## WHEN WE GET THERE

The case for a specialist transport service for young adults and children with cancer



## A MESSAGE FROM OUR FOUNDER

It's my 27th birthday and my phone is ringing. Because it's my dad, I think he's calling to congratulate me. Instead, he is terrified and crying. My little brother André, who is only 11, has just been diagnosed with an aggressive form of blood cancer. The doctors say if he's going to survive he'll need a bone marrow transplant.

Over the next three years, André, his parents and I travel more than 80 miles a week for treatment as I search for a donor. I appear on TV, write letters to newspapers and send hundreds of personal messages asking people to donate. My stepmother needs to be with André all the time and consequently loses her job, thereby halving the family income. Hope during this period is, like money, hard to come by.

We aren't just fighting cancer in these moments, we're also fighting with the worst of our fears - these are the hardest days of our lives. This painful experience is why Please Take Me There exists. Our mission is to help children with cancer access the services they need to survive, and to eliminate the stresses and costs of travelling to and from life-saving treatments. We aren't waiting for the future to arrive. We aren't waiting for our name to be called, because for thousands of young people with cancer, waiting is never an option.

Since our inception in 2015, we've helped more than 5,000 children worldwide. Now, through research and the trialling of new solutions, we hope to transform how children get to vital care, while supporting their families through some of the most challenging times they'll live through.

Had it not been for what happened to André, I never would have known these hardships for myself: how reliant one becomes on the generosity of loved ones; how devastating the impact can be on livelihoods, relationships and the dreams no longer dared to hope for.

#### But now I do.

My personal experiences, coupled with what we've learned as a charity mean Please Take Me There knows how to create this much-needed service. Now we just need you - our community - to make our ambitions a reality. I firmly believe all great things begin with a dream, and with dreamers who have the courage to make them come true. Our dream is to give every young adult and child with cancer access to specialised transport by 2030. Because our children are our future - our artists, scientists, teachers and world leaders - the legacy we leave behind when all is said and done.

We aren't waiting for the future to arrive. We aren't waiting for our names to be called, because for thousands of young people with cancer, waiting is never an option.

We need to come together and do this for them.

And with your help, I know we will.

Fernando Pinho

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## THE CASE FOR CHANGE

Every two hours in the UK, a young adult or child is told that they have cancer.

That's why **Please Take Me There** exists; to support the families affected by these devastating diagnoses by eliminating the stresses and costs of travelling to and from lifesaving treatments.

# picture the scene: Seraph

It's the middle of winter, 2018, and Cass – a dedicated mother of two – has received some shattering news. Holding tight to her precious four-year-old son, Seraph, in the wake of a conversation with his doctor, a strange new word, 'neuroblastoma', swirls around her head. Her child has an aggressive cancer of the nerve cells. Treatment must start immediately, she's told, at Addenbrooke's Hospital in Cambridge. So the following day, Cass and her partner, Liam, embark on the 60-mile round trip with a very sick Seraph in tow.

Over the next 16 months, they'll repeat this journey roughly 200 times, and not just for their scheduled appointments. Each time Seraph has a spike in temperature, the family must make the one-hour journey to Addenbrooke's with no delay.

Compounding the stress of this awful scenario is the fact that they don't have a car. Seraph's treatments weaken his immune system so public transport is out of the question – exposure to crowds could kill him. And though the hospital has offered to send an ambulance twice before, on one occasion, it didn't show up and, on the other, it was four hours late.

Twice bitten, three times shy – they no longer rely on this service for their highly vulnerable child. Faced with a gap in provision, they set up a Facebook group of volunteers. Every time they need a lift, they post a message and wait for a reply. It's a workable solution, to some extent, but the family remains in an insecure position. What if Seraph falls ill at 3 a.m. when few are up and online?

And it's not just travelling to and from the hospital, it's the long hours waiting for appointments in between. They rarely know exactly what time they'll be discharged, which means asking volunteers to keep whole days free, or wait around indefinitely with the family. That's a lot to ask of someone who's already doing them a massive favour.

