

CANCER COSTS AGAIN

The financial and
emotional impact
of relapse and
secondary cancer

YOUNG LIVES
vs CANCER
CLIC SARGENT

SUMMARY

We know that cancer costs. But for some children, young people and their families, cancer costs more than once. Like for those that relapse or develop a secondary cancer.

This report highlights how young cancer patients and their families who have dealt with a relapse or secondary cancer, experience the financial and emotional costs of cancer - again.

ABOUT CLIC SARGENT

CLIC Sargent is the UK's leading cancer charity for children, young people and their families. Our care teams provide specialist support to over 7,000 children, young people and families across the UK every year.

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FOREWORD

When I was diagnosed with cancer again, two years after I'd beaten it the first time, it was hard. But I'm a fighter, you have to stay positive. I'm on my own, my parents aren't around, and I support my brother where I can. My mum passed away from cancer, it makes it even more scary.

When I was diagnosed the first time, I was working full time as a care worker. I had to stop working, and I still can't work because of the effect of my treatment, so I rely on Personal Independence Payment and Employment Support Allowance to support myself.

I had to budget really carefully during treatment, I still do. Even with my accommodation paid for, I still had to find around an extra £200 a month for food, clothes and travel. When all my bills and expenses had come out at the end of each month, I only had £80 to spare.

I didn't really have much support, so having my CLIC Sargent Social Worker was really helpful. Managing everything on my own during treatment was difficult. Even getting to treatment was hard, when I couldn't drive myself anymore because I felt too ill, I had to get taxis, and that was expensive. Doing it a second time was even harder. If I'd had some of the costs covered the first time round, it would've made a huge difference.

Whether you experience cancer once or if you have to go through it again, support needs to be in place. It's great that CLIC Sargent is trying to make sure people like me are supported, and don't have to pay the price for having cancer.

Although I'm not able to work like I used to before treatment, I've been accepted to university and I'm looking forward to moving beyond my cancer diagnosis. I hope that other young people get that opportunity too.

Ebony, 24

EXECUTIVE SUMMARY

We know that cancer costs. Over the last two years, CLIC Sargent has explored the financial impact of cancer on children and young people, and their families. We know that families spend on average an extra £600 per month during treatment, can spend £180 on travelling to treatment when it's at its most intense, and experience considerable emotional stress when dealing with these expenses.

What we don't know enough about yet are the experiences of children and young people, and their families, who are diagnosed with cancer for a second time, and the support they need.

Our new research found that a quarter of our social care staff's workload was working with young cancer patients who had relapsed or developed secondary cancer. One in six cases were supporting families whose child had passed away after a relapse or secondary cancer.

For some young people and their families, cancer costs more than once: more travel costs, energy bills, depression, anxiety, and loneliness. £600 extra per month during treatment, again. £180 per month travelling to hospital, again. These costs come at a time when they're often still dealing with the financial fall-out from their first diagnosis. And trying to cope with cancer forcing them to put their lives on hold. Again.

We believe that support for young cancer patients and their families should be right the first time. So that if a family does experience cancer again, they do not have to pay the price.

CLIC Sargent is committed to supporting children and young people with cancer who have relapsed or had a secondary cancer diagnosis through our financial grants programme and the support of our social care staff. We'll also continue to

campaign for the government to reduce the burden of cancer costs by providing financial support like a Young Cancer Patient Travel Fund. So that families don't have to worry about mounting costs when their child is going through cancer.

KEY FINDINGS



A quarter of social care staffs' workload was working with young cancer patients who had relapsed.

One in six cases were supporting families whose child had passed away after a relapse or secondary cancer.

The costs of cancer hit a family experiencing relapse hard:

The emotional impact of the diagnosis is devastating, alongside the stresses of dealing with the financial burden

Travel costs quickly mount up as treatment is far from home and expensive to get to

Employment commitments have to be managed alongside looking after your child

Access to benefits is stressful and confusing, support is not available from day one when the costs start building

Debt is a reality for many as families might still be in debt from making ends meet the first time, when a relapse hits.

