

myCLLlife: My role in active monitoring and preparing for treatment discussions

Introduction

This guide aims to help people living with chronic lymphocytic leukaemia (CLL) prepare for treatment discussions during active monitoring (also known as ‘watch and wait’). Some information may also be helpful for care partners, family members and friends. Additionally, individuals living with small lymphocytic lymphoma (SLL) may also find this guide useful.

The guide has been designed so it can be used in a few different ways, depending on where you are in your CLL journey. You can choose to start at the beginning and work your way through or choose one of the three sections below.



**Taking care
of yourself
during active
monitoring**

**Considering
your treatment
goals**

**Deciding on
treatment with
your doctor**

You will find information and practical tools to help you prepare for discussions with your healthcare team (doctors, consultant haematologists, clinical nurse specialists, specialists from cancer organisations).

A group of people living with CLL shared their lived experiences and perspectives to help inform the content. Look out for their top tips, anecdotes and quotes throughout.

It is important to work with your healthcare team and make decisions about your care together. Dr Dima El-Sharkawi, consultant haematologist at The Royal Marsden NHS Foundation Trust, UK, provides her perspective on interactions with her patients and explains what healthcare professionals are considering at each stage of the CLL journey.

Remember, everyone’s experience of CLL is different and there is no ‘normal’. This guide aims to help you manage some of the questions or feelings you may have, but for any more information or advice on specific treatments, always speak to your healthcare team.

Foreword:



A letter from people living with CLL

From our own experiences, we know that living with CLL can often feel like an emotional rollercoaster. As you may not need treatment straight away, your healthcare team may recommend active monitoring, also known as ‘watch and wait’. For a lot of us, finding out that you have cancer and not immediately receiving treatment can be unsettling and feels counterintuitive.

During this time, learning about CLL and hearing from others who have gone through a similar experience can help you and your family or friends to improve your understanding of the condition and make you feel more settled.

A group of us came together to discuss our CLL experiences. We shared the things that helped us most as we prepared for treatment and what we wished we’d known along the way. This guide brings together our insights to help others along each step of the way.

To begin with, we’ve found that during active monitoring, there are certain things you can do to feel more in control. This can include knowing the signs and symptoms to look out for as your CLL progresses and taking care of your physical and mental health.

Fortunately, CLL research and available treatments are advancing, meaning that there may be numerous options for you and your healthcare team to discuss. For some of us, educating ourselves on the treatments available and thinking through our personal goals and factors to consider helped us feel ready to manage our expectations and the experience of treatment.

Finally, we know all too well how easy it is to forget what you were going to ask during healthcare appointments. That’s why we suggest taking the time to prepare for discussions in order to get the most out of them. Building an open and trusting relationship with your healthcare team is important. When considering treatment options, you can confidently make the decision together.

We hope that by engaging with this guide and completing the exercises, you will feel more knowledgeable and prepared, so that when the time for comes for you to start treatment, you and your healthcare team can make an informed choice.

We wish you well,

Bethan

CLL discussion group participant

David

CLL discussion group participant

Marc

CLL discussion group participant

Norah

CLL discussion group participant

Rebecca

CLL discussion group participant

Hilary Lindsay

Chair, CLL Support Association



Taking care of yourself during active monitoring

Not everyone diagnosed with CLL will need treatment. No matter how long or short the active monitoring period lasts for you, there are certain steps you can take to be physically and emotionally prepared so that you're ready when the time for treatment approaches.

How to prepare for treatment during active monitoring



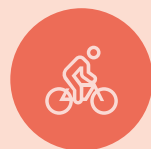
Prehabilitation

('prehab' or 'prehabbing') involves promoting healthy behaviours from the time you are diagnosed until you're ready to start your treatment, during your treatment and beyond.



Prioritising your mental health

Active monitoring can be an uncertain time. Activities that improve your wellbeing, such as talking therapy and mindfulness or yoga, can help alleviate anxiety as you wait to possibly start treatment. Engaging in these practices over time can also build resilience, helping you feel emotionally ready when you do commence treatment.



