

Optimal care pathway for children, adolescents and young adults with acute leukaemia

FIRST EDITION



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Endorsed by



Statement of acknowledgement

We acknowledge the Traditional Owners of Country throughout Australia and their continuing connection to the land, sea and community. We pay our respects to them and their cultures and to Elders past, present and emerging.

This work is available from the Leukaemia Foundation website <www.leukaemia.org.au/OCP> and from the Cancer Council website <www.cancer.org.au/OCP>.

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Contents

Welcome and introduction	i
Summary	1
Intent of the optimal care pathways	5
Optimal care pathway resources	7
Principles of the optimal care pathway	9
Principle 1: Patient-centred care	9
Principle 2: Safe and quality care	12
Principle 3: Multidisciplinary care	13
Principle 4: Supportive care	13
Principle 5: Care coordination	15
Principle 6: Communication	16
Principle 7: Research and clinical trials	17
Summary – optimal timeframes	19
Optimal care pathway	20
Step 1: Prevention and early detection	20
Step 2: Presentation, initial investigations and referral	21
Step 3: Diagnosis, staging and treatment planning	24
Step 4: Treatment	35
Step 5: Care after initial treatment and recovery	47
Step 6: Managing refractory, relapsed, residual or progressive disease	53
Step 7: End-of-life care	57
Contributors and reviewers	60
Appendix A: Supportive care domains	63
Appendix B: Psychological needs	64
Appendix C: Special population groups	65
Appendix D: Complementary therapies	71
Appendix E: Members of the multidisciplinary team for CAYA acute leukaemia	72
Resource list	73
Glossary	78
References	80

Welcome and introduction

Welcome to the optimal care pathways for blood cancer. These guides complement the second edition of the optimal care pathways, revised in 2020 under the stewardship of Professor Robert Thomas OAM, Cancer Council Victoria and the Victorian Government.

With support from the federal government, these latest optimal care pathways expand the suite of guides to include a wider range of blood cancers.

Some cancers are simple to treat; many are complex. But the principles of high-quality care are similar for all cancers and, if followed, are likely to achieve the best outcomes for patients and their families and carers.

Optimal care pathways outline best practice for cancer care in Australia – that is, what can, and should, be delivered for every person regardless of where they live or their personal circumstances. They provide the national standard for high-quality cancer care that all Australians should expect.

Access to optimal care is critical for people with blood cancer. The timeliness and accuracy of the diagnosis, getting the right treatment at the right time, and ongoing access to supportive care, all have an impact on a patient's survival and wellbeing. When it comes to blood cancers, we all believe our patients and their families deserve the best care available.

All those involved in cancer care should read and understand the optimal care pathways. This includes haematologists, radiation/medical oncologists, general practitioners, allied health professionals, nurses and managers of cancer services, along with others in the community sector and government. These pathways guide all practitioners from trainees to highly skilled specialists.

We also recommend the optimal care pathways to people living with blood cancer and their carers. These resources are designed to guide discussions with a patient's healthcare team and support individuals to make informed decisions about what is right for them. There is a specific optimal care pathway for Aboriginal and Torres Strait Islander people, and the *Guides to best cancer care* for consumers are available in different languages.

These optimal care pathways are endorsed by the federal government through Cancer Australia, and by all states and territories. They have Australia-wide clinical acceptance and government support.

Optimal care pathways are not clinical guidelines but sit alongside the diagnostic and clinical guidelines to which they refer. The decision about 'what' treatment is given is a professional responsibility and will usually be based on current evidence, clinical practice guidelines and the patient's preferences.

The blood cancer optimal care pathways project, covering six pathways, was completed in 2021 during the COVID-19 pandemic. The importance of optimal cancer care for all cannot be overstated at this time, considering the risks to vulnerable populations and immunosuppressed patients.

I would like to thank everyone involved for generously dedicating considerable time and effort to developing these pathways. This includes many individuals and organisations that contributed to reviewing these guides and the strong support of the federal, state and territory governments.



Associate Professor Peter Mollee

Chair, Blood Cancer Optimal Care Pathways Steering Committee

Summary

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

The optimal care pathways describe the standard of care that should be available to all cancer patients treated in Australia. The pathways support patients, families and/or 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.

This quick reference guide provides a summary for clinicians of the *Optimal care pathway for children, adolescents and young adults with acute leukaemia* (CAYA acute leukaemia). The pathway covers people aged 0-30 years.

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

Step 1: Prevention and early detection

Prevention

Although risk factors have been identified, the cause of CAYA acute leukemia is unknown. There is currently no evidence that lifestyle plays a role. It is important to ensure the patient and their family and/or carer are aware of this to avoid feeling responsible for the illness.

Risk factors

The risk factors for developing a CAYA acute leukaemia include:

- genetic predisposition to an increased likelihood of developing CAYA acute leukaemia in patients with Down syndrome, neurofibromatosis type-1,

ataxia telangiectasia and inherited bone marrow failure syndromes

- having a sibling with a CAYA acute leukaemia; however, the risk is so low there is no recommendation to routinely screen siblings
- treatment with certain chemotherapy agents for another cancer.

Early detection

There are no screening tools for early detection of newly diagnosed CAYA acute leukaemia. In patients with an identified cancer predisposition, a specialist may recommend screening full blood count examinations or bone marrow aspirates.

General health checklist

There are no specific prevention or early detection checks that are recommended unless the patient presents with signs or symptoms (refer to Step 2).

Step 2: Presentation, initial investigations and referral

Because CAYA acute leukaemia is rare it represents a major diagnostic challenge for primary healthcare professionals including GPs and emergency physicians. It is important to recognise parental concern and the need to escalate investigations, particularly after repeated visits to healthcare professionals.

The following **signs and symptoms** should be investigated and may warrant the consideration of a full blood count and peripheral blood film examination:

- persistent unexplained fever
- diffuse bone pain with no obvious trauma and/or refusal to walk in children
- generalised lymphadenopathy
- hepatosplenomegaly
- pallor

- unexplained bruising, unexplained bleeding or petechiae
- extreme fatigue
- recurrent infections.

Children can sometimes have only mild symptoms so the medical practitioner should be alert to the diagnosis, particularly when there is a constellation of the symptoms/signs above.

Initial investigations include a thorough clinical examination full blood count and blood film (performed immediately).

Referral options

A clinical suspicion or laboratory findings that suggest CAYA acute leukaemia warrants immediate telephone referral and presentation to the nearest specialist service. The patient and their family and/or

Checklist

- Signs and symptoms recorded
- Supportive care needs assessed and referrals to allied health services actioned as required
- Patient notified of support services such as Camp Quality 1300 662 267, Cancer Council 13 11 20, Canteen 1800 835 932, Leukaemia Foundation 1800 620 420 and Redkite 1800 733 548
- Referral options discussed with the patient, family and/or carer including cost implications

Step 2: Presentation, initial investigations and referral continued

carer should be warned they may need to transfer to a more specialised service after initial assessment.

At the referral stage, the patient's GP or other referring doctor should advise the patient and their family and/or carer about their options for referral, waiting periods, potential out-of-pocket costs and the range of services available. This will enable patients to make an informed choice of specialist and health service.

Communication

The GP's responsibilities include:

- explaining to the patient, family and/or carer who they are being referred to and why
- informing the patient, family and/or carer that they can contact Camp Quality 1300 662 267, Cancer Council 13 11 20, Canteen 1800 835 932, Leukaemia Foundation 1800 620 420 and Redkite 1800 733 548.

Timeframe

If there is suspicion of CAYA acute leukaemia, patients should be referred to a specialist **immediately**.

Test results should be provided to the patient, family and/or carer **immediately**.

Step 3: Diagnosis, staging and treatment planning

Diagnosis and staging

Perform pre-treatment medical investigations on the day of presentation to the specialist cancer service.

The diagnostic laboratory investigations should be performed as follows.

Urgent pathway

For urgent cases, if it is safe to do so, a diagnostic bone marrow aspirate and lumbar puncture should be performed on the day of presentation. Urgent patients include those who present with hyperleukocytosis, tumour lysis syndrome, mediastinal mass and coagulopathies, and those with suspected acute promyelocytic leukaemia.

If there is a suspicion of acute promyelocytic leukaemia, urgent treatment with all-trans retinoic acid should be instigated immediately.

Standard pathway

The diagnostic bone marrow aspirates and lumbar puncture should be performed by the next business day. Clinical trial requirements, as well as the level of institutional resources, should also guide timings.

Measurable/minimal residual disease

The importance of this test for measuring the patient's response to treatment cannot be overstated. (See the *Optimal care pathway for CAYA leukaemia* for principles for MRD in CAYA acute leukaemia subcategories.)

Genetic testing

Paired tumour/germline sequencing should be considered in some patients with a family history or clinical findings that suggest a possible cancer predisposition syndrome. Once a diagnosis is confirmed, a comprehensive family cancer history of at least three generations' pedigree will help further identify patients and families with potential cancer predisposition or inherited syndromes.

Treatment planning

Immediate treatment is often required before a full multidisciplinary meeting (MDM) ratifies the plan. Multidisciplinary input is likely after treatment begins.

Research and clinical trials

Consider enrolment where available and appropriate. See the OCP resources appendix and relevant steps for clinical trial resources relevant to CAYA acute leukaemia.

Checklist

- Diagnosis has been confirmed
- Performance status and comorbidities recorded
- Patient discussed at MDM and decisions provided to the patient, family and/or carer
- Clinical trial enrolment considered
- Supportive care needs assessed and referrals to allied health services actioned as required
- Consideration of future fertility consequences and referral to fertility specialist as required
- Patient referred to support services (such as Camp Quality, Cancer Council, Canteen, Leukaemia Foundation and Redkite) as required
- Treatment costs discussed with the patient, family and/or carer as appropriate

Step 3: Diagnosis, staging and treatment planning continued

Communication

The lead clinician's¹ responsibilities include:

- discussing a timeframe for diagnosis and treatment options with the patient, family and/or carer
 - explaining the role of the multidisciplinary team in treatment planning and ongoing care
 - encouraging discussion about the diagnosis, prognosis, advance care planning and palliative care
- while clarifying the patient's wishes, needs, beliefs and expectations, and their ability to comprehend the communication
- providing appropriate information and referral to support services as required
 - discussing the effect of leukaemia treatment on future fertility and referral to a fertility specialist as required
 - communicating with the patient's GP about the diagnosis, treatment plan and recommendations from MDMs.

Timeframe

Investigations should be completed immediately.

Prospective review at an MDM for all cases.

Step 4: Treatment

Intent of treatment for CAYA acute leukaemia is curative.

Treatment options

- Chemotherapy with or without immunotherapy is the key component for treating CAYA acute leukaemia.
- Radiation therapy has a role in some CAYA acute leukaemia patients with testicular disease or overt central nervous system disease. Radiation therapy is used as part of the conditioning regimen for patients undergoing haematopoietic stem cell transplantation. It can be useful in palliating symptomatic masses in advanced disease.
- haematopoietic stem cell transplantation is reserved for patients at greatest risk of relapse. It is used as a salvage where primary treatment has failed.

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. For more information, visit the Palliative Care Australia website <www.palliativecare.org.au>.

Communication

The lead clinician and team's responsibilities include:

- discussing treatment options with the patient, family and/or carer including the intent of treatment as well as risks and benefits
- discussing advance care planning with the patient, family and/or carer where appropriate
- communicating the treatment plan to the patient's GP
- helping patients to find appropriate support for exercise programs where appropriate to improve treatment outcomes.

Checklist

- Intent, risk and benefits of treatment discussed with the patient and/or carer
- Treatment plan discussed with the patient and/or carer and provided to GP
- Supportive care needs assessed and referrals to allied health services actioned as required
- Patient referred to support services (such as Camp Quality, Cancer Council, Canteen, Leukaemia Foundation and Redkite) as required
- Early referral to palliative care considered and advance care planning discussed with the patient and/or carer

Timeframe

As soon as possible after presentation.

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.

Step 5: Care after initial treatment and recovery

Provide a treatment and follow-up summary to the patient, family and/or carer and GP outlining:

- the diagnosis, including tests performed and results
- treatment received (types and date)
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health professionals
- potential long-term and late effects of treatment and care of these
- supportive care services provided
- a follow-up schedule, including tests required and timing

- contact information for key healthcare providers who can offer support for lifestyle modification
- a process for rapid re-entry to medical services for suspected recurrence.

Communication

The lead clinician's responsibilities include:

- explaining the treatment summary and follow-up care plan to the patient, family and/or carer
- informing the patient, family and/or carer about secondary prevention and healthy living
- discussing the follow-up care plan with the patient's GP.

Checklist

- Treatment and follow-up summary provided to the patient, family and/or carer and the patient's GP
- Supportive care needs assessed and referrals to allied health services actioned as required
- Patient referred to support services (such as Camp Quality, Cancer Council, Canteen, Leukaemia Foundation and Redkite) as required
- Patient-reported outcome measures recorded

Step 6: Managing refractory, relapsed, residual or progressive disease

Detection

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

Treatment

Evaluate each patient for whether referral to the original multidisciplinary team is appropriate. Treatment will depend on the extent of disease, previous management and the patient's preferences.

Advance care planning

Advance care planning is important for all patients 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 patient is unable to speak for themselves.

Survivorship and palliative care

Survivorship and palliative care should be addressed and offered early. Early referral to palliative care can improve quality of life. 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 patient, family and/or carer and the patient's GP.

Checklist

- Treatment intent, likely outcomes and side effects explained to the patient, family and/or carer and the patient's GP
- Supportive care needs assessed and referrals to allied health and community support services as required
- Advance care planning discussed with the patient, family and/or carer
- Patient referred 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.

Communication

The lead clinician's responsibilities include:

- being open about the prognosis and discussing palliative care options with the patient
- establishing transition plans to ensure the patient's needs and goals are considered in the appropriate environment.

Checklist

- Supportive care needs assessed and referrals to allied health and community support services as required
- Patient referred 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 OCP webpage <www.cancer.org.au/OCP> for the optimal care pathway and instructions on how to import these guides into your GP software.

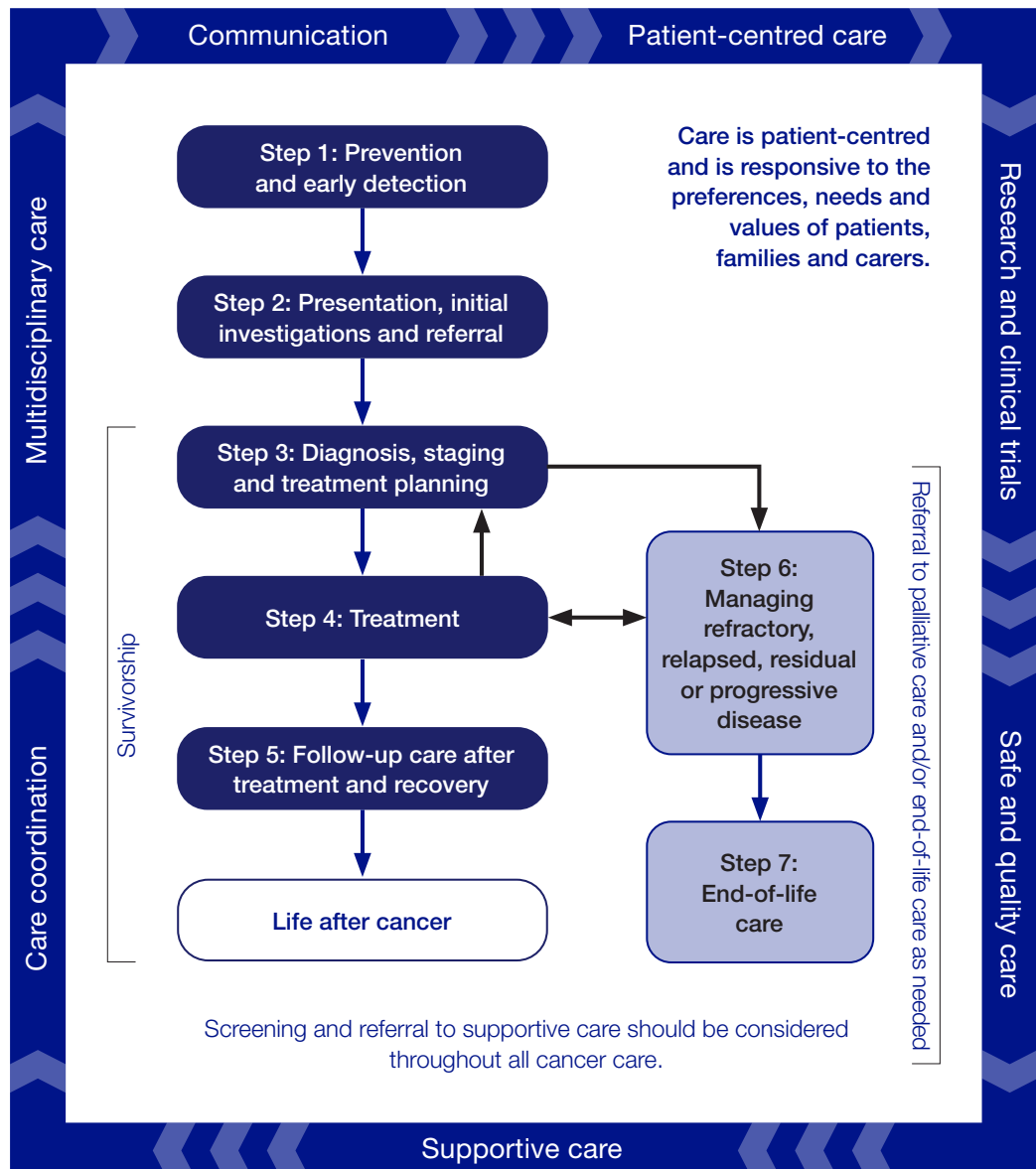
Intent of the optimal care pathways

Optimal care pathways map seven key steps in cancer care. Each of these steps outlines nationally agreed best practice for the best level of care. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (e.g. the type of cancer, the age of the patient, when and how the cancer is diagnosed, prognosis, management, the patients and carers decisions and their physiological response to treatment).

The principles underpinning optimal care pathways always put patients at the centre of care throughout their experience and prompt the healthcare system to deliver coordinated care.

The optimal care pathways do not constitute medical advice or replace clinical judgement, and they refer to clinical guidelines and other resources where appropriate.

Figure 1: The optimal care pathway



At the time of publication, a population based *optimal care pathway for adolescents and young adults* was under development. This resource provides a tool to help guide system safety and responsiveness to the unique needs of adolescents and young adults diagnosed with cancer and improve outcomes and experience. It can be used in conjunction with the optimal care pathway for each cancer type.

Optimal care pathway resources

There are three resources for each pathway: an optimal care pathway, a quick reference guide for health professionals and a guide to best cancer care for patients, carers and families.

Optimal care pathways

This optimal care pathway is designed for **health professionals and health services**. However, **patients and carers** may find useful information in this version to help understand the processes their treating health professionals are following.

This resource aims to:

- assist health professionals to provide optimal care and support to patients with cancer, their families and carers
- provide optimal timeframes for delivering evidence-based care
- emphasise the importance of communication and collaboration between health providers and people affected by cancer
- assist and inform new health professionals or trainees who are entering the cancer care workforce
- provide value to health systems to identify gaps in current cancer services, bring about quality improvement initiatives and improve how services are planned and coordinated. Adherence to the pathways should be measured wherever possible.

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the optimal care pathways.



Quick reference guides

The quick reference guides are for **health professionals and health services**. They provide a summary of each optimal care pathway for health professionals and patients.

The quick reference guides include:

- optimal timeframes within which tests or procedures should be completed
- checklists with indicators related to recommendations in the optimal care pathway.

Visit the Cancer Council website <www.cancer.org.au/OCP> to view the quick reference guide for this optimal care pathway.



Guides to best cancer care

The guides to best cancer care are **consumer** resources that help patients or their parents and carers understand the optimal cancer care that should be provided at each step. Other family and friends may also find the guides helpful.

The guides to best cancer care:

- include optimal timeframes within which tests or procedures should be completed
- include prompt questions to support patients and carers to understand what might happen at each step of their cancer journey and to consider what questions to ask
- provide information to help patients and carers communicate with health professionals
- are available in eight languages.

