

Self-management and remote monitoring

More and more people are living longer after a diagnosis of lymphoma. This has prompted some hospitals to change the way they organise long-term management and follow-up for people who have finished treatment for lymphoma. This page explains how self-management support and remote monitoring may be used for people who have finished treatment for lymphoma.

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Self-management

Most of the time, people make their own decisions about their health and wellbeing. When you have a long-term illness like lymphoma, it can feel as though many of those decisions are taken away from you.

Self-management involves taking control of your own health and wellbeing, even if you have a long-term condition. As well as your physical health, it includes taking an active role in managing your **diet**, **exercise** and **emotional wellbeing**.

Self-management is encouraged throughout your lymphoma care pathway, from diagnosis to treatment and beyond. It may become more formalised as you finish treatment and are offered the **recovery package**.

When you have a long-term illness like lymphoma, managing your own health can be daunting. This is why hospitals are developing self-management support pathways, which involve a combination of:

- personal **support** for you
 - **remote monitoring** of your health.
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Self-management support

Self-management support is a pathway that helps you develop the knowledge, confidence and skills you need to manage the physical, emotional and social impact of your lymphoma. It supports you to take an active role in your long-term care and to participate in health decisions with your medical team.

Self-management support is tailored to your individual needs. It aims to help you recognise and develop your own strengths and abilities so you can live an independent and meaningful life.

Although self-management support aims to put you in control, it's important to remember that you are **fully supported** by your lymphoma team throughout. Help and advice is always available if you need it. It is used together with **remote monitoring** to make sure you remain healthy.

Self-management support may also be called 'supported self-management'.

Why is self-management support used?

Self-management has a number of benefits for people with long-term conditions, such as lymphoma.

- It helps you achieve what's important to you.
 - It can increase your self-confidence.
 - It enables you to have meaningful discussions with your medical team.
 - It can improve your quality of life.
 - It gives you more sense of control over your life.
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Who is self-management support for?

Self-management support is beneficial for anybody with a long-term health condition. Exactly what it involves depends on your individual needs.

Remember, self-management support does not mean you're on your own –you are supported to make decisions about your health and wellbeing. For people with lymphoma, it is used alongside **remote monitoring** or regular **follow-up** pathways so you can always access your medical team if you need to.

How does self-management support work?

When you finish treatment, you have a needs assessment as part of the **recovery package**. This is usually a simple questionnaire that you fill in either yourself or with a member of your medical team. The needs assessment helps identify your physical, practical, emotional and social needs. Your medical team can use it to create a care and support plan that's specific to you.

You should also be invited to a workshop on how to live healthily after treatment. This includes practical advice on staying fit and active, adjusting to life beyond cancer and coping with long-term effects. It also covers signs and symptoms to look out for and who to contact if you notice them. If you have not attended a wellbeing workshop, many charities offer free, local events, such as our **Live your Life workshops** or **Macmillan's HOPE programme**.

If you are going on a **remote monitoring** scheme, you also have a discussion with a member of your team, or attend a specific workshop, on how the system works and how and when you should contact your lymphoma team to arrange a follow-up appointment.

Remote monitoring

Remote monitoring goes hand-in-hand with self-management. It is a way for your medical team to keep an eye on your health without routinely seeing you face-to-face.

Instead of a traditional **follow-up** schedule where you have regular outpatient appointments with your medical team, remote monitoring involves booking your own follow-up appointments as-and-when you feel you need them – for example:

- if you notice any new or worsening **symptoms**
- if you are worried your lymphoma might have relapsed (come back)
- if you are struggling with long-term or **late effects** of lymphoma or its **treatment**
- if you are finding it hard to cope emotionally.

You might also hear this called 'patient-triggered follow-up'.

Although remote monitoring may seem daunting at first, you are fully supported by your lymphoma team throughout. You are given clear guidance on what to look out for and when to contact your medical team.

Why is remote monitoring used?

Although some people find regular follow-up appointments reassuring, many people feel very anxious in the days and weeks beforehand. Follow-up appointments are also time-consuming, sometimes involving several hours of travelling and waiting around for a short appointment. If you are feeling well, this can seem unnecessary.