On top of all this, their lives must go on. Liam works full-time while still taking his turn at the hospital. Cass has stopped working to take care of Seraph, and also has another son, Logan, to care for – the family is frequently split. One parent is always at the hospital while the other is at work or with Logan. And the brothers never get to be brothers anymore – they're hardly ever together.

The impact of Seraph's illness affects all aspects of family life and cohesion. And this is just the very beginning of travelling with a child with cancer. Two years on, they will travel to the States in pursuit of a cure for their son.



## picture the scene: **Esmé**

Eighty miles away in Norfolk, around the same time Seraph starts treatment, Wendy discovers that her one-year-old, Esmé, has developed a rare brain tumour.



Esmé is the youngest child of four. Her older siblings are 3, 6 and 14. Wendy has been studying for a BA in counselling and her husband, Aaron, is a self-employed painter and decorator. Esmé's diagnosis shatters their world.

Aaron gives up work to care for their eldest three children, while Wendy gives up her studies to make the frequent trips to hospitals. Over the next 19 months, Wendy travels to and from Addenbrooke's over 200 times. Each return journey is more than 100 miles long.

Not counting the trips caused by temperature spikes, Esmé also has to make weekly visits to the Queen Elizabeth Hospital in King's Lynn. That's more than 80 visits of over 30 miles each time.

In less than two years, Esmé and her family travel over 14,000 miles for specialist medical care. That's five times the distance from Los Angeles to New York.

Each trip costs £20 in parking and petrol, which leaves very little for the family to survive on. Without a regular source of income from either parent, they just about manage to pay their monthly rent. And because their car is in constant use, it needs new tyres and maintenance. That's another £2,000 for them to whip up out of nowhere. A child with cancer affects everyone in the family. Wendy and Aarons's eldest son takes time off from school with anxiety. Later, he'll struggle with his GCSEs. Their six-year-old daughter develops eating disorders, which also require special care.

By day, Wendy and Aaron do the best they can for their children. By night, they write funding applications to charities and trusts, hoping for a break. For two years, they live in a constant state of stress over the welfare of their children and their untenable financial situation.

And who knows what impact all this will have on their own precarious wellbeing. Their loved ones organise a fundraiser that will help the family for the next two years. But not everyone is lucky enough to have such a network of support.



## A NATIONAL PROBLEM

Hospital

In The Part of the

### ACCESSING SPECIALIST CARE

Cass and Wendy's families are not alone in these challenges. Every year in the UK, almost 4,500 young adults and children are told that they have cancer. That's one young person every two hours.

Cancer in young people is considered a rare disease, which means those affected have to travel to specialist Principal Treatment Centres (PTCs) to access the care they need. PTCs are known to provide the best source of care for young people, but there are only 19 of them in and around the UK. So, young cancer patients often travel twice as far – a 60-mile round trip on average – and at double the cost of an adult diagnosed with the same illness.

And, in certain parts of the country, this average is considerably higher – roughly 90 miles in the East of England, and almost 130 in Cornwall. Not to mention all those children who have to travel abroad or stay away from home for long periods.

We spoke to over 100 families living with a child with cancer. And our findings make it clear – the financial and emotional duress of travelling to access lifesaving treatments cannot be understated.

Young people with cancer and the families who love them, like Cass, Wendy and so many more, need and deserve a better way.

Young cancer patients often travel twice as far as adults diagnosed with the same illness



## FACTS AND FIGURES

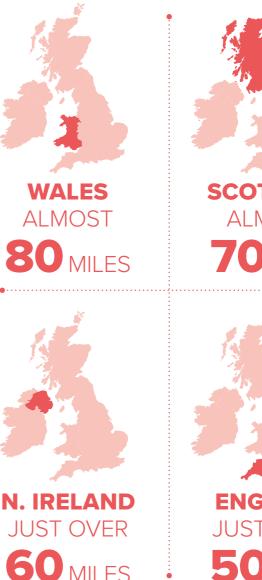
The UK charity, Young Lives vs Cancer, has produced a comprehensive series of reports on the impact of living with a young person with cancer. Its findings show that two thirds of parents supporting a child with this disease experience a significant reduction in income.

