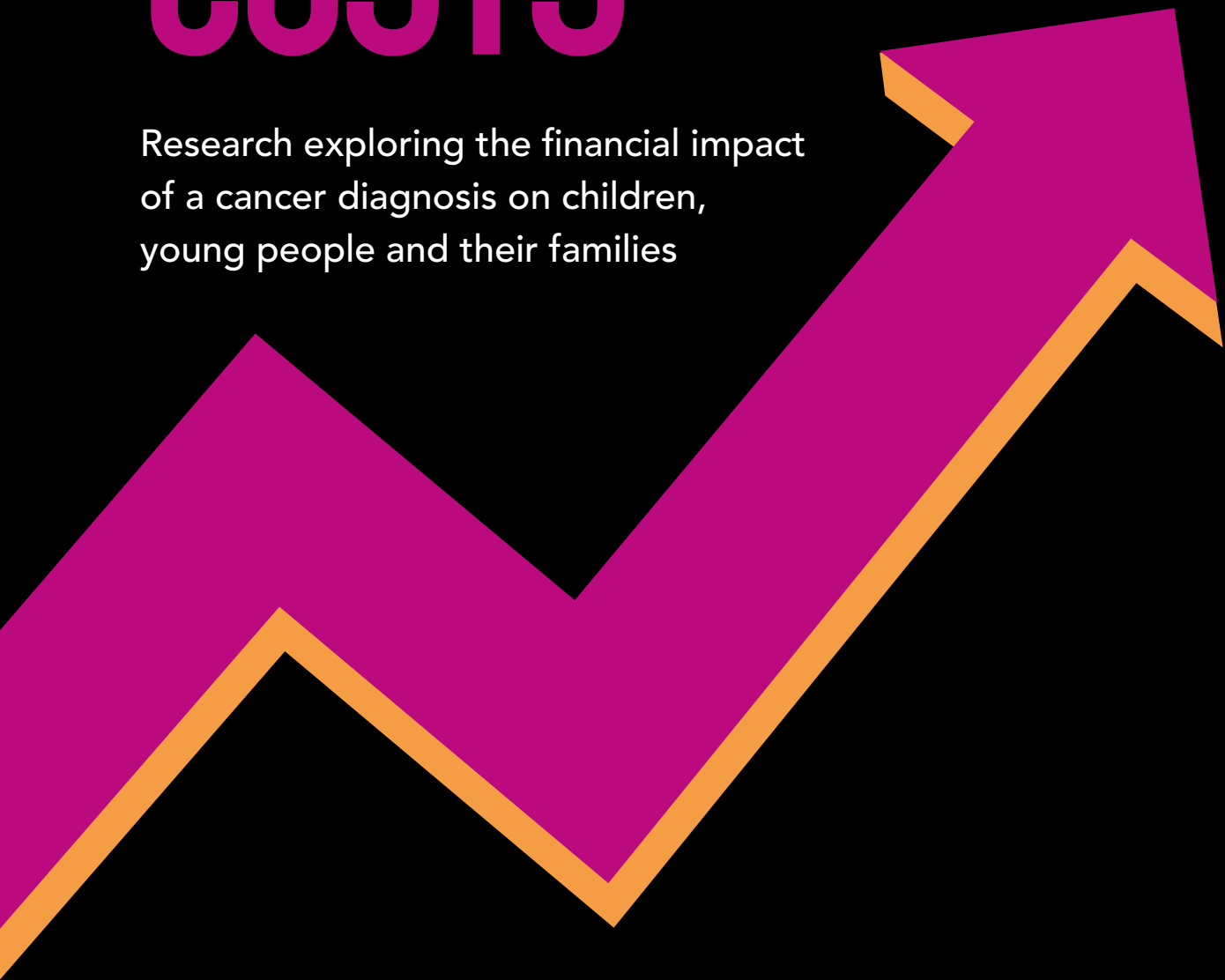


YOUNG LIVES

VS CANCER

CANCER COSTS

Research exploring the financial impact
of a cancer diagnosis on children,
young people and their families



September 2023

FOREWORD

As soon as a young person or their family hear the life changing word 'cancer' the costs start to mount up. Travel costs to get to treatment, car parking costs, food costs, and clothing costs. Cancer costs. And as all these extra costs come flooding in, many young people, their parents and carers are forced to reduce or give up paid work - so they can deal with the gruelling impact of treatment on themselves and their loved ones.

