

Adolescents, young adults and cancer

What GPs need to know

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GP care for adolescents and young adults with cancer can be vital for the wellbeing of patients through their diagnosis, treatment and follow up. It is important for GPs to be familiar with cancer services for this age group, including services that provide age-appropriate medical, nursing and psychosocial care.

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The adolescent and young adult (AYA) population in Australia is defined as people between 15 and 25 years of age. Data from the 2012 Census of Housing and Population show that young people in this age range account for 14% of the Australian population. Fifty-one per cent of them are male, 72% live in a major city, 42% live at home, 19% live in the lowest socioeconomic status quintile and 24% are unemployed.¹

During this period of their life, AYAs normal experience significant change as they undergo transition from childhood into adulthood.² It is a period of significant physical, cognitive and emotional change, meaning that the psychosocial needs of this age group differ substantially from

those of younger or older patients. AYAs start to experience an awareness of their body image and sexuality, and many are experiencing relationships for the first time. At the same time, they are meeting the demands of high school or university education, vocational training or entering the workforce for the first time. This is also a period in which a young person's autonomy is developing and they are balancing a need for independence with parental nurturing. Increased risk-taking behaviour and involvement in activities they have never before attempted are absorbing young people's attention, as they construct a platform for early adult life. With all these novel experiences, young people experience significant pressure and many





KEY POINTS

- GPs have an important role in providing care for adolescents and young adults (AYAs) with cancer, and their role should be encouraged, even for patients with complex needs.
- Dedicated AYA support services are essential for delivering developmentally and age-appropriate care to AYA patients, whose needs are significantly different from those of younger and older patients.
- CanTeen administers the Federal and State Government-funded age-specific Youth Cancer Services across Australia for cancer patients between 15 and 25 years of age.
- Challenges when caring for this age group include understanding the differences in cancer biology and the complex psychosocial needs of AYAs, and enabling participation in clinical trials and research.
- Young people attend their GP frequently but consultations involving symptoms related to cancer are rare. The *Early Detection of Cancer in AYAs* guideline has been developed for primary health professionals involved in the management of AYAs with cancer.
- Although cancer in the AYA age group is rare, a cancer diagnosis is the most common cause of death in this age group after accidents, murders and suicides.

struggle with mental health problems (just over one-quarter of people between 16 and 24 years of age have some form of mental health disorder).³

Understanding these psychological and social factors for the AYA population in Australia (as well as what constitutes normal development) is very important to be able to meet the complex care needs of AYA patients when they are diagnosed with cancer. Given that these issues describe normal development in AYAs, they will also influence how an AYA handles an acute and chronic illness, their care-seeking patterns and their adherence to recommended treatment and follow-up care.

The World Health Organization presented a detailed report, *Health for the*

World's Adolescents to the World Health Assembly in 2014.⁴ It clearly identified the growing and specific attention needed for services providing adolescent health care, which are distinct from those required by children's and adult health services. This was followed up with *The Lancet* commission on adolescent health and wellbeing in 2016, which emphasised the health and wellbeing benefits that improvements in adolescent health lead to, and the longer term benefits that continue into adult life.⁵

Statistics on cancer in adolescents and young adults in Australia

Each year, about 950 Australian AYAs are diagnosed with cancer.⁶ There are almost

twice as many AYAs diagnosed with cancer each year as children under 14 years of age. Cancer in AYAs is very rare, making up only 1.7% of all people diagnosed with cancer in Australia. The incidence of cancer in AYAs continued to increase by 1.5% per year until 1996 and has not changed significantly since then.

AYAs have a five-year relative survival rate of 88% and, although this varies by tumour group, survival for most tumour types has increased over the past 20 years, with the highest increases seen in acute leukaemias.⁶ Despite improvements in survival rates for AYAs with cancer, the survival improvements have not matched the improvements seen in paediatric or adult cancer types. A cancer diagnosis, although rare, is the most common cause of death in this age group, after accidents, murders and suicides.

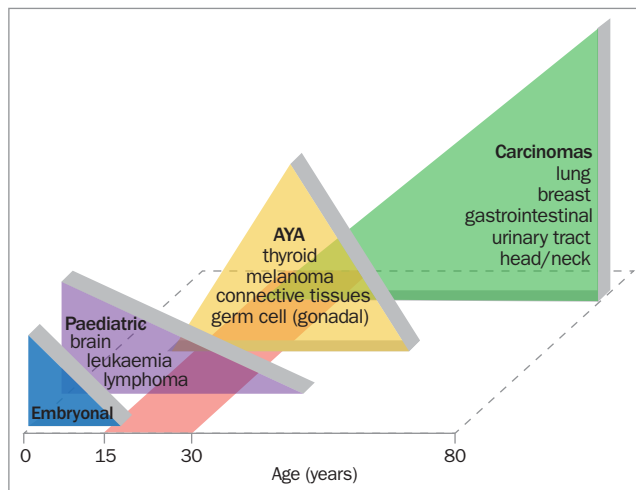
Types of cancer in adolescents and young adults

Nine major cancer groups are found in AYA patients with cancer: leukaemia, lymphomas, tumours of the central nervous

Figure 1. The interface between paediatric and adult oncology.

