

# Waiting for test and scan results

This information outlines reasons why it can take some time to get the results of tests and scans. It gives tips to help manage the wait. We have separate information about tests, scan and staging for lymphoma.

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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**.

# How long will I wait for the results of my tests and scans?

After you have been referred for tests by your GP, it can take time for test results to come back. The person referring you should be able to give you an idea of when to expect your test results and how you'll be told about them.

Often, it takes a couple of weeks to get test results. It can take longer to get the results of non-urgent tests, for example, those that are part of your routine follow-up.

Lucy Whiteman, lymphoma nurse specialist, explains why it can take a bit of time to get the results of tests and scans:

#### https://youtu.be/v-s5jJU8Hug

Waiting times also depend on the type of test you had. For example:

- Blood test results are usually available within a few days. However, occasionally, some specialist blood tests can take a few weeks.
- The tissue in a bone marrow biopsy has to have the calcium removed (decalcified) before the sample can be looked at in detail. It takes 1 to 2 weeks before test results are available, although can take longer if further tests are needed.
- The tissue from a lymph node biopsy has to be set in a substance to preserve it, cut into very thin slices and stained with chemicals to help make the cells show up more clearly under a microscope. Results usually take 1 to 2 weeks.
- Some tests use specialised equipment or need specially trained scientists to find out the exact genetic make-up of lymphoma cells. The samples might need to be sent to a different laboratory and it could take a number of weeks before your results are available.

Talk to a member of your medical team if you are waiting for longer than you expected for your results.

# What information will I be given about my test results?

You might be given a provisional diagnosis while you are waiting to have **further tests to find out more about the lymphoma**. For example, you might be asked to have an extra scan or, occasionally, another biopsy. These further investigations help your medical team recommend the most appropriate **treatment** for you.

Sometimes the result might be unclear. For example, the sample could have been too small to run the test accurately. If this happens, you might have to have the procedure again, or have a slightly different one. Your medical team will explain if this is the case for you.

## Who will tell me my test results, and when?

You should be given information before having your tests about how and when you'll be told the results of your tests.

Before you receive your test results:

- The specialists who look at the information from your tests or scans write a report about your test results. They send this to the consultant or other health professional who asked for the test to be done.
- Usually, your doctor reviews all the information from your tests before contacting you. This is to make sure that they have the diagnosis, so that they can offer you the most suitable treatment.

You are usually given a face-to-face appointment to talk about the results of your tests. You can ask to take a family member or friend with you if you would like to. You should have an opportunity to **ask questions** at this appointment, although you can also ask them at a later date. Some people find it helpful to write down questions so that they remember what they want to ask.

# Frequently asked questions about waiting for test and scan results

We answer some of the questions people often ask about waiting for test results. Speak to your GP or a member of your medical team if you have questions or concerns about your specific situation.

# What are the specialists doing while I am waiting?

Different health professionals with different specialities look at your tests and scans. This group of people is known as a multidisciplinary team (MDT). They meet to discuss the results.

The following people might be involved in looking at the information from your medical investigations:

- Biochemical scientists test blood samples in a laboratory.
- Radiologists examine scan images (including X-rays).

 Specialist pathologists examine samples from a biopsy, bone marrow biopsy and lumbar puncture.

If your **lymphoma type** is rare, there might be more specialised people involved, to help make sure you get the correct diagnosis and the most appropriate care.

The specialists write a report about your test results. This is sent to the doctor (usually your consultant) who asked for the investigation to be done.

In most cases, your doctor waits until they have reviewed the information from all of your tests before they contact you. This is to make sure you get the correct diagnosis and that you are offered the most suitable **treatment**.

## Why might my results take longer than expected?

There are a number of possible reasons for test results to take longer than expected. For example:

- The specialist looking at the test results might need the opinion of another specialist. This can mean sending the samples and scan images to an expert at another hospital, particularly if you have a rare type of lymphoma.
- The samples might need to be sent to a different laboratory for specialist tests, for example to look at the genes in lymphoma cells.
- A test might need to be repeated, for example, if there were not enough cells collected in the first sample or if the results of the first test were unclear.

You'd usually be invited back to the clinic for a member of your medical team to talk you through what is happening. If you need further tests, this will be explained to you, and dates for them to take place will be arranged.