INTRODUCTION

In 2016, we started building our evidence base on #CancerCosts, drawing on our previous work and academic research. We found that families spend an extra £600 per month on costs during treatment, on things like travel to hospital, car parking, and extra bills. When a parent has to give up or reduce their working hours to care for their child, debt starts to build and the financial stresses mount.

Our follow-up survey (2016) found that 95% of parents felt cancer had a negative impact on family finances. 62% found their energy bills increased and 46% struggled to pay their bills. 63% of parents found themselves in debt during their child's treatment.

As a key expense identified in #CancerCosts (CLIC Sargent, 2016), the cost of travel was further explored in our Are We Nearly There Yet? report (2018). This showed that young cancer patients are travelling on average 60 miles to access the treatment they need, costing £180 per month when treatment is at its most intense.

Hidden Costs (2017) explored the emotional costs of cancer. We discovered that:

79% of young people felt cancer had a serious impact on their emotional wellbeing

70% said they had experienced depression

90% said they had experienced anxiety, with 42% reporting they had panic attacks

83% experienced loneliness during treatment.

So we know cancer costs.

But for some people, cancer costs more than once. Like for those that relapse or get a secondary cancer. There is a lack of information about the experience of these children and young people and there is little data on the incidence of relapse for childhood and young people's cancer.

This year, the James Lind Alliance Priority Setting Partnership (a non profit making initiative working with stakeholders like clinicians, patients, carers and researchers to identify research priorities within health and social care areas) identified relapse related issues in the top ten research priorities for teenagers and young adults with cancer.

We did this research to explore:

- The extent of relapse and secondary cancers among the children and young people we support
- How those who have relapsed experience the costs of cancer – both financially and emotionally.

RESEARCH APPROACH

We conducted a literature search on open access journals, and CLIC Sargent's in house evidence base. We included the terms *relapse*, *refractory*, *recurrence*, *second*, *secondary cancers*, *children and young people* and *AYA* to identify key pieces of literature, gaps and ways forward. In spring 2018, we conducted a snap shot 'week in the life' survey of CLIC Sargent social care staff (CLIC Sargent Social Workers and Young People's Community Workers). We asked them how many of the children and young people they were working with related to relapse, secondary cancer, and bereavement in that week, to provide context and insight of the scope of those going through these issues. Around 55% (n=91) of our social care staff responded to the staff survey, from across the UK.

We used the following definitions in this survey

1. Relapse – the identification of new active disease that is the same classification of disease as the original, although it may return in a new area of the body. Sometimes also called "recurrence"

2. Secondary tumour/cancer – the identification of new active disease that is different from the original e.g. a child has a type of blood cancer and is treated with a bone marrow transplant, several years later they get a different kind of cancer as a consequence of the transplant.

We conducted telephone and Skype interviews with young people and parents about their experience of relapse, using the #CancerCosts framework to explore the financial issues and emotional context. We took a lay approach with these respondents and let people self-define, asking for the experiences of those who'd been diagnosed with cancer for a second time. Six parents and six young people took part in telephone interviews. Some were going through treatment at the time, three parents were bereaved. These responses are used to illustrate the common themes that have emerged during our cancer costs work, and show how those experiencing relapse are facing these costs.

Limitations

The survey provides a snap shot of the workload of social care staff in one particular week, this can be an illustration and insight into the scope and numbers of those affected by relapse only. Interview participants were self-selecting and are therefore not necessarily representative of all young cancer patients and their families. They were self-defining in terms of relapse, and this may not match clinical definitions.

FINDINGS

For CLIC Sargent social care staff the average number of cases relating to relapse or secondary cancer was three – a quarter of their workload. On average, social care staff had two open cases per week supporting families who were bereaved due to relapse or secondary cancer – one in six cases.

