

YOUNG LIVES

VS CANCER



THE PARKING PENALTY

Research exploring the parking costs young cancer patients and their families face as part of travelling for treatment

August 2023

YOUNG LIVES vs CANCER

CONTENTS

About Young Lives vs Cancer	4
Foreword	5
Summary of findings	6
Introduction	8
Findings	10
Travel patterns	10
Experience of parking	12
Parking costs	16
Lost income	17
Financial challenges	18
Existing parking structures	20
Conclusions and Recommendations	22

Young Lives vs Cancer is the only charity in the UK that helps children and young people (0-25) cope with the emotional and practical impact of their cancer. 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.
- 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.

FOREWORD

Children and young people with cancer need specialist and age-appropriate treatment and care, which is often provided far away from home. This can mean many young cancer patients and their families facing long, stressful and tiring journeys in order to receive their vital treatment.

As well as the emotional and physical cost, these long and frequent journeys also come at a financial cost, with young cancer patients and their families having to find an extra £250 each month to travel back and forth.

But even when they arrive at hospital, these costs continue to add up. Many are faced with a lottery of finding somewhere to park, adding time to their already long journeys. When they do find a space, the parking restrictions in place, combined with uncertain appointment and treatment schedules, can add further to their worries.

As a result of car parking fees, each month young cancer patients and their families are also faced with paying out an average of £24 to park, but for some, these costs can be much higher.

While free hospital parking is currently available in Scotland and Wales, and due to come in place in Northern Ireland, this is not the case in England. These figures demonstrate that any exemptions or concessions currently in place across England aren't going far enough, leaving many young cancer patients and their families running on empty, not only financially, but emotionally and physically too.

This is why we're calling on the government to take action and introduce a Young Cancer Patient Travel Fund, and make sure no young cancer patient has to worry about paying for parking, so they can focus on what matters – getting through treatment.

Helen Gravestock,
Director of Policy, Influencing and Voice, Young Lives vs Cancer

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

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

Most young cancer patients and their families make these journeys by car and need to park a vehicle.



Journeys were often described as long, stressful, uncomfortable, and both physically and emotionally tiring. For many, parking represented an additional obstacle in already difficult journeys.



Parking was a general source of worry for many. As well as being emotionally costly, parking was financially costly for young cancer patients and their families.



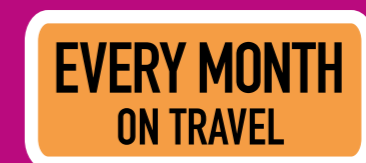
To change the current system, so it better supports all children and young people with cancer and their families, together with the introduction of a Young Cancer Patient Travel Fund, action should be taken in England to ensure no young cancer patient has to pay for parking during their treatment.



Most young cancer patients and their families are struggling to pay for travel costs to and from treatment.



Parking arrangements and existing concessions at hospitals and treatment centres are falling short for many young cancer patients and their families.



These charges contribute towards wider travel costs faced by young cancer patients and their families.

INTRODUCTION

Each year, around 4,000 children and young people in the UK are diagnosed with cancer.²

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 November 2022 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.

A Freedom of Information request (FOI) was also submitted to 139 NHS Hospital Trusts in England during November 2022 to explore parking tariffs and the details of any concessionary schemes already in place. Four in five of the Trusts (82%) provided a response to the FOI. Equivalent requests were not submitted in Scotland, Northern Ireland and Wales as free parking policies are in place, or due to be in place, in these nations.

This report summarises parking findings from our UK research and from the responses to the FOI request in England. Broader travel costs are explored further in Young Lives vs Cancer's *'Running on Empty'* 2023 research report.



