cancer say they have experienced this at some stage.

This fact sheet explains what fear of cancer recurrence is and suggests ways to cope with the fear of cancer coming back.

Key Messages in coping with fear of cancer coming back

- Fear of cancer recurrence is common.
- Fear of cancer recurrence can reduce over time.
- Speak with your doctor or health care team if fear of cancer recurrence is concerning you.
- Health care professionals can offer specialist support.

What is fear of cancer recurrence?

Fear of cancer recurrence is commonly referred to as the fear or worry that the cancer will return or progress in the same part of the body. It can also refer to fear of being diagnosed with a new cancer. The fear can relate to a number of things such as: Fear of needing further treatment, more life disruptions, or fearing how further cancer might affect the survivor's family or their ability to raise their children. Fear of recurrence does not necessarily relate to a person's actual risk of the cancer coming back.

Common worries or fears

People may experience fear or worry during or after treatment. You may find it helpful to know that worry is a common feeling and that your health professional team can provide you with useful strategies to cope.

You may feel worried about one or more of the following:

- how likely it is that your cancer will come back
- what symptoms to watch out for
- how your body looks and feels
- follow-up appointments
- significant events or dates that remind you of your cancer diagnosis
- getting another type of cancer.

For some people, these fears (especially of the cancer coming back) are so strong that day-to-day life can become a big struggle, making it difficult to move on from the cancer experience. Some survivors describe their feelings as:

- being fearful of planning ahead: one survivor said 'I feel too scared to live... too scared to die'
- life has 'stalled' or been 'put on hold' with no way of knowing how to 'get started' or 'move forward' again.

Although it can take time, it doesn't need to always feel this frightening. By acknowledging fears and taking control of them, most survivors find they can enjoy life again.

'It is always on your mind. Every innocent cough strikes at your heart.'



Cancer survivorship information for survivors and carers

Emotional impact of cancer and its treatment

You are likely to feel as though your life has been turned upside down. Despite this you may think you should be able to just pick up where you left off before your cancer diagnosis. But for many people who finish their cancer treatment, it isn't that simple.

Knowing what to expect after your treatment can help you and your family deal with the future and any changes that you may have to make.

'Every cancer sufferer needs to go through an extraordinary process of readjustment after the treatment.' (Neil)



Many survivors say they need to:

- go through a range of emotions: good and bad.
 - take time to understand, accept or adjust to any loss and change in their life.
- Be patient with yourself during this time. Don't expect to feel great about everything or anything! Go slowly. Give yourself the space to come to terms with all you have been through and what lies ahead.

Common feelings

Will the cancer come back?

Most survivors say they worry a lot about the cancer coming back. You may not have thought about this during your treatment but now treatment is over the possibility can be scary. The ACSG has information about fear of the cancer returning.

Feeling lonely

You may also feel quite lost and lonely after treatment finishes. This may not begin for a couple of months after you finish treatment or it may start straight away and go on for several weeks, months or sometimes longer. Trying to return to a 'normal' life or creating a 'new normal' life for yourself can be a big challenge.

Changes to your body

Your cancer may have changed the way your body looks or functions (e.g.

having a stoma, having a breast or limb removed, or changes in sexual function, weight or eating abilities). These changes can make you feel self-conscious about going out, meeting new people or being intimate with your partner.

Grief about other changes

Your work and financial state may have changed since your diagnosis. This can affect your self-esteem. You may find yourself grieving the losses and changes your cancer has brought into your life.

Feelings of sadness and anger commonly affect cancer survivors. This is very natural and the feelings usually go in time. However, for some people the feelings linger and may turn into depression.

Depression is different from sadness. It is a much more intense feeling than sadness. It can be serious and may need medical treatment. It is important you see your GP if you think you may be suffering from depression.

Friends and family

The people around you are also likely to go through strong emotions.

What has happened to you may make them question things about their own life and future. Your relationships may be stronger and more loving because of it.

But you may also find that some of their reactions may frustrate you. You

Resources

Follow-up of survivors with cancer-related fatigue

Fatigue is a common experience for people who have completed cancer treatment. The effects can be short term or long term. This fact sheet explains how health professionals, particularly primary care professionals, can assist their adult patients in managing cancer-related fatigue (CRF).

What is cancer-related fatigue?

The National Comprehensive Cancer Network's clinical practice guideline defines CRF as 'a distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning' (1). Unlike tiredness, CRF is not relieved by rest or sleep (2).

