



Counting the costs of cancer

The financial impact of cancer on children, young people and their families.





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December 2011

Summary

Counting the costs of cancer summarises research which shows that many families and young people have to bear significant additional financial costs as a result of a cancer diagnosis. The research builds on previous research conducted by Eiser and Upton in 2006 and takes into account the impact of the economic environment and current government programmes for families and young people.

About CLIC Sargent

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. We provide clinical, practical and emotional support for young cancer patients and their families, from diagnosis onwards.



Foreword



At CLIC Sargent we know cancer costs. This starts at initial diagnosis and lasts throughout treatment. Travel to vital cancer treatment at specialist hospitals which can be many miles from home; additional childcare for siblings while a parent is at their child's bedside; increased food and heating bills are among a few of the costs that families and young people face. And as costs rise the ability to earn can be compromised; treatment can last up to three years and parents may have to reduce their hours, take time off work, often unpaid, or give up a job altogether in order to care for their child. Likewise, young people with cancer often have to give up work or put their studies on hold.

Cancer is a long-term condition but the impact on costs is immediate. Families and young people must be able to access the financial support they need as quickly as possible. We know that families already have to wait before they can claim benefits, and that changes proposed to the benefits system are likely to mean that they will have to wait even longer in the future. This financial impact for families and young people is further compounded by the difficult economic situation in the UK today.

In light of this, CLIC Sargent decided to update research¹ we commissioned in 2006 by carrying out an in-depth study into the financial impact on families following a child or young person's cancer diagnosis. Our findings are drawn from an analysis of data gathered from a survey with parents and young people, as well as focus groups and telephone interviews with parents, young people and our social care professionals.

The research found that on average parents and young people spent £367 and £277 respectively on extra expenses, every month, as a result of a cancer diagnosis and its treatment, and that three in four (76%) families said that childhood cancer had been a 'big problem' for their finances. In addition to mounting expenses, many families are also faced with a drop in income as a result of a reduction in working hours, or having to give up work altogether. More than half (55%) of parents surveyed told us that they had to take time off as unpaid leave, and one in three (34%) took unpaid leave for three months or longer when their child was diagnosed.

"...two in three parents surveyed had built up debt..."

A particularly concerning finding is that two in three parents surveyed had built up debt as a direct result of the additional costs childhood cancer brings. Many families told us how their money

worries nearly brought them to breaking point at a time when they were already dealing with the life-changing impact of childhood cancer.

We hope that this report, published during Childhood Cancer Awareness Month, will help to raise awareness of the impact of the costs of cancer on families as well as drawing attention to the challenges facing young people with cancer.

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

Lorraine Clifton, Chief Executive
December 2011

¹ Eiser, C and Upton, P (2006) Costs of caring for a child with cancer: A questionnaire survey. Child Care Health Development 33: 455-459

Introduction

As the UK's leading cancer charity for children, young people and their families, CLIC Sargent provides clinical, practical and emotional support to help them cope with cancer and get the most out of life. We provide financial support to families and help them to access other forms of support such as benefits. We know from our 2010 Service User Survey that financial concerns are a top priority area.

Every day 10 families are told their child has cancer. Approximately 1,700 children aged up to 15 years and 2,300 young people aged 16 to 24 are diagnosed with cancer each year in the UK with more than 10,000 children and young people receiving treatment at any time.

We also know that there are significant additional costs associated with a cancer diagnosis, like travel and accommodation. Children and young people's cancer treatment usually starts straight away, but so do the side-effects of this treatment and the extra expenses. Some families and young people have to travel for miles for treatment and travel costs can be significant. This is often coupled with a loss of income from one or more parent, or a young person having to give up study or work. Treatment can last for as long as three years and this can create huge long-term financial strains.

'The shock of being told your five year-old son has leukaemia is so stressful. Trying to deal with everyday things is hard, especially if you're kept in hospital for weeks or days. You don't have the time or the strength to deal with money matters, because all that is on your mind is whether your child is going to be OK and live through this, whether he's going to be in hospital again and trying to find extra money for travelling, food and still look after the rest of the household.'

Parent of a child with cancer

Counting the costs of cancer

This report summarises research which found that many families have to bear significant additional financial costs as a result of supporting their child through their cancer diagnosis.

Our study built on previous research conducted for CLIC Sargent by Eiser and Upton in 2006. It takes into account the impact on families of the economic environment and current government reform programmes.

Our research aimed to better understand:

- the additional costs facing families and young people
- how a cancer diagnosis disrupts their employment and ability to earn income
- what financial support is available
- how families and young people cope with the financial impact of cancer.

The research reflects the experiences of young people aged 16-24, as well as parents, to understand the specific issues faced by children and young people with cancer. This report shows that the challenges facing young people with cancer are compounded by the fact that they may be unable to work and have difficulties accessing financial support.

Key findings

More than 330 young people and parents of children with cancer participated in this research.

The key findings are:

- On average parents and young people spent £367 and £277 respectively on extra expenses every month as a result of a cancer diagnosis and its treatment. This amounts to an additional annual spend of £4,400 for parents and £3,325 for young people
- The number of parents who said that money was 'often' or 'frequently' a worry increased eight fold after diagnosis, from 8% to 65%
- Three in four (76%) families said that childhood cancer had been a 'big problem' for their finances
- Two in three (66%) parents built up debt to make ends meet as a result of their child's cancer. Two in five (42%) parents borrowed from a credit card, and one in five (20%) took a loan out
- 6% of parents had borrowed from high interest, short-term payday loans to make ends meet
- Of those parents who acquired debt, two in five (41%) borrowed £1,000 or more and more than one in four (27%) borrowed over £2,000
- More than one in four (27%) parents were unemployed after their child had been diagnosed with cancer compared to only one in 10 (10%) before
- Two in three (65%) parents experienced a loss of earnings and three in five (58%) parents said they had to reduce the number of hours they worked
- More than half (55%) of parents surveyed told us that they had to take time off as unpaid leave and one in three (34%) took unpaid leave for three months or longer when their child was diagnosed
- More than one in eight (13%) parents said that they felt they had been demoted as a result of their child's cancer and three in five (58%) felt that they became less able to do their job well
- Three in four (75%) young people said that they would have liked improved information and access to financial support.

The economic and political context

Wider economic environment

The economic environment in the UK today is tough, especially for young people and families dealing with the additional challenge of childhood cancer. Youth unemployment is now over one million and is at its highest since records began in 1992². The situation is unlikely to improve in the foreseeable future.

New research from the Institute of Fiscal Studies has found that the next few years are likely to be dominated by a significant decline in incomes, with absolute poverty³ expected to increase significantly for both children and adults⁴. An International Monetary Fund report also predicts that British households will have £35 billion less in disposable income over the next five years⁵. For families and young people also coping with the additional costs a cancer diagnosis brings, there could be hard times ahead.

Welfare reform

Alongside this negative outlook for the UK economy, there is the impact of the significant programme of change in the welfare system as part of the broader government approach to cutting the deficit. This includes the government's flagship welfare reform policy of the introduction of a Universal Credit, which will subsume many existing benefits into one payment⁶.

In addition, the government is seeking to significantly overhaul Disability Living Allowance (DLA), a non-means tested benefit available to children and adults with disabilities and health conditions to help with additional costs. Currently DLA is the main source of additional support for children and young people with cancer and their families, with 88% of families we surveyed having applied for DLA. From 2013/14, a new benefit, Personal Independence Payment (PIP), will be introduced for working age people with disabilities (aged 16-64)⁷. There are also changes proposed to the Employment and Support Allowance (ESA) benefit, which is a work-related benefit available to those unable to work because of illness or disability.

The UK government's programme of welfare reform applies to England, Wales and Scotland. Social Security is a devolved matter in Northern Ireland, however, the government intends to continue to work closely with the devolved administration in Northern Ireland to seek to maintain a single system across the United Kingdom.

2 1.016 million or a rate of 21.9% for 16–24 year olds. Office of National Statistics (November 2011) Summary of key labour market statistics. Available at: <http://www.ons.gov.uk/ons/rel/lms/labour-market-statistics/november-2011/summary-of-key-statistics.pdf>

3 The absolute poverty line has been defined as 60% of the 1998-99 national median, but the 2010 Child Poverty Act says that the absolute poverty line will be rebased in 2010-11

4 The report estimates that absolute poverty is likely to increase by 600,000 children and 800,000 working-age adults. See Brewer, M et al (2011) Child working age poverty from 2010 to 2020. London: Institute for Fiscal Studies available at <http://www.ifs.org.uk/publications/5710>

5 See for example <http://www.telegraph.co.uk/finance/8676310/Families-to-be-1500-a-year-worse-off-IMF-warns.html>

6 Universal Credit is an integrated working age credit that will provide a basic allowance with additional elements for children, disability, housing and caring. It will support people both in and out of work, replacing Working Tax Credit, Child Tax Credit, Housing Benefit, Income Support, income-based Jobseeker's Allowance and income-related Employment and Support Allowance. Taken from Department for Work and Pensions (2011)

7 While PIP will also be introduced for children (under 16s), this will be done as part of a separate process and after the introduction of the benefit for those of working age

Previous research

There have been a limited number of studies exploring the costs of caring for a child with cancer and very few conducted in the UK.

