

A MANIFESTO FOR CHILDREN AND YOUNG PEOPLE WITH CANCER

Transforming the landscape of children and young people's cancer care

April 2024



INTRODUCTION

Every year in the UK, over 4,000 children and young people under 25 receive the devastating diagnosis of cancer. This means that every day, 12 children and young individuals confront the harsh reality of this disease and the disruption it brings to their lives. With 10 losing their lives each week, cancer is still the leading cause of death by disease among children and young people in the UK.

Despite these alarming statistics, young cancer patients frequently find themselves overlooked in policy decisions, leading to systemic inequalities compared to adults. Compounded by a lack of data and monitoring specific to children and young people's experiences and outcomes, this oversight further exacerbates the challenges they face.

While there are some commonalities with adult cancer, such as the need for a robust specialist workforce and earlier diagnosis, the unique aspects of cancer in children and young people demand a tailored strategic approach.

These individuals are navigating critical developmental stages of life, and their experiences differ significantly from those of adults. Combined with the distinct nature of childhood and adolescent cancer, marked by longer treatment durations, unique emotional and mental health impacts, and specific financial implications such as travel costs for accessing specialised care, these necessitate the urgent need for specialised strategies and targeted policy intervention to drive improvements in their well-being 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:

1

A Children and Young People's Cancer Plan – A national strategy for England to ensure young cancer patients are not left behind

2

Ensuring travel costs for children are not a barrier to accessing treatment – by introducing a Young Cancer Patient Travel Fund

3

Welfare and benefits support that works for children and young people with cancer and their families

4

Mental health provision that is available for young cancer patients and their families when they need it, where they need it

5

Improved patient experience of diagnosis and post treatment support

A CHILDREN & YOUNG PEOPLE'S CANCER PLAN

There is no national, long-term strategy for children and young people's cancer in England, to ensure they have care fit for their unique needs.

But this is essential - because their care, support and treatment needs are different to that of adults with cancer, and therefore require a bespoke strategy.

Young Lives vs Cancer and CCLG have developed a Children and Young People's Cancer Plan which sets out what needs to be delivered in the core areas of:

1. Diagnosis
2. Treatment
3. Patient experience
4. Research
5. Psychosocial needs
6. Survivorship

This plan is a blueprint which should be adopted by any incoming Government to ensure that world class diagnosis, treatment, holistic support, outcomes and post treatment support is delivered for children and young people with cancer.

[Learn more about our Children and Young People's Cancer Plan](#)

4,200
diagnosed
every year

Biggest
killer by
disease

A Children and Young People's Cancer Plan to address:



Diagnosis



Treatment



Patient
experience



Research



Psychosocial
needs



Survivorship

A YOUNG CANCER PATIENT TRAVEL FUND

Young cancer patients receive care at specialist centres far from home, so they and their families must find the money to travel to their essential treatment, at great cost.

The average round trip is 80 miles, stacking up to 350 miles every month. And the average monthly cost of travel is £250. For some, including those living remote areas or further from a specialist centre, costs will be much more.

The financial support available now isn't accessible to all those who need it and doesn't substantially cover these costs, amongst over spiralling costs associated with a cancer diagnosis such as increased energy bills and food costs. 71% are struggling with travel costs and one in 10 are missing or delaying their treatment as a result.

Young Lives vs Cancer calls on any incoming Government to introduce a £10 million Young Cancer Patient Travel Fund so that young people and families have the support they need to travel to their treatment.

Reducing the burden of these costs would ensure that they are not a barrier to equitable access to cancer treatment for children and young people with cancer and their families.

[Find out more about travel costs and our model for a Young Cancer Patient Travel Fund](#)



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

WELFARE & BENEFITS SUPPORT

Children and young people with cancer face a range of costs because of being, and as soon as they are, diagnosed with cancer.

The costs of cancer usually start from diagnosis, and often continue well beyond treatment into later life.

Disability Living Allowance (DLA) or Personal Independence Payment (PIP) (depending on the age of the young patient) are a vital source of support which this group is eligible for. But they cannot be applied for until three months after diagnosis, and after that there are often long wait times for applications to be processed, after completing the complex application process.

This results in a process which is stressful, long and difficult to engage with for families going through the worst, and who are accumulating significant costs from day one of diagnosis.

DLA and PIP are also a gateway to other support such as Carer's Allowance, Universal Credit Carer's Element, and Blue Badges, with delays having a knock-on domino effect on these vital sources of support as well.

DLA and PIP should be available to apply for from the point of diagnosis, and children and young people with cancer shouldn't have to wait for long periods before receiving this vital support.



**Stop the domino effect and
endless waits, through:**

**benefits support from the
point of diagnosis**

MENTAL HEALTH

The emotional and mental health impact of cancer on children and young people is immense.

Many young cancer patients and their families are struggling with their mental health.

Support is available through a range of providers and services, including;

- charities like Young Lives vs Cancer, whose specialist social workers provide emotional and wellbeing support;
- specialist psycho-oncologists for this age group;
- more generalist acute or early intervention from NHS or charity mental health services.

However, these services are often dependent on what is on offer in an individual's local area and aren't always available when they, or their family, need them in their cancer journey.

Treatment pathways and practice should provide referral and access to these services alongside the physical healthcare, and mental health should be an integral part of a Children and Young People's Cancer Plan.

All children and young people with cancer should have access to the mental health support they need, when they need it.



Mental health support alongside physical healthcare, when they need it

DIAGNOSIS

EXPERIENCE & POST

TREATMENT SUPPORT

Young cancer patients and their families report needing multiple visits to doctors before a cancer diagnosis is given, prolonging their diagnosis experience.

This experience can impact on trust and relationships with healthcare professionals throughout treatment and after, and this experience can be worse for people in minoritised groups.

Timely diagnosis is important to ensure the right treatment can be given at the right time, to get the best possible outcomes.

After treatment, many children and young people with cancer experience a lack of support with the ongoing physical, emotional and other lasting impacts of having cancer when you are young.

Their experience with cancer doesn't stop when their treatment stops.

Experience of diagnosis, and post-treatment support, are key elements of the Children and Young People's Cancer Plan.

Better diagnosis experience, and care and support after treatment, are integral to transforming the landscape of children and young people's cancer care.



**2 in 5
visit GP
three or more times**

**Support needed
during and beyond
treatment**



**Improve diagnosis experience and
post-treatment support**

CHILDREN AND YOUNG PEOPLE WITH CANCER DESERVE BETTER:

A cancer plan that delivers the care and support they need from diagnosis, through treatment and beyond; a system that reduces the barriers to receiving equitable access to treatment; support with the devastating financial and mental health impact of cancer, for them and their families.

Young Lives vs Cancer calls on the next Government to commit to transforming the experiences and futures of children and young people with cancer.

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

