

## Living Well with Watch and Wait

Guidance for finding information and support after a  
Chronic Lymphocytic Leukaemia diagnosis





# Contents

<b>The patient journey</b>	<b>4</b>
<b>My diagnosis</b>	<b>5</b>
What is CLL?	5
How do I tell people?	6
Where can I get emotional support?	8
<b>My Care Team</b>	<b>11</b>
Who's who?	11
My rights and involvement in my care	12
Carers rights	13
<b>My time on Watch and Wait</b>	<b>14</b>
What is Watch and Wait?	14
Regular Monitoring	15
Living with CLL	16
<b>My treatment</b>	<b>21</b>
Will I need treatment?	21
How can I prepare for treatment?	21
What are my options?	22
<b>Meet the patients</b>	<b>25</b>
<b>The CLL Dictionary</b>	<b>28</b>



# My diagnosis

Understanding and coming to terms with your diagnosis is the first step in the CLL journey for both you and your family. This can understandably be a difficult time, but there is very good information and support available to help you.

## 1. What is CLL?

You are not alone if you had never heard of chronic lymphocytic leukaemia prior to diagnosis. Indeed, most patients know the term leukaemia, but either don't know anything about it or have preconceived ideas relating to acute (or quickly progressing) leukaemia. CLL is, however, a chronic leukaemia, meaning that it tends to progress slowly over a number of years.

You may have been given an explanation about CLL at diagnosis. Failing to recall this or only remembering certain information is, however, relatively common, due to the emotions that you are feeling at the time. This is particularly an issue for those of you who were alone at diagnosis.

Learning more about CLL can help you to come to terms with your diagnosis and help you to explain it to other people.

*"On this occasion I took my wife in with me which I cannot recommend enough. She listened and picked up more facts and info than I could in my shock and fear... He [consultant] gave me a copy of the Macmillan book and a tip (too late!) to be careful of mock news of the internet. One good thing with my plunge into the internet world was discovering CLLSA, Chronic Lymphocytic Leukaemia Support Association. A great source of facts and links to other useful sites such as the Health Unlocked and Leukaemia Care. This not only helped me understand and order my knowledge and emotions around the disease, it also connected me to fellow CLLers via the Forum and CLLSA conferences." [Marc]*

### Here is a simple overview of what CLL is and what your staging means<sup>1</sup>:

CLL is a cancer of the B-lymphocytes (B-cells), a type of white blood cell that makes antibodies to help fight infection. Under normal conditions healthy white blood cells help our bodies fight infection and disease. Leukaemia develops when malignant (cancerous) white blood cells accumulate in the circulating blood and outnumber the normal-functioning cells.

Staging is a method of describing the extent that CLL is affecting the blood counts and lymph nodes. It can help the doctor to determine progression of the cancer, suitable treatments and when treatment should be administered. There are two scales used:

#### 1. Binet staging

- A** - No anaemia, normal platelet count and fewer than three areas (neck, armpits, groin, spleen or liver) with enlarged lymph nodes
- B** - No anaemia, normal platelet count and three or more areas enlarged lymph nodes
- C** - Anaemia and/or low platelet count with any number of areas enlarged lymph nodes

#### 2. Rai staging

- 0** - Low risk (absolute lymphocytosis)
- I** - Intermediate risk (absolute lymphocytosis and enlarged lymph nodes)
- II** - Intermediate risk (absolute lymphocytosis and enlarged spleen or liver, with or

<sup>1</sup>[www.leukaemiacare.org.uk/resources/chronic-lymphocytic-leukaemia](http://www.leukaemiacare.org.uk/resources/chronic-lymphocytic-leukaemia)

without enlarged lymph nodes)

III – High risk (absolute lymphocytosis and anaemia, with or without enlarged lymph nodes, spleen or liver)

IV – high risk (absolute lymphocytosis and low platelet count, with or without enlarged lymph nodes, spleen, liver or anaemia)

## Where you can get more information:

### 1. Ask your clinician questions

Macmillan have provided a list of questions you may wish to ask your clinician at diagnosis [www.macmillan.org.uk/information-and-support/treating/treatment-decisions/questions-to-ask/questions-after-diagnosis.html#19149](http://www.macmillan.org.uk/information-and-support/treating/treatment-decisions/questions-to-ask/questions-after-diagnosis.html#19149)

**2. Speak to your Clinical Nurse Specialists (CNS) or Macmillan nurse if you have been given the name of one**

**3. Information booklets from charities (normally available online or can be ordered as a hard copy)**

Leukaemia Care: [/www.leukaemiacare.org.uk/wp-content/uploads/2018/02/CLL-FOR-WEB.pdf](http://www.leukaemiacare.org.uk/wp-content/uploads/2018/02/CLL-FOR-WEB.pdf)

Bloodwise: [bloodwise.org.uk/document/chronic-lymphocytic-leukaemia-cll-booklet](http://bloodwise.org.uk/document/chronic-lymphocytic-leukaemia-cll-booklet)

Macmillan: [be.macmillan.org.uk/Downloads/CancerInformation/CancerTypes/MAC11620CLLE0820150930.pdf](http://be.macmillan.org.uk/Downloads/CancerInformation/CancerTypes/MAC11620CLLE0820150930.pdf)

**4. Visit the CLL Support Association (CLLSA) website:** [www.cllsupport.org.uk/article/welcome-family-professor-chris-fegan-september-2017](http://www.cllsupport.org.uk/article/welcome-family-professor-chris-fegan-september-2017)

**5. Other charity resources (e.g. phonedlines, conferences, webpages)**

[Leukaemiacare.org.uk](http://Leukaemiacare.org.uk) (Leukaemia Care – a national blood cancer support charity)

[Bloodwise.org.uk](http://Bloodwise.org.uk) (Bloodwise – a blood cancer research charity that provides information and advice for patients)

[Lymphomas.org.uk](http://Lymphomas.org.uk) (Lymphoma Association – supporting those affected by lymphoma)

Many patients report diving straight into the internet to find out more about CLL and end up either overwhelming or scaring themselves with the information, much of which can be less than accurate or helpful. Looking at trusted websites and resources will help to avoid this and give you relevant and up-to-date information.

Read this toolkit from Leukaemia Care for help on using the internet to find information: [www.leukaemiacare.org.uk/wp-content/uploads/2018/02/using-the-internet-safely-to-find-information.pdf](http://www.leukaemiacare.org.uk/wp-content/uploads/2018/02/using-the-internet-safely-to-find-information.pdf)

*"Before diagnosis, I knew nothing of CLL. All I knew was that it was a cancer but did not realise it had many faces. I would say to anyone, don't look anything up on the internet, as this frightened the life out of my wife. If you want anything explained, speak to the hospital staff, as I cannot praise them enough, or speak to organisations like Leukaemia Care, or Macmillan." [Paul]*

## 2. How do I tell people about my diagnosis?

This is something that is very personal to each CLL patient and there is no correct answer to this question. Some patients prefer to have as much information and understanding about

their diagnosis as possible before they tell family and friends, others prefer to have it out in the open from the start and some choose to tell people only when necessary. The benefit of being placed on Watch and Wait is that you have time to consider who you want to tell and how best to tell them.

