South Australian Lymphoma Pathway

Optimising outcomes for all South Australians diagnosed with lymphoma

Developed by the Lymphoma working party of the Statewide Cancer Clinical Network with project support from CanNET SA and ABHI Rural Cancer Care Coordinators
August 2010
The pathway development project was undertaken by the Lymphoma Working Party under the auspices of the Statewide Cancer Clinical Network.

The project was funded by CanNET SA and ABHI Rural Cancer Care Coordinators. CanNET is a Cancer Australia initiative, funded by the Australian Government. Australian Better Health Initiative (ABHI) is funded by the Australian, State and Territory Governments.

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¹CanNET SA is a Cancer Australia initiative, funded by the Australian Government
²ABHI Australian Better Health Initiative, funded by the Australian, State and Territory Governments
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EXECUTIVE SUMMARY

The South Australian (SA) Lymphoma Pathway was created under the auspices of the SA Cancer Clinical Network. It provides recommendations based on current evidence for best practice in the management of patients diagnosed with lymphoma.

The SA Lymphoma Pathway has been developed through a collaborative effort involving a wide range of health professionals, including haematology and oncology cancer specialists, generalist practitioners and consumers. It is a statement of consensus based on current best practice, evidence and accepted approaches to lymphoma management. Recommendations should be followed subject to the health professional’s independent medical judgment and the patient’s preference in each individual case.

The Pathway adopts a multidisciplinary approach to the care of people affected by lymphoma with involvement of all relevant health professionals.

In South Australia, lymphoma contributes to approximately 5% of all cancer deaths. Optimal cancer management is achieved through a coordinated service provision between private and public hospitals, general practitioners (GPs), Aboriginal Health Services – community controlled, community and palliative care services and is essential to expedite treatment and access to supportive care and maximise quality of life.

Key recommendations

This document contains 10 recommendations relating to the diagnosis, treatment and supportive care of people with lymphoma in South Australia. A complete list of recommendations is provided at Appendix A. Key recommendations are highlighted overleaf.
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<td>1 Prior to commencement of cancer therapy all patients to have the possibility of infertility addressed</td>
<td>• The possibility of infertility should be addressed as a component of the education and informed consent before cancer therapy commences. All patients of reproductive age or younger should have fertility preservation options discussed/offered.</td>
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| 2 Implement synoptic reporting of pathology as standard | • Implementation of synoptic reporting within all South Australian pathology services  
• Optimal patient management requires accuracy and consistency in histopathologic diagnosis. It is recommended that synoptic reporting of lymphoma becomes the standard for histopathologists. |
| 3 All lymphomas are referred to specialists with adequate experience and expertise in the management of lymphoma | • All patients with a diagnosis of lymphoma should be referred to specialists with experience in the management of lymphoma.  
• It is recommended that all patients with a diagnosis of lymphoma receive treatment where there are appropriately trained specialists available and have the required supportive care infrastructure. |
| 4 All lymphomas are referred to services with adequate workforce and infrastructure to safely and effectively care for patients with lymphoma | • All patients with lymphoma receive treatment where there are appropriately trained clinical specialists available (as per recommendation 3)  
• Acute care of lymphoma is be provided in a service with high standard supportive care infrastructure including  
• Lymphoma patients receiving active treatment including medical oncology and/or radiation oncology should be managed in a service with adequate access to these specialties. |
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| 5 100% of patients with lymphoma are prospectively discussed at a multidisciplinary team meeting within 4 weeks of confirmed diagnosis | • Participation in the MDT becomes an expectation of cancer health professional as core business.  
• Participation in the MDT and/or preparation of diagnostic materials and/or results is included as core business of diagnostic service providers within South Australia.  
• Introduce role of multidisciplinary team co-ordinator to coordinate, monitor and follow up function of MDT. |
| 6 Timely access to results of investigations including, radiology and pathology | • Urgent improvement to ICT links between public sites and across regions to enable adequate access to radiology images and pathology results. |
| 7 All patients with lymphoma have access to specialist nursing care and cancer care coordination throughout the cancer pathway | • Recognition of the role of Lymphoma Clinical Practice Coordinator (CPC) to provide and coordinate supportive care from diagnosis throughout treatment to follow up, survivorship or referral for end of life care.  
• Determine the number of CPCs required based on the volume and complexity of patients and the number of services/sites covered.  
• Patients with lymphoma should have their cancer journey streamlined by appropriate triage of urgency of referral, organisation of appointments and referral for social/cultural supports. |
| 8 Quality and safety of lymphoma care is monitored at state level. | • Statewide systematic centralised database that captures minimum data of all persons with a diagnosis of lymphoma. All treatment outcomes are reported, reviewed and measured.  
• To maintain a complete database of lymphoma.  
• Initiate process for centralised review and reporting of KPI’s and benchmarks of clinical and service outcomes. |
9  All patients with lymphoma have access to culturally appropriate care and effective communication throughout the cancer pathway

- Use qualified interpreters in all consultations where English proficiency and fluency are limited.
- Develop culturally appropriate resources and services.
- Provide cross-cultural training for all staff involved in cancer care.
- Foster links with culturally relevant resources and services.

10  Aboriginal Health Impact Statement for Cancer Pathway development in South Australia

- Implement the recommendations of the comprehensive ATSI Companion Document to the Statewide Cancer Control Plan 2011 – 2015 and SA Cancer Clinical Pathways.
- Address the South Australian Aboriginal Health Impact Statement checklist.
1. INTRODUCTION

1.1 Pathway development
The Lymphoma Pathway was developed by a multidisciplinary working party, under the auspices of the SA Cancer Clinical Network.

The Statewide Cancer Clinical Network Steering Committee (CCNSC) was formed by SA Health and first met in May 2007. The committee agreed that implementation of the Statewide Cancer Control Plan 2006–2009 would be its main objective and subcommittees were then created to address six key areas:

- Prevention and Early Detection
- Optimising Cancer Care
- Infrastructure Planning
- Information
- Workforce
- Research

The Optimising Cancer Care subcommittee prioritised the development of three cancer pathways as proof of concepts for the South Australian (SA) setting. The three pathways are:

- Upper gastrointestinal cancer
- Lymphoma
- Adolescents and young adults with cancer

A comprehensive cancer pathway model was developed with the aim of improving and standardising cancer care for all South Australians regardless of their location, origin, age or financial status. The pathways are based on available evidence and clinical expertise, with a strong emphasis on clinical and supportive care within the local SA context.

The Optimising Cancer Care subcommittee subsequently established working parties to undertake the development of each clinical pathway. The working parties were chaired by leaders in their clinical fields and included multidisciplinary membership from public and private health settings, non government organisations (NGOs), general practitioners and consumers.
Project support for the development of the three inaugural pathways was provided by the Cancer Service National Network Demonstration Program of South Australia (CanNET SA) and the Rural Cancer Care Coordinators, Australian Better Health Initiative (ABHI). CanNET is a Cancer Australia initiative, funded by the Australian Government. ABHI is funded by the Australian, State and Territory Governments.

Each working party utilised the common cancer pathway model\(^1\) (Figure 1) as a basis for individual pathway development to ensure consistency with the concept.

**Figure 1: Cancer Pathway**

- The pillars represent the key requirements that provide support for cancer services.
- The central cancer pathway illustrates the clinical aspects of the cancer journey.
- Integral to clinical care is supportive care, which is represented by the hands.
- The circles or “pods” surrounding the pathway highlight the key issues that require due consideration in planning all cancer clinical and supportive care.

\(^1\) Developed by DM Keefe and K Linke on behalf of the SA Cancer Clinical Network Steering Committee
1.2 Pathway target audience
Each pathway addresses the clinical aspects of the cancer journey and provides recommendations based on current evidence. It is anticipated that the pathway and the pathway recommendations will be of interest to:

- SA Health
- The three health regions in South Australia: Adelaide Health Service, Country Health SA and Child Youth Women’s Health Service
- The Cancer Clinical Network Steering Committee and associated committees and working groups
- Cancer care projects
- Consumers of cancer care
- Non government organisations (NGO)
- General practitioners
- All health care professionals involved in cancer care

1.3 SA Health Aboriginal Health Impact Statement and Checklist
A workshop for the Upper GI and Adolescent and Young Adult cancer pathways towards the preparation of a SA Health Aboriginal Health Impact Statement was held in November 2009. The workshop attendees provided support for these two initial statewide cancer pathways. It was acknowledged that there are many gaps in cancer care for Aboriginal and Torres Strait Islander People and that it would not be feasible to comprehensively address these for each individual cancer pathway developed in South Australia.

The key recommendation arising from this workshop was the requirement for a comprehensive companion health impact document that addresses Aboriginal and Torres Strait Islander cancer care needs in South Australia. This work was completed under the auspices of the Aboriginal and Torres Strait Islander Committee of the Cancer Clinical Network and is titled “Aboriginal and Torres Strait Islander Companion Document to the State-wide Cancer Control Plan (2010 – 2015) and Cancer Clinical Pathway”.

2. LYMPHOMA PATHWAY FOR SOUTH AUSTRALIA

2.1 Purpose
The South Australian Lymphoma Pathway is a guide to the optimal management and care of patients diagnosed with lymphoma. The pathway provides a guide for the patient journey to ensure patients with lymphoma and their families receive optimal care and support.

In South Australia lymphoma contributes to 5% of all cancer deaths. There is an identified need to improve outcomes for patients with lymphoma; both in terms of services to those patients with potentially curable disease and for the majority of the patients who die from their disease. As treatment modalities for patients with lymphoma become increasingly complex, a coordinated service provision between private and public hospitals, general practitioners, community and palliative care services is essential.\(^2\)

The pathway provides recommendations based on current evidence for best practice in the management of patients diagnosed with lymphoma. It adopts a multidisciplinary approach with involvement of all relevant professionals in the care of patients.

The South Australian Lymphoma Pathway has been developed through a collaborative effort of a wide range of health professionals including lymphoma specialists, generalist practitioners and consumers. It is a statement of consensus based on current best practice, evidence and accepted approaches to lymphoma treatment and management. Recommendations should be followed subject to the health professional’s independent medical judgment and the patient’s preference in each individual case.

Aims

- To improve care and outcomes for patients with lymphoma.
- To provide guidance and consistency of practice in patient management and to reduce the wide variation in current practice observed throughout South Australia.
- To encourage appropriate referral and early diagnosis in the general population and in high risk groups.
- To ensure that all patients with lymphoma are offered the best chance of cure or palliation irrespective of where they present or are treated.
- To optimise care delivery for lymphoma patients at all stages of their disease.
2.2 Structure
The South Australian Lymphoma Pathway provides a structured pathway of the patient journey and Figure 5 identifies the critical steps involved. Patient care may not always occur in this way as factors including the particular cancer, when and how it is diagnosed, prognosis, management decisions, patient decisions will all impact on individual management.

2.3 Key principles
There are several key principles that support each stage of the pathway:

Patient centred care
- Patients and their families/care givers are encouraged to be involved as active participants in care planning and decision making. Ultimately treatment decisions rest with the patient or designated person. This requires information and discussion to be provided in their preferred language and in a manner that is sensitive to their culture.

Safe and high quality care
- Cancer care is complex, involving a range of specialist providers and clinicians with varied clinical expertise. To ensure safe and high quality cancer care it is essential for clinicians to possess the technical skills and experience to undertake the relevant aspects of cancer care and have access to appropriate infrastructure to support such care.

Multidisciplinary care
- Best practice in cancer care involves multidisciplinary treatment planning and multidisciplinary care.
- Effective multidisciplinary approaches in the management of patients with cancer have demonstrated positive outcomes, including increased survival, a greater understanding that a comprehensive team is providing care, a greater likelihood of receiving care that is in accordance with clinical practice pathways (including psychosocial and practical support), increased access to information for patients and increased patient satisfaction with care.

Supportive care
- Patients with cancer have psychological and social needs that are frequently undetected and unmet, and have the potential to cause long-term distress.
Supportive care includes the acknowledgement of all domains of patient needs – physical, psychological, social, informational and spiritual – that may be required to support the patient and their families/care givers.  

**Care co-ordination**

- Patients require co-ordination of their health care. A variety of strategies have been shown to improve co-ordination of care and these include multidisciplinary team meetings, clinical protocols, access to cancer nurse specialists and utilisation of appropriate performance indicators.

### 2.4 Statement of intent

This pathway is not intended to be used as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve.

Adherence to pathway recommendations will not ensure a successful outcome in every case, nor should they be considered as including all proper methods of care or excluding other acceptable methods of care aimed at the same results.

The ultimate judgement must be made by the appropriate health care professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This decision should be made only after discussion of the diagnosis and available treatment options with the patient. It is advised, however, that significant departures from the South Australian Lymphoma Pathway should be documented in the patient's case notes at the time the relevant decision is taken.

### 2.5 Review and updating

The South Australian Lymphoma Pathway was released as final draft in 2010. It is expected that after refinement and review during 2010 it will be due for periodic review every two years. Interim updates of the Lymphoma Pathway will be undertaken as recommended by the Optimising Cancer Care Committee.

---

3. ibid
4. ibid


8 ibid

9 ibid
3. Lymphoma in South Australia

3.1 Incidence, mortality and trends

In South Australia, lymphoma was the sixth most common cancer in 2006, with non-Hodgkin lymphoma accounting for approximately 90 percent of cases, and Hodgkin lymphoma accounting for the other 10 percent.\(^\text{10}\)

The incidence of lymphomas for South Australia in 2006 accounted for 4.8 percent of all cancers, equating to 23 person cases per 100,000 and mortality comprising 4.5 percent of all cancers resulting in 7.9 person cases per 100,000.\(^\text{11}\)

Whilst incidence and mortality for both males and females steadily increased between the years 1977-2001, incidence shows a decreasing trend between the years of 2002-2006 (per annum) of -2.3 percent for males and -0.6 percent for females, with a mortality decrease of -3.7 percent for males and -3.1 percent for females.\(^\text{12}\)

In 2006, the lifetime risk for all lymphomas in males was 1 in 49 and females 1 in 69. The male incidence rate was 28.8 cases per 100,000 whilst lymphoma in females occurred 23 cases per 100,000. The reason for increased male incidence is not clear.\(^\text{13}\) The cause for most lymphomas is not known, however some risk factors have been identified.\(^\text{14}\) Refer to Lymphoma Clinical Practice Guidelines and Chapter 9, Screening and Early Detection http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/cp107/cp107.pdf

![Male Lymphoma - Incidence and Mortality* 1977-2005 All Ages](image)

Figure 2: Male Lymphoma – incidence and mortality 1977-2005 all ages. Includes Hodgkin and Non Hodgkin Lymphoma\(^\text{15}\)
Survival
For the period 1997-2007, there have been significant improvements in 5 year survival rates. For Hodgkin lymphoma this has increased from a base of 78 percent in 1977 to 86 percent 5 year survival in 2007. For non-Hodgkin lymphoma there has been an even more significant increase rising from 49 percent in 1977 to 68 percent in 2007. While lower survival rates applied to non-Hodgkin lymphoma than Hodgkin lymphoma, the outcomes varied for the former by grade, with the proportion surviving their disease at five years from diagnosis in 2007 ranging from 57 percent for high grade, 59 percent for intermediate grade and 78 percent for low grade lymphoma. Treatment advances have been responsible for the improvements in lymphoma survival over the past 2 decades in South Australia.

Aboriginal and Torres Strait Islanders
During 2000-2004, lymphoma incidence rates were found to be 34 percent lower for Aboriginal and Torres Strait Islander people than other Australians. South Australian data for years 1977-2000 also indicate a lower incidence of lymphoma among Aboriginal people, with 7.9 cases per 100,000 as compared with 10.8 cases in Asian peoples, and 12.7 cases occurring in Caucasian and other peoples. However, survival for Aboriginal and Torres Strait Islanders is markedly reduced when compared to all Australians, often
because disease is more advanced at diagnosis and they are less likely to receive specific cancer treatments. However, it is important to note that these factors do not fully explain the observed survival disadvantage.\textsuperscript{22}

### 3.4 Ethnic and socioeconomic differences

Within South Australia, the incidence of non-Hodgkin lymphoma in those born overseas was almost 20 percent less than Australians born between the years of 1977-2000. The metropolitan area of Adelaide has an incidence approximately 12 percent higher for non-Hodgkin lymphoma than country regions of South Australia. Although evidence is not consistent, data suggests a slightly higher level of incidence associated with peoples of upper socio-economic status, although evidence is not consistent.\textsuperscript{23} For Hodgkin lymphoma, data suggests that within South Australia between the years 1977-2000, residents born overseas have an incidence about three quarters that of the Australian born. Comparison of Hodgkin lymphoma incidence rates by socioeconomic status and region of residence is hampered by small numbers.\textsuperscript{24}

### 3.5 South Australian's less than 25 years of age

Lymphoma is the third most common form of cancer affecting young people under 25 years of age in South Australia. Between 1977-2004, 430 cases of lymphoma were diagnosed in this age group, with two thirds of cases occurring in 15-24 year olds. Approximately three in 100,000 young people under 25 years of age will develop lymphoma each year.\textsuperscript{25} The types of lymphoma diagnosed among young South Australians 0-24 years old can be seen below in Figure 7. Hodgkin lymphoma is more predominant among 15-24 year olds, whilst non-Hodgkin lymphoma was diagnosed more in children under the age of 15. Survival for young South Australians with lymphoma is good, with 81 percent surviving at least 5 years after diagnosis.\textsuperscript{26}
Figure 4: Types of lymphoma diagnosed among South Australians 0-24 years old (1977-2004)\(^{27}\)

Further Information:

- South Australian Cancer Registry - South Australian Government
- Cancer Council SA - Centre for cancer research
- Cancer Council SA - Graphical Presentation of Cancer Trends

\(^{10}\) Centre for Cancer Control Research. South Australian cancer statistics. monograph No 5. Lymphomas, Myeloma and Leukaemias. Adelaide South Australia: Cancer Council South Australia; 2003.


\(^{12}\) ibid

\(^{13}\) Centre for Cancer Control Research. South Australian cancer statistics. monograph No 5. Lymphomas, Myeloma and Leukaemias. Adelaide South Australia: Cancer Council South Australia; 2003.

\(^{14}\) ibid


\(^{16}\) ibid

\(^{17}\) South Australian Cancer Registry. Adelaide: South Australian Department of Health.

\(^{18}\) ibid

\(^{19}\)Centre for Cancer Control Research. South Australian cancer statistics. monograph No 5. Lymphomas, Myeloma and Leukaemias. Adelaide South Australia: Cancer Council South Australia; 2003.


\(^{24}\) ibid

\(^{25}\) ibid

\(^{26}\) ibid

\(^{27}\) ibid
4. LYMPHOMA PATHWAY

People affected by lymphoma have diverse and complex clinical and supportive care needs. Figure 5 illustrates and identifies the steps and optimal care requirements for the Lymphoma Pathway. The Pathway promotes care coordination and a consistent, standardised approach to managing care. A well-coordinated and managed cancer journey will ensure that people affected by lymphoma experience coordinated care.

It is acknowledged that many people affected by lymphoma may not follow every step of the Pathway, due to variations in clinical presentation that will influence individual decisions about patient care.

On the left side of the Pathway are recommended timeframes from presentation of symptoms to presentation at the multidisciplinary team meeting. Timeframes beyond the multidisciplinary team meeting are not considered in this Pathway due to complexity and variability of individual clinical and patient decisions.

