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Follicular lymphoma

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

On this page

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 follicular lymphoma?

Lymphoma is a type of blood cancer that develops when white blood cells called **lymphocytes** grow out of control. Lymphocytes are part of your **immune system**. They travel around your body in your blood and your **lymphatic system**, helping you fight infections. There are two types of lymphocyte: **T lymphocytes (T cells)** and **B lymphocytes (B cells)**.

Lymphomas can be grouped as **Hodgkin lymphomas** or **non-Hodgkin lymphomas**, depending on the types of cell they contain. Follicular lymphoma is a common type of slow-growing (low-grade) non-Hodgkin lymphoma that develops from B cells. It is called 'follicular' lymphoma because the abnormal B cells usually develop in clumps called 'follicles' inside **lymph nodes**.

Who gets follicular lymphoma?

Follicular lymphoma is the most common type of low-grade non-Hodgkin lymphoma. About 2,300 people are diagnosed with follicular lymphoma every year in the UK. It can develop at any age, but it is more common in people over 60.

In most cases, there is no known cause for follicular lymphoma. Some genetic changes are common in follicular lymphoma, but scientists don't know what causes them. There is not normally any family history of follicular lymphoma.

Symptoms

Follicular lymphoma is usually slow-growing so **symptoms** typically develop gradually over time. Some people have no symptoms at all and follicular lymphoma is noticed during tests for a different health issue. However, follicular lymphoma is variable and for some people it may be faster-growing and cause more symptoms.

The most common symptom of follicular lymphoma is one or more lumps. These are typically felt in your neck or just above your collar bones but they can develop in other places, such as your armpits or groin. The lumps are caused by lymphoma cells building up in your lymph nodes, which makes the lymph nodes swell. These **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 with follicular lymphoma have no other symptoms, although other possible symptoms include:

- **unexplained weight loss**
- **fevers** (temperature above 38ºC)
- **drenching sweats**, especially at night
- **frequent infections, or having difficulty getting over infections**
- **fatigue** (overwhelming tiredness).

Weight loss, drenching sweats and fevers can occur together and are called '**B symptoms**'. These B symptoms are less common in follicular lymphoma than in high-grade lymphomas.

Follicular lymphoma can be found outside of the lymph nodes. This is called 'extranodal' lymphoma. Extranodal lymphoma can cause a **variety of symptoms** depending where the lymphoma is growing.

Around 1 in 2 people with follicular lymphoma have lymphoma cells in their **bone marrow** (the spongy centre of larger bones where blood cells are made) when they are diagnosed. This might lead to:

- **anaemia** (low red blood cell count), which can cause tiredness and shortness of breath
- **thrombocytopenia** (low platelet count), which makes you more likely to bruise and bleed
- **neutropenia** (low neutrophil count – a type of white blood cell), which makes you more prone to infection.

Diagnosis and staging

The main way to diagnose follicular lymphoma is to take a sample of cells from your body and look at them under a microscope. This involves a procedure called a **biopsy**, which is usually done under a local anaesthetic.

The biopsy sample is examined by an expert lymphoma **pathologist**. The pathologist might also test the lymphoma cells for particular proteins and genetic changes. This can help your medical team decide on the most appropriate **treatment** for you.

You also have **blood tests** to look at your general health, check your **blood cell counts**, make sure your kidneys and liver are working well, and test for viral infections.

You have other tests to find out which areas of your body are affected by lymphoma. This is called **staging**. Staging usually involves having a **CT scan** or a **PET scan**. In some circumstances, you might have a sample of your bone marrow cells taken (a **bone marrow biopsy**), to check if you have lymphoma cells in your bone marrow.

You usually have your tests done as an outpatient. It can take a few weeks to get all the results. **Waiting for test results** can be a worrying time, but it is important for your medical team to have all the information they need so they can plan the most appropriate treatment for you.

As follicular lymphoma typically grows slowly and might not cause any symptoms, it is often **advanced** (stage 3 or 4) by the time it is diagnosed. There are treatments for all stages of follicular lymphoma, which can usually keep the lymphoma under control for many years.

Grading of follicular lymphoma

Your doctor might tell you the grade (1, 2, 3A or 3B) as well as the stage of your lymphoma. The grade relates to the number of large lymphocytes that the pathologist can see under a microscope. Grade 1 has the fewest large lymphocytes and grade 3B has the most. Grades 1 and 2 are often grouped together and referred to as ‘grade 1 to 2’ follicular lymphoma.

