

£1000  
PER MONTH

# CANCER COSTS

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

**YOUNG LIVES**  
**vs CANCER**  
**CLIC SARGENT**

# SUMMARY

Undergoing cancer treatment is a difficult and isolating time for young cancer patients and their families, with their ability to cope often seriously affected by the financial pressures of a diagnosis. Our research explores the financial impact of cancer treatment on children, young people and their families. It also provides an insight into how financial pressures affect families' emotional health and wellbeing.

This report aims to raise awareness among government and NHS policy makers, health and care professionals and the voluntary sector, of how the extra costs associated with cancer treatment impact on young cancer patients and their families, and how they could be better supported in the UK welfare, health and care systems.

# ABOUT CLIC SARGENT

When cancer strikes young lives CLIC Sargent helps families limit the damage cancer causes beyond their health.

We will fight tirelessly for children and young people with cancer, often when they feel they can't. We do this individually, locally and nationally, so that they can focus on the important things, like getting well.

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# FOREWORD



When the doctor says cancer it changes your life in an instant, particularly if you are young or your child is young. The financial impact of cancer begins immediately after diagnosis with

income often going down as time is taken off work, or jobs are left, and costs rise in front of your eyes. With treatment usually beginning straight away and often many miles from home, the immediate financial and emotional costs start to spiral. The financial costs of cancer continue to grow throughout treatment, and with cancer treatment often lasting up to three years, the impact on family finances can be nothing short of devastating.

CLIC Sargent has long been aware of the extent of this problem, having undertaken research on the costs of cancer in 2006 and 2011. Given changes in both the economic climate and the welfare system since our last report in 2011 (*Counting the costs of cancer*), we've updated our research to get a measure on the financial impact of cancer today on young cancer patients and their families.

Looking at the results of our research, I'm extremely concerned that parents are spending **an average of £600 a month extra** during active treatment on expenses due to their child's cancer, with the equivalent figure for young people around £360 a month. At the same time, incomes are decreasing with two in five (42%) parents telling us they

stopped working as a consequence of their child's cancer, and a fifth (19%) took over a year of unpaid leave. Young people are also forced to give up work or delay their studies, with their costs mounting up as they undergo treatment.

The biggest monthly expenses for families were travel, food and parking with energy bills and car-related costs also causing a great deal of worry. Three in five parents (61%) told us they had built up debt as a result of their child's diagnosis, with one in six (17%) having borrowed over £5,000.

The pressure of managing finances causes considerable stress and anxiety during what is an already impossible time for families.

**We don't believe this is right or fair for young cancer patients and their families.**

We want to see governments across the UK review travel assistance and support for energy bills available to young cancer patients and their families. We believe they should be given free or reduced hospital car parking in England, in line with other UK nations. And we ask energy companies and financial institutions to ensure their vulnerable customer policies include young cancer patients and their parents. We believe these changes will help alleviate the financial impact of childhood cancer on the thousands of families going through it every year.

Our social care professionals do an exceptional job of supporting young cancer patients and their families soon after diagnosis. They provide emotional support, as well as helping them apply for

benefits and grants, including the £170 CLIC Sargent grant to help them cover some of the initial upfront costs. Thanks to the generosity of our supporters, this year we've helped around 7,100 young cancer patients and their families. But, currently, we can only reach two out of the three young people who need our support. We want to be there for every single child or young person with cancer, and their family, for as long as they need us, so we can limit the damaging impact of cancer on their lives.

We hope our report, published during September's *Childhood Cancer Awareness*

*Month*, will help raise awareness of the impact of cancer costs on young cancer patients and their families. We'll be working with government and the NHS to take forward our recommendations around travel, hospital car parking and access to support to help ease some of the financial burden on families and help give young people, and their families, the best chance from the start.



**Kate Lee**

Chief Executive, CLIC Sargent



# EXECUTIVE SUMMARY

Undergoing cancer treatment is a difficult and isolating time for young cancer patients and their families, with their ability to cope often seriously affected by the financial pressures of a diagnosis. There is limited research on how cancer treatment affects young people and their families financially. However, previous work by CLIC Sargent has shown that families are under great financial pressure during this time, and that this can cause significant stress and anxiety. In the current economic climate and with changes to the welfare system ongoing, CLIC Sargent set out to investigate the current situation, including what support is available, and how families cope with the costs of cancer. 149 young people and 279 parents completed our online survey.

## Financial pressures

We found that parents spent an average of £600 in additional expenses a month as a result of their child's active cancer treatment. The top three expenses were travel, extra food, and other extras like toys and treats. For young people who were financially responsible for themselves, the top three costs were clothing, travel, and extra food costs, with average additional spend during active treatment coming in at around £360 a month. As families often have to travel many miles to access specialist treatment, at a time when income is already severely affected by an inability to work, we recommend that:

■ The government should conduct an urgent review of all travel assistance available to parents and young cancer patients, and make recommendations for reform by the end of 2017.

■ Transport companies should explore how they can support young cancer patients and their families who are struggling with travel costs.

Hospital parking was also a considerable cost for those living in England, costing parents an average of £44 a month. Although some exemptions are available at different treatment hospitals, almost a third of parents (29%) were not offered parking exemptions at their main treatment hospital. We recommend that:

■ All young cancer patients and their parents who visit hospitals in England should be given free or reduced hospital car parking, in line with the other UK nations. The concessions should be publicised so that people are aware of them.

Families were under great financial pressure, with three in five parents (61%) finding themselves in debt as a result of their child's treatment, with one in six (17%) borrowing over £5,000. We recommend that:

■ Financial services and energy companies should review their vulnerable customers' policies to ensure they include parents of children with cancer and young cancer patients.

## Getting support

Almost three in five (58%) parents who responded to our survey found applying for Disability Living Allowance (DLA) stressful, and around three-quarters (73%) of young people found applying for Personal Independence Payment (PIP) stressful, with most requiring help from our CLIC Sargent social care professionals to complete the form. We recommend that:

- The government should improve support for young cancer patients and their parents when applying for PIP and DLA, including providing training for all relevant DWP staff.

Parents and young people also told us how long they had to wait before they were able to receive financial support, at a time when costs rise and income declines. We recommend that:

- Immediate financial support from the point of diagnosis should be available for parents and young people to bridge the gap between experiencing symptoms and the three months' time limit when they can apply for benefits.

## Impact on employment and education

As a result of their child's cancer diagnosis, two in five (42%) parents stopped working, half (49%) experienced a loss of earnings, and almost a third (29%) felt they were able to do less at work. We recommend that:

- Employers should promote a range of mutually beneficial options available for parents with a caring role. These should include paid leave, flexible working, career breaks, bereavement leave, and practical support at work.

## Coping with the costs

The top three financial worries for parents were energy bills, car-related costs and parking. During treatment young people often spend large periods of time at home and are also often more susceptible to the cold due to treatment side-effects and a weakened immune system. Consequently, we recommend that:

- The government should review the financial support available for young cancer patients and their parents who are struggling to meet the costs of their energy bills.

## Campaigning for change

CLIC Sargent believes that all young cancer patients and their families should receive the financial and emotional support they need to cope with the impact of cancer, at every stage of their journey. We will continue to work with government, NHS leaders and other charities to campaign and lobby for these changes to happen.

We want to give all young cancer patients the best chance from the start, from diagnosis, through treatment and beyond. Together we can ensure no child or young person has to go through cancer alone.



# INTRODUCTION

Every year in the UK around 1,600 children aged 0 to 14 and 2,200 young people aged 15 to 24 are diagnosed with cancer (CRUK, 2015a; 2015b). Treatment usually starts straight away and can last up to three years. The different treatments used are as varied as cancer itself. They may include therapies such as surgery, chemotherapy, immunotherapy, radiotherapy, and other less common treatments which are sometimes used alone or in combination, depending on the type and stage of the cancer.

