Optimal care pathway for adolescents and young adults with cancer

Quick reference guide

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

This quick reference guide provides advice to health practitioners and service planners on optimal care for adolescents and young adults (AYA) with cancer, across the cancer continuum. Refer to the relevant cancer-specific optimal care pathways on the Cancer Council website <www.cancer.org.au/OCP>. The optimal care pathways describe the standard of care that should be available to all cancer patients treated in Australia. The pathways support patients and carers, health systems, health professionals and services, and encourage consistent optimal treatment and supportive care at each stage of a patient's journey. Seven key principles underpin the guidance provided in the pathways: patient-centred care; safe and quality care; multidisciplinary care; supportive care; care coordination; communication; and research and clinical trials. For AYA with cancer, timing of ill health coincides with a critical period for their growth and development, also demanding unique developmental considerations that are applicable across all steps of the care pathway.

This quick reference guide provides a summary of the *Optimal care pathway for adolescents and young adults with cancer.*

Key considerations to support optimal care for AYA with cancer

- **Model of care.** Optimal AYA cancer care is a hybrid patient-centred model of care that supports the individual's emerging or established autonomy while being adaptive to the involvement of parents/carers and significant others. Care becomes family-inclusive versus family-focused.
- **Care environment.** An age-appropriate hospital environment will provide the patient with a sense of control, offer access to positive distractions as well as access to social (non-professional) supports. The environment should promote a sense of normalcy and ability for the AYA to continue to achieve tasks, as well as include age-appropriate activities.
- **Care coordination.** AYA with cancer prefer an individualised approach that acknowledges and responds to their competing psychosocial commitments. A dedicated AYA care coordinator provides information, emotional support, empowerment, patient advocacy and development of health literacy, with a physical presence at key time points throughout the care continuum.
- **Communication.** Effective, age-appropriate communication from youth-friendly healthcare providers is a primary indicator of quality AYA health care. Youth-friendly communication training should be a requirement for staff working regularly with AYA.
- **Understand your patient.** A cancer diagnosis during this stage of life has the potential for far-reaching consequences including impacts on physical growth, mental health, peer and family relationships, establishment of new social roles, education/vocation attainment, and achieving independence. Understand and incorporate these unique considerations in all decision-making processes about treatment and ongoing care with AYA.

Please note that not all patients will follow every step of the pathway.

Step 1: Prevention and early detection

Prevention

Encourage AYA to:

- reduce UV exposure
- get vaccinated for human papillomavirus (if not undertaken during childhood)
- avoid smoking
- reduce alcohol intake
- promote physical activity and healthy eating.

Risk factors

In the absence of a familial cancer predisposition syndrome (CPS), most cancers in the AYA population are sporadic without known causes.

There is an increased risk of developing a second cancer during early adulthood as a result of exposure to chemotherapy and/or radiation therapy during childhood.

Early detection

There are currently no standardised screening tools that increase early detection while reducing the risk of mortality (without undue risk to the healthy population) in new cancer diagnoses in this group. However, screening AYA may be beneficial for some cancer sub-types such as cervical, breast or colorectal cancer, particularly if they have a CPS.

Checklist

- ☐ Recent weight changes discussed and the patient's weight recorded
- ☐ Alcohol intake discussed and recorded and support for reducing alcohol consumption offered if appropriate
- ☐ Smoking status discussed and recorded and brief smoking cessation advice offered to smokers
- ☐ Physical activity recorded
- ☐ Referral to a dietitian considered

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Step 1: Prevention and early detection continued

Screening recommendations

- AYA with a known familial CPS or family history of cancer at a young age should be aware of the importance of screening and early detection and encouraged to follow evidence-based recommendations.
- AYA survivors of childhood cancer should follow evidence-based guidelines that include reducing modifiable cancer risk factors and, if applicable, cancer risks associated with initial disease and treatment, such as secondary malignant neoplasms.

Checklist

☐ Referral to a physiotherapist or exercise physiologist considered

☐ Education on being sun smart considered

☐ Referral to tertiary a familial cancer service for those with known cancer predisposition

☐ Referral to cancer survivorship service for AYA with a history of childhood cancer

Step 2: Presentation, initial investigations and referral

Presentation

Cancer in AYA presents with a broad spectrum of signs and symptoms, the most common being the presence of a lump or swelling, extreme fatigue and pain. Barriers to timely diagnosis include the rarity of AYA cancer and low index of suspicion, the frequent development of non-specific symptoms, low health-seeking behaviours and a lack of cancer awareness among AYA.

Primary and emergency care providers should seek and promote education/awareness campaigns to understand both the types of diseases seen in AYA, as well as the presenting signs and symptoms to improve time to diagnosis.

Referral options

At the referral stage, the GP or other referring doctor should advise the AYA and, if applicable, their family about their options for referral, waiting periods, expertise, if there are likely to be out-of-pocket costs and the range of services available. This will enable informed choice of specialist and health service.

If cancer is suspected, the GP should have telephone discussions with a health service that has expertise in managing AYA cancer when planning tests and investigations to confirm or exclude a diagnosis of cancer.

