Leukaemia Care
YOUR Blood Cancer Charity

Watch and ~~Wait~~ Worry

The experience of Chronic Lymphocytic Leukaemia (CLL) patients living on Watch and Wait

Contents

Executive Summary

What is Watch and Wait?

There are approximately 13,000 people living in the UK with Chronic Lymphocytic Leukaemia (CLL) on 'Watch and Wait'[1]. A process otherwise known as 'active monitoring'.

Watch and Wait is a process of regularly monitoring the progression of CLL and only initiating treatment once intervention is required. This is done because traditional treatments are very intensive and can cause greater issues for patients than the CLL.

Why do people call it 'watch and worry'?

"'Watch and Wait' or 'Watch and Worry'? How long would this go on? I resigned myself to trying to put W&W to the back of my mind and get on with my life despite the restrictions that my condition were putting on me." [Ian, 69]

Half of patients on Watch and Wait express feeling more concerned or anxious since diagnosis, with 1 in 8 feeling constantly depressed or anxious. This can often be associated with 'living with the unknown' and is worsened by a lack of information and supportive care offered to patients on Watch and Wait.

How can we help patients to live well on Watch and Wait?

Ensuring that patients know how to find further information and are offered access to support could help them to live well on Watch and Wait, as opposed to 'watching and worrying'.

We have made five recommendations that could help to achieve this:

Recommendation 1: Timely signposting to resources from trusted sources to help patients better understand their diagnosis and Watch and Wait.

Recommendation 2: Improving doctor-patient communication to ensure patients are better informed and feel more involved in their care.

Recommendation 3: There is a need for guidance for healthcare professionals, on how to support clinical needs and aid patients to navigate some of the challenges involved with living with and coping with a chronic blood cancer diagnosis and Watch and Wait.

Recommendation 4: All chronic lymphocytic leukaemia (CLL) patients should have access to a named key-worker, normally a Clinical Nurse Specialist (CNS), who can support their clinical and holistic needs following diagnosis.

Recommendation 5: Charities such as Leukaemia Care and the CLL Support Association provide invaluable support for patients online, over-the-phone, and in-person. Patients need to be made aware of the range of support available to them at an early stage in their CLL journey.

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

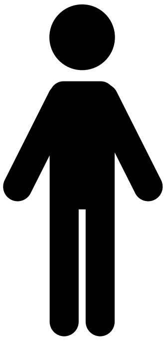
Each year 3,500 people in the UK are diagnosed with Chronic Lymphocytic Leukaemia (CLL)[2].

CLL is a slowly progressing (chronic) and currently incurable cancer of the blood (leukaemia) that causes over production of lymphocytes, a type of infection-fighting white blood cell. The leukaemia cells do not function properly and gradually take over space within the blood, causing a reduction in other healthy blood cells.

The slowly progressing nature of CLL means that many patients are diagnosed incidentally during routine blood tests and there can be many years before patients experience significant burden from their disease. Therefore, around two thirds of CLL patients will not require treatment straight away and will instead be placed on Watch and Wait[3].

Red will start treatment straight away

Green will be on W&W and later have treatment



Black will be on W&W and never require treatment

Leukaemia Care Patient Experience Survey

Between September and December 2016 Leukaemia Care carried out a survey of leukaemia patient experience from diagnosis, through to living with or beyond a blood cancer[4].

993 CLL patients responded to the survey, of which 763 had been placed on Watch and Wait at diagnosis instead of starting treatment. This equates to over three quarters (78%) of respondents not starting treatment straight away.

Watch and Wait patients at diagnosis

We used the survey data to learn more about Watch and Wait patients at diagnosis.

- 32% hadn't encountered any symptoms and 28% didn't think anything was wrong prior to visiting their GP.
- 42% are referred by a non-urgent pathway to secondary care suggesting that GPs may not be suspecting cancer, as this would be done via the 2-week referral route.
- 82% of patients were not expecting to be diagnosed with cancer.
- Over half (51%) of patients are by themselves at diagnosis.
- Two thirds (66%) of patients did not know anything about CLL at diagnosis, even if they had heard of it.

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[2] http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-cll#heading-Zero
[3] https://www.cllsupport.org.uk/article/welcome-family-professor-chris-fegan-september-2017
[4] https://www.leukaemiacare.org.uk/living-with-leukaemia

These findings highlight the need for a good level of communication and time to be given to a patient at diagnosis, as the majority are not expecting a cancer diagnosis and do not know anything about CLL.

