

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

**The costs of cancer on  
employment for young people  
and their families**

**HARD  
WORK**

# CONTENTS

Young Researcher foreword and testimonials	05
Societe Generale foreword	08
Executive summary	09
Key Findings	10
Introduction	13
Research approach	16
Findings	17
Government support	17
Support from employers	20
Long-term career impact	26
Conclusion and recommendations	28
References and acknowledgements	30

## ABOUT CLIC SARGENT

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

Cancer doesn't discriminate. Today, 12 more children and young people will hear the devastating news they have cancer. From diagnosis, CLIC Sargent's specialist care teams will step in, ready to help, support and guide. We provide a package of support tailored to each young cancer patient and their family.

CLIC Sargent will fight tirelessly for children and young people with cancer, often when they feel they can't. We do this individually, locally and nationally, so that they can focus on the important things, like getting well. And if the worst happens, we will work with bereaved families to get them support, to help them cope with their emotional pain.

This report was commissioned as part of a three year partnership between Societe Generale in the UK and CLIC Sargent which aims to help young people achieve their employment and education ambitions despite their cancer diagnosis.

March 2020



### Project team

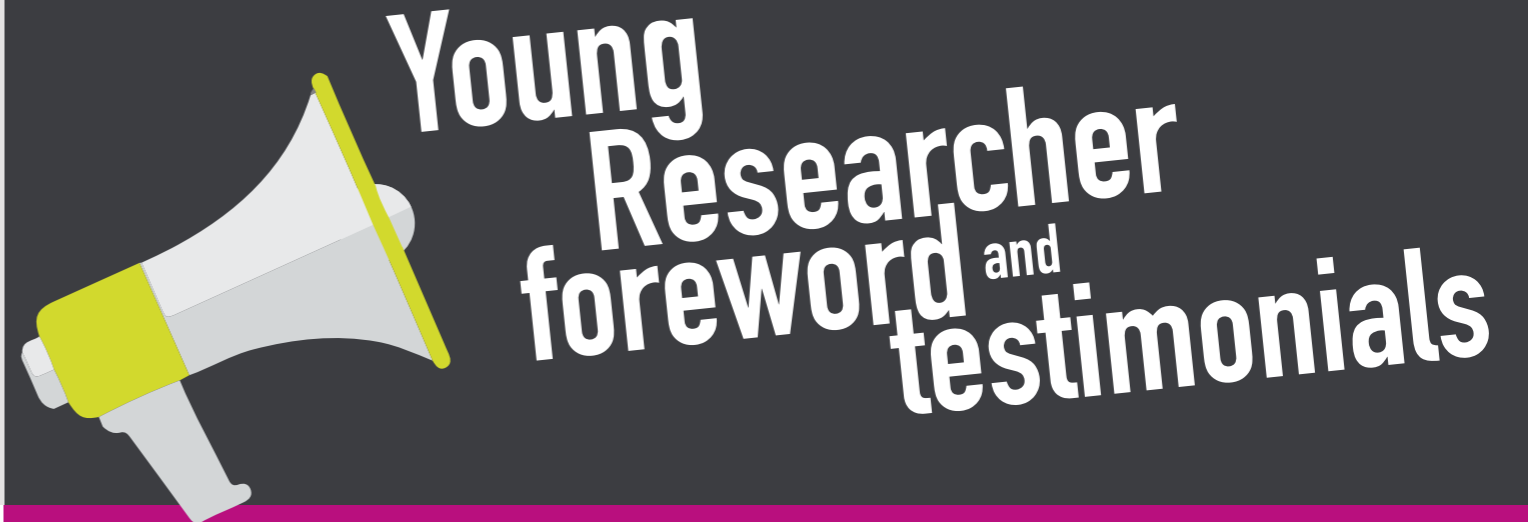
#### Young Researchers

Abigail Cresswell 21, Norfolk	Chloe Dresser 23, Solihull	Michela Quecchia 22, London	Vaishnavi Lalam 17, Birmingham
Anna Stark 22, Bristol	Emily Merten-Jones 25, Birmingham	Owen Bentley 19, Walsall	
Ayesha McGregor 22, Saltcoats	Georgia Jones 24, Manchester	Rebekah Birch 22, Lichfield	
Caoimhe Wills 23, Belfast	Leighann Hickinson 23, Coleraine	Sam Tredrea 26, Cornwall	

#### CLIC Sargent team

Helen Gravestock, Associate Director, Policy, Influencing & Voice  
 Hannah Khan, Research Officer (Maternity Cover)  
 Sonia Malik, Research Officer  
 Sarah Gilbert, Policy & Public Affairs Officer

For more information contact [campaigns@clicsargent.org.uk](mailto:campaigns@clicsargent.org.uk)



**We are CLIC Sargent's Young Researchers! We are young people aged 16 to 25 from all over the UK who have experienced cancer.**

We joined this project because we wanted our voices to be heard. We wanted to help bring about change and find new ways for the government and employers to help young people overcome some of the challenges of a cancer diagnosis.

