

YOUNG LIVES

vs CANCER

THE COST OF WAITING

Research exploring the experiences of children and young people with cancer and their families as they navigate the process of claiming disability benefits following their diagnosis.

March 2025



YOUNG LIVES vs CANCER

ABOUT YOUNG LIVES vs CANCER

When a child or young person is diagnosed with cancer, their whole world can feel like it's falling apart. They can only be treated in certain hospitals, because their cancer is different to adults'. And often, they have to travel miles just to get there.

The impact of cancer on young lives is far more than medical. And that impact can be felt by the entire family. Their anxieties are deep. Their education, mental health and social lives suffer. Their futures feel very uncertain. And on top of it all, the unexpected financial costs can hit hard and fast.

Young Lives vs Cancer is the only charity in the UK with specialist social workers dedicated to providing tailored psychosocial support to children and young people with cancer, and their families. We stop at nothing to make their voices heard and their unique needs understood, so they can get the right care and support at the right time.

This work includes providing children and young people with cancer and their families with support navigating the social security systems in the UK. In the last year, our specialist social workers provided more than 2,000 individual young people and families with benefits support.¹

In addition to the benefits support provided by our specialist social workers, we also offer a Welfare Advice Service in partnership with Citizens Advice. The service is run by trained advisers who understand the unique issues children and young people with cancer and their families face. They can answer any questions and carry out full financial checks to see what benefits children and young people with cancer and their families may be entitled to. In the last year, more than 630 children and young people with cancer and their families received support from the Young Lives vs Cancer Welfare Advice Service, gaining an estimated total of £1.4m in benefits support.²

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FOREWORD

A cancer diagnosis in a child or young person is a devastating and life-altering event. In an instant, children and young people with cancer and their families are faced with a whirlwind of hospital visits, medical treatment and intense caregiving. Their diagnosis takes a huge, damaging toll on their wellbeing and mental health. And for many, the unexpected financial costs hit hard and fast.

This research demonstrates how social security systems across the UK, which have been established to ease the burden of these costs, are currently failing children and young people with cancer and their families. They are left waiting an average of seven months before receiving the support they need and as a result they're forced into impossible situations. Exhausting their savings, borrowing money, surrendering their financial security and making desperate sacrifices. All at a time when they should be focused on getting through treatment.

This research amplifies the voices and experiences of children and young people with cancer and their families. They are loud and clear: the current system isn't good enough. It's damaging, stressful and not delivering what it sets out to do.

At Young Lives vs Cancer, we believe that no one should have to face financial hardship as a result of a cancer diagnosis. Together with the communities we support, we are calling for urgent reform to how social security systems operate across the UK, to ensure children, young people and their families get access to the financial support they need, as soon as they are diagnosed. We are urging the UK and Scottish Governments to ensure that disability benefits are made immediately available to all children and young people diagnosed with cancer, without lengthy applications and assessment processes.

This is more than a report and recommendations. This is an urgent call for vital change. By making these reforms a reality, we can ensure social security systems across the UK truly support children and young people with cancer and their families. We can make sure they have the financial stability and peace of mind they deserve.



Rachel Kirby-Rider
Chief Executive, Young Lives vs Cancer

ABOUT THE RESEARCH

In 2023, Young Lives vs Cancer conducted research to assess the financial impact of a cancer diagnosis on children and young people and their families. This research showed that a cancer diagnosis comes at a financial premium, with children, young people and their families facing a range of additional costs throughout their treatment. The research also exposed how a cancer diagnosis comes with an additional financial penalty, with many experiencing a loss of earnings too.

As a result, many young people with cancer and their families attempt to access welfare benefits through the UK's social security systems following their diagnosis. Our research shows that many face a range of challenges accessing these welfare benefits.

To better understand these challenges, Young Lives vs Cancer conducted research between June and October 2024. The research included an online survey with a total of 311 participants and follow-up interviews with 13 individuals. The participants included young people aged 16 to 26, and parents or caregivers of children and young people under 27, who have undergone cancer treatment within the past two years.

This report summarises the findings of this research and is part of a series of reports, focusing on the challenges faced by children and young people with cancer and their families. The other reports in this series are available at: younglivesvscancer.org.uk/research.





