

## SENATE ENQUIRY INTO PALLIATIVE CARE IN AUSTRALIA

### SOUTH AUSTRALIAN AND NORTHERN TERRITORY YOUTH CANCER SERVICE SUBMISSION

27<sup>TH</sup> February 2012

#### KEY POINT SUMMARY

- **Proposed service improvement includes addition of Palliative Nursing, Medical and Social Work expertise to current multidisciplinary SANT Youth Cancer Service.**
- **Recognition at National and State levels for the need for Adolescent and Young Adult Cancer teams to provide age appropriate care to this group.**
- **Existing multidisciplinary SANT Youth Cancer Service providing care to adolescents and young adults with cancer across all locations in South Australia and Northern Territory.**
- **SANT Youth Cancer Service provides age appropriate care to patients aged 15-25 with cancer across SA and NT including rural, indigenous and culturally and linguistically diverse populations.**
- **10-40% of adolescents and young adults with cancer will require palliative care services. Cancer is the second leading cause of death in this age group.**
- **There are key differences and unique issues in providing palliative care for adolescents and young adults with cancer making age specific services especially important for this group.**
- **Difficulties in transition, psychosocial care, complex symptomology, intensive medical treatments, ill defined limits between curative and palliative treatment and barriers to palliative referral in this age group all support the role for age specific palliative services within youth cancer services.**
- **Positioning of age specific services within existing youth cancer services improves communication, resource utilisation, efficiency, age specific expertise and continuity of care.**
- **Adolescent and young adult palliative care requires a high degree of education, training and support for staff involved in their care as well as increased supports for families and communities during care and into bereavement.**
- **Proposed service improvement requires the addition of these staff to current multidisciplinary service:**
  - **0.4 FTE Senior Palliative Care Nurse**
  - **0.4 FTE Specialist Palliative Physician**
  - **0.4 FTE Senior Social Worker**

## **YOUTH CANCER SERVICES**

The Australian government has recognised the need to develop an improved model of care for adolescent and young adults (AYA) affected by cancer. A 2005 Senate Community Affairs References Committee's Report recommended that Cancer Australia consider the particular difficulties confronted by AYAs with cancer. With this mandate, Cancer Australia established an AYA National Cancer Reference Group. In May 2007 this group prioritised the development of an AYA National Service Delivery Framework. This framework is based on a review of best available evidence and national consultations with AYA consumers, health professionals, cancer support organisations, and researchers. The Framework focuses on the service delivery needs of adolescents and young adults affected by cancer to optimise equitable outcomes for this group. It follows the adolescent and young adult cancer journey, identifying the specific needs of this group and recommending a cancer service response.

Key elements of the model include:

- lead adolescent and young adult cancer care sites
- access to support services and clinical trials
- comprehensive assessment at diagnosis
- coordinated care to empower adolescent and young adult decision making
- expert multidisciplinary teams skilled in adolescent and young adult cancer care (6).

The South Australian Adolescent Young Adult Care pathway was developed by the Adolescent and Young Adult Working Party of the Statewide Cancer Clinical Network with project support from CanNET SA in October 2010. As with the national framework, it also has recognised several factors impacting on the care of adolescents and young adults with cancer including:

- patients often being 'lost' in the gap between paediatric and adult services
- lack of clinical research data
- low participation rate in clinical trials
- significantly lower improvements in cancer survival rates compared with children and older adults
- differences in psychosocial issues and needs
- delayed diagnosis and referral
- recognised need for age-appropriate, safe and effective services provided as locally as possible, rather than local services as safely as possible. (1)

The South Australian and Northern Territory Youth Cancer Service was established in 2007 in order to address these needs and to provide better care to adolescents and young adults with cancer between the ages of 15-25 years. Its goal has been to provide expert care meeting the unique needs of adolescents and young adults with cancer through the development of a patient focussed, multidisciplinary approach to care of young patients with cancer across sites in SA and NT. This team currently includes full and part time staff including a program manager, lead clinician, psychologist, exercise physiologist, social worker, clinical practice coordinator, music therapist and training doctor.

