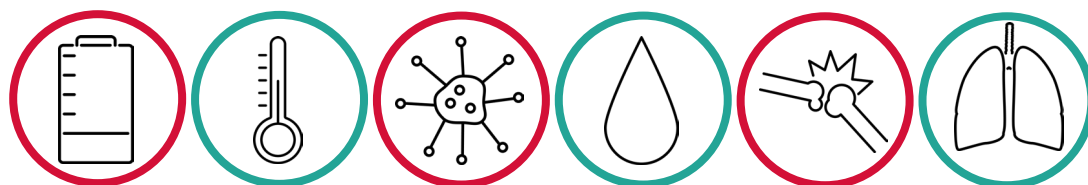


Spot Leukaemia: This is not an awareness campaign; it is an early diagnosis campaign.



Executive summary:

Nearly 10,000 people are diagnosed with leukaemia in the UK every year, or 27 people every day [1]. Yet awareness of leukaemia, and the signs and symptoms which patients present with, is still extremely low. However, raising awareness of leukaemia is not enough; it is early diagnosis that saves lives.

Leukaemia is a cancer which starts in blood-forming tissue, usually the bone marrow. It leads to the overproduction of abnormal white blood cells, which usually form a part of the immune system which defends the body against infection. Leukaemia can affect people of all ages. Leukaemia has a significantly **higher rate of emergency diagnosis (averaging at 37%)** than the overall cancer average (21%) [2]. Emergency presentation is associated with a reduced prospect of survival. A lack of leukaemia awareness could cause delays in presentation and testing, which could explain why leukaemia patients are more likely to present as an emergency, than patients diagnosed with other more common cancers. There are nearly **5000 deaths** attributed to leukaemia every year in the UK [1].

Leukaemia can be hard to spot because, whilst there are numerous signs and symptoms associated with leukaemia, they are non-specific and can be associated with other more common health problems. Although most leukaemia patients (85%) said they experienced symptoms before their diagnosis, very few people suspected (17%) that they may have cancer [3]. We recommend that 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). We're seeking to raise awareness of the common symptoms of leukaemia to encourage presentation to a GP and reduce the number of people diagnosed in an emergency. **Early diagnosis saves lives.**

"A friend of mine had been posting her symptoms during the Spot Leukaemia 2019 campaign and mine looked similar! That opened my eyes and made me wonder: could it be something as serious? I decided I would go to the GP the morning after." - An acute promyelocytic leukaemia patient, 48 hours before being diagnosed.



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We recommend the following:

1. Raise awareness of the training available for GPs about diagnosis of leukaemia and encourage uptake.
2. Provide more clarity about the available data for monitoring early diagnosis rates in blood cancer.
3. Work with charities, such as Leukaemia Care and Leukaemia UK, to improve public awareness of leukaemia.
4. Improve access to blood tests for those experiencing symptoms of leukaemia.

The impact of late diagnosis in leukaemia

Patients with leukaemia (one of the most common forms of blood cancer) have a significantly higher rate of emergency diagnosis than other forms of cancer. Being diagnosed early could significantly improve their outcomes, increasing their chances of survival.

Leukaemia has a significantly higher rate of emergency diagnosis (averaging at 37%), with the highest emergency presentation rates for any cancer type in acute lymphoblastic leukaemia (66%) [2]. This is much higher than the cancer average (21%) [2].

Emergency presentation is associated with significantly reduced survival outcomes. Leukaemia patients diagnosed via an emergency route have a significantly lower 12-month survival than those diagnosed by other routes. For example, only 34% of AML patients diagnosed by emergency route survive to 12 months [2].

By raising awareness, we're aiming to reduce the levels of leukaemia patients diagnosed in an emergency to the cancer average (21%) [2].

What are the barriers and challenges to early diagnosis in leukaemia?

Non-specific symptoms

Even though leukaemia is diagnosed in nearly 10,000 people every year, there is a lack of public awareness of the signs and symptoms of the condition.

Leukaemia can be hard to spot. The non-specific nature of these symptoms often leads patients to attribute their symptoms to other causes, such as lifestyle choices, other more common medical conditions and life stressors.



