

ARE WE
NEARLY
THERE
YET?

The financial impact
of travel on young
cancer patients and
their families

YOUNG LIVES
vs CANCER
CLIC SARGENT

SUMMARY

Cancer in children and young people can devastate families – emotionally, physically and financially. Our research shows that children and young people with cancer and their families are travelling significant distances to and from hospital for treatment. This isn't by choice. Many young cancer patients have to travel to specialist cancer centres to get the care they need – they can't just go to their local hospital.

This report highlights the cost of that travel and the lack of financial support available to families. Change is urgently needed. That's why we are calling on the government for a Young Cancer Patient Travel Fund to help children and young people with cancer, and their families, deal with the financial impact of a cancer diagnosis and limit the damage cancer causes to young lives.

ABOUT CLIC SARGENT

CLIC Sargent is the UK's leading cancer charity for children, young people and their families. Our care teams provide specialist support to thousands of children, young people and families across the UK every year.

CONTENTS

Foreword	04
Executive summary	05
Key findings	06
Recommendation	07
Context	07
Research approach	10
Findings	11
Conclusion and recommendation for change	16
References	18

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FOREWORD



When my daughter Phoebe was diagnosed with neuroblastoma when she was under a year old it was horrendous. Your world is just turned upside down. You don't understand

how on earth it could be happening to you. It had a massive impact on the family. Emotionally and financially.

At first, Phoebe had intensive treatment at our local hospital in Leicester. We found that car parking became a big thing for us. We could get a prepaid card to reduce the cost to £6 a day to park, but it's still an additional expense.

For high risk neuroblastoma, patients usually undergo chemotherapy followed by surgery, then high dose chemotherapy and a stem cell transplant. After the initial chemotherapy, none of this could be done at our local hospital in Leicester.

...it cost us around £1,000 in fuel and parking expenses.

We travelled up to Sheffield for a stem cell harvest, which cost us a couple of hundred pounds. Then in February 2017, we were transferred to Birmingham for Phoebe to go on trial. It was 44

miles away. We travelled every three weeks for five days – going back and forward every day.

We had 12 cycles of chemotherapy before surgery and would estimate that it cost us around £1,000 in fuel and parking expenses.

After the surgery, Phoebe spent months in hospital. We never anticipated how long this would go on for. Before Phoebe's diagnosis we were financially okay but things change when your child has cancer. It's the not knowing, you daren't do anything because you don't know if you're going to end up as an inpatient again. Cancer completely changes your finances.

That is why I'm so pleased to see CLIC Sargent making the voices of families like mine heard and why I'm putting my support behind a Young Cancer Patient Travel Fund.

If our family were able to get support from a travel fund, it would save us a considerable amount of money as well as a great deal of unnecessary, additional stress.

A Young Cancer Patient Travel Fund is vitally needed by families affected by childhood and young people's cancer. Without this, families really are paying the price for children and young people's cancer treatment.

Naomi Thomas

Mum to Phoebe, age three

EXECUTIVE SUMMARY

We know that **#CancerCosts**. It can cost a child or young person's education (CLIC Sargent, 2012, 2013). It can cost a young person's or parent's employment (CLIC Sargent, 2013, 2016). It can have significant emotional costs (CLIC Sargent, 2017). And it definitely costs financially (CLIC Sargent, 2016).

Cancer treatment can have a huge financial impact on families. We know parents spend an average of £600 in additional expenses a month as a result of their child's active cancer treatment

Parents spend an average of £600 in additional expenses a month.

(CLIC Sargent, 2016) and one of the top extra expenses is travel.

Our research has found that children and young people with cancer have to travel an average of 60 miles for treatment. This isn't by choice. Many young cancer patients have to travel to specialist cancer centres

to get the care they need – they can't just go to their local hospital. This means that families often have to stay away from home for long periods of time, or undertake regular long distance travel.

If all the children and young people supported by CLIC Sargent made their journey to hospital for treatment on the same day, they'd travel over 450,000 miles. That's 18 times around the world, or to the moon and back.