Fatigue is a common long-term effect of cancer treatments (3). It affects people receiving palliative care (4) as well as those having primary treatment with curative intent. CRF can adversely affect quality of life, impacting survivors' personal, social and working levels (4).

It is estimated that approximately 30% of survivors will experience some level of persistent CRF post-treatment (3) lasting from months to years (1-3). Those patients who report high levels of fatigue before treatment are more likely to report raised levels of fatigue post-treatment (2). CRF is perceived by survivors as the most distressing side

effect of cancer treatment (1, 4). However, it is often underestimated, underreported, underdiagnosed and undertreated (1).

Fatigue usually occurs alongside other symptoms, commonly pain, distress, anaemia and sleep disturbance (5). Fatigue may also result from things like pain, anxiety, depression, disturbed sleep, anaemia, adverse effects of medications and comorbidities (1). For example, beta-blockers, narcotics, anti-depressants and other drugs may contribute to fatigue, as may comorbidities such as cardiac, pulmonary and renal dysfunction and a number of other conditions (1). It is linked to physical inactivity and higher BMI (2).

The pathophysiological reasons for CRF are unclear (1).

Coordination between specialists and primary care providers

Fatigue is best managed by an interdisciplinary team who are able to tailor interventions to the needs of the individual patient (1). Irrespective of the follow-up model of care (e.g. specialist, GP shared care or transitioned to GP follow-up), all healthcare professionals have a role to play in monitoring and managing the survivor's CRF. Clear communication between the treatment team and primary care team will determine the responsibilities regarding monitoring and management of fatigue and who is best placed to provide this care. The aim is to optimise survivor outcomes, support self-management and avoid gaps or duplication in care.

Care of patients with cancer-related fatigue

Fatigue needs to be identified and managed promptly (1). The following recommendations are informed by international evidence-based guidelines for the assessment and treatment of CRF (3-6) and other emerging evidence (7). Recommendations are summarised in Table 1.

Key messages

- Fatigue is a common experience for people who have completed cancer treatment.
- Screening for CRF at regular intervals is recommended.
- Primary care plays a key role in monitoring and managing the survivor's CRF and educating them about self-management of CRF.
- Initiating timely referral to allied health professionals is recommended in treating CRF.
- Moderate-intensity physical activity is proven to combat CRF and improve a person's overall energy levels.
- A variety of mind-body treatments are likely to be effective in reducing CRF.

Follow-up of survivors of colorectal cancer

This fact sheet provides healthcare professionals with information and resources relevant to managing and caring for survivors of colorectal cancer. A companion fact sheet is available for survivors and carers of people with colorectal cancer.

Five- and 10-year survival (Australia)

In Australia, five-year survival rates range from 98.6% for people whose cancer was detected at the earliest stage (localised), to 13.4% for people diagnosed with metastatic cancer. However, improved survival rates are seen if metastatic cancer is resectable. Overall, the five- and 10-year survival rates for colorectal cancer are 70.6% and 64.4%, respectively (7).

Potential issues for survivors

Survivors of colorectal cancer may experience a range of issues after treatment. These experiences may impact physical health, psychosocial health, practical aspects of life and overall quality of life.

The five components of quality cancer survivorship care are (8):

- prevention and surveillance for recurrent and new cancers – assessing the risk of recurrence of primary cancer and the development of new cancers
- surveillance and measurement of physical effects – late or long-term effects related to cancer and its treatment
- surveillance and management of psychosocial effects – late or long-term effects related to cancer and its treatment
- surveillance and management of chronic medical conditions, either pre-existing or at risk of, and their impact on cancer and its treatment
- health promotion and disease prevention – importance improving overall health and wellbeing.

 CarePlan.org.au, the online survivorship care plan generator, includes early stage colorectal cancer. Survivors can generate their own survivorship care plan, which can be used to help coordinate their ongoing management.

Surveillance for cancer spread, recurrence or second primary cancer

After curative treatment, 30% of people with stage 1 to 3 and up to 65% of people with stage 4 colorectal cancer develop recurrent disease (7).

Timely follow-up is intended to detect cancer recurrence when it is at an early stage and is potentially curable. In general, this will mean detecting recurrence in an asymptomatic person with resectable future-line recurrence, or resectable liver and lung metastases (7).