Visit the Cancer Council's website <www.cancercareguides.org.au> to view the guides to best cancer care



Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* provides a tool to help reduce disparities and improve outcomes and experiences for Aboriginal and Torres Strait Islander people with cancer. This resource can be used in conjunction with the optimal care pathway for each cancer type.

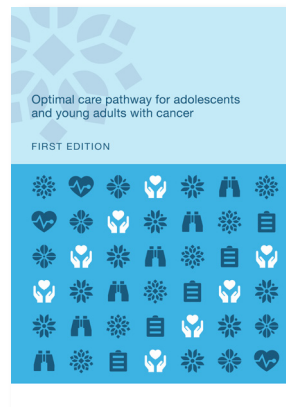
Visit the Cancer Australia website <<https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-health>> to view the optimal care pathway for Aboriginal and Torres Strait Islander people.



Optimal care pathway for adolescents and young adults with cancer and reference documents

At the time of publication, a population based optimal care pathway for adolescents and young adults with cancer was under development. This resource provides a tool to help guide system safety and responsiveness to the unique needs of adolescents and young adults diagnosed with cancer and improve outcomes and experience. It can be used in conjunction with the optimal care pathway for each cancer type.

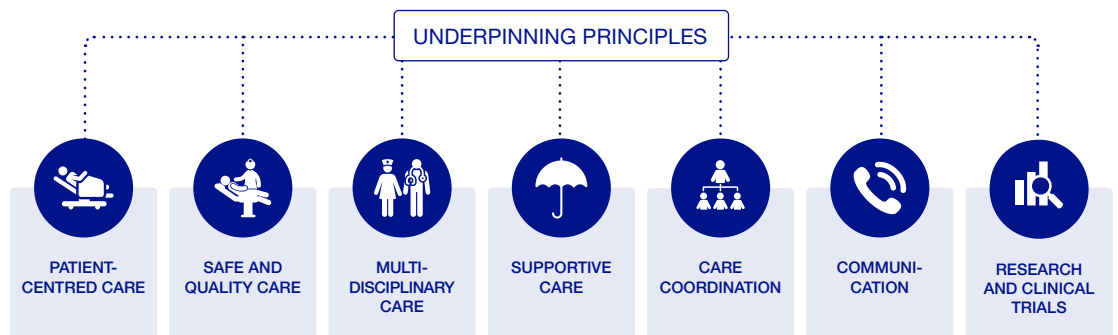
This resource and the OCP under development both draw extensively on the Victorian paediatric oncology care pathways: *Providing optimal care for children, adolescents with acute leukaemia, central nervous system tumours and solid tumours* (May 2019), developed by the Victorian Paediatric Integrated Cancer Service (PICS). Visit the PICS website <<https://www.vics.org.au/pics-health-professionals>> for more information.



Principles of the optimal care pathway

The seven principles of care define appropriate and supportive cancer care that is the right of all patients and the right of those caring for and connected with them.

Figure 2: The seven principles underpinning the optimal care pathway



Principle 1: Patient-centred care



Patient-centred care informs and involves patients in their care and respects and responds to the preferences, needs and values of patients, families and carers.

A patient-centred focus increases the experience and satisfaction of patients, their families and carers, and staff, as well as safety and cost-effectiveness (ACSQHC 2019a).

Patient-centred care means:

- patients are informed and involved in decisions about their cancer and the treatment, post-treatment and recovery program ahead
- patients, their families and carers are provided with access to appropriate and accessible health information
- respect for the cultural and religious beliefs of patients and their families is demonstrated when discussing the diagnosis of cancer
- active communication is used to engage patients, their families and carers in the care process – an essential step for children, adolescents and young adult patients to be informed and have an age-appropriate understanding
- care processes are mutually beneficial for patients and providers
- special needs are addressed – for example, the needs of people with disabilities or mental health issues.

Informed choice and consent

Informed patients and carers have greater confidence and competence to manage their cancer journey. Children should be involved in decision making at all times where possible in line with Federal and state/territory legislation.

Health professionals are responsible for enabling patients and carers to make informed choices according to their preferences, needs and values. Patients and carers should be provided with:

- individualised and timely information and guidance about their treatment
- details of their care, including the advantages and disadvantages of each treatment, the associated potential side effects, the likely outcomes on their performance status (how well a patient is able to carry out activities of daily life) and subsequently their quality of life and any financial implications, at each stage of the pathway (ACSQHC 2020).

Health professionals have a legal responsibility to obtain consent for all procedures from either the patient, legal guardian or substitute decision-maker if they are not deemed competent.

Referral choices and informed financial consent

Patients and carers have the right to receive the information they need to be able to make an informed decision on where to be referred for treatment. Treating specialists and practitioners should clearly explain the costs or how to find out the costs of services, tests and treatment options upfront to avoid consumers experiencing 'bill shock'.

At the time of referral, the patient's general practitioner or other referring doctor should discuss the different 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 patients and carers to make an informed choice of specialist and health service. Referral decisions influence the care patients receive along the pathway and the direct and indirect costs they and their carers may incur. Different referrals have different costs:

- referral to a public hospital, which may involve some costs
- initial referral to a private specialist with associated costs, with the option of ongoing treatment in a public hospital at any time
- referral to a patients and carers choice of practitioner for immediate and ongoing private hospital management with associated costs.

Patients should be made aware that even though public hospital health care is 'free' to all Australian citizens and most permanent residents of Australia, there are still associated direct costs such as:

- over-the-counter medication and prescriptions
- wound dressings
- travel costs
- parking fees
- tests that are not covered by Medicare.

A cancer diagnosis and treatment may affect a patient's or carer's income. This is an indirect cost associated with cancer. Social work support is essential to help patients and their families deal with this issue. Patients and carers should be advised not to undergo private care with significant out-of-pocket expenses if financially constrained. Specialists in private practice need to explain costs at the start of each new treatment to acknowledge the cumulative out-of-pocket expenses that patients can incur.

Patients and carers should be made aware of other forms of potential financial support that may be available, including whether the diagnosis or treatment triggers any insurance or access to superannuation, patient-assisted travel schemes, Centrelink or other forms of social security.

For more information on informed financial consent see Cancer Council's 'Standard for informed financial consent' <<https://www.cancer.org.au/health-professionals/resources/informed-financial-consent>>.

Financial counselling services can provide advice on dealing with financial difficulties. These services can be accessed publicly (via social workers at hospitals, financial counsellors at neighbourhood houses or rural financial aid), privately or through cancer support services such as local charity groups or social work services.

For practical and financial assistance, patients and carers may consider Cancer Council's financial services <<https://www.cancer.org.au/about-cancer/patient-support/practical-and-financial-assistance.html>>.

Shared care

Shared care between a cancer specialist and primary care health professional is delivered in two or more settings by two or more professionals. The primary care provider is usually a general practitioner but can include nurses and allied health practitioners. Shared care can be delivered throughout the care pathway including during treatment, follow-up care, survivorship care and end-of-life care.

Shared care offers several advantages to patients and carers, including the potential for treatment closer to home and more efficient care with less duplication and greater coordination. Evidence comparing shared care and specialised care indicates equivalence in outcomes including recurrence rate, cancer survival and quality of life in adults (Cancer Research in Primary Care 2016).

Telehealth can enable efficient shared care and should be explored for all post-acute children, adolescent and young adult patients. Patients in some rural or remote locations may access specialists via Medicare Benefit Scheme funded telehealth consultations. General practitioners working in rural or remote locations should be aware of specialist multidisciplinary teams with facilities to reduce the travel burden and costs for patients and carers.

Principle 2: Safe and quality care



Hospitals and health professionals are responsible for providing safe and quality care.

Health professionals need to have appropriate training and experience to undertake treatment for acute leukaemia in children, adolescents and young adults. Patients should be referred to an individual practitioner or service with appropriate expertise.

Safe and high-quality care is care provided by appropriately trained and credentialed health professionals who undertake regular quality reviews of their performance, contribute to regular audits of their care and are actively involved in continuing professional development. Hospitals and clinics must have the equipment, staff numbers, policies and procedures in place to support safe and high-quality care for cancer patients. Patients should be offered the safest options for care, which may include using telehealth (Cancer Australia 2020).

Hospital quality committees should ensure all health care is informed by evidence, and health professionals and health service managers (including executives) have a responsibility to evaluate and monitor their practice. Optimal care pathways provide a framework to help evaluate and monitor practice over time. Services should be routinely collecting relevant minimum datasets to support benchmarking, quality care and service improvement. Hospital committees and health professional peak bodies should be auditing this process (ACSQHC 2017; 2020).

The Australian Council on Health Standards <<https://www.achs.org.au>> has created a set of indicators that helps hospitals conform to appropriate standards.

All new diagnoses should be reported, as appropriate, to the relevant state or territory cancer registry.

Patient-reported experience and outcome measures

Patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) should be incorporated into routine cancer care.

PREMs are used to obtain patients' or carers' views and observations on aspects of healthcare services they have received (AIHW 2018). Patient experience data is collected for specific services and then relayed to service providers to instigate improvements in patient services (ACSQHC 2019b).

The Australian Hospital Patient Experience Question Set (AHPEQS) is a tool used to assess patient experiences of treatment and care in a private or public hospital. AHPEQS helps to improve the safety and quality of health care by allowing organisations to understand the patient's perspective (AIHW 2018; ACSQHC 2019b).

PROMs measure aspects of a person's health status such as symptoms, quality of life and needs and are collected directly from patients either online, via a smartphone or through paper-based means.

Collecting PROMs, and then instigating an appropriate clinical response, has been shown to prolong survival, reduce health system use and improve patients' quality of life. While there are many sets of PROMs questions that are relevant to any cancer patient, specific questions can be tailored to particular cancer types, populations or different phases of cancer care.

Principle 3: Multidisciplinary care



Multidisciplinary care is an integrated team approach that involves all relevant health professionals discussing all relevant treatment options and making joint recommendations about treatment and supportive care plans, taking into account the personal preferences of patients and carers.

Multidisciplinary care improves patient outcomes. Cancer Australia's 'Principles of multidisciplinary care' provides a flexible definition, allowing services to vary implementation according to cancer type and the service location. The principles stipulate:

- a team approach that involves core disciplines that are integral to providing good care, including general practice, with input from other specialties as required
- communication among team members about treatment planning and plans for follow-up
- access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution
- care delivery in accordance with nationally agreed standards
- patient involvement in decisions about their care (Cancer Australia 2019a).

In addition to these principles, treatment teams should consider clinical trial participation for all eligible patients.

Multidisciplinary meetings, often called MDMs, should be based on the principles outlined above.

For more information on the principles of multidisciplinary care and the benefits of adopting a multidisciplinary approach, see Cancer Australia's 'Principles of multidisciplinary care' <www.canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care/all-about-multidisciplinary-care/principles-multidisciplinary-care>.

Principle 4: Supportive care



Supportive care is a vital part of any cancer treatment program. Supportive care deals with issues that emerge for patients, families and carers from the effects of the cancer diagnosis and its treatment. It is made up of all the services, information and resources patients may need to meet their physical, psychological, social, information and spiritual needs from the time of diagnosis.

Supportive care may be 'patient-defined' and based on unmet needs. It is a core component of evidence-based clinical care and its benefits are well established. All cancer patients and their carers should be formally supported and have access to understandable, relevant information about the medical, practical and emotional aspects of the cancer and its treatment (Fitch 2008). The wishes and needs of the patient, their family and their carers should determine the level of support provided. Supportive care is a standard or routine aspect of cancer care and the treatment team should make patients aware of this.

Supportive care should begin from the time of diagnosis and continue throughout the cancer pathway.

For health professionals, supportive care involves:

- screening and assessing patients and families for their supportive care needs
- providing patients and carers with access to a range of multidisciplinary support services, groups and therapies designed to assist them to live with cancer and its treatment and optimise recovery
- optimising referral pathways to community support organisations (cancer-related non-government, not-for-profit and charities) that provide services to cancer survivors – these address many of the care-navigation, psychosocial and information needs of cancer survivors and those affected by cancer (Australian Cancer Survivorship Centre 2019)
- being aware of and delivering culturally appropriate care.

All members of the multidisciplinary team have a role in providing supportive care along the care pathway, with special attention at transition points.

Supportive care involves routinely and systematically assessing patients to determine their needs.

Health professionals can use a variety of validated screening tools for this task (see box below).

Clinical review and individual assessment are still required to ensure all patient concerns are identified.



More information

Visit the Cancer Council Australia website <https://wiki.cancer.org.au/australia/COSA:Psychosocial_management_of_AYA_cancer_patients> for guidance for healthcare professional for psychosocial management of AYAs diagnosed with cancer.

Visit the WeCan website <www.wecan.org.au> for information and resources on supportive care.

Validated screening tools

- Adolescent & Young Adult Psycho-Oncology Screening Tool (AYA-POST) (Patterson et al. 2021)
- Psychosocial Assessment Tool (PAT) (Kazak et al. 2011)

Key review points

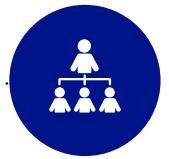
The treatment team should assess patients for supportive care needs at these key stages:

- initial presentation or diagnosis
- the beginning of treatment or a new phase of treatment
- change in prognosis
- if a patient is found to have a germline genetic mutation predisposing to cancer
- end of treatment
- throughout survivorship
- diagnosis of recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care
- other time points based on clinical judgement.

The team also needs to decide whether the patient requires ongoing referral to supportive care services. Access to services can be through general practice–led chronic disease management plans, team care arrangements and mental health plans. Community support services also have a role to play.

See Appendices A, B and C for more information on supportive care and the specific needs of people that may arise.

Principle 5: Care coordination



Care coordination is the responsibility of every professional, both clinical and non-clinical, who works with patients, their families and carers.

Seamless care coordination is essential for patients to successfully navigate the complex health system. Care coordination is a comprehensive approach to achieving continuity of care for patients. It aims to ensure care is delivered in a systematic, connected and timely way that promotes efficiency and reduces the risk of duplication and over-servicing to meet the medical and personal needs of patients, families and carers.

Care coordination includes:

- proactive and timely communication with patients, their families and carers
- treatment plans, survivorship care plans and/or advance care directives
- coordinated appointments to ensure timely diagnosis, treatment and survivorship care
- appropriate tests and results being available to the treating team so treatment decisions can be made
- medical records being available to all members of the treating team and at scheduled appointments
- translation or interpreter services arranged if the patient/carer is from a non-English-speaking background or has difficulty communicating due to a physical disability
- practical support such as transport, accommodation, advance care planning and financial support
- referral and access to supportive care including community support organisations
- access to clinical trials
- access to telehealth for people in rural and remote areas and for managing vulnerable patients.

Care coordination brings together different health professionals, teams and health services. It also encompasses MDMs, multidisciplinary assessment clinics, supportive care screening and assessment, referral practices, data collection, common protocols, information for patients and individual clinical treatment.

Care coordination should cross the acute and primary care interface and should aim to achieve consistency of care through clear communication, linkages and collaborative integrated care planning.

Care coordination can be facilitated through electronic health record management such as My Health Record. My Health Record is a secure online database that helps with data collection and care coordination (My Health Record 2019).

Formal care coordination through appointed care coordinators plays an important role in managing and supporting patients through the health system. The availability of dedicated care coordinators varies across states and territories according to the complexity of care required and local service capacity and resourcing.

Principle 6: Communication



Everyone employed in the healthcare system is responsible for ensuring the communication needs of patients, their families and carers are met.

Good and open communication is a key principle of care for cancer patients. This includes communication between oncology and primary care health professionals and with patients. General practitioners should be involved in care from the point of diagnosis, and patients should be encouraged to maintain a relationship with their general practitioner through all stages of cancer care. Communication should be regular and timely.

Attendance of a family member or carer at clinical appointments is beneficial for many patients, as the family member or carer can provide informational and emotional support. General practitioners and clinicians should encourage and support the involvement of family members and carers by providing an inclusive and supportive consultation environment (Laidsaar-Powell et al. 2018a). Laidsaar-Powell et al. provide evidence-based guidance on how to support family member or carer involvement in consultations (Laidsaar-Powell et al. 2018a; 2018b).

Every person with cancer will have different communication needs, including cultural and language differences. When anyone involved in treatment communicates with patients and carers, they should be truthful and transparent but aware of cultural and psychological sensitivities. In communicating with patients and carers, healthcare providers should undertake to:

- empower patients and carers to be active in treatment discussions
- use professionally trained interpreters if required – for example, when communicating with people from culturally diverse backgrounds whose primary spoken language is not English, and for people with a hearing impairment (visit the Translating and Interpreting Services website <www.tisnational.gov.au> for more information on interpreter and language services)
- use culturally sensitive and appropriate forms of communication for people from culturally diverse backgrounds and Aboriginal and Torres Strait Islander people, as appropriate
- provide appropriate information for people from culturally diverse backgrounds
- provide information on community-based supportive care services and resources to patients and their families and carer
- identify the patient's substitute treatment decision-maker to ensure they are involved in relevant discussions
- ensure patients, their families or their carers have the opportunity to ask questions
- seek consent before conveying information between health professionals or healthcare teams or with family and carers
- be respectful if a patient or carer seeks a second opinion from another health professional
- ensure patients do not have to convey information between areas of care (it is the provider's and healthcare system's responsibility to transfer information between areas of care)
- communicate in plain language (avoiding complex medical terms and jargon)
- ensure information is communicated at a level relevant to the patient's health literacy and that of their families and carers (ACSQHC 2020)
- use tools, diagrams and aids as appropriate (Gilligan et al. 2017)
- ensure the patient is aware of how to access electronic patient information, where appropriate

- allow enough time for communication, especially when conveying complex or sensitive information such as an initial diagnosis
- check the patient's and/or their family or carer's understanding by asking the patient and/or their family or carer to say in their own words what has been conveyed.

Healthcare providers should also consider offering patients and carers a question prompt list before a consultation and recordings or written summaries of their consultations afterwards. Question prompt lists are effective in improving communication and the psychological and cognitive outcomes of cancer patients. Recordings or summaries of key consultations improve patients' recall of information and satisfaction (Hack et al. 2012). Written care plans, treatment summaries, survivorship care plans and advance care directives are effective records and communication tools.

Communication skills training programs that use role-play to develop skills and observe patient interactions to provide feedback, should be available to health professionals at every level of practice (Gilligan et al. 2017).

Communication skills training programs and resources can be found on the following websites:

- Australian Commission on Safety and Quality in Healthcare, Communicating for safety resource portal <<https://c4sportal.safetyandquality.gov.au/>>
- state and territory Cancer Councils <www.cancer.org.au/about-us/state-and-territory-councils> for the relevant council
- eviQ <<https://education.eviq.org.au/>>
- VITAL talk <www.vitaltalk.org>.

Telehealth has become an increasingly acceptable alternative to face-to-face consultations. When using telehealth, the team must consider what is best for the patients and carers, including their preferences. A face-to-face consultation should be the first option, if it is safe, when delivering critical diagnosis information, a change in therapy or prescribing intensive treatment. If this is not an option, a video consultation should be considered, and the patient should be encouraged to have a support person with them to assist (Cancer Australia 2020).

Principle 7: Research and clinical trials



Research and clinical trials play an important role in establishing the efficacy and safety of diagnostic, prognostic and therapeutic interventions, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcberg 2013).

Clinical trials are the foundation for improved cancer outcomes, allowing new treatments to be tested and offering patients access to potentially more effective therapies than otherwise available to them.

Clinical trials are available for multiple types of cancer and may be a valuable option for people with rare, difficult-to-treat conditions for which there may be limited evidence about how the condition is best treated or managed (Australian Clinical Trials 2015).

Treating specialists and multidisciplinary teams should be aware of or search for clinical trials that may be suitable for their patients. Specialists are encouraged to refer appropriate patients to other treating centres to participate in research or clinical trials at any stage of the care pathway and be willing to discuss the importance of informed consent and the pros and cons of participating in such

trials. Any member of the multidisciplinary team can encourage cross-referral between clinical trials centres. Possible ineligibility to participate in a clinical trial should be discussed with the patient or carer. Acknowledge disappointment and offer support in this instance.

