

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Transforming Cancer Survivorship Care – An Australian Experience

*International Conference on Cancer Nursing
Monday 5th September 2016*

Amanda Piper and Nicole Kinnane

Session aims

Learning objective 1:

Understand the Australian experience of implementing innovative survivorship programs and how this transfers to a global setting

Learning objective 2:

Understand how to apply tools and resources to deliver survivorship care

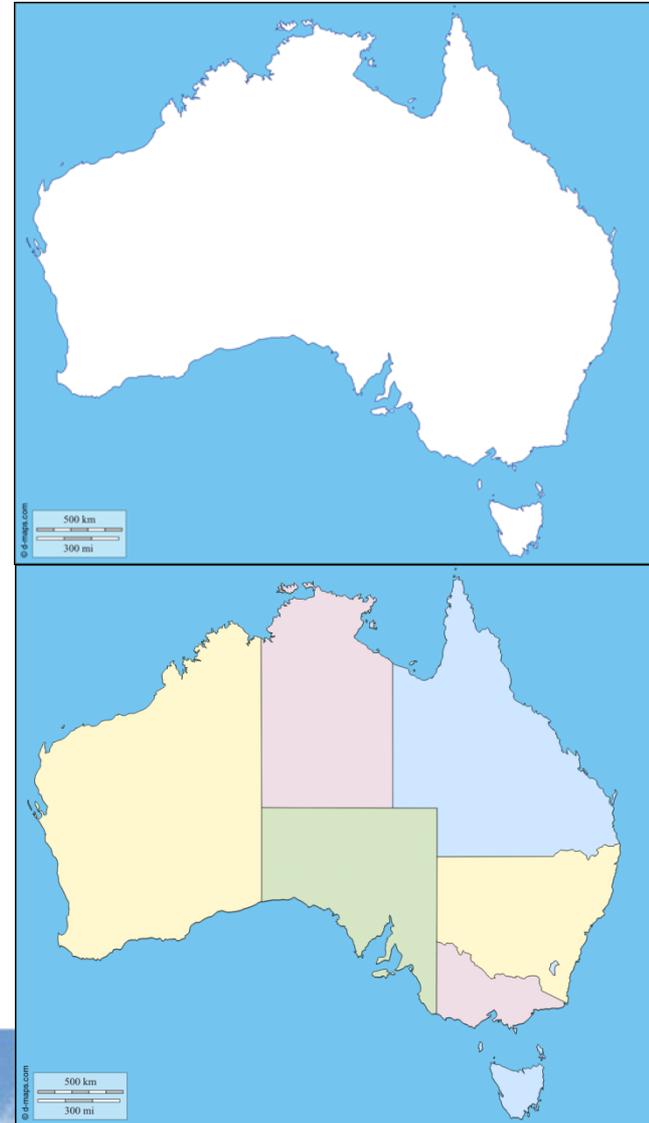


Overview

- Examples of some of our work in the post-treatment setting:
 - Victorian Cancer Survivorship Program
 - SCP initiatives
 - CALD resource development
 - General Practice (Primary Care) engagement
 - Resources to support practice
- Survivor preferences
- Challenges & enablers
- Application to nursing practice

Health care in Australia

- Shares similarities with UK
- Contrast to UK, responsibility for health split : federal and state and territory governments
- No national cancer plan
- Challenges a whole system approach to post-treatment care



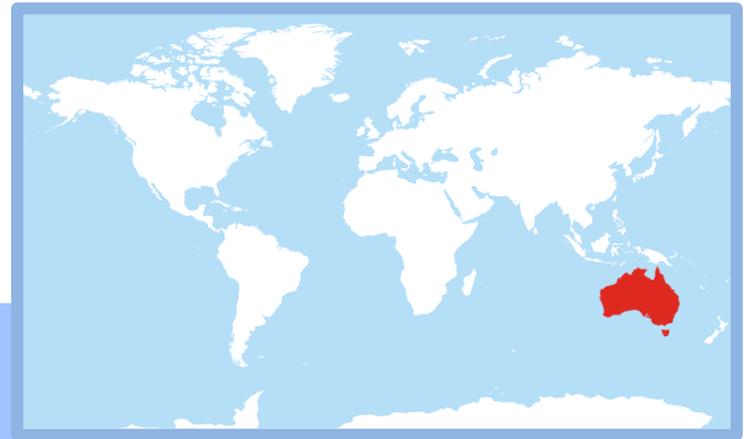
Cancer in Australia

Australian cancer prevalence exceeds 1 million: new estimates



Feb 2016

- 1 in 2 develop cancer by age 85
- 1 in 5 will have died by age 85
- Current follow up is neither sufficiently effective nor an efficient use of resources
- There is a need to trial novel models of care



Australian Cancer Survivorship Centre

A Richard Pratt Legacy

- Established in 2009
- Aim: to optimise health and wellbeing of cancer survivors and their carers
- Major funders are Peter MacCallum Cancer Centre, the Department of Health and Human Services (Victoria) and The Pratt Foundation
- Funding supports our small team to:
 - Improve care at Peter Mac
 - Influence survivorship care in Victoria
 - *Influence survivorship care nationally*
- *Not clinical service*

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Strategic Plan 2013-16



Our vision

To optimise the health and wellbeing of cancer survivors and their carers

Our purpose

To support and enable excellent survivorship care



Australian Cancer Survivorship Centre

A Richard Pratt Legacy

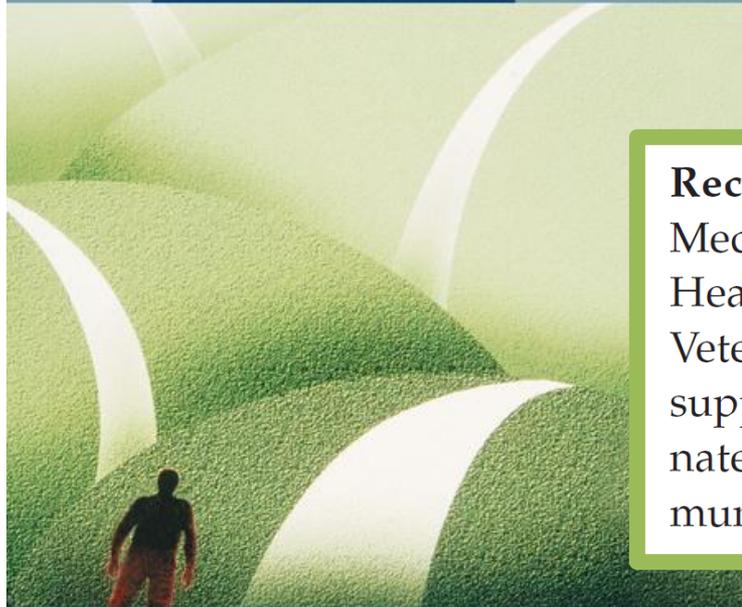


ACSC has supported and or undertaken the following:

- ***Victorian Cancer Survivorship Program***
- *SCP initiatives*
- *CALD resource development*
- *GP engagement*
- *Resources to support practice*

From Cancer Patient to Cancer Survivor

LOST IN TRANSITION



INSTITUTE OF MEDICINE AND
NATIONAL RESEARCH COUNCIL
OF THE NATIONAL ACADEMIES

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

FACT SHEET • NOVEMBER 2005

From Cancer Patient to Cancer Survivor: Lost in Transition Report Recommendations

Recommendation 5: The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.

Free PDF book

<http://www.nap.edu/catalog/11468.html>

Australian Cancer Survivorship Centre
A Richard Pratt Legacy



Excellent 17 minute video on YouTube

Victorian Cancer Plan 2016-2020

Focus for 2016–2020

- Implement survivorship programs to support people in their recovery and to reduce and manage consequences of treatment to achieve better long-term quality of life:
 - rehabilitation
 - long-term follow-up for late effects of treatment – follow-up programs with children and adolescents
 - link with chronic disease management in the community for those who have persisting effects of treatment.
- Develop agreed follow-up guidelines, including shared care with general practitioners, and implement across Victoria.
- Integrate the care of other conditions with cancer treatment, particularly for the elderly.

Victorian Cancer Survivorship Program



Supporting cancer survivors in Victoria
Learning from the Victorian Cancer Survivorship Program
pilot projects
2011-2014

- 2011-2014
- Government funded 6 projects
- Piloted different models of care
- Aimed to :
 - improve and evaluate new models
 - Understand and facilitate self-management

ACSC support to VCSP

- ACSC supported projects and evaluation of projects
- Develop resources
- Community of practice
 - Sharing of experiences
 - Updates on progress
 - Education
 - Discussion of issues
 - Evaluation
 - Primary care engagement
 - Needs assessment and risk stratification
 - Survivorship care plans
- ACSC concurrently implemented strategies in local context

VCSP Projects

Project	Specialist f/up	Shared care	D/C to GP	Needs assessment	Care coordination	Risk stratification	SCP	Self Mgt model
Breast cancer project		✓		✓	Nurse-led clinic 1 appt	Early breast cancer including DCIS	✓	
Barwon SW Survivorship Project (mixed tumour)		✓	✓	✓	Nurse-led clinic 2 appts	Case by case- Specialists decided	✓	
Melanoma project			✓		N.A.	Factors identified Specialists decided	✓ diary	
AYA project (Adolescent/ Young adult)	✓			✓	Allied health-led 7 reviews	All considered high risk	✓	
Moving forward with confidence (mixed tumour)	✓			✓	Nurse-led 4 reviews not clinic based	N.A.	✓	✓ MI
Positive change for life (haematology stem cell survivors)	✓			Existing late effects clinic SCP	Existing late effects clinic intervention	All considered high risk	✓	✓ COACH

ORIGINAL ARTICLE

Implementing novel models of posttreatment care for cancer survivors: Enablers, challenges and recommendations

Michael JEFFORD,^{1,2,3} Nicole KINNANE,¹ Paula HOWELL,⁴ Linda NOLTE,¹ Spiridoula GALETAKIS,⁵ Gregory BRUCE MANN,^{6,7} Lucio NACCARELLA,⁸ Julia LAI-KWON,¹ Katherine SIMONS,⁴ Sharon AVERY,⁹ Kate THOMPSON,¹⁰ David ASHLEY,^{11,12} Martin HASKETT,¹³ Elise DAVIES⁵ and Kathryn WHITFIELD⁵



VCSP: Challenges

- Individual level
 - Terms: ‘Survivor’ ‘Survivorship’ vs ‘Recovery’
 - Survivor readiness
- Organisational level
 - Identify treatment completion
 - Identification those who would receive the most benefit
 - Timing to maximise benefit
 - Resources to both implement and embed

VCSP: Challenges

- System level
 - Inclusion criteria a constraint
 - Framework for needs assessment at end of treatment
 - Limited guidance for risk stratification outside low risk patients
 - **Engagement with primary care**
 - **Reorientation from medical model to self-management**
 - **Evaluation focused on short-term data, diverse evaluation measures**

VCSP: Key Enablers

- Individual level
 - Preparation of patients for post-treatment care model and self-management
- Organisational level
 - Clinical leadership and strong project teams
 - Awareness of outcomes of survivorship models of care
- System level
 - Workforce education and training
 - Existing relationships with primary care
 - Access and capacity of community providers

Key Recommendations



ACSC has supported and or undertaken the following:

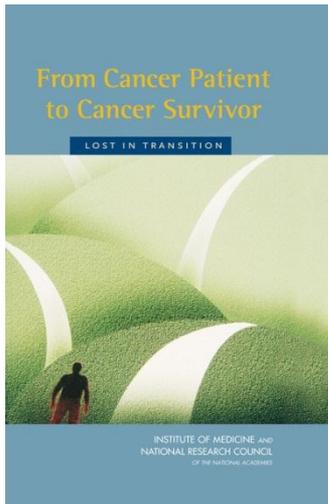
- *Victorian Cancer Survivorship Program*
- ***Survivorship Care Plan initiatives***
- *CALD resource development*
- *GP engagement*
- *Resources to support practice*

How will cancer survivors use survivorship care plans (SCPs)?



Background

- Widely endorsed
- Multi purpose communication tool



Recommendation 2: Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payors of health care.

Background

- Widely endorsed
- Multi-purpose communication tool
- **Components**
 - Treatment summary
 - Signs of recurrence
 - Late and long term effects
 - Recommended follow-up plan
 - Strategies to remain well
- Not standard of clinical practice in Australia

Cancer Survivorship Care Plan

Name: _____ Date of Preparation: _____

This Survivorship Care Plan summarizes information about your diagnosis, treatment, follow-up care, symptoms to watch for, and steps you can take to stay healthy.

The information in this care plan will be important for you to keep so that doctors and other health care providers that you see in the future will have information about your cancer, its treatment, and how best to work with you to monitor your health.

