

# A long way from home



The impact of travel on children  
and young people with cancer



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[www.clicsargent.org.uk](http://www.clicsargent.org.uk)





# Document Information

## Research

- **Charlotte Snelling**  
Communications & Campaigning team,  
CLIC Sargent
- **Katie McDowell**  
Policy & Public Affairs Manager,  
CLIC Sargent

## Data analysis

- **Peter Hall**  
Database Administrator, CLIC Sargent

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## Target audience

Commissioners, policy makers and service providers from across the health, education and social care sectors.

## Brief abstract

This report highlights the impact of travelling long distances for cancer treatment for children and young people aged up to 18 years-old. It explains how travelling can exacerbate the other challenges a cancer diagnosis can create for children, young people and their families. The report makes a number of recommendations aimed at minimising some of the impacts caused by travelling long distances for treatment while not jeopardising the safe and effective treatment of children and young people's cancer.

## What does CLIC Sargent do?

Every day, 10 children and young people are told they have cancer and diagnosis usually comes as a shock. Treatment normally starts straightaway and can last for up to three years. CLIC Sargent is the UK's leading cancer charity for children and young people. It provides clinical, practical and emotional support for young cancer patients and their families, from diagnosis onwards.

## Contact details

CLIC Sargent  
Griffin House  
161 Hammersmith Road  
London  
W6 8SG

Tel 020 8752 2800





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# Foreword



CLIC Sargent has a single aim: to reduce the impact of childhood cancer. With that in mind, we listen to the needs of the children and young people, we work with them to find out the key issues and challenges they face, and we provide support from the moment they are diagnosed with cancer, through treatment and beyond.

From our research with children, young people and families (particularly our *More Than My Illness* reports), we know that children and young people with cancer want to spend as much time as possible at home during treatment, and CLIC Sargent is taking forward various programmes of work to help support this.

One issue that we have not yet highlighted in detail is the travelling distances and times faced by children, young people and their families in order to access treatment. Thankfully childhood cancer is rare, but this means that services are necessarily organised around 19 specialist centres of excellence – principal treatment centres – which results in many families having to make significant, regular journeys for treatment.

An analysis of 10,000 records from our database of children and young people from 0 to 18 years-old that CLIC Sargent has supported looked at the travelling distances and times faced by these families, with some startling findings.

Whilst the development of specialist principal treatment centres has undoubtedly helped to improve survival rates, travel to and from treatment centres can create significant additional challenges for young cancer patients and their families – placing substantial increased pressure on families facing massive disruption to their work and family lives and their ability as a family to lead a ‘normal life’.

We hope this report will highlight the need to ensure children, young people and their families receive the support they need to help them cope with the many impacts of a cancer diagnosis.

A handwritten signature in black ink that reads "Lorraine Clifton".

**Lorraine Clifton**  
Chief Executive, CLIC Sargent

December 2010



# Introduction

Dealing with cancer in childhood or as a young person presents a range of challenges for the young people themselves and for their families or carers. We know that children, young people and families affected by childhood cancer can face significant emotional, practical and financial difficulties – at a time when family and social networks are disrupted by the illness and treatment. Children and young people also face significant disruption to their education, training and employment.

Equally, families may have to bear significant additional financial costs as a result of supporting their child through cancer treatment, with travel and accommodation key areas of expenditure.

The new research published in this report highlights that the impact of travelling for treatment can exacerbate these difficulties and create further burdens. Principal treatment centres are often far from home which can mean regular long-distance travel or staying away from home, sometimes for months on end. In this report, CLIC Sargent makes several recommendations aimed at minimising some of the impacts caused by travelling long distances for treatment while ensuring the safe and effective treatment of children and young people's cancer.

In its 2005 guidance *Improving Outcomes in Children and Young People with Cancer*, the National Institute for Health and Clinical Excellence (NICE) highlighted the trade-off between specialist treatment and local treatment; "Access to such facilities [principal treatment centres] should be with the least inconvenience to patients and families, but the rarity of cancer in these age groups means that treatment may involve considerable travel for families often beyond a closer, but less appropriate, cancer facility. This is generally well accepted by patients and families, but does impose additional burdens on them."<sup>1</sup>

Sir Ian Kennedy's wider review of NHS services for children in 2010, states that where local hospitals and specialist children's facilities fail to work in partnership, many children and families must travel unnecessarily long distances, causing inconvenience and frustration.<sup>2</sup>

Given the relative rarity of a childhood cancer diagnosis, the UK's current cancer services for children and young people are organised around 19 principal treatment centres. The limited number of specialist centres has encouraged the development of expertise in all aspects of children's cancer care, undoubtedly contributing enormously to the huge increase in survival rates over the past 30 years, with over 70% of childhood cancer patients today achieving five-year survival.