Almost
£700

**extra a month
in costs³**

4,200 children and young people in the UK are diagnosed with cancer each year.⁴ The impact of cancer on young lives is far more than medical. With it, comes a hidden and often devastating financial burden that many do not see or expect.



3 in 5

**faced extra costs
within one month
of their diagnosis**

Due to the immediacy, intensity and impact of cancer treatment, for most children and young people with cancer and their families, the burden of these additional costs starts almost immediately after diagnosis.



7 month

**average wait
from diagnosis
to decision**

While disability benefits are meant to help with these additional costs, many children and young people with cancer and their families are left waiting significant periods, for support they desperately need.

The disability benefit system is not just failing to deliver the crucial financial support children and young people with cancer and their families need. For many it is causing even more distress, during an already overwhelming and traumatic time. To respond to the challenges and reform priorities expressed by young people with cancer and their families, Young Lives vs Cancer believes that:

- Children and young people with cancer and their families should be entitled to access welfare benefits immediately following diagnosis and not be subject to a qualifying period.
- The application process for welfare benefits should be simple, efficient and streamlined, utilising medical evidence to quickly determine eligibility.



Nearly
£5,000
in extra costs
between diagnosis
and decision

This wait means children and young people with cancer and their families typically face thousands in extra costs before receiving a decision on their disability benefits.



3 in 5
had to use their
savings following
diagnosis

These sudden, unexpected costs of a cancer diagnosis, often coupled with significant drops in personal earnings and a prolonged wait for disability benefits, force young people with cancer and their families into impossible financial positions.



1 in 2
had to borrow
money following
diagnosis

Whether it's formal methods of borrowing money through loans, or getting financial help from family and friends, many young people with cancer and their families have to ask for other means of financial support in the absence and wait for disability benefits.

By making these reforms, the UK's social security systems will deliver what they were established to do. They will support the needs of children and young people with cancer and their families, giving them the financial stability they need, and the peace of mind they deserve, at the time they need it most.

THE COSTS

Each year, around 4,200 children and young people in the UK are diagnosed with cancer.⁵ The impact of cancer on young lives is far more than medical. With it, comes a hidden and often devastating financial burden that many do not see or expect.

Our 2023 research revealed that, on average, children and young people with cancer and their families face almost £700 each month in additional expenses during their treatment.⁶

Nearly
£700
extra a month in costs



The largest expense comes from having to **travel to and from treatment**. To get to specialist treatment centres, many have to travel long distances, several times a week, for the duration of their treatment. One parent/carer shared:

“The big expenses were the travel costs getting in and out every day. When he had his chemo, it was five days in a row one week, and then one day the following two weeks.”

Nearly all young people with cancer and their families (96%) reported having to incur additional travel costs following diagnosis, costing an average of £250 a month.⁷

Spending significant time travelling to and from treatment, whilst being without cooking or refrigeration facilities, forces many young people with cancer and their families to spend more on **food**. After returning home, being too unwell to work or attend school, and needing additional or specialised meals, also adds to these expenses. One parent/carer said:

“We had to buy a lot of food because in the first months of the treatment he was on steroids and I don’t know what was going on, but he literally lost so much weight. He could not keep weight on.”

Nearly all young people with cancer and their families (96%) reported spending more on food after diagnosis, an average of £144 extra a month.⁸

Three in five young people with cancer and their families (61%) also faced **higher energy bills** after diagnosis, averaging an extra £68 per month. These costs are due to spending more time at home following treatment, needing constant heating due to the side effects of treatment, and increased energy use for washing and cleaning.⁹

A parent/carer explained:

“The heating’s on constantly to keep him warm and then there’s all the constant washing, because he’s got no immune system. You have to be very, very careful.”

Beyond travel, food and energy, the extra costs faced by young people with cancer and their families also extend to areas such as **clothing, toys and treats, childcare, parking, accommodation and telephone charges**.

Due to the immediacy, intensity and impact of cancer treatment, for most young people with cancer and their families, the burden of these additional costs starts almost immediately after diagnosis.