Reproduced from: Bleyer A, et al. eds. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975–2000. Bethesda: National Cancer Institute; 2006.⁷

Abbreviation: AYA = adolescent and young adult.



system, bone cancers, soft tissue sarcomas, germ cell cancers, melanomas, carcinomas and other unspecified cancers.

The four most commonly diagnosed cancers among AYA patients in Australia are melanoma (accounting for one-quarter of all cancers in this age group), followed by gonadal germ cell cancers, Hodgkin lymphoma and thyroid carcinoma.⁶ Together, these four cancers represent just over half of all cancers in AYAs. In addition to these more common tumours in the AYA population, AYAs of any age can also have the epithelial malignancies commonly seen in adults (breast, colorectal and lung cancers) and embryonal cancers (neuroblastoma, Wilms tumours and teratomas). They can also have the leukaemias and brain tumours that are more commonly seen in paediatric patients. The variety in tumour types occurring in this age range requires specialist clinicians to have both paediatric and adult expertise to be able to provide age-appropriate and tumour-specific management.

The frequency of different tumours changes as patients get older (Figure 1). Among AYAs, lymphomas, leukaemias, sarcomas and brain tumours have the highest incidence in the 15- to 19-year age group. Melanomas, testicular cancer and carcinomas have the highest incidence in the 20- to 24-year age group (Figure 2).

Differences in the incidence of tumours between males and females are also seen in AYA patients. Gonadal tumours,

osteosarcoma and rhabdomyosarcoma are more commonly diagnosed in males, and thyroid cancer is more common in females.⁶

What are the causes of the differences in cancer survival for adolescents and young adults?

The reasons for differences in survival in AYAs are likely to be multifactorial, with variations in tumour biology, response to treatment and treatment protocols all having an impact. Some of these factors are discussed below.

Reduced awareness and delays in diagnosis and treatment

Cancers in the AYA age group are very rare and can be difficult to diagnose.⁹ Cancer-related symptoms account for a very low percentage of GP consultations with AYAs. In one review of AYA patients, only 4% of consultations were related to cancer symptoms. Despite the low incidence of cancer-related symptoms in AYAs, symptoms such as a lump, mass or swelling have been associated with a higher absolute risk of cancer.¹⁰

AYAs with cancer have longer symptom intervals,^{11–13} and it has been hypothesised that the longer delays in cancer diagnosis for this age group contribute to a decrease in survival, because AYAs tend to be at later cancer stages and have fewer treatment options available at presentation.

However, this link has not been clearly shown, as the symptom interval changes between cancer types and the reasons for longer symptom intervals are multifactorial. In a review of AYA consultations with GPs, 86% of AYAs had visited their GP in the three months before a diagnosis, and 42% had visited their GP four times or more before being referred to a cancer centre.¹⁰

It has been shown that a delay in cancer diagnosis has an impact on the relationship between AYA patients and clinicians.¹⁴ This impact may continue into treatment and have an effect on trust, adherence to treatment and survival. Delays often also occur because AYAs diagnosed with cancer are often seen by several specialists, including emergency, surgical, general, paediatric and adult specialists, when they are referred to hospital before they start treatment. AYAs may delay seeking medical advice due to the lack of importance these symptoms present for them, the need to plan a review at a time when parent can go with them, or the conflict of AYA life events and school taking a greater importance in their lives.

The Early Detection of Cancer in AYAs Cancer Guideline has been developed by the Clinical Oncological Society of Australia (COSA) for GPs and other primary health professionals involved in the management of AYAs with cancer.¹⁵ It provides evidence-based recommendations and practice points to assist GPs to recognise signs and symptoms that could be caused by cancer in AYA patients, make decisions about appropriate investigations and make timely and appropriate referrals for AYAs with suspected cancer.

Limited age-specific services

The treatment of AYAs with cancer in Australia has, until recently, been managed by paediatric or adult cancer centres.¹⁶ Internationally, some institutions have developed stand-alone AYA cancer facilities and others have developed AYA multidisciplinary care teams working alongside existing paediatric and adult treatment centres.^{17–20} For most