This Survivorship Care Plan has been sent to the following providers:

Health care provider	Address

In the future, your healthcare providers may need more details about your cancer and how you were treated. This Survivorship Care Plan may help you locate information related to your treatment.

Resources for cancer survivors are listed as part of the Survivorship Care Plan so that you may obtain additional information and identify support services immediately or in the future.

Known challenges and key enablers

Challenges

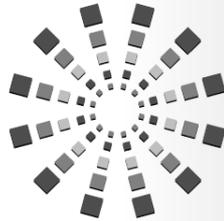
- Limited evidence
- Time to complete
- No identified personnel for preparation, delivery, update
- Remuneration

Key enablers

- Organisation commitment
- Clinical leadership
- Workforce education
- IT solutions
- Resourcing to support implementation

Brennan, Gormally et al (2014); Howell, Hack et al (2012); Keesing et al (2014)
Mayer, Birken et al (2015)

Copyright © 2016 Wolters Kluwer Health, Inc. All rights reserved.



Linda Nolte, BHSc (Nutrition Dietetics),
GradDipHlthServMgt

Nicole Kinnane, RN, OncCert, GradDipPsych-Onc

Julia Lai-Kwon, BMedSci/MBBS (Hon)

Priscilla Gates, BN, RN, GradDipCanNursing,
MPhil

Pauline Shilkin, BSW, GradDipAdEd

Michael Jefford, PhD, MBBS, MPH,
MHlthSerMt, GAICD, FRACP

The Impact of Survivorship Care Planning on Patients, General Practitioners, and Hospital-Based Staff

Nolte, Linda, et al. "The Impact of Survivorship Care Planning on Patients, General Practitioners, and Hospital-Based Staff." *Cancer nursing* (2016).

Key learnings

- Engage stakeholders
- Communication strategy required
- Strong clinical leadership and commitment essential
- Ownership and responsibility needs clarification
- **Challenges in supplying detailed SCPs**
- **More flexible approaches**
- **Risk stratification processes and needs assessment required**
- **Timing**
- **Engage primary care / general practice**

Sustainable approach to delivering SCPs

Aims and methods:

- Single site survey
- Assessed survivors' preferences
- Identify groups who did not want SCP
- Targeted people up to 12 months post treatment
- Across 10 tumour streams



(Breast, Gynaecology, Urology, Bone and soft tissue, Haematology, Upper GI, Lower GI, Melanoma, Head & Neck, Lung)

Why do survivors want SCPs? n=207

98% wanted to receive SCP

- 61% 'A record of cancer'
- 57% 'A reminder of things to do to look after myself'
- 55% 'Help me understand side effects of treatment'
- 55% 'Share with family and friends'
- 52% 'Share the information with the GP'



Information desired

- Top 5 information elements desired n=195
 - List of symptoms to watch out for and report
 - A summary of treatment received
 - Things I can do to look after myself
 - Plan for when I should have follow up
 - Strategies to reduce worry about cancer coming back
 - A list of tests I am going to have and when



itre



Information elements most desired within a survivorship care plan (top 5) per cohort

	*Breast	Gynaecology	Haematology	Head & Neck	*Lower Gastrointestinal	Upper Gastrointestinal	Melanoma	Bone and soft tissue	*Urology
Summary of the treatment I received	✓	✓	✓	✓	✓	✓		✓	
A list of symptoms to watch out for and report		✓	✓	✓		✓	✓	✓	✓
Information about side effects of treatment I received	✓		✓		✓				✓
A plan for follow-up appointments	✓						✓	✓	✓
Strategies for reducing worry about cancer coming back		✓		✓		✓		✓	
Name and contact details of who I should call if I have concerns			✓	✓					✓
A list of tests I am going to have and when		✓			✓	✓			✓
Things I can do to look after myself	✓				✓		✓		
Screening for other common cancers	✓	✓	✓				✓		
Special instructions to follow after treatment				✓	✓				✓
Pain and symptom management						✓			
Diet information	✓				✓				
Exercise information	✓								
Support group information							✓		
Coping after treatment is over								✓	

Strategies to stay well

- ‘Things I can do to look after myself,’ not specific information regarding lifestyle behaviours
e.g. diet, exercise, smoking cessation, reduced alcohol consumption, exposure to UV



SCP format and delivery n=212

- 91% preferred paper based
- Support for both brief (36%) and more detailed (42%) versions
- 55% preferred a face-to-face consultation with a health care professional
- Preference for discussion with a doctor (31%) or specialist nurse (27%)



