

Optimal cancer care pathway for people with Hodgkin and diffuse large B-cell lymphomas



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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 health care providers and covers a range of institutions, both public and private. The Optimal Cancer 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.

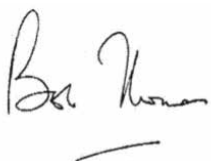
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established 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 Cancer 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
Chief Advisor Cancer, Department of Health and Human Services – Victoria

Summary

Please note that not all patients will follow every step of this pathway:

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: The causes of lymphoma are not fully understood. All ages and all demographic groups are at risk for Hodgkin and diffuse large B-cell lymphomas (DLBCL). However, they are most common in middle-aged to older adults. There is an additional 'peak' of incidence in Hodgkin lymphoma in adolescents and young adults. Other risk factors include

- intrinsically immunosuppressed patients or those receiving therapeutic immunosuppression
 - Epstein-Barr virus (EBV) infection with immune deficiency
 - family history
 - any past history of a lymphoproliferative disorder
 - obesity (a modest but modifiable risk factor).
- Early detection:** Individuals at risk of immunodeficiency-associated lymphoma should be made aware of this increased risk.

Step 2

Presentation, initial investigations and referral

Signs and symptoms:

The following should be investigated:

- a lump or mass
- lymphadenopathy, particularly persistent lymphadenopathy of up to four weeks
 - or associated with systemic symptoms (below)
 - despite treatment for presumed infection
 - pain in the lymph nodes following alcohol consumption
- one or more of these symptoms even without lymphadenopathy: fever, drenching sweats, unexplained weight loss, persistent severe itch
- undiagnosed back or abdominal pain without palpable lymphadenopathy
- unexplained elevation of lactate dehydrogenase (LDH)
- unexplained cytopenias.

Moderate or severe symptoms require consultation within two days. Persistent or enlarging lumps without other symptoms should be seen within two weeks.

General/primary practitioner investigations:

If there is a high likelihood of a malignant process, prompt referral to a specialist centre to facilitate a tissue diagnosis is appropriate.

For others, further investigations should be completed within four weeks and may include:

- full blood examination
- imaging (ultrasound for peripheral lesions, chest radiography and computed tomography (CT) scan)
- biopsy
- a period of observation of up to six weeks.

Referral: All patients with suspected lymphoma should be evaluated and cared for within a lymphoma-specific multidisciplinary team environment. Healthcare providers should provide clear routes of rapid access to specialist evaluation.

Communication – lead clinician to:¹

- 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: A tissue diagnosis is required prior to initiating definitive treatment. Excisional node biopsy is the preferred approach. Tissue suitable for anatomical pathology, flow cytometry, cytogenetics and gene mutation testing should be obtained.

Staging: The disease stage (Ann Arbor system), including evaluation of bone marrow status, should be determined in all patients. This should include fluorodeoxyglucose (FDG) positron emission tomography (PET) scanning.

Treatment planning: Ideally, a multidisciplinary team meeting should be conducted before treatment begins.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- 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:

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

Treatment options:

Systemic chemotherapy and drug therapy: Systemic chemotherapy is a key component of treatment. A range of biological and targeted therapies are increasingly being used to treat patients with these lymphomas.

Stem cell transplant:

High-dose chemotherapy and autologous stem cell transplant may benefit:

- fit patients with recurrent lymphomas that respond to salvage treatment
- some patients with responsive Hodgkin lymphoma who have failed to achieve a complete remission.

In selected patients, allografting may be considered.

Radiation therapy should be considered for suitable patients with localised disease or those

with more advanced disease with a dominant bulky lesion. This is almost always in the context of combined chemo-radiation.

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 <http://www.esmo.org/Guidelines-Practice/Clinical-Practice-Guidelines/Haematologic-Malignancies>

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
- tumour 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 (tests, ongoing surveillance)

- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Potential late effects of therapy that may require specific screening and monitoring will be determined by the primary treatment used.