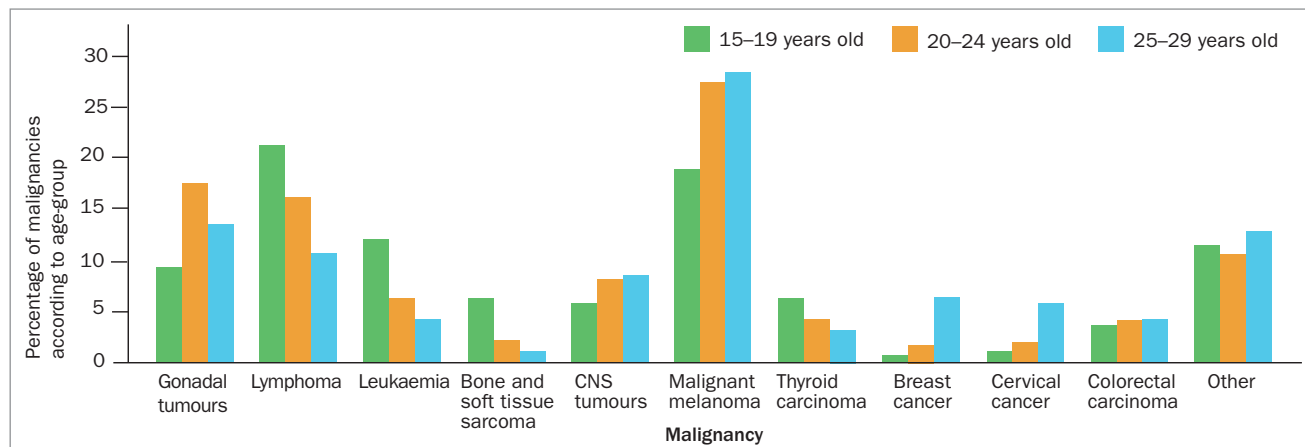


Figure 2. Cancer rates in adolescents and young adults, by age group. Based on 2013 Australian Institute of Health and Welfare data.⁸

patients (except those between 16 and 18 years of age, who can be treated in either location), the place of treatment is based on the patient's age without considerations of their developmental stage, psychosocial needs or tumour-specific needs.^{16,21} Not all young people at the same age are at the same stage in the key areas of physical, cognitive and socioemotional development. Ideally, clinical teams should be able to consider the most developmentally appropriate location for treatment.¹⁹

It is important for patients to have access to expertise specific to their cancer, which may not necessarily be found in the cancer centre they attend. It is also important for patients to have access to expertise specific to their age – for example, a paediatric patient with a tumour usually occurring in adults, or an adult patient with a tumour usually occurring in paediatric patients may benefit from the medical expertise of cancer specialists who routinely look after these tumours. These patients are also less likely to be enrolled and treated in a relevant clinical trial, which, as discussed below, has an impact on survival.

The physical environments of paediatric and adult cancer centres are usually more suitable for younger and older patients, respectively, and contact with other AYAs who could provide peer support may be limited.¹⁸ Cancer centres may not have access to staff with expertise in treating AYAs or

who can recognise, understand and support the individual needs of AYA patients.²²

Treating an AYA in a paediatric or adult cancer centre when it is not age-appropriate may have an effect on the patient's understanding of their diagnosis, treatment, decision-making and treatment compliance, which may ultimately affect their outcomes. Age-appropriate communication and consultations are essential for optimal care. Sometimes, clinicians may discuss care with the parents of an AYA patient when the AYA may wish to be more involved in the discussions.²² Other AYAs may be overwhelmed by their diagnosis, hospitalisation and the medical information they receive, and may struggle to take responsibility for their treatment decisions.²² This may be expected by clinicians working in an adult patient setting.

The effect of treatment location on AYA care and survival highlights the importance of having cancer services specific to this age group.

Different disease features

There is increasing evidence that cancers in the AYA age group have unique genetic and biological features compared with the same cancers in younger and older age groups, and that these biological differences may have an impact on survival.²³ It has been shown that increasing age is associated with unfavourable biological subgroups in

acute lymphoid leukaemia, and is also associated with poorer survival in many cancer types.²⁴ The biology of sarcoma is not fully understood, but when compared with children, AYAs have been shown to have increased rates of less favourable tumour locations (36.8% vs 12.9%), lymph node involvement (35.5% vs 21.7%) and metastatic disease at diagnosis (30.3% vs 17.8%).²⁵ Other studies have shown poorer outcomes for AYA patients with adult tumours such as breast cancer and colorectal cancer, and with paediatric tumours such as Wilms tumour and rhabdomyosarcoma, when outcome is adjusted for staging.^{23,24} A better understanding of the biology of cancers in AYA patients will help scientists and clinicians identify better targeted therapy.

Different treatment approaches

Traditionally, there have been different protocols for paediatric and adult patients for the same cancer types, leading to AYA patients being treated in different trials, depending on the treatment centre. There are multiple studies showing that AYA patients with acute lymphoblastic leukaemia have superior survival rates when treated in a paediatric trial, despite an increase in some side effects with these paediatric protocols.²⁶ Researchers in cancer of AYAs are currently looking at differences in outcomes in several tumour

groups, based on differences in treatment protocols, which will allow standardisation of treatment for this age group.

Different treatment side effects

AYA patients have been shown to experience more toxicity than paediatric patients when treated in the same trials. For example, for AYA patients treated for leukaemia, increases in peripheral neuropathy, glucose intolerance, pancreatitis and osteonecrosis have been seen, and increased toxicity has been seen in AYAs being treated for Ewing sarcoma.²⁷⁻²⁹ However, other trials have shown a reduced side-effect profile or different complications for AYA patients, or have shown that side effects are related to sex, not age.³⁰ Studies are needed to examine age-related and sex-related differences in pharmacology, pharmacogenetic distribution, delivery and metabolism of drugs.

