

Patient management framework

# Haematological tumour stream: intermediate grade non-Hodgkin lymphoma



a guide to  
**consistent**  
cancer care



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intermediate grade non-Hodgkin lymphoma**

## Acknowledgements

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## 1. Introduction

Cancer is the leading cause of death in Victoria, representing 28.9 per cent of all deaths in 2002<sup>22</sup>. Population ageing will significantly increase the number of new cases of cancer over the next ten years, with an estimated 10,000 more cases per annum in Victoria by 2016. In 2003, 1,176 Victorians were diagnosed with lymphoma and in 2002, 431 deaths in Victoria were due to lymphoma<sup>22</sup>.

Cancer is a complex disease to diagnose and treat, and represents a significant burden to patients and their families, the health system, and the community at large. Victoria's strategic and planned approach to cancer reform includes the establishment of a Ministerial Taskforce for Cancer, and implementation of the *Fighting cancer* policy<sup>3</sup> and *A cancer services framework for Victoria*<sup>23</sup>. Two significant directions of the Cancer Services Framework are the establishment of integrated cancer services in metropolitan and regional Victoria, and the development of service delivery and improvement through a tumour streams model.

Since 2004, eight integrated cancer services have been established in metropolitan and regional Victoria, based on specified geographic populations. The philosophy of an integrated cancer service is that hospitals and primary and community health services develop integrated care and defined referral pathways for the populations they serve. This requires effective collaboration between hospitals and community-based services, including general practitioners. This will promote more effective local coordination of care for cancer patients, and a more rational, evidence-based approach to cancer service planning and delivery. The Cancer Services Framework also recommended that organ or system-specific tumour streams be adopted to support the delivery and improvement of care. The reasoning behind the tumour streams is that a consistent approach to clinical management based on evidence-based practice will reduce unacceptable variations in care across the state.

## 2. Patient management frameworks

The Cancer Services Framework suggested some areas for improvement in the quality of care for cancer patients in Victoria. These included:

- under-treatment of patients with colorectal, lung and prostate cancer<sup>9,20,21</sup>
- inadequate follow-up surveillance of patients with testicular cancer<sup>24</sup>
- a high proportion of cancer patients undergoing surgery with surgeons who performed relatively few operations for colorectal cancer<sup>11,21</sup>
- a high proportion of surgery for ovarian cancer having been undertaken by generalists rather than specialist surgical oncologists<sup>10</sup>.

As a consequence, the Cancer Services Framework recommended that tumour streams be developed to reduce unwanted variation in practice. In response, the Ministerial Taskforce for Cancer recommended that patient management frameworks be developed to provide a consistent statewide approach to care management in each tumour stream. The patient management frameworks are a clear description of the care pathway, identifying the critical points along that pathway and the optimal model of care required. It is important that all patients are assessed and managed appropriately throughout each stage of their journey; however, it should be noted that not all patients will progress through each step of the relevant patient management framework. This is a consequence of many factors, including disease outcomes, management decisions, and patient decisions.

### 2.1 Purpose of the patient management frameworks

The patient management frameworks **are a guide** to the **optimal care management** of patients in each tumour stream. They are intended to improve patient outcomes by facilitating consistent care based on evidence and best practice across the state. They set out the key requirements for the provision of optimal care which need to be considered at each step of the care pathway. In contrast to clinical practice guidelines that guide appropriate practice and decision making, the patient management frameworks provide a guide to the patient journey to ensure patients with cancer and their families receive optimal care and support.

As a guide, the patient management frameworks are to be followed subject to the health professional's independent medical judgment and the patient's preference in each individual case. They are designed to provide information to assist in decision making and organisation of service delivery.

The patient management frameworks **are not rules** and **do not carry a sense of prescription**. The patient management frameworks represent the 'what', rather than seeking to prescribe the 'how'. Recognising that services should be responsive to the needs of different patients at different phases, the patient management frameworks draw on best practice and encourage local solutions. For example, while multidisciplinary care is an essential part of treatment planning, how it is organised depends on the local situation.

In their current format, the patient management frameworks are not designed for accreditation purposes, but may be used to facilitate local benchmarking, service mapping and service development.

The patient management frameworks have been developed in collaboration with a wide range of practitioners, consumers and carers. Wherever possible, the patient management frameworks are based on current best practice, including clinical guidelines, care pathways, standards and research that exist to support optimal care at the critical points. In many cases, however, they are a statement of consensus regarding currently accepted approaches to treatment.

## 2.2 Structure of the patient management frameworks

The patient management frameworks set out seven critical steps of the patient journey. The seven steps provide a consistent structure across the ten tumour streams. While the seven steps appear as a linear model, it is clear that in practice patient care does not always occur in this way but rather depends on the particular cancer, when and how the cancer is diagnosed, prognosis, management decisions, and patient decisions.