In 2017, Young Lives vs Cancer found that young cancer patients and their families were paying on average, £600 extra per month because of cancer. Now we know that this has increased to nearly £700 extra on average each month during a child or a young person's cancer treatment.

At a time where their focus should be on getting through treatment, too many young cancer patients and their families are forced to confront the premium they have to pay out, the penalty to their income, and the resulting financial difficulties and hardships that follow.

We want to see action to urgently ease the #CancerCosts burden faced by children, young people and their families, to ensure they get the immediate and lasting support they need; Action from all those who can make a difference – from governments, the third sector, and the private sector.

Young Lives vs Cancer is committed to being part of the solution, to helping those we support with the immediate and devastating financial impact of cancer, and the emotional costs that this brings. And to bringing others together to make the changes that will make truly make an impact to children and young people with cancer.



Rachel Kirby-Rider
Chief Executive,
Young Lives vs Cancer

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YOUNG LIVES vs CANCER

Young Lives vs Cancer is the only charity in the UK that gives children and young people (0-25) the vital support they need to thrive. We work tirelessly to make sure young cancer patients and their families get the help they need, and their voices and experiences are heard.

We do this by:

- Providing day-to-day support through our professionally qualified social workers based in all main children and young people's cancer hospitals, and who are experts in helping families handle the challenges that come with a cancer diagnosis. They work closely with NHS professionals, as an integral part of the multi-disciplinary care team, to make sure families get the support they need throughout treatment and beyond.
- Providing financial grants to support with the huge financial costs of cancer. Over the last year we have provided grants totalling over £1 million.
- Working in partnership with the NHS, other third sector organisations and partners to make sure that families get the best care and support possible. Standing alongside young cancer patients and their families to make sure their voices are heard.
- Offering free places for young cancer patients and their families to stay close to their treatment centre, through our 11 Homes from Home across the UK (England, Scotland, Northern Ireland).
- Standing alongside young cancer patients and their families to make sure their voices are heard.

ABOUT GUARDIAN

Guardian entered the protection market in 2018 to make a difference.

We believe that nothing is more precious than those we love. However, because of a lack of trust and awareness of protection insurance, too few people protect themselves and their families from the financial consequences of illness and death. We mean to change that. Our ambition is for every family to have protection that they truly believe in.

We're proud to sponsor this research to show the financial impact cancer has on young people and their families. We hope it raises awareness of the cost of cancer and will put a spotlight on the need for more financial support.

Find out more about Guardian at guardian1821.co.uk

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Each year, around 4,000 children and young people in the UK are diagnosed with cancer¹. This comes at a financial premium, with young cancer patients and their families facing a range of extra monthly costs.

As a result of this premium they have pay out, as well as this penalty they face to their income, a cancer diagnosis for many children, young people and their families means experiencing financial difficulties and hardships.

To address the considerable challenges faced by young cancer patients and their families, Young Lives vs Cancer recommend a range of measures that will provide financial support at the different points of their cancer journey. These measures are based on a body of evidence and insight from young cancer patients and their families:

- The creation of a Young Cancer Patient Travel Fund to help all children and young people, and their families, afford the cost of travelling for essential treatment
- The available of free parking for all young cancer patients and their families at and around all hospitals and treatment centres
- Financial services and energy companies ensure they have vulnerable customers' policies that include parents / caregivers of young cancer patients
- Relevant financial support, including through the social security system, to be made accessible to young cancer patients and their families from the point of diagnosis, to help with the immediate costs associated with receiving a cancer diagnosis
- Employers champion a range of measure to support workplace participation alongside illness or caring responsibilities.