Macmillan Cancer Support's *Cancer costs* research in 2006⁸ explored the hidden costs of getting cancer treatment and found that many adult cancer patients are dealing with a huge financial burden as a result of their illness. More recently Macmillan commissioned research in 2011 which found that financial problems affect more than two-thirds of adult cancer patients⁹.

Tsimicalis et al (2011)¹⁰ recently reviewed articles published on childhood cancer costs and only three of these were undertaken in the UK: Bodkin et al (1982)¹¹, Pentol (1983)¹², and Eiser and Upton (2006)¹³. This report builds on Eiser and Upton's 2006 study *Costs of caring for a child with cancer*, commissioned by CLIC Sargent, which found that cancer can have a significant adverse financial impact on families affected by childhood cancer. The study highlighted the expenses incurred as a result of a child's cancer diagnosis, how this is exacerbated by parents' lost income and limited sick-pay, as well as wider-ranging consequences, including using savings and borrowing money. Psychosocial effects, including depression, stress and anxiety, were also highlighted.

8 Macmillan Cancer Support (2006) *Cancer costs - The hidden price of getting treatment*. Available at: <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Campaigns/Cancercosts.pdf>

9 Macmillan 2011 http://www.macmillan.org.uk/Aboutus/News/Latest_News/StressedandstrappedCancerpatientstakefinancialhit.aspx

10 Tsimicalis, A et al (2011) The cost of childhood cancer from the family's perspective: A critical review. *Paediatric Blood Cancer* 56: 707-717

11 Bodkin, C M et al (1982) Financial burden of childhood cancer. *British Medical Journal (Clinical Research Edition)* 284:1542-1544

12 Pentol, A (1983) Cost bearing burdens. *Health Social Service Journal*. 93:1088-1089

13 Eiser, C and Upton, P (2006) Costs of caring for a child with cancer: A questionnaire survey. *Child Care Health Development* 33: 455-459

Our research methodology

Our research looked at the experiences of parents of children with cancer and of young people with cancer. We used the following research methods:

Quantitative survey of parents and young people

An online and paper survey was promoted to parents of children with cancer and to young people with cancer aged 19-24. Our target was to survey 150 parents to match the number collected by Eiser and Upton in 2006. A total of 239 parents and 74 young people completed the survey. The majority of surveys were completed online (180 parents and 53 young people).

Focus groups

Two focus groups, themed around the survey questions, took place with 10 young people with cancer, aged 19-24, from The Christie Hospital, Manchester, and John Radcliffe Hospital, Oxford. A further focus group also took place with nine CLIC Sargent social workers.

Interviews

Telephone interviews based on the survey questions were conducted with five parents (three of whom were bereaved), six young people aged 19-24 and one Young Person's Social Worker.

In total 245 parents, whose children were aged 0-16, and 90 young people aged 16-24 participated in the research.



We asked parents and young people to consider the following:

1. Expenses
2. Financial support
3. Impact on employment
4. Coping with finances
5. Issues specific to young people

This report looks at each issue in detail.

Respondent profile

Gender

- 87% of parents who responded to the survey were mothers and 13% were fathers¹⁴

Ethnicity

- 92% of parents and 87% of young people described themselves as 'White British'¹⁵

Time since diagnosis

- 61% of parents said their child had been diagnosed for a year or more, and 42% said that their child was in active cancer treatment
- 59% of young people said that they had been diagnosed for a year or more
- 19% of young people said they were in active treatment and 53% said that they had relapsed and were having further active treatment

Hospital appointments

- 20% of children and 17% of young people had hospital appointments fortnightly and 23% of children and 43% of young people had appointments once a week or more.

¹⁴ In general mothers may be more likely to take part in research of this type as they tend to be the child or young person's primary carer

¹⁵ This compares favourably with 2001 census data where 87.5% of the population identified themselves as 'White British'
<http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-211117>

1. Expenses

Three in four parents 'agreed' or 'strongly agreed' that their child's cancer had a major impact on family finances. The unexpected costs of caring for a child with cancer soon mount up and many families have to bear significant additional costs. The increased financial pressures add to an already difficult time for many families.

Here we explore the additional expenses incurred as a result of a child or young person's cancer diagnosis.

Abbie's story

Five year-old Annabel is undergoing fortnightly check-ups following treatment for leukaemia. Annabel, who has a younger brother, lives in Lincoln with her parents and attends primary school.

Her mother, Abbie, told us:

'We put our son in nursery for an extra day and a half a week, and there's the extra expense of going back and forth to hospital. We spend three hours, every other week, going to Sheffield for treatment by car from Lincoln.

There are times driving back and forth when you look at the price of petrol – it's so expensive. We use Annabel's DLA for fuel, food and the other costs associated with her treatment. We had an old car, and we were worried we would get stranded in Sheffield, so we bought a more reliable car.

Had Annabel's treatment lasted longer we would have struggled to cope with the extra costs. When we realised how long Annabel's treatment could last, we were worried about how we would cope with the additional expenses. We work because we have to, and have a mortgage to pay. We have met families with children who had been in hospital for six months and still had at least another six months in front of them. I don't know how they do it. It makes you cross that money is something you have to consider when your child is having treatment.'

The costs of cancer

We asked parents and young people how much they had spent above their normal every day expenses on childcare, travel, clothing, overnight accommodation, home help, food, toiletries and health products, telephone calls and other additional spending.

On average, parents and young people spent **£367** and **£277** respectively on extra expenses every month. This amounts to an additional annual spend of **£4,400** for parents and **£3,325** for young people.

The top three expenses were:

● Travel and car parking

● Clothing

● Extra food costs

Treatment for children and young people with cancer

For 0 to 15 year-olds, best practice National Institute for Health and Clinical Excellence (NICE) guidance states that diagnosis, treatment planning and initial treatment should be delivered in principal treatment centres, of which there are 18 in the UK. Young people aged 16 to 18 also receive age-appropriate care, but directed by specialist teenage and young adult multi-disciplinary teams based at teenage and young adult principal treatment centres, a model of care that has only recently been established.

According to NICE guidance, the teenage and young adult multi-disciplinary team should be notified of all young adults aged 19 to 24 who are diagnosed with cancer. Young people are then offered a choice: either to be treated at a teenage and young adult principal treatment centre or at a local adult cancer centre. This can impact significantly on whether, and how, their needs are met. By choosing to be cared for at an adult cancer centre, a young adult is more likely to be closer to home and therefore better able to keep up with education, employment and existing networks of friends. However, they may also find it difficult to access the specialist psychological and emotional support services available at teenage and young adult principal treatment centres, and it may be more difficult to meet and share experiences with other young people with cancer.

Travel and car parking

Principal treatment centres are often far from home and can mean regular long-distance travel. In 2010, CLIC Sargent published research¹⁶ which found that 77% of children and young people with cancer do not live in a city with a principal treatment centre. The average round trip distance travelled by car is 60 miles. Young people can also travel significant distances to receive treatment at teenage and young adult principal treatment centres and/or adult cancer centres.

During cancer treatment a reliable car is not a luxury, it is often essential. Repairs and new tyres are expensive, as is breakdown cover. Public transport is not an option for many children and young people with cancer as their immune system can be compromised by their treatment. It can also be very expensive for the whole family to travel by public transport.

Hospital car parks can be expensive. Many charge £10 a day, but some are a lot more. Children and young people with cancer may need to attend hospital appointments day-in, day-out for weeks on end. Some hospitals offer a discount for repeat or long-stay patients, but many parents and young people are not aware of this.

The cost of fuel has increased dramatically in the last five years, resulting in rising costs of travelling to receive treatment. In fact, the average price for a litre of unleaded petrol has increased by over 50% in the last four years from 88p in January 2007 to 136p in July 2011.¹⁷ Our research found that on average parents spend an additional £86 a month on travel. One in three parents (34%) spent over £100 a month on travel as a result of a cancer diagnosis, of which almost half (48%) spent over £200.