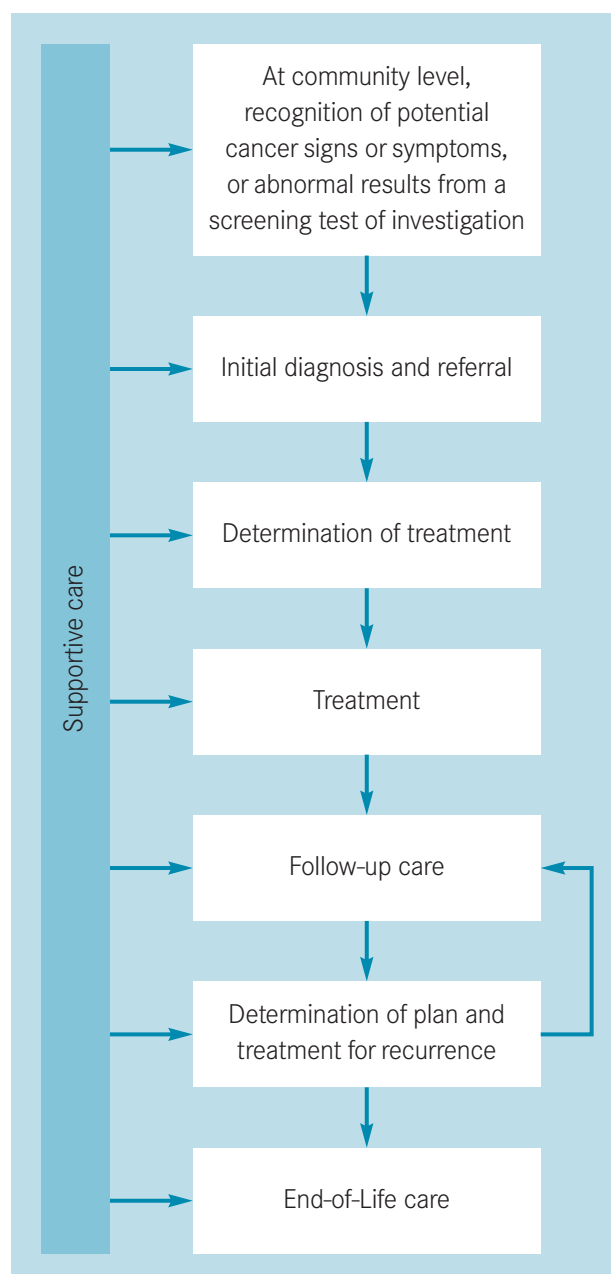
Underpinning the patient management frameworks are key principles that support all seven steps. These are:

**1. patient-centred care.** Patients should be involved as active participants in care planning and decision making, and wherever appropriate so should their partners, families and carers. Ultimately, any treatment decision rests with the patient or designated person. This requires information and discussion in their preferred language and sensitive to their culture

**2. safe and high quality care.** Cancer care is complex, involving a range of clinicians with different expertise. To ensure safe and high quality cancer care, it is important that clinicians have the technical skills and experience to carry out those aspects of cancer care they undertake and that there is institutional capacity to support such care, such as equipment, staffing and skill mix. Further detail is provided in section 3

**3. multidisciplinary care.** The cornerstone of best practice in cancer care is multidisciplinary treatment planning and multidisciplinary care. An effective multidisciplinary approach can result in survival benefit<sup>13</sup>, increased recruitment into clinical trials<sup>14,15</sup>, detection of emotional needs of patients<sup>5</sup>, reduction in service duplication and improved coordination of services<sup>4</sup>. Further detail is provided in section 4

Figure 1: Steps of the patient journey



**4. supportive care.** People with cancer have psychological and social needs that are frequently undetected and unmet<sup>17</sup>. This has the potential to result in long term distress. In the context of cancer, supportive care describes all services that may be required to support people with cancer and their carers to meet their physical, psychological, social, information and spiritual needs. Further detail is provided in section 5

**5. care coordination.** The cancer journey is complex and challenging, and it is not uncommon for patients to be seen by many health professionals within and across multiple health services and across different sectors. A variety of strategies are successful in improving the coordination of care. Some of these include strategies directed at the team, such as multidisciplinary team meetings, clinical protocols and case conferencing; strategies directed at the patient, such as personal patient records, appropriate information provision or case managers; and strategies directed at the health care system, such as electronic medical records, standards, performance indicators and funding models. To ensure patients experience care that is coordinated and integrated over time and settings, services need to consider the range of strategies required to facilitate care coordination.

## 2.3 Development of the patient management frameworks

The patient management frameworks have been developed over a 15-month period in consultation with more than 500 clinicians and consumers through workshops and written submissions. Further information on the development process can be obtained at <http://www.health.vic.gov.au/cancer/tumourstreams.htm>.

Fourteen patient management frameworks have been developed, addressing the following tumour streams and tumour categories:

- breast
- central nervous system (cerebral metastases)
- central nervous system (malignant glioma)
- colorectal (colon and rectal)
- genitourinary (prostate)
- genitourinary (testis)
- gynaecological (ovarian)
- haematological (acute myeloid leukaemia)
- haematological (intermediate grade non-Hodgkin lymphoma)
- head and neck (larynx, pharynx and oral)
- lung (non-small cell)
- skin (melanoma)
- upper gastrointestinal (oesophagogastric)
- upper gastrointestinal (pancreatic).