FINDINGS

TRAVEL PATTERNS

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

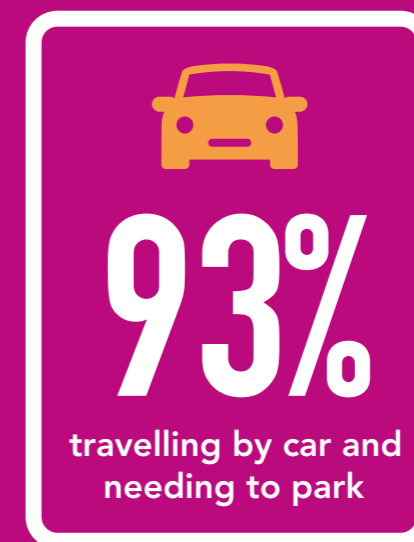
To get the cancer treatment they need, many children and young people have to travel outside their local area. Young Lives vs Cancer's *'Running on Empty'* 2023 research found that young cancer patients and their families lived on average 40 miles from their main cancer treatment centre. On average, respondents reported having to travel to two different locations for treatment; though more than a quarter of participants (29%) reported travelling to three or more.

Almost one in 10 of young cancer patients and their families (8%) said they had to travel to hospitals and treatment centres in different countries – this was 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.



Our research found that on average young cancer patients and their families travelled 350 miles a month to get to and from their treatment. However, the average distance travelled each month was significantly greater for some groups. Young cancer patients and their families reported spending an average of over nine hours a month travelling to and from treatment. This often extends over long periods of time, with over half of respondents (55%) reporting their cancer treatment lasting more than a year.

The majority of 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 these journeys, due to concerns over infection risk posed to immunosuppressed young cancer patients using public transport, poor public transport links and reliability, mobility difficulties, and travelling with substantial luggage and equipment.



EXPERIENCE OF PARKING

As a result of travelling by car, the majority of young cancer patients and their families (93%) needed to park their vehicle to attend treatment.

Journeys to and from hospitals and treatment centres were often described by participants as long, stressful, uncomfortable, and both physically and emotionally tiring. For many, parking represented an additional obstacle in already difficult journeys. For example, one parent / caregiver described their typical journey, "[It's] stressful. Windy B roads across the bridge with no other way to go, paying at the toll bridge for a short cut or going the long way round. Lots of little villages to go through with traffic jams, then windy roads over hills, traffic jams in [one city] and [another]. Child feeling sick, driving around and around to find parking, child feeling stressed, he can't walk far so no possibility of finding a space further away. Arriving at the hospital feeling stressed or upset".

Struggling to find somewhere to park was a common problem among young cancer patients and their families. Finding parking was described by research participants as "very difficult", "not easy", "a struggle", and "a nightmare".

One parent referred to parking as "the lottery" and described, "I can probably win the lottery better than I can get a parking space at the hospital". Regardless of where they were treated, research participants commonly reported difficulty parking, "[My daughter] is going to the local hospital two or three times a week and we'd struggle to get anywhere to park. In Yorkshire and Humber it was the same, and well you can imagine in London".

At times young cancer patients and their families found they had little choice but to park elsewhere, "[We] often had to park at a car park round the corner as the first one would be full. [We] would usually have been up for four hours by the time we got to the hospital."

"I can probably win the lottery better than I can get a parking space at the hospital"

We had to find parking as close to the treatment place due to fatigue and discomfort. Also having luggage for [overnight] stays to transport."

Because of their cancer and treatment, young cancer patients may have mobility difficulties, experience significant fatigue and discomfort, and can feel the cold more. Young cancer patients and their families also often negotiate long journeys with lots of equipment and luggage. The proximity of parking to treatment therefore becomes an important consideration for young cancer patients and their families. As illustrated by this participant, "We had to find parking as close to the treatment place due to fatigue and discomfort. Also having luggage for [overnight] stays to transport".