Cancer treatment has a wide ranging impact on children and young people. They may experience physical effects such as nausea, fatigue, dealing with infection risk, loss of appetite, and emotional effects such as loss of confidence, anxiety, depression and altered body image. In addition to the physical and emotional effects, they are likely to experience considerable disruption to their schooling, home and social life (CLIC Sargent, 2012; 2013a; 2013b). Those who stay in hospital for any length of time have to cope with staying away from their homes, friends and family. Cancer treatment also causes a number of financial costs for young cancer patients and their families.

There is limited research exploring the financial costs relating to cancer in children and young people, particularly in the UK. However, there is a small but growing body of literature exploring this issue, which CLIC Sargent has and continues to take an active role in developing. In 2006 Eiser and Upton carried out research for CLIC Sargent which found that cancer has a significant adverse financial impact on families. The research highlighted the expenses incurred, how they were exacerbated

by parents' lost income and limited sick pay, as well as wider ranging consequences, including using savings and borrowing money.

In our 2011 report, *Counting the costs of cancer*, we set out to update and build on this work, furthering our understanding of the financial costs many families and young people have to bear as a result of a diagnosis. The report concluded that the unexpected costs of caring for a child with cancer had a profound impact on a family's financial resilience. The additional expenses were a significant extra expenditure, making a real impact on family finances, and few families were able to cope without some form of additional financial support.

Research with adult cancer patients has found that many dealing with financial problems as a result of cancer are worse off because of their diagnosis (Macmillan, 2012a). In fact, Macmillan (2016) found that four in five cancer patients (83%) are hit with an average cost of £570 a month as a result of their illness and may only be left with a disposable income of £365 a month after paying for necessities, resulting in a £200 shortfall.

The additional emotional stress caused by financial pressures has emerged as a significant issue, with research indicating that money worries increase from diagnosis onwards (Eiser & Upton, 2006; CLIC Sargent, 2011) and continue to be a significant concern at a time when families are already coping with other challenges (Miedema et al, 2008). Psychosocial effects such as depression, stress and anxiety have also been reported (Eiser & Upton, 2006).



This is why CLIC Sargent decided to undertake this research which aims to:

- **Update the additional costs facing young cancer patients and their families**
- **Better understand how a cancer diagnosis is disrupting the employment and income of parents, and of young people who are supporting themselves financially**
- **Look into how far the financial support available meets the needs of young cancer patients and their families**
- **Explore the emotional impact of the financial burden of cancer.**

We hope that our findings add to the emerging body of literature demonstrating the financial pressures faced by the families of young cancer patients in the UK, and will help policy makers, health and care professionals and voluntary sector organisations support families and young people to help alleviate the financial burden of cancer treatment.

## CONTEXT

To understand the financial impact, and related emotional stress, for young cancer patients and their families, it is useful to examine the policy and practice context.

### Current economic climate

Financially, times are challenging for many people across the UK. Since 2008 the labour market remains a difficult place, particularly for young people. Recent figures indicate youth unemployment is at 14%, compared to 6% for the total working population (House of Commons Library, 2016). Many people are on zero hour contracts, with less job stability and entitlement to paid sick leave, flexible working and support which can be so vital when they have to take time off work because of cancer treatment.

The effects on everyday pockets can be seen in an increase in the use of food banks (House of Commons Library, 2014), and increases in household borrowing approaching pre-recession levels (BBC, 2015). As a parent or young person who faces supporting themselves and their dependants during cancer treatment, significant time off work or time out of the labour market can be a frightening prospect.

### Access to benefits and support

As part of the government's welfare reform programme, a number of changes have been made to the welfare system. These may have affected the support available to young cancer patients and their families, and further reforms are planned. From autumn 2016 the benefit cap will limit the total

amount of benefits those aged 16 to 64 can receive, potentially affecting families who are in receipt of out of work benefits, such as Employment and Support Allowance (ESA) and Housing Benefit.

The UK government's programme of welfare reform applies to England, Wales and Scotland, with social security in Northern Ireland a devolved matter. However, the government intends to work closely with the devolved administration in Northern Ireland to seek to maintain a single system across the UK. There are also plans for devolved powers to be given to Scotland on welfare issues.

CLIC Sargent has been monitoring the impact of the benefit changes on families and is working with other disability rights organisations, such as the Disability Benefit Consortium, on informing and influencing the government so that changes do not reduce the support available to those who need it.

## Accessing services

The different ways cancer services are accessed have practical implications for young cancer patients and their families. 0 to 18-year-olds are treated in specialist paediatric treatment centres, of which there are 18 throughout the UK. These treatment centres are often many miles from home, but provide improved outcomes as the support is centralised. When it is safe and appropriate, some may be able to receive care closer to where they live, in shared care hospitals. There are also 14 teenage and young adult specialist treatment centres across the UK, providing age-appropriate care for young people. However, many young people choose to be treated on adult wards for practical reasons, such as proximity to where they live.

Most children's wards have space for one parent or carer to stay with their child. This may also be the case on a young person's ward, but is unlikely on adult wards. As specialist treatment centres can be far from home for many families, it can mean regular long distance travel or staying away from home, sometimes for months on end.

Our CLIC Sargent Homes from Home help ease some of the burden for families, providing them with free self-catering accommodation within walking distance of the hospitals. We currently have 10 Homes from Home across the UK with plans to extend this service as funding allows.





# METHODOLOGY

## Literature review and scoping work

A literature review was conducted using a number of sources including CLIC Sargent's internal evidence database and open access journals. Evidence relating to adult cancer experiences, other chronic and long-term illnesses, as well as child and young people specific research was considered and rated according to relevance. Over 30 sources were reviewed initially, with 12 being rated of key relevance.

Workshops with children, young people and CLIC Sargent Young People's Social and Community Workers were used to scope the research and develop the interview schedules and questionnaires. Seven children, two parents, 14 young people and over 30 CLIC Sargent Young People's Social or Community Workers took part in this work.

## Qualitative research

In addition to the scoping work, we conducted five interviews with parents, five with young people and seven with CLIC Sargent Social Workers. Most of the interviews were conducted over the telephone and lasted between 30-60 minutes.

## Online surveys

Two online surveys were designed based on the literature review, and scoping work. Young people, parents and CLIC Sargent staff were consulted on the draft survey questions.

One survey explored the experiences of over 16-year-olds who have, or had, cancer before the age of 24. The other was for parents financially responsible for a child or young person who has, or had, cancer under the age of 24.

## Limitations of our research

Our surveys provide a snapshot of experiences. Participants were self-selecting and are therefore not necessarily representative of all young cancer patients and their families. However, given the rarity of childhood, teenage and young adult cancer, we believe we have consulted with a significant proportion of this population. Many of the accounts of experiences of treatment were retrospective, and therefore reliant on memory, and may have been affected by subsequent experiences.



## The survey respondents

A total of 149 young people and 279 parents completed the survey, recruited through CLIC Sargent's networks, care professionals and social media. All percentages reported are drawn from the number of people who answered each question, not the total sample size. The majority of young

people had finished treatment at the time of completing the survey – most between two and four years ago, with most between 22 and 24 years old.

The majority of parents reported that their child had finished treatment between six and 12 months ago, with most of the children under 11 years old.

## Jo's story

Jo's son was 7 when he was diagnosed with T-Cell Acute Lymphoblastic Leukemia. Now, two years into his three and a half year treatment, she shares their story.

"We are 99.99% sure your son has cancer" will echo in my mind forever when summoned to our GP following a blood test. His next words were "You will need to go straight to hospital and you don't know when you are coming home". He might as well have added that your current life ends here and you are about to step on to the longest scariest rollercoaster of your life.

Having a child with a life threatening illness changes your life forever. The impact affects not only the child with cancer but siblings and the rest of the family. After two and half years of riding this rollercoaster I've become so familiar with the medical side of cancer. However, the impact it has emotionally and financially are huge. The petrol costs of travelling to and from hospital, extra food, clothes and things to make my son

more comfortable in hospital, increased heating and energy bills at home, having to take time off work, the list goes on.

