

Turning ambition into progress for people with leukaemia in Wales

- ✔ Diagnose earlier, diagnose better.
- ✔ Access to world-class treatment.
- ✔ A cancer system that delivers.

FOREWORD:

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Wales has a critical opportunity to change what a leukaemia diagnosis means for people across the nation. Around 400 people are diagnosed with leukaemia every year, yet gaps remain in diagnosis, treatment, and care, exacerbated by unequal access to specialist treatment.¹

This Senedd must represent a moment of real change.

Leukaemia affects people of all ages across Wales. However, experiences of diagnosis, and access to, treatment, clinical trials, and specialist care are inconsistent. Data gaps make it harder to understand outcomes and drive improvements. The consequence is clear and unacceptable: too many people

are still dying from leukaemia. Only half of those diagnosed with leukaemia survive more than five years after their diagnosis.²

A stronger policy focus is needed. Wales lacks a national cancer strategy which would provide the credibility needed to improve cancer outcomes. Existing policies do not adequately address leukaemia. For instance, there is no National Optimal Pathway for leukaemia to support timely and consistent access to high-quality care for everyone diagnosed.

Leukaemia UK is a charity that funds life-changing research and campaigns for change, with a vision to stop leukaemia from devastating lives. We believe that together we have the power to transform survival and improve the quality of life for those living with leukaemia.

Wales has a committed clinical and expert community, and growing momentum around cancer improvement, across both the Government and NHS Wales. However, to drive the change needed, leukaemia and other blood cancers must not be overlooked by national health policy or by decision makers.

Throughout this Senedd, we have a real opportunity to ensure that everyone is supported to live well and as long as possible with and beyond leukaemia.

This report sets out how we can achieve this by working together to ensure earlier and better diagnosis, improve access to clinical trials and new treatments, and address system-wide gaps that hold patients back.

This is a pivotal moment; this Senedd must be one of delivery.

We are ready to work with the Welsh Government to turn ambition into progress for patients.

Together, we can improve outcomes and build a future where people across Wales can survive leukaemia and live well.

With your political leadership, the future for people affected by leukaemia in Wales can be transformed.

Let's work together to stop leukaemia devastating lives.

Why leukaemia must be a **priority** for Wales

Each year, around 400 people in Wales are diagnosed with leukaemia,³ and only half will survive for more than five years.⁴ Survival is even worse for acute myeloid leukaemia (AML), where shockingly just 15% of patients live beyond five years.⁵ Every diagnosis and death has a profound impact; devastating families and communities.

Leukaemia often presents with vague, non-specific symptoms, making it difficult for both patients and healthcare professionals to recognise.

This can result in a delayed diagnosis, or a diagnosis in an emergency setting. For too long, this has been accepted as the norm in leukaemia.

While it may sometimes be the fastest route, an emergency diagnosis is associated with poorer patient outcomes.

Experiences vary widely: some people are diagnosed after their first GP visit, while others endure prolonged uncertainty, multiple appointments, and the emotional strain of waiting for answers.

"Vinnie was four years old when he started complaining his legs were hurting. I noticed he was lethargic, short of breath, had constant ear infections and a strange lump on the back of his neck.

We first went to the doctor in June 2023, and again the following month as he was no better. Both times we were told he had a virus. Then we took him to A&E as he had an uncontrollable temperature. They thought it was meningitis initially, but they got everything under control with paracetamol and ibuprofen, and we were eventually sent home. In August he was admitted to the hospital but again we were sent home with the news that, yet again, it was just viral. Mother's instincts kept telling me something was wrong, but the doctors just told me I was being an over-protective parent.

In September, we went to A&E again and were told the same thing. In fact, at that point the GP referred us for physio for his aching legs. None of it made any sense but what choice did we have?

This continued, in November we went back in A&E and were again told it was viral. The following week I went back to the GP and this time I made them listen to me – this wasn't right and I wanted more investigations. We were sent to the children's ward in the Princess of Wales hospital where at last I talked to the best doctor who listened to my concerns and immediately acted by taking a simple blood test.