For those AYA with a confirmed diagnosis in primary care, the GP should strongly consider referral to a cancer centre with expertise in managing AYA cancers, particularly in the case of paediatric-like cancer types, rare and complex diagnoses and those AYA with complex psychosocial risk.

Communication

The GP's responsibilities include:

- explaining to the AYA and/or their family who they are being referred to and why
- supporting the AYA and/or their family while waiting for specialist appointments
- informing the AYA and/or their family that they can contact Cancer Council on 13 11 20.

Checklist

☐ Signs and symptoms recorded

☐ Discussion with a tertiary service undertaken

☐ Age-appropriate supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required

☐ Patient notified of support services such as Cancer Council 13 11 20

☐ Referral options discussed with the AYA and, if applicable, their family including cost implications

Timeframe

Timeframes for completing investigations and referral should be informed by evidence-based guidelines (where they exist) while recognising that shorter timeframes for appropriate consultations and treatment in AYA may improve clinical and patient-reported outcomes.

Step 3: Diagnosis, staging and treatment planning

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Diagnosis and staging

Work-up should be undertaken by a cancer centre with multidisciplinary experience in managing AYA cancers with access to clinical trials. At times, this may be within a paediatric tertiary cancer centre. This is particularly important in rare tumours, advanced-stage disease or those requiring complex and/or multidisciplinary diagnostic evaluation.

Diagnostic tests and investigations should be informed by evidence-based guidelines or, ideally, as determined by enrolment in the relevant clinical trial. Results should be interpreted by clinicians with experience in the relevant AYA cancer.

Genetic testing

A higher incidence of CPS has been seen in many cancer types in AYA compared with adult populations.

Consideration for referral includes those AYA with:

- atypical age at the time of diagnosis
- excessive, unanticipated toxicity to standard therapy
- family history of childhood/early-onset cancers and/or presence of hereditary factors
- presence of multiple primary cancers
- congenital anomalies or intellectual disabilities associated with a recognised CPS
- diagnostic clues strongly associated with a CPS (e.g. triple-negative breast cancer).

Fertility

- An individualised infertility risk assessment is made by the healthcare team at the time of confirming the prospective treatment plan and is documented
- Discussions about fertility risk and potential interventions such as preservation are part of the informed consent process at the time of diagnosis to facilitate decision making.

Treatment planning

All diagnostic work-up and prospective treatment planning via a disease-specific multidisciplinary meeting (MDM) should happen before starting treatment. Members of the multidisciplinary team (MDT) must be able to show appropriate expertise/experience in AYA cancer.

Concurrent referral should be made to an AYA-specific MDT that works in partnership with the disease-specific MDM. An AYA MDT will discuss the clinical and supportive care aspects of care, bringing a disease-specific, age-appropriate, psychosocial focus to prospective treatment planning.

Research and clinical trials

AYA are under-represented in clinical trial enrolment, having the lowest rates of participation of any age group. Clinical trial discussions should be part of the MDM agenda for all AYA and be documented. Access to trials may involve referral to or collaboration with an external paediatric or adult cancer centre.

Communication

In collaboration with the AYA care coordinator, the lead clinician's[1] responsibilities include:

- establishing if the AYA has a regular or preferred GP and, if they do not have one, encouraging them to find one
- exploring information preferences and providing age-appropriate written information about the diagnosis, treatment, treatment intent and prognosis
- providing a treatment care plan including contact details for the treating team and information on when to call the hospital
- discussing how they wish to have their family engaged in confidential and private discussions
- discussing the benefits of multidisciplinary care and gaining consent before presenting their case at an MDM.

Discussions around prognosis should be revisited with AYA over time as they become more accustomed to their diagnosis.

Checklist

☐ Diagnosis confirmed
☐ Performance status and comorbidities measured and recorded
☐ Referral to an AYA-specific MDT made
☐ Patient discussed at an MDM and decisions provided to the GP, AYA and family as applicable
☐ Clinical trial enrolment considered
☐ Age-appropriate supportive care needs assessment completed and recorded and referrals to allied health services actioned as required
☐ Patient referred to support services (e.g. Cancer Council) as required
☐ Treatment costs discussed with the AYA and, if applicable, their family

Timeframe

Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timeframes for appropriate consultations can reduce distress.

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[1] Lead clinician – the clinician who is responsible for managing patient care.
The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 4: Treatment

Establish intent of treatment

- Curative
- Treatment with uncertain or poor prognosis
- Anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- Symptom palliation

Treatment options in AYA also need to consider the increased risks of late effects and both disease and non–disease related mortality.

Whenever possible, AYA diagnosed with cancer should have a carefully planned path to enrolment in clinical trials for their specific disease.

Palliative care

Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis. Representatives from the palliative care team should be considered core members of the AYA MDT. For more, visit the Palliative Care Australia website <www.palliativecare.org.au>.

Communication

The lead clinician and team's responsibilities include:

- discussing treatment options with the AYA and, if applicable, their family and including the intent of treatment as well as risks and benefits
- communicating the treatment plan to the AYA's GP.