Looking after your physical health

Exercising and maintaining a healthy diet during active monitoring not only benefits your overall health and energy levels, but also enhances your fitness so you are in the best physical health possible when you start your treatment and aids in your recovery. This doesn't necessarily require joining a gym; activities like walking and gardening are also effective ways to stay active. This effectively integrates the 'active' aspect into 'active monitoring', allowing you to maintain a sense of control.



Building your knowledge

Learning about your condition and hearing from others who have gone through a similar experience can help you to feel more in control. There is a wealth of information out there, so always try to find credible and up to date sources, such as the NHS website and well-established patient advocacy groups and charities and be mindful of misinformation. If in doubt, make sure to check with your healthcare team.



Building the confidence to speak openly with your doctor or healthcare team

Speaking honestly with your doctor or healthcare team while on active monitoring not only helps you better understand your CLL symptoms and get answers to any questions you may have, but it can also strengthen your relationship with them for open communications in the future.



Tracking symptoms and identifying the time for treatment

A key aspect of active monitoring is observing any changes in symptoms that might indicate you are nearing time for treatment. Your doctor or healthcare team can help you with understanding which symptoms to look out for, suggest ways to track these and advise what to do if you notice any changes.



Dr Dima El-Sharkawi: Key things I look for from patients during active monitoring

Small changes can make a big difference

Making small changes to lifestyle and outlook can make a big impact on someone's life and their overall health and wellbeing. In my experience, if people are in a good place physically and emotionally, they're in a better position when the time comes to make treatment decisions.

Where to find advice

First off, I speak to my patients about their diet, exercise habits, whether they smoke or drink alcohol, how they feel mentally and make gentle recommendations to address any habits that could affect their health later down the line.

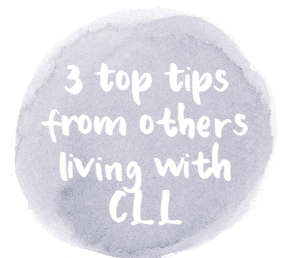
I encourage them to share any particular concerns they have so I can signpost them to the best place or person for advice. I have also found there's a wealth of information provided by reputable patient advocacy groups and charities.

Tracking changes in symptoms

It's important that people build confidence to speak about their health and symptoms and feel they can be as open and honest as possible. While I don't expect my patients to keep track of their blood tests, some like to and that is fine. However, what's more helpful is knowing how to notice changes in symptoms that might inform their care or treatment plans.

Some of my patients keep diaries or trackers for their symptoms, which are great tools to becoming more of an expert in their own health. As CLL is a complex condition in that there's not one single marker to signify when treatment should be started, it's important that patients notice changes in the symptoms they experience over time. I would say what's most helpful to healthcare professionals is for patients to notice any persistent changes and be able to summarise them at their appointments.

Looking back at my 'pre-habbing' experience, I wish I knew that...



1. As much as it's important to exercise, it's just as important to be patient with yourself. Appreciate that the fatigue that comes with CLL may limit you more than before. Try to find something you enjoy, start slowly, and work up to consistently exercising little and often.



2. While educating yourself on CLL can help reduce anxiety, it's also possible to experience 'information overload', especially with so much available online. Read small chunks of information at a time, so you don't feel overwhelmed.



3. Your CLL journey is unique and there is no such thing as 'normal'. Speak to your doctor about key symptoms you should look out for that may indicate you are ready to start treatment.



Considering your treatment goals

During prehab, you may feel well, and the time to start treatment could be months or even years away, or indeed it may never come. Despite this, as there are many factors to think through, it can be helpful to begin building your knowledge. This way, when the time for treatment approaches, you will be informed and ready for discussions with your healthcare team. You are likely to have advance notice that treatment may be required in the future.

Treatment goals are where you identify what you'd like to get from treatment and personal aspirations to work towards. It's okay if you don't yet know what these are, but when you're ready to start thinking about your goals, you can work through the questions in the thought flow tool below.

My lived experience

'CLL is different from lots of other cancers; it is a chronic, long-term condition. You may be on treatment for a large part of your life, so knowing your options can help you to **understand the treatment goals that are important to you.**'



Thought flow tool: Guiding you through treatment considerations

The **thought flow** below will take you through some of the **most common considerations** that people living with CLL may wish to **think about before speaking to their doctor** about treatment.