Difficulties finding parking at times pushed participants to park further from treatment, as one mother explained "[I]f I can't get a place in there then I'm really stuck because I'd be parking half a mile away

and it's very difficult to get her to walk half a mile. Because one of the problems is that if she doesn't know kind of where she's going, she gets very anxious". Having to park further away often introduced further challenges to already difficult journeys, "[T]here's two car parks either side of the hospital. If [we] park on the adult side he has to take his [mobility] pram in because he can't walk the distance from there to the kids part of the hospital. If we park in the kid's side, which is the easier access, he can walk because the clinics are downstairs [...] he'll stop in between, but not as much. But if we're over the other side which is nine times out of 10, then you know the pram has come in". Parking further away also often extended young cancer patients' door-to-door journey time, adding yet another challenge to accessing treatment.

It was common for participants to describe spending considerable amounts of time searching for parking spaces to attend treatment. For example, one mother stated, “[It’s] an absolute nightmare. [...] If you get [an appointment] after 11am in the day you’re basically onto plums. You’re then having to circle and circle for half an hour, sometimes I’ve seen myself sit there for 45 minutes just trying to get a space.”

Circling car parks and streets around treatment sites for limited spaces to become available seemed a common practice for young cancer patients and their families, “we eventually make it to have to drive around the car park a few times to find a space. There’s about six parent and toddler spaces so obviously it’s rare to find one of them”.

This ritual is often time consuming for young cancer patients and their families and can be especially difficult when passengers are experiencing sickness, discomfort or pain. One participant described the challenge of finding parking as “[the] worst part” and said “[it] could take longer than the journey time”. It was not uncommon for respondents to report allowing extra journey time to accommodate the search for parking, for example, “Although [the] journey is only around six miles we have to allow 45 minutes to one hour to ensure we can park”.

“Although [the] journey is only around six miles we have to allow 45 minutes to one hour to ensure we can park”

Participants experienced difficulty anticipating exactly how long hospital visits would take; and as a result, parking duration was often unknown beforehand and hard to plan for. One respondent said, “that’s another thing that’s quite difficult. Because when you’re having treatment like chemotherapy [...] for our children, it’s not an hour or two, one day it could be an hour sometimes it can be four hours [...] quite a few times we’ve had to rush out to try and move the car”. Needing to move the car during their treatment

and appointments was reported as a common occurrence and was a challenge to negotiate particularly for sole travel companions. Temporarily leaving young cancer patients alone in order to deal with parking prompted guilt among some parents / caregivers, while others felt unable to leave their child. For example, “obviously I can’t leave her to move the car either. I can’t leave her sitting in the [hospital] waiting room and think, ‘oh, I’m just going to pop down and move the car’”.

“I remember worrying about [parking costs], to be honest, because I think it was about £8 a night and we were there two months, so it would have been a quite a big bill, wouldn’t it?”

Parking was a general source of worry for many. Participants disclosed feeling worried about receiving parking fines, for example, “they will yellow tag your car if it’s not parked correctly. So you know even though I’d said to [the parking warden] that day ‘is it OK to park’ and they said ‘yeah’ I was then worrying in the hospital that, you know, I was going to get another [parking warden] who didn’t know the situation

just put a ticket on it. So, I was half expecting one when we get out”. The cost of parking prompted concern among young cancer patients and their families too. “I remember worrying about [parking costs], to be honest, because I think it was about £8 a night and we were there two months, so it would have been a quite a big bill, wouldn’t it?”

PARKING COSTS

Hospital parking is currently free in Scotland and Wales, and parking charges at hospitals in Northern Ireland are also due to be removed. NHS Trusts in England with visitor parking reported charging an average hourly rate of £2.25. However, some NHS Trusts across England charge as much as £4.50 per hour to park. Further, NHS Trusts reported charging on average £10.84 for 24 hours.

At Principal Treatment Centres, in England where young cancer patients' treatment is primarily focused, the daily parking rate tends to be even higher, averaging £12.98 for 24 hours. Where young cancer patients and their families had to park off-site, the private parking rates varied but could often exceed this.

