

# Cancer



## **South Australian Adolescent and Young Adult Cancer Care Pathway**

**Optimising outcomes for all adolescent and young adult South  
Australians with a cancer diagnosis**

Developed by the Adolescent and Young Adult Working Party of the Statewide  
Cancer Clinical Network with project support from CanNET SA  
October 2010

The pathway development project was undertaken by the Adolescent and Young Adult Working Party under the auspice of the Statewide Cancer Clinical Network.

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## EXECUTIVE SUMMARY

The South Australian (SA) Adolescent and Young Adult Cancer Care Pathway was created under the auspices of the SA Cancer Clinical Network. It provides recommendations based on current evidence for best practice in the management of adolescents and young adults aged 15–25 years with a cancer diagnosis.

The SA Adolescent and Young Adult Cancer Care Pathway has been developed through a collaborative effort involving a wide range of health professionals, including paediatric and adult cancer specialists, generalist staff and consumers. It is a statement of consensus based on current best practice, evidence and accepted approaches to the management of adolescents and young adults throughout their cancer journey. Recommendations should be followed subject to the health professional's independent medical judgment and the patient's preference in each individual case.

The Pathway adopts a multidisciplinary approach to the care of adolescents and young adults with a cancer diagnosis, with involvement of all relevant health professionals.

Important factors affecting the care of adolescents and young adults with cancer include:

- patients are often 'lost' in the gap between paediatric and adult services
- lack of clinical research data
- low participation rate in clinical trials
- lower improvement 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.

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.

## Key recommendations

This document contains 59 recommendations relating to the diagnosis, treatment and supportive care of adolescents and young adults with cancer in South Australia. A complete list of recommendations is provided at Appendix A. Key recommendations are highlighted below.

| Stage in cancer journey        | Pathway recommendations  | System recommendation   | Key Performance Indicators  |
|--------------------------------|--|---|---|
| Prevention and early detection | Education strategies should be developed to promote prevention and awareness messages about adolescent and young adult (AYA) cancers to health professionals and consumers   | Promotion of awareness/early detection AYA cancer education for both health care professionals and consumers  | Measurable change in cancer awareness and behaviour in 15-25 year age group   |
| Diagnosis and staging          | <p>GPs should have access to information to facilitate appropriate referral of adolescent and young adult cancer patients to cancer specialists</p> <p>Dedicated AYA Cancer Care Coordinators should be available to streamline access into AYA cancer care including supportive care</p>  | <p>State-based cancer service directory (no cost to health professionals)</p> <p>Access to on-call cancer specialists after-hours.</p> <p>Implement single AYA referral point of contact to AYA cancer care coordinators</p>                  | <p>Number of appropriate referrals to AYA Cancer Care Coordinators</p> <p>Number of patients treated in evidence recommended setting</p>                        |
| Multidisciplinary management   | <p>All cases of AYA cancer should be presented at a clinical multidisciplinary team meeting attended by specialists with relevant tumour- and age-specific expertise</p> <p>All adolescents and young adults with a cancer diagnosis should be referred to a psychosocial multidisciplinary team meeting for a discussion regarding ongoing support.</p> | <p>Every AYA be presented at both medical and psychosocial MDT meetings.</p> <p>Psychosocial meeting to be with 2 weeks from medical multidisciplinary meeting.</p> <p>Supportive care plan to be jointly developed by AYA themselves and</p> | <p>% of total number of Pts presented at MDT meeting</p> <p>% of AYA with Documented treatment plans following MDT assessment</p> <p>Time from diagnosis to</p> |

| Stage in cancer journey | Pathway recommendations   | System recommendation   | Key Performance Indicators  |
|-------------------------|---|-------------------------|---|
|                         | <p>Appointment of AYA MDT Coordinator</p> <p>Directory of services to include listing of AYA MDT meetings and services.</p> | appointed case manager. | MDT assessment<br>Identification of meetings when goals of care change. |

| Stage in cancer journey | Pathway recommendations   | System recommendation   | Key Performance Indicators   |
|-------------------------|---|---|--|
| Clinical research       | <p>All adolescents and young adults with a cancer should be treated by clinicians with demonstrated knowledge and expertise in AYA cancer</p> <p>Upon diagnosis all AYAs should be considered for eligibility into clinical trials</p>  | AYA cancer specialist is required to consult across paediatric and adult health services to ensure patient access to relevant clinical trial  | <p>Number of AYA assessed for eligibility for clinical trials</p> <p>Number of clinical trials available to AYA and number of enrolment into clinical trails</p> |
| Supportive care         | <p>All adolescent and young adults with cancer and their families should have equitable access to the highest quality age appropriate psychosocial and supportive care services.</p> <p>Increase access and equitable access to supportive care health care professionals across paediatric and adult health services</p> | <p>Implementation of 'roving' AYA cancer psychosocial multidisciplinary team.</p> <p>Standardised psychosocial evidenced based assessment tool be utilised across both paediatric and adult settings.</p> | time from diagnosis to referral to AYA psychosocial team   |

| Stage in cancer journey | Pathway recommendations  | System recommendation   | Key Performance Indicators   |
|-------------------------|--|---|--|
| Palliative care         | Adolescents and young adults with a terminal cancer diagnosis should have access to age-appropriate community based palliative care services, respite care and palliative care beds  | Integrated palliative care team within AYA cancer service   | <p>AYA patients place of death</p> <p>Number of families confirming appropriate supports and referrals to facilitate optimal end of life care.</p> <p>Numbers of AYA families with established bereavement plans</p> |
| Survivorship            | Late-effects clinics should be established and resourced as standard of care for all adolescent and young adults with a cancer diagnosis across paediatric and adult health services   | Implement appropriately resourced late effects clinics across health services, including paediatric and adult.  | <p>Patients report feeling informed and know where to seek help on completion of treatment.</p> <p>Number of documented AYA end of treatment plans</p>   |
| Workforce               | <p>A new discipline of AYA Oncology should be established to meet the needs of adolescents and young adults with cancer across SA health services</p> <p>All adolescents and young adults with a cancer diagnosis should have access to specialist AYA</p> | <p>Implement Cancer specialist to work across paediatric and adult health services.</p> <p>Establish role of AYA cancer clinical practice coordinator (CPC) to provide and coordinate supportive care from diagnosis throughout treatment to follow</p> |  |

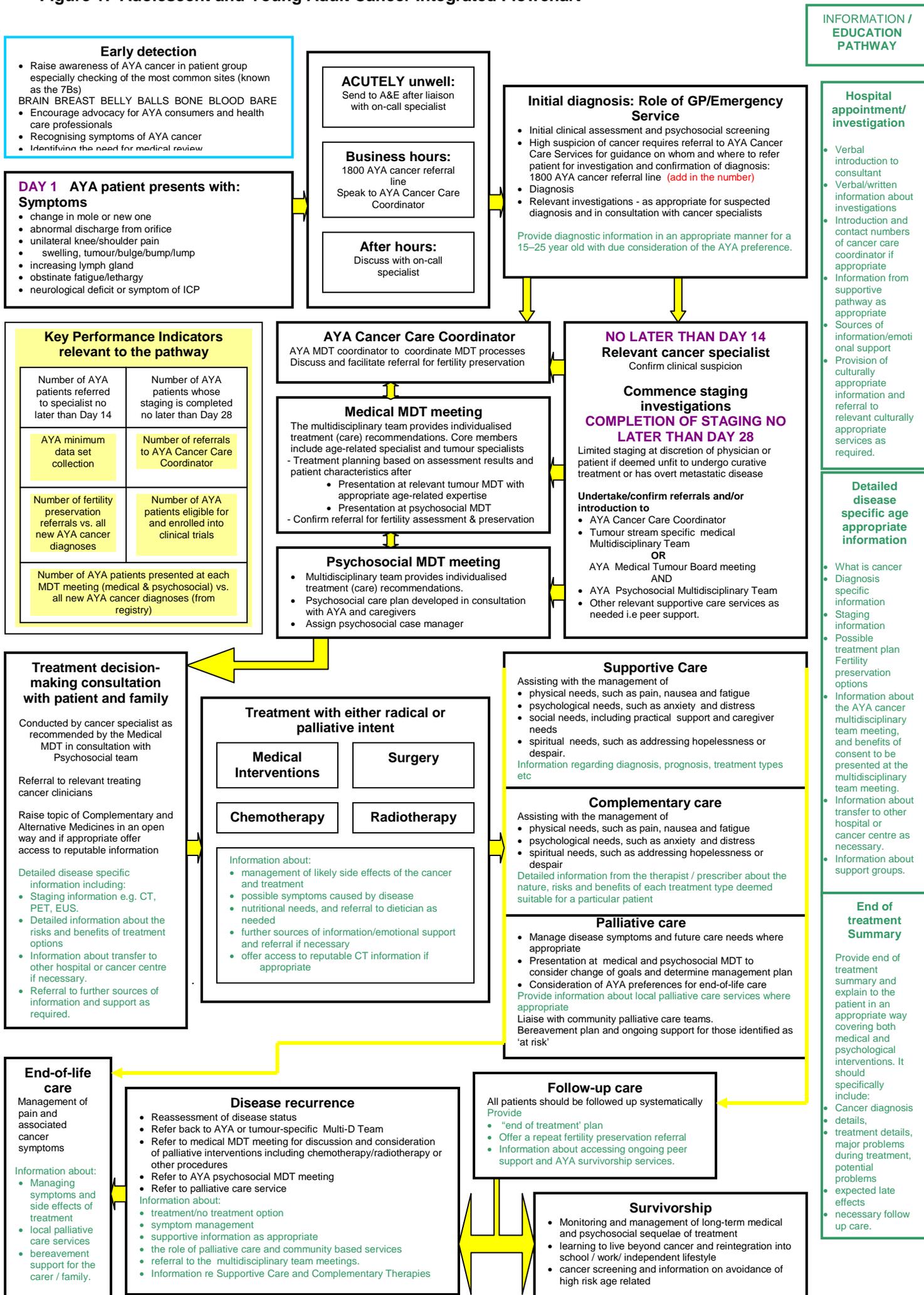
| Stage in cancer journey | Pathway recommendations  | System recommendation   | Key Performance Indicators   |
|-------------------------|--|---|--|
|                         | nursing care and cancer care coordination throughout the cancer pathway  | up, survivorship or referral for end of life care.<br>Determine the number of CPCs required based on the volume and complexity of patients and the number of services/sites covered.  |  |
| Fertility Preservation  | <p>All newly diagnosed adolescents and young adults with cancer should be referred to fertility preservation services for consultation</p> <p>All adolescents and young adults with a cancer diagnosis should be provided with age-appropriate fertility preservation information in a format to suit their need</p> <p>The existing funding model for cancer survivors and the high cost of long-term fertility preservation should be reviewed</p> | <p>Implementation of South Australian standardised fertility preservation referral form</p> <p>Supply and distribution of fertility preservation consumer information.</p> <p>Ensure information on fertility preservation is available for health care professionals (including how to refer) and consumers is readily accessible on the internet.</p> <p>Review of existing funding for long-term fertility preservation and storage costs for cancer survivors requiring infertility treatment</p> | Number of referrals to fertility preservation services for adolescents and young adults with a cancer diagnosis. |
| Safety and quality      | The quality and safety of AYA cancer care should be monitored at state level   | <p>Provision of a state -wide systematic centralised database that captures minimum agreed data of all adolescent and young adults with a diagnosis of cancer. All treatment outcomes are reported, reviewed and measured.</p> <p>Initiate process for centralised review and reporting of key performance</p>  |  |

| Stage in cancer journey                | Pathway recommendations   | System recommendation  | Key Performance Indicators |
|--|---|--|----------------------------|
|  |   | indicators (KPI's) and benchmarks for clinical and service outcomes.   |                            |
| Respecting diversity                   | All adolescents and young adults with a cancer diagnosis have access to culturally appropriate care and effective communication throughout the cancer pathway | <ul style="list-style-type: none"> <li>• Use of qualified interpreters in all consultations where English proficiency and fluency are limited.</li> <li>• Development of culturally appropriate resources and services.</li> <li>• Provision of cross cultural training for all staff involved in cancer care.</li> <li>• All cancer services foster links with culturally relevant resources and services.</li> </ul> |                            |
| Aboriginal and Torres Strait Islanders | Aboriginal Health Impact Statement for Cancer Pathway development in South Australia  | <ul style="list-style-type: none"> <li>• A comprehensive companion document be written to support all future cancer pathway development in South Australia and addresses the South Australian Aboriginal Health Impact Statement checklist.</li> <li>• This to be completed in 2010 under the auspices of the Aboriginal and Torres Strait Islander Committee of the Cancer Clinical Network.</li> </ul>               |                            |

## **Pathway Flow Chart**

This executive Summary includes a full-integrated flow chart (below) providing a detailed overview of the pathway for all users. The flowchart includes an outline of information requirements and maximum acceptable waits for the key pathway stages.

**Figure 1: Adolescent and Young Adult Cancer Integrated Flowchart**



# 1. INTRODUCTION

## 1.1 Pathway development

The South Australian (SA) Adolescent and Young Adult Cancer Care Pathway was developed by a multidisciplinary working party, under the auspices of the SA Cancer Clinical Network.

The statewide Cancer Clinical Network Steering Committee (CCNSC) was formed by SA Health and first met in May 2007. The main objective of the CCNSC was implementation of the Statewide Cancer Control Plan 2006–2009. Subcommittees were created to address six key areas:

- Prevention and Early Detection
- Optimising Cancer Care
- Infrastructure Planning
- Information
- Workforce
- Research.

The Optimising Cancer Care subcommittee prioritised the development of three cancer pathways as proof of concepts for the SA setting. The three pathways are:

- upper gastrointestinal cancer
- lymphoma
- adolescents and young adults with cancer.

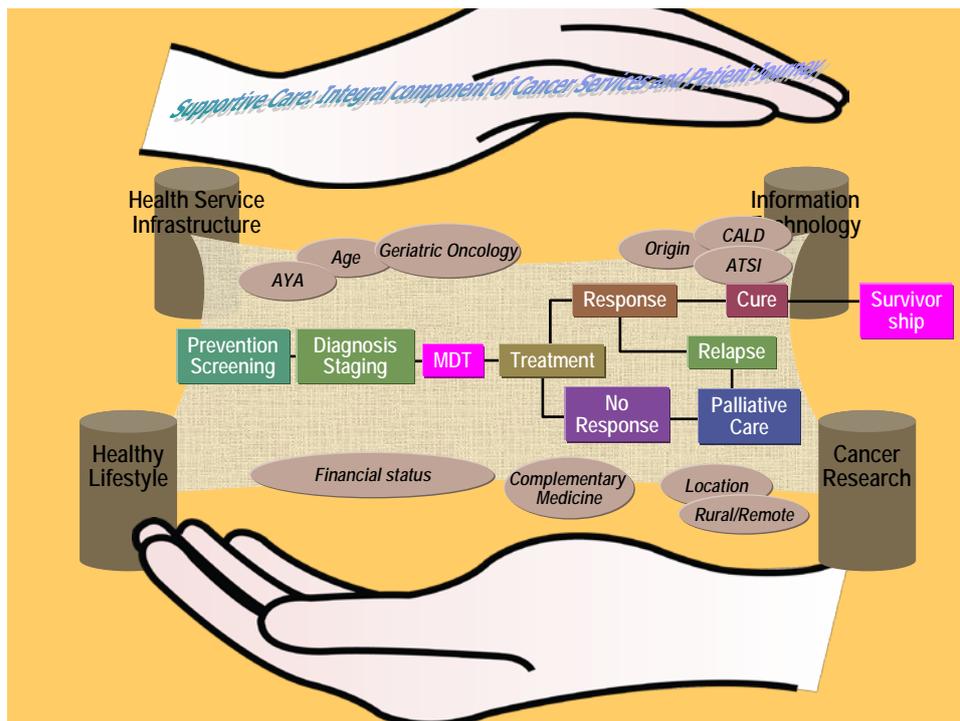
A comprehensive cancer pathway model was developed with the aim of improving and standardising cancer care for all South Australians regardless of their location, origin, age or financial status. The pathways are based on available evidence and clinical expertise, with a strong emphasis on clinical and supportive care within the local SA context.

The Optimising Cancer Care subcommittee subsequently established working parties to undertake the development of each clinical pathway. The working parties were chaired by clinical leaders in the relevant clinical field and included multidisciplinary membership from public and private health settings, non-government organisations (NGOs), general practitioners (GPs) and consumers.

Project support for the development of the three pathways was provided by the Cancer Service National Network Demonstration Program of South Australia (CanNET SA). CanNET is a Cancer Australia initiative, funded by the Australian Government.

Each working party utilised the common cancer pathway model<sup>1</sup> (Figure 2) as a basis for individual pathway development to ensure consistency with the concept.

**Figure 2: Cancer pathway model**



**Explanatory notes**

- Pillars represent the key requirements that provide support for cancer services.
- Central cancer pathway illustrates the clinical aspects of the cancer journey.
- Hands represent supportive care, which is integral to clinical care.
- Circles or 'pods' surrounding the pathway highlight the key issues that require due consideration in planning all cancer clinical and supportive care.

## **1.2 Pathway target audience**

Each pathway addresses the clinical aspects of the cancer journey and provides recommendations based on current evidence. It is anticipated that the pathway and the pathway recommendations will be of interest to:

- SA Health
- the four health regions in South Australia: Country Health SA, Central Northern Adelaide Health Service, Southern Area Health Service and Child Youth Women's Health Service
- Aboriginal community-controlled health services
- the CCNSC and associated committees and working groups
- people involved in cancer care projects
- consumers of cancer care
- NGOs
- GPs
- all health care professionals involved in cancer care.

## **1.3 SA Health Aboriginal Health Impact Statement and Checklist**

A workshop for the Upper Gastrointestinal and Adolescent and Young Adult cancer pathways towards the preparation of a SA Health Aboriginal Health Impact Statement was held in November 2009. The workshop attendees provided support for these two initial statewide cancer pathways. It was acknowledged that there are many gaps in cancer care for Aboriginal and Torres Strait Islander People and that it would not be feasible to comprehensively address these for each individual cancer pathway developed in South Australia.

The key recommendation arising from this workshop is the need to create a comprehensive companion health impact document that addresses Aboriginal and Torres Strait Islander cancer care needs in South Australia. This document would complement all future cancer pathways developed in South Australia. It was proposed that this work will be completed under the auspices of the Aboriginal and Torres Strait Islander Committee of the Cancer Clinical Network.

It was agreed that this pathway may proceed for implementation and will be linked to the companion document at the first review of this pathway.

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<sup>1</sup> Developed by DM Keefe and K Linke on behalf of the SA Cancer Clinical Network Steering Committee, 2007.

## 2. ADOLESCENT AND YOUNG ADULT CANCER CARE PATHWAY FOR SOUTH AUSTRALIA

### 2.1 Purpose

The SA Adolescent and Young Adult Cancer Care Pathway is a guide to the optimal management and care of adolescents and young adults diagnosed with cancer. The Pathway provides a guide for the patient journey to ensure that adolescents and young adults with cancer and their families receive optimal care and support.

The World Health Organization (WHO) defines individuals aged 10–19 years as adolescents and those aged 15–24 years as youth.<sup>2</sup> It is well recognised that patients in this age group fall in the gap between paediatric and adult medical care (see Section 3). The SA Adolescent and Young Adult Cancer Care Pathway focuses on the 15–24 year age group. However, these recommendations can be applied to any person with cancer. The Pathway provides recommendations based on current evidence for best practice in the management of adolescents and young adults with a cancer diagnosis. It adopts a multidisciplinary approach with involvement of all relevant professionals in the care of patients.

The SA Adolescent and Young Adult Cancer Care Pathway has been developed through a collaborative effort involving a wide range of health professionals including cancer specialist practitioners, generalist staff and consumers. It is a statement of consensus based on evidence, current best practice and accepted approaches to the treatment and management of AYA cancers. The Pathway is not intended to be used as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve.

Adherence to Pathway recommendations will not ensure a successful outcome in every case. The Pathway does not purport to include all proper methods of care or exclude other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate health care professional(s) responsible for clinical decisions about a particular clinical procedure or treatment plan. Recommendations should be followed subject to the health professional's independent medical judgment and the patient's preference in each individual case. Final decisions should be made only after discussion of the diagnosis and available treatment options with the patient and their

family. It is advised, however, that significant digression from the SA Adolescent and Young Adult Cancer Care Pathway should be documented in the patient's case notes at the time the relevant decision is taken.

### **Aims of the Pathway**

- To improve care and outcomes for all adolescents and young adults with a cancer diagnosis.
- To provide guidance and consistency of practice in patient management and to reduce the wide variation in current practice observed throughout South Australia.
- To encourage appropriate referral and early diagnosis of AYA cancers.
- To ensure that all adolescents and young adults with cancer are offered the best chance of cure or palliation irrespective of where they present or are treated.
- To optimise care delivery for all adolescent and young adult cancer patients at all stages of their disease.

## **2.2 Structure**

The SA Adolescent and Young Adult Cancer Care Pathway provides a structured pathway of the patient journey. Figure 3 identifies the critical steps involved. It is acknowledged that there will be some variation in approach, with factors including cancer type, timing and method of diagnosis, prognosis, management decisions and patient preference all impacting on the management of an individual patient.

## **2.3 Key principles**

Several key principles have been identified that support each stage of the Pathway.

### **Patient-centred care**

- Patients and their families/caregivers are encouraged to be involved as active participants in care planning and decision making. Ultimately treatment decisions rest with the patient or designated person. This requires information and discussion to be provided in their preferred language and in a manner that is sensitive to their culture.<sup>3</sup>

### **Safe and high-quality care**

- Cancer care is complex, involving a range of specialist providers and clinicians with varied clinical expertise. To ensure safe and high-quality cancer care, it is essential for clinicians to possess the technical skills and experience to undertake the relevant

aspects of cancer care and have access to appropriate infrastructure to support such care.<sup>4</sup>

### **Multidisciplinary care**

- Best practice in cancer care involves multidisciplinary treatment planning and multidisciplinary care.<sup>5</sup>
- Effective multidisciplinary approaches in the management of patients with cancer have demonstrated positive outcomes,<sup>6</sup> including increased survival, a greater understanding that a comprehensive team is providing care, a greater likelihood of receiving care that is in accordance with clinical practice pathways (including psychosocial and practical support), increased access to information for patients and increased patient satisfaction with care.

### **Supportive care**

- Patients with cancer have psychological and social needs that are frequently undetected and unmet, and have the potential to cause long-term distress.<sup>7</sup>
- Supportive care includes the acknowledgement of all domains of patient needs – physical, psychological, social, cultural, informational and spiritual – that may be required to support the patient and their families/caregivers.<sup>8</sup>

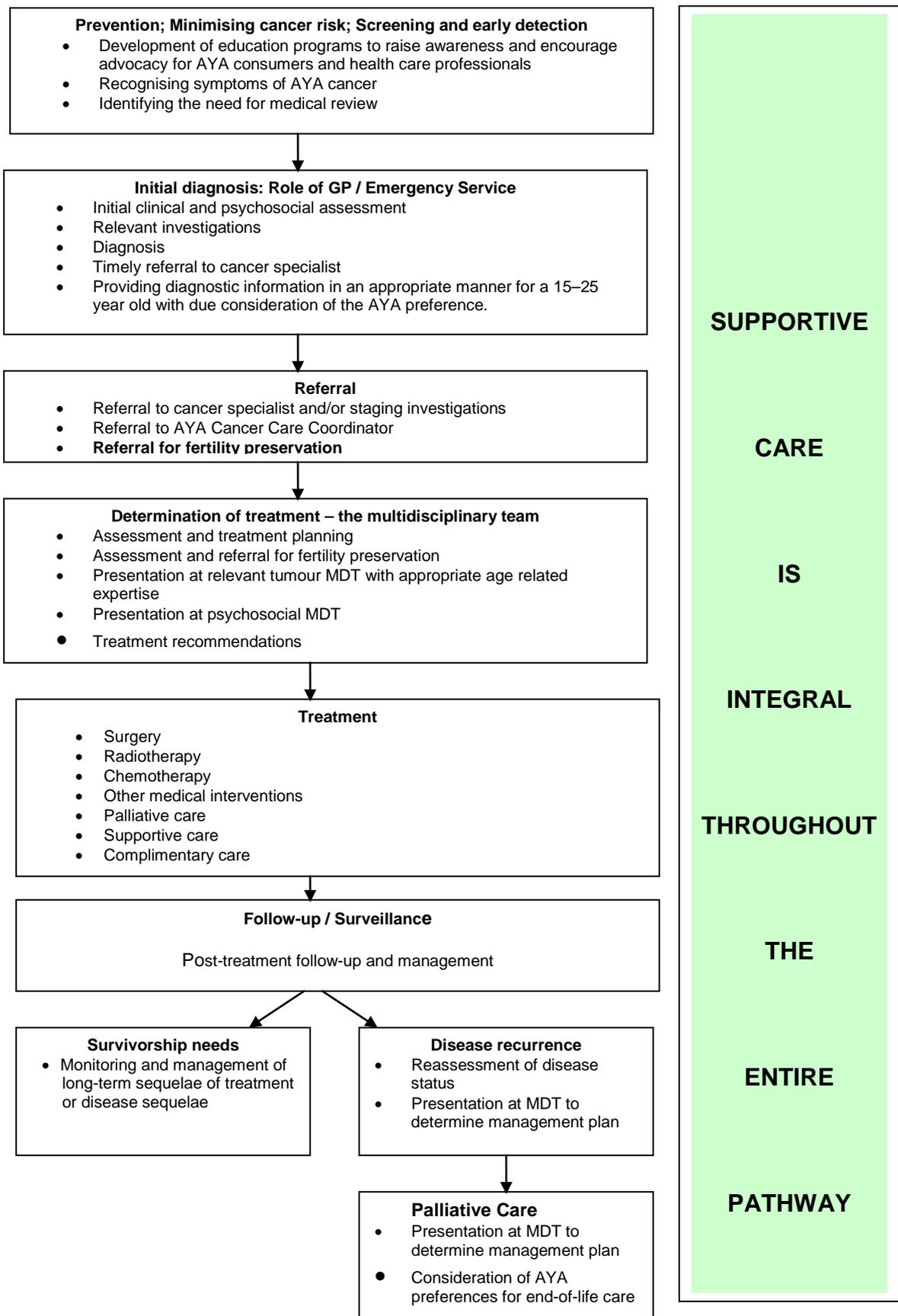
### **Care coordination**

- Patients require coordination of their health care. A variety of strategies have been shown to improve coordination of care and these include multidisciplinary team meetings, clinical protocols, access to cancer nurse specialists and utilisation of appropriate performance indicators.<sup>9</sup>

## **2.4 Review and updating**

The SA Adolescent and Young Adult Cancer Care Pathway was released as a final draft in mid-2009. It is expected that after refinement and review during 2009, it will be due for periodic review every 2 years. Interim updates of the Pathway will be undertaken through consultation with the original AYA Working Party members and/ or invited reviewers. This process will require monitoring from the Optimising Cancer Care subcommittee of the SA Cancer Clinical Network.

**Figure 3: Key stages in the Adolescent and Young Adult Cancer Care Pathway**



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<sup>2</sup> Thomas DM *et al.* Adolescent and young adult cancer: a revolution in evolution. *Intern Med J* 2006 May;36(5):302-307.

<sup>3</sup> Victorian Government Department of Human Services. *Patient management framework: Upper gastrointestinal tumour stream. Oesophagogastric cancer: a guide to consistent cancer care.* Victorian Government, Melbourne, 2006.

<sup>4</sup> *ibid.*

<sup>5</sup> *ibid.*

<sup>6</sup> National Breast Cancer Centre. Multidisciplinary care for women with early breast cancer in the Australian context: What does it mean? *Med J Aust* 2003; 179(10): 528-31.

<sup>7</sup> Victorian Government Department of Human Services. *Patient management framework: Upper gastrointestinal tumour stream. Oesophagogastric cancer: a guide to consistent cancer care.* Victorian Government, Melbourne, 2006.

<sup>8</sup> *ibid.*

<sup>9</sup> *ibid.*

### 3. ADOLESCENT AND YOUNG ADULT CANCERS IN SOUTH AUSTRALIA

Important factors affecting the care of adolescents and young adults with cancer are summarised in Table 1.

**Table 1: Important factors in the care of adolescents and young adults with cancer**

|  |
|--|
| Patients are often 'lost' in the gap between paediatric and adult services   |
| Lack of clinical research data   |
| Low participation rate in clinical trials  |
| Lower improvement 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 |

Available clinical research data for the AYA age group are currently lacking. There is a need to ensure that cancer registries that support AYA oncology research collect a more comprehensive data set. Data sets should include accurate tumour-specific staging and biological information, including cytogenetic and prognostic markers, detailed morphology and primary site information, and have tracking identifiers to promote long-term follow-up.<sup>10</sup> Separate classification schemes for tumours diagnosed in adolescents and young adults have also been proposed<sup>11</sup> and require consideration.

Little recent progress has been made in improving cancer survival among older adolescents and young adults. Survival improvement trends demonstrate that survival is improving by a smaller percentage each year among patients aged 20–45 years compared with older and younger age groups.<sup>12</sup> Mortality data suggest that outcomes are poorer for patients aged 15–45 years. In Victoria, the average improvement in survival for young people with cancer for the period 1973–2001 was half that seen in children or older adults.<sup>13</sup>

Questions remain as to why the relative improvement in cancer survival for adolescent and young adult cancer patients has not kept pace with improvements in younger children and older adults.