We've spent the past ten months researching the impact cancer has on employment for young people with cancer and parents of children with cancer. We've explored areas like taking time off work and how this affects income; problems overcoming gaps in employment; reasonable adjustments within the workplace and much more.

We were involved in all stages of this research project: from thinking about and developing research questions for the surveys, to testing the surveys and promoting them online. We have also analysed the data we collected, and helped write and design the final report.

We believe it is so important to have young people who have actually experienced cancer conducting and presenting this type of research. We know first-hand the effects cancer can have on employment and have used our own experiences to shape this research in a unique way.

It feels very empowering to be involved in this work. We have all turned one of our most challenging life experiences into something positive; to actually make a difference to others.

We weren't surprised to find out that half of young people with cancer had to take unpaid leave during their cancer treatment and that nearly half had a reduction in earnings. This was an experience that some of us have struggled with over the past few years. We think it is so important that there is more support from the government for employees, so that young cancer patients and their families are better able to access financial support.

Too often, young people with cancer and their parents or carers face unfair treatment at work or aren't properly supported. This isn't fair – people shouldn't be at a disadvantage as a result of something so awful and completely out of their control. We want this report to make a serious impact on how employers treat young people and parents. Cancer is already an excruciatingly difficult and stressful time; the last thing people need to worry about is job stability and income.

We hope this report makes you stop and think. And we hope those in positions of power will support us in working towards change for young cancer patients and their families.

## “ My employer was very supportive but this wasn't the case for my dad ”



**NAME:** Owen

**AGE:** 19

**FROM:** Walsall

My name is Owen. I'm 19 and from the West Midlands. In January 2018 I was diagnosed with leukaemia and underwent chemotherapy and eventually a stem cell transplant.

I was really keen to research this topic to raise awareness and benefit others. I also wanted to give something back to CLIC Sargent, who were so important in getting me through my treatment.

It's been great to work on this project. I've met some lovely people and it feels amazing to work toward something which will benefit people going through a very difficult time.

My employer was very considerate and supportive but this wasn't the case for my dad. He was given time off when I was first diagnosed but then only allowed one day compassionate leave. After that, any time off he needed to care for me had to come out of his holiday or he had to make the hours up. This is not acceptable and companies should not be able to get away with this. Going through treatment alone is very scary, meaning it's so important to have your parent or carer with you.

## “ I received a lot of support at university but I had no such help with employment ”



**NAME:** Michela

**AGE:** 22

**FROM:** London

My name's Michela. I live in London and am originally from Italy.

Three years ago when I was 20 I was diagnosed with stage IV-B Hodgkin lymphoma. I was given chemotherapy and have been in remission for 10 months.

I was motivated to take part in this project because life after cancer is much harder than people realise. I will graduate one year later than expected, with no relevant work or internship experience, and with lower grades. I received a lot of support at university but I had no such help with employment, where a wider understanding and acceptance of cancer patients' autonomy and requirements is needed, such as an agreement on medicine and rest breaks that can benefit both employer and employee, or part-time and freelance shifts.

## “ I had to fight to be allowed three weeks of paid leave, and any time off after that, to recover physically and emotionally, was unpaid ”



**NAME:** Emily

**AGE:** 25

**FROM:** Birmingham

Hi I'm Emily, I'm 25 and from Birmingham. I was diagnosed with non-Hodgkin lymphoma in 2018 and CLIC Sargent supported me throughout my diagnosis and treatment.

I got involved in this project because I really wanted to give something back to this charity after all of their support. I wanted to use my Psychology degree and understanding of research, alongside my experience of cancer, to help improve the lives of other young people with cancer. I feel it is crucial research is conducted in this area so we can create change to improve some of the difficulties of a cancer diagnosis.

We found that half of young people had to take unpaid leave during their treatment – just like me. During radiotherapy I had to take two and a half months off work and was told I would not be paid for this, leaving me worried about the financial impact on me and my family. I had to fight to be allowed three weeks of paid leave and any time off after that, to recover physically and emotionally, was unpaid.

## “ My mum had to leave her job as a doctor to become my carer... there's a real lack of support for carers and it just isn't fair ”



**NAME:** Vaishnavi

**AGE:** 17

**FROM:** Birmingham

Hi, I'm Vaishnavi. I'm 17 years old and from Birmingham. In May 2018, I was diagnosed with Hodgkin lymphoma halfway through my GCSE examinations. I worried a lot about my grades as they are so important for my further education and future career.

Taking part in this project allowed me to voice my concerns about the long term effects of cancer on employability due to the strain it can put on your wellbeing and education.

My mum had to leave her job as a doctor to become my carer for six months which caused our family a financial burden. There's a real lack of support for carers and this just isn't fair.