Different participation rates in clinical trials and research

Participation rates for AYA patients with cancer in clinical trials are lower compared with paediatric patients, and there continues to be a higher rate of clinical trial participation for AYA patients treated in paediatric centres compared with those treated in adult cancer centres.³¹⁻³⁴

Barriers to the establishment of clinical trials for this age group include the cost of, and the time taken, to open a clinical trial, and the lack of centralised care for this age group. This results in a smaller number of AYA patients in each adult cancer centre and low accrual rates, unless multiple centres are open.³⁵⁻³⁷ Patients participating in clinical trials show improved survival,^{38,39} so it is important that AYA patients have access to trials.

Differences in psychosocial needs

Compared with their healthy peers, AYAs with cancer are at higher risk of experiencing poor psychological wellbeing and distress that can last many years after treatment.⁴⁰ They may experience temporary loss of autonomy, increased

dependence on others, and physical and emotional rifts between peers and parents. These psychosocial effects on wellbeing can result in poorer adherence to cancer treatment or delays in disclosure of important symptoms, resulting in an increased frequency of side effects. Psychosocial screening of AYAs with cancer is essential for clinicians to be able to offer appropriate psychological support during and after treatment, and to prevent negative effects on cancer outcomes.⁴⁰ COSA developed guidelines on the *Psychosocial Management of AYA Diagnosed with Cancer: Guidance for Health Professionals* which is a useful resource for GPs providing psychosocial during or after cancer treatment.⁴¹

What additional needs do young patients with cancer have?

There is increasing recognition that AYA patients with cancer have some medical and psychosocial support needs that are different from those of other age groups, and these should be considered during and after cancer treatment.

Age-appropriate information

It is vital for the optimal care and future wellbeing of AYA patients that they have a good understanding of age-specific issues such as preserving fertility and maintaining education, finances, body image and identity, but several studies report this information for AYAs to be lacking.²²

Support and advocacy

Dedicated support services for AYAs are essential for delivering developmentally and age-appropriate care. This includes help navigating potentially complex treatment pathways, advocating for AYA patients, supporting their consent and assent processes and providing psychological screening and support (if increased levels of distress are identified). It is also important to support young people with cancer in the normal rites of passage and attending significant events for their age group, such as birthdays, school events, activities with friends, study

commitments and examinations. By understanding the importance of these normal life events, staff can work with AYA patients to achieve optimal care through the inevitable challenges of cancer diagnosis and treatment.

Education support

Cancer treatment has a significant impact on a patient's schooling, university education and vocational training. It often results in reduced class attendance and poorer concentration, and it is therefore necessary that health and education staff collaborate to ensure that AYA educational potential and needs are met.^{42,43} Additional educational support is provided by patient educational facilities, hospital schools and nursing and allied health staff. Advocacy agencies such as Ronald McDonald House and Redkite provide funding for additional educational support and career advice during and after cancer treatment (see Table).

Health advice and health promotion

It is normal for patients with cancer to participate in risk-taking behaviour, which may include smoking, drinking excessively, taking drugs and taking part in risky sexual behaviour. It is very important that health professionals looking after these patients discuss the risks of this behaviour and the possible effects on disease progression, treatment and longer term outcomes. At the primary care level, GPs routinely provide health interventions to AYAs and have established relationships with services in the community that can provide additional support if required.

Fertility preservation

Cancer treatment (chemotherapy, radiotherapy, bone marrow transplant and surgery) can be gonadotoxic, resulting in impaired fertility due to damage to the ovaries or testes. The neuroendocrine axis can be affected, resulting in impaired pituitary hormone secretion.^{44,45} In addition to infertility, patients can experience fatigue, delayed puberty, hypogonadism,

TABLE. SUPPORT AVAILABLE TO ADOLESCENTS AND YOUNG ADULTS (AYAs) WITH CANCER

Agency	Support offered
CanTeen Australia www.canteen.org.au 1800 226 833	Information and support for AYAs with cancer, their siblings, and AYAs whose parents or siblings have died from cancer; resources, peer support, camps and online support
Youth Cancer Services www.canteen.org.au/youth-cancer 1800 835 932	Information about medical and psychosocial treatment and support for AYAs with cancer, for each state and territory of Australia; resources for patients, siblings and parents
Redkite www.redkite.org.au 1800 733 548	Education grants, education and career support, free counselling, cancer support groups, bereavement support, financial assistance
Ronald McDonald Learning Program www.learningprogram.rmhc.org.au 1300 307 642	A national program helping children and AYAs to catch up on their learning
Cancer Council www.cancer.org.au 13 11 20	A free, confidential telephone information and support service with trained staff available to answer questions about cancer, offer emotional or practical support, and refer young people to age-appropriate support groups or services
Cancer Australia www.canceraustralia.gov.au 1800 624 973	Produces <i>Cancer – How are you Travelling?</i> , a booklet with information about the emotional and social impact of cancer for people diagnosed with cancer, and their families and friends
Leukaemia Foundation www.leukaemia.org.au 1800 620 420	Dedicated to care and cure of patients and families living with blood cancers (leukaemia, lymphoma and related blood disorders). Provides financial, accommodation and transport help and; information, education and support programs. Produces <i>Young Adults with a Blood Cancer</i> , a book providing information on diagnosis and treatment, side effects and the physical, social and psychological impacts of diagnosis and treatment; also discusses long-term effects and life after cancer
Fertility resources	<p>Several fertility resources are available providing resources for AYA patients with cancer and their parents and partners, about fertility concerns, fertility decision aids and sexual dysfunction:</p> <ul style="list-style-type: none"> • Future Fertility: www.futurefertility.com.au/resources • Maybe Later Baby? A guide to fertility for young people with cancer and after cancer www.canteen.org.au/resource • <i>Fertility and Cancer. A Guide for People with Cancer, their Families and Friends</i> www.cancer.org.au/content/about_cancer/ebooks/livingwithcancer/Fertility_and_cancer_booklet_May_2016.pdf • <i>Sexuality, Intimacy and Cancer, a Guide for People with Cancer and Their Partners</i> www.cancer.org.au/content/about_cancer/ebooks/aftercancer/Sexuality_intimacy_and_cancer_booklet_May_2016.pdf • <i>Fertility Related Choices: a Decision Aid for Younger Women with Early Breast Cancer</i> www.cancer.org.au/content/pdf/AboutCancer/OnlineResources/Decision_Aid_breastcancer_fertility_%20June2011.pdf • Fertility and cancer: www.cancercouncil.com.au/cancer-information/managing-cancer-side-effects/fertility-and-cancer