¹⁶ CLIC Sargent (2010) A long way from home

¹⁷ <http://www.petroprices.com/the-price-of-fuel.html>

Accommodation

Cancer treatment can take families miles away from home, adding to the stress and strains of a cancer diagnosis. 16% of parents said that they incurred additional costs for accommodation as a result of their child's treatment, over half of whom spent over £100 extra a month.

To help families stay close together, CLIC Sargent runs 'Homes from Home', which provide free accommodation for families near seven of the 18 principal treatment centres.

Many young people who had lived independently before they were diagnosed with cancer went back to live with their parents. This might be because they need extra support at home or because they cannot afford their rent, which may need to be paid until the end of a signed contract or lease. Moving back in with parents not only costs the young person their independence, it can also mean they, or their parents, have to pay for accommodation they are not even living in.

'When our daughter was diagnosed with cancer she lived in rented accommodation at university. We had to pay £300 a month up until the lease was up and then £120 on other health-related expenses. This amounted to £420 extra every month.'

Bereaved parent

Clothing

Children and young people's weight often fluctuates as a result of their cancer treatment. For example, chemotherapy may produce symptoms that lead to weight loss and steroids can cause weight gain, which may mean that new clothes need to be bought. Parents and young people also reported that they spent more money on clothes appropriate for hospitals, like pyjamas and other comfortable clothing. The costs of buying new clothing can quickly add up. Parents said they spent on average an additional £52 a month on clothing (including wigs). Young people spent an average of £55 a month on extra clothes and 20% spent over £100 a month extra on clothes.

Additional clothing is necessary for children and young people who spend lots of time in hospital. Due to impaired mobility (because of a drip for example), fluctuating room temperatures and clothes becoming soiled children and young people need sufficient change of clothes. As many families do not live near the principal treatment centres, they may not have easy access to a change of clothes and may have to buy new clothes so as to reduce time spent away from their child.

'My weight fluctuated so much that sometimes I had to wear the same jeans even if they were the wrong size. I got big and then small again. I tried to keep the same jeans because otherwise it becomes so expensive – especially when you only have money from grants. Jeans and tops do not come cheap – if you pay out for them then you have to cut back on other things like food.'

Young person with cancer

Extra food costs

On average, parents surveyed spent an additional £48 a month on food. 43% spent over £50 extra a month on food, and 22% spent over £100 a month. This cost was highest for parents of children on active treatment.

Children and young people with cancer can be in hospital for weeks, sometimes months, undergoing treatment. Cancer treatment can affect taste buds and the ability to eat, so food needs to be carefully planned. Steroids can also increase appetites and can trigger intense food cravings, especially for high-fat foods. When appropriate food isn't available on the ward, parents resort to buying in their own food. This extra expense soon mounts up for families already stretched by the cost of supporting their child through treatment.

'Cancer is expensive as my daughter craves certain foods because of chemotherapy and I want to make sure she gets the best food possible.'

Parent of a child with cancer

A significant number of parents and young people described hospital food as unappealing, poorly prepared, unsuitable for children who are not well, lacking in choice and not age-appropriate. Many children and young people stay in hospital for long periods to receive and respond to treatment, having all their meals in the hospital. During an extended hospital stay, the food they eat can have a considerable impact on their response to treatment. CLIC Sargent's 'Fit to Eat' campaign¹⁸, which aimed to improve the quality of hospital food, highlighted that good nutritious food is vital for children and young people undergoing treatment for cancer, as it helps them feel better and is a significant factor in keeping up their immunity against infections.

Additional spending to help keep children and young people occupied

Many parents felt that their children got bored, or needed cheering up on the wards, as they quickly tire of even the best equipped hospital entertainment rooms. Parents bought toys or games to keep their child occupied, or treats for siblings. Some parents and young people told us that they had to buy equipment to pass the time when spending long periods in hospital, such as portable DVD players and laptops to use for study. 86% of parents told us that they spent money on these extras. One in three (35%) spent over £50 a month and 15% spent over £100 a month.

Telephone calls

Communication is vital to keep in touch with family and friends when you have a child undergoing cancer treatment and parents and young people found that telephone bills increased significantly. Bedside telephones are available in hospitals, but many parents told us this was very expensive. The research found that one in three parents whose children were on active treatment spent between £25-50 extra a month on telephone calls.

Most hospitals have some type of play provision; some provide play specialists to create a sense of normality through play and activities, including some funded by CLIC Sargent.

'When I was initially diagnosed, the biggest thing we struggled with was the Patientline phones. As I had restricted visiting times I wanted to speak to family and friends as much as possible as I was scared. I ended up spending over £1,000 on phone bills.'

Young person with cancer

18 CLIC Sargent (2008) Fit to Eat – Food for children with cancer: guidelines for hospitals



Lesley's story

Three year-old Ross was diagnosed with rhabdomyosarcoma, a cancer of the soft tissue, around his right eye, when he was 18 months old. He lives in East Lothian, Scotland, with his mother, father and sister Katie who is five. Ross had his treatment at Edinburgh Children's Hospital.



His mother, Lesley, told us:

'I took 10 months off work and received sick pay for the first six months. We received a CLIC Sargent grant which was a huge help. Parking cost us £10 per day, and when you're at the hospital so regularly it really adds up. And that's on top of the petrol! Julie, our CLIC Sargent Social Worker, helped us fill out forms to apply for DLA, which was essential for us because my partner also took three months off when Ross was first diagnosed. His employer allowed him to work shifts, which were convenient for hospital appointments but there was a reduction in income as he was working fewer hours.'

"There are so many costs when you have a child with cancer."

There are so many costs when you have a child with cancer. One day I forgot to put money in the meter, so ended up with a parking ticket. Our CLIC Sargent Nurse, Daphne, took it away and dealt with it for me.

We had both been employed full time and when we were unable to work because we were with Ross at the hospital, we received no income once our sick pay was finished. Paying the bills was a worry. As if having a child with cancer isn't horrific enough to face, without money worries on top.'



Funeral costs

A small number of parents surveyed and interviewed had experienced bereavement. This is a traumatic experience and can be extremely overwhelming for families. Funerals are a significant additional expense and some parents told us that they found this a real strain both emotionally and financially.

'We also had the funeral costs and this set us back about £5,000. It was a big funeral as we wanted all our daughter's friends to be there.'

Bereaved parent

Home alterations

Cancer and its treatment can be very disabling. Sometimes alterations, like installing rails for support, are needed to make a home suitable for a child or young person who has limited mobility. Home alterations are a one-off cost and families may receive a Disabled Facilities Grant from their local council, but some alterations may exceed the grant that is given.

17% of parents surveyed had to make home alterations because of their child's illness. The average cost of home alterations for parents and young people was £300 and £200 respectively. Over a third of parents and young people said that they had spent £500 or more making alterations to their home.

Special treatment

High-energy proton beam therapy, a type of radiotherapy, is not currently available in the UK and families have to go overseas for the treatment. Plans are underway to develop high-energy proton beam therapy facilities in the UK although it is likely to be a number of years before they are in place.

Families are given between five and 10 working days' notice that they have been approved and accepted for proton beam therapy before they are required to travel abroad to undergo treatment, which can last for up to 10 weeks. Living abroad means additional costs soon mount up and families may not always be able to continue to receive benefits. Many families try to fundraise to support these costs but the reality is they may have very little time to do this before they travel.

Although the NHS pays for the treatment costs and the family's transport and accommodation, no additional funding is provided towards subsistence. CLIC Sargent provides some financial support for families and young people to assist with the non-recoverable subsistence and local travel costs. However, this does not cover all of the costs and is not a sustainable solution. A more long-term approach needs to be taken.

'We went to the US for two months for proton radiotherapy. During our stay we had to cover daily hospital travel expenses, food, days out and calls to home, all while I was on unpaid leave.'

Parent of child with cancer

2. Financial support

Many families and young people affected by cancer will need financial support from the outset as treatment often starts immediately after diagnosis, and so do the extra expenses incurred as a result. This section explores parents and young people's access to financial support from both statutory and charitable sources.

The need for financial support

There are clear direct financial costs to families when a child or young person is diagnosed with cancer, such as travel to treatment centres, buying clothing, extra food, treats and childcare for siblings. There are also indirect costs, for example, when a parent or carer (or a young person) has to give up work or take unpaid leave which can significantly reduce a family's income.

Young people need particular help and advice to cope with the financial pressures that a cancer diagnosis can bring. In fact three in four (75%) young people, when asked what one thing could be done differently, said that they would like improved information and access to financial support.

'There needs to be more help and financial support. Your world's turned upside down when you are told you have cancer.'