On 27th November 2023, Vinnie was diagnosed with precursor B-cell acute lymphoblastic leukaemia."

– Sarah Kent, 33, Mother of Vinnie

We often hear from our patient community that experiences of diagnosis, treatment and care vary depending on where people live.

Publicly available data reflects this and shows stark disparities in outcomes across Wales. Leukaemia mortality rates in the Welsh Health Boards with the highest mortality, such as Cwm Taf Morgannwg, are 30% higher than in others, including Cardiff and Vale.⁶

It should not be the case that an individual's postcode determines their chance of survival.

NHS cancer services in Wales are being held back by fragmented national leadership. Audit Wales has been clear that current arrangements do not provide the strong, coordinated leadership needed across Government and NHS systems to drive system-wide improvements.⁷

Our message for the Senedd is clear: include leukaemia in national policy, and ensure a future where everyone diagnosed with leukaemia, wherever they are from, survives and lives well.

Research has
the power to
change lives

Leukaemia^{UK}

The next decade:
A future
where more
people survive
leukaemia and
live well

Wales has a critical opportunity to change what a leukaemia diagnosis means for people across the nation. This Senedd could see significant progress made. We know that change is possible.

Over the next decade, we believe the landscape for leukaemia patients in Wales can be radically different: a country where more people survive leukaemia and live well, and where fewer lives are devastated by the disease.

It is our ambition at Leukaemia UK to work with decision makers in the Welsh Government and NHS systems to make this a reality.

With strong leadership and an empowered system, focused on diagnosing leukaemia earlier and better, and ensuring access to world-class treatments and care, we can achieve a future where:

1. Survival of leukaemia types with poorer prognosis, such as AML, is transformed.
2. Everyone diagnosed with leukaemia has the best possible quality of life.

Overall five-year survival rate for leukaemia Survival⁸



Diagnose earlier, diagnose better

If Wales is to transform survival for leukaemia types with poorer prognosis, it must deliver earlier and better diagnosis for leukaemia patients, and address existing disparities.

A full blood count is all that is needed to rule out or indicate leukaemia. Any patient presenting to their GP with suspected leukaemia symptoms should be referred for this simple and inexpensive blood test within 48 hours. Yet too many people are still diagnosed late.

National Optimal Pathways have been developed for twenty-one cancer types in Wales, providing professional guidance and standards for patients suspected of having the relevant cancer type, with the aim of reducing variation and ensuring consistency across the NHS.⁹ However, there is yet to be a National Optimal Pathway for leukaemia.

Incidence in Wales

400

people every year
are diagnosed with
leukaemia¹⁰



By working together with the NHS, the Senedd can create a new reality for people with leukaemia. Earlier and better diagnosis can be delivered through:

- ✓ Ensuring those who present with symptoms indicative of leukaemia are referred for an urgent full blood count within 48 hours of presentation.

- ✓ Integrating automatic prompts into Individual Health Records to encourage healthcare professionals to refer patients with suspected leukaemia for a full blood count.

- ✓ Running a symptom awareness campaign to empower the public and GPs to recognise leukaemia and act urgently.

- ✓ Funding and implementing a National Optimal Pathway for leukaemia.

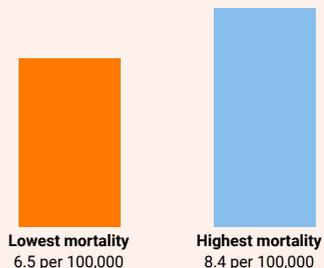
Access to world-class treatment and care across Wales

Wales cannot allow the significant variations in access to treatments and care outcomes to continue. These must be addressed if we are to stop leukaemia from devastating lives.

Every patient, regardless of where they live, deserves access to world-class leukaemia treatments, wherever and whenever they need them.

Mortality Rate Variation¹¹

Leukaemia mortality rates vary between Welsh Health Boards.