We met our CLIC Sargent Social Worker three weeks after diagnosis on Christmas Eve. We'd just been told we were being admitted and spending Christmas at hospital. She was a friendly face with time to talk to us and get to know us. Knowing how CLIC Sargent could help and support was one less worry to consider. From receiving our CLIC Sargent cheque on 27 December after completing the form on Christmas Eve, to the phone call to check how we are doing, assisting with lengthy forms that need completing and importantly just being there for us.

This report is only a snapshot of the emotional and financial pressure that families are under every day. CLIC Sargent works with families like mine every day who each have their own stories and also need support and help too.

# RESEARCH FINDINGS

From the day a child or young person gets the shocking news they have cancer the financial impact can be felt immediately. Treatment is often miles from home at specialist treatment hospitals, requiring families to stay away from home for considerable periods of time or to embark on regular long distance travel, sometimes for months or even years (CLIC Sargent, 2010).

Parents or carers may have to take an ever increasing amount of time off work to care for their child, take them to appointments and stay with them in hospital. In between treatment sessions their child may

be able to recover at home but will often need someone there to care for them. Our research findings highlight how these factors combine to create additional stress on young cancer patients and their families.

**"I could have seen us losing our house."**

## Financial pressures

■ Parents we asked spent an average of £600 in additional expenses a month during their child's active treatment.

■ Three in five (61%, n=169) parents had accumulated some form of debt as a result of their child's cancer diagnosis. One in six (17%) had borrowed over £5,000.

■ Almost a third of parents (29%, n=79) were not offered parking exemptions at their main treatment hospital.

As treatment continues and the costs continue to add up, family finances can start to feel the impact of a parent or carer who is no longer able to work, has reduced hours or is on unpaid leave. Because of the impact of treatment, a young cancer patient may need extra clothes, wigs or mobility aids. In between treatment sessions they may be able to recover at home, and with this comes extra costs such as increased energy bills, food and childcare. One parent we spoke to listed their costs:

*"Petrol, travelling to and from hospital; food for the adults as the hospital would feed [my child] but not us; clothes and things to make him more comfortable in hospital; heating bills – when he's at home we have to heat our home more than we would have. We spent £350 during my child's 19 day stay in hospital"* **Parent of a child with cancer**

We asked parents how much they spent on additional expenses incurred during an average month of active treatment (where their child was an inpatient or attending hospital as an outpatient for treatment).

*"In the first month, we spent an extra £600. We could not maintain these costs, our son was in hospital for nearly three months. We were 60 miles from home, had a younger daughter who was not even two and our son had major complications. If it wasn't for the Home from Home, CLIC Sargent and our family, I could have seen us losing our house."* **Parent of a child with cancer**

The top three expenses reported by parents were travel, extra food (in hospital and at home), and other extras like toys and 'treats'. On average parents found they were spending £131 a month extra on travel, £129 on food and £88 on other 'treats' which can help a child or young person cope during treatment. Taking into account the average spend on all the additional costs reported, this amounts to an extra **£600** a month for parents.

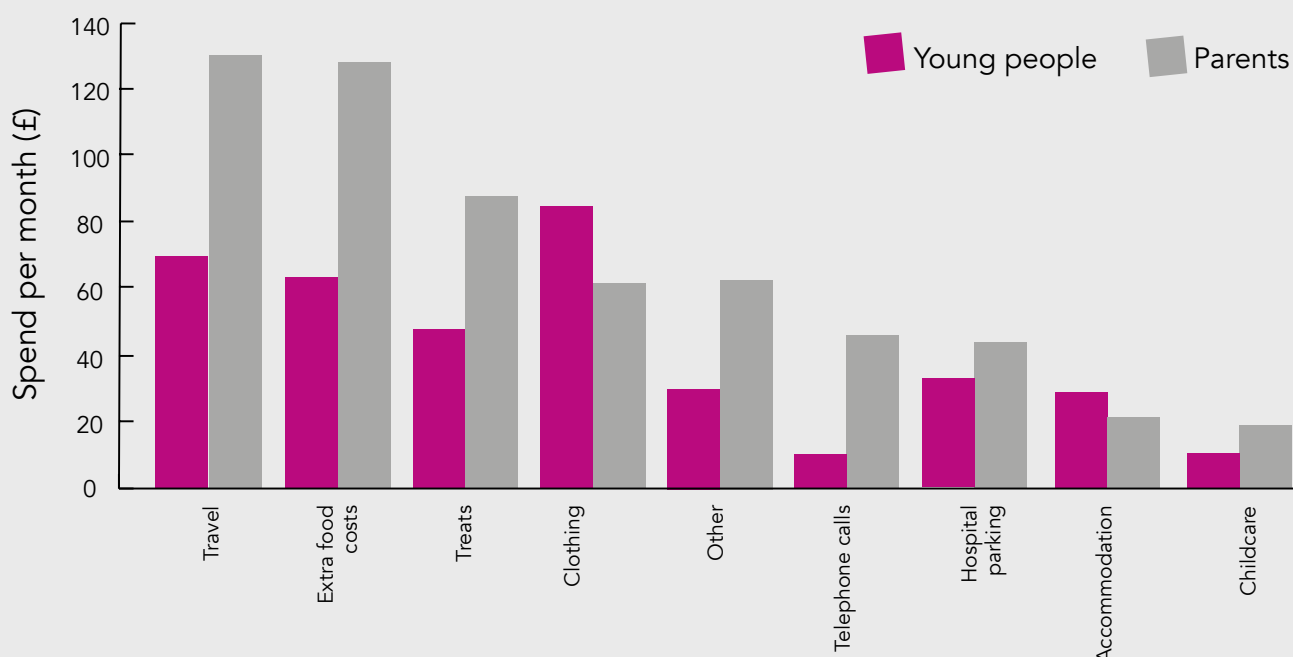
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**PARENTS SPENT**  
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**DURING THEIR CHILD'S**  
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*"We were spending a lot of money in the hospital the first few months as we practically lived there...they (the government) just don't realise how much more you spend, you can spend £100 on food in hospital, and obviously there's petrol, if you're running backwards and forwards with appointments."* **Parent of a child with cancer**

Seven in ten (71%, n=103) young people told us they were financially supported by their parents during treatment, despite three-fifths (61%, n=89) being over 18 when they were diagnosed. At a time when peers are starting to gain financial independence, young people with cancer are forced to delay moving on to this stage of life, with parents continuing to shoulder the financial responsibility for their grown up children longer than they might otherwise have done.

**Figure 1**

**Average additional spend per month during treatment**





*"I missed the money when I wasn't working...I was lucky because I live at my mum's so I didn't pay her keep while [treatment] was happening. So it's been OK."*

#### **Young person with cancer**

Only a quarter (23%, n=33) of young people considered themselves 'financially responsible for the majority of expenses during treatment' or shared responsibility with their partner. For these young people the top three expenses were clothing (£86), travel (£74), and extra food costs (£64).

When combined with other costs associated with their cancer, this amounts to an additional extra spend of around £360 a month.

Considering the relatively small sample size for these questions (n=33), findings are illustrative rather than representative.

These are significant costs for young people at a time when many are not working, or on relatively low incomes, in a transient labour market.

## **Travel and parking**

*"We travel about 45 miles each way [to hospital] and it has been a lot of journeys, at one point when [my child] had a lot of spells in hospital we were driving up and down once or twice a day, because we had [our other child] at home. And even now we're up there once a week."* **Parent of a child with cancer**

With many families travelling long distances to get to specialist treatment centres or hospitals, it is not surprising

that travel costs are a top expense for both parents and young people. Our previous research found that the average distance travelled by road is 60 miles. But for many families it can be a lot more. In our report *A long way from home* we reported that one family had a round trip of 902 miles to get treatment (CLIC Sargent, 2010).

