

YOUNG LIVES
vs CANCER

RUNNING ON EMPTY

Research exploring the costs
young cancer patients and their
families face travelling for treatment.

June 2023



YOUNG LIVES vs CANCER

ABOUT YOUNG LIVES vs CANCER

Young Lives vs Cancer is the leading UK charity for children and young people (0-25) with cancer. We work tirelessly to make sure that young cancer patients and their families get the support they need, and that their voices and experiences are heard. We do this by:

- Providing day-to-day support through our 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 care team, to make sure families get the support they need throughout treatment.
- Providing financial grants to support with the huge financial costs of cancer. Over the last year we have provided grants totalling over £1 million, with £300,000 given in crisis grants to date
- 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).
- 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.

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Each year, around 4,000 children and young people in the UK are diagnosed with cancer.¹

To receive the specialist treatment they vitally need, they and their families often have to travel **long distances, several times a week**, and sometimes this will last for years.

H 9 hours
350 miles

71%
Families experiencing a decrease in their income

For many, frequently having to travel to and from cancer treatment can also result in **lost household income** and earnings.

£250
EVERY MONTH


Not only can this be physically and emotionally exhausting, but it can also come at a **significant financial cost** for young cancer patients and their families.

The current support available is proving **inadequate in covering the travel costs** for many young cancer patients and their families.

12% **T**
Families receiving support covering their costs

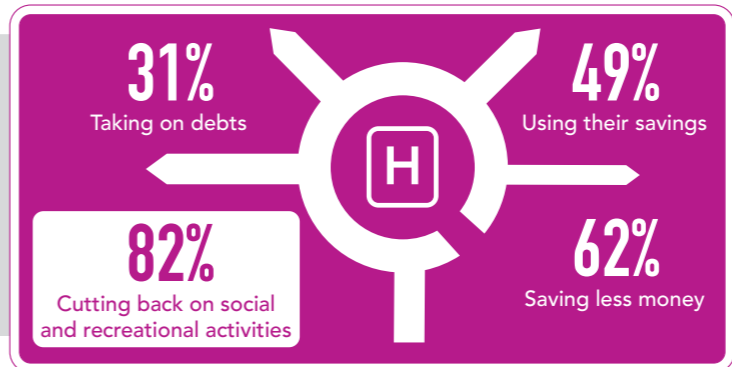
This means many young cancer patients and their families are **struggling to pay** for the costs of travelling to and from cancer treatment.

71% Families struggling to afford their travel costs



- Cutting back on food 27%
- Falling behind on bills 20%
- Selling possessions 20%
- Fundraising or crowdfunding 18%
- Delaying or missing treatment 10%

Less commonly, this can also result in families having to **cut back on food**, falling behind on household bills, selling their possessions and assets, fundraising to help meet costs, and delaying or missing cancer treatment and care.



For most, these financial struggles commonly result in them having to **make a range of sacrifices**. These often include going without much needed social and recreational activities, cutting back or going into their savings, and taking on debts.



These can have significant negative impacts on young cancer patients and their families' financial security, health and wellbeing, and future prosperity, leaving them running on empty. To address this, Young Lives vs Cancer is calling for a **Young Cancer Patient Travel Fund**.

¹Cancer Research UK, <http://www.cancerresearchuk.org/>

FOREWORD

When a child or young person is diagnosed with cancer, they are full of fear of the treatment, its side effects, and the impact it will have on their family and friends. The last thing they or their families should be worrying about is whether they can afford to travel for their treatment.

However, this research demonstrates that many young cancer patients and their families are having to spend significant amounts on travel each month. As a result, many young people and families are left 'running on empty', not only financially, but emotionally and physically too.

Children and young people with cancer and their families need better financial support to face these travel costs. That is why we believe a Young Cancer Patient Travel Fund is the solution to ensure they don't need to worry about the costs and can focus on what matters, getting through treatment.