If you are currently pre-habbing or are getting ready to start or re-start treatment, it may be helpful to **work through the section below** before going to **your next appointment**. This way, you will have a clearer idea of what you want to achieve from treatment, **so you can go into these discussions prepared**.



What are the goals of treatment for me?

You may find yourself with **a list of potential options to explore**. The aim of your treatment will depend on your individual situation, which you will come to **discuss with your healthcare team**.

Your healthcare team will outline the potential treatment options for you and what they involve.

When considering the options, think about what outcomes matter most to you.

What are the currently available options?

Some people find it helpful to **research potential treatment options** as part of 'prehabbing'. Others prefer to wait until nearer to treatment, when there may be other options including potential clinical trials. If you choose to carry out some research, ask yourself the following.

Does this information look credible and up to date? Always look for trusted, reliable sources, e.g., CLL organisations or your healthcare team.

What options are available for CLL?
Remember these will vary depending on your disease stage, any prior treatment, comorbidities, current fitness/health, etc.

Are there any relevant clinical trials in my area?

What questions do I have for my healthcare team?

What about practical considerations?

Often, the **practicalities around treatment** are just as important to consider. Go through the list below and highlight the most relevant to you.

- **What time will I need off work?**
- **How and where will I receive the treatment?**
- **If travel is required, location of treatment centre and travel time or costs**
- **How often and for how long will I need to take medication?**
- **Support that may be required from a partner, friend or carer**
- **Potential treatment side effects**

What is most important to me?

To help you decide on your personal treatment goals, it can be useful to think about your lifestyle, commitments and priorities. Try asking yourself:

What personal commitments do I need to consider?

E.g., work, childcare, other care arrangements.

What activities/hobbies do I value and want to continue doing while on treatment?

E.g., spending time with family and friends, cycling, swimming, walking, travelling.

What are my short- and long-term life priorities both during and after treatment?

E.g., family/friend/life events, retirement, moving abroad, returning to sports/hobbies/travelling.

Now that you've worked through some of the key considerations, why not **note down your answers to each of the above**, as well as a **list of the questions** you have for your doctor and take these along to your next appointment.



Even if you're not ready to start treatment now, these discussions will help you to **prepare for the next step** mentally and emotionally, when the time does come.



Dr Dima El-Sharkawi: My top considerations as patients approach treatment

It's not a quick decision

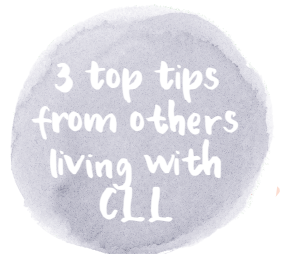
By the time I'm talking about treatment options with patients, I'm seeing them for appointments more frequently. Making the choice to start one treatment over another isn't something that is decided in one appointment, but rather over a series of sessions in the majority of cases.

Everyone is different and people need to feel comfortable to share their goals

Remembering that everyone is an individual is key, as they will likely have personal preferences in terms of treatment goals and lifestyle. Sometimes people feel 'silly' for voicing something that they might think appears trivial about their lifestyle or preferences, such as how far or often they have to travel for appointments during treatment.

But in reality, when healthcare teams have these details, they are able to build a better picture of the individual and help them to make the right treatment decision. It's my job as a healthcare professional to create the right environment in the appointment where patients feel comfortable voicing these preferences so that together we can come to a decision.

Looking back at my experience of choosing treatment, I wish I knew that...



1. Discussing your options with a friend or relative who knows you and your personal needs can be beneficial. Think about if and how you may want to reach out to loved ones about your CLL before starting treatment.



2. Researching treatment options isn't something you have to manage alone. Speaking to others with CLL who have already made these decisions can help you to better understand your options and prepare for what's ahead.



3. At the same time, what's right for someone else, might not be right for you. Consider how each treatment option may impact your own lifestyle and decide what matters most for you.



Deciding on treatment with your doctor or healthcare team

You may have heard about ‘shared decision-making’, where patients and doctors work together to decide on treatment and care. Openly sharing your personal treatment goals with your doctor or healthcare team, will help you work together to decide the most suitable option for you.