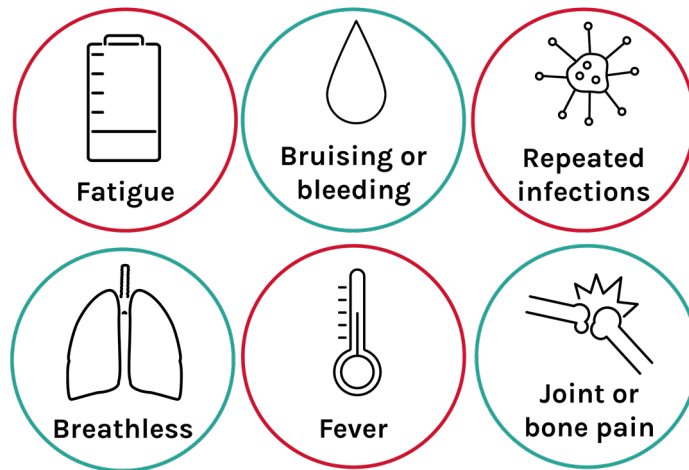
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The most common symptoms are:



In a YouGov poll conducted by Leukaemia Care and Leukaemia UK, only 38% of those polled reported that they would see a GP if they were suffering from fatigue, 21% for fever/night sweats, 37% for joint and bone pain and 39% for unusual bruising [4].

This reluctance to visit a GP is also seen in patients who are asked to reflect on their actions pre-diagnosis. A survey of leukaemia patients conducted by Leukaemia Care revealed that 45% of acute leukaemia patients and 73% of chronic leukaemia patients said they waited over a month after experiencing symptoms before going to see their GP [3].

The low levels of awareness of the signs and symptoms of leukaemia amongst the public, combined with reluctance to contact a GP when experiencing symptoms, could potentially contribute to driving the 'patient interval' (the delay in people presenting to primary care, resulting in them presenting with more severe symptoms later at A and E).

"I had done some Google searching and I had worked out there was something wrong with my blood. I noticed that I had most of the symptoms of leukaemia—paleness, fatigue, repeated infections, joint pain, night sweats and heavier periods—except for unexplained weight loss. I can't have cancer if I haven't lost any weight, I thought to myself." - An acute lymphoblastic leukaemia patient, before diagnosis.

Awareness in primary care settings

Low awareness of leukaemia among primary care health professionals also presents a challenge to achieving early diagnosis.

Results from a survey show that on average, 15% of leukaemia patients said they visited their GP more than three times before they were referred to hospital. Only half (48%) of leukaemia patients felt their GP had a complete understanding of blood cancers, and this has shown no significant improvement over time [3].

The non-specific nature of blood cancer symptoms and the relative rarity of leukaemia could contribute to a 'doctor interval' (delays in testing, referral and diagnosis once a patient



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presents to primary care, potentially leading to a patient to present as an emergency instead - e.g. in Accident and Emergency - as symptoms become more severe).

GPs need to know the signs and symptoms of leukaemia so that patients can be given a blood test and a decision about whether to refer to a specialist can be made quickly, ensuring prompt diagnosis or ruling out leukaemia as a cause of the symptoms. Prompt diagnosis is key for improving survival rates and patient outcomes. AML patients diagnosed as an emergency presentation are over 20% less likely to survive the first month following their diagnosis, compared to patients diagnosed via a GP referral [2].

Supporting ongoing learning and development of primary healthcare professionals can help raise the bar of suspicion of a leukaemia and facilitate early testing and diagnosis. However, recent additional research, conducted by Leukaemia Care and Leukaemia UK, has also highlighted that GPs are not always able to conduct the blood tests according to the National Institute of Health and Care Excellence (NICE) NG12 guidelines. There are a variety of factors for this; the full report can be read [here](#). This research highlights how training must include full blood count interpretation and that GPs also need support at the point of care to remember to think cancer in relation to the non-specific symptoms.

Recommendation 1: Raise awareness of the training available for GPs about diagnosis of leukaemia and encourage uptake.