In South Australia, approximately 75 people aged 15–24 years of age are diagnosed with cancer each year. This figure does not take account of patients who have relapsed, developed secondary cancers, or patients who live interstate and travel to Adelaide for their treatment (e.g. patients from Broken Hill, Mildura, Northern Territory). Coordinated service provision between private and public hospitals, general practitioners (GPs), Aboriginal Health Services, community and palliative care services is essential to expedite treatment, ensure access to age-appropriate supportive care and ensure a smooth transition to adult health care (1).

### **PALLIATIVE CARE FOR ADOLESCENTS AND YOUNG ADULTS**

Unfortunately cancer remains the second leading cause of death (second only to accidents, suicide and homicide) in people aged 15-24 (2). International literature suggests that 10-40% of adolescents with primary oncological disease will progress ultimately to palliation (1). The needs of adolescents and young adults with cancer who transition to palliative care are unique and often remain unmet by current models of adult and paediatric palliative care in South Australia and the Northern Territory.

Unique issues in palliative care for adolescents and young adults with cancer include:

- Difficulty in accessing age appropriate care in the gap between paediatric and adult services
  - Increased difficulties in transitioning to adult services at times of relapse and palliation
  - Unique and often complex psychosocial care needs
  - Complex symptomology and clinical care needs
  - Intensive medical care needs towards the end of life
  - Ill defined limits between curative and palliative treatments
  - Increased barriers to early palliative care referral
  - High levels of care giver burden and requirement for care giver support and communication
  - Lack of age appropriate inpatient care environments
  - Lack of community teams expert in the care of adolescents and young adults
  - High impact on health professionals caring for young people with cancer and increased requirement for resources, training and support
  - Wide family and social network and extensive bereavement care needs
- (1, 3, 4, 5)

For palliative care at home, there can be a gap in expertise, especially for young adults, causing reluctance amongst service providers to take on the home care of this group. General practitioners and their team should be involved, but may lack experience and support. Paediatric nurses will sometimes lack confidence in the symptom management of older patients and adult community teams and nurses may have similar concerns when faced with a young adult (5).

### **GUIDELINES FOR PALLIATIVE CARE FOR ADOLESCENTS AND YOUNG ADULTS**

Current state and national guidelines for the care of young people with cancer support the development of palliative care roles and expertise within youth cancer services (1, 5, 6, 7). The National Service Delivery Framework makes clear recommendations about the need for provision of specialised palliative care to adolescents and young adults advising that symptoms occur throughout the cancer journey and adolescents

and young adults need symptom and supportive management throughout their illness and need timely and integrated access to palliative care. It advises that the young patients and their family/carers need support in discussing their prognosis and in issues related to end of life as well as appropriate symptom control and support available with palliative care services to be introduced early, particularly for those with progressive disease (6).

The Clinical Oncological Society of Australia (COSA) psychosocial guidelines for the care of the adolescent with cancer reinforce the unique palliative care needs of this group. They strongly support early introduction of palliative and supportive care so that young people have the time to build a trusting relationship with palliative care teams, both hospital and community based. This is particularly important for clinical presentations where the prognosis is known to be poor although this is often not clear early in diagnosis and treatment. The COSA guidelines reinforce that referral to palliative care for symptom management and support can occur at any time and should be considered even when the individual is undergoing active treatment (5). Evidence supports the need for increased palliative and supportive care services for adolescents and young adults with cancer with high rates of interventions, chemotherapy, hospitalisations, complex symptomology and psychological symptoms in adolescents and young adults during palliation and at the end of life (3, 4, 5).

