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Late effects of lymphoma treatment

Some people experience late effects after having treatment for lymphoma. Late effects are health problems that develop months or years after treatment. Your medical team should talk to you about possible late effects before you start your treatment.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email **information@lymphoma-action.org.uk**.

What is my risk of developing late effects?

While it is not possible to say for certain whether you'll develop late effects, your medical team should discuss your individual risk of developing late effects with you. This is based on risk factors, including:

- lymphoma-related risk factors
- treatment-related risk factors
- other individual risk factors.

Your medical team should talk to you about the possible short-term (**side effects**) and long-term effects of your treatment before you start it. You might have longer-lasting side effects, such as **fatigue**. These are different to late effects in that they are ongoing, rather than being problems that develop some time after treatment. Your medical team can support you to manage these.

Understanding late effects is such an important part of rehabilitation after treatment. Knowing what organs might have been affected allows people to focus in on what areas are most important when planning life after treatment.

Charlotte Bloodworth, Advanced Nurse Practitioner in Haematology

When your treatment finishes, your medical team should give you and your GP a **treatment summary** that outlines what treatment you had, including any late effects it might cause. Knowing the health problems you might be at risk of developing and when to seek medical advice increases your chances of **living well with and beyond lymphoma**. You can also find out from your medical team **how you can help lower your risk** of developing late effects.

Lymphoma-related risk factors

The risk factors related to lymphoma include the **type of lymphoma** you had and which parts of your body it affects (**stage**).

In general, people treated for **Hodgkin lymphoma** have a slightly higher chance of developing late effects than people treated for **non-Hodgkin lymphoma**. One reason for this is age – people treated for Hodgkin lymphoma are often younger than people treated for non-Hodgkin lymphoma, which means that there is more time for late effects to develop.

Treatment-related risk factors

Risk factors relating to treatment include the type and amount of treatment you had.

The treatments used today generally have a lower risk of causing late effects than treatments that were used in the past. Although many of the same treatments are used, they are often now given at a lower intensity. This is because the results of research over time has shown that the same outcomes can be achieved with less intensive treatment. In addition, modern treatments more precisely target the lymphoma cells, reducing effects on healthy tissues as much as possible.

Radiotherapy

The late effects of **radiotherapy** depend on the area of your body treated and the dose of radiation. For example, radiotherapy given to the chest area can cause **lung problems**.

Your doctor should give you information about the risks associated with your individual treatment plan.

Chemotherapy

Possible late effects of **chemotherapy** depend on which drug or combination of drugs (**regimen**) you had, as well as the dose. In general, high-dose chemotherapy has a higher chance of causing late effects than lower-dose treatment.

Your doctor should give you more information about the drugs used in your treatment, including their possible **side effects** and late effects. Macmillan Cancer Support also have detailed information on the **side effects of particular drugs and combination regimens** used in cancer treatment.

Targeted treatments and antibody therapy

Targeted treatments and antibody therapies can 'target' and attack lymphoma cells more precisely than some other types of treatment. This means they generally cause fewer side effects. Scientists also expect these treatments to cause fewer late effects than chemotherapy and radiotherapy.

However, as these treatments are all quite new – scientists and doctors will be able to gather more information about them over time. This includes whether or not long-term effects of such treatments are different if they are given with traditional chemotherapy.

Individual risk factors

Individual risk factors can affect your likelihood of developing late effects. For example, if you have a family history of cancer, you might already be at an increased risk of developing cancer yourself – having chemotherapy can further increase this risk, even if only slightly. **Age** and **lifestyle** are also risk factors.

Age

In general, the risk of late effects is higher for people who have treatment in childhood or young adulthood. Younger people have more of their life ahead of them for late effects to appear than someone who is older. In addition, if treatment affects developing organs, late effects become more likely.

Lifestyle

Lifestyle can be a risk or a protective factor. In general, following a **healthy lifestyle** can help you to **live well with and beyond lymphoma**. This includes good **diet and nutrition**, taking **exercise**, **managing stress** and **getting enough sleep**. It is also recommended to **limit your alcohol intake** and **not to smoke**.

Other ('second') cancers

Treatment for lymphoma increases your risk of developing another type of cancer later on. This is known as a 'second cancer' and is different from a 'secondary cancer', which is where the original (primary) cancer spreads to another part of the body.

Most people who are treated for lymphoma do **not** go on to develop a second cancer. The risk is higher in people treated for **Hodgkin lymphoma** than those treated for **non-Hodgkin lymphoma**. Treatments for some non-Hodgkin lymphomas (for example, for **low-grade non-Hodgkin lymphoma**) can be less intensive than those used to treat Hodgkin lymphomas. Also, people treated for Hodgkin lymphoma are often younger than people treated for non-Hodgkin lymphoma, which gives more time for another cancer to develop. The risk of developing cancer is further increased with family history of cancer.