On the right side of the Pathway are recommended key performance indicators (KPI's). This is not a complete list of recommended KPI's for a cancer pathway but represent the priority performance measures required to close the gaps in current lymphoma care, as identified by the Lymphoma Working Party.
Figure 5: Lymphoma Treatment Pathway

This pathway sets out the steps along the treatment pathway and the optimal care required. Not all patients will follow every step of the pathway.

Prevention and Minimising Cancer Risk, Screening and Early Detection
Patient seeks advice/medical review for symptoms

Role of GPI Emergency Health Services in Initial Assessment
Relevant investigations using GP flow chart
Timely referral

Referral
Lymphoma specialist
Specialist lymphoma nurse – role to incorporate supporting patient throughout the cancer experience, from diagnosis to survival or end of life

Staging Investigations
Data set for presentation at MDT meeting:
- Biopsy (if not performed as part of GP investigation, using symptomatic request)
- CT (neck, chest, abdo, pelvis with contrast) PET (recommended for Hodgkin Lymphoma or high grade lymphoma)
- MRI (if pregnant)
- Bone Marrow Biopsy (not for stage 1-2A Hodgkin Lymphoma)
- Lumbar Puncture if indicated by sites or histology
- Baseline organ function: MUGA, ECHO, Liver, kidney and pulmonary function, viral serology (including Hep A, B, C)

Multidisciplinary team care
Presentation at Lymphoma MDT meeting
Assessment and Treatment
Individualised treatment recommendations

Treatment
- Surgery
- Chemotherapy
- Radiotherapy
- Palliative Care
- Supportive Care
- Active Monitoring

Follow Up
- All patients to have systematic post treatment surveillance
- End of treatment summary to GP and patient

Survivorship needs
- Specialist survivorship clinics

Survivorship
Monitoring and management of long term treatment or disease sequelae

Primary care providers
- GP
- Community Health / Nurses

Disease Recurrence
Reassessment of disease status
Present at MDT to determine management plan

Supportive Care

Integral

Throughout the Entire Pathway

Medium Timeline

Patients to be seen within 2.0 weeks of confirmed diagnosis

Diagnosis to presentation at MDT meeting within 3-4 weeks

End of Life

7 days from referral to surgical biopsy

10 days for PET scan for lymphoma as indicated

Submit urgent staging computer and biopsy from diagnosis (low grade lymphoma AC)

100% of patients will receive diagnosis by presence at MDT meeting

Number of patients referred to AYA covers all family presentation
5. MULTIDISCIPLINARY AND COORDINATED CARE

Multidisciplinary team care is an approach to health care that is critical to treatment planning and ongoing management and is provided by a team who meet regularly either face to face or via teleconferencing/videoconferencing to prospectively plan care and treatment for all patients with lymphoma. This approach to care is essential for patients with lymphoma regardless of location (rural/metropolitan) or insurance status (public/private).

5.1 Benefits of multidisciplinary care

Demonstrated benefits include:\(^ {28}\)

- increased provision of evidence-based care in accord with clinical practice pathways (where available) with implications for both clinical outcomes and cost effectiveness
- all treatment options are considered and treatment plans are individualised to each patient
- improved referral pathways
- decreased variation in care
- increased referrals for psychosocial support
- increased discussion of patient eligibility for clinical trials
- enhanced clinical education opportunities
- opportunity for clinicians to interact.

Positive outcomes identified for patients include: \(^ {29}\)

- increased survival when care is managed by a multidisciplinary team
- increased patient satisfaction with care
- increased access to information for patients, particularly psychosocial and practical support
- increased perception by the patient that care is being managed by a team.

5.2 Multidisciplinary care principles

1. A team approach \(^ {30} 31\)

- An established multidisciplinary team that comprises relevant core disciplines, including allied health and psychosocial health specialists.
- The general practitioner is regarded as a team member and effective communication processes between the multidisciplinary team and the general practitioner are established.
• Effective communication processes exist with access and referral links between all core and non-core team members.

2. Communication among team members.\textsuperscript{32, 33}

• All the core team members regularly attend multidisciplinary team meetings to provide input into diagnostic, treatment, supportive and palliative care planning.
• Processes are in place for communication of treatment recommendations and care plans between core team members.

3. Access to the full range of therapeutic modalities for all patients, regardless of geographical remoteness or size of institution.\textsuperscript{34, 35}

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

4. Provision of care in accord with agreed standards/pathway.\textsuperscript{36, 37}

• Decisions, protocols and care pathways are in line with current best practice, including standards, research and where these are not available, currently accepted approaches to treatment.
• All the relevant diagnostic results, reports and pathology and radiology images are available for multidisciplinary team meetings.
• Professional development activities for all multidisciplinary team members are offered and supported.

5. Involvement of patients in decisions about their care.\textsuperscript{38, 39}

• Patients are informed of the multidisciplinary team care.
• Patients are informed of the multidisciplinary team recommendations, provided with information about all aspects of their treatment and participate in the decision making process.
• Patients are routinely provided with suitable information about and access to supportive care services.
### 5.3 Role of the general practitioner in lymphoma care

#### Clinical

**Early detection, investigation and referral**
- Recognition of signs/symptoms of lymphoma.
- Documentation of history and clinical findings.
- Responsibility of initiating and review of results of initial investigations.
- Use GP diagnostic flow chart.
- Referral to lymphoma specialist using GP referral form.
- GP’s may wish to attend and participate in MDT.

**Throughout treatment and post treatment surveillance**
- Liaising with lymphoma specialist, possible roles include:
  - Patient assessment
  - Pre- chemotherapy assessment, haematological and biochemical status (particularly in rural areas)
  - Monitoring of toxicities

**Post treatment surveillance**
- Use of protocols that require regular tests/investigations.
- Monitoring of symptoms, including prompt referral back to specialist.
- Monitoring of long term complications that arises from chemotherapy, radiotherapy and surgery, reviewing and referring to supportive cancer services as required.

#### Supportive Care

**Psycho/social**
- Patients should be informed and educated of suspected diagnosis and possible treatment options.
- Ensure rural/remote patients receive additional information regarding services.
- All individuals, particularly those at high risk, i.e economically disadvantaged, intellectually challenged, mental health issues, limited or no family support, CALD, ATSI, AYA or geriatric and rural/remote locations should be provided ongoing psycho/social support and referral as required.
- Ensure patients have access to supportive organisations.
- Development of mental health plan and input from psychologist to assess for anxiety and other psychological symptoms.
- Provision of support and contact with care givers.

**Palliative Care**
- If focus of care is palliative, refer and participate in shared care with palliative services.
- Awareness of needs of patient and family.

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### Further Information
- Clinical Practice Guidelines for the diagnosis and management of lymphoma
- Clinical Practice Guidelines for the diagnosis and management of lymphoma – a guide for general practitioners.
- General practitioner lymphoma diagnostic flow chart
- Chapter 9 Screening and Early Detection
- GP referral form to lymphoma specialist
  [http://www.sahealth.sa.gov.au/wps/wcm/connect/b4b0c900459fcedbb4fd4519b2d33fa/Lymphoma+Pathway+ATTACHMENT+2+GP+Referral+to+Specialist+template.pdf?MOD=AJPERES&CACHEID=b4b0c900459fcedbb4fd4519b2d33fa&CACHE=NONE](http://www.sahealth.sa.gov.au/wps/wcm/connect/b4b0c900459fcedbb4fd4519b2d33fa/Lymphoma+Pathway+ATTACHMENT+2+GP+Referral+to+Specialist+template.pdf?MOD=AJPERES&CACHEID=b4b0c900459fcedbb4fd4519b2d33fa&CACHE=NONE)
- Appendix D – Referral for psychosocial support
- Appendix B – Cancer Resources in SA
5.4. Role of specialist nursing and care coordination in lymphoma care

Specialist nurses have been working in the haematology cancer setting in the United Kingdom (UK) for a number of years, with specific lymphoma clinical nurse specialists employed since 2004. Furthermore, the importance of this role has been realised in Australia with the appointment of a Lymphoma Clinical Nurse Specialist at the Peter MacCallum Cancer Centre in Victoria.

Establishment of these positions in South Australia is essential for the delivery of appropriate care to this patient group. Specialist lymphoma nurses such as the Nurse Clinical Practice Consultant, Nurse Practitioner or Cancer Care Coordinator are a central contact point for cancer patients, their family members and the primary treating team. This is a multi-faceted role, working with the multidisciplinary team to ensure continuity and coordination of care between multiple health providers and settings with the aim of improving the patient’s journey and quality of care. UK studies have demonstrated that not only do specialist lymphoma nurses contribute towards optimising practice through patient satisfaction but also have a positive effect on economic performance of their employing institution through streamlining patient journeys and reducing clinical risk.

Clinical
- Coordination and liaison with other health professionals
- Facilitating informed consent, including patients understanding of the disease, related investigations and treatment regime.
- Requesting appropriate investigations in accordance with protocols.
- Interpreting diagnostic results.
- Nurse led clinics for patients throughout the disease continuum.

Supportive Care
- Provision of verbal and written support.
- Counselling of potential benefits and/or risks of treatment.
- Assessment and screening of patient’s psychosocial needs and referral to appropriate professionals.

Further Information
- Distress thermometer [http://www.ecco-org.eu/01/MyImages/distress_thermometer.jpg](http://www.ecco-org.eu/01/MyImages/distress_thermometer.jpg)
- Appendix B – Cancer Resources in SA
Recommendations:

1. GP’s need access to information regarding available cancer services in rural and metropolitan locations either in leaflet format or email, better links with RACGP in providing up to date information.

2. Patient Information packages for all patients with potential diagnosis of lymphoma.

3. Rural patient package – disease information, practical information i.e – accommodation, PATS, Centrelink, social worker contact.

4. Cancer Council resources to be utilised as standard practice.

5. All patients with a lymphoma diagnosis have access to a specialist lymphoma nurse throughout the cancer pathway.

30 ibid
44 Cancer Nurses Society of Australia. Position Statement for Cancer Care Coordinators. Sydney, Australia; 2008
48 ibid
6 SUPPORTIVE CARE

6.1 Supportive care principles
Supportive care is a term used for all health services (generalist and specialist) that may be required to support people with cancer and their families and/or care givers.\textsuperscript{50}

The spectrum of supportive care includes:

- management of physical symptoms and side effects across the cancer continuum
- management of psychosocial issues
- enhancing rehabilitation
- promoting healthy lifestyles with health risk reductions strategies
- survivorship
- end of life care\textsuperscript{51}

Supportive cancer care addresses various domains including:

- physical
- psychological
- social
- spiritual
- information

All needs must be addressed in a culturally and linguistically appropriate manner.
Specific supportive care needs are considered in Chapter 7.
Figure 6: The diagram below identifies components required to achieve best practice supportive cancer care.⁵²

Providers of supportive care
All members of the multidisciplinary team have a role in the provision of supportive care. In addition the patient may have support from family, friends, support groups, volunteers and other community-based organisations.

As a specialist service, palliative care may provide many elements of supportive care and specific expertise such as management of refractory symptoms of cancer and/or its treatment, complex psychosocial issues and end of life and bereavement issues.⁵³

Supportive care for patients with lymphoma and their families and/or caregivers is an integral component of evidence based best practice clinical care. Research indicates that people with cancer who receive appropriate information and psychosocial interventions have lower rates of anxiety, mood disorders, nausea, vomiting, pain, as well as a greater knowledge and understanding about their disease and treatment.⁵⁴
Achieving best practice in supportive care

Supportive care service provision requires an initial assessment and identification of the patient’s specific needs. This is achieved through regular discussion and systematic review of the patient and their care givers. Regular reassessment is essential, as needs frequently change throughout the cancer journey.

This review process assists in identifying those patients who are experiencing significant levels of distress and are at higher risk of psychological morbidity, and facilitates appropriate referral for further assessment and specific interventions. The Australian Clinical practice guidelines for the psychosocial care of adults with cancer\(^57\) [http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/cp90.pdf](http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/cp90.pdf) and the National Comprehensive Cancer Network’s clinical practice guidelines for distress management\(^58\) recommend the use of a validated screening tool such as the distress thermometer.

Establishing a supportive care model

The type and level of interventions required to meet supportive care needs for patients and their carers will vary. Many patients’ needs will be adequately met through the provision of general information, while only a few patients will require specialised intervention.\(^59\)

As a range of professionals and services provide supportive care, it is important to have in place:\(^60\)

- processes that assist the identification of the patient’s, family’s and/or care giver’s supportive care needs
- a clear referral pathway to specialised supportive care services
- adequate training of staff in identifying and responding to supportive care needs of patients
- promotion of supportive care as an integral component of cancer service delivery.
- adequate communication between health services
6.2 Psychosocial needs

A routine and systematic approach should be used to identify patients who are experiencing high levels of psychosocial distress and are at risk of developing psychological morbidity.\textsuperscript{61} Identifying patients who are at a high risk provides opportunity for referral for assessment that is specific to their needs and recognises the individual factors that may place them at increased risk of psychological morbidity.\textsuperscript{62} A detailed assessment of supportive care needs will help identify those patients who will require more specific one-to-one intervention and follow up.

Managing psychosocial needs

- A screening tool (such as the Distress Thermometer - \url{http://www.ecco.org.eu/01/MyImages/distress_thermometer.jpg}) can indicate factors contributing to the distress, which may include practical, emotional, social/family, spiritual, physical or a combination of these.\textsuperscript{63}
- Referral can then be made to an appropriate supportive care professional, for example a specialist nurse, psychologist, social worker, welfare worker or allied health professional.
- Patients with significant levels distress may be at risk of developing symptoms including anxiety and depression. These patients will require further investigation of their distress and may require referral to a social worker, psychologist or psychiatrist depending on the nature of their distress and emotional concerns. Refer to Referral for psychosocial care, Appendix D.
- Patients with information or physical needs require referral to the specialist nurse or to a community support group.\textsuperscript{64, 65}
- Self management strategies such as relaxation techniques and meditation may also be beneficial.\textsuperscript{66}
- Where necessary, ensure patients and their care giver(s) have access to:
  - an interpreter
  - culturally appropriate resources
  - culturally appropriate support

Communication with patient and care givers

Patients require verbal and written information that is culturally appropriate and may require access to a qualified interpreter. Information required includes detail about the disease, the reasons for and likely effects of diagnostic procedures and treatment options
(including known risks and potential adverse effects). A clear explanation should be also given when interventions that patients might anticipate are not offered; for example, when histological confirmation of cancer is not sought. Patients and carers should receive both individual support and guidance and well-produced information leaflets.

It is recommended that health care providers ask patients if they want additional information and discuss how much they wish to be involved in decisions about treatment. Determine the patient’s needs and preferences regarding information about treatment, and encourage family members, care givers and/or others who may provide culturally appropriate support to the patient during consultations.67

All health professionals involved should know what information has been given to each patient. A record of this, along with the patient’s preferences for information and involvement in decision-making, should be included in the notes and given to the patient’s general practitioner, together with a comprehensive summary of the management plan. Communication needs to be effective, with fast and efficient links between hospitals and primary care teams.68

Patients with lymphoma have identified that there is a need for information to be given to their family and/or care giver about the patient’s supportive needs/requirements when returning home from treatment in hospital. The importance of patient support groups was stressed, as well as the need for a nurse specialist to support patients and their carers.69

6.3 Respecting diversity

Aboriginal and Torres Strait Islander peoples
Australia’s Indigenous population is comprised of Aboriginal and Torres Strait Islander people. Once in four Aboriginal and Torres Strait Islander people live in rural and remote regions of Australia. Aboriginal and Torres Strait Islander people are more likely to present with advanced illnesses and may have multiple co-morbid illnesses in addition to cancer.

The concept of health and wellbeing for Aboriginal and Torres Strait Islander people is a holistic one encompassing all aspects of physical, emotional, social, spiritual and cultural well being and a specific kinship with family.70 71 Many Aboriginal people believe that
wellbeing is determined socially, rather than biologically or pathologically. Given the powerful role of traditional beliefs about illness and health, it is important to include the input of those who are familiar with Aboriginal and Torres Strait Islander culture (a suitable cultural advisor) and language (as many patients may not have English as their first language) and to incorporate specific understandings of the needs of those residing in rural and remote areas.

Staff with specific expertise in the management and support of Aboriginal and Torres Strait Islander patients are located in the larger metropolitan public hospitals. Aboriginal health nurses and Aboriginal hospital liaison workers are available to provide assistance following patient referral by the multidisciplinary team and to provide advice on culturally safe and respectful care.

**Culturally and linguistically diverse communities**

Australia has one of the most culturally diverse communities in the world. In 2006, 22% of Australia’s population was born outside of Australia; therefore it is essential to consider the culturally and linguistically diverse needs of all people in relation to a diagnosis, treatment and management of cancer.

All consumers/patients are individuals and require a person focussed approach to care; with health care professionals engaging in respectful enquiry about preferences that intersect with health care, including religious or spiritual values, cultural values, gender preferences and dietary requirements. These aspects are connected to a successful health care experience and outcomes.

Overseas born South Australians tend to have lower incidence rates of lymphoma than the Australian born; however, ageing of the population is associated with increased cancer morbidity and mortality. Within the culturally and linguistically diverse community language barriers and lack of knowledge of the South Australian health care system limit access to health information and health care services.

People may have a variety of cultural perspectives or preferences, for example:

- Many patients will prefer to see a medical professional of their own sex.
- There are many myths and misconceptions about cancer diagnosis.
- Cancer may be a taboo subject or cause discrimination, contamination, shame, or retribution.
• Religion may play a fundamental role in the person’s attitude towards their disease and treatment,

• Family and extended families have a central role in many cultures. Family members often share rights and responsibilities and decision-making, and this may influence the choice of treatment.

Attitudes to caring and support may vary between cultures and within cultures. It is important not to make assumptions or stereotype. Encourage patients to seek support from family and friends, and community, ethnic and religious organisations, if appropriate. Wherever possible, offer the patient the opportunity to bring a family member or friend with them to consultations and treatment. People may not be accustomed to the concept of support from external agencies, so this requires a sensitive and respectful approach.

**Further information:**

- [Appendix B](#) lists cancer resources and support groups in South Australia.
- [Appendix C](#) lists key resources of information available for Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities.
- Referral for psychosocial care: [Appendix D](#)
- [Appendix E](#) lists common questions/concerns raised by people with cancer.
- Lymphoma Patient Information Pathway: [Appendix F](#)
- Complementary therapy information is provided in Chapter 13.
- Assistance with smoking cessation pre- and post-treatment may be required\(^1\); information is available from the lymphoma specialist nurse and the Quit line: 137848.
Recommendations:

6. Regular psychosocial assessment of patients/care givers along the cancer continuum is required to identify those experiencing significant levels of distress and who may be at risk of developing psychological morbidity.

7. All people with a cancer diagnosis have opportunity to receive culturally appropriate education and counselling (via a qualified interpreter if appropriate) regarding their diagnosis, options and care needs by a health professional with appropriate communication skills and knowledge of lymphoma.

8. Use of qualified interpreting services is essential for people of culturally and linguistically diverse backgrounds to ensure access to health care services.