The South Australian Adolescent and Young Adult Cancer Care Pathway makes key recommendations around the provision of palliative care to this group of patients highlighting the need for specialised adolescent and young adult palliative care services. These key recommendations include:

- Comprehensive discharge planning that includes multiple services for supportive care is required to address the complex clinical needs of adolescent and young adult cancer patients receiving palliative care.
- Age-appropriate respite and palliative care beds are required for adolescent and young adult cancer patients.
- Adolescent and young adult palliative care cancer patients should be involved in decisions about their end-of-life care.
- The caregiver burden associated with the provision of adolescent and young adult palliation should be recognised, prioritised and proactively addressed.
- Bereavement planning is essential for family members of adolescent and young adult cancer patients.
- The profound impact on staff of caring for an adolescent or young adult cancer patient with a terminal prognosis should be recognised and appropriate training in self-care as well as bereavement support and counselling should be provided (1)

### **ROLE FOR AGE SPECIFIC PALLIATIVE CARE SERVICES WITHIN EXISTING YOUTH CANCER SERVICE**

Evidence and experience strongly supports the positioning of palliative care resources and expertise within youth cancer services as it allows for better continuity of care and communication pathways as well as efficiency and effective use of resources. The overlap between curative and palliative approaches and intensive medical treatments in this age group make it especially relevant for palliative services to sit within specialist cancer services for adolescents and young adults (1, 3). Referral barriers, stigma surrounding palliation and the difficulties with the cure/palliation interface

may be overcome by integrating palliative and active treatment through a continuity of care model within palliative care. The *OnTrac@PeterMac* project at the Peter MacCallum Cancer Centre in Victoria has trialled the role of AYA palliative care nurses employed within the AYA cancer service with good results in supporting seamless transition and liaison between hospital and community multidisciplinary teams for adolescent and young adult cancer patients with a poor prognosis at diagnosis (1).

### **RECOMMENDATIONS / SERVICE GAPS**

The SANT Youth Cancer Service wishes to attain funding to support palliative and bereavement services to be provided by the team. This requires the addition of palliative nursing, medical and social work positions to the team. Such positions would allow the service to provide age appropriate palliative care across locations throughout SA and NT to patients between the ages of 15-25 years. Current pathways of communication between health care workers and patients and families would be enhanced and continuity of care could be provided in the transition to palliative care and across paediatric and adult services. Education, training and expert support to other agencies involved in the care of young people would also be provided including support to rural and indigenous communities. The social work role would also coordinate bereavement services and provide counselling support to carers and family. In order to provide this care the service requires:

- 0.4 FTE Senior Palliative Care Nurse
- 0.4 FTE Specialist Palliative Physician
- 0.4 FTE Senior Social Worker

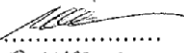
This small expansion to the SANT Youth Cancer Service team would allow a very large improvement to the care of adolescents and young adults dying with cancer and is a small and very attainable way in which palliative care services can be improved in South Australia and the Northern Territory.

## REFERENCES


- (1) Adolescent and Young Adult Working Party of the Statewide Cancer Clinical Network supported by CanNET SA, October 2010, '*South Australian Adolescent and Young Adult Cancer Care Pathway-Optimising outcomes for all adolescent and young adult South Australians with a cancer diagnosis*' viewed February 2012, <<http://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Health+information/Health+information+for+the+clinician/Cancer/Cancer+Care+Pathways/SA+Adolescent+and+Young+Adult+Cancer+Care+Pathway.>>>
- (2) UK Office for National Statistics Website viewed February 2012, <[http://www.statistics.gov.uk/downloads/theme\\_population/Table\\_2\\_Death\\_Registrations\\_Cause.xls](http://www.statistics.gov.uk/downloads/theme_population/Table_2_Death_Registrations_Cause.xls)>
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- (4) Thornes, R and Elston S (Ed.) on behalf of the Joint Working Party on Palliative Care for Adolescents and Young Adults 2001, *Palliative Care for Young People Aged 13-24*, Published jointly by: Association for Children with Life-threatening or Terminal Conditions & their Families and National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care, United Kingdom.
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- (6) Australian Government and Canteen 2009, *National Service Delivery Framework for Adolescents and Young Adults with Cancer*,
- (7) SA Health Publications 2009, *SA Health Palliative Care Services Plan 2009-2016*, South Australian Department of Health. Statewide Service Strategy Division.

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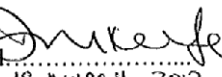
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