

STEPS FORWARD: TOWARDS A SERVICE DELIVERY IMPROVEMENT FRAMEWORK FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER

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Abstract

There is mounting national and international evidence to support targeted improvements in cancer care services for adolescents and for young adults; an age group defined in Australia as those between 15 and 25 years. Both paediatric and adult oncology and haematology services currently provide cancer care for adolescents and young adults. There are many unmet needs under the current service delivery paradigm - both physical and psychosocial. Improving cancer outcomes for young people is clearly multidimensional and must be achieved over time. Cancer Australia brought together a diverse set of stakeholders to form the Adolescents and Young Adults Cancers National Reference Group. With support from CanTeen, a peer support organisation for adolescents and young adults with cancer, the reference group developed a service delivery framework which aims to reduce the impact of cancer on young Australians. Adolescents and young adults are receiving treatment, across many centres throughout Australia, and will benefit from: better coordination of existing services; and, promotion of access to these coordinated services. At present, a broader consultation on the framework for adolescent and young adult cancer care has commenced with state and territory health jurisdictions.

Evidence base

There is mounting national and international evidence to support targeted improvements in cancer care services for adolescents and young adults. The incidence of cancer in adolescents and young adults, defined as those between the ages of 15 and 25, was less than 1% (907:489 male, 418 female; 0.92%) of new cases diagnosed in the overall population in Australia in 2004. Though a relatively small percentage of cancer incidence in the overall population, this is nearly two thirds more than new cases diagnosed in children (610; 0.62%).¹ Fortunately, survival rates of adolescents and young adults with cancer are relatively high and continue to improve.² The majority of young people diagnosed with cancer are expected to survive. Better health services for adolescents and young adults can help ensure that young people with cancer optimise their development to live full and healthy lives.

The most common cancers in adolescents and young adults in Australia are melanoma, testicular cancer, Hodgkin's and non-Hodgkin's lymphoma, and cancer of the thyroid. These cancers account for 61% of cancers diagnosed in adolescents and young adults.³ The most common cancers causing death among young people are brain cancer, bone cancers, leukaemia and lymphoma.⁴ Prevalence data provides evidence that adolescents and young people are living longer with a diagnosis of cancer than ever before. For diagnoses in 1998–2004, all cancer five year survival rates were highest for the 20–29 year age group for both males (86%) and females (89%).²

Improving cancer outcomes for young people is multidimensional. A Senate inquiry in 2005, *The Cancer Journey: Informing Choice*, identified the particular difficulties confronting young people with cancer and urged an improved model of cancer care to address the problems raised.⁵ For example, access to clinical trials for adolescents with cancer is poor. This means that this age group is less likely to have early access to new and experimental therapies. Further issues identified suggest they are less likely to have access to specialised multidisciplinary cancer care where the best results are achieved.⁵ They also lack access to referral guidelines for specialist care, often resulting in referrals to either paediatric or adult cancer physicians.⁶

Towards an improved model of care for adolescents and young adults with cancer

Both paediatric and adult oncology and haematology services currently provide cancer care for adolescents and young adults, but existing services may not be meeting their needs. The Clinical Oncological Society of Australia held a national workshop to focus on the needs of adolescents and young adults. Further, to begin to better understand the unique needs of this age group, in May 2007, Cancer Australia brought together a diverse set of stakeholders to form the Adolescents and Young Adults Cancers National Reference Group. At its first meeting, the reference group prioritised the development of a new national service delivery framework which would aim to reduce the impact of cancer on young Australians.⁷

CanTeen, a peer support organisation for adolescents and young adults with cancer, approached Cancer Australia to partner in discussions with individuals and groups across the country. During 2007 and 2008 consultations were held with adolescents and young adults affected by cancer, private and public sector oncologists, surgeons, epidemiologists, researchers, educators, general practitioners, nurses, psychologists and clinicians with experience in paediatric and adult cancer care. Researchers supporting the National Reference Group reviewed the National Service Improvement Framework for Cancer and state and territory cancer plans, as well as similar adolescent and young adult service frameworks in the United Kingdom and New Zealand.^{8,13}

The consultation process uncovered needs of adolescents and young adults affected by cancer, as well as the structural impediments to improving the way cancer care services are delivered to young people. Crucial to the process were consultations with adolescent and young adults who have gone through the existing cancer system in Australia.

"As a young person who has had cancer and has been part of the system it is vital that we are involved with the solution. Our need through this time is one of the keystones in improving the service delivery framework for adolescents and young adults affected by cancer." Liam Hunt

Young people with cancer have unique health needs that affect their quality of life, their long-term health, and their engagement in society, education and employment. The interviews pointed to specific physical, practical and psychosocial needs that remain largely unmet for adolescents and young adults under current service delivery protocols. For example, young people with cancer are often told how cancer treatments can affect their fertility. Young people need to consult a fertility counsellor to explore their fertility options and the potential impacts on their lives. However, it is rare that psychosocial impacts, both immediate and long-term, are addressed.

Young people who are in school or university and undergoing cancer treatment may require help to keep up with classes or with reintegration into the classroom. This may require additional educational assistance, liaising with teachers or school administrators, or talking to the school community about cancer. Additionally, the intensity of cancer treatment may have a significant impact on young people's ability to find or maintain work. They may need help with discussing appropriate leave with their supervisors or with their transition into the workplace once they are ready to return to, or start, work. The impacts of cancer may mean that some young people may need help with choosing new and appropriate career options after treatment.