Engagement with Primary Care

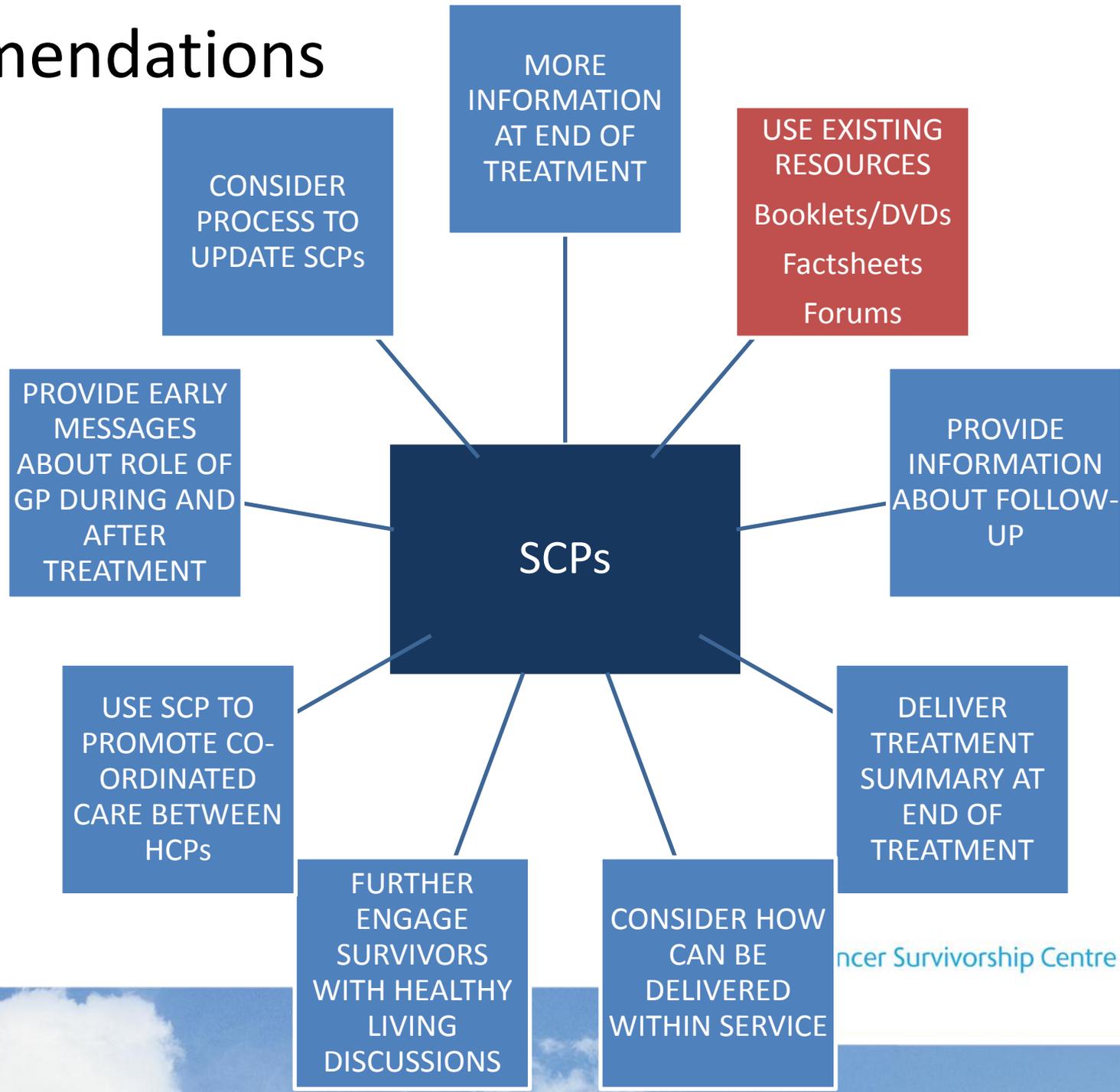
- 51% desired information 'when to contact GP' (n=219)
- 52% will share SCP with GP (n=207)
- 17% prefer to receive information from GP

- One page summary
- Early messages re role of primary care
- Translation of SCP to chronic disease management



Photo courtesy of Australian Primary Health Care Nurses Association (APNA)

Recommendations



Using evidence based resources

Australian Cancer Survivorship Centre
A Richard Pratt Legacy

Peter Mac

Surviving cancer: information for consumers



Follow-up of survivors of prostate cancer

This fact sheet is for people who have completed treatment for prostate cancer. It explains why follow-up appointments are important and possible effects from treatment. You may know that when prostate cancer is found and treated early, the outcome is often very good.

In Australia:

- 5-year survival for men treated for prostate cancer is about 85%. This means that for every 100 men treated for prostate cancer, about 85 will still be cancer free 5 years later.
- 10-year survival is about 75%. This means that for every 100 men treated for prostate cancer, about 75 will still be cancer free 10 years later.

For some men treated for prostate cancer, there is a chance the cancer could come back (recur).



Australian Cancer Survivorship Centre
A Richard Pratt Legacy

Peter Mac
Peter MacCallum Cancer Centre
Victoria Australia

Cancer survivorship information for survivors and carers



Coping with the fear of your cancer coming back



Living Well After Cancer

A guide for cancer survivors, their families and friends

Practical and support information

Peter Mac

Just take it day to day

A guide to surviving life after cancer



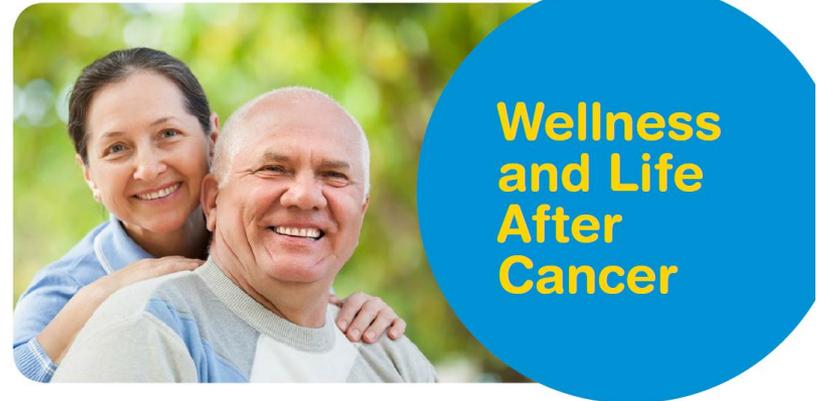
Australian Cancer Survivorship Centre
A Richard Pratt Legacy



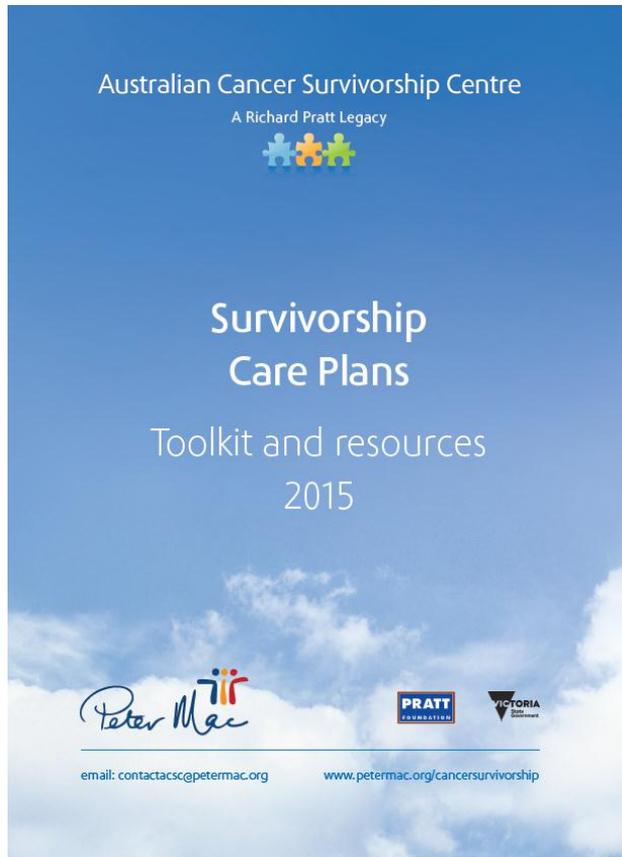
All available on our website

Wellness and life after cancer forums

- Developed in collaboration
- Group based education support transition to post-treatment
- Normalises post-treatment
- Links healthy living recommendations and community based supports
- Usually one off, can be half-day or full day
- Sustainable approach



Resources to support implementation



Next steps

- Strong support for SCPs
- Sustainable / flexible approaches
 - Trial brief care plan documents
 - Use existing resources
- Supporting clinical services to deliver at end of treatment (e.g. CDU)



ACSC has supported and or undertaken the following:

- *Victorian Cancer Survivorship Program*
- *SCP initiatives*
- ***Culturally and linguistically diverse (CALD) resource development***
- *GP engagement*
- *Resources to support practice*

Evidence based, consumer informed resources tailored to specific CALD groups



People from culturally and linguistically diverse (CALD) backgrounds have a poorer cancer experience when compared to dominant Anglo-English-speaking groups.