Several explanations have been proposed to explain gaps in care and associated patient outcomes based on experiences in the United States. The extent to which these apply in the Australian context is not clear. Suggested factors include:<sup>14</sup>

- differences in health insurance coverage
- less access to clinical trial participation due to site of care
- poorer understanding of the biology of AYA cancers
- less focus on research and treatment
- potentially more advanced disease at time of diagnosis.

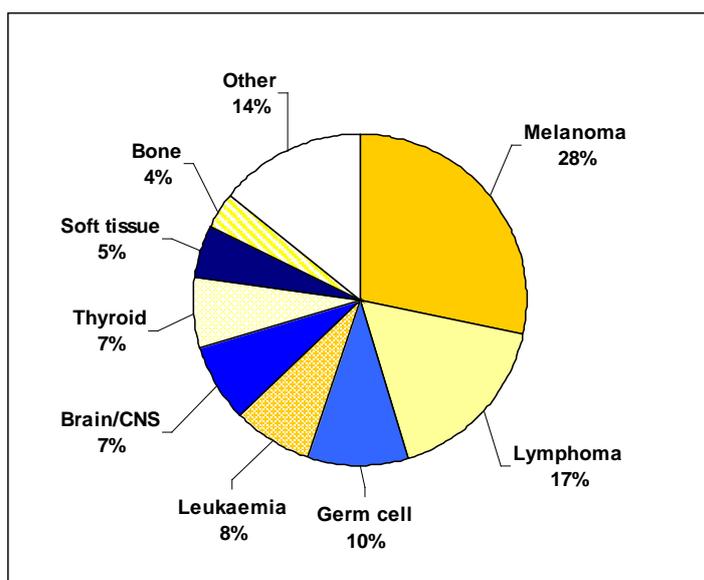
### **3.1 South Australian adolescent and young adult cancer data**

The scope of deficiencies or issues relating to AYA cancers in South Australia remains unknown. Approximately 75 people aged 15–24 years are diagnosed with cancer each year in South Australia.<sup>15</sup> 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).

No information is available from current data sources about where these patients were treated, whether treatment was delivered via public and/or private health services, what type of treatment was given, whether clinical trials were available to them and what the clinical trial participation rate was, whether delays were experienced during their cancer journey and what these delays were. The lack of available data makes service planning and delivery for this age group more difficult. A minimum data collection form has been developed by the AYA Working Party as a starting point for AYA data collection for South Australia (see Appendix B). However, it is strongly anticipated that a national AYA cancer registry as part of the national data strategy will be developed that will take into account the above-mentioned factors.<sup>16</sup>

The types of cancer seen in the 15–24 year age group in South Australia during 1977–2004 are shown in Figure 4.

**Figure 4: Types of cancer in patients aged 15-24 years, South Australia, 1977-2004**



Reproduced with permission from Cancer Council SA, *Cancer among young South Australians*. April 2008. Monograph No 10. Centre for Cancer Control Research, South Australia cancer statistics, Cancer Council SA.

Whilst cancer mortality has decreased since 1977 among young South Australians younger than 14 years of age, there has been little change in mortality rates in the 15–24 year age group. This is in line with international data<sup>17</sup>.

<sup>10</sup>Pollock BH, Birch JM. Registration and classification of adolescent and young adult cancer cases. *Pediatr Blood Cancer* 2008 May;50(5 Suppl):1090-1093.

<sup>11</sup>Barr RD *et al*. Classification schemes for tumors diagnosed in adolescents and young adults. *Cancer* 2006 April 1;106(7):1425-1430.

<sup>12</sup>Soliman H, Agresta SV. Current issues in adolescent and young adult cancer survivorship. *Cancer Control* 2008 January;15(1):55-62.

<sup>13</sup>Pollock BH, Birch JM. Registration and classification of adolescent and young adult cancer cases. *Pediatr Blood Cancer* 2008 May;50(5 Suppl):1090-1093.

<sup>14</sup>Bleyer A *et al*. The adolescent and young adult gap in cancer care and outcome. *Curr Probl Pediatr Adolesc Health Care* 2005 May/June:182-217.

<sup>15</sup>South Australian Cancer Registry. *Cancer in South Australia 2006 – with projections to 2009*. Adelaide: South Australian Department of Health, 2008.

<sup>16</sup>Cancer Australia. *A National Cancer Data Strategy for Australia*. Canberra: Commonwealth of Australia, 2008.

<http://www.canceraustralia.gov.au/media/29706/ncds%20final%20web.pdf> (NB No longer available on this webpage)

<sup>17</sup>Beckmann K, Roder D. *Cancer among young South Australians*. April 2008. Monograph No 10. Centre for Cancer Control Research, South Australia cancer statistics, Cancer Council SA.

## 4. ADOLESCENT AND YOUNG ADULT CANCER CARE PATHWAY

Adolescents and young adults affected by cancer have diverse and complex clinical and supportive care needs. Figure 5 illustrates and identifies the steps and optimal care requirements for the SA Adolescent and Young Adult Cancer Care Pathway. The Pathway promotes care coordination and a consistent, standardised approach to managing care. A well-coordinated and managed cancer journey will ensure that adolescents and young adults with cancer and their family/caregivers experience coordinated care.

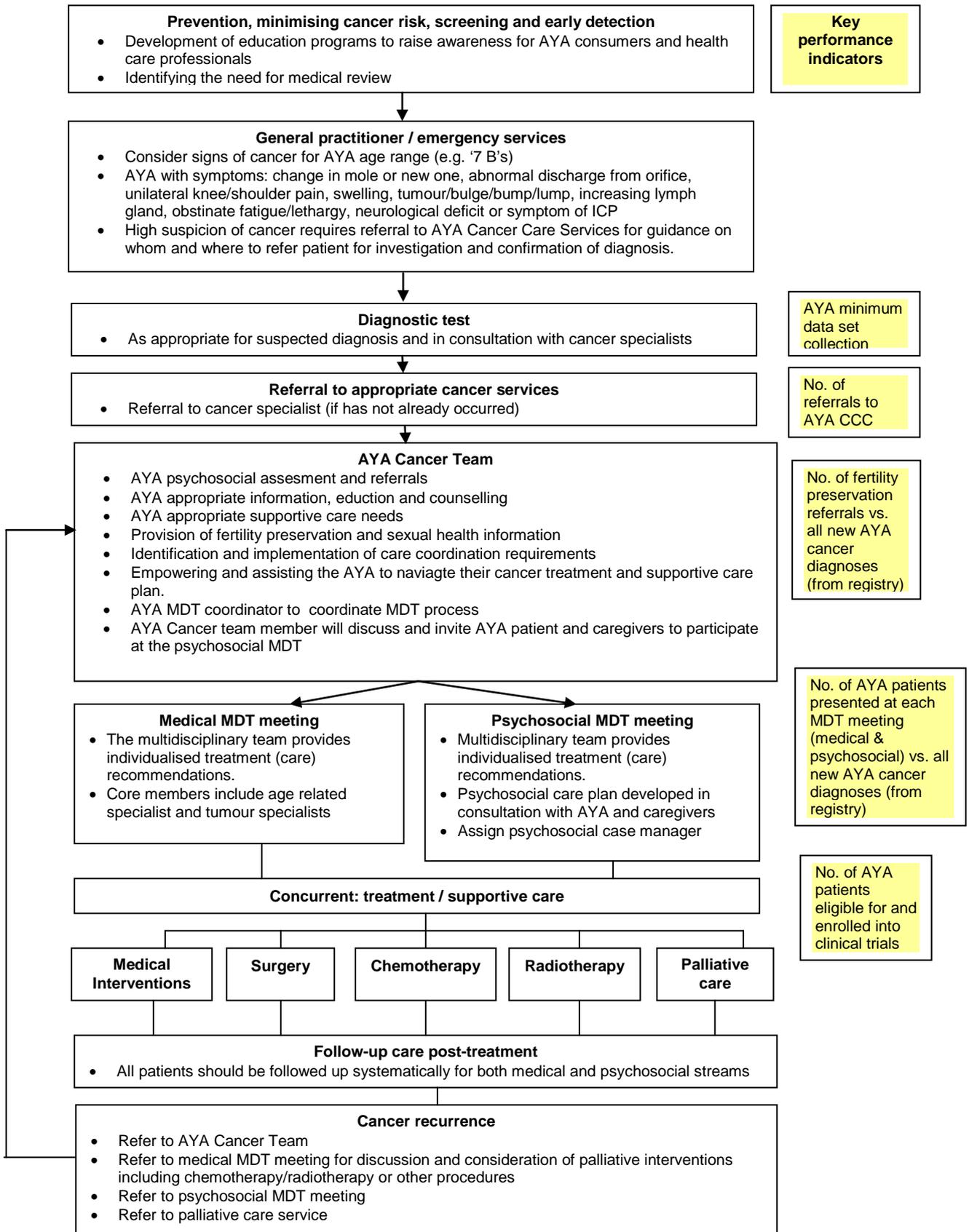
It is acknowledged that many people affected by cancer may not follow every step of the Pathway, due to variations in clinical presentation that will influence individual decisions about patient care.

This Pathway has been developed for an age range rather than for specific cancer types. Timeframes for care beyond the multidisciplinary team meeting are not considered due to the complexity and variability of individual clinical and patient decisions. It is anticipated that such timeframes will be identified in tumour-specific pathways.

On the right side of the Pathway are recommended key performance indicators (KPIs). This is not a complete list of recommended KPIs for an individual cancer pathway but represent the priority performance measures required to close the gaps in current AYA cancer care, as identified by the AYA Working Party.

**Figure 5: Adolescent and Young Adult Cancer Care Pathway**

This diagram shows the steps along the AYA cancer diagnosis and treatment pathway and the optimal care required. Not all patients will follow every step of the pathway.



## **5. EARLY DETECTION OF ADOLESCENT AND YOUNG ADULT CANCERS**

### **5.1 Delays in adolescent and young adult cancer diagnosis**

Adolescents and young adults can present with a variety of different cancers.

Delays in diagnosis of these cancers may occur and this may become a critical factor in prognosis. Patients in this age group often present to a range of health practitioners (e.g. physiotherapists, school health services, clinic services etc) and may present in an adhoc way to a local GP or hospital emergency department.

Many explanations have been put forward to explain the delay young adults face in seeking and gaining medical care. These include a lack of routine medical care,<sup>18</sup> a sense of invincibility and invulnerability, lack of familiarity by medical professionals with adolescent and young adult cancer signs/symptoms due to lack of training or experience in this age group, and subsequent under-recognition of possible cancer symptoms.<sup>19,20</sup> Embarrassment is a key part of the adolescent developmental experience,<sup>21</sup> and embarrassment and fear are also recognised as factors that can delay presentation for patients in this age group.<sup>22,23</sup> In South Australia, the recent establishment of a Australian Medical Association (AMA) SA initiative Youth friendly Doctor (YFD) program that promotes adolescent health care in general practice and teaches communication skills is a first step to addressing some of these issues. However, adolescents and young adults, their parents and GPs remain largely unaware of the risk of AYA cancers.<sup>24</sup> Education of health professionals and consumers is required to raise awareness of the possibility of cancer as a diagnosis in this age group, including symptoms and signs to look for.

#### **Education tools and health promotion**

AYA cancers are often unique to this age group, with different signs and symptoms to cancers seen in older adults or younger children. Common symptoms of AYA cancers include masses in the neck, testis, breast, abdomen or elsewhere; persistent or progressive fatigue and lethargy; abnormal discharge from an orifice; lymph gland swelling; unilateral knee/shoulder pain/swelling; change in a mole; or a specific neurologic deficit or symptom of increased intracranial pressure.<sup>25</sup>

Empowering adolescents and young adults provides them with important tools for self-care and detection. The role of education is important, as are techniques to promote self-examination of areas such as skin, breasts, and testes. Teaching these techniques to

adolescents and young adults requires skills to present the information in a non-confrontational and non-embarrassing way. Simple screening techniques, such as Pap smears and vaccination against Human Papilloma Virus (HPV) should also be encouraged. Presenting information in an AYA- friendly style will help promote important health messages. It is important to remember that it is often not the screening procedure itself but the awareness that matters, as delays tend to occur in this age group due to fear and embarrassment.<sup>26</sup>

A simple, yet effective, education strategy to promote awareness of cancer in adolescents and young adults is in development by Dr Archie Bleyer, a well-recognised clinical expert in adolescent and young adult cancer care in the USA. Dr Bleyer's education model is based on the 'seven signs and symptoms of cancer' (personal communication). Information is presented in an easy-to-remember visual format that can be used as the basis for an education program for both consumers and health professionals (see Appendix C).

The AYA Working Party recommends that AYA education tools for health professionals should be web-based, with the option for hard copy versions, following a similar approach to the lymphoma and melanoma awareness tools developed by the Cancer Council Australia.<sup>27,28</sup> Options to encourage uptake include developing an education scenario that attracts college professional development points (e.g. CPD/MOPS/CME), as well as publishing updates in relevant journals and newsletters (e.g. Australian Family Physician). Disease-specific education points relating to AYA cancers that fall outside the scope of the AYA education resource should be considered by tumour-specific working groups, with relevant information about the AYA age group included in disease-specific education packages. Examples include the fact that suspected sarcomas should only be biopsied by a surgeon specialising in oncology procedures, and large mediastinal masses should only be investigated in places with adequate anaesthetic support.

Similar education programs can be used to raise awareness of cancer among adolescents and young adults themselves. These education tools should be freely accessible in areas commonly visited by adolescents and young adults, such as schools, health centres (e.g. Second Storey), universities and TAFE. Information should be presented using a communication style appropriate to the AYA age group and in a culturally appropriate manner for cultural and linguistic diverse communities. Any education program targeting the AYA age group should utilise technology frequently accessed by individuals in this age

group (e.g. internet, social networking sites such as Facebook and MySpace, iPod, SMS and mobile technology) as well as more mainstream methods.

## **5.2 Prevention**

In addition to early detection, primary physicians are also responsible for promoting behaviours that prevent the development of cancers in healthy adolescents. Barr recognises that the most obvious targets for prevention are sun exposure, tobacco use and diet.<sup>29</sup>

### **Adolescent and young adult cancer risk factors**

Common cancers in the AYA age group in South Australia are outlined in a monograph published by the Cancer Council SA 'Cancer among Young South Australians'.<sup>30</sup> The main risk factors for each cancer have been summarised in table format by the Prevention Committee of the SA Cancer Clinical Network in Appendix D.

Most cancers in the AYA age group are sporadic, with familial syndromes and genetic conditions making up only a small proportion of cases. These include conditions such as Neurofibromatosis, Li-Fraumeni Syndrome, Xeroderma Pigmentosum, Ataxia – Telangiectasia, Fanconi pancytopenia, Hereditary Dysplastic Naevus Syndrome, Turner, Beckwith-Wiedemann, Gorlin and Bloom's syndrome and multiple endocrine neoplasia (MEN) syndromes. Tumours associated with familial cancer genes such as BRCA1/BRCA2 tumour suppression genes and breast and ovarian cancers, and colorectal cancer associated with familial adenomatous polyposis or Lynch syndromes (hMLH1/hMSH2, 6 mutations) also need consideration.<sup>31</sup>

Environmental factors appear to play little role in the development of AYA cancers, with the exception of clear cell adenocarcinoma of the vagina or cervix in adolescent females for which prenatal consumption by the mother of diethylstilbestrol appears to be a risk factor. Radiation-induced cancers occur in the older AYA group, usually resulting from exposure during early childhood. There is an increased risk of second malignant neoplasms in patients who were treated with chemotherapy, radiotherapy, or both, for a previous cancer, particularly if treatment occurred during childhood or adolescence.<sup>32</sup> GPs, adolescents and young adults and their families need to be aware of these late effects of treatment, so that appropriate monitoring and investigation can occur. Treatment summaries and late effects follow-up (discussed in Section 7), will help to address this.

## 5.3 Diagnosis and staging

### Referral delays

Once a presumptive diagnosis of cancer is made or suspected in an adolescent or young adult, the next critical step is to decide where or to whom the patient should be referred. The time taken to see an appropriate specialist is frequently called 'referral delay', and is recognised as the longest time segment, after patient delay, that influences timely diagnosis (see Figure 6).<sup>33</sup>

**Figure 6: Diagnosis Delay**

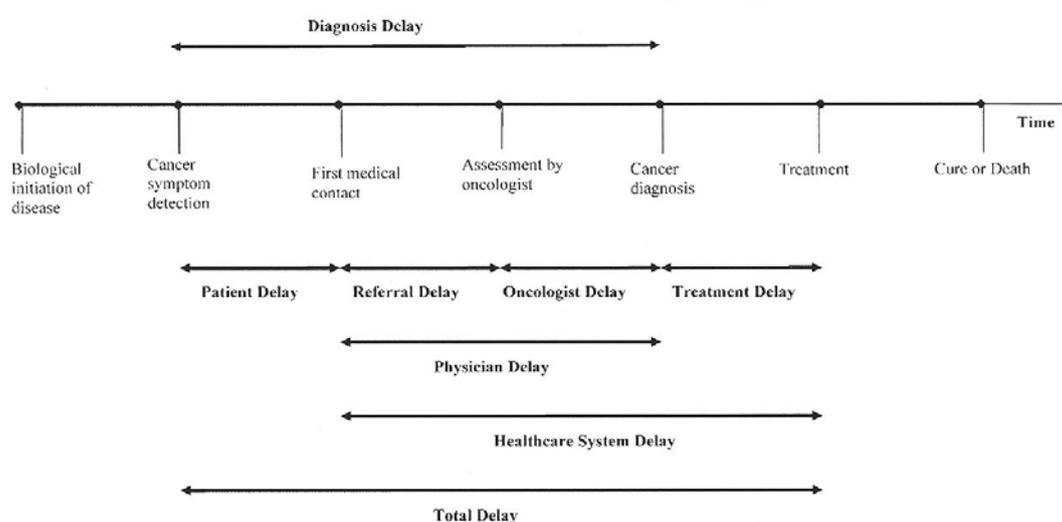


Fig. 1. Definition of delay variables along the cancer care continuum (relative distances between time points are not representative of actual time intervals).

Reproduced with permission from John Wiley & Sons, Inc. Dang-Tan T et al. *Pediatric Blood Cancer* 2008 Oct; 51(4):468-474.

Referral pathways for adolescent and young adult cancer patients may take many routes and the referral process is often confusing. Referral may be to a private specialist (surgeon, oncologist, haematologist, radiation oncologist) or to a paediatric or adult setting within the public health system. Referral issues are further compounded for GPs by questions such as:

- which specialist treats which disease
- whether investigations should be undertaken while the patient is waiting to be seen by a specialist
- how to ensure patients have timely access into a health system that has long waiting lists
- determining whether the patient needs urgent review and how to navigate timely access to the right specialist.

GP's may incorrectly assume that if the specialist to whom they refer the patient does not regularly deal with that cancer type, a secondary referral will be made by the specialist to another individual specialist or team with relevant expertise.<sup>34</sup> This adds to delays in timely referral.

### **Simplified referral system**

The complexity of the cancer referral system in general, combined with the additional challenge of AYA cancers that are often treated in both paediatric and adult settings, highlights the need for a simplified referral system for adolescent and young adult cancer patients. In developing this system, lessons may be learned from other sectors of the health care system.

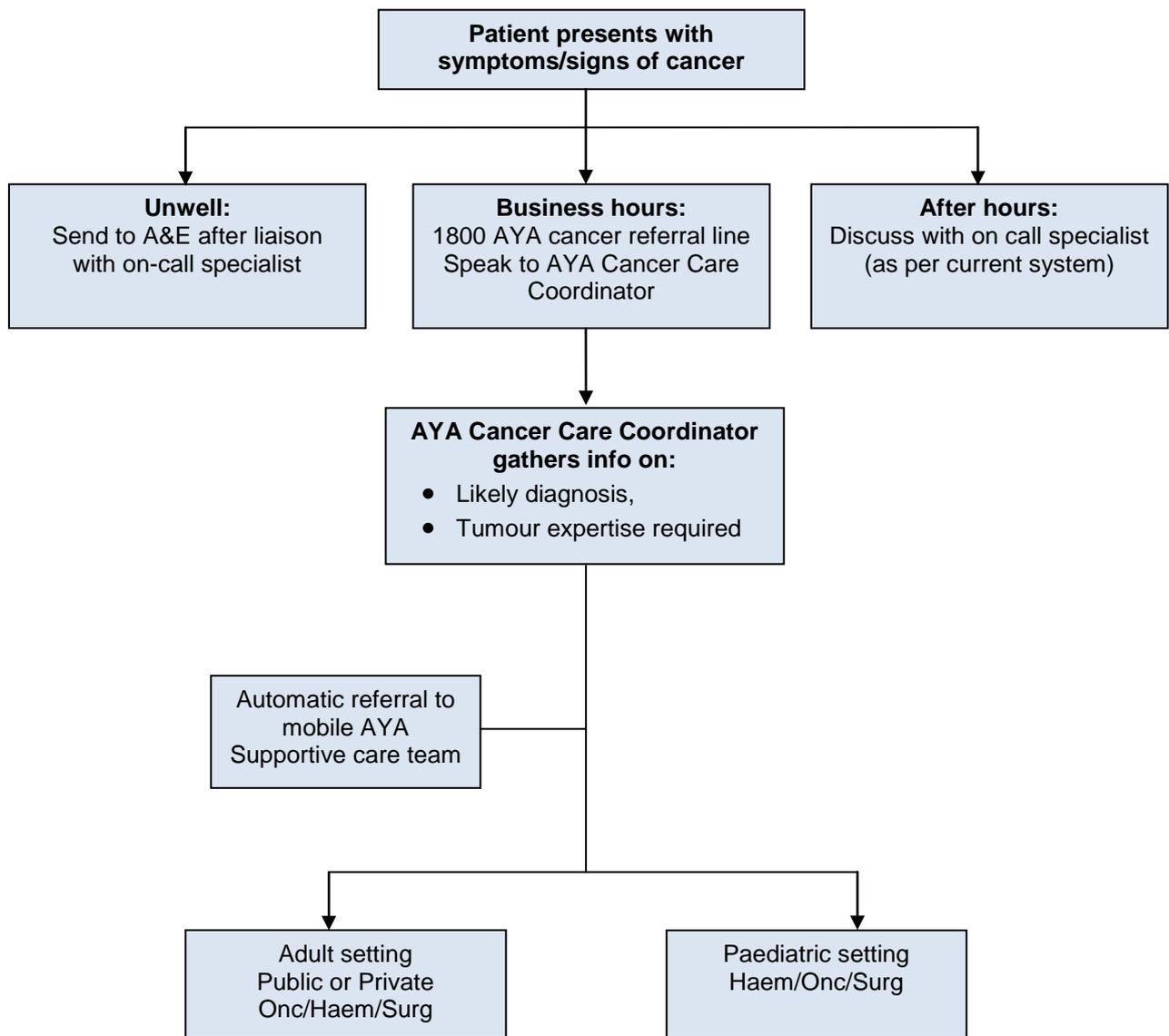
The Integrated Cardiovascular Clinical Network South Australia (iCCnet SA) has developed and implemented a Statewide Cardiology Paging System that provides rural/remote practitioners and nursing staff with timely critical access to a Cardiac Consultant for advice and assistance in the management and triage of all acute cardiac conditions.<sup>35</sup> Based on this model, it is envisaged that referrals for adolescents and young adults with a high suspicion or confirmed cancer diagnosis could be made through a single statewide telephone access number. For example, a resourced telephone referral line could be managed by AYA Cancer Care Coordinators during regular business hours (Monday to Friday), providing a central co-ordination point to ensure appropriate referrals. The role of these Care Coordinators would not be to provide medical advice, but to direct referrals based on agreed algorithms/system tools, using the cancer specialist service directory to ensure appropriate referral to specialists with expertise in AYA cancer care in South Australia. After hours, the referring doctor or GP would continue to contact an on-call specialist as per the current system.

Key points that may need to be considered by the Care Coordinator when implementing such a referral system include:

- relevant medical field (surgical/haematology/medical oncology)
- most likely diagnosis (tumour stream)
- age-appropriate tumour expertise (paediatric/adult),
- patient location
- available clinical trials
- patient preference for public/private care.

Based on these criteria, the AYA Cancer Care Coordinator could provide advice to the referring doctor on which specialist to contact to discuss the patient and their medical management. It is important to emphasise that under this model, unwell patients would continue to be referred to the nearest emergency services department as soon as possible (see Figure 7).

**Figure 7: Adolescent and young adult cancer referral pathway – proposed statewide referral line process**



Additional advantages of this system include streamlining the medical referral process and ensuring referral to psychosocial support. Mitchell recognises the important role of patient peer support at the time of cancer diagnosis, and the need to provide patients with relevant information.<sup>36</sup> Streamlining the referral process through AYA Cancer Care Coordinators would enable automatic referral to the AYA psychosocial support team of

care coordinators, social workers, psychologists and youth/vocational officers to facilitate early contact and support.

Patients from rural areas often report delays in seeing specialists, as they wait for an appointment with a visiting specialist. Appropriate waiting times for specialist appointments are tumour dependent and these should be addressed by the working party of each individual tumour stream. Rural patients may need to travel to metropolitan health services to aid timely review and investigations. A single statewide AYA referral line would enable patients living in both metropolitan and rural areas to have equitable access to this optimal model of care.

Given the approximate estimate of 70–90 new diagnoses of AYA cancer per year in South Australia, it is expected that staffing the referral line would not add significantly to the AYA Cancer Care Coordinator workload, with an anticipated 1–2 new patient referrals per week. This will require ongoing monitoring and evaluation.

### **Service directory**

One of the key deliverables for the CanNET SA program was to develop and implement a Statewide Cancer Services Directory. Due to local processes, this has not yet been achieved. However, work is ongoing by other cancer project groups to continue with this project under the auspice of the SA Cancer Clinical Network.

The AYA Working Party recommends that a web-based service directory of health professionals interested in AYA cancer care is included in the SA Statewide Cancer Services Directory. The directory should include the following:

- medical services
- age-appropriate resources
- psychosocial supportive cancer care services
- AYA Cancer referral telephone number
- how to contact cancer specialists after-hours
- links and contact details for relevant professional colleges and organisations (see Appendix E).

The directory should be updated regularly, and should be easily accessible, with links available through medical programs such as 'Medical Director'.

It is envisaged that implementation of a streamlined referral process, along with the service directory, will aid in addressing the current referral delay issues.

### **Staging**

It is envisaged that Cancer Care Co-coordinators (either AYA or tumour-stream specific) should be available to help co-ordinate and streamline this process as much as possible. However specific recommendations on staging for AYA cancers are beyond the remit of the AYA Working Party. Each individual tumour pathway working party is required to address appropriate and timeliness of investigations, timely access to multidisciplinary team meetings and timely access to treatment.

Health professionals involved in the care of an adolescent or young adult with cancer should have appropriate tumour expertise. This means that tissue samples (including biopsies) should be collected by specialists experienced in AYA oncology (especially if possible bone or soft tissue sarcoma). Pathologists and cytogenetic services should have appropriate tumour and age expertise, to ensure knowledge of tumours that occur in this age group. Equitable access is required to ensure all adolescents and young adults with a possible or confirmed cancer diagnosis have access to appropriate and relevant imaging facilities (MRI, PET scan), as well; as access to timely theatre lists for any required procedures such as biopsy or central line insertion.<sup>37</sup>

## Recommendations:

- 1. Education programs should be developed to promote awareness of the possibility of cancer as a diagnosis in the AYA age group for both (a) health professionals and (b) consumers (i.e. all adolescents and young adults and their parents).**
- 2. School-based cancer awareness and education programs targeting the 12–16 year old age group should involve AYA cancer survivors to maximise impact.**
- 3. Any education/awareness package targeting the AYA population needs to incorporate components using technology frequently accessed by adolescents and young adults.**
- 4. Although most cancers in the AYA age group are not hereditary, familial cancer syndromes should be thought of and appropriate referral to a genetic cancer service should be made if a familial syndrome is suspected.**
- 5. Health professionals involved in the care of an adolescent or young adult with cancer should have the appropriate tumour expertise and AYA age-related expertise.**
- 6. A web-based service directory of medical and supportive care health professionals with expertise and an interest in AYA cancer care should be included in the SA Statewide Cancer Services Directory.**
- 7. A single statewide telephone-based referral line should be established to facilitate direct AYA referrals to an appropriate specialist and best place of care and to encourage and facilitate early referral to the AYA mobile supportive care team.**
- 8. Adolescent and young adult patients who are unwell should be discussed with an on-call specialist and referred to the nearest emergency services as appropriate.**

<sup>18</sup> Booth M *et al.* Encounters between adolescents and general practice in Australia. *J Paediatr Child Health* 2008 Dec;44(12):699-705.

<sup>19</sup> Bleyer A. Young Adult Oncology: The patients and Their Survival Challenges. *Ca Cancer J Clin* 2007; 57:242-255.

<sup>20</sup> Albritton K, Bleyer WA. The management of cancer in the older adolescent. *European J Cancer* 2003;39:2584-2599

<sup>21</sup> Wilson C. Cancer among Adolescents and Young Adults (AYA). 2008, for the Prevention subcommittee of the state wide Cancer Clinical Network Steering committee.

