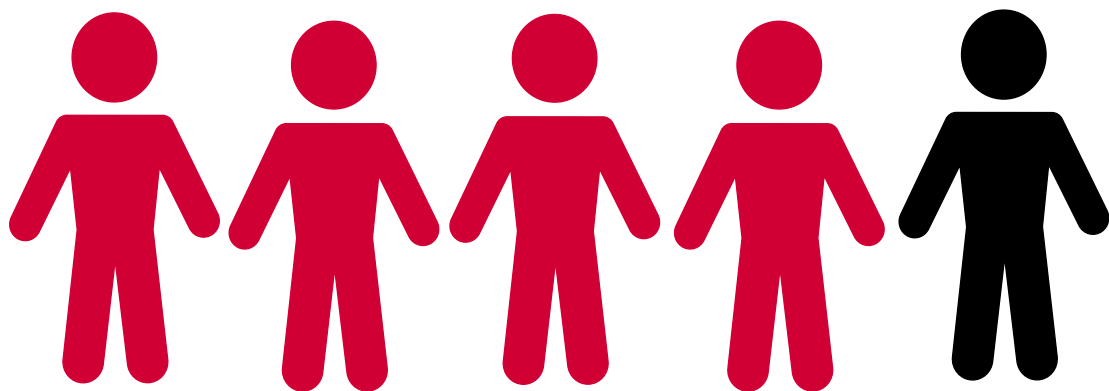


Leukaemia CARE: Living with Leukaemia

A survey of 2,019 leukaemia patients

Executive summary



4 in 5

83% did not suspect cancer before their diagnosis



Blood and Lymphatic cancers

Leukaemia CARE

supporting a quality of life

Over 9,500 people are diagnosed with leukaemia in the UK every year, meaning leukaemia is the 12th most common cancer diagnosed in the UK.¹

Leukaemia is a cancer which starts in blood-forming tissue, usually the bone marrow. It leads to the over-production of abnormal white blood cells, the part of the immune system which defends the body against infection. In most cases of leukaemia there is no obvious cause.

There are a number of different types of leukaemia, but the four most common are:

- Acute myeloid leukaemia (AML)** – Rapidly developing, affects myeloid cells (granulocytes)
- Chronic myeloid leukaemia (CML)** – Slowly developing, affects myeloid cells (granulocytes)
- Acute lymphoblastic leukaemia (ALL)** – Rapidly developing, affects lymphocytes
- Chronic lymphocytic leukaemia (CLL)** – Slowly developing, affects lymphocytes

Acute leukaemia progresses rapidly unless effectively treated, but it can sometimes be cured with standard treatments, such as bone marrow transplants. Chronic leukaemia progresses slowly and although it is not usually possible to cure chronic leukaemia with standard treatments, it can be treated and managed as a long-term condition.

Each year NHS England commission a national cancer patient experience survey (CPES). However, whilst there are similarities and common challenges, we often hear from leukaemia patients that their experiences are very different from other cancer types. Leukaemia CARE appointed Quality Health to undertake a survey of individuals who had received a leukaemia diagnosis. The aim was to gather data on patient's experiences of their diagnosis, care and treatment journey, quality of life, access to information/support and views on potential new treatments. This was done to build on the evidence available through the CPES survey, identifying issues that are specific to leukaemia.

Leukaemia CARE's follow-on survey was sent to 1711 leukaemia patients identified using the National Cancer Patient Experience 2015 Survey, and who had consented to be contacted again. There were 1320 responses received, resulting in a response rate of 78%.

In addition, an anonymous online survey of the wider blood cancer community was also run and publicised by blood cancer charities through various online and print channels. 1199 people completed the online questionnaire, of which 699 identified themselves as leukaemia patients.

The main profile of the leukaemia respondents was as follows:

- 65% came from CPES and 35% were from the anonymous cohort**
- 57% were male, 43% were female**
- Over half of the respondents (59%) were aged between 55 and 74; 16% were aged between 75 and 84; and 3% were aged over 85; 13% were aged 45 to 54; and 9% were under the age of 44**

The results from the survey have created a robust dataset, covering a number of themes. The data has revealed differing aspects of patient experience in relation to the variables present within leukaemia patients, and draws attention to areas where further policy and campaigning work should be undertaken. These areas are listed below.

¹www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero

Awareness of leukaemia as an aid to earlier diagnosis

Leukaemia (as a term) is well known, with 83% of patients reporting that they had heard of it before their diagnosis. However, there is little public understanding of leukaemia, with only a third of these patients reporting that they knew anything about it.

Recommendation 1: There is a need for greater public knowledge of leukaemia. That leukaemia is a cancer of the blood, that can affect people of all ages.

There are numerous signs and symptoms associated with leukaemia but they also are notoriously vague and non-specific. Although a doctor may suspect a patient has leukaemia based on signs and symptoms it can only be diagnosed by laboratory tests.