Young person with cancer

CLIC Sargent provides benefits advice and financial support to children, young people and their families. A CLIC Sargent report¹⁹ published in 2010 found that 54% of young people needed more financial advice in terms of getting a mortgage and insurance and that 34% needed more professional support in gaining access to DLA, other benefits and financial support.

Statutory support

DLA is a tax-free benefit for children and adults with disabilities to help with the extra costs of having a disability²⁰ and is a crucial form of support for families affected by childhood cancer across the UK. 71% of all parents surveyed and 54% of all young people surveyed received DLA.

'Receiving DLA was very helpful as I used it to pay for tutoring as I couldn't go into school after my transplant. The money was enough for me to pay for my most important needs.'

Young person with cancer

Around three in 10 of the parents surveyed received other benefits as a result of being on a low income, such as:

- ◉ Income Support

- ◉ Job Seeker's Allowance

- ◉ Working Tax Credit

- ◉ Child Tax Credit

- ◉ Employment and Support Allowance

- ◉ Educational Maintenance Allowance.

¹⁹ CLIC Sargent (2010) More than my illness – delivering quality care for young people with cancer

²⁰ While CLIC Sargent recognises that many children and young people with cancer do not self-define as disabled, children who have had a cancer diagnosis are covered by the Equality Act 2010. Claimants that can demonstrate the requisite level of care and/or mobility needs are able to receive the benefit



Families already in receipt of an income-related benefit may see no change as a result of a cancer diagnosis. But they may experience real difficulty in dealing with additional costs. Receipt of some benefits may also be tied to certain activities, for example seeking work, which can prove challenging to maintain.

Families on lower²¹ and middle incomes²², who are unable to access means-tested benefits, had more to lose in terms of lost income from work being interrupted or stopped entirely, with no safety net to fall back on. This is why DLA, a non means-tested benefit currently available to all families, is so important and plays a vital role in helping with the extra costs of cancer whatever the situation.

Applying for DLA

For some parents and young people this will be the first time they apply for benefits. This can add worry and confusion to an already difficult situation. Many parents and young people said that the DLA application forms were difficult to complete and almost two in three (63%) of parents said that they received help filling in benefit claim forms from their CLIC Sargent Social Worker.

'Applying for DLA to help us with some of the extra costs was very difficult. Jude, our CLIC Sargent Social Worker, recommended we apply and helped us to fill in the form. It's difficult as you're trying to be positive about your child's chances, but the form is asking you to write down the worst case scenario. It's very overwhelming. We wouldn't have been able to complete the DLA form without Jude. Without the benefit we wouldn't receive the financial support for the travel to and from hospital and the extra childcare costs for our son.'

Parent of a child with cancer

The number of parents who applied for DLA on behalf of their child increased from 84% in 2006²³ to 88% in 2011. The majority (84%) of parents who applied for DLA were successful on their first application and 81% of families were awarded the higher rate of DLA. 3% of parents were not successful with the application and did not re-apply, and 6% were still awaiting a decision.

As in 2006, a relationship was found between the successful receipt of DLA and the length of time since diagnosis. Success of parents' first application was highest for children who had been diagnosed for more than three months. This aligns with the government's current qualifying period for DLA – the length of time that you have to demonstrate care and/or mobility needs to be eligible to claim the benefit. No relationship was found between family size or marital status and receipt of benefits.

In 2011 CLIC Sargent undertook a survey of 45 social workers²⁴ to gain their perspective on the proposed changes to DLA. Some said that they were particularly concerned about the challenges facing young people when trying to claim the benefit. Our *More than my illness* report in 2010 also found that young people face difficulties gaining access to benefits. The 2011 data for this report shows that while 62% of young people who applied for DLA were successful on their first application, one in five (19%) had to apply a second time before they were awarded the benefit. The first time success rate for young people is notably lower than the success rate for parents applying on behalf of children. Three in four (75%) of young people said they would like improved information and access to financial support.

21 The most commonly used threshold of low income is a household income that is 60% or less of the median (typical) British household income in that year

22 For example those who are above the means-tested line but are not high enough earners not to be affected financially

23 Eiser, C and Upton, P (2006) Costs of caring for a child with cancer: A questionnaire survey. *Child Care Health Development* 33: 455–459

24 CLIC Sargent (2010) Social Worker Survey

Proposed changes to eligibility

Children and young people are eligible for DLA if they can prove that they have had disability-related mobility or care needs for three months and expect to need this help, or have these difficulties, for at least another six months. The Welfare Reform Bill 2011 proposes to extend the qualifying period from three to six months, meaning families are likely to have to wait longer before being able to claim the benefit that will replace DLA, Personal Independence Payment (PIP).

Treatment for children and young people with cancer usually starts immediately after diagnosis, but under the new system many will not receive any financial support until at least six months after diagnosis. Waiting to receive DLA can already be very difficult for families and young people.

'DLA takes a long time to come through. It is hard to get money when you need it most when everything is up in the air.'

Parent of a child with cancer

Our concern is that this proposed change would disproportionately affect children and young people with cancer, particularly those with sudden onset conditions. For example, children and young people with leukaemia often don't experience disabling symptoms before they are diagnosed, meaning that it could be six months into treatment before they receive DLA.

This tightening of the eligibility for PIP, which could altogether exclude many with shorter treatment periods, may mean that many of the families that remain eligible will have to wait up to six months before they are even able to start claiming the benefit. This could mean six months without any additional regular financial support for many families in a period when their income is likely to drop and their costs significantly increase.

Non-statutory support

CLIC Sargent grants

CLIC Sargent provides non-means tested grants as soon as a child or young person is diagnosed with cancer.

In 2010, nine out of 10 families²⁵ told CLIC Sargent that they needed financial support to help care for a child with cancer. That's why giving grants to parents, carers and to young people with cancer is such a vital part of our work. CLIC Sargent provides grants of £170 to help with immediate financial needs²⁶, and higher discretionary amounts for exceptional hardship.






In 2010/11 CLIC Sargent provided 4,507 children and young people with cancer a grant to help them cope with the costs of cancer. The total projected sum for grants in 2011/12 is over £1 million.²⁷

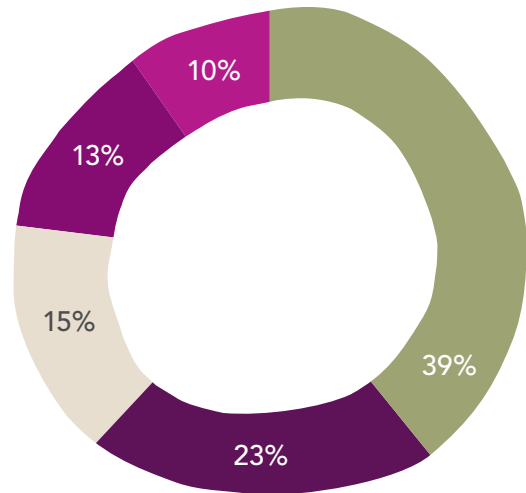
²⁵ CLIC Sargent (2010) Service User Survey: Analysis Report

²⁶ Exceptional Grants, Community Support Grants and Compassionate Grants are also available to some children and young people. The 2010 CLIC Sargent Service User Survey found that the majority of service users also reported that their need to access CLIC Sargent grants and benefits support was met

²⁷ £1,017,996 over 4,510 grants

Top 5 reasons for providing CLIC Sargent grants (2010/11)

	Travel for treatment	£331,082
	Family support	£195,102
	Compassionate crisis	£126,468
	Dietary	£113,915
	Community support	£81,486



In 2010/11 a total of £385,809 was awarded to 16 to 24 year-olds. The three most common reasons for children and young people receiving a grant were to cover the cost of travel for treatment (39%), family support (23%) and compassionate crisis²⁸ (15%).

Other charitable grants

Children and young people with cancer may be able to receive grants from a range of other charities and organisations, such as Macmillan Cancer Support, Candlelighters and the Family Fund, amongst others. Some are means-tested and may not be available to all families.

- ◉ 78% of parents and 69% of young people had received some financial help from one or more of these sources

- ◉ 51% of parents and 39% of young people said that they had been offered, or had received, a general grant to assist with the costs of cancer

- ◉ 37% of parents said that they received a grant for a holiday and 30% said they had received help towards travel

- ◉ On average, parents and young people received a total of £807 and £428 in grants respectively.

