Active monitoring (before and after treatment)

A guide for adults with:
Chronic leukaemia
Myeloproliferative neoplasms (MPNs)
Myelodysplastic syndromes (MDS)
Myelodysplastic-myeloproliferative neoplasms (MDS/MPN)

Leukaemia Care
YOUR Blood Cancer Charity

About Leukaemia Care

Leukaemia Care is the UK's leading leukaemia charity. We are here for you and your loved ones every step of the way. Here are some of the ways we can help.

Helpline

Contact us for advice, support or someone to talk to.

- Call our freephone helpline on **08088 010 444** (weekdays 9am to 4.30pm)
- Send a WhatsApp message to **07500 068065** (weekdays 9am to 5pm)
- Email support@leukaemiacare.org.uk

Support groups

Connect, share experiences and find comfort from other people who've been affected by leukaemia.

Buddy support

Chat to someone who's had a similar experience to you and understands what you're going through.

Facebook groups

Connect online with other people with leukaemia or their carers in our closed Facebook groups.

Leukaemia counselling service

Access up to six sessions of counselling to help you cope with the emotional impact of leukaemia.

Advocacy and welfare team

Get advice on financial support, housing, employment issues and more.

Cost of living service

Apply for a one-off grant to help with essential living costs.

Will service

Write a free, simple Will so you know what happens to your money, property and belongings when you die.

Information

Find trustworthy, easy-to-understand information online and in print.

Leukaemia Care magazine

Subscribe to our free magazine for inspirational stories, articles and updates.

To access our services or find out more:

- Scan the QR code
- Call **08088 010 444**
- Search ‘support’ at www.leukaemiacare.org.uk

In this booklet

Each chapter in this booklet has a summary at the beginning so you can get a quick overview if you need it. For more information on the different types of blood cancer we mention, see page 45.

There is a lot of information about cancer on the internet. Some of it may not be reliable or up to date. A lot of it may not apply to you. Your haematology team are your best source of information because they know your individual circumstances. If you want to search for information yourself, look for reputable organisations like the NHS or national charities. Check for a quality mark, such as the Patient Information Forum (PIF) tick.

This booklet includes addresses and QR codes that link to webpages for further support. If you cannot access the webpages, please email information@leukaemiacare.org.uk or call 08088 010 444.

Introduction

This booklet is about active monitoring for people with a chronic leukaemia, myeloproliferative neoplasm (MPN), myelodysplastic syndrome (MDS) or myelodysplastic-myeloproliferative neoplasm (MDS/MPN).

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice or guidance from your health professional.

We'd like to thank the expert reviewers and patient contributors who helped us with this information:

- Dr Dima El-Sharkawi, Consultant Haematologist, The Royal Marsden NHS Foundation Trust
- Prof Claire Harrison, Deputy Chief Medical Officer and Professor of Myeloproliferative Neoplasms, Guy's and St Thomas' NHS Foundation Trust
- Janet Hayden, Senior Myeloid Clinical Nurse Specialist, King's College Hospital NHS Foundation Trust
- Lianne Palmer, Clinical Nurse Specialist, CLL, Oxford University Hospitals NHS Foundation Trust
- Lucy Whiteman, Clinical Nurse Specialist, Lymphoma and CLL, The Royal Marsden NHS Foundation Trust
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- Patient reviewers: Chris, Diana, Jane, Joe, Katherine, and Lucy

We'd also like to thank everyone who shared a quotation of their experience of active monitoring.

About active monitoring

Summary

- Active monitoring is a way of monitoring your health when you have a blood cancer that doesn't need immediate treatment.
- It's a safe and common approach when you have a stable or slow-growing, chronic blood cancer that doesn't need treatment straight away.
- It's used when your condition isn't causing major problems, and treatment could do you more harm than good.
- Active monitoring is a partnership between you and your haematology team or GP. You have regular check-ups and you also monitor your symptoms at home.
- You have treatment if or when you need it. You may need treatment soon, after many years, or never.
- You might be on active monitoring when you're first diagnosed. Or you might be on it after a course of successful treatment.
- The main benefit of active monitoring is that you avoid unnecessary treatment and side effects.
- It's also an opportunity to improve your general health and fitness and to do things you've always wanted to do.
- The main challenges of active monitoring can be anxiety and uncertainty.

What is active monitoring?

Some slow-growing or stable types of blood cancer do not need treatment straight away. Some never need treatment. Instead, you might have regular check-ups to monitor your health and how your condition affects you. People call this active monitoring, active surveillance, or watch and wait.

You may be referred to a team of blood specialists (haematology team) in the hospital for active monitoring. Or you may see your GP.

Many people prefer the terms active monitoring or active surveillance. These make it clear that you and your haematology team or GP are actively involved in your care.

Active monitoring is a partnership between you and your haematology team or GP:

- Your haematology team or GP see you for regular check-ups
- You check your symptoms for changes at home

It's a way of making sure you have treatment if or when you need it.

Active monitoring is a safe approach if you have a chronic blood cancer that is under control.

> **"I am very much the glass is half full kind of person. I don't like to use the term 'watch and wait,' I prefer 'watch and live.'"**
>
> Eileen, living with CLL since 2015

Why is active monitoring used?