Although principal treatment centres currently provide the best clinical care and time in hospital is vital in the establishment of a treatment plan, it is also widely acknowledged that children and young people with cancer benefit from spending as much time at home as possible when not receiving direct treatment. The downside of the small number of principal treatment centres specialising in treating children and young people means that many childhood cancer patients are treated in hospitals hundreds of miles from home, requiring them to travel considerable distances on a regular basis and often for a significant period of time. Consequently, children and their families lose a lot of time which could otherwise be spent at home, at school or at work.

Some families already benefit from 'shared care' arrangements, where some aspects of care are delivered by hospitals more local to a child's home<sup>3</sup>, and paediatric oncology outreach nurse specialists (POONS), who help provide expert clinical care in the community. CLIC Sargent is also taking work forward on developing a key worker model of provision and believes that every child, young person and their family

1 National Institute for Health and Clinical Excellence (2005) *Improving Outcomes in Children and Young People with Cancer*

2 Sir Ian Kennedy (2010) *Getting it right for children and young people: overcoming cultural barriers in the NHS so as to meet their needs*

3 The provision of shared care arrangements is dependent on the type of cancer and the treatment required

should have a key worker who is responsible for the coordination of all their care and support in hospital and in the community.

This report builds on several studies conducted by CLIC Sargent over the last two years and includes newly commissioned research which looks at the impact on children, young people and their families of travelling long distances for treatment and how this impact can be lessened.

The Department of Health's 2010 report *Achieving Equity and Excellence for Children* stresses the importance of "being treated in age-appropriate settings, having care that enables children and young people to be at home with their families as much as possible, and treatment that enables children and young people to lead as normal a life as possible, at school and with their friends".<sup>4</sup>

## Key findings of this report

- **77%** of childhood cancer patients do not live in a city with a principal treatment centre. Where patients require extremely specialist treatments offered at only a small number of principal treatment centres (e.g. for retinoblastoma), even those living near a principal treatment centre may have to travel to another city for much of their care.
- The average round trip distance travelled (by road) by children, young people and their families is **60 miles**. For patients in day ward day care, this can mean travelling 60 miles in a single day.
- **42%** of children, young people and their families make round trips of 50 miles or more when undergoing treatment at a principal treatment centre.
- The average time it takes an individual and their family to travel to their principal treatment centre is **55 minutes**. This makes each round trip approximately **1 hour 50 minutes**.
- The maximum distance for travel found in this report is 451 miles one-way, amounting to a round trip of 902 miles taking just under 16 hours. In this instance, treatment necessarily requires at least one overnight stay, if not more.

<sup>4</sup> Department of Health (2010) *Achieving equity and excellence for children: How liberating the NHS will help us meet the needs of children and young people*



# Recommendations

CLIC Sargent fundamentally believes in a system of care and support for children and young people with cancer based on the development of specialist centres of expertise, however, we do believe that more could be done to mitigate the impact of cancer, and particularly travelling times, on the child and their family. We would therefore like to see:

## 1. Better coordinated care and support

CLIC Sargent believes that both improved patient experience and cost savings (e.g. minimising hospital bed days) could be achieved by better coordination of care and support for children and young people with cancer. Crucially this would enable children and young people and their families to spend more time at home during treatment, as well as easing the transition between different care settings, whether in the hospital, in the community or at home.

CLIC Sargent believes this better coordination could be achieved through key working and so is leading on work to assess the impact of key worker models of care as well as providing funding for a number of posts in principal treatment centres across the UK as part of our Charity of the Year partnership with Tesco. We hope the evaluation of these pilots will be used to inform work at hospitals across the UK and to ensure more children and young people with cancer spend time at home during treatment.

## 2. Prioritisation of information and awareness

Charities such as CLIC Sargent play a vital role in providing information and support to children and young people with cancer and their families. We would also encourage all hospitals to provide patients with timely information on local travel schemes and transport information. With regards to benefits, it is also important that families are made aware of their entitlements as soon as possible, something CLIC Sargent social workers can help with. We also hope current plans for welfare reform will result in a less complicated and more transparent system, making options and entitlements clearer for families.

## 3. Review of the Healthcare Travel Cost Scheme (HTCS)

Whilst the HTCS is able to assist some families with the additional costs of their child's cancer diagnosis, at present it only applies to low-income families. CLIC Sargent would argue that the additional costs of a cancer diagnosis fall on all families regardless of income. Such costs are often at their highest in the first year of diagnosis, resulting in an immediate need. It is also important to note that families will often be affected by loss of earnings as a result of one parent having to take on caring responsibilities. Whilst CLIC Sargent acknowledges the current constraints placed on public finances, we would be keen to see a review of the HTCS (and equivalent schemes in Scotland, Wales and Northern Ireland) to see how support might be better targeted towards those with significant additional needs, including children and young people with cancer and their families.