The Family Fund is the UK's largest provider of grants to low-income families raising disabled and seriously ill children and young people. In 2010/11 the Family Fund provided 874 children and young people with cancer with grants, of which 18% were aged 16-20. Hospital living costs were the most common reason for awarding such grants (48%); followed by clothing costs (37%) and bedding costs (15%). Other reasons included recreation, transport and holidays.²⁹

²⁸ A compassionate crisis grant is available to a family should the child/young person die as a result of their cancer diagnosis

²⁹ With thanks to the Family Fund for providing this information. <http://www.familyfund.org.uk>

3. Impact on employment

A child or young person's cancer diagnosis causes significant disruption to the whole family and often results in parents reducing their working hours and/or using up sick and annual leave to care for their child. In some cases they have to give up work altogether. Parents may be unsure when they can return to work and feel anxious about their job and future prospects.

In this section, we explore the impact a cancer diagnosis can have on parents and young people's employment, employer attitudes and the impact of changes in employment status.

Impact of diagnosis on employment

The survey found that as a result of their child's cancer diagnosis parents had:

- Reduced the number of hours worked
- Changed the type of work they do
- Experienced a loss of earnings
- Felt they had been demoted
- Changed responsibilities
- Become less able to do their job well.

Reduction in hours and loss of income

Parents often took time off, or left work, to care for their child, even if their child was aged 16-24. Likewise, for young people, a cancer diagnosis can also often mean giving up work and coping with a reduction in income.

Parents

- More than one in four (27%) parents were unemployed after their child had been diagnosed with cancer compared to only one in 10 (10%) before
- Two in three (65%) parents had experienced a loss of earnings compared to the time before their child had cancer
- Three in five (58%) parents told us they had to reduce the number of hours they worked³⁰
- One in eight (13%) parents told us they felt they had been demoted as result of their child's cancer
- Three in five (58%) parents felt that they had become less able to do their job well.

'I finished work when my daughter was on her treatment because I was only interested in getting her better.'

Parent of a child with cancer

³⁰ The average number of hours worked by parents at diagnosis was 31 compared to 23 after diagnosis

Abbie's story

'I didn't return to work so I could care for Annabel while she had treatment, so there was an unplanned drop in our household income. My husband agonised over the decision to take time off work. He thought he might be able to carry on working throughout Annabel's treatment for leukaemia but once we found out how gruelling the treatment would be we knew he couldn't work.

The system is not ideal for parents who need to take time off work to care for a child with cancer. In order to keep our income, my husband and I needed to be signed off sick with stress. We were technically stressed, but we needed to jump through hoops when all we wanted to do was focus on Annabel. Employers have insurance for maternity leave, but nothing for this kind of serious situation.

I felt a massive amount of guilt about not working. I had only recently started at a school and, although I wasn't put under any pressure, I felt bad for taking days off to make Annabel's hospital appointments.

Our employers have been supportive on a personal level, but we are frustrated by the system. As it turns out we have been lucky, if that is the right word, because Annabel completed the most difficult part of her treatment within six months, so we stayed on full pay. Had it taken longer for a match to be found for Annabel, or if there had been complications, my husband and I would have been reduced to half pay. There would have been a 50% reduction in our income, but no reduction in our outgoings.

My husband's employers are running out of patience. He may no longer be able to have Tuesday afternoons off every two weeks unless he takes unpaid leave, but he is looking at how he can plan his working hours so that he is still working full time.'

Young people

- 50% of young people were in employment when they were diagnosed compared to only 28% after diagnosis
- 66% of young people said that they had been less able to do their job and 37% said that they had been demoted since their cancer diagnosis
- 86% of those young people in employment at diagnosis said they had to reduce the number of hours they worked
- 50% had to stop working completely as a result of cancer.

Using unpaid and sick leave

More than half (55%) of parents surveyed told us that they had to take time off as unpaid leave and one in three (34%) took unpaid leave for three months or longer when their child was diagnosed. Two in three (66%) parents said they had to take sick leave and over two in five (44%) took sick leave for three months or longer.

Louise's story

Five year-old Alia was diagnosed with acute lymphoblastic leukaemia when she was three years old. She lives in Forres, Scotland.

Her mother, Louise, told us:

'My daughter spent the majority of a year almost continually in hospital. We were only granted four weeks' carers leave to be spread over in excess of two years of treatment. It had run out before she had finished her first block of treatment. Fortunately, as she was so desperately ill and we were so distraught, our doctor signed us off work with stress. Had they not, we would have emerged from her first admission to hospital homeless and bankrupt.'

Some parents told us that they resented taking sick leave to care for their child when they were not technically sick. Many, however, found that getting signed off sick themselves, for example with stress, was the only way to keep their job. Other parents had to use their annual leave entitlement, unpaid leave or a combination, to care for their child.

'My mum had to take time off work to look after me. She did receive about one or two weeks sick leave but after a while she went back to work two to three days a week and took the other two to three days off as holiday. This meant that she lost all her holiday. She could have gone to the doctor and asked to be signed off sick but she couldn't ask for one day off sick a week so she had to use her holiday instead. If she had reduced her hours then she would have lost out on her earnings.'

Young person with cancer

Self-employment

It's also difficult when parents own their own business. While self-employment might mean that parents have more flexibility to care for their child, it also means that there is often no one to manage the business when parents are away from work. This can negatively affect income and create significant long-term financial problems.

'Running my own business allowed me take time off work when I needed to take my daughter to hospital, and enabled me to share these tasks with my wife. However, during the course of her treatment there is no doubt that my business suffered as a result and turnover was reduced. Since she finished her treatment this has been hard to turn around due to the current economic situation.'

Parent of a child with cancer

Attitude of employers

The attitude of employers has a huge impact on parents and young people's ability to cope with the effects of childhood cancer. The majority of parents' employers were reported to have had a helpful attitude, both when their child was first diagnosed and at the time of the survey.³¹ 55% of those young people in employment at diagnosis said that their employer was 'helpful' or 'very helpful'.

However, some families reported very little support from their employers. For example, almost one in five parents (18%) felt their employer was 'unhelpful' or 'very unhelpful' at diagnosis.

Carol's story

Carol lives in Staines with her partner Neil and their three children. Her daughter Rachel, aged 16, was diagnosed with Hodgkin's lymphoma in 2007.

'I felt pressure to return to work full time – but I couldn't know how long it would take for my daughter to get better. There were no guarantees she would get better. I was moved from my usual office to a tiny office. I felt that my head of department was doing all he could to make me leave and I was signed off from work with stress.

My pay was reduced without warning. I was told it was because one of my sick notes was late and I didn't answer my phone. I explained that I couldn't answer my phone when I was in the hospital with Rachel, who by this time was having chemotherapy, but it was extremely stressful trying to justify why I was not able to go to work.'

Research³² conducted in 2006 showed that supporting carers at work can help an organisation to attract and retain staff, reduce sick leave, and produce cost savings. CLIC Sargent believes 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.

Returning to work

Even parents with supportive employers felt pressurised to return to work and, when they did, they felt torn between their work and their child. Employers often expect parents to return to work once their child has completed their treatment. However, even after treatment, children and young people still need on-going support. Some parents found it difficult to manage caring for their child and returning to work. This can have major long-term financial implications on families.

'I was due to return to work just after my son was diagnosed, however, due to his illness, I was unable to and had to become a stay-at-home mum. Because of the loss of earnings, we had to declare ourselves bankrupt a year into my son's treatment.'

Parent of a child with cancer

31 53% of parents felt their employer was 'helpful' or 'very helpful' at diagnosis; 65% of parents said that their partner's employer was 'helpful' or 'very helpful' when surveyed

32 Yeandle, S, et al (2006) Who cares wins: The social and business benefits of supporting working carers. London: Carers UK

Impact on long-term employment

Childhood cancer can have significant, long-term implications on both parents and young people's employment and earning potential. In fact, 43% of parents said that they had to rethink what they wanted to do with their lives because they had to take long periods of time off work. 56% of parents and 40% of young people feel that cancer has impacted on their long-term work prospects.

Parents have a right to care

CLIC Sargent has campaigned in the past for flexible working hours and paid leave for parents of children with cancer through the *Parents have a right to care* campaign, launched in December 2006. We sought to secure a comprehensive package of rights to time off, paid leave, carer's policies and flexible working. The campaign aimed to work with employers to encourage them to implement carer policies, educate carers with information on their rights and to raise awareness on employment policies. CLIC Sargent has developed "gold standard" guidelines and a template carer's policy for employers. We continue to campaign to ensure that families do not face additional disadvantage as a result of a child or young person's cancer diagnosis.

4. Coping with finances

Having to deal with the worry of financial hardship is difficult enough even for people not facing childhood cancer. For a parent of a child with cancer, or for a young person undergoing treatment, it is the last thing they need.