*"It felt strange telling family, friends and my employers that I had cancer. I had been so healthy all my life. Once I had told people, it was out in the open and I somehow knew that I could deal with the cancer more positively." [Sheila]*

The important thing to remember is that there is no obligation to talk about your diagnosis before you are ready to, but it can be helpful to share this with someone you trust and can help you to feel supported.

Macmillan have produced helpful information about telling friends and family about a cancer diagnosis. Within this they have included practical tips for the first conversation, information about how people might react, and tips on asking for support: [www.macmillan.org.uk/information-and-support/coping/talking-about-cancer/who-should-i-talk-to/friends-and-family.html#3575](http://www.macmillan.org.uk/information-and-support/coping/talking-about-cancer/who-should-i-talk-to/friends-and-family.html#3575)

One of the difficulties in a cancer diagnosis can be telling your children or grandchildren, particularly if they are younger. Again, patients approach this in different ways, but agree (sometimes in hindsight) that it is important to tell children as much as they can understand at the time.

Macmillan have also produced information for talking to children and teenagers about cancer: [www.macmillan.org.uk/information-and-support/coping/talking-about-cancer/talking-to-children](http://www.macmillan.org.uk/information-and-support/coping/talking-about-cancer/talking-to-children)

*"My wife was there from the start. Parents didn't really understand, but children were the hardest as they were so young at the start. As years went by and I was attending hospital and then in 2007 having my first lot of Chemo, we told them dad had funny blood. We found this was the best way to tell them, so we were not keeping them out the picture. As they got older they were told exactly what was happening." [Paul]*

Health Talk have helpful information about telling different people about your leukaemia diagnosis and includes videos from patients: [www.healthtalk.org/peoples-experiences/cancer/leukaemia/telling-others-about-diagnosis](http://www.healthtalk.org/peoples-experiences/cancer/leukaemia/telling-others-about-diagnosis)

## Support for your family

A cancer diagnosis affects the whole family and those closest to you may feel worry or concern about you and the changes that may happen in terms of employment, finances and lifestyle. It is important that you have good communication with your family throughout your CLL journey to be able to adapt to the changes that are happening.

Many charities provide services that your family and friends can access to help them gain understanding about your diagnosis and be supported throughout the journey.

You may also wish to seek family counselling or counselling specifically for your children. This can be done through your GP, your hospital cancer centre, or by finding a service yourself. Cancer Research UK have produced information about counselling: [www.cancerresearchuk.org/about-cancer/coping/emotionally/talking-about-cancer/counselling](http://www.cancerresearchuk.org/about-cancer/coping/emotionally/talking-about-cancer/counselling)

Maggie's Centres also have helpful information about telling others and links to counselling services: [www.maggiescentres.org.uk/cancerlinks/living-cancer/talking-about-cancer](http://www.maggiescentres.org.uk/cancerlinks/living-cancer/talking-about-cancer)

### 3. Where can I get support?

Patients use a variety of these support services during their CLL journey, and the level of use will vary depending on where you are at. Family and friends are often the main source of support, but it is important to ensure that these people are receiving support themselves and you are not over reliant on these people for your emotional needs. This is why outside sources of support can be important to have and are also a good way to receive support and advice from trained experts.

*"Support from friends and family was there but I don't think people fully understood how I felt both physically and psychologically. I've not met in person anyone else in the same boat so I've felt alone all along my present journey." [Ian]*

There is a huge variety of support available for CLL patients, both online and in-person, which can help you to feel less isolated and anxious during your CLL journey. Even for those of you who are feeling positive, knowing where to go to when you have questions can help.

#### Clinical Nurse Specialists

You should have a named key worker based at the hospital who is responsible for managing your care. This is normally a Clinical Nurse Specialist (sometimes known as a CNS, nurse practitioner or Macmillan nurse).

There are several CLL specific nurse specialists across the country, but all haematology CNSs should have expert insight into management of patients with CLL. The CNS should be your first point of contact for emotional, practical and physical support normally by phone, email or at nurse-led clinics.

*"Get support in any way possible. If you are fortunate to be offered support from a local hospital i.e. a CNS, take it." [Wendy]*

Learn more about the role of Clinical Nurse Specialists by reading the Leukaemia Care 'My CNS Matters' report: [www.leukaemiacare.org.uk/my-CNS-matters](http://www.leukaemiacare.org.uk/my-CNS-matters)

Some charities offer CNS support services. Leukaemia Care Nurse Advisors are available every weekday, call **08088 010 444**, or book a slot at a time convenient by emailing [support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk) for a nurse will call you back.

The Leukaemia Care Patient Services team and volunteers are also available on the helpline at the following times:

Monday - Wednesday 4:30pm - 10:00pm

Thursday - Friday 9:00am - 7:00pm

Saturday 9:00am - 12:30pm

#### Buddying

Buddying involves being matched up with another patient who volunteers their time to help

support others. It allows you to have one-to-one support either over the telephone or face-to-face from someone who understands what you are going through.

*"I passionately believe in supporting others with blood cancers and their families and friends and I do this either face to face or on the Facebook sites." [Erica]*

Buddying schemes are available from:

Leukaemia Care/CLLSA CLL Buddy scheme: [www.leukaemiacare.org.uk/news/CLL-buddy-support-scheme](http://www.leukaemiacare.org.uk/news/CLL-buddy-support-scheme)

Lymphoma Association: [lymphoma-action.org.uk/support-you/buddy-support](http://lymphoma-action.org.uk/support-you/buddy-support)

## Support groups

Support groups are normally run by patients, healthcare professionals or charity representatives and bring together patients and their families in the local area to provide support. It is an opportunity to meet others and share information, both of which can be invaluable for your emotional wellbeing.

*"I should very much like to meet other CLL sufferers in person and to be part of a mutually beneficent support group in my area." [Ian]*

Find your local support groups here:

Leukaemia Care, find a support group: [www.leukaemiacare.org.uk/support-and-information/support-for-you/find-a-support-group/](http://www.leukaemiacare.org.uk/support-and-information/support-for-you/find-a-support-group/)

Lymphoma Association, support group finder: [www.lymphomas.org.uk/how-we-can-support-you/lymphoma-association-support-groups/support-group-meetings-and-events](http://www.lymphomas.org.uk/how-we-can-support-you/lymphoma-association-support-groups/support-group-meetings-and-events)

## Online forums

A lot of patients express how the support and information provided on online forums, such as the CLL Support Association's (CLLSA) Health Unlocked forum, helps them to come to terms with their diagnosis and feel better prepared for the future journey.

*"I also found terrific knowledge and support from CLLSA particularly the forum. Being able to liaise with so many people who are either on watch and wait or who have had treatment was the most value to me." [David M]*

The forum can be accessed here: [healthunlocked.com/cllsupport](http://healthunlocked.com/cllsupport)

There is also another online community of CLL, SLL and HCL patients run by Macmillan: [https://community.macmillan.org.uk/cancer\\_types/cll\\_sll\\_hcl/](https://community.macmillan.org.uk/cancer_types/cll_sll_hcl/)

## Charity patient and carer conferences

Throughout the year charities will bring together patients, families and carers from across the nation to conferences. The conferences will feature talks from leading healthcare professionals

and may cover specific topics affecting blood cancer patients or cover the general areas of need.