# Types of treatment

Importantly there is no 'typical' childhood cancer patient, and the nature, frequency and duration of treatment necessarily varies from one child to another. The following examples, however, present an idea of the sorts of treatment many children and young people must undergo, and the subsequent travel requirements they and their families may face following a diagnosis.

## Acute lymphoblastic leukaemia (ALL)

The most common type of cancer found in children up to 15 years of age is acute lymphoblastic leukaemia, which affects 25% of all children diagnosed.

Chemotherapy is the main form of treatment for children with ALL, with each treatment requiring between one and two days in hospital, and typically administered every one or two weeks.

In most cases treatment lasts two or three years.

## Brain and spinal cord tumours

Brain and spinal cord tumours are the second most common type of childhood cancers. Most children have surgery and then receive a course of radiotherapy for six weeks. Radiotherapy may be administered once or twice a day, for five days a week.

Sessions can last 15 minutes but for many, particularly younger children who may require an anaesthetic, time spent in hospital can be much longer. After radiotherapy many children and young people will also receive chemotherapy. Many children and young people who have undergone treatment for brain and spinal cord tumours require specialist rehabilitation support both during and after treatment. This adds to the number of journeys for treatment they must make.

## Rarer cancers

Children and young people with rarer cancers may have to travel even further in order to receive the highly specialised care that they need.

For example, only hospitals in London and Birmingham provide the specialist care to treat retinoblastoma, a cancer of the eye, which affects around 20 children each year.

Treatment for retinoblastoma usually involves surgery, radiotherapy and chemotherapy, with patients also having to undergo monthly eye examinations under general anaesthetic for a number of years after their principal treatment.



# The facts about cancer in children and young people

- Every day 10 families are told that their child has cancer.
- Around 1,500 - 1,700 new cases of childhood cancer are diagnosed each year in children up to 15 years of age, and around 2,300 cases are diagnosed amongst young people aged between 16 and 24 in the UK<sup>5</sup>.
- 10,000 children and young people may be receiving treatment for cancer at any one time in the UK.
- CLIC Sargent gave in-depth support to more than 5,500 children and young people with cancer and their families last year and thousands more were helped through our information service and helpline.
- Although survival rates are over 70%, cancer remains the single largest cause of death from disease in children in the UK.
- Children and young people surviving cancer may live for 50+ years after cancer<sup>6</sup>.
- Cancer services for children are organised around 19 specialist principal treatment centres across the UK.
- Because of the wide number of agencies involved in treating and supporting a child or young person with cancer, coordination of services can vary from region to region and is often inadequate to meet their needs.



5 National Registry of Childhood Tumours

6 NHS (2010) Building the evidence: Developing the winning principles for children





Parent held oncology records

Please be sure this record is not used for any other purpose than the one for which it was intended. A complete record of all medical records is maintained in the hospital's records system. For more information, contact the hospital's records department.



# Rory's Story

Rory, aged 8, was diagnosed with acute myeloid leukaemia (AML) in November 2009. He lives with his mum, dad and older brother Calum (aged 10) in Portland, Dorset. His nearest principal treatment centre is Southampton General Hospital. He has also had treatment at Dorset County Hospital and Bristol Royal Hospital for Children. Rory continues to have outpatient appointments in Southampton.

Between February and March 2010, Rory needed to travel up to three times a week to either Dorchester or Southampton for routine procedures and treatment, a total of 818 miles, at a cost of £327.

**Rory says:** "When I was seven, I was diagnosed with acute myeloid leukaemia. I live in Portland but I had to go to the hospital in Southampton because they have a special ward for children with cancer and I could get the treatment I needed. At the beginning I had to stay in Southampton for six weeks, so my mum and dad took it in turns to come and see me because they had to look after my brother Calum too. They had to do a lot of travelling, even once I was moved to Dorchester, plus I still had to go to Southampton for some treatment and appointments.

"I didn't like the journeys. We had to be in Southampton for 10 o'clock so I had to get up really early. I'd be tired and nervous. Sometimes I would feel sick so didn't want to eat and drink during the journey, even though the doctors told me I should, to make sure I felt better after my treatment and put weight on.

"My cancer meant I needed a bone marrow transplant, which had to be done in Bristol. I had to stay in hospital for about two months but it was too far for my parents to travel all the time. They stayed at Sam's House<sup>7</sup>, and my brother could stay there too, so I got visits from all my family once I was allowed out of isolation. After I had my transplant we spent even more time going backwards and forwards. If it was too late to travel back from Southampton we'd sometimes stay at CLIC Haven<sup>8</sup> which was nice, but if the house was busy we'd stay in a hotel.