'I think when your child is diagnosed the last thing on your mind is your long-term financial problems. It is hard as a parent to think about funeral costs and the realisation you have to find a huge sum of money to pay for it. I do think there needs to be an interest-free payment option from the government to take away this worry. When your child is given a terminal diagnosis the last thing you want or need to be thinking about is your mortgage and bills but it is unfortunately one of the first things you do.'

Bereaved parent

Here we explore the impact of the additional expenses incurred and how this can increase worry and make families have to resort to borrowing.

Eileen's story

Eight year-old Ross has been in remission from cancer for six years. At 11 months, Ross was diagnosed with Wilms tumour, and had surgery and nine months of chemotherapy. He lives in Prestwick with his parents and older sister.

Ross' mother, Eileen, told us:

'My husband, Shaun, and I gave up work when Ross was having treatment so we had no income. We hadn't planned to give up work, but when you find out how much treatment is required and what is going to happen to your child you want to be with them at every moment.

When Ross was diagnosed, Shaun was working as a self-employed taxi driver. The stress we were facing meant that it was unsafe for him to drive because he would have been putting his life and that of his passengers in danger. There was also the fear that if something happened, Shaun might have been miles away and unable to make it to the hospital.

The bills were frightening. We had no income so had worries about paying the mortgage and bills, and other costs such as petrol and paying for food at the hospital while Ross was having treatment. So we borrowed £20,000 to pay the mortgage and cover our outgoings.

We'll be paying the loan off until Ross is starting secondary school. It's not ideal but it's the only thing we could do to have peace of mind. Now, as long as we have money to feed and clothe the children and pay the bills we're happy. Our experience has had a major impact on our outlook on life.'

"So we borrowed £20,000 to pay the mortgage and cover our outgoings."

Worrying about how to pay the bills, and fear of creditors or of defaulting on a mortgage, is emotionally draining. And this high level of financial distress has been shown to reduce the capacity to deal well with other problems.

But this is the everyday reality for almost all of the families and young people surveyed. It is also an unanticipated problem. Just as families were shocked by the news of a cancer diagnosis,

many of them had not considered how financially precarious their situations were. 29% of parents surveyed said that they had never worried about finances before their child received a cancer diagnosis. After being told that their child had cancer this number reduced to 7% – a quarter of the number who had previously never worried. Very few people are in a position to be insulated from the financial impact of childhood cancer.

For the rest, the emotional distress and worry caused by the financial implications of cancer can have a negative impact on parents' relationships, on their emotional health and wellbeing and ultimately on the child with cancer. It can also put a strain on extended families who are often asked to lend or give money to help out. And, ultimately, it can result in the loss of homes and livelihoods.

'There are so many financial implications of a cancer diagnosis. My health has deteriorated because of the stress caused by the diagnosis of my child's cancer.'

Parent of a child with cancer

Increased financial stress

Our research findings leave no room for doubt about the worries which parents face about their finances in the wake of a cancer diagnosis for their child.

The number of parents who said that money was 'often' or 'frequently' a worry increased eight fold after diagnosis, from 8% to 65%. Three in four parents said that childhood cancer had been a 'big problem' for their finances.

Even for young people, who may have a smaller number of financial commitments, fewer creditors and are less likely to have a mortgage, the figures are striking. The number of young people who said they were 'often' or 'frequently' worried about money rose from one in nine before diagnosis to one in two after – a more than four fold increase.

Overall the proportion of parents whose money worries had increased after diagnosis was 77%. In the 2006 Eiser and Upton study the increase had been 68%. The survey suggests that parents of children with cancer are more likely to be worried about finances now than they were in 2006. This, however, needs to be looked at in the context of the wider economic environment as the general population's money worries may have also increased in this time.

Resorting to borrowing

'I spent all my savings because I've had cancer at the same time. I've borrowed bits from the family, and used my child's DLA money to provide him with clothes and shoes on a regular basis.'

Parent of a child with cancer

At a time of general economic caution when many people are cutting back on their borrowing, many families told us that they had to go into debt as a result of the increased financial burden of a cancer diagnosis. Nearly half (44%) of all parents surveyed worried about their ability to repay consumer credit debts.

- Two in three (66%) parents told us that they had to borrow money as a result of their child's diagnosis
- Two in five (41%) parents borrowed £1,000. Of those parents who borrowed, one in four (27%) borrowed over £2,000

- Two in five (42%) parents borrowed from a credit card and one in five (20%) took a loan out
- 6% of parents had borrowed from high interest, short-term payday loans to make ends meet
- 39% of parents said that if they had to fund extra expenses as a result of their child needing more cancer treatment they would ask for money from friends and family.

Family lending can put a strain on relationships, but consumer credit can mean high interest costs.

'Initially I relied on friends and family and then my credit card. There is only so much that can be gained in this way and I was refused an overdraft due to the fact that I was off sick from work to look after my daughter.'

Parent of a child with cancer

Parents without friends and family who are able to help turned to high street lenders. When asked how they intended to find the extra money needed to deal with the impact of cancer:

- One in four (24%) parents said that they would take out a bank loan
- One in eight (13%) parents said that they would use an overdraft
- One in eight (12%) parents said that that they would use a credit card.

'We have accrued well over £10,000 of extra debt over our daughter's treatment, despite the help we were given, just to pay the bills and get by. We came very close to losing our home. I would never have believed how much having a child with cancer costs.'

Parent of a child with cancer

Five parents in our research even said that they would have to re-mortgage their home to fund the extra expenses.

'I don't know where I would find the money; I have had to enter into a debt management programme to make ends meet.'

Parent of a child with cancer

Young people and debt

'As I am unable to work I can't pay my car insurance, tax, phone bill, gym, petrol etc. I am now entirely reliant on my parents as I only get £57 a week which goes nowhere. Other expensive costs are things such as wigs, new make-up, clothes due to size changes, false eyelashes etc.'

Young person with cancer

We also found that young people, many who had also accrued student debt, and some who had young families themselves to look after, resorted to borrowing to cope with the financial demands made by their cancer.

- Half of young people had to borrow money as a result of their cancer
- More than 17% had borrowed over £1,000 and 6% borrowed over £2,000.

59% of young people said that they would have to ask family and friends for money to fund any extra expenses because of their cancer treatment. One in four young people would take out a bank loan, while 10% and 6% would use an overdraft and credit card respectively.

Financial concerns

The parents and young people we surveyed worried most about:

- 🔴 Losing their home
- 🔴 Not being able to afford to travel
- 🔴 Not being able to buy food
- 🔴 Not being able to pay the bills
- 🔴 Not being able to manage and repay debts.

Losing their home

50% of parents said that, in relation to their child's cancer, they were specifically worried about being able to meet mortgage repayments or pay the rent. Uncertainty about the security of your home is one of the most stressful things to be faced with, and many parents told us that they found their mortgage lenders or landlords inflexible in the face of their new situation.

'Our mortgage lender was very unhelpful and unsympathetic when we asked for a payment holiday due to temporary reduction in family income.'

Parent of a child with cancer

Not being able to afford travel

Most parents told us of the constant stress of travelling and having to think about how transport could be afforded, paid for or claimed for. Public transport may not be an option for children and young people with a compromised immune system, due to the increased risk of infection. It can also be confusing and unfamiliar for those families usually dependent on their own transport. Private transport is, however, increasingly expensive and often families only have one car.

Travel costs were the single item most worried about by parents, with three in four (73%) reporting concern in relation to their child's cancer.

Not being able to buy food

64% of parents were concerned about having enough money to pay for food and essential household expenses.

Not being able to pay the bills

'I think that the biggest financial stress was making sure all the bills were paid at home. I was scared of what would happen if I didn't pay them.'

Parent of a child with cancer

Four in seven parents (57%) were worried about fuel bills such as gas and electricity and two in five (41%) were concerned about their ability to afford telephone bills, including paying for mobile telephones which is often their only link with family and friends.

Not being able to manage and repay debts

One in three (34%) parents were worried about repaying debt.

'I found my financial situation harder to manage and deal with than the cancer itself.'

Parent of a child with cancer

5. Issues specific to young people

The young people that took part in our research were aged 16-24. We collected data through two focus groups with young people aged 19-24 and through the young people's survey for 16-24 year-olds.

For young people the costs of cancer are not just limited to the impact of their illness on their finances. There are many other areas where they perceive loss and disadvantage which can contribute towards a feeling that the cost of cancer is a price paid in ways which can be more difficult to measure – quality of life and life chances.

Young people identified the additional non-financial costs as being linked to:

- Social and emotional wellbeing
- Educational progress
- Aspirations and expectations.

