

Leukaemia Care

YOUR Blood Cancer Charity

Leukaemia Care Living with Leukaemia

Executive summary

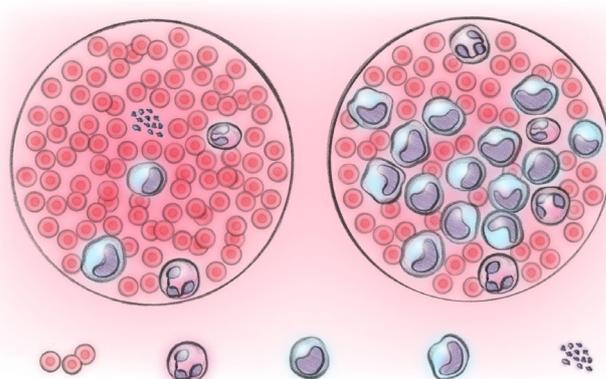


www.leukaemiacare.org.uk

Executive Summary

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:

1. **Acute myeloid leukaemia (AML)** – Rapidly developing, affects myeloid cells (granulocytes)
2. **Chronic myeloid leukaemia (CML)** – Slowly developing, affects myeloid cells (granulocytes)
3. **Acute lymphoblastic leukaemia (ALL)** – Rapidly developing, affects lymphocytes
4. **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. In 2016 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.

Following the success of the 2016 Living with Leukaemia Survey, Leukaemia Care decided to re-run the survey in 2017. The aim was to measure and track annual comparisons and explore certain topics and areas in more detail.

The 2017 survey was sent to 1680 leukaemia patients identified using the National Cancer Patient Experience 2016 Survey, and who had consented to be contacted again. There were 1205 responses received, resulting in a response rate of 73%.

Leukaemia Care also sent the survey to 1173 leukaemia patients identified from their database, where they had given consent to be contacted and just a postal address. There were 557 responses received, resulting in a response rate of 49%. Of these respondents, 508 identified themselves as leukaemia patients, and the rest were other blood cancer patients. In addition, an anonymous online survey of the wider blood cancer community was run, and

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

publicised by blood cancer charities through various online and print channels. 1122 people completed the online questionnaire, of which 616 identified themselves as leukaemia patients, and the rest were other blood cancer patients.

The main profile of the leukaemia respondents was as follows:

- 52% came from CPES, 22% came from Leukaemia Care database, and 26% were from the anonymous cohort
- 55% were male, 45% 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

Once again, the results from the survey have created a robust dataset. The data continues to reveal 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.

Awareness of leukaemia as an aid to earlier diagnosis

It is widely acknowledged that an early diagnosis can have a significant impact on the outcome for cancer patients, and this is certainly true for leukaemia. Patients diagnosed via an emergency route have a lower 1-month and 12-month survival, than those diagnosed by other routes, and this is true across all leukaemia types.

The difficulty faced, is that while there are numerous signs and symptoms associated with leukaemia, they are notoriously vague, non-specific, and can be associated with other health problems. Although a doctor may suspect a patient has leukaemia based on signs and symptoms, it can only be diagnosed by laboratory tests.



Following the results of our 2016 survey we recommended that there needed 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)**. Leukaemia Care launched the 'Spot Leukaemia' campaign with the aim of raising awareness of what leukaemia is, the symptoms to spot and who can be affected by leukaemia. We also host an eLearning tool in collaboration with the Royal College of General Practitioners (RCGP) to support GPs and equip them with the knowledge to spot the signs and symptoms of blood cancer earlier, as well as in person training events around the country.

The results of the 2017 survey show that although most patients (85%) said they experienced symptoms before their diagnosis, very few people expected (4%) or suspected (17%) that they may have cancer. 45% of acute leukaemia patients and 73% of chronic leukaemia patients said they waited over a month before going to see their GP. On average, 15% of leukaemia patients said they visited their GP more than three times before they were referred to hospital. These results show little change and no improvement since the 2016 survey or by year of diagnosis. In addition, less than half (48%) of respondents felt their GP had a complete understanding of

blood cancers, and this has shown no significant improvement over time (by respondents' year of diagnosis).

Recommendation 1: Work and campaigning needs to continue in order to improve 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).

Financial impact of living with leukaemia

One of the most important areas for leukaemia patients is the impact of cancer on their finances. On average, 43% of people reported experiencing a negative impact on their finances, and this ranges between 36% and 56% across the different leukaemia types.

64% of patients reporting a negative impact on their finances (23% of all respondents) had experienced an increase to their monthly costs.

