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Follicular lymphoma

This information page is about follicular lymphoma, the most common type of low-grade non-Hodgkin lymphoma (NHL).

On this page

Quick overview of follicular lymphoma

This section is an overview of the information on this page. There is more detail in the sections below.

What is it?

Follicular lymphoma is a cancer of the lymphatic system. It develops from B lymphocytes (white blood cells that fight infection). This type of lymphoma usually grows very slowly. It is difficult to cure but is usually kept under control for many years with treatment needed only from time-to-time.

What are the symptoms and how is it diagnosed?

You may have few symptoms or none at all. Most people find one or more painless lumps, often in the neck, armpit or groin. Some people have other symptoms too, such as weight loss, fevers, night sweats, fatigue, itching or being more prone to infection.

You need a biopsy and other tests like blood tests and scans to diagnose follicular lymphoma.

How is it treated?

Early-stage follicular lymphoma can sometimes be cured with radiotherapy. If radiotherapy isn't suitable, you might be monitored (known as 'active monitoring' or 'watch and wait'). You are then given treatment if the lymphoma worsens.

Most people have advanced-stage (widespread) follicular lymphoma when they are diagnosed and are treated to control the lymphoma. If you don't have troublesome symptoms, you might not need treatment straightaway. Some people have a short course of rituximab (antibody therapy) to delay the need for further treatment.

When treatment is needed, most people have chemo-immunotherapy (chemotherapy with antibody therapy). This is followed by maintenance treatment – regular antibody treatments to stop the lymphoma coming back. When follicular lymphoma relapses (comes back), there are lots of options including chemo-immunotherapy, radiotherapy to certain areas, or newer drugs. If you need more intensive treatment, your doctor might suggest high-dose chemotherapy and a stem cell transplant.

What is follicular lymphoma?

Lymphomas are cancers of the **lymphatic system**. They happen when a lymphocyte (a type of white blood cell that fights infection) grows out of control. There are two main groups of lymphomas: **Hodgkin lymphomas** and **non-Hodgkin lymphomas**. Non-Hodgkin lymphomas are further grouped into:

- Low-grade (slow-growing) or high-grade (fast-growing)
- **T-cell lymphoma** (develops from abnormal T lymphocytes or T cells) or B-cell lymphoma (develops from abnormal B lymphocytes or B cells).

Follicular lymphoma is the most common type of low-grade NHL and develops from B cells. The abnormal B cells often collect in lymph nodes (glands) as follicles (clumps).

Who gets follicular lymphoma and what causes it?

About 1,900 people are diagnosed with follicular lymphoma every year in the UK. Follicular lymphoma can occur at any age, but the average age at diagnosis is around 65.

There is a **paediatric (childhood) form** that can occur but follicular lymphoma is rare in children.

In most cases, there is no known cause for follicular lymphoma. Some genetic changes are common in follicular lymphoma, but it is not

known what causes them.

Symptoms

Follicular lymphoma is usually very slow-growing so **symptoms** develop gradually over time. Many people with follicular lymphoma have few symptoms and some even have none at all. Sometimes follicular lymphoma is picked up by chance in the results of a test done for another reason.

The most common symptom is a lump or several lumps, usually in your neck, armpit or groin. These are caused by lymphoma cells building up in your lymph nodes, causing them to swell. The swollen lymph nodes are usually painless. They might stay swollen or they might shrink a little and then come back from time-to-time. Most people have no other symptoms.

Some people have other common symptoms of lymphoma, which include:

- weight loss and loss of appetite
- fevers and being more prone to infections or finding it difficult to shake off infections
- night sweats (drenching sweats, especially at night)
- fatigue (extreme tiredness).

You might have other symptoms.

Weight loss, night sweats and fevers often occur together. These three symptoms are called ‘B symptoms’.

Tell your doctor about all of your symptoms as they can affect whether you need treatment straightaway.

Rarely, follicular lymphoma is found outside of the lymph nodes. It is then called ‘extranodal’. Extranodal lymphoma can cause a variety of symptoms depending where the lymphoma is growing. For example, if the lymphoma is growing in your lungs you might have a cough or be short of breath.

Follicular lymphoma can also occur in your bone marrow (the spongy centre of some of our bones). This can cause low blood counts as the lymphoma

cells take up the space of normal cells. You might develop:

- **Anaemia** (low red blood cells), which can cause tiredness and shortness of breath.
- **Thrombocytopenia** (low platelets), which makes you more likely to bruise and bleed.
- **Neutropenia** (low neutrophils – a type of white blood cell), which makes you more prone to infection.