osteoporosis and cardiovascular disease as a result of gonadal and hormone deficiency.⁴⁶ Impaired fertility can have a lasting emotional impact on patients, as well as adversely affecting current and future relationships.⁴⁷ Fertility preservation is the overarching term used for medical and surgical treatment to minimise the impact of cancer treatment on a patient's future

fertility,⁴⁵ and there are several techniques recommended as standard practice.^{44,48} To ensure that fertility preservation is done in a timely manner, GPs should ensure early specialist referral so consultations and procedures can be carried out at the same time as diagnosis and investigation of cancer treatment. COSA have guidelines on fertility preservation for AYAs, which

are a useful resource for GPs providing advice and referral for patients with reproductive concerns before, during or after cancer treatment.⁴⁴

Survivorship care

The completion of cancer treatment brings together particular issues for AYA patients to deal with, such as resuming normal life

and managing follow-up care. They have to manage the consequences of their cancer and treatment, which may include complications such as cardiac, renal and lung toxicity; cognitive deficits; reduced fertility and further malignancies.⁴⁶ After cancer treatment, survivors often experience a range of positive and negative emotions, including relief, a sense of gratitude to be alive, fear of recurrence, anger, guilt, depression, anxiety and isolation, and may need psychosocial support for many years.⁴⁹

Palliative care

There are many challenges in providing palliative care for AYA patients, some of which are very similar to the challenges of providing care at diagnosis for AYAs.⁵⁰ Palliative care teams with expertise in caring for AYA patients are essential members of the AYA care team,⁵¹ and should be integrated into the management of AYA patients as early as possible so the patients can better manage the large number of medical and psychological symptoms they experience.⁵² AYA patients with cancer are more likely to spend their palliative care period in an acute setting rather than at home or in a hospice. This may be due to end-of-life discussions occurring close to the time of death,⁵²⁻⁵⁴ the lack of hospice care for AYA in Australia, or AYA patients being keen to be supported by the teams that have provided their care during active treatment.

Advance care directives such as the *AYA Voicing My Choices*⁵⁵ document (currently being adapted for the Australian context) allow AYA patients to have open communication with health professionals and family members about how they would like to be cared for and what kind of treatment they would like at the end of their life. It also allows them an opportunity to document how they would like to be remembered and to communicate information to their families and friends. This approach has been shown to reduce psychological symptoms such as anxiety, sadness and fear.

Current access to adolescent and young adult cancer services

In 2005, a Federal Government senate committee inquiry recommended the development of specialised cancer care units for the care of adolescents 15 to 25 years of age with cancer.⁵⁶ In 2008, the Federal Government awarded \$15 million funding to CanTeen to establish the Youth Cancer Networks Program in each state of Australia.^{40,57,58} The government has subsequently given \$18.2 million for phase 2 in 2013, and additional funding has been confirmed in 2017 for phase 3.⁵⁸

CanTeen is a charity, which started in 1985 providing practical support, counselling and peer-support programs to AYAs with cancer, their siblings or AYAs who are dealing with the death of a parent or sibling. CanTeen has developed Youth Cancer Services nationally through collaborations between paediatric and adult hospitals which work closely together to deliver inpatient and outpatient care. They also provide support to patients and staff in cancer centres outside these specialised centres. Each state and territory has a Youth Cancer Service (or a service overseen by a Youth Cancer Service) and about 19 hospitals are involved nationally. These services (see www.canteen.org.au/youth-cancer) are staffed by health professionals who have expertise in medical and nursing care and support for AYAs, usually appointed between paediatric and adult services to reach patients across the AYA age range. Through these centres, AYA patients can access a full range of services developed for that age group from cancer care, counselling, allied health services, fertility preservation, clinical trials and educational and vocational support. The Youth Cancer Services in NSW, Melbourne and Perth also have 'You Can' cancer centres specifically designed for the AYA age group and funded by the Sony Foundation (www.sonyfoundation.org/about/you-can), with plans over time for the other states and territories to also have these centres.