"Now that I have finished my treatment I only have a few check-ups and appointments so I'm not travelling as much. It's also been nice that some things can be done at home when Jane (the community nurse) comes, like taking blood and flushing my central line. It would be nice if even more things could be done at home."



**Lyn, Rory's mum, told us:** "Living where we do, we often feel quite remote. There aren't many support services where we live, but our CLIC Sargent social worker was great at putting us in contact with some local organisations that could help us.

"Living so far away from the principal treatment centre, we also had fears about what would happen if we had an emergency with Rory and whether we'd be able to get to Southampton quickly enough.

"During the course of Rory's treatment we didn't actually calculate how much we've spent on travel; you have to do it, so you just get on with it. It was great to receive some money from CLIC Sargent within days of Rory being diagnosed, and our social worker helped us with filling in the benefits forms and claiming money. This was really important, particularly as Rory's dad, who normally works a lot of night shifts, lost income as he needed to help with looking after Rory and his brother Calum."

7 Sam's House is one of CLIC Sargent's Homes from Home situated in Bristol offering families free self-catering accommodation

8 A CLIC Sargent Home from Home located in Southampton

# The impacts of cancer

Children, young people and their families often have to face a number of challenges in dealing with cancer. These can range from the emotional to the practical, for example, managing the travel arrangements for regular hospital visits or organising accommodation. As well as dealing with these challenges, many families also express anxiety at having to negotiate with multiple agencies regarding the care, treatment and education of their child.

## 1. Travelling for treatment

**“It was devastating. Really, really terrible. One of the biggest things was the distance we lived from the treatment centre – a three-hour round trip by car and train.”** *Carly, mum to Charlie*

New research by CLIC Sargent has found that 77% of childhood cancer patients do not live in a city with a principal treatment centre, which means that many children, young people and their families need to travel long distances for their treatment, often on a regular basis.

Our research shows that 42% of children, young people and their families make round trips of 50 miles or more when undergoing treatment at a principal treatment centre. The average distance travelled by road for a round trip is 60 miles. For patients in day ward day care, this means travelling 60 miles in a single day.

Children and young people with rarer cancers, which require even more specialist treatment that is available at only a small number of principal treatment centres, may need to travel considerably longer distances. One family in our study faced a round trip journey of 902 miles for treatment.

There is considerable variation in the average distance travelled by patients and their families to the different principal treatment centres across the UK. Children and young people treated in Aberdeen, Belfast, Liverpool, Cambridge and Bristol typically travel significantly further than children and young people treated elsewhere in the UK.

The type of journeys taken by children and young people also vary considerably. Travelling across a city is a qualitatively different experience from a journey predominantly travelled on a motorway or a journey travelled on rural roads<sup>9</sup>. Similarly, the time a journey takes, its financial cost, and the patient's travel experience is affected by the mode(s) of transport used. Many patients are also not able to use public transport because of the risk of infection.

For some children and young people, journeys may have to be interrupted at regular intervals, for example if they feel unwell or have to take medication, lengthening the overall time spent travelling<sup>10</sup>.