70% of patients reporting a negative impact on their finances (27% of all respondents) had experienced a reduction to their income.

Despite improvement, only 61% of leukaemia patients from 2016 CPES said that hospital staff gave them information about how to get financial help or benefits they might be entitled to. Considering the number of leukaemia respondents reporting a negative impact (whether permanent or temporary), it is important that they are signposted to places they can find and access help.

Recommendation 2: The support and advice given by hospitals about the financial impact of leukaemia needs to continue to improve, incorporating signposting to organisations who offer specialised financial support.

Emotional impact

In 2016 we highlighted the emotional changes that can be caused by a leukaemia diagnosis. Understandably, patients reporting a negative change in their emotional well-being is an ongoing issue in the 2017 survey. Leukaemia patients will continue to 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.



We have identified that some groups of respondents are more likely to report a negative emotional impact, such as those still on 'watch and wait', who have relapsed, or are living with dependent children.

The 2017 survey showed that opportunities to offer emotional support are still being missed. 96% of leukaemia patients wanted information, but of these only 46% were given information on emotional support (59% acute, 39% chronic). In addition, on average only 18% of patients said they were offered counselling or psychotherapy, ranging from 43% 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 3: More importance needs to be placed on the psychological and emotional needs of leukaemia patients. Signposting to appropriate services should be offered to all patients, and should consider those who may be more 'at risk' from deterioration to their mental health, e.g. due to personal circumstances or treatment path.

Leukaemia type executive summary

The following section looks at each main type of leukaemia and highlights the issues that are markedly prevalent within each.

ALL

Awareness of ALL and route to diagnosis

Early diagnosis is a major factor in the prognosis for people with ALL. However, our results show that there are still barriers causing delays in diagnosis. The lack of awareness of potential ALL symptoms and delay in presentation to a healthcare professional is one such issue, as is the number of people who are initially treated for another condition.

The most common symptoms reported for ALL were:

- **Fatigue** 77%
- **Feeling weak or breathless** 64%
- **Fever / night sweats** 42%
- **Easily bruise or bleed** 41%
- **Unexplained weight loss (or loss of appetite)** 31%

Although 56% of ALL patients waited less than a month from experiencing symptoms to visiting a healthcare professional, around a third (34%) waited between 1- 3 months and 10% said they waited longer than 3 months.



35% of ALL patients were sent by their GP to the hospital on the same day and 22% were seen as an emergency/A&E patient. However, over a quarter (27%) were initially treated by their GP for another condition. The NCIN routes to diagnosis report highlights that 65% of patients with ALL are diagnosed by emergency presentation, which is the highest of any cancer type (all cancer average is 22%).

Recommendation 4: Campaigning needs to continue in order to improve awareness for ALL amongst both the public and healthcare professionals.

Financial impact of ALL

55% of ALL patients reported a negative impact on their financial situation. 70% of these said their monthly costs had increased, and 77% said their income had reduced. This is likely to be influenced by these patients undergoing or having undergone active treatment, and being affected by financial issues such as travel, childcare, and taking time off work for appointments. In addition, 65% of ALL patients who were in employment said they had had to stop working, either permanently or temporarily, as a result of their diagnosis.

Recommendation 5: ALL patients should be made aware of, or signposted to, where they can find out about benefits they may be eligible for, both during and after treatment, and where to find advice on employment e.g. their employee rights and returning to work.

AML

Awareness of AML and route to diagnosis

Early diagnosis is also important for patients with AML, as it accounts for over half of leukaemia related deaths. However, as with ALL, our results show that the same barriers are present: lack of awareness of potential symptoms, delayed presentation to a healthcare professional, and initial treatment for another condition.

The most common symptoms reported for AML were:

- **Fatigue** 69%
- **Feeling weak or breathless** 55%
- **Easily bruise or bleed** 35%
- **Fever / night sweats** 27%
- **Pain in bones / joints** 23%

54% of AML patients waited less than a month from experiencing symptoms to visiting a healthcare professional, but 31% waited between 1- 3 months and 15% said they waited longer than 3 months.

30% of AML patients were sent by their GP to the hospital on the same day and 22% were seen as an emergency/A&E patient. However, 23% were initially treated by their GP for another condition.



Recommendation 6: Campaigning needs to continue in order to improve awareness for AML amongst both the public and healthcare professionals.