Grades 1 to 2 and 3A follicular lymphoma are all slow-growing and are treated in the same way. The grade does not affect the likely outcome of treatment.

Grade 3B follicular lymphoma is usually fast-growing. Under a microscope, it looks like a type of high-grade non-Hodgkin lymphoma called **diffuse large B-cell lymphoma (DLBCL)**. It is treated the same way as DLBCL.

Your ‘prognostic score’

Your doctor might use your test results to give you a score that can help predict your response to treatment and this is sometimes used to help guide which treatment to use. This is called a ‘prognostic score’. There are a number of different scoring systems for follicular lymphoma. The most common in the UK is the ‘FLIPI’, which gives you a score based on:

- your age
- how widespread your lymphoma is
- the results of some of your blood tests.

Outlook

Follicular lymphoma often grows slowly, although in some people it can develop more rapidly. The speed of growth is variable and can be hard to predict when first diagnosed. Treatment is generally successful and long remissions are possible. But, at some point, the lymphoma usually comes back (relapses) and needs more treatment to keep it under control. It is hard to predict how long it might be before you need more treatment.

Most people live with follicular lymphoma for many years and are managed as if it is a chronic condition. You might have periods when you feel well and don't need treatment, and other periods when your symptoms get worse and you need more treatment.

Your doctor is best placed to advise you on your outlook (prognosis) based on your individual circumstances.

I slowly came to terms with the fact that I am facing a condition that is manageable but not curable. It has taken me some time to adjust to this being my new life; my new normal. A life that includes regular hospital checks, blood tests and treatment.

Nicola, diagnosed with follicular lymphoma

Transformation

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

If your doctor thinks your lymphoma might have transformed, you are likely to have a **biopsy** to check for faster-growing cells. Transformed follicular lymphoma is usually treated like a high-grade lymphoma such as **diffuse large B-cell lymphoma (DLBCL)**.

Treatment

Follicular lymphoma is usually slow-growing and there is rarely an urgent need for treatment. Some people might not need treatment for many years. Your medical team will consider carefully whether you need treatment straightaway and what treatment is best for you.

The treatment your medical team recommends for you depends on the stage of your lymphoma and the signs and symptoms you have. **Stage 1** or **stage 2** follicular lymphoma is known as ‘early-stage’ lymphoma. **Stage 3** or **stage 4** follicular lymphoma is known as ‘advanced-stage’ lymphoma. Most people have advanced stage follicular lymphoma when they are diagnosed.

When choosing your treatment, your team also takes into account:

- where your lymphoma is growing
- how big the lumps of lymphoma are
- how the lymphoma is affecting you, including any symptoms you’re experiencing and the results of your blood tests
- your general health and fitness
- your age
- your feelings about treatment.

Your team also considers any potential **side effects**, as well as long-term or **late effects** (health problems that develop months or years after treatment) of the treatment.

Treatment of early-stage follicular lymphoma

Around 1 in 5 people with follicular lymphoma are diagnosed when it is at an early stage. Early-stage follicular lymphoma that is only growing in one part of your body can sometimes be very effectively treated with **radiotherapy** to the affected area. Low doses of radiotherapy have few **side effects**.

Sometimes radiotherapy is not suitable – for example, if your lymphoma is close to important organs that could be damaged by the radiotherapy, or if you have other medical conditions that make radiotherapy unsuitable. If this is the case, and you are not experiencing troublesome symptoms, you might not need treatment straightaway. Instead, you might be monitored during regular visits to your doctor. This is called **active monitoring** or 'watch and wait'. This approach keeps treatment for when it is needed and allows you to avoid the side effects of treatment for as long as possible. Even if you don't have any symptoms, your medical team might recommend a short course of **rituximab antibody treatment**. This can help to delay your need for further treatment.

If you are experiencing troublesome symptoms you are likely to be treated in the same way as people with advanced-stage follicular lymphoma.

Treatment of advanced-stage follicular lymphoma

Most people have advanced-stage follicular lymphoma when they are diagnosed. Advanced-stage follicular lymphoma can be treated very successfully. Treatment aims to keep the lymphoma under control for as long as possible with as few side effects as possible. Although the lymphoma usually comes back (**relapses**) and needs more treatment at some point, most people with follicular lymphoma have long periods of feeling well between courses of treatment.

