

Supported self-management

More people are living longer after a diagnosis of lymphoma. Some hospitals now offer supported self-management, a form of **follow-up** where people are empowered to manage their ongoing health condition.

We have separate information about **follow-up** by pre-booked appointments, and about **active monitoring ('watch and wait') for lymphoma**.

On this page

What is supported self-management?

What is remote monitoring?

What is patient-triggered follow-up?

Benefits of supported self-management

Risks of supported self-management

When to book an appointment

Coping with supported self-monitoring and remote management

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 supported self-management?

Supported self-management is part of the **NHS long-term plan**. It aims to put people affected by long-term health conditions, including lymphoma, at the centre of their health care. It looks at the whole person. It considers your individual strengths, needs, preferences and the support you have access to.

An overall goal of self-management is to help you take control of your health and wellbeing so that you can **live well, physical and emotionally, with and beyond lymphoma**. It involves keeping track of any **symptoms** you might be experiencing as well as taking care of your overall health.

Supported self-management aims to give people choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths, needs and preferences.

NHS long-term plan

As part of your **recovery package** once you **finish treatment** and begin to recover, you might be offered more formal or structured supported self-management.

To help you develop skills, knowledge and confidence to take care of your health, supported self-management approaches might include the following:

- **Health coaching** – where you are supported to identify any current health issues and to take steps to manage your general health and wellbeing effectively.
 - **Self-management education** – which involves more formal education or training. Examples include our **Live your Life workshop** and **Macmillan's HOPE (help to overcome problems effectively) programme**.
 - **Peer support** – where people with similar long-term conditions or health experiences support each other to understand and manage their condition and to help their recovery. Peer support might be through a formal programme, or a more informal one, such as our **buddy service** or **support groups**.
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What is remote monitoring?

Remote monitoring is a type of supported self-management. It's a way for you to keep in contact with your medical team to check your health without you having to go for face-to-face appointments so often.

If you are on remote monitoring, you might have a **blood test** at your GP surgery to check:

- your **full blood count**
- your liver, bone and kidney function.

You and your GP should both receive a copy of the results of any **tests or scans** you have. If the results are normal, you might not need an appointment with your medical team. However, you can ask for one at any time if you have concerns you'd like to talk through.

How long does remote monitoring go on for?

Some hospitals offer follow-up appointments on request for the rest of your life. Others discharge you if you stay well for a set amount of time, which is sometimes after 2 years. Your GP then becomes your main point of contact for any concerns you have and can refer you back to your medical team if necessary. Many hospitals also provide contact details of the haematology department if you have any concerns about relapse and would like to talk to a member of your medical team.

Who might remote monitoring be suitable for?

Your medical team should discuss with you how they recommend that your follow-up should work and why.

If you are at low risk of **relapse**, you might be offered remote monitoring. However, not all hospitals offer it, even if you meet these criteria. If you are offered remote monitoring, it is up to you whether you choose to have follow-up in this way.

There are lots of reasons that remote monitoring might not be suitable for you. For example, if you would prefer closer monitoring or if you've been treated as part of a **clinical trial**. In this case, your follow-up care is set out in the trial protocol, which outlines how the trial should run.

What is patient-triggered follow-up?

In some cases, there might be a possibility to have patient-triggered follow-up. This is also a type of supported self-management. Instead of traditional **follow-up** (a schedule of regular pre-booked in-person appointments), you book your own follow-up appointments when you need to. For example, if you:

- notice any new or worsening **symptoms**
- are worried your lymphoma might have come back (**relapsed**)
- have long-term **side effects** or **late effects** of lymphoma or its treatment.

You can also speak to your clinical nurse specialist at any time if you would like any **practical** or **emotional support**.

Benefits of supported self-management

Your health professionals want to empower you to take an active role in your health and wellbeing from the point of diagnosis, through **treatment** and beyond. There are lots of potential benefits of self-management, including:

- having the knowledge, confidence and skills to live well physically, emotionally and socially
- recognising possible late effects and signs of recurrence, so that you can ask for medical attention early
- being involved in discussions with your medical team and making decisions about your long-term health care
- having a greater sense of independence and control over your situation
- having fewer pre-booked hospital appointments.

Some people prefer this approach of booking appointments as and when they need to – they find it more convenient to their lifestyle. For some people, it reduces the anxiety that comes with having a set of pre-arranged appointments in their diary.

The NHS also reports that people with high confidence, skills and knowledge about their health condition have fewer GP appointments and fewer A&E attendances.

Risks of supported self-management

Some people feel nervous at the thought of self-management. They think that fewer hospital appointments means a higher risk of recurrence that goes unnoticed. In reality, your medical team fully supports you throughout. Help and advice is always available if and when you would like it.

There is no evidence that regular follow-up appointments stop lymphoma from coming back, being noticed earlier, or affecting how long you live. Generally, as the person who's been diagnosed with lymphoma, **you** are more likely to first notice any problems. If you notice anything unusual or have any concerns, you can contact your medical team. They can offer advice and might arrange for you to have further **tests** if necessary.

When to book an appointment

Supported self-management should include information from your medical team before you start remote monitoring so that you know about:

- **signs and symptoms** of lymphoma coming back (**relapse**)
- **late effects** of treatment.

If you notice any of these signs, or you have any concerns about your lymphoma, you can request an appointment.

You should contact your medical team to book a follow-up appointment if you have:

- **swollen (enlarged) lymph nodes** lasting more than a week
- **drenching night sweats**
- unexplained weight loss
- worsening **fatigue**
- **itching** (pruritis)
- rash (if you have a **skin lymphoma**)
- unexplained, ongoing or worsening pain
- new or worsening **side effects**, possible side effects or **late effects** of your treatment
- any other concerns relating to your lymphoma or your treatment (for example, **difficulties eating** or **fertility** concerns).

If you would like support in coping physically or emotionally, your clinical nurse specialist is usually a good point of contact.

Coping with remote monitoring

Some people find the idea of remote monitoring daunting. However, many people like the approach once they've had some time to get used to it. After a while, they start to gain confidence in their knowledge and abilities to manage their health effectively.

There might be reasons you'd prefer to have traditional follow-up. If you are offered follow-up by remote monitoring, you don't have to accept it – speak to your medical team about your options.

Monitoring symptoms

Some people monitor changes in their symptoms or how they're feeling using a diary. Resources like [Macmillan's organiser](#) can also help you to do this. You could also consider using wearable technology to monitor things like your activity levels, sleep pattern, heart rate and blood pressure.

Coping emotionally

Living with and beyond lymphoma is a process of continual adjustment, both for the person diagnosed, as well as for their [family and friends](#). There is [support available](#) – speak to your clinical nurse specialist, or contact [our helpline team](#) to find out how we can support you and those close to you.

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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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

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