Active monitoring is a good approach when:

- You have no symptoms or symptoms that are not too troublesome and don't need treatment
- Early treatment could do you more harm than good due to side effects

This often applies to chronic blood cancers. You can live with these conditions, sometimes for a long time, before they might affect you. Early treatment won't improve your outcomes or make you live longer. And it could make your quality of life worse.

Remember you're on active monitoring because your blood cancer is a slow-growing or stable type. It's rare to need treatment urgently for chronic blood cancer.

Why isn't treatment needed straight away?

If you're told you have cancer but don't need treatment immediately, it can feel confusing and upsetting. It probably goes against what you understand about treating cancer. You're often told how important it is to spot cancer early and treat it as soon as possible.

Most people know very little about blood cancer. They don't know that there are many different types of blood cancer with different outcomes. They hear the word cancer and think the worst. You might have felt like this yourself.

Your knowledge of blood cancer might be based on what you've seen on television. If a blood cancer features in a drama or a movie, it's usually an aggressive, fast-growing one that needs treatment now! But not all blood cancers are like this.

It might help to understand more about the main types of blood cancer and how they are managed. Blood cancers can be acute (fast-growing) or chronic (slow-growing). Chronic blood cancers are more common than acute blood cancers:

- About 60 in 100 people with blood cancer have a chronic condition like yours
- The other 40 in 100 people with blood cancer have an acute condition

What's the difference between chronic blood cancer and acute blood cancer?

Chronic blood cancers:

- Are usually slow-growing conditions
- Can be kept under control with current treatments
- May not need treatment for many years or might never need treatment
- Can be actively monitored at a hospital day unit or GP clinic, if treatment is not needed

Acute blood cancers:

- Are usually aggressive, meaning they grow fast
- Can make you seriously ill quickly
- Often need immediate treatment with intensive treatments to cure them
- Often involve a long hospital stay for treatment and recovery

When is active monitoring used?

Active monitoring is used to look after people with chronic blood cancer who are not receiving treatment. It is not used for acute blood cancers.

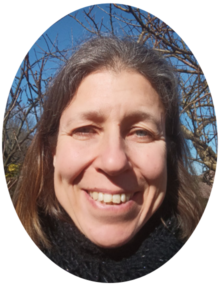
You may be on active monitoring if you have one of the following conditions:

- Chronic lymphocytic leukaemia (CLL)
- Chronic myelomonocytic leukaemia (CMML)
- Essential thrombocythaemia (ET)
- Hairy cell leukaemia (HCL)
- Large granular lymphocytic leukaemia (LGLL)
- Myelodysplastic syndromes (MDS)
- Myelodysplastic-myeloproliferative neoplasm (MDS/MPN)
- Myelofibrosis (MF) and pre-fibrotic MF
- Myeloproliferative neoplasm not otherwise specified (MPN NOS)
- Polycythaemia vera (PV)
- Prolymphocytic leukaemia (PLL)

We have separate information on these conditions. Follow the link, scan the QR code or visit www.leukaemiacare.org.uk and search for your condition.

You might be on active monitoring when you're first diagnosed. You might also go onto active monitoring after a successful course of treatment.

When you're recommended active monitoring, it means you have time on your side.



"I was relieved to be put on active monitoring and didn't need treatment right away for HCL. This helped me to get used to this new condition that I was suddenly diagnosed with."

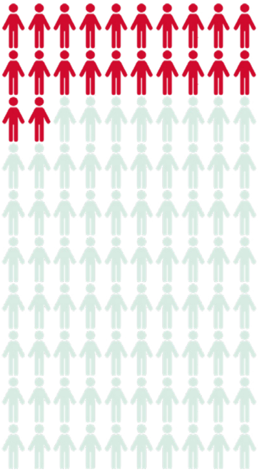
Diana, living with HCL since 2023

You may also have periods of monitoring in between treatments if you have chronic myeloid leukaemia (CML). In CML, this is called treatment-free remission rather than active monitoring.

We have separate information on treatment-free remission in CML. Follow the link, scan the QR code or visit www.leukaemiacare.org.uk and search for 'treatment-free remission'.

How common is active monitoring?

You are not alone! In the UK, about 27,000 people with blood cancer are on active monitoring.



Active monitoring is a common approach for people living with a slow-growing or stable blood cancer.

About 22 in every 100 people with chronic blood cancer are on active monitoring.

You might be interested to know that active monitoring is used for other cancers too, including prostate cancer and some forms of kidney and breast cancer.

Myths and misconceptions

You might hear other reasons for using active monitoring that are not true.

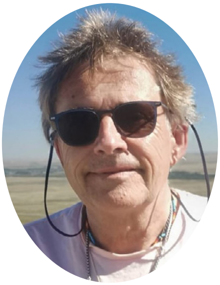
Active monitoring is:

- **Not** used to save the NHS money
- **Not** used because there is no treatment
- **Not** used because it's not worth treating you for some reason
- **Not** used because you're too old for treatment
- **Not** used because of a "postcode lottery" for treatment in your area

What are the benefits of active monitoring?