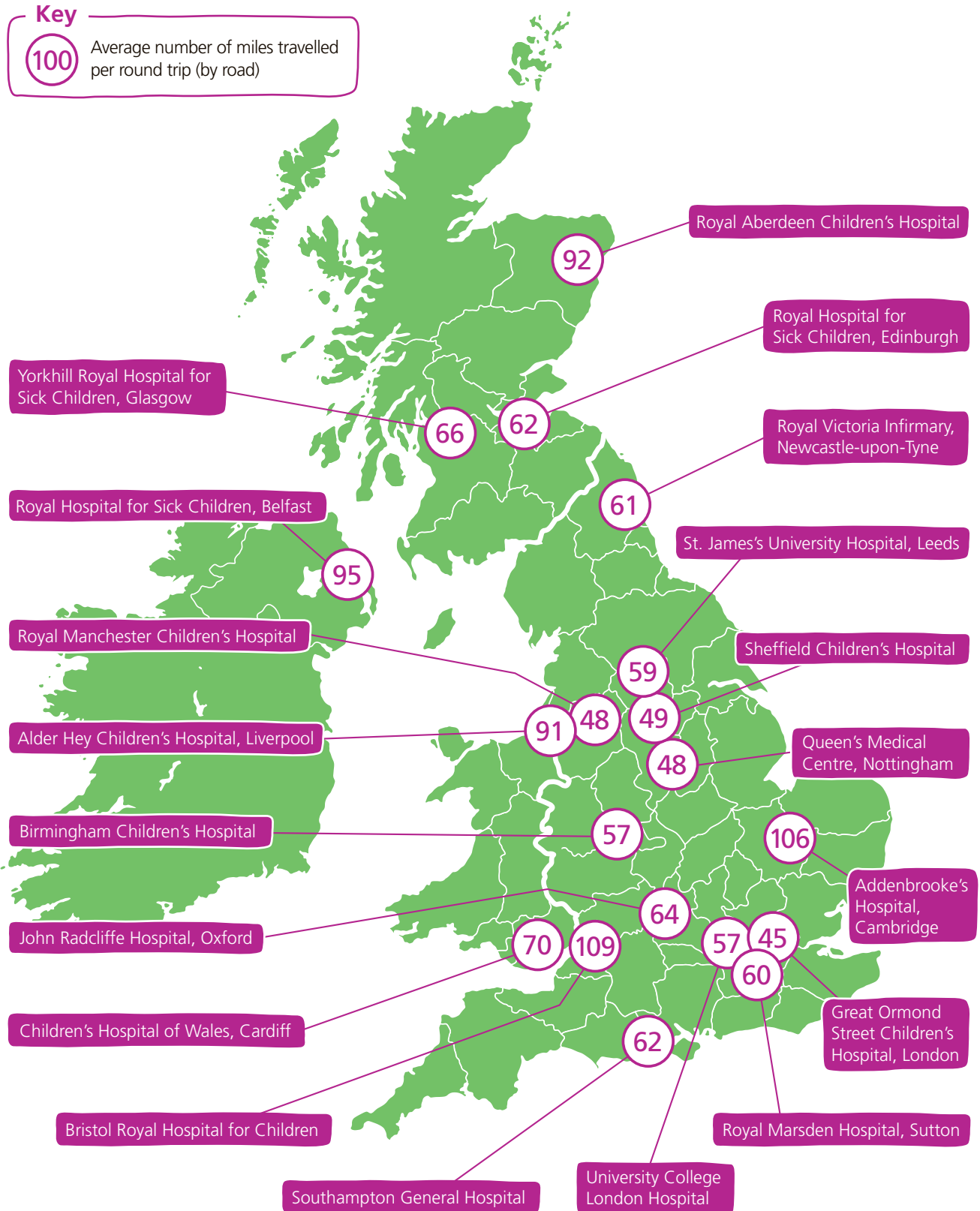
9 Payne, S, Jarrett, N and Jeffs, D (2000) 'The impact of travel on cancer patients' experiences of treatment: a literature review' *European Journal of Cancer Care*. Volume 9(4)

10 Lightfoot, N et al (2005) 'Psychological, physical, social, and economic impact of travelling great distances for cancer treatment' *Current Oncology*. Volume 12(4)



# Table 1

Average number of miles children, young people and their families travel per round trip for treatment at each principal treatment centres



## 2. Emotional

“I think that at night I will relapse and die. I’m scared that when I play I will badly hurt myself and will need to go to hospital. I don’t know what will happen to me, I hope I won’t die.”

*Jodie, age 9, two years post-treatment for leukaemia*

Dealing with cancer has a significant emotional impact on children as evidenced in CLIC Sargent’s report *The impact of cancer on a child’s world* (2010). Children told CLIC Sargent they felt powerless, isolated and sad and wanted emotional support to help them cope with the impact of cancer.

Young people also face challenges in dealing with the emotional impact of cancer. CLIC Sargent has found that 88% of young people with cancer surveyed believed it was important to have emotional support at home<sup>11</sup>.

Having to travel far from home for treatment, away from support networks of friends and family, can only add to the emotional impact of cancer, and may compound feelings of isolation, making coping more difficult.

The emotional impact of a cancer diagnosis is also often felt throughout the family. CLIC Sargent research has found that parents and siblings felt a need for professional emotional support to be provided.

## 3. Side-effects of treatment

“Sometimes I feel left out from my school friends and I sometimes lack confidence with groups of my friends. I know I look different as I have lost my hair and I feel upset sometimes as I am unable to do some of the activities like P.E.” *Louise, age 10, on treatment for leukaemia*

The side-effects of cancer and cancer treatments, particularly chemotherapy, often leave children and young people feeling physically weak and unwell. Children told CLIC Sargent that they felt significantly tired following treatment<sup>12</sup>. Other unwanted side effects of chemotherapy can include sickness, diarrhoea and constipation although drugs can be prescribed to help with these symptoms.

Children and young people suffering from such side-effects can find they are unable to take part in certain activities, both those that are school and friendship-based. This can make it difficult to maintain friendships and social networks, significantly affecting children and young people’s peer relationships and emotional wellbeing.