*"What did I come away with? First the staff from Liverpool Royal Hospital showed knowledge, care and understanding for both dealing with the condition but also the fear it raised in patients. I decided immediately to transfer my care to this hospital and gain from their knowledge and attitude. Secondly I finally realised I wasn't going to die in the next few months and had a better understanding of how to live my life with this condition." [David W]*

You may wish to keep an eye out for upcoming conferences from the following charities:

Leukaemia Care: [www.leukaemiacare.org.uk/support-and-information/support-for-you/patient-conferences](http://www.leukaemiacare.org.uk/support-and-information/support-for-you/patient-conferences)

CLL Support Association (CLLSA): [www.cllsupport.org.uk/events/upcoming-meeting-events](http://www.cllsupport.org.uk/events/upcoming-meeting-events)

Lymphoma Association: [www.lymphomas.org.uk/how-we-can-support-you/lymphoma-conferences-and-events](http://www.lymphomas.org.uk/how-we-can-support-you/lymphoma-conferences-and-events)

## Counselling

Counselling is a good way to speak to someone independent but trained to support patients. There are a variety of counselling options available, including those mentioned previously for family and children. One-to-one counselling involves talking to a counsellor to help you explore your thoughts and feelings. Cognitive Behavioural Therapy on the other hand aims to improve the way you respond to situations or emotions.

The best way to be referred to a counsellor is through your GP or your haematologist/clinical nurse specialist at the hospital.

Visit the CRUK website for more information on counselling: <http://www.cancerresearchuk.org/about-cancer/coping/emotionally/talking-about-cancer/counselling>

Maggie's Centres also offer access to a range of emotional support and expert advice: [www.maggiescentres.org/how-maggies-centres-can-help/help-available/?category=emotional-support](http://www.maggiescentres.org/how-maggies-centres-can-help/help-available/?category=emotional-support)

## Additional Services from charities

Charities have a wide range of resources available online, over-the-phone and in-person. Check out their websites to see how they can support you:

- Leukaemia Care: [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)
- CLLSA: [www.cllsupport.org.uk](http://www.cllsupport.org.uk)
- Maggie's Centres: [www.maggiescentres.org](http://www.maggiescentres.org)
- Macmillan: [www.macmillan.org.uk](http://www.macmillan.org.uk)
- Lymphoma Association: [www.lymphomas.org.uk](http://www.lymphomas.org.uk)
- Bloodwise: [bloodwise.org.uk](http://bloodwise.org.uk)
- Cancer Research UK: [www.cancerresearchuk.org](http://www.cancerresearchuk.org)

# My Care Team

Learning who's who and understanding both your rights and the rights of your carers can be invaluable for helping you feel involved in decisions and empowered to manage your own care during your CLL journey.

## 1) Who's who?

The nature of CLL may mean that you interact with different healthcare professionals, who are involved in the various aspects of your care.



**Haematologist** – This is a specialist in blood related disorders, including CLL. The haematologist is responsible for overseeing your clinical care, including diagnosing, managing and treating CLL. In some instances, if your CLL is stable or only very slowly progressing, the haematologist may refer you to the care of the GP, but if your CLL progresses or you are experiencing issues you will be referred back to the haematologist.

**Clinical Nurse Specialist** – CNSs are experts in a particular area of patient care. This may be specific blood cancers, clinical trials or stem cell transplants, just to mention a few relevant examples. They are responsible for leadership and training of other healthcare staff in their area of expertise. Every patient should have a named CNS who they are able to contact for support.

**GP** – You may be referred to your GP for regular monitoring if your CLL remains stable for a long period of time. Even if you are under the care of the haematologist, your GP will be a crucial point of call for management of symptoms and ensuring you are protected against infections. They should also be able to help provide you with support and information.

**Practice Nurses** – The nurses at your GP practice may take your bloods, administer vaccinations and be a key contact for providing you with support and information.

**Pharmacists** – As experts in medicines and their use, your pharmacists may play a crucial role in supporting your healthcare team to choose appropriate medications and ensure that they are safe to use in combination if you have multiple issues. They can provide you with advice on using medication and offer you choices for managing the symptoms of CLL or side-effects of treatment.

**Nurses** – Particularly during your time in hospital, either on the ward or in clinics, the nurses will be there to take care of your needs, monitor your condition and administer your treatment.

**Other consultants** – There is the likelihood that you will see specialists in other areas of the hospital during your CLL journey. For example, patients who are experiencing reoccurring infections that are causing issues may be referred to the immunologist.

Learning how to communicate well with the people involved in your care team can be crucial in helping you to feel listened to, involved in your care and overall more positive during your CLL journey.

The following resources give helpful advice for communication:

Maggie's 'Your Health Care Team': [www.maggiescentres.org/cancerlinks/about-cancer/your-healthcare-team](http://www.maggiescentres.org/cancerlinks/about-cancer/your-healthcare-team)

Macmillan 'Talking to Healthcare Staff': [www.macmillan.org.uk/information-and-support/talking-about-cancer/who-should-i-talk-to/healthcare-staff/html#247657](http://www.macmillan.org.uk/information-and-support/talking-about-cancer/who-should-i-talk-to/healthcare-staff/html#247657)

## Multidisciplinary teams (MDTs)

Multidisciplinary teams involve bringing together members of a patient's care team from different areas to ensure joined up care. This allows for a patient centered care approach so that complex care needs are accounted for by specialists.<sup>2</sup>

This is particularly important in the care of CLL patients who often develop complex needs. For example, there are patients living with other conditions (e.g. diabetes) who experience issues surrounding susceptibility to infections that are managed by other specialist consultants.

MDTs ensure that the professionals managing each condition are coming together to discuss the patient's unique condition and that treatment decisions are accounting for all the healthcare needs, as well as the holistic needs of the patient.

## 2) My rights and involvement in my care

The NHS pledges to provide free and equal healthcare to all UK citizens based on their clinical need, not their ability to pay. Every NHS patient has formal rights, as outlined within the NHS Constitution.<sup>3</sup>

The Constitution document includes the pledges of the NHS and covers your rights as a patient in the following areas:

1. Access to health services
2. Quality of care and environment
3. Nationally approved treatments, drugs and programmes
4. Respect, consent and confidentiality
5. Informed choice
6. Involvement in your healthcare and the NHS
7. Complaint and redress

These rights are designed to fulfil the principles of the NHS that includes ensuring that patients are given a comprehensive service without discrimination and that they are at the heart of the work the NHS does.