Our survey found that the majority of young cancer patients and their families in the UK (65%) paid to park their vehicle in order to attend treatment or care. Across all young cancer patients and their families, they reported an average monthly parking spend of £24. While more than one in 10 young cancer patients and their families (13%) reported spending more than £50 per month.

These parking charges contribute towards the broader financial burden experienced by young cancer patients and their families travelling for treatment or care. Young Lives vs Cancer's 'Running on Empty' research found that travel to and from treatment each month costs £250 on average.

P £24

£250
on travel

EVERY MONTH

LOST INCOME

Beyond these direct costs, the majority of households with a young cancer patient also experience income loss. 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. On average household income loss was £6,000 a year, though around one third (31%) experienced in excess of £10,000 a year income loss.

7 in 10
experiencing a
loss in income

FINANCIAL CHALLENGES

Seven in 10 young cancer patients and their families (71%) reported struggling to pay the costs of travelling for treatment. Many young cancer patients and their families disclosed experiencing financial hardship and commonly made a series of sacrifices. Namely, going without social and recreational activities, saving less, spending existing savings, and generally cutting back on spending. Less commonly, families described having to cut back on food, falling behind on household bills, selling possessions and assets, fundraising to help meet costs, and even delaying or missing cancer treatment and care.

Although those on lower incomes prior to diagnosis were more likely to report struggling to meet their travel costs, those on higher incomes struggled too. Half of households earning £50,000 a year prior to diagnosis reported struggling. One mother described, "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".

“...having to travel to and from the hospital maybe 15 times a month, pay for parking, pay for food...that's all money we didn't really have”

**PENALTY
CHARGE
NOTICE**

7 in 10

**struggling to pay the costs
of travelling for treatment**

EXISTING PARKING STRUCTURES

At present, parking concession schemes do not adequately support all young cancer patients and their families with the cost of parking. While free hospital parking is currently available in Scotland and Wales, and due to come in place in Northern Ireland, this is not the case in England. To help with parking costs, all NHS Trusts in England with visitor parking reported offering some form of parking concessions. In line with NHS England guidance, these are most commonly limited to supporting those defined as frequent outpatient attenders, and parents / caregivers staying overnight with their child.³ While a number of these concessions may apply to young cancer patients and their families, this isn't always the case. To mitigate this, two in three NHS Trusts in England (65%) reported having put in place parking concessions specifically targeting those receiving cancer treatment. However, parking arrangements and existing concessions at hospitals and treatment centres are falling short for many young cancer patients and their families.

Parking availability was a significant issue for young cancer patients and their families. Research participants consistently reported encountering a lack of available parking at hospitals and treatment centres. Limited designated off-street parking at hospitals and treatment centres resulted in many young cancer patients and their families having to negotiate blue-badge on-street parking restrictions, for instance one participant described, "they had disabled parking in the hospital [...] but there was only about three or four bays [...] And then the outside parking was three hours maximum. So we had a couple of times where we would go in and I'd have to leave my daughter with a nurse, so I could go and move the car".

Parking restrictions often did not meet families' need for flexibility around uncertain treatment and appointment schedules. As a result of the demands of their treatment, keeping track of parking durations can also sometimes be difficult.

"We had a couple of times where we would go in and I'd have to leave my daughter with a nurse, so I could go and move the car."

³ <https://www.gov.uk/government/publications/nhs-patient-visitor-and-staff-car-parking-principles/nhs-patient-visitor-and-staff-car-parking-principles>



Parking is very difficult [...] people who have disability badges need to park close to a place and [...] I think I could count the amount of disability parking spots on probably one hand, maybe two".

Some young cancer patients and their families consequently encountered fines. "[I've had] parking fines from parking on double yellows, putting the blue badge and then being too late. One occasion was where I'd taken her in and they'd had to admit her [...] into intensive care unit and I just completely forgot to move the car [...] now I'm a bit scared to park on double yellows, even though I'm allowed to [...] So I don't park there anymore". The unsuitability of blue badge parking restrictions in meeting young cancer patients and families' need for longer stays meant on-street parking was not considered a viable option for some.