Almost £700 extra a month in costs

These combined costs all add up to a significant monthly outlay for young cancer patients and their families.

More than £6,000 annual loss in income

A cancer diagnosis also comes with an additional financial penalty, with most young cancer patients and their families experiencing a loss of income and earnings.



INTRODUCTION

Each year, around 4,000 children and young people in the UK are diagnosed with cancer².

In 2017, Young Lives vs Cancer conducted research to assess the financial impact of cancer diagnoses on young cancer patients and their families. The research revealed these young cancer patients and their families were facing an additional financial burden averaging £600 a month.

Since Young Lives vs Cancer conducted this research, the UK has experienced significant economic upheaval. Annual inflation reached a four decade high in 2022, seeing sharp increases in the cost of living. Goods such as food, energy, and fuel have become less affordable for families as a result.³ The treatment and support available to young cancer patients has continued to develop and evolve in this time.

Young Lives vs Cancer conducted an evidence review 2022 to better understand existing knowledge around the costs encountered by young cancer patients and their families following diagnosis. Up to date UK evidence mostly relating to the direct costs experienced by families was found to be particularly lacking.

Recognising the need to address this knowledge gap, Young Lives vs Cancer conducted new research between February and April 2023.

The research involved an online survey with a total of 259 participants and follow-up interviews. The participants included young people aged 18 to 26, as well as parents or caregivers of children and young people under 27, who have undergone cancer treatment and care within the past two years. This research was kindly sponsored by Guardian.

This report is part of a series of reports published during 2023, focusing on the different costs faced by young cancer patients and their families. The other reports in this series, as well as previous [#CancerCosts](#) research reports, are available at: younglivesvs cancer.org.uk/research.

² Cancer Research UK, <http://www.cancerresearchuk.org>

³ <https://commonslibrary.parliament.uk/research-briefings/cbp-9428/>



THE CANCER PREMIUM

This cancer diagnosis comes at a financial premium, with young cancer patients and their families facing a range of extra monthly costs.



We had to travel over 50 miles return, daily for 10 days, during our teen being hospitalised and had travelled this same distance for weeks while under investigation. This same journey was made fortnightly for treatment sessions.”

The most common and significant of these, is the cost of travelling to treatment. Given its specialist nature, cancer treatment for children and young people largely takes place in a small number of hospitals and centres. To get to these hospitals and treatment centres many young cancer patients and their families often have to travel long distances, several times a week, as reported by this family, “We had to travel over 50 miles return, daily for 10 days, during our teen being hospitalised and had travelled this same distance for weeks while under investigation. This same journey was made fortnightly for treatment sessions from November to April inclusive and further return journeys from home to take our teen for treatment in Northern Ireland”.

As a result, nearly all young cancer patients and their families (96%) reported having to pay extra on travel following their diagnosis, and it cost them an average of £250 a month. The scale of costs involved is described by this young person, “If I’ve got to have treatment, I get a weekly ticket for both me and my mum [...]. You’re looking at £180 each, so [...] that’s £360 just for the train ticket. I’ve then got to get a single day ticket [...] so it’s then another £75 on top. Weekly parking is about £50. So, what’s that? £410, just for the train and the parking”.

While some young cancer patients and their families used different forms of transport to attend treatment, the majority (93%) reported using a car for at least some of their journey. Given the additional travel involved in getting to and from treatment, and dependence on cars to make these journeys, young cancer patients and their families can also face extra costs to keep their vehicles on the road. These extra costs included increased car maintenance and repairs (£17 a month), insurance premiums (£3 a month), and breakdown cover (£2 a month).



W When you've got two or more children you've obviously got to be at the hospital with one and then sort the other one out using other people."

To be able to make the journeys to treatment, some young cancer patients and their families also have to spend extra on childcare. This is particularly the case for those with other children who may be unable to call upon their family to look after siblings during treatment. One family described, "When you've got two or more children you've obviously got to be at the hospital with one and then sort the other one out using other people".