Intensive follow-up may improve survival by enabling earlier detection and treatment of recurrent cancer. It is within the first three to five years after diagnosis that the risk of colorectal cancer recurrence is the highest. A person with a history of colorectal cancer is also at a slightly higher risk of developing another primary colorectal cancer (not a recurrence) (7).

Follow-up recommendations

All people who have been treated for colorectal cancer should be followed up. At times, follow-up may vary according to the treating colorectal surgeon/oncologist, the individual's circumstances and risk of recurrence (see table 1). However, it is important that a concise follow-up plan is coordinated to avoid any unnecessary appointments.

Survivorship care in general practice: supporting patients to live well

This resource provides guidance for general practice when caring for people who have finished treatments for cancer.

Between 1982-1987 and 2006-2010, five-year survival from all cancers combined increased from 47% to 66% (1). With cancer survival increasing, more people are in need of health care following cancer treatment.

Cancer survivors can face many challenges as a result of their cancer diagnosis and treatment. General practice has an important role in caring for cancer survivors.

Research shows that 1 in 3 preventable cancers are caused by six lifestyle behaviours: smoking, UV radiation, poor diet, overweight, alcohol and inadequate daily physical activity (2). Other preventable cancers include cancers related to infections such as hepatitis B and HPV.

General practice and care of cancer survivors

Cancer survivors may experience a range of effects from cancer and its treatment, including emotional, physical, psychosocial and financial effects.

Survivors may be at increased risk of cancer recurrence, secondary cancers, functional impairment, fatigue, chronic diseases such as osteoporosis, heart disease and type 2 diabetes, weight gain, and death from non-cancer causes (3).

Obesity can contribute to morbidity from cancer treatment and the development of comorbidities. In addition, obesity poses a risk for developing second primary malignancies.

Many of these risks may be reduced through lifestyle interventions. General practitioners and other practice staff are well placed to promote lifestyle interventions to cancer survivors.

General practice care may include managing comorbid illness and considering strategies to reduce the risk of cancer recurrence and improve overall health and quality of life. Suitable approaches may include screening for cancer and non-cancerous conditions, managing health risks and immunisation.

Healthy lifestyle recommendations

- Cancer Council Australia (3) recommends that cancer survivors:
- maintain a healthy body weight – body mass index (BMI) between 18.5 and 25 kg/m²
 - be physically active – aim for at least 30 minutes of moderate activity daily
 - eat more vegetables and fruit – aim for two serves of fruit and five serves of vegetables a day
 - limit alcohol – no more than two standard drinks a day.

These recommendations are consistent with recommendations to reduce the risk of cancer and with national recommendations to promote general health.

Exercise regularly

Physical activity and resistance exercise are important for healthy living and have been shown to have important benefits for cancer survivors (4). Many cancer survivors are able to slowly increase exercise time and intensity.

Cancer Council Australia (3) recommends exercise during and after cancer treatment to:

- reduce anxiety and fatigue
- improve self-esteem
- increase feelings of optimism
- improve heart health
- maintain a healthy weight
- boost muscle

Physical activity may lower the risk of cancer recurrence by preventing obesity, reducing inflammation and hormone levels, and improving insulin resistance and immune system function (5).

Cancer-related fatigue is a common problem for cancer patients and is a side effect of treatment that often worsens during treatment and can persist as a long-term concern for many patients. There is high-quality evidence that increasing physical activity is associated with a reduction in fatigue. See our fact sheet: https://www.petermac.org/survivorship/files/medien/updates/CRF_Fatigue_FactSheet_FU_Fatigue_WEB.pdf