51 MASCC. Supportive care makes excellent cancer care possible. 2008.
52 MASCC. Supportive care makes excellent cancer care possible. 2008.
62 ibid
64 Gessler S et al. Screening for distress in cancer patients; is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. Psycho Oncology 2007; 17:538-547.
68 ibid


73 CALD steering committee for the Central Northern Adelaide Health Service. Cultural and linguistic diversity, a resource for health staff.

74 Ibid

75 Department of Immigration and Citizenship. The People of South Australia: statistics from the 2006 census. ACT. Australia; 2008

76 CALD steering committee for the Central Northern Adelaide Health Service. Cultural and linguistic diversity, a resource for health staff.

77 Ibid


7. SPECIFIC SUPPORTIVE CARE NEEDS

The specific supportive care needs of patients with lymphoma will vary in complexity and severity along the disease trajectory. A supportive care assessment includes assessment of the physical, psychosocial, spiritual and information needs of the patient and requires input from all members of the lymphoma multidisciplinary team.

1. Life-threatening infections

Patients may be at risk of developing life threatening infections. This requires strict adherence to universal guidelines, involvement of the infection control specialist and close monitoring of blood counts by the haematologist/oncologist. Patients require education regarding febrile neutropaenia, monitoring and care required at home and when to present to an emergency services department if they become febrile and/or feel unwell.

2. Infertility and premature menopause

Infertility may result from some therapies, therefore this possibility should be addressed as a component of the education and informed consent prior to treatment commencing. All patients of reproductive age or younger should have fertility preservation options discussed/offered. Sperm, ovarian tissue or egg banking may be suggested. If pregnancy is an option for particular patients after treatment, it is important to ensure that counselling addresses the issue of a potential reduced timeframe of fertility.

Normal functioning of the ovaries may also be affected by some therapies. This can lead to earlier than expected onset of menopause, even at a young age. The onset of menopause can be sudden and very distressing. Sensitive discussion is required regarding chemically induced menopause, such as atrophic vaginitis and dyspareunia, and changes in androgens that may alter libido.

For these issues, discussion and referral to social worker, gynaecologist, psychologist or psychiatrist may be appropriate.

3. Depression

Patients receiving therapy may find it both physically and emotional stressful and may continue to feel exhausted and depressed for long periods. Regular screening and ongoing monitoring for depression by clinicians as part of the long term follow up and referral to psychologist or psychiatrist may be required.
4. Fatigue
Fatigue is one of the most common and enduring effects of lymphoma and its treatment. Fatigue has been shown to be a debilitating and difficult issue, with many factors contributing such as immobility, sleep disorders, poor nutrition and reduced performance status, which then impact on physical, recreational and social activities. Further impacts may include possible delays in treatment, dose reductions or even discontinuation of therapy.\(^6\) Some patients report fatigue is extremely distressing and negatively impacts upon quality of life more so than other symptoms such as pain, nausea and depression.\(^7\)

Management of fatigue needs to target specific and reversible symptoms with appropriate treatments. Poor sleep hygiene and sub optimal nutrition remain important factors contributing to ongoing fatigue. Discussion of sleep strategies and referral to a dietitian may be of benefit. Evidence has shown that exercise interventions can have the strongest therapeutic benefit.\(^8\) Patients should be encouraged to maintain physical fitness and functional mobility by participating in a regular exercise regime during and after treatment.\(^9\)

5. Memory and cognitive disturbance
Patients who have a variety of treatments including cranial irradiation, systemic chemotherapy, haematopoietic transplantation and biological response modifiers, may experience cognitive deficits.\(^9\) This is particularly the case for patients who have undergone therapy to treat CNS lymphoma. Neurocognitive damage from chemotherapy or radiation affects tasks that involve psychomotor speed, attention and concentration, memory and learning abilities and executive functions.\(^9\) The variation and severity in cognitive deficit is dependent upon treatment regimens\(^9\), however symptoms can be seen shortly after treatment or be insidious in onset and persist for many years.\(^9\)

6. Sexuality
Sexuality not only encompasses the physical aspects of sexual function, but also refers to how people view themselves and express themselves sexually and how they think others see them.\(^9\) Some of these effects may be temporary, whilst others permanent. Physical problems which can occur include low libido, dyspareunia, and impotence.\(^9\) Other issues affecting sexuality include coping with changes in appearance, low self esteem and changes in roles and relationships. Issues of sexuality need to be raised with all patients and identification and referral to a counsellor with expertise in the area may be required.
7. Education, employment and social status

Studies involving Hodgkin lymphoma patients reflect issues with job discrimination, lower employment rates than the general population, and difficulty obtaining finance and life insurance policies, resulting in a negative socioeconomic effect from their diagnosis and treatment. Workplace discrimination has been an issue because of the time away for work required for cancer treatment and follow-up. Clinicians may need to communicate with the education facility and or workplace to counter discrimination in study or employment.

8. Dietary advice and nutritional support

Loss of taste, mucositis, bowel and physiological disturbances may cause dietary restrictions and nutritional complications. Patients can lose appetite for food, even ceasing to eat altogether, but concurrently have desires/fantasies for food that they cannot physically consume.

Chemotherapy induced mucositis is a common complication for up to 50 percent of patients undergoing conventional chemotherapy and up to 100 percent of patients undergoing high dose chemotherapy for stem cell transplantation developing symptoms. These patients can experience prolonged poor appetite with vomiting and diarrhoea. Where possible the use of oral diet or enteral feeding is preferred. However in the event of severe gastrointestinal failure, administration of parental nutrition may be necessary.

Weight loss is a risk factor for poor survival and may have an impact on response to cancer treatment, therefore all patients should be provided with practical information about diets and advice on minimising problems with eating pre, during and post cancer treatment by a dietitian.

Further Information:

Appendix B lists SA Non Government Organisations for Cancer Support
Referral for psychosocial care: Appendix D
Recommendation:

9. Education is given to all lymphoma patients regarding the risks of infection and the management of febrile neutropenia.

10. Fertility options are discussed prior to chemotherapy commencement.

11. All patients are assessed for fatigue prior to treatment and regularly throughout the care continuum. Patients receive education regarding self care abilities to cope with fatigue.

12. Education is given to all lymphoma patients about the possible cognitive side effects of the treatment they receive.

13. Education is given to all lymphoma patients regarding sexuality issues with referral to identified counsellors, who have expertise in the area if required.

14. Clinicians offer support to patients who are returning to their educational institution and/or workplace, including communication with these facilities if required.

15. All patients with a lymphoma diagnosis have access to information regarding nutrition throughout the cancer pathway with referral to a dietitian if required.

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84 National Breast Cancer Centre and National Cancer Control Initiative. Clinical practice guideline for the psychosocial care of adults with cancer, Camperdown NSW Australia; National Breast Cancer Centre; 2003.


88 ibid


94 The cancer council SA. Sexuality for women with cancer. A guide for women, their families and friends.
95 ibid
100 ibid
103 ibid
8. PREVENTION AND MINIMISING RISK

8.1 Cancer risk factors and prevention advice
Cancer incidence is expected to increase by 31 percent between 2002 and 2011, with more than 115,000 new cancer cases expected by 2011.\(^\text{105}\) Cancer now represents Australia’s greatest disease burden, ahead of cardiovascular disease.\(^\text{106}\) Given the ageing population, cancer incidence is projected to continue rising, with the number of people over 65 years of age set to double by 2051.\(^\text{107}\)

Current evidence indicates that approximately one-third of cancer deaths in Australia can be attributed to known and avoidable risk factors. Appropriate prevention strategies have the potential to reduce cancer incidence. Use of evidence-based screening programs and increased awareness of appropriate early detection measures can optimise outcomes following a diagnosis of cancer or early treatment of precancerous conditions.\(^\text{108}\)

<table>
<thead>
<tr>
<th>Risk factors(^\text{109})</th>
<th>Prevention strategies(^\text{110} \text{ 111})</th>
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<tbody>
<tr>
<td>Poor diet</td>
<td>Promotion of health lifestyles (stopping smoking, healthy diet, healthy weight, limiting alcohol intake)</td>
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<tr>
<td>Smoking tobacco/exposure to tobacco smoke</td>
<td>Screening (participating in national breast, cervical and bowel cancer screening programs)</td>
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<tr>
<td>High risk levels of alcohol consumption</td>
<td>Referral (encouraging appropriate and timely referral for investigation of suspicious lesions)</td>
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<tr>
<td>Inadequate exercise or being overweight</td>
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<tr>
<td>Exposure to ultraviolet radiation</td>
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8.2 Risk factors for lymphoma
There are no known ways to prevent lymphoma. However, there have been some risk factors identified.

Refer to Clinical Practice Guidelines for the diagnosis and management of lymphoma - 
and Chapter 9 Screening and Early Detection.

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106 ibid
107 ibid
108 ibid.
109 Cancer Council South Australia. Live smart: Your lifestyle guide
110 ibid.
9. SCREENING AND EARLY DETECTION

For many cancers, early detection and prompt and appropriate referral is associated with improved treatment outcomes and survival rates.

9.1 Screening

There are no formal screening programs for lymphoma. Surveillance is recommended for individuals at risk of Immunodeficiency-associated lymphoma.

9.2 People at higher risk

Risk factors for lymphoma include people undergoing immunosuppression following organ transplantation, viral infections such as EBV, HTLV-1, Helicobacter pylori and HIV. Contact with environmental carcinogens such as pesticides and herbicides and agricultural exposure are also shown to be associated with lymphoma.\(^{112}\) Refer to Clinical Practice Guidelines for the diagnosis and management of Lymphoma - http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/cp107/cp107.pdf

9.3 Improving community awareness

Consultation with a general practitioner and investigation of the following signs and symptoms are required.

Table 1: Signs and symptoms of lymphoma

<table>
<thead>
<tr>
<th>Signs and Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Lump or mass (large size, firm texture, fixed/tethered)</td>
</tr>
<tr>
<td>• Persistent lymphadenopathy (up to four to six weeks)</td>
</tr>
<tr>
<td>• Lymphadenopathy associated with systemic symptoms (for example, fevers, sweats,</td>
</tr>
<tr>
<td>unintentional weight loss, itch or pain)</td>
</tr>
</tbody>
</table>

Table 2: Time frame for consumer to present to GP for consultation

<table>
<thead>
<tr>
<th>Time</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediately</td>
<td>• Moderate or severe symptoms or unwell</td>
</tr>
<tr>
<td>Within two weeks</td>
<td>• Persistent LN with suspicious symptoms</td>
</tr>
<tr>
<td>Two to six weeks</td>
<td>• Persistent LN without suspicious symptoms</td>
</tr>
<tr>
<td></td>
<td>• Suspicious symptoms +/- lymphadenopathy</td>
</tr>
</tbody>
</table>
9.4 Managing a patient with lymphoma symptoms and referral

Patients presenting with symptoms that are potentially caused by lymphoma may require rapid access to assessment and appropriate investigations. These patients are often unwell/unstable at presentation. However, in many instances the patient can be quite stable and a number of investigations can be initiated by the general practitioner.

Initial Investigations and Management:

Table 3: Initial Investigations for lymphoma

<table>
<thead>
<tr>
<th>Investigations</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Examination</td>
<td>• As outlined in Table 4</td>
</tr>
<tr>
<td>Full Blood Count (FBC), Chemistry (MBA20)</td>
<td>• To be performed prior to any biopsy</td>
</tr>
<tr>
<td>and Chest X-ray</td>
<td></td>
</tr>
<tr>
<td>Ultrasound</td>
<td>• To assess for lymph node architecture</td>
</tr>
<tr>
<td>Fine Needle Aspirate</td>
<td>• Proceed ONLY if ultrasound is abnormal</td>
</tr>
<tr>
<td></td>
<td>• or suspicion is high of a lymphomatous lesion. This MUST be accompanied by a request for flow cytometry.</td>
</tr>
</tbody>
</table>

Further Information:

- Chapter 5 Multidisciplinary and Coordinated Care - Role of the general practitioner in lymphoma care
- General Practitioner: Lymphoma Diagnostic Flow

Table 4: Physical Examination
Physical Examination

Symptoms of Concern

- Weight loss, excessive sweating, unexplained fevers or pruritus, persistent lymphadenopathy, LN that are of large size, hard texture and/or fixed/tethered
- A higher degree of suspicion in any of the following - age greater than 40 yrs, supraclavicular location, node diameter over 2.25cms, firm-hard texture and lack of tenderness supraclavicular location, node diameter over 2.25cms, firm-hard texture and lack of tenderness

Symptoms/signs that are reassuring

- Lymphadenopathy that is tender, soft, small (less than 2 cm’s diameter) and mobile
- Note that cervical lymphadenopathy is common in children and often reactive

Indications for observation only (up to 3 months if appropriate)

- No predicted indicators for LN biopsy (see above)
- Patients without significant or progressive symptoms
- History is suggestive of infection or alternative diagnosis is made

Other possible diagnosis

- Viral infection, atypical mycobacteria, catscratch disease, dental/sinus infection, other malignancy

Table 5: Referral to which specialist?

<table>
<thead>
<tr>
<th>Patient demographic</th>
<th>Specialist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age &lt; 18</td>
<td>Referral and discussion with paediatric haematologist/oncologist</td>
</tr>
<tr>
<td>Age &gt; 18</td>
<td>Referral to appropriate specialist dependent on patient location.</td>
</tr>
<tr>
<td>Metropolitan</td>
<td>Haematologist or medical oncologist</td>
</tr>
<tr>
<td>Rural/Remote</td>
<td>May be general physician/paediatrician or surgeon. Discussion with a haematologist or medical oncologist is</td>
</tr>
</tbody>
</table>
Issues to consider:

- The degree of clinical suspicion, access to local versus centralised services and the urgency for a diagnosis.
- Phone consultation with appropriate specialist to streamline the process of referral and investigations.

Table 6: When to refer to a specialist?

<table>
<thead>
<tr>
<th>Time</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediately</td>
<td>• Moderate or severe symptoms</td>
</tr>
<tr>
<td></td>
<td>• Confirmed diagnosis of high grade lymphoma</td>
</tr>
<tr>
<td>Consultation with specialist</td>
<td>• If strong suspicion of lymphoma</td>
</tr>
<tr>
<td>or Lymphoma MDT on how to</td>
<td></td>
</tr>
<tr>
<td>proceed</td>
<td></td>
</tr>
<tr>
<td>Within 2 weeks</td>
<td>• Persistent or enlarging lymphadenopathy of</td>
</tr>
<tr>
<td></td>
<td>concern</td>
</tr>
<tr>
<td>After 2 weeks - Within 6</td>
<td>• Symptoms without lumps, if persistent</td>
</tr>
<tr>
<td>weeks</td>
<td>• GP initiated investigation consistent with</td>
</tr>
<tr>
<td></td>
<td>lymphoma (usually intermediate or low grade)</td>
</tr>
</tbody>
</table>

Issues to consider:

- If the symptoms are not explained by the results of investigations, or there is no improvement in symptoms after standard treatment, discussion with an appropriate specialist is required.

Table 7: How to refer to a specialist and what information is needed?

<table>
<thead>
<tr>
<th>How</th>
<th>What</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP referral form can be faxed, emailed or use web referral</td>
<td>• GP referral form to lymphoma specialist (see attachments on webpage)</td>
</tr>
<tr>
<td>Referral letter (if unable to use GP referral form)</td>
<td>• History of presenting symptoms</td>
</tr>
<tr>
<td></td>
<td>• All prior relevant investigations and imaging</td>
</tr>
<tr>
<td></td>
<td>• Past medical history, including current medications and allergies</td>
</tr>
<tr>
<td></td>
<td>• Relevant psychosocial history and/or</td>
</tr>
</tbody>
</table>
current concerns

- Patient preferences (if any)

Issues to consider:

- If referring for an investigational biopsy – comprehensive summary of all relevant information is required to ensure appropriate and timely triage. A standardised pathology request form should be used (see Appendix J). This will flag important disease information for diagnosis and staging.

Recommendation:

16. Creation and promotion of consumer information on lymphoma should include signs and symptoms of disease and time frames for review by general practitioner and general practitioner role in referral to lymphoma specialist.

17. Initiate a key performance Indicator (KPI) to monitor time from GP referral to specialist appointment.

18. A benchmark of 6 weeks from general practitioner identification of lymphoma symptoms to general practitioner referral to lymphoma specialist to be utilised.

---

Figure 7: General Practitioner: Lymphoma Diagnostic Flow Chart

- Suspect Lymphoma
  - Lymphadenopathy
  - Symptoms

- Patient unwell / unstable
  - Immediate referral for specialist consultation

- Full medical history
  - Physical examination
    - Lymphadenopathy
    - organomegaly

- Patient stable
  - Observation
    - If alternative Dx is possible

- Highly suspicious for lymphoma
  - Refer non-urgently for specialist consultation

  - Ultrasound lymph node

- Low grade disease confirmed
  - Arrange FNA/flow, using synoptic report request
    (NB for pediatric cases NO FNA, go straight to excisional biopsy)

- Abnormal
  - +ve result
    - Consider:
      - Referral to specialist
      - Observe
      - Excisional biopsy

  - -ve result
    - Disease progression
      - Resolved

  - Normal
    - Observe

- Disease progression
  - For primary diagnosis
  - Always for pediatric cases
  - Using synoptic report request

- Excisional biopsy is essential
  - Lymphoma diagnosis confirmed
10. DIAGNOSIS AND STAGING

10.1 Care required following confirmation of a diagnosis of lymphoma

Clinical

- Referral to specialist from GP using referral criteria and referral proforma.
- Triage of referral by the specialist lymphoma nurse in conjunction with specialist to determine urgency.
- Diagnostics and staging investigations as per 10.2 and 10.3.
- Use of formal calculation prognostic indices and performance status indices Appendix I.

Supportive Care

- Assessment of psychological status by haematologist or oncologist and liaising with primary physician.
- Application of distress tool by primary physician, specialist lymphoma nurse or social worker.
- All patients to be referred to a specialist lymphoma nurse.
- Fast tracking of referrals to allied health staff, particularly a social worker to assist with practical and financial matters.

Further Information

- Clinical Practice Guidelines for the diagnosis and management of lymphoma
- Clinical Practice Guidelines for the diagnosis and management of lymphoma – a guide for general practitioners.
- Tumours of Haematopoietic and Lymphoid Tissue Structured Reporting Protocol
- Clinical practice guidelines for the psychosocial care of adults with cancer
- Distress thermometer http://www.ecco-org.eu/01/MyImages/distress_thermometer.jpg
- Appendix D – Referral for psychosocial care
- GP referral form to lymphoma specialist
  http://www.sahealth.sa.gov.au/wps/wcm/connect/b4b0c900459fcdddb4f4519b2d33fa/Lymphoma+Pathway+ATTACHMENT+2+-+GP+Referral+to+Specialist+template.pdf?MOD=AJPERES&CACHEID=b4b0c900459fcdddb4f4519b2d33fa
- Lymphoma treatment pathway
HIV Associated Lymphoma: general points for consideration

HIV infection is associated with a 200 fold increased risk of lymphoma. Lymphoma in these patients is often aggressive/highly aggressive.

- Disease is predominantly systemic NHL with primary CNS or “primary effusion” lymphoma less commonly observed.