<sup>2</sup><https://www.england.nhs.uk/wp-content/uploads/2015/01/mdt-dev-guid-flat-fin.pdf>

<sup>3</sup><http://www.leukaemiacare.org.uk/resources/NHS-constitution-what-are-my-rights>

The NHS Constitution can be seen here: [www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england](http://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england)

In addition to the constitution, NHS England have produced The NHS Choice Framework that provides more detail on the rights and choices you have at every stage of your healthcare, including more information about finding services and how to make a complaint if you are not offered choices by your healthcare provider. It states: "The government is committed to giving patients greater choice and control over how they receive their health care, and to empowering patients to shape and manage their own health and care."<sup>4</sup>

The framework covers the following areas:

1. GP care
2. Referral to outpatients
3. Changing hospital
4. Right to a second opinion
5. Treatment options – being involved in clinical trials/research

You can view the full NHS Choice Framework or access their easy read documents at the following link: [www.gov.uk/government/publications/the-nhs-choice-framework](http://www.gov.uk/government/publications/the-nhs-choice-framework)

*"I feel more empowered to manage my care but still would like more key facts like how do I know where my nearest specialist centre and CLL specialist is." [Marc]*

Leukaemia Care have produced advocacy toolkits on the NHS Constitution, waiting times within the NHS and the complaints procedure. These can be accessed here: [www.leukaemiacare.org.uk/support-and-information/advocacy/know-your-rights-toolkit/](http://www.leukaemiacare.org.uk/support-and-information/advocacy/know-your-rights-toolkit/)

### 3) Carers rights

In some cases, patients require extra help from their partner, family or friends. This may be to carry out simple tasks at home, transporting to and from appointments or may include more physical care responsibilities. If this is the case, the person will be considered a carer.

Being able to recognise someone as a carer and for them to know their rights ensures that they are getting the physical, psychological and financial support they need to continue supporting the patient without detrimental impact on their own wellbeing. The carers rights act was established in 2014 to recognise the valuable role of, and protect the needs of, carers.<sup>5</sup>

Carers UK is a charity dedicated to helping carers. They provide help and advice both online and over the phone. They also have an online forum that can help connect and support carers.

[www.carersuk.org](http://www.carersuk.org)

Leukaemia Care also have an information booklet, *Caring for Carers* that is available to download or order here: [www.leukaemiacare.org.uk/wp-content/uploads/2018/02/LEU-0020-Caring-for-carers-V3-web.pdf](http://www.leukaemiacare.org.uk/wp-content/uploads/2018/02/LEU-0020-Caring-for-carers-V3-web.pdf)

<sup>4</sup><https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs>

<sup>5</sup><http://www.leukaemiacare.org.uk/cms/document-manager/download-file/36700>

# My time on Watch and Wait

Whether you are on Watch and Wait for the first time, or are returning after treatment, this can be an opportunity to live life and live well while your CLL is monitored.

## 1) What is Watch and Wait?

**Active Monitoring** - Clinicians will often refer to Watch and Wait as 'active monitoring'. The term is supposed to reflect the ongoing involvement of a patient's care team as their CLL is monitored over time.

Watch and Wait is a scheme for CLL patients, and some other blood cancer patients, who do not require treatment straight away. Instead the progression of your blood cancer will be monitored over time, by regular blood tests and check-up appointments.

In similar fashion to most patients your initial thoughts were probably 'get this out of me', which can make understanding and accepting Watch and Wait difficult.

*"At first I wanted something to get rid of it, but looking back now W&W is the best thing, as why interfere when there is potentially no need?" [Paul]*

But the reasons for Watch and Wait might help you to make sense of it:

1. Traditional treatments for CLL can be intensive, but newer treatments are improving. Therefore, it may be beneficial to wait for better treatment options.
2. Your CLL may be very slowly progressing meaning you never require treatment.
3. You may require treatment at some stage, but you can live well on Watch and Wait.
4. To date there is no evidence that treating patients with early asymptomatic stage disease actually do better.

Some find it easier than others, but patients often express how over time they learn to understand the reasons behind Watch and Wait and see it is a positive opportunity.

*"I can only say how I have managed W&W. In the past thirteen years that I have had CLL, I have lived a very busy life with travel and socialising. I belong to many clubs. I try to keep positive. During W&W when I'm feeling well, that's the time to take holidays and do things." [Sheila]*

*"I have started to learn to cope with living with the unknown. I consequently feel I enjoy life more, savour the moments and experiences more. My loved ones, the forum and conferences have done more to help me adjust to W&W than any specialist appointments or conversations." [Marc]*

The following resources can help you to find out more information about Watch and Wait and adjusting to life on Watch and Wait:

Leukaemia Care's Watch and Wait booklet:

[www.leukaemiacare.org.uk/wp-content/uploads/2018/02/Watch-and-Wait-WEB.pdf](http://www.leukaemiacare.org.uk/wp-content/uploads/2018/02/Watch-and-Wait-WEB.pdf)

CLLSA: [www.cllsupport.org.uk/cll-sll/start-here/watch-and-wait](http://www.cllsupport.org.uk/cll-sll/start-here/watch-and-wait)

CLLSA have also gathered together helpful posts from the Health Unlocked forum on "Things we can do to improve our CLL journey". View this here: [healthunlocked.com/CLLsupport/posts/private/137693056/things-we-can-do-to-improve-our-CLL-journey-an-update-of-coping-strategies](https://healthunlocked.com/CLLsupport/posts/private/137693056/things-we-can-do-to-improve-our-CLL-journey-an-update-of-coping-strategies)

Bloodwise: [bloodwise.org.uk/info-support/blood-cancer/watch-wait](https://bloodwise.org.uk/info-support/blood-cancer/watch-wait)

Lymphoma Association: [www.lymphomas.org.uk/about-lymphoma/treatment/watch-and-wait-lymphoma](https://www.lymphomas.org.uk/about-lymphoma/treatment/watch-and-wait-lymphoma)

Health Talk Online: [www.healthtalk.org/Cancer/Leukaemia/Topic/3782](https://www.healthtalk.org/Cancer/Leukaemia/Topic/3782)

## 2) Regular Monitoring

Your monitoring appointments will be at regular intervals, determined by the rate of progression of your CLL and how long it has been since diagnosis. Initially you will be seen every couple of months but if, after a year or so, your CLL is remaining stable you may be moved to 6 month or annual monitoring. In this case, your consultant may refer you back to the care of the GP for your monitoring.

You may prefer to continue having appointments with the consultant instead of your GP, or you may be happier not attending the hospital. This is a discussion that you can have with your care team and arrangements can be made to suit your needs.

*"For years I was on watch and wait and never saw a consultant, other than at diagnosis. After a telephone conversation with Leukaemia Care, I was encouraged to request a consultant appointment. I am very grateful to Leukaemia Care for this advice which I took and as a result now see a Consultant. This has been a great relief as watch and wait is worrying enough and made even more difficult if there is no contact with a haematologist." [Anon]*

### What tests will I have?

You will have a blood test either a few hours, or a couple of days, before your appointment with the consultant or GP. During the appointment, the doctor will check areas of lymph nodes for any changes, your spleen and liver for enlargement and your blood test results will be discussed.

### Understanding my results

The blood test is a full blood count, which indicates the amounts of the different cell types within the blood. This includes red blood cells, haemoglobin, platelets, and the white blood cell types, lymphocytes and neutrophils.