Second cancers that develop as a late effect to chemotherapy treatment for lymphoma include the blood cancers **myelodysplastic syndromes (MDS)** and **leukaemia**. Other cancers can include **lung**, **bowel**, **breast** and **skin cancer**. Some people treated for high-grade lymphoma go on to develop a low-grade lymphoma.

With radiotherapy, the type of second cancer you are most at risk of depends on the area of your body treated.

As targeted treatments are all still quite new, more time is needed before scientists can be sure of any links to second cancers.

You should receive a **treatment summary** from your medical team that outlines your individual risks.

Reducing your risk of developing a second cancer

- Follow a **healthy lifestyle** to help reduce your risk of health problems in general, including cancers.
- If you have had radiotherapy, check your skin in the treated area for changes. The British Association of Dermatologists has information on **how to reduce** the risk of a second skin cancer.
- Ask your medical team what second cancers you might be at a higher risk of.
 Make sure you know the symptoms of these; cancer is usually more effectively treated if it's found early.
- Find out from your clinical nurse specialist or your GP about cancer screening programmes, designed to find cancers early.

Find out more about reducing your risk of cancer on Cancer Research UK's website.

Heart (cardiovascular) problems

Some treatments for lymphoma increase your risk of developing heart problems including:

- hardening and narrowing of the blood vessels that take blood away from the heart (atherosclerosis), which can be serious if it blocks the blood flow to vital organs, including the brain
- heart (coronary) disease, including angina (reduced blood flow to the heart)
 and heart attack (sudden blockage of the blood to the heart)
- heart valve problems, because your heart is unable to pump efficiently
- heart rhythm abnormalities (arrhythmia).

People with heart damage often experience shortness of breath, especially after physical activity. It can also be very uncomfortable to lie flat, due to difficulty breathing. You might also have a cough and produce white, frothy phlegm. Other symptoms can include extreme fatigue and swollen ankles.

I developed an abnormal heart rhythm (arrhythmia) after my chemotherapy. Talking to the doctors helped me to understand the effects of the treatment, which took away some of the fear. Now, I have learnt to accept my limitations and manage the condition, living life to the full.

Andrea, diagnosed with Hodgkin lymphoma

The risk of developing heart problems is also heightened by other risk factors:

- age being over 65 years old
- obesity (being very overweight and carrying too much fat around your tummy)
- lifestyle being sedentary (not taking exercise), smoking, drinking a lot of alcohol
- high blood pressure
- high cholesterol
- diabetes
- family history of heart disease.

Treatments that have a risk of causing heart problems

Radiotherapy

Radiotherapy given to the chest carries a risk of causing heart problems. This increases with higher **doses of radiotherapy** and in people who are treated when they are under 50 years old.

Chemotherapy

Anthracyclines (for example doxorubicin) are a type of chemotherapy drug that can affect how well your heart pumps blood around the body. The risk of developing heart problems after having anthracyclines increases with higher doses and more courses of treatment. Scientists are looking into whether medication can be given to help reduce this risk.

Stem cell transplant

Having a **stem cell transplant** can increase your risk of developing heart problems, particularly within the first 10 years after treatment. You might be given medicines to help with heart health, such as tablets to lower blood pressure and to prevent **angina** (reduced blood flow).

Reducing your risk of developing heart problems

Follow a healthy lifestyle to reduce your risk of developing heart problems. This includes eating a **healthy diet**, taking regular **exercise**, limiting your **alcohol intake** and **not smoking**.

The **British Heart Foundation** has more information about heart problems. They also offer advice on keeping your heart healthy.

Lung problems

Some treatments for lymphoma can cause scarring of your lungs (pulmonary fibrosis). This can happen with radiotherapy to the chest. If the damage is slight, it might not cause any symptoms but can be seen on X-rays or scans of the lungs. If you have had radiotherapy, you might have scans to check for such damage.

More severe damage can cause symptoms such as shortness of breath. Pulmonary fibrosis can affect the type and amount of physical activity you're able to do – your medical team can give you advice about exercise that is suitable for you.

The chemotherapy drug: bleomycin

Pulmonary fibrosis can also happen with the chemotherapy drug bleomycin, given in some chemotherapy treatment plans (regimens), often to treat Hodgkin lymphoma.

Doctors try to limit the risk of lung problems. For example, if a **PET/CT scan** shows that your lymphoma has responded well to treatment, they might not give you bleomycin as part of your next cycles of chemotherapy.

After my treatment with radiotherapy, my lung capacity was reduced. However, 5 years later, just before my bone marrow transplant, I had my lung function tested. This showed that my lungs were back to working at full capacity, which is thanks to my trombone playing.

Carol, diagnosed with Hodgkin lymphoma

Reducing your risk of developing lung problems

If you are treated with bleomycin:

- Follow a healthy lifestyle it's particularly important not to smoke.
- If you need surgery in the future, tell the anaesthetist, so that they can take any necessary precautions.
- Check with your doctors about any activities you should avoid, such as scuba diving (due to the oxygen levels it exposes you to), which could increase your risk of developing lung problems).

