Australian Cancer Survivorship Centre
A Richard Pratt Legacy

in touch

News from the Ausralian Cancer Survivorship Centre August 2013

From the Director

The Australian Cancer Survivorship Centre is based at Peter MacCallum Cancer Centre. It receives funding from The Pratt Foundation, the Victorian Department of Health and from Peter Mac.

The ACSC aims to improve outcomes for people affected by cancer. We work with clinical providers (medical, nursing, allied health) at Peter Mac and throughout Victoria to facilitate improved care for suvivors.

Cancer survivors may experience a range of issues during and after completing treatment, yet current follow-up care is inadequate. The ACSC will help improve follow-up care.

Associate Professor Michael Jefford

Survivorship care: what is it?

Cancer survivorship is now recognised as a distinct phase of cancer care. More people are being cured of cancer and are living as cancer survivors, primarily due to advances in cancer treatment.

Survivorship care, as defined by the Institute of Medicine (US), is 'the phase of care that follows primary treatment' and should include the following essential elements:

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 (e.g. pain and fatigue)
4. coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met.

Our activities this year

The Australian Cancer Survivorship Centre, a Richard Pratt legacy (ACSC), has developed a range of consumer and health professional information resources that are available via www.petermac.org/cancersurvivorship. The ACSC is working with Cancer Council Victoria and Cancer Australia to produce online cancer survivorship education modules, initially for primary health care nurses and cancer nurses.

Progress on the Victorian Cancer Survivorship Program

One of our key recent activities has been to support the Victorian Cancer Survivorship Program (VCSP) and its cancer survivorship pilot projects. We facilitate a community of practice, bringing together the project teams and others passionate about improving survivorship care to network, share learning and form collaborations.

In 2011, the Victorian Department of Health funded the VCSP, a statewide program that aims to improve the management and care of people with cancer beyond active treatment by:

1. raising awareness and developing resources to support Victorian workforce capacity in cancer survivorship
2. trialling evidence-based survivorship models of care across the acute, primary and community sectors
3. fostering collaborative relationships to build capacity in cancer survivorship models of care
4. developing a framework to enable evaluation of cancer survivorship initiatives
5. actively engaging with the primary care sector including the General Practice Divisions and General Practice Victoria.

This edition of *in touch* provides an update on these important Victorian survivorship projects.

Alfred Health

Haematology: positive change for life survivorship is examining lifestyle modification to ameliorate the effects of treatment, minimise comorbidities and promote long-term wellness. Although stem cell transplant may result in cure for many people with blood cancer, survivors often have associated illnesses. Lifestyle modification programs focusing on

nutrition and physical activity may substantially improve overall health and quality of life.

Fifty-three long-term survivors of blood cancer treated with stem cell transplantation (and more than 2 years in remission) have been participating in this project. Following physician clearance, survivors receive an individually tailored, community-based physical activity program consisting of a 12-month membership at a local YMCA, health and fitness centre or equivalent program. Referrals to community-based exercise physiology and physiotherapy support people adopting a regular exercise regimen.

Survivors also receive ongoing dietary advice and coaching from a dietitian. A comprehensive resource manual includes health information, a weekly exercise diary, meal planners, food diaries and charts to measure and monitor weight change. Monthly newsletters contain healthy living recipes and practical tips for increasing physical activities and improving eating habits. Every 6–8 weeks group physical activities are conducted and participants meet other stem cell transplant survivors for informal peer support. A critical component of the program is shared care with the survivor's GP, who helps monitor their progress and supports them in achieving their lifestyle goals.

Results from 6-month follow-up data have demonstrated the potential of this program to significantly improve blood cancer survivors' levels of physical activity and eating behaviours, resulting in improved self-reported quality of life and reduced fatigue.

Further information: Helen McLauchlan, Project Manager, +61 3 9076 5406 / h.mclauchlan@alfred.org.au (Tuesday, Wednesday, Friday)

Melanoma shared care, a tripartite approach for survival! The patient, their GP and their specialist is a collaboration between Southern Melbourne Integrated Cancer Service, Gippsland Regional Integrated Cancer Service, Victorian Melanoma Service, Melanoma Patients Australia, Melanoma Consumer Alliance, Peninsula General Practice Network and Gippsland Medicare Local. The project aims to develop a sustainable program to meet the clinical and supportive care needs of malignant melanoma survivors using a shared care model. The project has developed a structured approach to follow-up care that fosters collaboration between the GP and specialist providers. It focuses on:

- survivors' self-management
- general practice/specialist shared care
- continuous supportive care screening
- survivor and family centred long-term care planning
- electronic reminders.

Clinical risk stratification and supportive care screening individualises the program to meet people's needs.

People who have finished treatment with the Victorian Melanoma Service (VMS) have displayed great interest in and support for the project. Recruitment began in February 2013 and the project currently has 85 participants.

Doctors working at the VMS are committed to improving shared care in melanoma survivorship. They complete a management plan, thereby helping survivors to understand and manage their shared care plans with their GPs.

Support and feedback from peak consumer bodies such as Melanoma Patients Australia (MPA) and Melanoma Consumer Alliance have greatly assisted the project. An electronic survey of 19 MPA members highlighted problems they encountered in the management of their melanoma. They reported problems such as the following:

- *My initial diagnosis was delayed as the melanoma was not recognised by a doctor (66.7%)*
- *I don't know what may occur in the future (66.7%)*
- *I have had a lot of side effects (20%)*

This feedback informed the development of resources for this project, including the melanoma diary and education packages. The project has also developed a flexible and practical learning module for GPs. It provides a comprehensive introduction to melanoma management and survivorship care planning and includes online learning and a supervised clinical placement and mentoring program with local dermatologists and plastic surgeons.

