



# Follow-up of survivors of Hodgkin lymphoma

Follow-up includes scheduling regular review and ensuring cancer survivors are aware of the risks and symptoms of late effects associated with their cancer treatment.

## Five- and 10-year survival (Australia)

Age is a factor in survival from Hodgkin lymphoma: young people's survival rates are generally better than those of older people.

In 2004, the Victorian five-year survival for people diagnosed with Hodgkin lymphoma was 86% and 10-year survival was 82%.

## Potential issues for survivors

Survivors may experience many different issues after completing treatment: physical, emotional, psychosocial and practical.

Survivorship care ideally addresses all of these issues. The four main aims of care during the survivorship phase, as detailed by the Institute of Medicine's report (see Hewitt et al. 2006) 'From cancer patient to cancer survivor: lost in transition', are:

- surveillance for cancer spread, recurrence or second primary cancers and of other late effects
- coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met (incl. health promotion, immunisation, screening for cancer and non-cancerous conditions, and the care of concurrent conditions)
- intervention for consequences of cancer and its treatment (e.g. problems such as lymphoedema and sexual dysfunction, symptoms including pain and fatigue, psychological distress experienced by cancer survivors and their caregivers, and concerns related to employment and insurance)
- prevention of recurrent and new cancers, and of other late effects.

Information in this section is based on the Clinical Practice Guidelines for Diagnosis and Management of Lymphoma, A guide for General Practitioners (October 2007)

The purpose of surveillance is to monitor the status of the disease and late adverse effects of therapy and to manage symptoms that arise following the initial treatment.

Follow-up will depend on the:

- patient's circumstances
- individual risk of relapse

- treatment intention if relapse should occur
- long-term risks associated with the initial treatment.

The frequency of follow-up immediately after treatment depends on the individual patient's needs.

The surveillance schedule for recurrent / progressive disease is based on the intended therapy should disease recur, so there should be a clear decision about therapy for recurrent disease before the schedule is devised. Therapy may range from palliation (in which case intensive surveillance for early detection of asymptomatic disease is not warranted) to prompt and intensive intervention with curative intent.

Recurrence is usually detected by investigating new physical findings or symptoms or by using 'non-specific' systemic tests, such as serum lactate dehydrogenase. Asymptomatic recurrences are rarely detected by routine CT scans.

## Which patients?

All patients who have been treated for Hodgkin lymphoma should be followed up. Follow-up should be indefinite. At times, follow-up may vary according to the treating Haematologist / Oncologist.



## Follow-up of survivors of Hodgkin lymphoma



### Review for cancer recurrence

Timing of review	Review type	Consider also
For first 2 years after treatment: every 3 months	<ul style="list-style-type: none"> <li>Clinical assessment with a careful history and physical examination</li> <li>Full blood examination</li> <li>Lactate dehydrogenase assessment</li> <li>The type of imaging investigations and frequency may depend on the site of original disease</li> </ul>	<ul style="list-style-type: none"> <li>Imaging studies, depending on the recurrence management plan:</li> <li>frequency depends on patient's risk</li> <li>modality (CT or functional imaging) depends on region considered to be at risk and the presence of residual radiological abnormalities in which structural imaging may be less sensitive to minor changes. Consider structural versus functional imaging</li> </ul>
For year 3 after treatment: every 4 months		
For years 4-5 after treatment: every 6 months, then annually thereafter		

Source: Adapted from Clinical Practice Guidelines for Diagnosis and Management of Lymphoma, A Guide for General Practitioners October 2007

Note: this schedule may change, due for example to the detection of recurrence or the development of other illnesses. The schedule needs to be tailored to individual situations.

Specific screening and monitoring for late effects from treatment may also be needed, depending on the primary treatment, and, if radiation was incorporated, the doses used and fields treated.

### Specific investigations and clinical assessments include

#### Thyroid function test

- Hypothyroidism can occur 1-20 years post-treatment
- Performed yearly for patients who have had radiotherapy to the neck

#### Clinical examination of the thyroid

- Excess risk of thyroid cancer, annual exam is advised
- Any abnormality should be fully investigated

#### Full blood count

- Risk of leukaemia and myelodysplastic syndrome is maximal between 3-12 years post-treatment
- Performed yearly

#### Annual breast examination:

##### Mammography / breast ultrasound

- Increased risk of breast cancer after radiotherapy is apparent 10 years post-treatment and risk persists >25 years after diagnosis
- Yearly mammographic screening in conjunction with breast self exam should commence 8 years following radiotherapy treatment.