Not only do families have to deal with cancer, they also have to worry about mounting travel costs: train tickets, fuel, car maintenance and taxi fares. Our research found that when treatment is at its most intense, families are spending £180 on travel to and from treatment every month if travelling five days a week. As treatment for young cancer patients can go on for years, families are often plunged into debt.

This isn't right, and the government isn't doing enough to help. Young cancer patients and their families get very little support for travel costs, and most of them don't qualify under the government's current system.

This has to change now. We are calling on the government to create a Young Cancer Patient Travel Fund. They shouldn't have to worry about mounting travel costs when they're going through treatment.

KEY FINDINGS

- Young cancer patients face a 60-mile round trip, on average, to get to treatment
- When treatment is at its most intense, this adds up to £180 a month, if travelling five times a week
- Young cancer patients and their families are travelling twice as far and spending twice as much on travel costs as adults with cancer
- If all of the young cancer patients we support travelled by car to one treatment appointment on the same day, they would rack up over 450,000 miles. They would be spending over £67,000 on petrol alone
- 40% of young cancer patients and their families make round trips of 50 miles or more when undergoing treatment at their main treatment centre
- Young cancer patients travelling to Bristol Royal Hospital for Children have the longest average journey of 63 miles each way, a round trip of 126 miles.

NHS Healthcare Travel Costs Scheme

The government (HC Deb, 9 February 2017, cW) has told us that the NHS Healthcare Travel Costs Scheme (HTCS) is the current solution to travel costs incurred by young cancer patients and their families travelling for treatment. This is the national assistance scheme that reimburses hospital travel costs to those on low incomes.

However, in July 2017 CLIC Sargent research with parents found that:

- Only **6%** of parents received help from the NHS HTCS
- **78%** of parents were not aware the NHS HTCS existed
- **40%** of parents thought that assistance from the government with travel expenses could help them cope better financially
- **66%** of parents told us they rely on some form of non-state assistance in order to meet additional travel costs during treatment, for example charity grants, help from family and friends and loans.



Children and young people with cancer **travel an average of 60 miles** to and from hospital to get treatment

Recommendation

The current system just doesn't work for young cancer patients and their families travelling hundreds of thousands of miles for treatment and spending tens of thousands of pounds. This is vital treatment recommended by the NHS in order to have the best possible clinical outcomes and support.

We believe that young cancer patients and their families are being let down by a hole in the system that doesn't help them access the treatment they need. We recommend the creation of a Young Cancer Patient Travel Fund that will go towards meeting some of the huge costs of travel they face.

CONTEXT

Specialist services for children and young people with cancer

There are around 4,450 new diagnoses of cancer in children and young people every year in the UK (Cancer Research UK, 2018).

Because of its rarity, treatment for children and young people's cancer is delivered in specialist treatment centres across the country, known as Principal Treatment Centres (PTCs). These are often a long way from home, meaning young cancer patients and their families have to travel far for treatment and stay away from home for long periods of time. They don't have a choice – local hospitals don't offer the specialist age appropriate treatment and care they need.

There are 19 PTCs in the UK. Children up to the age of 16 will typically be diagnosed and receive their cancer treatment there. These age appropriate cancer services are supported by other local hospitals so treatment and care can be closer to home. This is known as 'shared care'.

Young people aged 16 and over have more choice about where they receive treatment. They can receive treatment in

a PTC, however if appropriate they can also choose a hospital closer to home at a shared care centre or at their district general hospital.

We believe the model of age appropriate specialist treatment centres, supported by other services, delivers the best outcomes for young cancer patients and their families. However we recognise the significant impracticalities of treatment a long way from home and the emotional and financial stress this can put families under. This is why CLIC Sargent has services to support families with the financial and emotional impact and why we are calling for change in the system.

#CancerCosts

Dealing with cancer is tough enough without money worries but cancer costs young cancer patients and their families £600 more every month (CLIC Sargent, 2016). Because of treatment, families face additional costs for things like extra clothes, higher energy costs because parents need to make sure their home is warm enough and have to wash their child's clothes and bedding more frequently, as well as treats to make hospital more manageable.