Further information: Colleen Berryman, Cancer Service Improvement Coordinator, Southern Melbourne Integrated Cancer Services, +61 3 9928 8599 / colleen.berryman@southernhealth.org.au

Austin Health

Moving forward with confidence: increasing the capacity for self-management in cancer survivors aims to help cancer survivors feel more confident about managing their health and working towards greater wellness after treatment. Public health services across north-eastern Melbourne and Cancer Council Victoria have partnered to work with participants to create their own health and wellbeing plans.

The health and wellbeing plan focuses on the survivor's concerns and hopes. Participants have an appointment with a cancer nurse (in person or over the phone) to develop their plans. A treatment summary, medical follow-up plan and information about side effects, late effects and signs of recurrence are provided. Each survivor, their GP and the Cancer Council Victoria Helpline nurse receives a copy of the plan. A helpline nurse provides telephone support using the plan at 1 month, 4 months and 8 months.

Fifty-nine survivors have been recruited from breast, haematology, colorectal and cancer rehabilitation services at the participating health services.

Developing health and wellbeing plans has been challenging due to acute health service resource limitations and priorities. Further work is needed to establish their viability within the hospital.

Early feedback indicates that most participants have followed through with their plan and believe the plan has helped them manage their health. More detailed evaluation data will be available by March 2014.

Further information: Paula Howell, NEMICS Project Officer, +61 3 9496 3886 / paula.howell@austin.org.au

Barwon Health

Cancer survivorship project – improving health and wellbeing for survivors of cancer is a collaboration between Barwon Health, Barwon Medicare Local, Western District Health Service, Deakin University and Barwon South Western Regional Integrated Cancer Service. The project aims to develop and trial a model of care that meets service needs, improves health outcomes and enhances the lives of cancer survivors and their families.

Nurse-led survivorship clinics are running in Geelong and Hamilton. There is also an outreach clinic at Colac for survivors with limited mobility. Cancer specialists refer survivors who have completed radiation therapy and chemotherapy in the past 2 years. Survivors work with a survivorship nurse to complete a written care plan. A copy is sent to the person's GP with a one-page tumour-specific surveillance schedule, to assist in ongoing care and prompt rapid re-referral if concerns arise. Seventy-five people have been recruited so far, who were treated for Hodgkin lymphoma, non-Hodgkin lymphoma, breast, colorectal or a head and neck cancer.

Pathways of care between acute and primary providers are being strengthened. Rehabilitation and community resources have been identified to support survivors' health and wellbeing.

The Faculty of Health at Deakin University is completing research evaluations for participants and professionals on this new model. Initial evaluation indicates a high level of acceptance. Survivors report, for example, that the survivorship nurse helped them understand their follow-up care, manage symptoms and side effects and recognise signs for follow-up with a GP/specialist. The survivorship care plan helped reduce their concerns and helped them cope with finishing treatment and feel positive about moving forward.

Further information: Donna Lever, Survivorship Nurse, +61 3 4215 2788 / dlever@barwonhealth.org.au or Kate Schofield, Project Manager, +61 34215 2789 / kschof@barwonhealth.org.au

ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service

Survivorship connections: a pilot model of post treatment shared survivorship care for adolescent and young adult cancer patients (AYA) in Victoria is developing, implementing and evaluating a model of survivorship care for young people completing treatment for cancer. The model is based on key principles of AYA survivorship care, including care coordination and planning, the promotion of shared acute/primary healthcare, psychosocial assessment and empowering young people in managing their healthcare.

This is a collaborative project between Peter MacCallum Cancer Centre, the Royal Melbourne Hospital and Bendigo Health. Its cornerstone is the delivery of a clinician-led intervention that is integrated alongside usual care at each site. The intervention comprises:

- post-treatment survivorship consultations
- appropriate AYA psychosocial screening and assessment
- a survivorship care plan
- a clinician/GP case conference
- a patient/GP consultation
- regular reviews.

The University of Melbourne is evaluating project processes, effectiveness and economic viability and sustainability. The response from survivors and acute/primary health care services has been positive, particularly regarding information provision, the survivorship care plan and enhanced communication.

Major outcomes planned for the project include implementing and evaluating the clinician-led intervention and developing a toolkit for healthcare professionals. AYA-specific survivorship resources are being developed in collaboration with CanTeen Australia. Consultation with community and academic GPs and the Victorian/Tasmanian Youth Cancer Advisory Board has been critical throughout project development and implementation, and will also be important for project outcomes.

Further information: Samantha Van Staalduinen +61 3 9656 5896 / sam.vanstaalduinen@petermac.org

Royal Women's Hospital

The Survivorship program for patients completing definitive breast cancer treatment is a collaborative project involving the Royal Women's Hospital, Royal Melbourne Hospital and Western Health. The project is integrating an improved model of follow-up care into standard breast service practices. Collaborators have included BreaCan Gynaecological and Breast Cancer Support and Inner North West Melbourne Medicare Local.

Extensive consultation with women and GPs has shaped this model of care. Health and wellbeing management plans are being developed by breast care nurses as part of the follow-up care plan. They outline a shared care schedule for follow-up with the breast service and the woman's nominated GP.

To date, approximately 184 women with early breast cancer have been involved in the project across all sites, attending a nurse-led consultation to establish ongoing needs and improve quality of care. Evaluation surveys on the process and model of care are being sent to all women and GPs involved in the project.

Further information: Sita Vij E +61 3 8345 3070 / sita.vij@thewomens.org.au

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Locked Bag 1, A'Beckett Street, East Melbourne VIC 3002
Phone: 03 9656 5207 **Email:** contactacsc@petermac.org

www.petermac.org/cancersurvivorship