More than three out of five young people with cancer and their families (64%) begin to face extra expenses within the first month. Within three months, this increased to almost four in five (79%). A parent/carer said:

“Heating costs and petrol and food costs completely spiral following a diagnosis, especially for child cancer as treatments are intensive, involving lengthy journeys, as local hospitals cannot treat them.”

The challenge in meeting these extra costs is made even more difficult as many young people or parents/carers are forced to take time off work or change employment arrangements. As with the extra costs, the loss in earnings was also immediate for many young people with cancer and their families. One in three young people with cancer and their families (33%) experienced a loss in their household earnings within a month of their diagnosis. Meeting these extra costs has also been made more difficult by increases to cost of living, meaning goods such as food, energy, and fuel have become less affordable for families as a result.

Extra costs per month¹⁰

Travel	£250
Food	£144
Energy	£68
Clothing	£56
Toys and treats	£48
Childcare	£30
Parking	£24
Telephone	£15
Accommodation	£14

3 in 5



face extra costs within one month of their diagnosis

The Equalities Act 2010 (in England, Scotland and Wales) and The Disability Discrimination Act 1995 (in Northern Ireland) consider a diagnosis of cancer as a disability and apply to all people with cancer or those who have had cancer in the past.¹¹

To help with the extra costs caused by long-term ill health or a disability, there are a range of disability benefits in place across the UK. In England, Wales, and Northern Ireland, children under 16 can apply for Disability Living Allowance (DLA), while those 16 or over can apply for Personal Independence Payment (PIP). In Scotland, these benefits have been replaced by the Child Disability Payment (CDP) for children and the Adult Disability Payment (ADP) for adults.

To qualify for these welfare benefits, applicants must have a long-term physical or mental health condition or disability that requires extra care or makes everyday tasks or getting around more difficult. Children and adults must have had these difficulties for at least three months (the “qualifying period”) and expect them to last at least six months for children, or nine months for adults (the “prospective test”). If someone is expected to live 12 months or less, they do not need to meet the three-month qualifying period to be eligible, with ‘special rule’ exemptions being applied.

THE WAIT

While disability benefits are meant to help with these additional costs, many children and young people with cancer and their families are left waiting significant periods, for support they desperately need.

The current qualifying period means most children and young people with cancer must wait three months before they can apply for disability benefits. The intensity of the costs faced immediately following a diagnosis means this three month wait causes significant financial strain for many. Once the three months have passed, young people with cancer and their families can apply for the disability benefits they are potentially entitled to, however there is no option to receive backdated payments to cover the wait during the qualifying period. This leaves them without financial support to cover the outgoings that have mounted up during the critical early stages of treatment.

This three-month delay before application only tells part of the story of the overall wait experienced. After submitting their disability benefit application, children and young people with cancer are currently waiting an average of four months for a decision, and if successful, their first payment.

The three-month qualifying period and four-month average wait for approval after application means children and young people with cancer and their families endure a wait averaging seven months, from their diagnosis, to finally receiving a decision and their first disability benefit payments.



7 month
average wait from
diagnosis to decision

4 month
average wait from
application to decision



Young people with cancer and their families applying for PIP experienced an even longer average wait of eight months. For those claiming CDP and ADP, administered by Social Security Scotland, the average time from diagnosis to decision was six months.

How satisfied are you with the following elements of your disability benefits application?	Percentage satisfied
Waiting time for a decision (n=230)	21%
Telephone helpline (n=71)	29%
Application form (n=231)	35%
Ongoing communication (n=231)	35%
Assessment process (n=33)	36%
Ongoing claim management (n=181)	56%
Closing claim process (n=38)	65%
Payment amount (n=181)	78%
Overall (n=231)	56%

The prolonged waits mean many children and young people with cancer go through their entire treatment before receiving a decision on their application or any support from disability benefits. One in four children and young people with cancer (25%) finish their active cancer treatment before receiving a decision on their disability benefits application. While the impacts of cancer can persist long beyond treatment, the most significant financial costs for many children and young people with cancer and their families occur during treatment – particularly in the crucial first few months following diagnosis.

Just one in five young people with cancer and their families (21%) expressed satisfaction with the length of time they had to wait to receive a decision. This had the lowest satisfaction ratings of any element of the welfare benefit process asked about during the research.