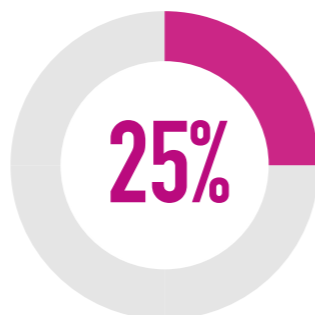
- A quarter of social care staff's workload was working with young cancer patients who had relapsed
- One in six cases were supporting families whose child had passed away after a relapse or secondary cancer.

Last year, CLIC Sargent supported around 7,000 children and young people across the UK, and their families. Our survey suggests that almost a quarter of those could be experiencing a relapse – around 1,500 families. This gives some insight into the number of young cancer patients that may be going through this experience. It should be noted, that this is just an indication based on the average cases of our social care staff in one particular week. We would encourage further research and analysis to continue to build a picture of the state of affairs.



7,000

Last year CLIC Sargent supported around 7,000 children and young people across the UK



Our survey suggests that almost a quarter of those could be experiencing a relapse

When life changes – again

When cancer treatment has finished, and there are fewer and fewer follow-up scans, life can slowly begin to return to something resembling normal. For some of the people we interviewed, relapse is the thing they most feared, but least expected:

“Finishing treatment, relapse was a big worry, but as time went on less and less. And then we got to two years and at that point I thought ‘we can relax a bit’ it was going off my radar, so it was a big surprise to us.”

Parent of a young person with cancer

“It was hard. I wasn’t expecting it. We found out on my birthday as well. It was kind of a shock and having to go away to another country for treatment was even more of a shock.”

Young person with cancer

Fear of recurrence is significantly higher among young adult survivors than those diagnosed when they were over 40 years old, and research suggests that managing this fear is a key unmet need amongst young cancer survivors (Shay, 2016).

Life can change a lot for a young person and their family between an initial cancer diagnosis and a relapse. A child who had cancer may now be a young person, attending college, university or in work. They may have a family of their own and new responsibilities. Families may have changed, relationships ended, careers changed.

“I was diagnosed in 2009 and again in 2011. I just recently had an operation at the end of last year. During that time, I’ve got married, done two degrees and had children. The first time I was at home and my parents supported me, the second time my husband supported me.”

Young person with cancer

A relapse diagnosis changes everything - again.

“Initially it knocked us all for six and I think we were so stunned into almost numbness. Then at other times I felt absolute grief and like everything was being pulled apart. The other overwhelming feeling I had, and I think my daughter had, was that it just wasn’t fair. We all know on one level life isn’t fair. But she’d been through so much before, she’d had an awful time.

She’d just got a place at a top University, she was so happy to be there and absolutely loving it, making friends and being challenged, it was like a dream come true. Something she wanted all her life and to have that ripped away seemed so so cruel.”

Parent of a young person with cancer

#CANCERCOSTS

Our #CancerCosts (2016) and Hidden Costs (2017) research detailed the additional costs that come with a cancer diagnosis and treatment. The parents and young people consulted for our 2016 research told us about the impact of extra food costs, energy bills, travel costs, among others. Income goes down and costs go up. We found that families were spending on average an extra £600 a month when treatment was at its most intense.

For this report, we talked to young people and parents who had experience of relapse about going through cancer and the related costs again. We also talked to our social care staff who support them. From what they told us, young cancer patients who have relapsed, and their families, feel these costs even more keenly.

“The financial impact is considerably greater. Usually going through treatment the first time has depleted any financial reserves that the family may have, and their earned income has often dropped due to reduced working hours. This is more pronounced the shorter the gap between end of treatment and the new diagnosis/relapse but the impact is felt even several years later due to the time it takes families to recover financially. It can be more difficult to find grants to support them as they were used the first time and many grants can only be applied for once.”