Public transport is often not an option as a young cancer patient's immune system can be compromised due to their treatment. A reliable car is often essential. Repairs, new tyres and breakdown cover are expensive, and UK petrol prices are some of the highest in Europe. Parents on a low income and/or in receipt of certain welfare benefits (e.g. income-based Employment Support Allowance, Jobseeker's Allowance or Universal Credit) can claim a refund of reasonable travel costs under the Healthcare Travel Costs Scheme (HTCS) in England. However, many do not know about the scheme, as the quote below illustrates.

*"It is a lot, apparently you can claim some back, but we've been doing this for a year and a half and it has cost a lot of petrol, because it's nearly a 100 miles round trip. At the start it was once or twice a day and it hit us really hard."*

#### **Parent of a child with cancer**

Hospital car parking can also be a significant extra cost for families. In Wales and Scotland hospital parking has been free in most hospitals since 2008, and in Northern Ireland parking is 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, 2012b).

Parents and young people responding to our survey from England reported paying an average of £44 (n=207) and £37 (n=28) respectively, a month, on hospital parking during treatment.

**Three in ten parents from England (29%, n=79) said their hospital had not offered them parking fee exemption or concessions.**

## Food

Meals are provided for inpatients in hospital but are usually not provided for parents who may have to purchase food in a hospital shop or canteen, which can be more expensive than shops outside of the hospital. Some parents told us that their hospital gave them meal vouchers, but this was not the case for everyone.

*"We took sandwiches in when we could, because sometimes [my husband] would have to stay in longer than expected with our child. The meal vouchers the hospital gave us were really useful."* **Parent of a child with cancer**

Children and young people told us that they often did not like hospital food, so their parents ended up buying them additional food to ensure they were eating. Treatment usually affects taste buds and the ability to eat, and steroids often increase appetites or trigger food cravings. One young person explained how food was a major issue during treatment:

*"Because you don't have any control over anything, food and what I ate was something I could control. I became very picky."*

### Young cancer patient

On average, our survey found that parents were spending an extra £129 a month on food during treatment, with two-thirds (67%, n=181) spending £75 and above, and nearly a third (31%, n=83) spending £150 extra a month.

*"Because of chemotherapy they don't want to eat a lot and when they do eat you just want to buy whatever they want, just to try and keep his weight up."* **Parent of a child with cancer**

*"I had to buy lots [of food] because of the mouth ulcers and stuff like that. Because of the problems with her digestive system we had to try buying all these different things they recommended to see which ones worked, so at one stage it was costing a fortune."* **Parent of a child with cancer**

Our survey indicated that food costs are a significant extra cost. However, these costs are made up of the many factors mentioned above – food for parents in hospital, inability to plan for food shopping and the impact of treatment on appetite and tastes. Without more research it is difficult to say exactly how each of these things adds to the household food budget or make policy recommendations to address these. However, things that may help to alleviate costs are:

- Hospitals make sure that parents know about available food preparation areas
- Hospital Trusts looking at pricing in hospital shops, particularly for food
- Hospital Trusts reviewing their policies on who is entitled to food vouchers.

Our conversations with parents suggest that some of this support is being offered to some parents, but not all.

## Treats

In our survey we asked parents and young people how much they spent on treats during treatment. This was the third highest cost for those who completed our survey and includes items such as magazines and books, games and larger value items like tablets or technology. From our interviews with parents and social workers, it emerged that to call such items treats does not perhaps do justice to the importance of all the little (and often big) things that parents buy their children to help them cope during treatment. These items can often be a lifeline for those spending long periods of time in hospital, away from family and friends.

*"Parents often have to buy treats for their children to cheer them up and the hospital shop can be very expensive."* **CLIC Sargent Social Worker**

*"We had to eat into our savings but you will do anything to keep your child happy during such a horrendous time."* **Parent of a child with cancer**

We know that loneliness, isolation and feeling down can be issues for young people during treatment. In our discussion groups and interviews, young people told us that even something as simple as hospital Wi-Fi can make it easier for them to 'get through' during long periods of boredom and isolation during treatment, as it can allow them to communicate with friends or other cancer patients whilst in hospital.

## Clothing

Parents told us that when their child went into hospital for treatment they had to buy appropriate clothes like pyjamas, or other comfortable clothing.

*"He needed all new clothes, pyjamas etc. that would accommodate the medical procedures – like his Hickman line."* **Parent of a child with cancer**

Frequent changes of clothing are sometimes needed due to side effects of treatment (for example vomiting or diarrhoea), and being away from home with limited access to washing facilities and having to regularly buy new clothes. Children and young people's weight often fluctuates as a result of treatment, with chemotherapy often leading to weight loss or steroids leading to weight gain. One young person said "because of the weight gain with the pills I take, I had to get a whole new wardrobe."

Parents reported spending an additional £61 (n=250) a month on average on clothing (including wigs), and young people who were financially responsible for themselves spent an average of £85 (n=32) on clothing.

## Accommodation

Being treated far from home not only adds to travel costs but also to the need for overnight accommodation. Around a third (35%, n=96) of parents stayed in a CLIC Sargent Home from Home during treatment, with the average stay between four to eight weeks. This saved them money at a time when every penny mattered. Staying in a hotel near Bristol Children's Hospital, for example, for this amount of time could cost between £2,100 and £4,200.

CLIC Sargent's 10 Homes from Home give families a free place to stay close to principal treatment centres in Bristol, Edinburgh, Glasgow, London, Belfast, Nottingham, Oxford, and Southampton. Other charities also help families stay near their children in hospital, and some hospitals offer free or reduced nearby accommodation.

*"CLIC Sargent Homes from Home and Ronald McDonald House helped us a lot as we could be a family, especially when my daughter had radiotherapy and was not an inpatient as it would have been a 200 mile round trip each day."* **Parent of a child with cancer**

## Borrowing and debt

Meeting the mounting costs of cancer can be difficult for many parents

and young people. 61% (n=169) of parents reported borrowing money or accumulating debt to make ends meet. More than two in five parents (44%, n=75) had borrowed against a credit card and two-thirds (66%, n=112) had borrowed money from family or friends.

A further third (34%, n=58) used their bank account overdraft facility to try and cover costs during their child's cancer treatment. Of the three in five (61%, n=169) who borrowed money, a quarter (24%, n=41) borrowed up to £500, two in five (39%, n=66) between £501 and £2,000 and one in five (20%, n=34) borrowed between £2,001 and £5,000. A further one in six (17%, n=28) borrowed over £5,000.



## Single parents

The cost of childhood cancer is likely to be felt even more by single parent families. A fifth (19%, n=43) of parents who completed our survey said they were single parents, divorced or separated. While this is a small number of responses, data can be seen as illustrative of the issues faced by single parents and those with less financial support. Almost three quarters (72%, n=32) of single or separated parents were employed before their child's diagnosis, falling to three-fifths (58%, n=25) at the time of completing the survey. This is a bigger drop than for all survey respondents as a whole.

Two in five (48%, n=12) reduced the hours they worked, with a similar proportion (46%, n=13) having experienced a loss of earnings. The same proportion (42%, n=12) stopped working completely. Our results suggest that single parents took less time off work – perhaps having to choose between spending time looking after their child or losing their only source of income. A higher proportion of single and separated parents were in debt (70%, n=30 vs. 61% for all respondents), with four in five (80%, n=24) borrowing mostly from family and friends.

*"I am really struggling financially, I'm getting by but it's really really tight and before that I was comfortably off... I'm a single parent and the buck stops with me financially. I've got to make sure I keep a roof over my child's head."* **Parent of a child with cancer**

## Getting support

■ Three in five (58%, n=91) parents found the process of applying for DLA stressful, and four in five (84%, n=133) needed help to complete the application form.

