

Optimal cancer care pathway for people with acute myeloid leukaemia



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Cancer Australia



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Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple healthcare providers and covers a range of institutions, both public and private. The optimal care pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

The optimal care pathways are based on a revision of the original patient management frameworks (Department of Health 2007a) which had, for the first time, attempted to map the cancer pathway in an easily understandable form.

The purpose of this work is to improve patient outcomes by facilitating consistent cancer care based on a standardised pathway of care. The pathways are applicable to care whether it is provided in a public or private service. The principles and the expected standards of good cancer care are not expected to differ, even though treatment regimens may vary from patient to patient for a whole variety of reasons.

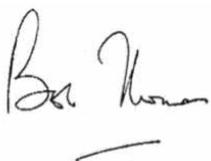
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments (COAG) in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care.

The NCERG has subsequently endorsed these new optimal care pathways, which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

A wide range of clinicians, peak health organisations, consumers and carers were consulted and/or participated in their development and I want to thank all concerned for their generous contributions.

I am sure that those providing cancer care will find the specific pathways useful in deciding how best to organise service delivery to achieve the best outcomes for those we care for.

Importantly, readers should note that these care pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.



Professor Robert Thomas OAM
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Summary

Please note that not all patients will follow every step of this pathway. The pathway covers acute myeloid leukaemia (AML) in adults including acute promyelocytic leukaemia (APML).

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

Step 1

Prevention and early detection

Risk factors: Most people have no identifiable risk factors. It is rare for AML to run in families. Known risk factors include:

- prior chemotherapy or radiation therapy

- known previous haematological disorder with a risk of leukaemic transformation
- known predisposing genetic disorders with a risk of leukaemic presentation
- tobacco smoking

- obesity
- environmental exposure to industrial chemicals such as benzene.

Early detection: There are no formal screening programs for AML.

Step 2

Presentation, initial investigations and referral

Signs and symptoms: Symptoms at presentation are usually non-specific and may include fatigue, anaemia, severe sepsis, unresolving infection/fever, abnormal bleeding/bruising, persistent sore gums, unexplained bone pain and unintentional weight loss. The following signs and symptoms require consultation as a medical emergency:

- patients with signs of severe sepsis
- patients with severe anaemia
- patients with major laboratory abnormalities
- patients with a very high white cell count displaying signs of hyperviscosity
- patients with uncontrolled bleeding or severe coagulation abnormalities.

General/primary practitioner investigations:

Full blood count and film should be done immediately.

Referral: A new diagnosis of AML (confirmed or suspected) requires immediate discussion with a clinical haematologist or haematology registrar. The patient should be referred to a clinical haematology unit with adequate experience in managing acute leukaemia and with links to a multidisciplinary team.

Patients with clinical features of severe sepsis or severe bleeding should be referred to an appropriate facility without necessarily waiting for results of laboratory tests.

Communication – lead clinician to¹:

- explain to the patient/carer who they are being referred to and why
- support the patient and carer while waiting for specialist appointments.

Step 3

Diagnosis, staging and treatment planning

Diagnosis: Confirmed through bone marrow aspirate (BMA) and trephine biopsy.

Classification and prognosis (staging): Every patient being considered for AML therapy should have samples taken for cytogenetics, flow cytometry and molecular diagnostics.

Input from an experienced infectious diseases clinician is beneficial to evaluate patients for the presence of occult infections.

Key results should be available within 72 hours of presentation.

In high-risk disease, early allogeneic stem cell transplant (allo-SCT) must be considered, and therefore, a donor search should be carried out as early as possible.

Treatment planning: Because of the urgency of treatment, every clinical haematology unit should have predefined peer-reviewed treatment models of care that have been endorsed by

the multidisciplinary team. Assessment of the premorbid state is essential.

Immediate treatment is often required before a full multidisciplinary meeting ratifies details of the ongoing management plan (which should include full details of the response assessment).

Research and clinical trials: Participation in clinical trials, registries and tissue banking is considered a standard of care for patients with AML.

Communication – lead clinician to:

- review fertility issues with the patient, where appropriate
- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

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 4

Treatment:

Establish intent of treatment:

- intensive
- non-intensive
- symptom palliation including active supportive care.

Treatment options to induce remission

Patients fit for intensive chemotherapy: Induction chemotherapy should only be started when all material needed for diagnostic testing has been satisfactorily sampled (except where emergency therapy may be required). Consolidation therapy is always indicated in therapy that is planned with curative intent once patients have reached complete remission.

Patients not fit for intensive chemotherapy: Low-dose chemotherapy or palliative/supportive care without chemotherapy to control symptoms.

Allo-SCT: Should be considered for selected patients (refer to the AML optimal care pathway).

Radiation therapy: May be used for symptom control and occasionally for treatment of the disease. Total body irradiation may be indicated as part of conditioning for allo-SCT.

Acute promyelotic leukaemia

Rapid initiation of APL-specific therapy is essential. Treating units must have protocols for intensive supportive care. Molecular monitoring after treatment to guide further therapy is required.

Refractory disease

- Carefully selected patients may be offered allo-SCT.
- Palliative systemic treatment is often a reasonable option.
- Clinical trials and experimental therapy should be considered.

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

Communication – lead clinician to:

- discuss treatment options with the patient/carer including the intent of treatment as well as risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

More information at the European LeukaemiaNET webpage at <<http://www.ncbi.nlm.nih.gov/pubmed/19880497>>.

Step 5

Care after initial treatment and recovery

Cancer survivors should be provided with the following to guide care after initial treatment.

Treatment summary (provide a copy to the patient/carer and general practitioner) outlining:

- diagnostic tests performed and results
- disease characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

Follow-up care plan (provide a copy to the patient/carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the patient/carer
- inform the patient/carer about secondary prevention and healthy living
- discuss the follow-up care plan with the patient's general practitioner.

Step 6

Managing residual or recurrent disease

Detection: Relapse occurs in more than 50 per cent of patients. Most cases are identified through routine follow-up or by the patient presenting with symptoms.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the extent of disease, previous management and patient preferences.

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

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Ensure that an advance care plan is in place.

Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the patient/carer
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Summary – optimal timeframes

Optimal timeframes: Timeframes should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress. The following recommended timeframes are based on expert advice from the AML Working Group.

Step in pathway	Care point	Timeframe
Presentation, Initial Investigations and Referral	2.1 GP investigations	<p>Results should be actively followed-up and progressed on in the same day.</p> <p>Patients with a laboratory diagnosis of possible AML should be referred for urgent assessment by a haematologist at an appropriate facility (within 24 hours unless advised otherwise by a haematologist).</p> <p>Patients with clinical features of severe sepsis or severe bleeding should be referred immediately to an appropriate facility without necessarily waiting for results of laboratory tests (same day).</p>
	2.3 Referral	<p>Patients with severe symptoms or major laboratory abnormalities should be regarded as a medical emergency and be referred to an appropriate facility immediately (same day).</p> <p>Patients with suspected AML who present to emergency departments should be triaged as a medical emergency and discussed with a clinical haematology service (same day).</p>
Diagnosis, Staging and Treatment Planning	3.1 Diagnosis and classification	Key results available within 72 hours of presentation.
	3.3 Multidisciplinary meeting	Immediate treatment is often required before a full multidisciplinary meeting ratifies details of the management plan.
Treatment	4.2 Induction chemotherapy	Occur immediately, once diagnosis is made and a treatment plan for intensive chemotherapy is confirmed.
	4.2 Consolidation chemotherapy	Within six weeks of induction chemotherapy commencing.
	4.2 Stem cell transplant	Donor searches should commence for all anticipated CR1 allo-SCT patients as soon as their risk status is known. Rapid access pathways are required for patients for whom urgent transplantation may be appropriate.

Intent of the optimal care pathway

The optimal care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased care for people with cancer.

The pathway aligns with key service improvement priorities, including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The optimal care pathway can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality improvement initiatives across all aspects of the care pathway. The pathway can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

The following key principles of care underpin the optimal care pathway.

Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Patient or consumer-centred care is increasingly being recognised as a dimension of high-quality healthcare in its own right, and there is strong evidence that a patient-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness as well as patient, family and staff satisfaction (ACSQHC 2013).

Safe and quality care

This is provided by appropriately trained and credentialed clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care. It incorporates collecting and evaluating treatment and outcome data to improve the patient experience of care as well as mechanisms for ongoing service evaluation and development to ensure practice remains current and informed by evidence.