The side-effects suffered by many children and young people may also make journeys to treatment uncomfortable experiences, whilst the act of travelling itself can make managing symptoms difficult when journeys are long.

<sup>11</sup> CLIC Sargent (2010) *More than my illness: delivering quality care for young people with cancer*

<sup>12</sup> CLIC Sargent (2010) *The impact of cancer on a child’s world: the views for children aged 7 to 13 living with and beyond cancer*  
<http://www.clicsargent.org.uk/Whatwedo/Impactofcancerreport>

## 4. Cost

**“The financial support offered by CLIC Sargent made a real difference because even though you have a child with cancer you still have to pay the bills and put petrol in the car.”** *Sally, parent of child with cancer*

For many families, cancer treatment leads to significant additional expense. As part of CLIC Sargent’s 2005 *Cut the red tape* campaign, we discovered that 83% of families surveyed found their finances suffered considerably from a position of relative financial stability when their child received treatment for cancer<sup>13</sup>.

In further research, CLIC Sargent found that 91% of families surveyed changed their working patterns when their child was diagnosed with cancer and that 49% of families used their own holiday or sick leave to care for their child<sup>14</sup>. Such decisions, whilst often necessary, can result in a family’s income plummeting.

Travel costs to and from principal treatment centres, as well as parking charges can add significantly to the financial burden of dealing with cancer.

The NHS Healthcare Travel Costs Scheme (and equivalent schemes in, Scotland, Wales and Northern Ireland) aims to reduce the costs of travelling for treatment but only provides financial support to people on low incomes thus leaving many families to bear the costs of travel themselves<sup>15</sup>.

Legislation has seen the abolition of parking charges in Scotland and Wales for the majority of hospitals, whilst in Northern Ireland parking is free for chemotherapy and radiotherapy patients. In England charges remain, with NHS trusts setting their own rates and exemption policies.

Families often have to arrange accommodation at their own expense to be near their children while they undergo treatment, as well as organising home help and additional child care.

<sup>13</sup> CLIC Sargent (2005) *Cut the red tape*

<sup>14</sup> CLIC Sargent (2008) *Parents’ Right to Care* <http://www.clicsargent.org.uk/Getinvolved/Campaignwithus/Parentsrighttocare/Issuesandfacts>

<sup>15</sup> Eligibility for the scheme requires the applicant to be receiving at least one of Income Support, income-based Jobseekers’ Allowance, income-related Employment and Support Allowance, or Guarantee Pension Credit, or on an income of £15,276 or less and receiving the Child Tax Credit or Working Tax Credit (with the disability or severe disability element)

## 5. Disruption to school

**“I want more help to catch up with other children in our class. I used to find school easy but now I have had cancer I find it very tricky.”** *Eleanor, age 8, two years post-treatment for metastatic medulloblastoma*

**“I missed the first three years of school because of my cancer. The cancer has damaged how I think so I get things wrong at school. It’s like I banged my head and it didn’t get better for three years and I can’t think very well, that’s what it’s like.”**

*Alice, age 7, on treatment for leukaemia*

Treatment for cancer can disrupt a child’s education and the social life they often build while at school. Children and young people themselves recognise this as a problem with 76% of up to 18 year-olds telling CLIC Sargent that keeping up with school or education is ‘important’ or ‘very important’ to them<sup>16</sup>.

Undergoing treatment and regularly attending hospitals for procedures and routine check-ups can mean that a significant amount of lesson time is missed. This time is increased if the hospital is far away and requires a whole day travelling, or an overnight stay.

Social workers can liaise with schools to ensure that children and young people are able to keep up with school work when they are unable to attend lessons because of the demands of their treatment.

However, it is also often through school that children and young people are able to keep in touch with their friends, develop key social skills and maintain a sense of normality. Spending additional time away from school can also mean missing out on important extracurricular activities and work experience opportunities, potentially impacting on future higher education or job prospects.

It is sometimes possible for specialist children’s nurses to carry out routine clinical procedures at school to reduce the amount of lesson time children and young people miss. However, there is considerable variation in the provision and quality of such services across the UK.

<sup>16</sup> CLIC Sargent (2009) *More than my illness: delivering quality care for children with cancer. Summary of consultation*



## 6. Employment

This report focuses on children and young people from 0 to 18 years-old. Some of those young people aged 16 to 18 may be in employment at the time of diagnosis; others will not yet be in employment, but the long-term effects of a cancer diagnosis and treatment can present additional barriers to work for childhood cancer patients as they move into adulthood, as many may have ongoing cognitive difficulties, physical disabilities or other effects.