Rachel Kirby-Rider
Chief Executive, Young Lives vs Cancer

INTRODUCTION

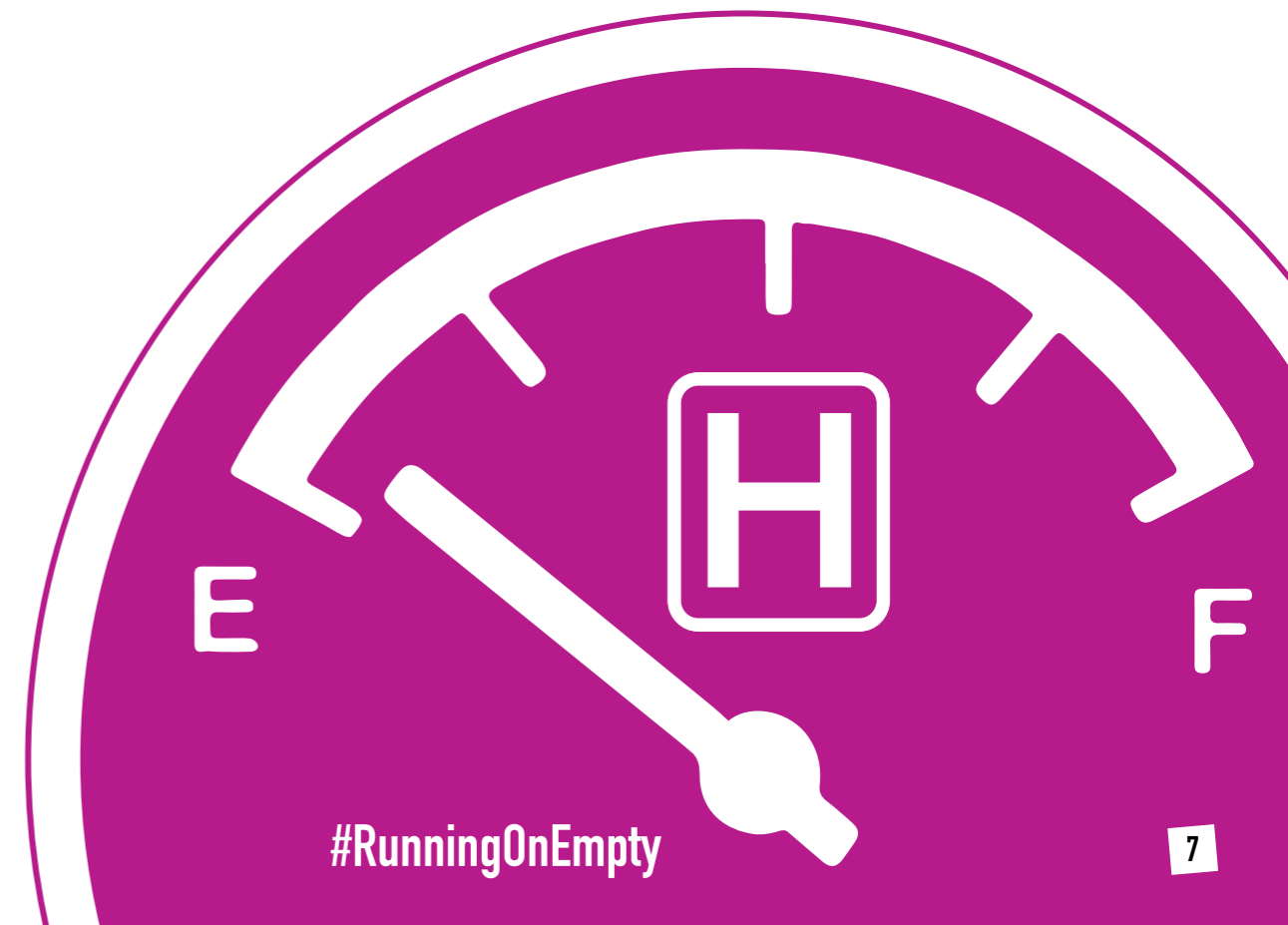
Each year, around 4,000 children and young people in the UK are diagnosed with cancer.¹

Given its specialist nature, cancer treatment for children and young people (0 to 25) largely takes place in a small number of hospitals and centres. These Principal Treatment Centres (PTCs) have specific expertise in treating children and young people with cancer, so that they can get the best possible care.

To better understand the costs young cancer patients and their families face travelling to these hospitals and treatment centres, Young Lives vs Cancer conducted research between February and April 2023.

The research comprised of an online survey and follow-up interviews. A total of 259 people participated in the research. This consisted of young people (aged 18 to 26) and parents or caregivers of children and young people, aged under 27, from across the UK who have experience of cancer treatment and care in the past two years.

¹ Cancer Research UK, <http://www.cancerresearchuk.org/>



TRAVEL PATTERNS

To receive the specialist treatment they vitally need, they and their families often have to travel long distances, several times a week, and sometimes this will last for years.

To get the cancer treatment they need, many children and young people have to travel beyond their local hospital and area. Those participating in this research reported living an average of 40 miles from their main cancer treatment centre. Young cancer patients and their families have little choice over where they are treated, "there's only two centres in the UK that treat my son's type of cancer in midlands and London [...] so that was really it. If they had chosen to go down a different treatment route like systemic chemo, we could have got that in mainland Scotland [...] so obviously we would just do whatever was needed for him to get the best, most appropriate treatment. So all the treatment is there and all the check-ups are there too".

This can also mean young cancer patients and their families having to travel to a range of different hospitals and treatment centres. On average, young cancer patients and their families reported having to travel to two different locations for their treatment. However, more than a quarter of those participating in the research (29%) reported travelling to three or more. As was the case for this family, "She went to Yorkshire and Humber in October and she was still being seen by the hospital there [...] and then we went to London [...] to begin with we would go to Yorkshire and Humber one day, and then we'd have to go to London the next day to start her new care plan. And then go back to our local hospital. So it's at one point where we were visiting all three hospitals at the same time. That was sort of really tiring because, you know, one day you're up north, then you're back at home, and then you're in London".