Here we explore each in turn.

Social and emotional wellbeing

'I used to get jealous of my brother and sister going to school, you want to be the same and it's horrible.'

Young person with cancer

Social and emotional wellbeing is increasingly recognised as playing a key role in life outcomes, with an associated 'cost' in having poor social support networks. Young people and children with cancer are at greater than average risk of being excluded from social networks while they are receiving treatment in hospital.

'It's funny because you would think that doing nothing would be really good but it's not, it's really boring.'

Young person with cancer

When asked about the impact of cancer on their quality of life young people were generally very clear. Only one in 10 of the young people surveyed thought that cancer had not affected their quality of life.

The major impact they reported was that of a feeling of isolation and the severe impact of treatment, hospitalisation and time off school or college on their most important social support networks – friends and family.

- Nine out of 10 (90%) young people said their cancer had made them feel isolated at times
- Five out of six (83%) young people felt that their quality of life had been affected by cancer
- Five out of six (83%) young people said that they missed their friends at work/college/university when they were unable to see them.



Scott's story

Scott was diagnosed with a brain tumour in November 2008 when he was 15. Scott had intensive chemotherapy that lasted three months at Pendle Community Hospital, brain surgery at the Hope Hospital in Manchester and radiotherapy at the Christie as part of his treatment. He is now studying for his A-levels and wants to study ancient history at Manchester University.

Scott told us:

'I actually really like school and the fact that I had to put my education on the backburner made me feel really frustrated. Although teachers came to visit me in hospital, I was so tired during treatment that I was falling really behind because I just couldn't keep up with the work. I got stuck in a cycle of feeling annoyed that I couldn't keep up, which would make me more tired and then I couldn't do all the work I wanted to.'

"...I'm going to have to pay more now to go to university..."

In the end I had to put my health before my education. I decided to focus on getting better. To stay with my school friends I progressed to sixth form college but because I was so far behind I had to re-sit year 12. I'm now in year 13 doing really well.

What makes me feel annoyed is the fact that I'm going to have to pay more now to go to university as the fees have just been raised. Education is so important to me and when I saw my friends go off to university it was really hard. It makes me slightly frustrated to think that because I had to go through treatment for cancer, and had to stay behind, I will also have to pay off more debt when I graduate and there won't be as much financial support that I can apply for to help me out.

I have some lasting effects from my treatment including severe fatigue and I still can't do my homework when I get back from college. Because I had an operation on my brain I have a permanent weakness down my right-hand side as well, so I'm not as able to do the things that most young people do.'



Educational progress

For many young people with cancer keeping up with their education is difficult.

'I think that education becomes more important once you have been ill.'

Young person with cancer

Many of the young people who participated in the research said that their educational experience has not been what it might.

Educational attainment may be affected for some children and young people with cancer or those who have had cancer in the past. 2010 research³³ shows that childhood cancer survivors had lower educational attainment than the general population, especially central nervous system (CNS) neoplasm and leukaemia survivors.

Even when a child or young person has gone into remission, learning can still be affected in the longer term with children and young people experiencing symptoms such as chronic fatigue, attention and concentration difficulties and even psychological and emotional problems.

In 2010 CLIC Sargent completed the second of two reports which examined the non-clinical needs of children and young people with cancer. *More than my illness*³⁴ focused specifically on young people aged 16 to 24 and found that 64% of 16 to 18 year-olds fell behind with studies or did not do as well as they thought they could have. 29% of all young people surveyed had to leave education altogether.

A number of young people surveyed and interviewed for this report felt that their schools and colleges were not well-prepared to deal with a pupil developing cancer and undergoing treatment.

'My school could have done with better information on how to support pupils with cancer. The first few days are OK and then they just forget about it.'

Young person with cancer

In our survey only four in seven young people said that, at the time of diagnosis, the staff working at their school or college were either 'helpful' or 'very helpful'. For those still in education post-diagnosis this had risen to two in three.

Many young people needed to take time away from education, or reduce their involvement in education, with the result that most perceived that their education had been disrupted and delayed, especially in comparison to their peers.

- Two in three had to reduce the amount of hours they were in education due to their cancer or cancer treatment

- Three in four reported they had missed a lot of time in education

- Two in three reported they had fallen behind with their studies.

33 Lancashire, E et al (2010) Educational attainment among adult survivors of childhood cancer in Great Britain: A population-based cohort study. Journal of the National Cancer Institute, 102: 254-270

34 CLIC Sargent (2010) More than my illness – delivering quality care for young people with cancer

'I was very unfortunate as, due to my cancer, I struggled to go back to school and had to retake the year. Whereas now my friends are paying £3,000 in university fees, I will have to pay £9,000. The course that I was going to do has been cancelled, but because I am 19 I will have to pay for my new course. If I was 17 then I wouldn't have to pay. It's unfair. I have been penalised but it is not my fault.'

Young person with cancer

Aspirations and expectations

Attitude to education

On the whole, the young people who participated in the research felt that having cancer had significantly affected their education.

- Two in three felt that they had become less able to study well.

While progress had been delayed, the vast majority were still determined to see it through and many even expressed increased determination and acknowledgement of the importance of getting qualifications.

- Five out of six young people said they had not had to give up education.

But for many of the young people, their approach to education and their choices had definitely been shaped by their experiences.

- Three in four of young people said they had changed their priorities when it comes to education.

'I have been affected as I can't get the grades that I was going to get which could lead to a better job. Because of all the treatment on my brain, it doesn't function in the same way. This will affect my grades and the degree that I get. I might not get into the universities that I would have hopefully done. You never know if you were ever going to get there, but you always think you could have done better if it had not been for the cancer.'

Young person with cancer

Attitude to career

Some young people felt that having a cancer diagnosis, and in particular on-going treatment and related side-effects, was defining what they could or couldn't do in terms of careers. Many were unsure about the long-term impact.

- Two in five (39%) young people felt that cancer had limited their future work prospects

- Two in seven (28%) young people weren't sure whether it had or not.

'Some young people don't cope after treatment. They can have emotional health issues for years after, which can prevent them from securing a job. I've also met some young people who had to change their choice of career because of their cancer. For example, I knew a young man who was about to go into the army, but got cancer and now he can't join because of his health status.'

A CLIC Sargent Young Person's Social Worker

Attitude to life

Most of the young people we spoke to think of cancer as a life-changing event, which made them think differently about their future. In some cases this was perceived as problematic, with previous hopes and plans largely taken away. In other cases it was treated as an opportunity, or even an inspiration to think differently about priorities and directions in life.

- Five in six (85%) young people said that cancer had made them rethink what they wanted to do with their life.

'I didn't know what I wanted to do before, but now I have decided that I want to study art as this is what I did in hospital. This encouraged me to take it further. It's something positive to take away from a bad experience.'

Young person with cancer



Conclusion

When your child is diagnosed with cancer, the primary focus is on treatment and helping them to get better. Unfortunately, as this research shows, an already difficult experience for families is compounded by increased costs at a time when they already have so much to deal with.

This research has aimed to better understand:

- the additional costs facing families
- how a cancer diagnosis disrupts their employment and ability to earn income
- what financial support is available
- how families cope with these various impacts on their finances.

Additionally, it has explored the specific challenges facing young people with cancer aged 16 to 24.

The costs of cancer

With three in four parents surveyed 'agreeing' or 'strongly agreeing' that their child's cancer had been a 'big problem' for family finances, the research found that the unexpected costs of caring for a child with cancer had a profound impact on the family's financial resilience. Costs increased for a variety of reasons including travel and car parking to get to principal treatment centres; additional clothing required as a result of the impact of treatment on the child or young person's weight; food to supplement that available in hospital and to help children and young people intake calories and eat nutritious food, which we know can aid their response to treatment; and other costs including telephone calls and accommodation.

Our research showed that on average parents and young people spent £367 and £277 respectively, each month, above their normal expenses as a result of the cancer diagnosis. This amounts to an additional annual spend of £4,400 for parents and £3,325 for young people. For most families this would be a significant extra expenditure that would have a real impact on family finances and few families would be able to cope without some form of additional financial support. We found that families access support in a variety of ways, including through state benefits (particularly DLA) and grants from charities like CLIC Sargent.

The life impact

The research found that in addition to mounting expenses, many families were simultaneously faced with a drop in income as a result of a reduction in working hours, or having to give up work altogether. While many parents reported that their employers were supportive, others had no choice but to use up their annual leave and even go on sick leave in order to look after their child. Many of the parents surveyed also felt there had been an impact on their long-term employment prospects.