Diagnosis and staging

Follicular lymphoma is diagnosed with a small operation called a **biopsy**. A sample of tissue that is affected by lymphoma, such as a swollen lymph node, is removed, usually under local anaesthetic. The sample is examined by an expert lymphoma pathologist. The pathologist then does tests on the tissue to find out what type of lymphoma it is.

You have other tests to find out more about your general health.
These tests usually include:

- a physical examination
- **blood tests** to look at your general health, including your blood cell counts
- a **scan** – usually a CT scan.

Increasingly, a PET scan might be done if your specialist thinks it would be helpful in planning your treatment. You might have a **bone marrow biopsy** to see if the lymphoma is affecting your bone marrow. If you have lymphoma in your bone marrow, you might need different treatment.

Although **waiting for the results of your tests** can be difficult, your doctor is collecting important information during this time. It is important that your doctor knows exactly what type of lymphoma you have so they can give you the most appropriate treatment.

What does 'stage' mean?

The tests you have are part of '**staging**' the lymphoma – working out how far it has spread and how much of your body is affected. There are four stages – 1 is 'lymphoma in one area' and 4 is the 'most widespread' lymphoma. Staging is important because it helps your doctor plan the best treatment for you.

What do 'early-stage' and 'advanced-stage' mean?

Early-stage lymphoma means stage 1 and some stage 2 lymphoma. You might hear it called 'localised'. Stage 1 or 2 lymphoma is found in a single area or a few areas close together.

'Advanced-stage' lymphoma is stage 3 and stage 4, and it is 'widespread lymphoma'. In most cases, the lymphoma has spread to parts of the body that are far from each other. Some stage 2 lymphomas are also treated as advanced-stage.

'Advanced' can sound alarming, but most people with follicular lymphoma are at an advanced-stage when they are diagnosed. Follicular lymphoma grows slowly and often doesn't cause symptoms until it is widespread. There are treatments for all stages of follicular lymphoma and these can usually keep the lymphoma under control for many years.

> I noticed a dull ache in my groin and felt a lump. After tests, a haematologist told me I had follicular B-cell non-Hodgkin lymphoma, probably stage 3. A month before I didn't even know there was anything wrong with me, and now I am diagnosed with a stage 3 cancer. How does that work?
>
> — Andy, diagnosed in 2009

What does 'grade' mean?

Your doctor might tell you a grade (1, 2, 3A or 3B) as well as a stage of your lymphoma. The grade relates to the number of large follicular cells that can be seen under a microscope. Grade 1 has the fewest large follicular cells and

grade 3B has the most. Grades 1, 2 and 3A are treated in the same way and the grade does not affect the likely outcome. Grade 3B follicular lymphoma is usually fast growing. It behaves and is treated like a high-grade NHL, for example, **diffuse large B-cell lymphoma (DLBCL)**.

Outlook

Only a few people with early-stage follicular lymphoma are treated with the intention of curing the lymphoma. Most people with follicular lymphoma are treated to keep the lymphoma under control, rather than to cure it. There are lots of good treatments for follicular lymphoma. It can usually be controlled for many years with several courses of treatment.

Survival statistics can be confusing as they don't tell you what your individual outlook is – they only tell you how a group of people with the same diagnosis did over a period of time.

The availability of rituximab and **newer, targeted drugs** are improving the outlook for people with follicular lymphoma. As people with follicular lymphoma generally live for many years, it takes a long time to find out how these newer treatments affect outcomes. Recent statistics suggest that follicular lymphoma may not affect the life expectancy of many people who live with it.

Your doctor is best placed to advise you on your outlook based on your individual circumstances. They can use the results of your tests and consider other factors, like your age, symptoms, and any other conditions you have to predict how likely you are to respond to a particular treatment. These factors are called 'risk factors'.

Your doctor might calculate a prognostic score, for example using the Follicular Lymphoma International Prognostic Index (FLIPI), which takes several different risk factors into account. Your score on the FLIPI or your risk factors may be used to plan your treatment.

Treatment

Around 1 in 5 people with follicular lymphoma never need treatment or the lymphoma does not cause problems for many years. Your doctor will consider carefully whether you need treatment straightaway and what treatment is best for you. When your medical team plan your treatment, they consider several factors, including:

- the stage of the lymphoma
- the size and location of the lumps of your lymphoma
- how the lymphoma is affecting you
- your general health
- your preferences.

Follicular lymphoma is slow-growing and there is rarely an urgent need for treatment.