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 recurrent, residual and metastatic disease

Detection: Most cases of recurrent Hodgkin lymphoma or DLBCL are identified through routine follow-up or by the patient presenting with symptoms, or by 'non-specific' systemic tests such as serum LDH.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will

depend on the location, extent of recurrent or residual disease, performance status, 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: Consider referral to palliative care if not already involved. 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

Timeframes for diagnosis and referral – Timeframes should be informed by evidence based guidelines where they exist, whilst recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress. The following recommended timeframes are based on expert advice from the Hodgkin and diffuse large B-cell lymphomas Working Group:

Step in pathway	Care point	Timeframe
Presentation, Initial Investigations and Referral	2.1 Signs and symptoms	Patients with moderate or severe symptoms require timely consultation within 2 days. Persistent or enlarging lumps without other symptoms should be seen within 2 weeks. Symptoms without lumps should be seen after 2 weeks if persistent.
	2.2 Initial investigations by GP	In patients without an indication for prompt referral, where investigation is undertaken in the community, it is recommended this be completed and a path of action be decided within a maximum of 4 weeks.
	2.3 Specialist appointment	Patients should be seen by a specialist as soon as possible and definitely within 2 weeks. Centres receiving a referral should promptly acknowledge the receipt and acceptance of the referral and indicate the anticipated timeframe for an appointment.
Diagnosis, Staging and Treatment Planning	3.3 Treatment planning	Ideally, a multidisciplinary discussion should be conducted before implementing treatment. Immediate treatment is often required before a full multidisciplinary meeting ratifies details of the management plan.
Treatment	4.2 Treatment	Treatment should commence within 2 weeks of diagnosis, unless a patient request delays this, for example to pursue fertility preservation measures. In cases with critical organ compromise or rapid clinical progression, emergent commencement of treatment, as early as within 24 hours of diagnosis, can at times be necessary.

Intent of the optimal cancer care pathway

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidence-based 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 cancer 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 cancer 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 (MDT) 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 these lymphomas that may require referral for support include:

- malnutrition (as identified using a validated malnutrition screening tool or presenting with weight loss)
- breathlessness
- pain
- difficulty managing fatigue
- difficulty sleeping
- distress, depression or fear
- poor performance status
- 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:
 - psychologist or psychiatrist
 - genetic counsellor
 - community-based support services (such as Cancer Council Victoria)
 - dietitian
 - exercise physiologist
 - occupational therapist
 - physiotherapist
 - peer support groups (contact the Cancer Council on 13 11 20 for more information)
 - social worker
 - nurse practitioner and/or specialist nurse
 - specialist palliative care
 - speech therapist.

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

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 cancer 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 and patient decisions, and physiological response to treatment).

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

The pathway covers Hodgkin lymphoma and diffuse large B-cell lymphoma (DLBCL) treated with curative intent.

Histologically indolent lymphomas are not included in this pathway – these cancers are not considered curable when disseminated and treatment is often deferred in favour of a ‘watch and wait’ approach if the patient is asymptomatic, which may last for many years.

The incidence of lymphoma has more than doubled over the past 20 years and is continuing to rise for no known reason (Cancer Council Australia 2014). DDLBCL is the most common subtype of non-Hodgkin lymphoma, accounting for 30–40 per cent of all cases. Hodgkin lymphoma is much rarer, accounting for 0.5 per cent of all cancer cases (Leukaemia Foundation Australia 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 Hodgkin lymphoma and DLBCL.

1.1 Prevention

The causes of lymphoma are not fully understood.

1.2 Risk factors

- All ages and all demographic groups are at risk for these lymphomas. However, they are most common in middle-aged to older adults. There is an additional ‘peak’ of incidence in Hodgkin lymphoma in adolescents and young adults.
- Intrinsically immunosuppressed patients or those receiving therapeutic immunosuppression (for example, transplant recipients, HIV-positive patients) are at higher risk.
- Epstein-Barr virus (EBV) infection in conjunction with immune deficiency is associated with increased risk (Cancer Council Australia 2007).
- Family history plays a role.
- Any past history of a lymphoproliferative disorder is a risk factor.
- Obesity is a modest but modifiable risk factor (Bhaskaran et al. 2014).

1.3 Early detection

1.3.1 Screening

There are no effective screening programs for these lymphomas. Individuals at risk of immunodeficiency-associated lymphoma should be made aware of this increased risk (Cancer Council Australia 2007).

Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral for Hodgkin lymphoma and DLBCL that is potentially suitable for treatment with curative intent. The types of investigation undertaken by the general or primary practitioner depend on many factors including access to diagnostic tests, medical specialists and patient preferences.