■ Around three-quarters (73%, n=49) of young people found applying for PIP stressful, with around four in five (84%, n=56) needing help to complete the form.

## Accessing benefits

One of the main benefits available for children with cancer under 16 is

Disability Living Allowance (DLA), a non-means tested benefit for people with health conditions to help with additional costs. Formerly available to both children (via their parents) and young people, this benefit is now only for children under 16. Young people over 16 are expected to apply for Personal Independence Payment (PIP). The application forms for DLA and PIP are over 30 pages long, and you can only apply after three months of symptoms, despite a diagnosis having an immediate impact as costs begin to mount up from day one.

Almost all parents (91%, n=158) who completed our survey had applied for DLA and nearly all of those (97%, n=154) were successful in their application. Almost three in five (58%, n=91) found the application process 'moderately' to 'very' stressful and four in five (84%, n=133) needed help to fill out the forms. 82% (n=98) of parents received help from a CLIC Sargent Social Worker to complete the form.

Forms were often completed at a time when parents or young people were still in a state of shock after their recent diagnosis. Respondents said they struggled to think clearly.

*"I can't remember how long we waited to find out, that period is a blur. It was extremely stressful. I found the forms too long, complicated and like a hoop to jump through. My son was very very ill and I didn't have the clarity for it... you should just be able to write the diagnosis and get the money automatically. It feels like they don't want you to apply."*

**Parent of a child with cancer**



*Without [my CLIC Sargent Social Worker's] guidance and support I don't know where I'd be, she was so valuable. She knew all of the benefits we could claim, she helped us sit down and fill in the form for DLA. That form is a complete and utter minefield, but she was so good. It must have taken us well over an hour to work out what should go in... Without the help I wouldn't have had a clue where to start."* **Parent of a child with cancer**

Almost half (46%, n=67) of young people who responded to the survey had applied for PIP, with three quarters (76%, n=51) of those applications successful. Around three quarters of young people (73%, n=49) found the process 'moderately' to 'very' stressful and around four in five (84%, n=56) needed help to fill in the forms. Around two-fifths (38%, n=21) had help from their CLIC Sargent Young People's Social or Community Worker and around a quarter (23%, n=13) had help from family or friends.

*"It is extremely long-winded and tedious to complete."* **Young person with cancer**

*"It would have been stressful if we hadn't had help from a CLIC Sargent Young People's Social Worker."* **Young person with cancer**

Parents told us they waited six weeks on average for a decision about their application, four weeks for a decision about an appeal, and five weeks to receive money after a successful

application. Young people waited eight weeks on average for a decision about their application, four weeks for a decision about an appeal, and three weeks before receiving any money once their application was successful. Both parents and young people told us how difficult the wait for government support was.

*"You're thrown into turmoil and get absolutely no support from the government. It's shocking you know, the Disability Living Allowance. You've got to wait three months of your child being ill before you get it... it's the first three months when it matters, when you have to buy stuff for hospital and whatever else."*

**Parent of a child with cancer**

Parents and young people who responded to our survey also reported that their household was receiving a range of other benefits, with the top three for parents being Working Tax Credit (30%, n=46), Family Tax Credit (47%, n=73), and Carer's Allowance (58%, n=90). The top three benefits reported by young people were Employment Support Allowance (47%, n=34), Working Tax Credit (23%, n=17), and Carer's Allowance (14%, n=10).

These benefits are often a lifeline for families, providing some sort of income, however small, to help them cope with increasing costs and falling incomes. However, often these benefits aren't able to cope with fluctuating or complicated circumstances. In our previous research young people studying at university raised issues around how student status can affect benefits eligibility (CLIC Sargent, 2013b). One young person we spoke to told us:

*"I was forced to suspend my studies as I wasn't allowed to attend university for almost a year and a half due to infection risks and being too poorly. This was really hard for me emotionally and financially. My CLIC Sargent Social Worker did a lot of the hard work contacting my university to suspend my studies and phoning student finance. I was expecting to lose my student loan but it was a real fight to get ESA as they still considered me as a student despite me having no income."*

#### **Young person with cancer**

It is likely that in future young cancer patients and their families may be affected by the benefits cap, placing greater pressure on finances. Some young cancer patients may be affected by changes to Employment and Support Allowance (ESA), to be introduced from April 2017, which will see new claimant's payments to the ESA work-related activity group (WRAG) fall by £30 a week. This could have a real impact on some young cancer patients, many who will be struggling with fluctuating health conditions, coping with pain and fatigue or recovering from illness.

### **Other financial support**

Parents and young people reported receiving a range of financial support from charities and other organisations. The top three for parents were a CLIC Sargent grant (68%, n=179), a holiday (45%, n=117), and a special outing for their child (31%, n=80). For young people they were: a CLIC Sargent grant (71%, n=96), a grant for wigs (33%, n=45) and a special outing (27%, n=37).

*"[Our CLIC Sargent Social Worker] knew of other grants that we could apply for and the help that you could get with the day to day things. There were organisations that I'd never heard of, and there were other grants we claimed."*

#### **Parent of a child with cancer**

Even with benefits and other financial support, almost half (45%, n=125) of parents and a quarter of young people (23%, n=33) said they had a shortfall between their income and outgoings due to the additional costs of cancer.

#### **On average, parents said this shortfall was £407 a month.**

Some young people at university told us that their student loans were an invaluable source of income to cover the costs associated with their treatment, although they do need to pay this back at a later date and may need an extra year's loan if they defer.

*"If it hadn't been for my final term's student loan coming in the day I was diagnosed and admitted to hospital, I wouldn't have been able to afford anything I needed or to help pay for my mum and sister's petrol to visit me (they lived two hours away). That money quickly disappeared. We were so grateful to get a clothing grant as I had to buy so many new pyjamas as I had to have a clean pair on each night I was staying."* **Young person with cancer**



## Impact on employment and education

■ As a result of their child's cancer diagnosis, two in five (42%, n=78) parents stopped working, half (49%, n=90) experienced a loss of earnings, and almost a third (29%, n=55) felt they were able to do less at work.

■ A fifth (19%, n=28) of parents who were employed at the time of diagnosis took over a year of unpaid leave during their child's treatment.

One of the first things a parent in employment will have to do is tell their employers that their child has cancer and that they will need to take time off work. At this time they are unlikely to know how much time they will need, or for how long this will continue. Over three quarters of parents (77%, n=166) said that they found their employer helpful when their child was first diagnosed. However, during treatment this fell to just over two thirds (67%, n=184).

*"It's very scary at the start. My employers pressed for a return to work date at the start of my son's treatment, which was impossible to give."* **Parent of a child with cancer**

*"I had to leave my job where I'd been for 17 years, they were very supportive for six months but our child's treatment lasted nearly a year."* **Parent of a child with cancer**

Depending on the terms of their employment, much of the time parents take off can be unpaid. Two thirds (66%, n=99) of parents who were employed at the start of their child's illness told us they took unpaid leave as a result of the cancer diagnosis. Of these, around a quarter (23%, n=35) took between two weeks and four months' leave, and **one in five (19%, n=28) of those took over one year of unpaid leave.** Three in five parents (60%, n=84) took sick leave, with a third (31%, n=44) of those taking between two and six months, and one in six (15%, n=21) took between seven months and a year's sick leave.

In 2015/2016 CLIC Sargent gave £1.11 million in grants to help young people and families cope with the extra costs of cancer, and secured £1.6 million of benefit entitlements. We also provided 1,339 families with free accommodation at our 10 Homes from Home.



Many parents also told us their doctor signed them off with anxiety or home/family related stress.