- Lymphoma is usually of B-cell type.
  - Diffuse large cell 70%
  - Burkitt’s 20%
  - Others include T cell, plasmablastic and indolent

- Viral infections are important in both pathogenesis and diagnosis.
  - CMV, Kaposi sarcoma associated herpes virus (KSHV) and EBV implicated in pathogenesis
  - Consider PCR analysis for specific viral DNA of any fluid/tissue samples obtained

- Poor prognostic factors include age >35 years, IV drug use, stage III/IV disease and/or CD4 count <100 x10^9/L.

- HAART strongly recommended as it results in higher CD4 counts, improved response to chemotherapy and better outcomes

- CNS prophylaxis recommended because of high risk of CNS relapse.

For more detail see “AIDS–related Malignant Lymphomas - literature review”
10.2. Biopsy and Histopathological Investigation

Recommendations for a lymph node biopsy and subsequent histopathological investigations for determining a diagnosis of lymphoma:

Table 8: Biopsy Requirements

<table>
<thead>
<tr>
<th>Type of specimen: needle/core/excisional</th>
</tr>
</thead>
<tbody>
<tr>
<td>• <strong>Excisional Lymph Node biopsy is essential</strong> for the primary diagnosis, subtyping and clinical management of lymphoma. <strong>NOTE:</strong> head and neck squamous cell cancers to be treated differently (risk of contamination of field)</td>
</tr>
<tr>
<td>• <strong>A core biopsy</strong> can be considered for deep seated lesions – <strong>minimum gauge needle 18 F and 2 passes</strong> - and should be accompanied by fine needle aspirate for flow cytometry and frozen section.</td>
</tr>
<tr>
<td>• If a highly invasive procedure would be required to make the diagnosis due to difficult access, a <strong>consultation</strong> between haematologist / medical oncologist and the person performing the biopsy (surgeon or interventional radiologist) should occur.</td>
</tr>
<tr>
<td>• Surgical biopsy should be of the <strong>most clinically significant site</strong> with attempts made to remove the intact lymph node. A lymphoma multidisciplinary team input at this time can be useful to determine the optimum site to be biopsied.</td>
</tr>
<tr>
<td>• The person performing the biopsy should have appropriate experience in biopsy techniques for the diagnosis of lymphoma and have a working relationship with both a histopathologist and haematologist and/or medical oncologist with experience in the diagnosis and management of lymphoma (e.g. interventional radiologist, surgeon, cytopathologist, other).</td>
</tr>
</tbody>
</table>

**Site**

**Operator**

Issues to consider:

• Requirement for tumour banking
• Requirements for clinical trials/biology studies
<table>
<thead>
<tr>
<th>Table 9: Histopathologic Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Specimen transport and handling</strong></td>
</tr>
<tr>
<td>• An appropriate laboratory should be informed before the biopsy takes place and specimens must be sent fresh and expeditiously</td>
</tr>
<tr>
<td>• Advise if the sample may be required for tumour banking</td>
</tr>
<tr>
<td>• Well prepared formalin fixed, paraffin embedded sections remain the gold standard for LN diagnosis and are the highest priority of triage</td>
</tr>
<tr>
<td>• A specimen should be sent with the appropriate request form (suggested template): Histopathology request form.</td>
</tr>
<tr>
<td><strong>Reporting</strong></td>
</tr>
<tr>
<td>• Synoptic reporting is optimal and a standard format for reporting should be utilised.</td>
</tr>
<tr>
<td>• Refer to RCPA Tumours of Haematopoietic and Lymphoid Tissue Structured Reporting Protocol</td>
</tr>
<tr>
<td><strong>Expertise</strong></td>
</tr>
<tr>
<td>• The biopsy should be reviewed by a pathologist (preferably in a Tumour board/ Multidisciplinary setting) who is a recognised expert in haematopathology.</td>
</tr>
<tr>
<td><strong>Histopathological Investigation</strong></td>
</tr>
<tr>
<td>• For information on histopathologic investigation refer to Clinical Practice Guidelines for the diagnosis and management of lymphoma.</td>
</tr>
</tbody>
</table>
## 10.3 Staging Investigations

**Recommended Staging Investigations for Lymphoma:**

### Table 10: Staging Requirements

<table>
<thead>
<tr>
<th>Investigation</th>
<th>Details</th>
</tr>
</thead>
</table>
| Clinical examination           | - Clinical findings documented with particular note of lymphadenopathy and organomegaly.  
                               | - Assessment of performance status.                                       |
|                               | - Geriatric/paediatric/AYA input as appropriate                          |
| Bone marrow biopsy            | - Histology                                                              |
|                               |   Morphology, flow cytometry and cytogenetics                            |
|                               | - Not for stage 1-2A Hodgkin lymphoma                                    |
|                               | - Consider for low grade lymphoma                                        |
|                               | - BM aspirate and 2 trephine samples recommended, for further information regarding adequacy of specimen, refer to Clinical Practice Guidelines for the diagnosis and management of lymphoma.  
| PET scan                      | - PET recommended for all Hodgkin lymphoma and high grade lymphomas      |
| (PET scan – positron emission tomography) |                                                                  |
| CT scan                       | - CT to include with contrast:  
                               |   - neck, chest, abdomen, pelvis  
                               |   - CNS imaging, if clinically indicated                                    |
| Baseline studies of organ function | - MUGA/GBPS                                                                    |
|                               | - ECHO                                                                     |
|                               | - Liver, Kidney, Pulmonary function                                       |
|                               | - Viral serology (including Hepatitis A/B/C)                              |
|                               | - If indicated by site or histology                                       |
| Lumbar puncture               | - If indicated, e.g. pregnancy                                           |
| MRI                            |                                                                           |

### Issues to consider:

- Early referral to radiation oncologist to document baseline disease extent if radiotherapy likely to be included in treatment program.
- Staging to be completed within 4 weeks of presentation unless clinically urgent or alternatively an indolent lymphoma (e.g. low grade lymphoma) where staging as clinically indicated.
Recommendations:

19. Optimal patient management requires accuracy and consistency in histopathologic diagnosis. It is recommended that synoptic reporting of lymphoma becomes the standard of histopathologists.

20. Staging investigations (note exceptions) to be done within 4 weeks of diagnosis.

11. PRESENTATION AT LYMPHOMA MULTIDISCIPLINARY TEAM MEETING

11.1 Multidisciplinary team meetings (MDT)

The benefits of multidisciplinary team care for patients, families and clinicians has been well documented in the literature, for information on principles and benefits refer to Chapter 5 Multidisciplinary and coordinated care.

Multidisciplinary team meetings provide opportunity for discussion of all new patient presentations; review of patients following surgery, neoadjuvant treatment and at tumour recurrence, including clinical trial access and eligibility. MDT meetings also provide clinicians with the opportunity to develop clinical protocols, contribute to professional development activities and provide a forum for the discussion of relevant issues with service delivery.\textsuperscript{113}

The multidisciplinary team members, who reflect both the clinical and psychosocial aspects of patient care, meet regularly and are able to provide treatment recommendations whilst taking into account the individual patients preferences and circumstances.\textsuperscript{114} Refer to Table 11 for MDT members.

Treatment and supportive care within MDT should be coordinated, ensuring patient, GP and MDT members are clear about individual responsibilities for coordination of care.\textsuperscript{115} The referring specialist to the MDT meeting is responsible for the patient care until care is formally referred or passes to another practitioner. Any health professional can refer to MDT meeting for additional treatment, discussion and management planning should complexities arise along the care continuum.\textsuperscript{116} See Table 12 for MDT referral instructions.
**Clinical**

- All patients diagnosed to be referred to next MDT meeting irrespective of whether staging tests have been completed.
- All patients regardless of stage of cancer should be referred to MDT meeting.
- Recommend interventional treatment procedures do not occur prior to MDT meeting, unless patient’s condition is serious/life threatening.
- Timely investigations and referrals as per KPI’s within lymphoma pathway.
- Primary care physician or proxy must attend MDT meeting.
- Generation of recommendations from the MDT review:
  - Consideration of treatment intent
  - Consideration of treatment method – observe
    - surgery
    - radiotherapy
    - chemotherapy
  - Consideration of eligibility for tumour trials/studies
  - Considerations of fertility issues and dental care
  - Nominations of person to generate a report of the MDT recommendations
  - Report to be placed in the patients file/case notes.
- Recommendations from MDT meeting to be written as brief summary and communicated to GP

**Supportive Care**

- Patient/family consent for presentation at MDT meeting.
- Comprehensive presentation including psychosocial history.
- Attendance of appropriate MDT members via referral as assessed by primary physician or via distress tool.

**Further Information:**

- Lymphoma MDT referral and consent  
  [http://www.sahealth.sa.gov.au/wps/wcm/connect/e9b0d000459fd4edbf5519b2d33fa/Lymphoma+Pathway+ATTACHMENT+4+-+MDTReferralConsent+Template.pdf?MOD=AJPERES&CACHEID=e9b0d000459fd4edbf5519b2d33fa](http://www.sahealth.sa.gov.au/wps/wcm/connect/e9b0d000459fd4edbf5519b2d33fa/Lymphoma+Pathway+ATTACHMENT+4+-+MDTReferralConsent+Template.pdf?MOD=AJPERES&CACHEID=e9b0d000459fd4edbf5519b2d33fa)
- Lymphoma MDT Report  
- Distress thermometer  
  [http://www.ecco-org.eu/01/MyImages/distress_thermometer.jpg](http://www.ecco-org.eu/01/MyImages/distress_thermometer.jpg)
- Appendix D – Referral for psychosocial care
- Clinical Trials | Cancer Australia  
- Australian New Zealand Clinical Trials Registry  
- Clinical trials  
- Cancer Trials Australia  
## 11.2 Lymphoma multidisciplinary team

### Table 11: Members of the MDT

<table>
<thead>
<tr>
<th>Core Members</th>
<th>Members via Referral Processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Haematologists</td>
<td>• Transplant Physician</td>
</tr>
<tr>
<td>• Medical Oncologists</td>
<td>• Surgeon</td>
</tr>
<tr>
<td>• Radiation Oncologists</td>
<td>• Psychologist</td>
</tr>
<tr>
<td>• Palliative Care Consultants</td>
<td>• GP</td>
</tr>
<tr>
<td>• Radiologist with expertise in nuclear medicine</td>
<td>• Dietitian</td>
</tr>
<tr>
<td>• Interventional Radiologist</td>
<td>• Geriatric Cancer Assessment Team</td>
</tr>
<tr>
<td>• Histopathologist</td>
<td>• Adolescent and Young Adult Cancer Assessment Team</td>
</tr>
<tr>
<td>• Specialist lymphoma nurse(s)</td>
<td>• CALD and ATSI services</td>
</tr>
<tr>
<td>• Social Worker</td>
<td>• Rural/remote Liaison Nurse</td>
</tr>
<tr>
<td>• Cancer Pharmacist</td>
<td></td>
</tr>
<tr>
<td>• Clinical Trials Coordinator</td>
<td></td>
</tr>
</tbody>
</table>

### Table 12: How to refer for MDT review and what information is needed?

<table>
<thead>
<tr>
<th>How</th>
<th>What</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Referring clinician to liaise with MDT coordinator</td>
<td>• Referring clinician to complete MDT referral form</td>
</tr>
<tr>
<td>• MDT coordinator receives referral and completes a template of</td>
<td>• Lymphoma MDT referral and consent</td>
</tr>
<tr>
<td>necessary data and information</td>
<td>• MDT coordinator to complete MDT template</td>
</tr>
<tr>
<td>• Referring clinician is required/requested to attend</td>
<td>• Lymphoma MDT Report</td>
</tr>
<tr>
<td>• MDT coordinator will facilitate venue and timing of regular</td>
<td></td>
</tr>
<tr>
<td>meetings</td>
<td></td>
</tr>
</tbody>
</table>

[http://www.sahealth.sa.gov.au/wps/wcm/connect/e9b0d000459fd4edb566f5519b2d33fa/Lymphoma+Pathway+ATTACHMENT+4-MDTReferralConsent+Template.pdf?MOD=AJPERES&CACHEID=e9b0d000459fd4edb566f5519b2d33fa](http://www.sahealth.sa.gov.au/wps/wcm/connect/e9b0d000459fd4edb566f5519b2d33fa/Lymphoma+Pathway+ATTACHMENT+4-MDTReferralConsent+Template.pdf?MOD=AJPERES&CACHEID=e9b0d000459fd4edb566f5519b2d33fa)
Recommendations:

22. All patients with lymphoma are prospectively discussed at a multidisciplinary team meeting within two to four weeks of confirmed diagnosis.

23. The multidisciplinary team assessment and discussion should occur after tissue diagnosis but prior to definitive treatment.

24. A copy of the lymphoma MDT treatment recommendations as well as the agreed treatment plan (specialist/patient) is to be provided to the GP and patient within 7 working days and a copy placed in the patient’s case file.

25. Determine a Key Performance Indicator (KPI) to monitor % of patients referred to the Lymphoma Multidisciplinary team for prospective treatment planning.

---

114 ibid
115 ibid
12. TREATMENT OF LYMPHOMA

12.1 Treatment Planning

<table>
<thead>
<tr>
<th>Clinical</th>
<th>Supportive Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Communications of recommendations from MDT review:</td>
<td>- Triage to appropriate supports to help with issues e.g:</td>
</tr>
<tr>
<td>- Primary specialist to discuss with patient/family MDT recommended treatment plan with discussion of options of treatment, either curative, disease control or palliative.</td>
<td>- Financial</td>
</tr>
<tr>
<td>- Treatment plan agreement between patient/family and specialist after this discussion.</td>
<td>- Employment</td>
</tr>
<tr>
<td>- Treatment plan to be communicated to GP and relevant team members</td>
<td>- Schooling/education</td>
</tr>
<tr>
<td>- MDT recommendations and final treatment plan to be incorporated in patient’s case notes/file and provided to patient/family.</td>
<td>- Fertility concerns</td>
</tr>
<tr>
<td>Further Information:</td>
<td>Consideration of social work and nurse specialist involvement at patient/family meeting discussing MDT recommendations.</td>
</tr>
<tr>
<td>- American Society of Clinical Oncology Recommendations on Fertility Preservation in Cancer Patients -- Lee et al. 24 (18): 2917 -- Journal of Clinical Oncology <a href="http://jco.ascopubs.org/content/24/18/2917.full.pdf+html">link</a></td>
<td></td>
</tr>
<tr>
<td>- Lymphoma treatment pathway</td>
<td></td>
</tr>
<tr>
<td>- Clinical Trials</td>
<td>Cancer Australia <a href="http://www.canceraustralia.gov.au/research-and-funding/support-clinical-trials">link</a></td>
</tr>
<tr>
<td>- Australian New Zealand Clinical Trials Registry <a href="http://www.anzctr.org.au">link</a></td>
<td></td>
</tr>
<tr>
<td>- Cancer Trials Australia <a href="http://www.cancertrialsaustralia.com/Home.aspx">link</a></td>
<td></td>
</tr>
<tr>
<td>- Appendix D – Referral for psychosocial care</td>
<td></td>
</tr>
<tr>
<td>- Current protocols website in development</td>
<td></td>
</tr>
<tr>
<td>- Australian national radiation therapy guidelines in development</td>
<td></td>
</tr>
</tbody>
</table>
### 12.2 Treatment

#### Clinical

- **Treatment Protocol**
  - To be documented in patient case notes/file
  - Evidence basis documented
  - Patient educated regarding potential side effects and risks of therapy
  - GP is aware and provided with treatment plan

- **Coordination of Treatment**
  - Consideration of different modalities required for individual patient care and timeframes for care delivery
  - Primary physician and/or Nurse coordinator to coordinate care
  - Primary physician concept (the person directing therapy). This can be delegated at different time points of therapy i.e during stem cell transplantation
  - Need for all multidisciplinary team members to be kept abreast of progress
  - Specialists to communicate with GP regarding patient non attendance to appointments.

- **Location of treatment**
  - Determine feasibility and safety issues when considering treatment provision
  - Liaise with local services
  - Consideration of processes/pathways for emergency care

- **Monitoring investigations**
  - Plan for when investigations required to assess disease response and what investigations to perform
  - Plan for when investigations required to monitor organ function

#### Supportive Care

- **Coordination of therapy by Lymphoma nurse coordinator/MDT coordinator:**
  - Ensure patient and family understand treatment plan, duration and side effects
  - Facilitate and coordinate appropriate appointments
  - Triage complications

- **Social worker to facilitate:**
  - Ongoing assessment, counselling and support, practical issues including PATS, accommodation, transport, family issues, Centrelink
  - Awareness of support groups and resources

- **Allied Health**
  - Consider need for dietetics, dentistry, physiotherapy and occupational therapy

- **Complementary therapies**
  - Look good feel better program
  - As appropriate and in consultation with specialist: meditation, massage and acupuncture

#### Further Information:

- Clinical Practice Guidelines for the diagnosis and management of lymphoma

- Appendix B – Cancer Resources in SA

- Distress Thermometer
  [http://www.ecco-org.eu/01/MyImages/distress_thermometer.jpg](http://www.ecco-org.eu/01/MyImages/distress_thermometer.jpg)

- Appendix D – Referral for psychosocial care
Haemopoietic Stem Cell Transplantation (HSCT) in Lymphoma

While modern chemotherapy regimens have excellent results in terms of disease control and potential for cure, a number of patients relapse after initial treatment. In most cases, these relapses will be sensitive to salvage chemotherapy but will not be cured. High dose therapy (HDT), incorporating chemotherapy and sometimes radiotherapy, followed by HSCT is a potentially curative treatment. HDT involves giving higher doses of chemotherapy for greater tumour kill. However, these doses are marrow ablative and patients will not recover bone marrow function. HSCT "rescues" the bone marrow. The haemopoietic stem cells (HSC) can be derived from the patient (autologous transplant) or from a tissue matched donor who may be related or unrelated (allogeneic transplantation).

Autologous transplantation is most commonly employed in patients with relapsed diffuse large B cell NHL or Hodgkin lymphoma as a potentially curative treatment. It is also employed in the initial treatment of mantle cell lymphoma, where it may prolong remission but not necessarily be curative. Allogeneic transplantation is a more intensive procedure with potential for significant treatment related complications and even death. It is therefore only used in selected patients with particular benefit in relapsed follicular lymphoma and Hodgkin lymphoma.