Background

Anglo-English speaking Australian groups

- The period after finishing treatment (the survivorship phase) can be distressing
- Survivors are often fearful of the cancer coming back
- Survivors can have financial, family, physical and/or emotional concerns
- Survivors are at risk of recurrence, long-term and late effects from cancer and its treatment

CALD

- Little is known if issues are the same
- Consideration of cultural differences and language important
- Cannot simply translate resources
- Identification of immigrant cancer survivorship concerns may support development of resources

Understanding the unique needs of cancer survivors from specific CALD groups

CALD 1:

Support Care Cancer
DOI 10.1007/s00520-015-2811-9



ORIGINAL ARTICLE

“I might not have cancer if you didn’t mention it”: a qualitative study on information needed by culturally diverse cancer survivors

Clare O’Callaghan^{1,2,3} • Penelope Schofield^{1,4,5} • Phyllis Butow^{6,7} • Linda Nolte⁸ •
Melanie Price^{6,7} • Spiri Tsintziras⁸ • Ming Sze^{6,7} • Thida Thein⁶ • Dorothy Yiu⁹ •
Shab Mireskandari⁶ • David Goldstein^{10,11} • Michael Jefford^{1,5,8}

CALD 2: On the road to recovery: developing evidence based, consumer informed resources for Arabic, Italian and Vietnamese cancer survivors living in Australia

Results

- Analysis revealed issues after treatment were similar
- Common issues included fear of recurrence, changes in physical appearance, practical community assistance, financial advice, support groups, nutrition, physical activity, genetics, physical side effects, psychological support
- Participants wanted resources in their language and specific to their culture and community
- Unique challenges and needs in each of the language groups were identified

Misunderstandings about cancer

' I saw on the TV they can extend life 10 years. I think, I've had six-and-a-half, so I have only three-and-a-half left '

Photo source:
CanRevive NSW



The concept of survivorship in different languages

‘Right word because it’s exactly true in reality’ (Vietnamese survivor)

‘It’s over, if it happens again then I’ll go through it again’ (Greek Survivor)

*‘I do not care, this name (survivor) is nothing’
(Mandarin survivor)*

‘According to Chinese tradition, [survivor] implies that the survival rate is very low’ (Cantonese survivor)

Using culturally appropriate language

Sexuality and fertility:

*'.....Sexuality and relationships are an important
.....It should also be discussed in a way that is
culturally appropriate.'* (Arabic survivor)

Having information own language and in simple terms (health literacy):

*'its hard (when information is only in English) –
especially when technical terms it's hard for these to be
translated by her sons.'* (Arabic survivor)

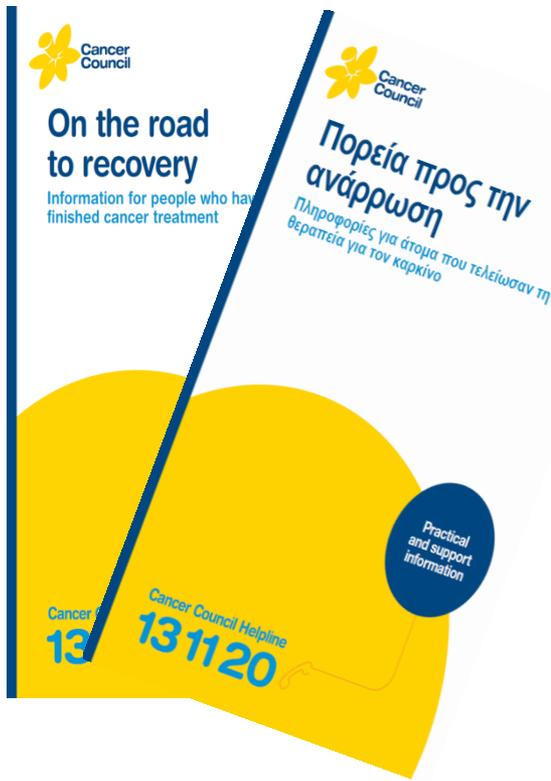
Key Learnings

Number of learnings throughout the development process:

- Awareness of how words/phrases are conceptualised by different groups
- Importance of engaging with community groups
- Budget for high costs of translation
- Robust translation processes are required
- Make resources bilingual



'First of their kind' Cancer Survivorship Resources CALD Communities



Australian Cancer Survivorship Centre
A Richard Pratt Legacy



Next Steps

Funding for development of:

- Written resources (Filipino and Hindi – speaking) – similar process
- Low literacy resources for cancer survivors in English
- Cancer glossary (400 key cancer terms) interpreted & translated in 15 languages
- Audio resources – English, Cantonese & Mandarin
- Develop education forum for Cantonese and Mandarin speaking survivors

Stretch



ACSC has supported and or undertaken the following:

- *Victorian Cancer Survivorship Program*
- *SCP initiatives*
- *CALD resource development*
- ***General Practice (Primary Care) engagement***
- *Resources to support practice*

Cancer survivorship and primary care

The Lancet Oncology Commission

The expanding role of primary care in cancer control



Greg Rubin, Annette Berendsen, S Michael Crawford, Rachel Dommett, Craig Earle, Jan Emery, Tom Fahey, Luigi Grassi, Eva Grunfeld, Sumit Gupta, Willie Hamilton, Sara Hiom, David Hunter, Georgios Lyraatzopoulos, Una Macleod, Robert Mason, Geoffrey Mitchell, Richard D Neal, Michael Peake, Martin Roland, Bohumil Seferik, Jeff Sisler, Jonathan Sussman, Stephen Taplin, Peter Vedsted, Teja Voruganti, Fiona Walter, Jane Wardle, Eila Watson, David Weller, Richard Wender, Jeremy Whelan, James Whitlock, Clare Wilkinson, Niek de Wit, Camilla Zimmermann

