This fact sheet is for people who have completed treatment for Hodgkin lymphoma. It explains why follow-up appointments are important and possible side-effects from treatment. You may know that when Hodgkin lymphoma is found and treated early, the outcome is often very good.

In Australia:

- 5-year survival for people with Hodgkin lymphoma is about 90%. This means that for every 100 people treated for Hodgkin lymphoma, nearly 90 will still be cancer free 5 years later.

For some people treated for Hodgkin lymphoma, there is a small chance the blood cancer could come back (recur).

Your doctor will schedule regular follow-up appointments to check on your health and look for any signs of Hodgkin lymphoma recurrence.

Your doctor will also talk to you about possible side effects from your Hodgkin lymphoma or treatment.

Potential issues

As a survivor of Hodgkin lymphoma, you may have physical, emotional, social and practical concerns after completing treatment. Care from your health care team should address all of these issues.

Your medical care should include:

- good communication between your haematologist or cancer specialist and GP about your health needs
- looking for any signs of cancer spread, recurrence or second primary cancers
- treating any side effects or late effects from your cancer and treatment
- advice about preventing new cancers and reducing your risk of your cancer recurring.

If cancer does come back, it tends to happen within 5 years after diagnosis. Sometimes, this can happen more than 20 years after the first diagnosis.

Follow-up frequency

Everyone who has been treated for Hodgkin lymphoma should be followed up. Follow-up is intended to find any recurring Hodgkin lymphoma while it may still be cured.

Your doctor will talk to you about how you have been feeling, do a physical exam and may also use other scans and tests to look for signs of recurrence.
Follow-up of survivors of Hodgkin lymphoma

Example follow-up schedule for people treated for Hodgkin lymphoma

<table>
<thead>
<tr>
<th>Type of review</th>
<th>Years 1 and 2</th>
<th>Years 3–4</th>
<th>Years 4–5</th>
<th>After 6 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>• History (talking about your health) and examination</td>
<td>Every 3 months</td>
<td>Every 4 months</td>
<td>Every 6 months</td>
<td>Every year</td>
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<tr>
<td>• Full blood examination</td>
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<tr>
<td>• Specific blood examination for lactate dehydrogenase (LDH)</td>
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<tr>
<td>• Scans and tests related to the site of the Hodgkin lymphoma</td>
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<tr>
<td>Other tests</td>
<td>Other test and scans may be prescribed depending on the treatment you received and your particular after treatment plan</td>
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Note: this schedule may vary, for example if your doctor suspects recurrence or if you have another illness.

When to contact your doctor
Contact your doctor if you notice any symptoms that concern you. You don’t have to wait for your follow-up appointment.
Contact your specialist nurse or doctor if you notice:
• unexplained persistent changes in your general condition (such as loss of weight, loss of appetite, loss of energy)
• unexplained persistent pain or discomfort
• any symptom that concerns you.

Coordinating follow-up
It is important that your follow-up is properly coordinated and you do not attend excessive appointments.
Your haematologist or cancer specialist and GP should consult and decide on who will coordinate your follow-up.
Ideally, this will be documented on your survivorship care plan. If you don’t have a survivorship care plan, please ask your GP, specialist or cancer nurse who should be able to provide this for you.

Possible long-term effects and late effects of treatment
Not everyone will have long-term or late effects. If you have had treatment for Hodgkin lymphoma, this does not mean you will get all or even any of the effects described here. Long-term and late effects will vary depending on the stage of your Hodgkin lymphoma as well as the treatment you had. Some effects from treatment for Hodgkin lymphoma are more common than others. Some are rare. Some will become less severe and disappear completely whilst others may be permanent. Please speak to your doctor if you have any concerns about effects from your cancer treatment.

Further information related to effects of treatment for Hodgkin lymphoma
• There is evidence that moderate-intensity exercise can help reduce cancer-related fatigue. Your doctor may refer you to a health professional who has experience in caring for people with cancer-related fatigue. (see our fact sheet www.petermac.org/sites/default/files/ACSC_FactSheet_Fatigue%20WEB.pdf)
• Your doctor will tell you if there is a risk of heart problems due to chemotherapy or radiotherapy. Your doctor will recommend regular long-term checks of your heart and advise you about smoking, alcohol, exercise and diet.
• Your doctor will tell you if there is a risk of endocrine problems (such as thyroid, pituitary, ovary or testes) due to radiotherapy delivered to these areas. Your doctor will recommend regular long-term checks if these are required.
• Your doctor will tell you if there is a risk of developing a second cancer, particularly breast cancer, if you are female and have received radiotherapy to the breast tissue area. Regular breast checks will be arranged.
• Your doctor will tell you if there is a risk of developing melanoma or non-melanoma skin cancer. Your doctor may recommend regular skin checks and advise about sun protection.
• Your doctor will tell you if there is a risk of developing bowel cancer if you have had radiotherapy to the pelvic area. Your doctor will recommend regular long-term checks if these are required.
• Your doctor will tell you if there is a risk of developing other blood cancers or blood disorders. Your doctor may recommend regular blood tests to monitor for the development of these.
• You may have particular needs if your fertility has been affected, or find it difficult in dealing with changes in sexuality. Your doctor may suggest that you see a fertility or menopause specialist or sex therapist.
• Depression and an underactive thyroid can all contribute to fatigue and can be treated.
• If your bone density is at risk, your doctor may suggest having regular bone scans. Your doctor may also discuss prevention strategies such as weight-bearing exercise, giving up smoking, and treatment with calcium and vitamin D supplements. Some people may be prescribed bisphosphonate drugs (medications that prevent loss of bone density).
• Smoking increases the risk of you developing lung cancer (particularly if you have had chemotherapy and radiotherapy) and increases the risk of you developing heart disease (if you have had radiotherapy to the chest). If you smoke, quitting is particularly important for you. If you need help quitting, speak with your GP, or call the Quitline. Quitline is a telephone information and advice or counselling service for people who want to quit smoking. You can call the Quitline on 13 7848 confidentially from anywhere in
Follow-up of survivors of Hodgkin lymphoma