We know from our research that having cancer can have an adverse effect on the employment prospects of young people. In a recent CLIC Sargent survey, 93% of young people said their employment had been affected by cancer and 45% of young people said it was important to get employment support, which became more important for them as age at diagnosis increased<sup>17</sup>.

<sup>17</sup> CLIC Sargent (2010) More than my illness: delivering quality care for young people with cancer

# How CLIC Sargent helps

CLIC Sargent provides a range of services for children, young people and their families to help reduce the impact of travelling for cancer treatment, and the many other impacts of cancer.

## Homes from Home

Our Homes from Home offer families free self-catering accommodation within walking distance of the main regional cancer centres in Bristol, Edinburgh, Glasgow, London, Nottingham, Oxford and Southampton.

CLIC Sargent's ambition is to extend our Homes from Home programme to ensure that as many families as possible have access to accommodation close to principal treatment centres across the UK. We continue to look for new opportunities to expand this service as funds allow.

## CLIC Sargent Nurses

Our nurses can arrange for children to have some procedures at home, such as blood tests and sometimes chemotherapy.

Tesco has chosen CLIC Sargent to be their Charity of the Year in 2010/11. With the help of staff and customers, Tesco aims to raise £5 million to support CLIC Sargent's work across the UK in ensuring children with cancer spend more time at home and less time in hospital. The money raised will help fund CLIC Sargent specialist children's nurses who will ensure that children get the treatment they need at home to manage their illness, as well as the support they and their families need to get on with their lives.

## Care grants

Many families caring for a child with cancer find that costs go up, but that their income goes down. That's why we offer CLIC Sargent Care Grants to help ease the pressure, which families can receive within 72 hours.

## Practical and emotional support

We can help individuals and families access organisations or agencies that provide practical support in the home or help with child care. We can also offer help with benefit forms and claiming expenses and we're there to help the whole family cope with the emotional impact of a cancer diagnosis.

## Information service

We provide information and advice through a wide range of age-appropriate materials.





# Faith's Story

Faith, aged 3, was diagnosed with neuroblastoma (stage 1) at 8 weeks old, and continued to have surgery until she was 1 year and 3 months old. She lives in the Highlands, but has had treatment at the Yorkhill Royal Hospital for Sick Children in Glasgow and Raigmore Hospital in Inverness. A round trip from the family's home to Glasgow is 488 miles and costs approximately £63 in fuel.

**Natalie, Faith's mother says:** "When Faith was diagnosed with neuroblastoma she was only 8 weeks old. She has had to have a number of surgeries in Glasgow, which is really far from where we live. My husband and I would drive to Glasgow, but we'd always need to stay there because you simply can't make the journey there and back in a single day. We benefitted a lot from being able to stay in CLIC Sargent's Cruachan House<sup>18</sup> without charge. It was great and at weekends, when she was well enough, Faith could stay there too so that the whole family was together.



"During the course of Faith's surgeries, we probably had to travel to and from the hospitals seven or eight times. Faith still has check-ups in Inverness every three months and one in Glasgow every year. On top of that, Faith has had additional surgery in Glasgow for a dropped foot (a result of one of the surgeries) and a splint fitted, meaning we continue to have regular appointments with the orthopaedic surgeon and physiotherapists.

"When there was a possibility that Faith might need to have chemotherapy in addition to her surgery, we seriously considered moving to Glasgow even though my husband and I both have jobs where we live. Personally, I just didn't think I'd be able to cope with making the long journey to Glasgow even more regularly. It just makes you so tired and even more emotional than you already are.

"The journey itself was one of the hardest parts of Faith's treatment. It always helped when I was able to travel with either my husband or my dad. It made the journey a lot easier because my head would be all over the place, worrying about what was going to happen at the hospital, plus I had a crying baby to look after. I don't think I could have made some of the journeys if I hadn't had someone there with me.

"We spent a lot of money because we had to travel so far. On top of petrol and parking, if you're staying overnight somewhere there are basic things like nappies or just a toothbrush that you need to buy, and you're eating out all the time because the hospitals don't provide food for the parents. The £200 we received early on from CLIC Sargent was great to keep us ticking over, and our social worker helped us work out what benefits and support we were entitled to, as well as assisting us with the forms."

**Evelyn, Faith's CLIC Sargent social worker, Inverness, told us:** "Being diagnosed with cancer in the Highlands usually means a family will have to travel very long distances to the principal treatment centres. If they have to use public transport travel time is often increased with the extra bother of waiting for connections. This need to travel long distances greatly increases the physical, emotional and financial burden on an already stressed patient and their family."