Services should routinely be collecting relevant minimum datasets to support benchmarking, quality care and service improvement.

Multidisciplinary care

This is an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient. There is increasing evidence that multidisciplinary care improves patient outcomes.

The benefits of adopting a multidisciplinary approach include:

- improving patient care through developing an agreed treatment plan
- providing best practice through adopting evidence-based guidelines
- improving patient satisfaction with treatment
- improving the mental wellbeing of patients
- improving access to possible clinical trials of new therapies
- increasing the timeliness of appropriate consultations and surgery and a shorter timeframe from diagnosis to treatment
- increasing the access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007b).

Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes. Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

All members of the multidisciplinary team have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool) of the patient and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key points along the care pathway, particularly at times of increased vulnerability including:

- initial presentation or diagnosis (first three months)
- commencement of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care
- survivorship.

Following each assessment, potential interventions need to be discussed with the patient and carer, with a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

Common indicators in patients with AML that may require referral for support include:

- malnutrition (as identified using a validated malnutrition screening tool or presenting with weight loss)
- immunosuppression
- pain
- difficulty managing fatigue
- difficulty sleeping
- distress, depression or fear
- poor performance status
- financial and employment issues
- living alone or being socially isolated
- having caring responsibilities for others
- cumulative stressful life events
- existing mental health issues
- Aboriginal or Torres Strait Islander status
- being from a culturally and linguistically diverse background.

Depending on the needs of the patient, referral to an appropriate health professional(s) and/or organisations should be considered including a(n):

- psychologist or psychiatrist
- community-based support service
- dietitian
- exercise physiologist
- occupational therapist
- physiotherapist
- peer support group (contact the Cancer Council on 13 11 20 for more information)
- social worker
- nurse practitioner and/or specialist nurse
- specialist palliative care service
- speech therapist.

See the **appendix** for more information on supportive care and the specific needs of people with AML.

Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure that care is delivered in a logical, connected and timely manner so the medical and personal needs of the patient are met.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including multidisciplinary meetings, supportive care screening and assessment, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of individual patients and should therefore be considered in their practice. Enhancing continuity of care across the health sector requires a wholeof-system response; that is, initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007c).

Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families and carers are met. Every person with cancer will have different communication needs, including cultural and language differences. Communication with patients should be:

- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families.

In communicating with patients, healthcare providers should:

- listen to patients and act on the information provided by them
- encourage expression of individual concerns, needs and emotional states
- tailor information to meet the needs of the patient, their carer and family
- use professionally trained interpreters when communicating with people from culturally and linguistically diverse backgrounds
- ensure the patient and/or their carer and family have the opportunity to ask questions
- ensure the patient is not the conduit of information between areas of care (it is the providers' and healthcare system's responsibility to transfer information between areas of care)
- take responsibility for communication with the patient
- respond to questions in a way the patient understands
- enable all communication to be two-way.

Healthcare providers should also consider offering the patient a Question Prompt List (QPL) in advance of their consultation, as well as recordings or written summaries of their consultations. QPL interventions are effective in improving communication and the psychological and cognitive outcomes of cancer patients (Brandes et al. 2014). Providing recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway. Research and clinical trials play an important role in establishing efficacy and safety for a range of interventions in treatment of cancer, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcberg 2013).

While individual patients may or may not receive a personal benefit from the intervention, there is evidence that outcomes for participants in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation in research and clinical trials will contribute to care of cancer patients in the future (Peppercorn et al. 2004).

Optimal cancer care pathway

The optimal care pathway outlines seven critical steps in the patient journey. 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 (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management, patient decisions and physiological response to treatment).

The pathway describes the optimal cancer care that should be provided at each step.

The pathway covers acute myeloid leukaemia (AML) in adults including acute promyelocytic leukaemia (APL). AML is the most common form of acute leukaemia in adults (NCCN 2013). The yearly incidence rate of AML in Australian adults is 3.8 cases per 100,000, with a five-year survival rate of 24.5 per cent (AIHW 2014).

Step 1: Prevention and early detection

Eating a healthy diet, avoiding or limiting alcohol intake, taking regular exercise and maintaining a healthy body weight may help reduce cancer risk. This step outlines recommendations for the prevention and early detection of AML.

1.1 Prevention

The causes of AML are not fully understood.

1.2 Risk factors

Most people have no identifiable risk factors. It is rare for AML to run in families. In a small proportion of patients, risk factors can be identified; currently known risk factors include:

- prior chemotherapy or radiation therapy
- a known previous haematological disorder with a risk of leukaemic transformation (such as myelodysplastic syndromes, myeloproliferative diseases, congenital neutropenic syndrome)
- known predisposing genetic disorders (such as Down syndrome or Fanconi anaemia) with a risk of leukaemic presentation
- tobacco smoking
- obesity
- environmental exposure to industrial chemicals such as benzene.

1.3 Early detection

1.3.1 Screening

In the absence of any evidence as to its effectiveness in reducing mortality, there are no formal screening programs for AML.

Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral for AML.

2.1 Signs and symptoms

Symptoms at presentation are usually non-specific. They may include:

- fatigue, pallor or other symptoms of anaemia
- severe sepsis
- unresolving or unusual infection or fevers
- abnormal bleeding/bruising
- persistent sore gums or mouth ulcerations
- unexplained bone pain
- unintentional weight loss.

The following signs and symptoms require consultation as a medical emergency:

- patients with signs of severe sepsis
- patients with severe anaemia
- patients with major laboratory abnormalities
- patients with a very high white cell count displaying signs of hyperviscosity (such as visual disturbance, confusion, severe headache or breathlessness)
- patients with uncontrolled bleeding or severe coagulation abnormalities.

People with AML may have only mild symptoms. Occasionally, a patient with few or no symptoms is diagnosed unexpectedly on a blood test conducted in primary care.

2.2 Assessments by a general or primary medical practitioner

If a serious blood disorder is suspected a focused medical history and thorough clinical assessment should be undertaken.

Full blood count and film should be done immediately. Pathology laboratories should directly contact the referring doctor if leukaemia is suspected (such as unexplained pancytopenia or blasts detected in the blood). Results should be actively followed up and acted upon on the same day.

Patients with a laboratory diagnosis of possible acute leukaemia should be referred for immediate assessment by a haematologist at an appropriate facility.

Patients with clinical features of severe sepsis or severe bleeding should be referred to an appropriate facility without necessarily waiting for results of laboratory tests.

Timeframe for completing investigations

Timeframes for completing investigations should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The above recommended timeframes are based on the expert opinion of the AML Working Group.¹

¹ The multidisciplinary experts group who participated in a clinical workshop to develop content for the AML optimal care pathway are listed in the acknowledgements list.

2.3 Referral

A new diagnosis of AML (confirmed or suspected) requires immediate discussion with a clinical haematologist or haematology registrar. The patient should be referred to a clinical haematology unit with adequate experience in managing acute leukaemia and with links to a multidisciplinary team (MDT) in order to facilitate rapid assessment and management. All patients with suspected AML should be evaluated and cared for within an acute leukaemia-experienced MDT environment. Readily accessible contact referral details for leukaemia treatment centres should be available.

Haematologists must expedite assessment of referred patients. Healthcare providers should facilitate patients' rapid access to acute leukaemia treatment services.

Referral for suspected AML should also incorporate appropriate documentation sent with the patient including:

- a letter that includes the patient's contact details, important psychosocial history and relevant past medical history (including details of prior cancer therapy), family history, current medications and allergies
- results of current clinical investigations
- results of all prior relevant investigations
- any prior imaging, ideally in electronic format where online access is not available (lack of a hard copy should not delay referral)
- notification if an interpreter service is required.

Timeframe for referral to a specialist

Timeframes for referral should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the AML Working Group:

- Patients with severe symptoms or major laboratory abnormalities should be regarded as a medical emergency and be referred immediately. A deferred assessment should only be done after a discussion between the referring doctor and the responsible haematologist.
- Patients with suspected AML who present to emergency departments should be triaged as a medical emergency and discussed with a clinical haematology service.

2.4 Support and communication

2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified needs of an individual, their carer and family; referral should be as required.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- identification of weight loss and consideration of the need for a nutritional assessment
- treatment for physical symptoms
- the emotional distress of dealing with a potential cancer diagnosis including anxiety and depression, interpersonal problems, stress and adjustment difficulties
- financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients as well as caring arrangements for other family members)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds and other populations with special needs (identified in the appendix).