As you read this report I hope you get a sense of the major disruption something like cancer can have on your life and family and feel some compassion. I want to see more effective provisions to support families like mine through employment and education.



## SOCIETE GENERALE FOREWORD

Unlike so many individuals and families, I have never had to experience the extraordinary challenge of having cancer as a young man or having to support a child with cancer. I have been fortunate, almost taken for granted, that I have been able to focus on living my life. The sad truth is that the **impact of cancer goes beyond an individual's health**. It destroys dreams and ambitions, of course, but, perhaps less well understood, is how it also has a significant detrimental impact on young people's and parents' employment and finances.

This new report, commissioned as part of a three-year partnership between Societe Generale in the UK and CLIC Sargent, aims to shed light on this very issue, and the findings are startling. Most strikingly, the findings are not limited to the period between the moment of diagnosis and the culmination of treatment – **it's long-term**.

As shocking as the findings are, the objective of this report is not to point fingers. **It can be hard for employers** to know how to adequately support young people with cancer or their parents, often due to their own financial constraints or institutional policies.

As Chairman of the City HR Association, which supports Human Resources professionals working in or partnering with the financial services sector, I see many initiatives put in place across organisations to help staff, regardless of their personal circumstances. At the same time, **I am convinced that we as employers can do more** by building on our existing practises.

As technological barriers come down, we need to ensure cultural barriers follow suit, and this begins with managers setting the tone.

By providing greater **flexibility and agility**, whether it relates to working from home or encouraging a change in mindset from one of hours worked to one of delivering, young people and the families of children with cancer will have the flexibility they need to cope during and after treatment – a time of great emotion and stress. We cannot underestimate the positive impact this can have, whilst mitigating any loss of earnings for individuals.

Having a safe and secure psychological contract between an employer and an employee is more and more important as organisations want their people to realise their full potential by being their true and authentic selves. **It is our role as employers to support them in their journey**, whatever the circumstances.

As UK Head of HR for my own organisation, I take great pride in the support services we provide our staff. This being said, upon reading this report, **I believe we can do more**. I am therefore committed to sharing the Young Researchers' proposals with our Executive Committee in the hope of bringing about further change **to ensure our young people with cancer and their families don't just survive, but thrive**.

I hope every individual reading this report will be as inspired as I am.

**Ben Higgins,**  
Head of Human Resources, UK and Ireland,  
Societe Generale Group

 SOCIETE  
GENERALE

**YOUNG LIVES  
vs CANCER**  
CLIC SARGENT

## EXECUTIVE SUMMARY

At CLIC Sargent we've been shouting about #CancerCosts for years. The young people and families we support tell us again and again just how tough it is to manage the financial impact of cancer.

### We've been shouting about #CancerCosts for years

Our previous research showed that **families face an extra £600 per month of costs during treatment** on things like travelling to hospital, car parking and extra bills. **Young people are spending an extra £360 per month** (CLIC Sargent, 2016). These costs come at a time when many parents and young people are **forced to give up work** for long periods of time and take **unpaid leave**, leaving them struggling to cope.

### Our previous research showed that families face an extra £600 per month of costs during treatment

Our social care staff are working hard to support young people and parents to deal with issues at work: from **struggling to access paid leave and reasonable adjustments**, to feeling unsupported and facing outright discrimination.

### Young people are spending an extra £360 per month

**It simply isn't right** that so many people are facing these struggles, especially when they're already going through something as overwhelming, isolating and unfair as cancer. We wanted to understand what's really going on, and what we can do to change this.

### It simply isn't right

**But we knew we couldn't undertake this project alone**. The best people to research issues are those directly affected by them. Which is why we set up the Young Researchers Group – a team of 14 young people who've been supported by CLIC Sargent. The group have drawn on their own experiences to help us design, conduct, analyse and disseminate the research. **We've been led by them and learnt from them – and now you can too**.

### The best people to research issues are those directly affected by them

# #CancerCosts

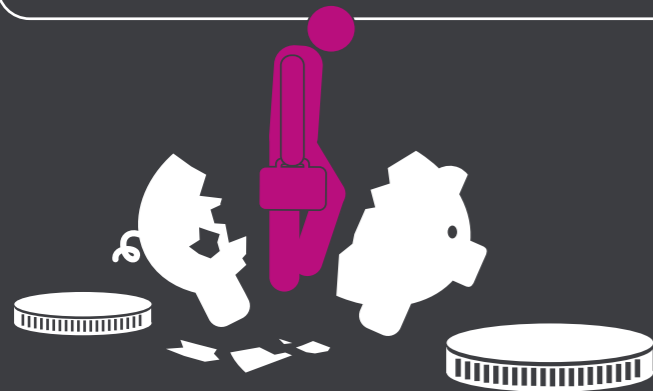
Key findings

Nearly half of young people and two out of three parents reported a **reduction in earnings because of cancer**