## 2.4 Future review and development of the patient management frameworks

The 14 patient management frameworks that have been developed will be reviewed in December 2007. Further development of patient management frameworks relevant to the ten major tumour streams will commence in January 2007.

### 3. Credentialling and scope of practice

In 2004, the *National standard for credentialling and defining the scope of clinical practice*<sup>2</sup> was endorsed by the Australian Health Ministers. Developed by the Australian Council for Safety and Quality in Health Care, the standard provides a credentialling framework for all medical practitioners. Credentialling is a formal process for verifying qualifications, competence and performance of individual clinicians as well as defining their scope of practice within a specific health service. The process takes into account the skills and ability of the clinician as well as the capacity of the institution to support the clinician's practice.

This has particular relevance to clinicians working in the area of cancer care. Cancer care is complex for a number of reasons. These include:

- the large number and type of cancers that vary greatly in their pathology and management
- the range of clinicians with different professional expertise (medicine, nursing, allied health) that are involved in care
- the range of specialities for specific treatment modalities, such as breast or colorectal surgeons, radiation and medical oncologists, breast care nurses
- the life-threatening nature of many cancers and the serious complications and side-effects of some treatments
- the advances in technology and research that are changing best practice care at a rapid pace<sup>8</sup>.

In Victoria, the complexity of cancer care poses specific challenges for health professionals working in the area of cancer. The large distances between health services and the relatively low numbers of complex cancers that will be seen at individual health services or by individual health professionals require that innovative approaches to care be developed. These include developing links between health professionals and multidisciplinary teams and initiatives such as the expansion of telemedicine, specific mentoring and upskilling programs.

For patients to have access to safe and high quality services, it is important that professionals working in the area of cancer care ensure:

- they have the necessary skills to carry out those aspects of cancer care they undertake and there is institutional capacity to support such care (for example, equipment, staffing and skill mix)
- they have clear links with a range of specialties or multidisciplinary care team required for cancer care, for the purpose of clinical advice, referral and continuing education
- they follow evidence-based practice or treatment recommendations of a multidisciplinary care team
- they undertake regular review of their performance and contribute to regular audit of their cancer care
- they are actively involved in continuing professional development
- their patients can make an informed choice about their care, including the options of referral to other professionals or specialised centres<sup>8</sup>.

## 4. Multidisciplinary care

### 4.1 Achieving multidisciplinary care

Multidisciplinary care is an approach that includes both treatment planning and ongoing care. The ‘gold standard’ for multidisciplinary care is a team who meets regularly (whether in person or via teleconferencing) to prospectively plan care and treatment for all patients within a tumour group; however, it is expected that different components of multidisciplinary care will be implemented depending on the setting, the location of the team and the number and type of cancer patients being treated. While it may not always be possible to hold a multidisciplinary team meeting prior to surgery, for instance, it would be expected that some other form of multidisciplinary discussion around treatment planning take place. It is likely that regional multidisciplinary care will look different from metropolitan, while being guided by the principle that interaction between multidisciplinary team members is critical in the determination and effective implementation of the treatment plan. It is also acknowledged that patients move between the private and public sector and multidisciplinary care needs to take this into account.

### 4.2 Principles of multidisciplinary care<sup>16</sup>

#### The team

- There is an established multidisciplinary team comprising all core disciplines, including allied health and psychosocial health practitioners.
- The patient’s general practitioner is regarded as a team member and processes to ensure effective communication with general practitioners are implemented.
- Effective communication and referral linkages are made to all core and non-core team members.

#### Communication

- All core disciplines where appropriate and relevant regularly attend multidisciplinary meetings to provide input to diagnostic, treatment, supportive and palliative care planning.

- In instances where not all patients within a tumour group or groups are discussed, team protocols are developed to outline those patients who will be presented at meetings.
- Processes for communicating treatment and care plans for team members who are absent are developed and implemented.

#### Full therapeutic range

- All patients regardless of where they reside will have information about and access to relevant treatments and services.
- Clinical trial involvement is considered for all eligible patients who will be undergoing cancer treatment.

#### Quality

- Decisions, protocols and care pathways are in line with current best practice, including standards, guidelines, research and where these are not available, currently accepted approaches to treatment.
- All relevant diagnostic results, reports and pathology and radiology images are available for multidisciplinary meetings.
- Collaborative links will be formed with smaller and larger referring centres and practitioners. The result will be a network of multidisciplinary teams and practitioners across and between integrated cancer services.
- Professional development activities are supported and held for all team members.

#### Involvement of patient

- Patients are informed of the multidisciplinary team process.
- Patients are informed of the recommendations of the multidisciplinary discussion, provided with information about all aspects of their treatment and participate in the decision making process.
- Patients are routinely given information about and access to supportive care services.

## 5. Supportive care

‘Supportive care is an ‘umbrella’ term for all services, both generalist and specialist, that may be required to support people with cancer and their carers’<sup>19</sup>. It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care<sup>19</sup>.

Supportive care is required throughout the diagnostic, treatment and follow-up phases of care<sup>6</sup>.