If you have advanced-stage follicular lymphoma that is not causing troublesome symptoms, there are two options that your medical team will discuss with you:

- a short course of low intensity treatment with an antibody called **rituximab**. This would be given once a week for four weeks and has been shown to significantly delay the time until more intensive treatment is needed.
- an approach called '**active monitoring**' (or 'watch and wait'). This involves having regular check-ups with your medical team to monitor your health and to see how the lymphoma is affecting you. Active monitoring means that while you are well, you avoid the side effects of treatment for as long as possible. Treatment is still available when you need it, but this might not be for months or years.

If your lymphoma is causing troublesome symptoms, your medical team are likely to recommend a course of **chemotherapy** combined with **antibody therapy**. This is called chemo-immunotherapy.

The most common **chemotherapy regimens** (combinations of drugs) used to treat follicular lymphoma are:

- bendamustine
- CVP – **c**yclophosphamide, **v**incristine and **p**rednisolone
- CHOP – **c**yclophosphamide, doxorubicin (also known as **h**ydroxydaunorubicin), vincristine (also known as **O**ncovin®) and **p**rednisolone)
- chlorambucil.

They are usually given with one of the following antibody therapies:

- **rituximab** – in which case an 'R' is added to the name of your chemotherapy regimen (for example R-CHOP)
- **obinutuzumab** – in which case an 'O' is added to the name of your chemotherapy regimen (or sometimes a 'G', after the trade name of obinutuzumab: Gazyvaro®).

If you respond well to your course of chemo-immunotherapy, you are likely to be offered **maintenance treatment**. This aims to keep your lymphoma under control and make your **remission** (the time when your lymphoma has shrunk or gone completely) last as long as possible. Maintenance treatment involves having an injection of your antibody therapy (either rituximab or obinutuzumab) every 2 to 3 months for up to 2 years.

What came as a further shock was that, not only did I have a form of cancer, but they were not going to treat it until I felt really unwell. In reality, the active monitoring (watch and wait) with 6 monthly reviews lasted for nearly 5 years before I was treated with six cycles of bendamustine and rituximab. This was followed by 2 years of rituximab maintenance therapy which ended in 2020.

Jeff, diagnosed with follicular lymphoma

Follow-up

If you are in **remission** after treatment, you'll have regular **follow-up appointments** in the clinic. Your follow-up appointments are to check that:

- you are recovering well from treatment
- you have no signs of the lymphoma relapsing or getting worse
- you are not developing any **late effects** (side effects that develop months or years after treatment).

At each appointment, your doctor or nurse specialist examines you and asks if you have any concerns or symptoms. You are unlikely to have a scan unless you have troubling symptoms.

Some people go onto a **self-management scheme**. Your medical team gives you information on what to look out for and how to book an appointment if you need one. If you are worried about your lymphoma, you can contact your medical team at any time.

Specific types of follicular lymphoma

Most people who have follicular lymphoma do not have a particular type. However, there are some rare variants of follicular lymphoma that behave, and are treated, differently.

Duodenal-type follicular lymphoma

Duodenal-type follicular lymphoma grows in the small intestine (small bowel or gut). It is slow-growing and is usually diagnosed at an early stage. Duodenal-type follicular lymphoma is unlikely to spread to other parts of your body or change (transform) into a faster-growing type of lymphoma. People with duodenal-type follicular lymphoma might be observed (**active monitoring**), treated with **rituximab** (on its own or with **chemotherapy**) or treated with **radiotherapy**. Treatment is usually very successful.

Paediatric-type follicular lymphoma

Paediatric-type follicular lymphoma is a very rare form of follicular lymphoma. It typically affects children but it occasionally develops in adults. It is more common in males than females. Paediatric-type follicular lymphoma most commonly develops in lymph nodes in the head or neck. It is typically diagnosed at an early stage and is usually cured with treatment. Most people have surgery to remove the affected lymph nodes. Occasionally, some people need **radiotherapy** or **chemotherapy**. Paediatric-type follicular lymphoma does not usually come back (relapse) after successful treatment.

Relapsed or refractory follicular lymphoma

Treatment for follicular lymphoma is usually effective. However, follicular lymphoma usually comes back (**relapses**) and needs more treatment at some point.