The Youth Cancer Services have a national, evidenced-based model of care which is underpinned by the National

Service Delivery Framework for AYAs with Cancer, created in 2007 through collaboration between Cancer Australia and CanTeen,⁵⁹ and updated in 2016. The Framework outlines key elements for the care of AYAs with cancer, including the establishment of lead AYA cancer care sites, healthcare professionals with adolescent general and subspecialty expertise improving access to clinical trials, co-ordinated care, psychosocial support services, support for AYA decision-making and expert multidisciplinary care teams trained in cancer care for AYAs.

Role of the GP

GPs have an essential role in the medical and psychosocial care of AYA patients with cancer, and cancer specialists should encourage this relationship, even for patients with complex problems. Many GPs will already have a relationship with the young person or their parents and siblings. They will be able to provide key information about the patient's clinical or family history that may be critical to their medical care, and may also provide vital insight into the best way to support them. An AYA patient who does not have a GP should be encouraged to choose one as soon as they can, and the GP should be included in the patient's care in a shared-care model with clear written communication.⁶⁰

Clinical and support needs for AYA patients during and after treatment for cancer can be complex, and there is a wide range of services in the community to which GPs can refer patients, such as Headspace for concerns relating to mental health.

GPs can provide ongoing management of chronic and complex disease as well as regular adolescent health services and interventions; they can co-ordinate acute treatment or additional consultations when required; and they can refer patients, siblings and parents for psychosocial and practical support. If a patient cannot be cured, the GP can co-ordinate the palliative care phase of their life, with the support of inpatient and community palliative services, including bereavement support.

GPs are central to this holistic approach to patient-centred care of AYA patients with cancer.

Other support and resources

Several Australian resources and support services are available to AYA patients with cancer and their siblings and parents (see Table). Some of these resources can be ordered for medical clinics and all can be accessed online.

Summary

Over the past 10 years, Australian AYA patients with cancer have had access to Youth Cancer Services in each state and territory. These services provide specialist medical, nursing and psychosocial care as well as providing treatment via age-appropriate, peer-supported services. They also allow access to clinical trials for AYAs, enable transition of support between paediatric and adult services, and facilitate long-term, follow-up care. Youth Cancer Services also provide health promotion materials, health surveillance, psychosocial screening and educational, psychological and practical support.

We need better understanding of the reasons behind the differences in long-term survival of AYA patients with cancer compared with adult and paediatric patients, such as biological differences, and difference in responses to, and side effects of, treatment.

Continued primary care for AYA patients and their families by GPs is essential during and after cancer treatment, and should be encouraged even for patients with complex problems. It is important that all AYA patients have a GP who understands their cancer history, is familiar with the potential for medical and psychosocial complications and the benefits of adolescent health care and screening, and can provide support to their siblings and parents. **MT**

References

A list of references is included in the online version of this article (www.medicinetoday.com.au).