In the context of cancer, supportive care needs include:

- physical needs (for example, pain, fatigue)
- psychological needs (for example, anxiety, distress)
- social needs (for example, practical supports, carer needs)
- information needs (for example, regarding diagnosis, prognosis, types of treatment)
- spiritual needs (for example, addressing hopelessness, despair).

### 5.1 Providers of supportive care

Supportive care is provided by generalist and specialist health services as well as community services.

All members of the multidisciplinary team, including general practitioner, surgeon, radiation oncologist, medical oncologist, nurse, social worker and other allied health staff, have a role in the provision of supportive care. In addition, community capacity to support people with cancer makes an important contribution to supportive care. This includes support from family, friends, support groups, volunteers and other community-based organisations.

As a specialist service, palliative care may provide many of the elements of supportive care; however, palliative care also includes specific areas of expertise that may be required, such as unresolved symptoms, and complex psychosocial, end-of-life and bereavement issues<sup>19</sup>.

### 5.2 Achieving supportive care

An important step in the provision of supportive care services is to identify, by routine and systematic questioning of the patient and family, views on issues they require help with for optimal health and quality of life outcomes<sup>7</sup>. Reassessment of their needs is not a ‘once only’ incident because a person’s needs change along the disease trajectory<sup>12</sup>.

A routine and systematic approach to identifying supportive care needs will help to identify people who are at higher risk of psychological or social distress. This identification provides the opportunity for further referral for assessment that is specific to their needs and recognises the individual factors that may place them at increased risk of psychological morbidity. Such factors include characteristics of the individual, such as age and marital status, and characteristics of the disease, such as time of diagnosis or recurrence, stage of disease and prognosis<sup>17</sup>.

A detailed assessment will help to identify those patients who require more specific one-to-one intervention and follow-up.

### 5.3 Establishing a supportive care model

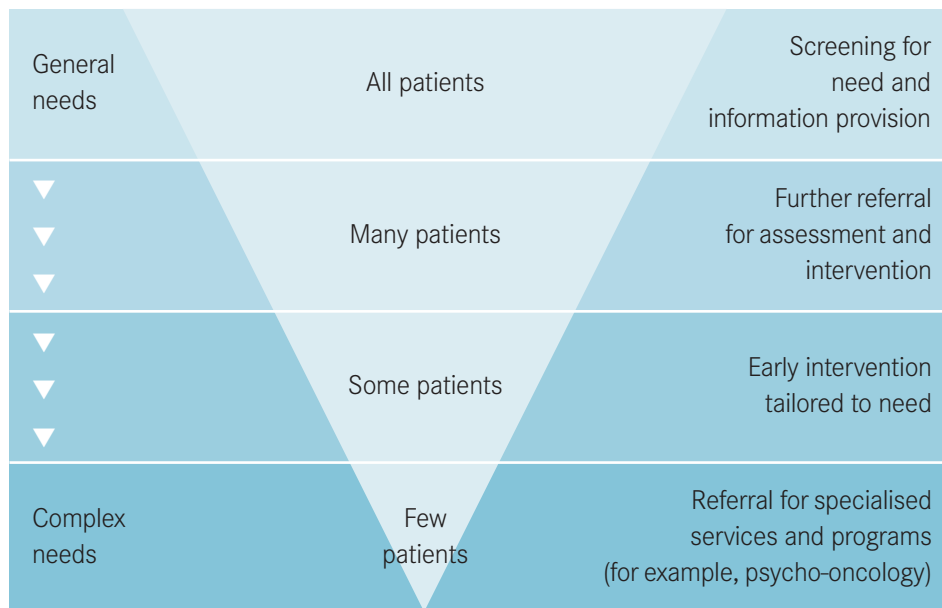
A supportive care model should recognise the variety and the level of intervention required at each phase and be specific to the individual. Such a model (see Figure 2) targets the type and level of intervention required to meet patients' supportive care needs. While there needs to be provision of general information to all patients, only a few patients will require specialised intervention.

As supportive care is provided by a range of services, it is important the following are considered in ensuring cancer patients have access to supportive care:

- processes that assist the identification of patient, family and carer supportive care needs
- clear referral pathways to specialised supportive care services
- adequate staff training in identifying and responding to supportive care needs
- promotion of supportive care as an important element of cancer service delivery.

**Figure 2: Supportive care model**

(Adapted from Fitch<sup>6</sup>. Reproduced with kind permission of Peter MacCallum Cancer Centre).



## 6. Steps in the care of patients with intermediate grade non-Hodgkin lymphoma

This section sets out the steps along the treatment pathway and the optimal care required. Not all patients will follow every step of the pathway. This will depend on particular features of the lymphoma at diagnosis and the patient's decisions about his or her care.

### Step 1:

#### At community level, recognition of potential cancer signs or symptoms, or abnormal results from a screening test or investigation

*This step identifies screening programs, the types of people who may be at higher than average risk of developing cancer, and the types of symptoms that require further investigation by the general practitioner.*

##### 1.1 Screening

- There are no screening programs for non-Hodgkin lymphoma.