The nature of cancer control is changing, with an increasing emphasis, fuelled by public and political demand, on prevention, early diagnosis, and patient experience during and after treatment. At the same time, primary care is increasingly promoted, by governments and health funders worldwide, as the preferred setting for most health care for reasons of increasing need, to stabilise health-care costs, and to accommodate patient preference for care close to home. It is timely, then, to consider how this expanding role for primary care can work for cancer control, which has long been dominated by highly technical interventions centred on treatment, and in which the contribution of primary care has been largely perceived as marginal. In this Commission, expert opinion from primary care and public health professionals with academic and clinical cancer expertise—from epidemiologists, psychologists, policy makers, and cancer specialists—has contributed to a detailed consideration of the evidence for cancer control provided in primary care and community care settings. Ranging from primary prevention to end-of-life care, the scope for new models of care is explored, and the actions needed to effect change are outlined. The strengths of primary care—its continuous, coordinated, and comprehensive care for individuals and families—are particularly evident in prevention and diagnosis, in shared follow-up and survivorship care, and in end-of-life care. A strong theme of integration of care runs throughout, and its elements (clinical, vertical, and functional) and the tools needed for integrated working are described in detail. All of this change, as it evolves, will need to be underpinned by new research and by continuing and shared multiprofessional development.

Part 1: Introduction

Cancer control in high-income countries has long been dominated by highly technical, disease-centred interventions intended to save or prolong life. This is changing as health policies drive an increased emphasis on public

identifies emerging examples of good practice worldwide. The Commission brings together leading members of the international primary care cancer community, together with cancer specialists and policy researchers. We have elected to restrict our Commission to high-income

Lancet Oncol 2015; 16: 1231-72
See Comment pages 1225-30
School of Medicine, Pharmacy and Health, Durham University, Stockton on Tees, UK
(Prof G Rubin FRCP, Prof D Hunter PhD); Department of General Practice, University of Groningen, Groningen, Netherlands (A Berendsen PhD); Airedale National Health Service Foundation Trust, Keighley, UK
(S M Crawford MD); School of Clinical Sciences, University of Bristol, Bristol, UK
(R Dommett PhD); Ontario Institute for Cancer Research, Toronto, ON, Canada
(Prof C Earle MD, Prof E Grunfeld PhD); Department of General Practice, University of Melbourne, Melbourne, VIC, Australia (Prof J Emery DPhil);

- Continuous
- Coordinated
- Comprehensive

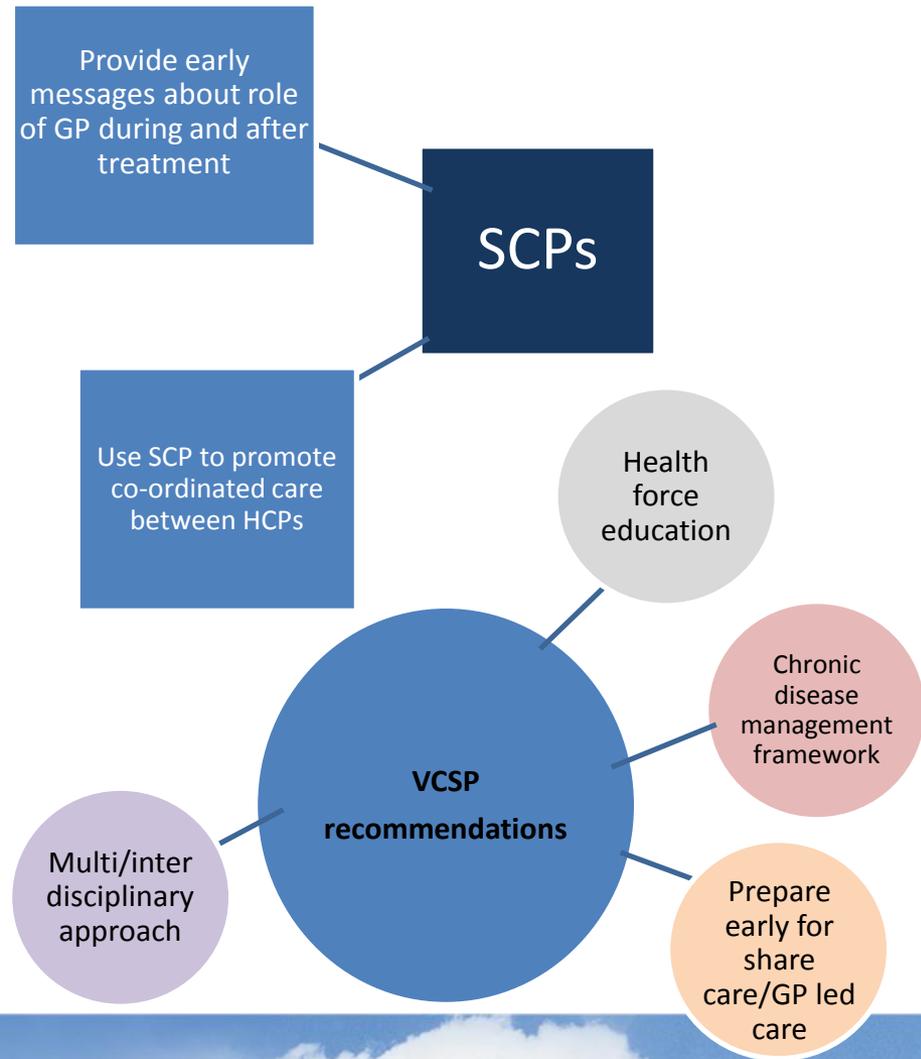
- Shared cancer care – transition to increased role for primary care

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



General Practice Placement Program - pilot



- Support development of models of shared care
 - Perceptions regarding scope
 - Engagement
 - Education

Inter-professional experiential learning

GP placement program

- Design:
 - Two existing models of experiential learning/placement programs
 - General practice views and preferences
- Deliver:
 - General practice attended 10 clinical hours in cancer centre
 - Attend ambulatory care/clinic appointments
 - Focus on cancer survivorship
 - Financial stipend and reimbursement for generalists
 - Accredited for continuing professional development points
- Aims:
 - Feasible; clinically and professionally valuable; knowledge and skills transfer; identify barriers/enablers to shared care

A clinical placement program for primary care professionals at a comprehensive cancer centre