Limited on-site parking at hospitals and treatment centres often pushed young cancer patients and their families to rely instead on off-site car parks. One participant described, "the children's hospital have a car park but there's only about 10 spaces and it's 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". Maximum stay blue-badge parking restrictions similarly pushed young cancer patients and their families to use off-site car parks, "my daughter's got a disability badge, but it's useless really around the

hospital. I could park certain places on double yellows with a disabled badge, but it's a three hour [...] maximum. And I've had parking tickets because of that. Because I never know how long we're going to be in hospital for and it's very rare we're in for less than three hours. So I'm just faced with parking in the expensive [private] car park". Having to park in private car parks came at a significant personal cost to many.

Participants' awareness of NHS Trust concession schemes indicated that information on schemes was not suitably forthcoming. Awareness of concession schemes varied, with some having little knowledge of the concessions offered, for example, "we weren't aware that you could get things like parking [paid for] [...] we eventually found out from the hospital that we get a letter [...], but initially 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 to be honest". In addition to a lack of information, inconsistency was also an issue; young cancer patients and their families described facing variable parking charges dependent on appointment type, "Parking was free on treatment days but not for tests, check-ups and meeting the consultant".

CONCLUSIONS AND RECOMMENDATIONS

Parking can be emotionally and financially costly for young cancer patients and their families – and contributes towards broader travel costs impacting their financial security, health and wellbeing, and future prosperity, leaving them running on empty.

This research found that the majority of young cancer patients and their families used a car and needed to park to attend specialist treatment or care. Young cancer patients and their families travelled an average of 350 miles per month to attend. For many, parking represented an additional hurdle in already difficult journeys and challenges finding parking often extended their journey times. At times this compounded young cancer patients' discomfort and introduced further worry. Due to the nature of treatment, young cancer patients and their families found it hard to plan parking duration and restrictions were unhelpful.

While free hospital parking is currently available in Scotland and Wales, and due to come in place in Northern Ireland, this is not the case

in England. Concession schemes are in place at hospital sites across England, however their relevance to young cancer patients and their different appointment types; the availability of parking spaces; the time restrictions imposed; and the awareness of these schemes leave many routinely still paying for parking.

Across all young cancer patients and their families in the UK, the average monthly parking spend was £24, but for some, this could be more.. These ongoing charges come on top of the average £250 a month they spend just getting to and from treatment. For many young cancer patients and their families, the impact of these costs is significant and long-lasting.

To address the issues identified in this research and bring parity across the UK, in addition to our call for a Young Cancer Patient Travel Fund to support with costs of travelling to treatment, in England we believe action should be taken by the UK Government **to ensure free parking is available to young cancer patients and their families at all hospitals and treatment centres.** Almost two thirds of young cancer patients and their families (64%) believed free or discounted parking at hospitals and treatment centres would be most helpful to them and other children and young people diagnosed with cancer.

For those young cancer patients and their families who are forced to park away from hospitals and treatment centres, including as part of staying overnight for treatment, action should be taken **to ensure they are not left out of pocket by off-site parking costs.**

To change the current system, so it better supports all children and young people with cancer and their families, together with the introduction of a Young Cancer Patient Travel Fund, action should be taken in England to ensure no young cancer patient has to pay for parking during their treatment.

For this parking support to be effective, it needs to:

- 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

Future consideration should also be given to the availability and suitability of parking for blue badge holders in and around hospitals and treatment centre sites, so that it meets their needs.

#RunningOnEmpty

younglivesvscancer.org.uk/travelcosts

Young Lives vs Cancer is an operating name of CLIC Sargent Cancer Care for Children.
A registered charity in England and Wales (1107328) and in Scotland (SC039857).
Registered office: 4th Floor, Whitefriars, Lewins Mead, Bristol, BS1 2NT.