Health services should strive to implement policies and procedures that facilitate equitable access to clinical trials for all patients, including culturally diverse patients, regional patients and those from Aboriginal or Torres Strait Islander communities.

The use of telehealth technology, such as the Australasian Tele-trial Model, hopes to improve access to trials for patients being treated in rural and regional areas (COSA 2016). The principles outlined in the Australasian Tele-trial Model are consistent with the National Teletrials Compendium (Australian Government Department of Health 2021b), which provides guidance on the national approach to teletrials that has been agreed by all states and territories. Clinical trials must adhere to the Good Clinical Practice quality standards, which provide assurance that the data and reported results are credible and accurate and that the rights, integrity and confidentiality of clinical trial participants are protected (Australian Government Department of Health 2021b).

Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. Search for a trial <www.australiancancertrials.gov.au> via its website.

You can also search the Australian New Zealand Clinical Trials Registry <www.anzctr.org.au>, the Australasian Leukaemia and Lymphoma Group trials website <<https://www.allg.org.au/clinical-trials-research/current-clinical-trials>>, ClinTrial Refer <www.clintrial.org.au>, ClinicalTrials.gov <www.clinicaltrials.gov> for international studies, as well as the Australian & New Zealand Childrens Haematology/Oncology Group <www.anzchog.org/clinical-trials-research/clinical-trials> for clinical trials for children and adolescents.

Education and training

Research and clinical trials provide an opportunity to educate health professionals who are in training. Cancer centres may be affiliated with teaching hospitals, universities or research groups to promote higher education or to develop the academic workforce, leading to more sustainable practice. Specialists should be encouraged to take up and retain active membership to professional societies and organisations that can assist with professional development opportunities.

Summary – optimal timeframes

Evidence-based guidelines, where they exist, should inform timeframes. Treatment teams need to recognise that shorter timeframes for appropriate consultations and treatment can promote a better experience for patients. Three steps in the pathway specify timeframes for care (Figure 3). They are designed to help patients understand the timeframes in which they can expect to be assessed and treated, and to help health services plan care delivery in accordance with expert-informed time parameters to meet the expectation of patients. These timeframes are based on expert advice from the Acute Leukaemia in Children, Adolescents and Young Adults (CAYA) Working Group. The pathway covers people diagnosed with acute leukaemia from birth up to the age of 30 years.

Figure 3: Timeframes for care of acute leukaemia in children, adolescents and young adults

Step in pathway	Care point	Timeframe
Presentation, initial investigations and referral	Signs and symptoms	Patients with suspicious clinical and/or laboratory findings should be immediately discussed with an appropriate specialist service and clinically triaged with a health professional.
	Initial investigations initiated by GP	The GP/emergency physician should begin investigations immediately and the laboratory results should be processed and followed-up on the same day .
	Referral for emergency assessment / initial referral	Patients with bleeding, sepsis or severe symptoms should be regarded as a medical emergency and be referred immediately to an appropriate emergency facility without necessarily waiting for results of laboratory tests (same day). CAYA with a laboratory diagnosis of acute leukaemia should be referred on the same day to a specialist service and have an urgent assessment within 24 hours (unless advised otherwise by a specialist).
Diagnosis, staging and treatment planning	Diagnosis and staging	Making the diagnosis of CAYA acute leukaemia should begin immediately , including a morphological assessment of blood film by a specialist. Other results necessary for immediate management decisions should be available within 72 hours of the patient presenting.
	Multidisciplinary team meeting and treatment planning	Immediate treatment is often required before a full MDM ratifies the plan. Multidisciplinary input is likely after treatment begins.
Treatment	Treatment options	Once the diagnosis is confirmed then systemic therapy should start immediately , with the offer of a clinical trial, if eligible. Note: Consider fertility preservation, if clinically appropriate.

Optimal care pathway

Seven steps of the optimal care pathway

Step 1: Prevention and early detection

Step 2: Presentation, initial investigations and referral

Step 3: Diagnosis, staging and treatment planning

Step 4: Treatment

Step 5: Care after initial treatment and recovery

Step 6: Managing refractory, relapsed, residual or progressive disease

Step 7: End-of-life care

This optimal care pathway is intended as a resource in managing children, adolescents and young adults (CAYA) diagnosed with acute leukaemia from birth up to the age of 30 years.

In 2021, the yearly incidence of acute lymphocytic leukaemia (ALL) in people aged 0–29 years was estimated to be 2.6 cases per 100,000 (or 271 cases). The yearly incidence of acute myeloid leukaemia (AML) in people aged 0–29 years was estimated to be 0.5 cases per 100,000 (or 52 cases) (AIHW 2021).

This optimal care pathway outlines seven critical steps for CAYA patients diagnosed with acute leukaemia (ALL and AML). The critical steps will require realignment and adjustment to best meet the needs of patients and their families as well as care providers, without undermining the effectiveness of the treatment and supportive care program.

Step 1: Prevention and early detection

This step outlines recommendations for the prevention and early detection of childhood, adolescent and young adult acute leukaemia (CAYA leukaemia).

Evidence shows that not smoking, avoiding or limiting alcohol intake, eating a healthy diet, maintaining a healthy body weight, being physically active, being sun smart and avoiding exposure to oncoviruses or carcinogens may help reduce general cancer risk (Cancer Council Australia 2018).

1.1 Prevention

Although risk factors have been identified, the cause of CAYA acute leukaemia remains unknown. There is currently no evidence that lifestyle plays a role in CAYA acute leukaemia. It is important to ensure the patient and their family are aware of this to avoid feeling responsible for the illness.

1.2 Risk factors

The risk factors for developing CAYA acute leukaemia include the following.

Genetic predisposition

Some genetic disorders may increase the likelihood of developing CAYA acute leukaemia. These include, but are not limited to, Down syndrome, neurofibromatosis type-1, ataxia telangiectasia, inherited bone marrow failure syndromes and, rarely, inherited cancer predisposition syndromes (D'Orazio et al. 2010; Eden et al. 2010). Most cases of CAYA acute leukaemia do not have a genetic predisposition identified.

Siblings

Although the risk is still extremely low, siblings of CAYA acute leukaemia patients have a slightly increased risk of developing leukaemia compared with the general population.

Environmental factors

There is no evidence to suggest environmental factors contribute to CAYA acute leukaemia. CAYA patients who have been treated with certain chemotherapy agents for another cancer may be at a marginally increased risk of developing a secondary leukaemia, particularly treatment-related AML.

1.3 Early detection

1.3.1 Screening recommendations

There are no screening tools for early detection of newly diagnosed CAYA acute leukaemia at the moment. In CAYA with an identified cancer predisposition, a specialist may recommend screening full blood count examinations or bone marrow examination. Routine full blood count examination is not indicated for asymptomatic siblings of those diagnosed with CAYA acute leukaemia.

Step 2: Presentation, initial investigations and referral

This step outlines the process for the general practitioner to initiate the right investigations and refer to the appropriate specialist in a timely manner. The types of investigations the general practitioner undertakes will depend on many factors, including access to diagnostic tests, the availability of medical specialists and patient and carer preferences.

Because CAYA acute leukaemia is rare it represents a major diagnostic challenge for primary healthcare professionals including general practitioners and emergency physicians. It is important to recognise parental concern and the need to escalate investigations, particularly after repeated visits to healthcare professionals.

2.1 Signs and symptoms

The clinical manifestations of acute leukaemia depend on the level of leukaemic infiltration into the marrow and extramedullary sites at the time of presentation, resulting in a wide spectrum of signs and symptoms. It is important to recognise parental and carer concern and the need to escalate investigations, particularly after repeated visits to healthcare professionals.

The following signs and symptoms may warrant consideration of a full blood count and peripheral blood film examination:

- persistent unexplained fever
- diffuse bone pain with no obvious trauma and/or refusal to walk in children
- generalised lymphadenopathy
- hepatosplenomegaly
- pallor
- unexplained bruising, unexplained bleeding or petechiae
- extreme fatigue
- recurrent infections.

Children can sometimes have only mild symptoms, so the medical practitioner should be alert to the diagnosis, particularly when there is a constellation of the symptoms/signs as described above.

Rarely, leukaemia can manifest itself without an abnormal full blood count. Signs and symptoms include testicular swelling in males (testicular involvement with CAYA acute leukaemia) or isolated neurological symptoms such as cranial nerve palsies/headaches (central nervous system [CNS] CAYA leukaemia).

2.1.1 Timeframe for general practitioner consultation

Patients with a suspicion of CAYA acute leukaemia on clinical and/or laboratory findings should be discussed **immediately** with an appropriate specialist service. Usually, this should lead to a **same day** recommendation to be seen in either a local or in a specialist hospital, preferably with a specialist cancer service.

2.2 Assessments by the general practitioner

Although rare, general practitioners should be mindful of CAYA who present with the symptoms described above. It is important that there is a thorough clinical examination because the finding of significant lymphadenopathy or hepatosplenomegaly with petechiae/significant pallor and bruising will be an alert to the potential diagnosis.

A full blood count and blood film should be performed **immediately**.

If the patient is unwell with fever, bleeding, sepsis, respiratory distress (particularly orthopnoea and dyspnoea) or signs of hyperviscosity (respiratory distress or neurological signs) they should be referred **immediately** to a specialist centre, without waiting for laboratory blood results.

If CAYA acute leukaemia is suspected by pathology laboratories (e.g. high white cell count, pancytopenia or presence of blasts on the blood film), the pathology laboratory should contact the general practitioner by telephone **immediately**.

If the CAYA acute leukaemia diagnosis is suspected but not confirmed or the results are inconsistent or indeterminate, the general practitioner must **immediately** refer the patient via telephone to an appropriate specialist (paediatric or adult haematologist/oncologist) to make the diagnosis.

2.2.1 Timeframe for completing investigations

A clinical suspicion or laboratory findings that suggest CAYA acute leukaemia warrants **immediate** telephone referral and presentation to the nearest specialist service. The patient and their family/carer should be warned they may have to transfer to a more specialised service after initial assessment.

2.3 Referral for emergency assessment / initial referral

CAYA with a confirmed or a suspected laboratory diagnosis of acute leukaemia should be referred **on the same day** to a specialist service and have an urgent assessment **within 24 hours**, unless advised otherwise by a specialist.

The ideal referral should have the following minimum documentation, but collating this information should never delay the telephone referral:

- the patient and their family's demographics including language barriers and need for an interpreter, relevant medical history, medications and allergies
- results of clinical investigations (including imaging and pathology reports)

- recognised significant psychosocial issues or other barriers to accessing care
- a written summary of what the patient, carer and family understand to be the reason for referral to local or more specialised service.

Aboriginal and Torres Strait Islander patients will need a culturally appropriate referral. To view the optimal care pathway for Aboriginal and Torres Strait Islander people and the corresponding quick reference guide, visit the Cancer Australia website <<https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-health>>. Download the consumer resources – *Checking for cancer* and *Cancer* from the Cancer Australia website <<https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-people>>.

2.3.1 Timeframe for referring to a specialist

All CAYA with a suspicion of acute leukaemia on clinical or laboratory findings should be discussed on the same day with a specialist cancer service and, if required, referred to the specialist service on the same day. It should be treated as a medical emergency.

2.4 Support and communication

2.4.1 Supportive care

The patient's general practitioner should consider an individualised supportive care assessment where appropriate to identify the needs of an individual, their carer and family. Refer to appropriate support services as required. See validated screening tools mentioned in Principle 4 'Supportive care'.

A number of specific needs may arise for patients and carers at this time:

- assistance for dealing with the emotional distress and/or anger of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems and adjustment difficulties
- management of physical symptoms as needed and advised by the specialist
- encouragement and support to increase levels of exercise (Cormie et al. 2018; Hayes et al. 2019).

For additional information on supportive care and needs that may arise for different population groups, see Appendices A, B and C.

2.4.2 Communication with patients, carers and families

The general practitioner is responsible for:

- providing patients with information that clearly describes to whom they are being referred, the reason for referral and the expected timeframes for appointments
- requesting that patients notify them if the specialist has not been in contact within the expected timeframe
- considering referral options for patients living rurally or remotely without delaying the referral
- supporting patients and carers while waiting for the specialist appointment and/or diagnosis confirmation (Camp Quality 1300 662 267, Cancer Council 13 11 20, Canteen 1800 835 932, Leukaemia Foundation 1800 953 081 and Redkite 1800 733 548 are available to act as a point of information and reassurance during the anxious period of awaiting further diagnostic information).



More information

Refer to Principle 6 'Communication' for communication skills training programs and resources.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis of CAYA acute leukaemia and for planning subsequent treatment. The guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.

All CAYA with acute leukaemia should be managed by a specialist cancer service.

Urgent pathway

Some patients may present with oncological emergencies including, but not limited to, hyperleucocytosis, tumour lysis syndrome, mediastinal mass, sepsis and coagulopathies. For these patients, **urgent, immediate** emergency assessment and diagnostic investigations need to be completed to allow early commencement of therapy. These patients may require initial intensive care support during their inpatient admission to a tertiary oncology/haematology centre.

Standard pathway

For clinically stable patients with a new diagnosis of acute leukaemia, the diagnostic interventions can be planned **for the next business day**. These patients still will require inpatient admission to a tertiary oncology/haematology centre.

3.1 Specialist diagnostic work-up

The diagnostic evaluation is a critical time for these patients. It should provide a complete diagnosis according to the most recent classification system (Swerdlow et al. 2017), assess the presence of and manage any comorbidities, plus identify any predisposition syndrome.

This is essential to ensure accurate diagnosis, accurately classify the subtype of leukaemia, inform prognosis and ensure treatment decisions are evidence-based.

To achieve this the treatment team should perform a series of investigations, outlined below.

Pre-treatment laboratory examinations include:

- full blood count and blood film review (note: morphological assessment of the blood film to identify acute promyelocytic leukaemia [APL] should be conducted immediately and the result conveyed to the treating physician)
- urea and creatinine, electrolytes including calcium and phosphate, liver function tests
- uric acid and lactate dehydrogenase
- blood group, antibody screen and red blood cell phenotype
- coagulation studies
- consideration of pharmacogenomic testing (e.g. TPMT and G6PD)
- haemoglobin electrophoresis
- immunoglobulins and T- and B-cell subsets
- for relevant or appropriate groups, pregnancy tests (urine or blood BHCG).

Pre-treatment medical imaging includes a chest x-ray to exclude a mediastinal mass.

Diagnostic laboratory investigations include work-up tests performed on bone marrow and/or trephine biopsy and, at times, also on peripheral blood morphology:

- immunophenotyping, karyotyping and FISH analysis
- molecular genetic analysis
- minimal residual disease (MRD) sample (either PCR-MRD or FLOW or by NGS).

Other tests may include:

- DNA microarray (or chromosomal microarray)
- biobanking
- other investigations dictated by clinical trial enrolment.

Lumbar puncture (LP) is performed to establish if there is any CNS disease. Most paediatric acute leukaemia protocols and adolescent and young adult (AYA) ALL protocols currently recommend that a diagnostic LP should occur **before starting systemic chemotherapy**. Some patients cannot have an LP before therapy such as those with coagulopathies. Therapy should be performed with adequate platelet cover and performed by an experienced clinician to reduce the risk of a traumatic tap contaminating the CSF with blasts. To further minimise this complication, intrathecal chemotherapy should be given at the same time as the diagnostic LP.

In children and adolescents, diagnostic tests should be organised to reduce the number of procedures requiring general anaesthesia. For example, use peripheral blood flow cytometry to confirm the immunophenotype to allow central line placement, diagnostic LP and bone marrow (including collection for clinical trial enrolment), all under the same general anaesthetic.

Infection screening

It is important that infection screening is undertaken **at diagnosis and before** blood product support and definitive treatment. The purpose of this screening is to establish a baseline before administering blood products and to investigate serostatus to herpes family viruses, which may reactivate in immunosuppressed patients.

This screening should include routine serology – HBV, HCV, HIV, HTLV, HSV, VZV, EBV, CMV, syphilis and toxoplasma. For patients born or who have travelled overseas, particularly to tropical regions or tuberculosis-endemic countries, consultation with infectious diseases should be sought. Other investigations are as clinically indicated and on discussion with the infectious diseases service (e.g. malaria screen, melioidosis serology in patients from Far North Queensland and the Top End of the Northern Territory).

Biobanking

Consent for biobanking of diagnostic material should be sought. In many upfront clinical trials in leukaemia, biobanking is a prerequisite to enrolment.

Measurable/minimal residual disease

An MRD level is a strong and independent predictor of relapse in CAYA acute leukaemia and widely used for risk stratification (Cave et al. 1998; Van Dongen et al. 1998). This requires a diagnostic marrow or peripheral blood specimen to enable identification of leukaemia-specific marker or leukaemia associated immunophenotype.

Clinical trial investigations

Further laboratory tests may be required for enrolment into clinical trials.

3.1.1 Timeframe for completing investigations

Pre-treatment medical investigations will be performed **on the day of presentation** to the specialist cancer service. Other results necessary for immediate management decisions should be available **within 72 hours** of the patient presenting.

The diagnostic laboratory investigations should be performed as follows.

Urgent pathway

For urgent cases, if it is safe to do so, the diagnostic bone marrow aspiration and LP should be performed **on the day of presentation**. Urgent patients include, but are not limited to, those who present with hyperleukocytosis, tumour lysis syndrome, mediastinal mass and coagulopathies, and those with suspected APL.

If there is a suspicion of APL, urgent treatment with all-trans retinoic acid should be instigated **immediately**.

Standard pathway

The diagnostic bone marrow aspiration and LP should be performed **by the next business day**; however, clinical trial requirements, as well as the level of institutional resources, should also guide timings.

Measurable/minimal residual disease

As above, the importance of this test for measuring response to treatment in CAYAs with acute leukaemia cannot be overstated. A sample for MRD is collected at diagnosis and then at regular time points during therapy to assess response. The exact time points depend on the diagnosis (ALL or AML), the enrolled clinical trial or treatment algorithm for the patient.

Refer to sections 4.2.1 and 4.2.2 for general principles for MRD monitoring in CAYA leukaemias.

3.1.2 Genetic testing (family risk)

Recent reports using genome-scale germline sequencing of paediatric cancer cohorts not selected for genetic risk suggest at least 10 per cent of paediatric cancer patients have a germline mutation in known cancer predisposition genes (Pui et al. 2019; Zhang et al. 2015).

Genetic abnormalities predisposing to ALL are rare individually, but as a group they account for a growing proportion of ALL cases. Recognising an underlying leukaemia predisposition syndrome is essential to the clinical management. It is also relevant to relatives, who might also be at risk of developing the disease or may be potential stem cell donors.

The features that suggest a genetic predisposition may include:

- family history of the same or related cancers
- bilateral multifocal or multiple cancers
- earlier age at diagnosis than sporadic tumours of the same type
- physical findings that suggest a predisposition syndrome
- specific tumour types or certain pathological subtypes of cancer (determined by tumour genetic tests) that frequently occur in genetic predisposition.

Paired tumour/germline sequencing should be considered in some patients with a family history or clinical findings that suggest a possible cancer predisposition syndrome.

Once a diagnosis is confirmed, a comprehensive family cancer history of at least three generations' pedigree will help further identify patients and families with potential cancer predisposition or inherited syndromes.

Anyone diagnosed with cancer should have a detailed personal and family cancer history taken. Consult relevant guidelines <<https://www.eviq.org.au/cancer-genetics/referral-guidelines>> to determine if referral to a familial cancer service is appropriate.

A familial cancer service assessment can determine if genetic testing is appropriate. Genetic testing is likely to be offered when there is at least a 10 per cent chance of finding a causative 'gene error' (pathogenic gene variant; previously called a mutation). Usually testing begins with a variant search in a person who has had cancer (a diagnostic genetic test). If a pathogenic gene variant is identified, variant-specific testing is available to relatives to see if they have or have not inherited the familial gene variant (predictive genetic testing).

Medicare funds some genetic tests via a Medicare Benefits Schedule (MBS) item number but most are not. Depending on the personal and family history, the relevant state health system may fund public sector genetic testing.