One in five young cancer patients and their families (21%) reported having to pay extra each month on childcare following their diagnosis. On average, young cancer patients and their families had to spend an extra £30 a month on childcare. As one family described, in addition to the costs, this often involved lots of planning, "Lots of organisation before leaving to sort out sibling childcare, a drive down to the South West, often in rush hour to get to appointments and register for treatment".



W I have to pay high prices of parking due to spending hours in the hospital."

The extra costs don't stop when they arrive at their treatment. Almost two thirds (65%) are faced with parking costs. The frequency and length of time young cancer patients and their families can have to spend at hospitals and treatment centres, can mean these costs quickly build up.

While free parking and concessions are available to some at a number of hospitals and treatment centres, this is far from a universal offer for all young cancer patients and their families across the UK. As this family reported, "Even though at times I have access to free parking, it isn't applied to all my appointments I have had, so at times I have to pay high prices of parking due to spending hours in the hospital".

Due to limited availability of parking spaces at hospitals and treatment centres, many young cancer patients are also forced to park in more expensive off-site car parks. As one parent described, "The children's hospital has a car park but there's only about 10 spaces and its blue badge holders only. So, you have to park in either off-street parking, which unless you get there at silly time in the morning, there isn't any. So, you have to park in a private car park. Which is really expensive. And [our son's] treatment meant that for one week of the cycle we were there every day".

This results in young cancer patients and their families spending on average £24 a month extra on parking at, or near to their hospitals and treatment centres, but for some this was higher.

W It's a really long day. So, it's better really to stay the night either one side or the other, you know. That's what we do sometimes, but it's not as easy now really because they cost at least £100 for a night in a hotel."

Given the distance from home of young cancer patients' hospitals and treatment centres, the length of time and frequency they are expected to be there, as well as the timings of the appointments they are given, many reported staying over in accommodation during their treatment.

As one parent described, "I know we don't have to, but sometimes when it's early morning and usually she has a scan in the morning and she has the consultation in the afternoon, which is good in a way, because it's two appointments in one day, but it's a really long day. So, it's better really to stay the night either one side or the other, you know. That's what we do sometimes, but it's not as easy now really because they cost at least £100 for a night in a hotel".

While many young cancer patients and their families could stay in accommodation provided by the health service or charities, at no cost to them; this was not the case for all, with one in 10 (12%) reporting having to pay to stay over during treatment. Across all young cancer patients and their families, on average they spent an extra £14 a month on accommodation.



W Having to buy every sort of bottle of water and snack and meal. You kind of don't think of it at the time [...] but when you come home and look at your account after the weekend, you're like, oh my God, how could we spend that much money on food?"

Spending significant time travelling to and from treatment and commonly being without cooking or refrigeration facilities while at their hospital or accommodation, left many with little choice but to pay extra for food. One family described, "If you're home, you would just be making your meals and it wouldn't cost that much but having to buy every sort of bottle of water and snack and meal. You kind of don't think of it at the time [...] but when you come home and look at your account after the weekend, you're like, oh my God, how could we spend that much money on food?".

Even on returning home from treatment, not being well enough to attend education or employment means many young cancer patients and their families continued to face extra food costs, as one parent described, "He's at home every day eating, so food prices have gone up".

Following treatment, young cancer patients and their families also reported having to buy more specific or specialist food, and having to take extra hygiene caution in the food they buy, both of which often came with an extra cost. One family described, "You have to be really careful with food. So, normally we do a big weekly shop, but then we were doing an online shop every two to three days, you don't realise how much it adds up, because obviously nothing could go past its use by date or best before date".

All these factors combine to mean nearly all young cancer patients and their families (96%) reported paying more on food after their diagnosis, spending an average of £144 extra a month.



To make long travel and treatment time more bearable, many young cancer patients and their families reported spending extra on toys and treats. As one family described, "When travelling we sit around for hours in the car, then sit for hours in a waiting room. It's really boring for an adult let alone a 3 year-old. We give him treats".