This wait means children and young people with cancer and their families typically face thousands in extra costs before receiving a decision on their disability benefits. Based on the average extra costs experienced during treatment, alongside the seven-month average wait for a decision, this leaves children and young people with cancer and their families having to find and pay out nearly £5,000 in extra costs.¹²

Nearly **£5,000**  in extra costs between diagnosis and decision

These sudden, unexpected costs of a cancer diagnosis, coupled with often significant drops in personal earnings and prolonged waits for disability benefits, force young people with cancer and their families into impossible financial decisions.

For those young people with cancer and families fortunate enough to have savings, three fifths of them (60%) reported these decreased following diagnosis. One parent/carer said:

“Since he was diagnosed, I’d say we probably had a few thousand in savings, and now we’ve maybe got like £100 in savings.”



3 in 5
had to use their
savings following
their diagnosis

Given the abrupt rise in costs and fall in earnings, a quarter of young people with cancer and their families (27%) had begun drawing upon their savings within a month of their diagnosis. By the average seven-month wait for a decision on disability benefits, almost three in five (56%) said they had used their savings to get by.

The long-term impact on finances is stark. At the time of diagnosis, 27% of young people with cancer and their families had no savings. Post diagnosis, this figure escalated to 44%, leaving many financially vulnerable to any further unexpected expenses. As one parent/carer shared:

“Six months with loss of income, no help, and extra costs meant we used all our savings. This could have been avoided.”

In addition, more than half (53%) had to borrow money following their diagnosis. For one in five young people with cancer and their families (19%), this happened in the first month following the diagnosis. By the seven-month mark, almost half (47%) were forced to take on new or additional debt.



1 in 2 had to borrow money following their diagnosis

For some this involved more formal forms of borrowing, such as bank loans. For others, friends and family provided this financial support. As this parent/carer described:

“I have been left minus in my account every month since diagnosis, with me having to borrow money off family members or beg for hand-me-down clothes from friends, and food cooked for us by my sister, as I had no money for shopping.”

Prior to their cancer diagnosis, 43% of those surveyed reported having no debts or borrowing, however post diagnosis, just 30% of young people with cancer and their families reported being debt-free.

In a number of cases, the wait for support also meant many young people with cancer and their families struggled to pay their household bills. As this parent/carer described:

“We fell behind with our gas and electric payments because we had to use the money for travel and extra costs of living in hospital.”

Disability benefits act as a gateway to other forms of support. So, waiting months to receive this initial financial support causes additional delays and problems.

After securing disability benefits, children and young people with cancer and their families are able to apply for other forms of support which most commonly include being eligible for a Blue Badge for parking, Carer’s Allowance or Carer Support Payment, and additional Universal Credit top-ups.

More than two in five young people with cancer and their families (43%) said that the delay to a decision on their disability benefit application prevented them from receiving additional benefits and services they needed. Unlike with disability benefits, which can be backdated from the date the application form is received, many of these additional benefits and services cannot be backdated at all.

“By the time he was assessed, he had completed treatment, and I had to borrow over £1,000 to fund transport and living expenses. No PIP award meant that I am continuing to pay this back now, having taken on extra work, while still trying to support my son with monthly follow up appointments and ongoing health issues.”

Parent/carer

THE EXPERIENCE

The disability benefit system is not just failing to deliver the crucial financial support children and young people with cancer and their families need. For many it is causing even more distress, during an already overwhelming and traumatic time.

Just one in three young people with cancer and their families (35%) reported being satisfied with the application forms in place throughout the disability benefits process.

Described as 'long-winded', 'laborious', and 'repetitive', the application forms require significant amounts of valuable time and energy completing them. For parents and carers, the process takes them away from their role caring for their child.

For young people, time spent completing the application forms came on top of dealing with their cancer and treatment, as one young person explains:

"It took a pretty long time for me to fill out the form and I was ill from chemo and in a lot of pain."

These difficulties are compounded by how complicated many found answering the questions, in particular the suitability and relevance to the experience of children and young people facing cancer. As one parent/carer said:

"The form was over complicated and aimed at additional needs rather than long-term illnesses such as cancer. It's one size fits all, when it should be more specific to cancer."