*"If I had gone in [to my employer] and said 'my son is not well I need time off' it would've been unpaid...but my doctor said 'you're going off with stress' so... they paid ok and eventually I ended up with half pay, because of the amount of time."* **Parent of a child with cancer**

Half of parents (49%, n=90) told us they had experienced a loss of earnings, and two in five (42%, n=78) had stopped working altogether. Almost a third (30%, n=56) had reduced the number of hours they worked, or felt they had become less able to do their job as a result of their child's illness (29%, n=55). Half of parents (52%, n=119) also said that their partner's employment was affected by their child's diagnosis.

# 42%

OF PARENTS

**STOPPED WORK**

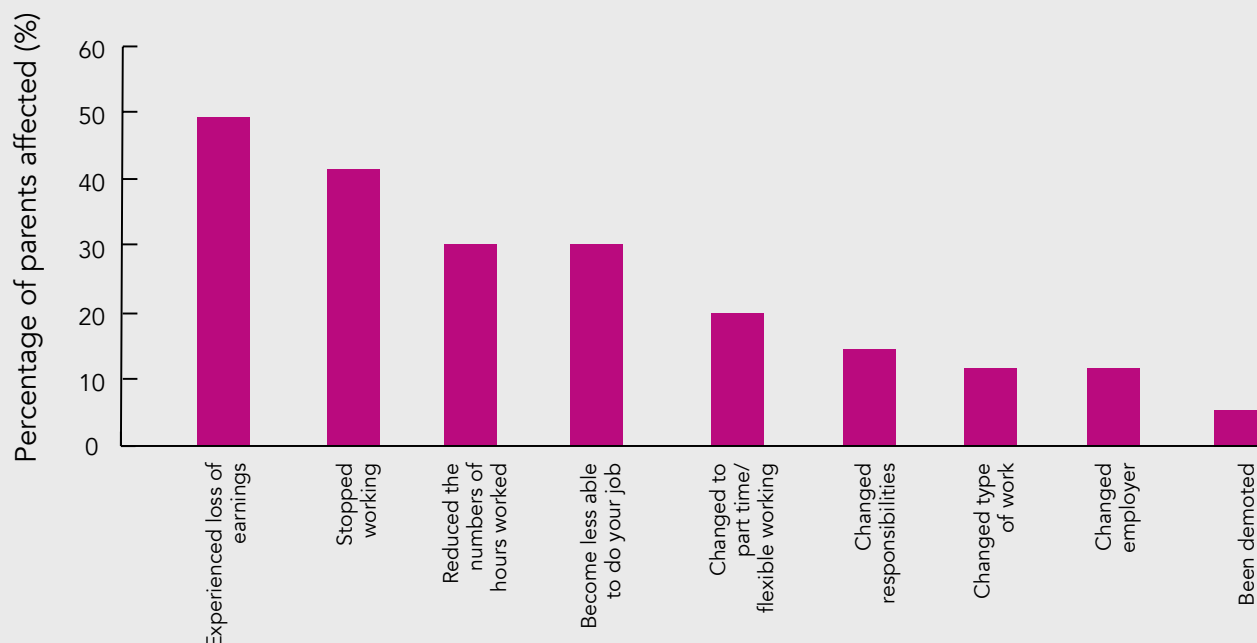
**DUE TO THEIR CHILD'S CANCER TREATMENT**

Four in five (79%, n=219) parents told us they were employed when their child was diagnosed. This dropped to 67% (n=184) at the time of completing the survey. With 58% (n=161) of parents who completed the survey also reporting that their child's treatment had finished, this suggests the impact on employment, and therefore income, can be long-lasting.

Part of the vital support our CLIC Sargent Social Workers offer is assistance with talking to employers and helping parents and families explore flexible working options, as well as understanding their employment rights.

**Figure 2**

**Impact of cancer treatment on parent's employment**



## Young people's employment and education

CLIC Sargent's *No young person with cancer left out* (2013) highlighted the significant impact of cancer on a young person's education, training and employment. The research indicated that cancer presents significant barriers to young people progressing as their peers without cancer might do. Three in five (61%) agreed that having cancer had presented barriers to their education and over two thirds (67%) said they were worried about the impact it would have on their education in the future. Almost three quarters (74%) were worried about the impact cancer would have on their future employment, and over one third (37%) said that having cancer presented barriers to finding a job. One in three (33%) also said that having cancer made it hard to keep a job.

*"They sacked me because I was poorly and then I couldn't claim any sort of benefits to help pay my mortgage or any of my bills."*

### Young person with cancer

The current research findings suggest these remain key issues and concerns for young people. In particular, the long-term side effects of treatment can impact a young person's ability to study or work:

*"I'm on disability benefits. Hopefully one day I'll feel capable of going to work, but just now it wouldn't be practical because I could be working and then all of a sudden...I just stop being able to do anything and I need to go and lie down for a couple of hours."* Young person with cancer

Half of young people surveyed (49%, n=71) were employed when they were first diagnosed, and of those, half (49%, n=35) were signed off work during treatment. Around two in five (38%, n=27) gave up work during treatment, with only one in ten (11%, n=8) able to continue in their employment in a reduced or flexible way.

Two in five (43%, n=39) reported that as a result of having cancer generally (i.e. not just during treatment) they had stopped working and slightly fewer (38%, n=34) experienced a loss of earnings. A further third (31%, n=28) had changed career.

Almost a third (30%, n=27) of young people had reduced the number of hours they worked during treatment or had changed to part time/flexible working arrangements (30%, n=27) and one in six (13%, n=12) changed responsibilities.

Given the physical and emotional impact of cancer treatment, changes to working patterns and responsibilities are not surprising. However, almost half of our respondents (48%, n=70) were not employed at the time of completing the survey, which given that three-quarters (77%, n=114) had finished treatment, might suggest that many are unable to work or find work long after diagnosis.

Around half of young people (47%, n=68) were in higher or further education at the time of diagnosis and around half (46%, n=31) chose to defer or suspend their studies during treatment. **Almost a third (29%, n=20) ended or stopped their studies completely, while one in six (16%, n=11)** continued in a reduced or part time way, and one in ten (9%, n=6) continued studying mostly in the same

way. For the 29% who had stopped their studies, there is also a potential life-long financial impact as they may have missed out on qualifications that could have provided opportunities to receive greater pay.

*"I am concerned about the long-term financial implications of my child having missed out on education. Access to higher education, and some career options may now be difficult."*