The length of **remission** after successful treatment can vary widely, so it can be difficult to predict how long it might be before you need more treatment. Some people stay in remission for several years but others need more treatment sooner.

Occasionally, lymphoma doesn't respond well to your first treatment. This is called 'refractory' lymphoma. Refractory lymphoma is usually treated in a similar way to relapsed lymphoma.

If you have follicular lymphoma that comes back, you might have the same symptoms you had before or you might have different symptoms. If your medical team suspects your lymphoma has come back, they are likely to recommend that you have another **biopsy** to check if it has changed (transformed) to a faster-growing type of lymphoma. You are also likely to have more scans to check the stage of your lymphoma.

Treatment for relapsed or refractory follicular lymphoma

If your lymphoma is not causing troublesome symptoms, you might have a period of **active monitoring** (watch and wait) before starting any further treatment. If you need treatment, several different options are available for relapsed and refractory follicular lymphoma. Your medical team will consider all of the same factors they considered before as well as:

- the treatment you've already had
- how well your lymphoma responded to previous treatment

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

Your medical team might discuss several treatment options with you. You should have time to consider the options carefully and discuss the risks and benefits with your team to help you decide what treatment is best for you. We outline some of the more common approaches here but your medical team might recommend a different option.

- If you have not had rituximab as part of your treatment before, or you had a long remission after rituximab-based treatment, you might be offered rituximab, combined with chemotherapy. This might be the same **chemotherapy regimen** you had before, or a different one. If you have not had **maintenance therapy** before, you might have a course of rituximab maintenance therapy afterwards.
- If you have had rituximab as part of your treatment before but you did not respond to it, or you relapsed within 6 months of having it, you might be offered **obinutuzumab** plus bendamustine, followed by obinutuzumab maintenance therapy.
- You might have treatment with **rituximab** combined with a **targeted drug** called **lenalidomide** (also known as **R**evlimid®) which is taken as a tablet. This combination is sometimes called R^2.
- If chemotherapy or targeted therapy isn't suitable for you, your medical team might suggest that you have rituximab on its own.
- If your lymphoma is causing problems in one particular area of your body, you might be offered **radiotherapy** to the affected area to help control your symptoms.

If you respond well to more treatment, your medical team might recommend a course of higher-dose chemotherapy with a **stem cell transplant** to help your remission last as long as possible. This would usually be using your own stem cells (autologous stem cell transplant) but sometimes stem cells from a donor are used. Stem cell transplants are a very intensive form of treatment and you have to be fit enough to have one.

Research

Scientists are testing many different **targeted treatments** in **clinical trials** for follicular lymphoma, including some treatments that are already approved for other types of lymphoma. Many of these new targeted drugs work by helping your own immune system get rid of the lymphoma.

New types of treatment that are being tested for follicular lymphoma include:

- New **antibody therapies**, including antibodies that bind to two different targets (one on lymphoma cells and one on T cells, which helps the T cells find and destroy the lymphoma cells). These are called ‘bispecific’ antibodies. A bispecific antibody called mosunetuzumab has a licence for use in relapsed follicular lymphoma but is not currently available through the NHS. Studies are ongoing to determine how this treatment will be used in the future.
- **Antibody–drug conjugates** (antibodies joined to chemotherapy drugs). The antibody sticks to a protein on the surface of lymphoma cells and carries the chemotherapy drug directly to it.
- **Cell signal blockers**, which block signals that B cells send to help them divide or stay alive. Cell signal blockers include targeted drugs such as BTK inhibitors, PI3K inhibitors and BCL-2 inhibitors, named after the particular proteins they block.
- **CAR-T cell therapy**, which involves genetically modifying your own T cells so they can recognise and kill lymphoma cells. CAR-T cell therapy has a licence for use in relapsed follicular lymphoma but is not currently available through the NHS. Studies are ongoing to determine how this treatment will be used in the future.
- Drugs that block proteins linked to particular genetic changes in lymphoma cells.

Some of these might be available to you through a clinical trial or special access scheme. If you are interested in taking part in a clinical trial, ask your doctor if there is a trial that might be suitable for you. To find out more about clinical trials or to search for a trial that might be suitable for you, visit **Lymphoma TrialsLink**.

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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