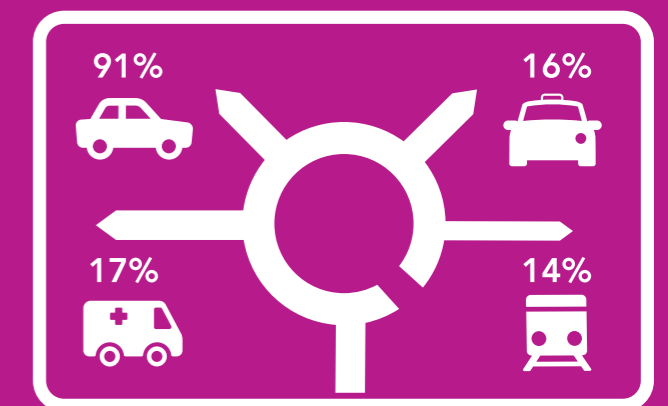
Obviously we would just do whatever was needed for him to get the best, most appropriate treatment. So all the treatment is there and all the check-ups are there too.

For almost one in 10 young cancer patients and their families (8%), this included travelling to hospitals and treatment centres in different countries. This is most common among those living in Wales (73%), Northern Ireland (31%) and Scotland (17%), with most having to travel to hospitals and treatment centres in England.

Nine in 10 young cancer patients and their families (93%) used a car to make all or at least part of their journeys to and from hospitals and treatment centres. Many respondents viewed car travel as the "only viable way" to make the required journeys.

Participants described how public transport presented significant infection risk for young cancer patients when immunosuppressed, particularly in the context of the COVID pandemic, and that car travel felt "a lot safer". One mother described her decision making, "the one time we tried the train, two of the carriages that were supposed to be on weren't, so basically the train was absolutely rammed [...] you didn't necessarily have to wear masks on public transport. So literally I spent five days with my daughter in complete isolation, no one was allowed in the room without a mask on, to all of a sudden with all these people not wearing masks. [...] So after that we were just like, 'no, we're not going to do that'".

Many young cancer patients and their families described how poor public transport links in their area and the lack of reliability would make transport by other means "horrendous" or "absolutely impossible". Indeed, one young person described having to make a risky journey when let down by public transport, "the problem with taxis is if anything comes. We had a few times where we'd tried to order one, [would wait] and by that point we're starting to get late [...] we cut our losses and took the underground metro and sort of risked it just so that we could get to the appointment on time".



In addition to travelling by car, the other forms of transport most utilised to get to and from treatment included non-emergency hospital transport (17%), taxi (16%) and train (14%). For some young cancer patients and their families, public transport offered them a refuge from traffic congestion and shortened journey times, when compared to the cost of driving to and from treatment.

The travel back and forth to their hospitals and treatment centres can be very frequent for many, with half of young cancer patients and their families (50%) reporting having to travel more than once a week across the duration of their cancer treatment and care. As this mother described, "we were running back and forth a lot, and sometimes she would be allowed home, but you'd go back in the next day to get blood tests anyway and you could just end up there for the day if they're doing various bits and pieces. And then I don't think we ever went more than three days at that stage without having a trip back in".

To help reduce some of the travel pressures, some young cancer patients and their families stay in accommodation closer to their hospitals and treatment centres. Two in five young cancer patients and their families (39%) reported staying away from home to reduce their travel. Those young cancer patients and families living further away from their hospitals and treatment centres and in more rural locations are more likely to stay in accommodation to reduce their travel. Of those staying closer to their hospitals and treatment centres, half of young cancer patients and their families choose to stay in accommodation offered by the health service (54%) or by charities (54%).

The distance and the regularity with which many go back and forth for treatment, combine to result in many young cancer patients and their families having to travel a significant number of miles each month. On average, young cancer patients and their families travelled 350 miles a month to get to and from their treatment. For some groups, the average distance they need to travel each month is significantly higher. These include those living in more rural areas, those living in Wales and Scotland, and those having to travel to another country for treatment.

All these factors mean young cancer patients and their families are spending an average of more than nine hours a month travelling to and from treatment. For many, these levels of travel to and from cancer treatment takes place over long periods of time. For more than half the respondents taking part in the research (55%), their cancer treatment had lasted more than a year.

"I don't think we ever went more than three days at that stage without having a trip back in."

H **9 hours**
350 miles

EVERY MONTH

DIRECT TRAVEL COSTS

Not only can this be physically and emotionally exhausting, but it can also come at a significant financial cost for young cancer patients and their families.

For many young cancer patients and their families, the travel to and from treatment can be “intense” both practically and emotionally, with most describing worrying and or experiencing stress associated with travelling.