**Parent of a child with cancer**

## Coping with the costs

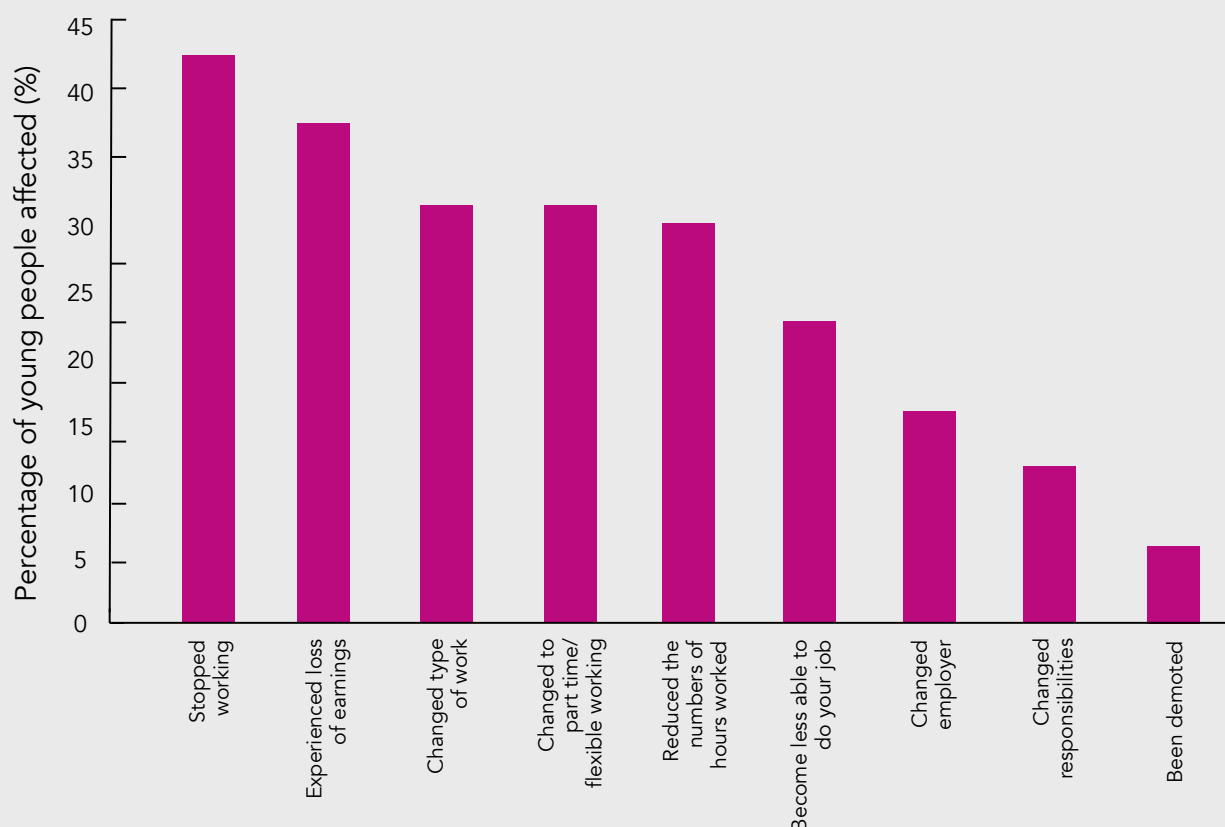
■ Three-quarters (76%, n=183) of parents and over half (54%, n=78) of young people felt that managing their finances during treatment caused them additional stress and anxiety.

■ Money was a concern for 5% (n=13) of families before cancer, rising to 59% (n=145) during active treatment.

## Specific financial concerns

Parents who responded to our survey had a range of financial worries related to their child's cancer. The top four were travel (51%, n=96), car-related costs

**Figure 3**  
Effect on young people's employment







(47%, n=90), energy bills (45%, n=85) and food (43%, n=84). For young people who were financially responsible for themselves the top three costs were energy bills (50%, n=12), travel (50%, n=12) and food (46%, n=11). These correlate to the most costly expenses for families during cancer treatment.

*"The electricity bills and gas bills more than doubled, going from no one at home in the day to having the electricity and gas fire on constantly due to my child being ill at home."* **Parent of a child with cancer**

*"When your child is in hospital car park charges must be taken into consideration. We were there about seven weeks in total for treatment, that's 35 days' fees. We then attended another hospital as an outpatient for five weeks of radiotherapy – more fees. Add to that petrol, a good reliable car to*

*be used, we in fact bought a new car for this reason – more cost."*

**Parent of a child with cancer**

A total of 27 bereaved parents responded to our survey. Many told us that funeral costs were a significant financial concern for them. For some, this may come after a long period of treatment, remission, relapse or repeated relapses, and hit them at the point that they are already deep in debt. The needs of this group were not explored in detail for this research, but we recognise this is work that should be taken further.

*"If it hadn't been for my son's sport's team I would have had to pay for his funeral, but because of the fundraising that they did, that's how the funeral got paid for. Families have to pay for funerals, and the cheapest you're talking is £4,000."*

In 2015 we carried out a small survey and asked our health and care professionals about funeral payments. Over half (55%, n=18) reported that the average cost of a funeral in their area was £2,001-£3,000. Many had helped families claim for support for funeral costs from the government's Social Fund, although they felt this process was far from ideal and tried to make use of other charities that offer similar support. They highlighted the extreme emotional stress on parents of trying to find money for their child's funeral, at a time when they are already struggling financially and suffering the devastating loss of a child.

We believe that support for funeral payments should reflect the real costs of a funeral and welcome many of the recommendations outlined in the recent Work and Pensions Select Committee Inquiry into Support for the Bereaved

(House of Commons Work and Pensions Committee, 2016).

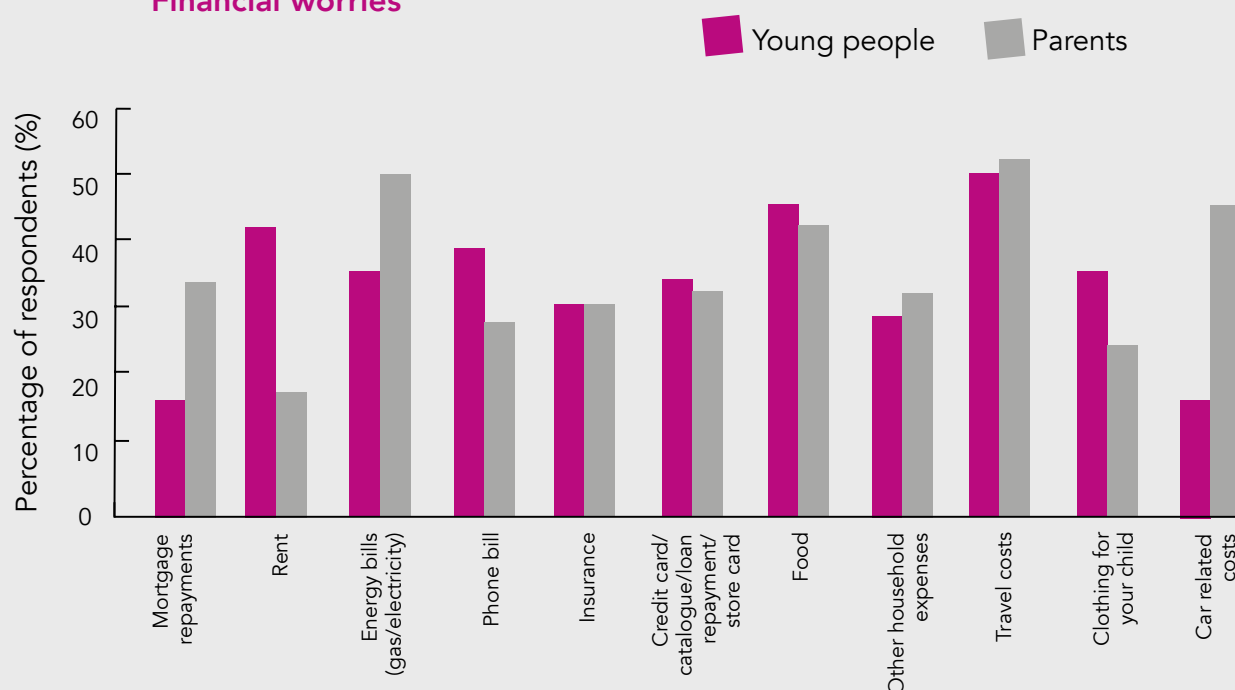
## The emotional burden

The financial burden of cancer can have a significant emotional impact on families, adding to the stress and worry which comes with a cancer diagnosis and its treatment, particularly if the prognosis is uncertain.

*"It was a lot, because you have to take into consideration you're dealing with an awful lot of information to start with psychologically, without thinking about all the financial side."* **Parent of a child with cancer**

Before diagnosis only 5% (n=14) of parents and 12% (n=17) of young people

**Figure 4**  
**Financial worries**



said money was often or frequently a particular concern to them and their family. During treatment this rose to 59% (n=161) for parents and 44% (n=64) for young people (an increase of 54% for parents and 32% for young people). This is in line with the finding from our 2011 *Counting the costs of cancer* report which suggests that little has improved.

Two-thirds of parents (65%, n=161) and two in five (42%, n=61) young people agreed that cancer treatment was 'a big problem' for their family finances.

Three-quarters of parents (76%, n=183) and over half (54%, n=78) of young people agreed that managing their finances during treatment had caused them additional stress and anxiety.