Pre-test counselling and informed consent is required before any genetic testing. In some states the treating team can offer 'mainstream' diagnostic genetic testing, after which referral is made to a familial cancer service if a pathogenic gene variant is identified. The familial cancer service can provide risk management advice, facilitate family risk notification and arrange predictive genetic testing for the family.

Visit the eviQ website <www.eviq.org.au/cancer-genetics/paediatric> for information on testing, referral and risk management guidelines for a number of inherited cancer predisposition syndromes.

Visit the Centre for Genetics Education website <<https://www.genetics.edu.au/SitePages/Cancer.aspx>> for basic information about cancer in a family.

3.1.3 Pharmacogenetics

Pharmacogenetics describes how individual differences can lead to differences in the way certain medicines interact with the body. These interactions can affect the effectiveness of medications and any side effects. Applying pharmacogenetics to treatment planning may help patients to be prescribed the most appropriate treatment at the optimal dose from the beginning of treatment (NHMRC 2013).

3.2 Staging, prognostic assessment and risk stratification

Staging is not clinically relevant in CAYA acute leukaemias other than for the presence of CNS disease and, in boys, testicular disease. However, appropriate prognostic assessment and risk stratification is a critical element in treatment planning and should be clearly documented in the patient's medical record. This should be evidence-based to ensure patients at the highest risk of relapse receive appropriately intensified therapy while those with more favourable prognosis (the lowest risk of relapse) receive therapy of reduced intensity to reduce complications.

The most important current factors for prognostic assessment and risk stratification are cytogenetics and response to treatment using MRD. Newer molecular markers with prognostic and potentially therapeutic relevance in acute leukaemia will become clinically routine in the near future (Pui et al. 2018; Tasian & Hunger 2017).

3.3 Performance status

Patient performance status is a central factor in cancer care and should be clearly documented in the patient's medical record.

Performance status should be measured and recorded using an established scale such as the Karnofsky/Lansky scale or the Eastern Cooperative Oncology Group (ECOG) scale.

3.4 Treatment planning

New diagnostic techniques in the biology of CAYA acute leukaemia continue to develop rapidly. The multidisciplinary team needs to be aware of these changes and advances and ensure they are translated to clinical management. CAYA acute leukaemia patients being enrolled in clinical trials is important and associated with superior outcome. The team must know which suitable clinical trials are available for CAYA acute leukaemia. If there is no open clinical trial then every specialist CAYA acute leukaemia service should have a predefined, peer-reviewed treatment model that the multidisciplinary team has endorsed.

3.4.1 Key considerations beyond treatment recommendations

A number of factors should be considered at this stage:

- the patient's overall condition, life expectancy, personal preferences and decision-making capacity
- discussing the multidisciplinary team approach to care with the patient
- appropriate and timely referral to an MDM
- pregnancy and fertility
- support with travel and accommodation
- teleconferencing or videoconferencing as required
- educational support.



More information

For more information see the Victorian paediatric oncology care pathways: *Providing optimal care for children and adolescents – acute leukaemia, central nervous system tumours and solid tumours* (May 2019) <<https://www.vics.org.au/pics-health-professionals>>.

3.4.2 Timing for multidisciplinary team planning

Induction treatment is **often required before** a full MDM ratifies details for the ongoing management plan. All CAYA will be inpatients when treatment starts, allowing their initial multidisciplinary management to be performed on the ward.

All CAYA acute leukaemia should be discussed **as soon as possible** after diagnosis at an appropriate MDM, with further discussions at the time of response assessment or final risk stratification.

All CAYA acute leukaemia should also be discussed at suitable MDMs that will include psychosocial and supportive care assessment.

Results of all relevant tests and access to images should be available for the MDM. Information about the patient's concerns, preferences and social and cultural circumstances should also be available.

3.4.3 Responsibilities of the multidisciplinary team

The multidisciplinary team requires administrative support in developing the agenda for the meeting, for collating patient information and to ensure appropriate expertise around the table to create an effective treatment plan for the patient. The MDM has a chair and multiple lead clinicians. Each patient case will be presented by a lead clinician (usually someone who has seen the patient before the MDM). In public hospital settings, the registrar or clinical fellow may take this role. A member of the team records the outcomes of the discussion and treatment plan in the patient history and ensures these details are communicated to the patient's general practitioner. The team should consider the patients, families and carers values, beliefs and cultural needs as appropriate to ensure the treatment plan is in line with these.

3.4.4 Members of the multidisciplinary team for CAYA acute leukaemia

The multidisciplinary team should be composed of the core disciplines that are integral to providing good care. Team membership should reflect both clinical and supportive care aspects of care. Pathology expertise is essential for most but not all teams. The core staff required for an MDM should reflect the purpose of the specific MDM.

See Appendix E for a list of team members who may be included in the multidisciplinary team for CAYA acute leukaemia.

Core members of the multidisciplinary team are expected to attend most MDMs either in person or remotely via virtual mechanisms. Additional expertise or specialist services may be required for some patients. An Aboriginal and Torres Strait Islander cultural expert should be considered for all patients who identify as Aboriginal or Torres Strait Islander.

3.4.5 Responsibilities of individual team members

The general practitioner who made the referral is responsible for the patient until care is passed to another practitioner who is directly involved in planning the patient's care.

The general practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment, shared follow-up care, post-treatment surveillance, coordination and continuity of care, as well as managing existing health issues and providing information and support to the patient, their family and carer.

A nominated contact person from the multidisciplinary team may be assigned responsibility for coordinating care in this phase. Care coordinators are responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase (COSA 2015). The care coordinator may change over the course of the pathway.

The lead clinician is responsible for overseeing the activity of the team and for implementing treatment within the multidisciplinary setting.

3.5 Research and clinical trials

Participation in clinical trials, patient registries and tissue banking, where available, is encouraged for patients with CAYA acute leukaemia. The most important factor contributing to the improvement in survival in childhood leukaemia over the past 50 years has been the widespread participation in well-conducted phase 3 clinical trials (Pui et al. 2015). Clinical trial protocols are rigorously peer reviewed and are a means to ensure CAYA are receiving the best available treatment. These are expected to continue to be important in increasing survival rates for future generations. Enrolment in a clinical trial should be considered the standard of care for CAYA acute leukaemia, whenever possible.

For more information visit:

- Cancer Australia <www.australiancancertrials.gov.au>
- Australian New Zealand Clinical Trials Registry <www.anzctr.org.au>
- Australasian Leukaemia and Lymphoma Group <www.allg.org.au>
- Australian & New Zealand Childrens Haematology/Oncology Group <www.anzchog.org/clinical-trials-research/clinical-trials>
- ClinTrial Refer <www.clintrial.org.au>
- clinicaltrials.gov <www.clinicaltrials.gov> for an international view.

For more information see the Victorian paediatric oncology care pathways: *Providing optimal care for children and adolescents – acute leukaemia, central nervous system tumours and solid tumours* (May 2019) <<https://www.vics.org.au/pics-health-professionals>>.

3.6 Support and communication

3.6.1 Prehabilitation

Cancer prehabilitation uses a multidisciplinary approach combining exercise, nutrition and psychological strategies to prepare patients for the challenges of cancer treatment such as systemic therapy and radiation therapy. Team members may include anaesthetists, oncologists, surgeons, haematologists, clinical psychologists, exercise physiologists, physiotherapists and dietitians, among others.

Patient performance status is a central factor in cancer care and should be frequently assessed. All patients should be screened for malnutrition. The lead clinician may refer obese or malnourished patients to a dietitian.

Patients who currently smoke should be encouraged to stop smoking before receiving treatment. This should include an offer of referral to Quitline in addition to smoking cessation pharmacotherapy if clinically appropriate.

Evidence indicates that patients who respond well to prehabilitation may have fewer complications after treatment. For example, those who were exercising before diagnosis and patients who use prehabilitation may improve their physical or psychological outcomes, or both, and this helps patients to function at a higher level throughout their cancer treatment (Cormie et al. 2017; Silver 2015).

For patients with CAYA acute leukaemia, the multidisciplinary team should consider these specific prehabilitation assessments and interventions for treatment-related complications or major side effects:

- conducting a physical and psychological assessment to establish a baseline function level
- identifying impairments and providing targeted interventions to improve the patient's function level (Silver & Baima 2013)
- reviewing the patient's medication to ensure optimisation and to improve adherence to medicine used for comorbid conditions.

Following completion of primary cancer treatment, rehabilitation programs have considerable potential to enhance physical function.

3.6.2 Fertility preservation and contraception

Cancer and cancer treatment may cause fertility problems. Infertility can range from difficulty having a child to the inability to have a child. Infertility after treatment may be temporary, lasting months to years, or permanent (AYA Cancer Fertility Preservation Guidance Working Group 2014).

Patients and carers need to be advised about and referred for discussion about fertility preservation **before starting treatment** and need advice about contraception **before, during and after treatment**. Patients and their family should be aware of the ongoing costs involved in optimising fertility. Fertility management may apply in both males and females. Fertility preservation options are different for males and females and may be specific to a patient's age. The need for ongoing contraception applies to both men and women.

The potential for impaired fertility should be discussed and reinforced at different time points as appropriate throughout the diagnosis, treatment, surveillance and survivorship phases of care. These ongoing discussions will enable the patient and, if applicable, the family to make informed decisions. All discussions should be documented in the patient's medical record.



More information

See the Cancer Council website <www.cancervic.org.au/living-with-cancer/common-side-effects/fertility/fertility-overview.html> for more information.

See also the Victorian paediatric oncology care pathways: *Providing optimal care for children and adolescents – acute leukaemia, central nervous system tumours and solid tumours* (May 2019) <<https://www.vics.org.au/pics-health-professionals>>.

3.6.3 Supportive care

See validated screening tools mentioned in Principle 4 'Supportive care'.

A number of specific challenges and needs may arise for patients and carers at this time:

- assistance for dealing with psychological and emotional distress while adjusting to the diagnosis; treatment phobias; existential concerns; stress; difficulties making treatment decisions; anxiety or depression or both; psychosexual issues such as potential loss of fertility and premature menopause; history of sexual abuse; and interpersonal problems
- management of physical symptoms such as pain and fatigue (Australian Adult Cancer Pain Management Guideline Working Party 2019), including pain management for mucositis or peripheral neuropathy
- physiotherapy/exercise support in managing chemotherapy induced peripheral neuropathy and muscle weakness
- neuropsychology supports: referral to neuropsychology should be considered for patients who have experienced potential neurocognitive insult from triggers such as CNS-directed therapy (cranial radiation and intrathecal chemotherapy), those patients receiving high-dose methotrexate and patients who experience any significant CNS morbidity during treatment such as cerebral bleed, stroke, acute meningitis and encephalopathies
- nutritional assessment at diagnosis and subsequently for all patients. This should include malnutrition or undernutrition, noting that many patients with a high BMI (obese patients) may also be malnourished (WHO 2018)
- education and school support (where applicable)
- support for families or carers who are distressed with the patient's cancer diagnosis (including support for siblings where applicable)
- support for families/relatives who may be distressed after learning of a genetically linked cancer diagnosis
- specific spiritual needs that may benefit from the involvement of pastoral/spiritual care.

Additionally, palliative care may be required at this stage.

3.6.4 Supportive therapies

A number of supportive therapies may be necessary at this time including:

- managing acute symptoms in newly diagnosed patients
- providing blood product support and managing electrolyte abnormalities, including tumour lysis syndrome
- managing clinical symptoms at diagnosis due to extramedullary disease
- management and prevention of infection.

For more information on supportive care and needs that may arise for different population groups, see Appendices A, B and C.

3.6.5 Communication with patients, carers and families

Communication with patients should always be tailored to their age and developmental stage. For adolescents, and some children, it is important to involve them in the discussion rather than just speaking to their parent/carer. Similarly, the participation of young adults' parent or support person should also be encouraged (Osborn et al. 2019).

In discussion with the patient and their families and carers, the lead clinician should undertake the following:

- establish if the patient has a regular or preferred general practitioner and if the patient does not have one, then encourage them to find one
- provide written information appropriate to the health literacy of the patient about the diagnosis and treatment to the patient and carer and refer the patient to the *Guide to best cancer care (consumer optimal care pathway) for CAYA acute leukaemia*, as well as to relevant websites and support groups as appropriate
- provide a treatment care plan including contact details for the treating team and information on when to call the hospital
- discuss a timeframe for diagnosis and treatment with the patient and carer
- discuss the benefits of multidisciplinary care and gain the patient's or carer's consent before presenting their case at an MDM
- provide brief advice and refer to Quitline (13 7848) for behavioural intervention if the patient currently smokes (or has recently quit), and prescribe smoking cessation pharmacotherapy, if clinically appropriate
- recommend an 'integrated approach' throughout treatment regarding nutrition, exercise and minimal or no alcohol consumption among other considerations
- communicate the benefits of continued engagement with primary care during treatment for managing comorbid disease, health promotion, care coordination and holistic care and supporting the family
- where appropriate, review fertility needs with the patient and refer for specialist fertility management (including fertility preservation, contraception, management during pregnancy and of future pregnancies)
- be open to and encourage discussion about the diagnosis, prognosis (if the patient or carer wishes to know) and survivorship and palliative care while clarifying the patient or carer's preferences and needs, personal and cultural beliefs and expectations, and their ability to comprehend the communication
- encourage young adult patients to participate in advance care planning including considering appointing one or more substitute decision-makers, or a legal guardian, and completing an advance care directive to clearly document their treatment preferences (each state and territory has different terminology and legislation surrounding advance care directives and substitute decision-makers)
- discuss clinical trials (if available), explaining how this may differ from standard therapy and providing adequate information and time to enable an informed decision about participation (sites without open clinical trials may consider referring the patient to a site that does)
- refer 15–25-year-old patients to the jurisdiction's Youth Cancer Service for psychosocial support
- offer referral to community support organisations such as Canteen, Camp Quality, Leukaemia Foundation, Redkite and other state-based NGOs; these frequently help support parents and siblings too.

Additionally, patients, family and carers should be provided with both verbal and written information on the following topics:

- management of fever and neutropenia
- side effects of treatment
- central line care
- caring for the child at home
- orientation to the hospital and overview of the healthcare team (key members)
- blood counts
- follow-up appointments.

Information specifically targeted to children with acute leukaemia immediately following diagnosis includes neutropenia precautions, medication adherence, chemotherapy side effects, bleeding precautions, managing procedures, nutrition and anaemia.

Verbal education to families and patients, where appropriate, should be paced throughout the initial admission and time allowed to process the diagnosis. Education should not be left to the moment of discharge, and families and patients, where appropriate, should be aware that education is ongoing and accessible throughout treatment.

Written and/or audio-visual educational information should be provided as part of the discharge plan following diagnosis and should also include information targeted to CAYA.



More information

For more information see the Victorian paediatric oncology care pathways: *Providing optimal care for children and adolescents – acute leukaemia, central nervous system tumours and solid tumours* (May 2019) <<https://www.vics.org.au/pics-health-professionals>>.

3.6.6 Communication with the general practitioner

The lead clinician has these communication responsibilities:

- involving the general practitioner from the point of diagnosis
- ensuring regular and timely communication with the general practitioner about the diagnosis, treatment plan and recommendations from MDMs and inviting them to participate in MDMs (consider using virtual mechanisms)
- supporting the role of general practice both during and after treatment
- discussing shared or team care arrangements with general practitioners or regional cancer specialists, or both, together with the patient.



More information

Refer to Principle 6 'Communication' for communication skills training programs and resources.

Step 4: Treatment

Step 4 outlines the optimal treatments for CAYA acute leukaemia, the training and experience required of the treating clinicians and the health service characteristics required for optimal cancer care.

All health services must have clinical governance systems that meet the following integral requirements:

- identifying safety and quality measures
- monitoring and reporting on performance and outcomes
- identifying areas for improvement in safety and quality (ACSQHC 2020).

4.1 Treatment intent

The intent at diagnosis for all CAYA with acute leukaemia is cure. Patients who develop refractory or relapsed disease are discussed in Step 6: Managing refractory, relapsed, residual or progressive disease.

The treatment intent should be established in a multidisciplinary setting, documented in the patient's medical record and conveyed to the patient and carer as appropriate.

The lead clinician should discuss the advantages and disadvantages of each treatment and associated potential side effects with the patient and their carer or family before treatment consent is obtained and begins so the patient can make an informed decision. Supportive care services including community support organisations should also be considered during this decision-making process. Patients and carers should be asked about their use of (current or intended) complementary therapies (see Appendix D).

Timeframes for starting treatment should be informed by evidence-based guidelines where they exist. The treatment team should recognise that shorter timeframes for appropriate consultations and treatment can promote a better experience for patients.

Where appropriate, initiate advance care planning discussions with patients before treatment begins (this could include appointing a substitute decision-maker and completing an advance care directive). Formally involving a palliative care team/service may benefit any patient, so it is important to know and respect each person's preference (Australian Government Department of Health 2021a).

4.2 Treatment options

Treatment options – newly diagnosed acute lymphoblastic leukaemia (ALL)

Advances in treating CAYA ALL have been achieved through successive well-designed international clinical trials (Pui et al. 2015). It is considered standard of care to enrol CAYA ALL patients into an open clinical trial for newly diagnosed ALL.

Most treatments for CAYA acute leukaemia patients start as inpatient; however, standard-risk leukaemia treatment can be delivered in an outpatient setting. Currently, treatment lasts approximately **two years** and the treatment plan depends on risk stratification. Treatment includes CNS-directed therapy.

All AYA with ALL should be treated according to a paediatric (or paediatric-inspired) protocol because there is consistent and compelling evidence that these confer superior survival outcomes (Siegel et al. 2018; Stock et al. 2019).

MRD is an important test for measuring response to treatment in CAYA ALL. The general principles for MRD monitoring for CAYA ALL are:

- diagnostic (baseline MRD panel) specimen
- end of induction therapy
- end of consolidation for those who are positive at end of induction
- end of induction therapy in relapsed disease
- prior to a transplant for patients preceding HSCT
- additional timepoints may be required in patients receiving novel/cellular immunotherapies, including CAR T-cell therapy.

These time points will vary according to the clinical protocol and the requirements of clinical trials.

Treatment options – acute myeloid leukaemia (AML)

Systemic chemotherapy-based treatment is the backbone of AML therapy and is divided into two phases: induction therapy to achieve remission and consolidation therapy once a remission has been achieved to maintain ongoing remission or as a bridge to HSCT in some patients. Currently, total duration is **four to six months**, depending on risk stratification. Treatment is risk-stratified based on cytogenetics and response using MRD. CNS-directed therapy is given during treatment.

MRD is an important test for measuring response to treatment in CAYA AML. The general principles for MRD monitoring for CAYA AML are:

- diagnostic (baseline MRD panel) specimen
- end of the first course of induction
- consideration at end of subsequent course, if positive at end of induction.

These time points will vary according to the clinical protocol and the requirements of clinical trials.

Treatment options – infant leukaemia

Infants diagnosed with ALL are at high risk of relapse and have significantly inferior outcomes than school-aged children (Kotecha et al. 2014; Pieters et al. 2009; 2019). Current event-free survival remains at 50 per cent, despite best-practice international collaborative trials. Treatment is intensive and predominantly inpatient-based. New therapies are examining the addition of specific targeted therapies (Clesham et al. 2020) because current treatment regimens have reached dose-limiting toxicities.

MRD is an important test for measuring response to treatment in infant ALL. The general principles for MRD monitoring for infant ALL are as per section 4.2.1. MRD at the end of induction may identify some infants that would benefit from AML-like consolidation (Stutterheim et al. 2021).

It is important that infants with a leukaemia diagnosis are enrolled in clinical trials, wherever possible.

Treatment options – acute promyelocytic leukaemia

Although CAYA APL is rare, many patients at diagnosis have significant coagulopathy. The presentation of APL is a medical emergency because of the high risk of death as a result of the associated coagulopathy. If APL is suspected, treatment should start **without delay**. These patients are managed at diagnosis as inpatients in specialist centres with ready access to intensive care and blood products to manage the life-threatening coagulopathy. These patients do not get a diagnostic LP because of the coagulopathy. Patients undergo molecular monitoring to guide treatment (e.g. quantitative molecular MRD for PML-RARA gene fusion). Consolidation therapy after induction can usually be outpatient-based.