▮ The time spent applying, was time away from looking after my children and at the time I wasn't sure if this was the right thing to be doing. ▮

Parent/carer

Another parent/carer described the confusion:

“The questions were impossible to understand, and I wasn’t sure how to answer them. For example, did I talk about how my child was that week? That day? Things changed so quickly – I had to list all her medication and chemo drugs, but they would change a few weeks later. It was exhausting and upsetting and then at the end they said it would be six to nine months before I heard – at which point I imagine things will be different again and I’ll have to get back in touch to change all my previous answers.”

Many also found the questions to be ‘invasive’, forcing them to confront the trauma they were experiencing, at a time in their cancer journey where so much uncertainty persists.

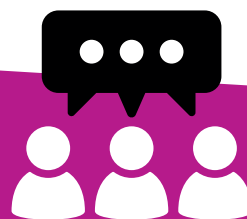
The questions asked, as well as the wider communications and processes, also leads many young people with cancer and their families to feel they are mistrusted, and that the system is trying to catch them out. As this young person described:

“They’re constantly trying to catch you out on everything. You can’t say anything.”

Gathering the required evidence also adds to the time and stress of completing the application forms. As one parent/carer described:

“There was a lot of information I had to gather from doctors and Macmillan nurses, it was very stressful at a time when I was looking after our daughter.”

Given these challenges, many young people with cancer and their families rely heavily on external support. Three quarters of young people with cancer and their families (76%) reported receiving help making an application, and a further 14% reported needing but not receiving support. Just one in 10 (10%) reported not needing any help making their application. Social workers or key workers (57%), and health/medical professionals (19%) were the main sources of the support received, providing a key role in getting individuals through the disability benefits system.



3 in 4

accessed support to help complete the application

▮ When you are emotionally drained from what's happening, filling out a booklet wanting to know how poorly your child is, it just adds to the emotional trauma you feel as a parent. ▮

Parent/carer

For those accessing PIP and ADP, the assessments and consultations can further add to the distress experienced. This is evidenced by only a third of young people with cancer and their families (36%) being satisfied with their assessment. The most common reasons for dissatisfaction were the knowledge and expertise of the assessors, in particular in relation to cancer, and the questions asked. One young person shared:

"The application process is very invasive, and traumatising, and the assessor seemed incredibly uninformed and unsympathetic."

The stress of filling out the application forms and taking part in the assessments is only made worse by the long waiting periods that follow. After spending valuable time and energy on these processes, young people with cancer and their families are often left unsure of when, or even if, they will receive the financial support they need.

This uncertainty makes it difficult for young people and family members to plan and make decisions such as when to return to work. One parent/carer explained:

"[It] was very stressful, and I have had to return to work when I maybe would have had more time at home with the payments in place. My mental health has really suffered, and I am worried about making a mistake at work."

The situation is exacerbated by a perceived lack of updates and communication. This is evidenced by just one in 10 young people with cancer and their families (11%) reporting they were kept completely up to date about the progress of their application, and just a third (35%) expressing satisfaction with the ongoing communication.

In many cases, this uncertainty forces young people with cancer and their families to chase for updates themselves. Unlike other welfare benefits, such as Universal Credit, there are limited self-service options to check the status of disability benefits applications. As a result, applicants are often left with no choice but to call the telephone helplines for updates.

Three in five of those who called the telephone helplines (60%) expressed dissatisfaction with the service.

1 in 10

kept completely up to date about their application

In most cases (82%), the dissatisfaction stemmed from long wait times to speak to someone. For young people with cancer, this time is especially precious and detracts from their focus on treatment and recovery:

“The wait time to talk on the phone is unbearable when ill.”

For parents and carers, it pulls them away from their caregiving duties:

“My daughter’s fighting for her life and I’ve got to spend time trying to get through, then placed in a queue of 10 people, when all I want do is care for my seriously ill daughter.”

This overall experience of the application forms and processes is reflected in the most common words young people with cancer and their families used to describe the current benefit system being ‘stressful’ and ‘difficult’.

