CLL SUPPORT AstraZeneca

# LIVING WITH CLL TOGETHER:

**Emotional coping and practical support for people who have been recently diagnosed, and their partners.**



**This booklet has been developed and funded by AstraZeneca and is intended for people who have received a CLL diagnosis and their loved ones. This has been developed in collaboration with CLL Support and their members who have provided expert input into the content.**

It is intended for people in the UK living with CLL and their partners.

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The PIF Tick is the independent trust mark for health information. This lets you know information is evidence-based, up-to-date, and easy to use and understand.

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# WHAT IS CLL?

Chronic lymphocytic leukaemia (CLL) is a form of cancer that affects the blood, specifically a type of white blood cell called lymphocytes, and bone marrow. **Around 3,800 people in the UK are diagnosed with CLL each year**.[1,2]

A CLL diagnosis can be a huge shock. But the first thing to know is that **many people with CLL live long, full lives**.[1,2]

Our knowledge of CLL has improved in recent years.[3] Most people live longer with CLL than in the past.[3] This is due to many factors, including how we monitor CLL to catch any complications early, and updates to disease management. In fact many people can stay active and keep on doing the things they love.[3,4] When diagnosed with CLL, you may experience many different emotions. You may feel several emotions all at once.





Some people start treatment when they're told they have CLL and some people will start with a period of "active monitoring".[3] Active monitoring can go on for many years without needing treatment.[5]



**Active monitoring can help your healthcare team monitor your health and see how CLL is affecting you.[5]**




If your treatment involves active monitoring, it might help to know **you're not alone – around 8 in 10 people living with CLL go onto active monitoring. With around one in three people never needing treatment**.[6] More information about active monitoring can be found on page 8 of this booklet.

**You can learn more about active monitoring here by scanning the QR code.**

Click the QR code if viewing online. This will take you to an independent resource without AstraZeneca involvement.

**I'm still going to be around a long time. Do not worry about that. And I'm still going to watch your World Cup with you. Do not worry, I'm going to be around** - Troy, living with CLL

This leaflet shares practical advice to support you and your loved ones. Being able to manage your emotions can help improve your quality of life and help you feel more in control.



**Here are some common emotions that people diagnosed with CLL may feel**



anger



worried



scared



sadness



hopelessness



anxiety



confusion



frustration

Some people may also feel numb or even relief from a diagnosis.

# HOW DOES CLL AFFECT YOUR BODY?

Many people living with CLL, and their partners, families or friends, find it useful to learn about their condition and treatment options. There is a lot of information online and it can feel confusing. We have resources that can help you learn more about what to expect when you are first diagnosed with CLL.

**Scan the QR code to learn more about diagnosis on the CLL Support website.**

Click the QR code if viewing online. This will take you to an independent resource without AstraZeneca involvement.

CLL is a slow-growing cancer that starts in the bone marrow, the place where your body makes blood cells. It causes lymphocytes, which are a type of white blood cell, to grow in a way that isn't quite normal.[7]



It might be helpful to think of your bone marrow as a garden. Normally, this garden grows healthy plants – your blood cells. Each plant has a job: some fight infection and some carry oxygen. Some help your blood clot when needed, like when you get a cut and it develops into a scab.

With CLL, a few plants start to grow that shouldn't be there, like slow growing weeds. These weeds are abnormal lymphocytes. At first, they may not cause much harm, and the garden still looks okay. But over time, they can take up more space and begin to crowd out the healthy plants.

However, these weeds usually grow very slowly. That's why CLL often develops gradually and might not cause problems for a long time. Doctors keep a close eye on how the garden is doing and decide when, or if, they need to step in and attempt to slow the growth of the weeds.

# WHAT IS ACTIVE MONITORING ('WATCH AND WAIT')?

CLL is often a slow-growing or chronic cancer.[1] Research shows that treatment tends to work well when you start to experience symptoms that affect your quality of life.[3,7] Many people who are told they have CLL but do not have any symptoms of the disease, do not need to have treatment.[3] Saving treatment for when it's needed can help it make a bigger difference. During this time, you will be on active monitoring which may be called "watch and wait." This name is not commonly used today because it sounds worrying and does not reflect the regular checks and care you will get, but you may still hear it sometimes.