Parents and carers described using treats as bribes to encourage children and young people to attend difficult appointments or treatments which they were resistant to attending. For example, this mother described, "When she's having a day in hospital, it's buying her things from Costa, which is never cheap. Buying her things from the hospital canteen, which isn't too bad, but it's still a lot more than I'd usually spend. [...] it's also the bribery as well, like 'If you if you come and let them do your blood test, then I'll take you out for a nice lunch?' and then she'll choose something that's really expensive and then leave half of it".

Three in five young cancer patients and their families (61%) reported spending more on toys and treats following their diagnosis, spending an average of £48 extra a month.

To stay connected and help make the long travel and treatment time more bearable, one in three young cancer patients and their families (32%) also reported spending extra each month on their telephone and mobile bills. On average, they spent £15 extra a month on their telephone and mobile bills.



[Her size] was forever changing, so her size might go up. You know within a month again, and then you need a whole new set of clothes. [...] And that's a massive cost."

Because of the treatment, young cancer patients and their families also spend extra on clothing and their energy costs. Almost two thirds (65%) reported having to spend extra on clothing, with young cancer patients and their families having to spend an average of £56 a month extra in this area.

These extra costs result from many young cancer patients and their families having to buy additional clothing in response to the impact treatment has on their bodies; "I was kind of surprised by the cost of clothes and stuff. I didn't even realise those things because she did really need a whole new wardrobe

and a comfortable one and it was forever changing, so her size might go up. You know within a month again, and then you need a whole new set of clothes. [...] And that's a massive cost".

In addition to this, needing to buy suitable and sufficient clothing for their time on the ward and their journeys back and forth also added an extra cost. As one family described: "We had to buy like 10 pillowcases and 10 blankets because she had to have clean bedding and clothes every day".



URGENT

£68 EXTRA
a month on energy

W Constantly needing to have heating on as he was cold due to losing weight."

Three in five young cancer patients and their families (61%) reported having to pay more on their energy bills following their diagnosis. On average, this cost them an extra £68 a month.

These extra energy costs resulted from a range of factors. These included spending more time at home in between their hospital visits, as was the case for this family, "Obviously [my son] is at home every day which means we have to have the heating on every day. So, gas and electric prices have gone up". This can also be because of young cancer patients being immunocompromised or feeling colder because of their treatment, as this family described, "Constantly needing to have heating on as he was cold due to losing weight".

The extra energy costs also extended beyond heating. As a result of their treatment and being immunocompromised, many young cancer patients and their families also had to use extra energy on washing and cleaning; "Increase in washing and laundry due to him being incontinent at times so increased energy costs". Many even having to use extra energy in preparing their food and drink, as one family reported, "Our daughter could only have boiled water for six months, so every time she had a drink, we had to boil the kettle".



Almost
£700
extra a month
in costs

These costs all add up to a significant monthly outlay for young cancer patients and their families, averaging £691 extra a month.

Lone parents were among the groups that reported paying the most in extra costs. The research suggested those from minoritised ethnic groups and those for whom English wasn't their first language, also paid more in extra costs. Those families with younger children and larger household sizes also reported spending more on average. Among those also having to pay most in extra costs, were young cancer patients and their families earning the least and living in more deprived areas prior to their diagnosis.

Not only are these extra costs significant, but they also appear to have increased substantially in recent years. Since undertaking our previous research on this issue in 2017, which found young cancer patients and their families spent an average of £600 extra a month, this latest data suggests a 15% increase on this figure.⁴ The most substantial increases appear to have taken place in the areas of travel, childcare and food.

15%
INCREASE
in extra costs
since 2017

⁴Young Lives vs Cancer, Cancer Costs, 2017



THE CANCER PENALTY

A cancer diagnosis also comes with a financial penalty, with most young cancer patients and their families experiencing a loss of income and earnings.



It's a lot of financial worry which you don't need while going through the worse time of your life."

Having to take time off or away from work, or needing to change employment arrangements because of treatment, meant seven in 10 young cancer patients and their families (71%) experienced a loss in income.