MRI will become available in this group of patients

- The use of mammography in women <30 years is controversial
- Any breast mass should be investigated, this may include ultrasound and biopsy

#### Consider:

- endocrine surveillance (pituitary, if cranial irradiation for pituitary function; gonadal function monitoring for all patients who received chemotherapy that may impair fertility)
- cardiac assessment (for those who were treated with anthracycline chemotherapy and / or chest irradiation)
- osteoporosis (if prolonged steroids or premature menopause / androgen deficiency)
- renal function (if treated with cisplatin or ifosfamide chemotherapy)
- secondary malignancies, particularly bowel cancer where radiation encompasses pelvis
- these patients, regardless of treatment, are at increased risk of melanoma and non-melanoma skin-cancer and should have appropriate surveillance



Smoking significantly increases risk of lung cancer in patients treated previously with chemotherapy and radiotherapy; and the risk of cardiac disease in those who have had chest irradiation.

All patients should be encouraged to stop smoking and to minimise cardiac risk factors (lipids / obesity / monitor for hypertension / diet and lifestyle). The role of routine chest X-ray (and surveillance low-dose CT) is unclear.

#### New symptoms: advice for survivors

Cancer survivors may wait to discuss some symptoms if they know a surveillance / follow-up appointment is scheduled. Advise the cancer survivor to contact their specialist cancer nurse or GP if they notice any new, persistent or unexplained symptoms.



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### Coordination between specialists and primary care providers

It is important that follow-up care is coordinated and that survivors are not required to attend excessive appointments.

Guidelines included in the Victorian Government's Patient Management Framework (Haematological Tumour Stream: Intermediate Grade non-Hodgkin Lymphoma) advise that follow-up should be by a multidisciplinary team, although not all disciplines need to be involved in longer term follow-up.

They recommend that the primary treating clinician is best qualified to supervise and guide the follow-up of the patient, with

input from the GP, other specialists and allied health practitioners as required.

Responsibility needs to be agreed between the primary treating clinician, the GP and the patient, with an agreed survivorship care plan documented, including notification to the GP or multidisciplinary team member if the patient does not attend follow-up appointments. The GP has a key role in follow-up.

### Intervention for consequences of cancer and its treatment

#### Late effects of treatment for Hodgkin lymphoma

*Note to cancer survivors: late effects from cancer treatment are generally uncommon and often rare. Do not assume that you*

*will get a late effect if you had a treatment described here. Please speak to your doctor if you have any concerns about late effects from your cancer treatment.*

Late effects can occur as a consequence of surgery, chemotherapy, and radiotherapy.

For survivors and their partners, there may be relationship effects from cancer and its treatment, including difficulties over changed roles and fear of recurrence. Some survivors may fear being a burden.

Survivors who go through and beyond cancer treatment without partners or close family and friends may experience great loneliness.

### Late and long term effects of treatment for Hodgkin Lymphoma

Late effect	Cause / association
Fatigue	Association with cancer treatment is not well understood; may occur in association with depression and anxiety
Cardiac toxicity <ul style="list-style-type: none"> <li>• Appears to be dose-dependent</li> <li>• May appear during or shortly after treatment or months to years after treatment ends</li> </ul>	Anthracycline-containing chemotherapy regimens Mediastinal radiotherapy
Lymphoedema	Surgical axillary / groin dissection or radiotherapy or both. This is not usually a major clinical problem.
Premature menopause	Chemotherapy
Depression and anxiety	Association with treatment is not well understood
Pain or discomfort	Surgery, chemotherapy and radiotherapy
Peripheral neuropathy	Chemotherapy
Impaired sexual functioning or sexual discomfort <ul style="list-style-type: none"> <li>• May also be associated with ageing</li> <li>• May especially affect younger survivors</li> </ul>	Chemotherapy or radiotherapy to the pelvis may lead to premature menopause



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### Late and long term effects of treatment for Hodgkin Lymphoma (continued)