Financial impact of AML

56% of AML patients reported a negative impact on their financial situation. 65% of these said their monthly costs had increased, and 78% said their income had reduced. As with ALL, this is likely to be influenced by these patients undergoing or having undergone active treatment, and being affected by financial issues such as travel, childcare, and taking time off work for appointments. 75% of AML patients who were in employment said they had had to stop working, either permanently or temporarily, as a result of their diagnosis.

Recommendation 7: AML patients should be made aware of, or signposted to, where they can find out about benefits they may be eligible for, both during and after treatment, and where to find advice on employment e.g. their employee rights and returning to work.

CLL

‘Watch and wait’

78% of CLL respondents who completed the survey reported having been placed on ‘watch and wait’, and of these over a quarter (28%) are still in active monitoring.

60% of the patients said when they were placed on ‘watch and wait’, that they fully understood the reasons why. Over half of patients (53%) had concerns or worries: 42% had some concerns and worries, and 11% were very concerned/worried. Whilst the majority of people (84%) wanted written information about ‘watch and wait’, only around half (56%) were given it and found it easy to understand; 10% said they were given written information, but found it difficult to understand, and the remaining 34% said they were not given written information.



In the 2016 survey we identified that there was a correlation between the amount of written ‘watch and wait’ information given and how easy it is to understand to how worried a patient feels. The same analysis was run again in 2017 and once again shows the same relationship. Patients not given any information were 3 times more likely to be very concerned/worried about being put on ‘watch and wait’ than those who were given written information they understood. However, patients who were given information but found it difficult to understand were over 5 times more likely to be very concerned/worried than those who understood the information, and over 1.5 times more likely than those who were not given any information at all. Overall, it was those patients who were given information they found difficult to understand that were most likely to have worries/concerns.

Recommendation 8: CLL patients placed on ‘watch and wait’ should receive a full and understandable explanation about what this means. Written information should be provided, but should be reviewed to ensure it is clear and understandable, and patients should be given the opportunity (and encouraged) to ask questions about any aspect of ‘watch and wait’ they do not understand.

Clinical Nurse Specialist

It is widely accepted that the presence of a Clinical Nurse Specialist (CNS) is one of the most powerful positive influences on a cancer patient’s experience. Results from the 2016 Cancer Patient Experience Survey reported that 88% of leukaemia patients were given the name of a CNS who would support them through their care. However, the results from our survey indicate that CNS provision is not even across all leukaemia types.

Just 56% of all CLL patients reported that they were given access to a CNS: 61% of those that started treatment straight away, and 54% of those who went onto ‘watch and wait’. In addition, only 29% of the CLL respondents who are still on watch and wait said they have access to a CNS.

There continues to be a gap, where patients living with a chronic disease and are not in active treatment are missing the opportunity to access a CNS and the support and benefits they offer.

Recommendation 9: The provision of CNSs needs to be increased within CLL, and in particular those still on 'watch and wait'.

CML

Treatment options and involvement

CML patients were least likely to say they were 'definitely involved' as much as they wanted to be in decisions about their care and treatment (69%), and also least likely to say they were offered a choice of treatment options (28%).

The main way in which CML is treated is by targeted therapy, through the use of tyrosine kinase inhibitors (TKIs). However, there is still the option to give patients choice, as there are five TKIs that are licensed for use in the UK.

The decision about which TKI is suitable for a patient should take into account the treatment's effectiveness, likely side effects, and how the drug is taken. Side effects vary between TKIs and are likely to be an important factor for a patient, so should be included in treatment discussions. It could also be considered/discussed if the patient would like to ultimately try and achieve treatment-free remission, as there is research to suggest that the use of certain TKIs can be beneficial to this.

Recommendation 10: All clinically appropriate treatment options should be discussed with patients, so that they feel there is an informed choice.

Clinical Nurse Specialist

As with CLL, CML patients were less likely to say that they were given access to a CNS than those patients with an acute leukaemia.

63% of all CML patients reported that they were given access to a CNS compared to 71% of those with an acute leukaemia.

CML patients are most likely to be on continuous treatment for a long period of time, or even indefinitely. Therefore, they may have to manage ongoing long-term side effects and the impact this will have on their work and home life. Even if they are one of a gradually increasing number of patients who will start to try treatment-free remission, they may have to deal with the withdrawal effects from medication, and the emotional impact caused by the worry of disease reoccurrence. Therefore, it is still important that CML patients are given access to a CNS who can support and advise with all of these impacts.



Recommendation 11: The provision of CNSs across CML needs to be increased, to ensure the support of patients living long term with a chronic disease.

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