Not everyone feels naturally confident about speaking openly with their doctor and taking an active role in discussions with them can sometimes feel daunting. Preparing in advance for interactions can help you build confidence over time, so you feel more comfortable and ready to participate in decision-making.



The benefit of expert guidance

While you should feel encouraged to share your treatment goals during discussions, and you may feel you have an idea of what treatment you would like, you are not alone in making these decisions. Your doctor or healthcare team will provide information and guidance, answer your questions, and will likely have recommendations. Together, you can discuss all the considerations and make a decision that’s most suitable for you.

My lived experience

‘I went to my appointment with a very clear idea of the treatment I wanted. After speaking with my doctor though, **I ultimately changed my mind, and we went for an alternative.**’





Knowing which questions to ask

After working through the thought flow tool on [page 8](#), you may already have some questions for your doctor. Or maybe you're not sure where to start or when to ask your questions.

Having a pre-prepared list of questions with you in your appointments can help structure your discussion and make you feel more informed and confident to actively participate. This can help you to make the most of the time with your doctor or healthcare team.

Here are some examples to get you started.

- What do each of these treatment options do?
- What are the benefits of the options? Why would that be important for me?
- What are the associated risks/side effects?
- How often will I need to take this treatment? How long will it last?
- Will I be able to continue my daily activities (e.g., working/hobbies/activity)?
- Is there a clinical trial I may be eligible for?
- Can I change my mind after I start treatment?
- How will I know if this treatment has worked?



Dr Dima El-Sharkawi: How I help my patients decide the right treatment option for them

Before I go into the detail, I highlight that there isn't a 'wrong decision'. Just because we decide to start with one treatment, it doesn't mean there aren't alternative options if that one doesn't suit the person or doesn't give the desired result. There have been many advancements in this area over the last decade, and research continues, meaning that we have different routes we can consider. Being able to select a treatment from a variety of options really is a luxury!

As I mentioned before, because everyone is an individual, they will want to approach this decision in a way that's right for them. Some of my patients, for example, prefer to defer to me as the doctor to make the bulk of the decision, whereas others want to review all the information with family and friends and make the decision in a shared way, and then some people are somewhere in between.

All approaches are valid for each individual and at any point, someone may also alter the way they want to make decisions. Because we rarely make a decision about treatment for CLL in one appointment, I often advise patients to go away and think things through, and maybe speak to their family or friends, or with a patient advocacy group/charity, if they find that helpful.

Once we have agreed on the route the patient is comfortable with, we initiate treatment as agreed, and then have regular check-ins on how things are going and make changes if needed.

Looking back at my own treatment decision, I wish I knew that...



1. You're never wasting your doctor's time. Remember that it's a two-way conversation and your doctor is there to listen and support you.



2. A second pair of ears can be incredibly helpful at appointments. Consider taking someone with you to treatment discussions to help ease the pressure on you having to remember everything. You could also write down key takeaways either during your appointment or shortly after, so that you can digest and reflect on what was discussed at a later stage.



3. Writing a checklist of what to speak to the doctor about helps structure the conversation with them. This ensures that you won't forget to ask any of your burning questions. Keep the checklist to hand during the appointment and tick off each question after it's been answered.

Further support:

MyCLLife is a campaign for people living with CLL and their care partners, providing useful information and guidance, helping you to learn more about managing your CLL. The resources are dedicated to give you the support and knowledge to have better, more informed conversations with your healthcare team and help you manage and live well with CLL.

Visit www.MyCLLife.co.uk for further information and resources, including:



A **video featuring Dr Dima El-Sharkawi and Stuart**, who is living with CLL, as they discuss active monitoring and how to make the most of medical appointments.



A collection of **videos and podcasts** from the CLL community, allowing patients and care partners to learn from other's experiences.



Mindfulness practice sessions which teach you how to use your breath and body to reframe thoughts and manage uncertainties.



The **Small Things Big Difference** booklet, which shares a collection of heart-warming anecdotes, tips, and coping mechanisms for living with a CLL diagnosis.

For further support, please visit [CLL Support Association](#)

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