All the common cancer treatments (surgery, chemotherapy, or radiotherapy) can cause both long-term and late effects. Possible long-term and late effects following treatment for Hodgkin lymphoma and their causes include:

<table>
<thead>
<tr>
<th>Long-term and late effects</th>
<th>Cause</th>
</tr>
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<tbody>
<tr>
<td>Fatigue (extreme tiredness that isn’t helped by sleep or rest)</td>
<td>Sometimes occurs following treatment, however the reasons are not clear. May be associated with depression or anxiety.</td>
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<tr>
<td>Heart problems</td>
<td>Can be caused by some chemotherapy drugs. Can be caused by radiotherapy to the central chest area.</td>
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<tr>
<td>Kidney problems</td>
<td>Can be caused by some chemotherapy drugs.</td>
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<tr>
<td>Lymphoedema (persistent swelling in the limb)</td>
<td>Can occur when underarm or groin lymph nodes are surgically removed or treated with radiotherapy. This is not usually a problem.</td>
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<tr>
<td>Premature menopause</td>
<td>Due to chemotherapy.</td>
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<tr>
<td>Depression and anxiety</td>
<td>Sometimes occurs following treatment, however the reasons are not clear.</td>
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<tr>
<td>Pain or discomfort</td>
<td>Surgery, chemotherapy or radiotherapy.</td>
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<tr>
<td>Peripheral neuropathy (changes to feelings in your toes and fingers, numbness, pain)</td>
<td>Can be caused by some chemotherapy drugs.</td>
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<tr>
<td>Sexual problems</td>
<td>Premature menopause or vaginal dryness from treatment. Cancer treatment can affect a person’s libido, self-image and sexual confidence.</td>
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<td>Fertility problems</td>
<td>Due to chemotherapy.</td>
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<tr>
<td>Bone density problems, increased risk of fractures</td>
<td>Due to ovarian failure following chemotherapy, high dose steroids.</td>
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<tr>
<td>‘Chemo brain’ or ‘Chemo fog’, which may include poor concentration and forgetfulness</td>
<td>It is common in people who have had chemotherapy but is not well understood.</td>
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<td>A second primary cancer</td>
<td>May occur rarely due to radiotherapy or chemotherapy.</td>
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<td>Thyroid or pituitary gland problems</td>
<td>Due to radiotherapy.</td>
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<td>Raised cholesterol</td>
<td>Lifestyle choices and treatment.</td>
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<tr>
<td>Increased risk of developing serious infections</td>
<td>Absence of normal spleen function or reduced spleen function.</td>
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<tr>
<td>Metabolic syndrome (a group of risk factors that occur together such as obesity, high blood pressure, high blood sugar, raised blood triglycerides) that can lead to development of diabetes, heart disease or stroke</td>
<td>Can be caused by the effects of some chemotherapy drugs.</td>
</tr>
<tr>
<td>Development of melanoma or nonmelanoma skin cancer</td>
<td>Due to radiotherapy or can be the result of risk factors related to the survivor themselves.</td>
</tr>
<tr>
<td>Other blood cancers</td>
<td>Due to chemotherapy.</td>
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</tbody>
</table>
Follow-up of survivors of Hodgkin lymphoma

Survivors who go through and beyond cancer treatment without partners or close family and friends may experience great loneliness. Speak with your doctor or specialist nurse about how you are feeling. Support groups and/or contact with a fellow survivor through a service such as Cancer Connect may be helpful. Contact via Cancer Council Information and support line (13 11 20). Other support is available through Lymphoma Australia Lymphoma Care Nurse Hotline (1800 953081) and the Leukaemia Foundation Blood Cancer Support and advice line (1800 620 420).

Staying well

Having cancer and treatment often makes people think about their health in different ways. Some people decide they want to live a healthier lifestyle than they did before getting cancer. Some people look for ways to prevent a new cancer developing. It’s a great time to make some changes and commit to staying healthy. This includes:

• having a healthy diet
• maintaining a healthy weight
• stopping smoking
• increasing physical activity (most people need to do at least 30 minutes of moderate-intensity physical activity on most, preferably all, days).

These simple measures may help to prevent a new primary cancer. They may also reduce many of the physical and emotional effects of cancer treatment.

Screening

It’s important to have screening for other cancers.

• Have regular Pap tests. (Women)
• A regular mammogram is recommended every two years for all women aged between 50-74 years of age (if you have had radiotherapy to the chest area you will be advised to have this done annually)
• If you are over 50 years, talk to your doctor about screening for bowel cancer.
• If you are at increased risk of ovarian cancer, your doctor may refer you to a family cancer clinic.

In addition:

• Have your usual cholesterol, blood pressure and blood glucose checks.
• Have regular dental examinations.
• Take care to protect your skin from the sun.

Acknowledgment

Thank you to the health professionals and survivors who reviewed this document.

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