Timeframes for starting treatment

Urgent pathway

Treatment should begin **on the day** of presentation **immediately** following diagnostic interventions. Urgent patients include, but are not limited to, those who present with hyperleucocytosis, tumour lysis syndrome, mediastinal mass and coagulopathies.

Standard pathway

Treatment for should start **by the next business day** following diagnosis. In clinically stable patients, clinical trial requirements and the level of institutional resources available on the day to provide optimal care should guide timings.

'After-hours' admission of newly diagnosed patients

The timing of diagnostic and therapeutic interventions should be flexible and reflect clinical need, particularly for patients who present with oncological emergencies.

Chemotherapy is the key component for treating CAYA acute leukaemia. Due to the complexity and toxicity of administering cytotoxic agents to patients, adherence to medication safety standards (e.g. mini-bag vincristine infusions) and the demands for supportive care, intravenous chemotherapy should be delivered via a central venous access device.

Urgent pathway

Central venous access should be established **on the day of presentation**, if possible.

Standard pathway

Insertion of a central venous access device should be undertaken **before initial treatment**, if possible. However, this may vary and institutional guidelines should be followed.

Training and experience required of the appropriate specialists

Paediatric or adult haematologist/oncologists treating CAYA acute leukaemia must have training and experience of this standard:

- Fellow of the Royal Australian College of Physicians (or equivalent)
- adequate training and experience that enables institutional credentialing and agreed scope of practice within this area (ACSQHC 2015).

Cancer nurses should have accredited training and demonstrate competency in these areas:

- anti-cancer treatment administration
- specialised nursing care for patients undergoing cancer treatments, including side effects and symptom management
- the handling and disposal of cytotoxic waste (ACSQHC 2020).

Systemic therapy should be prepared by a pharmacist whose background includes this experience:

- adequate training in systemic therapy medication, including dosing calculations according to protocols, formulations and/or preparation.

In a setting where no medical oncologist is locally available (e.g. regional or remote areas), some components of less complex therapies may be delivered by a general practitioner or nurse with training and experience that enables credentialing and agreed scope of practice within this area. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required.

The training and experience of the appropriate specialist should be documented.

Health service characteristics

Treatment for CAYA acute leukaemia is administered by a specialist cancer service.

Consideration for supportive care and some aspects of treatment such as administering chemotherapy in shared care centres outside the specialist cancer service and referral to community support organisations should be made after consultation with the patient's multidisciplinary team.

Episodes of chemotherapy in regional shared care centres should be conducted via telehealth between the local health service and the child's oncologist or haematologist.

4.2.1 Supportive therapies

Managing and preventing infection

Treatment-related mortality in AML in CAYA has been shown to be as high as 10 per cent. Time to antibiotics greater than one hour in managing febrile neutropenia in high-risk groups has been shown to have negative outcomes in paediatric studies. Patients with Down syndrome ALL are also at increased risk of treatment-related mortality and morbidity. Strategies to mitigate infection risk in CAYAs with acute leukaemia are identified below.

- Mandatory hospitalisation should be considered for all patients with AML and those patients with Down syndrome ALL during induction.
- Consideration for hospitalisation during induction for non-Down syndrome ALL should be made based on clinical factors.
- Patients undergoing HSCT or treatment for AML must be treated in facilities appropriate to provide sufficient isolation from airborne pathogens, particularly fungal disease, in facilities such as HEPA filtration and positive pressure rooms.
- Strategies and policies should be in place for managing infectious patients within the oncology clinical environment and waiting areas.
- For patients with febrile neutropenia, antibiotics must be administered within an hour of presentation to hospital, or within 30 minutes for inpatients.
- Patients with AML/ALL during the induction and intensification phases of treatment or those immediately (+ 30 days) post HSCT are at high risk of sepsis.
- *Pneumocystis jirovecii* prophylaxis should be considered in patients where appropriate and anti-fungal prophylaxis administered to all AML and high-risk ALL patients according to national guidelines or those published by cooperative groups (COG 2020).

Adherence and compliance to treatment for acute leukaemia

Frontline treatment for CAYA ALL lasts approximately **two years**, with much of the treatment (oral chemotherapy) delivered in the home. The rate of medication errors in the home for patients with cancer has been shown to be very high. Suboptimal adherence to oral chemotherapy in ALL increases the risk of relapse (Bhatia 2012). Non-adherence is associated with socioeconomic adversity, highlighting the importance of universal social work referrals in CAYA acute leukaemia.

Clinical pharmacists also play a role in ensuring patients, carers and families have a clear understanding of the medication schedule as well as exploring other potential barriers to adherence that the multidisciplinary team could address. Cancer services must have strategies to support patients, families and carers in adhering to the treatment plan, particularly the role of long-term oral chemotherapy in the home.

The cancer service should have in place a mechanism to measure and record compliance with home-based oral medication administration, including how changes to oral chemotherapy doses are communicated to families in both written and verbal forms.

4.2.2 Radiation therapy

Radiation therapy still has a role in CAYA acute leukaemia. A number of patients may benefit from radiation therapy.

Overt CNS disease

Although using radiotherapy to treat CNS prophylaxis was an important advance in the treatment of CAYA ALL, it is now recognised that this treatment can have significant long-term effects. Prophylactic CNS radiotherapy has been universally replaced by intrathecal chemoprophylaxis in CAYA.

A meta-analysis of 16,623 patients aged 1–18 years with newly diagnosed ALL treated by 10 cooperative groups found that only patients with overt CNS disease at diagnosis benefited from CNS radiotherapy (Vora et al. 2016). Consequently, most groups continue to recommend CNS irradiation for patients with overt CNS disease at diagnosis or select groups at particularly high risk of CNS recurrence.

Testicular disease

Radiotherapy has had a role in some patients for treating testicular disease.

Haematopoietic stem cell transplantation

Total body irradiation and cranial radiation is used as part of the conditioning regimen for some patients undergoing HSCT (see section 4.2.7).

Palliative care

Radiation therapy in the context of non-curative intent, such as symptom management, can be very effective.

Patients receiving radiotherapy are sometimes treated outside of the specialist cancer service. It is important that these patients are managed under the recommendations of the local service frameworks of the appropriate state service. This helps to provide a coordinated, sustainable and consistent model of care for delivering radiotherapy to CAYA with acute leukaemia.

Training and experience required of the appropriate specialists

Fellow of the Royal Australian and New Zealand College of Radiologists (or equivalent) with adequate training and experience that enables institutional credentialing and agreed scope of practice in CAYA acute leukaemia.

The training and experience of the radiation oncologist should be documented.

Health service unit characteristics

To provide safe and quality care for patients having radiation therapy, health services should have these features:

- linear accelerator (LINAC) capable of image-guided radiotherapy
- dedicated CT planning
- access to MRI and PET imaging
- automatic record-verify of all radiation treatments delivered
- a treatment planning system
- trained medical physicists, radiation therapists and nurses with radiation therapy experience
- coordination for combined therapy with systemic therapy, especially where facilities are not co-located
- participation in Australian Clinical Dosimetry Service audits
- an incident management system linked with a quality management system.

4.2.3 Haematopoietic stem cell transplantation

HSCT is an established treatment for haematological malignancies in CAYA. HSCT is reserved for those patients at greatest risk of relapse. As the understanding of the biology of leukaemia and treatment with chemotherapy and targeted therapy has improved, the indication for HSCT has reduced in some groups. HSCT is used as a salvage where primary treatment has failed.

Indications for HSCT in acute leukaemia

The indications for HSCT in acute leukaemia should be reassessed continuously by the cancer service. At this point in time, consideration for HSCT may include:

- ALL with high-risk features – for example, hypodiploidy or induction failure
- AML patients with high-risk features
- mixed-phenotype acute leukaemia (MPAL)
- infant leukaemia with poor prognostic criteria
- relapse during or shortly after first remission
- persistent-positive MRD.

All patients being considered for HSCT will be discussed at a leukaemia MDM.

Timeframes for starting treatment

Donor searches should begin as soon as the CAYA is identified as a potential HSCT candidate. All newly diagnosed AML, MPAL and infant leukaemia patients and all relapsed patients should be human leukocyte antigen (HLA)-typed as part of their initial investigations. Institutional practice will determine which family members should have HLA tissue typing.

Training and experience required of the appropriate specialists

Paediatric or adult haematologist/oncologists treating CAYA acute leukaemia must have training and experience of this standard:

- Fellow of the Royal Australian College of Physicians (or equivalent)
- adequate training and experience that enables institutional credentialing and agreed scope of practice within this area (ACSQHC 2015).

Cancer nurses should have accredited training in these areas:

- anti-cancer treatment administration
- specialised nursing care for patients undergoing cancer treatments, including side effects and symptom management
- the handling and disposal of cytotoxic waste (ACSQHC 2020).

Systemic therapy should be prepared by a pharmacist whose background includes this experience:

- adequate training in systemic therapy medication, including dosing calculations according to protocols, formulations and/or preparation.

Where no medical oncologist is locally available (e.g. regional or remote areas), some components of less complex therapies may be delivered by a general practitioner or nurse with training and experience that enables credentialing and agreed scope of practice within this area. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required.

The training and experience of the appropriate specialist should be documented.

Health service characteristics

To provide safe and quality care for patients having HSCT therapy, health services should have these features:

- a clearly defined path to emergency care and advice after hours
- access to an accredited diagnostic pathology laboratory including haematology, biochemistry, flow cytometry, cytogenetics, molecular pathology, HLA-tissue typing, microbiology
- access to blood products and a transfusion laboratory
- access to medical imaging, including CT and MRI
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including preparation, waste procedures and spill kits (eviQ 2019)
- guidelines and protocols to deliver treatment safely (including dealing with extravasation of drugs)
- coordination for combined therapy with radiation therapy, especially where facilities are not co-located
- an intensive care unit and other medical subspecialties including infectious diseases
- participation in cooperative group trials for CAYA with acute leukaemia, with adequate support from clinical research associates or research nurses
- established quality management systems at both the institution and departmental level

- allied health staff with experience in working with CAYA, including social work, psychology and dietetics (ideally, there should also be access to physiotherapy and/or exercise physiology)
- specific support for Aboriginal and Torres Strait Islander patients
- transplant coordinator.

HSCT/cellular therapies centres require stem cell collection and processing facilities, a dedicated quality manager and data management system. Such sites also require additional accreditation by organisations such as NATA and JACIE-FACT.

4.2.4 Targeted therapies and immunotherapy

There are many therapies that have a targeted approach. This is an ever-expanding group of therapies, and the multidisciplinary team must be mindful of this field.

Therapies include:

- *BCR-ABL*-like ALL – addition of tyrosine kinase inhibitor
- bispecific T-cell engagers in bispecific T-cell engagers in ALL – blinatumomab
- antibody-drug conjugate targeting CD33 antigen in AML – gemtuzumab ozogamicin
- antibody-drug conjugates targeting CD22 antigen in ALL – inotuzumab ozogamicin
- chimeric antigen receptor (CAR) T-cells – genetically engineered T-cells to produce a receptor that recognises a cancer target such as CD19 antigen in B-cell ALL.

4.2.5 Emerging therapies

The key principle for precision medicine is prompt and clinically oriented communication and coordination with an accredited laboratory and pathologist. Tissue analysis is integral for access to emerging therapies and, as such, tissue specimens should be treated carefully to enable additional histopathological or molecular diagnostic tests in certain scenarios.

4.3 Palliative care

Palliative care is a multidisciplinary approach to symptom management and psychosocial support and helps identify care goals for patients with serious illness and their families. Note, a significant number of patients with CAYA acute leukaemia are cured.

Paediatric palliative care services can also support and provide care coordination with other care providers such as schools, NDIS providers, equipment services and community services to enhance care of the patient and their family. Sibling support and grandparent support can also be provided. Bereavement care, including anticipatory grief, is a core element of paediatric palliative care.

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for cancer with poor prognosis.

The lead clinician should ensure patients receive timely and appropriate referral to paediatric palliative care services. Referral should be based on need rather than prognosis. When given an evidence-based process to safely address these confronting issues, young people and their families are highly engaged. Addressing the value of palliative care and advance care planning with young people has been shown to reduce their anxiety, does not affect depression, improves symptom management and quality of life for patients and their carers (Wiener et al. 2008; 2012).

The 'Dying to Talk' resource may help health professionals, where appropriate, initiating discussions with patients, family or carer about future care needs (see 'More information'). Ensure that carers and families receive information, support and guidance about their role in palliative care (Palliative Care Australia 2018).

Where appropriate, patients, their family or carer should be encouraged to initiate advance care planning. Advance care planning discussions can be triggered at the time of diagnosis to ensure care is informed by respect and knowledge of the patient or caregiver's preferences.

Therapies such as HSCT, treatment for high-risk AML and targeted therapies within the context of clinical trials can result in high levels of physical, psychological and existential distress, despite having curative intent. CAYA with an uncertain prognosis and high symptom burden should be able to access palliative care support alongside curative-intent therapies.

Discussion should be held within a CAYA acute leukaemia MDM to offer the family referral to palliative care services where there is a likely need to escalate care to manage symptoms and distress in high-risk curative regimens such as HSCT, as well as support when cure is no longer the intent of the multidisciplinary team.

Refer to Step 6 for a more detailed description of managing patients with refractory, relapsed, residual or progressive or refractory disease.



More information

These online resources are useful:

- Advance Care Planning Australia <www.advancecareplanning.org.au>
- CareSearch Children & Adolescents <<https://www.caresearch.com.au/caresearch/tabid/602/Default.aspx>>
- the Palliative Care resource kit <www.health.gov.au/health-topics/palliative-care>
- Palliative Care Australia (for patients and carers) <www.palliativecare.org.au>
- Quality of Care Collaborative Australia <<https://www.quocca.com.au/>>
- Canteen <www.canteen.org.au/youth-cancer>
- Australian best practice guidelines on end-of-life communication with CAYA (Sansom-Daly et al. 2020)
- Agency for Clinical Innovation Transition Care Network <<https://aci.health.nsw.gov.au/resources/transition-care/palliative-care/palliative-care-resources>>.

4.4 Research and clinical trials

The team should support the patient to participate in research or clinical trials where available and appropriate. Many emerging treatments are only available on clinical trials that may require referral to certain trial centres.

For more information visit:

- Cancer Australia <www.australiancancertrials.gov.au>
- Australian New Zealand Clinical Trials Registry <www.anzctr.org.au>
- Australasian Leukaemia and Lymphoma Group <www.allg.org.au>
- Australian & New Zealand Childrens Haematology/Oncology Group <www.anzchog.org/clinical-trials-research/clinical-trials>
- ClinTrial Refer <www.clintrial.org.au>
- clinicaltrials.gov <www.clinicaltrials.gov> for an international view.

4.5 Support and communication

4.5.1 Supportive care

See validated screening tools mentioned in Principle 4 'Supportive care'.

A number of specific challenges and needs may arise for patients, families and carers at this time:

- assistance for dealing with emotional and psychological issues, including body image concerns, fatigue, quitting smoking, traumatic experiences, existential anxiety, treatment phobias, memory and concentration difficulties, anxiety/depression, interpersonal problems and sexuality concerns
- pre-school children may exhibit distress relating to unfamiliar hospital settings and staff, separation from parents, and changes in daily routine
- loss of school and contact with peers, and a longing to 'return to normal' are common concerns among school-aged children
- issues described by CAYA relate to education/work, relationship with parents, boredom, sadness and fear, missing doing 'normal stuff' with friends, forced dependence, hair loss, sleeping difficulties and physical fitness/fatigue (Patterson et al. 2021); it is also important to consider other routine aspects of CAYA health including substance use and sexual health
- potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment
- managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications – referral to a pharmacist may be required
- management of physical symptoms such as nausea/vomiting, and loss of physical fitness, change in weight/appetite/taste, hair loss and sleeping difficulties
- decline in mobility or functional status as a result of treatment
- assistance with beginning or resuming regular exercise with referral to an exercise physiologist or physiotherapist (COSA 2018; Hayes et al. 2019)
- psychosocial and health issues in parents and siblings, including marital discord and/or interpersonal difficulties with the patient, other children or extended family; anxiety; exacerbation of mental health problems; sibling issues.

Early involvement of general practitioners may lead to improved cancer survivorship care following acute treatment. General practitioners can address many supportive care needs through good communication and clear guidance from the specialist team (Emery 2014). Early engagement of patient and community support organisations may also lead to improve survivorship care and help address patient and carer supportive care needs.

Siblings experience significant levels of distress and psychosocial need as a result of their brother or sister's cancer (Patterson et al. 2017). Addressing siblings' psychosocial needs is important and is a standard of care in paediatric, adolescent and young adult oncology (COSA 2014; Gerhardt et al. 2015; Long et al. 2018; 2020; Patterson et al. 2014).

Patients, carers and families may have these additional issues and needs:

- financial issues related to loss of income (through reduced capacity to work or loss of work) and additional expenses as a result of illness or treatment
- advance care planning, which may involve appointing a substitute decision-maker and completing an advance care directive
- legal issues (completing a will, care of dependent children) or making an insurance, superannuation or social security claim on the basis of terminal illness or permanent disability.

The Cancer Council 13 11 20 and Leukaemia Foundation 1800 953 081 can assist with information and referral to local support services.

CAYA age-specific information and support lines can be accessed from community-based organisations such as Canteen 1800 835 932 <<https://www.canteen.org.au/youth-cancer>> Camp Quality 1300 662 267 <<https://www.campquality.org.au/>> and Redkite 1800 733 548 <www.redkite.org.au>.

For more information on supportive care and needs that may arise for different population groups, see Appendices A, B and C.

4.5.2 Rehabilitation

Rehabilitation may be required at any point of the care pathway. If it is required before treatment, it is referred to as prehabilitation (see section 3.6.1).

Patients being treated for acute leukaemia benefit from exercise, nutrition and psychological strategies. Early referral to a clinical psychologist, exercise physiologist, physiotherapist and dietitian should be considered.

All patients should be weighed at each clinic appointment, or daily during inpatient admissions, and screened for malnutrition using a tool that has been validated in CAYA. Obese or malnourished patients should be referred to a dietitian.

Rehabilitation may be required at any point of the care pathway. Exercise in older adults with cancer is associated with improved cardiorespiratory function and, in some studies, better quality of life and less fatigue (Cormie et al. 2017; Silver 2015). There is emerging data showing that participating in an exercise program during cancer treatment is safe, feasible and beneficial (Atkinson et al. 2021).

All members of the multidisciplinary team have an important role in promoting rehabilitation. Team members may include occupational therapists, speech pathologists, dietitians, social workers, psychologists, physiotherapists, exercise physiologists and rehabilitation specialists.

To maximise the safety and therapeutic effect of exercise for people with cancer, all team members should recommend that people with cancer work towards achieving, and then maintaining, recommended levels of exercise and physical activity as per relevant guidelines. Exercise should be prescribed and delivered under the direction of an accredited exercise physiologist or physiotherapist with experience in cancer care (Vardy et al. 2019). The focus of intervention from these health professionals is tailoring evidence-based exercise recommendations to the individual patient's needs and abilities, with a focus on the patient transitioning to ongoing self-managed exercise.

Other issues that may need to be dealt with include managing cancer-related fatigue, improving physical endurance, achieving independence in daily tasks, optimising nutritional intake, returning to work and ongoing adjustment to cancer and its consequences. Referrals to dietitians, psychosocial support, return-to-work, educational and vocational programs and community support organisations can help in managing these issues.

4.5.3 Communication with the child, patients, carers and families

The lead or nominated clinician should take responsibility for these tasks:

- discussing treatment options with patients and carers, including the treatment intent and expected outcomes, and providing a written version of the plan and any referrals
- providing patient and carers with information about the possible side effects of treatment, managing symptoms between active treatments, how to access care, self-management strategies and emergency contacts
- encouraging patients to use question prompt lists and audio recordings, and to have a support person present to aid informed decision making
- initiating a discussion about advance care planning and involving carers or family if the patient wishes.

4.5.4 Communication with the general practitioner

The general practitioner plays an important role in coordinating care for patients, including helping to manage side effects and other comorbidities, and offering support when patients have questions or worries. For most patients, simultaneous care provided by their general practitioner is very important.