The level of these cell types differs within healthy individuals, particularly between men and women. Therefore, there are 'normal ranges' given to indicate healthy levels.

In CLL, the lymphocyte count is the main one to watch, as it is these cells that have become cancerous and are increasing in number. However, as they take up space within the blood this may cause other cell levels to reduce in number, which will cause problems.

CLLSA have detailed information on the different blood cell types, the normal ranges and how

they are affected in CLL. The page also directs you towards helpful videos on understanding your results: [www.cllsupport.org.uk/cll-sll/start-here/understanding-your-blood-results](http://www.cllsupport.org.uk/cll-sll/start-here/understanding-your-blood-results)

You may also find the Lab-Tests Online-UK site helpful for understanding your results: [labtestsonline.org.uk/](http://labtestsonline.org.uk/)

When you are given your results, your doctor should discuss with you what they mean and what implication the results have for your CLL journey. They may also offer to give you a copy of your results, but do not be afraid to ask for a copy if you would like one.

*"As the disease is progressing slowly I have been moved from 3 monthly to 6 monthly checks. I always ask for and receive a copy of the results and my specialist is happy to answer any questions I have regarding the results." [Marc]*

### Self-monitoring

Monitoring your own CLL can be in relation to your symptom progression and how you are feeling, or developing an understanding of your blood test results and finding trends or changes.

*"I have recorded and graphed my blood test results and from those, I can readily see for myself, any variations or trends in my condition. This is my only practical way of accepting W&W." [Ian]*

While these things may seem small, it can help you to feel in control of your CLL and be empowered to make, or contribute to, decisions about treatment and management.

*"I feel I can monitor my own progression well and I have always tracked my key blood results. For quite a few years I charted my blood tests, that were quarterly then, on graph paper, but it got a bit unwieldy like a toilet roll. I have also always charted all my blood test results on my own word document, although I believe there are word or excel type templates available." [Erica]*

The following resources can help you monitor your blood test results:

Bloodwise, My blood counts toolkit: [bloodwise.org.uk/sites/default/files/documents/watch\\_and\\_wait\\_my\\_blood\\_counts\\_fact\\_sheet.pdf](http://bloodwise.org.uk/sites/default/files/documents/watch_and_wait_my_blood_counts_fact_sheet.pdf)

CLLSA, Excel workbook that you can record test results, wellness and appointments: [www.cllsupport.org.uk/cll-sll/start-here/understanding-your-blood-results](http://www.cllsupport.org.uk/cll-sll/start-here/understanding-your-blood-results)

Remember: Even patients who have been on Watch and Wait for years report feeling heightened concerns approaching monitoring appointments. It is normal to feel this way. Building a good relationship with your doctor, ensuring you are supported, and feeling confident in self-monitoring can all help to reduce your concern.

*"Over the years I have adjusted to watch and wait, my emotions have subsided a bit although I still get a sick, yukky feeling in the pit of my stomach before my appointments, blood tests and results." [Erica, W&W for 14 years]*

### 3) Living with CLL

Watch and Wait can be a great thing as you can continue to live your life. However, dependent

on both the stage of your CLL and your normal lifestyle, there may be practical and physical issues that you experience during this time.

## Symptom burden and management

The most common symptom experienced by CLL patients is fatigue – a persistent tiredness that is not relieved by increasing amounts of sleep. The best way to manage fatigue is to learn the triggers or patterns and adjust your lifestyle accordingly.

*"I tire more easily now so plan action days and rest days where possible, I enjoy my allotment, two days looking after grandchildren, church life, theatre etc. Just need to plan well." [Marc]*

Leukaemia Care have produced a "how to combat fatigue" video: [www.youtube.com/watch?v=Ej5ByrzhzHE](https://www.youtube.com/watch?v=Ej5ByrzhzHE)

Macmillan have produced information about coping with fatigue and a fatigue diary that can help you to identify the times your fatigue is worse: [be.macmillan.org.uk/be/p-284-coping-with-fatigue.aspx](https://be.macmillan.org.uk/be/p-284-coping-with-fatigue.aspx)

Additionally, Health Talk have helpful videos and information on living with the symptoms of CLL: [www.healthtalk.org/peoples-experiences/cancer/leukaemia/living-symptoms-cll](https://www.healthtalk.org/peoples-experiences/cancer/leukaemia/living-symptoms-cll)

In addition to fatigue, the main symptom experienced in early stage disease is frequent infections, but as your disease progresses you may begin to experience other symptoms. It is important that you record and report your symptoms to the doctor during your monitoring appointments. If you are struggling either contact your Clinical Nurse Specialist (CNS) or visit your GP as soon as possible.

## Infections

Due to the infection-fighting white blood cells being affected in CLL, patients are immune-compromised. This means you are more at risk of catching infections and it will have a greater effect on you than someone who has a healthy immune system.

Patients report having issues with shingles, which is a reactivation of chicken pox, respiratory infections during the winter are common, and mouth or dental related infections can be a problem.

*"My general health over the past 6 years has been generally good, the most 'serious' issue was the shingles. Annoyingly, this current winter has seen me with persistent colds developing into chesty coughs dealt with by over the counter medication. Luckily, no chest infection has occurred. I habitually receive a flu jab and to date, they have protected me from it." [Ian]*

Your risk of getting infections, and how often you get them, will depend on the stage of your CLL, whether you've previously had treatment, and your lifestyle (e.g. if you are often in crowds your exposure to infection will be greater).

There are, however, several ways that you can decrease your risk of catching an infection<sup>6</sup>:

- Ensure you have had vaccinations, but ask your haematologist, CNS or GP for advice on

<sup>6</sup><https://www.cllsupport.org.uk/cll-sll/living-with-cll-sll/self-help-strategies>

suitable vaccines first as there are some that are unsuitable for CLL patients e.g. live strain vaccines.

- Ensure that your family, partner or those you live with are vaccinated, as it is most likely these people who you will catch infections from.
- Wash your hands well and carry antibacterial gel or wipes, particularly if you are going on public transport.
- Avoid being around people who are ill or have recently been ill.
- Avoid exposure to bacteria or fungi e.g. spoilt food, hot tubs and communal baths unless disinfected regularly, gardening, mould, compost heaps.

There are intervention options for CLL patients who are regularly experiencing infections, including courses of antiviral tablet, antibiotics, or intravenous immunoglobulin (IVIG) therapy. Your consultant will be able to discuss options with you and may refer you to an immunologist.

For more information on reducing infection risk with CLL visit the following links:

Self-help strategies from Bloodwise: [bloodwise.org.uk/info-support/chronic-lymphocytic-leukaemia/living-with](https://bloodwise.org.uk/info-support/chronic-lymphocytic-leukaemia/living-with)

CLLSA: [www.cllsupport.org.uk/cll-sll/living-with-cll-sll/self-help-strategies](https://www.cllsupport.org.uk/cll-sll/living-with-cll-sll/self-help-strategies)

## Employment

If you are still in employment, you may be concerned about the impact that a CLL diagnosis will have on your ability to work. Fortunately, cancer is considered to meet the definition of a disability and you therefore have greater protection at work under the Equality Act of 2010 and your employer should make reasonable adjustments for you.