Many patients express how at diagnosis they find it hard to hear what is being said and take in information due to shock and therefore, great consideration must be made to account for this. Particularly for the large numbers of patients who are by themselves at diagnosis.

CASE STUDY – Marc

"After my annual well-man check up with my GP in November 2015, I was called back twice for blood tests because of unusual blood counts. My GP finally referred me to the local oncologist as he suspected I might have a type of blood cancer called chronic lymphocytic leukaemia (CLL). The 'C' word immediately unnerved me, and I started to google info on CLL.

I received a letter two weeks later offering an appointment 4 weeks hence! I was in a position of being able to fund seeing the specialist privately and got an appointment within two days. He advised that it looked like CLL, and from the annual blood counts thought it may have been developing for the last five years. Emotions were high from anger. Why had I not been told earlier by my GP? It was incurable. I was likely to be on Watch and Wait, but it was a less aggressive cancer and I may never need treatment. On this occasion, I took my wife in with me which I cannot recommend enough. She listened and picked up more facts and information than I could in my shock and fear. She attended all consultations with the oncologist."

Understanding Watch and Wait at diagnosis

It can often be very confusing for patients to hear that they have leukaemia, but nothing is going to be done immediately, as common perception in the public is that cancer is a medical emergency that requires treating as soon as possible.

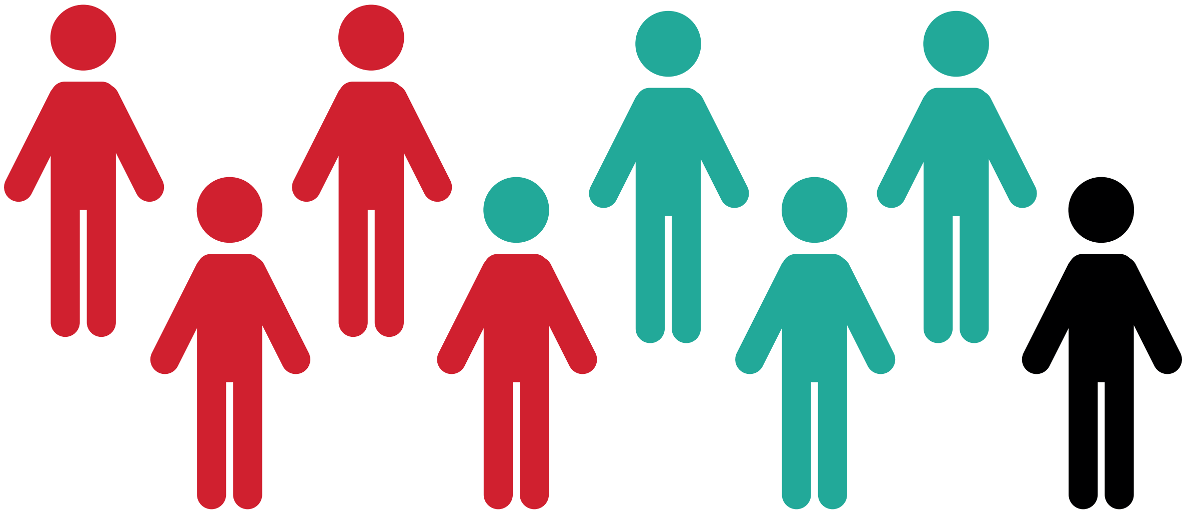
"I was by myself for my appointment and told 'you have leukemia' which immediately scared me to death, I thought, this is it, I am going to die, soon." [Diane]

However, as CLL is currently incurable, 2 in 3 patients may benefit from Watch and Wait. This is because, the treatments are intensive and can lead to greater issues than CLL does in the early stages. Once the CLL has progressed, treatment is necessary to 'reset the clock' and get rid of as many leukaemia cells as possible.

However, 2 in 5 patients (41%) are left without a full understanding of the reasons behind Watch and Wait after diagnosis.

Additionally, just 56% of patients are provided with easily understandable, written information to help them understand Watch and Wait. A third of patients do not receive any written information despite wanting it.

Not providing patients with a good explanation of Watch and Wait could be contributing to over half (53%) of patients having, to some extent, concern or worries about being placed on 'Watch and Wait'. 1 in 4 of these patients reported being very worried or concerned.