Table 13: Indications for Allogeneic Stem Cell Transplant

<table>
<thead>
<tr>
<th>Disease</th>
<th>Status</th>
<th>Recommendation</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follicular B Cell</td>
<td>CR1</td>
<td>NR</td>
<td>• Age: up to 65</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>Relapse ≥ CR2</td>
<td>CO</td>
<td>• Hospitals: WCH (sibling only), RAH</td>
</tr>
<tr>
<td></td>
<td>Refractory</td>
<td>NR</td>
<td></td>
</tr>
<tr>
<td>Hodgkin Lymphoma</td>
<td>CR1</td>
<td>NR</td>
<td>• Advantages: potentially curative and graft vs lymphoma effect</td>
</tr>
<tr>
<td></td>
<td>Relapse ≥ CR2</td>
<td>CO</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Refractory</td>
<td>NR</td>
<td>• Disadvantages: significant morbidity/ mortality</td>
</tr>
</tbody>
</table>

S = Standard, CO= Clinical Option, NR= Not Recommended
### Table 14: Indications for Autologous Stem Cell Transplantation

<table>
<thead>
<tr>
<th>Disease</th>
<th>Status</th>
<th>Recommendation</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diffuse Large Cell Lymphoma (DLBCL)</strong></td>
<td>CR1</td>
<td>NR</td>
<td>• Age: up to 70</td>
</tr>
<tr>
<td>Relapse</td>
<td>S</td>
<td></td>
<td>• Hospitals: WCH, RAH, QEH, FMC</td>
</tr>
<tr>
<td>CR2</td>
<td>CO</td>
<td></td>
<td>• Advantages: Low morbidity and potentially curative</td>
</tr>
<tr>
<td>Refractory to 1st line therapy</td>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapse &gt;CR2</td>
<td>NR</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mantle Cell Lymphoma</strong></td>
<td>CR1</td>
<td>S</td>
<td>• Disadvantages: No graft v lymphoma and graft contamination</td>
</tr>
<tr>
<td>Relapse ≥CR2</td>
<td>NR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refractory</td>
<td>NR</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hodgkin Lymphoma</strong></td>
<td>CR1</td>
<td>NR</td>
<td></td>
</tr>
<tr>
<td>Relapse</td>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CR2</td>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refractory to 1st line therapy</td>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapse &gt;CR2</td>
<td>NR</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>T Cell NHL</strong></td>
<td>CR1</td>
<td>CO</td>
<td></td>
</tr>
<tr>
<td>Relapse</td>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CR2</td>
<td>CO</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refractory to 1st line therapy</td>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapse &gt;CR2</td>
<td>NR</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

S= Standard, CO= Clinical Option, NR= Not recommended

### Table 15: Clinicians with an interest in HSCT

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Clinicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Royal Adelaide Hospital (Auto)</td>
<td>• Dr Ian Lewis</td>
</tr>
<tr>
<td>(Autologous and Allogeneic)</td>
<td>• A/Prof Peter Bardy</td>
</tr>
<tr>
<td></td>
<td>• Dr Devendra Hiwase</td>
</tr>
<tr>
<td>Women’s and Children’s Hospital (Allogeneic and Autologous)</td>
<td>• Dr Heather Tapp</td>
</tr>
<tr>
<td></td>
<td>• A/Prof Tom Revesz</td>
</tr>
<tr>
<td></td>
<td>• Dr Michael Osborn</td>
</tr>
<tr>
<td>The Queen Elizabeth</td>
<td>• A/Prof Peter Bardy</td>
</tr>
<tr>
<td></td>
<td>• Dr Uwe Hahn</td>
</tr>
<tr>
<td></td>
<td>• Dr Cindy Lee</td>
</tr>
<tr>
<td>Flinders Medical Centre</td>
<td>• Dr David Ross</td>
</tr>
<tr>
<td></td>
<td>• Dr Doug Couglin</td>
</tr>
</tbody>
</table>
Recommendations:

26. Clinicians providing cancer therapy to lymphoma patients should be appropriately credentialed for those purposes.

27. Lymphoma treatments should be provided within accredited institutions and have access to supporting facilities, as indicated by the level and intensity of therapy required.

28. Where possible, patients should be offered clinical trial enrolment.

29. Where possible, patient treatment should proceed according to established protocols.
13. COMPLEMENTARY THERAPIES

The term ‘complementary therapies’ encompasses a range of approaches to health-care aimed at enhancing quality of life and improving well-being. They may be used alongside standard evidence-based medical (conventional) cancer treatments, such as surgery, radiotherapy, chemotherapy, hormonal therapies or biological therapies. Complementary therapies that have been shown to be helpful in the management of the symptoms of cancer and its treatment include: counselling, meditation and relaxation, support groups, art and music therapy, spiritual practices, massage, aromatherapy, reflexology, acupuncture, yoga and physical activity, tai chi, qi gong, some herbal medicine and nutritional advice\textsuperscript{117}.

Although the term ‘Complementary and Alternative Medicine (CAM) is frequently used, it is important to distinguish between complementary and alternative therapies. Alternative therapies are used instead of standard evidence-based medical cancer treatments. There is no evidence to support the use of alternative therapies in the treatment of cancer.

It is important that the primary treatment team are aware of complementary therapies, recognise the potential for impact of such therapies in the clinical setting\textsuperscript{118} and promote open discussion about these therapies with their patients.

13.1 How complementary therapies may help cancer patients

Complementary therapies are intended to support patient well-being and are not considered treatments for cancer\textsuperscript{119}. Although large-scale clinical trials are still needed, there have been many studies of complementary therapies involving patients with cancer. Scientific data is not available that shows an effect on survival, however the results of studies suggest therapeutic benefits of complementary therapies for management of both the symptoms of cancer and the side effects associated with conventional cancer treatment\textsuperscript{120}

Beneficial effects reported for some complementary therapies include\textsuperscript{121}

- reducing pain or use of analgesia
- reducing chemotherapy-related fatigue
- reducing menopausal symptoms such as hot flushes
- reducing acute nausea
- promoting relaxation
• improving sleep
• improving the sense of well-being
• reducing stress, anxiety and depression
• improving overall coping capacity
• promoting a feeling of self worth;

However, some complementary therapies can interact with conventional cancer treatments and make them less effective. Others may actually be harmful if taken in combination with conventional cancer treatments.\textsuperscript{122}

13.2 Discussing complementary therapies with patients and/or caregivers

Based on current guidelines,\textsuperscript{123, 124} it is recommended that oncology health professionals provide an opportunity for patients to talk openly about complementary therapies in the context of the overall health care plan. The multidisciplinary team should identify which member of the clinical team should be best placed to conduct this discussion.

• All patients with cancer should be asked specifically about their use of complementary and alternative therapies (CAM) at multiple time points in the treatment pathway
• Communication about CAM should be conducted in an open, evidence-based and patient-centred manner by the cancer-specialist clinician.
• Detailed enquiries by the patient and family/carers about those complementary therapies deemed suitable in their particular case should be directed to the complementary therapist/prescriber.
• Responses to questions about CAM use should be documented in the case notes.
• In order to ensure that those patients considering Complementary Therapy are well informed, they should be offered the Understanding Complementary Therapies\textsuperscript{125} booklet and/or the Cancer Council SA Helpline number (13 11 20) both of which provide balanced, evidence-based information about the advantages and limitations, including contraindications, of complementary therapies. A brochure\textsuperscript{126} providing guidance to identifying qualified complementary therapists should also be offered.
It is also recommended that patients seeking complementary therapies should be encouraged to ask questions of any complementary health practitioners to ensure the appropriateness and safety of their care. Questions may include:

- what is your training?
- exactly what is the therapy you are proposing?
- what do you hope it will do?
- what is the evidence for the success of this therapy?
- what side effects could there be?
- how common are the side effects?
- will this therapy affect other treatments I am receiving?
- how much will this therapy cost?

**Information for patients and caregivers**

The Cancer Council Australia ‘urges people with cancer to remain in the care of qualified doctors who use proven methods of treatment and participate in clinical trials of promising new treatments. If you are using, or considering, a complementary or alternative treatment, it's important to discuss it with your doctor or call the Cancer Helpline for advice’.

Also, ‘If (people) are thinking about using any other method instead of conventional medical treatment, (they) should carefully consider and investigate the claims made and any evidence for those claims, the credentials of the people or organisation promoting the treatment, the costs and the potential risks of delaying conventional treatments.’

The American Cancer Society (ACS) recommends the following checklist to flag approaches or therapies that might be open to question and advises that if the answer to any of these questions is 'yes’, people should carefully consider whether the proposed treatment is of any value.

- Is the treatment based on an unproven theory?
- Does the treatment promise a cure for all cancers?
- Are you told not to use conventional medical treatment?
- Is the treatment or drug a ‘secret’ that only certain providers can give?
- Does the treatment require you to travel to another country?
- Do the promoters attack the medical/scientific establishment?

**Further information resources**
• Cancer Council resources on complementary care are available online or by phoning the Cancer Helpline (13 11 20):
  o Cancer Council Victoria brochure: ‘Complementary and alternative cancer therapies – for people with cancer, their family and friends’.
  o Cancer Council NSW brochure: ‘Understanding Complementary Therapies’.
  o Brochure listing professional organisations representing qualified practitioners of complementary therapies in South Australia.

Useful web sites on complementary and alternative therapies
• Quackwatch is an international network of people who are concerned about health-related frauds, myths, fads, fallacies, and misconduct. The website has a search engine of therapies and services. http://www.quackwatch.com/
• The Memorial Sloan Kettering Cancer Center (US) webpage ‘About Herbs, Botanicals & Other Products’ at www.mskcc.org/mskcc/html/11570.cfm provides objective information for oncologists, healthcare professionals, and consumers.
  Note: this is an American website and not all of the products listed may be available in Australia.

Recommendations:
30. All patients with cancer should be specifically asked about their use of complementary and alternative therapies (CAM).

31. Responses to questions about CAM use should be documented in the case notes.

32. Patients should have access to the Understanding Complementary Therapies booklet and the Cancer Council SA Helpline number (13 11 20)
118 ibid
125 Understanding Complementary Therapies, Cancer Council publication (Nov 2008)
14. FOLLOW-UP CARE

14.1 Post treatment surveillance
Post treatment surveillance encompasses appropriate monitoring for the detection of recurrent disease and long term side effects of therapy. Surveillance is conducted by the cancer specialist in conjunction with the general practitioner and other specialists as required, and is part of a larger survivorship plan. At the end of treatment, some patients may be unable to comprehend all information regarding late effects. By producing a written care plan, the patient and family along with clinicians are able to refer to the document at any time, be aware of what treatment was provided, who is responsible for implementing future care, who is responsible for what aspects of care, and what are next steps.

Late effects have become more common with the increasing use of more complex and intensive cancer interventions. Treatment for lymphoma may result in premature onset of common conditions associated with aging such as diabetes mellitus, cardiovascular disease, hypertension and hyperlipidaemia. Some late effects may also be present without exhibiting symptoms. There may be lack of awareness by both the survivor and health professionals regarding the risks for long term effects, which may limit the survivor’s participation in screening and risk reducing interventions.

Whilst the importance of long term follow-up for childhood lymphoma survivors is well recognised, adult late effect clinics are gaining increased recognition as an integral part of care for lymphoma survivors. Long term follow-up for childhood survivors occurs at all paediatric centres, and currently in Australia there are two adult late effects clinics, at The Peter MacCallum Cancer Centre in Victoria and The Queen Elizabeth Hospital in South Australia.
Clinical

- Recommended monitoring investigations:
  - Document planned investigations for disease recurrence and organ function

- Summary of treatment exposures and morbidities:
  - Document exposures and cumulative doses of chemotherapy, radiotherapy
  - Document any side effects of disease or treatment

- Risk categorisation:
  - Assessment of exposures, age at exposure and combined therapeutic modalities for risks of late effects
  - This can be used to determine referral for survivorship services and required frequency of follow up

- Regular review for at least 5 years post completion of treatment, thereafter as clinically indicated, monitoring for disease recurrence and organ function as per individual surveillance schedule

- Organ function monitoring as per long term surveillance guidelines

Supportive Care

- End of treatment MDT meeting: summary of therapy and recommendations for follow up.

- Communication and letter regarding follow up to GP.

- Use of distress tool and referral to psychosocial support as required for issues identified such as:
  - Integrating back into community, school, employment
  - Loss of hospital support 'in limbo'
  - Fear of relapse, change of perception of life expectations, change in priorities
  - Depression, chronic fatigue, fertility

- Access to support groups.

Further Information

- [www.childrensoncologygroup.org/disc/le/](http://www.childrensoncologygroup.org/disc/le/)

- Appendix B – Cancer Resources in SA

- Appendix D – Referral for psychosocial care

- Chapter 17 Survivorship
Table 16: Surveillance Schedule Guide

Note: this may vary dependent on individual circumstance

<table>
<thead>
<tr>
<th>Duration</th>
<th>Frequency</th>
<th>Investigations and Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediately post therapy</td>
<td>Weekly to 6 weekly</td>
<td>• Frequency determined by individual needs&lt;br&gt;• Care to be coordinated by primary treating specialist with input from allied health professionals.</td>
</tr>
<tr>
<td>2 to 3 years post therapy</td>
<td>3 monthly</td>
<td>• Clinical assessment including:&lt;br&gt;  o History and examination&lt;br&gt;  o Full blood exam and LDH assessment&lt;br&gt;• Imaging studies as required, dependent on therapeutic plan&lt;br&gt;• Late effects specific screening such as:&lt;br&gt;  o Endocrine surveillance&lt;br&gt;  o Cardiac assessment&lt;br&gt;  o Osteoporosis&lt;br&gt;  o Myelodysplasia&lt;br&gt;  o Renal function&lt;br&gt;  o Secondary malignancies</td>
</tr>
<tr>
<td>3 to 5 years post therapy</td>
<td>4 to 6 monthly</td>
<td>• As above</td>
</tr>
<tr>
<td>Indefinitely</td>
<td>Annually</td>
<td>• As above</td>
</tr>
</tbody>
</table>

Issues to consider:

• The timing and intensity of surveillance for recurrent/progressive disease will be determined by the intended therapy if recurrent disease is identified. A clear decision about the likely approach to therapy for relapse should be formulated for each patient before deciding on a surveillance schedule.

• When new recurrences occur, they are usually detected by investigations of new symptoms/physical findings or by non specific systemic test such as serum lactate dehydrogenase. After 12 to 24 months, routine scanning is not recommended.

• Imaging type and frequency will depend on the plan for management of relapse, level of individual patient risk and specific modality based on the region considered to be at risk and presence of residual radiological abnormalities.

• Potential late effects of therapy screening will be determined by the primary disease and treatment exposures.

Table 17: Late Effect Issues
<table>
<thead>
<tr>
<th>Medical Issues</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immunisation status</td>
<td>• Some patients may require re-vaccination after stem cell transplant.</td>
</tr>
<tr>
<td></td>
<td>• Refer to lymphoma specialist for further information and schedule.</td>
</tr>
<tr>
<td>Sexuality</td>
<td>• Physical and psychological issues may affect sexuality. Refer to Chapter 7 Specific Supportive Care needs.</td>
</tr>
<tr>
<td></td>
<td>• Further information and support is available at Cancer Council South Australia <a href="http://www.cancersa.org.au/aspdx/home.aspx">http://www.cancersa.org.au/aspdx/home.aspx</a></td>
</tr>
<tr>
<td>Second malignancy</td>
<td>• Some chemotherapy agents, radiation doses and transplant treatments can increase the risk of secondary cancers, particularly breast cancer in young females where radiation therapy encompasses breast tissue.</td>
</tr>
<tr>
<td></td>
<td>• Refer to COG guidelines for information on cancer screening: <a href="http://www.childrensoncologygroup.org/disc/e/">http://www.childrensoncologygroup.org/disc/e/</a></td>
</tr>
<tr>
<td>Fertility assessment</td>
<td>• Issues post treatment includes infertility and premature menopause.</td>
</tr>
<tr>
<td></td>
<td>• Referral to specialists and counsellors may be required:</td>
</tr>
</tbody>
</table>
### Table 17: Late Effect Issues

<table>
<thead>
<tr>
<th>Medical Issues</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive impairment</td>
<td>- Poor memory, learning problems, shorter attention span (more common for those in receipt of CNS treatment) can be experienced after lymphoma therapy. Refer to <a href="#">Chapter 7 Specific Supportive Care needs</a>.</td>
</tr>
<tr>
<td>Fatigue</td>
<td>- Regular exercise/health lifestyle may improve fatigue. Refer to <a href="#">Chapter 7 Specific Supportive Care needs</a>.</td>
</tr>
<tr>
<td>Other morbidities relating to therapy</td>
<td>- Clinical conditions may include:</td>
</tr>
<tr>
<td></td>
<td>- Cardiovascular disease Reduced pulmonary function</td>
</tr>
<tr>
<td></td>
<td>- Endocrine disorders including DM</td>
</tr>
<tr>
<td></td>
<td>- Sight and hearing deficiencies</td>
</tr>
<tr>
<td></td>
<td>- Renal dysfunction</td>
</tr>
<tr>
<td>Growth</td>
<td>- Effects on the endocrine system may lead to growth hormone deficiency, hypothyroidism and hypopituitarism all of which impact on growth.</td>
</tr>
</tbody>
</table>
Table 17: Late Effect Issues

<table>
<thead>
<tr>
<th>Medical Issues</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone Health</td>
<td>Issues include:</td>
</tr>
<tr>
<td></td>
<td>o Avascular necrosis</td>
</tr>
<tr>
<td></td>
<td>o Osteoporosis</td>
</tr>
<tr>
<td></td>
<td>• Usually occurs in weight bearing joints resulting in pain and loss of mobility.</td>
</tr>
<tr>
<td></td>
<td>• Most common sites are hips, shoulders and knees.</td>
</tr>
<tr>
<td></td>
<td>• Consider bone density assessment.</td>
</tr>
<tr>
<td></td>
<td>• Over time, joint replacement maybe necessary.</td>
</tr>
<tr>
<td>Nutrition</td>
<td>• Patients may experience weight loss or obesity.</td>
</tr>
<tr>
<td></td>
<td>• Aim for healthy weight range through monitoring and health promotion strategies.</td>
</tr>
<tr>
<td></td>
<td>• Consultation with a dietitian may be required.</td>
</tr>
<tr>
<td>Quality of life</td>
<td>• Provide ongoing assessment of patients, carers and families, offer interventions, encouragement and support to improve QOL issues.</td>
</tr>
</tbody>
</table>

**Recommendation:**

33. **At the conclusion of treatment, documentation and communication of a summary of therapy and recommendations for follow-up are given to the patient and their general practitioner.**

---


131 ibid


15. CANCER RECURRENCE

Treatment for recurrent lymphoma can be either curative in intent or focused on palliation/disease control. Clinical evaluation and patient wishes will determine the intent of treatment. Clinicians need to ensure that patients are referred to the appropriate supportive care professionals as many patients and families report substantial distress at this time.

Clinical

- Investigations will be as per post treatment surveillance protocol or as clinically indicated, including blood samples, CT scan, +/- PET scan.
- All patients should be referred to the MDT for discussion.
- GP and palliative care participation is essential.
- Either the referring specialist or nominated specialist has responsibility for managing treatment of recurrence.
- Treatment will be dependant on location, extent of recurrence and previous management.
- Treatment may include:
  - Chemotherapy
  - Radiotherapy for localised disease
  - Surgery may be required to confirm histological category and recurrence and for insertion of intravenous access devices
  - No treatment
- Where appropriate a major component of therapy should be participation in a clinical trial.

Supportive Care

- Refer to Chapter 6 Supportive Care

Further information:

- Appendix B – Cancer Resources in SA
- Appendix D – Referral for psychosocial care
- Distress Thermometer
- Chapter 10 Diagnosis and Staging
- Chapter 11 Presentation at a lymphoma MDT meeting
- Chapter 16 Palliative Care

Recommendation:

34. All patients with recurrent lymphoma are to be referred to the lymphoma multidisciplinary team meeting for discussion and consideration of curative and/or palliative interventions including chemotherapy and/or radiotherapy or other procedures and to the review plan for ongoing supportive care.

16. PALLIATIVE CARE

16.1 Palliative interventions and care

The World Health Organization defines palliative care to be ‘an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems’. 138

A palliative approach is delivered by primary health care providers which include the GP, haematologist, medical and radiation oncologists, hospital nursing and allied health professionals and community nursing services.