The best advice from patients is to ensure you have good communication with your managers and employers. Help them understand what you are going through, explain what Watch and Wait is, discuss the progression of your CLL, and express how your symptoms are affecting you. This will then allow your employers to give you, to the best of their ability, appropriate support and flexibility you need to continue working.

*"With my job, I told my managers in confidence and they were really good and kept it in confidence. Work colleagues were told as things worsened. I must say after being on long term illness with an injury and with no support before this, I could not fault them with the help and support with the cancer diagnosis"*  
[Paul]

Bloodwise have produced information on Watch and Wait that you can give your employer: [bloodwise.org.uk/sites/default/files/documents/watch\\_and\\_wait\\_employers\\_fact\\_sheet\\_0.pdf](https://bloodwise.org.uk/sites/default/files/documents/watch_and_wait_employers_fact_sheet_0.pdf)

Macmillan have produced a variety of information on Work and Cancer: [www.macmillan.org.uk/information-and-support/organising/work-and-cancer/information-for-employees#161440](https://www.macmillan.org.uk/information-and-support/organising/work-and-cancer/information-for-employees#161440)

There are benefits available to you, if you are struggling at work and decide to leave employment or are on unpaid leave due to long-term sickness. You can learn more about these in the 'Your finances' section on page 19.

<sup>7</sup><https://www.macmillan.org.uk/information-and-support/organising/travel-and-holidays/travel-insurance>

## Travel Insurance

*"I do like to travel but I have had some very expensive quotes. I can get an insurance that gives good cover. I just have to look around." [Sheila]*

Unfortunately, getting travel insurance can be difficult with a CLL diagnosis<sup>7</sup> and many patients report receiving unaffordable quotes. Some patients prefer to travel only within the UK after diagnosis to avoid this, however, there are ways to find reasonable travel insurance:

- 1. Check an existing policy** - If you have insurance through your workplace or bank, for example, your policy may still cover you as you weren't diagnosed at the time of taking out the policy.
- 2. Search online and compare deals from different providers.**
- 3. Use dedicated insurers** - There are providers that offer specialist insurance for those with a medical condition.
- 4. Ask other patients** - While the price of quotes may change over time, it is often quicker and easier to ask other patients where they have got their travel insurance from.

During early stage CLL, and particularly before you have had treatment, it is encouraged that you travel as normal if you feel able to do so. For more information on travelling and travel insurance visit: [www.leukaemiacare.org.uk/support-and-information/information-about-leukaemia/living-well-with-leukaemia/practical-issues/travel/](http://www.leukaemiacare.org.uk/support-and-information/information-about-leukaemia/living-well-with-leukaemia/practical-issues/travel/)

## Life Insurance

*"Recently I was refused Life Insurance when my husband and I had applied for a mortgage, which annoyed me, why should I be penalised for something I have never had to have treatment for and may never affect me." [Diane]*

If you already have life insurance, your provider should honour the contract you are already in providing you were honest about your medical history at the time of taking out the policy.

If you don't have life insurance, you may be rejected from taking out a new policy with a diagnosis of CLL, because it is currently incurable. It is worth discussing with your consultant about the evidence that the insurance provider will gather before attempting to take out a policy.

For more information, Macmillan is the best organisation to get advice on life insurance: [www.macmillan.org.uk/information-and-support/organising/your-finances/insurance/buying-and-claiming-life-insurance.html#261948](http://www.macmillan.org.uk/information-and-support/organising/your-finances/insurance/buying-and-claiming-life-insurance.html#261948)

## Your finances

*"After the transplant they [Macmillan] got in touch to help with a disability allowance claim, which my wife found out they could help with." [Paul]*

Finances can be something that cause significant worry, particularly if you are still working and are the main earner in the household. Macmillan have dedicated teams of financial advisors that can provide guidance on the support available to you.

Some of the financial support available to you is:

1. Benefits for those of working age or pension age
2. Carer's allowance for those looking after someone with CLL
3. Disability allowance
4. Help with healthcare costs - including free prescriptions
5. Help with household bills
6. Support from your bank

To get financial support from Macmillan, visit their website: [www.macmillan.org.uk/information-and-support/organising/benefits-and-financial-support](http://www.macmillan.org.uk/information-and-support/organising/benefits-and-financial-support) or call 0808 808 00 00

Maggies also have a helpful selection of advice relating to money, work and travel on their website: [www.maggiescentres.org/cancerlinks/living-cancer/money-work-and-travel/](http://www.maggiescentres.org/cancerlinks/living-cancer/money-work-and-travel/)

# My Treatment

Time will be the biggest indicator of whether you will get to this stage in your CLL journey. Around a third of patients never have treatment, whereas other patients will have multiple rounds of treatment. Being prepared for this time, however, can help you to feel more positive and in control of your CLL.

## 1) Will I need treatment?

Not knowing when, or if, you will require treatment can be the greatest difficulty when living on Watch and Wait. The staging of your CLL can be indicative of when you will require treatment and there are also known prognostic biomarkers, which are genetic changes within the CLL cells, that can be used to predict progression. Your consultant can give you more information about this.

Time is, however, the greatest indicator of your CLL progression. Over time you will be able to get a broader picture of how your blood test results are changing and whether your symptoms are worsening. This is where self-monitoring comes in, which helps patients to feel in control and better informed about their cancer progression.

Patient's advice is generally to take your time, enjoy the periods you are feeling well, take steps to improve your general fitness, and only prepare for treatment when you are getting closer to that stage.

*"I know I am an extremely lucky girl as I have been on watch and wait for 14 yrs without having any treatment. I have really got to know myself physically, mentally and spiritually over the last 14 yrs. Before diagnosis I went through life on auto pilot thinking life would pan out in a certain way as a wife, mother and employee." [Erica]*

*"If you are feeling well during W&W try and enjoy life. When it's treatment time, ease up and concentrate on getting better." [Sheila]*

*"I would say nothing really hit me until things went downhill a number of years later, and as the consultant was positive, this helped me a lot. The only times things really hit me, was when I was coming up to treatment, as probably reality was hitting then." [Paul]*

If you would like more information about the progression of CLL and when you may require treatment read 'Welcome to the Family', an article by Professor Chris Fegan, on the CLLSA website: [www.cllsupport.org.uk/welcome-family-professor-chris-fegan-december-2014](http://www.cllsupport.org.uk/welcome-family-professor-chris-fegan-december-2014)

Or visit the CRUK website about CLL treatment and 'treatment decisions':

[www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll/treatment/](http://www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll/treatment/)

## 2) How can I prepare for treatment?

There are simple methods that can help you feel more positive and better prepared for when you need treatment.

### Improving general fitness and health

Patients often decide to take steps to make their lifestyle healthier and improve their general

fitness. This may seem difficult as your symptom burden begins to increase over time, but in general the fitter you are, the better able you are to tolerate treatment.