2.4.2 Communication with the patient, carer and family

Effective communication is essential at every step of the care pathway. Effective communication with the patient and carer is particularly important given the prevalence of low health literacy in Australia (estimated 60 per cent of Australian adults) (ACSQHC 2013).

The general or primary practitioner should:

- provide the patient with information about the reason for tests and the possible implications
- provide the patient with information that clearly describes who they are being referred to, the reason for the referral and the expected timeframe for appointments
- support the patient while waiting for the specialist appointment.

Step 3: Diagnosis and treatment planning

Step 3 outlines the process for confirming the diagnosis, as well as planning subsequent treatment for AML. The guiding principle is that interaction between appropriate MDT members should determine the overall treatment plan.

3.1 Diagnostic investigations

A diagnosis of AML is confirmed through bone marrow aspirate (BMA) and trephine biopsy.

Pathology specimens should be collected and reviewed by a pathologist with expertise in diagnosing AML, preferably at the treatment centre before a treatment plan is instituted.

Key additional tests include cytogenetics, flow cytometry and molecular pathology.

3.2 Classification and prognosis (staging)

The classification of AML is based on clinical, morphological, flow cytometric, cytogenetic and molecular features. Therefore, every patient being considered for AML therapy should have samples taken for cytogenetics, flow cytometry and molecular diagnostics prior to the initiation of therapy. Classification should be based on the World Health Organization (WHO) classification of AML tumours (WHO 2009).

Stratification by clinical and laboratory features allows separation into groups with different clinical outcomes. The most important prognostic features are age and performance status, karyotype, selected molecular abnormalities (currently FLT3-ITD, NPM1 and CEBPA mutation status) and response to induction chemotherapy. Newer molecular markers with prognostic relevance in AML are likely to become clinically routine in the near future (Grimwade et al. 2016).

Other adverse prognostic factors include central nervous system involvement with leukaemia, systemic infection at diagnosis, hyperleukocytosis, treatment-induced AML and history of myelodysplastic syndromes or another antecedent hematological disorder (Döhner et al. 2010, 2015).

3.2.1 Other pre-treatment investigations

It is important in all patients to evaluate and document relevant organ functions (respiratory, cardiac, hepatic, renal). Overall functional status (ECOG performance status) and physiological robustness should be evaluated and documented. Wherever possible, validated assessment tools should be used. These issues are especially important in the context of older patients (Klepin et al. 2013).

Given the immunosuppressive effects of treatments used for these diseases, input from an experienced infectious diseases clinician is beneficial to evaluate patients for the presence of occult infections that may be affected by therapy. Before the commencement of therapy, infectious disease markers for tuberculosis, HBV, HCV, HIV and CMV should be taken.

Careful clinical and haematological assessment is required to identify patients in whom the start of chemotherapy could or should be delayed until active infection has been treated. In addition to clinical examination, the following additional investigations are recommended:

- A coagulation status should be obtained to detect leukaemia-related coagulopathy (Döhner et al. 2010).
- Patients potentially suitable for allogeneic stem cell transplantation (allo-SCT) and those at risk for having allo-immunisation should have human leukocyte antigen (HLA) typing and HLA antibody screening at diagnosis.
- Each unit should have a policy about if, and when, HLA-typing of available first- and second-degree family members should occur. This policy should be agreed with the allo-SCT unit to which referrals are usually directed.
- In high-risk disease, early allo-SCT must be considered, and therefore, a donor search should be carried out as early as possible (Döhner et al. 2010) in accord with agreed policies of the allo-SCT unit to which referrals are usually directed.

Timeframe for completing investigations

Timeframes for completing investigations should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the AML Working Group: Key results available within 72 hours of presentation.

3.3 Treatment planning

Because of the urgency of treatment, every clinical haematology unit should have predefined peer-reviewed treatment models of care that have been endorsed by the multidisciplinary team. Assessment of the premorbid state is an essential component of the treatment planning process.

Immediate treatment is often required before a full multidisciplinary meeting ratifies details of the ongoing management plan (which should include full details of the response assessment). The majority of patients will receive their initial treatment as inpatients, allowing their initial multidisciplinary treatment planning to be established on the ward. For patients undergoing induction chemotherapy, presentation to and consideration within an MDT is most important once the outcome of the induction therapy is known. At this point, a review of the patient is required to inform further management and supportive care needs. For patients not eligible for induction chemotherapy, or where uncertainty of the approach exists, a review at an MDT should occur as soon as practicable to establish the recommended treatment plan and all aspects of supportive care.

3.3.1 Responsibilities of the multidisciplinary team

These are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided)
- nominate a team member to coordinate patient care
- develop and document an agreed treatment plan at the multidisciplinary meeting
- circulate the agreed treatment plan to relevant team members, including the patient's general practitioner.

3.3.2 Responsibilities of individual team members

The general or primary medical practitioner who made the referral is responsible for the patient until care is passed to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment and coordination and continuity of care, as well as providing information and support to the patient and their family.

The care coordinator is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The care coordinator may change over the course of the pathway.

The lead clinician is responsible for overseeing the activity of the team.

3.3.3 Members of the multidisciplinary team for AML

The MDT should comprise the core disciplines integral to providing good care. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care. Full consideration of the implications of the entire treatment program need to be considered. Additional expertise or specialist services may be required for some patients (Department of Health 2007c).

Team members may include (in alphabetical order):

- care coordinator (as determined by MDT members)*
- clinical haematologist *
- infectious diseases physician*
- nurse (with appropriate expertise)*
- pathologist*
- pharmacist*
- radiologist/imaging specialists
- clinical trials coordinator
- dentist
- dietitian
- general practitioner
- geriatrician
- nuclear medicine physician
- occupational therapist
- palliative care specialist
- physiotherapist
- psychiatrist
- psychologist
- radiation oncologist
- social worker.

* Core members of the MDT are expected to attend most multidisciplinary meetings either in person or remotely.

3.3.4 The optimal timing for multidisciplinary team planning

The multidisciplinary treatment plan should commence as soon as possible after the diagnosis is confirmed. Such planning must be reviewed and documented at a team meeting. Typically people having treatment for AML will have serial reviews.

Immediate treatment is often required before a full meeting ratifies details of the management plan.

There may also need to be a review of existing treatment plans for patients who have been discussed previously.

Results of all relevant tests and imaging should be available for the MDT discussion. The care coordinator or treating clinician should also present information about the patient's concerns, preferences and social circumstances (Department of Health 2007c).

3.4 Research and clinical trials

Participation in clinical trials, where available, is considered a standard of care for patients with AML. Cross-referral between clinical trials centres should be encouraged to facilitate participation. Participation in registries and tissue banking is also considered a standard of care for patients with AML.

- 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. For more information visit <www.australiancancertrials.gov.au>.

3.5 Prehabilitation, support and communication

3.5.1 Prehabilitation

Cancer prehabilitation uses a multidisciplinary approach combining exercise, nutrition and psychological strategies to prepare patients for the challenges of cancer treatment such as chemotherapy, immunotherapy and radiation therapy.

Evidence indicates that prehabilitation of newly diagnosed cancer patients prior to starting treatment can be beneficial. This may include conducting a physical and psychological assessment to establish a baseline function level, identifying impairments and providing targeted interventions to improve the patient's health, thereby reducing the incidence and severity of current and future impairments related to cancer and its treatment (Silver & Baima 2013).

Medications should be reviewed at this point to ensure optimisation and to improve adherence to medicines used for comorbid conditions.

Where appropriate, fertility issues should be reviewed with the patient.

3.5.2 Supportive care

Screening with a validated screening tool (for example, the National Comprehensive Cancer Network's distress thermometer and problem checklist), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific needs that may arise at this time include:

- identification of weight loss and consideration of the need for a nutritional assessment
- access to peer support (such as through Cancer Connect)
- treatment for physical symptoms
- support for the emotional distress of dealing with a potential cancer diagnosis including anxiety and depression, interpersonal problems, stress and adjustment difficulties
- support for the carer – referrals to psychosocial support from a social worker, psychologist or general practitioner should be encouraged
- help with financial and employment issues (such as loss of income, travel and accommodation requirements for rural patients, caring arrangements for other family members)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds and other populations with special needs (identified in the appendix).