Just as important as the tangible physical and practical needs, young adults raised a host of psychosocial factors that had a particularly acute impact on them as they faced cancer. Young people diagnosed with cancer are not immune from the pressures common to their age group. Adolescents and young adults are in a

transformative stage of their psychological development, which affects their social behaviour. As young people become increasingly independent, they make decisions about sexuality, alcohol, drugs and peer interactions. Health professionals must be able to discuss issues with young people openly and honestly and provide support when needed. Age appropriate psychosocial support can positively affect adherence to treatment regimes, pain management, treatment for depression and managing communication with health professionals.⁹

In addition, the years during adolescence and young adulthood are often quite mobile times. Young people may be relocating for tertiary studies or simply travelling to gain life experiences. Coordinated care was identified as a strong need to ensure appropriate follow-up and screening during diagnosis, treatment and supportive care.

Consultations with professionals caring for adolescents and young adults with cancer exposed structural barriers that must be addressed. First, there is little clinical data available on adolescent and young adult cancer outcomes.¹³⁻¹⁴ Second, there is only a limited body of evidence to guide the efficacy of clinical approaches to cancer care for adolescents and young adults.¹⁵ Third, there is a relative scarcity of specific training options for all health professionals engaged with adolescents and young adults to broaden their knowledge of cancer in this age group.¹¹ Fourth, improved research and participation in clinical trials is pivotal to attaining better long-term outcomes for adolescents and young adults with cancer. Bolstering both research and training are necessary to improved cancer care for young people.⁹

Steps forward

The consultation process drew together the needs of adolescents and young adults with cancer and the gaps in knowledge, treatment and services from professional experts. The result is a framework that focuses on aspects of service delivery most likely to increase survival of young people and to enhance short and long-term quality of life outcomes for adolescents and young adults, their families and carers. It articulates an approach for adolescent cancer care that crosses jurisdictional boundaries, is based on the best available evidence and sets an aspirational national standard to achieve and continually refine over time.

Its implementation will better address the needs of young people affected by cancer and improve access to coordinated services and has been achieved through agreement of an expert group drawn from paediatric and adult cancer services, researchers and policy makers from across the country. It will require changes in practice to focus on the needs of adolescents and young adults, in order to build skills in treatment and supportive care, improve access to cancer clinical trials, strengthen professional development in adolescent health and provide access to multidisciplinary cancer care across a broad range of needs – psychosocial, psychosexual, physical, treatment and supportive care, cultural and relationship needs.

A broader consultation on the framework for adolescent and young adult cancer care has commenced with state

and territory health jurisdictions. The aim is to engage cancer services on the agreed framework to guide practice and effectively serve the unique needs of adolescents and young adults facing a cancer diagnosis.

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CHILDHOOD SOLID TUMOURS OCCURRING IN ADOLESCENTS AND YOUNG ADULTS

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Abstract

A small number of adolescents and young adults are diagnosed with solid tumours that typically occur in childhood – the most common are neuroblastoma, Wilms' tumour and rhabdomyosarcoma. In general, these cancers are often more locally advanced or metastatic when they occur in adolescents and young adults compared with childhood presentations. Multidisciplinary and multimodality care is indicated, usually including surgery, chemotherapy and radiotherapy. Although these tumours often respond to treatment, the overall survival of adolescents and young adults is inferior to that of children. Retrospective analyses of subsets of older patients with Wilms' tumour and rhabdomyosarcoma suggest that prognosis is improved when treatment is delivered according to paediatric guidelines. However, tumour biology must, at least in part, account for the differences in outcome observed between adolescents and young adults and children. A paradigm of cooperative care between adult and paediatric oncologists is encouraged – entry on to age-appropriate clinical trials should be standard of care. Taking these considerations into account, a national Adolescents and Young Adults Cancer Service has been established in New Zealand, premised upon multidisciplinary cooperative care for adolescents and young adults with cancer and their families.

A wide variety of cancers occur in adolescents and young adults (AYA) aged 15-29 years, the most common being lymphoma, skin cancer, thyroid carcinoma and tumours of the testis, ovary and female genital tract.¹ The common extra-cranial solid tumours of childhood account for a small proportion of cancers in AYA. However, these cancers are important. Compared with carcinoma, they are particularly responsive to chemotherapy and radiotherapy; for some tumours, prognosis has been shown to improve when treated according to paediatric trials and guidelines. A paradigm of multidisciplinary care involving close cooperation between adult and paediatric oncologists is essential.²

Childhood solid tumours are so-called embryonal tumours – their genesis likely represents an arrest of cellular differentiation with retention of foetal characteristics.

However, the biological mechanisms responsible for their occurrence later in life, although currently unclear, are likely to result in more aggressive clinical behaviour.³ The most common embryonal tumours are neuroblastoma, Wilms' tumour and rhabdomyosarcoma; less common are cancers of the liver (hepatoblastoma) and eye (retinoblastoma).

Neuroblastoma

This tumour is the most common and lethal extra-cranial solid malignancy of childhood, accounting for 8-10% of cancers in patients <15 years of age. Neuroblastoma is the most common cancer of infancy – the median age at diagnosis is 19 months and 98% are detected before 10 years of age.⁴ An enigmatic cancer, the biological behaviour spans metastatic tumours that regress spontaneously (stage 4S – table 1) to widely metastatic