<sup>22</sup> Albritton K, Bleyer WA. The management of cancer in the older adolescent. *European J Cancer* 2003;39:2584-2599

<sup>23</sup> Mavinkurve-Groothuis AMC *et al.* Patient delay due to embarrassment and fear in two adolescents with a malignant tumour. *Pediatr Blood Cancer*. 2008 May;50(5)1083.

<sup>24</sup> Wilson C. Cancer among Adolescents and Young Adults (AYA). 2008, for the Prevention subcommittee of the state wide Cancer Clinical Network Steering committee.

<sup>25</sup> Bleyer, A. Young Adult Oncology: the patients and their survival challenges. *Ca Cancer J Clin* 2007; 57:242-255.

<sup>26</sup> Albritton K, Bleyer WA. The management of cancer in the older adolescent. *European J Cancer* 2003;39:2584-2599

<sup>27</sup> Australian Cancer Network. *Clinical practice guidelines for the diagnosis and management of lymphoma, a guide for general practitioners*. Edition 1 Cancer Council Australia, RACP, NHMRC, October 2007.

<sup>28</sup> Australian Cancer Network. *Melanoma – An aide Memoir to Assist Diagnosis*. Cancer Council Australia, Dec 2008

<sup>29</sup> Barr RD. On cancer control and the adolescent. *Med Pediatr Oncol*. 1999 Jun;32(6):404-10.

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- <sup>30</sup> Beckmann K, Roder D. *Cancer among young South Australians*. April 2008. Monograph No 10. Centre for Cancer Control Research, South Australia cancer statistics, Cancer Council SA.
- <sup>31</sup> Pentheroudakis G, Pavlidis N. Juvenile cancer: improving care for adolescents and young adults within the frame of medical oncology. *Annals of Oncology* 2005;16:181-188.
- <sup>32</sup> Bleyer A. Older adolescents with cancer in North America deficits in outcome and research. *Pediatr Clin North Am*. 2002 Oct;49(5):1027-42.
- <sup>33</sup> Dang-Tan T *et al*. Delays in Diagnosis and Treatment Among Children and Adolescents With Cancer in Canada. *Pediatric Blood Cancer* 2008 Oct; 51(4):468-474.
- <sup>34</sup> Mitchell GK. The role of general practice in cancer care. *Aust Fam Physician* 2008 Sep; 37(9):698-702.
- <sup>35</sup> Integrated Cardiovascular Clinical Network SA Newsletter. Issue 2 | August 2008. Integrated Cardiovascular Clinical Network SA in collaboration with Country Health SA [https://iccnetsa.org.au/Adelaide\\_Cardiovascular\\_index.php](https://iccnetsa.org.au/Adelaide_Cardiovascular_index.php) (NB No longer available on this webpage)
- <sup>36</sup> Mitchell GK. The role of general practice in cancer care. *Aust Fam Physician* 2008 Sep; 37(9):698-702.
- <sup>37</sup> National Institute of Clinical Excellence. *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*. August 2005.

## 6. MULTIDISCIPLINARY AND COORDINATED CARE

Multidisciplinary care is a collaborative approach to health care that aids treatment planning and ongoing management and is integral to providing coordinated care to people diagnosed with cancer.

Multidisciplinary care is provided by a team that meets regularly, either face-to-face or via teleconference/videoconference, to prospectively plan care and treatment for patients.<sup>38</sup>

This approach to care is essential for adolescent and young adult cancer patients with in both public and private health care settings. When considering cancer in the AYA age group, it is important to recognise that there is a need for both a medical and a psychosocial/supportive care multidisciplinary team approach.

### 6.1 Benefits of multidisciplinary care

Evidence supporting a multidisciplinary approach to cancer care is increasing.

Demonstrated benefits include:<sup>39</sup>

- increased provision of evidence-based care in accord with clinical practice pathways (where available) with implications for both clinical outcomes and cost effectiveness
- all treatment options are considered and treatment plans are individualised to each patient
- improved referral pathways
- increased referrals for psychosocial support
- increased discussion of patient eligibility for clinical trials
- enhanced clinical education opportunities
- opportunity for clinicians to interact.

Positive outcomes identified for patients such as:<sup>40</sup>

- increased survival when care is managed by a multidisciplinary team
- increased patient satisfaction with care
- increased access to information for patients, particularly psychosocial and practical support
- increased perception by the patient that care is being managed by a team.

## 6.2 Multidisciplinary care principles

A set of principles underpinning multidisciplinary care have been identified.<sup>41</sup>

### **A team approach**<sup>42,43</sup>

- There is an established multidisciplinary team that comprises relevant core disciplines including allied health and psychosocial health specialists.
- The GP is regarded as a team member and effective communication processes between the multidisciplinary team and the GP are established.
- Effective communication processes exist with access and referral links between all core and non-core team members.

### **Communication among team members**<sup>44,45</sup>

- All the core team members regularly attend the multidisciplinary team meetings to provide input into diagnostic, treatment, supportive and palliative care planning.
- Processes are in place for communication of treatment recommendations and care plans between core team members.

### **Access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution**<sup>46,47</sup>

- All patients, regardless of where they live and their cultural background, will have information about and access to relevant treatment and services.
- Clinical trial involvement is considered for all eligible patients who will be undergoing cancer treatment.

### **Provision of care in accord with agreed standards/pathway**<sup>48,49</sup>

- Decisions, protocols and care pathways are in line with current best practice, including standards, research and where these are not available, currently accepted approaches to treatment.
- All the relevant diagnostic results, reports and pathology and radiology images are available for multidisciplinary team meetings.
- Professional development activities for all multidisciplinary team members are offered and supported.

## **Involvement of patients in decisions about their care<sup>50,51</sup>**

- Patients are informed of the multidisciplinary team approach to care.
- Patients are informed of the multidisciplinary team recommendations, provided with information about all aspects of their treatment and participate in the decision-making process.
- Patients are routinely provided with culturally appropriate information about and access to supportive care services.

## **Adolescent and young adult cancer multidisciplinary care**

Adolescents and young adults have unique needs and management of their care requires an approach that includes medical and supportive care (including psychosocial care). The model of care for AYA cancers proposed for South Australia involves establishment of clear referral processes to an appropriate tumour-based multidisciplinary team as well as clear referral processes and a mobile team to provide multidisciplinary supportive and psychosocial care.

Under this model, every AYA cancer case should be discussed at an AYA psychosocial multidisciplinary team meeting as well as a medical multidisciplinary meeting. Figure 8 provides an overview of the AYA multidisciplinary team meetings.

### **6.3 The medical AYA multidisciplinary team**

Adolescents and young adults with cancer have unique needs that require tumour- and age-specific medical expertise. Additional core team members required for AYA case discussion at tumour-specific MDT's include:

- AYA oncologist/haematologist (or an adult oncologist/haematologist and a paediatric oncologist/haematologist)
- AYA Cancer Care Coordinator
- clinical trials representation/data manager
- AYA multidisciplinary team coordinator.

Tumour-specific core multidisciplinary team members are dependent on the tumour type, but are likely to include:

- Radiation Oncologist
- Surgeon with expertise in the relevant cancer type
- Histopathologist with expertise in the relevant cancer type
- Radiologist

- Nuclear Medicine Specialist
- Palliative Care Specialist
- Pharmacist (with knowledge of the likely drugs used and age-specific side effects)
- Allied health team
- Nursing specialist with expertise in the relevant cancer type.

It is proposed that the core members of the AYA multidisciplinary team (the 'AYA team') would be informed that a newly diagnosed adolescent and young adult patient was to be discussed by the AYA cancer care coordinator. It is acknowledged that some tumours are treated urgently on protocol, such as acute leukaemia. These patients should be discussed at relevant local haematology clinical team meetings or appropriate tumour specific MDT as soon as practical. Adolescent and young adult cancer cases that require paediatric-type treatment should be referred for presentation at the Women's and Children's Hospital Haematology/Oncology Department Tumour Advisory Committee (TAC) meeting.

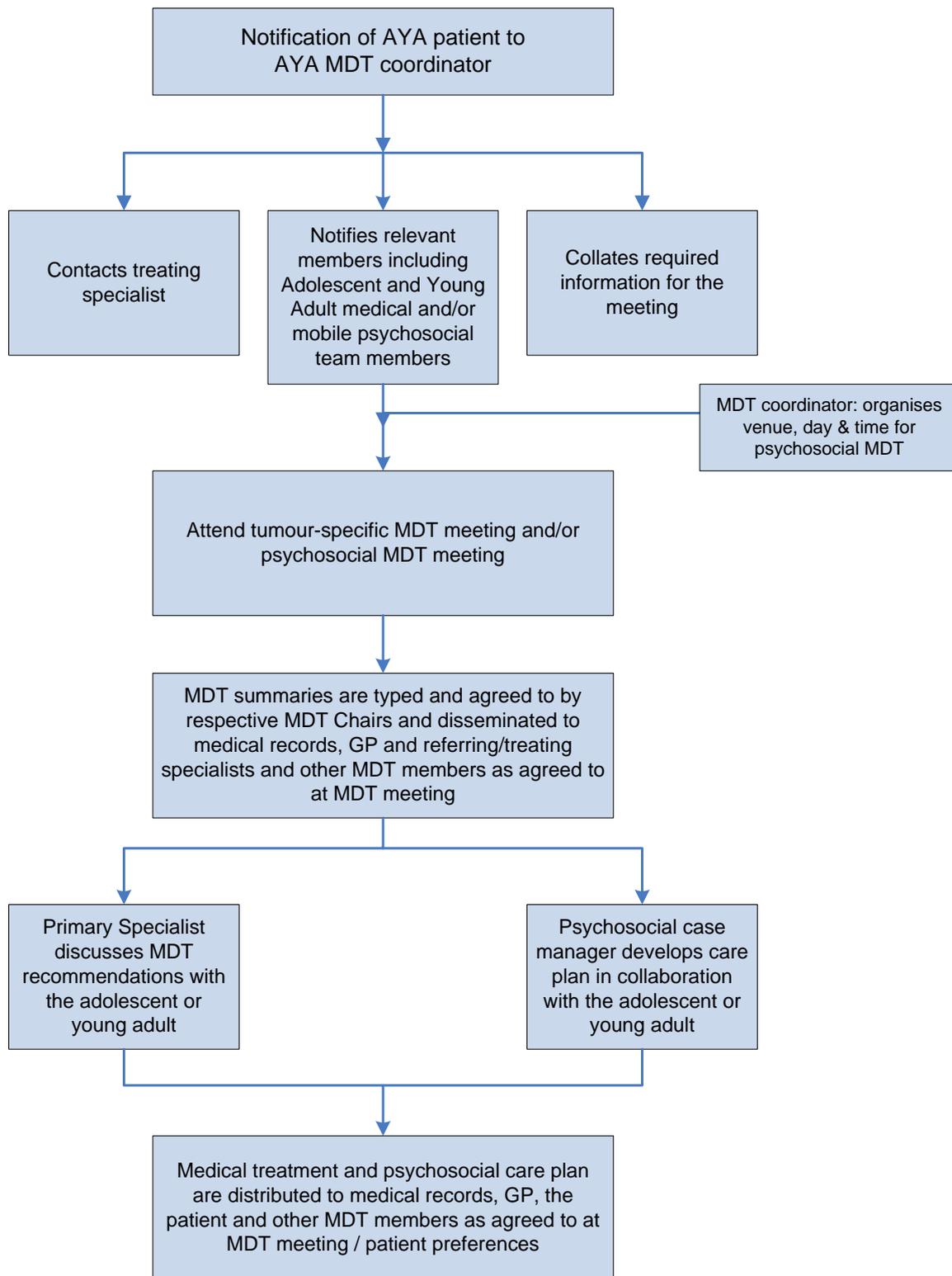
Where possible, all patients should be referred for multidisciplinary discussion where specialists with tumour and age specific expertise are present as soon as possible after diagnosis and prior to commencement of definitive treatment. Discussion may also be required at the time of restaging, neoadjuvant treatment, surgery or relapse. Any health professional involved in the patient's treatment should be able to refer the patient for discussion.

Medical multidisciplinary team meetings should be held frequently enough to ensure discussion of patients in a manner that does not delay their treatment, and to allow their treatment plan to commence within current best practice for that particular disease.

It is expected that a report summarising discussions at the MDT meeting, will be typed and prepared for distribution by the AYA multidisciplinary team coordinator to other members of the AYA team within 7 days of the MDT meeting.

It is the treating specialist's responsibility to discuss treatment recommendations with the patient (and family/caregivers as per patient preferences) and to finalise a treatment plan. Following guidelines already developed on multidisciplinary cancer care, dissenting views about a recommended treatment approach should be recorded in the treatment recommendations and communicated to the patient.<sup>52,53,54</sup>

**Figure 8: Adolescent and young adult cancer multidisciplinary team flow diagram**



#### **6.4 The AYA psychosocial (or supportive care) multidisciplinary team**

Every AYA cancer case should be discussed at an AYA psychosocial multidisciplinary team meeting as well as a medical multidisciplinary meeting. The constitution of the psychosocial team will not vary by cancer type, but rather by a person's psychosocial needs, to be determined at diagnosis through a comprehensive needs assessment. Thus, the psychosocial multidisciplinary team will care for adolescents and young adults across the range of cancer types and across health services.<sup>55</sup>

Consent from the patient is required for the AYA psychosocial multidisciplinary team to discuss their case with the treating medical specialist. The AYA psychosocial core team should include:

- treating cancer specialist
- AYA Cancer Care Co-coordinator
- AYA social worker
- AYA vocational/educational officer
- Nurse from treating health service.

Other non-core members who may attend as required or require referral processes to include:

- Dietitian
- Physiotherapist
- Occupational therapist
- Psychologist
- Psychiatrist
- Pharmacist
- Hypnotherapist
- Palliative care representative
- Pastor/spiritual advisor.
- GP
- Community health teams
- Rehabilitation services (e.g. Drug and Alcohol, Corrective services)

Given that it is likely that not all disciplines will be able to attend the psychosocial meeting, referral processes should be well established for AYA cancer supportive care.

Requirements for services will vary depending on patient needs, and where the patient is in their cancer journey. However, adolescents and young adults with cancer, their families

or caregivers should have access to services provided by members of the psychosocial team regardless of where they are being treated.

The psychosocial multidisciplinary team meeting should be held soon after diagnosis once a comprehensive needs assessment has been performed. If a case manager has not been appointed prior to the meeting this should occur at the meeting and determined by the designated Chair of that meeting. The case manager would be responsible for ensuring a summary of the discussion is documented and for developing a psychosocial care plan in collaboration with the patient. Both summaries should be typed and filed into clinical records and disseminated to the relevant AYA psychosocial team members as agreed to at the meeting. The care plan should be made available to the patient, treating specialist, GP and the patient's medical records within 7 days. A list of other members of the psychosocial multidisciplinary team who may require a copy of the care plan should be agreed at the meeting.

The administrative assistant for the AYA multidisciplinary team should be responsible for typing and appropriately distributing all team correspondence.

Any health professional involved in the patient's care may refer the patient for discussion at the psychosocial multidisciplinary meeting. Meetings will be required at diagnosis or tumour relapse, at the end of treatment, and at any other stage deemed necessary along the patient's cancer journey. Figure 7 shows the flow diagram for the psychosocial multidisciplinary team.

### **6.5 Role of the AYA administrative multidisciplinary team coordinator**

Identified responsibilities for the AYA administrative multidisciplinary team coordinator are outlined below.

General:

- Central referral point of all AYA with cancer receiving notification from GP's, Specialists and other MDT's coordinators.
- Ensure that all AYA patients discussed at appropriate medical MDT
- Ensure all AYA patients receive urgent comprehensive assessment and is discussed at psychosocial MDT.
- Coordinate late effects clinic and any test required.
- Keep central database of all AYA cases on record.

### **Medical multidisciplinary team**

- Receive notification of any new (or existing) adolescent or young adult patients requiring discussion at a tumour-specific medical multidisciplinary team to ensure a relevant age specialist is notified to attend.
- Confirm patient discussion with the primary treating specialist if referral is received from another member of the health care team.
- Organise relevant pathology/radiology/investigations required for review at the medical tumour-specific multidisciplinary meeting.
- Identify and notify key relevant specialists of the patient's discussion at the medical multidisciplinary meeting.
- Invite any non-core medical team members required for discussion of an individual patient to attend the medical multidisciplinary meeting.
- Keep an up-to-date schedule of all medical multidisciplinary meetings in South Australia relevant to the AYA age group.
- Prepare a weekly agenda of AYA cases for discussion at medical multidisciplinary meetings.
- Keep a copy of medical MDT report for each AYA patient.
- Ensure the written summary of treatment recommendations is sent to the treating specialist, medical records, and GP within 7 days of the medical multidisciplinary meeting.
- Maintain multidisciplinary team meeting database.

### **Psychosocial multidisciplinary team:**

- Receive notification of any new patients requiring discussion at a psychosocial multidisciplinary meeting
- Confirm the patient discussion with the primary treating specialist and check that patient consent has been obtained (liaison with AYA Cancer Care Coordinator)
- Notify relevant core psychosocial team members of the patient discussion at a psychosocial multidisciplinary meeting.
- Invite any non-core psychosocial team members required for the patient discussion to attend the psychosocial multidisciplinary meeting (liaison with AYA Cancer Care Coordinator).
- Liaise closely with AYA Cancer Care Coordinator to ensure that all patients are discussed at psychosocial multidisciplinary meeting when necessary.
- Co-ordinate and organise an appropriate venue, time and date when everyone involved in the patient's psychosocial care is able to attend.

- Prepare a written summary of the care plan after the nominated case manager has met with the patient (to be available within 7 days after this occurs).
- Distribute the summary of the psychosocial care plan to the patient, treating specialist, medical records and GP and others as agreed during the meeting.
- Maintain a database of all adolescent and young adult cancer patients discussed at psychosocial multidisciplinary meetings.

**Recommendations:**

- 9. All adolescents and young adults with cancer should be discussed prospectively at a medical multidisciplinary team\* meeting where specialists with relevant tumour- and age-specific expertise are present.**
- 10. Adolescent and young adult cancer cases that require intensive paediatric-type treatment should be referred for presentation at the Women's and Children's Hospital Haematology/Oncology Department Tumour Advisory Committee (TAC) meeting.**
- 11. All adolescent and young adult cancer cases that require adult-type treatment should be referred to the relevant tumour-specific multidisciplinary team meeting.**
- 12. All adolescent and young adults with cancer should be discussed at a psychosocial multidisciplinary team\* meeting. The constitution of the psychosocial multidisciplinary team will be determined by the person's psychosocial needs, as determined at diagnosis through a comprehensive needs assessment.**
- 13. An online cancer service directory should be developed and implemented for South Australia that includes a list of tumour-specific multidisciplinary team meetings across sites and how to refer to the meeting.**
- 14. Administrative support should be available for all multidisciplinary team meetings. A statewide administrative AYA multidisciplinary team coordinator should be available to provide administrative support for both medical and psychosocial AYA multidisciplinary teams.**

\*It is recognised that with the current level of resources within both the public and private sector, not all listed members of both the medical and psychosocial multidisciplinary teams will be available and able to attend all meetings. Team membership and responsibilities require dedicated time and should be recognised in job plans.

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## 7. TREATMENT

### 7.1 Where to treat adolescent and young adult cancers

One of the major and recurring themes raised by young people with cancer and their families is where and how adolescents are best managed.<sup>56,57</sup> Feelings of isolation from peers, other young people with cancer, expertise and research, and from the treatment team are common.<sup>58</sup> There is a requirement for a physical ward space for adolescents and young adults with cancer. The setting should:

- be decorated appropriately and equipped to allow for a relaxed atmosphere
- enhance daily activities normal for this age group
- permit adolescents and young adults to develop peer relationships
- allow adolescents and young adults to receive appropriate care by trained nursing and psychosocial support staff and by medical staff expert in their disease.

This concept has led to the development of Teenage Cancer Trust (TCT) Units in the UK.<sup>59,60,61</sup> In Australia, the National Service Delivery Framework for Adolescents and Young Adults with Cancer supports the development of single principal AYA cancer care site in each state that serves as the centre of a network of improved AYA service delivery.<sup>62</sup> This model works best when paediatric and adult cancer centres are co-located. In South Australia, within the current plans for our health care system, this is unlikely to occur. Therefore, as a principle AYA site is not able to be identified within current health services in South Australia consideration should be given to establishing treatment spaces within both the paediatric and adult settings that address the issues outlined above.

#### **AYA treatment protocols**

As adolescents and young adults with cancer are treated within both adult and paediatric health services, there has been significant debate on which treatment protocols should be used. The choice of paediatric or adult protocol for the treatment and care of adolescents and young adults with cancer needs to be based on clear evidence of best outcomes. Survival is enhanced at centres where there is a critical minimum caseload and where tumour expertise is located. Examples include the lower mortality rates seen in centres that routinely perform bone marrow transplantation, and the higher rates of limb salvage procedures compared with amputations seen in centres that specialise in the treatment of osteosarcoma.<sup>63</sup>

This type of evidence-based best practice requires collaboration between specialists and health services in both the paediatric and adult settings. Adolescents and young adults with adult type tumours (e.g. melanoma, thyroid, breast, and colorectal cancers) should be treated at a health service with expertise in managing these tumour types.<sup>64</sup> In South Australia, this would require patients to be treated within the adult oncology system.

There is increasing evidence that for some tumours, survival for adolescents and young adults is improved when treated using paediatric-type intensive treatment protocols compared with adult protocols. This is especially so for acute lymphoblastic leukaemia (ALL).<sup>65,66,67,68,69,70,71</sup> In the absence of an AYA-specific unit, these patients should be treated at a paediatric health service (if younger than the Women's and Children's Hospital admitting age of 18 years) or in conjunction with paediatric haematology-oncology input (if older than 18 years of age). Adolescent and young adult cancer patients with paediatric-type solid tumours, such as rhabdomyosarcoma, Ewing's sarcoma and osteosarcoma, will benefit from the expertise of a paediatric oncologist, at least in the form of consultation.<sup>72,73,74,75,76</sup> Adolescents and young adults with other paediatric-type tumours, such as medulloblastoma and neuroblastoma, should be managed in a paediatric setting, or in conjunction with paediatric oncology input.<sup>77</sup> To facilitate provision of best practice evidence-based treatment and clinical trial enrolment, ultimately a new discipline 'AYA oncology' is required to meet the needs of these young patients.<sup>78,79,80</sup>

There is now excellent evidence for a variety of cancers that survival is best at centres with a critical minimum caseload.<sup>81</sup> Further collaboration is required between paediatric and adult haematologists and oncologists to determine the best model of care for South Australia. The National Service Delivery Framework for Adolescents and Young Adults with Cancer includes a lead adolescent and young adult cancer care site in each state as one of its key elements.<sup>82</sup> Based on the relatively small number of adolescent and young adult patients with a cancer diagnosis in South Australia, agreement is required between specialists within the adult health care system to determine the best way forward. Centralisation of services and tumour-specific expertise, especially with regard to specific diseases such as sarcoma and leukaemia, needs to be seriously considered.

## **7.2 Clinical trial enrolment**

The 'gold standard' for assessment of cancer care is a randomised clinical trial.<sup>83</sup> It is widely recognised that adolescents and young adults are enrolled less often on clinical trials than their paediatric or adult counterparts. Published studies have consistently demonstrated that children and adolescents with a variety of cancer types have higher

survival rates if treated in clinical trials and at specialised centres. Entry into clinical trials seems to be a more important determinant of outcome than the place of treatment.<sup>84</sup> Further information relating to clinical research in the adolescent and young adult age group is included in Section 13.

### **7.3 Access to care**

As important as access to clinical trials and evidence-based care is access to the care required to implement these in a timely manner. This is especially the case when patients are treated outside a larger cancer care health service. The UK's National Institute for Clinical Excellence (NICE) guidelines summarise these well.<sup>85</sup> Adolescent and young adult cancer patients require timely access to theatre, chemotherapy and radiotherapy facilities in line with the relevant disease and treatment protocol. A pharmacist with expertise in chemotherapy who is familiar with tumour-specific protocols and age-related side effects should also be involved in patient care. Computerised electronic chemotherapy prescribing systems should be made available to minimise prescribing errors, and chemotherapy should be administered by appropriately trained staff familiar with its use and side effects. Finally, all staff involved with direct patient contact should have expertise and be trained in communicating with patients in the AYA age group.

### **7.4 Adherence with cancer treatment in adolescents and young adults**

Adherence is defined as 'the extent to which a person's behaviour (in terms of taking medications, following diets or executing lifestyle changes) coincides with medical or health advice.'<sup>86</sup> Higher rates of non-adherence have been found in the adolescent population in comparison to children and adults, in the treatment of cancer and other life-threatening illnesses.<sup>87,88</sup> Estimated rates of non-adherence in adolescent patients with cancer range between 33 and 60%.<sup>89,90</sup> Adherence is also known to decrease with the duration of therapy.<sup>91</sup>

Measurement of adherence is in its infancy compared to assessment tools utilised in other specialties (e.g. behavioural problems), and further research is needed. The wide range of estimated adherence rates is likely to reflect measurement difficulties as well as differences in definition.<sup>92</sup> Literature suggests that, although assays or electronic monitors are superior measures of medication adherence compared to other methods of assessment (e.g. observation, pill counts, provider estimates, patient/caregiver reports), they are not routinely available or particularly cost-effective. Thus, reliance on patient/caregiver reports continues.

Several risk factors for sub-optimal adherence with cancer treatment have been identified. These include low socio-economic family status, communication barriers (including cultural and linguistic differences), time constraints, mental health problems in caregivers and pre-existing behavioural disturbances in adolescent and young adult patients. Communication issues between adolescents and parents around treatment appear to be a significant contributor. A shift to increasing self-care responsibility for managing medical illness begins during the adolescent period and there is the potential for confusion, with discrepancies in understanding about the illness and its treatment strongly predictive of sub-optimal adherence behaviours. Compliance, or non-adherence to treatment, appears to be worse in adolescents and young adults and those with a poorer understanding of their illness and greater levels of denial.

The Society of International Oncology (SIOP) Working Committee on Psychosocial Issues in Paediatric Oncology has identified five major strategies to prevent non compliance (Table 2).

Other strategies to prevent non-adherence include tracking, with the aim of monitoring adherence to each component of the regimen (e.g. diet, oral medication) at regular intervals. Where adherence is low or decreasing, intensive education is provided in case adherence is linked to lack of information. Finally, harm minimisation methods (e.g. regimen simplification) should be considered, as decreasing the burden of treatment may improve adherence.<sup>93</sup>

**Table 2: SIOP Recommendations for prevention of treatment non-compliance<sup>94</sup>**

|  |  |
|--|--|
| Communication  | Encourage open, honest communication by members of the health care team with adolescents and their families, with an emphasis on consistency of communication between different members of the team.   |
| Identifying risk                                     | Identify families with risk factors predictive of non-adherence, such as missed appointments or education sessions during the initial stages of treatment, and intervene early.  |
| Social support                                       | Provide social supports, such as accommodations near the hospital, financial assistance with transportation, and assistance in problem solving around childcare issues, for families with limited resources.   |
| Addressing questions and exploring treatment options | Be available to questions that the family may have about treatment options that they may have researched independently, discussing why the recommended treatment is the best option for the patient and being open to obtaining a second opinion when the family has doubts about the recommended treatment. |
| Open-mindedness                                      | Remain open and non-patronizing regarding alternative therapies with sensitivity to the family's cultural and religious background. Allow families to incorporate alternative therapies when there is no significant risk to the patient in doing so.  |

**Recommendations:**

- 15. It is essential that all adolescents and young adults with cancer receive the best evidence-based treatment available in a centre that can provide tumour-specific and age-specific expertise. Ultimately a new discipline, AYA oncology, should be established to meet needs of these young patients across health services (e.g. paediatric and adult settings).**
- 16. A system should be implemented to address and meet the unique psychosocial needs of the AYA age group.**
- 17. Further collaboration is required between paediatric and adult haematologists and oncologists to determine the best model of care for adolescent and young adult cancer patients in South Australia. Serious consideration should be given to centralisation of services and tumour-specific expertise.**
- 18. All adolescents and young adults should be offered entry to clinical research trials for which they are eligible with adequate resources provided to support such trials. Participation in trials should be an informed choice.**
- 19. Administration and data management support should be established to maintain a web-based clinical trials register in South Australia that includes age eligibility.**

- 20. A statewide central ethics approval process should be established to facilitate enrolment of clinical trials across health services in South Australia.**
- 21. One of the roles of an AYA Cancer Care Coordinator should be to maintain open communication with adolescents and young adults with cancer to address issues around compliance, adherence, risk-taking behaviour and provide education and information regarding the individual's health care needs.**
- 22. In the case of persistent low or declining adherence, regular multidisciplinary team reviews/updates involving mental health team members should occur and consultation with mental health professionals should be sought.**

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## 8. FOLLOW-UP AND SURVIVORSHIP

### 8.1 End of treatment

The end of treatment is recognised as one of the most stressful times in an adolescent and young adult's cancer journey. Frequent visits to cancer treatment facilities and medical reviews no longer occur, and the reassurance that these visits provided ceases. The adolescent or young adult no longer has a 'sick' role, but is often not yet well enough to return to their life pre-cancer. Priorities have also often changed since the initial cancer diagnosis and treatment, adding to the challenge of returning to a normal life. Support services are essential at this stage to help with this transition back into normal life. A psychosocial assessment and psychosocial multidisciplinary team meeting is required at the end of treatment to identify needs, determine strategies and help the patient face the next stage of their cancer journey.