CLIC Sargent's #CancerCosts campaign, launched in 2016, seeks to lessen the financial impact of childhood and young people's cancer. Our #CancerCosts (2016) report identifies the burden of regular travel costs and recognises that existing hospital travel schemes across the UK are inaccessible to many who struggle to cover the costs of regular journeys to and from hospital.

Government travel schemes

The government's means-tested Healthcare Travel Costs Scheme (HTCS) in England is a national assistance scheme that reimburses reasonable travel costs for travel to and from hospital. Similar schemes also exist in Wales, Scotland and Northern Ireland. Scotland also has a bespoke scheme for those in particularly remote areas, recognising the significant and impractical journeys they may face to access hospital treatment.

However, none of the schemes in any of the four nations are fit for purpose or reflect the unique needs of children and young people with cancer. Our #CancerCosts report (2016) includes a call for an urgent review of hospital travel assistance schemes. This is mirrored by the All-Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer (APPG CTYAC) Inquiry into Patient Experience. This also calls for governments across the UK to commit to reviewing the travel assistance available to young cancer patients and their parents/carers and make recommendations for reform.

Hospital car parking

On top of fuel costs, families are often faced with significant hospital car parking charges. Hospitals should be offering free or reduced parking to young cancer patients and their families. However, CLIC Sargent knows the guidance is not implemented effectively.

Car parking in Wales and Scotland has been free at most hospitals since 2008. In Northern Ireland it's free for chemotherapy and radiotherapy patients. In England, government guidance states hospitals should offer free or reduced parking to cancer patients, but the application of this has been found to be varied (Macmillan Cancer Support, 2012).

Our 2016 #CancerCosts survey found that in England parents and young people paid an average of £44 and £37 a month respectively, on hospital parking during treatment, and that three in 10 parents said they hadn't been offered any parking concessions by their hospital. The guidance on parking can only work if it is promoted, and our evidence shows it is not being promoted.

The APPG CTYAC's report *Listen up!* (2018) highlights hospital car parking as a huge issue for families in England. Evidence collected for the inquiry highlighted the difficulties families face in meeting the additional costs of parking their car. The APPG CTYAC calls for the Department of Health and Social Care to ensure full implementation of its NHS (2014) guidance on hospital car parking in England, and to make sure Trusts are clearly promoting this.

The APPG CTYAC also heard about the challenges of finding a parking space in hospitals, which can add to the stress and anxiety of treatment. The unique pressures that parents of children with cancer face were highlighted, for example having to accompany children during hospital visits and being unable to drop off their child for treatment as they might if they were dropping off an

adult patient. As a solution, the APPG has recommended that the Department of Health and Social Care ensure NHS Trusts provide designated parking spaces for families of children and young people undergoing treatment or make other arrangements to help parents to park when bringing children for cancer treatment.

Paula's story

When Paula's daughter Heidi was two years old Heidi was diagnosed with acute lymphoblastic leukaemia. She finished two and a half years of treatment in February, and Paula estimates they spent over £1,000 on travelling to and from hospital, and car parking.

Here Paula tells their story:

"It was having to pay for car parking that really hit us financially – it could cost anything from £2 to £15 per visit. When on treatment for two and a half years, that soon adds up to a huge amount. We always drive but, as we don't have a blue badge, parking is not only costly but stressful.

"Heidi had a lot of her treatment in Bristol, where parking spaces are very limited. A lot of the time we had to park in the nearby multi-story car park, which is a 10 minute walk away and at city centre pricing. Sometimes we'd have to pay for two cars as well, if Heidi had been admitted whilst my husband was at work, he'd drive in to visit us".

CLIC Sargent believes that hospital car parking should be free for young cancer patients and their families and call on the government in England to implement this change without delay.