One in five leave work to become full-time carers and / or take several months of unpaid leave. All this at a time when they sorely need more money, not less. (Having a child with cancer costs, on average, an extra £600 per month, one third of which goes on travel.) Treatment for young cancer patients can go on for years. So, families facing this reduction in income are often thrown into debt, simply to cover the costs of getting to and from PTCs.

According to Young Lives vs Cancer, young people in the UK have to travel at least 60 miles to access the treatments they need. These figures translate into roughly 1.5 hours of travel per day. Yet, only 6% of families are entitled to assistance from the NHS Healthcare Travel Cost Scheme (see page 19). And nearly 70% of parents and carers rely on charities and loved ones for financial and practical assistance with travel.

If every young person supported by Young People vs Cancer travelled to hospital on the same day, their collective journey would amount to almost half a million miles. That's nearly twenty trips around the world or two thousand to the International Space Station. And all this travel doesn't just affect finances. Nine in ten children say their diagnosis has affected their school life, with many reporting a negative change in their relationships with their peers. A diagnosis of childhood cancer is painful enough. Families shouldn't have to face the additional burden of significant financial and emotional duress caused by travelling long distances.

#### HERE ARE THE AVERAGES BROKEN DOWN BY COUNTRY:



**SCOTLAND** ALMOST 



**ENGLAND** JUST OVER 50 MILES Nearly 70%

of parents and carers rely on charities and loved ones for financial and practical assistance with travel.

Only

of families are entitled to assistance from the NHS Healthcare Travel Cost Scheme.

## MAPPING THE SCALE OF THE PROBLEM

Research from Young Lives vs Cancer brought the stress families face to our attention. But, it was our own experience on the ground that showed us the true extent of the problem.

Between 2018 and 2019, we ran a pilot project in the East of England, offering transport support to over 100 families living with a child in need of specialist care. Our offer included:

- flights across the UK or abroad for treatment, or to visit friends and family; and
- grants for other forms of self-determined transport.

During this time, we received on average, one request for help every three days, many of which came from outside of our test area. Families in need of such services spanned the country from Manchester to Cornwall, Scotland to Northern Ireland, and beyond. Our pilot also allowed us to approach medical professionals, social workers and, of course, affected families, to collect additional data on the impact of inadequate transport support. What we discovered not only corroborated the findings from Young Lives vs Cancer, it also deepened our understanding of what families and their children are up against. That said, our investigation clearly highlighted a need for even more information, to better get to grips with the scope of the challenge.

After our pilot ended in 2019, we sent Freedom of Information (FOI) requests to each of the UK's 19 PTCs to find out how far each child in their care had to travel to access their services.

The responses we received allowed us to map the region of origin for every young person being treated at a given PTC.

Not only did this data make clear the scale of the problem, it also gave us a detailed insight into the distances travelled by thousands of young people.

## ARE WE NEARLY THERE YET?

In 2019, the PTC at Addenbrooke's treated almost 250 young people (aged 0– 24). Only 9% of these actually lived in Cambridgeshire, while over 30% were based in Norfolk or Suffolk.

Much like little one-year-old Esmé, most patients live some distance from Addenbrooke's, and are forced to travel up to two hours each way for vital, lifesaving treatments.

Also in 2019, the PTC at Birmingham Children's Hospital treated over 650 young people. 515 lived within 30 miles of the hospital. But, nearly 140 came from all over the country, travelling up to 300+ miles each way from as far afield as Cornwall, Yorkshire, Wales and Northern Ireland.