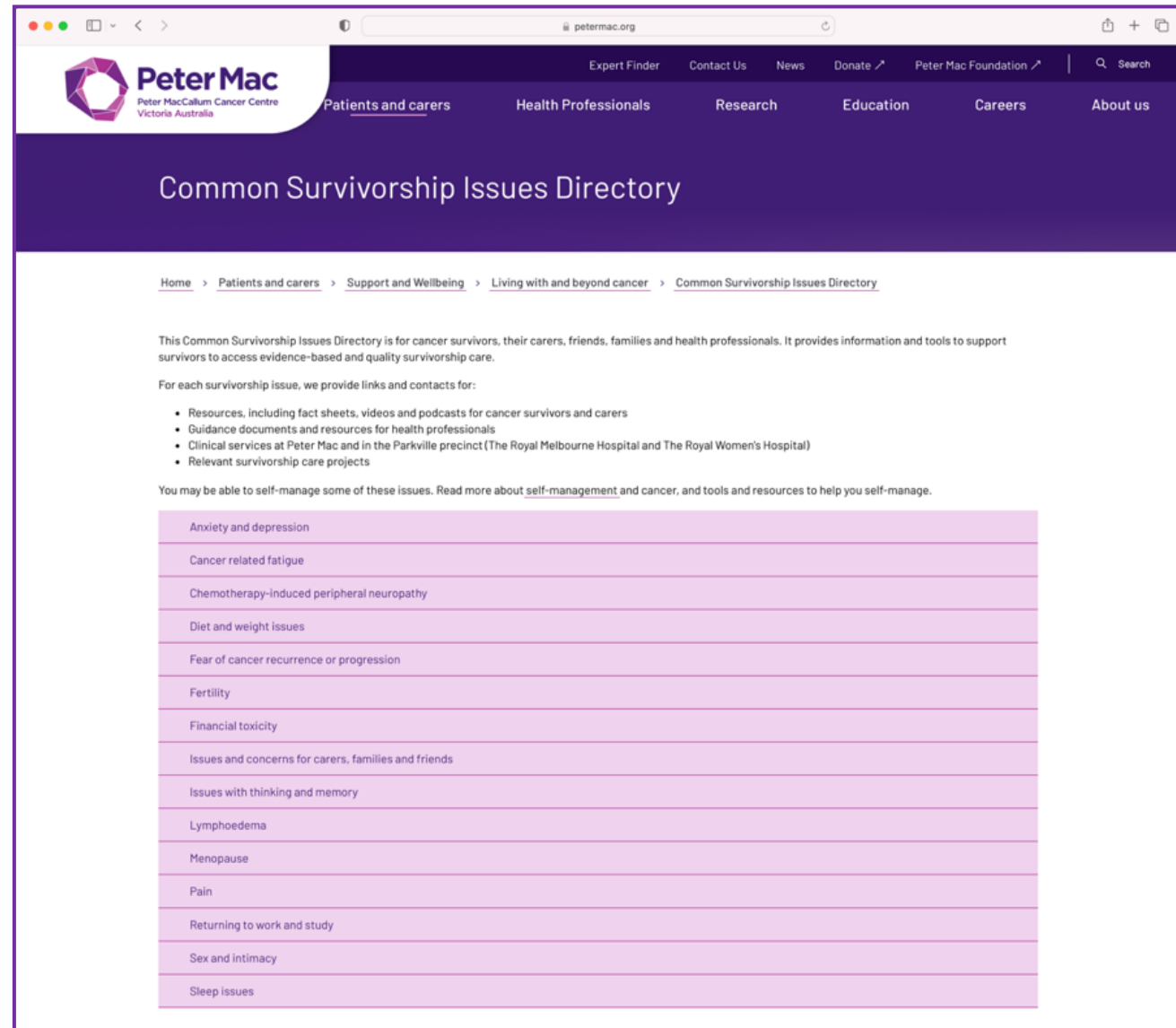
Key messages

- Between 1982 and 2010, five-year cancer survival rates increased from 47% to 66%.
- There is growing evidence that weight management and physical activity can improve the quality of life of cancer survivors, reduce the risk of cancer recurrence and extend survival.
- General practice has an important and growing role in addressing the needs of cancer survivors.

Resources

Includes

- information for survivors and carers
- resources and guidance for health professionals
- list of local services



The screenshot shows the Peter Mac website (petermac.org) with a navigation bar at the top. The main heading is "Common Survivorship Issues Directory". Below this, a breadcrumb trail reads: Home > Patients and carers > Support and Wellbeing > Living with and beyond cancer > Common Survivorship Issues Directory. The text explains that the directory is for cancer survivors, their carers, friends, families, and health professionals, providing information and tools to support survivors. It lists resources such as fact sheets, videos, podcasts, guidance documents, and clinical services. A list of 17 survivorship issues is provided in a table:

Anxiety and depression
Cancer related fatigue
Chemotherapy-induced peripheral neuropathy
Diet and weight issues
Fear of cancer recurrence or progression
Fertility
Financial toxicity
Issues and concerns for carers, families and friends
Issues with thinking and memory
Lymphoedema
Menopause
Pain
Returning to work and study
Sex and intimacy
Sleep issues