Many young people and parents told us that practical support, particularly negotiating what financial support is available, is one of the most important things to help them cope, especially during the early stages of treatment. The help and support from CLIC Sargent social care professionals was greatly valued.

*"As a family when she was first diagnosed, we were in shock, I could barely speak to anyone let alone wade through paperwork and phone calls. Our social worker took care of things such as dealing with the paperwork and calls to my daughter's university. She has assisted us every way she can and we are so grateful."* **Parent of a child with cancer**

*"The cost of having to give up work, drive to hospital, buy all your meals on the go from canteens or cafes, and just centre your life around medical treatment is a huge burden. But I would say the emotional cost is the worst... we still don't know when it'll end. We may need to move house to a home with no stairs because our son is very immobile now. The uncertainty of our future and his is very hard to live with."*  
**Parent of a child with cancer**

The emotional burden of cancer stretches far beyond the stresses and anxieties associated with the financial costs. To get a snapshot of this, and to help us think about the direction of future research, we asked parents and young people to tell us what helped them cope with the emotional impact of cancer during treatment. The top three for parents were feeling included in decision-making (70%, n=159), talking to others with similar experiences (68%, n=154) and keeping in touch with family and friends (67%, n=152). For young people these were keeping in touch with family and friends (80%, n=102), talking to others with similar experiences (73%, n=93) and access to the internet whilst in hospital (72%, n=92).

We recognise that there is so much more that can be said about the emotional impact of cancer and what helps young cancer patients and their families to build and maintain resilience. Our plan is to do future research on this area, exploring the emotional effects both during and beyond cancer treatment.

It is important to acknowledge that some parents, while appreciating the



help CLIC Sargent and other charities provide, needed more support, and for longer. Currently, we are only able to reach 60% of young people but only 60% of young people diagnosed with cancer who may be treated in different hospital settings. We have ambitious

plans to help all young cancer patients and their families, and to raise the funds we need to do this, so that no child or young person has to go through cancer alone.



# CONCLUSIONS AND RECOMMENDATIONS

## The system needs to change to make sure families do not end up with serious long-term financial problems as a result of cancer.

These findings have added to the growing body of literature highlighting the financial impact of cancer on young people and their families. Our report illustrates the significant financial and emotional impact of cancer treatment on families, with cancer costing parents an average of £600 a month.

The main costs of cancer are travel and parking, food, clothing and energy

costs, all of which are a source of concern for those we spoke to. Cancer also has a significant effect on parental employment, with a fifth (19%) of parents telling us they took over a year of unpaid leave during treatment, two-fifths (42%) stopped work altogether and half (49%) experienced a loss of earnings.

Cancer can also have a significant impact on young people's education and employment, not just during treatment. Almost half of respondents (48%) were not employed at the time of completing the survey, which, given that three-quarters (77%) had finished treatment, might suggest that many are unable to work or find work long after diagnosis. For young people the true cost of cancer may also not be fully realised until years

later due to how it affects their education and employment opportunities, and the issues caused by late effects.

Although a number of benefits are available to young cancer patients and their parents the amount received does not even cover basic costs. Parents told us they had an average shortfall of £407 a month as a result of cancer costs.

To make ends meet they told us they had no choice but to borrow money from friends or relatives, or borrow against credit cards or overdraft facilities, with three in five parents (60%) accumulating debt. One in six (17%) had accumulated debt of over £5,000.

Added to this, many found the DLA and PIP forms long and stressful to complete, with four in five (84%) of young people requiring help to fill them out. Parents and young people told us how much help they received from CLIC Sargent through grants, welfare advice and access to support from other organisations, as well as the vital emotional support they felt was invaluable at such a stressful time in their lives.

Despite this help, three quarters of parents (76%) and over half (54%) of young people felt that managing their finances during treatment caused them additional stress and anxiety at a time when they already have so much to deal with.

## Recommendations for change

We believe that all young cancer patients and their families should receive the financial and emotional support they need to cope with the impact of cancer, at every stage of their journey. Our recommendations for change are:

**1.**

The government should conduct an urgent review of all travel assistance available to parents and young cancer patients, and make recommendations for reform by the end of 2017.

**2.**

All young cancer patients and their parents who visit hospitals in England should be given free or reduced hospital car parking, in line with the other UK nations. The concessions should be publicised so that people are aware of them.

**3.**

Transport companies should explore how they can support young cancer patients and their families who are struggling with travel costs.

**4.**

Financial services and energy companies should review their vulnerable customers' policies to ensure they include parents of children with cancer and young cancer patients.

**5.**

Immediate financial support from the point of diagnosis should be available for parents and young people to bridge the gap between experiencing symptoms and the three months' time limit when they can apply for benefits.

**6.**

The government should improve support for young cancer patients and their parents when applying for PIP and DLA, including providing training for all relevant DWP staff.

**7.**

Employers should promote a range of mutually beneficial options available for parents with a caring role. These should include paid leave, flexible working, career breaks, bereavement leave, and practical support at work.

**8.**

The government should review the financial support available for young cancer patients and their parents who are struggling to meet the costs of their energy bills.





CLIC Sargent will continue to work with government, NHS leaders and other charities to campaign for these changes to happen. We want to give all young cancer patients the best chance from the start – from diagnosis, through treatment and beyond – to ensure that they, and their families, are able to stay as resilient as possible. Together we can ensure no child or young person has to go through cancer alone.

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All the charities that helped to promote our survey on social media

All of the CLIC Sargent health and social care professionals who shared their experiences in interviews

All of the CLIC Sargent staff who helped to promote our surveys and arrange our interviews



# HOW CLIC SARGENT HELPS

## ■ When the doctor says cancer

CLIC Sargent is there to help families after they hear the overwhelming news their child has cancer. CLIC Sargent care teams provide expert support tailored to each child, young person and family. They help families navigate the complex world of cancer: this might be through emotional support, information and guidance so families feel less overwhelmed; clinical care to help families deal with cancer treatment at hospital and at home; or specialist play to ease children through treatment.

## ■ There's no place like home

CLIC Sargent nursing teams can provide personal care and support at home, or arrange for treatment to be given closer to home, so families can avoid travel and stay together where possible. CLIC Sargent Homes from Home are havens for patients and families during treatment, reducing the financial cost and emotional strain of cancer so that families can stay together during the toughest times.

## ■ Helping them thrive, not just survive

CLIC Sargent knows it takes a team of professionals working with children and young people to minimise the disruption cancer has on their education, social life and future prospects. Our CLIC Sargent care teams support young cancer patients emotionally – building their resilience so they can continue to learn, regain their confidence and self-belief and be inspired to think beyond cancer. They work with schools on a child or young person's behalf, helping them keep in touch with friends, organising work at home so they don't fall behind or helping schools prepare for when the child goes back to school.

## ■ Cancer costs

CLIC Sargent care teams work with young people and families to help get them financial support. They arrange CLIC Sargent grants and advocate for them to help them get the benefits and other support they're entitled to. We know that the rest of day-to-day life doesn't stop with a cancer diagnosis. CLIC Sargent care teams help liaise with workplaces or sort out housing issues to help families keep on track.

## ■ When a child dies

Hearing your child isn't going to get better and that they are going to die is one of the hardest things any parent will ever have to deal with. Around 500 families hear this unimaginable news every year. We help young cancer patients and families prepare for death, we encourage them to think about how the child or young person can be remembered and help them all deal with their worries. Our care teams provide bereavement support through home visits, local support groups and memory days.

## ■ Making change happen

We fight to create change in health, benefits and wider systems around young cancer patients and their families, so that they get the support they need. We do this through our research and campaigning for policy change. We raise awareness of children and young people's experiences and champion their voices to politicians and decision makers across the UK. We fight tirelessly for young lives against cancer.

We can't provide our vital services  
without our supporters. If you would  
like to donate to CLIC Sargent,  
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