These losses of income and earnings appear to be even more common among those living outside of England, with the research suggesting that those living in Northern Ireland, Wales and Scotland were more likely to see their income and earnings decrease following a cancer diagnosis.

The age that children and young people are diagnosed also seems to influence whether households experienced a loss of income and earnings, with those with younger

children being more likely to report income losses. One mother described "It's a lot of financial worry which you don't need while going through the worse time of your life, my husband's work didn't pay him to begin with, so this was very very difficult, I was on maternity leave to begin with, so we weren't receiving much money."

The research also suggests the longer treatment goes on, the more likely young cancer patients and their families are to experience a loss in income, with the time they had to take away from work building up and their ability to juggle work and treatment becoming increasingly difficult. For some young cancer patients, their treatment can last for years.

THINGS DONE TO ATTEND TREATMENT

- Take sick leave - 40%
- Take compassionate leave - 35%
- Changed to more flexible working arrangements - 35%
- Stopped working - 32%
- Reduced their hours - 31%
- Take unpaid leave - 30%
- Take holiday / annual leave - 29%
- Other - 6%



W We ran our own business and due to it will have to get rid of our business as we can't work from hospital [...]. Financially we are ruined now."

The reasons for income losses were varied, as young cancer patients and their families were forced to utilise a range of approaches in taking time off or away from paid work following their diagnosis.

Some young cancer patients and their families experienced these losses while still maintaining their employment, by taking additional holidays (29%), sick (40%) and compassionate leave (35%), changing to more flexible working arrangement (35%), and reducing their working hours (31%). One mother described, "I was on maternity pay which then rolled into statutory sick pay, so our income was a lot less than pre diagnosis". Another family described, "We were fortunate enough to still be being

paid on compassionate leave however as my son's treatment went on, I would have had to take unpaid leave".

For almost a third of households with someone employed prior to the diagnosis (32%), income losses resulted from at least one of the adults stopping work entirely. One family described, "Becoming a full-time carer for all the days my son didn't have medical appointments meant I had to give up working. The loss of income had the biggest impact." The impact also extended to those who are self-employed; "We ran our own business and due to it will have to get rid of our business as we can't work from hospital [...]. Financially we are ruined now".


W I haven't been able to work during my treatment, so the total household income dropped by nearly £29,000 a year. We've had to be really tight with money.

These income losses can be significant. For those households experiencing a loss in income and earnings, this averaged £6,117 a year. For three in 10 of those households (31%) experiencing a reduction in income, this loss exceeded £10,000 a year.

One young person described, "I haven't been able to work during my treatment, so the total household income dropped by nearly £29,000 a year. We've had to be really tight with money." Another family described, "I have had to give up work and my husband has had to lower his hours to look after our infant when I have to take my son to his appointments. Our yearly income has dropped by two thirds".

These losses came despite the social security system and many young cancer patients and their families receiving additional benefits following their diagnosis. Almost three in five (58%) reported receiving some new or increased benefits. In most cases these were disability benefits, such as Disability Living Allowance (DLA) (66%), Carer's Allowance (28%), Personal Independence Payments (PIP) (19%), or Child Disability Payments (7%) for those living in Scotland. In addition to these, the other most common new or additional benefits claimed was Universal Credit (UC) (23%).





CONCLUSIONS AND RECOMMENDATIONS


As a result of this premium they have pay out, as well as this penalty they face to their income, for many young cancer patients and their families a diagnosis means financial difficulties and hardships.

As set out in this research, the costs, both the premium incurred and the income penalty faced, were commonplace, wide ranging, and significant in their financial value. The costs resulting from a diagnosis were immediate and something young cancer patients and their families could not budget or plan for. At a time where their focus ought to have been on getting through treatment, many young cancer patients and their families were forced to confront the difficulties created by this. As one family described, "It was an extra burden to carry when my sole focus should have been on my son's health".

For many young cancer patients and their families, these difficulties involved exhausting what **savings** they had, and in doing so, sacrificing future opportunities and impacting prospects. One family described,

"Simply the sadness of having to use savings you wanted to use to improve your quality of life just to be able to survive."