“I didn’t hear from them for months. When I called them, I spent hours on the phone to speak to someone for two minutes or even less and every time they said the same thing, it’s under process and takes 12 weeks. When I rang them again a month later, as I tried to ask them to make it a bit faster as we were there without any income, they said the same thing.”

Parent/carer



THE SOLUTIONS

The effects of cancer are more than medical – there is a hidden financial burden that many do not see or expect. For children and young people with cancer and their families, the impact of diagnosis and specialist treatment results in immediate, intense and unavoidable costs.

These financial pressures are intensified even more for young people and parents/carers who have no option but to reduce or stop working, leading to abrupt and significant losses in earnings for many.

While disability benefits are meant to provide help with these extra costs, the way these welfare benefits are currently designed, along with the long processing times, means the basic needs of children and young people with cancer are not currently being met.

Disability benefits are not just failing to deliver crucial financial support and forcing children and young people with cancer and their families into impossible financial situations. For many, it's causing even more distress, during an already overwhelming and traumatic time. Children and young people with cancer deserve better.

To address these challenges and better support children and young people with cancer and their families, action is needed to:

1. **Shorten the waiting time between diagnosis and payment, so financial support is received when it's needed most.**

In addressing the long waiting times, action is also needed to:

2. **Ease the administrative burden, so young people and families can focus on their treatment and recovery.**
3. **Alleviate the stress and emotional strain caused by the application processes, during an already traumatic time.**

To help tackle these issues, young people with cancer and their families prioritised a number of suggested reforms.

The first is the introduction of automatic entitlement to disability benefits for children and young people diagnosed with cancer. More than seven in 10 young people with cancer and their families (72%) believed introducing automatic entitlement would be most helpful to them and other children and young people diagnosed with cancer.

To help achieve this, many young people with cancer and their families felt that medical evidence could be better utilised in the process. As this parent/carer set out:

"A letter from the hospital consultant shortly after diagnosis to the DLA to confirm that the child/adult has been diagnosed with a particular condition should be sufficient and the finance claimed immediately; the amount of time needs to be severely reduced between diagnosis and the benefit received itself."

Beyond the introduction of automatic entitlement, young people with cancer and their families prioritised being able to apply for benefits immediately following the diagnosis, without a qualifying period. Almost seven in 10 young people with cancer and their families (68%) felt being able to apply for financial support immediately following their diagnosis would be the most helpful reform.

As this young person describes:

“It shouldn’t be only for after three months since diagnosis, it should be for all time that cancer affects you, which includes before the three-month mark. If anything, the first three months is when the support would be more helpful as for acute leukaemia, that’s when we’re in hospital the most frequently as treatment must start as soon as possible and requires near daily hospital visits in the first month and would be where financial support for things like petrol would be most helpful.”

In addition, young people with cancer and their families prioritised reforms to the application form, including better tailoring of the form (56%) and reducing its length (53%). As this parent/carer suggests:

“There should be a separate, much simpler form, for those claiming DLA for children with cancer that can be done online and can upload a proof of a diagnosis letter or anything else needed.”

To respond to the challenges and priorities expressed by young people with cancer and their families, Young Lives vs Cancer believes that:

- **Children and young people with cancer and their families should be entitled to access welfare benefits immediately following diagnosis and not be subject to a qualifying period.**
- **The application process for welfare benefits should be simple, efficient, and streamlined, utilising medical evidence to quickly determine eligibility.**

Right now, children and young people with cancer and their families are not only being failed by a system which was established to support them, they are being left with more stress because of it. It cannot continue. It’s time to understand their experiences, hear their voices and make vital change.

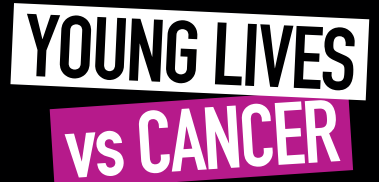
By making these reforms, the UK’s social security systems will deliver what they were established to do. They will support the needs of children and young people with cancer and their families, giving them the financial stability they need, and the peace of mind they deserve, at the time they need it most.

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Registered office: 4th Floor, Whitefriars, Lewins Mead, Bristol, BS1 2NT. 25012