We also found a significant impact on the lives of young people who had cancer. In fact, five in six surveyed told us that their quality of life had been affected by cancer. Two in three young people reported that they were less able to study well, and two in five felt their long-term work prospects had been affected. It is clear that cancer will have a lasting legacy on their lives. Half of those surveyed had also accrued debt as a direct result of their illness, meaning a lasting financial impact as well.

Increased financial worries

The research found that worry about their financial situation was a daily reality for almost all the families and young people surveyed. Indeed, the number of parents who said that money was 'often'

or 'frequently' a worry increased eight fold after diagnosis, from 8% to 65%. Our research found that grants and benefits were not sufficient to meet all costs and many families had resorted to borrowing, with two in three of all parents surveyed doing so.

The impact and worry of a cancer diagnosis on the whole family cannot be underestimated and families have to call on every ounce of strength to get through the child's diagnosis and treatment. Again and again the families we surveyed told us of the profound effect of the financial impact on their ability to cope. This can only further impact on the families' emotional resilience and ability to support their child. For young people without family support, already dealing with the illness and its treatment, this situation can be even more challenging.

Support for families dealing with childhood cancer

Young cancer patients and their families need support from those around them and from statutory and voluntary agencies to 'get through' the cancer diagnosis and treatment. The government, charities such as CLIC Sargent, wider family and friends and employers can all play their part in helping support the family or young person.

CLIC Sargent's goal is to lessen the impact of childhood cancer. We provide clinical, practical and emotional support for families and young people including financial information and benefits advice as well as providing grants. We believe that:

- ◉ As well as the support that CLIC Sargent and other charitable organisations provide, families must be able to access support through the benefits system, with DLA currently acting as an important source of support. Any changes to the benefit system, such as the proposed introduction of the new PIP benefit, must continue to cater for the needs of families and young people dealing with a complex and fluctuating long-term condition like cancer. This is particularly important when the highest financial impact is felt immediately after diagnosis.
- ◉ As the financial impact of cancer can be immediate, we believe families should not be made to wait for up to six months before they can claim benefits, nor should the length of their treatment plan make the difference between getting benefit and receiving no state support at all. If a child or young person is not eligible for PIP, it is vital that other support mechanisms are put in place otherwise many families may be pushed to their financial limits.
- ◉ For children and young people who require high-energy proton beam therapy treatment, the establishment of a centre in the UK will not only mean they can access this specialist treatment, but that they will also incur significantly lower additional costs. In the meantime, it is essential that families are given financial support to help with the significant additional financial impact of accessing the treatment abroad.
- ◉ The benefits system must not treat young people the same as adults. Young people with cancer are particularly vulnerable in terms of the impact of cancer on their life, their studies and their ability to earn, not to mention the immediate financial implications. We believe the government should look to better align the various age limits and eligibility arrangements to ensure that young people have fair access to benefits to help them cope with the costs of cancer, and are not additionally disadvantaged in terms of the options available to them.
- ◉ Research conducted in 2006³⁵ showed that supporting carers at work can help an organisation to attract and retain staff, reduce sick leave, and produce cost savings. CLIC Sargent believes 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. A flexible and open approach from employers will help to reach a solution that is better for the employer and family.

35 Yeandle, S, et al (2006) Who cares wins: The social and business benefits of supporting working carers. London: Carers UK

Glossary

Chemotherapy

Chemotherapy is one of the three main ways to treat cancer. Chemotherapy is the use of anti-cancer drugs to destroy cancer cells.

Children and young people

In this report 'children and young people' refers to all children and young people aged up to and including 24.

Disabled Facilities Grant

A Disabled Facilities Grant is a local council grant. It helps towards the cost of adapting your home to enable you to continue to live there. A grant is paid when the council considers that changes are necessary to meet your needs, and that the work is reasonable and practical.

Disability Living Allowance (DLA)

DLA is a tax-free benefit for disabled children and adults to help with extra costs they may have because they are disabled.

Family

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

National Institute for Health and Clinical Excellence (NICE)

NICE is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

Personal Independence Payment (PIP)

DLA is to be replaced with a new benefit, PIP, from 2013. The new benefit will remain a non-means tested, non-taxable cash benefit claimed by disabled people whether they are in or out of work.

Principal treatment centre (PTC)

All children with cancer are diagnosed at one of the 18 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.

Proton beam therapy

High-energy proton beam therapy is a type of radiotherapy which uses a beam of protons to irradiate diseased tissue.

Radiotherapy

Radiotherapy treats cancer by using high energy rays which destroy the abnormal cells, whilst doing as little harm as possible to normal cells.

Annex

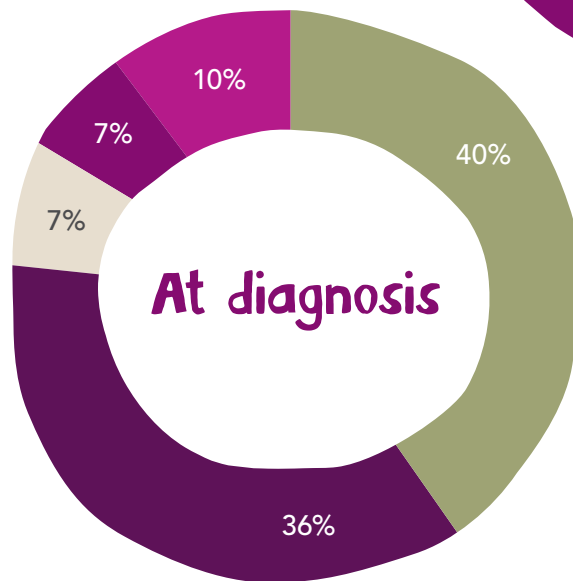
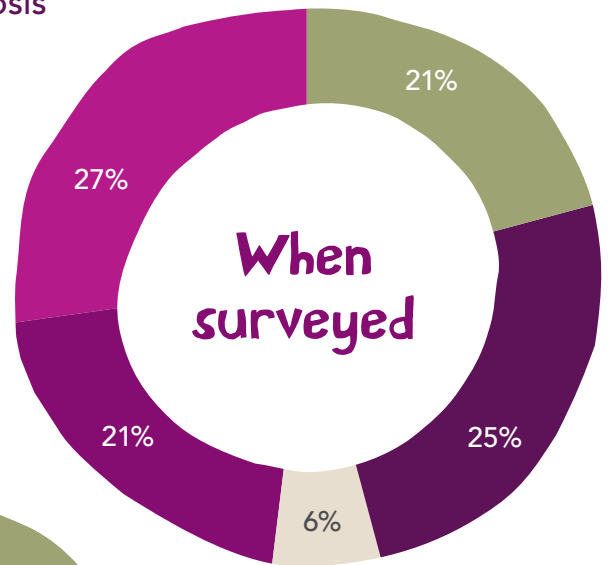
Average monthly extra expenses on different items for parents and young people

Expense	Parents	Young People
Travel	£86	£68
Clothing	£52	£55
Extra food costs	£48	£29
Extras ³⁶	£42	£17
Telephone calls	£29	£22
Toiletries/health products	£25	£27

³⁶ Additional spending to keep the child or young person occupied, for example toys, games and IT equipment

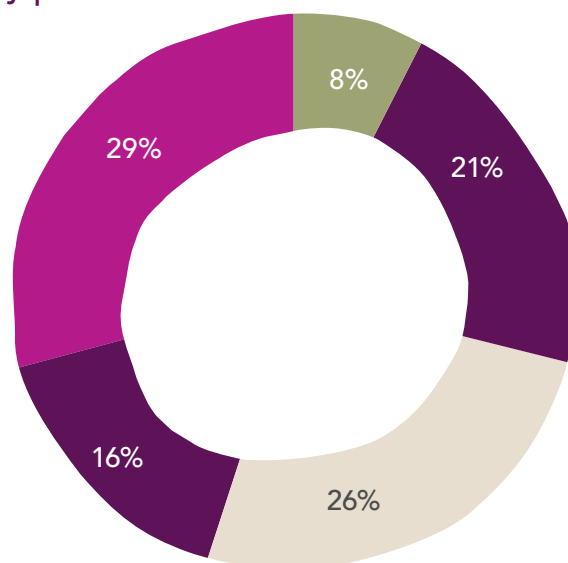
Employment status of parents at diagnosis compared to when surveyed

- Full-time employed
- Part-time employed
- Self-employed
- Working from home
- Not employed outside the house



Amount of money borrowed by parents

- Up to £100
- £100-£500
- £500-£1,000
- £1,000-£2,000
- £2,000+



Counting the costs of cancer

The financial impact of cancer on children, young people and their families.

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