Half of young people and two out of five parents have **taken unpaid leave during cancer treatment**

Nearly one in five parents have **taken over four months of unpaid leave** during their child's cancer treatment. Two out of five young people have **taken over a month**

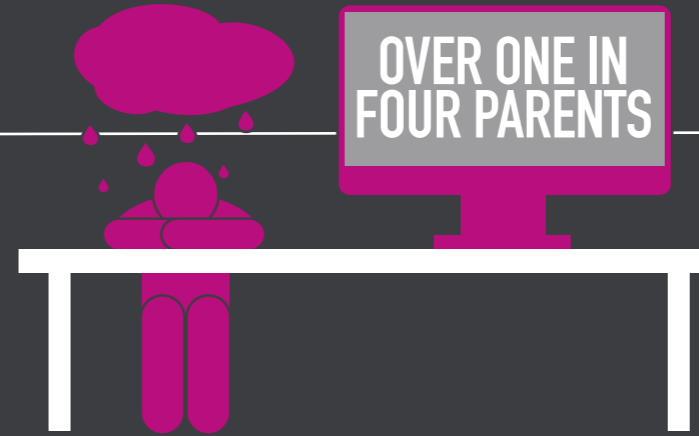


Half of young people and three out of five parents **went back to work before they felt ready**

One in four young people have felt **discriminated against at work** or when applying for a job because of their cancer or treatment

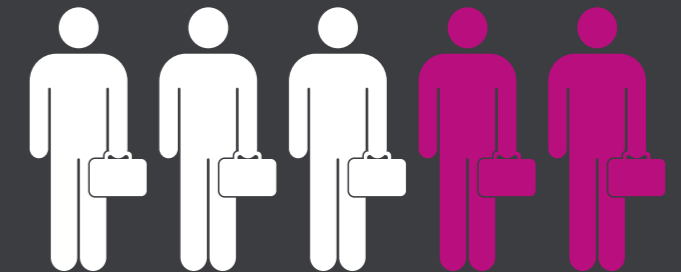


OVER ONE IN FOUR PARENTS



Over one in four parents have felt **unfairly treated at work** or when applying for a job because of their child's cancer

Three out of five young people feel they have **missed out on an employment opportunity** due to cancer



Nearly three out of four young people with cancer did not know **employers have a legal duty to make 'reasonable adjustments'** so they aren't disadvantaged

Half of young people with cancer have **never received any 'reasonable adjustments' at work.** Of those, nearly three out of four would have liked to



Nearly half of parents of children with cancer have **never accessed flexible working arrangements.** Of those, three out of five would have liked to



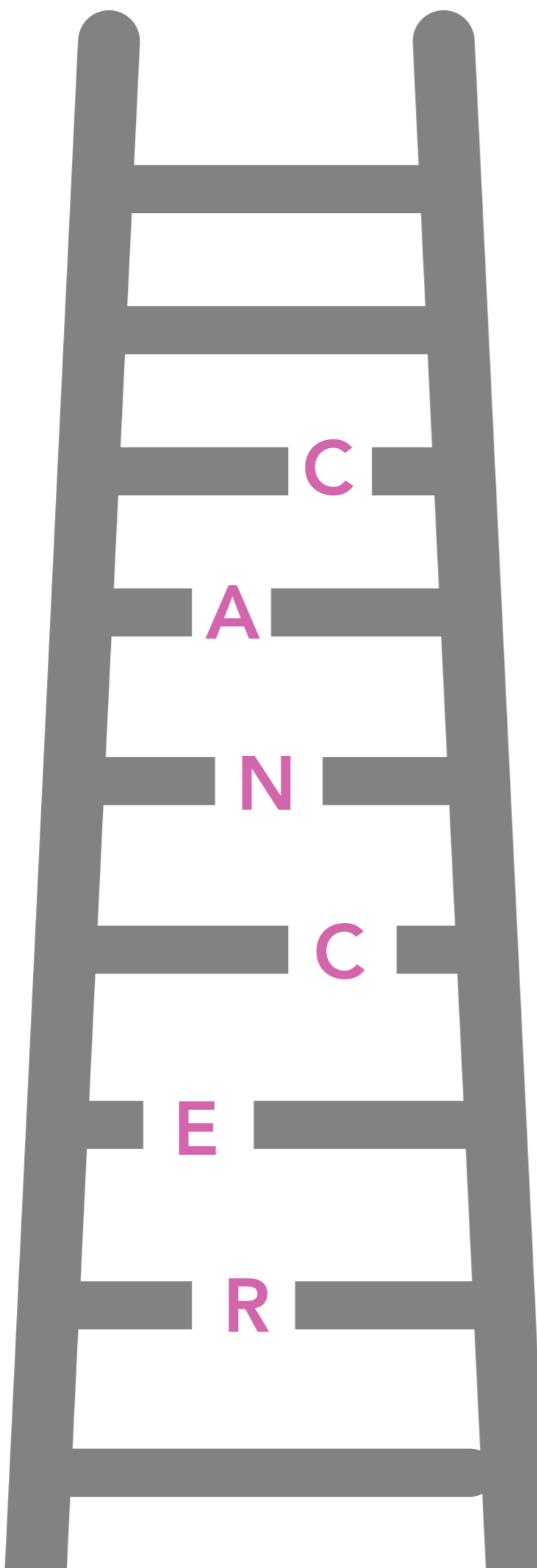
Our new research shows that **cancer causes a significant long-term disruption on employment and finances** for both young people and parents. Most require significant periods of time away from work, often unpaid, and not enough are able to access government support. This makes it difficult to manage their finances at a time when costs are likely to be mounting. Because of this, many young people and parents **return to work before they feel ready**, leaving them unable to recover from the physical, emotional and psychological costs of cancer.