Research has shown that if lymphoma **relapses** (comes back), it's usually noticed first by the person with lymphoma. Although it can be upsetting thinking about potential relapse, there is no evidence that regular follow-up appointments prevent relapse, pick-up relapses any earlier, or affect how long you might live.

Remote monitoring avoids the anxiety and inconvenience of regular follow-up and puts you in control – after all, you know what is normal for you and, with support, you will recognise when you need to be seen by your medical team.

Remote monitoring has a number of benefits:

- Any concerns can be dealt with quickly because you request an appointment as soon as you notice issues rather than waiting for a pre-booked appointment.
- You don't have to attend appointments when you feel well.
- You are actively involved in your recovery, which has the potential to improve your quality of life.
- You are less likely to need urgent appointments or emergency hospital admissions because you are better able to monitor and manage your own health needs.
- You get to take back some control over your life.

Remote monitoring may not be the right choice for everyone. You may have particular concerns or issues that make a traditional follow-up schedule more appropriate for you. Your medical team will discuss these with you.

Who is remote monitoring for?

Remote monitoring is suitable for people who are in full or partial **remission** and are at low risk of **relapse**. It is not offered at all hospitals so you may not be eligible even if you fit these criteria. It may not be suitable for you if you have had a **stem cell transplant** or had treatment as part of a **clinical trial**.

If you are worried about remote monitoring, tell your medical team. They can answer any questions you have. They consider your individual circumstances when planning your follow-up care and, in some cases, they may decide you are better suited to a traditional follow-up pathway.

Don't be concerned if you are not offered remote monitoring. There are lots of reasons that it may not be suitable for you. If you are worried, ask your medical team why they have recommended your particular follow-up plan.

How does remote monitoring work?

If you are on remote monitoring, you usually have regular **blood tests** to check your **full blood count**, liver, bone and kidney function, and any signs of inflammation. These are usually done at your GP surgery. Some people might have regular chest **X-rays**. The results should be sent to you and to your GP.

If your test results are normal, you are not given an automatic appointment with your hospital team. You can, however, request one whenever you have any concerns you'd like to discuss.

How long you are on remote monitoring for depends on several factors, including the type of lymphoma you have, your individual circumstances, and the usual practice at your hospital.

Some hospitals offer follow-up appointments on request indefinitely. Others discharge you if you remain well for a specified period, often 5 years. If you are discharged from remote monitoring, your GP becomes your main point of contact for any concerns you have. They can refer you back to your hospital team if necessary.

When to book an appointment

Your medical team will tell you the **signs and symptoms** of **relapse** (lymphoma coming back) or **late effects** to look out for before you start remote monitoring. Although it can be upsetting thinking about potential relapse, it is important to know what to look out for and to recognise if you need to book an appointment. Most people become more comfortable with these signs as they get used to being on remote monitoring.

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:

- enlarged lymph nodes lasting more than a week
- drenching night sweats
- unexplained weight loss
- worsening fatigue
- itching
- rashes (if you have a **skin lymphoma**)
- persistent or unexplained pain
- any new symptoms in any part of your body that last for more than 2 weeks
- any new or worsening **side effects**, possible side effects or **late effects** of your treatment
- difficulty coping emotionally or physically
- any other concerns relating to your lymphoma or your treatment (for example, fertility concerns).

Life on self-management and remote monitoring

Self-management gives you back responsibility for your own health. Although this has a lot of benefits, it can also be daunting, especially at first. You might feel anxious that you won't be attending regular appointments any more. It may take a while for your confidence to come back.

Remember that you are **fully supported** by your medical team at all times. They should make sure you have the information, skills and support you need to cope with the physical, social and emotional impact of lymphoma and to adjust to life after treatment. This may be written down in a personalised care plan as part of your **recovery package**. If you don't have one, or if there is anything you don't understand, ask your medical team.

When you are on remote monitoring, you can contact your medical team at any time.

Some people use diaries or apps, such as **Macmillan's organiser**, to track changes in symptoms or emotions. Other people use wearable technology to monitor their activity levels, sleep patterns, heart rate and blood pressure. You may also find it helpful to join a **support group** or an **online forum** where you can connect with other people in a similar situation.

References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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