Red - No concerns **Green** - Some concerns or worries **Black** - Very concerned

What we did

To understand how Watch and Wait affects people after diagnosis we split the Watch and Wait group into two categories – those who have been treated (WWT) and those who continue to Watch and Wait (WWC). Using the WWC group we can see the experience that patients have while living on Watch and Wait, which can significantly differ from the experience during treatment.

"During Watch and Wait I felt very much alone, until I found a support charity. This was important because I really did not have any information. This all changed when treatment was needed, as I gained access to a Clinical Nurse Specialist. She held my hand through treatment and provided me with all the information and support I needed." [Nick]

The distribution of survey respondents was: 55% had started on Watch and Wait and then been treated (WWT); 23% started treatment at diagnosis: and 22% had only been on Watch and Wait (WWC).

	Started treatment (ST)	**W&W + treated (WWT)**	**W&W Continues (WWC)**
Number of respondents	230	549	214

Living with a blood cancer

Patients on Watch and Wait are often managing progressively worsening symptom burden; of those in the WWC group just 15% hadn't experienced symptoms since diagnosis.

1. The most commonly experienced symptoms are:
2. Fatigue (68%)
3. Sleeping problems (36%)
4. Swollen Lymph nodes (36%)
5. Feeling weak or breathless (31%)
6. Itchy skin (30%)

Fever or night sweats (27%)

Patients on Watch and Wait (WWC) do, however, report less impact on their ability to walk, perform daily tasks and be independent since diagnosis compared to those who have been treated.

Patients are also more likely to be employed and be able to continue employment despite reporting experiencing pain more frequently.

While these patients appear to experience fewer physical and practical issues following diagnosis, the effect on emotional well-being of patients is significant.

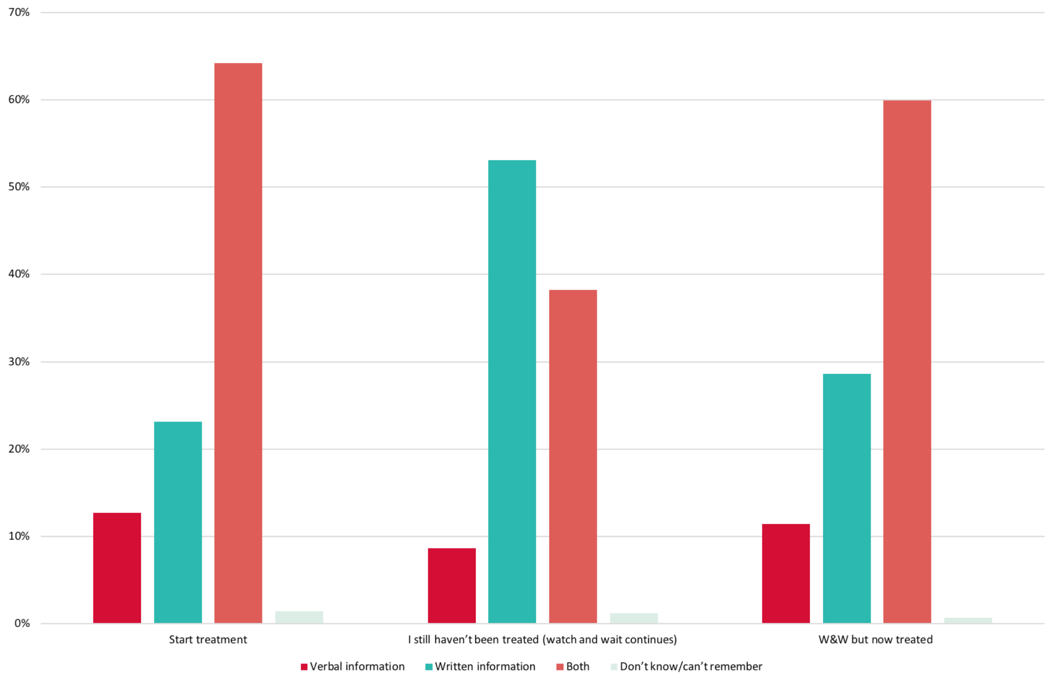
Over half (53%) of patients on Watch and Wait (WWC) reported feeling more depressed or anxious since diagnosis, compared to 35% of ST patients and 38% of WWT patients.

"During the last thirteen years, I have had a lung infection. Two lots of shingles. A few other minor infections. I feel fortunate that I was diagnosed during the last six months of working as the illness didn't impact on my work or finances. I can only say how I have managed W&W. I have lived a very busy life with travel and socialising. I belong to many clubs. I try to keep positive." [Sheila]

Finding further information

Patients often express how support groups can help them come to terms with a diagnosis, as they have the opportunity to speak with others who understand their situation and get answers to their questions. At diagnosis it is important that patients are sign-posted towards this.