Training is available and free for all GPs, from both the Royal College of General Practitioners (RCGP) and GatewayC. Gateway C are also working to encourage medical students at university to take these courses too, work which should be supported by the NHS. Cancer Alliances, CCGs and local trusts should be encouraged to promote the learning materials to GPs in their area.

"Eventually, I got an infection in my mouth, so I went to the doctors for antibiotics. They asked if they could do a blood test as well. Two hours later, I got a phone call from them saying there was a bed waiting for me on the haematology ward: 'We think you might have cancer'." - An acute myeloid leukaemia patient, before diagnosis.

However, studies have shown about one-third of emergency presenters (particularly those in older and more deprived groups) have had no GP consultations prior to diagnosis [6]. Therefore, it is important that primary care campaigns are accompanied by public campaigns to encourage presentation to primary care at an early stage.

Measuring progress on early diagnosis in leukaemia

The NHS committed to improving early diagnosis of cancer in the Long-Term Plan, which was published in 2019. This Long Term Plan sets out goals to improve outcomes for patients with cancer. This plan proposes that by 2028, the proportion of cancers diagnosed at stages 1 and 2 will rise from around 50% to 75% of cancer patients. By achieving this, 55,000 more cancer patients each year will survive their diagnosis for at least 5 years after diagnosis [7]. However, this target may struggle to measure progress in blood cancer patients, including



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leukaemia patients, because leukaemia is a cancer that is not diagnosed in stages. Therefore, there is a need for another way to track the progress of early diagnosis for leukaemia patients. Blood cancers are the 5th most common cancer, so the ambition to increase the number of cancers caught early are unlikely to be successful without improvements in blood cancers, including leukaemia.

Recommendation 2: Provide more clarity about the available data for monitoring early diagnosis rates in blood cancer.

As such, NHS England and Public Health England need to work together with blood cancer charities to provide clarity or potentially create proxy measures for the rate of early diagnosis in unstageable cancers, such as leukaemia, to ensure progress of reducing late stage diagnosis can be measured in blood cancer patients too. Providing clarity on the available data for monitoring early diagnosis rates in blood cancer is essential for encouraging development in tackling early diagnosis delays.

We await the new 10 year Cancer Plan, announced in February 2022 and intended to supersede the Long Term Plan, as well as a new Scottish Cancer Strategy. Both of these strategies must include an acknowledgement that leukaemia cannot be staged and make commitments to monitor and publish the emergency diagnosis rates in a more timely manner.

The impact of COVID-19 on diagnosis

The COVID-19 pandemic continues. In 2020, four in ten people were too concerned about being a burden on the NHS to seek help from their GP [8]. Furthermore, reduced capacity and longer waiting times in diagnostic services reduced rates of early diagnosis and reduced survival of cancer patients earlier in the pandemic [9]. Recent media reports show that pressure on the NHS has not decreased in 2022, so there is reason to believe that COVID continues to impact upon leukaemia diagnosis. However, there has not been formal analysis published on this. Analysis has focused on 2 week wait referrals [9], but a more comprehensive review is urgently needed, including all routes to diagnosis.

There is an urgent need to fully quantify the impact of COVID-19 on cancer diagnoses in the future, to ensure those affected receive support and to plan for the future. We previously called for this to happen by January 2021. We still await this analysis, although we acknowledge the start of a COVID-19 inquiry very shortly.

Public awareness of leukaemia and misconceptions

Leukaemia is not just a childhood disease, affecting people of all ages. Despite this, 30% of people still think leukaemia mostly affects 0-15-year olds [4].

It is true that leukaemia is the most common cancer in children, accounting for over 31% of all cases of childhood cancer [5]. The most common type of leukaemia in children is acute lymphoblastic leukaemia (ALL), where incidence rates are highest in 0-4-year-old children [5]. Leukaemia awareness is still important in this group, as over 65% of children (0-14 years old)



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with these acute leukaemia are diagnosed via emergency presentation [2].