CLIC Sargent Social Worker

Travel and parking

Families have told us that travel costs are a key issue. Our report *Are We Nearly There Yet?* (2018) found that young cancer patients travel 60 miles on average for treatment, and can spend £180 per month when treatment is at its most intense. #CancerCosts (2016) showed that parents spend an average of £43 per month on hospital car parking. For those experiencing relapse, this is not the first time they've had to make these long, expensive journeys.

The people we interviewed for this research told us about the long drives, the difficult and expensive parking, and the need to sometimes stay away from home to cope with the travelling.

“The car parking is a total nightmare. Technically we ought to be able to park for free in the parent and child area. There's never space there, so we have to pay. I've paid out £100 for an annual pass, but before I did there were a couple of times where I thought we were going in for half an hour, but it took the whole day – like when she was diagnosed again – so that was £50.”

Parent of a young person with cancer

“My hospital is two hours away and sometimes I wouldn't feel so great so we'd stay in a hotel. Most of the time we did manage to come straight home but there were a few occasions when we'd come the night before. It's a long drive.”

Young person with cancer

In September 2018, CLIC Sargent called on the government to create a Young Cancer Patient Travel fund to help children and young people with cancer and their families with the cost of travelling for treatment. More than 30,000 people signed our petition asking the government to create a Fund, and the Labour Party pledged its support. We also believe all hospital car parking should be free for young cancer patients and their families.

Employment

As our previous research highlighted, the costs of cancer come at a time when income is likely going down as at least one parent is forced to give up work and care for their child. We previously found that two in five parents stopped working, half experienced a loss of earnings, and almost a third felt they were able to do less work (CLIC Sargent, 2016).

For this report, young cancer patients and parents told us about the continued barriers they faced in trying to carry on working during their or their child's relapse.

“About a week before my daughter was diagnosed it became clear that I would be made redundant. On the positive side it meant I could take time off because they're a much smaller company; they wouldn't have been able to give me the amount of time off or flexibility as my employers the first time. It's really uncertain, I have no idea when I can apply for another job.”

Parent of a young person with cancer

“I'm a teacher, but my memory isn't what it used to be after treatment and so it's difficult to work. My first treatment I was financially supported by my parents, this time we're completely reliant on my husband's income.”

Young person with cancer

In 2019/20, we'll be looking at the barriers young people on treatment and parents face in keeping a job during and beyond cancer treatment.

Family life

The costs of cancer can hit a single parent household even harder. Our previous research found that more single parents were out of work post treatment, compared to two parent households. More single parents were in debt.

The single parents we spoke to during this research told us about the difficulties of managing the costs in a single parent household.

“I want to spend more time with my daughter, but I'm on my own, I'm the only one bringing in the money, so I can't give up work.”

Parent of a child with cancer

“At a hospital level there's still such an outdated assumption that everyone lives in nuclear families. We're divorced, so things like organising for her to get blood taken before she goes back into chemo to check her blood count are more difficult. You have to be listed at one address, you can't be listed at two. Which means by default I have to do even more stuff and it can't be shared by two parents living at different addresses...It makes it harder, just trying to keep some semblance of normal life going, is much harder, if you're trying to move between two family homes - which makes the costs higher”

Parent of a young person with cancer

COPING WITH THE COSTS

Benefits

#CancerCosts (2016) showed how difficult parents and young people found the process of applying for Personal Independence Payments (PIP) or Disability Living Allowance (DLA). Young people and their families told us getting access to benefits when they needed them should be a priority, and that the application process needs to be a lot more straightforward.

Even having navigated the system once before, those who have relapsed don't find this any easier.

"I've got two degrees and my daughter's at Cambridge University but we couldn't make head or tail of the form. The 50 page long forms are actually designed to put people off and therefore you won't get what you're entitled to."

Parent of a young person with cancer

We believe the government should improve support for young cancer patients and their parents by making changes to the way benefits such as PIP and DLA are accessed. Treatment starts immediately and is often a long way from home, so the costs start building from day one. But young cancer patients have to wait three months before they can apply for benefits designed to help with the cost

of an illness or disability. That's why we're asking the government to review this, so that they get financial support backdated from the day of diagnosis.