Active monitoring can have many benefits:

- You can avoid treatment until your test results or symptoms show you need it.
- You can delay treatment until it will have the most positive impact on your condition.
- You avoid unnecessary treatment for your condition. Some people never need treatment.
- You avoid or delay side effects of treatment, which might affect your quality of life in the short or long term.
- You have the chance to improve your general health, which may help you feel better. It can also help you prepare for treatment, if or when you need it (see page 43).
- You might find there are new treatments available by the time you need them.
- You may have fewer hospital appointments and check-ups in the long run.
- You have time to fulfil life ambitions you might otherwise put off, such as travel or study.



"Use it as a wake-up call to do all the things you said you would do. Spring clean your life. Little things don't matter anymore. Concentrate on what you like and who you love. It is not the end. It is the beginning."

Steve, living with CLL since 2011

What are the challenges of active monitoring?

The main challenges of active monitoring can be:

- Coping with anxiety and uncertainty
- Coming to terms with having cancer but not being treated immediately
- Understanding the approach

Some people find it hard to get on with their lives. Not because of their condition but because of how they feel emotionally. See page 36 for information on living well while on active monitoring.

> **"Give equal time to finding ways to manage your mental health and wellbeing. Many support services offer counselling and talking therapies while you're on active monitoring. Seek them out if worries are invading your thoughts or causing you distress."**
>
> Dr Scott Marshall, Haematology Consultant

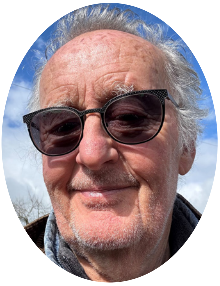
How long does active monitoring last?

It's hard to predict how long you might be on active monitoring:

- Some people need to start treatment quite soon
- Some are on active monitoring for months, years or even decades
- Some people stay on active monitoring forever and never need treatment

Some people have several periods of active monitoring in between treatments during their illness. While their condition is under control (in remission) they can get on with their lives.

Modern targeted treatments are becoming better at keeping some conditions under control. This can mean longer periods of remission in between treatments.



"The more informed you are about your blood cancer the better. You'll be more able to have an informed discussion and to shape the best decisions for you."

Joe Kuipers, living with MDS since 2016

Are there alternatives to active monitoring?

Your haematology team will discuss other options with you. These might vary depending on which condition you have. They will listen to your concerns and preferences and share any decision-making with you.

New treatments for chronic blood cancers are being approved every year. Research continues to explore whether treatment should start soon after diagnosis. Or whether it’s better to delay.

> **"Keep up to date with the latest advice for your condition. Ask at your appointments if there’s anything new or join an online support group. Leukaemia Care often run webinars with haematologists or clinical nurse specialists as part of their online support groups."**
>
> Professor Claire Harrison, Haematology Consultant and Deputy Chief Medical Officer

Active monitoring check-ups

Summary

- Active monitoring includes regular check-ups to monitor your condition and how you are feeling.
- You might have check-ups with a haematologist, a clinical nurse specialist or a GP.
- A typical appointment will involve a physical examination, general health checks, blood tests and other tests if you need them.
- You'll also have preventative care, such as vaccinations, skin checks, and advice on healthy living.
- The frequency of your check-ups will vary depending on your condition and how it's affecting your health.
- You might have some check-ups by telephone or video call. In this case, the discussion will focus on your test results, symptoms, and advice, such as healthy living and sun safety.

Active monitoring check-ups

You will have regular check-ups with your haematology team or GP as part of active monitoring.

They will look for signs that you may need to start treatment. Your haematologist, clinical nurse specialist, or GP will monitor your signs and symptoms. They'll also do tests to see if your condition is stable or progressing.

A typical appointment may include

- Discussion about how you've been feeling. Whether you've noticed any new symptoms since your last check-up.
- Physical examination to check for new signs, such as enlarged lymph nodes, spleen or liver.
- General health checks, such as temperature, blood pressure, and pulse.
- A weight check because it's important to keep yourself fit and healthy.
- Blood tests to check your blood cell counts and your liver and kidney health.
- Other tests depending on your condition, such as occasional bone marrow tests or CT scans.
- Advice on sun safety and checks for skin changes, such as new moles.
- Preventative measures, such as vaccination and vitamin and mineral supplements.
- Treatment for infections.
- Advice on how to live a healthy lifestyle while on active monitoring (see page 43).

> **"I strongly advise people on active monitoring to be proactive. Take good care of their general health, watch their weight, exercise, don't smoke, monitor their blood pressure and cholesterol – this also reduces their risk of blood clots including stroke and heart disease."**
>
> Professor Claire Harrison, Haematology Consultant and Deputy Chief Medical Officer

Your diagnosis and your individual case will influence how often you have your check-ups, where you have them and exactly what happens at each appointment.

Tips to help you get the most from your appointment

- It can help to take a family member or friend with you for support.
- Ask any questions you have – write them down beforehand. If you don't understand something, ask your haematology team or GP to explain. They will be used to this.
- You can take notes on your phone or on paper during your check-up to help you remember. Or you can ask your doctor or nurse to make notes or ask if they are happy for you to record the conversation.
- Be open and honest when discussing your symptoms and how you are coping. You and your haematology team are working together to keep you well.
- You might like to keep track of your blood test results and look them up before your appointments.