Young cancer patients and their families often must negotiate long journeys with lots of equipment and luggage. As reported by one mother, “all the practical elements of the logistics of being in a city that you’re not familiar with a pram and a child and a suitcase and all the rest of it”. One young person described his difficulties travelling to and from treatment with luggage and equipment, “during chemo that gets quite heavy [...] carrying that stuff. I’ve also got a backpack on which is feeding me [...] So it’s a tiny thing, but I wasn’t able to put my backpack on my back so. Then it gets even heavier [...]”. Travel for treatment was described by most young cancer patients and their families as tiring and exhausting.

Many young cancer patients and their families reported living with a “very admin heavy” logistical burden that was stressful. One mother said, “You end up spending most of your thoughts and emotional stress on the logistics instead of the actual medical situation. [...] It’s a lot of added stress”. Anticipating issues in travel plans was also described as “stressful because [...] it’s constantly a worry”. The unpredictability of treatment scheduling and frequent disruption to everyday life appeared to contribute to the stress felt by young cancer patients and their families.

Many families also have to arrange additional childcare for siblings to travel for treatment and this can introduce additional time and strain, “we had to take [the kids] to whoever could have them basically. So it was a bit of a mishmash disaster, you know, we could never plan. [...] It was always going somewhere before you went to the hospital to drop the kids off, to take him to the hospital [...] you were just trying to split yourself in two all the time”.

“You were just trying to split yourself in two all the time.”

“You end up spending most of your thoughts and emotional stress on the logistics instead of the actual medical situation.”

The anxiety experienced by young cancer patients about travelling to treatment also created an additional challenge, “she gets really anxious about going. And I mean, once she’s there, she’s not too bad. It’s just that anxiety of kind of getting up, going in the car to the hospital”. The negotiations which occur between parent or caregiver and child to encourage travel to treatment can be stress inducing, one parent said “It’s stressful and I dread it”. The long travel times and distances appeared to compound cancer and treatment related pain, with many young cancer patients experiencing discomfort and pain during journeys, and travel sickness was the norm.

Young cancer patients and their families reported routinely needing to drive to treatment when physically and emotionally fatigued, “You’re tired driving too... you have to be more careful I think and try and be more alert as well”. Participants reported needing to travel long journeys to and from treatment whilst upset and experiencing significant stress, “driving there you were always really worried [...] when we were driving back it was normally bad news [...] it became a little bit too much towards the end [...] I get stress induced migraines, so quite often having to drive back was not kind of an option. So my husband did start making the journey with us”.

It’s stressful and I dread it.

Having little say over appointment times and long days contributed towards exhaustion, “it was quite horrendous. When she was having chemotherapy [...] quite often I had to get it up at 5 am and just lift her from bed and into the car [...] I’m sure a couple of times I was nodding off on the roads [...] And it was same on the way home because when she was finishing her chemo for that session it would be late evening by the time everything had been completed and she was fit to be going home. So we’d be driving home at night as well. So it was quite tiring”.

My daughter was actually really unwell and trying to get back into the hospital was like it was just it was horrendous.

In addition, the time and distance between their home and their hospital and treatment centres also created anxiety and fear among young cancer patients and their families about how they reach urgent medical care if needed. One parent explained, “my daughter was actually really unwell and trying to get back into the hospital was like it was just it was horrendous. You’re constantly making sure she’s OK and trying to drive safely and get her in as fast as you can. So that was really stressful [...] I would be really worried that I was that bit away from the hospital and if something happened what was I gonna do. You know you’re constantly anxious... it’s scary actually”.

In addition to these physical and emotional costs, for many young cancer patients and their families, there are significant financial costs. Travel to and from treatment each month costs an average of £250. Those travelling more often, further, and for longer, on average spend more getting to and from cancer treatment. One parent said, “if all this was to happen at the local hospital it would never be an issue financially for us [...] but because we’re an hour plus from the hospital, that’s when it got expensive for us”. Those living in more rural areas and those having to travel to other countries for treatment similarly tend to spend more.

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 face extra costs to keep their vehicles on the road. These extra costs include increased car maintenance and repairs, breakdown cover and insurance premiums, and total an average of an additional £22 a month for young cancer patients and their families. For many, these costs go beyond simply maintaining their current vehicle. Almost a quarter of young cancer patients and families (24%) reported having to obtain a newer or more reliable vehicle to ensure they were able to get to and from their treatment. On average, those young cancer patients and their families purchasing a vehicle spent £10,467 doing so.

The extra travel costs faced by many young cancer patients and their families continue when they arrive at their hospitals and treatment centres. Given the most common mode of travel is car, almost two thirds (65%) are forced to incur parking costs while receiving treatment. This results in young cancer patients and their families spending on average £24 a month on parking at, or near to their hospitals and treatment centres. Accommodation closer to hospitals and treatment centres can also come at an additional cost to individuals. While the majority can stay in accommodation provided, by the health service (54%) or by charities (54%), at no cost to them; this is not the case for all. Those having to pay to stay in accommodation closer to their hospitals and treatment centres face an additional average cost of £37 a month.