Where savings weren't an option or where they had been completely exhausted, many young cancer patients and their families reported being forced to take on "ever increasing" debts. As one family reported, "Every month we were going into negative in the bank which we have never done before. I received full pay for six months but that still wasn't enough to cover extra costs". For many of those going into debt, there were persistent worries around how they were going to be able to escape them; "I'm scared. I don't know how I'm going to pay this back. I don't have a plan of action yet".



"It was an extra burden to carry when my sole focus should have been on my son's health."



[We're] worried about how we'd keep up with rent and utilities and grocery bills and day-to-day expenses.

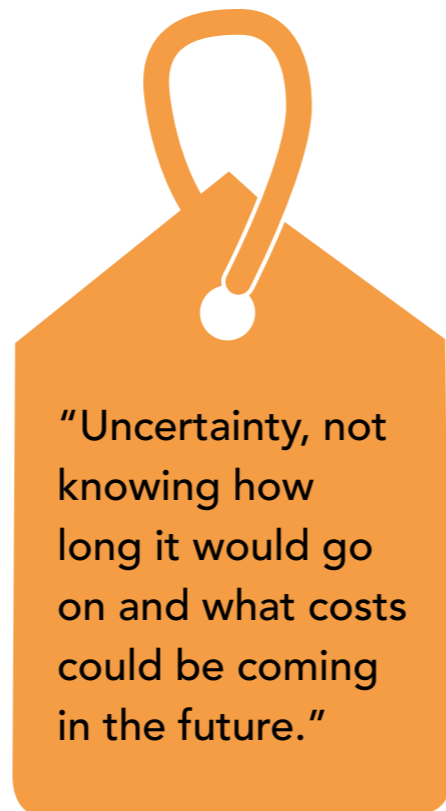
The costs faced following their diagnosis also left many young cancer patients and their families **struggling to pay their household bills** and to afford the day-to-day essentials they needed. These included falling behind on their energy bills, finding it difficult to afford to feed themselves and their families, and struggling to keep a roof over their heads. As one family described, "[We're] worried about how we'd keep up with rent and utilities and grocery bills and day-to-day expenses".

For some, the financial struggles also extended to being worried if they would be able to afford the costs of **attending their treatment and appointments**. One family described, "I'm scared of what could happen if we didn't have money to go to treatment".

All these experiences prompted uncertainty – not knowing how long their treatment would last, what costs lay ahead, and if or when they'd be able to recover and return to 'normal'. As one family described, "Uncertainty, not knowing how long it would go on and what costs could be coming in the future". The ability to take another hit is further

highlighted by another family, "We could manage from savings and DLA during first round treatment but if my son relapses, I won't be eligible for sick pay/leave from my company and will lose my job".

For many, these financial struggles and worries also created an **emotional toll**, as one family described, "The general anxiety about costs relating to cancer treatment are present all the time".



To address the considerable challenges faced by young cancer patients and their families, Young Lives vs Cancer recommend a range of measures that will provide financial support at the different points of their cancer journey. These measures are based on a body of evidence and insight from young cancer patients and their families:

- The creation of a Young Cancer Patient Travel Fund to help all children and young people, and their families, afford the cost of travelling for essential treatment
- The available of free parking for all young cancer patients and their families at and around all hospitals and treatment centres
- Financial services and energy companies ensure they have vulnerable customers' policies that include parents / caregivers of young cancer patients
- Relevant financial support, including through the social security system, to be made accessible to young cancer patients and their families from the point of diagnosis, to help with the immediate costs associated with receiving a cancer diagnosis
- Employers champion a range of measure to support workplace participation alongside illness or caring responsibilities.

Young Lives vs Cancer are commitment to being part of the solution and working with all those who can make a positive difference to ensure all young cancer patients and their families get the immediate and lasting support they need to ease the #CancerCosts burden they currently face.

#CancerCosts

younglivesvscancer.org.uk/cancercosts

Young Lives vs Cancer is an operating name of CLIC Sargent Cancer Care for Children.
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