##### 1.2 Those at higher risk

- All ages and all demographic groups are at risk for non-Hodgkin lymphoma.
- Intrinsically immunosuppressed patients or those receiving therapeutic immunosuppression (for example, transplant recipients, human immunodeficiency virus (HIV) positive patients) are at risk.
- Family history is a moderate risk factor.
- Any past history of Hodgkin or non-Hodgkin lymphoma is a risk factor.
- Any of these factors suggests a higher than usual level of clinical suspicion is required.

##### 1.3 Signs and symptoms that should lead to general practitioner consultation

- Lump or mass
- Lymphadenopathy
- Persistent lymphadenopathy (up to four to six weeks) or lymphadenopathy associated with systemic symptoms (for example, fevers, sweats, unexplained weight loss, itch or pain)
- Symptoms (such as undiagnosed back or abdominal pain) without palpable lymphadenopathy may also be a mode of presentation.
- Rarely, sudden onset of new respiratory symptoms may be a presenting feature of mediastinal obstruction, particularly in the paediatric population and may require urgent early imaging.

##### 1.4 Timeframe for general practitioner consultation

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

## Step 2: Initial diagnosis and referral

*This step details the process for establishing the diagnosis and appropriate referral. The types of investigations undertaken require discussion and agreement between the general practitioner, specialist and patient. Early referral to establish a diagnosis is essential and discussion with a clinical haematologist or medical oncologist with sufficient skills and experience is often appropriate even in the absence of abnormalities from screening tests.*

### 2.1 General practitioner

#### **Required diagnostic tests**

- Lump/lymphadenopathy
  - A period of observation of up to four to six weeks may be appropriate for patients without any significant or progressive symptoms.
  - Patients with a high likelihood of a malignant process (large mass with significant symptoms, such as weight loss or fevers) should be referred for further assessment.
  - Patients not clearly in this higher risk group should have screening blood tests (full blood examination, urea and electrolytes, liver function tests, uric acid, lactate dehydrogenase) and imaging of the affected area (ultrasound for peripheral lesions, chest radiography and computed tomography (CT) scan as appropriate. Imaging should be undertaken in an accredited imaging facility).
  - Fine needle aspirate with the aim of diagnosing non-Hodgkin lymphoma is inappropriate.
- Symptoms only
  - Screening blood tests: full blood examination, urea and electrolytes, liver function tests, uric acid, lactate dehydrogenase. Abnormalities require immediate further investigation.

### 2.2 Referral

- Referral to an appropriately experienced surgeon (see step 4), clinical haematologist (see step 4) or medical or radiation oncologist (see step 4) for early discussion to guide the referral process is optimal. Pre-biopsy discussion with a surgical oncologist, clinical haematologist or medical oncologist is necessary to ensure appropriate diagnostic tests are performed on the biopsy material.
- Appropriate documentation, including the results of all prior relevant investigations and imaging, relevant past history, and current medication and allergies, should be sent with the patient.
- If the initial specialist is a surgeon, he or she should be experienced in biopsy techniques for the diagnosis of non-Hodgkin lymphoma and have a working relationship with a haematologist or medical oncologist with appropriate experience in the management of non-Hodgkin lymphoma.
  - If a highly invasive procedure would be required to make the diagnosis (for example, laparotomy or thoracotomy), consultation with an appropriately experienced haematologist or medical oncologist is required before the procedure.

- Patients with severe symptoms or clinically significant test abnormalities should be regarded as a medical emergency and be referred immediately. Others should be seen within two weeks.
- The specialist should provide timely communication to the general practitioner about the assessment and should notify the general practitioner if the patient does not attend.

### 2.3 Staging

- Staging is the cornerstone of treatment planning.
- Appropriate pathologic investigations on any biopsy material must be assured.
- Synoptic reporting of pathology is optimal<sup>1</sup>.

### Step 3: Determination of treatment

*This step identifies the members of the multidisciplinary team who need to be involved in initial treatment planning for this type of cancer. An experienced team, including a clinical haematologist with expertise in the management of lymphoma, should determine the recommended treatment path.*

#### 3.1 Multidisciplinary team

- The multidisciplinary team comprises (in alphabetical order):
    - general practitioner
    - haematologist/medical oncologist
    - nurse specialist
    - pharmacist
    - radiation oncologist
    - social worker
    - surgeon
    - symptom management specialists, such as palliative care or pain specialists
- with access to:
- allied health services where appropriate (dietitian, physiotherapist, occupational therapist)
  - infectious diseases physician
  - psycho-oncology services where appropriate (psychologist/psychiatrist).

#### 3.2 Multidisciplinary planning

- Pathology specimens referred from an outside source should be reviewed by a pathologist expert in the diagnosis of non-Hodgkin lymphoma, preferably at the treatment centre before a treatment plan is instituted.
- Details of final diagnosis, staging and treatment plan must be clearly documented.
- A haematologist/medical oncologist expert in stem cell transplantation should be available and consulted to enable early consideration of stem cell transplantation although not necessarily at that centre or as part of initial therapy.
- Every patient with apparently localised intermediate grade non-Hodgkin lymphoma should have access to functional imaging, including positron emission tomography (PET). This is of particular importance where disease distribution will have a significant impact on treatment planning.
- If radiation is planned as part of therapy, this should be documented at this stage and the time from end of chemotherapy to radiation should be monitored.