2.1 Signs and symptoms

A focused medical history and thorough clinical assessment should be undertaken. The following should be investigated:

- a lump or mass
- lymphadenopathy, particularly persistent lymphadenopathy of up to four weeks
 - or associated with systemic symptoms (see next bullet point)
 - despite appropriate treatment for presumed infection
 - pain in the lymph nodes following alcohol consumption
- one or more of these symptoms even in the absence of lymphadenopathy: fever, drenching sweats, unexplained weight loss, persistent severe itch
- undiagnosed back or abdominal pain without palpable lymphadenopathy
- unexplained elevation of lactate dehydrogenase (LDH)
- unexplained cytopenias.

Rarely, sudden onset of new respiratory symptoms may be a presenting feature of mediastinal obstruction, particularly in the paediatric population, and may require urgent imaging. Any symptoms of mechanical obstruction require prompt attention.

Timeframe for general practitioner consultation

- Moderate or severe symptoms require timely consultation (within two days).
- Persistent or enlarging lumps without other symptoms should be seen within two weeks.
- Symptoms without lumps should be seen after two weeks if persistent.

2.2 Assessments by the general or primary medical practitioner

If there is a high likelihood of a malignant process based on clinical assessment, prompt referral to a specialist centre to facilitate a tissue diagnosis is appropriate.

For others, where there is a less immediate concern or lower index of suspicion, further investigations that may be helpful include:

- blood tests that may indicate organ dysfunction requiring further investigation including full blood examination (FBE), urea and electrolytes (U&E), liver function tests, erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), LDH (no laboratory test can exclude these lymphomas)
- imaging of the affected area (ultrasound for peripheral lesions, chest radiography and computed tomography (CT) scan) as appropriate
- biopsy as appropriate (a negative fine-needle aspiration (FNA) does not exclude these lymphomas)
- a period of observation of up to six weeks, which can be appropriate for patients without any significant or progressive symptoms.

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 Lymphoma Cancer Working Group:¹

- In patients without an indication for prompt referral, where investigation is undertaken in the community, it is recommended this be completed and a path of action be decided within a maximum of four weeks.

2.3 Referral

All patients with suspected lymphoma should be evaluated and cared for within a lymphoma-specific MDT environment (Cancer Australia 2013a).

- **Urgent** hospital admission is recommended for patients with severe symptoms, clinical progression or instability, or presence of or impending mechanical obstruction.
- Patients **diagnosed** with one of these lymphomas should be referred to a haematologist or medical oncologist with professional expertise in lymphoma management.
- Patients without a histologic diagnosis but **suspected** of having one of these lymphomas should be referred to an appropriate specialist for diagnostic workup.

Healthcare providers should provide clear routes of rapid access to specialist evaluation.

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

- a letter that includes the patient's contact details, important psychosocial history and relevant past history, family history, current medications and allergies
- results of current clinical investigations (imaging and pathology reports)
- 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.

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

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 Lymphoma Working Group:

- Patients should be seen as soon as possible and definitely within two weeks.

Centres receiving a referral should promptly acknowledge the receipt and acceptance of the referral and indicate the anticipated timeframe for an appointment.

The supportive and liaison role of the patient's general practitioner and practice team in this process is critical.

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:

- treatment for physical symptoms
- evaluation of weight loss and consideration of need for nutritional assessment
- emotional distress of dealing with a potential cancer diagnosis, 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, caring arrangements for other family members)
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

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 that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
- support the patient while waiting for the specialist appointment.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer, as well as planning subsequent treatment for hodgkin lymphoma and DLBCL. The guiding principle is that interaction between appropriate MDT members should determine the treatment plan.

3.1 Diagnostic workup

A tissue diagnosis is always required prior to initiation of definitive treatment.

If the initial managing specialist is a surgeon, the surgeon should be experienced in biopsy techniques for diagnosing these lymphomas and have a close collaborative relationship with a lymphoma-focused MDT. FNAs are **not** suitable for diagnosing these conditions. Tissue suitable for anatomical pathology, flow cytometry, cytogenetics and gene mutation testing should be obtained (fresh and fixed tissue is required). Nodal architecture is a key part of the pathological examination and therefore excisional biopsy is preferred wherever possible.

Extensive surgery rarely has a therapeutic role in managing these lymphomas. The least invasive procedure to establish the diagnosis is usually optimal. If a highly invasive or extensive surgical procedure is being considered, consultation with the MDT is required before the procedure.

Pathology specimens should be reviewed by a pathologist expert in diagnosing these lymphomas, preferably at the treatment centre before a treatment plan is instituted.