3.5.3 Communication with the patient, carer and family

The lead clinician should:

- establish if the patient has a regular or preferred general practitioner
- discuss a timeframe for diagnosis and treatment with the patient and carer
- offer all patients of childbearing years undergoing allo-SCT the opportunity of preserving their fertility (where possible) prior to treatment – referral to fertility counselling may be appropriate
- discuss the benefits of multidisciplinary care and make the patient aware that their health information will be available to the team for discussion at the multidisciplinary meeting
- offer individualised AML cancer information that meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information from websites, community sources and national cancer services
- offer advice to patients and carers on the benefits of and how to access support from peer support groups, groups for carers and special interest groups
- clarify the patient's wishes/needs and factor these into recommendations from the MDT
- if the patient is a smoker, provide information about smoking cessation
- utilise a professionally trained interpreter when communicating with people from culturally or linguistically diverse backgrounds (NICE 2004).

3.5.4 Communication with the general practitioner and referring practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the patient's general practitioner regarding the treatment plan and recommendations from multidisciplinary meetings and notify the general practitioner if the patient does not attend appointments
- gather information from the general practitioner, including their perspective on the patient (psychological issues, social issues and comorbidities) and locally available support services
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss management of shared care
- invite the general practitioner to participate in multidisciplinary meetings (consider using video- or teleconferencing).

Step 4: Treatment

Step 4 outlines a framework for delivering treatment for AML. For detailed information on treatment options refer to:

- European LeukaemiaNET (ELN), Diagnosis and management of acute myeloid leukemia in adults: recommendations from an international expert panel, on behalf of the European LeukemiaNet. Available at <<http://www.ncbi.nlm.nih.gov/pubmed/19880497>>.

4.1 Treatment intent

The intent of treatment can be defined as one of the following:

- intensive
- non-intensive
- symptom palliation including active supportive care.

The potential benefits need to be balanced against the morbidity and risks of treatment. The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the patient.

The lead clinician must discuss the treatment intent and prognosis with the patient and carer prior to beginning treatment and obtain consent to proceed.

If appropriate, advance care planning should be considered with patients at this stage, based on the patient's circumstances and wishes, as there can be multiple benefits such as ensuring a person's preferences are known and respected after the loss of decision-making capacity (AHMAC 2011).

4.2 Treatment options

4.2.1 Treatment with intention to induce remission

4.2.1.1 Patients fit for intensive chemotherapy

Systemic chemotherapy for AML is a key component of treatment and is divided into two phases: induction therapy to achieve complete remission and consolidation therapy once a remission has been achieved. Induction chemotherapy should only be started (if possible) when all material needed for diagnostic testing has been satisfactorily sampled (Döhner et al. 2010). An exception to this rule is a patient with suspected APL or severe hyperleucocytosis. In these circumstances, emergency therapy may be required prior to completion of diagnostic sampling.

It is important to assess the response to initial treatment including complications (such as the severity of side effects and sepsis) as well as disease state because patients who fail to achieve remission have a poor prognosis (Milligan et al. 2006).

Consolidation therapy is always indicated in therapy that is planned with curative intent once patients have reached complete remission (defined by the ELN) (Döhner et al. 2010). Following induction therapy it is important that additional treatment is given, as the median disease-free survival for patients who receive no additional therapy is only four to eight months (Cassileth et al. 1998). The aim of consolidation therapy is to prevent relapse with maximal efficiency and minimal toxicity. Current approaches to induction and consolidation therapy include short-term, relatively intensive chemotherapy, or high-dose chemotherapy (summarised in Döhner et al. 2015).

There is no consensus on a single 'best' post-remission treatment schedule, nor the optimal number of cycles of consolidation chemotherapy.

All patients undergoing intensive chemotherapy need a central intravenous line inserted (with platelet transfusion if necessary). Such devices should only be inserted by proceduralists experienced in such procedures.

4.2.1.2 Patients not fit for intensive chemotherapy

Treatment may also include low-dose chemotherapy for elderly patients or patients with significant comorbidities or palliative/supportive care without chemotherapy to control symptoms.

Timeframe for commencing chemotherapy

Timeframes for commencing chemotherapy should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the AML Working Group:

- Induction therapy: Immediately, once a diagnosis is made and a treatment plan for intensive chemotherapy is confirmed
- Consolidation therapy: A maximum of six weeks after induction chemotherapy commences.

4.2.1.3 Allogeneic stem cell transplant

Allo-SCT is potentially curative but carries a significant risk of toxicity and morbidity. Potential candidates for allo-SCT (scheduled for the consolidation phase) must be identified early at diagnosis or during induction chemotherapy (Döhner et al. 2015). A formal recommendation to proceed to allo-SCT should only occur after discussion at a focused bone marrow transplant MDT.

Allo-SCT should be considered for:

- all younger patients depending on prognostic factors, potential for long-term remission and patient preferences
- patients with high-risk AML in first remission who have an acceptable allogeneic donor(s), although it is accepted that only a minority of patients will benefit
- some patients whose disease fails to go into remission with intensive chemotherapy (Döhner et al. 2015)
- selected patients beyond CR1.

Part of this assessment should include a haematopoietic cell transplantation (HCT)-comorbidity assessment.

Where appropriate, fertility issues should be reviewed with the patient.

For patients with good-prognosis AML in first complete remission (APL, core binding factor AML, CEBPA with double mutation), the risks of allo-SCT are considered to exceed the benefits and a survival advantage has not been proven.

Autografting may be appropriate for patients with relapsed core-binding factor (CBF) AML in second remission. The role of autografting in managing other forms of AML is contentious. Autografting in these circumstances should be carried out in a clinical trial (Milligan et al. 2006).

Timeframes for planning allo-SCT

Timeframes for planning allo-SCT should be informed by evidence-based guidelines where they exist while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the AML Working Group:

- Donor searches should commence for all anticipated CR1 allo-SCT patients as soon as their risk status is known.
- Individual treating units should ensure referral pathways for transplantation are established that minimise delays. Rapid access pathways are required for patients for whom urgent transplantation may be appropriate.

4.2.1.4 Radiation therapy

Radiation therapy may be used for symptom control in palliation and occasionally for treatment of the disease.

Total body irradiation (TBI) may be indicated as part of conditioning for allo-SCT and should only be given in centres with appropriately qualified and experienced staff and equipment.

Training, experience and treatment centre characteristics

The following training and experience is required of the appropriate specialist(s):

- Haematologists (or medical oncologists) (FRACP or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).
- Nurses must have adequate training in chemotherapy administration and handling and disposal of cytotoxic waste.
- Interventional radiology and/or certified proceduralists must be competent in inserting central venous access devices.
- Chemotherapy should be prepared by a pharmacist with adequate training in chemotherapy medication, including dosing calculations according to protocols, formulations and/or preparation.
- In a setting where no haematologist or medical oncologist is locally available, some components of less complex therapies may be delivered by a medical practitioner and/or nurse with training, experience and credentialling within this area under the guidance of a haematologist or medical oncologist. 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.
- Radiation oncologists (FRANZCR or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice in haematological malignancies (ACSQHC 2004).

Hospital or treatment unit characteristics for providing safe and quality care include:

- dedicated standard isolation rooms (single rooms with ensuite and clinical hand-washing facilities)
- access to a cell separator for collecting peripheral blood progenitor cells
- HEPA-filtered environment/rooms in the inpatient setting
- immediate blood product support
- a clearly defined path to emergency care and advice after hours
- access to total parenteral nutrition
- access to a dental service familiar with mouth care issues experienced by haematology patients
- accessible emergency apheresis for managing hyperleukocytosis
- access to basic haematology and biochemistry testing
- rapid access to an interventional radiologist/proceduralist
- an infectious disease specialist
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding the handling of cytotoxic drugs including safe prescribing, preparation, dispensing, supplying, administering, storing, manufacturing, compounding and monitoring the effects of medicines (ACSQHC 2011)
- guidelines and protocols for delivering treatment safely (including dealing with extravasation of drugs)
- timely access to pathology
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not collocated.

Radiation oncology centre characteristics for providing safe and quality care include:

- access to computed tomography (CT) scanning for simulation and planning
- staff to be familiar with AML-specific radiation therapy techniques
- TBI-based preparative regimens only being delivered in centres with experience using TBI conditioning and autologous/allogeneic transplantation (minimum 10–15 procedures per year).

Centres that do not have sufficient caseloads (for TBI and for overall management) should refer cases to a high-volume centre.

4.2.2 Treatment options – acute promyelotic leukaemia

Treatment of APL differs in several important aspects from therapy of all other AML types. The presentation of APL is a medical emergency due to the high risk of death as a result of the associated coagulopathy. Rapid initiation of APL-specific therapy is essential and in some cases may precede formal confirmation of the diagnosis. Treating units must have protocols for intensive supportive care including blood products (Iland et al. 2014, 2015; Lo-Coco et al. 2013).