Specialist Palliative Care teams will often work in a consultative role with the patients’ primary health providers arranging the provision both of relief from symptoms and symptom control, social and psychological support for patients and their carers when these needs cannot be met by primary care teams, across a range of health care services, from the acute setting to hospice or in the community.

When the end of life phase is approaching, the focus of care moves much more toward comfort and care. This is where the palliative care team may become the primary specialist service involved, working alongside the patients’ general practitioner and other primary care providers. Such transition is best done in a coordinated fashion between the specialist groups so that the patient understands the reason for transition, how it will occur and ensures the patient continues to feel well supported.

Table 18: When to refer to a specialist palliative care service?

<table>
<thead>
<tr>
<th>When</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early referral</td>
<td>• Recommended for patients with particularly complex problems.</td>
</tr>
<tr>
<td>Anytime along disease trajectory</td>
<td>• When the patient or significant others associated with the patient have physical, psychological, social or spiritual needs that are not being adequately addressed</td>
</tr>
</tbody>
</table>
16.2 Palliative interventions for lymphoma

The range of symptoms experienced by patients with lymphoma may vary from individual to individual and in severity. Symptoms and complications related to bone marrow failure are common in patients with advanced lymphoma, such as anaemia, bleeding and infections. Blood product support is often required. Lymphomatous masses may result in obstruction, and the most common sites affecting patients with lymphoma include superior vena cava and biliary tree obstruction. Chemotherapy, radiotherapy, corticosteroids and stenting may be appropriate options for treatment of such complications. Pain is not as common in lymphoma patients as with solid cancers, but can be an issue. Other symptoms may include poor appetite, loss of weight, fatigue and breathless with a possibility of confusion and agitation developing in the terminal phase of life. Therapeutic guidelines provide a useful resource for symptom control. [www.tg.com.au](http://www.tg.com.au)

**Advanced Care Planning**

Advanced care planning is a process that enables an individual to express their wishes about his or her future health care.


**Table 19: Legal Advanced Care Directives in SA**

<table>
<thead>
<tr>
<th>Advanced Directives</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipatory Direction</td>
<td>• Patients or parents of children can give directions about the medical treatment they do, or do not want for themselves or their child towards the end of life.</td>
</tr>
<tr>
<td>Medical Power of Attorney</td>
<td>• Patient may appoint a medical agent with the power to make medical decisions, in case the patient loses the ability to make or communicate such decisions themselves.</td>
</tr>
<tr>
<td>Enduring Power of Guardianship</td>
<td>• Patient may appoint a guardian to make lifestyle decisions towards the end of life, in case the patient loses the ability to make or communicate such decisions themselves.</td>
</tr>
</tbody>
</table>
16.3 End of life care

In Australia palliative care is most often provided for patients in the last three to six months of life,\textsuperscript{139} with up to 90\% of terminally ill adult patients spending the majority of their last year of life at home.\textsuperscript{140}

During end of life care, patients, their family and/or care givers, GPs and acute hospital staff require 24 hour access to a member of the specialist palliative care team for advice and consultative support. Often multiple community based services may be required as disease advances. A specialist palliative care team member (e.g. community outreach nurse or liaison nurse) will often be responsible for ensuring effective coordination of palliative care services, continuity of care and rapid communication, both between professionals and with patients and their families.

All efforts are required to ensure that it is possible for patients to spend their remaining time in the place of their choice, whether this is in their home, hospital or inpatient hospice unit, care providers should be alert to the possibility that this preference may change as death approaches.

Quality of life in people with advanced cancer is affected by symptoms, loss of function and curtailment of activity and physical effects of treatment.\textsuperscript{141} Patients with metastatic disease have a significantly greater unmet need for assistance with physical aspects of daily living compared with the needs of patients without evidence of active disease.\textsuperscript{142}

The physical burden of disease in patients with cancer exerts a major influence on the emotional coping ability of the patient and their carers. This may be exacerbated by the weight of existential and spiritual issues arising from facing death. Distress and worry that arises from confrontation with their own mortality or the death of their child and existential concerns are reported to be at least as important as the physical, psychological and social support domains in determining quality of life.\textsuperscript{143}

Further information:

- Therapeutic Guidelines \url{www.tg.com.au}
- Palliative Care Australia \url{www.palliativecare.org.au}
- Palliative Care Council of Australia \url{www.pallcare.asn.au}

**Recommendation:**

**35. All patients and their families and/or caregivers should have access to specialist palliative care services if required.**

---

136 World Health Organisation Definition of Palliative Care 2004.
137 Bellzhear, A. The changing face of dying in Australia. MJA 2001;175, 10, pp508-570
138 Palliative Care Australia. State of the nation 1998 – report of the national census of palliative care services. Palliative Care Australia; 1999
17. SURVIVORSHIP

Significant improvements in early detection and treatment of cancer have resulted in increasing survival of patients.\textsuperscript{144} A review of studies of patients with cancer who had survived for five or more years reported that many continued to experience negative effects of cancer and/or treatment in their daily lives well beyond the completion of therapy.\textsuperscript{145} Previously, research into cancer survivorship had focused on physical, psychosocial and economic issues during treatment; however survivorship now also encompasses quality of life after treatment.\textsuperscript{146} Quality of life after cancer treatment is an important goal, secondary only to achieving remission.\textsuperscript{147}

**Figure 8:** Cancer Care Trajectory\textsuperscript{148}

Survivors face many issues affecting quality of life, refer to figure 10 – survivorship support, including socioeconomic, psychological, functional and family domains.\textsuperscript{149} Many of these issues are integrated; therefore if there is a problem in one area, other domains may also be affected. For example, a survivor may experience a decline in their
functional status, restricting family and work-related responsibilities, in turn affecting their socioeconomic status and psychological wellbeing. Due to the complexity of survivorship needs, it is important that survivorship support plans are implemented and coordinated addressing both medical and psychosocial aspects of care. The planning process is not limited to doctors and should be seen as a quality-related multidisciplinary team activity. Specialist nurses are in a unique position to assist with survivorship planning and provide the coordination of survivorship care. Through nurse-led clinics, advanced nursing practice roles such as the nurse practitioner, advanced nurse clinical practice consultant and nurse clinical practice consultant can work alongside medical practitioners, benefiting both clinicians and patients. Survivorship plans should be dynamic and working documents, updated as patient circumstance changes and additional research becomes available.

Figure 9: Survivorship support

[Diagram of Survivorship Support]

- **Medical Issues**
  - Depression
  - Fatigue
  - Fertility
  - Cognitive impairment
  - Chronic illness
  - Change in appearance

- **Health Promotion**
  - Smoking
  - Alcohol use
  - Weight control
  - Diet/nutrition
  - Exercise
  - Sun care

- **Fear of Relapse**
  - Changes in perception of life expectations
  - Change in priorities

- **Survivorship Support**
  - Specialised clinics to coordinate care
  - Support groups
  - Counseling, social worker, psychologist
  - General practitioner
  - Use of distress tool and refer accordingly
  - Staying healthy after cancer program
  - Exercise classes for cancer patients

- **Life long surveillance**
  - Late effects—i.e. secondary malignancy, hypothyroidism, cardiovascular effects

- **Psychosocial**
  - Integrating back into the community
  - School
  - Employment
  - Change in role/relationships
  - Loss of hospital support ‘in limbo’

To have the best chance of survival the patient and caregiver/family needs information, support and education.
Table 20: Benefits of a survivorship plan

- A vehicle for communication between treating physicians and local health providers.
- Help specialists and primary care physicians address questions that patients raise, perhaps years after treatment.
- Allows the patient to make informed health choices and promote healthy lifestyles in an attempt to reduce other co morbid conditions.
- Allows the patient to take some responsibility for their care. It may also ensure adherence to follow up recommendations.
- Can support and facilitate moving the focus of care back to the community.
- Early detection of health complications that can be ameliorated

Table 21: Key elements of a survivorship plan

- Patient diagnosis, age at diagnosis/treatment and stage.
- Treatment protocol/plan and exposures – including dates of therapy.
- Toxicities/morbidities experienced during therapy and potential long term toxicities.
- Guidelines for required screening for both recurrence and toxicities.
- Assessment of psychosocial/vocational/educational/financial needs.
- Recommended preventative behaviours/ interventions e.g. weight control, diet/nutrition, exercise, alcohol use, smoking, sun care, complementary medicine use, osteoporosis prevention, and immunisations.
- Information on the availability of community based psychosocial services e.g. an online searchable database of local resources according to postcode and/or links to national/international websites providing survivorship information and services.
- Contact information of the treating hospital and individual providers.
- Identification of a key contact and coordinator of continuing care.

It is increasingly recognised that the Haematology/Oncology community does not have the resources or capacity to provide care for survivors. Establishment of partnerships with primary health providers (e.g. GP’s, local community health services) is required to achieve quality survivorship care in the health care issues for this growing population. Other requirements for the implementation of survivorship planning include:

- Coordination of plans to ensure cohesive and efficient care, including an identified survivorship coordinator, i.e. specialist nurses such as nurse practitioners, nurse clinical practice consultants and advanced nurse clinical practice consultants.
- Time to create and deliver plans.
- Training of health professionals (inclusive of specialists) in needs of survivors and how to act on care plan recommendations.
• Research to expand the evidence base.
• Recognition of cancer as a chronic condition.

There are no specific survivorship guidelines for the lymphoma patient. Paediatric evidence based guidelines utilise both specific and cumulative exposures and age at exposure to determine recommendations for long term monitoring. The development of evidence based recommendations or support for the benefit of survivorship planning for adults has been impeded by the lack of evidence in these areas.\textsuperscript{153} Two factors which confound research into late effects in adult cancer survivors include recognition that co-morbid conditions (frequently seen in the adult population) may complicate interpretation of data and secondly, data from long term follow up studies often reflect outmoded therapies and techniques, making them not particularly applicable to modern treatment. Ongoing research is recommended taking into consideration the above factors.

ASCO is developing long term medical care guidelines for adult cancer survivors which focus on cardiopulmonary late effects, bone health, second cancers, hormone deficiencies and anxiety/depression.\textsuperscript{154} The Lance Armstrong Foundation through its Livestrong survivorship centre of excellence network is working to harness the expertise/experience/creativity/productivity of 5 leading cancer centres to develop knowledge and resources and ultimately improve delivery of services to survivors. The Cancer Research Network supported by the NCI is working with research organisations affiliated with non-profit health care providers in the US to establish databases from which evidence for such guidelines can be obtained.

Further Information:

1. ASCO websites:
   “People living with cancer”
   \url{www.plwc.org/portal/site/PLWC}.
   Survivorship
   \url{www.cancer.net/patient/survivorship}
   General information
   \url{www.asco.org/portal/site/ASCO/}
   The ASCO website contains templates for treatment summaries

2. Lance Armstrong Livestrong website
   \url{www.livestrong}
3. NCI booklet “Facing Forward: A guide for cancer survivors”
4. Cancer Survivor Toolbox
5. National Coalition for Cancer Survivorship
   www.canceradvocacy.org
6. Paediatric Long Term Follow up Guidelines
   www.survivorshipguidelines.org
7. Office of Cancer Survivorship
   http://dccps.nci.gov/ocs
8. National Comprehensive Cancer Network
   www.nccn.org/professionals/physician_gls
9. Oncolink – onc.life survivorship care plans
   www.oncolink.org/oncolife

Recommendations:

37. Survivorship plans to be provided to all lymphoma survivors.
38. Training in the issues for survivors should be undertaken by all professionals caring for lymphoma patients.
39. Establishment of partnerships between lymphoma specialists and primary health care providers should occur to facilitate improvements in achieving quality survivorship care for lymphoma patients.
40. An identified survivorship coordinator is required for cohesive and efficient care.
41. Development of survivorship guidelines is required for adult cancer survivors.

### Appendix A: Summary of recommendations

#### Key recommendations

<table>
<thead>
<tr>
<th>Pathway Recommendation</th>
<th>Service/System Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Prior to commencement of cancer therapy all patients to have the possibility of infertility addressed</td>
<td>• The possibility of infertility should be addressed as a component of the education and informed consent before cancer therapy commences. All patients of reproductive age or younger should have fertility preservation options discussed/offered.</td>
</tr>
</tbody>
</table>
| 2. Implement synoptic reporting of pathology as standard | • Implementation of synoptic reporting within all South Australian pathology services  
• Optimal patient management requires accuracy and consistency in histopathologic diagnosis. It is recommended that synoptic reporting of lymphoma becomes the standard for histopathologists. |
| 3. All lymphomas are referred to specialists with adequate experience and expertise in the management of lymphoma | • All patients with a diagnosis of lymphoma should be referred to specialists with experience in the management of lymphoma.  
• It is recommended that all patients with a diagnosis of lymphoma receive treatment where there are appropriately trained specialists available and have the required supportive care infrastructure. |
| 4. All lymphomas are referred to services with adequate workforce and infrastructure to safely and effectively care for patients with lymphoma | • All patients with lymphoma receive treatment where there are appropriately trained clinical specialists available (as per recommendation 3)  
• Acute care of lymphoma is be provided in a service with high standard supportive care infrastructure including  
• Lymphoma patients receiving active treatment including medical oncology and/or radiation oncology should be managed in a service with adequate access to these specialties. |
5. **100% of patients with lymphoma are prospectively discussed at a multi-disciplinary team meeting within 4 weeks of confirmed diagnosis**

- Participation in the MDT becomes an expectation of cancer health professional as core business.
- Participation in the MDT and/or preparation of diagnostic materials and/or results is included as core business of diagnostic service providers within South Australia.
- Introduce role of Multi-disciplinary team co-ordinator to coordinate, monitor and follow up function of MDT.

6. **Timely access to results of investigations including, radiology and pathology**

- Urgent improvement to ICT links between public sites and across regions to enable adequate access to radiology images and pathology results.

7. **All patients with lymphoma have access to specialist nursing care and cancer care coordination throughout the cancer pathway**

- Recognition the role of Clinical Practice Coordinator (CPC) to provide and coordinate supportive care from diagnosis throughout treatment to follow up, survivorship or referral for end of life care.
- Determine the number of CPCs required based on the volume and complexity of patients and the number of services/sites covered.
- Patients with lymphoma should have their cancer journey streamlined by appropriate triage of urgency of referral, organisation of appointments and referral for social/cultural supports.

8. **Quality and safety of lymphoma care is monitored at state level.**

- Statewide systematic centralised database that captures minimum data of all individuals with a diagnosis of lymphoma. All treatment outcomes are reported, reviewed and measured.
- To maintain a complete database of lymphoma.
- Initiate process for centralised review and reporting of KPI's and benchmarks of clinical and service outcomes.
<table>
<thead>
<tr>
<th>Pathway Recommendation</th>
<th>Service/System Recommendations</th>
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</table>
| **9** All patients with lymphoma have access to culturally appropriate care and effective communication throughout the cancer pathway | • Use qualified interpreters in all consultations where English proficiency and fluency are limited.  
• Develop culturally appropriate resources and services.  
• Provide cross-cultural training for all staff involved in cancer care.  
• Foster links with culturally relevant organisations and services and facilitate access to their resources. |
| **10** Aboriginal Health Impact Statement for Cancer Pathway development in South Australia | • Implement the recommendations of the comprehensive Aboriginal and Torres Strait Islander companion document to the State-wide Cancer Control Plan 2011 -2015.  
• Address the South Australian Aboriginal Health Impact Statement checklist. |
South Australian Lymphoma Pathway Recommendations:

1. GP’s need access to information regarding available cancer services in rural and metropolitan locations either in leaflet format or email, better links with RACGP in providing up to date information.

2. Patient Information packages for all patients with potential diagnosis of lymphoma.

3. Rural patient package – disease information, practical information i.e. accommodation, PATS, centrelink, social worker contact.

4. Cancer Council resources to be utilised as standard practice.

5. All patients with a lymphoma diagnosis have access to a specialist lymphoma nurse throughout the cancer pathway.

6. Regular psychosocial assessment of patients/care givers along the cancer continuum is required to identify those experiencing significant levels of distress and who would be at risk of developing psychological morbidity.

7. All people with a cancer diagnosis have opportunity to receive culturally appropriate education and counselling(via a qualified interpreter if appropriate) regarding their diagnosis, options and care needs by a health professional with appropriate communication skills and knowledge of lymphoma.

8. Use of qualified interpreting services is essential for people of culturally and linguistically diverse backgrounds to ensure access to health care services.

9. Education is given to all lymphoma patients regarding risks of infection and the management of febrile neutropaenia.

10. Fertility options are discussed prior to chemotherapy commencement.

11. All patients are assessed for fatigue prior to treatment and regularly throughout the care continuum. Patients receive education regarding exercise and self care options to cope with fatigue.

12. Education is given to all lymphoma patients about the possible cognitive side effects of the treatment they receive.

13. Education is given to all lymphoma patients regarding sexuality issues with referral to identified counsellors who have the expertise in the area if required.

14. Clinicians offer support to patients who are to return to their educational institution and/or workplace, including communication with these facilities if required.

15. All patients with a lymphoma diagnosis have access to information
regarding nutrition throughout the cancer pathway with the possibility of referral to a dietitian if required.

16. Creation and promotion of consumer information of lymphoma should include signs and symptoms of disease and time frames for review by general practitioner and general practitioner role to lymphoma specialist.

17. Initiate a key performance indicator (KPI) to monitor time from GP referral to specialist appointment.

18. A benchmark of 6 weeks from general practitioner identification of lymphoma symptoms to general practitioner referral to lymphoma specialist to be utilised.

19. Optimal patient management requires accuracy and consistency in histopathological diagnosis. It is recommended that synoptic reporting of lymphoma becomes the standard of histopathologists.

20. Staging investigations (note exceptions) to be done within 4 weeks of diagnosis.


22. All patients with lymphoma are prospectively discussed at a multidisciplinary team meeting within two to four weeks of confirmed diagnosis.

23. The multidisciplinary team assessment and discussion should occur after the issue diagnosis but prior to definitive treatment.

24. A copy of the lymphoma MDT recommendations as well as the agreed treatment plan (specialist/patient) is to be provided to the GP and patient within 7 working days and a copy placed in the patient's case file.

25. Determine a Key Performance Indicator (KPI) to monitor % of patients referred to the Lymphoma Multidisciplinary team for prospective treatment planning.

26. Clinicians providing cancer therapy to lymphoma patients should be appropriately credentialed for those purposes.

27. Lymphoma treatments should be provided within accredited institutions and have access to supporting facilities, as indicated by the level and intensity of therapy required.

28. Where possible, patients should be offered clinical trial enrolment.
29. Where possible, patient treatment should proceed according to established protocols.

30. At the conclusion of treatment, documentation and communication of a summary of therapy and recommendations for follow-up are given to the patient and their general practitioner.

31. All patients with recurrent lymphoma are to be referred to the lymphoma multidisciplinary team meeting for discussion and consideration of palliative interventions including chemotherapy and/or radiotherapy or other procedures and to review the plan for ongoing supportive care.

32. All patients with cancer should be specifically asked about their use of complementary and alternative therapies (CAM).

33. Responses to questions about CAM use should be documented in the case notes.

34. Patients should have access to the Understanding Complementary Therapies booklet and the Cancer Council SA Helpline number (13 11 20)

35. All patients and their families and/or caregivers should have access to specialist palliative care services if required.