Available literature indicates that the majority of adolescent survivors of cancer in childhood carry the burden of their illness and treatment experience into their teen and young adult years. There is a need to continue to anticipate these difficulties and develop strategies to support young people.<sup>95</sup> Psychosocial care should continue post-treatment for a period of time agreed on by the psychosocial multidisciplinary team to assist adolescents and young adults in their return to 'normal life'.

Barriers to optimal health care of survivors include survival-related and physician-related factors. Survivors are often not aware of potential late effects of treatment and future health risks, and often do not know the details of their cancer and their cancer therapy. Physician-related barriers include a lack of capacity for survivor care within cancer health services, a lack of familiarity by primary care physicians of issues for adolescent and young adult cancer patients, and limited communication between cancer centres and primary care physicians.<sup>96</sup> At the end of treatment, every adolescent and young adult cancer patient should be provided with a summary of their treatment, including any expected late effects. End-of-treatment resources have been developed<sup>97</sup> and should be available to all adolescent and young adult cancer patients and their primary care providers.

## 8.2 Follow-up care

A major focus of cancer survivorship is long-term follow-up. This has several purposes,<sup>98</sup> including:

- monitoring for the late effects of cancer treatment (which may affect up to two-thirds of survivors)
- providing health-related teaching to patients and their families that emphasises health maintenance and prevention of future health problems
- educating clinicians (especially community-based practitioners) about the health care needs of cancer survivors
- conducting research on the late effects of cancer and its treatment.

Several long-term follow-up guidelines have been developed to aid in the care of cancer survivors,<sup>99,100</sup> and several long-term follow-up clinics have been established, mainly within the paediatric setting. In the USA, almost 90% of long-term follow-up programs do not provide continuing care for survivors over the age of 21 years. In Australia, the upper admitting age of paediatric hospitals is usually 18 years or less. Bleyer and other notable AYA cancer specialists recommend transitioning of medical care from long-term follow-up programs to primary care physicians.<sup>101</sup> This model provides linkages to enhance risk-based care. However, patients at high risk of complications should continue to be seen regularly at long-term follow-up clinics, and collaboration needs to exist between primary care physicians and cancer specialists. In general, late effects clinics should be a routine part of standard of care for adolescent and young adult cancer patients, and should be based within the adult services where investigation of potential problems and specialist review can occur if required.

## 8.3 Healthy lifestyle

Anecdotal reports suggest that risk taking behaviour is a common problem in survivors of AYA and childhood cancers. The “*I survived cancer, I can survive anything*” mentality, combined with the adolescent sense of invincibility, can lead to tragic consequences. Risk taking behaviour in relation to health care also exists. Childhood cancer survivors are less likely to be smokers and binge drinkers than the population controls of the same age and gender, however, almost one quarter of survivors reported being a smoker or binge drinker.<sup>102</sup> Further research is required to understand why these individuals are adopting unhealthy behaviours despite their risk for late effects, and to design interventions to minimise harm and promote positive lifestyle behaviours. The frequent contact that

adolescents and young adults with cancer have to health professionals should be utilised to provide information on healthy lifestyle choices in the future<sup>103</sup>.

### Smoking prevention strategies

The following table outlines the steps for health care professionals Health care Provider - Delivered Smoking Prevention and Cessation in Paediatric Cancer Patients.

**Table 3: Health care provider-delivered smoking prevention and cessation in paediatric cancer patients<sup>104</sup>**

|                  |  |
|------------------|--|
| Basic steps      | <ul style="list-style-type: none"> <li>• Ask about past and current tobacco use at each medical visit</li> <li>• Advise about health risks associated with tobacco use</li> <li>• Emphasize short-term negative social consequences of smoking</li> <li>• Encourage abstinence/cessation</li> <li>• Establish signed agreement for abstinence/cessation</li> <li>• Discuss resistance/refusal skills or provide self-help literature, discuss behavioural smoking cessation strategies, and establish quit dates</li> <li>• Arrange follow-up telephone contact or return visit</li> </ul> |
| Additional steps | <ul style="list-style-type: none"> <li>• Inform of acute complications of tobacco use during therapy</li> <li>• Inform of chronic complications of tobacco use after therapy</li> <li>• Explain increased risk of adverse health effects relative to healthy peers</li> <li>• Provide personalized risk information relative to treatment history</li> <li>• Address accuracy of perceived health risks</li> <li>• Discuss smoking behaviours of family members and social networks or social support for quitting</li> </ul>  |

#### Recommendations:

**23. Health care providers should routinely incorporate enquiries about patients' lifestyle choices, including risk-taking behaviours and health-promoting behaviours (e.g. exercise, nutrition), into consultations.**

### 8.4 Transitional care

Transitional care is defined as the continuum of care that begins during a patient's paediatric care and ends as the patient safely and securely finds their place in the adult health care system.<sup>105</sup> This process is described well by Bleyer *et al.*<sup>106</sup>

*"There is the paediatric world this adolescent cancer patient is expected and trying to leave behind, and there is the adult world ahead that presents inordinate challenges and*

*stresses. Under the best of circumstances this transition is one of the most difficult, if not challenging, in life.”*

Transition to adult health care services is, however, not just a transfer of place. It is also a change in orientation from family-centred to individually focused services.<sup>107</sup> The importance of transition for an adolescent and young adult patient is now recognised, and a policy statement on the transition to adult health care for adolescents with chronic conditions has been developed by the Royal Australasian College of Physicians.<sup>108</sup>

Several adolescent chronic disease transition models have been proposed. Research suggests that successful transition of care correlates with beginning the process very early, empowering the adolescent with knowledge and self-responsibility, preparing the survivor, parents and paediatric care providers well in advance, and establishing a transition plan that addresses continuation of appropriate medical care, as well as financial, educational and vocational guidance.<sup>109</sup> The On-Trac model of transition involves early, middle and late transitional stages, and occurs slowly over years in line with the adolescent’s developmental stage.<sup>110</sup> A similar approach has also been used by the Royal College of Nursing in the UK.<sup>111</sup>

The plan for transition needs to take into account the patient’s individual needs, their specific disease and treatment requirements. The AYA Cancer Care Coordinator would play a vital role in supporting the patient at this stage and working with them to develop a specific plan that will ensure a smooth transition. Ideally, an AYA oncologist would be well placed to support this process. Transition planning needs to occur early, and importantly, at a stage in the individual patient’s care where their health needs are stable.

### **Transition to palliative care**

The international literature suggests 10–40% of adolescents with primary oncological disease will progress ultimately to palliation.<sup>112</sup> Adolescent and young adult palliative care patients in South Australia are cared for by every adult metropolitan palliative care service (inpatient and community) and many regional community nursing services, yet limited resources are available for respite and terminal care. These patients frequently face complex symptomology.<sup>113</sup> Home care may be perceived as a potential significant burden on parents, peers and partners, yet home care is often the preferred option for adolescents and young adult patients for a number of reasons that include the young person’s desire to remain at home and, at times an active rejection of transfer to a hospice or hospital.<sup>114</sup>

Current experience in South Australia has taught us that it is very difficult to transition patients from paediatric to adult services at the time of relapse/palliation, highlighting the need for good transition care planning. Transition specifically seeks to recognise the significance of transfer from the paediatric palliative to adult palliative care setting, slowly building up young people to transition, ensuring services are in place and working as closely to transition care framework as able ([www.act.org.uk](http://www.act.org.uk)).<sup>115</sup> NOT AVAILABLE

Referral barriers, stigma surrounding palliation and the difficulties with the cure/palliation interface may be overcome by integrating palliative and active treatment through continuity of care model. The *OnTrac@PeterMac* project at the Peter MacCallum Cancer Centre in Victoria is currently examining the role of AYA palliative care nurses employed within the AYA cancer service to ensure seamless transition and liaison between hospital and community multidisciplinary teams for adolescent and young adult cancer patients with a poor prognosis at diagnosis.

When communicating with this small but unique group of young people and their families open, honest communication is vital, as is the offer of involving them, where possible, in decisions about their life and ongoing treatment. Whilst each palliative adolescent and young adult cancer patient will have individual needs, end-of-life decision-making tools, such as Five wishes<sup>116</sup> could be used to facilitate this process.

A bereavement care plan detailing ongoing support for the patient's partner, parents or identified other should be developed prior to or in the early days following the patient's death and should include detail of the frequency of contact and the role of face-to-face and telephone support. This plan should include referral to an established directory of appropriate community supports, grief and loss organisations and other relevant resources. As many adolescent and young adult patients access peer supports it is also important for this population that permission is sought so that individuals close to the patient within the peer support networks can be informed by a trusted person in a sensitive and timely manner.

The impact on health care professionals (e.g. oncology, palliative care and community health teams) caring for an adolescent and young adult person at the end of life should not be underestimated. Resources should be in place to ensure adequate staff training and optimal psychological support is available and provided as required.

**Recommendations:**

- 24. At the end of treatment, every adolescent or young adult cancer patient requires a psychosocial assessment and discussion at the AYA psychosocial multidisciplinary team meeting to aid transition back into normal life**
- 25. An end-of-treatment summary, including expected late effects of treatment, should be provided to all adolescent and young adult cancer patients and their primary care physicians.**
- 26. Late effects clinics should be established as standard of care for all adolescent and young adult cancer patients, and should be situated within adult health services where investigation of potential problems and specialist review can occur if required.**
- 27. Transition planning should commence early in an adolescent or young adult cancer patient's care and should be appropriate to the individual's disease, treatment and developmental stage. Optimal transition care occurs when the patient's cancer and health care needs are stable.**
- 28. An AYA Cancer Care Coordinator is essential in planning and supporting adolescents and young adults with cancer and their families during transition.**
- 29. A dedicated AYA oncologist across health services would aid in supporting transitional care between paediatric and adult health care services.**
- 30. 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.**
- 31. Age-appropriate respite and palliative care beds are required for adolescent and young adult cancer patients.**
- 32. Adolescent and young adult palliative care cancer patients should be involved in decisions about their end-of-life care.**
- 33. The caregiver burden associated with the provision of adolescent and young adult palliation should be recognised, prioritised and proactively addressed.**
- 34. Bereavement planning is essential for family members of adolescent and young adult cancer patients.**
- 35. 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.**

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## **9. SUPPORTIVE AND PSYCHOSOCIAL CARE**

Management of AYA cancers is associated with many complex supportive care issues, both medical and psychosocial, that require assessment and attention. The need for resources to effectively assess and manage these factors will change depending on the stage of the patient's cancer journey. There is a need for frequent re-evaluation and support, which may be well provided by an AYA Cancer Care Coordinator, members of the psychosocial multidisciplinary team, and all health care professionals involved in the care of adolescents and young adults with cancer.

### **9.1 Psychosocial assessment**

Transition through adolescence and young adulthood involves a set of unique developmental tasks. These include the completion of growth and pubertal development, the completion of identity formation, the development of abstract thinking, the challenges of achieving educational success, personal and financial independence from parents, and beginning intimate relationships with others.<sup>117</sup>

Psychosocial assessment primarily seeks to understand the psychosocial functioning of the patient and assist with care planning, including specific patient wishes in relation to the medical treatment plan. It also seeks to elicit and build upon the individual's self-identified strengths and supports. Routine assessment includes addressing the factors listed in Table 4. Psychosocial assessment should be undertaken close to diagnosis with reassessment at appropriate intervals to determine the impact of the cancer journey on the patient. Psychosocial assessment and resources should be available regardless of where the treating health service is and whether the patient is receiving care in the public or private system.

An identified best-practice psychosocial assessment tool specifically designed for adolescents and young adults with cancer should be utilised by a trained AYA health care professional. Currently, the AYA cancer care team utilise the AYA psychosocial assessment tool developed by onTrac@PeterMac (originally adapted from HEADDS tool Goldenring & Cohen 1998) (see Appendix F). An evidence-based symptom burden tool should accompany the assessment.

**Table 4: Psychosocial factors requiring consideration when supporting adolescents and young adults with cancer**

|                                     |  |
|-------------------------------------|--|
| Fertility                           | Body image                             |
| Psychosocial or mental health input | Complementary or Alternative therapies |
| Access to care                      | Nutrition/exercise/drugs/alcohol       |
| Vocation/Education                  | Self esteem                            |
| Relationships                       | Spirituality/culture                   |
| Finances                            | Independence/dependence                |
| Peers                               | Sexuality                              |
| Partners                            | Compliance                             |
| Parents                             | Supports                               |

### **Role of the AYA Cancer Care Coordinator**

Care coordination is essential to improving the delivery of AYA cancer care and seeks to enhance the experience of the patient and family during diagnosis and treatment. Care coordination should occur concurrently at both at a systems level (service development, policy, procedure) and at a clinical level (assisting adolescents and young adults in navigating the health care system).

The Cancer Nurses Society of Australia (CNSA) has released a position statement outlining key components integral to cancer care coordination from a system, organisation and team level<sup>118</sup> and highlights the need for system change to support consumer need. The *National Service Delivery Framework for Adolescents and Young Adults with Cancer*<sup>119</sup> outlines the role of the key clinical worker (in South Australia this is the AYA Cancer Care Coordinator) as:

- providing navigation throughout the entire cancer journey
- undertaking comprehensive assessment
- attending medical and psychosocial multidisciplinary team meetings
- empowering young people to make informed decisions
- acting as a resource for clinical questions
- liaising across network boundaries.

Consistent with the CNSA care coordination position statement, the South Australian AYA Cancer Care Coordinator job description includes:

- advocacy
- resource mobilisation

- timely referral
- provision of information and education for both consumers and health care professionals
- facilitation of the delivery of care consistent with established evidence-based guidelines.

## 9.2 Fertility

Fertility and its preservation has been identified as an important issue for adolescents and young adults with cancer. Infertility is functionally defined as the inability to conceive after 1 year of intercourse without contraception.<sup>120</sup> The American Society of Clinical Oncology (ASCO) recognises that the role of the oncologist in advising patients about fertility preservation options includes:

- a. discussion of infertility as a potential risk of therapy
- b. answering basic questions about whether fertility preservation options decrease the chance of successful cancer treatment, increase the risk of maternal or perinatal complications, or compromise the health of offspring
- c. referral of patients, as needed, to reproductive specialists and psychosocial providers.<sup>121</sup>

Unfortunately, fertility preservation and treatment options are often costly, with minimal rebate from the current Medicare health system. These often substantial costs come at a time when adolescents and young adults are striving to become independent, often with limited financial resources available to them. Beginning a family is often something the adolescent or young adult has not considered, and therefore is not high on their priority list. Embarrassment about discussing topics related to sexuality also exists, which prevents many individuals from raising the topic voluntarily. Many do, however, value the opportunity to address these issues, and health care providers should be aware of this and offer opportunities for discussion.

Canadian data suggest that utilisation of fertility preservation options is limited for adolescent and young adult cancer patients. Neal et al. (2007) showed that only 17.8% of newly diagnosed male cancer patients, aged 14–30 years, used sperm cryopreservation technology<sup>122</sup>

Confusion also exists for health care professionals. Although there are excellent publications outlining the effects of cancer therapies on fertility and possible treatment

options, the availability of these treatment options vary from state to state. It is currently unclear:

- which fertility treatment options are considered standard and are available in South Australia
- how to access fertility preservation and treatment options
- who in the available services has experience in dealing with relatively young cancer patients
- how to refer a patient who needs to begin their cancer treatment urgently.

One of the aims of the AYA Working Party has been to improve knowledge in this area. A standardised South Australian (statewide) AYA cancer fertility referral form has been developed, in conjunction with Repromed and Flinders Reproductive Medicine (see Appendix G) as well as information sheets on the referral process and steps involved in assessment (see Appendix H, I, J). These identify a point of contact for each facility to streamline the referral process for all adolescent and young adult cancer patients, and act as a source of information about the steps involved in assessment of individuals in this age group with a cancer diagnosis and the health care professionals managing their care. Information about the effects of cancer treatment on sperm production in males (Appendix K) and on menstrual function in females (Appendix L) has been collated, and charts outlining the fertility preservation options available in South Australia and their associated costs have been developed for both males (Appendix M) and females (Appendix N).

This information needs to be freely accessible in a web-based format for both patients and health care providers. Although fertility resources are currently being developed nationally, additional information specific for South Australian services needs to be developed in age-appropriate language and communication styles.

Following an adolescent or young adult patient's consultation for fertility preservation - The attending service ideally generates correspondence back to the referring health care providers and treating specialists outlining what options are available and any follow up required. Many patients do not return to the fertility service for a fertility assessment once they have completed cancer treatment. However, this is important, as it provides an opportunity to gain further information about how their fertility has been affected and, if tissue or sperm samples were obtained for preservation, to decide on the need for long-term storage. This follow-up appointment should be conducted 1 year after cancer treatment is completed. The current recall system requires review. Ideally, this process should involve the treating specialist to avoid contacting patients and families who have

not responded to treatment or have died during treatment. Clear guidelines are also required to determine what happens to stored tissue samples following a patient's death to avoid additional stress and trauma for family members.

### **9.3 Sexual health**

Contraceptive and sexual health needs of adolescents and young adults undergoing cancer therapy must be addressed as a separate issue from fertility preservation. Sexual health is a topic that is not discussed openly in this age group, and questions often remain unanswered unless health care providers are able to provide information in a non-threatening manner.

The median age for first sexual intercourse is now 16 years in most industrialised countries, and over 50% of young adults remain fertile after their cancer treatment.<sup>123</sup> Provision of adequate age-appropriate and relevant information should be freely available from staff taking care of adolescent and young adult cancer patients. Many younger patients may find it too confronting or personal to discuss this topic, and therefore practical written information in the form of pamphlets or brochures should be easily accessible in the treatment setting and in a web-based format.

Sexual health counselling may be undertaken at the time of the patient's fertility assessment appointment, although other organisations in South Australia such as Shine, Second Story, and Family Planning clinics also specialise in this area. The health care team working with adolescent and young adult cancer patients should strive to develop close working relationships with family planning and sexual health counselling services.

The literature recommends the use of physical barriers such as condoms at commencement of chemotherapy until 48 hours post completion following chemotherapy administration<sup>124</sup>. These protective measures apply to both the AYA receiving chemotherapy and their sexual partner. Mandatory pregnancy testing for all potentially sexually active female AYAs following appropriate discussion and prior to commencement of treatment is recommended.

### **9.4 Education**

Education regarding the management and support of adolescents and young adults with cancer is required for all health care professionals. A survey performed in the UK demonstrated that 50% of teenagers with cancer felt that information provided to them regarding their cancer and its treatment was not suitable for their age group.<sup>125</sup> Health

professionals require appropriate communication skills, addressing the patient instead of their family or parents and providing information in a language appropriate to the patient's age and level of education. Education materials should also be available to ensure that all health professionals working with patients in this age group are aware of their unique needs. Currently, there is a lack of training in AYA cancer care however, there may be nationally in 2010. Currently, the Teenage Cancer Trust in the United Kingdom in conjunction with Coventry University and young people with personal experiences with cancer, have developed multidisciplinary postgraduate studies at certificate, diploma and masters levels able to be taken online internationally - although they attract considerable cost for students<sup>126</sup>

### 9.5 Medical supportive care

There are many medical aspects of supportive care that require consideration for cancer patients (Table 5). Standard operating procedures should be adhered to when providing medical supportive care, for example, guidelines regarding the management of episodes of febrile neutropenia, and when to administer blood product transfusions.

**Table 5: Medical factors requiring consideration when supporting adolescents and young adults with cancer**

|                        |                      |
|------------------------|----------------------|
| Reviewing when unwell  | Exercise             |
| Access to venous lines | Nutrition            |
| Blood transfusions     | Drugs and alcohol    |
| Analgesia requirements | Mental health access |
| Nausea and vomiting    | Sexual health        |
| Dental care            |                      |
| Rehabilitation         |                      |

Adolescents and young adults with cancer have some specific needs in relation to medical supportive care. Once treatment has commenced, the referral path into hospital for a patient who is unwell can often be confusing and time consuming. A pocket-sized treatment card containing necessary information, such as diagnosis, treatment plan, blood group and specialists involved in the patient's care, may help to facilitate this process. A treatment summary based on the discussions at medical and psychosocial multidisciplinary team meetings should also be available in the case notes to aid assessment of the patient. A copy of the treatment summary should be given to the patient for presentation when seeking medical care outside the treating health service.

### **Venous access devices**

Appropriate assessment for venous access is required for all adolescent and young adult cancer patients to ensure that central venous access devices are appropriate for the treatment intensity and lifestyle. Skilled staff and theatre time/radiology intervention time is required for the insertion and removal of these lines in a timely manner. Written instructions should be provided to the patient, including information on regular line care and emergency line management in the case of an adverse event. All equipment required to manage regular and emergency care should be provided. Comprehensive discharge planning is required to ensure that other health services or community-based health services are informed and equipped to provide regular and emergency central venous access device care.

### **Blood transfusions**

Adolescent and young adult cancer patients often have concerns regarding the risks associated with any blood transfusions they may require, and often request information on directed donations and autologous transfusions. Verbal and written information on these should be provided. This information is available from the Australian Red Cross Blood Service.

### **Pain management**

It is recommended that the World Health Organization guidelines for cancer pain relief and analgesic ladder are followed as these are well established systematic approaches to pain control. It is important to recognise that for adolescents and young adults, recurrent procedures, such as bone marrow biopsies or lumbar punctures, may cause anxiety and therefore increased pain. Psychological input to manage anxiety, and use of complementary therapies, such as meditation and hypnotherapy, may be of benefit and should be made available if required.

### **Nausea and vomiting**

Anticipatory nausea and vomiting is a common problem in adolescents and young adult cancer patients and it is therefore extremely important to provide the patient with adequate anti-emetic cover prior to first administration of emetogenic chemotherapy.

### **Dental care**

Dental care in adolescents and young adults is vitally important. This age group is at risk of dental disease without the additional burden of cancer treatment. Adolescents and young adults have often left the care of the school dental service, are often non-compliant

with ongoing dental care, and may no longer be covered by the family private health care fund. The often substantial financial costs of treatment also contribute to poor dental hygiene. Dentistry in cancer care involves supportive and therapeutic care. Toxic reactions in the oral cavity can limit the amount of therapy delivered, and mucositis from chemotherapy or radiotherapy can lead to dose reductions and interval delays, malnutrition or systemic infections.<sup>127</sup> The group most at risk from failure of dental services is young adults who have received radiotherapy to the mandible or maxilla or total body irradiation followed by bone marrow transplantation. All adolescents and young adults require dental assessment prior to commencing chemotherapy or radiotherapy treatment, and regular ongoing check-ups should become a standard in routine cancer care.

### **Rehabilitation**

All adolescents and young adults with cancer should have access to appropriate rehabilitation services if required. This includes speech and language therapy, physiotherapy, occupational therapy and psychology services. These service providers should be non-core members of the psychosocial multidisciplinary team. Exercise is also an important part of rehabilitation, and being able to participate in physical activities and usual hobbies is an important factor in maintaining self esteem for patients in the AYA age group. Exercise programs and an emphasis on holistic health care should be considered an important part of the patient journey and appropriate facilities should be available for this to occur. Development of a resource that lists suitable exercise tools for use during treatment would be beneficial.

### **Diet**

Adolescents and young adults, along with all cancer patients, should be encouraged to maintain optimal nutrition during their cancer treatment. They may require access to dietetic support and supplemental feeding, and access to these services needs to be equitable across all health care services, including the public and private sectors. Many adolescents and young adults have concerns about their diet and the need to stay healthy, and this often conflicts with their increased caloric requirements. It is well recognised that chemotherapy affects taste buds, yet the changes this causes in diet are not well addressed in the health care system. Food is often not available within the hospital at times when adolescents and young adults prefer to eat, as they often wake late and stay up well into the night.<sup>128</sup> There are also cultural issues with the foods available within the health care system, with individuals from differing ethnic backgrounds finding it difficult to adapt to the Australian hospital diet.

Adolescence and young adulthood is a time where experimentation with alcohol and/or drugs typically occurs. However, there is very little information available regarding interactions with chemotherapy, and patient resources need to be developed on this topic. Support from drug and alcohol services is often required, yet access is limited.

**Recommendations:**

- 36. Every newly diagnosed adolescent and young adult with cancer in South Australia should be referred to the AYA Cancer Care Coordinator for an initial and ongoing age-appropriate psychosocial assessment.**
- 37. Individuals employed in AYA Cancer Care Coordinator roles should have the appropriate skills and experience or should be provided with training to meet the requirements to fulfil the role.**
- 38. All adolescent and young adult cancer patients require referral for discussions about fertility assessment and counselling on sexual health and contraception. Consent for referral to fertility, sexual health and contraception services should be obtained from the patient (not the parents).**
- 39. A recall system should be developed to ensure that adolescent and young adult cancer patients utilising fertility preservation services have a follow-up appointment 1 year post-cancer treatment. This system should include the treating specialist to avoid sensitive recall errors.**
- 40. Introduction of mandatory pregnancy testing should be implemented as standard care during cancer pre-treatment workup in females of childbearing age.**
- 41. Printed and web-based education resources on fertility preservation and sexual health should be accessible for adolescent and young adult cancer patients within all cancer treatment settings.**
- 42. Health care professionals working with adolescent and young adult cancer patients should undertake and teach necessary clinical skills for working with this population, particularly in the area of communication.**
- 43. The complex supportive care issues (both medical and psychosocial) faced by adolescent and young adult cancer patients should be recognised, assessed and managed. The need for resources to deal with these factors will change depending on the stage of the patient's cancer journey. There is a need for frequent re-evaluation and support by all members of the multidisciplinary team.**
- 44. Equitable access to anti-nausea medications is required across all health care services inclusive of public and private sectors in South Australia.**

<sup>117</sup> Fallon S *et al.* 'Pizza, patients and points of view': Involving young people in the design of a post registration module entitled the adolescent with cancer. *Nurse Education in Practice* 2008;8:140-147.

<sup>118</sup> Cancer Nurses Society of Australia. *Position statement for Cancer Care Coordinators*. CNSA March 2008

<sup>119</sup> *National Service Delivery Framework for Adolescents and Young Adults with Cancer*. Draft for discussion 2008. Australian Government, Cancer Australia, CanTeen

<sup>120</sup> Bowering S Personnel communication April 6 2008. Paediatric Palliative Care Nurse Consultant South Australia

<sup>121</sup> Neal M. (2007) Effectiveness of Sperm Banking in Adolescents and Young Adults with Cancer, A Regional Experience. *Cancer* Sep 1; 110(5):1125-1129

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- <sup>124</sup> Cancerbackup.org.uk
- <sup>125</sup> Berg J, Bleyer A. Pediatric dentistry in care of the cancer patient. *Pediatric Dentistry* 1995;17(4):257-258.
- <sup>126</sup> *ibid*
- <sup>127</sup> Lewis H. *Telling it like it is*. DVD Dec 2007.

## 10. COMPLEMENTARY THERAPIES

Many adolescents and young adults are interested in the use of complementary medicines and complementary care, and often use them to aid their cancer treatment. Clinicians need to be aware of this, and should routinely ask about their use. Adolescents and young adults should be made aware of any potential interactions with their chemotherapy or radiotherapy treatment. Open discussion regarding the use of complementary medicines should be encouraged.

The term 'complementary' therapies encompass a range of approaches to care aimed at enhancing quality of life and improving wellbeing. They may be used alongside standard evidence-based medical (conventional) cancer treatments such as surgery, radiotherapy, chemotherapy, hormonal therapies or targeted therapies. Complementary therapies include acupuncture, relaxation therapy and meditation, exercise, guided imagery, music or art therapy, massage, aromatherapy, dietary therapies including herbal supplements and some support group programs.

It is important that the primary treating team is aware of complementary therapies, to recognise the potential for impact in the clinical setting<sup>128</sup> and to promote open discussion with their patients.<sup>129</sup>

It is also important to distinguish between complementary and alternative therapies. Alternative therapies are used instead of standard evidence-based medical cancer treatments. There is no evidence to support the use of alternative therapies in the treatment of cancer.

### 10.1 How complementary therapies may help cancer patients

Complementary therapies are, in general, intended to support wellbeing and are not considered treatments for cancer. A number of complementary therapies have not been tested in large well-conducted clinical trials, so information on their effectiveness and safety may be limited.

There have been many studies using complementary therapies involving patients with cancer. Despite no evidence of impact on survival, benefits have been demonstrated in symptom management and coping with side effects associated with standard medical cancer treatments.<sup>130</sup> Beneficial effects reported for some complementary therapies include:<sup>131</sup>

- reducing pain or the use of analgesia
- promoting relaxation
- improving sleep
- improving the sense of wellbeing
- reducing stress, anxiety and depression
- improving overall coping capacity
- providing a feeling of self worth; of being cared for after what can be harsh effects of standard medical treatment.

However, some complementary therapies can interact with standard medical cancer treatments and make them less effective. Others may actually be harmful if taken with standard medical treatments.

## **10.2 Discussing complementary therapies with patients and/or caregivers**

It is essential for health professionals to create an atmosphere in which a patient is encouraged to talk openly about complementary therapies in the context of the overall health care plan, and is informed of possible risks of interactions with standard medical cancer care.

Patients seeking complementary approaches to their care should be encouraged to ask questions of any complementary health practitioners they consult to ensure the appropriateness and safety of their care. Questions may include:

- what is your training?
- exactly what is the therapy you are proposing?
- what do you hope it will do?
- what is the evidence for the success of this therapy?
- what side effects could there be?
- how common are the side effects?
- will this therapy affect other treatments I am receiving?
- how much will this therapy cost?