You might be able to access your test results through the NHS app. Scan the QR code or visit www.nhs.uk and search for 'view your test results'.

Frequently asked questions

How often will I have check-ups?

This depends on the type of blood cancer you have, and how it is affecting you.

- When you're newly diagnosed, you may have more frequent check-ups. You might start with appointments every 2 to 3 months.
- If your condition is stable, you might have regular check-ups once or twice a year. This may happen from the start or after a period of more frequent monitoring.
- After successful treatment, you might have more frequent check-ups at first. Then have regular check-ups once or twice a year.

If there are signs of your blood cancer changing or progressing, you'll have more frequent appointments.

"I had many years of 3-monthly appointments with very stable blood test results. I decided it was less stressful for me to have fewer check-ups and opted for 6-monthly appointments. This has worked really well."

Chris, living with CMML since 2008

Where will I have my check-ups?

This depends on the type of blood cancer you have and local services.

- At first, you usually have your check-ups at a hospital haematology clinic with your haematologist or clinical nurse specialist.
- You might carry on having your check-ups at the hospital clinic.
- Or, if your symptoms and blood test results are stable, you might be transferred to a named GP for further appointments or to telephone or video call appointments.
- If there are signs that your condition is changing or progressing, you'll be referred to the hospital again.

Will I see the same doctor or nurse at each appointment?

You might do. It depends on where and how you have your appointments and how frequently you need to be seen. You may not see the same haematologist or clinical nurse specialist each time if you attend a big haematology centre.

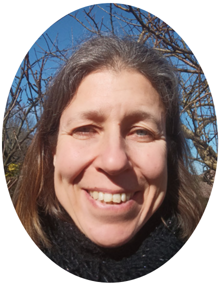
What's it like to attend a check-up?

It's natural to feel a bit anxious before a check-up. You might worry that you'll hear your condition has progressed and needs treatment. But you'll probably notice you're starting to feel less well before you need to start treatment. So you usually have some warning.

If you feel unwell between appointments don't wait until your next check-up. Contact your haematology team or GP (see page 27).

You'll get used to the practicalities of where to go and how your clinic is set up. If you attend a busy haematology clinic, you may have to wait between having your blood taken and seeing your haematologist or clinical nurse specialist. It's best to have something with you to help pass the time like a book or a podcast on your phone.

In some settings, you may be able to have your blood tests done before your appointment. This can save time, as your results will be in your notes ready to review either in person, over the phone or by video call.



"Being on active monitoring with regular blood tests has helped in the diagnosis of other health conditions."

Diana, living with HCL since 2023

Questions about your appointments

- How often will I have check-ups?
- Where will I have check-ups?
- What tests will I need?
- What might these tests show?
- How long will it take to get the results back?
- Where can I get help dealing with my feelings?

Monitoring your symptoms

Summary

- Your role in active monitoring is to watch for changes to your symptoms.
- Your haematology team or GP will tell you which symptoms to monitor and how to record them.
- They might include symptoms like extreme tiredness, unusual bleeding or bruising, or frequent infections.
- You might record your symptoms using a paper diary, notebook or an app.
- You usually record new or changing symptoms and how they are affecting you.
- It's best to try to get on with your life without having symptoms on your mind all the time.
- Your haematology team or GP will tell you what symptoms need urgent attention and what can wait until your next check-up.

Monitoring your symptoms

You have an important part to play in active monitoring by looking out for changes to your symptoms. You should note changes to your existing symptoms or any new symptoms you get.

You are an expert on your body and how you usually feel. This makes you the best person to check your symptoms over time.

Your haematology team or GP can explain which symptoms are key to your condition, how to record them and when to seek help.

You should be given a list of symptoms to look out for. You might want to keep a copy of this list somewhere handy to refer to.

"I take pride in knowing my own body. I might look okay on paper, but how I actually feel might be a completely different story."

Andrea, living with PV since 2011

What symptoms should you monitor?

The key symptoms to monitor depend on your diagnosis. They often include:

- Extreme tiredness
- Unusual bleeding or bruising
- Frequent or long-lasting infections
- Unexplained fever
- Losing weight without trying to
- Swollen glands
- Breathlessness
- Feeling generally unwell
- Night sweats
- Losing your appetite
- Feeling full quickly when you eat
- Pressure or bloating in your tummy
- Itchy skin
- Joint or bone pain

How to monitor your symptoms

You can keep a symptom diary using a paper diary or notebook. Or there may be an app available to help you record your condition. It's best to make a note when you notice a change in your symptoms.

You need to be able to get on with your life without thinking about your symptoms all the time. Some people find it tricky to strike a healthy balance.

You should record:

- Symptoms that are new or changing, particularly if they're getting worse
- How your symptoms are affecting your daily life

You can tell your haematology team or GP at your next appointment or sooner, if you need to.