Many people living with CLL go through active monitoring. Your healthcare team will regularly monitor how you are doing and if your CLL is progressing through blood tests and a physical examination to check symptoms.[5,7]

During these appointments, it's important to speak up about your needs and ask questions. You may find it helpful to write down what you want to talk about before your appointment, bring a list of questions, or take notes during the visit so you can remember what was said.

**I see monitoring appointments a bit more like an MOT. You get through it and you know you're fine for another spell** - Keith, supporting a loved one living with CLL

Often, people living with CLL do not need treatment right away.[3] Some people with CLL never need treatment.[3,7] Healthcare teams advise active monitoring as a way to help extend your quality of life for longer.

Being diagnosed with a form of cancer and not being treated with medicine immediately can feel frustrating or upsetting. Do not worry, this is a normal part of CLL treatment, and you aren't alone in how you feel.

A lot of people who have been recently diagnosed might feel that they do not really have a type of blood cancer because they are not on treatment. This is not true. It may be helpful to think of active monitoring as a chance to look after your health and focus on what matters to you. You might use this time to do things you enjoy and keep as healthy and well as you can.

**It's a chronic long-term illness. [My doctor says] "We'll treat you when you need treatment. In the meantime, go away and live your life". It is hard to forget about, but actually you kind of do after that initial shock of diagnosis** - Marianne, living with CLL

# HOW CAN YOU TALK ABOUT YOUR DIAGNOSIS WITH OTHERS?

Opening up to others about your diagnosis can help you feel less alone and allow you to get support if you need it. It can feel difficult to talk about your diagnosis. Some people worry that they might make others upset.



Talking about it can feel scary at first but it doesn't have to be. You can take it one step at a time. Share only what feels right for you. If you don't feel ready to talk a about your diagnosis with other people, that is okay, too.



If you tell people, they may have questions about CLL. You can tell them about your experience if you want to, but some may find this stressful. Our page about CLL can answer many of their questions.

**Scan the QR code to learn more about CLL on the CLL Support website.**

Click the QR code if viewing online. This will take you to an independent resource without AstraZeneca involvement.

If you need support talking about your diagnosis, you do not have to manage this on your own. The CLL Support community on Health Unlocked is an online space where people affected by CLL can share experiences, ask questions, and support each other.

**Scan the QR code to join the CLL Support community on the Health Unlocked website.**

Click the QR code if viewing online.
This will take you to an independent resource without AstraZeneca involvement.



When discussing your diagnosis, remember that it is your story. It is okay to set clear boundaries with those that you choose to tell. This may sound like, **"I would prefer if you do not ask me about my CLL diagnosis. I will update you with changes when I am ready."**



Some symptoms of CLL may not always be visible to others, which can sometimes lead to questions or misunderstandings. If this happens, you may find it helpful to explain how CLL affects you, but it's also okay to keep things simple or share only what you feel comfortable with.



Some people may worry about intrusive questions or unwanted advice. It is okay to set boundaries here, too. This may sound like, **“I am thankful for you wanting to help, but I trust my healthcare team,”** or saying, **“I know you are asking because you care, but I do not want to discuss that today. Shall we talk about ____ instead?”**



Some people may ask why you aren’t on treatment if you have cancer. If you want to respond to this, it may sound something like, **“CLL is a slow-growing cancer, and treatment isn’t always needed straight away as early treatment doesn’t improve outcomes. My doctor monitors me closely and will start treatment if it is needed.”**

# HOW CAN YOU SUPPORT YOUR WELLBEING?

No matter whether you are on active monitoring or on treatment, there are things you can do to look after yourself. While living with CLL can feel uncertain at times, taking small steps can help you gain control. This is sometimes called prehabilitation (or prehab): preparing your body and mind to cope as well as possible with your condition and any future treatment.[8]



**Practice mindfulness.** This means paying attention to what's happening right now and can help you take each day as it comes. CLL Support offers Support ACT, which has lots of tools to help you practice these skills.



**Finding community** can help with feelings of loneliness and support you on your journey. At CLL Support, we have an active online community, Buddy Schemes, and a list of local support groups.

