

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

Over 10,000 people are diagnosed with leukaemia in the UK every year, or 28 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. Prior to the COVID-19 pandemic, leukaemia had a significantly higher rate of emergency diagnosis (averaging at 42%) than the overall cancer average (21%) [2]. Data indicates this has only got worse during the pandemic, as the rate of leukaemia patients presenting as an emergency has increased further. This suggests there is, or was for a period, public reluctance to visit the GP and a general lack of leukaemia symptom awareness on top of this could cause the delays in presentation seen. Emergency diagnosis is associated with a reduced prospect of survival; there are nearly 5000 deaths attributed to leukaemia every 2 years in the UK [1]. This is why our Spot Leukaemia campaign is vital now, more than ever, to tackle early diagnosis and save lives.

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]. Furthermore, YouGov results from 2020 show that the majority of people would not visit a medical professional when experiencing the common leukaemia symptoms [4]. Additionally, 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 [5]. 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 calling on the NHS and UK governments to work with us to improve awareness of the issues faced by leukaemia patients in getting diagnosed early. 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.



Can you #SpotLeukaemia?
spotleukaemia.org.uk

Leukaemia Care
YOUR Blood Cancer Charity



But we cannot do this alone. Therefore, we recommend the following actions:

1. Work with charities, such as Leukaemia Care, to improve public awareness of leukaemia and undertake a mass awareness campaign as part of existing public health initiatives
2. Ensure anyone presenting with one or more symptoms of leukaemia has a blood test to either rule out or diagnose leukaemia as early as possible
3. Make leukaemia learning a mandatory part of GP continuing professional development, and increase training for other healthcare professionals, e.g. opticians and pharmacists.
4. Provide more clarity about the available data for monitoring early diagnosis rates in blood cancer and urgently publish data covering the COVID-19 pandemic.

The impact of late diagnosis in leukaemia

Leukaemia has a high 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 or more [2].

By raising awareness, we're aiming to reduce the levels of leukaemia patients diagnosed in an emergency to below the cancer average.

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

Non-specific symptoms

Even though leukaemia is diagnosed in 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.

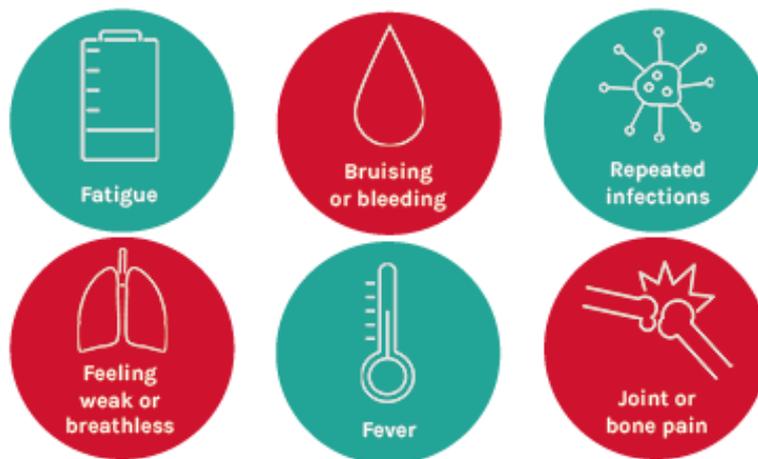


Can you #SpotLeukaemia?
spotleukaemia.org.uk

Leukaemia Care
YOUR Blood Cancer Charity



The most common symptoms are:



In a YouGov poll conducted by Leukaemia Care in 2020, only 23% of those polled reported that they would see a GP if they were suffering from fatigue, 28% for fever/night sweats, 42% for joint and bone pain, and 45% for easily bruising and bleeding [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 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.

Public awareness of leukaemia and misconceptions

Leukaemia is not just a childhood disease, affecting people of all ages. Despite this, 27% 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 [6]. The most common type of leukaemia in children is acute lymphoblastic leukaemia (ALL), where incidence rates are highest in 0-4-year-old children [6]. Leukaemia awareness is still important in this group, as over 65% of children (0-14 years old) with this 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



Can you #SpotLeukaemia?
spotleukaemia.org.uk

Leukaemia Care
YOUR Blood Cancer Charity



strongly with increasing age, with the majority of cases being diagnosed in people over 75 [1]. Furthermore, for most types of leukaemia, one-year survival significantly decreases as age increases across most routes to diagnosis [2].

