Cancer Survivorship – Quality care from and beyond the cancer setting

Cathie Pigott - Acting Project Manager
Australian Cancer Survivorship Centre
A Richard Pratt Legacy
• Who are cancer survivors

• Tools and strategies to assist with the transition

• Identifying successful survivorship models
Figure 11.1: 23-year prevalence as at the end of 2004

Note: Numbers refer to the number of persons, not the number of cancers, prevalent at the end of 2004.

Source: National Cancer Statistics Clearing House, AIHW.
Cancer survivors in Australia

In the last 23 years approximately 3.2% (654 977) of the Australian population have been diagnosed and are living with cancer people (AIHW 2004)

Risk of getting all cancers combined in Australia (2007)

<table>
<thead>
<tr>
<th>Age group</th>
<th>Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-49</td>
<td>1 in 21</td>
</tr>
<tr>
<td>50-64</td>
<td>1 in 8</td>
</tr>
<tr>
<td>65-79</td>
<td>1 in 4</td>
</tr>
<tr>
<td>80+</td>
<td>1 in 4</td>
</tr>
</tbody>
</table>

Defining survivorship

When does survivorship begin?

Where are the gaps in the cancer care service provision that we may be able to improve?
Australian Cancer Survivorship Centre

Utilising the perspective that survivorship begins at diagnosis the Centre aims to improve a range of outcomes for people affected by cancer.

The Centre is a virtual centre with a project team working with clinical providers (medical, nursing, allied health) at Peter Mac and throughout Victoria to facilitate improved care for survivors.
Australian Cancer Survivorship Centre

Funding

With funding from The Pratt Foundation the Centre focuses on integrating survivorship care across the cancer journey.

With funding from the Victorian Department of Health the Centre focuses specifically on improving post-treatment care.
Impact of finishing primary treatment

- Fear of recurrence
- Ongoing treatment side effects (fatigue)
- Late and long-term effects of treatment (incl. risk of second cancers)
- Psychological distress
- Relationship issues
- Vocational and employment issues
- Financial and practical issues
Essentials of Survivorship Care

1. Supportive care interventions, rehabilitation and self-management strategies tailored to need

2. Promotion of healthy behaviours

3. Surveillance and early detection for cancer recurrence, new cancers or late effects

4. Coordination between specialists and primary care providers to maximise outcomes for people affected by cancer

(Adapted from the Institute of Medicine (IOM) and National Research Council From Cancer Patient to Cancer Survivor – Lost in Transition)
Case Study

In 2002 Joe was diagnosed at the age of 26 with Hodgkin’s lymphoma, localised stage II supraclavicular area

Joe lived with partner

Worked mostly on his own managing a dairy farm, 3 hours drive from Melbourne

No prior history of mental health issues

Parents divorced when he was a teenager has 2 sisters

Treatment - 3 cycles of chemotherapy and mantle radiation

Whilst having radiotherapy Joe was reviewed by psychologist as he was tearful and feeling low

Plan was for follow up visit with the psychologist – but this did not occur
Case Study

2003 - 2009

Joe had regular follow up in the cancer service outpatients first 6 monthly and then yearly.

Follow up visits indicated Joe was clear of any recurrence, no other issues were identified.

Joe had moved a couple of times with different jobs – now living one and a half hours from Melbourne.
Case Study

• 2011 – Reviewed in Late Effects Clinic
  – Joe now has 2 children, experiencing tiredness
  – Completed a Supportive Care Needs Screening tool and self-identified anxiety and depression and suicidal ideation
  – Discussed with Nurse Coordinator his feelings of hopelessness and helplessness and said they had been with him since completion of treatment.
  – Had not been able to return to job as farm manager because of fatigue and he had difficulty accepting this
  – Had admitted himself to a psychiatric hospital a year ago because of suicidal tendency

• Could we have improved on these outcomes for Joe?
At completion of primary treatment

Risk factors included (NHMRC, 2003)

• Young age <30
• Living in a rural area

Nurse Practitioner made referral to psychologist because of feelings of sadness

No written follow up as to why no further psychology appointments were made

No mention of psychologist involvement in discharge letter

No referral to community services
At follow up

- Reviews by oncologist focused on presence or not of cancer, not on supportive care needs
- Joe did not initiate discussion of his supportive care needs
- GP had changed because Joe had moved but the new GP address was not updated on system – so there was no communication with GP or any other community services
• Who are cancer survivors

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**Supportive Care Screening**

**Distress Management**

<table>
<thead>
<tr>
<th>Screening Tools for Measuring Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.</td>
</tr>
</tbody>
</table>

**Extreme distress**

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Problems</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>Fears</td>
</tr>
<tr>
<td>Family Problems</td>
<td></td>
</tr>
<tr>
<td>Dealing with children</td>
<td>Dealing with partner</td>
</tr>
</tbody>
</table>

**Other Problems:**

**YES**

| Physical Problems |
| Appearance | Bathing/dressing | Breathing | Changes in urination | Constipation | Diarrhea | Eating | Fatigue | Feeling Swollen | Fevers | Getting around | Indigestion | Memory/concentration | Mouth sores | Nausea | Nose dry/congested | Pain | Sexual | Skin dry/itchy | Sleep | Tingling in hands/feet |

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.
Communication Skills Video Training Resources

These freely available video resources were developed in response to an identified gap in available flexible education resources. The 8 video case studies and accompanying Facilitator Manual aim to supplement current supportive cancer care education resources and focus on improving clinician’s communication skills when undertaking a discussion of supportive care needs with people affected by cancer.