<sup>18</sup> CLIC Sargent's Home from Home in Glasgow

# Annexes

## Key working for children and young people with cancer

In February 2009, CLIC Sargent published its *More Than My Illness* review of the community based clinical and non-clinical care and support needs of children and young people with cancer and their families which drew heavily on the views of both service users and experts in the field.

A clear finding was that children and young people with cancer want to go home as much as possible during their treatment in order to maintain a normal family life, with 97% of those surveyed as part of the report highlighting this as a key need.

*More Than My Illness* therefore recommends that every child and young person with cancer should have a dedicated specialist children's cancer nurse who acts as a key worker responsible for ensuring a consistent and coordinated service both in and out of hospital, helping with a smooth transition from hospital, into the home, into education and into independence.

The key worker would be responsible for bringing together hospital doctors and nurses with community-based professionals such as the GP, the social worker, the teacher and the children's community nurse. They would take a holistic view of the child's clinical and non-clinical care needs and coordinate every element of the child's care and support, ensuring that care is planned both in and out of hospital. This model builds on guidance<sup>19</sup> from the National Institute for Health and Clinical Excellence (NICE) which specifies that care and support should be delivered as close to the child's home as possible and that each child or young person with cancer should have a key worker.

## The key worker function

Successful key working should encompass a number of areas to provide maximum benefit to children, young people and their families including:

### Assessment and care planning

Ensuring the child and family's needs, both clinical and non clinical are assessed and a care plan is maintained.

### Co-ordinating service delivery

Being a named individual who acts as a single point of contact for multiple services.

Enabling a shared understanding of goals and approaches amongst those closely involved in the child and family's care.

Ensuring information is shared across agencies and amongst practitioners.

### Advocating for and empowering the child and family

Ensuring families know about and can access the services to which they are entitled.

Acting as an advocate and helping the family to develop their self-advocacy skills.

Empowering children and families and where possible enabling them to increasingly take on coordination of the child's own care plan.

### Providing specialist cancer support

Ensuring that the child, the family and others acquire new skills required for the child's care.

Ensuring understanding of cancer treatment and side effects.

Advising the child, family and others on pain and symptom management.

Supporting local agencies and professionals more generally in knowing what to expect from a cancer diagnosis and how to manage the consequences.

<sup>19</sup> NICE (2005) Improving outcomes in children and young people with cancer

# Report methodology

1. A desktop literature search of current research, policy, advice and guidance.
2. Interviews with service users and staff, both to inform the report and illustrate it using real-life stories. Two case studies have been chosen to feature in the report.
3. Data analysis using postcode sector data taken from the CLIC Sargent CARE database to calculate the distances travelled by children and young people (aged 18 years or less at diagnosis) registered with CLIC Sargent since 2005.
  - The research covered a total of 9,889 children and young people.
  - The website [driving-distances.com](http://www.driving-distances.com)<sup>20</sup> was used to calculate the distance by road between the child or young person's home and their PTC, based on the assumptions that drivers take the most direct route and use priority roads (e.g. motorways).
  - Journey times were calculated according to the maximum speed limit on each road.
  - Fuel costs are estimated at 13 pence per mile (for cars valued at £12-16,000)<sup>21</sup>.
  - All distances are rounded to the nearest mile, times to the nearest 5 minutes and fuel costs to the nearest pound.

## Glossary – descriptions and definitions

### Children and young people

In this report 'children and young people' refers to all children and young people aged up to and including 18.

### Community

In this report community is defined as anywhere the child and family are when not in a hospital. This includes being in their home, in another person's home, at school and at work.

### Family

Family includes informal carers and all those who matter to the patient.

### Paediatric oncology outreach nurse specialist (POONS)

Paediatric oncology outreach nurse specialists are specialist nurses providing outreach services for children diagnosed with cancer. They support children and families from the point of diagnosis through to end of life care, where this is needed.

### Principal treatment centre (PTC)

All children with cancer are diagnosed at one of the 19 principal treatment centres in the UK. The PTC makes the definitive diagnosis and initiates treatment. The PTC directs the child's cancer treatment throughout the care pathway.

### Shared care centres/paediatric oncology shared care unit (POSCU)

Shared care centres, or POSCUs, are local hospitals working in partnership with a PTC to provide some aspects of the care a child with cancer needs. The type of care provided in a shared care centre depends on a number of factors such as the location of the hospital, the facilities and expertise available, the type of cancer being treated and the age of the child. Levels of shared care are agreed with each PTC.

<sup>20</sup> <http://www.driving-distances.com/distances-between-calculator.php>

<sup>21</sup> [http://www.theaa.com/motoring\\_advice/motoring\\_costs.html](http://www.theaa.com/motoring_advice/motoring_costs.html)



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CLIC Sargent  
Griffin House  
161 Hammersmith Road  
London  
W6 8SG



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