Recommendation 1: Work with charities, such as Leukaemia Care, to improve public awareness of leukaemia and undertake a mass awareness campaign as part of existing public health initiatives

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.

This could be improved by supporting existing campaigns (such as Spot Leukaemia) or incorporating a campaign about leukaemia into the next iteration of the Be Clear on Cancer campaign strategy, run by Public Health England or any successors. Cancer Alliances should also be encouraged to promote this campaign at a local level, especially among black and ethnic minority members of the community.

Awareness in primary care settings

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

Results from Leukaemia Care's Living with Leukaemia 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 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. A blood test is all that is needed to either diagnose leukaemia or rule it out, and may give information about a potential alternative diagnosis. Subsequently, a decision about whether to refer to a specialist can be made quickly if leukaemia is suspected. It is vitally important that blood testing and pathology capacity is increased to meet this demand. Prompt diagnosis via a blood test is key for improving survival rates and patient outcomes; early diagnosis will save lives. 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 and ensuring quick access to simple tests can help raise the bar of suspicion of a blood cancer and facilitate early testing and 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 [5]. Therefore,



Can you #SpotLeukaemia?
spotleukaemia.org.uk

Leukaemia Care
YOUR Blood Cancer Charity



it is important that primary care campaigns are accompanied by public campaigns to encourage presentation to primary care at an early stage.

Recommendation 2: Ensure anyone presenting with one or more symptoms of leukaemia has a blood test to either rule out or diagnose leukaemia.

Recommendation 3: Make leukaemia learning a mandatory part of GP continuing professional development, and increase training for other healthcare professionals, e.g. opticians and pharmacists.

We've been working to make sure training is available and free for all GPs, in partnership with both the Royal College of General Practitioners (RCGP) and GatewayC. GatewayC are also working to encourage medical students at university to take these courses too, work which should be supported by the NHS. Leukaemia Care have also developed a course for pharmacists and is working with pharmacists to develop learning events. Cancer Alliances, CCGs and local trusts should be encouraged to promote the learning materials to GPs and other primary care professionals 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.

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, the NHS has failed to publish any data on their progress on meeting this target, nor any information on the impact of COVID-19 on this specific target. Additionally, this target may struggle to measure progress in blood cancer patients, including 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.

The impact of COVID-19 on diagnosis

We believe that this campaign is even more important now, in 2021, than it was prior to the COVID-19 pandemic. Preliminary data shows there is likely to be an impact on rates of early diagnosis as a result of the COVID-19 pandemic.



Can you #SpotLeukaemia?
spotleukaemia.org.uk

Leukaemia Care
YOUR Blood Cancer Charity



Four in ten people were too concerned about being a burden on the NHS to seek help from their GP during the first wave of the pandemic in 2020 [8]. Furthermore, reduced capacity and longer waiting times in diagnostic services were shown to have reduced rates of early diagnosis and reduced survival of cancer patients [9]. Cancer Research UK noted a drop in two-week-wait figures, with 290,000 less people being referred to secondary care over 10 weeks [10]. Urgent two-week wait referrals dropped to 25% of the usual levels at the start of the pandemic and although have increased since, they are still significantly lower than usual at the time of writing [10]. The drop in referral rate is potentially influenced not only by a 30% drop in GP appointments during March 2020 [11] but also GPs' reluctance to send patients to hospitals, as well as some diagnostic services being suspended.[10]. Patients and clinicians are also reporting difficulties in accessing blood tests in the primary care setting. A backlog of referrals for cancer presentation via 2 week wait pathway over a 3 month lockdown has been estimated to result in a significant loss of life [9]. Furthermore, the UK has seen 6,000 fewer people than expected receiving chemotherapy during the lockdown [10].

Leukaemia is amongst the worst performing cancers for rates of emergency diagnosis. Data from the CancerData dashboard for emergency presentation suggests that more people presented as an emergency during the pandemic than in late 2019. For people diagnosed with a leukaemia¹, the rate of people presenting as an emergency has increased from 41.9% in the last quarter of 2019 to 46.3% in quarter 3 of 2020 (the most recent available) [12]. Whilst this is a small increase, any increase on a baseline that was already much higher than the cancer average rate of emergency presentation is concerning. This data also shows a small increase in emergency presentations in chronic lymphocytic leukaemia (CLL) [12], a condition that is slow to develop and therefore should be caught early when symptoms first begin. We urgently require further data to understand how these people were subsequently diagnosed and whether this emergency presentation affected their outcomes.