**Scan the QR code to visit the CLL Support website and see what support is available to you.**

Click the QR code if viewing online. This will take you to an independent resource without AstraZeneca involvement.

**Eating healthily** can help you feel good. Eating immune boosting foods that are packed with vitamins and minerals can help your body fight off viruses and reduce inflammation.



**Keeping active** can help you to feel your best as you live with CLL. Keeping active doesn't have to mean going to the gym or for a run, unless that's what you like to do. It can be any type of movement. Gardening, walking the dog, gentle yoga, or playing with your children or grandchildren, if you have them, are all great ways to stay active. If you are feeling very tired, try to plan your day so you do not do too much at once and do what feels right for you. This can help you do what you enjoy without feeling worn out. Aim to do around 30 minutes of activity five days a week if you can.[9]



**Talking freely with your doctor and loved ones** can help you manage things better. Ask your healthcare team about what support is available to you, including services, advice, or resources that could help you feel more in control. When speaking with your healthcare team, be honest with them about how you're feeling so they can provide support better tailored to you. Talking with your loved ones can also help you feel supported and more connected.



**If you are travelling**, you will need to tell your insurance company that you have CLL. Some companies may not know much about it, so it can help to explain it simply. You could say: **"I have a type of blood cancer called chronic lymphocytic leukaemia, also known as CLL. It usually grows slowly. I am not on treatment as I do not need it at the moment."** If you are unsure what to say, your doctor or healthcare team can help you explain your condition and check what support is available for you when travelling.



**Know your life doesn't have to change.** While it's important to take steps to protect your health, such as getting your recommended vaccinations to try to avoid infections, eating well and being active, you can still do the things you enjoy such as seeing friends and family. If you have questions about this, you can discuss them with your healthcare team.

> **23 years ago, I was told I had got leukaemia. And here I am, 23 years later, still managing to live a fairly interesting life** - Shaun, living with CLL

# HOW CAN YOU SUPPORT YOUR PARTNER THROUGH THEIR CLL DIAGNOSIS?

It can be tough when someone you love has been diagnosed with CLL. Things may feel different, and your roles may change. It can be hard to balance looking after your partner while also needing to take care of yourself and other family members.



**Looking at trusted sources** can help you and your partner learn about CLL. This can make it easier to know what to expect and how to support each other.



**Finding and building a support network** can be important for you and your partner living with CLL. Joining peer groups, in-person and online can help.





**Talking with your partner** can make you both feel cared for. When you speak honestly and kindly, you can support each other better. You or your partner may also find it helpful to attend appointments together, so you can both hear information and ask questions. You may want to discuss their needs at appointments or how things may look day to day. You can also talk about what support you might need. It can be hard to start these conversations, but they can be worthwhile.

## Prompts to start a conversation with your partner

- "What can we do to help you feel better? Shall we go on a walk or a drive?"
- "Would you like to talk about how you're feeling?"
- "Is there anything you want to talk about before your next appointment? How can I help you prepare?"
- "How are you feeling today compared to a week or a month ago, and what could we do to help each other feel a bit better?"
- "Would you like to share what's on your mind, and then I can share too?"

It's important to remember sometimes your partner may not want advice. They may just want someone to listen. Taking time to listen can help them feel heard and cared for.

> **Janice has some days where she's not feeling great because of it. And it's recognising that and suggesting we do something that isn't too draining but is nice. And it normally involves cake** - Keith, supporting a loved one living with CLL



**Try to keep in touch with friends and family.** This can help make life feel more 'normal'. If you or your partner worry about seeing others or doing your usual activities, you should speak with your healthcare team. They can give you tips to help you keep doing the things both of you enjoy.



**Practice self-care.** Many partners of people living with CLL put their own feelings and health last. To be there for your partner, you need to take care of yourself too. Keep doing things that you enjoy, try to be active and eat healthily to support your overall wellbeing.

**Thank you to the people living with CLL, and their partners, who have reviewed and provided feedback on this resource.**

**Reporting of side effects:** If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at **https://yellowcard.mhra.gov.uk/**. By reporting side effects, you can help provide more information on the safety of this medicine

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