

Supported self-management after lymphoma treatment

This information is about supported self-management, an approach to **follow-up** after lymphoma treatment that some hospitals offer. Self-management can include remote monitoring and patient-triggered follow-up.

We have separate information about traditional **follow-up** by pre-booked appointments, **active monitoring ('watch and wait') for lymphoma** and **recovery after 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 supported self-management?

Self-management is an approach designed to help you take control of your health and wellbeing. The aim is for you to be able to **live well, physically and emotionally, with and beyond lymphoma.**

Supported self-management is a partnership between you and your healthcare professionals. It can empower you to take control of your condition, overall health and wellbeing. The approach involves keeping track of any symptoms or side effects related to your lymphoma diagnosis and discussing any concerns or changes with your medical team. Through this tailored approach, it can minimise the need for regular hospital visits.

Chrissie Kirby, Haematology Clinical Nurse Specialist

Treatment developments over the years mean that more people are **living well, with and beyond lymphoma.** In recognition of this, supported self-management forms part of the **NHS long-term plan.** NHS England sets out that good self-management approaches consider individuals as a whole person, including their relationships and interests. They state that it should also support them with challenges, help people to make plans, find solutions to difficulties, and break down their health and care goals into smaller, manageable goals.

After treatment, patients will move to a follow-up pathway that suits their needs, and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred.

NHS England

What does supported self-management involve?

If it is suitable for you, your hospital might offer you supported self-management once you start to **recover after treatment.**

Before you start supported self-management, your medical team should give you information about the possible [signs and symptoms](#) of lymphoma coming back ([relapse](#)). They should also talk to you about [late effects](#) of the treatment you've had and who to contact if you have any questions or concerns.

Self-management might also include:

- **Peer support** – where people with similar long-term conditions or health experiences support each other in their recovery to understand and manage their condition. Peer support might be on a group or one-to-one basis; through a formal programme, or a more informal one. Examples of peer support include our [Buddy Service](#) and [support groups](#). Find out more about [peer support on the NHS England](#) website.
- **Health coaching** – where you are supported to manage your general health and wellbeing effectively. Find out more about [health coaching on the NHS England website](#).
- **Self-management education** – which involves more structured education or training, for example, through webinars, online learning modules and group training sessions. Examples include our [Live your Life programme](#) and [Macmillan's HOPE \(help to overcome problems effectively\) programme](#). Find out more about [self-management education on the NHS England website](#).

Whichever approach to follow-up you're on, you can always contact your medical team and arrange an appointment if you have symptoms or concerns.

Dr Wendy Osborne, Consultant Haematologist

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 travel for face-to-face appointments so often. You might have some of your follow-up conversations by phone or videocall.

Will I need blood tests on remote monitoring?

If you are on remote monitoring, there might be occasional times when you have a **blood test** to check:

- your **full blood count**
- kidney function and other specialist tests as requested by your medical team.

You will have these at your GP surgery or local hospital pathology department.

You and your GP should both get a copy of the results of any **tests or scans** you have. Depending on the results, you might not need an appointment with your medical team. However, you can ask for one at any time if you have any questions or concerns. You should be given information about who to contact and how to do so.

How long does remote monitoring go on for?

Many hospitals discharge you if you stay well for a set amount of time. Often, this is 2 years. However, it depends on the type of lymphoma and the practices of your hospital.

After this time, your GP becomes your main point of contact for any concerns you might have. They can refer you back to your medical team if necessary. Your hospital might also give you contact details of their haematology department. You can then contact them if you have any concerns about your lymphoma coming back (**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. If you are offered remote monitoring, it is up to you whether you choose to have follow-up in this way. If you choose to go onto remote monitoring and then change your mind, you can discuss this with your medical team and ask to have your follow-up arranged in a different way.

Why might remote monitoring not be suitable for me?

There are lots of reasons why remote monitoring might not be suitable for you. For example, you might prefer face-to-face appointments if you need blood tests or

have hearing difficulties. Some people simply feel more comfortable with having regular pre-booked appointments.

For people who have been treated as part of a **clinical trial**, follow-up care is set out in the trial protocol, which outlines how the trial should run.

What is patient-triggered follow-up?

Patient-triggered follow-up is a type of supported self-management. It is also known as 'patient-initiated follow-up' and 'patient-led follow-up'.

With this approach, you are given information and support to **book your own follow-up appointments as and 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.

Some hospitals have an online tool where you can communicate with your health professionals and ask questions. They can ask you to complete questionnaires about any symptoms you are experiencing and let you know when to book a blood test. You can then see your test results through the tool.

The approach helps empower patients to manage their own condition and plays a key role in enabling shared decision making and supported self-management in line with the personalised care agenda.

NHS England

When should I book an appointment?

Your medical team will tell you when to contact them. As general guidance, you should book a follow-up appointment if you have:

- **swollen (enlarged) lymph nodes** lasting more than around 2 to 4 weeks
- **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 notice any of these signs, or you have any concerns about your lymphoma, including about it coming back (**relapsing**), you can request an appointment. Some people keep a record of any symptoms or how they're feeling. Resources like **Macmillan's organiser** can also help you to do this.

If you have any symptoms that could signal that your lymphoma might be coming back (**relapsing**) or you notice any signs of late effects, it is time to contact your medical team.

Your clinical nurse specialist is usually a good point of contact for physical, practical and emotional support.

Our **Helpline Team** is also here to support you.

What are the benefits of supported self-management?

Although it can take a bit of getting used to, many people like being able to take control of their follow-up schedule. They feel it gives them more flexibility to plan other areas of their life, without so many appointments they need to travel to. For some people, it also reduces the **anxiety that they feel** with having a schedule of pre-booked appointments.

From the available research, it seems that supported self-management is a helpful approach. It can be beneficial both to the person with lymphoma and to the hospital. Most of the time, the person with the lymphoma diagnosis is the first person to notice if something isn't right – they can then contact their medical team and book an appointment. It is rare that people who feel well and have no symptoms have a problem found at a routine follow-up appointment.

Some of the other potential benefits of self-management include:

- having a greater sense of independence and control over your situation
- feeling more able to make plans without so many pre-booked hospital appointments
- spending less time and money travelling to hospital appointment
- gaining the knowledge, confidence and skills to live well physically and emotionally
- recognising possible late effects and signs of recurrence, so that you can ask for medical attention early if you need it
- being involved in discussions with your medical team and making decisions about your long-term health care.

The NHS also reports that people with high confidence, skills and knowledge about their health condition have fewer GP appointments and fewer hospital Emergency Department attendances.

You can read [case studies about communication between health professionals and patients, including examples of supported self-management on the NHS England website](#).

What are the disadvantages of supported self-management?

Some people feel uncomfortable at the thought of supported self-management. They think that fewer hospital appointments could mean a higher risk of relapse that goes unnoticed.

However:

- Your medical team fully supports you throughout. You can contact them for advice and you can book an appointment whenever you would like to.
- There is no evidence that regular follow-up appointments stop lymphoma from coming back, being noticed earlier, or affecting how well and long you live.
- Most of the time, the person who's been diagnosed with lymphoma is the first to notice any problems – they are the person who best knows what is normal for them. 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.

If you are offered self-management, you don't **have** to accept it – speak to your medical team about your options. If you choose self-management but then would prefer to go onto a more traditional system of follow-up by pre-booked appointments, ask your medical team about this.

How can I cope emotionally with supported self-management?

Your medical team should offer support with **your emotional wellbeing** throughout self-management follow-up. 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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