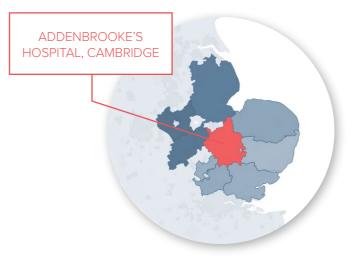
Across the UK's four nations, we see these same patterns emerge – families travelling from region to region to access the best possible care for their children. See the following maps for more on this.

On average

of young people being treated for cancer in PTCs **do not live in the same county as the hospitals they have to travel to.** 



Birmingham Children's Hospital treated 654 children and young adults in 2019. 139 young patients came from all around the country, doing in some cases, over 200-mile round trips from Cornwall, East of England, Yorkshire, Wales and Northern Ireland.

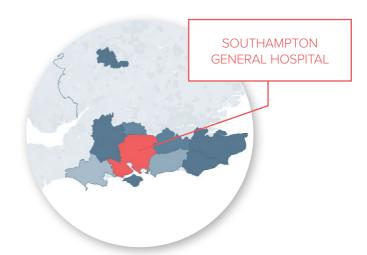


In 2019, Addenbrooke's Hospital in Cambridge treated almost 250 young people (aged 0–24). Only 9% of these actually lived in Cambridgeshire, while over 30% were based in Norfolk or Suffolk, up to two hours away.

#### WHEN WE GET THERE | SPECIALIST TRANSPORT SERVICE



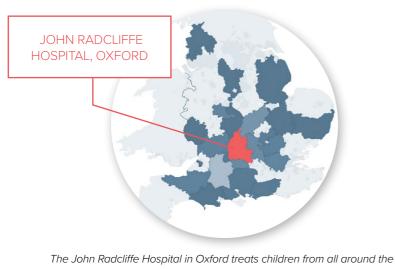
An estimated 72% of young people with cancer treated at the Royal Hospital for Sick Children in Edinburgh don't live in Edinburgh city.



The Southampton General Hospital treats children throughout the whole of the south of England. An estimated 46% travel from outside Hampshire.



An estimated 70% of young people with cancer treated at the Bristol Royal Hospital for Children don't live in Bristol county. Children from Cornwall travel up to three hours each way to get to cancer treatment.



country. An estimated 76% travel from outside Oxfordshire.

County in which hospital is based Shaded blue areas show where patients travel from The information we received for Wales and Liverpool allowed us to better calculate distances with precision. Each dot on the maps shows the number of young people living in that area in receipt of treatment at Cardiff's Noah's Ark Hospital and Liverpool's Alder Hey Children's Hospital.

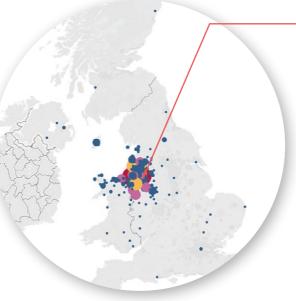
In 2019, a total of 1,105 young patients were treated at this site. Just over 800 of these lived within 30 miles of the hospital, and just under 200 lived within a distance of 60 miles.

Almost 65 had to travel 90 miles each way, and just over 50 made a 300-mile round trip.

In the same year, the Alder Hey Children's Hospital treated 950 children and young adults with cancer. Nearly 300 young people lived in Liverpool, and 477 lived within a distance of 30 miles.

176 patients travelled from all over the United Kingdom, making an overall round trip of up to 550 miles.





#### NOAH'S ARK HOSPITAL, CARDIFF

178 patients travel up to 120 miles.