Unfortunately, almost half (47%) of patients on Watch and Wait (WWC) did not receive any information about support or self-help groups even though they would have liked it.
Of those who did receive information, WWC patients are twice as likely to receive only written information about support than patients who have been treated. The majority of the treated patients (64% ST and 60% WWT) received both written and verbal information about finding support groups.



The form that patients were given information about support or self-help groups, of those who received it.

Overall, just 1 in 2 patients on Watch and Wait (WWC) are given recommendations for finding further information by their health professionals at diagnosis.

"From the day of my diagnosis, I was offered no professional support other than the reassurance from my hospital doctor that my condition was stable. 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]

Finding further information: The Internet

People on Watch and Wait (WWC) are much more likely to use the internet to find information (84% WWC compared to 47% ST and 60% WWT) and fortunately, do receive slightly better signposting towards trusted websites.

Unfortunately, however, two thirds of patients (68%) are not given any guidance on using the internet.

It is important that patients are provided with guidance on using the internet to find information, because there are websites with out-of-date and inaccurate information. Simply directing patients towards some key websites, such as those from Leukaemia Care or NHS Choices that are verified by the Information Standard, can help to avoid patients being misinformed and unnecessarily concerned.

Support provision

Almost 9 in 10 patients (87%) on Watch and Wait (WWC) state that they would have liked to have support after diagnosis.

Unfortunately, 60% of these patients are not offered any additional support from their hospital, which may explain why they are more than twice as likely to reach out to charities for support than patients who have been treated.

Clinical Nurse Specialists (CNS) are the biggest influencing factor in positive patient experience[5], as they provide emotional and physical support for patients and their families and act as a patient advocate.

Disappointingly, just 24% of patients on Watch and Wait (WWC) said that they had been offered access to a CNS. Access was highest in the WWT group (42%). This may be because Watch and Wait patients are becoming informed and empowered about the support that they should be receiving and access this once treatment begins.

CASE STUDY – David

"With limited knowledge, you are in a dangerous place, and with previous knowledge about a friend but without the understanding of differing types of leukaemia, symptoms or treatment, I did not understand that support, respect and medical help could help to manage my life.

Following the Google search, we found the Leukaemia Care site and that they were running a conference

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[5] http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

day in Liverpool, which is close to me, and welcomed patients, carers and medical staff. What a relief, and I immediately signed up for the day. A quick reply was received by email and welcomed me to joining the participants on the course. I read more about the condition, and as the day approached, I was concerned regarding my ignorance but excited to link with an organisation that appeared supportive and interested in individuals.

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. Thanks to everyone on that day for giving me my life back and confidence to succeed."

GP care provided

Instead of the hospital, some patients may see their GP for their regular follow up appointments and be referred back to consultant care once their disease progresses. Some guidelines suggest that patients with stable disease who only require annual monitoring are suitable for GP follow ups[6].

Even those patients who attend their follow-up appointments at the hospital may have significant interaction with the GP, due to being immune compromised and having to manage symptoms. Therefore, it is important that GPs are aware of a patient's diagnosis and helping to provide the necessary support.

"I continue to have a good relationship with my GP who knows of my condition and will talk to me if I have concerns about any issues which may be caused due to my CLL. I recently had shingles and her response and prescription of medication was rapid and the results effective." [Ian]

It is again disappointing to see that 1 in 4 Watch and Wait (WWC) patients felt their GP was not given enough information about their condition and half of patients said the GP could have done more, or was of no help.

The nature of support received from the GP was, in most cases, simply having access to hospital records (52%). Only 1 in 5 patients discussed signs and symptoms of progression and 1 in 10 (13%) were directed to further support.