### 3.3 Next steps in starting treatment

- Every patient being considered for active therapy should have samples taken for flow cytometry, molecular diagnostics and potentially cytogenetics prior to the initiation of therapy.
- Immediate treatment is often required before a full multidisciplinary meeting ratifies details of the management plan.
- The management plan must include details of proposed response assessment, including timing and method of assessment of such.
- The lead clinician should ensure there is adequate discussion with the patient (and family) of the diagnosis and recommended treatment, including rationale and aim, likely effects, possible outcomes, other treatment options (including access to other clinical trials or no active treatment), and psychosocial supports for patient and family.
- There should be timely communication to the general practitioner about the agreed treatment plan.
- Progression of care within the multidisciplinary team should be coordinated, ensuring the patient, general practitioner and multidisciplinary team members are clear on their responsibilities for coordination of care.

## Step 4: Treatment

*This step is concerned with the scope of clinical practice to deliver quality and safe practice. Scope of practice reflects both the expertise and experience of the individual as well as the organisational capability for the provision of safe, high quality cancer services<sup>2</sup>. Where appropriate, a major component of therapy should be participation in a clinical trial.*

### 4A: Surgery

#### 4A.1 Patients who may benefit from surgery

- Surgery is occasionally required for some patients with non-Hodgkin lymphoma.
- Vascular access devices should only be inserted by proceduralists experienced in such procedures.

#### 4A.2 Training and experience of surgeon

- Surgeon (FRACS or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice in the management of non-Hodgkin lymphoma<sup>2</sup>

#### 4A.3 Hospital or treatment unit characteristics

##### **Staff**

Staffing includes:

- Readily available haematologists/medical oncologists and hospital medical officers
- Designated nursing staff with appropriate qualifications and experience
- Accessible specialty staff, including intensive care, infectious diseases and other sub-specialty services
- Multidisciplinary team members as previously designated

##### **Facilities**

The following are available:

- Appropriate inpatient and ambulatory care facilities for managing these patients, including complications
- Availability of imaging
- Pharmacy

### 4B: Radiotherapy

#### 4B.1 Patients who may benefit from radiotherapy

- Radiation should be considered for adult patients with localised disease (Stage I–II) or those with more advanced disease with a dominant bulky lesion.

#### 4B.2 Training and experience of radiation oncologist

- Radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice in the management of non-Hodgkin lymphoma<sup>2</sup>

### 4B.3 Hospital or treatment unit characteristics

#### **Staff**

Staffing includes:

- Nurse specialist
- Radiation oncology medical physicist
- Radiation therapist

#### **Facilities**

The following are available:

- Dual modality LINACS
- Treatment planning system
- CT planning for sophisticated radiation planning
- Capacity for PET-CT planning
- Staff to be familiar with non-Hodgkin lymphoma-specific radiation techniques

## 4C: Drug therapy

### 4C.1 Patients who may benefit from drug therapy

- The majority of patients being treated with curative intent will have drug therapy. Most other patients are also likely to have drug therapy.

### 4C.2 Training and experience of medical oncologist

- Clinical haematologist or medical oncologist (FRACP or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice in the management of non-Hodgkin lymphoma<sup>2</sup>

### 4C.3 Hospital or treatment unit characteristics

#### **Staff**

Staffing includes:

- Nursing staff with adequate training in chemotherapy administration, handling and disposal of cytotoxic waste
- Pharmacist with adequate training in chemotherapy medications, including dosing calculations according to protocols, formulations and/or preparation
- Readily available clinical haematologists or medical oncologists and hospital medical officers
- Accessible speciality staff, including intensive care, infectious diseases and other sub-specialty services
- Multidisciplinary team members as previously designated

### **Facilities**

- Appropriate inpatient and ambulatory care facilities for managing these patients, including complications
- The facility has a clearly defined path to emergency care and advice after hours
- Access to an emergency department with written protocols for the management of complications such as neutropenic fever
- Access to haematology testing
- Preparation of cytotoxic drugs in a pharmacy with appropriate facilities
- Occupational health and safety guidelines followed in relation to handling of cytotoxic drugs including preparation, waste procedures and spill kits<sup>25</sup>
- Guidelines and protocols, in the case of extravasation of drugs, available and understood.
- Medical imaging
- Some components of less complex therapies may be delivered in a setting where no haematologist or medical oncologist is available, by another qualified physician with training and experience that enables credentialling and agreed scope of practice within this area. This must always be in strict adherence with the detailed treatment plan and with constant communication as decided by the primary managing facility. This adherence must be completely documented and forwarded to the primary treatment centre. Response assessments should be undertaken in the primary treatment centre.