£250

EVERY MONTH

LOST INCOME

For many, frequently having to travel to and from cancer treatment can also result in lost household income and earnings.

As well as facing these extra costs, most households with a young cancer patient also experience a loss in household income, described by one respondent as a “double whammy”. Having to take time away from paid work or needing to change employment arrangements to travel to and from treatment results in seven in 10 young cancer patients and their families (71%) experiencing a loss in income. This appears to be more common among those with younger children and those where the treatment takes place over a longer period of time.

71%

Families experiencing a decrease in their income



Some young cancer patients and their families experience 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%). Those with variable incomes lose out by not being able to work their usual hours, one young person said, “I just get paid my salary. I get nothing on top, which I’d normally do some overtime throughout the week [...] But I sort of depend on my overtime. [...] So the time I do have treatment, I’m not getting that overtime, I’ve only got my salary”.

Managing travel demands alongside maintaining employment was a challenge for many though and consumed considerable energy, “[it was] really difficult [...] just a constant strain [...] it’s very draining and you’re trying to keep on top of everything”. Though most respondents described their employers as supportive, at times the level of disruption created by travel for treatment meant scheduling became too difficult. One lone parent said, “I did have two jobs before she got leukaemia. [...] But I had to give one job up because it was just a bit too much. [...] I had to commit to being there Mondays and Wednesdays and sometimes other days [...] and I just couldn’t commit to those specific days.”

Indeed, 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 to be able to travel to treatment. One father described, “She did have a part time job prior to diagnosis. Following that she’s been signed off... [...] she’s used up any statutory sick pay allowance from the company, so it’s now a case of we’re having to manage without her money. It wasn’t a huge amount, but it was getting us close to balancing out each month”.

Income losses can be significant. For those households experiencing a loss in income, this averages at more than £6,000 a year. For three in 10 of those households (31%) experiencing a reduction in income because of travelling to and from treatment, this loss exceeds £10,000 a year, “when one of you has to stop working and that income disappears [...] It was literally half of our income. Well more so”. One mother described, “my husband is self-employed and on average, we’re at least a week per month away at the moment. So that’s kind of 1/4 of his income gone. So that’s our biggest hit with travel [...] the lack of earnings” she continued “it is significant money every month [...] he would be expecting to have about £700-800 for his week, so it’s a lot of money that’s just gone from the start”.

“She did have a part time job prior to diagnosis. Following that she's been signed off... she's used up any statutory sick pay allowance from the company, so it's now a case of we're having to manage without her money”

EXISTING SUPPORT

The current support available is proving inadequate in covering the travel costs for many young cancer patients and their families.

To help with some of the financial challenges that come with a cancer diagnosis, almost three in five young cancer patients and their families (58%) received additional benefits following the diagnosis. In most cases these were disability benefits, such as Disability Living Allowance, Personal Independence Payments, or Child Disability Payments for those living in Scotland.

As well as these benefits, there are healthcare schemes providing travel support in each country in the UK, primarily targeting those on lower incomes. For those living in Scotland, reclaiming their travel costs is also a possibility for some young cancer patients and their families through the Young Patient Family Fund. As well as these schemes, non-emergency patient transport services exist in many areas of the UK. Across these government travel schemes currently available, just three in 10 young cancer patients and their families (30%) were able to access any support.

I'll be honest, I wasn't really aware of what kind of support there would be. I guess it's kind of a bit late now.

The most common reasons for people not applying centred on them not being aware the schemes existed (59%) or them not believing they would be eligible to receive support (50%). Young cancer patients and their families often reported that communication about existing support schemes was not forthcoming and many expressed having little knowledge of the schemes available, "I'll be honest, I wasn't really aware of what kind of support there would be. I guess it's kind of a bit late now". According to families, communication of support availability was more *ad hoc* than formal, "I had no idea of the support that was available. We didn't know about the funded accommodation, a nurse happened to mention to us [...] when she said, 'can you not go home?' and I said, 'well, it's a bit of a trek'. And she said, 'well, you should be staying in the funded accommodation'. So. [...] you know word of mouth when we were in hospital". Young cancer patients and their families appeared to learn as much from each other as they did through formal communication structures.

Many of those with knowledge of schemes expressed having been ineligible for awards. Due to income level, "we don't qualify for it because of earnings [...] that's what's kind of really difficult [...] you never imagined all this, you know, because you are cutting back, because we are eating into our savings and it's just very difficult"; and having savings, "the worst thing is, I can't actually apply for any grants because I've got Help-to-Buy ISA, that I can't touch the money in, because obviously it's there saving for a house. I've been saving for about five years, so I can't actually apply because I've got [that]".

