

A MANIFESTO

FOR CHILDREN

AND YOUNG PEOPLE

WITH CANCER

IN WALES

YOUNG LIVES

vs CANCER

Transforming cancer care and support for children and young people in Wales.



INTRODUCTION

Every year in Wales, around 180 children and young people under the age of 25 are diagnosed with cancer. Despite medical advances, cancer remains the leading disease-related cause of death for this age group.

Yet the voices and experiences of children and young people with cancer are too often missing from national strategies and policy decisions. The current strategic approach to cancer in Wales is adult-focused, with a lack of data and monitoring on experiences and outcomes in younger age groups, and misunderstandings of their unique needs. As a result, they face systemic inequalities compared to older adults.

Some challenges — such as the need for timely diagnosis and a robust cancer workforce — are shared with older adults. However, children and young people have a distinct experience, facing cancer during critical stages of development with their whole lives ahead of them. They commonly face different cancer types, longer treatment duration, different care pathways, unique long-term effects, and significant emotional and financial challenges, including the cost of travelling to specialist centres.

Whether they live in Cardiff or Carmarthen, Aberystwyth or Anglesey, their unique needs demand a tailored approach to truly improve outcomes and long-term wellbeing, ensuring no one is left behind.

OUR MANIFESTO COMMITMENTS:

To transform cancer care and support for children and young people, we're calling on political parties to commit to:



A dedicated strategic approach for children and young people with cancer



A Young Cancer Patient Travel Fund



Improved experience of diagnosis



Comprehensive support during and beyond treatment

Whilst using devolved powers to the fullest, all parties should also be champions for children and young people with cancer in Wales on reserved issues.

STRATEGIC APPROACH

The current Cancer Improvement Plan (2023 – 26) lacks specific actions for children and young people, despite acknowledging their unique needs.

Without a comprehensive long-term strategy with a clear direction for children and young people, we can't make considered progress towards improved care, support and outcomes.

Children and young people's cancer care and support needs are different to older adults. They need and deserve a bespoke approach which recognises the specialist services and pathways they access, types of cancer they face, and unique psychosocial impacts they experience.

The next Welsh Government should work with children and young people, the third sector and NHS to develop a long-term strategic approach to cancer care in Wales that includes dedicated actions for children and young people.

Ideally through a National Cancer Strategy, this must be accompanied by improving the data landscape, ensuring data for children and young people is available consistently and distinctly, and by implementing an Under-16 Cancer Patient Experience Survey.



Solution:
**A strategic approach for children
and young people**

YOUNG CANCER PATIENT TRAVEL FUND

Due to the specialist nature of their cancer treatment and care, children and young people visit a UK-wide network of specialist centres far from home. They have no choice but to make the long journeys to get there, and find the money to do so.

This is unique to children and young people, who travel twice as far and spend twice as much as older adults with cancer, and is especially true in Wales, where they travel the furthest and spend the most in the UK.

There is only one specialist treatment centre in Wales, located in Cardiff. Combined with Wales' unique geography, this means the majority frequently travel significant distances, and often to England, for their treatment and care. This can be a barrier to access.

The financial support in place now isn't available to all who need it, and those who can access it report that it falls far short of covering their costs.

The next Welsh Government must introduce a Young Cancer Patient Travel Fund to support with travel costs.

This would ensure no child or young person misses or delays treatment and care because they can't afford the journey. Our modelling estimates the Fund would cost £420,000 annually in Wales.



**Solution:
A Young Cancer Patient Travel Fund**

IMPROVED DIAGNOSIS EXPERIENCE

Many children and young people with cancer, and their families, report having to repeatedly engage with healthcare services before cancer is considered, or a referral or diagnosis is given.

Too often, we hear about misdiagnoses, multiple visits to doctors, concerns being dismissed, or cancer being diagnosed in an emergency setting. Many children, young people and families report needing to self-advocate to get the right care, which can be especially challenging.

These experiences can damage trust in the system and relationships with healthcare professionals, as well as delay access to treatment and care. An early diagnosis is important to ensure timely and effective treatment which delivers the best possible outcomes.

We call on the next Welsh Government to improve diagnosis experiences for children and young people with cancer.

This should be supported by education and resourcing of frontline healthcare to spot and refer suspected cancer, promoting signs and symptoms awareness, including children and young people in early diagnosis initiatives and responding to their experiences.



Multiple visits to healthcare services before diagnosis.

Early diagnosis is key to timely and effective treatment.



**Solution:
Improved diagnosis experience**

COMPREHENSIVE SUPPORT

A cancer diagnosis can affect every part of a child or young person's life — emotional, social, educational, financial and practical. The impact, stress and challenges are felt by the whole family, not just during treatment, but beyond.

Support can come from a range of providers, including generalist NHS services, specialist psycho-oncology, and the charity sector — including Young Lives vs Cancer social care and other charity services.

Yet the support available, most commonly from statutory services, is too often determined by postcode, not need. In particular, support for the long-term effects of cancer can be inconsistent once treatment ends, when many struggle with the lasting physical, emotional, financial, and social impacts of cancer.

The next Welsh Government should ensure children and young people with cancer and their families have access to comprehensive, holistic support during and beyond treatment.

Treatment pathways and practice should provide referral and access to these services alongside their physical care where and when they need them.



Solution:
Comprehensive support during and beyond treatment

CHILDREN AND YOUNG PEOPLE WITH CANCER IN WALES DESERVE BETTER.

This means a strategic approach which meets their unique needs, a Young Cancer Patient Travel Fund, an improved diagnosis experience which catches signs and symptoms early, and tailored, comprehensive support during and beyond treatment.

Achieving this vision means working in partnership — with children and young people, their support networks, the NHS, and third sector organisations like Young Lives vs Cancer. It means displaying leadership, using devolved powers to the fullest, and championing the needs of children and young people with cancer on reserved issues.

The time is now to truly transform the experiences, outcomes and futures of children and young people with cancer in Wales.



**YOUNG LIVES
vs CANCER**