Debt & budgeting

Cancer costs add up, and for many the consequence is debt. Our 2016 research found that 61% of parents accrued debt during their child's cancer treatment. They borrowed against credit cards, friends and families, and used their overdraft to cover costs. One in five borrowed up to £5,000.

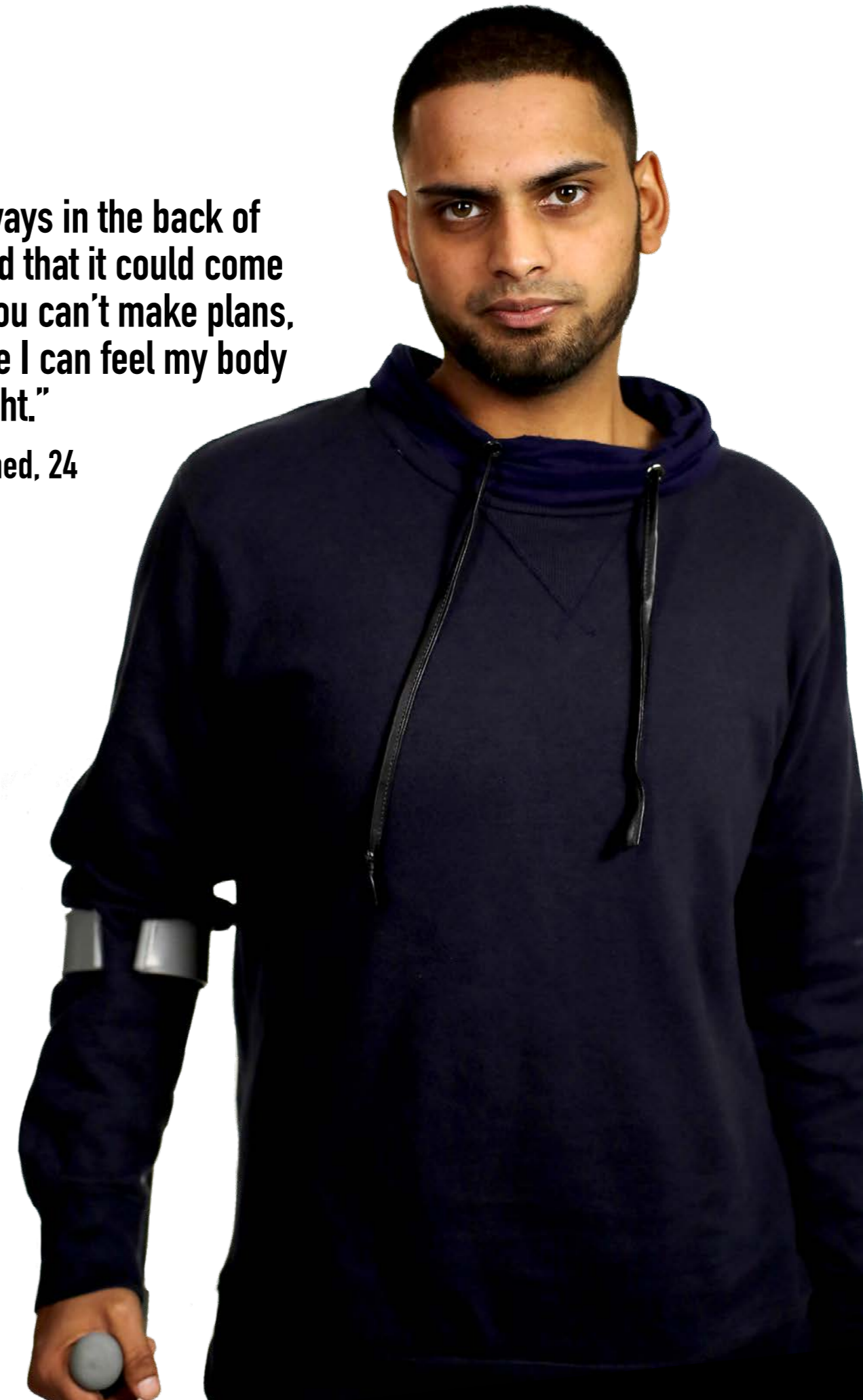
It can take years to dig yourself out of debt - those who experience a second diagnosis may not have financially recovered from the first time. The emotional impact of dealing with another diagnosis makes this even more difficult to manage.