Judy Evans, Linda Nolte, Amanda Piper, Liz Simkiss, Kathryn Whitfield, Michael Jefford

GP placement program – Phase II

- Funded by Department of Health and Human Services, Victoria
 - Expand and improve on first pilot; test at additional hospitals
- Deliverables:
 - Toolkit
 - Video resources

Emerging program results

General practitioners and General Practice Nurses

- ✓ Knowledge and skills transfer
- ✓ Program learning outcomes met
- ✓ Learning outcomes met

Oncologists and Nurse specialists

- ✓ Program learning outcomes met
- ✓ Increased understanding of chronic disease management

✓ Shared enthusiasm to support shared care

✓ Clinically and professionally valuable

Learning opportunities skewed

GP Videos

- Initially for specialist audience only
- Stakeholder engagement informed an evolution
- Delivered suite of videos:
 - Consumers
 - General practice
 - Specialist
- Broader reach beyond placement program



Key messages

- Shared care
 - provides better care
 - is better because patients receive holistic, coordinated care
 - requires quality information from specialist
- Clarity around roles and responsibilities
- Patients appreciate and accept shared care
- Optimal Care Pathways (best practice care pathways) are a useful resource

Cancer Survivorship and General Practice Video

Whilst watching the video consider the role of general practice (primary care) in your setting

[8 min](#) Cancer survivorship and general practice

[4 min](#) Cancer survivorship and general practice

**Cancer survivorship
and general practice**

For hospital-based
health professionals

Australian Cancer Survivorship Centre
A Richard Pratt Legacy



Evaluation

Recognising your health system may be different, having watched the video:

- General practice has an important role in survivorship care?



For hospital based health professionals - cancer survivorship and general practice

ACSC has supported and or undertaken the following:

- *Victorian Cancer Survivorship Program*
- *SCP initiatives*
- *CALD resource development*
- *GP engagement*
- ***Resources to support practice***
 - *Online education modules*
 - *Training program for HCPs*
 - *Fact sheets for HCPs*

Call for additional education for healthcare professionals



Health professionals need to receive education and training to ensure proper care is provided to the growing number of cancer survivors. Although physicians and nurses are the primary providers of care, other care givers, such as rehabilitation specialists and psychosocial and mental health providers, also play an integral role in the overall cancer health care team.

Training and Education

Cancer survivorship care as a distinct phase of the cancer trajectory is a relatively new construct, and health professional schools' curricula have generally not included much content in this area. This needs to change, but a larger task is providing continuing medical education to professionals who have completed their formal training and are encountering cancer survivors in their practices.

Providers need to be apprised of the risks of cancer treatments, the probabilities of cancer recurrence and second cancers, the effectiveness of surveillance and interventions for late effects, the need to address psychosocial concerns, the benefits to patients of prevention and lifestyle change, and the complexities of integrating survivorship concerns with care for other chronic conditions. Education and training must also stress the need for multidisciplinary approaches, integrated and coordinated care, and effective use of community-based resources.

Opportunities for Increased Training

Physicians

Cancer survivorship has yet to be well represented in undergraduate medical school curriculum and only a few schools currently offer courses or clerkships pertaining to cancer survivorship. Some medical schools have incorporated survivorship issues into their curriculum by including cancer survivors as "standardized patients" in what are referred to as "structured clinical instruction modules."

Suggested Essential Content of Survivorship Training

- Prevention of secondary cancers
- General discussion of survivorship
- Long-term complications/sequelae of treatment
- Trends and statistics in health care access
- Health care systems/quality assurance/models of care
- Rehabilitation services

Ac
on
sor
(e.g.
che
pat
sur

For
prc
are
me
low
tio
uin
onl
dev
in
ma



American Society of Clinical High-Quality Cancer Surviv

Mary S. McCabe, Smita Bhatia, Kevin C. Oeffinger, Gregory H. Reardon, Courtney Lyne, Anna S. Williams, and Melissa M. Hudson

Table 2. Areas Essential to Survivorship Education Curricula
Essential area
Epidemiology of incidence and prevalence of cancers and major types of cancer
General discussion of survivorship (including quality-of-life issues)
Health care systems/quality assurance/models of care
Health promotion after cancer
Pain management, sleep management
Palliative care/end-of-life care
Prevention, diagnosis, evaluation, and treatment of recurrence
Prevention, diagnosis, evaluation, and treatment of secondary cancers
Prevention, diagnosis, evaluation, and treatment of nonmalignant long-term and late-occurring complications/sequelae of treatment
Psychosocial assessment and care
Rehabilitation services
Trends and statistics in health care access
Trends and statistics in survivorship including the interface of cancer and aging

ASCO Core Curriculum for Cancer Survivorship Education

Charles L. Shapiro, MD, Paul B. Jacobsen, PhD, Tara Henderson, MD, MPH, Arti Hurria, MD, Larissa Nekhlyudov, MD, MPH, Andrea Ng, MD, MPH, Antonella Surbone, MD, PhD, Deborah K. Mayer, PhD, RN, and Julia H. Rowland, PhD

DOI: 10.1200/JOP.2015.009449; published online ahead of print at jop.ascopubs.org on January 26, 2016.

Drawn from *From Cancer Patient to Cancer Survivor: Lost in Transition*



Free online education module

- Asked cancer nurses' perceptions of their survivorship learning needs
- Preference for online education
- Engaged with survivorship experts internationally who have developed survivorship training programs and competency guidelines
- Collaborative initiative:



Queensland University of Technology



Australian Government
Cancer Australia

Australian Cancer Survivorship Centre
A Richard Pratt Legacy


Cancer survivorship fundamentals

Cancer Learning Survivorship

Why is it important?

What can I do?

Learning modules ▾

Survivorship fundamentals

Key elements

Toolbox

Common health concerns

Promoting self-management

Promoting wellness

Resources ▾

Videos

About us ▾

Acknowledgments

This module is about understanding the health needs and experiences of cancer survivors. It will touch on topics such as the prevalence of cancer in the community; demographic characteristics of cancer survivors in Australia; common health concerns; short and long term experiences of cancer survivorship; and cultural perspectives.

Learning Objectives

- Describe key features of the cancer survivorship experience
- Outline the epidemiological profile of cancer survivorship in Australia
- Recognise the importance of incorporating cancer survivorship care into health care practice.