Not being an inpatient was also given as reason for ineligibility, "only if you're actually as an inpatient. So you have to have a consecutive number of nights stay. A lot of the time these kids on the cancer wards are diagnosed...they're released in a day release [...] we were practically there every day. But you're not entitled to pick anything up if that's the case because you didn't stay overnight. That makes no sense. You know, you're still there, spending exactly the same as every other person. You just didn't put your head down in the bed for the night".

In addition to the government schemes, several charities offer support help young cancer patient's travel to and from treatment. Almost half of young cancer patients and their families (47%) reported receiving some support from charities to help pay for the costs of travelling to and from treatment. However, unlike the government schemes, in most cases these were one-off grant payments, rather than ongoing financial support available throughout their treatment.

Most significantly, across all the support currently available, they are not covering the costs of travelling to and from treatment for many young cancer patients and their families. Just one in 10 young cancer patients and their families (12%) reported receiving support that covered the direct costs of travelling to and from treatment.

12%

Families receiving support covering their costs



FINANCIAL CHALLENGES

This means many young cancer patients and their families are struggling to pay for the costs of travelling to and from cancer treatment.

As a result of all these costs, and current support arrangements largely failing to cover them, seven in 10 young cancer patients and their families (71%) reported struggling to pay for the costs of travelling for treatment. One mother who described her family as in financial disaster disclosed, "we're in hospital most of the day tomorrow so I'll have to borrow some money to pay for parking tomorrow cause I haven't got it". One participant stated, "we are haemorrhaging money faster than we're earning it"; and another, "we were just paying a lot of costs out [...] her health was the biggest stress and then the finance was the next worry on the list".

Many young cancer patients and their families disclosed experiencing financial hardship and sought to generally cut back, one mother said, "everybody lives to their means so [...] things are tighter". On observing cutbacks, some parents and caregivers felt their children had become worried too. One mother described, "she came out last week from school she said 'Mummy my shoes have got holes in them' [...] She hadn't told me [...] and she was like 'it's okay Mummy I can still wear them.' [...] and that made me feel dead low because she said it in front of all the other families. [...] It's things like that you try to put your mum face on, try to protect them and shield them from what's happening but reality is you can't shield them from everything".

71% Families struggling to afford their travel costs



You try to put your mum face on, try to protect them and shield them from what's happening but reality is you can't shield them from everything.

The struggles faced appear to increase in line with treatment length and travel frequency, distance and time. Those on lower incomes prior to diagnosis, were also more likely to report struggling to meet their travel costs. One mother reported, "me and my partner both work full time [...] and before my son's diagnosis we didn't really have much spare income any way [...] and having to travel to and from the hospital maybe 15 times a month, pay for parking, pay for food when we're there, that's all money we didn't really have in the first place. You know spare. So we've had to find the money to be able to get him his treatment".

However, even among those earning more than £50,000 a year prior to a diagnosis, more than half (52%) reported struggling. Similarly, those living in more deprived areas were more likely to report struggling to meet the costs of travelling to cancer treatment, but even in the least deprived areas, more than half of young cancer patients and their families still reported struggling.

CUTTING BACK

For most, these financial struggles commonly result in them having to make a range of sacrifices. These often include going without much needed social and recreational activities, cutting back or going into their savings, and taking on debts.

Among the sacrifices that young cancer patients and their families make, the most common is going without much needed social and recreational activities. Four in five young cancer patients and their families (82%) reported cutting back on things like holidays, leisure, entertainment and social activities, to help meet the costs of travelling to treatment. One mother described the difficulties created by the financial constraints, "we can't make no plans. We can't go anywhere with the kids". At times, these decisions to cutback were contrary to their wellbeing needs, "we've come to realise prior to this that our mental health needed looking after. So it was very much, let's say we take time out to do stuff for ourselves [...] so for my wife it was going out and socialising with her friends [...] for me, I was very busy doing sports [...] so it's realising we don't have the finance to".

You're thinking all the time about money, and can we afford to do this?

As a result of cutting back, children and young people may also miss out on development opportunities, "So my son, bless him [...] school trips are quite expensive. I think he's been aware as well [...] and he's like 'no, no, no, I'm not going to go it is too expensive'. That's quite sad to have your son acknowledging that actually it's a little bit more than you can afford". Decisions to cut back on enjoyable activities were often fraught, "you want to keep things as normal as possible, but also you can't because of what's going on. You're thinking all the time about money, and can we afford to do this? [...] I think one of the things we were so worried about is because our daughter was so poorly, at one point she was on palliative care, we were like, 'but how do you say no?' And it's kind of sort of weighing that up all the time. You know, like you've got to be sensible because there's not a never ending pot of money. But also, when you think there's a possibility your daughter is dying, you also don't want to say 'oh no, we can't do that'. So that was quite difficult".