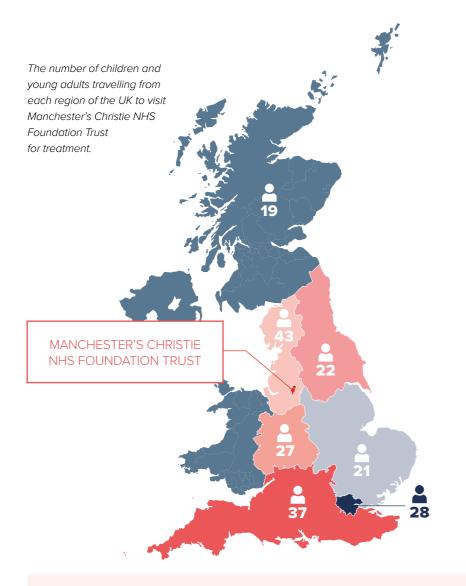
64 young people travel up to 180 miles.

**52** young people travel up to a **300-mile** round trip.

#### ALDER HEY CHILDREN'S HOSPITAL

**477** young patients living within a**60-mile** return journey of Alder HeyChildren's Hospital.

**176** patients travel from all over the United Kingdom, making an overall round trip of up to **550 miles.** 



8 in 10 patients receiving treatment in Manchester travel from outside the North West region



### A LONG AND WINDING ROAD

As well as travelling to their nearest PTC, young people with cancer and the families who support them sometimes have to journey even further.

This might be because they're offered participation in a clinical trial, or specialised treatments like proton beam therapy, currently only available at Manchester's Christie NHS Foundation Trust and University College London Hospital (UCLH) NHS Foundation Trust.

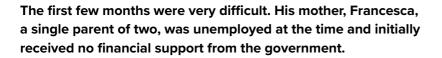
Between October 2019 and September 2020, the Christie treated just under 200 children and young adults, 80% of whom travelled from outside of the North West region.

Proton beam therapy requires two separate week-long visits to the Christie. Families travelling long distances for this treatment made a total of more than 600 lengthy trips, punctuated by days-long stays in an unknown city, far from home.

Sidney is a child from one such family.

## Sidney

In 2019, five-year-old Sidney was diagnosed with a soft tissue cancer at Addenbrooke's.



The entire family made **three-hour round trips** for each of Sidney's hospital appointments. They were reliant on help from an extended family member who gave them a lift in their car (though loved ones eventually bought Francesca her own vehicle).

As the treatment progressed, the family became eligible for financial support from charities and, later, from the government. At this point, Francesca was spending over £200 a month on fuel, just to get Sidney to his treatments at Addenbrooke's.

Sidney was eventually referred for proton beam therapy, which required a four-hour journey from Suffolk to Manchester by car, and a six-hour journey by train. During our pilot project, when we met the family, Sidney needed to get to Manchester on two separate occasions. We were delighted to be able to fly him there and back on the first of these occasions – one outbound and one return journey, just 45 minutes each way.

#### FRANCESCA RECALLS THE EXPERIENCE:

"It was something exciting at a time when there wasn't much to be excited about. It was brilliant. The impact of going to Manchester was hugely reduced, because I didn't have to worry about Sidney getting sick, or the length or cost of the journey. And I trusted [Please Take Me There] completely. I was much less stressed and I could cope with everything better. Also, Sidney got to experience something fun at a really horrible period of his life."

A few months after our pilot project ended, Sidney returned to Manchester for his second visit. Francesca had no choice at the time but to take him on public transport. During the six-hour journey, he became unwell and developed a high temperature. As soon as they arrived at the train station in Manchester, Sidney was rushed to hospital in an ambulance.

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### THE NHS HEALTHCARE TRAVEL COSTS SCHEME

In certain circumstances, under the Healthcare Travel Costs Scheme (HTCS), the NHS will reimburse the cost of travelling to hospital appointments, 'for the cheapest suitable mode of transport... which in most cases will be public transport.'

As Sidney's story shows, public transport can be life threatening for vulnerable children with cancer, which makes the scheme unusable for many. What's more, to be eligible, families must be in receipt of Universal Credit (or an equivalent), or earn less than £16,000 per year. This excludes a lot of people.

The scheme also works on a system of reimbursement, i.e., the presumption that families have such money to spend in the first place. And, if all that wasn't prohibitive enough, according to research from Young People vs Cancer, nearly 80% of parents don't even know the scheme exists.