RESEARCH APPROACH

- We used postcode data from CLIC Sargent's database to generate our key findings. The travel distance by car between the 7,195 home postcodes and the postcodes for the hospitals where children and young people received their cancer treatment was calculated. Journey time by car was also calculated. This follows the approach taken to generate data for CLIC Sargent's (2010) 'A long way from home' research.
- In addition, a data exercise was undertaken to calculate the distance between the 7,195 postcodes from the CLIC Sargent database and the postcodes of adult cancer treatment centres. This is to better understand the travel implications of cancer for those aged 25 and above, who do not need to travel to specialist children and young people's cancer centres.
- As part of our ongoing #CancerCosts campaign, in 2017 we developed an online survey to better understand the costs of travel during a child's cancer diagnosis. A total of 106 parents/carers from across the UK responded to the survey recruited through CLIC Sargent's networks, care professionals and social media. The findings from this survey have been used in this report to supplement the findings from the data exercise.

Limitations

This research provides a snapshot of experiences and it is not intended to provide a holistic account of the issue.

The data provided in this report is based on travel by car. Often journeys are by car – public transport is not always an option because a child or young person may be at risk of getting a serious infection because their immunity has been reduced as a result of treatment.

Survey participants were self-selecting and therefore not necessarily representative of all parents of children with cancer.

FINDINGS

Funding journeys to and from hospital

Many families travel long distances for cancer treatment.

Our new research has found that young cancer patients face a 60-mile round trip, on average, to get treatment, which is often delivered in specialist treatment centres far from home. This costs them £180 per month when treatment is intense and families are travelling every day for treatment. We also found that young cancer patients and their families are travelling twice as far for treatment as adults with cancer and spending twice as much.

Two-fifths of young cancer patients make round trips of 50 miles or more when undergoing treatment at a PTC. And children travelling to Bristol Royal Hospital for Children for treatment have the longest average journey of 63 miles each way, a round trip of 126 miles.

Regional variation

Every family's journey to and from treatment centres is different and our research uncovered significant regional variation in travel distances.

Average travel distance to main treatment centre, by home country (miles)	Round trip
England (n=5,783)	54
Scotland (n=561)	68
NI (n=309)	64
Wales (n=199)	76

Travel time varies greatly based on where a young cancer patient lives. For example:

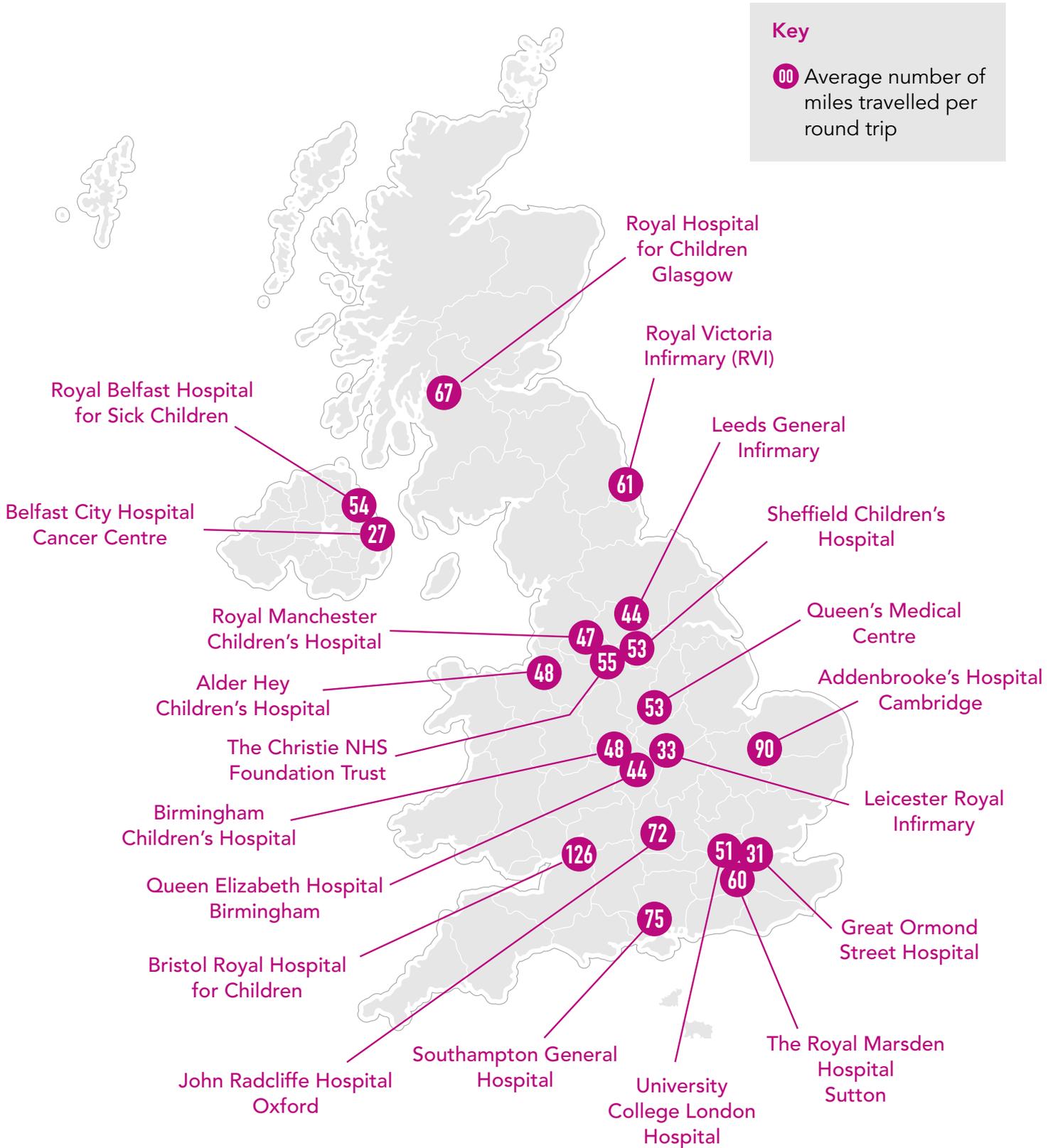
- On average, those living in the county of Avon in England travel 16 miles, whereas those living in Cornwall travel 177 miles
- Those living in County Antrim in Northern Ireland have a 30 mile round trip on average, whereas those in Londonderry travel 126 miles
- On average, those in Midlothian in Scotland travel 12 miles, and those in Ayrshire travel 76 miles for treatment
- Those in South Glamorgan in Wales travel on average 14 miles for treatment, and those in West Glamorgan travel 105 miles.

The **cancer commute** to and from hospital can cost families **£180 a month** when treatment is intense



Figure 1

Average number of miles children, young people and their families travel per round trip for treatment.



Given the distances listed in figure 1, it is not surprising that travel costs are a top expense for both parents and young people. Often journeys are by car – public transport might not be an option because a child or young person’s immune system can be compromised – and filling your car with fuel is expensive. In fact the UK has some of the highest fuel costs in Europe (The AA, 2018).

If each of the young cancer patients we support travelled by car to one treatment appointment on the same day, they would rack up over 450,000 miles. And spend over £67,000 on petrol alone.

But let’s not forget that travel costs don’t only include petrol or diesel. Costs for car repairs, new tyres and breakdown cover all build up adding further stress and financial pressure for families. Journeys to and from treatment can take a long time too. Our research found the average round trip journey time for a young cancer patient is one hour 33 minutes – costing families fuel, car maintenance and vital time away from family life.

Alexa’s story

Alexa’s son Louis was diagnosed with acute lymphoblastic leukaemia in January 2014 and has gone through four years of treatment.

Here Alexa tells their story:

“We live in the country in Cockermonth, and it takes about two and a half hours with traffic to get to the Royal Victoria Infirmary hospital in Newcastle, so it’d cost us about £40 every time. Everything had to come to a stop – you just do without basic things. You get by the best you can. What money we did have, we spent on getting to the hospital.