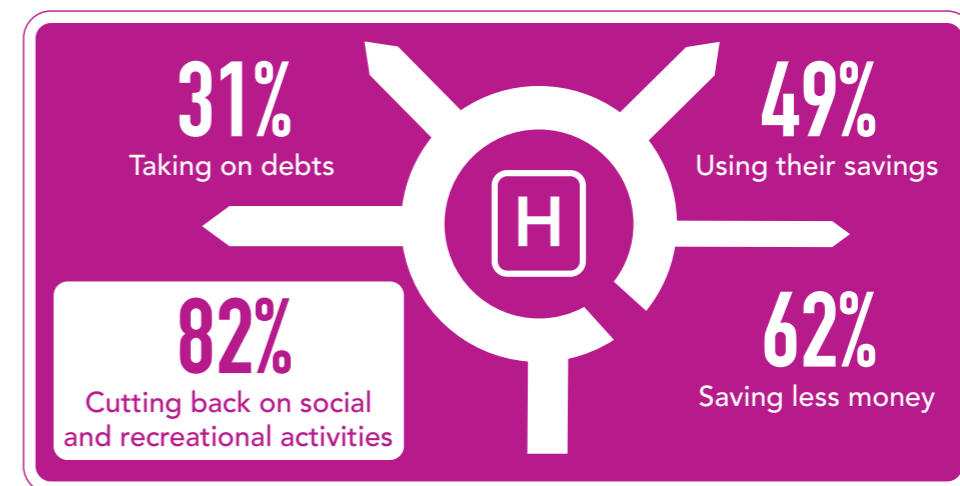
To help pay for the costs of travelling for treatment many have gone into their savings. Half of young cancer patients and their families (49%) used their savings to fund their travel costs. On average, those going into their savings and investments, reported spending more than £1,600 of these on travelling to and from cancer treatment. Many disclosed that their savings were all spent, "we don't have any [savings] now. [...] we had to dip into the children's savings and that's just ridiculous and now the kids don't have savings and that angers me more than anything because it's one thing using your own savings but then having to then take your own kids savings". As well as using their existing savings, three in five young cancer patients and their families (62%) reported being less able to save and cut back what they were saving.

To help meet the costs of travelling to treatment many are forced to borrow money. Three in 10 young cancer patients and their families (31%) had to borrow or take on debts to help pay for the costs of travelling to the cancer treatment and care. One father reported, "we didn't have a lot of savings, that was cleared out fairly fast. We're now running into credit. And to be honest [...] at the moment the credit cards are supporting our treatment journey". For those taking on additional debts to pay for their travel, this averaged more than £1,800. One young person disclosed, "the actual travel works out something like £450 to £500 pounds each round of treatment, you know and I've got to put that on my credit card because I can't afford to pay that at the time" he continued "I don't have £500 just sitting there, you know? I'd absolutely love it if I did. But you know, that's something that does worry me".

Those whose treatment has lasted several years can build up significant debt, one mother disclosed, "so we owe between £20-25,000 on our cards, right? And that might sound like a lot, but that's over four years of crap. So we've put that down to four years, it's £120.00 a week that we've been spending our cards, which to be honest, given the situation, it could be so

much more worse than that. But we're trying to control it back [...] because of the interest now, if we pay £250 on one of them, £50 goes to outstanding balance and £200 goes to interest. Seriously, how am I supposed to get out that situation?". Many young cancer patients and their families found it difficult to see how their debt could be addressed, one father said "it's running into thousands on the card. I think we're about £6,000 at the moment just with. Everything we've had to do. Stuff we've had to pay for. [...] I'm keeping on top of the repayments at the moment. But that's only the minimum. That's not going to actually get rid of my debt".

Experiencing reduced household income during treatment and growing debts placed "more pressure" on some young cancer patients and their families to try make up funds by taking working additional hours. One mother described, "[it's] not even workable, like we're sitting on how we're going to pay that bill [...] you just get your head slightly above water and then it gets chucked back under again and that's just the way it is all the time. And it's got to the stage, you know, the kids are saying, 'why is Daddy not in, we never see Daddy'. Because Daddy's always having it work".



Less commonly, this can also result in families having to cut back on food, falling behind on household bills, selling their possessions and assets, fundraising to help meet costs, and delaying or missing cancer treatment and care.

The difficult decisions being made also extend to some young cancer patients and their families reducing the food they buy and eat so they can afford to travel to and from treatment. More than a quarter of young cancer patients and their families (27%) report cutting back on food to help meet the costs of travelling. This mother described dividing a tin of custard between five, "I'm quite good at kind of making things go further [...] The kids wanted pudding last night [...] I bought them a little cake and I said 'we'll just open one tin of custard'. I'd have never have done that... one tin between five people is like... it's just ridiculous [...] That's just one example".

To be able to pay for the costs of travelling to and from treatment, some young cancer patients and their families are also forced to fall behind on household bills, such as food, energy, rates, and rent or mortgage payments. Falling behind on essential household bills to be able to travel to cancer treatment was the reality for one in five young cancer patients and their families (20%).