In short, HTCS is not fit for purpose, and doesn't go far enough to help people most in need. This results in almost 70% of parents and carers relying on charity, family and friends to help with the costs of travelling to hospital.

### THE YOUNG CANCER PATIENT **TRAVEL FUND**

Since 2017, Young Lives vs Cancer have been campaigning for the establishment of a Young Cancer Patient Travel Fund.

#### THE FUND WOULD:

- be available to anyone under 25 living with cancer in the UK;
- based on need, not income; and
- cover the costs of travelling to and from hospitals or treatments.

As they state at the end of their report, Are We Nearly There Yet?, significant gaps in the current service provision make this travel fund sorely needed.

But despite a wealth of research, education and lobbying, the government is yet to respond to their appeal.

## A DEDICATED TRANSPORT SERVICE

FOR YOUNG ADULTS AND CHILDREN WITH CANCER



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We can create the services that families need, both now and for years to come.

As much as we support the development of the Young Cancer Patient Travel Fund, our own experience and research shows that the solution to this wide-ranging problem requires more than just financial support.

Finance solves only a part of the problem and depends on political will. By harnessing the power of community and networks, we can be our own solution to a lack of transport provision. We can create the services that families need, both now and for years to come.

Young people with cancer who need to travel to PTCs are in a fundamentally insecure position. They rely on tolerant employers to give their parents the time off they need. They rely on friends and family to give them lifts so they can avoid public transport. And they rely on the goodwill of charities and loved ones for much-needed funds to cover long lists of costs. This is the case, day in and day out, up, down and across the UK. We need to do better for these families already struggling with a shattering diagnosis of childhood cancer.

Families like Esmé's, who can barely make ends meet and just about scrape by each month.

Families like Seraph's, who juggle full-time work with the care of a very sick child, and rely on the kindness of strangers to make their appointments at the hospital.

Families like Sidney's, who need to access specialised treatment without risking the life of their child on crowded trains.

With your help, we will take them all there.

#### Here's how we intend to do it.

## THREE NEW ESSENTIAL SERVICES

Our proposal outlines three new essential services for young adults and children with cancer.



Starting in the East of England, ahead of a national roll out, we'll provide free, net-zero, non-emergency transport, to and from their hospital appointments, for every child with cancer.

Access to our overland service will mean families no longer have to worry about paying for transport or asking friends and family for a lift. They'll also be able to pre-book or request the service as needed, seven days a week. Our electric cars will be driven by specially trained staff, and will provide the comfort of a spacious family vehicle, complete with multimedia activities for kids. Over 60% of respondents to our survey would be extremely likely to request this service.

#### ANSWERS TO THIS QUESTION WERE VERY MOVING:

'Long car journeys with sick children on chemo are one of the hardest things imaginable. No one can understand the stress involved... unless they're unlucky enough to live through it.'

'Quite often [on journeys to the hospital] my daughter would need a cuddle or to hold my hand, which I just couldn't do while driving.'

'It would eradicate the stress of trying to find parking at the hospital, which is incredibly difficult when you have a toddler with cancer who can't walk in by themselves.'



For those patients who have to travel hundreds of miles for specialist treatments, like proton beam therapy, we'll provide an air transport service to get them there in no time at all. Journeys that could take up to six hours on public transport will be cut down to less than an hour.

Designed to take one family at a time and to operate from regional airfields, this non-emergency service will allow families to minimise the time spent travelling to and from scheduled PTC appointments, and eliminate the need for public transport. This means that very sick children with profoundly weakened immune systems won't have to risk serious infection or even worse, their lives, in crowded terminals and stations or on busy planes or trains. Instead, they'll be able to travel quickly and comfortably in a safe and pristine environment.

The air transport service will be available to any eligible family living in the UK, and prioritise the most vulnerable children living in the most remote regions (the South West and the East of England). 82% of respondents to our survey would be extremely likely to request this service.