Many young people and parents told us **their employer wasn't supportive and didn't understand the impact cancer had on their ability to work**, particularly if treatment lasted a long time or they experienced a relapse or secondary cancer. We also heard worries about **discrimination and unfair treatment** by employers and found that many young people and parents are unaware of their rights and unsure where to turn for help.

The long-term impact of cancer cannot be overstated. Many young people struggle for years to overcome **gaps in their education or employment history**, limiting their **opportunities, confidence and ambition**.

### But it doesn't have to be like this.

With the right support from government and employers, and a better awareness of childhood, teenage and young adult cancer, **we know things can get better** – not just for young people and parents, but also for employers and society as a whole.



## INTRODUCTION

We know **life is tough** for many families and young people across the UK. More and more people are **struggling to manage financially**. Child poverty has been rising across the country since 2011 (Joseph Rowntree Foundation, 2018) and up to 8.3 million people are now unable to pay off debt or meet the cost of household bills (Money Advice Service, 2017).

**Life at work is hard too.** One in nine workers are in insecure employment such as zero-hour contracts, self-employment, agency work or casual work (TUC, 2019). Many are struggling with low pay, bad conditions and having to balance multiple jobs. Young people face an increasingly competitive job market and are often expected to have built up work-experience and skills for free.

### All of this, even before cancer strikes.

In 2016 our research showed that families spend an **extra £600 per month** during treatment on things like hospital car parking and extra bills. Much of this is spent on travel; in 2018 our research showed that young cancer patients are travelling on average **60 miles to access the treatment they need**, costing **£180** when treatment is at its most intense (CLIC Sargent, 2018). As financial stresses pile up, debt can start mounting (CLIC Sargent, 2016).



These additional costs come at a time when many parents and young people are forced to give up work for long periods of time and take unpaid leave. Our #CancerCosts research in 2016 found that:

- Around **two in five** young people **gave up work** during treatment and **two in five** parents **stopped working** due to their child's diagnosis
- **Two out of five** young people and **half of** parents experienced a **loss in earnings**
- **Two out of three** parents took **unpaid leave**, with a **fifth** having to take **over a year**.



Through this research we wanted to know more about the short and long-term issues around:

- Gaining and keeping employment
- Career progression, ambition and confidence
- Time away from work and returning to work
- Reasonable adjustments and flexible working
- Work experience and skills
- Government support for employers and employees.

Existing research has already been done in these areas. In 2018, YouGov and Macmillan Cancer Support found that 18% of people who return to work after being diagnosed with cancer go back before they feel ready and one in five face discrimination from an employer or colleague (YouGov and Macmillan Cancer Support, 2018). In 2012 research commissioned by Maggie's (a cancer support charity) and Unum (a leading employee benefits provider) showed that 63,000 people with cancer in the UK are held back from returning to work because of the lack of support available to employers and employees. If these barriers were overcome, work could play a vital part in recovery; respondents said it gave them a sense of normality and purpose and improved their self-esteem (Maggie's, Unum & Oxford Economics, 2012).

Existing research shows that adult survivors of childhood cancer have higher levels of **unemployment** (Pang et al, 2008; De Boer et al, 2006), **lower career readiness** and **lower earnings** (Strauser et al, 2014; Kirchoff et al, 2011).

**Cancer type also has an impact.** A 2006 meta-analysis found that adult survivors of childhood central nervous system (CNS) and brain tumours were nearly five times more likely to be unemployed compared to healthy controls (de Boer, Verbeek & van Dijk, 2006).

**Age** is also a factor, with research finding increased risks of unemployment in adult childhood cancer survivors if they had a CNS tumour, bone cancer, treatment with radiotherapy or were aged less than four at diagnosis (Pang et al, 2008).