Checklist

☐ Intent of treatment established
☐ Risks and benefits of treatments discussed with the AYA and, if applicable, their family
☐ Treatment plan provided to the GP
☐ Treating specialist has adequate qualifications, experience and expertise
☐ Supportive care needs assessment completed and recorded, and referrals actioned
☐ Early referral to palliative care based on need

Timeframe

Timeframes to treatment should be informed by evidence-based guidelines (where they exist).

Step 5: Care after initial treatment and recovery

Needs at this time include individualised information and advice, counselling and psychological support, and social support/relationships.

AYA with cancer experience the adverse effects of cancer and its treatment at a dynamic time point, impacting on or delaying key developmental milestones. These effects can persist well beyond the completion of treatment.

Provide a treatment summary to the GP, AYA and, if applicable, their family outlining:

- the diagnosis
- staging, grading and/or risk stratification
- the treatment protocol, including clinical trial enrolment if applicable
- chemotherapy (if applicable), including cumulative doses
- radiation therapy, as applicable
- significant morbidities and/or adverse events experienced during treatment
- fertility preservation strategies if applicable
- the treatment end date
- contacts at each speciality service where care was delivered

Provide a follow-up cancer surveillance schedule, including tests required and timing.

Provide aa process for rapid re-entry to medical services for suspected recurrence.

Cancer survivorship

At the end of cancer surveillance, a periodic evaluation with a focused history, physical examination and risk-based screening should be facilitated. High-priority targets for consideration include secondary cancers, cardiovascular and respiratory toxicity, endocrine screening and neurocognitive screening.

The survivorship plan should also cover:

- timing for surveillance of potential primary and secondary malignant neoplasms
- timing of evidence-based screening recommendations for potential late effects, tailored to the AYA's disease, treatment and age at diagnosis
- wellbeing, primary and secondary prevention health recommendations that align with chronic disease management principles.

Checklist

☐ Treatment and follow-up summary provided to the GP, AYA and, if applicable, their family
☐ On completion of follow-up, a survivorship summary provided to the GP, AYA and, if applicable, their family

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 5: Care after initial treatment and recovery continued

AYA with a low risk of late effects should be transitioned to their GP with documentation; those with medium risk should be seen within a shared-care model between a cancer survivorship service and their GP. Those with a high risk of late effects (e.g. bone marrow transplant, high-dose chemotherapy and radiation therapy) should remain engaged in dedicated cancer survivorship care.

Communication

The lead clinician's responsibilities include:

- explaining the treatment summary follow-up and survivorship care plan to the AYA and, if applicable, their family
- providing information about secondary cancer prevention and healthy living
- discussing the follow-up care plan with the AYA's GP.

Checklist

☐ Age-appropriate supportive care needs assessment completed and recorded at both time points and referrals to allied health services actioned as required

Step 6: Managing recurrent, residual or metastatic disease

Detection

Most residual or recurrent disease will be detected via routine follow-up or by the AYA presenting with symptoms.

Treatment

Evaluate each patient for whether referral to the original MDT is appropriate. Treatment will depend on the location and extent of disease, previous management and the AYA's and, if applicable, family's preferences.

Clinical trials

The treatment team should support the AYA to participate in research and clinical trials where available and appropriate. Trials in relapsed refractory cancer for AYA are more readily available but are also more specialised and resource-intensive.

Advance care planning

Advance care planning is important for all AYA but especially those with advanced disease. It allows them to plan for their future health and personal care by thinking about their values and preferences. This can guide future treatment if the AYA is unable to speak for themselves.

Palliative care

Palliative care should be addressed and offered early. Early referral to palliative care can improve quality of life and in some cases survival. Referral should be based on need, not prognosis.

Communication

The lead clinician and team's responsibilities include:

- explaining the treatment intent, likely outcomes and side effects to the GP, AYA and, if applicable, their family
- maintain open and candid communication with the AYA at all times.

Checklist

☐ Treatment intent, likely outcomes and side effects explained to the GP, AYA and, if applicable, their family

☐ Age-appropriate supportive care needs assessment completed and recorded and referrals to allied health services actioned as required

☐ Advance care planning discussed with the AYA and, if applicable, their family

☐ Early referral to palliative care if appropriate

☐ Routine follow-up visits scheduled

Step 7: End-of-life care

Palliative care

Consider a referral to palliative care. Ensure an advance care directive is in place. The treating team need to be aware that the AYA and their family may not have the same level of acceptance.

Communication

The lead clinician's responsibilities include:

- being open and candid about the prognosis and discussing palliative care options with the AYA and, if applicable, their family
- establishing transition plans to ensure the AYA's needs and goals are considered in the appropriate environment.

Checklist

☐ Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required

☐ Referral to palliative care

☐ Advance care directive in place

Visit the guides to best cancer care webpage <www.cancercareguides.org.au> for consumer guides. Visit the optimal care pathways webpage <www.cancer.org.au/OCP> for the optimal care pathways and instructions on how to import them into your GP software.

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