Some of Louis’ treatment meant that he needed to be there every day for five days in a row, every month. We couldn’t possibly afford to do the journey every day, so I learnt to give Louis his chemo at home – one of the nurses taught me on the ward. It was the worst thing I’ve ever done but we just couldn’t afford £40 a day – it was just impossible.”

WHAT TRAVEL ASSISTANCE DOES THE GOVERNMENT ALREADY PROVIDE?

Healthcare Travel Costs Scheme

The government's Healthcare Travel Costs Scheme (HTCS) in England is a national assistance scheme that reimburses hospital travel costs for travel to and from hospital. The scheme is run by local hospitals and it is funded nationally by NHS England.

To qualify for help with travel costs under the scheme, you must:

- Receive an income related benefit or allowance (eg income-based Employment Support Allowance, Jobseeker's Allowance or Universal Credit) or
- Meet the eligibility criteria for the NHS Low Income Scheme, which is currently set at £16,000 and
- Have a referral from a healthcare professional.

Parents can claim travel costs for their children and those over 16 have to make their own claim.

These criteria, in particular the £16,000 threshold, mean that many families affected by childhood and young people's cancer cannot access the scheme.

Our #CancerCosts research (2016) and subsequent follow-on research undertaken in 2017 found that many parents do not know about the scheme.

Our 2017 research found that:

78% of parents were unaware the NHS HTCS existed

6% of parents reported having received help from the NHS HTCS

40% of parents stated that assistance from the government with travel expenses could help them cope better financially.

Schemes also exist in Wales, Scotland and Northern Ireland. However none of the schemes in any of the four nations are fit for purpose or reflect the unique needs of children and young people with cancer.

In Northern Ireland the Hospital Travel Costs Scheme helps those on a low income with travel costs to and from treatment and has criteria similar to the scheme in England. However, those in receipt of the scheme will only ever be reimbursed the equivalent amount of the same journey using the cheapest form of public transport. This means that if a bus journey to the hospital costs £5, but a journey by car costs £10 (and public transport may not be possible because a child's immune system could be compromised), you will only receive £5 back for your journey.

In Scotland, people living in particularly remote areas, such as the Highlands, can get help with the cost of travel to hospital for NHS treatment regardless of income, provided they have to travel at least 30 miles, or more than five miles by sea, to get to hospital.

In all of the four nations the schemes are administered via a reimbursement scheme. This means that families would need to collect receipts and regularly take them to a hospital cashier to be reimbursed. This is not a practical option for families or young people who already have cancer treatment and daily family life to juggle.

The government travel schemes across the UK are designed to assist people on low incomes to access hospital treatment. They are not designed to meet the needs of travel to highly specialised treatment like that for childhood and young people's cancer.

Cancer doesn't discriminate – it costs all families regardless of income.

CLIC Sargent argues that with a maximum household income threshold of just £16,000 to qualify for the HTCS, too many families where a child has cancer are left struggling without the financial support they need. 66% of families affected by childhood and young people's cancer rely on some form of non-state assistance in order to meet additional travel costs during treatment, for example, charity grants, help from friends and family, and CLIC Sargent loans.

We don't think it's right that families are in a position where they can't afford to access their child's cancer treatment. That's why we are calling for a Young Cancer Patient Travel Fund that meets their unique needs.

Judith's story

Judith's daughter Gabrielle was diagnosed with acute lymphoblastic leukaemia, aged three, in 2014. She went through two years of intense chemotherapy and ended treatment in March 2016.

Here, Judith tells their story:

"We live in Cumbria and travelled to Newcastle for Gabrielle's treatment, which is a 180 mile round trip costing around £25 in petrol for each journey. During stays in hospital I would stay on the ward with Gabrielle and her dad would either sleep in the car or at nearby Crawford House (accommodation provided by The Sick Children's Trust) when there was room. I was taught to give chemo at home to avoid us having to make the journey so often when Gabrielle was on maintenance treatment.