However, not enough is understood about the reasons for this or what can be done to help. In 2019, the James Lind Alliance Priority Setting Partnership (a non-profit initiative bringing together clinicians, patients, carers and researchers to identify research priorities within health and social care) concluded that **understanding effective interventions helping teenagers and young adults with cancer return to work and education is a top priority for teenagers and young adults with cancer** (James Lind Alliance, 2018).

There has already been research into the challenges carers of disabled or unwell children face, but not enough is known about those caring for a child with cancer. This is a **uniquely challenging situation** because of the need to travel for treatment, the length of treatment, the long-term side effects, the psychological and emotional impact and the additional costs.

That's why CLIC Sargent and Societe Generale in the UK wanted to know more about the impact cancer has on employment for young people with cancer and their parents. If we better understand what can prevent young people getting and keeping a job, **we can help employers provide better support and campaign for structural changes.**

## The best people to research issues are those directly affected.

But we knew we couldn't undertake this project alone. The **best people to research issues are those directly affected.** Which is why we set up the **Young Researchers Group** – a team of 14 young people who have had cancer and been supported by CLIC Sargent. The group have drawn on their own experiences to help us design and conduct the research, and to analyse and disseminate the findings. This means that the **experiences and voices of young people with cancer continue to be at the heart of everything we do.**

## Policy context

Young people with cancer automatically **meet the legal definition of a disabled person from the day of diagnosis** and are therefore covered by the Equality Act 2010 in England, Scotland and Wales and by the Special Educational Needs and Disability Order 2005 and the Disability Discrimination Act 1995 in Northern Ireland.

This means **employers can't discriminate** by, for example, rejecting someone's job application for cancer-related reasons or penalising them for time off sick without taking cancer into account.

Employers are also required to make **reasonable adjustments** so young people are **not disadvantaged by cancer.** These could include **physical alterations** such as making the workplace accessible for someone using a wheelchair or crutches, or providing a designated parking space. Or a **change to working practices** such as time off for treatment or appointments, a phased return to work, or flexible hours. Whether an adjustment is 'reasonable' depends on whether it is practical, effective and affordable, as well as considering the organisation's size and resources, and the availability of financial support.

Employers also **cannot legally treat parents less fairly because their child has cancer.** This means they cannot refuse to offer them a job or promotion or give them less favourable employment terms (such as lower pay). Parents of a child with cancer are entitled to request **flexible working** if they meet certain criteria. Some parents can also request **parental leave** if they have worked at an organisation for over a year. Some employers will approve **compassionate leave** in an emergency for short periods of time.

Young people with cancer and parents and carers of children with cancer may also qualify for **Statutory Sick Pay (SSP)** meaning they can receive weekly payments of £94.25. However, **only those who earn an average of at least £118 per week are eligible.** The government is currently reviewing SSP in order to reduce ill-health-related job loss. We will monitor the outcome of any changes for young cancer patients and their families.

Parents whose child requires 35 or more hours of care per week may be entitled to **Carer's Allowance** if they are on a low income and receive certain benefits.



Employers are required to make reasonable adjustments so young people are not disadvantaged by cancer



# RESEARCH APPROACH

## CLIC Sargent Young Researchers

When we began this research, we wanted to make sure the voices of young people with cancer were heard at every stage. We knew the best way to do this was to team up with those with direct experience of cancer. So we formed the CLIC Sargent Young Researchers Group – a team of 14 people aged 16 to 25 who have had cancer and have been supported by CLIC Sargent.

**We wanted to make sure the voices of young people with cancer were heard at every stage**

The group have received ongoing training on research methods, ethics and policy issues. They helped us explore the issues discussed in this report by sharing their own experiences of the ways cancer impacts employment. Crucially, they helped us design and test our surveys, as well as assisting in the analysis of qualitative and quantitative data – drawing on their training and personal experiences. The group went on to assist in the production of this report and will be key to getting the message of its findings and recommendations out there.



## Literature review

Before we started the survey, we reviewed and evaluated existing research in this field, identifying gaps in understanding and guiding the development of our research themes. We drew on a variety of sources, including CLIC Sargent’s internal evidence database and open access journals. We found a total of 16 texts of key relevance and included those in the final review.

## Online surveys

We created two online surveys, based on the literature review and our preparation work: one aimed at 16 to 25-year-olds who have or have had cancer, and one for parents of children who have or have had cancer. The CLIC Sargent Young Researchers played a key role in designing and testing the young people’s survey. Parents were consulted on the draft survey questions. CLIC Sargent social care staff were also consulted on the content of both surveys.

The surveys went live in April 2019 and were promoted through our website, social media channels and social care staff. A total of 258 parents and 152 young people responded.

## Qualitative research

We conducted workshops with young people, parents and CLIC Sargent social care staff at various stages of the project to scope the research, develop key themes and provide detailed qualitative evidence. A total of 31 young people, 17 parents and 17 CLIC Sargent social care staff participated.

