Patient Experience Survey 2018

Our Living with Leukaemia report shares what people told us about diagnosis, treatment, support and everyday life after a leukaemia diagnosis. The report is based on responses from 2,329 people with leukaemia and helps us understand where patients need better information, better support and better care.

Living with Leukaemia (2018) Full Report

Living with leukaemia in 2018

In 2018, Leukaemia Care published the second *Living with Leukaemia* report. It built on our earlier survey work and looked in more detail at the real experiences of people living with leukaemia in the UK.

The report explored what happened before diagnosis, how people were told they had leukaemia, their treatment and care, the effect on work, money and emotional wellbeing, and whether they got the support they needed. It also highlighted differences between types of leukaemia, including AML, ALL, CLL and CML.

Why this report matters

Leukaemia patients often face different challenges from people with other cancers. Some people become seriously unwell very quickly. Others live for years with an incurable blood cancer and may spend long periods on active monitoring, sometimes called watch and wait. The report shows that these different experiences can lead to very different support needs.

By listening to patients directly, we can use this evidence to improve our services, shape our campaigns and push for better support across the UK.

Key findings

Too many people still face delays before diagnosis

The report found that 85% of patients had symptoms before diagnosis, but only 4% expected cancer and 17% suspected it might be cancer. This shows how easy it can be for leukaemia symptoms to be missed, both by the public and by professionals.

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Many patients also waited a long time before seeing a GP. Forty five percent of people with acute leukaemia and 73% of people with chronic leukaemia said they waited more than a month after symptoms started before getting medical help. Fifteen percent of patients said they saw their GP more than three times before being referred to hospital.

Less than half of respondents, 48%, felt their GP had a complete understanding of blood cancers. The report found little sign of improvement over time.

Leukaemia can have a major impact on money and work

Living with leukaemia often affects more than health. The report found that 43% of people said leukaemia had a negative impact on their finances. Among those affected, 64% said their monthly costs had gone up and 70% said their income had gone down.

This was especially clear for people with acute leukaemias. Fifty five percent of people with ALL and 56% of people with AML reported a negative financial impact. Many also said they had to stop working for a time or permanently because of their diagnosis and treatment.

The report also found that many patients were still not getting enough information about benefits or financial help.

Emotional wellbeing needs more attention

The emotional impact of leukaemia remained one of the strongest messages in the report. Many patients said their emotional wellbeing had got worse after diagnosis, especially people on watch and wait, people who had relapsed, and people with dependent children.

The report found that 96% of patients wanted information, but only 46% were given information on emotional support. On average, only 18% said they were offered counselling or psychotherapy.

This shows that emotional support is still being missed, even though it is a vital part of living with leukaemia.

Watch and wait can be hard to cope with

For many people with CLL, watch and wait was a major issue. Seventy eight percent of CLL respondents said they had been placed on watch and wait, and more than a quarter of them were still being actively monitored.

Only 60% said they fully understood why they had been placed on watch and wait. More than half had concerns or worries. Most people wanted written information, but only around half said they were given information that was easy to understand. The report found that people who received unclear information were much more likely to feel very worried.

This is a strong reminder that clear, compassionate communication matters.

Access to a Clinical Nurse Specialist is not equal

The report found gaps in access to a Clinical Nurse Specialist, also called a CNS. For people living with chronic leukaemias, this was a particular concern.

Just 56% of people with CLL said they had access to a CNS. Among those still on watch and wait, this dropped to 29%. In CML, 63% reported access to a CNS, lower than for people with acute leukaemias.

Patients living long term with leukaemia still need expert support, even if they are not having active treatment.

What needs to change

The report made clear that more must be done to improve awareness of leukaemia symptoms, support earlier diagnosis, and make sure patients get the right information at the right time. It also showed the need for better financial signposting, stronger emotional support, clearer information about watch and wait, and better access to Clinical Nurse Specialists.