Symptom diary apps

There are several apps available to help you record your symptoms. They are usually designed to work on a smartphone or tablet and are usually free. They include:

- CLL & Me
- CLL Manager
- MDS Manager
- My MPN Voice

Ask your haematology team if they recommend an app for you. Or search for an app that's relevant to your condition.

When to seek help

Your haematology team or GP will tell you which symptoms or changes:

- Should prompt you to seek urgent medical help
- Can wait until your next appointment

If you're unsure how to check your symptoms or which ones are most important, contact them for advice.

If you're worried about your health or become concerned about new or worsening symptoms at any time, contact your GP or haematology team. You don't have to wait until your next check-up.

Questions to ask your haematology team

- How should I monitor my symptoms?
- Which symptoms are most important to look out for?
- Who should I contact if I'm worried about my symptoms?

"Information, support and help has come a long way since I was first diagnosed with large granular lympocytic leukaemia."

Katherine, living with LGLL since 2007

Starting treatment

Summary

- Over time you might develop signs or symptoms that signal you need to start treatment.
- You might have signs that your condition is progressing from tests, checks or scans at your appointments.
- Your symptoms might also be causing you problems or affecting your daily life.
- Your haematology team will involve you in deciding next steps.
- You might have more frequent check-ups at first.
- You and your haematology team will discuss different treatment options before making a treatment plan.
- You usually start treatment when the benefits of treatment outweigh the risks.
- You may also start treatment when a new medicine becomes available.
- It’s normal to have a mix of emotions if, or when, you need to start treatment. These might include shock, relief and anxiety.

Starting treatment

At some point in the future, you might have signs or symptoms that signal you need to start treatment. If or when you reach this point, you and your haematology team will make a plan of action together.

Treatment for chronic blood cancer usually aims to get your condition under control rather than to cure it.

Remember, with some chronic blood cancers:

- You may not need treatment for a long time, or you might never need treatment
- You may need several different treatments throughout your illness and have periods of remission in between

"The confidence to push back or ask questions doesn't always come naturally or quickly; it takes time to build. But when you do, you know you're advocating for your best care, and it's empowering to be able to do that."

Andrea, living with PV since 2011

What prompts starting treatment?

Your haematology team might suggest you start treatment soon if:

- Your blood tests show your blood counts have got worse
- Your symptoms or test results suggest your condition is progressing or becoming more aggressive
- Your blood tests or scans show your major organs are being affected
- You're starting to get troublesome symptoms like night sweats, unexplained fever or unexplained bleeding (see page 24)
- Symptoms like fatigue are affecting your daily life

If you have signs and symptoms like these, your haematology team will involve you in deciding what happens next.

At first, they might recommend more regular check-ups to keep a closer eye on what's happening.

In general, they'll recommend you start treatment when your condition impacts your health or daily life more than the treatment is likely to.

Treatment options

Different conditions have different treatment options. Your haematology team will discuss your treatment options with you. By the time you need them, they might differ from what's available now.

Your haematology team may suggest starting treatment when a new treatment becomes available.

We have separate information on leukaemia, MPNs and MDS and their treatment. Scan the QR code or visit www.leukaemiacare.org.uk and search for your condition.

"Treatments have changed drastically and improved so much over the years. I'm certainly proof that you can survive HCL and live life to the full."

David, living with HCL since 2003

Preparing to start treatment

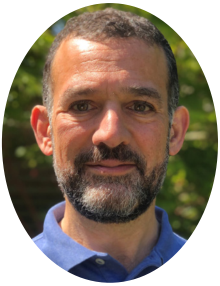
You might have a mix of emotions if you need to start treatment. You might feel shocked, relieved, upset, anxious or fearful. Everyone reacts differently and you might feel different things at different times. There is no right or wrong way to feel.

If you'd like to talk to someone who understands what you're going through:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

If you have enough time before your treatment starts, you might want to do some preparation. You might find it helpful to:

- Improve your general health and fitness, where possible and if you feel well enough (see page 43).
- Tell your employer, or clients if self-employed, that you are about to start treatment.
- Plan for time off work or study, or reduce your workload, if needed.
- Tell friends and family, if you want to.
- Get a support network in place, such as friends and family who can give you emotional or practical support.
- Explore other avenues of support. Your Haematology Team or GP may be able to refer you for counselling.



"Friends and family really come together and the medical teams are amazing. There is lots of support out there, with people providing advice to make life so much better."

James, living with MF since 2023

Questions to ask your haematology team

- What treatment do you recommend?
- Is there a clinical trial suitable for me to join?
- What are the success rates of available treatments?
- Where do I have my treatment?
- How do I have it?
- How long will I need to have it for?
- How often will I have check-ups while I'm on treatment?
- What side effects should I look out for and how long will they last?
- When should I seek help for side effects?
- Who should I contact if side effects make me very unwell?
- Can I continue working or should I have time off?