The lead clinician, in discussion with the patient's general practitioner, should consider these points:

- the general practitioner's role in symptom management, supportive care and referral to local services
- using a chronic disease management plan and mental health care management plan
- how to ensure regular and timely two-way communication about:
 - the treatment plan, including intent and potential side effects
 - supportive and palliative care requirements
 - the patient's prognosis and their understanding of this
 - enrolment in research or clinical trials
 - changes in treatment or medications
 - the presence of an advance care directive or appointment of a substitute decision-maker
 - recommendations from the multidisciplinary team.



More information

Refer to Principle 6 'Communication' for communication skills training programs and resources.

Step 5: Care after initial treatment and recovery

The term ‘cancer survivor’ describes a person living with cancer, from the point of diagnosis until the end of life. Survivorship care in Australia has traditionally been provided to patients who have completed active treatment and are in the post-treatment phase. But there is now a shift to provide survivorship care and services from the point of diagnosis to improve cancer-related outcomes.

Cancer survivors may experience inferior quality of life and cancer-related symptoms for up to five years after their diagnosis (Jefford et al. 2017). Distress, fear of cancer recurrence, fatigue, obesity and sedentary lifestyle are common symptoms reported by cancer survivors (Vardy et al. 2019).

Due to an ageing population and improvements in treatments and supportive care, the number of people surviving cancer is increasing. International research shows there is an important need to focus on helping cancer survivors cope with life beyond their acute treatment. Cancer survivors often face issues that are different from those experienced during active treatment for cancer and may include a range of issues, as well as unmet needs that affect their quality of life (Lisy et al. 2019; Tan et al. 2019).

Physical, emotional and psychological issues include fear of cancer recurrence, cancer-related fatigue, pain, distress, anxiety, depression, cognitive changes and sleep issues (Lisy et al. 2019). Late effects may occur months or years later and depend on the type of cancer treatment. Survivors and their carers may experience impacted relationships and practical issues including difficulties with return to work or study and financial hardship. They may also experience changes to sex and intimacy. Fertility, contraception and pregnancy care after treatment may require specialist input.

The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes the essential components of survivorship care listed in the paragraph above, including interventions and surveillance mechanisms to manage the issues a cancer survivor may face (Hewitt et al. 2006). Access to a range of health professions may be required including physiotherapy, occupational therapy, social work, dietetics, clinical psychology, fertility and palliative care. Coordinating care between all providers is essential to ensure the patient’s needs are met.

Cancer survivors are more likely than the general population to have and/or develop comorbidities (Vijayvergia & Denlinger 2015). Health professionals should support survivors to self-manage their own health needs and to make informed decisions about lifestyle behaviours that promote wellness and improve their quality of life (Australian Cancer Survivorship Centre 2010; Cancer Australia 2017; NCSI 2015).

Referral to community support organisations for support related to survivorship issues is strongly recommended.

5.1 Transitioning from active treatment

The transition from active treatment to post-treatment care is critical to long-term health. In some cases, people will need ongoing, hospital-based care, and in other cases a shared follow-up care arrangement with their general practitioner may be appropriate.

Shared follow-up care involves the joint participation of specialists and general practitioners in the planned delivery of follow-up and survivorship care. A shared care plan is developed that outlines the responsibilities of members of the care team, the follow-up schedule, triggers for review, plans for rapid access into each setting and agreement about the format, frequency and triggers for communication.

After completing initial treatment, a designated member of the multidisciplinary team (most commonly nursing or medical staff involved in the patient's care) should provide the patient with a needs assessment and treatment summary and develop a survivorship care plan in conjunction with the patient. This should include a comprehensive list of issues identified by all members of the multidisciplinary team involved in the patient's care and by the patient. These documents are key resources for the patient and their healthcare providers and can be used to improve communication and care coordination.

The treatment summary should cover, but is not limited to:

- the diagnostic tests performed and results
- diagnosis including stage, prognostic or severity score
- cancer characteristics
- treatment received (types and dates)
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health providers
- potential long-term and late effects of treatment
- supportive care services provided, including referral to survivorship programs
- follow-up schedule and planned surveillance
- contact information for key healthcare providers.

Survivorship

A referral to a survivorship program should occur at the end of treatment with the view of transitioning to the survivorship program at the end of the surveillance period. Where appropriate this should include referral to community support organisations such as, Camp Quality, Cancer Council, Canteen, Leukaemia Foundation and Redkite.

All patients should be given an updated treatment summary and a roadmap for late-effects surveillance on entering the survivorship program.

Patients and their families should be provided with educational material about survivorship, including adopting a healthy lifestyle. Large cohort studies show there is a prevalence for significant adverse long-term outcomes in ALL and recommend regular, primary care consultations.

Transition from paediatric to adult care

Most survivors of CAYA acute leukaemia will transition to a general practitioner with a treatment summary and roadmap outlining investigations and surveillance required. For patients who have undergone a transplant, transition to an adult transplantation service may be appropriate.

5.2 Follow-up care

Responsibility for follow-up care should be agreed between the lead clinician, the general practitioner, relevant members of the multidisciplinary team and the patient. This is based on guideline recommendations for post-treatment care, as well as the patient's current and anticipated physical and emotional needs and preferences.

Evidence comparing shared follow-up care and specialised care indicates equivalence in outcomes including recurrence rate, cancer survival and quality of life (Cancer Research in Primary Care 2016).

Ongoing communication between healthcare providers involved in care and a clear understanding of roles and responsibilities is key to effective survivorship care.

In particular circumstances, other models of post-treatment care can be safely and effectively provided such as nurse-led models of care (Monterosso et al. 2019). Other models of post-treatment care can be provided in these locations or by these health professionals:

- in a shared care setting
- in a general practice setting
- by non-medical staff
- by allied health or nurses
- in a non-face-to-face setting (e.g. by telehealth).

A designated member of the team should document the agreed survivorship care plan. The survivorship care plan should support wellness and have a strong emphasis on healthy lifestyle changes such as a balanced diet, a non-sedentary lifestyle, weight management and a mix of aerobic and resistance exercise (COSA 2018; Hayes et al. 2019).

This survivorship care plan should also cover, but is not limited to:

- what medical follow-up is required (surveillance for recurrence or secondary and metachronous cancers, screening and assessment for medical and psychosocial effects)
- model of post-treatment care, the health professional providing care and where it will be delivered
- care plans from other health providers to manage the consequences of cancer and cancer treatment
- wellbeing, primary and secondary prevention health recommendations that align with chronic disease management principles
- rehabilitation recommendations
- available support services including community support services
- a process for rapid re-entry to specialist medical services for suspected recurrence.

Survivors generally need regular follow-up, often for five or more years after cancer treatment finishes. The survivorship care plan therefore may need to be updated to reflect changes in the patient's clinical and psychosocial status and needs.

Processes for rapid re-entry to hospital care should be documented and communicated to the patient and relevant stakeholders.

Care in the post-treatment phase is driven by predicted risks (e.g. the risk of recurrence, developing late effects of treatment and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is based on evidence and is consistent with guidelines. Not all people will require ongoing tests or clinical review and may be discharged to general practice follow-up.

The lead clinician should discuss (and general practitioner reinforce) options for follow-up at the start and end of treatment. It is critical for optimal aftercare that the designated member of the treatment team educates the patient about the symptoms of recurrence.

General practitioners (including nurses) can:

- connect patients to local community services and programs
- manage long-term and late effects
- manage comorbidities
- provide wellbeing information and advice to promote self-management
- screen for cancer and non-cancerous conditions.



More information

Templates and other resources to help with developing treatment summaries and survivorship care plans are available from these organisations:

- Australian Cancer Survivorship Centre
- Cancer Australia – Principles of Cancer Survivorship
- Cancer Council Australia and states and territories
- Clinical Oncology Society of Australia – Model of Survivorship Care
- eviQ – Cancer survivorship: introductory course
- MyCarePlan.org.au
- South Australian Cancer Service – Statewide Survivorship Framework resources
- American Society of Clinical Oncology – guidelines.

5.2.1 Preventing recurrence

Not smoking, eating a healthy diet, being sun smart, avoiding or limiting alcohol intake, being physically active and maintaining a healthy body weight may help reduce the risk of a second primary cancer, however none of these factors have been shown to impact the risk of CAYA acute leukaemia recurrence.

Encourage and support all cancer survivors to reduce modifiable risk factors for other cancers and chronic diseases. Ongoing coordination of care between providers should also deal with any comorbidities, particularly ongoing complex and life-threatening comorbid conditions.

5.3 Research and clinical trials

Support cancer survivors to participate in research or clinical trials where they are available and appropriate. These might include studies to understand survivors' issues, to better manage treatment side effects, or to improve models of care and quality of life.

For additional information visit:

- Cancer Australia <www.australiancancertrials.gov.au>
- Australian New Zealand Clinical Trials Registry <www.anzctr.org.au>
- Australasian Leukaemia and Lymphoma Group <www.allg.org.au>
- Australian & New Zealand Childrens Haematology/Oncology Group <www.anzhog.org/clinical-trials-research/clinical-trials>
- ClinTrial Refer <www.clintrial.org.au>
- clinicaltrials.gov <www.clinicaltrials.gov> for an international view.

5.4 Support and communication

5.4.1 Supportive care

See validated screening tools mentioned in Principle 4 'Supportive care'. Additionally, the 'Cancer Survivors Unmet Needs (CaSun)' is another validated screening tool that may help health professionals to identify the unmet needs of patients during survivorship.

A number of specific challenges and needs may arise for cancer survivors, carers and families:

- financial and employment issues (e.g. loss of income and assistance with returning to education programs/work, and the cost of treatment, travel and accommodation)
- appointing a substitute decision-maker and completing an advance care directive
- legal issues such as completing a will.

5.4.2 Supportive therapies

Supportive therapies may be necessary for CAYA with acute leukaemia, particularly due to the risk of cardiotoxicity and secondarily to using anthracyclines.

Late complications specifically related to CAYA acute leukaemia may include:

- deficits in neurocognitive functioning, particularly with CNS-directed therapy
- impaired cardiac function due to anthracycline chemotherapy
- neuropathy
- risk of obesity and metabolic syndrome, particularly in those patients treated with cranial radiation.

All patients who have been treated for leukaemia should participate in a survivorship program for at least three years after completing treatment.

Increased surveillance and monitoring are necessary for those who have undergone a transplant due to the increased toxicities of therapy, particularly during conditioning and graft-versus-host disease.

For more information on supportive care and needs that may arise for different population groups, see Appendices A, B and C.

5.4.3 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway from the pre-treatment phase through to disease-free survival and palliative care (Cormie et al. 2017).

Issues that may need to be dealt with include managing cancer-related fatigue, coping with cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to study or work and ongoing adjustment to cancer and its consequences.

Exercise is a safe and effective intervention that improves the physical and emotional health and wellbeing of cancer patients. Exercise should be embedded as part of standard practice in cancer care and be viewed as an adjunct therapy that helps counteract the adverse effects of cancer and its treatment.

Cancer survivors may find referral to specific cancer rehabilitation, optimisation programs or community-based rehabilitation appropriate and beneficial where available. Other options include referral to allied health supports through team care arrangements and mental health plans. Some community support organisations (cancer-related non-government, not-for-profit and charities) provide services to cancer survivors.

5.4.4 Communication with patients, carers and families

The lead clinician (themselves or by delegation) should take responsibility for these tasks:

- explaining the model of post-treatment care and the roles of health professionals involved in post-treatment care including the role of general practice
- explaining the treatment summary and follow-up care plan
- discussing the development of a shared follow-up and survivorship care plan where a model of shared follow-up care has been agreed
- discussing how to manage any of the physical, psychological or emotional issues identified
- providing information on the signs and symptoms of recurrent disease
- providing a survivorship care plan with information on secondary prevention and healthy living
- providing contact details of the care team involved
- providing clear information about the role and benefits of palliative care and advance care planning.

5.4.5 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the general practitioner about:

- the patient's progress
- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- any shared care arrangements
- clarification of various roles in patient care
- a process for rapid re-entry to medical services for patients with suspected recurrence or if there are other concerns.



More information

Refer to Principle 6 'Communication' for communication skills training programs and resources.

Step 6: Managing refractory, relapsed, residual or progressive disease

Patients who present with relapsed or refractory disease should be managed by a multidisciplinary team and offered timely referral to appropriate physical, practical and emotional support.

Step 6 is concerned with managing relapsed or refractory disease in CAYA acute leukaemia.

Despite approximately 90 per cent of CAYA with ALL being cured of their disease, relapse remains the most common cause of treatment failure, occurring in 15–20 per cent of all patients. Of children who relapse, cure only occurs in about 50 per cent of patients, with survival in AYA with relapsed ALL being dismal (Hunger & Raetz 2020; Sellar et al. 2018). Significant improvements in survival have been achieved with incorporating newer targeted therapies into salvage regimens (Brown et al. 2021; Locatelli et al. 2021; Maude et al. 2018).

Refractory ALL in the frontline setting also confers a poor prognosis. Children with induction failure have a 10-year survival of 32 per cent (Schrappe 2012).

In AML, 30 per cent of all patients will relapse, and recent studies show only 30–40 per cent of those patients survive (Hoffman et al 2021).

6.1 Signs and symptoms of relapsed or refractory disease

Some patients may present with symptoms of relapsed disease after a previous cancer diagnosis. The relapse may be discovered by the patient or by surveillance in the post-treatment period. Access to the best available therapies, including clinical trials, as well as treatment overseen by a multidisciplinary team, are crucial to achieving the best outcomes for anyone with relapsed or refractory disease.

There should be an **immediate** referral to a leukaemia multidisciplinary team specialist cancer service for all patients with suspected or confirmed relapse.

6.2 Managing relapsed or refractory disease

All CAYA with relapsed or refractory acute leukaemia should be managed by a specialist cancer service.

From the time of diagnosis, the team should offer patients appropriate psychosocial care, supportive care, advance care planning and symptom-related interventions as part of their routine care. The approach should be personalised to meet the patient's individual needs, values and preferences. The full complement of supportive care measures as described throughout the optimal care pathway and in Appendices A, B and C should be offered to assist patients and their families and carers to cope. These measures should be updated as the patient's circumstances change.

Survivorship issues should be considered as part of routine care. Health professionals should therefore be ready to change and adapt treatment strategies according to disease status, prior treatment tolerance/toxicities and the patient's quality of life, in addition to the patient's priorities and life plans.

6.2 Multidisciplinary team

If there is an indication that a patient's cancer has returned, care should be provided under the guidance of a treating specialist.

There should be an immediate referral to a leukaemia multidisciplinary team within a CAYA cancer service for all with suspected or confirmed relapse. As with frontline therapy, routine involvement of allied health (e.g. social work, psychology) within the team is required. The team may include new members such as palliative care specialists.

6.3 Treatment

Treatment will depend on the timing of relapse, location of relapse (isolated bone marrow relapse, isolated extramedullary relapse, combined relapse), immunophenotype in ALL (B-cell vs T-cell), previous management, response to salvage therapy (including MRD response in ALL), number of previous relapses and the patient's preferences.

CAYA with relapsed ALL are often eligible for enrolment in clinical trials for relapsed disease. These typically involve systemic chemotherapy, newer targeted agents and/or immunotherapy, together with HSCT for selected patients.

In relapsed AML, achieving rapid remission via systemic chemotherapy, targeted therapies and/or immunotherapy followed by HSCT is currently the most effective curative strategy.

Immunotherapy or immune effector cell therapy is used in certain relapsed acute leukaemia patients. Current examples of immunotherapy used in acute leukaemia include BiTEs (e.g. blinatumomab), antibody drug conjugates (e.g. gemtuzumab, inotuzumab) and CAR T-cells (e.g. tisagenlecleucel). A number of additional immunotherapies are currently under investigation in CAYA acute leukaemia.

Access to new therapies that have not yet been approved by the Pharmaceutical Benefits Scheme may sometimes be challenging. This highlights the importance of enrolling CAYA with relapsed/refractory disease onto clinical trials wherever possible.

The potential goals of treatment should be discussed, respecting the patient's cultural values. Wherever possible, written information should be provided.

6.4 Advance care planning

Advance care planning is important for all patients with a cancer diagnosis but especially those with advanced disease. Where appropriate, patients, their family or carer should be encouraged to think and talk about their healthcare values and preferences and consider developing an advance care directive to convey their preferences for future health care (Australian Government Department of Health 2021 a). The lead oncologist, haematologist, palliative care team or general practitioner are best placed to assist with a CAYA-centred approach and assist in developing an advance care directive.



More information

Refer to section 4.3 'More information' for links to resources.

Refer patients and carers to Advance Care Planning Australia <www.advancereplanning.org.au> or to the Advance Care Planning National Phone Advisory Service on 1300 208 582.

Refer patients, their family or carer to the *Thinking ahead framework* <www.rch.org.au/thinkingahead/framework> or call (03) 9345 5522.

6.5 Palliative care

Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). The treatment team should emphasise the value of palliative care in improving symptom management and quality of life to patients and their carers. Refer to section 4.3 for more detailed information.

CAYA with an uncertain prognosis and a high symptom burden should be able to access palliative care support alongside curative-intent therapies.

Cases of relapse should trigger a referral to palliative care services.

The lead clinician should ensure timely and appropriate referral to paediatric palliative care services. Referral to palliative care services should be based on the patient's need and potential for benefit, not prognosis.



More information

Refer to the end of section 4.3 'Palliative care' for links to resources.

6.6 Research and clinical trials

The treatment team should support the patient to participate in research and clinical trials where available and appropriate.

For additional information visit:

- Cancer Australia <www.australiancancertrials.gov.au>
- Australian New Zealand Clinical Trials Registry <www.anzctr.org.au>
- Australasian Leukaemia and Lymphoma Group <www.allg.org.au>
- Australian & New Zealand Childrens Haematology/Oncology Group <www.anzhog.org/clinical-trials-research/clinical-trials>
- ClinTrial Refer <www.clintrial.org.au>
- clinicaltrials.gov <www.clinicaltrials.gov> for an international view.

6.7 Support and communication

6.7.1 Supportive care

See validated screening tools mentioned in Principle 4 'Supportive care'.

A number of specific challenges and needs may arise at this time for patients, carers and families:

- assistance for dealing with emotional and psychological distress resulting from fear of death or dying, existential concerns, anticipatory grief, communicating wishes to loved ones, interpersonal problems and sexuality concerns
- potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment
- cognitive changes as a result of treatment and disease progression such as altered memory, attention and concentration (a patient may appoint someone to make medical, financial and legal decisions on their behalf – a substitute decision-maker – before and in case they experience cognitive decline)

- management of physical symptoms
- decline in mobility or functional status as a result of recurrent disease and treatments (referral to physiotherapy or occupational therapy may be required)
- coping with hair loss and changes in physical appearance (refer to the Look Good, Feel Better program – see ‘Resource list’)
- appointing a substitute decision-maker and completing an advance care directive
- financial issues as a result of disease recurrence such as gaining early access to superannuation and insurance
- legal issues (completing a will, care of dependent children) and making an insurance, superannuation or social security claim on the basis of terminal illness or permanent disability. financial and employment issues (e.g. loss of income and assistance with returning to work, and the cost of treatment, travel and accommodation)
- referral to supportive care services and community support services.

6.7.2 Supportive therapies

Treatment for relapsed acute leukaemia has a high-risk of treatment-related morbidity and mortality, particularly infectious complications. HSCT, novel agents and cell therapies used in refractory leukaemia may also be associated with significant treatment-related side effects. Families and patients from regional centres may need to move closer to the specialist cancer service due to the toxicity of therapy. Support of the patient and family, including access to information, should be managed under the family-centred care principles discussed in Principle 4 ‘Supportive care’.

6.7.3 Rehabilitation

Rehabilitation may be required at any point of the care pathway, from preparing for treatment through to palliative care. Issues that may need to be dealt with include managing cancer-related fatigue, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to cancer and its consequences.

Exercise is a safe and effective intervention that improves the physical and emotional health and wellbeing of cancer patients. Exercise should be embedded as part of standard practice in cancer care and be viewed as an adjunct therapy that helps counteract the adverse effects of cancer and its treatment.