## Step 5: Follow-up care

*The focus of this step is to monitor the status of the disease and late adverse effects of therapy and to manage symptoms that arise following the initial treatment. It is important that a clear plan of follow-up is established to avoid excessive follow-up by multiple specialists. Follow-up may vary depending on the individual circumstances of the patient, the intrinsic risk of relapse of their disease, the treatment intention if relapse were to occur, and the long term risks associated with the initial therapy delivered.*

### 5.1 Plan for follow-up

- In the immediate post-therapy setting, the frequency of consultations will be determined by the individual patient's needs and may be between weekly and every six weeks. The primary treating specialist should coordinate these, with input from the full spectrum of allied health professionals.
- The timing and intensity of surveillance for recurrent/progressive disease will be determined by the intended therapy if recurrent disease was identified. This can vary from palliation directed towards symptom control (in which case intensive surveillance for early detection of asymptomatic disease is not warranted) to prompt and intensive intervention with curative intent. Thus, a clear decision about the likely approach to therapy for relapse should be formulated for each patient before deciding on a surveillance schedule.
- When recurrences occur, they are usually detected by investigations of new physical findings or patients' symptoms or by 'non-specific' systemic tests, such as serum lactate dehydrogenase. It is uncommon for asymptomatic recurrences to be detected by routine CT scans, which are relatively expensive.
- A reasonable surveillance schedule is clinical assessment with a careful history and physical examination, full blood examination and lactate dehydrogenase 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 may be added to this schedule depending on the therapeutic plan for management of relapse, with the frequency determined by the level of individual patient risk and specific modality (CT or functional imaging) 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, and if radiation was incorporated, the doses used and fields treated. 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 encompasses breast tissue.

### 5.2 Persons involved in follow-up care

- Not all disciplines need to be involved in longer term follow-up.
- The primary treating clinician is best qualified to supervise and guide the follow-up of the patient with input from the general practitioner, other specialists and allied health practitioners as required.
- Responsibility for follow-up investigations needs to be agreed between the primary treating clinician, the general practitioner and the patient, with an agreed plan documented, including notification to the general practitioner or multidisciplinary team member if the patient does not attend.

## Step 6: Determination of plan and treatment for recurrence

*The focus of this step initially is treatment for recurrence where the intent may be either curative or disease control, acknowledging that in many situations the intent will be palliative. Clinical evaluation and patient decision making will determine the focus of the treatment. A major component of therapy for recurrence should, where appropriate, be participation in a clinical trial.*

### 6.1 Investigative tests

- CT scanning with comparison to post-treatment scans and functional imaging with PET scanning can be supportive.
- Re-biopsy of lesions may be considered, but is not always required. Bone marrow biopsy may be necessary if aggressive treatment is being considered.
- Lactate dehydrogenase levels and other testing necessary may be used to determine prognostic and risk factors.

### 6.2 Multidisciplinary team

- As for initial diagnosis, a team with a clinical haematologist or medical oncologist and/or radiation oncologist
- For applicable patients, access to facilities for high dose therapy and autologous stem cell transplantation and collection of peripheral blood stem cells

### 6.3 Treatments that a patient is most likely to have for recurrence

Where appropriate, a major component of therapy for recurrence should be participation in a clinical trial.

- **Surgery:** Surgery may be required to confirm recurrence and to establish histological category at recurrence, and for insertion of intravenous access devices.
- **Radiotherapy:** Radiotherapy may be required as part of a potentially curative approach, usually in combination with systemic therapy (including total body irradiation), or may be used for palliation. Radiotherapy may be required, usually in combination with chemotherapy, or may be used alone for palliation.
- **Drug therapy:** Systemic chemotherapy is the key component of treatment for recurrent aggressive non-Hodgkin 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 non-Hodgkin lymphomas. Rarely, allografting may be considered.

## Step 7: End-of-life care

*The focus of this step is quality of life for the patient and their families through addressing physical, psychological, emotional and spiritual issues. For the family and carer, this may include bereavement support. Palliation is often complex in these patients, requiring multidisciplinary care, including important roles for palliative chemotherapy and radiotherapy to optimise quality of life.*

### 7.1 Multidisciplinary team

- The multidisciplinary team should include (in alphabetical order):
  - allied health staff as appropriate
  - general practitioner
  - medical oncologist/clinical haematologist
  - nurses with working knowledge of haematologic malignancies
  - palliative care service—relevant team members
  - pastoral care services—relevant team members.
- Close liaison between the palliative care team, the general practitioner and the clinical haematologist or medical oncologist is essential.

### 7.2 Services that may be required

- Palliative care service: community-based and inpatient. Ideally, an integrated community/domiciliary program
- Home and community care
- Community nursing
- Allied health: dietitian, occupational therapy, pastoral care, physiotherapy
- Access to radiotherapy/chemotherapy facilities and transfusion support for some patients

Patients often require recurrent admissions for symptom stabilisation; therefore, ease of access for family is a significant issue.