36. Survivorship plans to be provided to all lymphoma survivors.

37. Training in the issues for survivors should be undertaken by all professionals caring for lymphoma patients.

38. Establishment of partnerships between lymphoma specialists and primary health care providers should occur to facilitate improvements in achieving quality survivorship care for lymphoma patients.

39. An identified survivorship coordinator is required for cohesive and efficient care.

# Appendix B: Cancer Resources in South Australia

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Contact details</th>
<th>Available resources</th>
</tr>
</thead>
</table>
| Cancer Council South Australia | 202 Greenhill Road, Eastwood SA 5063  
Tel: 08 8291 4111  
Freecall: 1800 188 070  
Fax: 08 8291 4122  
Website: [www.cancersa.org.au](http://www.cancersa.org.au) | Services include information on cancer, its treatment, side effects, and medical terminology, support services such as counselling, self care programs, accommodation and research.  
CCSA also provides links to other reliable cancer information websites, along with an online library.  
Cancer Council SA - Online Library  
| Cancer Council Helpline | Tel: 13 11 20  
Email: [chl@cancersa.org.au](mailto:chl@cancersa.org.au) | Nurses and health counsellors  
Cancer Connect - for telephone peer support from people who have had cancer experiences. |
| Cancer Council Australia | Website: [www.cancer.org.au](http://www.cancer.org.au) | Fact sheets:  
| Cancer Care Centre | 76-78 Edmund Ave, Unley SA  
Cancer support line: 08 8272 2411  
Administration: 08 8373 1470  
Fax: 08 8357 1979  
Website: [www.cancercarecentre.org.au](http://www.cancercarecentre.org.au)  
Email: admin@cancercarecentre.org.au | |
| Leukaemia Foundation | 24 Crittenden Rd, Findon SA  
Tel: 08 8273 3555  
Fax: 08 8357 7656  
Website: Leukaemia Foundation | Services include emotional support and counseling, education and support programs including look good feel better, Look Good...Feel Better : Home  
accommodation, transport and practical assistance, consumer information on clinical trials |
| Palliative Care Council of SA Inc | 202 Greenhill Road, Eastwood SA 5063  
Tel: 8291 4137  
Website: [www.pallcare.asn.au](http://www.pallcare.asn.au) | |
Appendix C: Resources for Aboriginal and Torres Strait Islander People and Culturally and Linguistically Diverse Communities

Resources for Aboriginal and Torres Strait Islander Peoples

| Aboriginal Health Council of South Australia Inc (AHCSA) | 9 King William Rd Unley SA 5061  
(08) 8273 7200  
Website: [http://www.ahcsa.org.au/home/](http://www.ahcsa.org.au/home/) | The primary role of this council is to be the 'health voice' for all Aboriginal People in South Australia through advocating for the community and supporting workers with appropriate Aboriginal health programs. The Council consists of several Aboriginal Health Advisory Committees and local Aboriginal Community Controlled Health Services. The location of these are shown on the map at this web link: [http://www.ahcsa.org.au/media/docs/ahcsa_map_new.pdf](http://www.ahcsa.org.au/media/docs/ahcsa_map_new.pdf) |
| --- | --- | --- |
| Members of the AHCSA | Each member group of the AHCSA provides local information and programs. NB Not all members have a web site  
2. Ceduna/Koonibba Aboriginal Health Service  
3. Eyre Aboriginal Health Advisory Committee  
4. Hills Mallee Aboriginal Health Advisory Committee  
6. Mid North Aboriginal Health Advisory Committee  
8. Northern Aboriginal Health Advisory Committee  
11. Oak Valley Health Service  
15. Riverland Aboriginal and Islander Health Advisory Group  
16. South East Aboriginal Health Advisory Committee  
17. Tullawon Health Service  
19. Wakefield Aboriginal Health Advisory Committee |
| National Aboriginal Community Controlled Health Organisation (NACCHO) | Website: [http://www.naccho.org.au/](http://www.naccho.org.au/) | Information on national roles and activities for Aboriginal Community Controlled Health Services across Australia |
### Resources for Aboriginal and Torres Strait Islander Peoples

<table>
<thead>
<tr>
<th>Aboriginal Health Liaison Units located in Adelaide hospitals.</th>
<th>This service is provided at the following metropolitan health services:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. The Queen Elizabeth Hospital Aboriginal Liaison Officers Woodville Road Woodville, SA 8222 6000 (via switch board) Or office 82228597</td>
</tr>
<tr>
<td></td>
<td>3. Lyell McEwin Hospital Muna Paidendi Aboriginal Health Team Haydown Road, Elizabeth Vale (08) 8182 9206</td>
</tr>
<tr>
<td></td>
<td>5. Women’s and Children’s Hospital Aboriginal Health Unit Ph (08) 8161 7036 Web site: <a href="http://www.wch.sa.gov.au/services/az/other/aboriginal/">http://www.wch.sa.gov.au/services/az/other/aboriginal/</a></td>
</tr>
</tbody>
</table>

A list of Community Health services in SA is available at the following web sites: [http://www.caesa.org/commhealth.html](http://www.caesa.org/commhealth.html) [http://www.caesa.org/acsd.htm](http://www.caesa.org/acsd.htm)  

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<table>
<thead>
<tr>
<th>Australian Indigenous Health Info Net</th>
<th>This is a national website to promote knowledge and information sharing on all health issues for Aboriginal and Torres Strait Islander People. Information is provided for both consumers and health care professions.</th>
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## Resources for culturally and linguistically diverse communities

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<thead>
<tr>
<th>Service</th>
<th>Address/Contact Information</th>
<th>Description</th>
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<tbody>
<tr>
<td>Migrant Health Service</td>
<td>21 Market Street, Adelaide 5000 Tel: 8237 3900</td>
<td>Provides information and health services that are culturally appropriate. For example access to bilingual nurse, doctors and counsellors.</td>
</tr>
<tr>
<td>Migrant Resource Centre of South Australia</td>
<td>59 King Williams St Adelaide SA 5000 (08) 8223 3604 Website: <a href="http://www.mrcsa.com.au/profile">http://www.mrcsa.com.au/profile</a> .html</td>
<td>Provides a range of services including health</td>
</tr>
<tr>
<td>Multicultural Communities Council of SA (MCC)</td>
<td>113 Gilbert Street, Adelaide 5000 Tel: 8410 0300 Website: <a href="http://www.multiwebsa.org.au">www.multiwebsa.org.au</a></td>
<td>Information and referral to appropriate services for people of non-English speaking background.</td>
</tr>
<tr>
<td>Multicultural SA</td>
<td>24 Flinders Street, Adelaide 5000 Tel: 8226 1944 Interpreting and Translation Centre, Tel: 8226 7990 Website: <a href="http://www.mulitcultural.sa.gov.au">www.mulitcultural.sa.gov.au</a></td>
<td>Interpreting and Translation Centre provides telephone and face to face translation to and from English into 80 different languages. A health interpreting service is provided to all public hospital and health care units.</td>
</tr>
<tr>
<td>Translating and Interpreting Service (TIS)</td>
<td>Casselden Place, 2 Lonsdale Street, Melbourne VIC 3000 Tel: 13 14 50</td>
<td>Interpreting services in over 150 languages to all people requiring this assistance over the telephone.</td>
</tr>
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## Women’s health information and resources

<table>
<thead>
<tr>
<th>Service</th>
<th>Address/Contact Information</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Women’s Health Statewide Information Service</td>
<td>64 Pennington Terrace, North Adelaide 5006 Website: <a href="http://www.whs.sa.gov.au">www.whs.sa.gov.au</a> Rural Women’s Telephone Counselling Service, Tel: 8239 9600 or 1800 182 098 Health line: 1300 882 880</td>
<td>Services include women’s health line and counselling.</td>
</tr>
</tbody>
</table>
Appendix D: Referral for Psychosocial Care

It is important to screen patients for elevated distress and emotional concerns at every medical appointment, but particularly at times of increased vulnerability e.g. at time of diagnosis, prior to commencement of treatment or at the end of treatment, discharge from hospital, surveillance appointments and recurrence / progression of disease.

It is common for people who are experiencing increased distress to have difficulty recalling and remembering information. To assist in reducing anticipatory anxiety, be sure the patient understands their disease and treatment options. Refer the patient to education materials and advise patients and their families that times of transition may bring increased vulnerability to distress.

Before referring for psychosocial care please consider the following:

- Is the person and/or family member experiencing an acute exacerbation in distress following a period of increased vulnerability? (as listed above)
- Is the person’s distress directly related to:
  - Sadness associated with loss of usual good health
  - Preoccupation with thoughts about illness and treatment
  - worry about future
  - worry about the impact the illness is having on their family
  - relationship or family issues
- Are there significant practical concerns for person? (e.g. financial stress, transport issues, power of attorney, end of life decisions, etc)
- Is the person experiencing chronic elevated distress that is impacting on pain or symptom control or on their normal functioning or ability to complete cancer treatment
- Has a past history of mental health concerns
- Has trauma history or symptoms (i.e. PTSD)
- Is experiencing severe anxiety related to their medical condition
- Is hyper vigilant, experiencing panic attacks or highly irritable
- Appears to be depressed or reporting suicidal ideation
- Is describing illness specific fears and phobias (i.e. needle phobia, hypochondriasis)
- Is exhibiting behaviours that are challenging to manage (i.e. aggression)
- Is reporting issues with body image or sexuality concerns
- Is concerned by chronic disruption to sleep, appetite and/or concentration
- Is the person’s primary presentation psychiatric in nature?
- Are there imminent risk issues? (e.g. suicidal plan/intent or aggression)
- Does the person have a previous psychiatric history or do they have current psychiatric input?
- Is there evidence of a thought disorder or psychosis?
- Is the person non-compliant?
- Are there signs or symptoms of suspected delirium?
- Does the person appear to have borderline cognitive status?
- Is there uncertainty about the nature and extent of cognitive issues?
- Is there difficulty identifying or distinguishing possible diagnoses / aetiologies?
- Has the person experienced any particular event that may impact on their cognitive function? e.g. brain injury, cancer metastases to brain).
- If the person is over the age of 65, has the person been triaged to Geriatric Medicine for formal assessment? (Ext: 25212)

Consider consulting or referring to these Disciplines:

**Social Work**
- Supportive counselling for patient and family
- Linking with external psycho-social supports
- Support groups and/or individual counselling
- Family meetings
- Grief counselling

**Clinical Psychology**
- Dependent on the presenting complaint, psychological intervention may include a combination of formal assessment, cognitive behavioural therapy, hypnotherapy, management suggestions, and other relevant therapeutic interventions.

**Psychiatric Referral**
- Formal Psychiatric Assessment and Review (e.g. history/medications)

**Clinical Neuropsychological**
- Formal Neuropsychological Assessment

Appendix E: Patient and carer questions that may arise about their cancer diagnosis, treatment and care during consultation with health care professionals.

(Scottish SIGN Guidelines: Management of oesophageal and gastric cancer, June 2006)

At the time of diagnosis and staging
- Will I live?
- What can be done?
- Who can I talk to?
- What is the staging process?
- What are the options available for the treatment of my cancer?
- Although an operation may be available to cure my cancer are there any alternatives?
- What are the advantages and disadvantages of each of the alternative options?
- Although my cancer may be operable are there reasons why an operation is not felt to be the best way to treat the Cancer?

Around the time of surgery
- What is involved in the surgery?
- How often is this operation carried out at this hospital?
- What are the risks involved?
- What happens immediately after surgery?
- How much pain will be involved?
- What immediate difficulties will I face?
- What are the long term prospects?
- What effect will this surgery have on my quality of life? (Including eating/drinking, Fatigue, sleeping, work/social activities)
- What about scarring?
- What follow up will there be?
- Practical issues- care planning, financial security etc

Around the time of chemotherapy
- What is involved in having chemotherapy?
- What are the risks involved?
- How much pain will be involved?
- Will I loose my hair?
- Will the chemotherapy make me feel sick?
- What immediate difficulties will I face?
- What are the long term prospects?
- What effect will this chemotherapy have on my quality of life? (Including eating/drinking, Fatigue, sleeping, work/social activities)
- If I live in a rural/country area will I have to relocate or can I have the chemotherapy locally?
- Can the chemotherapy be given as an inpatient/outpatient or at home?
- Can I protect my fertility?
- What follow up will there be?
- Practical issues- care planning, financial security etc
- Are there any clinical trials that I should consider?

Around the time of radiotherapy
- What is involved in having Radiotherapy?
• What are the risks involved?
• How much pain will be involved?
• Will the Radiotherapy make me feel sick?
• What immediate difficulties will I face?
• What are the long term prospects?
• What effect will this Radiotherapy have on my quality of life? (Including eating/drinking, Fatigue, sleeping, work/social activities)
• If I live in a rural/country area will I have to relocate or can I have the chemotherapy locally?
• What follow up will there be?
• Practical issues- care planning, financial security etc
• Are there any clinical trials that I should consider?

Potential physical problems
• Diarrhea/constipation
• Acid reflux
• Vomiting
• Unintentional Weight loss
• Problems sleeping comfortably
• Fatigue
• Reduced capacity for physical activity
• Need for long term medication/dietary supplementation (iron, folate, vitamin B12, vaccination, and antibiotic therapy).

On commencing palliative treatment
• What does palliative care mean?
• What treatment do you recommend?
• Why?
• Which symptoms can it help?
• How will it help?
• What is involved?
• What are the side effects/drawbacks/limitations?
• What alternatives can be considered?
• Are there any clinical trials that I should consider?
Appendix F: South Australian Lymphoma Patient Information Pathway

South Australian Lymphoma Patient Information Pathway

Information to be provided to patients with lymphoma

- **Information may be written, verbal or both depending upon patient choice**
- Patients/carers/families may be offered a range of information either verbal or written according to patient need and preference. Patients have the option to refuse or accept written information offered.

<table>
<thead>
<tr>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>May present with a range of symptoms</td>
</tr>
<tr>
<td>Lymphadenopathy</td>
</tr>
<tr>
<td>Fever, night sweats, unintentional weight loss, itch, pain</td>
</tr>
<tr>
<td>Lump or mass</td>
</tr>
<tr>
<td>Persistent Lymphadenopathy (up to four to six weeks)</td>
</tr>
</tbody>
</table>

**General practitioner visit**

Information probable verbal about:

- Referred for lymph node ultrasound, if abnormal for fine needle aspirate
- Being referred to a lymphoma specialist (haematologist/oncologist for investigation within four weeks.
- Possible investigations.

**Hospital appointment/investigations**

- Verbal introduction of consultant
- Verbal/written information about investigations e.g. ultrasound, fine needle aspirate, excisional biopsy.
- Introduction and contact numbers of specialist lymphoma nurses if appropriate.
- Information from supportive pathway as appropriate.
- Information to sources of information/emotional support.
- Dietary advice, referral to dietitian if appropriate.
- Given information and referral to CALD and ATSI social worker as required.

**Prior to first lymphoma specialist appointment**

- Information from the hospital appointment department (public/private).
- Patients referred urgently may be given their appointment via the telephone.
- Alternatively patients should receive an appointment letter detailing:
  - The appointment time
  - Which clinic
  - Which consultant/team
  - Likely length of time of appointment
  - Any likely investigations
  - Car parking

**Results**

- Disease specific information.
- Realistic information about the disease and the range of individual variation in its impact and rate of progression.
- Contact details/introduction to the specialist lymphoma nurse.
- Staging information e.g. CT, PET, baseline function of organ function.
- The aims, risk and likely effects of proposed diagnostic procedures, each procedure should be explained to the patient before it is undertaken.
- Possible treatment plan
- Supportive information as appropriate.
- Given information and referred to sources of information/emotional support.
- Information about transfer to other hospital or cancer centre if necessary.
- Dietary advice if appropriate/dietitian referral.
- Information about the lymphoma multidisciplinary team meeting, and benefits of consent to be presented at the multidisciplinary team meeting.
- Given patient information leaflet on the lymphoma multidisciplinary team meeting.

**Treatment**

Detailed information including the risk and benefits for the consent about treatment options such as:

- Surgery
- Chemotherapy
- Radiotherapy
- Palliative care
- No active treatment
- Given information and referred for further sources of information and support as required.
- Information from supportive pathway as appropriate.
- Information on complimentary therapies.
- Information on clinical trials.
Follow up
- Response to treatment
- The follow up arrangements

Continuing care
- Management of likely side effects from the disease and treatment.
- Information on possible symptoms
- Information from supportive pathway as appropriate.
- Dietary information and referral as appropriate.
- Given information and referred for further sources of information/emotional support.
- Information on complementary therapies.

Recurrence
Information about:
- Treatment/no treatment option.
- Symptom control.
- Supportive information as appropriate.
- Information and introduction about palliative care services.
- Information about the lymphoma multidisciplinary team meeting.

Palliative care
Information about:
- Managing symptoms.
- Side effects of treatment.
- Palliative care services.
- Bereavement support for the carer/family.

Survivorship
- Given information about rehabilitation therapy.
- Given information about nutrition, referral to dietitian.
- Given information to learn to live beyond cancer
- Information about screening and maintaining wellness, eg. QUIT - smoking, healthy diet, exercise.
- Information on complementary therapies.
Appendix G: Safety and Quality

Key Performance Indicators (KPIs)

- **Time from service request to service provision**
  - Obtaining a surgical biopsy identified as a potential barrier to pathway progress, time to achieve surgical biopsy after referral - **Recommendation – 7 days.**
  - Obtaining a PET scan for those lymphomas for which it is indicated also identified as a potential barrier to pathway progress - **Recommendation – 10 days.**
  - Referral from GP to lymphoma specialist once lymphoma symptoms identified - **Recommendation – no more than 6 weeks.**

- **Staging**
  - Recognised that lymphoma diagnosis ranges from high to low grade disease and some variability in urgency for staging exists. When staging is required it should be completed in a timely fashion - **Recommendation – 4 weeks from diagnosis.**

- **Multidisciplinary meetings**
  - Percent of new diagnoses discussed at Lymphoma MDT meeting.
  - Percent of MDT recommendations placed in patient case file.
  - Percent of patients discussed at MDT with consent documented.
  - MDT recommendations to be sent to GP and patient within 7 working days.
  - Time from confirmed lymphoma diagnosis to presentation at MDT meeting - **Recommendation – 2 - 4 weeks.**

- **Appropriate Referrals**
  - Number of patients of reproductive age or younger referred for fertility preservation.
  - Number of AYA patients referred to AYA specialist/nurse coordinator/social worker.
Audit

- Appropriate investigations performed prior to referral/diagnosis
- Time from presentation to GP/? symptoms until diagnosis made
- Measurement of attendance numbers to MDT meetings
- Attendance of MDT core members to MDT
- Recommendation regarding what attendance is thought to be mandatory for MDT
- Number of new patients presented to MDT vs. diagnosis of lymphoma in SA
- Time point of MDT review
  - Prior to diagnosis
  - At diagnosis but before treatment
  - After treatment has begun
  - At conclusion of treatment
  - At recurrence
- Time from diagnosis to MDT meeting recommendations
- Documentation of MDT recommendations in patient file, sent to GP and provided to family
- Availability of written information about treatment program
- Documentation and number of treatment delays and reasons
Appendix H: Lymphoma Glossary of Terms

Acute
Sudden or severe, in onset

Adjuvant treatment
Treatment used in addition to main treatment, usually radiotherapy or chemotherapy given after surgery.