6.7.4 Communication with patients, carers and families

The lead clinician should ensure there is adequate discussion with patients and carers about the diagnosis and recommended treatment, including treatment intent and possible outcomes, likely adverse effects and the supportive care options available.



More information

Refer to Principle 6 ‘Communication’ for communication skills training programs and resources.

Step 7: End-of-life care

Step 7 is concerned with maintaining the child, adolescent or young adult's quality of life and meeting their health and supportive care needs at the end of life and in bereavement, as well as the needs of the patient's family or carers.

Informed patients and carers have greater confidence and competence to manage their end-of-life care. Because laws regarding consent in children is governed federally and by each state/territory, children should be involved in decision making whenever possible.

Some patients may reach a time when active treatment is no longer appropriate. The team needs to share the principles of a palliative approach to care when making decisions with the patient and their family or carer. End-of-life care is appropriate when the patient's symptoms are increasing and functional status is declining.

See section 4.3 for more information on palliative care in CAYA with acute leukaemia.

7.1 Multidisciplinary palliative care

If the treatment team does not include a palliative care member, the lead clinician should consider referring the patient to palliative care services. This may include inpatient palliative unit access (as required) hospice, and support for end-of-life care at home, and is often done as a collaboration between haematology, paediatric oncology and the palliative care team.

The multidisciplinary team may consider seeking additional expertise from these professionals:

- clinical psychologist
- clinical nurse specialist or practitioner
- social worker
- palliative medicine specialist
- pain specialist
- pastoral or spiritual carer
- bereavement counsellor
- music therapist
- art therapist
- cultural expert
- Canteen for children of parents with cancer <www.canteen.org.au/young-people/my-parent-has-cancer>.

The team might also recommend that patients access:

- home- and community-based care
- specialist community palliative care workers
- community nursing.

If the patient does not already have an advance care directive in place, a designated member of the treatment team should encourage them to develop one in collaboration with their family or carer (Australian Government Department of Health 2021a).

It is essential for the treatment team to consider the appropriate place of care, the patient's preferred place of death and the support needed for the patient, their family and carers.

The treatment team should also ensure that carers and families receive the information, support and guidance about their role according to their needs and wishes (Palliative Care Australia 2018).



More information

The treatment team can refer patients and carers to these resources:

- Palliative Care Australia <www.palliativecare.org.au/health-professionals-resources/end-of-life> and children's hospice information <<https://palliativecare.org.au/childrens-hospices-in-australia>>
- Advance Care Planning Australia <www.advancecareplanning.org.au> or to Advance Care Planning Australia's National Advisory Service on 1300 208 582.

7.2 Research and clinical trials

Clinical trials may help improve palliative care and in managing a patient's symptoms of advanced cancer (Cancer Council Victoria 2019). The treatment team should support the patient to participate in research and clinical trials where available and appropriate.

For more information visit:

- Cancer Australia <www.australiancancertrials.gov.au>
- Australian New Zealand Clinical Trials Registry <www.anzctr.org.au>
- Australasian Leukaemia and Lymphoma Group <www.allg.org.au>
- Australian & New Zealand Childrens Haematology/Oncology Group <www.anzchog.org/clinical-trials-research/clinical-trials>
- ClinTrial Refer <www.clintrial.org.au>
- clinicaltrials.gov <www.clinicaltrials.gov> for an international view.

7.3 Support and communication

7.3.1 Supportive care

See validated screening tools mentioned in Principle 4 'Supportive care'.

A number of specific challenges and needs may arise for patients at this time:

- assistance for dealing with emotional and psychological distress from anticipatory grief, fear of death or dying, anxiety/depression and interpersonal problems
- management of physical symptoms

- decline in mobility or functional status, affecting the patient's discharge destination (a referral to physiotherapy, exercise physiology, occupational therapy or social work may be needed)
- appointing a substitute decision-maker and completing an advance care directive
- legal issues (completing a will, care of dependent children) and making an insurance, superannuation or social security claim on the basis of terminal illness or permanent disability specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs
- arranging a funeral.

These services and resources can help with:

- referral to the Cancer Council Australia's Pro Bono Program (13 11 20) for free legal, financial, small business accounting and workplace assistance (subject to a means test)
- *Sad news sorry business* (Queensland Health 2015) for the specific needs of Aboriginal and Torres Strait Islander people
- referral to Redkite (1800 733 548) for financial assistance during palliative care, with funerals and in the first year of bereavement, as well as counselling and social work services during end-of-life care and bereavement support and counselling
- referral to Canteen (1800 226 833) for similar supports (not financial assistance)
- referral to the Leukaemia Foundation (1800 620 420) for emotional, physical and psychosocial support for the challenges of a cancer diagnosis, treatment and survivorship.

For more information on supportive care and needs that may arise for different population groups, see Appendices A, B and C.

7.3.2 Communication with patients, carers and families

The lead clinician is responsible for:

- being open to and encouraging discussion with the patient, carer and family about the expected disease course, considering the patient's personal and cultural beliefs and expectations
- discussing palliative care options, including inpatient and community-based services as well as dying at home and subsequent arrangements
- providing the patient and carer with the contact details of a palliative care service
- referring the patient to palliative care in the community according to the carer's wishes
- referring the carers and family to bereavement support from community support services.

7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning to ensure the CAYA patient's needs and goals are met in the appropriate environment. The patient's general practitioner should be kept fully informed and involved in major developments in the patient's illness path.



More information

For support with communication skills and training programs, see these sources:

- *Sad news sorry business* <www.health.qld.gov.au/__data/assets/pdf_file/0023/151736/sorry_business.pdf>
- Principle 6 'Communication'.

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Allied Health Professions Australia
Australian and New Zealand Children's Haematology/Oncology Group
Australia and New Zealand Transplant and Cellular Therapies
Australasian Association of Nuclear Medicine Specialists
Australasian College of Emergency Medicine
Australasian Leukaemia and Lymphoma Group
Australian and New Zealand Society of Palliative Care
Australian College of Nursing
Australian College of Rural and Remote Medicine
Australian Government Department of Health and Ageing
Australian Medical Association
Beyond Blue
Cancer Australia
Cancer Council of Australia
Cancer Council Victoria
Cancer Institute NSW
Cancer Nurses Society of Australia
Canteen
Clinical Oncology Society of Australia
Haematology Society of Australia & New Zealand
Launceston General Hospital
Leukaemia Foundation
Lymphoma Australia
Medical Oncology Group of Australia
Myeloma Australia
Northern Territory Department of Health

Palliative Care Australia
Private Cancer Physicians of Australia
Queensland Health
Rare Cancers Australia
Redkite
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Royal Australian and New Zealand College of Radiologists
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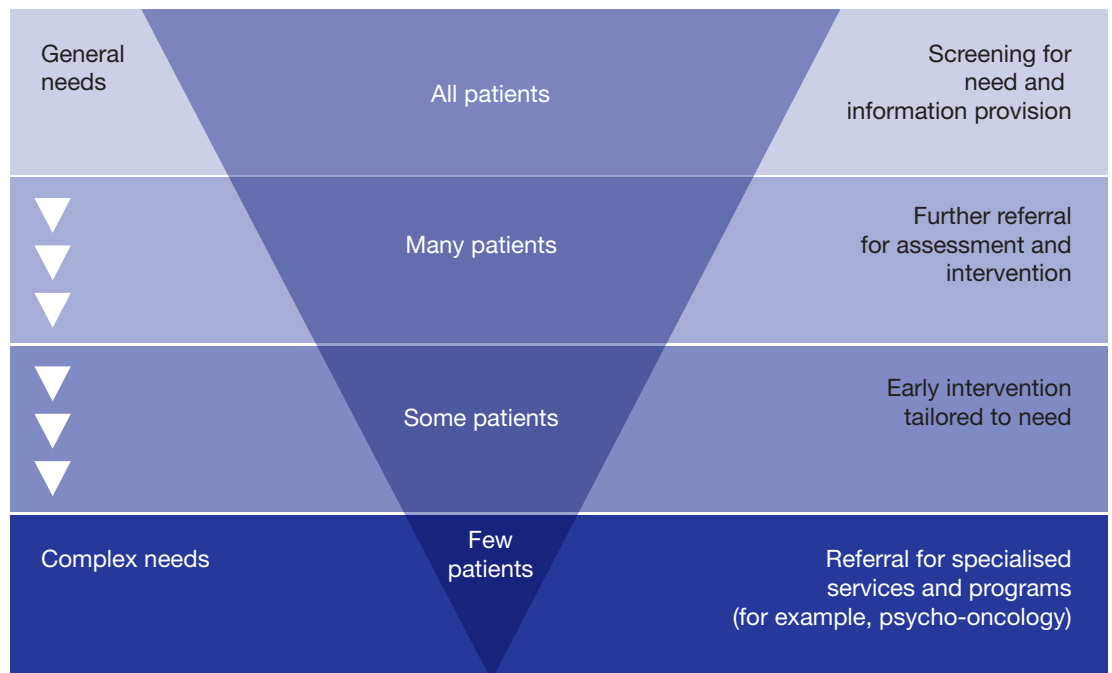
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Our thanks also to the Blood Cancer Taskforce, which recommended the development of optimal care pathways for all the major blood cancer subtypes as part of the *National Strategic Action Plan for Blood Cancer (2020)*. The National Action Plan was commissioned by the Federal Government and developed by the Blood Cancer Taskforce, with support from the Leukaemia Foundation.

Appendix A: Supportive care domains

- Supportive care in cancer refers to the following five domains:
- the physical domain, which includes a wide range of physical symptoms that may be acute, relatively short lived or ongoing, requiring continuing interventions or rehabilitation
- the psychological domain, which includes a range of issues related to the patient's mental health wellbeing and personal relationships
- the social domain, which includes a range of social and practical issues that will affect the patient, carer and family such as the need for emotional support, maintaining social networks and financial concerns
- the information domain, which includes access to information about cancer and its treatment, recovery and survivorship support services and the health system overall
- the spiritual domain, which focuses on the patient's changing sense of self and challenges to their underlying beliefs and existential concerns (Palliative Care Victoria 2019).
- Fitch's (2000) model of supportive care recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual patient (Figure A1). The model targets the type and level of intervention required to meet patients' supportive care needs.

Figure A1: Fitch's tiered approach to supportive care



Appendix B: Psychological needs

Clinicians need to be aware that these may vary according to the age and developmental stage of the child or young person. Children frequently manifest distress as changes in behaviour. While acting out or oppositional behaviour may be readily identifiable, behavioural change may be more subtle, such as withdrawn, irritable, psychosomatic or regressed behaviour. Specific issues of concern also vary according to age and level of understanding.

Consider a referral to a psychologist, psychiatrist, pastoral/spiritual care practitioner, social worker, specialist nurse or a relevant community-based program if the patient, family or carer has these issues:

- displaying emotional cues such as tearfulness, distress that requires specialist intervention, avoidance or withdrawal
- being preoccupied with or dwelling on thoughts about cancer and death
- displaying fears about the treatment process or the changed goals of their treatment
- displaying excessive fears about cancer progression or recurrence
- worrying about loss associated with their daily function, dependence on others and loss of dignity
- becoming isolated from family and friends and withdrawing from company and activities that they previously enjoyed
- feeling hopeless and helpless about the effect that cancer is having on their life and the disruption to their life plans
- struggling to communicate with family and loved ones about the implications of their cancer diagnosis and treatment
- experiencing changes in sexual intimacy, libido and function
- struggling with the diagnosis of relapsed or refractory disease
- having difficulties quitting smoking (refer to Quitline on 13 7848) or with other drug and alcohol use
- having difficulties transitioning to palliative care.

Additional considerations that may arise for the multidisciplinary team include:

- support for the carer – encourage referrals to psychosocial support from a social worker, psychologist or general practitioner
- referral to an exercise physiologist or physiotherapist as a therapeutic approach to prevent and manage psychological health
- referral to wellness-after-cancer programs to provide support, information and offer strategies.

Appendix C: Special population groups

The burden of cancer is not evenly spread across Australia. People experiencing socioeconomic disadvantage, Aboriginal and Torres Strait Islander communities, culturally diverse communities, people living with a disability, people with chronic mental health or psychiatric concerns and those who live in regional and rural areas of Australia have poorer cancer outcomes.

Aboriginal and Torres Strait Islander people

Cancer is the third leading cause of burden of disease for Aboriginal and Torres Strait Islander people. While Australia's cancer survival rates are among the best in the world, Aboriginal and Torres Strait Islander people continue to experience a different pattern of cancer incidence and significant disparities in cancer outcomes compared with non-Indigenous Australians.

For Aboriginal and Torres Strait Islander people, health and connection to land, culture, community and identity are intrinsically linked. Health encompasses a whole-of-life view and includes a cyclical concept of life–death–life.

The distinct epidemiology of cancer among Aboriginal and Torres Strait Islander people, and unique connection to culture, highlight the need for a specific optimal care pathway for Aboriginal and Torres Strait Islander people with cancer. Ensuring this pathway is culturally safe and supportive is vital to tackling the disparities for Aboriginal and Torres Strait Islander people.

Published in 2018, the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* provides guidance to health practitioners and service planners on optimal care for Aboriginal and Torres Strait Islander people with cancer across the cancer continuum.

In addition to the key principles underpinning tumour-specific pathways, these are the key concepts that are fundamental to Aboriginal and Torres Strait Islander health:

- providing a holistic approach to health and wellbeing
- providing a culturally appropriate and culturally safe service
- acknowledging the diversity of Aboriginal and Torres Strait Islander peoples
- understanding the social determinants and cultural determinants of health (Cancer Australia 2015).

To view the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*, visit the Cancer Australia website <<https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-health>>. To view the consumer resources – *Checking for cancer* and *Cancer*, visit the Cancer Australia website <<https://www.canceraustralia.gov.au/affected-cancer/atsi/resources-people>>.

Culturally diverse communities

For people from culturally diverse backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In many languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in people from culturally diverse backgrounds and this can affect their understanding and decision making after a cancer diagnosis. In addition to different cultural beliefs, when English language is limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for patients.

A professionally trained interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those with a non-Anglo culture, and members of the treatment teams should pay particular attention to supporting these patients.

The Australian Cancer Survivorship Centre has developed a glossary of more than 700 cancer terms in nine different languages. The multilingual glossary has been designed as a resource for professional translators, interpreters and bilingual health professionals working in the cancer field. The glossary is a unique tool that enables language professionals with access to accurate, consistent and culturally appropriate terminology.

Visit the Peter Mac website <www.petermac.org/multilingualglossary> to see the glossary.

People with disabilities

Disability, which can be physical, intellectual or psychological, may have existed before the cancer diagnosis or may be new in onset (occurring due to the cancer treatment or incidentally). Adjusting to life with a disability adds another challenge to cancer care and survivorship.

Several barriers prevent people with disabilities from accessing timely and effective health care (AIHW 2017):

- physical limitations
- competing health needs
- the trauma of undergoing invasive procedures
- potential barriers associated with obtaining informed consent
- failure to provide assistance with communication
- lack of information
- discriminatory attitudes among healthcare staff.

In caring for people with disabilities and a cancer diagnosis, the Australian Institute of Health and Welfare disability flag should be used at the point of admittance to correctly identify and meet the additional requirements of a person with disability. Facilities should actively consider access requirements, and health practitioners should make reasonable adjustments where required.

Patients aged between seven and 65 years who have a permanent or significant disability may be eligible for support or funding through the NDIS (National Disability Insurance Agency 2018). More information can be found on the NDIS website <www.ndis.gov.au>.

Patients aged 65 years or older (50 years or older for Aboriginal or Torres Strait Islander people) may be eligible for subsidised support and services through aged care services. An application to determine eligibility can be completed online over the phone. More information can be found at the My Aged Care website <www.myagedcare.gov.au>.



More information

'Talking End of Life' is a resource that shows how to teach people with intellectual disability about end of life. It is designed for disability support workers but is also helpful for others including families, health professionals and educators.

To view the resource, visit the Talking End of Life website <www.caresearch.com.au/tel/tabid/4881/Default.aspx>.

Adolescents and young adults

Adolescence and young adulthood is a dynamic and distinct developmental period and in recent years has emerged as a distinct field in oncology (Cancer Australia 2008; Canteen 2017). This focus has helped address the lack of progress in survival and quality-of-life outcomes for this group (Ferrari et al. 2010).

The needs of adolescents and young adults with cancer

(This section has been reproduced with permission from the *Australian youth cancer framework*, Canteen 2017, pp. 4–5.)

Young people with cancer face an unexpected, life-changing and extraordinary challenge to accept, manage and overcome a critical illness during this transformative stage of life. In addition to facing a potentially life-threatening illness at a time that is usually filled with life-affirming potential, young people with cancer face a range of challenges that have particularly significant impact at this stage of life (see diagram below).



In caring for young people with cancer, akin to the comorbidities that require specific care in the older cancer population, the treatment team needs to pay careful attention to promoting normal development (COSA 2014). This requires personalised assessments and management involving a multidisciplinary, disease-specific, developmentally targeted approach that adheres to the following principles:

- understanding the developmental stages of adolescence and supporting normal adolescent health and development alongside cancer management
- understanding and supporting the rights of young people
- communication skills and information delivery that are appropriate to the young person
- meeting the needs of all involved, including the young person, their carers and their family
- working with educational institutions and workplaces
- considering survivorship and palliative care needs.

An oncology team caring for an adolescent or young adult with cancer should be able to demonstrate these specific areas of expertise:

- be able to ensure access to expert adolescent and young adult health providers who have knowledge specific to the biomedical and psychosocial needs of the population
- understand the biology and current management of the disease in the adolescent and young adult age group
- consider participating in research and clinical trials for each patient
- engage in proactive discussion and management of fertility preservation, late effects of treatment, ongoing need for contraception, and psychosocial and psychosexual needs
- provide treatment in an environment that is friendly to adolescents and young adults.

If a young person is aged 15–25 years, contact with Youth Cancer Services <<https://www.canteen.org.au/youth-cancer>> is recommended for advice or referral regarding developmentally appropriate treatment and support.

The comprehensive model of care offered by Youth Cancer Services is consistent with national optimal care pathways developed by the Australian Government's National Cancer Expert Reference Group. Specialist, age-appropriate medical, nursing and allied health treatment and support is offered to young cancer patients via a national network of hospitals.

At the time of publication, a population based optimal care pathway for adolescents and young adults with cancer was under development. This resource provides a tool to help guide system safety and responsiveness to the unique needs of adolescents and young adults diagnosed with cancer and improve outcomes and experience. It can be used in conjunction with the optimal care pathway for each cancer type.

People experiencing socioeconomic disadvantage

In general, people from lower socioeconomic groups are at greater risk of poor health, have higher rates of illness, disability and death, and live shorter lives than those from higher socioeconomic groups (AIHW 2016). People experiencing socioeconomic disadvantage are less likely to participate in screening programs, more likely to be obese, less likely to exercise and much more likely to smoke, which are all risk factors for cancer.

In 2010–2014 age-standardised cancer incidence rates were higher in the lowest socioeconomic areas compared with the highest socioeconomic areas for all cancers combined (Cancer Australia 2019b).

Socioeconomic status and low health literacy are closely correlated. Therefore, effective communication with patients and carers is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults) (ACSQHC 2014).

Consideration should be taken for cancer patients experiencing socioeconomic disadvantage to reduce their risk of being underserved for health care.

People with chronic mental health or psychiatric concerns

A diagnosis of cancer may present additional challenges to people who have pre-existing chronic mental health or psychiatric concerns, resulting in exacerbation of their mental health symptoms. This may include heightened anxiety, worsening depression or thoughts of self-harm.

As poor adjustment and coping can affect treatment decisions, people who are known to have a mental health diagnosis need psychosocial assessment in the oncology setting to formulate a plan for ongoing support throughout treatment.

Psychosocial support can assist with challenges in communicating with health professionals, enhance understanding of the treatment journey, ensure capacity for consent to treatment options and improve compliance with treatment requests. A referral for psychosocial support from a health professional to the psycho-oncology team can ensure these patients are provided with targeted interventions or referrals to community-based services that may mitigate problems associated with the impacts of social isolation that frequently accompany chronic mental ill-health.