### **Information for patients and caregivers**

Cancer Council Australia makes the following statement to people on their website:

*‘The Cancer Council Australia urges people with cancer to remain in the care of qualified doctors who use proven methods of treatment and participate in clinical trials of promising new treatments. If you are using, or considering, a complementary or alternative*

*treatment, it's important to discuss it with your doctor or call the Cancer Helpline for advice.*

*If you are thinking about using any other method instead of evidence-based medical treatment, you should carefully consider and investigate the claims made and any evidence for those claims, the credentials of the people or organisation promoting the treatment, the costs and the potential risks of delaying conventional treatments.'*<sup>132</sup>

This webpage also includes questions to consider when deciding whether to access non-conventional therapies.

The American Cancer Society (ACS) recommends the following checklist to flag approaches or therapies that might be open to question:

- Is the treatment based on an unproven theory?
- Does the treatment promise a cure for all cancers?
- Are you told not to use conventional medical treatment?
- Is the treatment or drug a "secret" that only certain providers can give?
- Does the treatment require you to travel to another country?
- Do the promoters attack the medical/scientific establishment?

The ACS advises that *'if the answer to any of these questions is 'yes', you should carefully consider whether the proposed treatment is of any value.'*<sup>133</sup>

### **Further information/resources**

- Cancer Council resources on complementary care are available online or by phoning the Cancer Helpline (131120):
  - Cancer Council Victoria brochure: 'Complementary and alternative cancer therapies – for people with cancer, their family and friends'.  
[www.cancervic.org.au/downloads/brochures/CISS\\_brochures/Complimentary\\_Altern\\_therapies1.pdf](http://www.cancervic.org.au/downloads/brochures/CISS_brochures/Complimentary_Altern_therapies1.pdf)
  - Cancer Council NSW brochure: 'Understanding Complementary Therapies'.  
[http://www.cancercouncil.com.au/html/patientsfamiliesfriends/livingwithcancer/complementary\\_therapies/downloads/complementary\\_therapies.pdf](http://www.cancercouncil.com.au/html/patientsfamiliesfriends/livingwithcancer/complementary_therapies/downloads/complementary_therapies.pdf)

## Useful web sites on complementary and alternative therapies

- Quackwatch at is an international network of people who are concerned about health-related frauds, myths, fads, fallacies, and misconduct. The website has a search engine of therapies and services. <http://www.quackwatch.com/>
- The Memorial Sloan Kettering Cancer Center (US) webpage 'About Herbs, Botanicals & Other Products' at [www.mskcc.org/mskcc/html/11570.cfm](http://www.mskcc.org/mskcc/html/11570.cfm) provides objective information for oncologists, health care professionals, and consumers. *Note: this is an American website and not all of the products listed may be available in Australia.*
- The National Cancer Institute (US) 'Complementary and Alternative Medicine' web pages at <http://www.nci.nih.gov/cancertopics/treatment/cam> provide information summaries for health professionals that are comprehensive, peer-reviewed and evidence-based.
- The National Cancer Institute (US) 'Complementary and Alternative Medicine' web pages at <http://www.cancer.gov/cancertopics/pdq/cam/cam-cancer-treatment> are written in less technical language and are suitable for patients, their families and caregivers.

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<sup>128</sup> Sanderson C, Koczwara B, Currow D. The "therapeutic footprint" of medical, complementary and alternative therapies and a doctor's duty of care. *MJA* 2006; 185(7):373- 376.

<sup>129</sup> Cassileth B, Rockefeller S. New Developments in the Realm of Complementary Medicine. *The Journal of Supportive Oncology* 2005; 3(3):238-245.

<sup>130</sup> MAPCARE. *Palliative care resource, 2007*. [www.mapcare.org.au/pdf/2.Complementarytherapies.pdf](http://www.mapcare.org.au/pdf/2.Complementarytherapies.pdf) NB No longer available on this webpage.

<sup>131</sup> Ibid .

<sup>132</sup> Cancer Council Australia <http://www.cancer.org.au/aboutcancer/complementaryandalternativetherapies.htm> (accessed July 2009)

<sup>133</sup> American Cancer Society <http://www.cancer.org> (accessed July 2009)

## 11. FINANCIAL STATUS

Diagnosis and treatment for cancer impacts greatly on an individual's ability to work and maintain financial independence. Faced with this loss of financial independence, many adolescent and young adult cancer patients find it extremely difficult to navigate their way through the maze of paperwork and regulations. This creates additional pressure and stress for the patient and their family, with many young people having to rely on parental financial support. Patients are often unaware of their financial entitlements through Centrelink or other grants from which they may be able to benefit, e.g. Austudy, Newstart. Tutoring schemes are also available to assess vocational needs and support study throughout the patients' cancer journey. Access to an AYA social worker as soon as possible after diagnosis is essential to ensure that adolescent and young adult cancer patients gain access to the full range of services that they are eligible for.

In the USA, there is emerging evidence that individuals who do not have adequate private health insurance present later for diagnosis and treatment.<sup>134</sup> This has not been looked at specifically in Australia. Access to AYA cancer care and support services within the health care system should be equal regardless of financial or health insurance status. This is potentially complicated with regard to fertility preservation services which in South Australia are currently predominately located in the private sector and can be associated with considerable costs to patients.

The end of treatment marks a significant change in a cancer patient's role, and is a time that often produces a great deal of stress. Returning to paid work is often an important milestone for patients and can be seen as an important part of the transition from patient to survivor.<sup>135</sup> However, little help is provided to ensure the transition back to work or study is not too overwhelming, or that expectations and goals are appropriate. Support from the AYA team post-treatment is necessary for many adolescents and young adults who are returning to paid work and normal life, given that supportive relationships will already have been built between the patient and team.

Financial assistance for cancer survivors in the AYA age group needs to be integrated into a survivorship plan.<sup>136</sup> The financial hardship experienced during treatment can be prolonged, and many individuals need help in setting up and adjusting their long-term goals and commitments. Long-term goals, employment or study prior to diagnosis may no longer be desirable or appropriate for some individuals, with new life goals commonly

developing as a result of a cancer diagnosis or its treatment. Financial support for adolescent and young adult cancer patients may be needed in order to help the patient develop and achieve their goals and this should be addressed in the survivorship plan.

**Recommendations:**

- 45. Access to an AYA social worker as soon as possible after diagnosis is essential to ensure that patients in this age group have access to the full range of financial and vocational support services for which they are eligible.**
- 46. Access to AYA cancer care and support services within the health care system should be equal regardless of financial or health insurance status.**
- 47. Financial assistance for adolescent and young adult cancer survivors should be integrated into a survivorship plan.**

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<sup>134</sup> Martin S *et al.* Delays in Cancer Diagnosis in Underinsured young adults and older adolescents. *The Oncologist* 2007;12:816-824.

<sup>135</sup> Amir Z *et al.* Cancer survivors' views of work 3 years post diagnosis: A UK perspective. *European Journal of Oncology Nursing* 2008;12:190-197.

<sup>136</sup> Thomas DM. Adolescents and young adults with cancer: the challenge. *Palliat Support Care* 2007 Jun;5(2):173-4.

## **12. NEEDS OF SPECIFIC POPULATIONS**

### **12.1 Patients living in rural and remote locations**

Within South Australia, all tertiary cancer treatment centres are located in metropolitan Adelaide. Studies have shown that survival is best at centres with a critical minimum caseload, where the tumour expertise is located.<sup>137</sup> Country GPs are likely to see extremely small numbers of cancer patients in the AYA age group throughout their career. It is therefore critical that all cases of suspected invasive AYA cancer are referred to a centre of expertise for diagnosis and staging. In principal, it is recognised that what is required are age-appropriate, safe and effective services as locally as possible, not local services as safely as possible.

Referral links to expert services should be equal, regardless of location or whether the patient comes from an urban or rural setting. It is hoped that the '1800 AYA cancer referral line' will ensure timely referral and access to appropriate treatment.

As most adolescents and young adults with invasive cancer from rural areas need to relocate to Adelaide during treatment, it is essential that they are provided with adequate accommodation and support during this time. Relocation often means separation of family members for a period of time. It is highly likely that one or both parents or the patient's partner will need to remain in the rural or remote area for employment. Separation may also impact on siblings or the patient's own children and their involvement in local community networks (e.g. preschool, playgroup) and the education system. Patients of school age who attend non-metropolitan schools may also face changes to their study program and can be forced to take time off or consider options such as open access education. This places an additional emotional burden on all involved and the complexity of arrangements and needs requires the skills of a suitably experienced social worker and educational/vocational consultant.

### **12.2 Aboriginal and Torres Strait Islander Peoples**

Australia's Indigenous population is comprised of Aboriginal and Torres Strait Islander people. One in four Aboriginal and Torres Strait Islander people live in rural and remote regions of Australia. Aboriginal and Torres Strait Islander people are more likely to present with advanced illnesses and may have multiple co-morbid illnesses in addition to cancer

<sup>139</sup> 140138

The concept of health and wellbeing for Aboriginal and Torres Strait Islander people is a holistic one, encompassing all aspects of physical, emotional, social, spiritual and cultural wellbeing and a specific kinship with family.<sup>139,140</sup> Many Aboriginal and Torres Strait Islander people believe that wellbeing is determined socially, rather than biologically or pathologically.<sup>141,142</sup> Given the powerful role of traditional beliefs about illness and health, it is important when managing the health care of Aboriginal and Torres Strait Islander people to include the input of those who are familiar with their culture<sup>143</sup> and language and to incorporate specific understandings of the needs of those residing in rural and remote areas.

Staff with specific expertise in the management and support of Aboriginal and Torres Strait Islander patients are located in the larger metropolitan public hospitals. Aboriginal health nurses and Aboriginal hospital liaison workers are available to provide assistance following patient referral by the multidisciplinary team and to provide advice on culturally safe and respectful care. For more information and resources see Appendix O.

### **12.3 Culturally and linguistically diverse communities**

Australia has one of the most culturally diverse communities in the world. In 2004, one in four Australians was born outside Australia.<sup>144</sup> It is therefore essential to consider the culturally and linguistically diverse needs of all people in relation to diagnosis, treatment and management of cancer.<sup>145</sup>

All consumers/patients are individuals and require a person-focused approach to care. Health professionals should engage in respectful enquiry about preferences that intersect with health care, including religious or spiritual values, cultural values, gender preferences and dietary requirements. These aspects are connected to a successful health care experience and outcomes<sup>146</sup>

Within the culturally and linguistically diverse community, language barriers and lack of knowledge of the South Australian health care system limit access to health information and health care services.<sup>147</sup>

Cultural perspectives or preferences may include:<sup>148</sup>

- patient preference to see a medical professional of their own sex
- myths and misconceptions about cancer diagnosis

- cancer may be a taboo subject or cause discrimination, contamination, shame, or retribution
- religion may play a fundamental role in the person's attitude towards their disease and treatment
- patients may have perceptions attributed to pain and suffering.
- family (including extended family) have a central role in many cultures with family members often sharing the rights and responsibilities for decision-making, which may influence the choice of treatment.

Attitudes to caring and support may vary between and within cultures. It is important for health professionals not to make assumptions or stereotype individual patients. Patients should be encouraged to seek support from family and friends, and from community, ethnic and religious organisations, if appropriate. Regardless of cultural background, wherever possible, patients should be offered the opportunity to bring a family member or friend with them to consultations and treatment. People may not be accustomed to the concept of support from external agencies, so this requires a sensitive and respectful approach.

#### **Further information**

Appendix O lists key sources of information for South Australian people with cancer including services available for Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities.

#### **Recommendations:**

- 48. All adolescents and young adults from rural and remote areas of South Australia who are suspected of having invasive cancer should be referred to a metropolitan centre of expertise for diagnosis and staging in order to access age-appropriate, safe and effective services as locally as possible.**
- 49. All adolescents and young adults from a rural/remote area of South Australia who have a new diagnosis of cancer should be presented to the most appropriate metropolitan AYA multidisciplinary team for discussion, treatment planning and access to clinical trials. They should be represented if goals of care change (e.g. palliation) to ensure needs are accurately assessed and resourced prior to the patient returning to the rural/remote area.**
- 50. GPs in rural and remote South Australia should have easy access to information to streamline rapid referral to metropolitan specialists.**

51. Adolescent and young adult cancer patients from rural and remote areas of South Australia should be contacted by a social worker with appropriate skills in linking with support programs and provision of assistance with their specific travel and accommodation needs.
52. On completion of the treatment phase, adolescent and young adult cancer patients from rural and remote regions should be linked in with local GP and support services on their return home.
53. Qualified interpreting services are essential for people from culturally and linguistically diverse backgrounds to ensure equitable access to health care services.
54. All adolescents and young adults with a cancer diagnosis should have the opportunity to receive culturally appropriate information and counselling (via a qualified interpreter if appropriate) regarding their diagnosis, options and care needs by a health professional with appropriate communication skills and knowledge of issues for individuals in this age group.

<sup>137</sup> Thomas DM *et al.* Adolescent and young adult cancer: a revolution in evolution. *Intern Med J* 2006 May;36(5):302-307

<sup>138</sup> MAPCARE. *Palliative care resource, 2007*. [www.mapcare.org.au/pdf/2](http://www.mapcare.org.au/pdf/2). (NB No longer available on this webpage) Section 6 Aboriginal and Torres Strait Islanders.pdf

<sup>139</sup> National Aboriginal Health Strategy Working Party. *A National Aboriginal Health Strategy*. AGPS, Canberra, 1989.

<sup>140</sup> ABS and AIHW (Australian Bureau of Statistics and Australian Institute of Health and Welfare). *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander. Mental health and social and emotional wellbeing, 2004-2009*. ABS & AIHW, Canberra, 2001.

<sup>141</sup> National Aboriginal Health Strategy Working Party. *A National Aboriginal Health Strategy*. AGPS, Canberra, 1989.

<sup>142</sup> CALD steering committee for the Central Northern Adelaide Health Service. *Cultural and linguistic diversity, a resource for health staff*.

<sup>143</sup> *ibid*

<sup>144</sup> Australian Government Department of Health and Ageing, A Snapshot of Palliative Care in Australia. Commonwealth of Australia, ACT, 2003.

<sup>145</sup> CALD steering committee for the Central Northern Adelaide Health Service. *Cultural and linguistic diversity, a resource for health staff*.

<sup>146</sup> *ibid*

<sup>147</sup> Australian Department of Health and Ageing. *National Health Strategy*. Commonwealth of Australia, Canberra, 1993.

<sup>148</sup> National Breast Cancer Centre and National Cancer Control Initiative. *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, 2003.

### 13. CLINICAL TRIALS AND RESEARCH

The reduction in cancer mortality rate among 15–39 year olds has lagged behind the reduction in children and older adults. Survival and mortality rates have mirrored clinical trial accrual patterns, with little improvement compared with younger and older patients.<sup>149,150</sup> This is apparent in both males and females, in all ethnic groups, and for individual cancer types.

The relative lack of progress in treating cancer in adolescents and young adults is in part due to a lack of appreciation of the differences in the biology of malignant diseases in this age group relative to younger and older persons.<sup>151</sup> Whilst many clinical trials are available for paediatric and adult cancer patients, there is a noticeable lack of available clinical trials and research dedicated to the AYA age range and tumour biology.<sup>152</sup>

Access to, and treatment in, national clinical trials is of paramount importance in the AYA age group. In line with data from the USA, Mitchell *et al.* have shown that adolescents and young adults with cancer are poorly recruited into clinical trials in Victoria.<sup>153</sup> This is no doubt the situation across Australia. Canadian data also suggest that adolescents treated in an adult cancer centre are significantly less likely to be enrolled in a clinical trial compared with those treated in a paediatric centre.<sup>154</sup> Older adolescents are disadvantaged with respect to access to national clinical trials, regardless of their age or ethnicity.<sup>155,156</sup>

In the USA, only 5% of 15–25 year olds with cancer are entered onto clinical trials, in contrast to 60–65% of younger patients.<sup>157</sup>

To address the unique aspects of cancer in adolescent and young adult patients, the Children's Oncology Group formed the Adolescent and Young Adult Committee in 2000. The Children's Oncology Group is the largest childhood and adolescent cancer research and clinical trial network in the United States of America (USA) of which Australia and New Zealand are members. The Adolescent and Young Adult Committee is enhancing opportunities for participation in clinical trials by increasing the number of new trials available for this age group, including new combined therapeutic protocols with the adult co-operative groups. To date, combined protocols have been developed for sarcoma, melanoma, acute lymphoblastic leukaemia and Hodgkin's lymphoma.<sup>158</sup> Currently in South Australia, patients can only be treated on these protocols through the Women's and

Children's Hospital, limiting access to those patients greater than 18 years of age. An appropriate clinical trial principal investigator, as well as administration and data support is required to open these and other available clinical trials at other health services in South Australia.

Involvement in clinical trials may benefit participating adolescent and young adult patients, regardless of treatment outcome, at least in terms of quality of care and quality of life during trial participation. The additional rigor and quality of care provided through a clinical trial is an often unrecognised positive secondary gain of trial participation.<sup>159</sup>

A cancer clinical trials register has been established in South Australia by health professionals. The current website is:

[http://cancersa.org.au/asp/clinical\\_trials\\_search.aspx](http://cancersa.org.au/asp/clinical_trials_search.aspx).

However, this database is incomplete and does not include all trials offered by all health services that provide cancer care and age eligibility criteria need to be included. More administration and data support is required to keep the register updated and complete. A statewide central ethics approval process would also facilitate clinical trial establishment across health sites.

### **13.1 Research priorities in adolescents and young adults with cancer**

The Children's Oncology Group AYA committee has indicated that its research priorities include gaining a better understanding of the unique biologic characteristics of cancers that affect the AYA age group. Suggested solutions to overcome the limitations of AYA oncology are:<sup>160</sup>

- to increase the number of trials in the adolescent and young adult age group with an emphasis on obtaining biologic samples and prospective data
- to change the age eligibility limits of available studies
- to increase collaboration between cooperative groups
- to advocate for education initiatives, insurance coverage, and research funding, and
- to provide education of the general public as well as integration of increased medical school education.

The national Clinical Oncological Society of Australia AYA Steering Group has an important role to play in facilitating research into this area.

## 13.2 Tissue banking

The importance of tissue banking, especially in poor prognosis tumours, also needs to be considered. In the USA, tissue banks have disproportionately fewer tumour specimens from individuals aged 15–18 years than expected relative to incidence pattern.<sup>161</sup>

Contributions towards tumour banks need to be set up in Australia, again on a national level, given the relatively few cases that present each year in each state.

Cancer registries currently collect limited clinical data on co-morbid conditions, cancer stage, treatment approaches, recurrence, and other outcomes.<sup>162</sup> South Australian data on AYA-specific factors have been very difficult to access. There is a need to develop a national AYA data registry, with state-level involvement, to enable service development in each state in the future.

The AYA perspective is often invisible in research reports. Reports usually do not distinguish AYA data from that of adults or children, and the usual demarcation of age 18 years may no longer be appropriate.<sup>163</sup> Measures of Health Related Quality of Life (HRQL) also need to be included in clinical trials.<sup>164</sup> These will provide baselines for better understanding of issues influencing the patient's life during and after treatment, and of family interaction and influence of family relationships on the HRQL of pts. It will also ensure optimisation of treatment strategies and palliative care and the development of appropriate interventions.<sup>165</sup>

### Recommendations:

- 55. Research into AYA cancer care should be facilitated at a national level, and should take account of the unique biology of tumours in this age group, Measures of Health Related Quality of Life (HRQL) should be included and data relevant to this age group should be separated.**
- 56. Contributions towards tumour banks are vital for AYA tumours, especially those with a poor prognosis.**
- 57. A minimum AYA data set should be established. There is an urgent need to develop a national AYA data registry with state-level input to facilitate service delivery planning for the future.**

<sup>149</sup> Ferrari A, Bleyer A. Participation of adolescents with cancer in clinical trials. *Cancer Treat Rev* 2007 Nov;33(7):603-8.

<sup>150</sup> Ferrari A *et al.* The Challenges of Clinical Trials for Adolescents and Young Adults with Cancer. *Pediatr Blood Cancer* 2008;50:1101-1104.

<sup>151</sup> Bleyer A *et al.* The distinctive biology of cancer in adolescents and young adults. *Nat Rev Cancer* 2008 April;8(4):288-298.

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- <sup>152</sup> Bleyer A *et al.* Adolescents and Young Adults With Cancer: The scope of the problem and criticality of clinical trials. *Cancer* 2006 Oct 1;107(7 Suppl):1645-1655.
- <sup>153</sup> Mitchell AE *et al.* Cancer in adolescents and young adults: treatment and outcome in Victoria. *Med J Aust* 2004 Jan 19; 180(2):59-62.
- <sup>154</sup> Klein-Geltink J *et al.* Use of paediatric versus adult oncology treatment centres by adolescents 15-19 years old: the Canadian Childhood Cancer Surveillance and Control Program. *Eur J Cancer* 2005 Feb;41(3):404-410.
- <sup>155</sup> Bleyer WA *et al.* National cancer clinical trials: children have equal access, adolescents do not. *J Adolesc Health* 1997 Dec;21(6):366-373.
- <sup>156</sup> McTiernan A. Issues surrounding the participation of adolescents with cancer in clinical trials in the UK. *Eur J Cancer Care* 2003 Sep;12(3):233-239.
- <sup>157</sup> Bleyer WA. Cancer in older adolescents and young adults: Epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Med Pediatr Oncol* 2002 38:1:1-10.
- <sup>158</sup> Pollock BH. Where Adolescents and Young Adults With Cancer Receive Their Care: Does It Matter? *J Clin Oncol* 2007 Oct;25(29):4522-4523.
- <sup>159</sup> Ferrari A, Bleyer A. Participation of adolescents with cancer in clinical trials. *Cancer Treat Rev* 2007 Nov;33(7):603-8.
- <sup>160</sup> Burke ME *et al.* Challenges in the recruitment of adolescents and young adults to cancer clinical trials. *Cancer* 2007 Dec 1;110(11):2385-2393.
- <sup>161</sup> Bleyer A. Adolescents and young adult (AYA) oncology: the first A. *Pediatr Hematol Oncol* 2007 Jul-Aug;24(5):325-36.
- <sup>162</sup> *National Service Delivery Framework for Adolescents and Young Adults with Cancer*. Draft for discussion 2008. Australian Government, Cancer Australia, CanTeen
- <sup>163</sup> Haase JE, Phillips CR. The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing* 2004;21:145-149.
- <sup>164</sup> Barr RD, Sala A. Quality-adjusted survival: A rigorous assessment of cure after cancer during childhood and adolescence. *Pediatr Blood Cancer* 2005 Mar;44(3):201-204.
- <sup>165</sup> Calaminus G, Barr R. Economic evaluation and health-related quality of life. *Pediatr Blood Cancer* 2008 May;50(5 Suppl):1112-1115.

## 14. INFORMATION TECHNOLOGY

The AYA age group is a technology-driven group, and all resources and recommendations arising from this Pathway should be accessible using information technology. Patients often self-diagnose or seek further information from the internet, and some guidance is required from health care professionals about useful and reputable websites for adolescents and young adults.

Adolescents and young adults with cancer indicate that they prefer to visit cancer websites that contain cancer-related information, provide the ability to chat with other individuals in their age group with cancer, and offer some type of game. Few websites contain those features identified as most desired by adolescent and young adult cancer patients.<sup>166</sup>

A table of websites for adolescents and young adults with cancer is included in the article by Bleyer A *et al.*<sup>167</sup> Local resources are needed in this area. Suggested websites for use in the AYA cancer population in Australia are listed in Table 6.

**Table 6: Useful websites for adolescent and young adult cancer patients in Australia**

|  |  |
|--|--|
| Cancer Council SA<br><a href="http://www.cancersa.org.au">www.cancersa.org.au</a>                            | CanTeen<br><a href="http://www.Canteen.org.au">www.Canteen.org.au</a>  |
| onTrac@PeterMac<br><a href="http://www.petermac.org/ontrac">www.petermac.org/ontrac</a>                      | Cancer Backup<br><a href="http://www.cancerbackup.org.uk">www.cancerbackup.org.uk</a>                        |
| Teen info on cancer (UK)<br><a href="http://www.click4tic.org.uk">www.click4tic.org.uk</a>                   | Oncofertility Consortium<br><a href="http://www.myoncofertility.org">www.myoncofertility.org</a>             |
| Teens Living with Cancer<br><a href="http://www.teenslivingwithcancer.org">www.teenslivingwithcancer.org</a> | Leukaemia Foundations network for Young Adults<br><a href="http://www.teamrevive.com">www.teamrevive.com</a> |

Many professional education resources are also IT-based. This ensures ease of access. This needs to be kept in mind when distributing education materials, including these Pathway recommendations.

**Recommendations:**

- 58. All resources and recommendations arising from the AYA Cancer Care Pathway and associated Working Group activities should be accessible using information technology.**
- 59. Professional education resources, including the AYA Cancer Care Pathway recommendations, should be freely available and IT-based.**

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<sup>166</sup> Schiffman JD *et al.* Internet use among adolescent and young adults (AYA) with cancer. *Pediatr Blood Cancer* 2008;51:410-415.

<sup>167</sup> Bleyer A *et al.* Proceedings of a workshop: Bridging the gap in care and addressing participation in clinical trials. *Cancer* 2006 October 1;107(7Suppl):1656-1658.

## 15. HEALTH SERVICE INFRASTRUCTURE

The development of an AYA cancer service is a relatively new contribution to cancer care in South Australia. Current funding provided through the Australian Better Health Initiative (ABHI) has provided a much needed resource for an AYA Nurse Cancer Care Coordinator at 0.6FTE. This role encompasses both care coordination (health system navigation) and AYA cancer care project management that includes system service development. At the time of writing funding for this position is anticipated to complete late 2010. An AYA social work position at 0.5FTE is also working in AYA cancer care coordination (care navigation), with funding provided through RedKite (RedKite is a national non government organisation paediatric cancer organisation that provides support for children and adolescents up to 21 years of age). This arrangement will be revised annually.

The key elements of the model developed by the National Service Delivery Framework for Adolescents and Young Adults with Cancer,<sup>168</sup> includes

- 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.

There are many recommendations that the AYA Working Party have made to optimise AYA cancer care in South Australia. . To adequately set up an AYA service in South Australia, a number of resources are required (refer to Table 7). It should be noted that these resources should be available to all adolescents and young adults with a cancer diagnosis regardless of place of treatment, whether it be within the public or private health services.

**Table 7: Resources required for setting up an AYA cancer service in South Australia**

| Resource   | Detail   |
|--|--|
| Funding for education program to raise awareness of cancer in adolescents and young adults and aid diagnosis | Required for: <ul style="list-style-type: none"> <li>• health professionals</li> <li>• consumers</li> </ul>          |
| Web-based AYA medical and supportive care service directory, including how to refer to the AYA cancer        | Content coordinator required to regularly update web information<br>Referral number to be managed by AYA Cancer Care |

|   |   |
|---|---|
| team and the AYA dedicated referral telephone number                    | Coordinators<br>Will require a system tool/algorithm to standardise referral process  |
| Medical multidisciplinary team  | <ul style="list-style-type: none"> <li>• Adult and paediatric haematologist/oncologist (AYA oncologist)</li> <li>• AYA Cancer Care Coordinator</li> <li>• Clinical trials principal investigator</li> <li>• Data manager</li> <li>• AYA multidisciplinary team coordinator</li> </ul>   |
| Psychosocial multidisciplinary team                                     | <ul style="list-style-type: none"> <li>• AYA Cancer Care Co-coordinator</li> <li>• AYA social worker</li> <li>• AYA vocational/educational officer</li> <li>• AYA psychologist</li> <li>• AYA activities coordinator</li> </ul>   |
| Workforce   | <ul style="list-style-type: none"> <li>• Funding for AYA multidisciplinary team coordinator</li> <li>• medical cancer consultant working across paediatric and adult health services (ideally to act as clinical trial Principal Investigator)</li> <li>• Improved collaboration between paediatric and adult cancer specialists</li> <li>• AYA clinical trial data manager</li> <li>• Access to clinical trial and data manager administrative support</li> <li>• Data registry support</li> <li>• Care coordinators: 2 FTE</li> <li>• Social worker: 1 FTE</li> <li>• Psychologists: 0.6 FTE</li> <li>• Vocational support: 1 FTE</li> <li>• Oncologist/haematologist: 1 FTE</li> <li>• Admin support: 1 FTE</li> <li>• IT support: 1 FTE</li> <li>• AYA fellow: 1 FTE</li> </ul> |
| Clinical trials   | <ul style="list-style-type: none"> <li>• Lobby for statewide clinical trial ethics approval.</li> </ul>   |
| AYA treatment space   | <ul style="list-style-type: none"> <li>• Physical ward and day centre space appropriate for the needs of adolescents and young adults</li> </ul>  |
| Patient care  | <ul style="list-style-type: none"> <li>• End of treatment summaries/outline of expected late effects of treatment</li> <li>• Resources for late effects clinics in adult setting</li> <li>• Development of transitional care model</li> <li>• AYA palliative care resources</li> <li>• Resources to progress fertility information/forms</li> </ul>   |
| Rural / remote, including links to interstate (e.g. Northern Territory) | <ul style="list-style-type: none"> <li>• Teleconferencing</li> <li>• Web-based support</li> </ul>   |
| Others  | <ul style="list-style-type: none"> <li>• Development of treatment card/tools</li> <li>• Rehabilitation and exercise facilities/programs</li> <li>• Nutrition</li> </ul>   |

|                        |  |
|------------------------|--|
|                        | <ul style="list-style-type: none"> <li>• Drug and alcohol input</li> <li>• Vocational support officer</li> <li>• Psychologist</li> </ul>   |
| Information technology | <p>Support programs:</p> <ul style="list-style-type: none"> <li>• Peer support (outside of canteen)</li> <li>• Site support ( treatment with peers) <ul style="list-style-type: none"> <li>▪ Facilitate incidental opportunities for adolescents and young adults to meet</li> </ul> </li> <li>• Web-based peer support group</li> </ul> |

<sup>168</sup> *National Service Delivery Framework for Adolescents and Young Adults with Cancer*. Draft for discussion 2008. Australian Government, Cancer Australia, CanTeen

## Appendix A: Full list of recommendations

### Recommendations:

1. Education programs should be developed to promote awareness of the possibility of cancer as a diagnosis in the AYA age group for both (a) health professionals and (b) consumers (i.e. all adolescents and young adults and their parents).
2. School-based cancer awareness and education programs targeting the 12–16 year old age group should involve AYA cancer survivors to maximise impact.
3. Any education/awareness package targeting the AYA population needs to incorporate components using technology frequently accessed by adolescents and young adults.
4. Although most cancers in the AYA age group are not hereditary, familial cancer syndromes should be thought of and appropriate referral to a genetic cancer service should be made if a familial syndrome is suspected.
5. Health professionals involved in the care of an adolescent or young adult with cancer should have the appropriate tumour expertise and AYA age-related expertise.
6. A web-based service directory of medical and supportive care health professionals with expertise and an interest in AYA cancer care should be included in the SA Statewide Cancer Services Directory.
7. A single statewide telephone-based referral line should be established to facilitate direct AYA referrals to an appropriate specialist and best place of care and to encourage and facilitate early referral to the AYA mobile supportive care team.
8. Adolescent and young adult patients who are unwell should be discussed with an on-call specialist and referred to the nearest emergency services as appropriate.
9. All adolescents and young adults with cancer should be discussed prospectively at a medical multidisciplinary team\* meeting where specialists with relevant tumour- and age-specific expertise are present.
10. Adolescent and young adult cancer cases that require intensive paediatric-type treatment should be referred for presentation at the Women's and Children's Hospital Haematology/Oncology Department Tumour Advisory Committee (TAC) meeting.