Hormone problems

Treatment for lymphoma can affect your body's production of hormones (chemical messengers) in your body. This can lead to:

- problems with thyroid function
- diabetes
- reduced fertility.

Thyroid function

The thyroid gland produces a hormone called thyroxine, which controls how your body uses energy.

If you've had radiotherapy to the neck or upper chest, you might develop an underactive thyroid (hypothyroidism). This is where your thyroid gland makes less thyroxine than it should, which can make you feel tired, sensitive to the cold and constipated. You might also gain weight easily.

The risk of developing hypothyroidism is at its highest in the first 5 years after treatment. However, it stays increased after this time compared to if you had not ever had treatment for lymphoma. Hypothyroidism is diagnosed by a blood test and is easily treated with thyroxine tablets. You might be offered regular blood tests to keep checks on your thyroid functioning.

If you think you might be affected by thyroid problems and you're no longer having **follow-up appointments**, speak to your GP. Tell any doctors treating you that you have had treatment for lymphoma so that they are aware of your increased risk of thyroid problems.

British Thyroid Foundation has more information about the thyroid, and about living with hypothyroidism.

Diabetes

If you have radiotherapy to your tummy area (abdomen), you have a slightly higher risk of developing diabetes than people who haven't had radiotherapy.

This can happen if your treatment affected your pancreas – a gland that sits just behind your stomach. The pancreas produces the hormone insulin, which helps to lower your blood sugar levels. If radiation goes to your pancreas, it can stop the pancreas from making as much insulin as it needs to, leading to diabetes.

For more information about diabetes reducing your risk of developing it, visit the **Diabetes UK website**.

Reduced fertility

Women's ovaries and men's testicles can be affected by some treatments for lymphoma. This can happen with radiotherapy given to your tummy (abdomen) area or to the area below your belly button (pelvis). It can also happen with chemotherapy. Less is known about the effects of newer, targeted treatments. In women, treatment can also lead to an early menopause.

We have separate information about **reduced fertility**, including fertility preservation options for men and women, and about **early menopause**.

Less common late effects

There are some other, less common late effects of lymphoma treatment. We cover some here. However, your medical team are best-placed to tell you about any specific risks you should be aware of.

Eye problems

Eye problems can include dryness and cataracts (cloudy patches in the lens of your eye that reduce your vision). In some people, steroids can cause high pressure inside your eye (glaucoma), which can affect your vision.

Have regular check-ups with your optometrist (optician) and tell them what lymphoma treatment you've had.

Dental problems

Radiotherapy to the head and neck increases your risk of tooth decay. Have regular check-ups with your dentist and follow their advice to **keep your teeth healthy**.

Bone health

Treatment for lymphoma can affect bones, leading to brittle bones (osteoporosis). With radiotherapy, the effects can happen in the area of the body treated with radiation.

In children and young people, lymphoma treatment can also affect bone growth. We have a separate section on our website with more detailed information about lymphoma in children and young people.

Reducing your risk of developing late effects

Monitoring your health and how well you are recovering from treatment is an important part of your **follow-up after treatment**. You can't always prevent late effects but noticing problems early gives you a better chance of treating or managing them effectively.

Follow-up is all about empowering people to seek attention and get all worries investigated. Be aware of what to look out for, and if you are no longer being followed-up at your hospital, speak to your GP. Never wait for routine appointments – if you have any concerns, seek advice straightaway.

Charlotte Bloodworth, Advanced Nurse Practitioner in Haematology

Your medical team should tell you what signs and symptoms of late effects to look out for and who to contact if you notice any. They can also give you information about what you can do to reduce your risk of developing them. We give some tips about this below:

Healthy lifestyle

- Follow a healthy lifestyle this includes eating well, taking exercise, limiting your alcohol intake and managing stress.
- Protect your skin from the sun, especially if you have had radiotherapy.
- Keep up-to-date with appointments with your optometrist (optician) and dentist.
- Go to any follow-up appointments you're offered. These allow doctors to check your health and to find any problems early. This increases the chances of treating or managing them effectively.
- Take up any health screening programme invitations you're offered. In the UK, these might include screening for breast, cervical, bowel and prostate cancer. Note that if you have had radiotherapy treatment to the breast area under the age of 40, you are likely to be invited to for breast screening appointments sooner and more frequently than if you had not had treatment. The NHS has more information about screening.

Staying informed about your health

- Ask your medical team to tell you exactly what treatment you've had this should be recorded on your treatment summary.
- Speak to your medical team about your individual risks. Find out what symptoms you should look out for and what to do if you notice them.
- If you have any health concerns, seek advice from your medical team or GP. Tell any health professionals that you've had treatment for lymphoma.

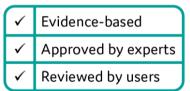
References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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