#### HERE'S WHAT SOME OF THEM SAID:

'It would be amazing. We had to use a commercial flight to have proton [beam therapy] and it was awful and stressful. This would have been incredible. Calmer, cleaner - the list [of benefits] is endless.'

'Our son required a bone marrow transplant in Bristol and we live in Northern Ireland. Air travel would be a lot less stressful than taking the ferry and driving hundreds of miles.'



In addition to free rides to the hospital, families struggling to pay for transport will be able to apply for modest pots of funding.

'Travel money', our small emergency grant scheme, will cover the costs of fuel, parking and essential vehicle maintenance.

Our survey of parents of children with cancer shows that 85% of respondents would be likely to access a fund of this nature.

In the face of a government that continues to ignore this need, we have no choice but to act, and act now.

#### BUT DON'T TAKE OUR WORD FOR IT, HERE'S WHAT FAMILIES SAY:

'The costs of travelling were crippling.'

'All the travelling costs a lot of money, at a time when your income is likely to be reduced and money is the last thing you should have to worry about.'

'Travelling to and from hospital is expensive. [Our] debts are mounting.'

## OUR IMPLEMENTATION **ROADMAP**

#### Families need support as a matter of urgency. There's no time to lose - we need to act now.

Our national transport service will be implemented over nine years in three stages, prioritising the regions most affected by a lack of provision, as funding campaigns run in tandem.

### **STAGE 1:**

#### EAST OF ENGLAND - OVERLAND TRANSPORT AND TRAVEL MONEY

Stage 1 will commence in the East of England, where the average round trip is 90 miles.

Operational by no later than 2023, the project will provide free, non-emergency return transport to hospital for each child with cancer.

Additionally, families struggling financially will be able to apply for small, emergency grants for transport. At launch, 40 grants will be available each month.

The estimated cost of this phase of implementation, and the first year of operation is £249,000. The estimated operational cost in the following five years is £335,000 per year.

### **STAGE 2:**

## UK - AIR TRANSPORT FOR PATIENTS AND FAMILIES

Families across the UK with especially vulnerable children will be able to request non-emergency air transport for specialised treatments, or to participate in clinical trials.

With an estimated average annual operational cost of £334,000 (first five years), the service will be able to transport up to 3,000 passengers each year.

The estimated cost for both implementation and the first year of operation is £2,400,000, much of which will be allocated to the cost of the plane. The plane will be in service for a minimum of 25 years. So, while the total upfront costs of stage 2 are higher than those of stage 1, when broken down annually, the plane represents a sustainable investment of £71,000 a year.

Subject to funding and regulations, we will implement this service no later than 2026.

### **STAGE 3:**

#### UK - OVERLAND SERVICE FOR ALL YOUNG ADULTS AND CHILDREN WITH CANCER

Once stages 1 and 2 are complete, we'll initiate a UK-wide rollout of overland services, starting in the regions most affected by a lack of provision.

The stage 3 roadmap and budget will be presented during stage 2 of implementation. Our aspiration is a full national transport service, in place by 2030.

## MAKING IT Happen

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We believe there's something special in each and every one of us that calls out to fulfil our potential and do something truly amazing. That's why we dream big. 66

This service can be your legacy - your gift to every parent who hears the news we wish they never had to hear - Your child has cancer.

By coming together, we can help to ensure that every young person living with cancer receives the vital care they need within the next ten years.

If a child has to travel long distances for treatment, we'll make sure they don't have to pay for it, or have to get there by public transport. In this way, they'll spend less time away from their homes, schools, families and friends.

Parents and carers won't need to burden family, friends and neighbours with requests for lifts at all hours of the day and night, or to find hundreds, if not thousands, of pounds for travel to take their children to treatment.

To make our dream come true, we will build on our network of interested parties and invest in the infrastructure required to support those families in need.