However, contrary to popular perceptions, leukaemia is most common in over 75 year olds, who account for almost 4 in 10 of all new leukaemia cases [1]. Leukaemia incidence correlates strongly with increasing age, with the majority of cases being diagnosed in people over 75 [2]. Furthermore, for most types of leukaemia, one-year survival significantly decreases as age increases across most routes to diagnosis [2].

Recommendation 3: Work with charities, such as Leukaemia Care and Leukaemia UK, to improve public awareness of leukaemia.

There needs to be greater public awareness of the signs and symptoms of leukaemia and a better understanding that leukaemia can affect people of all ages. It is also important the GPs are aware of this age misconception, to ensure an older patient's symptoms are seen in the appropriate context.

We welcome recent announcements from NHS England that a blood cancer campaign will be conducted. We hope this will be extended to all UK nations. It should also take into consideration the differences between blood cancer types. Cancer Alliances should also be encouraged to promote this campaign at a local level, especially among black and ethnic minority members of the community.

The role of blood testing

A full blood count is all that is needed to diagnose leukaemia early or to rule it out, and this report explores this issue in particular. Leukaemia Care and Leukaemia UK conducted a large patient survey to understand more about patient experience of obtaining the full blood count. We also spoke with our GP advisors. Our key findings include:

- According to the NICE NG12 guidelines, everyone presenting with the symptoms of leukaemia should get an urgent 48-hour full blood count. However, in our survey, only 1/3 reported that they got a blood test straight away after seeing a GP about their symptoms (i.e. following one appointment only).
- In addition 23.5% of acute leukaemia respondents said it took up to 3-4 months after first presenting to the GP to get a blood test.
- Furthermore, our GP advisors informed us that the system and capacity pressures they face stop them from conducting full blood counts every time they see a patient with the symptoms in the NG12 guidelines, even though they are aware that they should be.

GPs are in need of further support beyond the publication of guidelines. Therefore, the recommendations we propose to address these issues are:

- All stakeholders should promote GP education tools that are available on the topic of leukaemia, to help GPs become more familiar with the symptoms of leukaemia. NICE should conduct a review of the guidelines to ensure the description of symptoms is accurate according to the experiences of general practitioners and patients.



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- All relevant stakeholders should come together to create decision support tools that work based on symptoms experienced by a patient, leading GPs to discover NICE guidelines regardless of whether they are already suspecting cancer. This must cover non-specific symptoms.
- Local and national NHS bodies should work together to ensure that GPs to have better access to advice and guidance from haematology and access to education around interpreting full blood counts.
- Departments of Health across the UK must address the GP and other primary care or diagnostic workforce pressures, providing adequate investment.
- The Royal College of Pathologists should advise members on best practice for providing information to GPs alongside the full blood count test results, abnormal or otherwise, and ensure an urgent blood film is done on all abnormal full blood counts.
- Pharmacists should receive equivalent training on the symptoms of leukaemia. They should be able to refer patients presenting with symptoms to GPs for urgent appointments. Studies investigating the potential of conducting blood testing elsewhere in the community, including pharmacies, must also be encouraged.

The full report into blood testing can be found [here](#).



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ABOUT LEUKAEMIA CARE

Leukaemia Care is the UK's leading leukaemia charity.

For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support. We are here for everyone affected by leukaemia and related blood cancer types – such as myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN). We believe in improving lives and being a force for change. To do this, we have to challenge the status quo and do things differently.

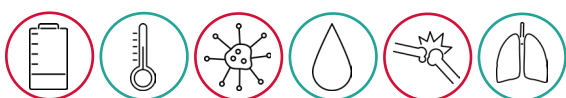
ABOUT LEUKAEMIA UK

We are Leukaemia UK. We believe research has the power to stop leukaemia devastating lives.

Despite decades of incredible progress, only half of leukaemia patients live longer than five years after their diagnosis*. We won't stop until we change this.

Bringing together the leukaemia community, we will accelerate progress through life-changing research, doing everything we can to make sure that the next person with leukaemia has the best possible experience of diagnosis, treatment and care.

*(53.5% - 5 year survival rate across all leukaemia types and age groups, Office for National Statistics, Cancer survival by stage at diagnosis for England, 2019).



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