The most common symptoms reported before diagnosis were fatigue, bleeding or bruising, bone or joint pain, fever or night sweats, sleeping problems and shortness of breath. Additionally, despite most patients (81%) experiencing symptoms before their diagnosis, very few people expected (3%) or suspected (14%) that they may have cancer. This suggests that people are not aware of the symptoms that could indicate a potential leukaemia. As a result, 44% of acute leukaemia patients and 66% of chronic leukaemia patients said they waited over a month before going to see their GP. On average 1 in 5 (22%) leukaemia patients said they visited their GP more than 3 times before they were referred to hospital.

Our results show that there are big differences between the four main types



of leukaemia in the reported route to diagnosis, but overall an emergency presentation was the most common route. In addition, there should be concerns that overall 13% (ranging between 8% and 24% across the different leukaemia types), were initially treated by their GP for another condition. Less than half (44%) of respondents felt their GP had a complete understanding of blood cancers.

Recommendation 2: There needs to be an overall improvement of awareness for the signs and symptoms of leukaemia, amongst both the public and the healthcare professionals who can aid in earlier diagnosis (such as general practitioners).

"GPs need a checklist available in front of them for the symptoms, as I went to them several times with many symptoms, however on blood testing it didn't show at that point. Yet I was very ill and felt I was being a pain, to the point I didn't go see them the last time I felt ill and ended up in the A&E with an issue that had been triggered by cancer." - [Other leukaemia patient, 45-54]

Different types of leukaemia



Whilst some aspects of patient experience are common to all leukaemia types, our results show a number of significant differences between the different types of leukaemia. The most pronounced differences are between acute leukaemia and chronic leukaemia patients. For example, route to diagnosis, being unaccompanied to the diagnosis meeting, impact on work or education, provision of additional support and provision of a Clinical Nurse Specialist.

Recommendation 3: Provision of support and information should be given on a tailored basis, to recognise the different needs of patients with different types of leukaemia.

Understanding of leukaemia diagnosis



On average, only half of all leukaemia patients fully understood the explanation of what was wrong with them, 44% only had a partial understanding and 6% did not understand the explanation at all. Those from the anonymous online cohort of patients were much less likely to say they understood the information, suggesting that this may be a reason that they contact charities for additional information/support.

Recommendation 4: The information and explanation given at diagnosis needs to be improved, to ensure leukaemia patients fully understand what is wrong with them. This should incorporate the provision of written materials at each stage of their journey.

"The way the diagnosis is delivered can be poor and should include an information and contact pack for newly diagnosed patients and their carers." - [CLL patient, 55-64]

"The consultant should have had a nurse or someone to take me aside and explain everything instead of leaving me in shock." - [CLL patient, 75-84]

"I would have liked to have been asked by staff if I would have liked to have a friend or relative with me prior to informing me of my diagnosis (I was taken into a room on a few occasions, told my diagnosis, but never asked if I would like someone with me)." - [CML patient, 35-44]

‘Watch and wait’

The survey confirmed many points about ‘watch and wait’ that patients had raised with us anecdotally. Primarily this focuses on CLL, with over three-quarters (77%) of CLL patients in our sample having been placed on ‘watch and wait’. Almost all patients with CML or with acute leukaemia will start treatment soon after diagnosis. However, there were a small number of non-CLL leukaemia patients that said they were placed into active monitoring.

The majority of people (92%) said they understood the reasons for being placed on ‘watch and wait’, but over half (54%) either had some concerns and worries (42%) or were very worried (12%). Of those who wanted written information about ‘watch and wait’, 56% were given it and found it to be understandable, a third were not given any written information and a further 8% were given information but found it difficult to understand.

Our results show there is a direct correlation between the amount of written information given, how easy it is to understand and to how worried a patient feels. Patients not given any information were 4 times more likely to be very concerned and worried about being put on ‘watch and wait’. In addition, those who said they received information, but that it was difficult to understand were nearly 6 times more likely to be very concerned/worried than those who found the information easy to understand, and 1.5 times more likely than those who were not given any information. Overall, the patients who were most worried were those who received information but found it difficult to understand.

Recommendation 5: Leukaemia patients placed on ‘watch and wait’ should receive a full and understandable explanation about what this means, and this should also include the provision of written information specifically about ‘watch and wait’.

Clinical Trials



Across all types of leukaemia 50% of respondents said they were not given the opportunity to join a trial, although within these responses there was variation between leukaemia types. When people were offered the opportunity to enter a trial, 82% went on to join. There is a clear missed opportunity here for more people to access new and innovative therapies, treatments and regimes which would not otherwise be available on the NHS. Similarly, failure to recruit more people on to trials hinders progress and advances in clinical and observational research.

In addition to this, our survey confirms that older patients are less likely to be given the opportunity to join a clinical trial: 46% of those 65 and over were given the option, compared to 55% of those under 65.

Recommendation 6: Where appropriate, health professionals should speak to leukaemia patients about the option to participate in clinical trials, regardless of the age of the patient.