*"I ensure my life is more balanced now. This meant giving up some things and not going out in the evenings. My weight is now stable. My diet is slightly healthier, I get more fresh air and I definitely do more exercise, either walking or in the gym doing Pilates or Zumba." [Erica]*

Ideas from patients on improving fitness are:

- Having a balanced diet
- Joining a gym or fitness classes
- Quit smoking
- Walking places instead of driving
- Ensuring you are getting your recommended daily amount of vitamins

You do not need to feel pressured to lead a healthier lifestyle, but it can be a positive change that helps to relieve stress, feel happier and even less isolated. For example, going to a gym class, such as Pilates, can improve your fitness over time, boost your 'happy hormones', and help you to meet and make friends who don't know about your diagnosis.

### **Have support in place**

Having both practical and emotional support in place, or knowing where to go, before treatment is a great way to prepare. Ensuring this is organised beforehand can save you stress and pressure when you are dealing with treatment.

One patient, for example, said that during treatment people were scared to visit due to increased susceptibility to infection and would really have appreciated having organised video calls with friends.

Another way patients seek support when preparing for treatment is from the wider patient community. Speaking to other patients that have gone through it all before can help you to discuss your concerns and get answers to your questions on the practicalities of treatment.

### **Manage other conditions**

Before starting treatment, it is important that you manage any pre-existing conditions or ensure that your general health is in good shape, including dental health. These are things that may worsen or be difficult to manage during treatment.

Ensure to discuss this with your haematologist prior to treatment, who should have multidisciplinary team (MDT) meetings with your other healthcare specialists to ensure the best course of action is taken to suit your needs.

## **3) What are my options?**

Particularly for CLL, in the current treatment landscape there are many options, ranging from traditional chemotherapies, to immunotherapy treatments, and emerging therapies too. It can be difficult to know what your options are and what treatment is available to you within the NHS or clinical trials.

Learning more can help you to make informed decisions about your treatment and be prepared for possible outcomes.

When considering your options for treatment here's what you can do:

- 1. Discuss the options with your care team.**
- 2. Get a second opinion** – there are specialist centres and leading experts in CLL who may be able to give you more information about the options available to you, particularly around clinical trials. You are within your rights to ask for a second opinion should you want one.
- 3. Use charity resources** – charities have produced a wide range of literature that can give you more information about how treatments work and who they are suitable for. There may also be conferences that you can attend for more information, which normally feature leading experts who will update you on treatments.
- 4. Speak to other patients** – other patients can be a valuable source of information, whether they have been through it previously or have done detailed research into different treatment options. Seek the information that others have on forums, such as the CLLSA Health Unlocked forum. However, do exercise caution, as someone else's experience or what is suitable for them may not be applicable to yourself.

To find more information about treatment for CLL:

Leukaemia Care: [www.leukaemiacare.org.uk/resources/chronic-lymphocytic-leukaemia](http://www.leukaemiacare.org.uk/resources/chronic-lymphocytic-leukaemia)

CLLSA: [www.cllsupport.org.uk/cll-sll/treatment](http://www.cllsupport.org.uk/cll-sll/treatment)

Cancer Research UK: [www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll/treatment](http://www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll/treatment)

Bloodwise: [bloodwise.org.uk/info-support/chronic-lymphocytic-leukaemia/treatment](http://bloodwise.org.uk/info-support/chronic-lymphocytic-leukaemia/treatment)

## Clinical Trials

Clinical trials involve testing the safety and effectiveness of new treatments that are not yet available for routine use. Within the trials there are different groups of patients, one of which will be given the current standard of treatment. Therefore, there is a chance you will not be given a new therapy, but one which is standardly used.

Within CLL the main clinical trials are:

- 1. Trials Accelerated Program (TAP) studies** - These are accelerated phase 1 or phase 2 trials, meaning they assess the safety and appropriate dosage of new treatments, or assess the optimal dosage and side effects, respectively. TAP was established in 2011, to ensure the new blood cancer drugs are efficiently trialed and are made available for use on the NHS more quickly. To find out more information about TAP studies and those currently available for CLL, visit the Bloodwise website: [bloodwise.org.uk/research/clinical-trials/tap](http://bloodwise.org.uk/research/clinical-trials/tap)
- 2. FLAIR trial** - This is a stage three trial that involves larger numbers of patients, to assess the long-term safety and effectiveness of new treatments. FLAIR is an adaptive trial, which means that new treatment regimes are being introduced over time. It allows comparison between all new therapies, or combinations of therapies for CLL. Cancer Research UK have the most up-to-

date information on the FLAIR trial: [www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-trial-ibrutinib-rituximab-chronic-lymphocytic-leukaemia-flair](http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-trial-ibrutinib-rituximab-chronic-lymphocytic-leukaemia-flair)

There are a number of things to consider before entering a clinical trial, therefore ensure that you do your research and are well informed.

The following resources can help with this:

Leukaemia Care: [www.leukaemiacare.org.uk/resources/clinical-trials](http://www.leukaemiacare.org.uk/resources/clinical-trials)

Cancer Research UK: [www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll/research-clinical-trials](http://www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll/research-clinical-trials)

The NHS UK Clinical Trials Gateway (UKCTG) lists UK trial details and locations: [www.ukctg.nihr.ac.uk](http://www.ukctg.nihr.ac.uk)

## Meet the Patients

Introducing the patients who have provided their experience and advice for living well on Watch and Wait.

### Ian

Diagnosed: 2012

Time on Watch and Wait: 6 years

Achievement since diagnosis:

*"This had no detrimental effect on my completing my work project and I left 4 months after my 65th birthday with best wishes and a handsome gift from my colleagues. Also, my own self-determination to live as best I can with my condition."*

*"Simply do the best you can – there are others far worse off. Not very outstanding advice but it is seeing me through."*

### David M

Diagnosed: 2016

Time on Watch and Wait: Since diagnosis, monitoring every 10 – 12 weeks

Achievement since diagnosis:

*"Coming to terms with CLL and getting on with my life has been major for me personally. Most people, unless diagnosed, will not truly understand this feeling. On initial diagnosis I believed (through lack of knowledge) that I would not survive more than a few months. Since then I have seen my daughter get married and have recently become a grandad. Life is great."*

*"Try not to worry, get all the help and advice you can and get on with enjoying life. Difficult to do in the initial stages following diagnosis but you can't let CLL control your life."*

### Sheila

Diagnosed: 59 years old

Time on Watch and Wait: 4 years until I needed treatment with chemotherapy in 2008 followed by more treatment in 2011, 2015 and 2018.