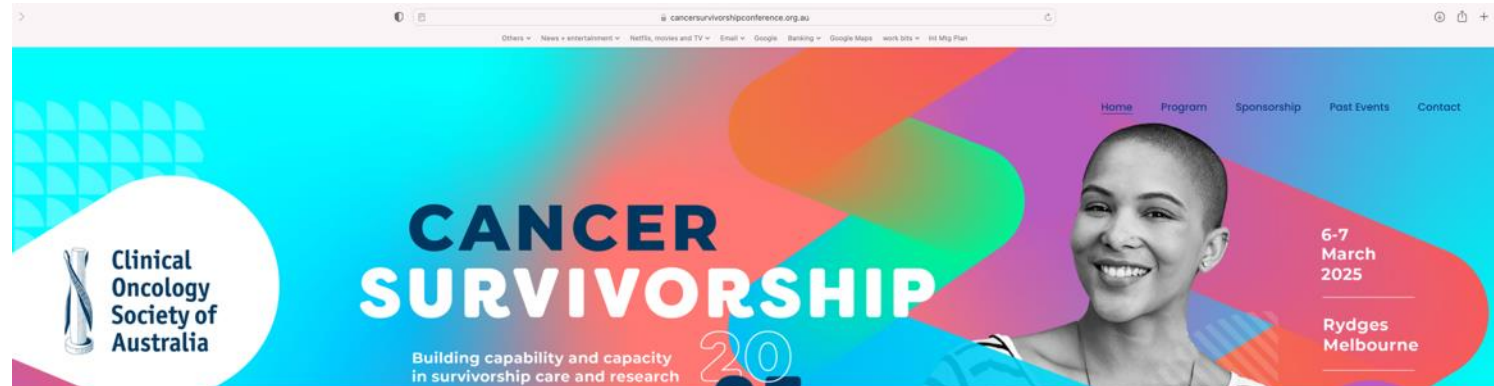
Education and training – online training

The screenshot shows the 'Cancer survivorship' course page. The header includes the NSW Health and eviQ Education logos, a search bar, and navigation links for Log in and Register. A purple navigation bar contains links for Course library, Rapid learning, Videos & Podcasts, Resources & Tools, Facilitators, and Get involved. The main content area is titled 'Cancer survivorship' and includes a description: 'This introductory course is for all health professionals with an interest in cancer survivorship.' Below this is an 'About' section and a list of six modules: 'Module 1: Survivorship fundamentals', 'Module 2: Models of survivorship care', 'Module 3: A multidisciplinary approach', 'Module 4: Survivorship care plans', 'Module 5: Self-management', and 'Module 6: Wellbeing'. Each module has a 'this' link and a duration of 0.75hrs. An 'Additional Information' section mentions the course was developed in 2013 and funded by the Australian Cancer Survivorship Centre, based at Peter MacCallum Cancer Centre, in collaboration with Cancer Australia, Queensland University of Technology and the University of Sydney.

The screenshot shows the 'Cancer survivorship' rapid learning module page. The header is identical to the previous screenshot. The main content area is titled 'Cancer survivorship' and includes a description: 'Cancer survivorship provides a focus on the health and wellbeing of a person living with and beyond cancer. An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Health professionals play an important role in identifying and managing issues and unmet needs experienced by cancer survivors and linking survivors with supportive resources and services.' Below this is a 'Survey' section titled 'Rapid Learning evaluation: Cancer survivorship' with a question: '1. How satisfied were you with this rapid learning?'. The survey shows a 'Satisfied' response with a green smiley face icon. A 'Module' section features a graphic with the text 'Cancer survivorship' and a 'START' button. A 'Start making a difference today' section lists four bullet points: 'Screen your patients for potential survivorship issues and unmet needs, provide supportive resources and information and make timely referrals to appropriate services.', 'Support survivors to make informed decisions about lifestyle behaviours that promote wellness and improve their quality of life.', 'Ensure all patients completing active cancer treatment have a survivorship care plan.', and 'Encourage patients to engage with their local GP during and after active treatment.'

6 module course and rapid learning module

Education and training – conferences



The National Cancer Survivorship Conference is hosted by COSA in partnership with



CONVENORS' WELCOME

We were honoured to be co-convening the 2025 National Cancer Survivorship Conference hosted by COSA in partnership with Flinders University, the Australian Cancer Survivorship Centre (based at Peter MacCallum Cancer Centre), and the VCCC Alliance.