Treatment of early-stage follicular lymphoma

Early-stage follicular lymphoma that is not causing problems can sometimes be cured with **radiotherapy** to the affected area. Low doses of radiotherapy can be effective and have few **side effects** (unwanted effects).

Sometimes radiotherapy is not suitable, for example if the affected areas are far apart. You might instead be monitored during regular visits to your doctor until more treatment is needed. This is sometimes called '**watch and wait**' or 'active monitoring'. This approach keeps treatment for when it is needed and allows you to avoid the side effects of treatment for as long as possible. When treatment is needed, you are treated the same way as if you had an advanced-stage follicular lymphoma.

Treatment of advanced-stage follicular lymphoma

Advanced-stage follicular lymphoma can be treated very successfully, but usually **relapses** (comes back) at some point after treatment. Treatment aims to keep the lymphoma in remission (under control) for as long as possible

with as few side effects as possible. Most people have long periods of feeling well between courses of treatment.

Advanced-stage follicular lymphoma that is not yet causing problems might not need treatment straightaway. You might be monitored regularly by your doctor until you need treatment (**'watch and wait'** or 'active monitoring'). Your doctor might suggest a short course of an **antibody treatment** (for example **rituximab**), which can help to delay your need for more treatment.

If a certain area of lymphoma is causing problems, you might have **radiotherapy** to that area. This can shrink the lymphoma in that area and reduce symptoms. Afterwards, you might not need any other treatment until you start having problems again.

If your lymphoma causes problems and your doctor thinks you need to start treatment, you are likely to have chemo-immunotherapy (**chemotherapy** with antibody treatment).

There are lots of different chemotherapy regimens (combinations of drugs) that people with follicular lymphoma might be offered. The most common are:

- CVP (cyclophosphamide, vincristine and prednisolone)
- CHOP (cyclophosphamide, doxorubicin, vincristine and prednisolone)
- bendamustine
- chlorambucil.

All of these chemotherapy regimens are usually given with the antibody treatment rituximab. An 'R' is then added to the name, for example R-CVP.

Your doctor might suggest you have **maintenance treatment** after your main course of chemoimmunotherapy. You are given antibody treatment (for example rituximab) every 2 months for up to 2 years. Maintenance treatment helps to keep the lymphoma under control and reduce the risk of relapse.

All treatment has a risk of **side effects**. Your medical team can give you more information about the typical side effects of the treatment they recommend for you.

I was diagnosed with stage 4 follicular lymphoma and had 6 cycles of R-CHOP chemotherapy. I think I had prepared myself for a horrible experience, so, although I felt queasy at times, treatment wasn't as bad as I had expected. I had been warned that I would lose my hair, but this wasn't something I really worried about - in fact, I have more hair now that it has grown back than I did before.

— Douglas, diagnosed in 2010

Paediatric follicular lymphoma

Paediatric (childhood) follicular lymphoma is very rare but behaves differently from the more common type of follicular lymphoma and can usually be cured. Although mainly seen in children, it can occasionally be seen in adults.

Paediatric follicular lymphoma is often localised (early stage) when it is diagnosed. It is most commonly found in lymph nodes in the neck, in the tonsils or at extranodal sites such as the testicles. It can often be cured with surgery alone if all the abnormal tissue can be removed. If surgery isn't suitable, the vast majority of people with paediatric follicular lymphoma can be cured with chemotherapy. This type of follicular lymphoma does not usually relapse.

Follow-up

You have regular **follow-up appointments** after treatment, usually every 3–6 months. These appointments allow your medical team to check how well you are recovering from treatment. They give you an opportunity to raise concerns and ask questions. Your medical team also check for signs of the lymphoma relapsing.

You are likely to have a physical examination and **blood tests**. **Scans** are not usually done unless there is a particular reason for them.

If you stay well, your appointments may become less frequent.

Some people go onto a self-management scheme. You are given information on what to look out for and how to look after yourself. You might have blood tests at your GP surgery.

If you are worried about your health at any time, contact your GP or medical team. They can reassure you or arrange an appointment for you to have a check-up.

> My last chemotherapy was 10 years ago. I have now been lymphoma free since then and have done things I could barely have dreamed of doing before I was diagnosed
>
> — Caroline, diagnosed in 2006

Transformation

Sometimes follicular lymphoma **transforms** (changes) into a faster-growing type of lymphoma. Follicular lymphoma transforms in about 2 to 3 in every 100 people each year.