- 11. All adolescent and young adult cancer cases that require adult-type treatment should be referred to the relevant tumour-specific multidisciplinary team meeting.**
- 12. All adolescent and young adults with cancer should be discussed at a psychosocial multidisciplinary team\* meeting. The constitution of the psychosocial multidisciplinary team will be determined by the person's psychosocial needs, as determined at diagnosis through a comprehensive needs assessment.**
- 13. An online cancer service directory should be developed and implemented for South Australia that includes a list of tumour-specific multidisciplinary team meetings across sites and how to refer to the meeting.**
- 14. Administrative support should be available for all multidisciplinary team meetings. A statewide administrative AYA multidisciplinary team coordinator should be available to provide administrative support for both medical and psychosocial AYA multidisciplinary teams.**
- 15. It is essential that all adolescents and young adults with cancer receive the best evidence-based treatment available in a centre that can provide tumour-specific and age-specific expertise. Ultimately a new discipline, AYA oncology, should be established to meet needs of these young patients across health services (e.g. paediatric and adult settings).**
- 16. A system should be implemented to address and meet the unique psychosocial needs of the AYA age group.**
- 17. Further collaboration is required between paediatric and adult haematologists and oncologists to determine the best model of care for adolescent and young adult cancer patients in South Australia. Serious consideration should be given to centralisation of services and tumour-specific expertise.**
- 18. All adolescents and young adults should be offered entry to clinical research trials for which they are eligible with adequate resources provided to support such trials. Participation in trials should be an informed choice.**
- 19. Administration and data management support should be established to maintain a web-based clinical trials register in South Australia that includes age eligibility.**
- 20. A statewide central ethics approval process should be established to facilitate enrolment of clinical trials across health services in South Australia.**
- 21. One of the roles of an AYA Cancer Care Coordinator should be to maintain open communication with adolescents and young adults with cancer to address issues around compliance, adherence, risk-taking behaviour and provide education and information regarding the individual's health care needs.**

- 22. In the case of persistent low or declining adherence, regular multidisciplinary team reviews/updates involving mental health team members should occur and consultation with mental health professionals should be sought.**
- 23. Health care providers should routinely incorporate enquiries about patients' lifestyle choices, including risk-taking behaviours and health-promoting behaviours (e.g. exercise, nutrition), into consultations.**
- 24. At the end of treatment, every adolescent or young adult cancer patient requires a psychosocial assessment and discussion at the AYA psychosocial multidisciplinary team meeting to aid transition back into normal life**
- 25. An end-of-treatment summary, including expected late effects of treatment, should be provided to all adolescent and young adult cancer patients and their primary care physicians.**
- 26. Late effects clinics should be established as standard of care for all adolescent and young adult cancer patients, and should be situated within adult health services where investigation of potential problems and specialist review can occur if required.**
- 27. Transition planning should commence early in an adolescent or young adult cancer patient's care and should be appropriate to the individual's disease, treatment and developmental stage. Optimal transition care occurs when the patient's cancer and health care needs are stable.**
- 28. An AYA Cancer Care Coordinator is essential in planning and supporting adolescents and young adults with cancer and their families during transition.**
- 29. A dedicated AYA oncologist across health services would aid in supporting transitional care between paediatric and adult health care services.**
- 30. 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.**
- 31. Age-appropriate respite and palliative care beds are required for adolescent and young adult cancer patients.**
- 32. Adolescent and young adult palliative care cancer patients should be involved in decisions about their end-of-life care.**
- 33. The caregiver burden associated with the provision of adolescent and young adult palliation should be recognised, prioritised and proactively addressed.**
- 34. Bereavement planning is essential for family members of adolescent and young adult cancer patients.**
- 35. 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.**

- 36. Every newly diagnosed adolescent and young adult with cancer in South Australia should be referred to the AYA Cancer Care Coordinator for an initial and ongoing age-appropriate psychosocial assessment.**
- 37. Individuals employed in AYA Cancer Care Coordinator roles should have the appropriate skills and experience or should be provided with training to meet the requirements to fulfil the role.**
- 38. All adolescent and young adult cancer patients require referral for discussions about fertility assessment and counselling on sexual health and contraception. Consent for referral to fertility, sexual health and contraception services should be obtained from the patient (not the parents).**
- 39. A recall system should be developed to ensure that adolescent and young adult cancer patients utilising fertility preservation services have a follow-up appointment 1 year post-cancer treatment. This system should include the treating specialist to avoid sensitive recall errors.**
- 40. Introduction of mandatory pregnancy testing should be implemented as standard care during cancer pre-treatment workup in females of childbearing age.**
- 41. Printed and web-based education resources on fertility preservation and sexual health should be accessible for adolescent and young adult cancer patients within all cancer treatment settings.**
- 42. Health care professionals working with adolescent and young adult cancer patients should undertake and teach necessary clinical skills for working with this population, particularly in the area of communication.**
- 43. The complex supportive care issues (both medical and psychosocial) faced by adolescent and young adult cancer patients should be recognised, assessed and managed. The need for resources to deal with these factors will change depending on the stage of the patient's cancer journey. There is a need for frequent re-evaluation and support by all members of the multidisciplinary team.**
- 44. Equitable access to anti-nausea medications is required across all health care services inclusive of public and private sectors in South Australia.**
- 45. Access to an AYA social worker as soon as possible after diagnosis is essential to ensure that patients in this age group have access to the full range of financial and vocational support services for which they are eligible.**
- 46. Access to AYA cancer care and support services within the health care system should be equal regardless of financial or health insurance status.**
- 47. Financial assistance for adolescent and young adult cancer survivors should be integrated into a survivorship plan.**

- 48. All adolescents and young adults from rural and remote areas of South Australia who are suspected of having invasive cancer should be referred to a metropolitan centre of expertise for diagnosis and staging in order to access age-appropriate, safe and effective services as locally as possible.**
- 49. All adolescents and young adults from a rural/remote area of South Australia who have a new diagnosis of cancer should be presented to the most appropriate metropolitan AYA multidisciplinary team for discussion, treatment planning and access to clinical trials. They should be represented if goals of care change (e.g. palliation) to ensure needs are accurately assessed and resourced prior to the patient returning to the rural/remote area.**
- 50. GPs in rural and remote South Australia should have easy access to information to streamline rapid referral to metropolitan specialists.**
- 51. Adolescent and young adult cancer patients from rural and remote areas of South Australia should be contacted by a social worker with appropriate skills in linking with support programs and provision of assistance with their specific travel and accommodation needs.**
- 52. On completion of the treatment phase, adolescent and young adult cancer patients from rural and remote regions should be linked in with local GP and support services on their return home.**
- 53. Qualified interpreting services are essential for people from culturally and linguistically diverse backgrounds to ensure equitable access to health care services.**
- 54. All adolescents and young adults with a cancer diagnosis should have the opportunity to receive culturally appropriate information and counselling (via a qualified interpreter if appropriate) regarding their diagnosis, options and care needs by a health professional with appropriate communication skills and knowledge of issues for individuals in this age group.**
- 55. Research into AYA cancer care should be facilitated at a national level, and should take account of the unique biology of tumours in this age group, Measures of Health Related Quality of Life (HRQL) should be included and data relevant to this age group should be separated.**
- 56. Contributions towards tumour banks are vital for AYA tumours, especially those with a poor prognosis.**

- 57. A minimum AYA data set should be established. There is an urgent need to develop a national AYA data registry with state-level input to facilitate service delivery planning for the future.**
- 58. All resources and recommendations arising from the AYA Cancer Care Pathway and associated Working Group activities should be accessible using information technology.**
- 59. Professional education resources, including the AYA Cancer Care Pathway recommendations, should be freely available and IT-based.**



Date Started & Finished      Field (Target)      Total Dose      Treatment Technique  
Health Service/Clinician

\_\_\_\_/\_\_\_\_/\_\_\_\_.\_\_\_\_/\_\_\_\_/\_\_\_\_.

**Clinical Trials – additional Information**

Date assigned Protocol      Protocol Description      125      Health  
Service/Clinician

\_\_\_\_/\_\_\_\_/\_\_\_\_

**Form completed by – Name:** \_\_\_\_\_ **Health Service:**

\_\_\_\_\_  
Email:

Please contact \_\_\_\_\_ to clarify any questions about this  
survey.

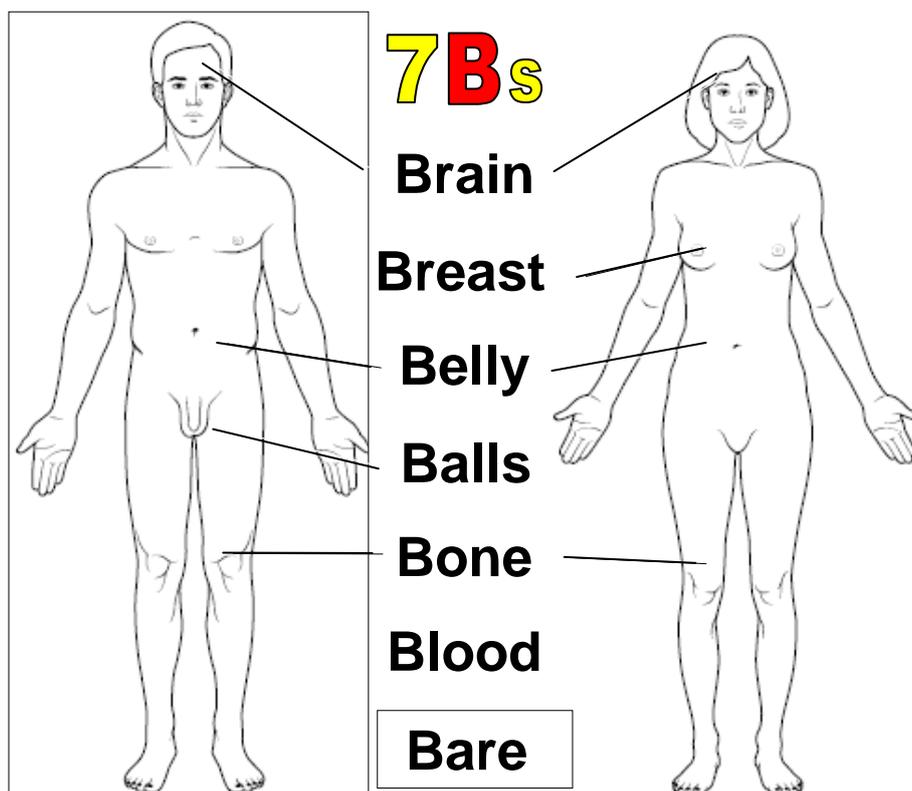
## Appendix C: Dr Archie Bleyer: Educational slides to promote awareness of cancer in adolescents and young adults

A simple, yet effective, education strategy to promote awareness of cancer in adolescents and young adults is in development by Dr Archie Bleyer, a well-recognised clinical expert in adolescent and young adult cancer care in the USA. Dr Bleyer's education model is based on the 'seven signs and symptoms of cancer'. Information is presented in an easy-to-remember visual format that can be used as the basis for an education program for both consumers and health professionals

- Slide 1: Signs of Cancer in AYA
- Slide 2: Education "CAUTION"
- Slide 3: Abnormal discharge (diagram)

Permission to reproduce these slides has been granted by Prof Archie Bleyer via personal email correspondence to Dr Petra Ritchie 2008.

### Slide 1: Signs of Cancer in AYAs



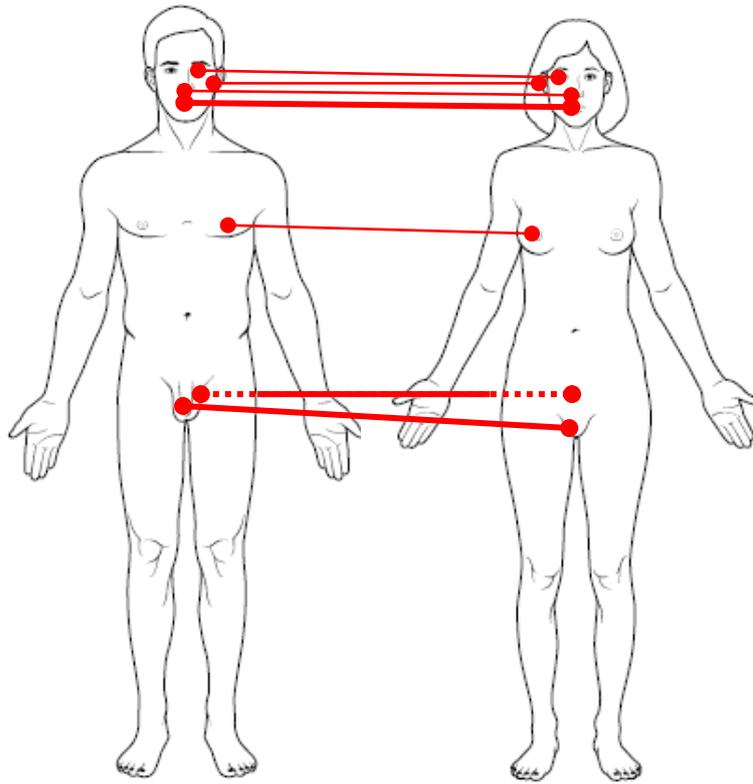
## Slide 2: Education



### Symptoms of Cancer in AYAs

- C** Change in mole or new one
- A** Abnormal discharge from orifice
- U** Unilateral knee/shoulder pain/swelling
- T** Tumour / bulge / bump / lump anywhere
- I** Increasing lymph gland
- O** Obstinate fatigue, lethargy
- N** Neurologic deficit or symptom of ICP

### Slide 3: Abnormal Discharge



## **Appendix D: Overview of common cancers followed by table of risk factors for the development of cancer in adolescents and young adults with cancer**

### **Overview of common tumours in Adolescent and Young Adults**

The following table provides an overview of common cancers in Adolescent and Young Adults (15-25 years of age). All information has been taken from the Cancer Council of South Australia's *Cancer Among Young South Australians Monograph 10*.

The table indicates the tumour, known risk factor, possible risk factors and the page number where the information was sourced.

For indication of trends, prevalence and age to sex ratio, refer to the following document:

- Cancer Council South Australia 2008, "Cancer Among Young South Australians", *Centre for Cancer Control Research, South Australia cancer statistics, Monograph No 10*, [http://www.cancersa.org.au/cms\\_resources/documents/CancerAmongYoungSouthAustralians1.pdf](http://www.cancersa.org.au/cms_resources/documents/CancerAmongYoungSouthAustralians1.pdf)

#### **Cancers of Focus**

##### **1. Leukaemia**

Leukaemia is the most common childhood cancer and the fourth most common cancer affecting young people aged 15–24 years in South Australia.

Leukaemia is a cancer of the white blood cells. Different types of leukaemia are classified according to the type of cells in which they originate and how quickly they progress.

Lymphatic leukaemia involves malignant transformation of immature lymphocytes, while myeloid leukaemia involves transformations of immature myelocytes. Acute forms of leukaemia develop rapidly whereas chronic forms develop and progress quite slowly.

The majority of leukaemias in children and young people are acute forms. Acute lymphoid leukaemia (ALL) is the most common type of leukaemia in children and young adults. Acute myeloid leukaemia (AML) is rare in the early years of life but is a significant contributor to the cancer burden in adolescents and young adults.

When leukaemia occurs, immature stem cells in the blood develop uncontrollably within the bone marrow, eventually affecting the development of other blood cells. These immature cells are not able to fight infections and leave less room for healthy white cells, red blood cells and platelets to function.

Symptoms that may signal leukaemia in young people include:

- Fatigue, weakness, paleness, dizziness
- Joint pain, headache, trouble walking
- Bruising, bleeding from the nose/gums
- Repeated infections
- Persistent fever
- Loss of appetite, weight loss

Leukaemia is usually treated by chemotherapy and sometimes radiotherapy. Advances in treatments have dramatically improved survival outcomes for children with leukaemia over the past three decades, with the vast majority now achieving remission and three quarters surviving five years or more after diagnosis.

##### **2. Lymphomas**

Lymphoma is the third most common cancer in children and the second most common cancer in young people 15–24 years of age in South Australia.

Lymphomas are cancers that originate in the lymphatic system, which is part of the immune system that fights infection and disease. There are two main types of lymphoma commonly referred to: **Hodgkin lymphoma** and **non-Hodgkin lymphoma**. Both types have various subcategories which are classified according to the main mix of cell types involved.

Hodgkin lymphoma (HL) was the first of the lymphomas to be described on the basis of a distinctive cell type observed within these tumours. Other types of lymphoma identified since then have been referred to as non-Hodgkin lymphoma (NHL).

Lymphomas develop when a lymphatic cell undergoes a malignant change and starts dividing uncontrollably. Eventually these crowd out the healthy lymphatic cells and form tumours within the lymph glands or other parts of the lymphatic system. While most lymphomas start in the lymph glands, some occur in or spread to other parts of the body such as the chest, stomach and intestines, where there is a large amount of lymphatic tissue.

Symptoms associated with Hodgkin and non-Hodgkin lymphoma are similar. These include:

- Swelling of lymph nodes (usually in the neck, under the arms or in the groin)
- Fever, night sweats
- Weight loss, loss of appetite

Usually the swelling is painless. Occasionally glands in the chest are involved which cause difficulty breathing or coughing, while involvement of glands in the abdomen can cause bowel blockages. Most childhood lymphomas are high grade which means that they are fairly aggressive and often quite extensive when diagnosed.

Treatments are different for different types of lymphoma but most involve chemotherapy. Occasionally radiation therapy is also used. In cases of NHL that recur, bone marrow transplants are sometimes required. Survival prospects are generally good for most forms of lymphoma in young people.

### 3. Malignant tumours of the brain and central nervous system

Tumours of the brain and central nervous system (CNS) can be malignant or benign. They may be primary tumours that start in the brain or CNS or they can be secondary tumours that spread from other parts of the body to the brain.

Brain/CNS tumours are the second most common cancer in children after leukaemia and are one of the main cancer groups affecting adolescents and young adults. They are a diverse group of tumours that originate from cells in the brain, spinal cord or other parts of the CNS such as the pituitary gland. It is the histological type (cell type) rather than the site of the tumour that determines the behaviour of these cancers in young people.

The International Classification of Childhood Cancers includes five major types of tumours within the broader category of CNS tumours. These are *ependymomas*, *astrocytomas*, *primitive neuroectermal tumours (PNET)*, other *gliomas* and other *miscellaneous intracranial and intraspinal tumours*. Tumours that originate from *glial cells (supporting cells)* are called *gliomas*. Gliomas include *astrocytomas* and *ependymomas*. Astrocytomas are the most common type of brain tumours found in young people.

Symptoms of brain tumours vary, Symptoms can include:

- Headaches
- Irritability, drowsiness
- Change in personality
- Periods of unconsciousness
- Weakness, clumsiness, balance problems
- Vision problems
- Fits/seizures
- Persistent vomiting, nausea
- Back pain
- Excessive thirst or urination

Treatment may include surgery to remove the tumour. Radiotherapy and/or chemotherapy may also be necessary.

#### **4. Sympathetic nervous system tumours**

Tumours of the sympathetic nervous system (SNS) are malignancies of immature nerve cells that control bodily organs such as the heart, lungs and liver, in response to various stressors. These tumours account for around one in twelve cancers in children under 15 years of age but are rarely seen in adolescents and young adults.

The majority of SNS tumours are neuroblastomas. Neuroblastomas develop from immature cells (neuroblasts) from the neural crest which runs from the neck to the base of the spine. In a few cases, SNS tumours occur in other parts of the body including the chest, neck and near the spinal cord.

Neuroblastomas occur most often in very young children (under five years) and are the most common type of cancer in infants under 12 months. During the first few months after birth, clumps of neuroblasts can be detected in some infants but these immature cells will usually mature and the clumps dissolve. In some cases, these neuroblasts do not mature but continue to divide and grow causing a solid tumour to develop. The inability to mature and stop growing is due to an abnormality in the cellular DNA.

By the time neuroblastomas are detected, they have usually spread and metastasised to other parts of the body, for example, the liver, lymph nodes or bone marrow.

Common symptoms include:

- A lump in the abdomen, neck or chest (with or without pain)
- A swollen stomach
- Trouble breathing (in infants)
- Weakness or paralysis
- Bulging eyes
- Dark rings under the eyes.

Less common signs include:

- fever
- fatigue
- Shortness of breath
- High blood pressure
- Jerky muscle movements
- Uncontrolled eye movements
- Swelling in the feet, legs or scrotum.

Prognosis (chances of surviving) for children diagnosed with neuroblastoma depends on a number of different factors including the age at diagnosis, the site of the tumour, the degree of cell change and the stage of the cancer (degree of spread) at diagnosis.

Survival outcomes are generally better for the younger ages at diagnosis.

Treatment options vary according to the risk profile of the patient. The three risk groups, defined as low, medium and high depending on age, stage, site and histology of the tumour, are treated differently.

A combination of chemotherapy and surgery is often used when treating medium risk patients. Radiation may be used in cases where the tumour is causing serious problems. For high risk patients, treatment may involve high-dose chemotherapy followed by surgery and/or radiation therapy. Children treated for neuroblastoma have an increased risk of developing other cancers.

## 5. Retinoblastomas

Retinoblastoma is a cancer of one or both eyes that develops in young children. Retinoblastoma occurs in the retina, the light sensitive layer at the back of the eye that enables sight. About three quarters of cases are unilateral (occur only in one eye) while one quarter are bilateral (occur in both eyes). Bilateral retinoblastoma is usually a sign of a hereditary form of the disease.

Specific genes are known to control the cell division of retinal cells. In retinoblastoma cases, a gene that suppresses cell growth is missing or damaged so cells of the retina continue to divide, developing into a tumour. This genetic defect can either be inherited (in which case the defect occurs in all cells throughout the body) or develop spontaneously (only appearing in cells of the eye).

Signs of retinoblastoma are varied. The most common sign is the white appearance of the pupil. Other signs include:

- Crossing of the eyes
- One eye turned outwards or inwards
- Red painful eyes
- Inflammation of the tissue around the eye
- An enlarged or dilated pupil
- Poor vision
- Failure to thrive/not eating or drinking.

More than 95% of children with retinoblastoma are successfully cured. Ninety percent will retain vision in at least one eye and 80% are likely to retain perfect vision.

Treatment depends on the age of the child but will usually involve surgery to remove the eye. Children who have surgery are able to have a prosthetic (artificial) eye implanted after their surgery has healed. When both eyes are involved, the second eye (less affected eye) is treated with radiotherapy or by other methods such as laser therapy or cryotherapy in an attempt to retain some vision.

Children with bilateral (hereditary) retinoblastomas and children treated with radiotherapy are at increased risk of developing other tumours (unrelated to the eye) later in life, particularly bone and soft tissue sarcomas, and melanomas.

## 6. Renal tumours

Renal tumours account for about 6% of the cancer burden in children (under 15 years) but only a small proportion of cancers in adolescents and young adults.

Renal tumours are cancers of the cells in the kidneys. Wilms tumour is the most common type of renal tumour found in children. It occurs when immature cells of the kidney (nephroblasts) continue to divide in their immature form rather than develop into functioning cells, eventually forming a solid tumour that compresses normal tissue around it. This type of cancer accounts for around 90% of renal tumours in children.

It usually occurs in children under the age of seven years and is most likely to be diagnosed in children around three years of age. Wilms tumours are related to particular defects in the DNA of one of two genes on chromosome 11, which affect the development and control of the genital and urinary systems.

Renal cell carcinoma, another form of kidney cancer, is very rare in children but does occasionally occur in adolescents and young adults. Other forms of renal cancer are extremely rare in children, adolescents and young adults.

Wilms tumour (also referred to as nephroblastoma) usually occurs in one kidney but can sometimes affect both kidneys. Often these tumours are not detected early because they can grow to be quite large without causing pain. The main sign of Wilms (and other renal tumours) is a mass in the abdomen. Other symptoms include:

- Swelling or pain in the abdomen
- Blood in the urine
- Unexplained fever

- Reduced appetite.

Prognosis is generally good for children diagnosed with Wilms tumour. Outcomes do vary, however, depending on age, grade (how much the cells in the tumour differ from normal healthy kidney cells) and stage (degree of spread). Even though in many cases tumours are quite large, it is unusual for the cancer to have metastasised (spread to other parts of the body) at the time of diagnosis.

Prognosis is less favourable for other types of renal cancers which have a greater tendency to spread outside the kidney.

Wilms tumour and other childhood renal cancers are usually treated by surgery to remove the affected kidney (nephrectomy). Standard treatment usually involves chemotherapy but radiotherapy may also be needed depending on characteristics of the tumour (stage and grade). If both kidneys are involved, only part of the kidney(s) is removed, with chemotherapy and radiotherapy being used to shrink the tumour to leave some kidney function. Around 85% of children diagnosed with Wilms tumour will be disease free after treatment.

## **7. Hepatic tumours (cancers of the liver)**

Hepatic tumours are cancers that form in the liver. The liver is a vital organ in the body which helps to filter harmful substances in the blood, makes important enzymes to digest fat and regulates the storage of energy in the body (glycogen).

There are two types of primary liver cancers that affect young people. These are hepatoblastoma, a type of cancer originating from immature liver cells, which usually occurs in children under five years of age, and hepatocellular carcinoma, which usually affects older children and young adults. This latter type is more likely to spread to other parts of the body.

Liver cancer is very rare in children and young adults. One or two children per million develop liver cancer each year. Eight out of ten hepatic tumours in children (under 15 years) are hepatoblastomas. Signs of liver cancer include:

- swelling in the abdomen with or without pain
- weight loss
- loss of appetite
- Nausea or vomiting.

Surgery to remove the tumour is the most likely treatment. The liver can continue to function even when only a small part is working. The liver has four sections or lobes and cancer can be present in one or more lobes. If the tumour is present in all four lobes a liver transplant may be necessary depending on the tumour type.

Treatment will usually also include chemotherapy. Sometimes chemotherapy and radiotherapy are used to shrink the tumour before surgery. Other specialised treatments are often considered for hepatocellular carcinoma, such as chemoembolisation (administering chemotherapy locally to the vein going to the liver) and antiangiogenic treatment (preventing the tumour from developing a blood supply).

Prognosis (chances of cure) depends on several factors including whether the cancer affects all or part of the liver and whether it can be completely removed by surgery, the type of cancer (hepatoblastoma or hepatocellular carcinoma) and grade (amount of cellular change in the cancer cells).

## **8. Malignant bone tumours**

Half of all bone tumours that occur in children and young adults are non malignant. This section only relates to primary bone tumours that are malignant (referred to as bone cancers in this report).

Primary malignant bone tumours are cancers that start in the bones, as opposed to secondary bone tumours which start in other parts of the body but spread to the bones.

Primary bone tumours have the potential to spread to other parts of the body.

Bone cancers are rare in children and young people, accounting for around 5% of cancers in those under 25 years of age.