Many patients with chronic mental health problems may be well known to external service providers. Psycho-oncology health professionals can form meaningful partnerships with existing service providers to optimise patient care throughout treatment and beyond.

Drug use disorders fall within the area of mental health conditions. People who are opiate dependent may have specific and individual requirements regarding pain management and their own preference for type of opiate prescribed or used.

Sexually and gender diverse groups

People who identify as sexually or gender diverse may have unique needs following a cancer diagnosis. Sexually or gender diverse identities include (but are not limited to) people who identify as lesbian, gay, bisexual or transgender. There is no universally agreed upon initialism to describe this community, with other terms such as queer/questioning (Q), intersex (I), asexual (A) and pansexual (P) often included, as well as a plus symbol (+) indicating inclusivity of other identities not explicitly mentioned. For the purposes of this document, this community is referred to as LGBTQI+.

Sexual orientation and gender identity are relevant across the entire spectrum of cancer care, from prevention to survivorship and end-of-life care. LGBTQI+ people are less likely to participate in cancer screening, and some segments of the LGBTQI+ community exhibit elevated rates of specific cancer risk factors – for example, higher rates of smoking and alcohol use. Regarding treatment, there may be unique factors relevant to LGBTQI+ people that may affect decision making. Additionally, the LGBTQI+ population experiences higher rates of anxiety, depression and stressful life circumstances, and may be at risk of inferior psychosocial outcomes following a cancer diagnosis. LGBTQI+ people are also more likely to be estranged from their families of origin, and for older people, less likely to have adult children who may provide support and care.

Barriers to care for LGBTQI+ people include past negative interactions with healthcare systems, experiences or fear of discrimination and harassment in healthcare settings, assumptions of cisgender/heterosexual identity, lack of recognition or exclusion of same-sex partners from care, and a lack of relevant supportive care and information resources.

To provide safe and appropriate care for LGBTQI+ people with cancer, healthcare providers should:

- display environmental cues to show an inclusive and safe setting for LGBTQI+ patients
- avoid assumptions about the sexual orientation or gender identity of patients and their partners
- facilitate positive disclosure of sexual orientation or gender identity
- include same-sex/gender partners and families of choice in care
- be aware of relevant supportive care and information resources
- provide non-judgemental, patient-centred care.

Appendix D: Complementary therapies

Complementary therapies may be used together with conventional medical treatments to support and enhance quality of life and wellbeing. They do not aim to cure the patient's cancer. Instead, they are used to help control symptoms such as pain and fatigue (Cancer Council Australia 2019).

The lead clinician or health professional involved in the patient's care should discuss the patient's use (or intended use) of complementary therapies not prescribed by the multidisciplinary team to assess safety and efficacy and to identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the patient's reason for using these therapies and the evidence base. A transparent and honest discussion that is free from judgement should be encouraged.

While some complementary therapies are supported by strong evidence, others are not. For such therapies, the lead clinician should discuss their potential benefits and use them alongside conventional therapies (NHMRC 2014).

If the patient expresses an interest in using complementary therapies, the lead clinician should consider referring patients to health providers within the multidisciplinary team who have expertise in the field of complementary and alternative therapies (e.g. a clinical pharmacist, dietitian or psychologist) to assist them to reach an informed decision. Costs of such approaches should be part of the discussion with the patient and considered in the context of evidence of benefit.

The lead clinician should assure patients who use complementary therapies that they can still access a multidisciplinary team review and encourage full disclosure about therapies being used.



More information

- See Cancer Australia's position statement on complementary and alternative therapies <www.canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>.
- See the Clinical Oncological Society of Australia's position statement *Use of complementary and alternative medicine by cancer patients* <www.cosa.org.au/publications/position-statements.aspx>.

Appendix E: Members of the multidisciplinary team for CAYA acute leukaemia

The multidisciplinary team may include the following members.

Diagnostic/treatment multidisciplinary team:

- haematologist
- oncologist
- clinical nurse consultant
- haematopathologist
- pharmacist
- clinical research associate.

Psychosocial multidisciplinary team:

- CAYA specialist
- fertility coordinator
- social worker
- psychologist
- allied health and other professionals – physiotherapist, exercise physiologist, speech pathologist, occupational therapist, music therapist, teacher, child life therapist, Back on Track team, dietitian
- Aboriginal health practitioner, Indigenous liaison officer
- general practitioner
- spiritual/pastoral carer.

The CAYA multidisciplinary team may include the following members:

- CAYA nurse coordinator
- CAYA program lead
- CAYA medical oncologist/haematologist clinical lead
- social worker
- mental health specialist
- physiotherapy and occupational therapy
- art and music therapists
- exercise physiologist
- palliative/supportive care clinician
- dietitian
- educational/vocational advisor
- fertility/sexual health clinician
- clinical trials coordinator.

Resource list

For patients, families and carers

Advance Care Planning Australia

Advance Care Planning Australia provides national advance care planning resources for individuals, families, health professionals and service providers. Resources include a national advisory service, information resources, a legal forms hub and education modules.

- Telephone: 1300 208 582
- Website <www.advancecareplanning.org.au>

Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre has developed information resources and events to help people move from initial treatment to post treatment and beyond, including those receiving maintenance treatments. While they do not provide clinical advice, they connect with a range of providers to enable improved care.

- Telephone: (03) 8559 6220
- Website <www.petermac.org/cancersurvivorship>

Australian Commission on Safety and Quality in Health Care

The Australian Commission on Safety and Quality in Health Care has developed a resource for patients and carers explaining the coordination of care that patients should receive from their health service during cancer treatment. The resource is called What to expect when receiving medication for cancer care <<https://www.safetyandquality.gov.au/publications-and-resources/resource-library/what-expect-when-receiving-medication-cancer-care>>.

Beyond Blue

Beyond Blue provides information about depression, anxiety and related disorders, as well as about available treatment and support services.

- Telephone: 1300 22 4636
- Website <www.beyondblue.org.au>

Camp Quality

Camp Quality gives kids facing cancer the chance to be kids again. Camp Quality's services and programs are created specifically to support children aged up to 15 years who are dealing with their own cancer diagnosis or the diagnosis of someone they love, like a brother, sister, mum, dad or carer.

Camp Quality provides kids, their siblings and parents with fun experiences, education, specialised cancer care, counselling and a supportive community that is delivered in hospital, online, at school and away from it all on camps and retreats.

- Telephone: 1300 662 267
- Website <campquality.org.au>

Cancer Australia

Cancer Australia provides information for consumers, carers and their families including printed resources and video content.

- Website <www.canceraustralia.gov.au>

Cancer Council's Cancer Information and Support Service

Cancer Council 13 11 20 is a confidential telephone support service available to anyone affected by cancer. This service acts as a gateway to evidence-based documented, practical and emotional support available through Cancer Council services and other community organisations. Calls will be answered by a nurse or other oncology professional who can provide information relevant to a patient's or carer's situation. Health professionals can also access this service.

- Telephone: 13 11 20 – Monday to Friday, 9.00am to 5.00pm (some states have extended hours)
- Website <<https://www.cancer.org.au/about-us/about-cancer-council>>

Cancer Council's Cancer Connect

Cancer Connect is a free and confidential telephone peer support service that connects someone who has cancer with a specially trained volunteer who has had a similar cancer experience. A Connect volunteer can listen with understanding and share their experiences and ways of coping. They can provide practical information, emotional support and hope. Many people newly diagnosed with cancer find this one-to-one support very beneficial.

For more information on Cancer Connect call Cancer Council 13 11 20.

Canteen

Canteen is the Australian organisation for adolescents and young adults (12–25 years) who have been impacted by their own or a family member's cancer diagnosis.

Canteen has youth-specific treatment teams providing national support through information, individual case management, counselling, therapeutic programs and education and career support. Canteen also provides support to the parents of these young people.

Phone 1800 835 932 to talk to a health professional about information and support for young people or 1800 226 833 for other enquiries.

- Website <www.canteen.org.au>

CareSearch Children and Adolescents

CareSearch's paediatric page provides information for children and adolescents with life-limiting illness.

- Website <<https://www.caresearch.com.au/caresearch/tabid/602/Default.aspx>>.

Leukaemia Foundation

The Leukaemia Foundation provides specialist support, funds leading-edge research and advocates for Australians diagnosed with blood cancer. The foundation guides patients and their loved ones through the emotional, physical and psychosocial challenges of a blood cancer diagnosis, treatment and survivorship.

The foundation's team of qualified health professionals can answer questions, talk through concerns and connect patients to blood cancer support groups. The team can also help with practical concerns such as accommodation close to treatment, transport to appointments and financial assistance.

- Telephone: 1800 620 420
- Website <www.leukaemia.org.au>

Clinical trial information

For a collection of clinical trials available in Australia and internationally, see the following sources of information:

- Cancer Australia <www.australiancancertrials.gov.au>
- Australian New Zealand Clinical Trials Registry <www.anzctr.org.au>
- Australasian Leukaemia and Lymphoma Group <www.allg.org.au>
- Australian & New Zealand Childrens Haematology/Oncology Group <www.anzchog.org/clinical-trials-research/clinical-trials>
- ClinTrial Refer <www.clintrial.org.au>
- clinicaltrials.gov <www.clinicaltrials.gov> for an international view.

CanEAT pathway

A guide to optimal cancer nutrition for people with cancer, carers and health professionals.

- Website <<https://education.eviq.org.au/courses/supportive-care/malnutrition-in-cancer>>
- Website <<https://patients.cancer.nsw.gov.au/coping-with-cancer/physical-wellbeing/eating-well>>

Guides to best cancer care

These short guides help patients understand the optimal cancer care that should be provided at each step and can be used to complement the optimal care pathways. Carers, family and friends may also find them helpful.

The guides to best cancer care are located on an interactive web portal, with downloadable PDFs in plain English and translations in multiple languages.

- Website <www.cancercareguides.org.au>

Kids Helpline

Kids Helpline is Australia's only free (even from a mobile), confidential 24/07 online and phone counselling service for young people aged 5 to 25. Qualified counsellors at Kids Helpline are available via WebChat, phone or email anytime and for any reason.

- Telephone: 1800 55 1800
- Website: <<https://kidshelpline.com.au>>

Look Good, Feel Better

A free national community service program, run by the Cancer Patients Foundation, dedicated to teaching cancer patients how to manage the appearance-related side effects caused by treatment for any type of cancer.

- Telephone: 1800 650 960
- Website <<https://lgfb.org.au>>

Paediatric palliative care

Paediatric palliative care provides practical information about paediatric palliative care to families who have a child with a life-limiting illness, as well as the people who support them. Information is also available for health professionals to better support families and provide quality paediatric palliative care.

- Website <palliativecare.org.au/children>

Quitline

Quitline is a confidential, evidence-based telephone counselling service. Highly trained Quitline counsellors use behaviour change techniques and motivational interviewing over multiple calls to help people plan, make and sustain a quit attempt.

Quitline is a culturally inclusive service for all, and Aboriginal counsellors are also available. Health professionals can refer patients to Quitline online.

- Telephone: 13 7848
- Website <www.quit.org.au> or the relevant website in your state or territory.

Redkite

“Redkite is Australia's leading childhood cancer support organisation, providing free practical, emotional and financial support for all members of families with a child with cancer (aged 18 or under). Redkite support is confidential and free to anyone connected to a child with cancer. Support includes counselling for all members of the family including children, peer support groups, financial assistance and help to connect with other relevant support services.”

- Telephone: 1800 733 548
- Website: <www.redkite.org.au>

Ronald McDonald House

Ronald McDonald Houses are a home-away-from-home for families of seriously ill children being treated at nearby hospitals. Rather than spending the night in a hospital waiting room, family members can stay in comfort at a Ronald McDonald House and receive support from staff, volunteers or other families that are sharing similar experiences.

- Telephone: 1300 307 642
- Website: <<https://www.rmhc.org.au>>

Youth Cancer Service

Youth Cancer Services are hospital-based multidisciplinary teams providing care and support for 15–25-year-olds with cancer. In addition to providing high-quality, age-appropriate cancer care, Youth Cancer Services provide leadership and support to other health professionals and services. There are five Youth Cancer Service lead sites across Australia linked to a network of more than 25 hospitals to enable every young person with cancer to access age-appropriate psychosocial and medical care.

Youth Cancer Services provide information for patients and healthcare providers on finding a Youth Cancer Service, the services offered, and many aspects of cancer treatment and life after cancer.

- Website <www.canteen.org.au/youth-cancer>

For health providers

Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre provides expertise in survivorship care, information, support and education. Its purpose is to support and enable optimal survivorship care.

- Telephone: (03) 8559 6220
- Website <www.petermac.org/cancersurvivorship>

Australian Commission on Safety and Quality in Health Care

The Australian Commission on Safety and Quality in Health Care has developed a guide for clinicians containing evidence-based strategies to support clinicians to understand and fulfil their responsibilities to cancer patients. This guide is particularly relevant to Steps 3 to 6 of the optimal care pathway. The guide is titled NSQHS Standards user guide for medication management in cancer care for clinicians <<https://www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-medication-management-cancer-care-clinicians>>.

Cancer Australia

Information for health providers including guidelines, cancer learnings, cancer guides, reports, resources, videos, posters and pamphlets.

- Website <www.canceraustralia.gov.au>

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority.

- Website <www.cancer.org.au>

CanEAT pathway

A guide to optimal cancer nutrition for people with cancer, carers and health professionals.

- Education website <<https://education.eviq.org.au/courses/supportive-care/malnutrition-in-cancer>>
- Patient website <<https://patients.cancer.nsw.gov.au/coping-with-cancer/physical-wellbeing/eating-well>>.

eviQ

A clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment.

- Website <www.eviq.org.au>

National Aboriginal Community Controlled Health Organisation

The National Aboriginal Community Controlled Health Organisation (NACCHO) is the national leadership body for Aboriginal and Torres Strait Islander health in Australia. NACCHO provides advice and guidance to the Australian Government on policy and budget matters and advocates for community-developed solutions that contribute to the quality of life and improved health outcomes for Aboriginal and Torres Strait Islander people.

- Website <www.naccho.org.au/about>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment.

- Website <www.nhmrc.gov.au>

National consensus statement: essential elements for safe and high-quality paediatric end-of-life care

Produced by the Australian Commission on Safety and Quality in Health Care, the consensus statement <www.safetyandquality.gov.au/sites/default/files/migrated/Consensus-statement-essential-elements-for-safe-and-high-quality-paediatric-end-of-life-care-Dec-2016.pdf> describes the elements that are essential for delivering safe and high-quality end-of-life care to children in acute care settings in Australia.

Optimal care pathway for adolescents and young adults with cancer

At the time of publication, a population based optimal care pathway for adolescents and young adults with cancer was under development. This resource provides a tool to help guide system safety and responsiveness to the unique needs of adolescents and young adults diagnosed with cancer and improve outcomes and experience. It can be used in conjunction with the optimal care pathway for each cancer type.

- Website <www.cancer.org.au/OCP>

Quality of Care Collaborative Australia

The QuoCCA project delivers paediatric palliative care education to health professionals in urban, rural, regional and remote areas who may care for children and young people with palliative and end-of-life care needs.

- Website <www.quocca.com.au>

Thinking ahead framework

The *Thinking ahead framework* helps plan ahead for interventions that reflect the preferences of the child and their family and the recommendations of the treating team in the event of an acute deterioration.

- Telephone: (03) 9345 5522
- Website <<https://www.rch.org.au/thinkingahead/framework>>

Youth Cancer Service

Youth Cancer Services are hospital-based multidisciplinary teams providing care and support for 15–25-year-olds with cancer. There are five Youth Cancer Service lead sites across Australia linked to a network of more than 25 hospitals.

Youth Cancer Services teams conduct outreach and secondary consultations with their colleagues across the health system to support best practice care of young cancer patients, regardless of treatment setting. Each state/territory adapts this coordinated, multidisciplinary model of care to align with local needs, network structures, local frameworks and broader adult and paediatric service models. Integration with primary and community-based care is critical both in facilitating referrals into Youth Cancer Service teams and ensuring continuity of care post-treatment.

The overall program is coordinated at the national level by Canteen. This facilitates a consistent national approach to youth cancer care and drives critical national initiatives, including professional development, national data collection and research, improved access to clinical trials and the development and implementation of national guidelines. Importantly, young people with cancer and their families are engaged and consulted at all stages of development, implementation and delivery of the Youth Cancer Services program to ensure optimal outcomes for young Australian cancer patients (Canteen Australia 2017, p. 8).

- Website <www.canteen.org.au/youth-cancer>

Glossary

advance care directive – voluntary person-led document that focus on an individual's values and preferences for future health and medical treatment decisions, preferred outcomes and care. They are completed and signed by a competent person. They are recognised by specific legislation (statutory) or common law (non-statutory). Advance care directives can also appoint the substitute decision-maker(s) who can make decisions about health or personal care on the individual's behalf if they are no longer able to make decisions themselves. Advance care directives focus on the future health care of a person, not on the management of his or her assets. They come into effect when an individual loses decision-making capacity.

advance care planning – the process of planning for future health and personal care, where the adolescent or young adults' values, beliefs and preferences are made known so they can guide decision making at a future time when they cannot make or communicate their decisions. For children, the values, beliefs and preferences of families or carers should guide decision making.

alternative therapies – treatments used in place of conventional medical treatment.

care coordinator – the health provider nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and the location and care in which care is being delivered.

complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life and help people deal with the side effects of cancer.

end-of-life care – includes physical, spiritual and psychosocial assessment, and care and treatment, delivered by health professionals and ancillary staff. It also includes support of families and carers and care of the patient's body after their death.

genomics – the study of multiple genes and their relationships with one another.

immunotherapy – a type of cancer treatment that helps the body's immune system to fight cancer. Immunotherapy can boost the immune system to work better against cancer or remove barriers to the immune system attacking the cancer.

indicator – a documentable or measurable piece of information regarding a recommendation in the optimal care pathway.

informed financial consent – the provision of cost information to patients, including notification of likely out-of-pocket expenses (gaps), by all relevant service providers, preferably in writing, before admission to hospital or treatment (Australian Government Department of Health 2017).

lead clinician – the clinician who is nominated as being responsible for individual patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

minimal residual disease (MRD) – a small number of cancer cells left in the body after treatment.

multidisciplinary care – an integrated team approach to health care in which medical and allied health providers consider all relevant treatment options and collaboratively develop an individual treatment plan for each patient.

multidisciplinary team – comprises the core disciplines that are integral to providing good care. The team is flexible in approach, reflects the patient's clinical and psychosocial needs and has processes to facilitate good communication.

multidisciplinary team meeting – a meeting of health professionals from one or more clinical disciplines who together make decisions about recommended treatment of patients.

optimal care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care for all people affected by cancer.

performance status – an objective measure of how well a patient can carry out activities of daily life.

primary care health professional – in most cases this is a general practitioner but may also include general practice nurses, community nurses, nurse practitioners, allied health professionals, midwives, pharmacists, dentists and Aboriginal health workers.

prognostic assessment – evaluation of clinical features (e.g. pathological, biochemical, molecular, genetic, simple clinical measurements) to predict a patient's likelihood of responding to treatment, developing disease or experiencing a medical event.

relative survival rate – the probability of being alive for a given amount of time after diagnosis compared with the general population.

risk stratification – a systematic process to target and identify select patients who are at risk of poorer health outcomes, and who are expected to benefit most from a particular intervention or interventions.

relative survival – the probability of being alive for a given amount of time after diagnosis compared with the general population.

spiritual care – the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.

substitute decision-maker – a person permitted under the law to make decisions on behalf of someone who does not have competence or capacity.

supportive care – care and support that aims to improve the quality of life of people living with cancer, cancer survivors and their family and carers and particular forms of care that supplement clinical treatment modalities.

survivorship – an individual is considered a cancer survivor from the time of diagnosis, and throughout their life; the term includes individuals receiving initial or maintenance treatment, in recovery or in the post-treatment phase.

survivorship care plan – a formal, written document that provides details of a person's cancer diagnosis and treatment, potential late and long-term effects arising from the cancer and its treatment, recommended follow-up, surveillance, and strategies to remain well.

targeted therapy – a medicine that blocks the growth and spread of cancer by interfering with specific molecules.

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