"Our savings definitely took a hit. We normally have a monthly budget, but because I sort of struggled mentally, that went out the window. We stopped budgeting and it was like, if we need to spend it, we'll spend it and we'll worry about it later. And we did overspend quite a lot because we weren't paying attention to it, we just thought we'll find the money at some point - put it on the credit card."

Parent of a child with cancer

"It's always in the back of my mind that it could come back. You can't make plans, because I can feel my body isn't right."

Mohammed, 24



EMOTIONAL IMPACT

The emotional impact of a cancer diagnosis can be devastating. Our Hidden Costs research (2017) found that young people with cancer struggled with a range of emotional and mental health problems. 70% experienced depression during treatment and 90% had anxiety. 83% felt lonely, and 42% had panic attacks.

Going through all this a second time can be even more traumatising. Anxiety and post-traumatic symptoms in family, related to the uncertainty and lack of control experienced with their children's relapsed cancer, is well established in the literature we reviewed (e.g. Arruda-Colli et al, 2015).

"You have that sense of things being out of control, the uncertainty, the lack of agency, you're in the hands of other people. They explain things to you but you don't know what they're not explaining. For me one of the ways of coping, was thinking 'what can I practically do to make things better and more bearable' so whether that's making a real effort with the food I cook or taking my daughter places or helping to arrange massage sessions or pilates or tai chi to make things more bearable, that's one of the coping mechanisms.

She knows it's not like some of the adult cancers where they are diet related, but she was like 'well I was eating incredibly healthily and that didn't stop it coming back' so it's almost like a desperation, the last chance she's got to be cured".
Parent of a young person with cancer

"Working with patients who have relapsed or have a secondary cancer often brings additional issues for these families. They have already been through treatment once and so understand more about it. The emotional impact is usually greater as they understand how difficult it can be and usually the prognosis is less certain. Consequently, more emotional support can be needed".
CLIC Sargent social care staff

Financial stresses

The costs of cancer can also have a significant emotional impact on families. Three-quarters of parents and over half of young people spoken to for #CancerCosts (2016) felt that managing their finances during treatment had caused them additional stress and anxiety. Energy bills were among the top three financial stresses for parents during treatment.

Parents of those experiencing another cancer diagnosis experience these same stresses.

"As a result of the chemotherapy and surgery she was at home, and when she's unwell she really feels that cold so I was having to keep central heating turned up to 22 all the time, and had she been at university that wouldn't have happened."

Parent of a young person with cancer

Since 2016 CLIC Sargent has been working with British Gas and Scottish Power to offer tailored support to young people and families struggling with the costs of cancer. Together, we've helped families reduce their energy bills and to get the help they need from their energy supplier. We want to see this replicated across the sector.

Children in families with debt problems are five times more likely to be at risk of having low well-being than their peers and are at greater risk of experiencing mental health problems (Children's Society, 2018). The government are currently consulting on a 'breathing space' scheme which would allow for time, space and support for families to put plans in place to deal with debt. We welcome a scheme that supports the families of children and young people with cancer. It should be: an appropriate amount of time to allow families to recover and plan, easily accessible, include all existing debts, and be flexible. We'll be submitting our detailed response to the government's plans in January 2019.

Funeral costs

For some families, the death of a child is a reality they have to deal with. When the unthinkable happens, they can also face funeral costs of around £3,000 (CLIC Sargent, 2015).