There are several different types of bone cancer that occur in children and young people. The most common types are osteosarcoma and Ewing sarcoma. Osteosarcomas are tumours that develop in

the newly forming bone tissue and commonly occur in bones around the knee during adolescence and early adulthood. Ewing sarcomas are thought to start in immature nerve tissue around the bone and can occur in a variety of bones but most commonly in bones of the pelvis or upper leg.

Both oestrosarcoma and Ewing sarcomas occur in young people around the time of rapid bone growth. The peak incidence of these cancers is seen at around 14–16 years of age.

Another type of bone cancer that is relatively rare in young people is chondrosarcoma. This type of cancer begins in the cartilage and tends to grow relatively slowly. Chondrosarcoma tends to be diagnosed most frequently among people aged 40–75, years but can occur in children and young adults.

Symptoms of bone cancer vary depending on which part of the body is affected as well as the size of the tumour. Common signs of bone cancer include:

- Pain or swelling in the affected area
- Weakness
- Unexplained broken bones
- Fatigue, weight loss, anaemia, fever.

Treatment also depends on the location of the tumour as well as the size and degree of spread. The main treatments include:

- Surgery to remove the tumour
- Radiotherapy
- Chemotherapy.

For tumours of the arms and legs, amputation may be necessary to remove all of the cancer, although in some cases, limb saving surgery may be possible, where only part of the bone is removed and replaced through bone grafting or metal prostheses. Radiotherapy may be given in conjunction with, or instead of, surgery. Chemotherapy may also be used in combination with other treatments.

## **9. Soft tissue sarcomas**

Childhood soft tissue sarcomas are a group of malignant tumours that start in immature cells of the soft tissues that support, surround and connect various organs and other parts of the body. These tumours are classified according to the type of tissue they resemble.

Rhabdomyosarcomas, tumours that start in the striated muscle, are the most common type of soft tissue sarcoma found in children. These tumours, along with undifferentiated sarcomas that behave like rhabdomyosarcomas, account for 50% of soft tissue sarcomas in children.

They often start in the muscles behind the eye (causing the eye to bulge), in the nasal cavity (causing congestion, nose bleeds or bloody mucous), around the testis or vagina (presenting as a lump or lumps, or as vaginal bleeding) or in the genitourinary track (leading to blockages in the bladder or blood in the urine).

Other soft tissue sarcomas, sometimes referred to as non-rhabdomyosarcomas, are more common in adults than children. These tumours are often found in the trunk, arms and legs. They can present as a solid mass in the affected part of the body without any other symptoms. Occasionally if the tumour interferes with particular body functions, other symptoms may be present.

These other soft tissue sarcomas include Kaposi sarcoma. Kaposi sarcoma is a cancer that often presents as lesions under the skin around the nose, mouth, throat and other organs. This form of sarcoma is most likely to develop when the immune system is weakened by disease or drugs. It often occurs in patients with acquired immunodeficiency syndrome (AIDS). A large increase in Kaposi sarcomas was observed in the US during the 1980s and 1990s among young males.

Treatment for soft tissue sarcomas may involve surgery, chemotherapy and/or radiotherapy, depending on the type of tumour. Standard treatment usually involves surgery to remove the tumour, which may be preceded by chemotherapy or radiotherapy to shrink the tumour. If the tumour has spread, radiotherapy or chemotherapy generally would be administered after surgery. In some cases, a second round of surgery may be undertaken to remove some residual tumour.

Survival outcomes for children with rhabdomyosarcoma depend on the age of the patient, the site of the tumour, whether the tumour can be removed completely by surgery, the extent of spread or metastases and subtype of tumour cell. Survival at five years ranges from 50% to 90% depending on

these factors. Survival outcomes for children with non rhabdomyosarcomas are more favourable (especially for infants and very young children).

Children who have had multimodal treatment (a combination of chemotherapy and radiotherapy or different types of chemotherapy) for soft tissue sarcomas are at increased risk of developing other cancers.

## **10. Germ cell, trophoblastic and other gonadal neoplasms (GCTOG tumours)**

Germ cell tumours are a group of tumours that develop from germ cells or other cells involved in reproduction. During foetal development, germ cells normally migrate to the ovaries or testes to form the ova (eggs) or sperm cells.

Tumours arise when these cells fail to mature properly and become cancerous (divide uncontrollably). They most commonly occur in the ovaries and testes but can occur in other places of the body such as the brain, abdomen and base of the spine if the immature germ cells fail to migrate. Other cells such as trophoblasts (cells involved in assisting fertilised eggs to attach to the wall of the uterus and in the development of the placenta) can become cancerous.

Germ cell tumours in young people are categorised into five subtypes under the International Classification of Childhood Cancers, based on the cell type (germ cell, trophoblast or other) and the site of the tumour (brain, gonads or other). However, there is considerable variation in the biological characteristics and clinical behaviour of tumours within some of these subtypes. Germ cell tumours in children are quite distinct from those occurring in adolescents and young adults.

The major types of germ cell tumours include testicular germ cell tumours in infants, young children, adolescents and adults (each with distinct characteristics); ovarian germ cell tumours; germ cell tumours that occur in the brain and germ cell tumours that occur outside the gonads but not in the brain in young children, and in adolescents and young adults (again with distinct characteristics).

Symptoms will vary depending on the location of the tumour but testicular cancers will often present as a lump where the tumour develops.

The main treatment for germ cell tumours involves surgery or chemotherapy or a combination of both. Tumours that can be removed completely by surgery may not require chemotherapy, whereas tumours that have spread or can't be removed would normally be treated with a combination of different chemotherapy drugs.

Age and location of the tumour affect prognosis. More than 90% of patients with germ cell tumours will be cured.

The incidence of germ cell tumours has doubled over the past four decades. In children, rates of tumours outside the gonads have increased while gonadal tumour rates have remained steady. In adolescents and young adults, most of the increase is due to an increase in the incidence of gonadal tumours.

## **11. Carcinomas (epithelial neoplasms)**

Carcinomas are malignancies that arise in epithelial cells. Epithelial cells are cells that line the external surface of the body, the internal cavities and many of the glands and organs of the body. Carcinomas include cancers of the lung, bowel, breast and skin. These cancers are much less common in children than other cancers like leukaemia, lymphoma and brain cancers. However, carcinomas represent a substantial cancer burden among adolescents and young adults.

Melanoma (a type of skin cancer) and carcinoma of the thyroid are the most common epithelial carcinomas in young people and will be the major focus of this section of the report.

### **Melanoma**

Melanoma develops from melanocytes, cells in the skin that produce melanin, a pigment that gives the skin its colour. Melanomas can develop in the skin on any part of the body, but very rarely they may develop in other parts of the body such as the eye, mouth or internally. Melanoma is the most serious form of skin cancer, due to its potential to spread to the lymph nodes and, via the lymphatic system, to other parts of the body such as the brain, bone and liver.

While melanoma is relatively rare in young people, it is the most common cancer affecting adolescents and young adults. Rates of melanoma have been rising in many western countries including Australia. Melanomas are more common in females than males. Females tend to present with melanomas on the upper and lower limbs, whereas males have a higher proportion occurring on the trunk of the body. Earlier diagnosis and better treatment outcomes tend to occur among females.

Melanomas usually present as a change in the shape, colour, size or feel of an existing mole or new mole. Common changes include:

- darker colouration or uneven colour
- asymmetrical shape
- ill-defined edges or ragged borders
- increases in the size of a mole
- Itchiness or bleeding.

Treatment for melanoma usually involves surgery to remove the cancer and sometimes additional treatments to reduce the chance of melanoma recurring (immunotherapy or chemotherapy), and radiotherapy to control the cancer if it has spread to the brain or bones.

Depending on the size of the tumour, a skin graft may be required. Chemotherapy may be given either orally or locally to an affected limb. Immunotherapy may involve giving Interferon and Interleukin to enhance the immune system.

Survival outcomes for patients with melanoma are generally good. Prognosis varies according to age, site of the tumour, level of invasion and extent of spread. Patients who are younger, female or have melanomas on their limbs generally have a better prognosis. Chances of cure are very high for melanomas that have not invaded the surrounding tissue or spread to other areas of the body.

### **Thyroid cancer**

Thyroid cancer starts in cells of the thyroid gland. The thyroid gland is located in the base of the neck. It produces hormones which control normal bodily functions. To produce thyroid hormones, the thyroid gland requires iodine which it acquires through dietary sources. It is the only organ in the body to absorb iodine from the blood stream (which is significant in relation to treating thyroid cancer).

Thyroid cancer rarely affects children under 10 years of age, but sometimes it affects adolescents and young adults. The biological and clinical characteristics of thyroid cancer in young people are distinct from thyroid cancer in older people. The long term prognosis for young people with thyroid cancer is very good.

There are several types of thyroid cancer which affect adolescents and young adults. These include papillary thyroid carcinoma, follicular thyroid carcinoma and medullary thyroid carcinoma. Papillary and follicular thyroid carcinomas are the most common in adolescents and young adults.

Thyroid cancer often causes no symptoms. The most common sign is a lump or nodule in the neck near the Adam's apple. Other signs can include:

- Hoarseness or difficulty speaking
- Difficulty swallowing
- Swollen lymph glands in the neck
- Pain in the throat or neck.

There are different treatment options depending on age, type of cancer and degree of spread. The standard treatment usually involves surgery (either a complete or partial thyroidectomy) to remove the cancer. This may be followed by hormone therapy to suppress hormones that stimulate the thyroid cells to produce hormones themselves and/or radiotherapy treatment using radioactive iodine.

Because thyroid cells are the only cells to absorb iodine, radioactive iodine becomes concentrated within these cells, destroying them but leaving other cell types undamaged. Hormone treatment may be required for life to replace the functions of the thyroid gland in cases where it is completely removed.

Survival outcomes are extremely good for young people with papillary and follicular thyroid cancers, with five-year survival around 95%.

The following table provides an overview of common cancers in Adolescent and Young Adults (15-25 years of age). All information has been taken from the Cancer Council of South Australia's *Cancer Among Young South Australians Monograph 10*.

The table indicates the tumour, known risk factor, possible risk factors and the page number where the information was sourced.

For indication of trends, prevalence and age to sex ratio, refer to the following document:

- Cancer Council South Australia 2008, "Cancer Among Young South Australians", *Centre for Cancer Control Research, South Australia cancer statistics, Monograph No 10*, [http://www.cancersa.org.au/cms\\_resources/documents/CancerAmongYoungSouthAustralians1.pdf](http://www.cancersa.org.au/cms_resources/documents/CancerAmongYoungSouthAustralians1.pdf)

## AYA Cancer Table:

|   | TUMOUR                         | KNOWN RISK FACTOR  | POSSIBLE RISK FACTORS   | Pg |
|---|--------------------------------|--|---|----|
| 1 | Leukaemia                      |  |   |    |
|   | Acute Lymphoid Leukaemia (ALL) | <p>Factors that are known to be associated with increased risk of ALL include:</p> <ul style="list-style-type: none"> <li>• Age (incidence peaks between two and five years of age)</li> <li>• Sex (30% more common in males)</li> <li>• Higher socio-economic status (this may be related to lack of or later exposure to certain infections)</li> <li>• Ionising radiation in utero (prenatal x-rays: unlikely to be a major cause in SA today due to protocols for protection of mothers pre-natally)</li> <li>• Ionising radiation post-natally (therapeutic radiation has been associated with increased risk of ALL)</li> <li>• Genetic predisposition (a 20-fold increased risk of leukaemia has been observed among children with Down syndrome).</li> </ul> | <p>Other risk factors have been suggested. However, evidence is inconclusive at this stage. These include:</p> <ul style="list-style-type: none"> <li>• High birth weight (&lt;greater than 4000 g)</li> <li>• First born or only child (which may relate to exposure to infections)</li> <li>• Parents' occupational exposure to chemicals</li> <li>• Electromagnetic fields</li> <li>• Vitamin K at birth</li> </ul>  | 22 |
|   | Acute Myeloid Leukaemia (AML)  | <p>Established risk factors for AML include:</p> <ul style="list-style-type: none"> <li>• Chemotherapy</li> <li>• Ionising radiation in utero</li> <li>• Genetic predisposition (young people with Down syndrome have a 500-fold increased risk of developing AML)</li> </ul>  | <p>Other suggested risk factors for which evidence is inconclusive include:</p> <ul style="list-style-type: none"> <li>• Maternal alcohol consumption during pregnancy (relates particularly to AML in the first three years of life)</li> <li>• Parental exposure to benzene</li> <li>• Parental and child exposure to pesticides.</li> </ul>  | 22 |
| 2 | lymphoma                       | <p>Factors that are known to be associated with an increased risk of Hodgkin lymphoma in young people include:</p> <ul style="list-style-type: none"> <li>• a family history of HL (99-fold increase for identical twins and seven fold increase among siblings)</li> <li>• Epstein-Barr virus infection (EBV is linked with 50% of HL but the association varies with age, gender and level of economic development of the region)</li> <li>• Socio-economic status</li> </ul>  | <p>Potential risk factors for non-Hodgkin lymphoma include:</p> <ul style="list-style-type: none"> <li>• immune suppression (immunotherapy, immune deficiency syndromes, HIV)</li> <li>• infections (including EBV, helicobacter, pylori)</li> <li>• chemical exposures (pesticides, fertilisers and solvents)</li> <li>• Genetic predisposition (family clusters are known to occur although this could relate to environmental exposures rather than genetic factors).</li> </ul> | 30 |

|   | TUMOUR                                   | KNOWN RISK FACTOR  | POSSIBLE RISK FACTORS  | Pg |
|---|--|--|--|----|
| 3 | Brain / CNS                              | <p>The few factors that have been linked with tumours of the CNS explain only a small proportion of the brain cancers in young people. These factors include:</p> <ul style="list-style-type: none"> <li>• Genetic predispositions associated with a few rare syndromes</li> <li>• Previous exposure of the brain to ionising radiation</li> </ul>   | <p>Other factors for which evidence is still inconclusive include:</p> <ul style="list-style-type: none"> <li>• Maternal diet during pregnancy</li> <li>• Parents or siblings with brain tumours</li> <li>• Family history of other cancers (leukaemia, lymphoma or bone cancer)</li> <li>• Electromagnetic fields/mobile phones</li> <li>• Pesticides</li> <li>• Father's occupation/chemical exposures</li> <li>• Head injuries</li> <li>• Family history of epilepsy/mental impairment</li> </ul> | 38 |
| 4 | Neuroblastoma/sympathetic nervous system | <p>The causes of tumours of the sympathetic nervous system among children are unknown. The vast majority of SNS tumours are neuroblastomas. Research findings on the causes of neuroblastoma are inconsistent or limited.</p> <p>Studies have suggested links with the following factors:</p> <ul style="list-style-type: none"> <li>• Medications taken during pregnancy (tranquillisers, amphetamines, diuretics, muscle relaxants)</li> <li>• Sex hormones (fertility drugs during or prior to pregnancy)</li> <li>• Low birth weight (however preterm birth appears to be protective)</li> <li>• Previous miscarriage or foetal death</li> <li>• Alcohol consumption during pregnancy</li> </ul> | <p>A very small proportion of neuroblastomas (1–2%) are likely to be hereditary. The familial form is suspected when tumours develop in two different places within the body or where neuroblastoma has occurred in several members of the family.</p>   | 46 |

|   | TUMOUR               | KNOWN RISK FACTOR   | POSSIBLE RISK FACTORS  | Pg |
|---|----------------------|---|--|----|
| 8 | Bone Cancers         | <p>The causes of bone cancers are not well understood.</p> <p>Different risk factors have been implicated for the different types of bone cancer. Known risk factors for osteosarcomas include:</p> <ul style="list-style-type: none"> <li>• Radiotherapy treatment for cancer during childhood</li> <li>• Chemotherapy treatment (alkylating agents) for cancer during childhood</li> <li>• Retinoblastoma and other rare syndromes</li> <li>• Exposure to radium (known to be linked with bone cancer • in adults).</li> <li>• The potential for exposure through drinking water to cause bone cancer in adults or children is unclear.</li> </ul> <p>Risk factor for which evidence is limited or inconsistent include:</p> <ul style="list-style-type: none"> <li>• Being taller</li> <li>• Prior injury of the affected area</li> <li>• Shorter birth length</li> <li>• Foetal X-rays</li> <li>• Parental exposure to fertilisers, herbicides or pesticides</li> <li>• Fluoride in drinking water.</li> </ul> <p>The only known risk factor for Ewing sarcoma is race. Tumours are almost exclusively found in Caucasian children.</p> | <p>Other risk factors for which evidence is limited or inconclusive relate to:</p> <ul style="list-style-type: none"> <li>• height/weight/age at onset of growth spurt</li> <li>• having had a hernia</li> <li>• parental occupation in agriculture</li> <li>• ingestion of poison/medication overdose</li> </ul>  | 66 |
| 9 | Soft Tissue Sarcomas | <p>Children with certain rare genetic syndromes (e.g. Li-Fraumeni syndrome, Beckwith-Wiedemann syndrome, Recklinghausen's disease) are at increased risk of developing soft-tissue sarcomas. However, most cases of soft-tissue sarcoma develop sporadically and are not linked with any inherited genetic abnormality.</p>   | <p>Several environmental factors have been indicated in studies looking at potential causes of rhabdomyosarcoma in children. However, the evidence for each of these is limited to one study. These factors include:</p> <ul style="list-style-type: none"> <li>• Low socio-economic status</li> <li>• Foetal exposure to x-rays</li> <li>• Parental use of recreational drugs (i.e. marijuana and • cocaine) during pregnancy.</li> </ul> <p>The extent to which these factors apply to tumours in adolescents and young adults is unknown.</p> | 72 |

|    | TUMOUR   | KNOWN RISK FACTOR   | POSSIBLE RISK FACTORS  | Pg |
|----|--|---|--|----|
| 10 | Germ Cell, Trophoblastic and Gonadal Tumours                     | <p>Risk factors for germ cell tumours in children and young people are not well understood. The only confirmed risk factor for testicular germ cell cancer is cryptorchidism (testes that have not developed or descended properly).</p> <p>The dramatic increase in incidence of germ cell cancers over the past few decades implies that environmental factors play an important role. However, these factors are not known.</p> <p>Suggested risk factors arise mainly from studies of testicular cancers among adults. These include:</p> <ul style="list-style-type: none"> <li>• Use of oral contraceptives or high levels of maternal hormones during pregnancy</li> <li>• Preterm birth</li> <li>• Hernia</li> <li>• Trauma</li> </ul>  | <p>Other possible risk factor (for which evidence is inconsistent or limited) includes:</p> <ul style="list-style-type: none"> <li>• High birth weight</li> <li>• Viral infection</li> <li>• Parental occupation (medical, aircraft industry, exposure to solvents, plastics and resins)</li> <li>• Pre-natal Xrays</li> </ul> | 78 |
| 11 | Malignant Epithelial Tumours: Thyroid & melanoma<br><br>-Thyroid | <p>Thyroid cancer in young people is a poorly studied disease.</p> <p>Thyroid cancer is much more common in females than males, suggesting that hormonal factors play a role. It is also more common among Asians and Caucasians than among other races.</p> <p>The only known risk factors for thyroid cancer are: exposure to ionising radiation through:</p> <ol style="list-style-type: none"> <li>Treatment therapies (e.g. prior treatment for cancer, acne, tinea, enlarged thymus).</li> <li>Environmental sources (radiation fallout, especially radioactive iodine fallout as at Chernobyl)</li> </ol> <p>Genetic factors (increased risk for people with mutations • linked to regulation of cell growth, and other inherited cancer susceptibility syndromes e.g. FAP) and benign thyroid disease</p> | No information available   | 87 |

|  | TUMOUR         | KNOWN RISK FACTOR  | POSSIBLE RISK FACTORS   | Pg    |
|--|----------------|--|---|-------|
|  | Melanoma       | <p>The exact causes of melanoma in young people are not well understood. Exposure to ultraviolet radiation (UVR) from the sun is the primary risk factor for melanoma but determining the precise nature of high-risk exposure is complex. Known risk factors, in addition to sun exposure, include:</p> <ul style="list-style-type: none"> <li>• having fair skin</li> <li>• having a large number of moles (particularly abnormal moles)</li> <li>• having a family history of melanoma/inheritance of specific gene mutations</li> <li>• being female</li> <li>• having exposure to artificial UV (eg through solarium/tanning beds).</li> </ul> <p>Because of the increased risk among females, researchers have explored possible hormonal links. However there is no conclusive evidence that melanoma risk is related to use of hormonal contraception, high internal hormone level or pregnancy related factors.</p> | <p>The relationship between occupational exposure and melanoma risk, and total sun exposure and melanoma risk, is less clear.</p> <p>The extent to which sun exposure is linked to increased risk of melanoma in children, adolescents and young adults has been questioned</p> | 88-89 |
|  | Retinoblastoma | <p>About 30% of retinoblastomas are thought to be familial. Genetic factors involved in hereditary retinoblastomas are well understood. Offspring of patients with bilateral retinoblastoma have a 50% risk of inheriting the gene mutation, and a 90% chance of developing the disease.</p> <p>Reasons for the sporadic development of genetic mutations that lead to retinoblastoma are not known. One study has examined father's occupation and found an association with certain occupations that involve metal manufacturing, welding and employment in the military, but this evidence is limited.</p>  | No information available  | 52    |

|  | <b>TUMOUR</b> | <b>KNOWN RISK FACTOR</b>  | <b>POSSIBLE RISK FACTORS</b>   | <b>Pg</b> |
|--|---------------|---|--|-----------|
|  | Renal tumours | <p>Most research on causes of renal cancers in young people has focused on Wilms tumour.</p> <p>Wilms tumours are often associated with genetic syndromes (birth defects) involving abnormalities in urinary and genital tract development. Syndromes include WAGR, Beckwith Wiedemann, Denys-Drash and Simpson-Golabi-Behmel syndromes.</p> <p>There appears to be a familial link in 1–3% of cases (inheritance abnormal gene). There are also differences in the likelihood of developing Wilms tumour according to race/ethnicity (e.g. lower incidence in Asian children), further supporting a genetic link.</p> <p>Evidence is unclear in relation to environmental factors. Several have been suggested but evidence is limited to only one or two studies or measures of exposure that have not been reliable. Paternal occupation involving welding or mechanics has been suggested as a risk factor, but evidence is not yet conclusive.</p> | <p>Other factors where evidence is even more limited include:</p> <ul style="list-style-type: none"> <li>• high birth weight</li> <li>• parental exposure to pesticides</li> <li>• exposure to X-rays in utero</li> <li>• consumption of tea or coffee during pregnancy</li> <li>• maternal use of hair dyes</li> <li>• use of certain medications during pregnancy</li> </ul> <p>Maternal occupation (electronics, clothes manufacturing, hair dressing, laboratory and dental assistants).</p> | 22        |

|  | TUMOUR                                | KNOWN RISK FACTOR   | POSSIBLE RISK FACTORS    | Pg |
|--|---------------------------------------|---|--------------------------|----|
|  | Hepatic tumours(cancers of the liver) | <p>The causes of liver cancer in children in more developed countries are not well understood.</p> <p>In less well developed countries, hepatitis B infection, transferred from mother to child at birth, is linked to the development of hepatocellular carcinoma in older children and young adults.</p> <p>Risk factors for hepatoblastoma include:<br/>being male•</p> <ul style="list-style-type: none"> <li>• having the familial adenomatous polyposis (FAP) gene•</li> <li>• having Beckwith-Wiedemann syndrome•</li> <li>• Having a very low birth weight. •</li> <li>• Certain parental occupations (related to metals, petroleum products and paints) have been implicated but evidence is limited to one study.</li> <li>• Being male, having hepatitis B or C infection, or having other diseases causing liver damage, increases the risk of hepatocellular carcinoma.</li> </ul> | No information available | 62 |

**Reference:**

- Cancer Council South Australia 2008, "Cancer Among Young South Australians", *Centre for Cancer Control Research, South Australia cancer statistics, Monograph No 10*, [http://www.cancersa.org.au/cms\\_resources/documents/CancerAmongYoungSouthAustralians1.pdf](http://www.cancersa.org.au/cms_resources/documents/CancerAmongYoungSouthAustralians1.pdf) **NOT AVAILABLE???**

## **Appendix E: Organisations and professional colleges to be included in the statewide cancer directory**

The AYA Working Party recommends that a web-based service directory of health professionals interested in AYA cancer care is included in the SA Statewide Cancer Services Directory. The directory should include the following:

- medical services
- age-appropriate resources
- psychosocial supportive cancer care services
- AYA Cancer referral telephone number
- how to contact cancer specialists after-hours
- links and contact details for relevant professional colleges and organisations

The SA Cancer Services Directory should contain links to the following professional organisations and colleges:

- Australasian Chapter of Palliative Medicine, Royal Australasian College of Physicians
- Australasian Leukaemia and Lymphoma Group
- Australian Orthopaedic Society
- Clinical Oncological Society of Australia (COSA)
- Haematology Society of Australia
- Medical Oncology Group of Australia (MOGA)
- Royal Australian and New Zealand College of Obstetrics and Gynaecology (RANZOG)
- Royal Australasian College of Physicians (RACP)
- Royal Australasian College of Surgeons (RACS)
- Royal Australian College of General Practitioners (RACGP).
- Royal College of Pathologists of Australasia (RCPA)
- The Faculty of Radiation Oncology, Royal Australian and New Zealand College of Radiologists (RANZCR).

The SA Cancer Service Directory should also contain links to the resources listed in Appendix O: Resources for Adolescents, Young Adults with cancer and their families in South Australia.



## Appendix F: OnTrac@PeterMac Psychosocial Assessment Tool

onTrac@PeterMac psychosocial assessment: Adapted from HEADDSS tool (Goldenring & Cohen,1998) to incorporate medical issues and a strength-based approach

onTrac@PeterMac

PSYCHOSOCIAL ASSESSMENT

### PATIENT DETAILS

- i. Name \_\_\_\_\_
- ii. Age \_\_\_\_\_
- iii. Date of Assessment \_\_\_\_\_

### GOAL OF ASSESSMENT

The first step of the assessment process involves discussing the goals of the psychosocial assessment. Many young people may not have had contact with health services or a mental health professional prior to their diagnosis. They may find the experience anxiety provoking and intimidating. It is important that the young person is assured that the process is preventative and is in recognition of the inherent stress associated with a diagnosis during the AYA years, rather than an indication that the team feels the young person is not coping. It is important that the role of the assessment in treatment planning is explained, in particular its role in supporting the young person in other areas of their life and supporting them throughout treatment and into survivorship.

### CONFIDENTIALITY

Confidentiality should be discussed with all young patients at the beginning of the assessment. Young people are unlikely to discuss personal and sensitive information without understanding the confidentiality arrangements of the assessment. It is important to let the young person know what will remain confidential (i.e. the difficulties in their relationships with parents or partner), what cannot remain confidential (i.e. if young person is in danger, if they are a danger to themselves, if they are a danger to others) and what is open to a negotiated arrangement (i.e. those issues that may impact upon the team's ability to provide the best care possible). Any institutional requirements for documenting assessments and ongoing contact should be made clear at the outset so as to avoid any misconceptions about confidentiality as the relationship progresses.

### DETAILED HISTORY OF CANCER EXPERIENCE

Despite their current involvement with the health system, the "whirlwind" nature of a cancer diagnosis can leave the young person feeling like they have been treated like another number and have not been addressed like a person. One of the ways that the assessment can assist in this process is providing the young person with the opportunity to tell their "story" from start to finish. This can be a very cathartic process for the young person, but it also gives the clinician an insight into the roles of support people within the patient's life, the process leading to the diagnosis (i.e. delays that may be associated with residual anger). This is also a gentle way to get the young person talking and to build trust – most young people are very comfortable talking about their medical history.

#### *Example prompts...*

*A cancer diagnosis can be a pretty crazy experience. I am really interested to learn more about what your life has been like over the past few weeks. Are you able to tell me "your story" from the time you first realised something was not quite right to how you ended up here talking to me?*

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## MENTAL HEALTH STATUS (SUICIDE / DEPRESSION)

Many of the issues that identify a young person's mental health status or risk for pathological functioning will already have been addressed throughout the assessment. These include family problems, changes in school performance, changes in friendships, sexual acting out, drug and/or alcohol abuse. However, direct questions to be addressed at this stage include a history of mental health problems or suicide in family members or close friends. Further, if the assessment indicates that depression is likely, it is important to ask directly and clearly about self-harm. Be vigilant to comments about feeling "bored" as this can be an indicator of depression in this age group. Feelings of hopelessness, changes in eating patterns, sleep disturbance, and diminished affect should also be noted. If the young person does have a history of previous mental health issues, determine what interventions they have had in the past, what worked for them and what did not work...

### **Example prompts...**

*How do you feel in yourself at the moment on a scale of 1 to 10? Do you ever have really good/bad times? Do you ever have worries that keep you awake? What sort of things do you do if you are feeling sad, angry, or hurt? Is there anyone you can talk to about these things? Do you feel this way often? Some people who feel really down often feel like hurting themselves or killing themselves, have you ever felt this way? Have you ever tried to hurt yourself? What prevented you from doing so? Do you feel the same way now? Do you ever feel that life is just not worth it? Have you ever thought of just ending your pain once and for all? How strong are these feelings at the moment? Do you have a plan? What is your plan?*

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## CURRENT STRESSORS

With everything that is going on in the life of the young person, they may feel pressure from other areas of their life that are not related to their cancer experience. It is important to know all aspects of the pressure and stress going on in their life in order to provide a holistic plan of support during their experience.