Recommendation 4: Provide more clarity about the available data for monitoring early diagnosis rates in blood cancer and urgently publish data and analysis of the period covering the COVID-19 pandemic.

As such, NHS England/NHS Digital (due to take over the data analysis when Public Health England ceases to exist) and equivalent bodies in the devolved nations (e.g., Public Health Scotland) 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. To help us fully understand and address the impact of the COVID-19 pandemic on emergency presentations, we're also asking the NHS to release the most recent data on this.

¹Any leukaemia except AML and CLL



Can you #SpotLeukaemia?
spotleukaemia.org.uk

Leukaemia Care
YOUR Blood Cancer Charity



ABOUT LEUKAEMIA CARE

Leukaemia Care is a national blood cancer support charity. We are dedicated to ensuring that anyone affected by blood cancer receives the right information, advice and support.

A diagnosis of a blood cancer can have a huge impact on someone emotionally, as well as physically. We understand that feelings of shock, anger and loneliness are all common at the time of diagnosis, during treatment and recovery and having someone to talk to, as well as the right information available can be a huge comfort. We not only support patients, but carers and families too who can often carry a lot of the emotional strain when someone they love is diagnosed with a blood cancer. We focus on the support that is needed now to help those affected by blood cancer cope during a diagnosis and beyond.

Leukaemia Care launched the 'Spot Leukaemia' campaign with the aim of improving outcomes for leukaemia patients by improving early diagnosis rates. We're aiming to do this through raising awareness of what leukaemia is, the symptoms to spot and who can be affected by leukaemia. This requires both increased public awareness and also working with healthcare professionals such as GPs, dentists and pharmacists to help them spot leukaemia in their patients.

References

- [1] Cancer Research Leukaemia (all subtypes combined) statistics, available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia>
- [2] National Cancer Registration and Analysis Service Routes to Diagnosis workbook 2006-2016, available at: http://www.ncin.org.uk/publications/routes_to_diagnosis
- [3] Leukaemia Care Living with Leukaemia 2017 Survey, available at: <https://www.leukaemiacare.org.uk/our-campaigns/living-with-leukaemia/>
- [4] World Leukaemia Awareness 2020 YouGov Poll (UK results). Conducted by YouGov on behalf of Leukaemia Care
- [5] Abel et al, Emergency diagnosis of cancer and previous general practice consultations: insights from linked patient survey data, available at: <https://bjgp.org/content/67/659/e377>
- [6] National Cancer Registration and Analysis Service Childhood Cancer Statistics, England Annual report 2018, available at: <http://www.ncin.org.uk/publications/reports/>
- [7] NHS England, The NHS Long Term Plan, available at <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>
- [8] NHS England, Help Us Help You: NHS Urges Public To Get Care When They Need It. [online] available at: <https://www.england.nhs.uk/2020/04/help-us-help-you-nhs-urges-public-to-get-care-when-they-need-it/>



Can you #SpotLeukaemia?
spotleukaemia.org.uk

Leukaemia Care
YOUR Blood Cancer Charity



[9] Sud et al, Effect of delays in the 2-week-wait cancer referral pathway during the COVID-19 pandemic on cancer survival in the UK: a modelling study, available at: [https://doi.org/10.1016/S1470-2045\(20\)30392-2](https://doi.org/10.1016/S1470-2045(20)30392-2)

[10] Cancer Research Over 2 million people waiting for cancer screening, tests and treatment, available at: <https://scienceblog.cancerresearchuk.org/2020/06/01/impact-of-coronavirus-on-cancer-services-revealed-over-2-million-people-waiting-for-screening-tests-and-treatments/>

[11] NHS England Appointments in General Practice - March 2020, available at: <https://digital.nhs.uk/data-and-information/publications/statistical/appointments-in-general-practice/march-2020>

[12] CancerData dashboard. Emergency Presentations. Available at: <https://www.cancerdata.nhs.uk/emergencypresentations>. Last accessed 18th August 2021.



Can you #SpotLeukaemia?
spotleukaemia.org.uk

Leukaemia Care
YOUR Blood Cancer Charity