Achievement since diagnosis:

*"I feel very proud of all the nurses and doctors at Ipswich hospital who have looked after me so well these last thirteen years."*

*"If you are feeling well during W&W try and enjoy life. When it's treatment time, ease up and concentrate on getting better. Ask the oncologist and support nurse plenty of questions."*

### David W

Diagnosed: 1 year ago

Achievement since diagnosis:

*"Found Leukaemia Care, assist in any way I can and continue my lifestyle."*

*"Enjoy life and share as much as you can with your family and friends in a positive way."*

## **Marc**

Diagnosed: 2015

Time on Watch and Wait: No treatment yet

Achievement since diagnosis:

*"Becoming a trustee of the CLLSA to help create/strengthen the resources available to fellow patients and their family. Sharing my story and connecting to new sufferers to hopefully help them through the initial emotional roller coaster."*

*"Connect to CLLSA, Leukaemia Care, and Health Unlocked Forum for facts and friendship, it helps!"*

## **Diane**

Diagnosed: 41 years old

Time on Watch and Wait: 8.5 years

Achievement since diagnosis:

*"I passed my driving test, my two children have now grown up and I am very proud of them. My son met a lovely girl and they have given me a beautiful granddaughter. I have stopped smoking and I am trying to get fit."*

*"Don't let your consultant discharge you from his / her care, if you are lucky enough to have a say on the decision, (I wasn't)."*

## **Paul**

Diagnosed: 38 years old

Time on Watch and Wait: 4 years before treatment in 2007. This reduced my cell count, until 2011 when chemo was given again. This did not work and I started the process of transplant.

Achievement since diagnosis:

*"Apart from having to go through a different cancer diagnosis, I feel proud to say I am back at work full time, doing what a non-cancer sufferer is doing. My wife keeps saying I should do a marathon again, but it has always been a lifelong goal to do a full marathon. My reaction then and still is, getting back to where I was before cancer was my goal and it was achieved with flying colours - i.e. going the full circle."*

*"Don't worry about the what ifs. I know it isn't easy, but treatment is not fun and really hard. Having that time where the count is behaving itself or only steadily rising is a good thing. Just keep remembering that the more time you have before treatment starts the more chance they have of finding something that will be a better treatment."*

## **Erica**

Diagnosed: 54 years old

Time on Watch and Wait: 14 years without treatment

Achievement since diagnosis:

*"When I was still working full time I did a one years part time course which I passed. I helped out after the 7/7 bombings. I received a Mayors award for services to local government and a London Mayors award for long term volunteering. I became an ambassador for a charity and I joined a gym."*

*"Give yourself time to take the diagnosis in, you are not alone. Write a list of questions you want to ask professionals before appointments. Watch and Wait is good news as it means the professionals can get*

*to know you, research is advancing every day and if you were to need treatment in the future it is now very targeted to your particular needs. Lastly take care of yourself."*

## **Wendy**

Diagnosed: New Year's Eve 2014

Time on Watch and Wait: First treatment January 2018

Achievement since diagnosis:

*"Being here! Keeping my faith and sense of humour. Supporting my children and grandchildren in any way I can. Starting a little sewing group making quilted bags as gifts, completing a quilted bed cover and currently a quilted wall hanging."*

*"Get support in any way possible. If you are fortunate to be offered support from a local hospital i.e. a CNS, take it".*

# The CLL Dictionary

Explaining some of the terms that you may hear during you CLL journey:

## Anaemia

A medical condition in which the red blood cell count or haemoglobin is less than normal.

## Blood cells

Blood cells have many different functions including transporting oxygen and nutrients to the lungs and tissues, forming blood clots to prevent excess blood loss and carrying cells and antibodies that fight infection.

## Blood count

A common test to check a person's general health or to screen for anaemia.

## Bone marrow

The soft blood-forming tissue that fills the cavities of bones and contains fat, immature and mature blood cells, including white blood cells, red blood cells and platelets.

## Chemotherapy

A form of cancer treatment that uses one or more anticancer drugs as part of a standardised chemotherapy regimen.

## Chronic

A human health condition or disease that is persistent or otherwise long-lasting in its effects. The term chronic is usually applied when the course of the disease lasts for more than three months.

## Chronic Leukaemia

A type of blood cancer that affects the white blood cells. This tends to progress over many years but some patients will go ten years without having started treatment.

## Clinical trial

A medical research study involving patients with the aim of improving treatments and their side effects. You will always be informed if your treatment is part of a trial.

## Chronic Lymphocytic Leukaemia (CLL)

A cancer that effects the blood and bone marrow derived from lymphocytes.

## Clinical Nurse Specialist (CNS)

A specialist nurse in cancer care.

## Fatigue

Extreme tiredness, which is not alleviated by sleep or rest. Fatigue can be acute and come on suddenly or chronic and persist.

## Full Blood Count (FBC)

A blood test that counts the number of different blood cells.

## Haematologist

A doctor who specialises in diseases affecting the blood. They are concerned with any abnormality of the blood, including blood cells and coagulation.

## Lymph node or lymph gland

An oval-shaped organ of the lymphatic system that catches viruses and bacteria. It contains white blood cells that fight off infections.

## Lymphocyte

A type of white blood cell which forms the body's immune system.

## Multi-Disciplinary Team (MDT)

A meeting of the group of professionals from one or more clinical disciplines who together make decisions regarding recommended treatment of individual patients.

## Neutropenia

A condition in which the number of neutrophils (a type of white blood cell) in the bloodstream is decreased.

## Platelet

A disc-shaped element in the blood that assists in blood clotting. During normal blood clotting, the platelets clump together (aggregate).

## Prognosis

A complete prognosis includes the expected duration, function, and description of the course of the disease, such as progressive decline, intermittent crisis, or sudden, unpredictable crisis.

## Red blood cell

The blood cell that carries oxygen. Red cells contain haemoglobin, which permits them to transport oxygen (and carbon dioxide).

## Relapse

The return of a disease or the signs and symptoms of a disease after a period of improvement.

## Remission

A period of time when illness is less severe or is not affecting someone.

## Staging

Cancer staging is a description of the size of the cancer and whether, and if so by how much, it has spread.

## White blood cell (or leukocytes)

One of the cells the body makes to help fight infections. There are several types of white blood cells. The two most common types are the lymphocytes and neutrophils.

For more information about terms you may come across during your blood cancer journey, please read our A-Z of Leukaemia at <http://www.leukaemiacare.org.uk/wp-content/uploads/2018/02/A-to-Z-of-Leukaemia-FOR-WEB.pdf>

## For more information:

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

### Leukaemia Care

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Helpline: **08088 010 444** (free from landlines and all major mobile networks)

[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

[support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)

### CLLSA

CLL Support Association are a patient-led charity, helping to empower patients and their families through relevant and accurate information.

**0800 977 4396**

[www.clisupport.org.uk](http://www.clisupport.org.uk)

### Lymphoma Association

Lymphoma Association offer support and information to patients with lymphoma, including small lymphocytic lymphoma (SLL).

**0808 808 5555**

[www.lymphomas.org.uk](http://www.lymphomas.org.uk)

### Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

**020 7504 2200**

[www.bloodwise.org.uk](http://www.bloodwise.org.uk)

### Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

**0808 800 4040**

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

### Macmillan

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

**0808 808 0000**

[www.macmillan.org.uk](http://www.macmillan.org.uk)

### Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

**0300 123 1801**

[www.maggiescentres.org](http://www.maggiescentres.org)



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

Office line: 01905 755 977

Campaigns and advocacy: [advocacy@leukaemiacare.org.uk](mailto:advocacy@leukaemiacare.org.uk)

Help line freephone: 08088 010 444

[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

Registered charity number 259483

Scotland Registered Charity Number SC039207

**Leukaemia Care**  
YOUR Blood Cancer Charity