3.2 Staging

The disease stage (Ann Arbor system), including evaluation of bone marrow status, should be determined in all patients. This should include FDG PET scanning. Where treatment may include radiation therapy, consultation with the radiation oncologist is required to determine further imaging and evaluation needs before commencing treatment.

3.2.1 Prognostic score

An internationally recognised and disease- and stage-specific prognostic score should be determined and recorded for all patients such as the International Prognostic Score for Hodgkin lymphoma (Hasenclever & Diehl 1998) or the International Prognostic Index (IPI) for DLBCL (Shipp 1993).

3.2.2 Comorbidities

It is important in all patients to evaluate and document relevant organ functions (respiratory, renal). Overall functional status and physiological robustness should be evaluated and documented. These issues are especially important in the geriatric context, where geriatric assessment can be very useful.

Given the immunosuppressive effects of treatments used for these diseases, input from an experienced infectious diseases clinician prior to treatment may be beneficial to evaluate patients for the presence of occult infections (such as HIV or hepatitis B) that may be affected by therapy or pose a risk of reactivation.

3.3 Treatment planning

Optimal treatment planning should include presentation to, and consideration within, an MDT.

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.

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

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 these lymphomas

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)*
- haematologist/medical oncologist*
- nurse (with appropriate expertise)*
- pathologist*
- radiation oncologist*
- radiologist/imaging specialists*
- clinical trials coordinator
- dietitian
- general practitioner
- nuclear medicine physician
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- psychiatrist
- psychologist
- 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

Ideally, a multidisciplinary discussion should be conducted before implementing treatment.

There may also need to be a review of existing treatment plans for patients who have been discussed previously. See section 4.2.

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 research and/or clinical trials should be encouraged where available and appropriate.

- 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 surgery, 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.

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:

- treatment for physical symptoms
- evaluation of weight loss and consideration of the need for a nutritional assessment
- support for the emotional distress of dealing with a potential cancer diagnosis, anxiety and depression, interpersonal problems, stress and adjustment difficulties
- 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.

3.5.3 Communication with the patient

The lead clinician should:

- clarify the patient's wishes/needs and adapt recommendations from the MDT accordingly
- establish if the patient has a regular or preferred general practitioner
- discuss a timeframe for diagnosis and treatment with the patient and carer
- discuss benefits of multidisciplinary care and make the patient aware their health information will be available to the team for the discussion at the multidisciplinary meeting
- if the patient is a smoker, provide information about smoking cessation
- offer individualised lymphoma 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 and support from websites, community and national cancer services and support groups
- 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 Hodgkin lymphoma and DLBCL. For detailed information on treatment options refer to:

- Hodgkin's lymphoma: ESMO clinical practice guidelines for diagnosis, treatment and follow-up at <<http://www.esmo.org/Guidelines-Practice/Clinical-Practice-Guidelines/Haematologic-Malignancies/Hodgkin-s-Lymphoma>>
- Diffuse large B-cell lymphoma (DLBCL): ESMO clinical practice guidelines for diagnosis, treatment and follow-up at <<http://www.esmo.org/Guidelines-Practice/Clinical-Practice-Guidelines/Haematologic-Malignancies/Diffuse-Large-B-Cell-Lymphoma>>
- British Society of Haematology: Guidelines for the first line management of classical Hodgkin lymphoma (Follows et al. 2014).

4.1 Treatment intent

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

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

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

The lead clinician must discuss 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

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the patient.

Timeframe for commencing treatment

Timeframes for commencing treatment 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 Lymphoma Working Group:

- Within two weeks of establishing the diagnosis, unless a patient request delays this, for example to pursue fertility preservation measures. In cases with critical organ compromise or rapid clinical progression, emergent commencement of treatment, as early as within 24 hours of diagnosis, can at times be necessary.

4.2.1 Chemotherapy or drug therapy

Systemic chemotherapy is a key component of treatment.

Occasionally vascular access devices are required to deliver chemotherapy. Such devices should only be inserted by proceduralists experienced in such procedures.

A range of biological and targeted therapies are increasingly being used to treat patients with these lymphomas. Efforts should be made to identify those patients who may benefit from such therapies.

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.
- 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 and experience with credentialling and agreed scope of practice 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.

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

- a clearly defined path to emergency care and advice after hours
- access to basic haematology and biochemistry testing
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding 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 and blood products
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not collocated.