A short delay of around a couple of weeks is very unlikely to affect your outcome. Your doctor will try to ensure that your test results are prioritised. If you have any concerns, speak to your clinical nurse specialist or medical team.

If the results take a long time, it doesn't meant that it's bad news. It just means that we need more information and more time to look at some of the results. You might need further tests so that your medical team can find out more about the type of lymphoma you have.

Lucy Whiteman, Lymphoma Clinical Nurse Specialist

If the test results take longer than expected, any follow-up appointments already scheduled might be re-arranged for when the final results are expected to be available. Alternatively, your doctor might still want to see you while waiting for the results so that they can keep a check on your symptoms.

If any of your symptoms worsen while you're waiting to hear test results, contact a member of your medical team or your GP.

# Coping with waiting

Many people find the uncertainty of waiting for test results very challenging to deal with. You might feel scared or anxious. While these emotions are natural and might not go away completely, there are some strategies you could try to help manage them. We give some ideas below.

It can be hard not to start guessing about the outcome of your test results. Many people search for information online. It's natural to want answers. However, it can be more helpful to wait until your test results are back and you have an appointment to discuss them with your doctor. Note that there is a lot of health information available of varying quality. If you do look online, check that information is up-to-date and trustworthy. One easy way to check that it is reputable is to look for the Patient Information Forum (PIF)-TICK quality mark.

# Write your worries down

It can be exhausting when worries go around in your head. Try to notice them early, before they take over your thoughts.

Simply writing your thoughts down can take away some of their power and bring a sense of freedom. Seeing your worries in writing might also help you to notice any links between them so you can then think about how to address them.

- Write down worries or concerns as they come into your mind. For some people, this helps to 'free up' mental space in their mind to focus on other things.
- If you find that worries take over your thoughts, try to set aside 'worry time'. You could think of this as a container or box for your worries.
- Keep a notepad by your bed to write down any worries that come to you during the night. Make an agreement with yourself that you'll return to them the next day when you can give them your full attention during your 'worry time'.

## Try to think differently about your worries

Try to break down your worries. You can then think about what you could do to help yourself. For example:

- Worry: The doctors will tell me I've got lymphoma. I don't know anything about it and won't know how to deal with it.
- New thought: I don't have a diagnosis so will take one day at a time. If I am diagnosed with lymphoma, I'll have opportunities to ask my medical team questions so that I can find out what this means and can discuss my treatment options. I can also get information about lymphoma and emotional support from Lymphoma Action.

# Talk about how you feel

Many people find that talking about how they feel helps them to process difficult emotions. You might choose to speak to someone you're close to, or you could get in touch with our **helpline team**. Tell a member of your medical team how you feel too – a clinical nurse specialist or other **key worker** is often a good first point of contact.

You might prefer to talk to a professional who is trained in a **talking therapy** such as **counselling**. You could speak to your GP about the possibility of a referral on the NHS. If you are in a position to pay for it, you can search online for a private therapist. The **British Association for Counselling and Psychotherapy** and the **British Psychological Society** both have search tools to help you find a therapist.

# Make time for yourself

It's important to make time for yourself and to do things that are enjoyable and relaxing. This can help to improve your overall wellbeing, including managing anxiety.

#### You could consider:

- social activities with people you care about
- ways of managing stress, such as breathing exercises, meditation and mindfulness
- physical activity and exercise, which can improve your mood
- doing something creative, such as painting, drawing, model-making or singing.

## Spend time in nature

Many people find that nature helps them feel calmer. For example, you could go for a walk if you are able to, or do other activities outside. Some people find that just looking at plants, animals or natural landscapes through a window or on television helps. Feeling a connection with the natural world can help us to feel more 'grounded' and peaceful.

You might have heard of 'forest bathing', which originated in Japan. It means spending time among trees, taking note of your natural surroundings, and breathing deeply. The idea is that this can help to bring a sense of calm, and lower stress. You can search on the Forestry England UK website for tips on forest bathing for beginners. Forestry and Land Scotland also has information about forest bathing in Scotland.

MIND, a mental health charity, has information about nature and mental wellbeing, including some ideas to try.

# 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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