Living well on active monitoring

Summary

- You may experience a range of emotions while on active monitoring. There is no right or wrong way to feel.
- Some people feel anxious, uncertain and fearful about their situation. You might need to find coping strategies and ways of supporting your mental health.
- Some people find active monitoring brings them a sense of relief, a chance to change their priorities and to feel cherished.
- You might want to tell people you're on active monitoring. Remember, if or when you tell people is your choice.
- You might experience fatigue. Pacing yourself and saving your energy for things that are important to you can help.
- If you work or are in education, you might need adjustments or support to help you continue work or study.
- It's important to look after yourself. Try to follow a healthy lifestyle, attend your medical appointments and enjoy life.
- You can also improve your health and fitness as 'prehabilitation' in case you need treatment in the future.

Living well on active monitoring

Everyone is different in their response to being on active monitoring and how they cope with it. Some people adapt well, while others find it harder to come to terms with.

One of the hardest parts of active monitoring can be living with uncertainty. No one can tell you exactly when or whether you'll need treatment or what the outcomes might be. You cannot control this aspect of your life, but there are other parts of your life that you do have influence over.

You may find some information and advice in this chapter that suits you and is useful. There might be other parts that are less useful that you might ignore. Over time, your feelings might change depending on what's happening with your condition and how it affects your life.

"When my symptoms let me, I love gardening, reading, watching films, writing, drawing, catching up with my friends, cooking, and (slowly) walking the dog. My job now is to remain as well as I can. I am more than just surviving with this cancer. I am living with it in the best way that I can, and I'm so grateful for what I have."

Lucy, living with MF since 2020

Feelings, emotions and coping

It's common for people to feel anxious, fearful, and sometimes distressed, while they're on active monitoring. You have to live with uncertainty in your life due to your condition. Some people find this very difficult. You might find coping with your feelings and emotions the hardest part of being on active monitoring.

You may feel:

- Helpless and out of control
- Sadness, depression and anxiety
- Relief at getting a diagnosis while avoiding treatment side effects
- Worry about other people's reactions
- Isolation and that other people don't understand what you're going through
- Acceptance that active monitoring is the right approach for you
- Frustration about not knowing what will happen
- Like an imposter because you're not unwell or receiving treatment
- Your life priorities changing in a good way
- Like you're shifting between feelings of wellness and illness all the time
- A new lease of life
- More cherished and valued by your loved ones

Everybody reacts in their own way. You may experience some of these feelings but not others. You might have different emotions at different times. There is no right or wrong way to feel.

Tips to help with anxiety and uncertainty

- Avoid dwelling on things you can't change or control. Focus instead on things you can do to help you to feel better.
- Try using relaxation exercises, such as guided meditations or calming breathing exercises.
- Use exercise as therapy. Walking, running, swimming and yoga can all help you relax and feel calmer.
- Eat healthy meals regularly to keep your energy up and to boost your mental health.
- Try to keep to a regular sleep schedule.
- Talk about how you're feeling to friends, family or to other people with chronic blood cancer by using our support services.
- Remember you are not alone.

The NHS has more tips for coping with anxiety. Scan the QR code for details or search for 'anxiety and fear' at www.nhs.uk

"I believe in staying positive and take each day as it comes with a relaxed yet positive attitude which has certainly helped me through the difficult times."

Peter, living with HCL since 1989

Although it can take time, many people adapt well to living on active monitoring. They find a way to live with the uncertainty and unpredictability of their situation. You might find the more you understand active monitoring, the easier it gets.

You are not alone

Sometimes you need to talk to someone who really understands what you're going through. Our peer support groups, Facebook groups, and buddy service can connect you with people who've been there too. If you'd like to talk to someone who has the same condition or a similar condition as you:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

"I would recommend the buddy scheme to anybody who needs someone to talk to. You need someone who understands what you're going through and all of the silly little things that go along with it. Just to say to somebody, 'Yes, I know what you mean."'

Margaret, living with ET since 2002

Telling other people

You may need time to adjust to active monitoring before you tell other people about it. It's up to you who you tell and how much you tell them.

You might come across some misconceptions when you tell people. You might hear people say things like 'You can't have cancer if it doesn't need treating straight away' (see page 15 for more myths and misconceptions). You might find this lack of understanding makes telling people difficult.

You might wait to tell people until your symptoms start to impact your life or you need treatment. It's a tricky balance as you might feel isolated and unsupported if you don't tell some people. And friends and family might feel shocked and unprepared if your condition worsens.

"I decided to tell other people – family, friends, people at work and in my choir. I needed their understanding and support because of my vulnerability to infections. I felt safer knowing they knew they should avoid me if they had any signs of infection."

Chris, living with CMML since 2008

In conversations, you might want to:

- Explain you have a chronic blood cancer that is slow-growing or stable.
- Tell them it does not need treatment straight away.
- Tell them the symptoms you might get and how they might affect you.
- Explain you will have regular check-ups to see if your condition is stable or progressing.
- Explain that treatment is available when you need it but there is no way of telling when you might need it.
- Be open and honest about how you feel. People will usually want to help you as best as they can.
- Have a print-out or factsheet handy so you don't have to remember everything. Or you could use this booklet.

Everyday life

It's common for people on active monitoring to have fatigue. This feeling of extreme tiredness or lack of energy can interfere with your usual activities. You may find you have to make changes to your life and how you do things.

Tell your haematology team or GP if you are experiencing fatigue. They may be able to suggest things to help or refer you for support if you need it.