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References

1. Australian Bureau of Statistics (ABS). 2011 Census Australia. Canberra: ABS. Available online at: <http://www.abs.gov.au/websitedbs/censushome.nsf/home/2011information?opendocument&navpos=310> (accessed May 2017).
2. Santrock JW. Adolescence. 15th ed. New York: McGraw-Hill Education; 2013.
3. Australian Institute of Health and Welfare (AIHW). Young Australians: their health and wellbeing 2011. Cat. no. PHE 140. Canberra: AIHW; 2011.
4. World Health Organization (WHO). Health for the world's adolescents: a second chance in the second decade. Geneva: WHO; 2014. Available online at: <http://apps.who.int/adolescent/second-decade> (accessed May 2017).
5. Patton GC, Sawyer SM, Santelli JS, et al. Our future: a Lancet commission on adolescent health and wellbeing. *Lancet* 2016; 387: 2423-2478.
6. Australian Institute of Health and Welfare (AIHW). Cancer in adolescents and young adults in Australia. Cancer series no. 62. Cat. no. CAN 59. Canberra: AIHW; 2011.
7. Bleyer A, O'Leary et al. M, Barr R, Ries LAG, eds. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975–2000. Bethesda: National Cancer Institute; 2006.
8. Australian Institute of Health and Welfare (AIHW). 2013 Australian Cancer Database pivot table. Canberra: AIHW; 2017. Available online at: <http://www.aihw.gov.au/cancer-data> (accessed May 2017).
9. Fern LA, Campbell C, Eden TO, et al. How frequently do young people with potential cancer symptoms present in primary care? *Br J Gen Pract* 2011; 61: e223-230.
10. Dommett RM, Redaniel MT, Stevens MC, Hamilton W, Martin RM. Features of cancer in teenagers and young adults in primary care: a population-based nested case–control study. *Br J Cancer* 2013; 108: 2329-2333.
11. Goyal S, Roscoe J, Ryder WD, Gattamaneni HR, Eden TO. Symptom interval in young people with bone cancer. *Eur J Cancer* 2004; 40: 2280-2286.
12. Veneroni L, Mariani L, Lo Vullo S, et al. Symptom interval in pediatric patients with solid tumors: adolescents are at greater risk of late diagnosis. *Pediatr Blood Cancer* 2013; 60: 605-610.
13. Dang-Tan T, Trotter H, Mery LS, et al. Delays in diagnosis and treatment among children and adolescents with cancer in Canada. *Pediatr Blood Cancer* 2008; 51: 468-474.
14. Dixon-Woods M, Findlay M, Young B, Cox H, Heney D. Parents accounts of obtaining a diagnosis of childhood cancer. *Lancet* 2001; 357: 670-674.
15. Early Detection of Cancer in AYAs Working Group. Cancer Guidelines Wiki. Early detection of cancer in AYAs. Sydney: Cancer Council Australia. Available online at: http://wiki.cancer.org.au/australia/COSA:Early_detection_of_cancer_in_AYAs (accessed May 2017).
16. Thomas DM, Seymour JF, O'Brien T, Sawyer SM, Ashley DM. Adolescent and young adult cancer: a revolution in evolution? *Int Med J* 2006; 36: 302-307.
17. Livestrong Young Adult Alliance. Closing the gap: research and care imperatives for adolescents and young adults with cancer. Austin, Texas: Livestrong; 2006. Available online at: https://d1un1nybq8gi3x.cloudfront.net/sites/default/files/what-we-do/reports/AYAO_PRG_Report_2006_FINAL.pdf (accessed May 2017).
18. Morgan S, Davies S, Palmer S, Plaster M. Sex, drugs, and rock 'n' roll: caring for adolescents and young adults with cancer. *J Clin Oncol* 2010; 28: 4825-4830.
19. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer* 2011; 117: 2329-2334.
20. Ferrari A, Thomas D, Franklin AR, et al. Starting an adolescent and young adult program: some success stories and some obstacles to overcome. *J Clin Oncol* 2010; 28: 4850-4857.
21. Eden T. Keynote comment: challenges of teenage and young-adult oncology. *Lancet Oncol* 2006; 7: 612-613.
22. Bibby H, White V, Thompson K, Anazodo A. What are the unmet needs and care experiences of adolescents and young adults with cancer? A systematic review. *J Adolesc Young Adult Oncol* 2017; 6: 6-30.
23. Bleyer A, Barr R, Hayes-Lattin B, Thomas D, Ellis C, Anderson B. The distinctive biology of cancer in adolescents and young adults. *Nat Rev Cancer* 2008; 8: 288-298.
24. Tricoli JV, Blair DG, Anders CK, et al. Biologic and clinical characteristics of adolescent and young adult cancers: acute lymphoblastic leukemia, colorectal cancer, breast cancer, melanoma, and sarcoma. *Cancer* 2016; 122: 1017-1028.
25. Bisogno G, Compostella A, Ferrari A, et al. Rhabdomyosarcoma in adolescents: a report from the AIEOP Soft Tissue Sarcoma Committee. *Cancer* 2012; 118: 821-827.
26. Ram R, Wolach O, Vidal L, Gafter-Gvili A, Shpilberg O, Raanani P. Adolescents and young adults with acute lymphoblastic leukemia have a better outcome when treated with pediatric-inspired regimens: systematic review and meta-analysis. *Am J Hematol* 2012; 87: 472-478.
27. Bukowski AJ, Burns KC, Parsons K, Perentesis JP, O'Brien MM. Toxicity of cancer therapy in adolescents and young adults (AYAs). *Semin Oncol Nurs* 2015; 31: 216-226.
28. Juergens C, Weston C, Lewis I, et al. Safety assessment of intensive induction with vincristine, ifosfamide, doxorubicin, and etoposide (VIDE) in the treatment of Ewing tumors in the EURO-E.W.I.N.G. 99 clinical trial. *Pediatr Blood Cancer* 2006; 47: 22-29.
29. Larsen EC, Salzer W, Nachman J, et al. Treatment toxicity in adolescents and young adult (AYA) patients compared with younger patients treated for high risk