For over 10 years, there have been two Australian cancer survivorship conferences, hosted by different organisations, based in different cities. For the first time, these two events came together to deliver a unified Australian event.

The 2025 National Cancer Survivorship Conference was held

6-7 March 2025 | Rydges Melbourne | 186 Exhibition Street | Melbourne, Victoria

Together with the Program Committee, an exciting program was created which showcased innovation in survivorship care, research, advocacy and policy.

With the theme **"BUILDING CAPABILITY AND CAPACITY IN SURVIVORSHIP CARE AND RESEARCH"** we highlighted the importance of advancing survivorship care from the individual to the health system perspective.

Plenary sessions included:

- **What is capability and capacity in survivorship and how to build it** explored capacity and capability at the individual and system level from patients and providers perspectives, with a focus on how we can build this, collectively.
- **Building capacity at home** focused on patients and caregivers, and considered support in and outside of the 'home' including within community settings.
- **Implementation and health system planning** looked at implementation of survivor-centred, coordinated and accessible care that is acceptable, safe, effective and sustainable.
- **The basic science of cancer survivorship** session explored how our understanding of survivorship in the lab can improve outcomes for cancer survivors and care in the clinic.
- **Global survivorship** considered Australia's role in the global survivorship community with focus on how global partnerships can be harnessed for the greater good of survivors.
- And the increasingly important topic of **metastatic cancer survivorship** was discussed as an exemplar of effective advocacy which has expanded the focus of cancer survivorship, and how this enhanced focus should translate to improved care and outcomes.

We accepted abstracts in all these categories as well as abstracts on any other topics of relevance to cancer survivors and survivorship care. As always, we particularly welcomed submissions from survivors themselves and those whose work is in partnership with survivors.

The Conference prompted bold discussions and lively exchange of ideas among clinicians, researchers, policymakers, and consumers to truly advance survivorship care and truly strengthen capability and capacity in this important field.

We thank you for joining us in Melbourne.

Conference Co-Convenors



Professor Bogda Kaczwaro AM
Conference Co-Convenor



Professor Michael Jefford
Conference Co-Convenor



Australian Cancer
Survivorship Centre

Education and training – webinars


YouTube AU


Search


ONLINE WEBINAR


Fear of Cancer Recurrence


CNSA is proud to partner with the Australian Cancer Survivorship Centre, Cancer Council and COSA to present this free webinar for nurses and allied health professionals on Fear of cancer recurrence.


 Emeritus Professor Phyllis Butow

 Associate Professor Ben Smith

 Dr. Jenny Liu


 Professor Louise Sharpe


 Kate Barber


 KA

Tuesday 27 June | 1.5 CPD Points
7:00 - 8:30pm AEST

In Collaboration with

 Clinical Oncology Society of Australia

 Cancer Council

 Australian Cancer Survivorship Centre


YouTube AU


Search


ONLINE WEBINAR


Cancer-Related Neuropathic Pain


CNSA is proud to partner with the Australian Cancer Survivorship Centre, Cancer Council and COSA to present this free webinar for nurses and allied health professionals on Cancer-Related Neuropathic Pain


 Professor Jane Phillips

 Associate Professor Melanie Lovell

 Dr. Jessica Lee


 Michael Collins


 Dr. Tim Hucker


 Karen Sanderson

Tuesday 14 November | 1.5 CPD Points
7:00 - 8:30pm

In Collaboration with

 Clinical Oncology Society of Australia

 Cancer Council Victoria

 Australian Cancer Survivorship Centre

www.cnsa.org.au

ONLINE WEBINAR

Conversations in Cancer Survivorship

CNSA is proud to partner with the Australian Cancer Survivorship Centre, Cancer Council Australia and COSA to present this free webinar for nurses and allied health professionals.

 Daniel Johnstone Consumer

 Natasha Keir Nurse Practitioner

 Dr. Jenny Liu Medical Oncologist Senior Research Officer Clinical Lecturer

 Chelsey Upston Cancer Nurse Cancer Council Victoria

 Dr. Matthew Wallen Academic Lead and Deputy Lead of Survivorship Program, Flinders University

Tuesday 1 May | 1.5 CPD Point
7:00 - 8:30pm AEST

In Collaboration with

 Clinical Oncology Society of Australia

 Cancer Council

 Australian Cancer Survivorship Centre


YouTube AU


Search


ONLINE WEBINAR


Redefining Survivorship – supporting people with treatable but not curable cancers.