Patients should undergo molecular monitoring after treatment to guide further therapy.

4.2.3 Treatment options – refractory disease

Resistance to therapy (refractory AML) is the major cause of treatment failure, rather than mortality due to infections and other treatment-related complications. Patients failing to respond to one or two cycles of induction treatment are considered refractory and are at very high risk of ultimate treatment failure.

Carefully selected patients with an HLA-matched donor may be offered allo-SCT, albeit with limited chances of success and at the cost of considerable morbidity from this procedure. For patients unsuited to this approach, palliative systemic treatment is often a reasonable option with limited toxic effects (Döhner et al. 2010).

Clinical trials and experimental therapy should be considered.

4.3 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 lead clinician should ensure patients receive a timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

This is particularly important for AML to ensure optimal symptom control in the context of highly toxic treatment regimens and disease recurrence.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

Further information

- Refer patients and carers to Palliative Care Australia via <www.palliativecare.org.au>.

4.4 Research and clinical trials

Participation in clinical trials, where available, is considered a standard of care for patients with AML. Cross-referral between clinical trials centres should be encouraged to facilitate participation. Participation in registries and tissue banking is also considered a standard of care for patients with AML.

- For more information visit <www.australiancancertrials.gov.au>.

4.5 Complementary or alternative therapies

The lead clinician should discuss the patient's use (or intended use) of complementary or alternative therapies not prescribed by the MDT to discuss safety and efficacy and 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.

Most alternative therapies and some complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective.

Some complementary therapies may assist in some cases and the treating team should be open to discussing the potential benefits for the individual.

If the patient expresses an interest in using complementary therapies, the lead clinician should consider referring them to health professionals within the MDT who have knowledge of complementary and alternative therapies (for example, a clinical pharmacist, dietitian or psychologist) to help them reach an informed decision.

The lead clinician should assure patients who use complementary or alternative therapies that they can still access multidisciplinary team reviews (NBCC & NCCI 2003) and encourage full disclosure about therapies being used (Cancer Australia 2010).

Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <<http://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>>.
- See the Clinical Oncology Society of Australia's position statement available at <www.cosa.org.au/publications/position-statements.aspx>.

4.6 Support and communication

4.6.1 Supportive care

Screening with a validated screening tool, assessment and referral to appropriate health professionals and/or organisations is required to meet the needs of individual patients, their families and carers.

Therapy is often associated with a constellation of symptoms and physiological abnormalities. Patients are highly susceptible to infection, and prolonged neutropenia can result in significant comorbidity and mortality. Strict adherence to universal guidelines, reverse isolation and infection control specialists, as well as close monitoring of full blood count, is essential. Patients need to be advised that careful attention to personal hygiene and dental care is critical in reducing/minimising infection, and antibiotic and anti-infective therapy is often administered both prophylactically and to treat suspected/confirmed infections.

In addition to the above and the common issues outlined in the **appendix**, specific issues that may arise include:

- side effects resulting from high-dose therapy including: alopecia, fatigue, damage to the bone marrow and other quickly growing tissues of the body, immunosuppression, fluid retention, dyspnea, graft-versus-host disease (GVHD) (following allo-SCT), organ toxicity (interstitial pneumonitis, veno-occlusive disease), episodic hypotension and pulmonary infiltrates
- chemically induced menopause (such as atrophic vaginitis and dyspareunia) and changes in androgens that may alter libido and orgasm – these require sensitive discussion
- differentiation syndrome – early recognition and prompt initiation of corticosteroids is required (NCCN 2015)
- gastrointestinal symptoms (such as nausea, vomiting, severe mucositis, loss of appetite, dysgeusia, diarrhoea or constipation) as a result of treatment require optimal symptom control (with medication, total parenteral nutrition, analgesia, mouth care) and referral to a dietitian if dietary intake is affected
- cognitive impairment, which patients treated with allo-SCT report to be a major component of quality-of-life impairment, even one year after the procedure (NICE 2003)
- assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications (referral to a pharmacist may be required)
- decline in mobility and/or functional status as a result of treatment
- emotional and psychological issues including, but not limited to, boredom/sensory deprivation related to isolation, body image concerns, fatigue, existential anxiety, treatment phobias, anxiety/depression, interpersonal problems and sexuality concerns
- potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment
- financial issues related to loss of income and additional expenses as a result of illness or treatment
- legal issues including advance care planning, appointing a power of attorney and completing a will
- the need for appropriate information for people from culturally and linguistically diverse backgrounds and other populations with special needs (identified in the appendix).

For patients who have undergone allo-SCT, additional supportive care may be required to address the immunosuppressive effects and long-term side effects of therapy (Majhail et al. 2012). Issues in the acute and semi-acute phases may include infertility, GVHD, ongoing increased risk of infection, anaemia, bleeding, mouth ulcers and fatigue. Issues on long-term follow-up may include fatigue, GVHD, infections, infertility, altered sexuality, depression, decrease in functional status, increased risk of secondary cancers and heart failure.

4.6.2 Communication with the patient, carer and family

The lead clinician should:

- ensure patients and their carer(s) are made aware of their susceptibility to infection and bleeding and the importance of presenting early to hospital – all patients should have emergency contact details
- offer advice to patients and carers on the benefits of and how to access support from peer support groups, groups for carers, and special interest groups
- discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes – provide a written plan
- provide the patient and carer with information on the possible side effects of treatment, self-management strategies and emergency contacts
- initiate a discussion regarding advance care planning with the patient and carer.

4.6.3 Communication with the general practitioner

The lead clinician should:

- discuss with the patient's general practitioner their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding:
 - 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 and/or clinical trials
 - changes in treatment or medications
 - recommendations from the MDT
 - an emergency contact number (for the general practitioner to access the haematology treatment team).

Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completing the initial treatment for AML, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of the issues identified by all members of the MDT. The transition from acute to primary or community care will vary depending on the type and stage of cancer and needs to be planned. In some cases, people will require ongoing, hospital-based care.

5.1 Survivorship

In the past two decades, the number of people surviving AML has increased. Approximately 60–70 per cent of adults under 60 years of age with AML receiving intensive chemotherapy can expect to attain complete remission. More than 25 per cent of adults with AML (about 45 per cent of those who attain complete remission) can be expected to survive three or more years and may be cured.

International research shows there is an important need to focus on helping cancer survivors cope with life beyond their acute treatment. Cancer survivors experience particular issues, often different from people having active treatment for cancer.

The side effects experienced by cancer patients often persist beyond the completion of active cancer treatment. Emotional and psychological issues include distress, anxiety, depression, cognitive changes and fear of cancer recurrence. Late effects may occur months or years later and are dependent on the type of cancer treatment. Survivors may experience altered relationships and may encounter practical issues, including difficulties with return to work or study, and financial hardship.

Survivors generally need to see a doctor for regular followup, often for five or more years after cancer treatment finishes. The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes four essential components of survivorship care (Hewitt et al. 2006):

- the prevention of recurrent and new cancers, as well as late effects
- surveillance for cancer spread, recurrence or second cancers; and screening and assessment for medical and psychosocial late effects
- interventions to deal with the consequences of cancer and cancer treatments (including managing symptoms, distress and practical issues)
- coordination of care between all providers to ensure the patient's needs are met.

All patients should be educated in managing their own health needs (NCSI 2015).

Units treating AML should seek to develop specialised survivorship programs for patients who have completed anti-leukaemia therapy.

5.2 Post-treatment care planning

5.2.1 Treatment summary

Upon completing the initial treatment, the patient, their nominated carer (as appropriate) and their general practitioner should receive a treatment summary outlining:

- the diagnostic tests performed and results
- disease characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

5.2.2 Follow-up care

Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues) as well as individual clinical and supportive care needs. It is important that post-treatment care is evidence-based and consistent with guidelines.

Responsibility for follow-up care should be agreed between the lead clinician, the general practitioner, relevant members of the MDT and the patient, with an agreed plan outlining:

- what medical follow-up is required (surveillance for cancer spread, recurrence or secondary cancers, screening and assessment for medical and psychosocial effects)
- care plans from other health professionals to manage the consequences of cancer and treatment
- a process for rapid re-entry to specialist medical services for suspected recurrence.

For follow-up immediately post-therapy, the frequency of consultations will be determined by the patient's needs, and may range between several times a week and six-weekly. The primary treating clinical haematologist should coordinate these, with input from the full spectrum of allied health professionals.