Learning Activity



Cancer Learning
Cancer survivorship fundamentals
Start module >

Test your knowledge



Start Quiz >

Resources

- A personal story from Meg Rynderman
<http://www.petermac.org/cancersurvivorship/ApersonalstoryfromMegRynderman>
<http://www.youtube.com/watch?>

Learning Modules



Six practical learning modules in survivorship care

Downloadable tools



Checklists, factsheets and other resources

Personal challenge



Things you can do to improve cancer survivorship care

Organisation challenge



Things your organisation can

Flexible self-directed learning:
6 easy to use interactive learning modules

Further relevant up to date resources, readings and videos

Personal challenge – how can you improve survivorship care?



Evaluation – response to question on satisfaction and learning preferences (n=21)

Questions	Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
I found it easy to navigate the website.	9 (42.9)	9 (42.9)	3 (14.3)	0	0
The content engaged my attention.	7 (33.3)	13 (61.9)	1 (4.76)	0	0
I found the information applicable to me in my everyday practice.	8 (38.1)	13 (61.9)	0	0	0
Interactive learning opportunities, such as quizzes or videos, are important to me when completing online learning.	9 (42.9)	11 (52.4)	1 (4.8)	0	0
Links to external resources are important to me.	9 (42.9)	12 (57.14)	0	0	0
Downloadable fact sheets and practical tips are important to me.	12 (57.1)	9 (42.9)	0	0	0
Accreditation for continuing professional development would be a key motivator for visiting this website.	5 (23.8)	10 (47.6)	5 (23.8)	0	1 (4.8)
I would recommend this site to colleagues.	8 (38.1)	10 (47.6)	3 (14.3)	0	0

Delivering Innovative Cancer Survivorship Care

Training program for HCPs to improve post-treatment care

Australian Cancer Survivorship Centre
A Richard Pratt Legacy



Delivering Innovative Cancer Survivorship Care workshop



Date: Wednesday, 11 May 2016
Time: 9.00am - 4.30pm
Venue: Peter Mac, East Melbourne
Further Details: Georgina Wiley
via email georgina.wiley@petermac.org or 9656 9040

This intermediate course is open to all nursing and allied health staff. It will provide participants with key knowledge, skills and resources for implementing cancer survivorship care. Participants will be given the opportunity to work through a case study and conceptualise the practicalities of how to implement survivorship care into their own work environments. The program is designed to allow participants to further understand their role within a cancer survivor's journey.

The program will include:

- Key elements of survivorship including the common experiences of cancer survivors
- The role of general practice in survivorship care
- Promoting wellness and self-management
- tools and resources including survivorship care plans and needs assessment tools
- Interactive sessions to acquire and apply new skills

The day will be facilitated by staff members of the Australian Cancer Survivorship Centre. A cancer survivor will be also present throughout the day.

Participants will be required to undertake pre-reading and a pre-workshop survey.

To register please visit: <http://www.petermac.org/education/nursing-education/continuing-nursing-education>

Peter Mac staff members can register on the [nursing education intranet page](#).



Aims:

- Group based education
- Focus on implementation of survivorship care
- Asked to come prepared with a concept
- Provided with education, information and resources to support implementation
- Demand for both basic and intermediate workshops



Post workshop evaluation $n=75$

Participants nursing, allied health, organizational level attendees e.g. program managers

“The importance of the patient during their survivorship as much as the medical profession”

“Resources available, chronic disease management”

“That there are all these programs and services out there that I wasn’t aware of “

- 75% completed the post workshop evaluation

Of these:

- 93% were motivated and inspired to promote and implement survivorship care within their clinical setting
- 76% workshop had met their learning needs
- 88% would recommend the workshop

Resources supporting health professionals provide survivorship care



Cancer survivorship information for professionals



Follow-up of survivors of thin melanoma

Thin melanoma is defined as less than 1 mm in thickness using the Breslow method for measuring melanomas under the microscope.

recurrence or second primary cancers and for other later effects.

- coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met (incl. health promotion,

including at least annual full skin checks for the remainder of their lives. The frequency of skin checks will be determined by the patient's risk factors, such as their degree of sun damage, family history including genetic predispositions, and number and

Cancer survivorship information for professionals



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).

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(1). Fatigue may also result from things like pain, anxiety, depression, disturbed sleep, anaemia, adverse effects of medications and comorbidities(2). Examples have been

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.

All available on our website



Nurses providing survivorship care

“Changing lives one light bulb moment at a time!”

Rachel Parrott
18 Feb 2013 10:23 pm

Nurses make a difference to the lives of people affected by cancer:

Provide leadership

Work as part of multi-disciplinary team

Promote healthcare change

Support survivor self-management



ACSC Team members



Acknowledgements

All the survivors, volunteers , community groups and staff who participated in the projects and the funders who supported the projects:

Alfred Health
Australian Primary Health Care Nurses Association
Austin Health
Australian Association of Practice Managers
Barwon Health
Barwon Medicare Local
Barwon South West Regional Integrated Cancer Service
Bendigo Health
BreaCan
Cancer Australia
Cancer Council Australia
Cancer Council Victoria
Canteen Australia
Chinese Cancer Society
Deakin University
Department of Health and Human Services
Eastern Health
Gippsland Regional Integrated Cancer Service
Great South Coast Medicare Local
Health Networking Victoria

Inner North West Melbourne Medicare Local
Melanoma Patients Australia
North Eastern Melbourne Integrated Cancer Service
Northern Health
ONTrac at Peter Mac Victorian Adolescent and Young Adult Cancer Service
Peninsula General Practice Network
Peter MacCallum Cancer Centre
Psycho-oncology Cooperative Research Group
Queensland University of Technology
Royal Australian College of General Practitioners
Southern Melbourne Integrated Cancer Services
Swinburne University
The Leukaemia Foundation
The Pratt Foundation
The Royal Melbourne Hospital
The Royal Women's Hospital
The University of Melbourne
The Western Hospital

Conclusion

- ACSC has been instrumental in transforming survivorship care
- Underpinning our efforts is striving to understand survivors concerns and preferences regarding their post treatment care
- The Australian experience of implementing innovative survivorship programs can transfer to the global setting
- Our learnings and the resources are likely to be applicable internationally

For further information and links to our
resources:

Amanda.Piper@petermac.org

Nicole.Kinnane@petermac.org

www.petermac.org/cancersurvivorship

Resource sheet

https://www.petermac.org/sites/default/files/ICCN_2016_ACSC_resource_sheet.pdf

On ACSC website - News and Events



Peter MacCallum Cancer Centre
(cancer hospital and research facility)