## Limitations

Respondents were self-selecting and so they don’t necessarily represent the experiences of all young cancer patients and their families.

However, given the rarity of childhood cancer we feel confident that we have consulted with a significant proportion of the population and thus have a good understanding of the impact cancer has on employment for young people and families.

We recognise that this report doesn’t explore all experiences relating to the impact cancer has on employment for young people and their families. In particular it does not capture the unique experiences of parents if a child dies.

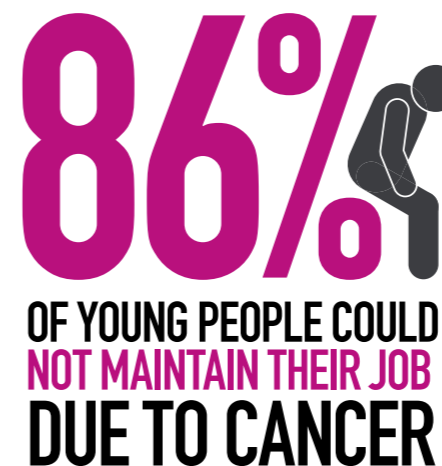
Many accounts were retrospective and therefore reliant on memory and potentially affected by subsequent events.

# FINDINGS

## Government support

### Time away from work

Cancer treatment is intense, long and brings a range of side-effects. This means most young people and parents often need long periods of time away from work or education while they or their child undergoes treatment. This can last anything from a few months to several years.



Our survey found that the vast majority (86% n=98) of young people and two out of three (62% n=213) parents **could not maintain their job due to cancer**.

We also found that, of those parents who stopped working, **nearly half (46% n=113) stopped for over a year and nine out of 10 (87% n=113) stopped for over six months**.

The type of leave available to young cancer patients and their parents can vary significantly, often depending on the Human Resources policies of the employer. Although parents and carers are entitled to take time off work after a cancer diagnosis, there is no legal obligation for their employer to pay them.

We know that lots of young people and parents are taking long periods of unpaid leave, leaving them struggling to cope with the spiralling costs of cancer. Our previous research showed that cancer costs families an extra £600 per month on things like travel, hospital car parking and bills. For young people this figure is £360 per month (CLIC Sargent, 2016).

Half of young people (50% n=64) and two out of five parents (41% n=160) have taken unpaid leave during cancer treatment.



Nearly one in five parents (17% n=160) have taken over four months of unpaid leave during their child’s cancer treatment. Two out of five young people (39% n=64) have taken over a month.

More than two out of three parents (67% n=160) took sick leave to care for their child during treatment, with more than one in four (26% n=160) taking over six months.

One in three parents (34% n=160) took annual leave to care for their child during treatment.



**ONE IN FIVE PARENTS TOOK OVER FOUR MONTHS OF UNPAID LEAVE**

**TWO OUT OF FIVE YOUNG PEOPLE TOOK OVER A MONTH OF UNPAID LEAVE**





## Sick Pay

Young people with cancer and parents or carers of children with cancer may qualify for Statutory Sick Pay (SSP). This means they can receive weekly payments from their employer. To do so they must see a medical professional, often their GP, who assesses them and issues a statement that they are not fit to work.

However, young people and parents have told us it can be difficult to access SSP. We know that many young people don't qualify due to the terms of their contract. This could be because of the types of roles they have, or because they are in part-time or insecure work.

Parents and CLIC Sargent social care staff have reported that doctors are sometimes unwilling to sign off parents so they can look after their child if they themselves are not ill.

What's more, the maximum time period to receive SSP is 28 weeks. As cancer treatment can go on for much longer than this, young people and parents can be left struggling to cope.

Our survey found that, over half (52% n=51) of young people and nearly two out of five parents (38% n=81) were signed off sick when they or their child were diagnosed with cancer.

"I had to go on unpaid leave after my sick leave was used up. I was fortunate that my child survived and my job was kept open for me. However, due to the unpaid leave and then returning to reduced hours in my job, we got into debt and had to sell our home a few years after treatment finished."

Parent of a child with cancer

## Becoming a carer

Some parents can claim Carer's Allowance if their child's cancer means they require 35 hours or more of care per week. However, parents and social care staff that we spoke to feel the criteria to receive this support are too narrow and that the amount is too low. We also know that Carer's Allowance is inconsistent across the UK, with carers in England, Wales and Northern Ireland worse off than those in Scotland (Carers UK, 2018).