Specific screening and monitoring may be required for some potential late effects of therapy, depending on the primary treatment used.

For longer term follow-up and surveillance for recurrent/progressive disease, the timing and intensity of the surveillance will depend on the intended approach should recurrent disease be detected.

A reasonable surveillance schedule is:

- for the first two to three years after treatment: full blood examination (FBE) every one to three months, and clinical assessment with a careful history and physical examination every three months
- up to five years post-treatment: FBE and clinical review every three to six months
- then as deemed appropriate for individual patients: annual FBE and clinical review indefinitely.

Patients who have received allo-SCT will require specific long-term follow-up plans coordinated by the survivorship program at the transplant unit (Majhail et al. 2012).

In particular circumstances, follow-up care can safely and effectively be provided:

- in the primary care setting
- by other suitably trained staff (nurse-led follow-up)
- in a non-face-to-face setting (for example, by telehealth).

Access to a range of health professions may be required including physiotherapy, occupational therapy, nursing social work, dietetics, clinical psychology and palliative care.

5.3 Research and clinical trials

Participation in clinical trials, where available, is considered a standard of care for patients with AML. Cross-referral between clinical trials centres should be encouraged to facilitate participation. Participation in registries and tissue banking is also considered a standard of care for patients with AML.

- For more information visit <www.australiancancertrials.gov.au>.

5.4 Support and communication

5.4.1 Supportive care

Screening using a validated screening tool, assessment and referral to appropriate health professionals and community-based support services is required to meet the needs of individual patients, their family and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- endocrine effects (gonadal), cardiac effects, osteoporosis, transfusional iron overload and secondary myelodysplasia in the late stages of therapy
- malnutrition post-treatment due to ongoing treatment side effects (such as gastrointestinal symptoms, reduced appetite and reduced oral intake); this requires monitoring and nutrition intervention where indicated
- decline in mobility and/or functional status as a result of treatment
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- emotional distress arising from fear of disease recurrence, changes in body image, returning to work, anxiety/depression, interpersonal problems and sexuality concerns
- a need for increased community supports as patients recover from treatment
- financial and employment issues (such as loss of income and assistance with returning to work; and cost of treatment, travel and accommodation)
- legal issues (such as appointing a power of attorney or advance care planning)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds and other populations with special needs (identified in the appendix).

5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care.

Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

5.4.3 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 lead clinician should ensure timely and appropriate referral to palliative care services.

This is particularly important for AML to ensure optimal symptom control in the context of highly toxic treatment regimens and disease recurrence.

Patients should be encouraged to develop an advance care plan (AHMAC 2011).

Ensure carers and families receive the information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Further information

- Refer patients and carers to Palliative Care Australia via <www.palliativecare.org.au>.

5.4.4 Communication with the patient, carer and family

The lead clinician should:

- explain the treatment summary and follow-up care plan
- provide information on the signs and symptoms of recurrent disease
- provide information on secondary prevention and healthy living.

5.4.5 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the patient's general practitioner regarding:

- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- the patient's progress
- recommendations from the MDT
- any shared care arrangements
- a process for rapid re-entry to medical services for patients with suspected recurrence.

Step 6: Managing residual and recurrent disease

Step 6 is concerned with managing recurrent or residual disease.

6.1 Signs and symptoms of residual or recurrent disease

Relapse occurs in more than 50 per cent of patients, and treatment outcomes will vary depending on individual prognostic factors. Most cases of recurrent AML are identified through routine follow-up or by the patient presenting with symptoms.

Molecular monitoring for minimal residual disease (MRD) is recommended for patients with APL, CBF leukaemia and NPM1 mutant AML (Döhner et al. 2015). In general, bone marrow sampling is more sensitive than peripheral blood monitoring. The optimal frequency and duration of testing remains to be established.

If recurrence is suspected, there should be:

- full blood count with blood film examination
- bone marrow aspirate and trephine, including flow cytometry, and cytogenetic analysis and molecular testing (depends on clinical context).

6.2 Multidisciplinary team

There should be timely referral to the original MDT (where possible), with referral on to a specialist centre for recurrent disease as appropriate.

On occasion, referral to another centre may be appropriate when considering allo-SCT, access to clinical trials or novel agents.

6.3 Treatment

6.3.1 Anti-leukaemia treatment for recurrent disease

Treatment will depend on the location, extent of residual or recurrent disease, performance status, previous management and patient preferences.

The morbidity and risks of treatment need to be balanced against the potential benefits.

The lead clinician should discuss treatment intent and prognosis with the patient and carer prior to beginning treatment, ensuring they are involved in the decision-making process.

Patients presenting with relapse after a first remission may be offered intensive re-induction, for which the chances of success are better after a longer duration of first remission. Consideration should be given to salvage chemotherapy and/or using novel agents in a clinical trial.

Allo-SCT should be considered.

Fitter patients presenting with relapse after a first remission may be offered intensive re-induction. The chances of long-term success can be estimated using the European Prognostic Index (Breems et al. 2006). Consideration should be given to salvage chemotherapy and/or use of novel agents in a clinical trial.

Irradiation of infiltrative/mass lesions (solitary choromas) and craniospinal irradiation in the event of central nervous system disease may be appropriate. Regular transfusional support with red cells and platelets should be administered when appropriate.

Note: If treatment is given with ultimate curative intent, the facilities need to be of the same level as for the initial therapy. Palliative chemotherapy may be delivered in a less specialised environment. Allo-SCT must be delivered only in specialised units with appropriate human and physical resources.

6.3.2 Palliative and supportive treatments for residual or recurrent disease

If not already involved, a shared care model with the treating MDT and palliative care team should be considered (including pastoral care, palliative medicine specialist support, inpatient palliative bed access as required, social work and bereavement counselling, community palliative care) with general practitioner engagement. This is particularly important for AML in the context of disease recurrence to ensure optimal symptom control and complex symptom management, appropriate transfusion support and transition to end-of-life care (where appropriate).

Patients should be encouraged to develop an advance care plan (AHMAC 2011). Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Begin discussions with the patient and carer about preferred place of death.

Further information

- Refer patients and carers to Palliative Care Australia via <www.palliativecare.org.au>.

6.4 Research and clinical trials

Participation in clinical trials, where available, is considered a standard of care for patients with AML. Cross-referral between clinical trials centres should be encouraged to facilitate participation. Participation in registries and tissue banking is also considered a standard of care for patients with AML.

For more information about trials visit <www.australiancancertrials.gov.au>.

6.5 Support and communication

6.5.1 Supportive care

Screening, assessment and referral to appropriate health professionals and community-based organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the above and common issues outlined in the **appendix**, specific issues that may arise include:

- side effects resulting from high-dose therapy including alopecia, fatigue, damage to the bone marrow and other quickly growing tissues of the body, immunosuppression, fluid retention, dyspnea, GVHD, organ toxicity (interstitial pneumonitis, veno-occlusive disease), episodic hypotension and pulmonary infiltrates
- chemically induced menopause (such as atrophic vaginitis and dyspareunia) and changes in androgens that may alter libido and orgasm, which require sensitive discussion
- differentiation syndrome – early recognition and prompt initiation of corticosteroids is required (NCCN 2015)
- gastrointestinal symptoms (such as nausea, vomiting, severe mucositis, loss of appetite, dysgeusia, diarrhoea or constipation) as a result of treatment, which requires optimal symptom control (with medication, total parenteral nutrition, analgesia, mouth care) and referral to a dietitian if dietary intake is affected
- cognitive impairment, which patients treated with allo-SCT report to be a major component of quality-of-life impairment, even one year after the procedure (NICE 2003)
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- decline in mobility and/or functional status as a result of recurrent disease and treatments
- increased practical and emotional support needs for families and carers, including help with family communication, teamwork and care coordination where these prove difficult for families
- emotional and psychological distress resulting from fear of death/dying, existential concerns, anticipatory grief, communicating wishes to loved ones, interpersonal problems and sexuality concerns
- financial issues as a result of disease recurrence (such as early access to superannuation and insurance)
- legal issues (such as advance care planning, appointing medical and financial powers of attorney, developing a will)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds and other populations with special needs (identified in the appendix).

For patients treated with allo-SCT, additional supportive care may be required to address the immunosuppressive effects and long-term side effects of therapy. Issues may include infertility, GVHD, increased risk of infection, anaemia, bleeding, mouth ulcers and fatigue.