As part of your follow-up, your medical team check for signs of transformation. These include:

- a change in your symptoms, for example very fast growing lymph nodes or organs (such as the spleen), or development of B symptoms
- an increase in certain chemicals measured in **blood tests**, for example lactate dehydrogenase (LDH) or calcium.

If your doctor suspects transformation, you might have a **biopsy** to check for faster-growing cells.

Transformed follicular lymphoma is usually treated like a high-grade lymphoma, for example **diffuse large B-cell lymphoma (DLBCL)**. Due to advances in drug developments, the outcome for transformed follicular lymphoma has greatly improved over recent years. In many cases, it is now treated successfully.

Relapse

Remissions (time when the lymphoma is under control) are increasing in length with new and more effective treatments for follicular lymphoma. Many people stay in remission for several years after a course of treatment. However, follicular lymphoma usually **relapses** (comes back) and most people need several courses of treatment during their illness.

> A diagnosis isn't necessarily as bad as it may seem at first. Since by all accounts I should not have had this type at a young age I feel very lucky that each time it has relapsed new treatments were offered and that many years later I am able to tell my story
>
> — Carole, diagnosed in 1984

If your lymphoma doesn't respond well to your first treatment, it is called 'refractory' and you might need a different or stronger treatment.

Treatment for relapsed or refractory follicular lymphoma

There are many possible treatment options for relapsed and refractory lymphoma. Your doctor will consider all of the same factors they considered before as well as:

- what treatment you had before
- how you coped with your previous treatment
- how quickly your lymphoma relapsed.

Your doctor might suggest several treatment options. You should have time to consider the options carefully and discuss the risks and benefits with your medical team to help you decide what treatment is best for you.

When treatment is needed, options include:

- **radiotherapy**
- chemo-immunotherapy with the same regimen you had before or a different regimen
- **targeted drugs**

- more intensive treatments like high-dose chemotherapy and a **stem cell transplant**.

If you had early-stage lymphoma and were treated with a standard dose of radiotherapy previously, you can't have it again to the same area. Most people then have chemo-immunotherapy.

Most people have chemo-immunotherapy with a different regimen to the one they had previously or with a regimen that includes **newer, targeted drugs**. A few people who had a long remission after their last treatment might be able to have the same treatment again. Some people have radiotherapy to troublesome areas and then are monitored to see if further treatment is needed.

If your lymphoma came back quickly after your last treatment and you are fit enough, your doctor might suggest a more intensive form of treatment, such as high-dose treatment and a stem cell transplant.

Research and targeted treatments

Newer, targeted drugs are often available first for people with relapsed and refractory lymphoma. There are several newer drugs already approved for follicular lymphoma and many clinical trials testing newer drugs for this type of lymphoma. Our newer drugs page has the latest information on drugs available for follicular lymphoma and other types of lymphoma. You can also search our clinical trials information service, **Lymphoma TrialsLink**, to find clinical trials suitable for people with follicular lymphoma.

At the time of writing, the following newer drugs are approved for some people with follicular lymphoma and might be available on the NHS in some parts of the UK, although the funding available varies. Your medical team can give you more information about newer drugs that might be suitable for you.

Idelalisib

Idelalisib is a cell signal blocker. It blocks signals that B cells send to help them stay alive and divide. It is approved for some people with follicular

lymphoma who have already had two courses of treatment.

Obinutuzumab

Obinutuzumab is a newer antibody that attaches to the same target as rituximab does, a protein called 'CD20'. It could be an effective alternative to rituximab for some people. Obinutuzumab in combination with chemotherapy is approved to treat some people with relapsed or refractory follicular lymphoma.

Further information and support

Most people live with follicular lymphoma for many years. We have **more information** covering many aspects of living with a chronic condition like follicular lymphoma.

If you would like further information or would like to talk about any aspect of your lymphoma, please call our confidential Freephone helpline on 0808 808 5555 or email **information@lymphoma-action.org.uk**. Our **Information and Support team** may be able to put you in touch with someone else with a similar experience to you – a '**buddy**'. We also have **support groups** and forums where you can get in touch with other people affected by follicular lymphoma.

References

These are some of the sources we used to prepare this information. The full list of sources is available on request. Please contact us by email at **publications@lymphoma-action.org.uk** or phone on **01296 619409** if you would like a copy.

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Further reading

- Active monitoring ('watch and wait')
- Glossary
- What is lymphoma and how does it develop?
- Targeted drugs for lymphoma
- Chemotherapy
- Rituximab
- Biosimilar rituximab
- Living with lymphoma

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