### **Example prompts...**

*With everything that is going on in your life at the moment, what is creating the greatest stress for you? What about your cancer experience is the most worrying? What is it outside of your cancer experience that is creating the greatest stress?*

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## FINISHING THE ASSESSMENT

It is good to finish the assessment with a brief summary of what you heard is going on in the life of the young person. Identifying the specific stressors they have noted, the strengths they have identified, and the areas that the clinician feels they can offer support or interventions to assist. It is important to get the young person to comment on whether this is an accurate summary and to incorporate any additions or changes they feel are more representative. If possible, finish the assessment with a plan for how the young person will be supported over the coming months.

### *For example...*

*"I notice that you have been having problems with your sleep since your diagnosis and that you don't feel like there is anyone in your life that you can be totally honest with about your experience. These are things that I can help you with. I would recommend that we make another appointment for you to come back next week for us to tackle your sleep problems and it will also give you an opportunity to have a chat about how things have been going over the past week. What do you think of that idea?"*

## AREAS TO ADDRESS

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_

## Appendix G: OnTrac@PeterMac Transfer Document

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## Appendix H: AYA cancer statewide fertility referral form

|   |
|---|
| <b>South Australian Adolescent and Young Adult<br/>Fertility Preservation Referral Form</b> |
|---|

Date of Referral: \_\_\_\_\_/\_\_\_\_/\_\_\_\_

**Patient Details:**

Patient Surname: \_\_\_\_\_

First Name: \_\_\_\_\_

Date of Birth: (dd/mm/yyyy): \_\_\_\_\_/\_\_\_\_/\_\_\_\_

Male

Female

Address: \_\_\_\_\_  
\_\_\_\_\_

Suburb: \_\_\_\_\_ Postcode: \_\_\_\_\_

Partners Surname: \_\_\_\_\_ First Name \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

**Referee Details:**

Referring Doctor: \_\_\_\_\_

Treating Hospital: \_\_\_\_\_ Hospital UR: \_\_\_\_\_

Name of Cancer Specialist: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Contact Numbers: \_\_\_\_\_ FAX: \_\_\_\_\_

Email: \_\_\_\_\_  
\_\_\_\_\_

Provider Number Referring Doctor: (where applicable) \_\_\_\_\_

**Clinical Information:**

Diagnosis:

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Disease Extent (specifically abdominal/pelvic involvement):

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Planned/current treatment:

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Estimated time available before treatment starts:

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**Additional Information:**

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**To make an appointment please PHONE AND FAX referral to either:**

1. Repromed – head office at Rose Park (male and female)  
Tel: (08) 8333 8111  
Fax: (08) 8333 8188
2. Flinders Reproductive Medicine (male)  
Tel: (08) 8204 4578  
Fax: (08) 8204 7025
3. Fertility SA: WCH Campus (male and female)  
Tel: (08) 8100 2900  
Fax: (08) 8100 2000

\*Please file this referral form in patient medical records

|   |
|---|
| <b>South Australian Adolescent and Young Adult<br/>Fertility Preservation Referral Form</b> |
|---|

## Recommendations

1. It is essential that every Adolescent and Young Adult is offered fertility and sexual health counselling.
2. Discussion of fertility issues should be introduced prior to a fertility preservation referral being made.

3. In females pregnancy status must be ascertained and testing arranged as necessary prior to commencing cancer treatment.
4. Fertility status and ongoing reproductive health should be actively addressed as part of long term follow up.
5. Written information should be provided to the Adolescent or Young Adult and any relevant family members.

## Appendix I: Steps in fertility assessment Repromed (males)

### Fertility Preservation Referral Process Repromed (Male)

#### STEP ONE: REFERRAL

##### Referral by Medical Officer (GP or Treating Medical Team)

Please provide details by telephone **AND** fax the referral form to Repromed. Ensure pathology request form is completed.

**Details:** Advise Repromed receptionist that this is an Adolescent and Young Adult (AYA) person with cancer:

Tel (08) 8333 8111      Fax (08) 8333 8188

The receptionist will log the call as urgent (same day response) and email the New Patient Coordinator who will return phone call to referring clinician on the same day. All AYA patients with a cancer diagnosis are flagged/colour coded for priority within Repromed System.

The New Patient Coordinator will contact the patient to discuss services and will make appointments for semen collection, semen assessment, consent for storage and counselling. Written information is provided to the patient (mailed to either home/hospital)

#### STEP TWO: SEMEN COLLECTION

##### Semen collection and storage at Repromed.

Collection at Repromed is preferred. If the patient circumstances do not allow this, please discuss this with the New Patient Coordinator.

A letter is sent to the patient detailing results and if further samples are required.

For further information on male fertility preservation options please refer to accompanying table overleaf.

#### STEP THREE: MEDICAL CONSULT

**Fertility preservation assessment and review:** An appointment is made with a Repromed fertility specialist either on the same day as the semen collection or within 7 days of semen collection. The consultation includes the results of the semen collection, storage and future options.

This consult may take place via the telephone if the patient is an inpatient and/or unable to attend in person. Alternative fertility preservation options may be discussed at this appointment as required.

A letter is sent to the patient and referring cancer specialist outlining semen collection results and relevant discussion points.

Medical consults and semen assessments are bulk billed to Medicare.

#### STEP FOUR: COUNSELLING

**Counselling services are offered at initial telephone contact and are available to patients/family.**

Appointments may be made at any stage during or after fertility preservation.

Counselling services are free of charge.

Sexual health needs may be discussed and referrals to other services are made for ongoing support.

#### STEP FIVE: FOLLOW UP

##### Fertility Preservation Follow Up:

A letter is sent to the patient annually offering follow up appointment regarding review of current fertility status.

Patients are sent invoices 6 monthly after the first 12 months of storage.

## Appendix J: Steps in fertility assessment, Repromed (female)

### Fertility Preservation Referral Process Repromed (Female)

#### STEP ONE: REFERRAL

##### Referral by Medical Officer

(GP or Treating Medical Team)

Please provide details by telephone **AND** fax the referral form to Repromed.

**Details:** Advise Repromed receptionist that this is an Adolescent and Young Adult (AYA) person with cancer:

Tel (08) 8333 8111 Fax (08) 8333 8188

The receptionist will log the call as urgent (same day response) and email the New Patient Coordinator who will return phone call to referring clinician on the same day. All AYA patients with cancer are flagged/ colour coded as priority patients within the Repromed system.

The New Patient Coordinator will contact the patient to discuss services and will make an appointment for fertility preservation assessment and counselling.

Written information is provided to the patient (Mailed to either home/hospital)



#### STEP TWO: MEDICAL CONSULT

##### Fertility preservation assessment and review:

An appointment is made with a Repromed fertility specialist (either Dr Morgan Valani or Dr Kelton Tremellen)

Fertility preservation options are discussed with the patient/family/partner. The discussion considers each persons individual context, i.e. cancer diagnosis, patient wishes and viable fertility preservation options. (refer to accompanying tables that provide information on options and associated costs in South Australia)

Medical Consults and investigations for fertility preservation are bulk billed to Medicare.

A letter is sent to the patient and referring cancer specialist outlining key discussion points and recommendations for fertility preservation.

For further information on female fertility preservation options please refer to accompanying table overleaf.



#### STEP 3: COUNSELLING

**Counselling services are offered at initial telephone contact and are available to patients/family at any stage during or after fertility preservation.**

Counselling services are free of charge.

Counselling is a core component for all females who proceed with IVF treatment for fertility preservation.

Sexual health needs may be discussed and referrals to other services are made for ongoing support.



#### STEP FIVE: FOLLOW UP

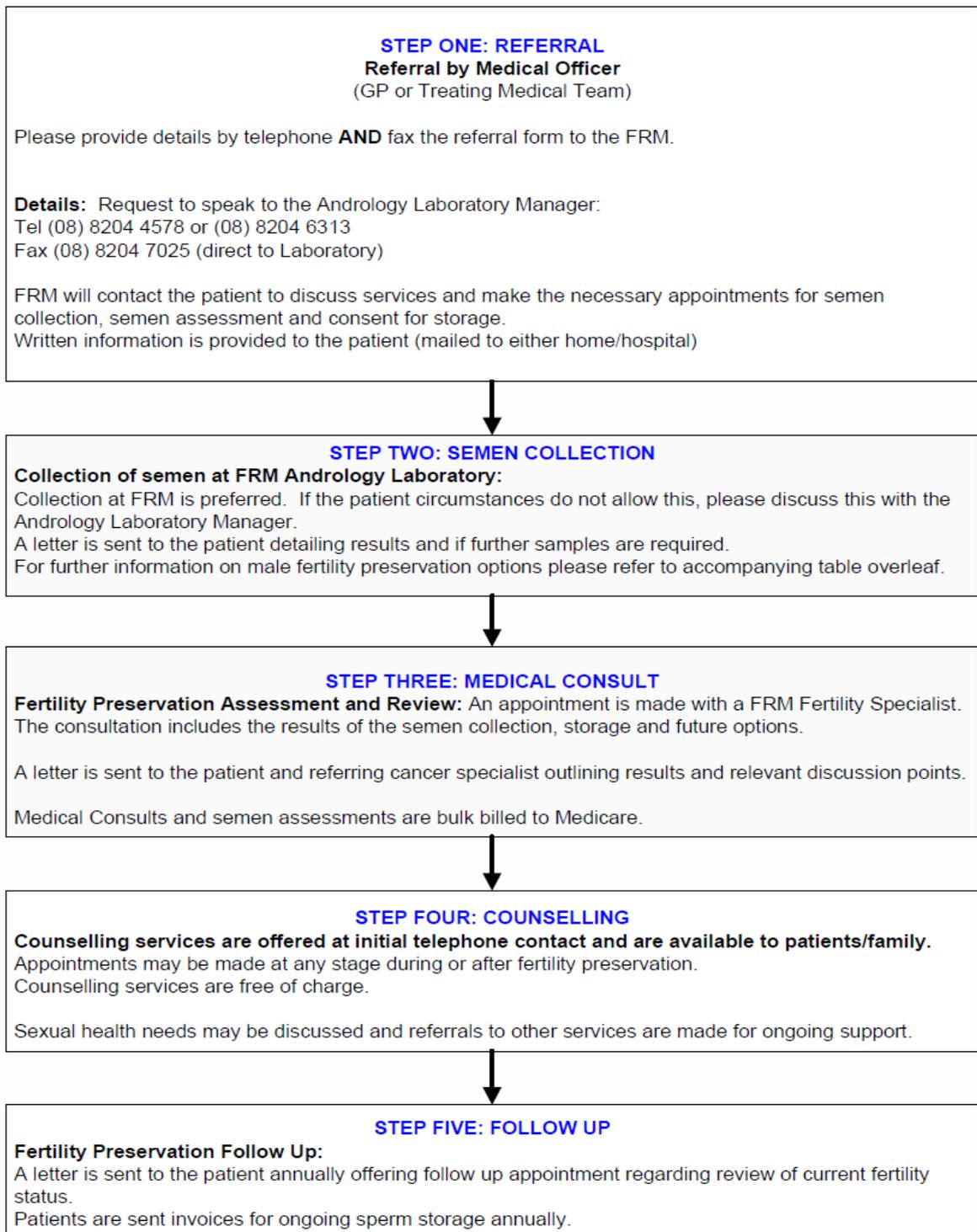
##### Fertility Preservation Follow Up:

A letter is sent to the patient annually offering a follow up appointment regarding review of current fertility status.

Patients are sent invoices 6 monthly after the first 12 months of storage .

## Appendix K: Steps in fertility assessment, Flinders Reproductive Centre (males)

### Fertility Preservation Referral Process Flinders Reproductive Medicine (MALE)



## Appendix L: Effects of Cancer Treatments on Sperm Production in Males

**Table 1 outlines the likely adverse effect of cumulative doses of individual drugs/ treatments.**

“c” denotes that when the therapy is used in combination there is an increased risk.

Risk is defined as a high risk to permanent azoospermia, medium risk to permanent azoospermia, temporary azoospermia likely, low risk for permanent azoospermia and unknown risk to sperm production.9,12,13,32-34, 36-38

| Treatment                              | High >80% | Medium | Temporary | Low <20% | Unknown |
|--|-----------|--------|-----------|----------|---------|
| 6-mercaptopurine (unknown)             |           | c      | •         |          |         |
| Actinomycin D (unknown)                |           | •      |           |          |         |
| Amascrine (unknown)                    |           | c      | •         |          |         |
| Ara-c (1g/m <sup>2</sup> )             |           | c      | •         |          |         |
| Bevacizumab (unknown)                  |           |        |           |          | •       |
| Bleomycin (unknown)                    |           | c      | •         |          |         |
| Busulphan (1g/m <sup>2</sup> )         |           | •      |           |          |         |
| Carboplatin (2g/m <sup>2</sup> )       |           | •      |           |          |         |
| Carmustine (300mg/m <sup>2</sup> )     |           | •      |           |          |         |
| Carmustine (1g/m <sup>2</sup> )        | •         |        |           |          |         |
| Cetuximab (unknown)                    |           |        |           |          | •       |
| Chlorambucil (1.4g/m <sup>2</sup> )    | •         |        |           |          |         |
| Cisplatin (500mg/m <sup>2</sup> )      | •         |        |           |          |         |
| Cyclophosphamide (19g/m <sup>2</sup> ) | •         |        |           |          |         |
| Dacarbazine (unknown)                  |           | c      | •         |          |         |
| Daunorubicin (unknown)                 |           | c      | •         |          |         |
| Doxorubicin (770mg/m <sup>2</sup> )    |           | c      | •         |          |         |
| Epirubicin (unknown)                   |           | c      | •         |          |         |
| Erlotinib (unknown)                    |           |        |           |          | •       |
| Etoposide (unknown)                    |           | c      | •         |          |         |
| Fludarabine (unknown)                  |           | c      | •         |          |         |
| Fluoruracil (unknown)                  |           | c      | •         |          |         |
| Ifosphamide                            |           | •      |           |          |         |

|                                   |   |   |   |   |   |
|-----------------------------------|---|---|---|---|---|
| (42mg/m <sup>2</sup> )            |   |   |   |   |   |
| Imatinib (unknown)                |   |   |   |   | • |
| Interferon (unknown)              |   |   |   | • |   |
| Irinotecan (unknown)              |   |   |   |   | • |
| Lomustine (500mg/m <sup>2</sup> ) | • |   |   |   |   |
| Melphalan (140mg/m <sup>2</sup> ) | • |   |   |   |   |
| Methotrexate (unknown)            |   | c | • |   |   |
| Mitoxantrone (unknown)            |   | c | • |   |   |
| Nitrogen mustard (unknown)        |   | • |   |   |   |
| Oxaliplatin (unknown)             |   |   |   |   | • |
| Prednisolone (unknown)            |   |   |   | • |   |
| Procarbazine (4g/m <sup>2</sup> ) | • |   |   |   |   |
| Radiation (2.5 Gy to testis)      | • |   |   |   |   |
| Taxanes (unknown)                 |   |   |   |   | • |
| Thioguanine (unknown)             |   | c | • |   |   |
| Thiotepa (400mg/m <sup>2</sup> )  |   | c | • |   |   |
| Trastuzumab (unknown)             |   |   |   |   | • |
| Vinblastine (50g/m <sup>2</sup> ) |   | c | • |   |   |
| Vincristine (8g/m <sup>2</sup> )  |   | c | • |   |   |

## Appendix M: Effects of Cancer Treatments on Menstrual Function in Females

**Table 2 outlines the likely adverse effect of cumulative doses of individual drugs / treatments.**

“c” denotes that when the therapy is used in combination there is an increased risk. The risk of permanent amenorrhea is graded from high risk to low risk, as well as unknown (Ages are shown where appropriate). 9, 12, 32-34, 36, 41-42

| Treatment                                | High >80% | Medium | Low <20% | Unknown |
|--|-----------|--------|----------|---------|
| Ara-c (unknown)                          |           | c      |          |         |
| Bevacizumab (unknown)                    |           |        |          | •       |
| Bleomycin (unknown)                      |           |        | c        |         |
| Busulphan (Unknown)                      | •         |        |          |         |
| Carmustine (unknown)                     | •         |        |          |         |
| Cetuximab (unknown)                      |           |        |          | •       |
| Cyclophosphamide (< 5g/ m <sub>2</sub> ) | C40+      | C30+   | C<30     |         |
| Cyclophosphamide (5g/m <sub>2</sub> )    | • 40+     |        |          |         |
| Cyclophosphamide (7.5g/m <sub>2</sub> )  | • <20     |        |          |         |
| Dacarabazine (unknown)                   |           |        | c        |         |
| Doxorubicin (unknown)                    | C40+      | C30+   | C<30     |         |
| Epirubicin (unknown)                     | C40+      | C30+   | C<30     |         |
| Erlotinib (unknown)                      |           |        |          | •       |
| Fluoruracil (unknown)                    | C40+      | C30+   | • C<30   |         |
| Ifosphamide (unknown)                    | •         |        |          |         |
| Imatinib (unknown)                       |           |        |          | •       |
| Interferon (unknown)                     |           |        | •        |         |
| Irinotecan (unknown)                     |           |        |          | •       |
| Lomustine (unknown)                      | •         |        |          |         |
| Melphalan (unknown)                      | •         |        |          |         |
| Methotrexate (unknown)                   | C40+      | C30+   | • C<30   |         |
| Oxaliplatin (unknown)                    |           |        |          | •       |
| Prednisolone (unknown)                   |           |        | •        |         |
| Procarbazine (unknown)                   | •         |        |          |         |

|                            |   |   |   |   |
|----------------------------|---|---|---|---|
| Radiation (25 Gy to spine) |   | • |   |   |
| Radiation (40 Gy to Brain) | • |   |   |   |
| Radiation (6 Gy to pelvis) | • |   |   |   |
| Taxanes (unknown)          |   |   |   | • |
| Thiotepa (unknown)         |   |   |   | • |
| Trastuzumab (unknown)      |   |   |   | • |
| Vinblastine (unknown)      |   |   | • |   |
| Vincristine (unknown)      |   |   | • |   |

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## Appendix N: Male Preservation Options South Australia

Developed in line with QLD fertility preservation project (A Thompson) in the hope of nationally collated and formatted data

| <b><u>Male Preservation Options SOUTH AUSTRALIA</u></b> |   |   |  |  |
|---|---|---|--|--|
| Option  | Masturbation  | Testicular Sperm Extraction   | Testicular Cortical biopsy                                   | Gonadal Shielding  |
| Medical Status  | Standard  | Standard  | Experimental   | Standard   |
| Definition  | Sperm is obtained via masturbation & cryopreserved  | Sperm is obtained via aspiration or open extraction & cryopreserved | Testicular tissue is obtained through biopsy & cryopreserved | Use of shielding to reduce the dose of radiation delivered to the testes |
| Pubertal Status   | Puberty required  | Puberty required  | Can be done pre puberty                                      | Puberty status is irrelevant   |
| Time Requirement  | Same day – 48 hrs   | 72hrs – 1 week  | 72hrs – 1 week   | During treatment   |
| Success Rate for Quality Sperm                          | Generally high, if able to produce sample.  | Generally high if normal sperm quality is good                      | Sperm not mature. No live births from this method            | Unknown due to internal scatter radiation                                |
| Initial Cost  | Bulk billed – or Medicare gap \$15.00<br>Repromed - \$95.00 for repeat analysis and \$95.00 per freezing sample |   | N/A  | Included in the cost of radiation  |
| Yearly Cost   | \$200 – \$400 increases by 15% annually<br>Billed 6 monthly   |   | N/A  | N/A  |
| Timing  | Before Treatment  | Before Treatment  | Before Treatment   | During Treatment   |
| Special Information                                     | Can be done as inpatient or outpatient  | Private patients only   | Currently experimental and not available in SA               | Does not protect against chemotherapy / surgery                          |

## Appendix O: Female Preservation Options South Australia

Developed in line with QLD fertility preservation project (A Thompson) in the hope of nationally collated and formatted data

| Female Preservation Options South Australia |   |  |  |  |  |
|---|---|--|--|--|--|
| Options                                     | Embryo Cryopreservation                             | Oocyte Cryopreservation                    | Ovarian Cortex   | Gonadal Shielding                                    | Ovarian Suppression                              |
| Medical Status                              | Standard  | Experimental                               | Experimental   | Standard   | Experimental                                     |
| Definition                                  | Harvesting egg & fertilizing, then freezing embryo. | Harvesting egg & freezing unfertilized egg | Ovarian tissue is obtained through biopsy or wedge resection & cryopreserved | Shielding to reduce radiation to reproductive organs | Gonadotrophin analogues used to suppress ovaries |
| Pubertal Status                             | Pubertal  | Pubertal                                   | Can be done pre puberty  | Puberty status is irrelevant                         | Pubertal   |
| Time Requirement                            | As outpatient 10-14 days from menses.               | As outpatient 10-14 days from menses.      | 72hrs – 1 week   | During treatment                                     | Pre & during treatment                           |
| Success Rate                                | Approximately 25 - 40% per transfer                 | Less successful than embryo 3-4 times so.  | Few live births from this method   | Unknown due to internal scatter radiation            | Unknown due to conflicting data                  |
| Initial Cost                                |   |  |  | Included in the cost of radiation                    | Dependant on drug used                           |
| Yearly Cost                                 | \$200 - 400 for freezing storage cost               | \$200 - 400 for freezing storage cost      |  | N/A  | N/A  |
| Timing                                      | Before or after treatment                           | Before or after treatment                  | Before or after Treatment  | During Treatment                                     | Pre & during treatment                           |
| Hormone Stimulation                         | Required  | Required                                   | Not required   | Not required   | Not suggested for hormone sensitive tumours      |
| Special Information                         | Requires partner or Donor Sperm                     | Does not require partner or donor sperm    | Available in South Australia 2009  | Does not protect against chemo / surgery             | Does not protect against surgery or radiation    |

## Appendix P: Resources for Adolescents, Young Adults with cancer and their families in South Australia

|                                | Contact details  | Available resources  |
|--------------------------------|--|--|
| Cancer Council South Australia | 202 Greenhill Road, Eastwood SA 5063<br>Tel: 08 8291 4111<br>Freecall: 1800 188 070<br>Fax: 08 8291 4122<br>Website:<br><a href="http://www.cancersa.org.au">www.cancersa.org.au</a>   | For information on cancer, its treatment and side effects, support services, medical terminology, and research.<br><br>CCSA also provides links to other reliable cancer information websites:<br><a href="http://www.cancersa.org.au/resource_library/3/16/Cancer_information_on_internet_Jun2008.pdf">http://www.cancersa.org.au/resource_library/3/16/Cancer_information_on_internet_Jun2008.pdf</a><br>NOT AVAILABLE |
| Cancer Council Helpline        | Tel: 13 11 20<br>Email: <a href="mailto:chl@cancersa.org.au">chl@cancersa.org.au</a>   | For telephone peers support from people who have had cancer experiences or for information on cancers.   |
| Canteen                        | PO Box 107<br>North Adelaide<br>Tel: 8161 7488 or 1800 226833<br><a href="http://www.canteen.org.au">www.canteen.org.au</a> or <a href="mailto:sa.nt@canteen.org.au">sa.nt@canteen.org.au</a> email<br>Adelaide 5006   | Peer support organisation for 12-24 year olds. Supporting, developing and empowering young people living with cancer. Patient, offspring, siblings and bereavement support for siblings and offspring. Group activities, recreation days and camps.  |
| Cancer Council Australia       | Website: <a href="http://www.cancer.org.au">www.cancer.org.au</a>  | Fact sheets:<br>Lifestyle: <a href="http://www.cancer.org.au/lifestyle">www.cancer.org.au/lifestyle</a><br>Early detection: <a href="http://www.cancer.org.au/earlydetection">www.cancer.org.au/earlydetection</a><br>Post diagnosis: <a href="http://www.cancer.org.au/diagnosis">www.cancer.org.au/diagnosis</a>   |
| Cancer Care Centre             | 76-78 Edmund Ave, Unley SA<br>Cancer support line: 08 8272 2411<br>Administration: 08 8373 1470<br>Fax: 08 8357 1979<br>Website:<br><a href="http://www.cancercarecentre.org.au">www.cancercarecentre.org.au</a><br>Email:<br><a href="mailto:admin@cancercarecentre.org.au">admin@cancercarecentre.org.au</a> | Non profit integrative medicine approach for complementary care with hospital-based cancer treatments, psychological supportive services including counselling, support groups, spirituality courses, mens and womens groups, massage, reiki, shiatsu, yoga and range of other organic and supportive therapies. Extensive library.  |

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| The Leukaemia Foundation                | 8273 3515 or 1800 620 420<br>Fax: 8357 7656<br><a href="http://www.leukaemia.org.au">www.leukaemia.org.au</a><br><a href="http://www.talkbloodcancer.org.au">www.talkbloodcancer.org.au</a><br>NOT AVAILABLE<br><a href="http://www.teamrevive.com">www.teamrevive.com</a> | National organisation dedicated to care of people living with blood cancers. Financial, accommodation, transportation and educational assistance. Support for patients and families. Specific support for 15-24 year olds with blood cancers and blood disorders.   |
| Redkite                                 | National Office<br>PO Box 3220<br>Redfern NSW 2016<br><br>Tel: 02 9219 4000<br><a href="http://www.redkite.com.au/index.aspx">www.redkite.com.au/index.aspx</a> NOT AVAILABLE<br>Email: <a href="mailto:national@redkite.org.au">national@redkite.org.au</a>               | Emotional support, financial assistance, music therapy, family support, bereavement and funeral assistance for children and young people and their families living with cancer. (0-21years)<br>Educational scholarships for young cancer survivors. On-line social work services. AYA 24hr social worker email counselling and telegroups support.                                    |
| Cancer Voices                           | Ashleigh Moore<br>Email:<br><a href="mailto:info@cancervoicessa.gov.au">info@cancervoicessa.gov.au</a><br><a href="http://www.cancervoices.org.au">www.cancervoices.org.au</a>   | Consumer advocacy - Website contains info for AYA's and their families. Special interest in this age group 15-24 years.   |
| Childhood Cancer Association            | Level 1/55 King William Road<br>North Adelaide 5006<br>Tel: 82391444   | Focus on support for children and families experiencing cancer aged between 0-20 years. Family support services, practical, emotional, social. Tutoring programme. Sibling support and, bereaved parents support groups   |
| CAN DO 4 KIDS                           | Townsend House<br>28 King George Avenue<br>Hove 5048<br>PO Box 43 Brighton 5048<br><a href="mailto:info@cando4kids.com.au">info@cando4kids.com.au</a><br><a href="http://www.cando4kids.com.au">www.cando4kids.com.au</a>  | Early intervention including small group activities for children and young adults aged up to 25. This includes - speech pathology, occupational therapy, home and school support, family support including counselling, specialised recreational and social programs, loan equipment, mentoring program for youth with sensory impairment. Dedicated youth worker for 16-25year olds. |
| Gay and Lesbian Counselling Services SA | Tel: 8334 1623 or<br>1800 182 233<br><a href="http://www.glcssa.org.au">www.glcssa.org.au</a>  | Confidential peer base counselling service Mon-Fri. 7pm-10pm<br>Sat-Sun.2-5pm   |
| Shine SA                                | Tel: 1300 883 793<br>South: 8352 8164<br>West: 8300 5300<br>North: 8252 7955<br><a href="http://www.shinesa.org.au">www.shinesa.org.au</a>   | Sexual health information, networking, information and clinical services<br>Library telephone information and referral.   |
| Camp Quality                            | Tel:08 8239 0844   | Support for those experiencing  |

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|-----------------------------------|---|---|
| SA                                | Fax: 08 82390833<br><a href="http://www.campquality.org.au">www.campquality.org.au</a>  | childhood cancer 0-18 years.<br>Recreational activities for children with cancer, siblings and parents. Focus on camps and Fun / Laughter as therapy.<br>Companion support programme.<br>Education in schools – Puppet programme.<br>Tutoring assistance.   |
| Headroom                          | Norwich Centre<br>Level 3, 77 King William Road<br>North Adelaide 5006<br>Tel: 8161 6983<br><a href="http://www.headroom.net.au">www.headroom.net.au</a><br><b>NOT AVAILABLE</b><br>Email: <a href="mailto:info@headroom.net.au">info@headroom.net.au</a> | Web based information for young peoples' mental health promotion.   |
| Look Good Feel Better             | c/- 3 Chelsea Avenue<br>Flagstaff Hill 5159<br>Tel: 8370 4110<br>Fax: 8370 4136   | Workshops free of charge focus on body changes following cancer diagnosis.<br>Non-commercial – product neutral products supplied free of charge. Teen girl's workshops for 12-16years and young adults' women's workshop for 18-25 years both co facilitated by AYA social worker and LGFB staff. Men's workshops also run regularly. |
| Southern Fleurieu Health Service  | Harbour View Terrace Victor Harbour 5211<br>Tel: 8552 0600<br>Fax: 8552 0616  | Primary health care agency – information, counselling, social work, carers groups, community nursing. Indigenous women's health clinical assessment and management. Pregnancy/ parenting support network 15-25yrs   |
| Palliative Care Council of SA Inc | 202 Greenhill Road<br>Eastwood SA 5063<br>Tel: 8291 4137<br>Website: <a href="http://www.pallcare.asn.au">www.pallcare.asn.au</a>   | Resources to comfort relieve pain and distress for people who are dying, and to support parents, families and friends in approaching death and into bereavement.  |