6.5.2 Rehabilitation

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

6.5.3 Communication with the patient, carer and family

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

Step 7: End-of-life care

End-of-life care is appropriate when the patient's symptoms are increasing and their functional status is declining. Step 7 is concerned with maintaining the patient's quality of life and addressing their health and supportive care needs as they approach the end of life, as well as the needs of their family or carer. The principles of a palliative approach to care need to be shared by the team when making decisions with the patient and their family.

7.1 Multidisciplinary palliative care

If not already involved, referral to palliative care should be considered at this stage (including nursing, pastoral care, palliative medicine specialist back-up, inpatient palliative bed access as required, social work and bereavement counselling) with general practitioner engagement.

If not already in place, the patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

The MDT may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or spiritual advisor
- bereavement counsellor
- therapist (for example, music or art).

The team might also recommend accessing:

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

Consideration of the appropriate place of care and the patient's preferred place of death is essential.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Further information

- Refer patients and carers to Palliative Care Australia via <www.palliativecare.org.au>.

7.2 Research and clinical trials

Participation in clinical trials, where available, is considered a standard of care for patients with AML. Cross-referral between clinical trials centres should be encouraged to facilitate participation. Participation in registries and tissue banking is also considered a standard of care for patients with AML.

For more information about trials visit <www.australiancancertrials.gov.au>.

7.3 Support and communication

7.3.1 Supportive care

Screening, assessment and referral to appropriate health professionals and community-based organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues identified in the **appendix**, specific issues that may arise at this time include:

- transfusion support, which requires specialised clinical transfusion knowledge
- physical symptoms such as pain and fatigue, reduced appetite, early satiety and weight loss
- decline in mobility and/or functional status impacting on discharge destination
- emotional and psychological distress from anticipatory grief, fear of death/dying, anxiety/depression, interpersonal problems and anticipatory bereavement support for the patient as well as their carer and family
- practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the patient
- legal issues relevant to people with advanced disease such as accessing superannuation early, advance care planning, powers of attorney and completing a will
- information for patients and families about arranging a funeral
- specific spiritual needs that may benefit from the involvement of pastoral care
- bereavement support for family and friends
- specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs.

7.3.2 Communication with the patient, carer and family

The lead clinician should:

- be open to and encourage discussion about the expected disease course, with due consideration to personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the patient and carer with the contact details of a palliative care service.

7.3.3 Communication with the general practitioner

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

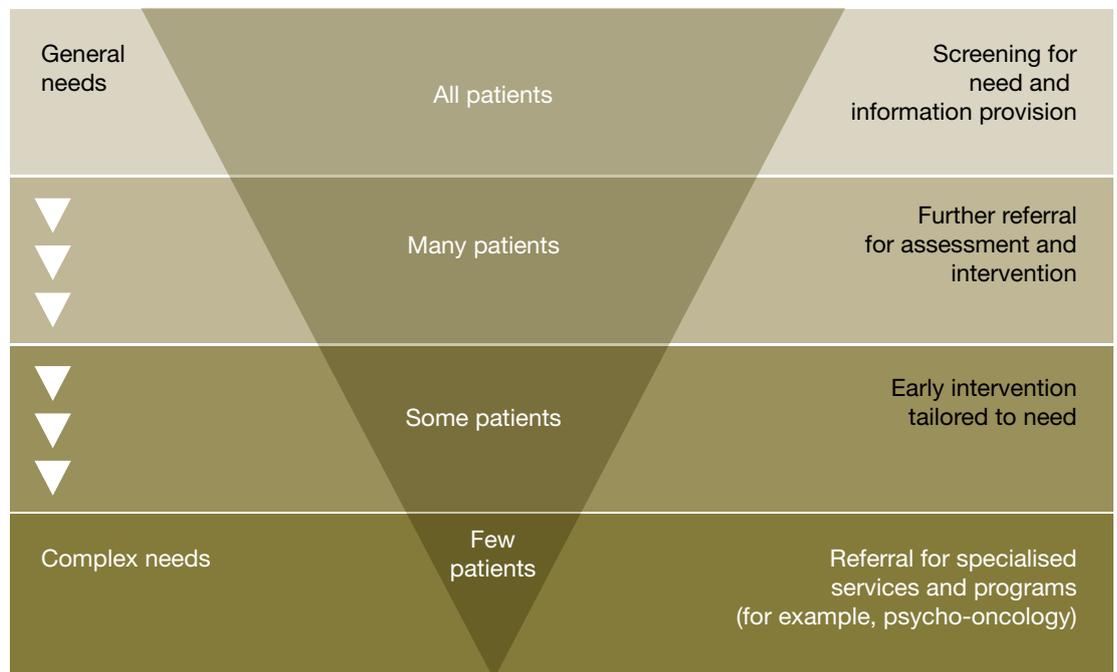
Appendix: Supportive care

Supportive care in cancer refers to the following five domains:

- physical domain, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation (NBCC & NCCI 2003)
- psychological domain, which includes a range of issues related to the person's mental health and personal relationships (NBCC & NCCI 2003)
- social domain, which includes a range of social and practical issues that will impact on the individual and family such as the need for emotional support, maintaining social networks and financial concerns (NICE 2004)
- information domain, which includes access to information about cancer and its treatment, support services and the health system overall (NBCC & NCCI 2003)
- spiritual domain, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns (NICE 2004).

Fitch's (2000) model of supportive care (Figure 1) recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual. The model targets the type and level of intervention required to meet patients' supportive care needs.

Figure 1: The tiered approach



While all patients require general information, only a few will require specialised intervention. Common indicators in patients with AML that may require referral to appropriate health professionals and/or organisations include the following:

Physical needs

- Side effects can result from high-dose therapy including alopecia, fatigue, damage to the bone marrow and other fast-growing tissues of the body, immunosuppression, fluid retention, dyspnea, graft-versus-host disease (GVHD), organ toxicity (interstitial pneumonitis, veno-occlusive disease), episodic hypotension and pulmonary infiltrates.
- Early recognition and prompt initiation of corticosteroids is required for differentiation syndrome (NCCN 2015).
- Gastrointestinal symptoms (such as nausea, vomiting, severe mucositis, loss of appetite, dysguesia, diarrhoea and constipation) can occur as a result of treatment. These require optimal symptom control (with medication, total parenteral nutrition, analgesia or mouth care) and referral to a dietitian if dietary intake is affected.
- Malnutrition can occur as a result of disease or treatment. Validated malnutrition screening tools should be used at the key points in the care pathway to identify patients at risk of malnutrition and refer to a dietitian for nutrition intervention.
- Referral to a pharmacist may be useful for people managing multiple medications.
- Decreased functional capacity may interfere with people being able to manage activities of daily living. Referral to physiotherapist or exercise physiologist may be required.
- For patients treated with allo-SCT, additional supportive care is required to address the immunosuppressive effects and long-term side effects of therapy. Issues may include infertility, GVHD, increased risk of infection, anaemia, bleeding, mouth ulcers and fatigue.

Psychological needs

- High-dose chemotherapy is both physically and emotionally stressful, and people who go through it may continue to feel exhausted and depressed for a long period (NICE 2003). Regular screening and ongoing monitoring for distress, anxiety and/or depression is part of the long-term follow-up, and referral to a psychologist or psychiatrist may be required.
- Issues regarding chemically induced menopause, such as atrophic vaginitis and dyspareunia, and changes in androgens that may alter libido and orgasm, require sensitive discussion. If further information is required, referral to a health professional, such as a social worker, psychologist or psychiatrist able to provide counselling in this area is necessary.
- Alteration of cognitive functioning in patients treated with chemotherapy and radiation therapy can be an issue.
- Patients treated with allo-SCT report cognitive impairment to be a major component of quality-of-life impairment, even one year after the procedure (NICE 2003). Longer term follow-up for at least one year and strategies to help manage cognitive impairment, such as maintaining written notes and a diary, may be helpful.
- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, gay, bisexual, transgender and intersex (LGBTI) communities) a cancer diagnosis can come with additional psychosocial complexities. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some people may have disabling symptoms and may benefit from referral to counselling/ psychology services.
- Distress and depression can be just as common in carers and family members including children. Proactive models of referral for psychosocial support should be considered.
- Consider a referral to a psychologist, psychiatrist or social worker if the patient is:
 - displaying emotional cues such as tearfulness, distress, avoidance or withdrawal
 - preoccupied with or dwelling on thoughts about cancer and death
 - displaying fears about the treatment process and/or the changed goals of their treatment
 - worried 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 impact that AML is having on their life and the disruption to their life plans
 - struggling with communicating to family and loved ones about the implications of their cancer diagnosis and treatment
 - experiencing changes in sexual intimacy, libido or function
 - struggling with the diagnosis of advanced disease
 - having difficulties with drug and alcohol use
 - having difficulties transitioning to palliative care.