Tips for coping with fatigue

Plan activities and pace yourself:

- Prioritise things that are important to you and save energy for these
- Accept help where you can

Balance rest and exercise:

- Take regular, gentle exercise
- Rest when you need to
- Try yoga or meditation as these can help

Keep to a regular sleep schedule:

- Try to go to bed and wake up at around the same time each day
- Keep your bedroom quiet and at a comfortable temperature
- Avoid eating or drinking alcohol, coffee, tea, or chocolate before bedtime
- Avoid using laptops, tablets, or smartphones before going to bed

"Always listen to your body and adapt accordingly. I'm a positive person and determined to enjoy life to the full. But recognise there are some days when I've just got to rest."

Katherine, living with LGLL since 2007

Work and education

If your condition affects your work, your doctor can write a letter to your employer to confirm your diagnosis. This can help your employer make adjustments to help you continue working.

If you are at school or university, you should tell them if your condition is making it hard to study. They might be able to offer you extra support, pause your studies, or defer your attendance for a while if you need it.

"I made the decision to let colleagues at work know about my situation. The concept of 'watch and wait' is the hardest part to explain. Work was very supportive and offered me a permanent contract with reduced hours, which better suited my needs."

Anton, living with CLL since 2016

Life on active monitoring may also affect your finances if you have to change your hours or take time off from work.

Charities and financial support

We have a range of services that can help you, including a welfare service and cost of living hub. Follow the link, scan the QR code or search for 'support for you' at leukaemiacare.org.uk

Macmillan have information on benefits and financial support. Follow the link, scan the QR code or search for 'benefits and financial support' on www.macmillan.org.uk. Or contact them on **0808 808 0000** to discuss your eligibility for benefits, grants and support available.

Looking after yourself

It's important to look after yourself while you're on active monitoring. Living healthily has many benefits besides improving the quality of your life.

You might find it helps you:

- Manage fatigue
- Cope with the emotional side of living with your condition
- Prepare for treatment, if or when you need it (prehabilitation)
- Feel empowered, as it's something within your control

What is prehabilitation?

Prehabilitation or prehab is a way of getting ready for treatment before it starts. Your time on active monitoring is an opportunity to improve your general health in readiness. This will benefit you while you're on active monitoring and might improve your outcomes from treatment, if or when you need it.

You might want to:

- Manage your weight through healthy eating and exercise
- Stop smoking and cut back on alcohol
- Look after your mental wellbeing

The NHS has information and guidance on living well, which includes exercise, eating well, and many other ways to take care of yourself. Scan the QR code, or go to the 'live well' section at www.nhs.uk

"I'd put on a lot of weight. But having my brush with HCL, I decided I'd be crazy to mess it up myself. So, I adopted a healthier lifestyle and, through diet and exercise, I lost 12 stone. I kept the weight off and decided to take early retirement to enjoy life to the full!"

David, living with HCL since 2003

You should go to your medical appointments, including those for screening tests and recommended vaccinations. You may feel anxious before your appointments, which is understandable. But most people find it reassuring when they attend their check-ups.

In between your appointments, you might like to focus on things you enjoy and that make you happy. You could take up a new hobby, spend time with family or friends or plan some travel.

If you want to travel abroad, ask your haematology team for advice on travel vaccinations, insurance and other precautions.

Our advocacy officer and nurse advisors can also offer information and support to help you travel safely and well:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

Words you might see or hear

Bone marrow test: a test to take a sample of the spongy tissue from the centre of a bone, usually your pelvis.

Chronic lymphocytic leukaemia (CLL): a slow-growing type of blood cancer that affects blood cells called lymphocytes.

Chronic myeloid leukaemia (CML): a slow-growing type of blood cancer that starts in blood-forming cells called myeloid stem cells.

Chronic myelomonocytic leukaemia (CMML): a rare type of blood cancer that affects blood cells called monocytes.

Clinical trials: research studies that aim to find out what treatments work best for particular conditions.

CT scan: a scan that uses X-rays and a computer to make detailed pictures of the inside of your body.

Essential thrombocythaemia (ET): a type of myeloproliferative neoplasm where your body makes too many platelets.

Haematologist: a doctor who specialises in diseases of the blood.

Haematology: the branch of medicine that deals with diseases of the blood.

Hairy cell leukaemia (HCL): a very rare slow-growing type of blood cancer that affects blood cells called lymphocytes. When you look at them under a microscope, the cells look hairy.

Large granular lymphocytic leukaemia (LGLL): a rare slow-growing type of blood cancer that affects white blood cells called lymphocytes. When you look at them under a microscope, the cells are larger than usual and contain granules.

Leukaemia: a group of cancers that usually start in the bone marrow and lead to high numbers of abnormal blood cells.

Lymphocyte: a type of white blood cell that helps fight infections.

Myelodysplastic syndromes (MDS): a type of cancer where your bone marrow produces immature, abnormal blood cells that do not work properly.

Myelodysplastic-myeloproliferative neoplasm (MDS/MPN): blood cancers that have features of both a myelodysplastic syndrome (MDS) and a myeloproliferative neoplasm (MPN).