"I was discharged and told that I only need 6 monthly blood tests that I can have with my GP surgery. I now feel like I have just been forgotten about and I am sometimes scared that I feel I don't have any support." [Diane]

Involvement in care and patient empowerment

"I am positive due to all knowledge gained from CLLSA that when the time comes for me to receive treatment whilst it may not be an easy time I will come through it and be in good health once again." [David]

It is vital that patients, whether they are going through treatment or Watch and Wait, are given the information and opportunity to make informed decisions about their own care. This allows

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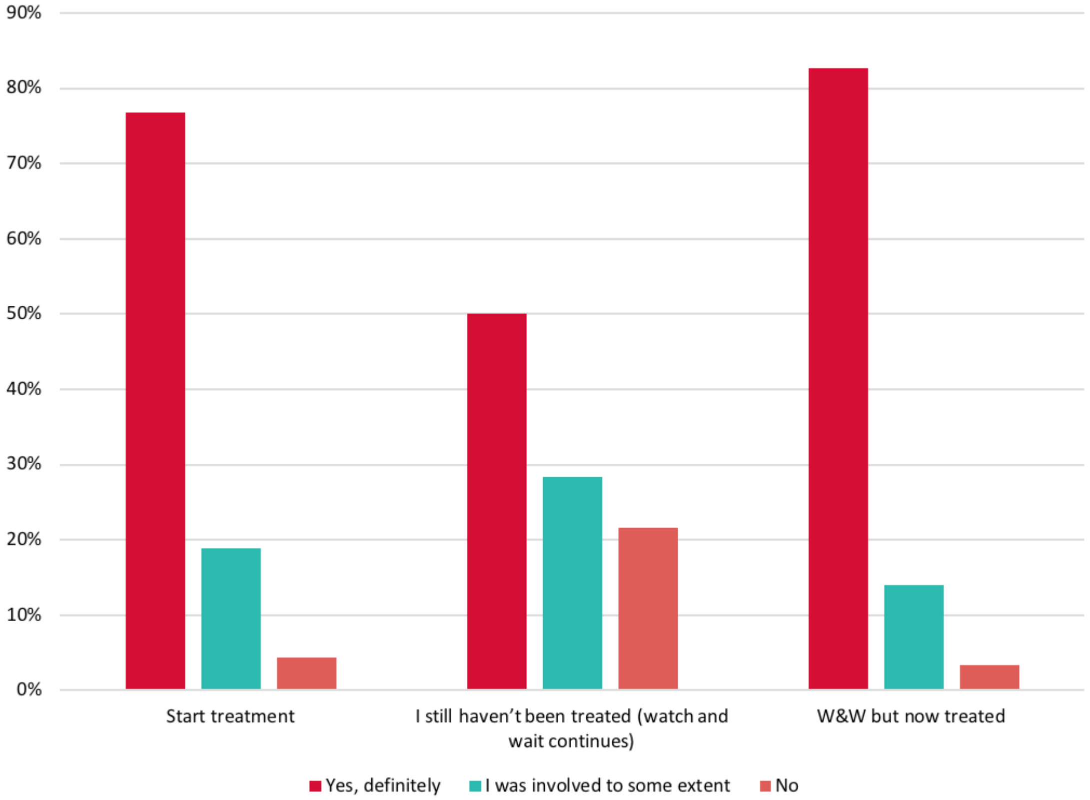
[6] http://www.londoncancer.org/media/123091/Chronic-Lymphocytic-Leukaemia_London-Cancer-Guidelines.pdf

patients needs to be considered.
Unfortunately, patients who have only been on Watch and Wait (WWC) are much less likely to feel involved in their treatment decisions than those who have been treated.



Whether patients felt as though they were involved in decisions about their care as much as they wanted to be.

CLL patients are monitored regularly during Watch and Wait. Part of ensuring CLL patients feel involved in their care, is to ensure they understand their blood test results and feel empowered to monitor their own disease progression.

Watch and Wait (WWC) patients were overall ten times more likely to not be given an explanation at all, compared to patients who have been treated.

61% of the Watch and Wait continues group were monitored every 6 to 12 months, whereas treated patients are monitored more regularly.

Of the WWC patients who were given an explanation, only 44% said they completely understood the explanation of their results and 2 in 5 were not given a copy of their results, despite wanting one.

Involvement in care: views on new treatments

Patients may also feel better empowered and involved in their care if their preferences on new treatments are taken into consideration, where possible.

Perhaps unsurprising, Watch and Wait (WWC) patients are far more likely than treated patients to say they 'don't know' when asked how they would prefer to be treated. For example, where they would prefer treatment; the method of treatment delivery; and side effects vs effectiveness.

Despite this, 98% of Watch and Wait patients said they would like more choice of treatment options – perhaps a reflection on living with an incurable cancer. Numbers were lower for treated patients (72% ST and 80% WWT).

Summary and Recommendations

The emotional impact of Watch and Wait is something that patients often speak about and the findings of our survey clearly demonstrate the extent of this. While patients will be required to adjust to life on Watch and Wait and come to terms with their diagnosis, it should not be a time of constant concern or anxiety as it is for 1 in 8 patients.