For a family experiencing relapse, this fear is more acute and a reality that they may have to plan for.

"From the second that he relapsed we knew that we were going to have to find the money for a funeral. He was cremated so that is cheaper than a burial, and we got some money from a charity to help. We had a lot of good will. Our undertaker didn't charge us for anything that he wasn't legally required to charge us for, the church waived the fee, where we had the wake waived the fee - we didn't have to pay for food there. I think it cost £1000, which is a lot of money, but not as much as it could have been."

Parent of a child with cancer

This is why we campaigned for the government to create a Children's Funeral Fund, in collaboration with Carolyn Harris MP and the Fair Funerals campaign. The Welsh Government announced that bereaved parents will no longer have to pay burial charges for children in Wales. In November 2017 the Department for Work and Pensions committed to making improvements to the Social Fund's Funeral Expenses Payment Scheme to help those accessing the scheme for financial support for children's funerals. In March 2018 the Scottish Government waived burial fees for children, and in April 2018, the Prime Minister announced a Children's Funeral Fund for England where parents will no longer have to pay for burials or cremations.

CONCLUSION

We know cancer costs financially and emotionally, and can cost young cancer patients' life chances – on education, employment and health (for example, see CLIC Sargent, 2014). For those that experience relapse or a secondary cancer there is no doubt that cancer costs more than once, in many different ways. This report has outlined the additional financial impact that a relapse or secondary cancer diagnosis can have on young cancer

patients and their families. There is a clear need to help children and young people with cancer, and their families, cope with the costs of cancer – for example through a Young Cancer Patient Travel Fund – to stop cancer destroying young lives. More research should be done into the experiences of children and young people who relapse. The support of young people should include appropriate mental health and emotional support.



Tom, 24

We're calling for:

Creation of a Young Cancer Patient Travel Fund

We're calling for a Young Cancer Patient Travel Fund, so families don't have to worry about mounting travel costs during treatment.

It should be:

- Based on need not income
- Easy to access, and
- Cover all costs associated with travel to and from hospital for cancer treatment.

Financial support from the day of diagnosis

We're asking the government to review access to DLA and PIP for young cancer patients so that they get financial support backdated from the day of diagnosis. Children, young people and their families shouldn't have to wait three months before they can access the financial support they are entitled to, at the time when they most desperately need it.

Our commitment to people and young families

Financial support

Young people with cancer who have relapsed or had a secondary cancer diagnosis can access financial support through our grants programme, and we will continue to make sure this support meets their needs.

Digital services

We are continually developing our Information Resources and Digital Services so that all young people who need us can access support and our ambition is to be able to reach everyone who needs us.

Support from our Social Care Staff

Our Social Workers and Young People's Community Workers will continue to be there for families who need us, providing the emotional and practical support they need.

Research into employment

In 2019 we'll be looking into the barriers young people with cancer face in getting and staying in employment, and that parents face staying in employment during and after their child's treatment.

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Cancer Costs

CLIC Sargent (2016)

Cancer Costs follow up survey

CLIC Sargent (2017)

Hidden Costs

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A Review of Health Behaviours in Childhood and Adolescent Cancer Survivors: Toward Prevention of Second Primary Cancer

James Lind Alliance (2018)

Teenage and Young Adult Cancer: research priorities

NCIN (2012)

Occurrence of cancer among 5-year survivors of childhood cancer

Shay et al (2016)

Prevalence and correlates of fear of recurrence among adolescent and young adult versus older adult post-treatment cancer survivors

The Children's Society (2018)

Life Events: How any family can fall into debt

“After every scan, I cry with relief. Sometimes I’m scared it will all be taken away. But for now, I’m happy.”

Sara, 18



**YOUNG LIVES
vs CANCER
CLIC SARGENT**

“Whether you experience cancer once or if you have to go through it again, support needs to be in place.”

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