



Surviving cancer: information for consumers



# Follow-up of survivors of Diffuse Large B Cell Lymphoma (DLBCL), a non-Hodgkin lymphoma subtype

This fact sheet is for people who have completed treatment for Diffuse Large B Cell Lymphoma (DLBCL), non-Hodgkin lymphoma subtype. It explains why follow-up appointments are important and possible effects from treatment. You may know that when DLBCL is found and treated early, the outcome is often very good.

## In Australia:

- 5-year survival for people with DLBCL is about 53%. This means that for every 100 people treated for DLBCL, nearly 53 will still be cancer free 5 years later.
- 10-year survival is about 46%. This means that for every 100 people treated for DLBCL, nearly 46 will still be cancer free 10 years later.
- These numbers have very likely improved since the introduction of rituximab treatment.

For some people treated for DLBCL, 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 DLBCL recurrence.

Your doctor will also talk to you about possible effects from your DLBCL or treatment.



## Potential issues

As a survivor of DLBCL, 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 / 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 DLBCL should be followed up.

Follow-up is intended to find any recurring DLBCL 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.



### Example follow-up schedule for people treated for DLBCL

Type of review	Years 2–3	Years 4–5
<ul style="list-style-type: none"> <li>History (talking about your health) and examination</li> <li>Full blood examination</li> <li>Specific blood examination for lactate dehydrogenase (LDH)</li> </ul>	Every 3 months	Every 4–6 months
Other tests	Other test and scans may be prescribed depending on the treatment you received and your particular after treatment plan	

*Note: this schedule may vary, for example if your doctor prefers a different time frame for you or 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 cancer 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 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 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 DLBCL, 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 DLBCL as well as the treatment you had. Some effects from treatment for DLBCL 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.





## Surviving cancer: information for consumers



### Possible long-term effects and late effects of treatment

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 DLBCL and their causes include:

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

### Further information related to effects of treatment for DLBCL

- 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 kidney problems due to chemotherapy. If required, your doctor will recommend regular blood tests to monitor kidney function
- Your doctor will tell you if there is a risk of developing a second cancer, particularly breast cancer, if you are a young woman and you 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 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 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).
- Your doctor will advise about any increased risks of developing serious infections. Yearly flu and Pneumococcal vaccinations are recommended. If required, your doctor may also refer you to the Victorian Spleen Registry (03 9076 9328) email spleenregistry@alfred.org.au



### Further information related to effects of treatment for DLBCL

The Victorian Spleen Registry aims to prevent serious infections in people with reduced splenic function by raising awareness and educating patients, their families and doctors.

- You may begin or continue to have fears about the future. You may be feeling worried, sad or unable to get through the day. Many of these feelings are normal when adjusting to life after a cancer diagnosis and usually lessen with time. You may find it helpful to attend a support group and/or speak with a fellow survivor. Contact via the Cancer Council (13 11 20), through the Leukaemia Foundation (1800 840 240) or you may wish to contact Lymphoma Australia (1800 359 081). If you feel low in mood or depressed for long periods, it is very important that you speak to your doctor and get treatment.

### Getting help and support

Any change in how your body looks, feels or functions can be very hard to deal with. Certain late or long-term effects may be annoying but manageable. However others can be more severe and have a big effect on your quality of life.

There are things that can be done to help control or treat many long-term and late effects from treatment for DLBCL. It is important you find the right support to help you manage and cope with any side-effects you have or may develop.

For you and your partner, there may be relationship effects, including issues about changed roles, fear of recurrence of DLBCL and fear of 'being a burden'.

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 Blood Cancer Connect may be helpful. Contact via the Cancer Council Helpline (13 11 20) or through Leukaemia Foundation (1800 840240).

### 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 50-69 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 vaccinations annually ( flu and pneumococcal vaccination )
- Have your usual cholesterol, blood pressure and blood glucose checks.
- Have regular dental examinations.
- Take care to protect your skin from the sun.

### Further information

#### Leukaemia Foundation of Australia

The Leukaemia Foundation is a not-for-profit organisation that aims to provide information and support to patients and their families living with leukaemia, lymphoma, myeloma and related blood diseases. This website has information on statistics and publications on the different diseases and treatments in a number of languages. It also has information on the support services the organisation provides in Victoria, including practical assistance with accommodation and transport. Freecall: 1800 620420

[www.leukaemia.com](http://www.leukaemia.com)

#### Leukaemia Foundation's online support and information forum

A moderated virtual support group for patients, families, and carers living with leukaemia, lymphomas, myeloma and other related blood disorders that allows participation in discussion forums with others going through similar situations related to blood cancers and their treatment.

[www.talkbloodcancer.com](http://www.talkbloodcancer.com)

#### Lymphoma Australia

This organisation also supports Lymphoma research with fund raising initiatives. Lymphoma Australia provides information to the community at no cost to enable both patients and the Australian community to be aware of the signs and symptoms of this cancer. They work toward ensuring that early diagnosis of lymphoma is paramount so that the best possible outcome can be achieved for anyone diagnosed with this cancer. The goals of LA are to: To provide education and support for individuals with lymphoma and their support network; to fund medical research to find a cure for lymphatic cancer; to advocate for the best treatment and care for lymphoma patients; to promote further research and new treatments in lymphoma and to promote rapid access to new developments. Freecall: 1800 359081

[www.lymphoma.org.au](http://www.lymphoma.org.au)

#### The Australian Cancer Survivorship Centre – A Richard Pratt Legacy

The Australian Cancer Survivorship Centre – A Richard Pratt Legacy is a web-based centre. It is funded by Peter MacCallum Cancer Centre, The Pratt Foundation and the Victorian Department of Health. The Australian Cancer Survivorship Centre aims to help improve services and care for cancer survivors in Australia as well as focusing on increased awareness, especially about issues that affect survivors after their treatment ends. The information on this site is divided into four sections: Health Professionals, Survivors, Family & Friends and Research. There are links to useful information and reliable websites.

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

#### Cancer Council

Contact the Cancer Council Helpline on 13 11 20 for information about side effects from treatment, or any other questions you have about cancer and surviving cancer. Cancer Council booklets include 'Living well after cancer: a guide for cancer survivors, their families and friends'. Call the Cancer Council to find out about Life after Cancer forums. Through the Cancer Council Helpline you can speak with a cancer nurse: ask about Family Cancer Connect and support groups and other support services that may help you. Cancer Connect is a free phone peer support service that puts people in touch with others who've had a similar cancer experience.

[www.cancer.org.au](http://www.cancer.org.au)

All of these services may be accessed through their websites