4.2.2 Stem cell transplant

High-dose chemotherapy and autologous stem cell transplantation should be considered in fit patients with recurrent lymphomas of these types that respond to salvage treatment. Some patients with responsive Hodgkin lymphoma who have failed to achieve a complete remission may be considered for this treatment as well. In selected patients, allografting may be considered.

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, with appropriately trained nursing staff available for the operation of cell separators.

4.2.3 Radiation therapy

Radiation therapy should be considered for suitable patients with localised disease or those with more advanced disease with a dominant bulky lesion. This is almost always in the context of combined chemo-radiation.

Training, experience and treatment centre characteristics

Training and experience required of the appropriate specialist(s):

- radiation oncologist (FRANZCR or equivalent) with adequate training and experience with institutional credentialling and agreed scope of practice in lymphoma (ACSQHC 2004).

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

- access to PET and electronic transfer of PET data for planning
- access to allied health, especially nutrition health and advice
- access to CT scanning for simulation and planning
- staff to be familiar with lymphoma-specific radiation therapy techniques.

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). This is particularly important for these lymphomas in the context of disease recurrence to ensure optimal symptom control – the boundary between active treatment and palliative can be more fluid than many other types of malignancy.

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.

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 <www.palliativecare.org.au>.

4.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

- 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 assist them to 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.

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

- side effects resulting from high-dose therapy, such as damage to the bone marrow and other quickly growing tissues of the body, immunosuppression, chemically induced menopause (such as atrophic vaginitis and dyspareunia) and changes in androgens that may alter libido and orgasm, require sensitive discussion
- patients treated with stem cell transplantation report cognitive impairment to be a major component of quality-of-life impairment, even one year after the procedure (NICE 2003)
- life-threatening infections for patients who have undergone high-dose chemotherapy are a risk requiring strict adherence to universal guidelines, reverse isolation, involvement of wound nurse specialists and infection control specialists and close monitoring of blood levels by the medical specialist
- treatment for physical symptoms
- gastrointestinal symptoms (such as nausea, vomiting, mucositis, loss of appetite, dysguesia, diarrhoea or constipation) as a result of treatment, requiring optimal symptom control with medication and referral to a dietitian if dietary intake is affected
- 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, 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 and/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.

4.6.2 Communication with the patient, carer and family

The lead clinician should:

- 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 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.

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 Hodgkin lymphoma and DLBCL, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the MDT. 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 cancer has increased. 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.

Many cancer survivors experience persisting side effects at the end of 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).

5.2 Post-treatment care planning

5.2.1 Treatment summary

Upon completing the initial treatment, the patient, carer and general practitioner should receive a treatment summary outlining:

- the diagnostic tests performed and results
- tumour 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.

A reasonable surveillance schedule is clinical assessment with a careful history and physical examination, FBE and LDH assessment every three months for the first two to three years after treatment, then every four to six months until five years, then annually indefinitely.

Imaging studies should not be performed routinely in patients in first remission but may be added to this schedule in selected patients. This, however, depends on the therapeutic plan for managing relapse, with the frequency determined by the level of individual patient risk and specific modality (CT or functional imaging). This is based on the region considered to be at risk and the presence of residual radiological abnormalities in which structural imaging may be less sensitive to minor changes.

Potential late effects of therapy that may require specific screening, and monitoring will be determined by the primary treatment used. If radiation therapy was incorporated, the doses used and fields treated will also be monitored. These may include endocrine surveillance (pituitary, thyroid, gonadal), cardiac assessment, osteoporosis, myelodysplasia, renal function and secondary malignancies (particularly breast cancer in young females where radiation therapy encompasses breast tissue).

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

- in the primary care setting
- by other suitably trained staff (i.e. 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 research and/or clinical trials should be encouraged where available and appropriate.

- 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:

- side effects resulting from high-dose therapy, such as damage to the bone marrow and other quickly growing tissues of the body, immunosuppression, chemically induced menopause (such as atrophic vaginitis and dyspareunia) and changes in androgens that may alter libido and orgasm, require sensitive discussion
- malnutrition post-treatment due to ongoing treatment side effects (such as gastrointestinal symptoms, reduced appetite, 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.

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). This is particularly true for poor prognosis cancers (Temel et al. 2010).