## 7. Specific supportive care needs to consider for patients with intermediate grade non-Hodgkin lymphoma

The supportive care needs of patients with lymphoma will vary in severity and complexity depending on disease type, stage and treatment along the disease trajectory. Identifying and assessing the supportive care needs of people with lymphoma involves a general assessment of the physical, psychological, social, information and spiritual needs as detailed in section 5. In addition to these general needs, all members of the multidisciplinary team should be aware of the particular needs related to lymphoma detailed below which may require intervention from specific members of the multidisciplinary team.

### Physical needs

- Lengthy treatments require patients to remain in hospital for long periods of time<sup>18</sup>. Monitoring and maintaining nutritional status is important during this time and referral to a dietitian may be required.
- Life-threatening infections for patients who have undergone high dose chemotherapy are a risk<sup>18</sup> 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.
- Chronic graft-versus-host disease can cause persistent malaise<sup>18</sup>. Review by the medical specialist and possible referral to a social worker, physiotherapist and occupational therapist to arrange extra supports and equipment may be needed.
- Patients treated with stem cell transplantation for lymphoma report cognitive impairment to be a major component of quality life impairment, even one year after the procedure<sup>18</sup>. Longer term follow-up for at least one year and strategies to help manage cognitive impairment, such as maintaining written notes, diary and so on, may be helpful.
- Issues regarding chemically-induced menopause, such as atrophic vaginitis and dyspareunia, and changes in androgens that may alter libido and orgasm, require sensitive discussion<sup>18</sup>. 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.

### Psychological needs

#### Infertility

- Infertility as a result of treatment<sup>18</sup> requires sensitive discussion and possible referral to a social worker, psychologist or psychiatrist. Sperm or egg banking may be suggested.

#### Sexuality

- Sexual function may be slow to recover or libido may be low following high dose chemotherapy<sup>18</sup>. Issues regarding sexuality should be raised with all patients. Possible referral to a counsellor with expertise in the area may be required.

#### Depression

- High dose chemotherapy is both physically and emotionally stressful and people who go through it continue to feel exhausted and depressed for a long period<sup>18</sup>. 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.

### Information needs

- Information about follow-up is required because long term problems are common after high dose treatment and allogeneic bone marrow transplant<sup>18</sup>.
- For people adapting to life after receiving bone marrow transplant, there is a BMDI Bone Marrow Transplant Support Group (telephone 9342 7965; [www.bmdi.org.au](http://www.bmdi.org.au)).
- The Leukaemia Foundation provides practical support, transport and accommodation for people and their families with leukaemia and related blood disorders. Telephone 1800 555 021 or visit the web site at [www.leukaemia.com](http://www.leukaemia.com).

## 8. Resource list

### For patients, families and carers

#### 1. The Cancer Council Victoria

1 Rathdowne Street  
Carlton 3053

Telephone: 03 9635 5000  
Facsimile: 03 9635 5270  
Email: [enquiries@cancervic.org.au](mailto:enquiries@cancervic.org.au)  
Web site: <http://www.cancer.org.au>

For information on cancer, its treatment and side effects, support services, medical terminology, and research

#### 2. Cancer Helpline (operated by The Cancer Council Victoria)

Telephone: 13 11 20  
Hours: Monday to Friday, 8.30 am–5.30 pm

For telephone peer support from people who have had cancer experiences or for information on more than 120 cancer support groups across Victoria

#### 3. The Cancer Council Australia

<http://www.cancer.org.au>

##### *Fact sheets:*

Lifestyle: [www.cancer.org.au/lifestyle](http://www.cancer.org.au/lifestyle)  
Early detection: [www.cancer.org.au/earlydetection](http://www.cancer.org.au/earlydetection)  
Post diagnosis: [www.cancer.org.au/diagnosis](http://www.cancer.org.au/diagnosis)

### For health professionals

#### 4. National Health and Medical Research Council

<http://www.nhmrc.gov.au/publications/subjects/cancer.htm>

For downloading clinical practice guidelines for cancer prevention and treatment

#### 5. The Cancer Council Australia

*Fact sheets for health professionals providing advice to patients:*

<http://www.cancer.org.au/factsheets>

One-page fact sheets to help general practitioners and other health professionals advise their patients about cancer prevention, screening and diagnosis. These can also be downloaded from the patient education browser in the latest version (2.86) of the general practice software package, Medical Director.

*Cancer resources for primary health care professionals:*  
[www.cancer.org.au/primarycare](http://www.cancer.org.au/primarycare)

Directory of cancer resources to support general practitioners and other health professionals. Developed by the General Practice Committee of The Cancer Council Australia, the directory provides a single point of access to state, territory and national cancer resources.

#### 6. Clinical trials

A national, online register of clinical trials being undertaken in Australia, the Australian Clinical Trials Registry, is available at <http://www.actr.org.au>. The Australian Clinical Trials Registry includes trials from the full spectrum of therapeutic areas, trials of pharmaceuticals, surgical procedures, preventive measures, lifestyle, devices, treatment and rehabilitation strategies and complementary therapies.

## 9. Abbreviations

FRACP	Fellow of Royal Australasian College of Physicians
FRANZCR	Fellow of Royal Australian and New Zealand College of Radiologists
FRACS	Fellow of Royal Australasian College of Surgeons
LINAC	linear accelerator

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