- B-precursor acute lymphoblastic leukemia (HR-ALL): a report from the Children's Oncology Group Study AALL0232 [abstract]. *Blood* 2011; 118: 1510.
30. Gupta AA, Anderson JR, Pappo AS, et al. Patterns of chemotherapy-induced toxicities in younger children and adolescents with rhabdomyosarcoma: a report from the Children's Oncology Group Soft Tissue Sarcoma Committee. *Cancer* 2012; 118: 1130-1137.
31. Bleyer A, Budd T, Montello M, et al. Adolescents and young adults with cancer: the scope of the problem and criticality of clinical trials. *Cancer* 2006; 107: 1645-1655.
32. Collins CL, Malvar J, Hamilton AS, Deapen DM, Freyer DR. Case-linked analysis of clinical trial enrollment among adolescents and young adults at a National Cancer Institute-designated comprehensive cancer center. *Cancer* 2015; 121: 4398-4406.
33. Fern LA, Whelan JS. Recruitment of adolescents and young adults to cancer clinical trials – international comparisons, barriers, and implications. *Semin Oncol* 2010; 37: e1-8.
34. Shaw PH, Ritchey AK. Different rates of clinical trial enrollment between adolescents and young adults aged 15 to 22 years old and children under 15 years old with cancer at a children's hospital. *J Pediatr Hematol Oncol* 2007; 29: 811-814.
35. Bleyer A, Budd T, Montello M. Adolescents and young adults with cancer: the scope of the problem and criticality of clinical trials. *Cancer* 2006; 107: 1645-1655.
36. Ferrari A, Montello M, Budd T, Bleyer A. The challenges of clinical trials for adolescents and young adults with cancer. *Pediatr Blood Cancer* 2008; 50: 1101-1104.
37. Tai E, Buchanan N, Eliman D, et al. Understanding and addressing the lack of clinical trial enrollment among adolescents with cancer. *Pediatrics* 2014; 133 Suppl 3: S98-S103.
38. Chow CJ, Habermann EB, Abraham A, et al. Does enrollment in cancer trials improve survival? *J Am Coll Surg* 2013; 216: 774-780.
39. Unger JM, Cook E, Tai E, Bleyer A. Role of clinical trial participation in cancer research: barriers, evidence, and strategies. *Am Soc Clin Oncol Educ Book* 2016; 35: 185-198.
40. Palmer S, Patterson P, Thompson K. A national approach to improving adolescent and young adult (AYA) oncology psychosocial care: the development of AYA-specific psychosocial assessment and care tools. *Palliat Supportive Care* 2014; 12: 183-188.
41. Clinical Oncology Society of Australia. Cancer Guidelines Wiki. Psychosocial management of AYAs diagnosed with cancer: guidance for health professionals. Sydney: Cancer Council Australia. Available online at: http://wiki.cancer.org.au/australia/COSA:Psychosocial_management_of_AYA_cancer_patients (accessed May 2017).
42. Choquette A, Rennick JE, Lee V. Back to school after cancer treatment: making sense of the adolescent experience. *Cancer Nurs* 2016; 39: 393-401.
43. McLoone JK, Wakefield CE, Butow P, Fleming C, Cohn RJ. Returning to school after adolescent cancer: a qualitative examination of Australian survivors' and their families' perspectives. *J Adolesc Young Adult Oncol* 2011; 1: 87-94.
44. AYA Cancer Fertility Preservation Guidance Working Group. Cancer Guidelines Wiki. Fertility preservation for AYAs diagnosed with cancer: guidance for health professionals. Sydney: Cancer Council Australia. Available online at: <http://wiki.cancer.org.au/australiawiki/index.php?oldid=110662> (accessed May 2017).
45. Levine J, Canada A, Stern CJ. Fertility preservation in adolescents and young adults with cancer. *J Clin Oncol* 2010; 28: 4831-4841.
46. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med* 2006; 355: 1572-1582.
47. Ramphal R, Aubin S, Czaykowski P, et al. Adolescent and young adult cancer: principles of care. *Curr Oncol* 2016; 23: 204-209.
48. Loren AW, Mangu PB, Beck LN, et al. Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol* 2013; 31: 2500-2510.
49. Carretier J, Boyle H, Duval S, et al. A review of health behaviors in childhood and adolescent cancer survivors: toward prevention of second primary cancer. *J Adolesc Young Adult Oncol* 2016; 5: 78-90.
50. Donovan KA, Knight D, Quinn GP. Palliative care in adolescents and young adults with cancer. *Cancer Control* 2015; 22: 475-479.
51. Wiener L, Weaver MS, Bell CJ, Sansom-Daly UM. Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. *Clin Oncol Adolesc Young Adults* 2015; 5: 1-18.
52. Cohen-Gogo S, Marioni G, Laurent S, et al. End of life care in adolescents and young adults with cancer: experience of the adolescent unit of the Institut Gustave Roussy. *Eur J Cancer* 2011; 47: 2735-2741.
53. Bell CJ, Skiles J, Pradhan K, Champion VL. End-of-life experiences in adolescents dying with cancer. *Support Care Cancer* 2010; 18: 827-835.
54. Keim-Malpass J, Erickson JM, Malpass HC. End-of-life care characteristics for young adults with cancer who die in the hospital. *J Palliat Med* 2014; 17: 1359-1364.
55. Wiener L, Zadeh S, Battles H, et al. Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics* 2012; 130: 897-905.
56. The Senate Community Affairs References Committee. The cancer journey: informing choice. Canberra: Commonwealth of Australia; 2005. Available online at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2004-07/cancer/report/index (accessed May 2017).
57. Anazodo A, Chard J. Medical and psychosocial challenges in caring for adolescent and young adult patients with cancer. *Cancer Forum* 2013; 37: 23-6.
58. Osborn M, Little C, Bowering S, Orme L. Youth cancer services in Australia: development and implementation. International perspectives on AYA0, Part 3. *J Adolesc Young Adult Oncol* 2013; 2: 118-124.
59. Cancer Australia. National service delivery framework for adolescents and young adults with cancer. Canberra: Cancer Australia; 2008. Available online at: <https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-service-delivery-framework-adolescents-and-young-adults-cancer> (accessed May 2017).
60. Kinahan KE, Kircher S, Altman J, et al. Promoting the shared-care model for adolescent and young adults with cancer: optimizing referrals and care coordination with primary care providers. *J Natl Compr Canc Netw* 2017; 15: 38-44.