Contributing to poor emotional wellbeing of patients on Watch and Wait is:

1) The lack of information provided at different stages

This includes diagnosis and understanding Watch and Wait, receiving and understanding monitoring results, and finding further information on support.

Recommendation 1: Timely signposting to resources from trusted sources to help patients better understand their diagnosis and Watch and Wait.

Recommendation 2: Improving doctor-patient communication to ensure patients are better informed and feel more involved in their care.

2) Lack of support provision for patients

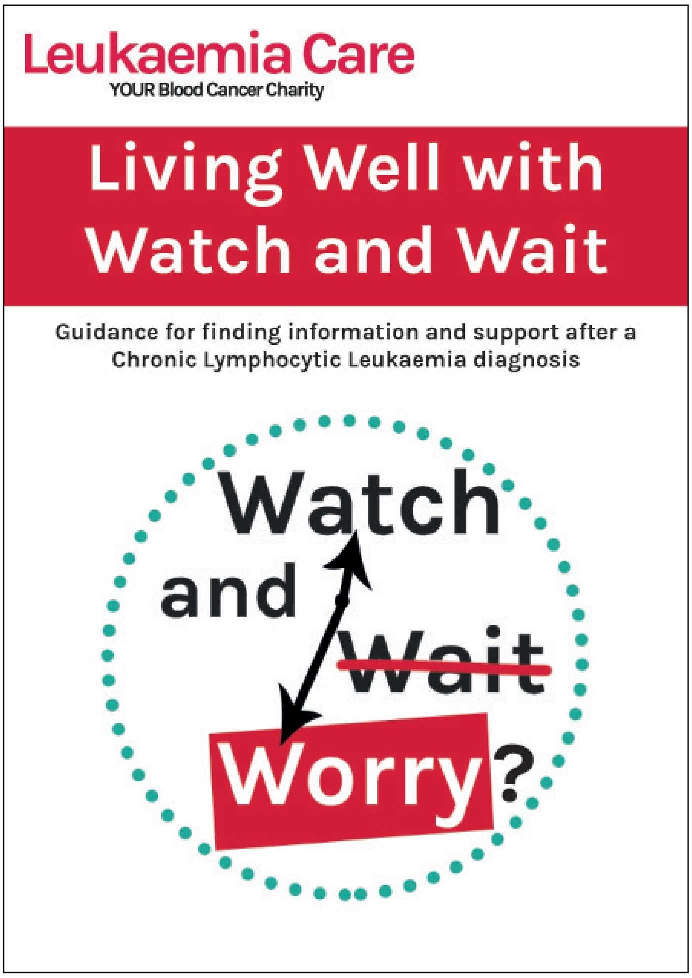
There is evidence of failure to direct patients towards the support services, including provision of a Clinical Nurse Specialist. It is often when patients go online, that they find the support they require from charities and other patients.

Recommendation 3: There is a need for guidance for healthcare professionals, on how to support clinical needs and aid patients to navigate some of the challenges involved with living with and coping with a chronic blood cancer diagnosis and Watch and Wait.

Recommendation 4: All chronic lymphocytic leukaemia (CLL) patients should have access to a named key-worker, normally a Clinical Nurse Specialist (CNS), who can support their clinical and holistic needs following diagnosis.

Recommendation 5: Charities such as Leukaemia Care and the CLL Support Association provide invaluable support for patients online, over-the-phone, and in-person. Patients need to be made aware of the range of support available to them at an early stage in their CLL journey.

"Once I'd been to Liverpool Royal, I had a clear view and am happy that I always have a way of contacting someone if questions arise or advice is required about my condition. Weak and worthless were the feelings I had initially, but now I am a warrior and worthy to assist and enjoy life." [David]



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Living Well with Watch and Wait

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

Watch and ~~Wait~~ Worry?

If you would like more information about the experience of a CLL patient on Watch and Wait or would like to know more about where to seek advice and support from, read Leukaemia Care's patient guidance document *Living Well with Watch and Wait*.

For free, verified information on leukaemia and blood cancer:

Phone the help line: **08088 010 444**

- Order physical copies of our free information
- Talk to a trained nurse

Go to our website: **www.leukaemiacare.org.uk**

- Download free information
- Learn more about our services

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

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Campaigns and advocacy: advocacy@leukaemiacare.org.uk

Help line freephone: 08088 010 444
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