"I appreciated being included at all stages of my treatment, with making decisions in an inclusive manner." - [ALL patient, 55-64]



Living with Leukaemia

Our survey findings also show a wide range of physical impacts on leukaemia patients. For example, just over half of patients (51%) reported experiencing pain as a result of their condition. Additionally, 43% reported that it had impacted on their mobility, highest in the ALL group (61%). Acute leukaemia patients also reported it impacting on their ability to perform daily routines, such as cooking or cleaning (65% ALL, 59% AML).

One of the areas we were interested to understand, was patients' day-to-day experiences of living with leukaemia. One of the most important areas for leukaemia patients is the impact of their cancer on finances. On average 40% of people reported experiencing a negative impact on their finances, but this ranges between 32% and 60% across the different leukaemia types. Considering that only 55% of leukaemia patients from 2015 CPES said that hospital staff gave them information about how to get financial help or benefits they might be entitled to, this suggests that many patients are not receiving valuable help and advice.

Recommendation 7: The support and advice given by hospitals about the financial impact of leukaemia needs to be improved, incorporating signposting to organisations who offer specialised financial support.

The Internet



Our findings clearly show that there are a variety of different reasons leukaemia patients reach out for support. In addition, the method of support or information desired is different for every patient.

The internet can be a valuable resource, with the NHS stretched to provide time for patients, charity websites can be an excellent source of information and support for people. However, our survey revealed two-thirds of patients weren't told anything about the internet by their health professional, even though 61% had used it to find further information. Those who had spoken with their health professional, and had been advised to look at trusted websites were more likely to find the information useful.

Recommendation 8: When discussing support with leukaemia patients, health professionals should give guidance on using the internet and direct patients to verified websites.



"I felt financial judgements were made about me and did not ask if I needed financial help. The options should be explained carefully and more than once, as the drugs have strong effects." - [ALL patient, 55-64]

"Would like all the financial side and benefits entitled to, explained a lot more in depth and help into getting the right financial help as it's all so hard, stressful and worrying." - [AML patient, 25-34]

"Financial assistance, would be beneficial if someone would fill in and apply for all benefits available, as due to chemotherapy etc. makes it difficult to apply straight away, so lose out on benefits and much needed financial assistance. Car parking fees. Car parking availability." - [CLL patient, 45-54]



Emotional Impact



The emotional impact of a cancer diagnosis should not be underestimated. Leukaemia patients will be challenged in different ways, whether an acute patient dealing with an aggressive illness and invasive treatments, or a chronic patient living with the knowledge they have an incurable disease. There is also the possibility that a patient may relapse, and our research has shown that this has a clear impact on their emotional well-being. Disappointingly, the survey showed that on average only 16% of patients said they were offered counselling or psychotherapy, ranging from 34% down to 8% across the different types, with chronic patients much less likely to say they were offered it compared to their acute counterparts.

Recommendation 9: More consideration should be taken for the psychological and emotional needs of patients, with signposting to appropriate services, and in particular for those on 'watch and wait' and for those who have relapsed.

"GPs and consultants should point the way to support groups. Trawling the internet is not useful to the newly diagnosed. New patients should have a care / treatment / support pack that explains basic things such as what to ask at your next consultation." - [CLL patient, 55-64]

Clinical Nurse Specialists

The survey findings challenge the data available for the provision of Clinical Nurse Specialists (CNSs) to leukaemia patients. 85% of 2015 CPES leukaemia patients said they had been given the name of a CNS, but on average only 38% of the people we surveyed said they had been given access to a CNS. This was even lower for those with a chronic leukaemia and those on 'watch and wait'. There is a clear gap where patients are living with a chronic disease, not in active treatment and are missing the opportunity to access a CNS. As it is widely accepted that the presence of a CNS is one of the most powerful positive influences on a patient's cancer experience, it is imperative that they are made available to all leukaemia patients.

Recommendation 10: The provision of CNSs across all leukaemia types needs to be increased, including patients with a chronic form of leukaemia and those still on 'watch and wait'.



"Specialist nurses do not always have experience of all cancers and concentrate their work on the patients who are suffering from acute cancers with chronic disease being relegated because of urgency and time limitations." - [CLL patient, 65-74]

"On seeing a doctor, when I asked about a support nurse/link nurse, I was sharply told that I would only be allocated one when treatment commences!" - [CLL patient, 55-64]



"I have had wonderful care from day one. Having a named person I could contact for advice was the best thing, hardly ever needed to, but the assistance was there." - [AML patient, 55-64]

"The CNS nurse was invaluable" - [AML patient, 25-34]



For the full report, go to: www.leukaemiacare.org.uk/living-with-leukaemia

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

 01905 755 977  advocacy@leukaemiacare.org.uk

CARE line freephone: 08088 010 444
www.leukaemiacare.org.uk

Registered Charity Number 259483
Scotland Registered Charity Number SC039207