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

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 at <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

Most cases of recurrent Hodgkin or DLBCL are identified through routine follow-up or by the patient presenting with symptoms, or by 'non-specific' systemic tests such as serum LDH.

When there is clinical suspicion of recurrence:

- PET/CT or CT scans with comparison to prior imaging can help confirm recurrence, direct biopsy and re-stage extent of disease if recurrence is proven.
- Bone marrow biopsy may be necessary if aggressive treatment is being considered.
- LDH levels and other testing necessary may be used to determine prognostic and risk factors.

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.

6.3 Treatment

Treatment will depend on the location, extent of recurrent or residual 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.

Systemic chemotherapy is the key component of treatment for recurrent aggressive lymphoma and may be used with potentially curative intent or for palliative purposes. High-dose chemotherapy and autologous stem cell transplantation should be considered in fit patients with recurrent aggressive lymphomas. In selected patients, allografting may be considered. Radiotherapy may be required, usually in combination with systemic therapy (including total body irradiation (TBI)).

Discussion of treatment may include advance care planning and referral to other health professionals.

6.4 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).

Referral to palliative care services should be based on need, not prognosis.

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 at <www.palliativecare.org.au>.

6.5 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

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

6.6 Support and communication

6.6.1 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 outlined in the **appendix**, specific issues that may arise include:

- side effects resulting from high-dose therapy, such as damage to the bone marrow and other quickly growing tissues of the body, immunosuppression, chemically induced menopause (such as atrophic vaginitis and dyspareunia) and changes in androgens that may alter libido and orgasm, require sensitive discussion
- 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, high-dose chemotherapy, 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.

6.6.2 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.

6.6.3 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 backup, 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 multidisciplinary palliative care team may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or spiritual advisor
- bereavement counsellor
- therapist (for example, music, 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 at <www.palliativecare.org.au>.

7.2 Research and clinical trials

Participation in research and clinical trials should be encouraged where available and appropriate.

- For more information 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:

- physical symptoms such as pain and fatigue, reduced appetite, early satiety, 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.

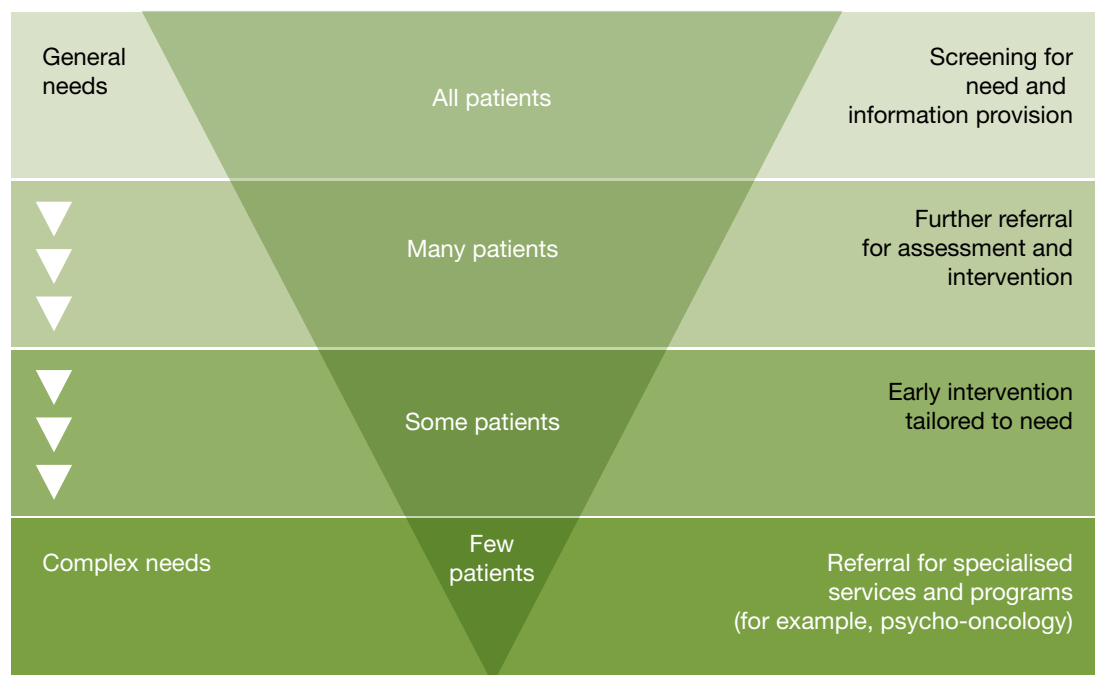
Appendix: Supportive care

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 lymphoma that may require referral to appropriate health professionals and/or organisations include the following:

Physical needs

- 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.
- Alteration of cognitive functioning in patients treated with chemotherapy and radiation therapy requires strategies such as maintaining written notes or a diary and repetition of information.
- Referral to a pharmacist may be useful for people managing multiple medications.
- Although treatments have improved, nausea and vomiting are still serious side effects of cancer therapy. Some patients are bothered more by nausea than by vomiting. Managing both is important for improving quality of life.

Psychological needs

- 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.
- 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 depression by clinicians is part of the long-term follow-up, and referral to a psychologist or psychiatrist may be required.
- Patients treated with stem cell transplantation 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 psychology services.
- Distress and depression can be just as common in carers and family members including children.

- Consider a referral to a psychologist, psychiatrist or social worker if the patient is:
 - displaying emotional cues such as tearfulness, distress, avoidance and 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 lymphoma 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 quitting drug and alcohol use
 - having difficulties transitioning to palliative care.

Fertility preservation

- Consider the need for sperm storage or egg banking before treatment. Referral to fertility counselling may be appropriate.

Social/practical needs

- A diagnosis of lymphoma 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.

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 (aged over 70 years)

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 implications of cognitive impairment on 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

The rarity and complexity of child cancer provides a real challenge in delivering optimal care. Despite overall survival rates of greater than 80 per cent (NICE 2005), treatment modalities for paediatric cancer are often prolonged and complicated and have a narrow therapeutic index. Side effects of systemic therapy for treating cancer can be more severe for children, including 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 cancer should be managed by specialised paediatric services under a 'shared care' model to ensure a critical mass. These specialised services work with others to enable the provision of supportive care closer to home when it is safe to do so. Children's cancer services actively participate in clinical trials as a way of participating in research and improving outcomes for children.

Evidence shows that best outcomes demand a well-coordinated, timely, multidisciplinary approach requiring effective collaboration of health services working together as a team (Children's Oncology Group 2012; Corrigan & Fieg 2004). Integrated care is fundamental to paediatric cancer care and service delivery.

Adolescents and young adults

Recent years have seen the emergence of adolescent and young adult (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, 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 2013b). 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 2013b):

- 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)

A 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, 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 lymphoma, 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 cancer 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 framework – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal cancer 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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Dr Phillip Campbell, Head of Haematology, Barwon Health
Dr Duncan Carradice, Haematologist, Western Health
Dr Geoff Chong, Medical Oncologist, Austin Health, Ballarat Regional Integrated Cancer Centre
Ms Tracey Dryden, National Lymphoma Coordinator, Leukaemia Foundation
Ms Jane Farrow, Senior Occupational Therapist, Peter MacCallum Cancer Centre
Associate Professor Michael Hofman, Nuclear Medicine Physician
Ms Lynda Katona, Manager, Psychological Service, Alfred Health
Dr Kylie Mason, Haematologist, Royal Melbourne Hospital, The University of Melbourne
Dr Françoise Mechinaud, Director, Royal Children's Hospital Cancer Centre
Ms Yvonne Panek-Hudson, Nurse Practitioner, Haematology and Bone Marrow Transplant, Peter MacCallum Cancer Centre
Mr Peter Shuttleworth, Haematology Clinical Nurse Consultant, Austin Health
Mr Graeme Still, Manager, Blood and Marrow Transplant Network, Agency for Clinical Innovation
Professor Robert Thomas, Chief Advisor on Cancer, Department of Health & Human Services
Professor Andrew Wirth, Radiation Oncologist, Peter MacCallum Cancer Centre, The University of Melbourne
Ms Kathryn Whitfield, Acting Manager Cancer Services, Department of Health & Human Services
Alexandra Viner, Project Manager – Optimal care pathways

Governance – project steering committee representation

Ballarat Health Services
Cancer Australia
Cancer Council Victoria, Strategy and Support
Consumer representatives
Department of Health & Human Services, Cancer Strategy and Development
Grampians Integrated Cancer Service
Monash University
North Eastern Melbourne Integrated Cancer Service
Peter MacCallum Cancer Centre
Royal Hobart Hospital
Western Health

Medical colleges and peak organisations

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