

A MANIFESTO

FOR CHILDREN

AND YOUNG PEOPLE

WITH CANCER

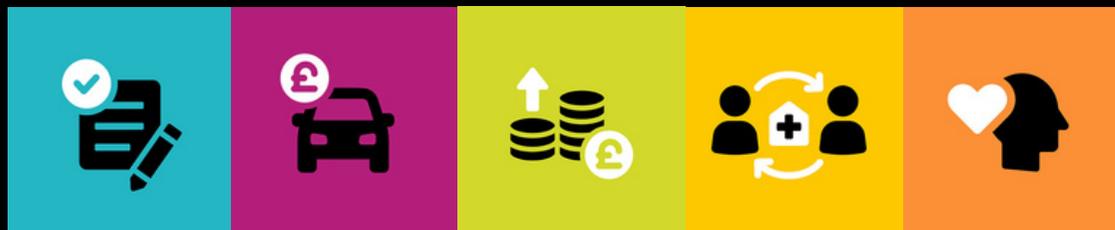
IN SCOTLAND

YOUNG LIVES

vs CANCER



Transforming cancer care and support for children and young people with cancer.



INTRODUCTION

Every year in Scotland, around 320 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 strategic approaches and policy decisions. Whilst progress has been made with “Collaborative and Compassionate Cancer Care: cancer strategy for children and young people”, the wider approach to cancer remains largely adult-focused, with gaps in age-specific data and monitoring. This leaves the unique needs of children and young people misunderstood, and systemic inequalities persist.

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 Aberdeen or Ayr, Stornoway or Stirling, children and young people with cancer need targeted action, to address their unique challenges and drive improvements in their care and outcomes.

OUR MANIFESTO COMMITMENTS:

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



Delivering the next Cancer Strategy for children and young people



Expand the Young Patients Family Fund to support all travel costs



Improve access to disability benefits



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 Scotland on reserved issues.

CANCER STRATEGY

Scotland is the only nation in the UK that has a dedicated national cancer strategy for children and young people. "Collaborative and Compassionate Cancer Care: cancer strategy for children and young people", published in 2021, reaches the end of its lifecycle in 2026.

This acknowledges that a comprehensive long-term strategy with a clear direction for children and young people is essential to drive progress towards improved care, support and outcomes.

Children and young people's needs will always be 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 Scottish Government must commit to a new, up to date national cancer strategy for children and young people from 2026 and beyond.

Progress against the current strategy must be assessed and built upon, working with children and young people with cancer, the third sector and NHS to go further to deliver the care and support needed.

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 refreshed cancer strategy for children and young people in 2026

YOUNG PATIENTS FAMILY 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.

It is especially true in Scotland – with specialist centres in Glasgow, Edinburgh, and Aberdeen, and some treatments only available in England, the frequent long-distance travel can be a barrier to access.

Financial support 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 Young Patients Family Fund helps, but is limited to inpatients under 18. Day patients are excluded despite most cancer care happening on a day-patient basis, and 18 - 25s making the same journeys cannot access the Fund at all.

The next Scottish Government should expand the Young Patients Family Fund eligibility criteria, so it is open to all children and young people with cancer in Scotland.

This would ensure no child or young person misses or delays treatment and care because they can't afford the journey. This can be largely funded within the Fund's existing budget underspend.



**Solution:
Expand the Young Patients Family Fund
to support all travel costs**

ACCESS TO DISABILITY BENEFITS

Beyond the medical impacts, children, young people and families face the spiralling, unavoidable additional costs that come with cancer — which total £700 every month.

Disability benefits like Child Disability Payment (CDP), Adult Disability Payment (ADP), and support such as Carers Support Payment, are meant to help with these costs.

However, an average six-month wait from diagnosis to benefits award is leaving young people and families struggling with the costs of cancer. It forces many into impossible situations, using their savings, borrowing money or cutting back in essential areas.

The 'qualifying period' means applicants must wait three months before they are even eligible for disability benefits, even if their diagnosis is confirmed. After this, children and young people with cancer are waiting an average of three more months for a decision and payment. This comes alongside navigating the complex and stressful process.

We ask the next Scottish Government to remove the qualifying period for children and young people with cancer, so they and their families can access welfare benefits immediately following diagnosis.

In addition, better use of medical evidence would simplify the application process to quickly determine eligibility and reduce waiting times.



**Solution:
Quicker and easier access to benefits**

IMPROVED DIAGNOSIS EXPERIENCE

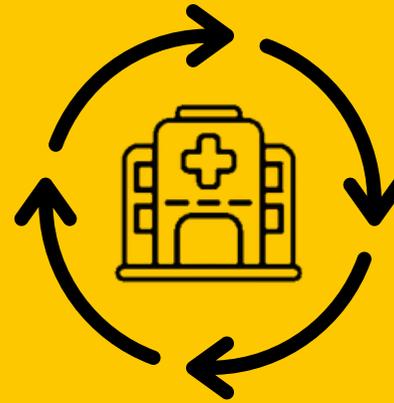
Many children and young people with cancer, and their families, report having to repeatedly engage with healthcare services before cancer is considered, or a referral or diagnosis is given.

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 Scottish 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, and 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 Scottish 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 SCOTLAND DESERVE BETTER.

This means delivering the next Cancer Strategy for children and young people, expanding the Young Patients Family Fund, a reformed disability benefits system, an improved diagnosis experience that catches signs and symptoms early, and 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 Scotland.

For more information, meetings or briefings on the evidence and insight underpinning these calls please contact: campaigns@younglivesvscancer.org.uk