CNSA is proud to partner with the Australian Cancer Survivorship Centre (ACSC), Cancer Council Victoria and New South Wales and the Clinical Oncology Society of Australia (COSA) to present this free webinar for nursing, medical and allied health professionals.

 Associate Professor Nicolas Hart

 Professor Melanie Lovell


 Dr. Andrea Smith


 Megan McDowell


 Kim Hobbs

Tuesday 14 May | 1 CPD Point
7:00 - 8:30pm AEST

In Collaboration with

 Clinical Oncology Society of Australia

 Cancer Council

 Australian Cancer Survivorship Centre

www.cnsa.org.au

Community of practice




Australian Cancer Survivorship Centre




Tracey Mander - Aus...

Victorian Cancer Survivorship Community of Practice


10 July 2025
2:00 – 4:00pm

 **Peter Mac**
Peter MacCallum Cancer Centre
Victoria Australia

 **VICTORIA**
State Government

Community of Practice


Unlisted Australian Cancer Survivorship Centre A... - 8/8

2  **Victorian Cancer Survivorship Community of Practice - 24...**
Australian Cancer Survivorship ...

3  **Victorian Cancer Survivorship Community of Practice, 15...**
Australian Cancer Survivorship ...

4  **Victorian Cancer Survivorship Community of Practice**
Australian Cancer Survivorship ...

5  **Victorian Cancer Survivorship Community of Practice -...**
Australian Cancer Survivorship ...

6  **Victorian Cancer Survivorship Community of Practice, 29...**
Australian Cancer Survivorship ...

7  **Victorian Cancer Survivorship Community of Practice...**
Australian Cancer Survivorship ...

 **Cancer Survivorship Community of Practice - July...**
Australian Cancer Survivorship ...

Community of practice

Survivorship Group

[GROUP OVERVIEW](#)[ACTIVITIES](#)[RESOURCES](#)[JOIN GROUP](#)


FOUNDED
2012

Overview

COSA members formed the cancer survivorship group in November 2012 in recognition of the growing importance of survivorship care of people diagnosed with cancer. Our multidisciplinary Group provides a platform for the discussion and ongoing development of survivorship care in Australia. We recognise that quality survivorship care is essential to supporting the well-being of people diagnosed with cancer and their families.

The overarching aim of the COSA Survivorship Group is to advance care and research to improve outcomes for all Australians after cancer treatment.

Group Chair



GROUP CHAIR

Nicolas Hart

Survivorship Group Chair

Australian survivorship research priorities

Supportive Care in Cancer
<https://doi.org/10.1007/s00520-021-06744-2>

ORIGINAL ARTICLE



Defining research and infrastructure priorities for cancer survivorship in Australia: a modified Delphi study

Fiona Crawford-Williams^{1,2} · Bogda Koczwara^{3,4} · Raymond J. Chan^{1,2,5} · Janette Vardy^{6,7} · Karolina Lisy^{8,9,10} · Julia Morris^{11,12} · Mahesh Iddawela^{13,14} · Gillian Mackay¹⁵ · Michael Jefford^{8,9,10}

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DOI: 10.1111/ajco.13914

ORIGINAL ARTICLE

WILEY

Current landscape of cancer survivorship research in Australia

Julia N Morris¹ | Fiona Crawford-Williams² | Bogda Koczwara^{3,4} |
Raymond J Chan^{2,5} | Janette Vardy^{6,7} | Karolina Lisy^{8,9,10} |
Mahesh Iddawela^{11,12} | Gillian Mackay¹³ | Michael Jefford^{8,9,10}

International community (IPOS)

ORIGINAL ARTICLE

WILEY

Psychosocial care for cancer survivors: A global review of national cancer control plans

Louise Mullen¹ | Christina Signorelli^{2,3} | Larissa Nekhlyudov⁴ |
Paul B. Jacobsen⁵ | Isaiah Gitonga^{6,7} | Tania Estapé⁸ | Beverly Lim-Hoeg⁹ |
Anne Miles¹⁰ | Cristina Sade¹¹ | Carolyn Mazariego¹² | Csaba L. Degi¹³ |
Fuchsia Howard¹⁴ | Sharon Manne¹⁵ | Luzia Travado¹⁶ |
Michael Jefford^{17,18,19} | on behalf of the
International Psycho-Oncology Society Survivorship Special Interest Group