Fertility preservation

- All patients of childbearing years undergoing intensive induction chemotherapy or allo-SCT should be offered the opportunity of preserving their fertility (where possible) prior to treatment (Milligan et al. 2006). Referral to fertility counselling may be appropriate. The requirement for lifesaving induction therapy may limit the timeframe available for some fertility preservation options.

Social/practical needs

- A diagnosis of AML can have significant financial, social and practical impacts on patients, carers and families as outlined above.
- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.
- People from regional or rural areas may require assistance from organisations for accommodation and/transport needs during periods of treatment/appointments.

Information needs

- Offer individualised AML cancer information that meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources).
- Offer advice on how to access information from websites, community sources and national cancer services.
- Offer advice to patients and carers on the benefits of and how to access support from peer support groups, groups for carers and special interest groups (for example, through Leukaemia Foundation Australia).

Spiritual needs

- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.
- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.

Populations with special needs

Elderly people with cancer

Remission rates in adult AML are inversely related to age. Data suggests that once attained, duration of remission may be shorter in older patients (NCI 2015). Older patients are more likely to have drug-resistant disease, frequently have major comorbidities and are less able to tolerate intensive chemotherapy.

Planning and delivery of appropriate cancer care for elderly people presents a number of challenges. Improved communication between the fields of oncology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as the implications of cognitive impairment on the suitability of treatment and consent (Steer et al. 2009).

A national interdisciplinary workshop convened by the Clinical Oncology Society of Australia recommended that people over the age of 70 undergo some form of geriatric assessment, in line with international guidelines (COSA 2013). Assessment can be used to determine life expectancy and treatment tolerance as well as identifying conditions that might interfere with treatment including:

- function
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional status
- social supports.

Paediatrics

Despite very intensive therapeutic options, paediatric patients diagnosed with AML still have a relatively poor prognosis in comparison with many paediatric or adolescent and young adult (AYA) patients with alternate cancer diagnosis. Toxicity from current regimens leaves little room for further intensification to improve outcome. The side effects of intensive systemic therapy can be even more severe for children and include acute organ toxicities, prolonged immunodeficiency and infection. As a result of these complexities, high-quality evidence-based care is required not only to deliver therapy and supportive care but is essential in the diagnosis phase, post-treatment surveillance and long-term follow-up care. Children with AML must have their treatment delivered by a statewide referral centre for paediatric oncology. Shared care may be considered for surveillance following completion of treatment. Children's cancer services actively participate in clinical trials as a way of participating in research and improving outcomes for children.

Adolescents and young adults

Recent years have seen the emergence of AYA oncology as a distinct field due to lack of progress in survival and quality-of-life outcomes (Ferrari et al. 2010; NCI & USDHHS 2006; Smith et al. 2013). The significant developmental change that occurs during this life stage complicates a diagnosis of cancer during the AYA years, often leading to unique physical, social and emotional impacts for young people at the time of diagnosis and throughout the cancer journey (Smith et al. 2012).

In caring for young people with cancer, careful attention to the promotion of normal development is required (COSA 2011). This requires personalised assessments and management involving a multidisciplinary, disease-specific, developmentally targeted approach informed by:

- 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
- addressing the needs of all involved, including the young person, their family and/or carer(s)
- working with educational institutions and workplaces
- addressing survivorship and palliative care needs.

An oncology team caring for a young person with cancer must:

- ensure access to expert AYA health professionals who possess knowledge specific to the biomedical and psychosocial needs of the population
- understand the biology and current management of the disease in the AYA age group
- consider clinical trials accessibility and recruitment for each patient
- engage in proactive discussion and management of fertility preservation, the late effects of treatment and psychosocial needs
- provide treatment in an AYA-friendly environment.

Culturally and linguistically diverse communities

For people from culturally and linguistically 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 those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis. In addition to different cultural beliefs, when English language skills are 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 born overseas, and particular attention should be paid to supporting these patients (Department of Health 2009).

Aboriginal and Torres Strait Islander communities

The burden of cancer is higher in the Australian Indigenous population (AIHW 2014). Survival also significantly decreases as remoteness increases, unlike the survival rates of non-Indigenous Australians. Aboriginal and Torres Strait Islander people in Australia have high rates of certain lifestyle risk factors including tobacco smoking, higher alcohol consumption, poor diet and low levels of physical activity (Cancer Australia 2013). The high prevalence of these risk factors is believed to be a significant contributing factor to the patterns of cancer incidence and mortality rates in this population group (Robotin et al. 2008).

In caring for Aboriginal and Torres Strait Islander people diagnosed with cancer, the current gap in survivorship is a significant issue. The following approaches are recommended to improve survivorship outcomes (Cancer Australia 2013):

- Raise awareness of risk factors and deliver key cancer messages.
- Develop evidence-based information and resources for community and health professionals.
- Provide training for Aboriginal and Torres Strait Islander health workers and develop training resources.
- Increase understanding of barriers to care and support.
- Encourage and fund research.
- Improve knowledge within the community to act on cancer risk and symptoms.
- Improve the capacity of Aboriginal and Torres Strait Islander health workers to provide cancer care and support to their communities.
- Improve system responsiveness to cultural needs.
- Improve our knowledge through targeted priority research.
- Improve our understanding of gaps through data monitoring.

Resources

For patients, families and carers

Australian Cancer Survivorship Centre

Has general and tumour-specific information, primarily focused on the post-treatment survivorship phase

- Telephone: (03) 9656 5207
- <www.petermac.org/cancersurvivorship>

beyondblue

Information on depression, anxiety and related disorders, available treatment and support services

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

Cancer Australia

Information on cancer prevention, screening, diagnosis, treatment and supportive care for Australians affected by cancer, and their families and carers

- Telephone: 1800 624 973
- <www.canceraustralia.gov.au>

Cancer Council (operated by Cancer Council Victoria)

Confidential telephone support service for people affected by cancer that provides information on treatment, cancer support groups and other community resources

- Telephone: 13 11 20
(Monday to Friday, 8.30 am – 5.30 pm)
- <www.cancervic.org.au>

Care Search: Palliative Care Knowledge Network

Information for patients and carers on living with illness including practical advice on how to care and finding services

- Telephone: (08) 7221 8233
- <www.caresearch.com.au>

The Leukaemia Foundation

Provides information, education and support programs, emotional support, practical assistance, transport and accommodation for people with leukaemia, their families and friends

- Telephone: 1800 620 420
(Monday to Friday, 9.00 am – 5.00 pm)
- <www.leukaemia.org.au>

For health professionals

Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are recruiting new participants

- <www.australiancancertrials.gov.au>

Cancer Australia

Information for health professionals including guidelines, cancer guides, reports, fact sheets, DVDs, posters and pamphlets

- <www.canceraustralia.gov.au>

Cancer Council Australia

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

- <www.cancer.org.au>

eviQ

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

- <www.eviq.org.au>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment

- <www.nhmrc.gov.au>

Glossary

Advance care planning – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

Alternative therapies – treatments that are used in place of conventional medical treatment, often in the hope they will provide a cure.

Care coordinator – the health professional 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 where care is primarily located.

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 – a distinct phase of palliative care, appropriate when a patient's symptoms are increasing and functional status is declining despite anti-cancer therapy.

General/primary medical practitioner – the practitioner to whom the patient first presents with symptoms; this may be the general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

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.

Multidisciplinary care – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each patient (Department of Health 2007b).

Multidisciplinary team – comprises the core disciplines 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.

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.

Palliative care – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

Patient management frameworks – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal care pathways are updated versions of these models, being developed by the Victorian Government from 2013.

Prehabilitation – one or more interventions performed in a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the patient undergoes treatment and beyond.

Primary specialist – the person who makes the referral to the multidisciplinary team (for example, specialist physician, surgeon, oncologist, palliative care specialist). This person will also make referrals for treatment and will be responsible for oversight of follow-up care.

Rehabilitation – comprises multidisciplinary efforts to allow the patient to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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Medical colleges and peak organisations

Allied Health Professions Australia
Australian Association of Nuclear Medicine Specialists
Australian and New Zealand Society of Palliative Care
Australian College of Emergency Medicine
Australian College of Nursing
Australian Institute of Radiography
Australian Medical Association
Cancer Nurses Society of Australia
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