## A CALL TO CARING ARMS

During our 2018–19 pilot project, we made new connections all around the country. From nurses to social workers, to families affected by cancer, over and over and over again, the need for this specialist transport service was made clear.

We invite all organisations working with young people with cancer to join us in the realisation of our ambitious vision.

This includes UK charities and Principal Treatment Centres. If you are a member of one of these communities and feel you could contribute, we would love to hear from you.

## GET INVOLVED

This isn't your typical charity appeal. Because we don't just need money, we also need you. Your skills, your ideas, your networks and your time.

Cancer isn't something that just happens to 'other people'. It affects your friends, your family, your neighbours and your colleagues. And, sadly, sometimes, your children. That's why we need you to join us in this fight.

#### There's no such thing as too small a contribution.

Whether five minutes or five months, £5 or £5,000, each second and every penny counts. Whatever you can give will help us do something amazing – create a much-needed transport service for children and young adults with cancer.

Please share this report with anyone you think could help or might be interested. Or, you can contribute to the realisation of our vision by donating, organising fundraisers, sporting challenges or other exciting events. Let this be your legacy, a lasting contribution to the youth of our nation for the benefit of generations to come.



Working together to spread the word and share resources, we know we will see you when we get there.



### GET ONLINE

Visit our website for more details of how to get involved: www.pleasetakemethere.org

## TALK TO US



Call us for more information or arrange a face to face visit:

01223 653 133

Email us at: hello@pleasetakemethere.org

## GET SOCIAL



Follow us, support us and help us spread the word...



🔰 /takemethereuk

## VISIT US



Come and say hello, swing by our office for a chat:

Please Take Me There Nine Hills Road, Cambridge, CB2 1GE, UK

## LIMITATIONS

At the time of writing, we've submitted 21 FOI requests to 19 hospitals and ambulance services, and have received 19 responses. The two outstanding replies have been delayed due to the impact of COVID-19.

The responses from NHS Trusts vary slightly from site to site. Some organisations provided the exact number of cases per region or city, while others omitted those figures where the cases were fewer than five.

Where Trusts included cases that did not include a patient's county of residence, we excluded these numbers from our research.

Our research provides a time-limited snapshot of patients' experiences (2019). It is not intended to offer a more holistic account of the issue.

The individual families highlighted in our case studies are not necessarily representative of all parents of children with cancer.

## REFERENCES

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Freedom of Information Ref. 21.212, Cardiff and Vale University Health Board, submitted by Please Take Me There.

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Freedom of Information Ref. 16950, NHS Greater Glasgow and Clyde, submitted by Please Take Me There.

Freedom of Information Ref. FOIRQ6319 , Great Osmond Street Hospital for Children, submitted by Please Take Me There.

Freedom of Information Ref. CD/DB/JN/FOI ID-CB7B55B2, The Newcastle and Tyne Hospitals, submitted by Please Take Me There.

Freedom of Information Ref. NUH 60858, Nottingham University Hospitals NHS, submitted by Please Take Me There.

Freedom of Information Ref. F21-5183, Oxford University Hospitals NHS, submitted by Please Take Me There.

Freedom of Information Ref. FOI 3320, Sheffield Children's NHS Foundation Trust, submitted by Please Take Me There. Freedom of Information Ref. FOI 7403, University Hospital Southampton NHS Trust, submitted by Please Take Me There.

Freedom of Information Ref. FOI/2021/0278, University College London Hospital (UCLH), submitted by Please Take Me There.

Freedom of Information Ref. FOI 34258, East of England Ambulance Service NHS Trust, submitted by Please Take Me There.

Freedom of Information Ref. FOI L344, The Christie NHS Foundation Trust, submitted by Please Take Me There.

Freedom of Information Ref. FOI 5631, Alder Hey Children's NHS Foundation Trust, submitted by Please Take Me There.

CLIC Sargent (2010), A long way from home.

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Please Take Me There survey to families of young people with cancer, 2021, 105 participants.

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