Original Reports | Supportive Care & Symptom Control



International Survey of Psychosocial Care for Cancer Survivors in Low-/Middle- and High-Income Countries: Current Practices, Barriers, and Facilitators to Care

Christina Signorelli, PhD^{1,2} | Beverley Lim Høeg, PhD³; Chioma Asuzu, PhD⁴ | Isabel Centeno, MEd⁵ | Tania Estapé, PhD⁶ |
Peter Fisher, PhD⁷; Wendy Lam, PhD⁸ | Inbar Levkovich, PhD⁹ | Sharon Manne, PhD¹⁰ | Anne Miles, PhD¹¹; Louise Mullen, MSc¹² |
Larissa Nekhlyudov, MD, MPH¹³ | Cristina Sade, MD¹⁴ | Joanne Shaw, PhD¹⁵ | Anna Singleton, PhD¹⁶ | Luzia Travado, PhD¹⁷ |
Miyako Tsuchiya, PhD^{18,19} | Jesse Lemmen, MSc^{20,21} | Jie Li, PhD^{22,23} | and Michael Jefford, MBBS, PhD^{24,25,26} | On behalf of the
International Psycho-Oncology Society Survivorship Special Interest Group

International community (MASCC)



REVIEW

The efficacy, challenges, and facilitators of telemedicine in post-treatment cancer survivorship care: an overview of systematic reviews

R. J. Chan^{1,2*}, M. Crichton^{1,3}, F. Crawford-Williams^{1,2}, O. A. Agbejule^{1,2}, K. Yu⁴, N. H. Hart^{1,2,5,6}, F. de Abreu Alves⁷, F. D. Ashbury^{8,9}, L. Eng^{10,11}, M. Fitch¹², H. Jain¹³, M. Jefford^{14,15,16}, D. Klemanski¹⁷, B. Koczwara¹⁸, K. Loh¹⁹, M. Prasad²⁰, H. Rugo²¹, E. Soto-Perez-de-Celis²², C. van den Hurk²³ & A. Chan²⁴, on behalf of the Multinational Association of Supportive Care in Cancer (MASCC) Survivorship Study Group

Special Articles



Survivorship Care for People Affected by Advanced or Metastatic Cancer: MASCC-ASCO Standards and Practice Recommendations

Nicolas H. Hart, PhD^{1,2,3,4,5} ; Larissa Nekhlyudov, MD, MPH⁶ ; Thomas J. Smith, MD⁷ ; Jasmine Yee, PhD⁸ ; Margaret I. Fitch, RN, PhD⁹ ; Gregory B. Crawford, MBBS, MD^{10,11} ; Bogda Koczwara, MBBS^{12,13} ; Fredrick D. Ashbury, PhD^{14,15} ; Maryam B. Lustberg, MD, MPH^{16,17} ; Michelle Mollica, RN, PhD, MPH¹⁸ ; Andrea L. Smith, PhD¹⁹ ; Michael Jefford, MBBS, PhD, MPH^{20,21} ; Fumiko Chino, MD²² ; Robin Zon, MD^{23,24} ; Meera R. Agar, MBBS, MPC, PhD²⁵ ; and Raymond J. Chan, RN, PhD²⁴

Chan RJ et al. Ann Oncol 2021; 32(12): 1552-1570 /
Hart N et al. JCO Oncol Pract 2024; 20(9): 1160-1172

Ongoing challenges...

- Ensuring focus on all goals of survivorship care
 - Replacing specialist-led follow up
 - Attention also to
 - Chronic disease management
 - Health promotion and disease prevention
- Focus on those with high risk of late effects
 - Survivors of cancer treated in childhood / adolescence
 - People treated with radiotherapy for pelvic malignancies
- Long-term monitoring of people treated with newer therapies
 - e.g. immunotherapy, CAR-T, etc

Conclusions

- A terrific opportunity to enable improved care and outcomes for cancer survivors in Denmark
- Stepped care models are central to late effects services
- There may be learnings from Australia that are relevant
- Please share your own experience, learnings



Thank you!



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petermac.org/cancersurvivorship
mycareplan.org.au
petermac.org/survdirect



Michael Jefford
Australian Cancer
Survivorship Centre

ACSC receives funding from the Victorian Government and from Peter Mac