Aetiology
The origins or causes of disease.

Age-standardised incidence
A method of more accurately comparing incidence rates between populations by removing differences in the age distributions of those populations.

Alkylating agents
A family of drugs that prevent the division of cancer cells by damaging DNA.

Allogeneic transplantation/allograft
A procedure in which a patient receives bone marrow or blood stem cells from a genetically matched donor following high dose therapy to destroy their own bone marrow.

Anaemia
A condition in which the number of red blood cells in the blood is below normal.

Antibodies
Proteins made by plasma cells in response to a foreign substance (antigen) in the body.

Antigen
Any molecule recognised by the immune system as being foreign and therefore provoking the production of antibodies.

Anorexia
Loss of appetite; inability or refusal to eat.

Audit
A method used by service providers to measure quality of care. Results of a process or intervention are assessed, compared with a pre-existing standard, changed where necessary, and reassessed.

Autologous transplantation/autograft
A procedure in which a patient receives their own bone marrow or stem cells which were collected prior to a course of high dose therapy to destroy their remaining bone marrow.

Axilla
The armpit

Biopsy
A sample of tissue or cells is removed from the body to aid diagnosis of a disease.

Blood products
Whole blood or components of the blood including red blood cells, platelets and plasma.

Blood stem cells
Progenitor cells which give rise to red blood cells and immune system blood cells.

Bone marrow
The soft inner part of the bone. Bone marrow produces the stem cells which develop into three different types of blood cells: red blood cell, white blood cells and platelets.

Bone marrow transplantation (BMT)
A procedure to replace bone marrow that has been destroyed by high dose therapy. There are two types of transplant-allogeneic where healthy bone marrow is taken from a donor who has a similar tissue type to the patient and autologous, where the patients own bone marrow is used.

Brachytherapy
Radiotherapy delivered within an organ.

Central venous catheter/central line
A thin plastic tube which is inserted through the skin into a vein in the chest through which blood test can be taken and intravenous chemotherapy and blood transfusions can be given. Once in place it can remain in the vein for many months.

Chemotherapy
The medication used to treat cancer is commonly referred to as chemotherapy. The aim of chemotherapy is to kill cancer cells, or prevent or slow cancer cell growth.

Computed tomography (CT)
A specialist x-ray imaging technique.

Chronic
Long lasting or slowly progressing.
Colony-stimulating factors (CSF)
Substances which stimulate the production of certain blood cells e.g. G-CSF stimulates granulocytes. They may be used to produce extra stem cells prior to a stem cell harvest, or to promote the recovery of white blood cells following chemotherapy.

Combination chemotherapy
The use of more than one drug to kill cancer cells.

Core biopsy
The removal of a tissue sample with a needle for laboratory examination. This test uses a slightly larger needle than the one used for fine needle aspiration (FNA) and is usually done under local anaesthetic.

Cytogenetic abnormalities
Abnormalities of chromosomes.

Cytogenetic abnormalities
The study of chromosomes and chromosomal abnormalities.

Cytology
The study of the appearance of individual cells under a microscope.

Cytotoxic
"cyto" – cells: cytotoxic – meaning toxic to cells. This term is used to describe medications that kill cancer cells or slow their growth.

Dysplasia
Abnormal changes in the morphology (form, appearance or nature) of tissues.

Fibrotic tissue
Fibrous tissue that replaces normal tissue e.g. scars or tissue that is left after the cancer has been killed by treatment.

Fine needle aspiration (FNA)
The removal of cells using a fine needle for examination in the laboratory.

Granulocyte
A white blood cell that is an essential component of the immune system.

Haematological cancer
Cancers of the blood and blood forming tissues.

Haematologist
A doctor who specialises in disorders of the blood and blood forming tissues.

Haematology
A branch of medicine concerned with the study and treatment of cancers of the blood and blood forming tissues.

Haemopoietic or haematopoietic
The process by which blood cells are produced in the bone marrow.

Hepatosplenomegaly
Abnormal enlargement of both the liver and the spleen.

Heterogeneous
Of differing origins, or different types.

High dose therapy
Intensive treatment with chemotherapy and/or radiotherapy to kill malignant cells in the bone marrow. As the treatment also kills healthy bone marrow cells, it must be followed by Bone marrow or stem cell transplantation.

High grade lymphomas
Faster growing, clinically aggressive lymphomas.

Histological grade
Degree of malignancy of a neoplasm, usually judged from its histological features.

Histological type
The type of tissue found in a tumour.

Histology
Examination of the microscopic structure of tissue.

Hodgkin lymphoma
A type of cancer in which cells of the lymph tissue are produced in excess and result in the progressive, painless enlargement of lymph nodes, the spleen and general lymph tissue. A particular abnormal cell, known as the Reed-Sternberg cell is found in Hodgkin’s lymphoma.

Immunosupression
Suppression of the immune system.
Indolent lymphomas
Lymphomas that grow and spread slowly (also called low grade lymphomas)

Interventional radiologist
A doctor who specialises in imaging and the use of imaging techniques to guide the placement of therapeutic devices like stents inside the body.

Intrathecal
Into the fluid space around the spine

Intravenous
Into a vein

Intra-luminal radiotherapy
See brachytherapy.

Localised disease
Tumour confined to a small part of an organ.

Lymph node status
The presence or absence of tumour in a lymph node.

Lymph nodes
Small organs which act as filters in the lymphatic system. Lymph nodes close to the primary tumour are often the first sites to which cancer spreads.

Lymphadenopathy
Disease or swelling of the lymph nodes

Lymphocytes
A class of white blood cell that fights infection and disease by producing antibodies and other protective substances. There are two categories - B cells and T cells.

Lymphoid cell
Pertaining to cells involved in lymph or lymphatic tissue

Lymphoma
Cancer of the lymphatic system. There are two main types of lymphoma – Hodgkin’s lymphoma and non-Hodgkin’s lymphoma.

Magnetic resonance imaging (MRI)
A non-invasive method of imaging which allows the form and metabolism of tissues and organs to be visualised.

Medical oncologist
A doctor who specialises in the treatment of cancer. (chemotherapy).

Meta-analysis
A form of statistical analysis used to synthesise results from a collection of individual studies.

Metastases/metastatic disease
Spread of cancer away from the primary site.

Monoclonal antibody therapy
Antibodies produced in the laboratory from a single copy of a human antibody that can target specific cancer cells wherever they may be in the body.

Neo-adjuvant treatment
Treatment given before the main treatment; usually chemotherapy or radiotherapy given before surgery.

Neutropaenia
A condition in which the number of granulocytes (neutrophils) in the blood is below normal.

Non-Hodgkin lymphoma (NHL)
Any cancer of the lymphatic system other than Hodgkin lymphoma. There are two main groups - high grade which are aggressive and fast growing and low grade which are slow growing (also known as indolent lymphomas). High grade lymphomas include: diffuse large B-cell lymphoma (DLBCL), peripheral T-cell lymphoma, Burkitt’s lymphoma, mantle cell lymphoma and AIDS-related lymphoma. Low grade include: follicular lymphomas, waldenstroms lymphoma and marginal zone lymphomas. Extranodal lymphomas are those that develop outside lymph nodes such as those affecting the skin or intestine.

Oncologist
A doctor who specialises in treating cancer.

Oncology
The study of the biology and physical and chemical features of cancers. Also the study of the cause and treatments of cancers.
**Palliative**
Anything which serves to alleviate symptoms due to the underlying cancer but is not expected to cure it. Hence palliative care, palliative chemotherapy.

**Positron emission tomography (PET)**
An imaging method which reveals the level of metabolic activity of different tissues. PET scans are used in diagnosis.

**Prophylaxis**
An intervention used to prevent an unwanted outcome.

**Protocol**
A policy or strategy which defines appropriate action

**Psychosocial**
Concerned with psychological influence on social behaviour.

**Quality of life**
The individuals overall appraisal of their situation and subjective sense of well-being.

**Randomised controlled trial**
A type of experiment which is used to compare the effectiveness of different treatments. The crucial feature of this form of trial is that patients are assigned at random to groups which receive the interventions being assessed or control treatments. Randomised controlled trials offer the most reliable form of evidence on effectiveness.

**Radiotherapy**
The use of radiation, usually X-rays or gamma rays, to kill tumour cells.

**Radical radiotherapy**
Radiotherapy given with curative, rather than palliative intent.

**Recurrence**
The return of cancer.

**Remission**
A period when cancer has responded to treatment and there are no signs of tumour or tumour-related symptoms.

**Spleen**
An organ which is part of the lymphatic system. It produces lymphocytes, stores blood cells, filters the blood and removes and destroys worn out red blood cells.

**Squamous cell carcinoma**
A common type of cancer which originates in superficial layers of tissue (squamous epithelium)

**Staging**
The allocation of categories (stage I to IV) to tumours defined by internationally agreed criteria. Stage I tumours are localised, whilst stages II to IV refer to increasing degrees of spread through the body from the primary site.

**Stem cell harvesting**
Collection of stem cells either from the bone marrow (for bone marrow transplantation) or the bloodstream (for stem cell transplantation). Stem cells are normally found in the bone marrow. However, the bone marrow can be stimulated to produce lots of stem cells by the administration of growth factors causing the stem cells to spill into the bloodstream for easier collection.

**Stem cell rescue**
See stem cell transplantation.

**Stent**
A tubular devise made of metal or polythene designed to hold open a tube or opening in the body.

**Stenting**
Putting the stent in place.

**Steroids**
Steroids are hormonal substances naturally produced in the body. They can also be made artificially and used as drugs. Some types of steroid have been found to destroy some types of cancer cells and can make chemotherapy more effective.

**Tumour penetration**
The depth of extension of tumour into tissue

**Ultrasound**
High frequency sound waves used to create images of structures and organs within the body.

**White blood cells**
Blood cells that do not contain haemoglobin. They are part of the immune system and are present in the blood and lymphatic system, including the lymph glands and spleen. The bone marrow produces a number of different types of white blood cells which work together to fight infection.
Appendix I: Prognostic and Performance Indices

Follicular Lymphoma International Prognostic Index (FLIPI)\(^{155}\):

1 point per risk factor

<table>
<thead>
<tr>
<th>Risk Factors</th>
<th>Risk Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age - ≥ 60</td>
<td></td>
</tr>
<tr>
<td>Stage - III-IV</td>
<td>Low risk (0-1 points)</td>
</tr>
<tr>
<td>Nodal sites - &gt; 4</td>
<td>Intermediate risk (2 points)</td>
</tr>
<tr>
<td>Serum Haemoglobin - &lt; 120g/L</td>
<td>High risk (3-5 points)</td>
</tr>
<tr>
<td>Serum LDH - above normal</td>
<td></td>
</tr>
</tbody>
</table>

International Prognostic Index (IPI)\(^{156}\):

1 point per risk factor

<table>
<thead>
<tr>
<th>Risk Factors</th>
<th>Risk Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age - &gt;60</td>
<td>Low risk (0-1 points)</td>
</tr>
<tr>
<td>Stage – III-IV</td>
<td>Low-intermediate risk (2 points)</td>
</tr>
<tr>
<td>Extranodal involvement - &gt; 1 site</td>
<td>High-intermediate risk (3 points)</td>
</tr>
<tr>
<td>ECOG Performance status - 2-4</td>
<td>High risk (4-5 points)</td>
</tr>
<tr>
<td>Serum LDH - &gt; 1x normal</td>
<td></td>
</tr>
</tbody>
</table>

Mantle Cell Lymphoma International Prognostic Index (MIPI)\(^{157}\):

1 point per risk factor

<table>
<thead>
<tr>
<th>Points</th>
<th>Age</th>
<th>ECOG</th>
<th>LDH</th>
<th>WBC (10^9/L)</th>
<th>Risk Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>&lt; 50</td>
<td>0-1</td>
<td>&lt;0.67</td>
<td>&lt;6.700</td>
<td>Low risk (0-3 points)</td>
</tr>
<tr>
<td>1</td>
<td>50-59</td>
<td>-</td>
<td>0.67-0.99</td>
<td>6.700-9.999</td>
<td>Intermediate risk (4-5 points)</td>
</tr>
<tr>
<td>2</td>
<td>60-69</td>
<td>2-4</td>
<td>1.000-1.49</td>
<td>1.000-14.999</td>
<td>High risk (6-11 points)</td>
</tr>
<tr>
<td>3</td>
<td>&gt; 70</td>
<td>-</td>
<td>≥ 1.5000</td>
<td>≥ 15000</td>
<td></td>
</tr>
</tbody>
</table>
Eastern Cooperative Oncology Group (ECOG) performance status:\(^{158}\):

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light house work, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self care, confined to bed or chair more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled, cannot carry on any self care, totally confined to bed or chair</td>
</tr>
<tr>
<td>5</td>
<td>Dead</td>
</tr>
</tbody>
</table>

Karnofsky performance scale\(^{159}\):

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Normal, no complaints, no signs of disease</td>
</tr>
<tr>
<td>90%</td>
<td>Capable of normal activity, few symptoms or signs of disease</td>
</tr>
<tr>
<td>80%</td>
<td>Normal activity with some difficulty, some symptoms or signs of disease</td>
</tr>
<tr>
<td>70%</td>
<td>Caring for self, not capable of normal activity or work</td>
</tr>
<tr>
<td>60%</td>
<td>Requiring some help, can take care of most personal requirements</td>
</tr>
<tr>
<td>50%</td>
<td>Requires help often, requires frequent medical care</td>
</tr>
<tr>
<td>40%</td>
<td>Disabled, requires special care and help</td>
</tr>
<tr>
<td>30%</td>
<td>Severely disabled, hospital admission indicated but no risk of death</td>
</tr>
<tr>
<td>20%</td>
<td>Very ill, urgently requiring admission, requires supportive measures or treatment</td>
</tr>
<tr>
<td>10%</td>
<td>Moribund, rapidly progressive fatal disease processes</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
</tr>
</tbody>
</table>
### LANSKY SCORE (used in paediatric setting)\(^{160}\):

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Fully active, normal</td>
</tr>
<tr>
<td>90</td>
<td>Minor restrictions in strenuous physical activity</td>
</tr>
<tr>
<td>80</td>
<td>Active, but tired more quickly</td>
</tr>
<tr>
<td>70</td>
<td>Greater restriction of play and less time spent in play activity</td>
</tr>
<tr>
<td>60</td>
<td>Up and around, but active play minimal; keeps busy by being involved in quieter activities</td>
</tr>
<tr>
<td>50</td>
<td>Lying around much of the day, but gets dressed, no active playing, participates in all quiet play and activities</td>
</tr>
<tr>
<td>40</td>
<td>Mainly in bed; participates in quiet activities</td>
</tr>
<tr>
<td>30</td>
<td>Bed bound; needs assistance even for quite play</td>
</tr>
<tr>
<td>20</td>
<td>Sleeping often; play entirely limited to vary passive activities</td>
</tr>
<tr>
<td>10</td>
<td>Doesn’t play; does not get out of bed</td>
</tr>
<tr>
<td>0</td>
<td>Unresponsive</td>
</tr>
</tbody>
</table>

---


Appendix J: Synoptic Request Form template

This template is intended to demonstrate how to obtain clinical information to assist in diagnosis.

**Lymphoma - Synoptic Request Form**

<table>
<thead>
<tr>
<th>Affix Patient details here</th>
</tr>
</thead>
<tbody>
<tr>
<td>(DOB, Gender)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Managing Clinician</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Biopsy performed by</th>
</tr>
</thead>
</table>

**CURRENT BIOPSY**

<table>
<thead>
<tr>
<th>Site of Biopsy</th>
<th>L</th>
<th>R</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Reason for Biopsy:</th>
<th>Primary Diagnosis</th>
<th>Relapse</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Staging</td>
<td>Transformed Disease</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other</th>
</tr>
</thead>
</table>

**CURRENT DISEASE**

<table>
<thead>
<tr>
<th>Sites, or pattern of disease</th>
<th>Nodal vs Extranodal</th>
<th>Nodal</th>
<th>Extranodal</th>
<th>Unknown</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Apparent disease extent</th>
<th>Solitary</th>
<th>Localised</th>
<th>Generalised</th>
<th>Unknown</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Constitutional symptoms</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Relevant Lab Test results</th>
<th>(e.g. LDH, Paraprotein, lymphocytosis)</th>
</tr>
</thead>
</table>

**RELEVANT HISTORY**

**Previous haematolymphoid diagnosis**

<table>
<thead>
<tr>
<th>WHO Category</th>
<th>Anatomical Site</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Laboratory</th>
<th>Type of Biopsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lab No.</td>
<td>Date of Biopsy</td>
</tr>
</tbody>
</table>

**Relevant Previous Treatment**

**Predisposing factors**

<table>
<thead>
<tr>
<th>Immunocompromised / Autoimmune</th>
<th>Hereditary / Congenital</th>
<th>Autoimmune disease</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Organ Transplantation</td>
<td>Drugs: Specify below</td>
<td>Other: Specify</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Infective:</th>
<th>EBV</th>
<th>HHV8</th>
<th>HIV</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HTLV1</td>
<td>HepC</td>
<td></td>
<td>Other: Specify</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Any COMMENT from clinician on reverse</th>
</tr>
</thead>
</table>

ATTACHMENTS

Attachment 1: Clinical Practice Guidelines for the diagnosis and management of Lymphoma 2005 NHMR

Attachment 2: GP referral form to lymphoma specialist
http://www.sahealth.sa.gov.au/wps/wcm/connect/b4b0c900459fcddbb4fdf4519b2d33fa/Lymphoma+Pathway+ATTACHMENT+2+-+GP+Referral+to+Specialist+template.pdf?MOD=AJPERES&CACHEID=b4b0c900459fcddbb4fdf4519b2d33fa

Attachment 3: PET scan indications
http://bloodjournal.hematologylibrary.org/cgi/reprint/110/10/3507

Attachment 4: Lymphoma MDT meeting referral and consent
http://www.sahealth.sa.gov.au/wps/wcm/connect/e9b0d000459fd4edb566f5519b2d33fa/Lymphoma+MDT+meeting+referral+and+consent?MOD=AJPERES&CACHEID=e9b0d000459fd4edb566f5519b2d33fa

Attachment 5: Lymphoma MDT meeting report
http://www.sahealth.sa.gov.au/wps/wcm/connect/b609d900459fd852b57ef5519b2d33fa/Lymphoma+Pathway+ATTACHMENT+5+-+Lymphoma+MDT+meeting+report+template.pdf?MOD=AJPERES&CACHEID=b609d900459fd852b57ef5519b2d33fa

Attachment 6: AIDS–related Malignant Lymphomas - literature review
http://www.sahealth.sa.gov.au/wps/wcm/connect/3ac87d00459fdcc1b595f5519b2d33fa/Lymphoma+pathway+ATTACHMENT+6+-+AIDS%E2%80%93related+Malignant+Lymphomas+literature+review.pdf?MOD=AJPERES&CACHEID=3ac87d00459fdcc1b595f5519b2d33fa

Attachment 7: Fertility preservation guidelines
American Society of Clinical Oncology Recommendations on Fertility Preservation in Cancer Patients -- Lee et al. 24 (18): 2917 -- Journal of Clinical Oncology
http://jco.ascopubs.org/content/24/18/2917.full.pdf+html