Late effect	Cause / association
Impaired fertility	Chemotherapy
Accelerated loss of bone density, fracture risk	Ovarian failure following chemotherapy. High-dose corticosteroids (the mechanism is distinct from premature menopause)
Impaired cognitive functioning	Association with treatment is not well understood. May be associated with chemotherapy
Second primary cancer	Treatment for original cancer, including increased risk of cancer in areas exposed to radiation, increased risk of leukaemia due to some chemotherapy agents
Endocrine dysfunction (thyroid and pituitary gland)	Chemotherapy
Raised cholesterol	Lifestyle choices and treatment
Increased risk of life threatening infection with encapsulated organisms	Asplenism / hyposplenism
Metabolic syndrome	General metabolic effects of chemotherapy (mostly platinum based compounds)
Melanoma and non-melanoma	Radiotherapy and intrinsic patient related factors
Other haematological malignancies : ALL , CML and NHL	Chemotherapy and intrinsic patient-related factors

### Further information related to late effects

Enquire about mood and whether the person feels they are coping. Assess survivor's level of distress / depression. Psychological distress generally declines over time. Psychosocial interventions (e.g. support groups) may be effective. Support groups and / or contact with a fellow survivor through a service such as Blood Cancer Connect (contact via the Cancer Council Helpline on 13 11 20 or Leukaemia Foundation 1800 840240) may be helpful.

### Prevention and detection of new cancers

Patients should be informed about the risks of developing another cancer as a result of their initial treatment

(at the time of treatment as well as when treatment finishes). They should be advised that lifelong surveillance for secondary cancers is appropriate.

A management plan should be organised for surveillance relevant to each individual patient, with the patient, their family, the GP, and the specialist.

Follow-up care for all patients should include counselling about adopting healthy lifestyle behaviours. For example about improved diet, maintaining a healthy weight, smoking cessation and increasing physical activity as these may help to prevent a new primary cancer. They may also reduce many of the psychosocial consequences of cancer treatment.

Advise survivors (unless there are health reasons that indicate otherwise) to do at least 30 minutes of moderate-intensity physical activity on most, preferably all, days. The NHMRC has produced dietary guidelines for Australian adults (information about the types and amounts of foods, food groups and dietary patterns that aim to promote health and well-being; reduce the risk of diet-related conditions, such as high cholesterol, high blood pressure and obesity; and reduce the risk of chronic diseases such as type 2 diabetes, cardiovascular disease and some types of cancers) on which advice to survivors can be based.



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Advise regarding annual vaccinations including flu vaccine and Pneumococcal vaccination (this is every 5 years together with repeat Meningococcal vaccination). Also provide specific advice regarding travel to malaria-prone areas, and management of dog or cat bites. If the survivor has had a splenectomy or is asplenic refer to Victorian Spleen Registry (03 9076 3928) email spleenregistry@alfred.org.au

Don't neglect other aspects of primary health care. Monitor survivors' cholesterol, blood pressure and blood glucose. Survivors should have regular dental examinations and be counselled on routine sun protection.

Survivors need appropriate screening for other cancers at recommended time intervals. Mammography every two years is recommended for all women at average risk aged between 50 and 69. Mammography is recommended annually for women who have had upper torso radiotherapy as part of their treatment. All women who have ever been sexually active should commence having Pap



tests between the ages of 18 and 20 years, or 1 to 2 years after commencing sexual activity, whichever is later. In some cases screening for cervical cancer may be appropriate before 18 years of age. Women over 70 years of age who have had two normal Pap tests in the past five years do not require further Pap tests. If a woman over 70 years has never had


a Pap test, or requests a Pap test, they should be screened. Patients over 50 years should be counselled regarding screening for bowel cancer. There is insufficient evidence for population-based screening for ovarian cancer; however, women who are at potentially high risk should be referred to a familial cancer clinic for assessment and management.


### Further information

This overview was prepared with reference to:

-  Australian Institute of Health and Welfare, Cancer Australia, Australasian Association of Cancer Registries 2008. Cancer survival and prevalence in Australia: cancers diagnosed from 1982 to 2004. Cancer Series No. 42. Cat. No. CAN 38. Canberra: AIHW.
-  Cancer Council Australia 2011. Lymphoma. Sydney: Cancer Council Australia. Available from [www.cancer.org.au/aboutcancer/cancertypes/lymphoma.htm](http://www.cancer.org.au/aboutcancer/cancertypes/lymphoma.htm)
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**Australian Cancer Survivorship Centre**  
A Richard Pratt Legacy



**Australian Cancer Survivorship Centre**

Locked Bag 1, A'Beckett Street  
East Melbourne VIC 3002

Phone: 03 9656 1111

Email: [contactacsc@petermac.org](mailto:contactacsc@petermac.org)

[www.petermac.org/cancersurvivorship](http://www.petermac.org/cancersurvivorship)