- Introduction
- Scenario 1: Responding to anger
- Scenario 2: Responding to emotional cues
- Scenario 3: Making referrals
- Scenario 4: Multidisciplinary team communication
- Scenario 5: Spiritual awareness
- Scenario 6: Building on existing strengths
- Scenario 7: Cultural awareness
- Scenario 8: Responding to depression
- Facilitator guides
## Survivorship Care Plan

### Allied Health and Supportive Care Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Location</th>
<th>Provider Name</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychology</td>
<td>Peter Mac</td>
<td>Justine D</td>
<td>Counselling</td>
</tr>
<tr>
<td>Social Work</td>
<td>Peter Mac</td>
<td>Mary B</td>
<td>Emotional support</td>
</tr>
<tr>
<td>Psychiatry</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fertility/Andrology</td>
<td>Royal Women's</td>
<td>Dr Cate S</td>
<td>Fertility preservation</td>
</tr>
<tr>
<td>Smoking Cessation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontrac@Petermac</td>
<td>Peter Mac</td>
<td>Kate T</td>
<td>Employment, Emotional support</td>
</tr>
</tbody>
</table>

Adapted from the IOM's Template for “Cancer Survivorship Care Plan” V: 1 April 2011
Cancer-related resources
The Australian Cancer Survivorship Centre aims to improve health outcomes for cancer survivors, and provides timely and relevant information on important issues related to cancer survivorship. www.petermac.org/cancersurvivorship/Home

The Cancer Council in your state provides information and support for cancer survivors. The helpline runs a free telephone based support service called Cancer Connect, where you can speak with another cancer survivor: Telephone 13 11 20 for details.

Obtain a free copy of the DVD ‘Just take it day to day, a guide to surviving life after cancer’ and the free booklet ‘Life after cancer, a guide for cancer survivors’ from the Cancer Council Helpline on 13 11 20 or the Australian Cancer Survivorship and Information Centre at Peter Mac: Telephone 9656 3547 or email contactacsc@petermac.org
<table>
<thead>
<tr>
<th>No.</th>
<th>Approx Date</th>
<th>Investigations</th>
<th>Discipline</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>Assessment Discuss end of Treatment Plan</td>
<td>Haematologist Nurse Coordinator</td>
</tr>
<tr>
<td>2</td>
<td>(1 month)</td>
<td>Assessment CT and blood test</td>
<td>Haematologist</td>
</tr>
<tr>
<td>3</td>
<td>(3 months)</td>
<td>Assessment Investigations</td>
<td>Haematologist</td>
</tr>
<tr>
<td>4</td>
<td>(6 months)</td>
<td>Assessment CT and blood test</td>
<td>Haematologist</td>
</tr>
<tr>
<td>5</td>
<td>(9 months)</td>
<td>Assessment Investigations</td>
<td>Haematologist</td>
</tr>
<tr>
<td>6</td>
<td>(12 months)</td>
<td>Assessment CT and blood test</td>
<td>Haematologist</td>
</tr>
<tr>
<td>7</td>
<td>(15 months)</td>
<td>Assessment Investigations</td>
<td>Haematologist</td>
</tr>
<tr>
<td>8</td>
<td>(18 months)</td>
<td>Assessment CT and blood test</td>
<td>Haematologist</td>
</tr>
<tr>
<td>9</td>
<td>(21 months)</td>
<td>Assessment Investigations</td>
<td>Haematologist</td>
</tr>
</tbody>
</table>

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Victorian Cancer Survivorship Program
Pilot Projects

• Follow-up care is tailored to meet individual needs and considers diverse population groups
• Care will be delivered in the community
• The project will have strong engagement with consumers
• There is linkage of survivors to existing services and ‘packages of care’
• Specialist cancer clinicians, primary care providers, nursing and allied health providers are engaged in a formalised transition pathway, from the acute to community care settings, and vice versa
• Self-management strategies for cancer survivors and their families/carers and peer support opportunities are included as a component of follow-up care.
Role of the Australian Cancer Survivorship Centre

- Support the development of a community of practice with the pilot project teams
- Support the pilot projects in development of resources
- Continue to develop information resources for people affected by cancer focused on survivorship issues
Improving survivorship care in Australia

The Australian Cancer Survivorship Centre is working to help improve health outcomes for cancer survivors.

Numbers of cancer survivors are increasing due to advances in early detection, treatment and population ageing. International research shows there is an important need to address issues faced by cancer survivors coping with life during and beyond acute treatment.

The ACSC is advocating for and assisting the development of services, as well as promoting research, education and discussion within the health system to increase knowledge about cancer survivorship. In these ways we aim to promote coordinated, evidence-based care, improve collaboration between health professionals and within the health system, and promote survivor-focused solutions to barriers that exist within the health system.
Acknowledgements

• Associate Professor Michael Jefford
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• Professor Sanchia Aranda
• Rachid Annab

Australian Cancer Survivorship Centre - a Richard Pratt Legacy

http://www.petermac.org/cancersurvivorship/Home
Keep moving forward