Our car always had to be ready to make the journey to hospital and I had to make sure there was always enough petrol in the tank to get there and back. We couldn't get MOTs and services for the car in advance, just in case Gabrielle was poorly that day and we'd need to get her to hospital. Travelling to and from hospital has taken all of our family's savings and we had to rely heavily on our parents financially and to care for our two sons when we took Gabrielle to hospital."

Examples of good practice**A Scottish travel fund for new parents**

In 2018 the Scottish government introduced a new £1.5 million fund to help ease the financial burden of travel on parents of premature and sick newborn babies and help meet the additional costs they face as a result of their baby being in hospital.

The Neonatal Expenses Fund is designed to provide a contribution towards the cost of having a baby within neonatal care and covers costs such as travel, parking and food. We'll be looking to learn from this fund to explore how this approach can lend itself to support families affected by childhood and young people's cancer.

CONCLUSION AND RECOMMENDATION FOR CHANGE

Creation of a Young Cancer Patient Travel Fund

Our research shows that too many families are left unsupported, and are reliant on charities, family and friends or credit cards in order to meet costs for vital treatment. With a large proportion of families we asked not knowing about the HTCS and many families not eligible for financial assistance, there is a clear need for a dedicated travel scheme for young cancer patients and their families.

We believe the financial and practical impact of travelling for specialist cancer treatment needs to be taken into consideration. That's why we're calling for a Young Cancer Patient Travel Fund, so they don't have to worry about mounting travel costs during treatment. This will be a flexible fund which is based on need, not income.

A Young Cancer Patient Travel Fund should:

- Be available to all children and young people with cancer in the UK
- Be based on need not income
- Easy to access
- Cover all costs associated with travel to and from hospital for cancer treatment.

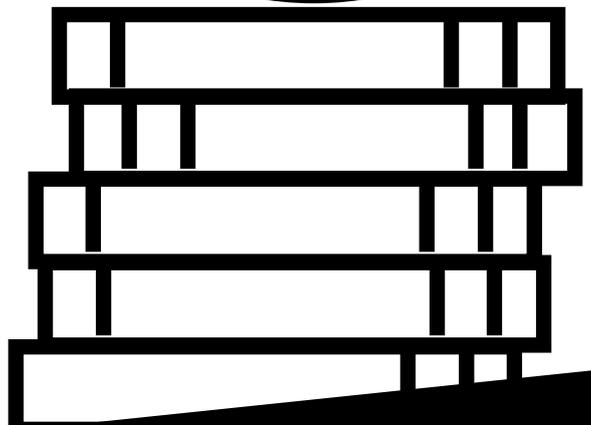
We are calling for a £5 million annual fund to be made available for children and young people with cancer and their families to help with the cost of travel to and from hospital for treatment. CLIC Sargent believes the NHS should consider these costs as an essential part of delivering children and young people's cancer services.

Some of these costs could be met through the savings from no longer funding travel and accommodation costs for overseas proton beam therapy services (PBT). In the long term CLIC Sargent will also be looking at ways of redirecting the grants we provide to families for overseas travel for PBT as this treatment becomes more widely available in the UK.

Proton beam therapy (PBT) is a relatively new treatment. It's like radiotherapy but it uses tiny particles found in atoms to target certain cancers more precisely – and this could reduce the side effects, especially in children who are still growing. Up until recently, PBT was only available at special treatment centres abroad. The NHS paid for treatment, flights and accommodation, usually to the USA. Now there are new PBT centres opening in the UK in the next two years.

Cancer in children and young people can devastate families – emotionally, physically and financially. We want to see more support for young people and families who travel thousands of miles across the UK and spend thousands of pounds to get the treatment they need. Change is urgently needed. Young people and families are making those journeys today and it is costing them. A Young Cancer Patient Travel Fund will go some way towards helping children and young people with cancer, and their families, deal with the financial impact of a cancer diagnosis and limit the damage cancer causes to young lives.

Ask the government
to create a
**Young Cancer Patient
Travel Fund**



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**“CANCER
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