Access to high-quality cancer treatment and care must be a priority. Bone marrow transplants, and other life-saving treatments such as innovative CAR-T therapy, must be accessible in Wales so patients do not need to travel to England to receive them.

Leukaemia presents in both acute and chronic types. Chronic types typically develop more slowly over time. Whereas acute types, like AML, progress more quickly and aggressively, often requiring immediate treatment.

Timely decision-making is critical for patients to have the best chance of survival. This is particularly important in cases of aggressive leukaemias such as AML.

Timely genomic testing is also essential to ensure patients can access the most appropriate and effective treatments for their cancer. Patients must have equitable access to genomic testing where clinically appropriate.

The Senedd can work with NHS systems to save and improve more lives affected by leukaemia in Wales by:

- ✓ Protecting, maintaining, and expanding bone marrow transplant services in Wales.
- ✓ Ensuring genomic testing is available as a standard of care to those patients who would benefit.
- ✓ Increasing the number of beds available in the NHS for CAR-T therapy to ensure Welsh leukaemia patients can be treated in Wales.

Building a cancer system that delivers for leukaemia

Wales remains the only UK nation without a long-term cancer plan, leaving patients without clear, accountable leadership to drive improvements across the system. Any new strategy must be underpinned by strong governance and accountability measures including effective targets. This must be supported by clear and consistent leadership at all levels.

Any future strategy must include leukaemia and other blood cancers on an equal footing with solid tumours. As a non-stageable cancer, leukaemia is currently excluded from existing early diagnosis targets, meaning progress is neither measured nor prioritised. An alternative measure of earlier diagnosis for non-stageable cancers must therefore be developed to ensure leukaemia is fully embedded in national efforts to diagnose cancer earlier.

The Welsh Government must deliver cutting-edge and high-quality treatments to all patients, from the best treatments currently available to clinical trials developing the next big breakthroughs.

Robust, transparent data is essential if Wales is to deliver meaningful progress for leukaemia. Inconsistent data collection and publication currently limit the ability to monitor performance, address inequalities, and hold the system to account across diagnosis, treatment, and care. To maximise its value, data must be granular,

site-specific, and comparable with other UK Nations. For leukaemia, this means that breakdowns with sufficient granularity across the four main leukaemia types must be available.¹²

National Cancer Audits provide crucial benchmarking across Wales and England. They help to highlight where and why patterns of diagnosis, treatment and care vary. These audits support local quality improvement and help spread best practice across regions.

However, there is no National Cancer Audit for leukaemia, leaving gaps in our understanding of outcomes and limiting opportunities to drive improvements.¹³

Ambition alone will not deliver change. The cancer system cannot deliver the changes needed to stop leukaemia devastating lives without an adequate and appropriately specialised workforce, particularly across diagnostics, haematology, and pathology.

The Welsh Government should ensure leukaemia is represented in national health policy and that the system delivers for all patients by:

- ✓ Undertaking a National Cancer Audit for leukaemia.

- ✓ Developing a long-term cancer plan for Wales, with clear leadership, governance, accountability, and measurable targets.

- ✓ Creating an alternative measure for earlier diagnosis that works across cancers, including non-stageable cancers.

- ✓ Establishing a taskforce to improve cancer data collection and publication across the patient pathway.

✓ Ensuring data is comparable with other UK nations.

✓ Supporting world-class leukaemia research in Wales to find kinder, more effective treatments.

✓ Investing in the infrastructure needed to support clinical trials, research, and genomics.

By championing leukaemia throughout this Parliament, you can help us turn ambition into progress and ensure that everyone living with and beyond leukaemia has the best possible experience and outcomes.

References

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- 13 [National Cancer Audit Collaborating Centre Audits](#)



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Together, we can change the future for people affected by leukaemia

With your leadership and
commitment, Wales can transform
the future of leukaemia. Let's
work together to stop leukaemia
devastating lives.