For some young cancer patients and their families, being able to afford the costs of travelling back and forth to treatment, was only possible by them selling things they own. One in five young cancer patients and their families (20%) sold possessions and assets to help meet the costs of travelling to treatment. For some this may involve selling their home, "I don't know how I'm going to pay [the debt] back. I don't have a plan of action yet. We are talking about selling up where we live [...] to release some money [...] we've got to do something different [...] The biggest problem is [...] it's been in the family a long time. [...] that is going to be quite a wrench. When the time comes".

Cutting back on food	27%
Falling behind on bills	20%
Selling possessions	20%
Fundraising or crowdfunding	18%
Delaying or missing treatment	10%

To be able to get to and from treatment, some young cancer patients and their families had to rely on the generosity of others. Almost one in five (18%) fundraised or crowdfunded because of the costs of travelling to cancer treatment and care. Community initiated funds were a significant help to some young cancer patients their families "my sister [...] set up a GoFundMe page when my daughter was diagnosed, which really helped cause each time we went to hospital, you were talking about at least £100 for each journey [...] on top of the food or whatever you needed on top of that [...] we manage, but people have been very very kind with us really. You know, we've got a close-knit community here and everybody chipped in [...] to help us fund the treatment, the travelling and food and stuff because, you know nothing's cheap nowadays anyway is it really".

When no further cutbacks or sacrifices were possible to meet the costs of travelling to and from treatment, some young cancer patients and their families are faced with no alternative but to delay or miss treatment and care. This is the case for one in 10 young cancer patients and their families (10%), who reported missing or delaying treatment and care appointments because the cost of travelling.



We are talking about selling up where we live.



CONCLUSIONS AND RECOMMENDATIONS

These can have significant negative impacts on young cancer patients and their families' financial security, health and wellbeing, and future prosperity, leaving them running on empty. To address this, Young Lives vs Cancer is calling for a Young Cancer Patient Travel Fund.

At a time where young cancer patients and their families should be focused entirely on getting through their treatment, as this research sets out, they are often also dealing with the direct and indirect costs of travel. For many young cancer patients and their families, the impact of these costs is significant and long-lasting.

Some young cancer patients and their families spoke of how these costs had interfered with specific ambitions, for example, "if you look at it over the last two years, I've had treatment five times and that roughly has cost about £500 each time. So you're looking at £2,500 [...] about 1% to 2% of your [house] deposit [...] and again, I'm having another one and let's say I have another one or two this year [...] It could potentially be £4,000 that I've not been able to save [...] purely because of having to pay to go to hospital. It could potentially have delayed me being able to buy a house by about a year possibly. But then I also don't know how long this is going go on for. So you know, at the moment it just seems like it's a never ending cycle".

Wellbeing was widely impacted by the financial effects of travel costs, and income loss related to travelling for treatment. Participants spoke of worry, stress, strain, pressure, concern, panic, and fear. For some, concerns felt all consuming, with one participant disclosing, "you're thinking all the time about money"; and another "[it's] eating me up".

It was common for young cancer patients and their families to struggle to see an end to the negative impacts, "we're in financial disaster because of everything and it's not ending because we're still in that life and we can't get out of it and try to describe that to someone it's hard because it's like people don't get it because they see the kids with their hair and tube out and think that's normal [...] everything else we can cope with you know all the stuff that comes with the illness but it's the financial impact that having a sick child totally strains you".

To help address these challenges, the most common solution identified by young cancer patients and their families was a scheme that refunded their travel costs to and from cancer treatment. Three in five young cancer patients and their families (62%) believed a scheme that refunded their travel costs would be most helpful to them and other children and young people diagnosed with cancer. Beyond a travel refund scheme, the other forms of support that young cancer patients and their families identified as being potentially helpful included schemes that provide free or discounted fuel (60%), travel costs upfront (43%) and free hospital transport (35%).

For any travel support to be effective, young cancer patients and their families identified a range of different principles this should be centred around. These include:

- Be available from point of diagnosis;
- Be available throughout the duration of the cancer treatment;
- Be non-means tested;
- Be adequate to cover costs;
- Be well promoted;
- Be simple to access / apply for; and
- Be paid immediately or quickly.

To change the current system, so it better supports all children and young people with cancer and their families, Young Lives vs Cancer proposes the governments in England, Wales and Northern Ireland create a Young Cancer Patient Travel Fund to help all children and young people with cancer, and their families, afford the cost of travelling for essential treatment.

In Scotland, Young Lives vs Cancer proposes the Scottish Government expand the current Young Patient Family Fund, so it is available to all young people with cancer (up to age 25), day patient/ outpatient care, and travel outside of Scotland for those who must get their treatment somewhere else in the UK.

#RunningOnEmpty

younglivesvscancer.org.uk/travelcosts

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