Myelofibrosis (MF): a type of cancer where your bone marrow becomes filled with scar tissue, which stops it making enough healthy blood cells.

Myeloproliferative neoplasms (MPN): blood cancers that develop when cells in your bone marrow grow out of control and make too many blood cells.

Myeloproliferative neoplasm not otherwise specified (MPN NOS): a myeloproliferative neoplasm (MPN) that is not a particular type.

Polycythaemia vera (PV): a type of cancer where your bone marrow makes too many red blood cells.

Pre-fibrotic myelofibrosis (pre-fibrotic MF): early stage myelofibrosis before your bone marrow becomes scarred.

Prehabilitation (prehab): a way of getting ready for treatment before it starts by improving your general health.

Prolymphocytic leukaemia (PLL): a very rare type of blood cancer that affects immature white blood cells called prolymphocytes.

Prostate cancer: a common cancer in men that starts in the prostate gland. This is a walnut-sized gland at the base of the bladder.

Remission: when tests or scans after treatment can find little or no cancer left in your body.

Targeted treatments: medicines designed to block specific proteins on cancer cells.

Useful contacts and further support

Coping while on active monitoring can be a challenge. You may need support from:

- Your healthcare team
- Family and friends
- Leukaemia Care
- Other charities

Here are some organisations you might find helpful.

Leukaemia Care
Helpline: **08088 010 444** (Monday to Friday, 9am to 4:30pm)
WhatsApp: **07500 068065** (Monday to Friday, 9am to 5pm)
www.leukaemiacare.org.uk
support@leukaemiacare.org.uk

Blood Cancer UK
Leading charity into the research of blood cancers.
0808 2080 888
bloodcancer.org.uk

Cancer Research UK
Leading charity dedicated to cancer research.
0808 800 4040
www.cancerresearchuk.org

Macmillan

Provide free practical, medical and financial support for people facing cancer.

0808 808 00 00

www.macmillan.org.uk

Maggie's

Offer free practical, emotional and social support to people with cancer and their loved ones.

0300 123 1801

www.maggies.org

Carers UK

Offer advice, information and support for carers.

0808 808 7777

www.carersuk.org

Citizens Advice

Offer advice on benefits and financial assistance.

0800 144 8848 (England)

0800 702 2020 (Wales)

0800 028 1456 (Scotland)

www.citizensadvice.org.uk

The Citizens Advice service does not cover Northern Ireland but their website lists contact details for local community advice agencies, depending on where you live.

How you can help us

Share your story

If you're on active monitoring, sharing your story can help others in a similar situation. It can also help people understand it better.

To share your story:

- Go to www.leukaemiacare.org.uk/share-your-story
- Scan the QR code
- Email communications@leukaemiacare.org.uk

Volunteer with us

Volunteering can help you develop life skills, find a sense of purpose, and make a difference to other people. There are lots of ways to get involved, depending on how much time you have to give – and we'll be there to provide the support you need. You could:

- Become a Buddy to help someone going through a similar experience
- Join our patient panel to help us shape what we offer

To find out more, email volunteering@leukaemiacare.org.uk

Tell us what you think of this booklet

Please follow the link or scan the QR code to complete a short survey to let us know how we can improve our information. Or get in touch by email, phone or post.

- Email information@leukaemiacare.org.uk
- Call our Head Office on **08088 010 444**
- Write to us at Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG

You can also contact us for a list of the sources we used.

If we’ve helped you - here’s how you can give back

We are here for people with leukaemia and their families, purely because of public support and generosity – kind people like you.

You can help

- Fancy the chance to win £25,000? Join our weekly lottery from as little as £1 a week.
- Organise your own event. You could host a quiz night or bake sale with friends, at work or school.
- Does your employer make charitable grants or donations to good causes?
- Ask your society, group or sports club about their charity of the year partner.
- Prefer to get outdoors? Take on one of our challenges of varying levels. Walk, run or for the more adventurous, a skydive?

No fuss options

- Make a one-off donation.
- Sign up for monthly donations.
- Or simply spread the word. Raising awareness of Leukaemia Care with your family and contacts is invaluable.

Contact our fundraising team

- Scan the QR code
- Email fundraising@leukaemiacare.org.uk
- Call **08088 010 444**

Plenty of ways to give

There are so many ways you can give to help support people affected by leukaemia. Find one that fits you!

By bank transfer

You can transfer your donation straight from your account to ours:

- Account name: **Leukaemia Care**
- Sort code: **20-98-61**
- Account number: **80823805**

By cheque

Please make your cheque payable to **Leukaemia Care** and pop it in the post to: Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG.

Online

Simply visit www.leukaemiacare.org.uk/donate or scan the QR code to donate.

By phone

You can call us on **08088 010 444** to donate by debit or credit card over the phone.

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Every year, 10,000 people are diagnosed with leukaemia in the UK. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

- Call our freephone Helpline: **08088 010 444** (weekdays 9am to 4.30pm)
- Send us a WhatsApp message: **07500 068065** (weekdays 9am to 5pm)
- **www.leukaemiacare.org.uk**
- **support@leukaemiacare.org.uk**

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

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Leukaemia Care
YOUR Blood Cancer Charity

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