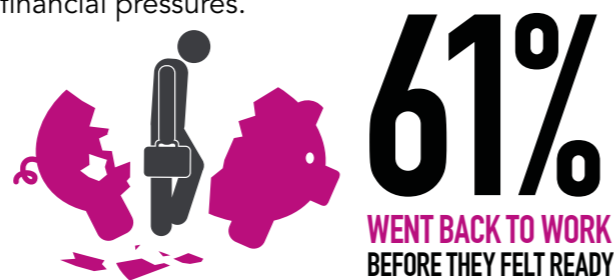
We found that one in five parents who were employed when their child was diagnosed (19% n=41) **left work to become a full-time carer for their child.**

One father told us that he chose to take early retirement so he could become a full-time carer for his daughter. He was sad to leave a job he had been doing for decades but felt forced to by financial necessity.

## Return to work

In 2018, YouGov and Macmillan Cancer Support found that 18% of people diagnosed with cancer returned to work before they felt ready (YouGov and Macmillan, 2018).

Our research showed that that lots of young people and parents go back to work much sooner than they would like following their or their child's cancer treatment, often due to financial pressures.



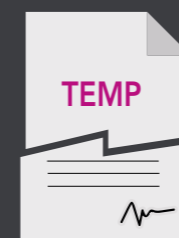
Nearly half of young people (48% n=46) and nearly one in three parents (61% n=98) **went back to work before they felt ready.** Of these, four out of five young people (80% n=36) and over half of parents (56% n= 76) said this was **because they needed the money.**

"I felt like I went into work much sooner than I was ready to, purely out of financial necessity. I had waited six months for Personal Independence Payment and I didn't get any sick leave... I had to go to work because I was bogged in my overdraft and couldn't get any financial support. So I literally finished radiotherapy and the week after I got a job... the hospital said 'you're running before you can walk' and I was like 'well, I need food'."

## A young cancer patient

### Insecure work and challenging conditions

Some young people and parents face additional challenges due to temporary contracts, zero-hour contracts, agency work or casual work. People in insecure work are significantly more likely to face low pay. They are also at risk of missing out on basic rights and entitlements including SSP and the right to request flexible working (TUC, 2017).



25% of young people  
20% of parents  
did not have a  
permanent contract

One in four young people (25% n=94) and one in five (20% n=213) parents who responded to our survey did not have a permanent contract.

Bad conditions, long hours and shift work can put additional pressures on parents already struggling to cope with their child's cancer. One mum told us how difficult it was for her partner to juggle night shifts alongside taking her son to treatment and looking after their other children.

"It nearly killed him. It killed our relationship. Because it was too much."

Parent of a child with cancer

It's clear that the current welfare system doesn't provide adequate support for young cancer patients or their families who are forced to take time off work. SSP is not available to enough young cancer patients and their parents. Carer's Allowance is too low, difficult to access and inconsistent across the country.

It's simply not good enough that so many young people who've experienced cancer and their families aren't able to access the financial safety net they're entitled to.

Improvements to these welfare benefits will help parents better manage the costs of cancer and may reduce their reliance on other government benefits later on. It will also ensure young people and parents aren't forced to return to work before they're ready.

## Recommendation:



**More support from the government for employees.** The current welfare system doesn't provide adequate employment support for young cancer patients or their families. Statutory Sick Pay is available to too few young cancer patients and their parents, and is inflexible to the modern workplace. All young cancer patients who are in employment when diagnosed should be able to access Statutory Sick Pay to help them manage the costs of cancer and time away from work. Similarly, Carer's Allowance is difficult to access and the amount is too low and inconsistent across the UK. Carer's Allowance should be reviewed to ensure ensure parents are able to support their child throughout cancer treatment and in the aftermath.

## Support from employers

### Feeling the pressure

Some young people and parents told us they went back to work before they felt ready. Some felt pressure from their employer. Others felt guilty for being off work or felt indebted to their organisation, manager or colleagues because of the support they'd received during treatment.

We also know that young people are facing an increasingly competitive job market where work experience is key. And so some young people feel they have to re-enter the workforce before they're ready.

Going back too soon means young people struggle to adequately recover from treatment and parents aren't able to support their children. For some, an early return means they require additional time off in the future.



**ONE IN FOUR FELT PRESSURE TO RETURN TO WORK**

One in four parents (24% n=108) and one in four young people (24% n=36) returned to work even though they didn't feel ready because they felt pressure from their employer.

"I felt quite guilty because I couldn't work for so long but they kept the job [open]. But also it felt like there was pressure on me to start earlier than I was necessarily ready to in terms of fatigue and stuff because they'd been so nice and let me keep the job."

A young cancer patient

"I soon felt pressure to return to work and was unable to reach my employer's expectations as my child was still in treatment and often admitted to hospital for infections. I was made redundant within nine months of diagnosis."

Parent

### Recommendation:



**More understanding of the ongoing impact of childhood, teenage and young adult cancer.** It's not right that young cancer patients and their parents are facing pressure to go back to work before they feel ready. We want to see better awareness of the long-term impacts of cancer so that employers understand that young people and parents can't return so soon after treatment.

### Recommendation:



**Better access to reasonable adjustments and flexible working opportunities.** We want to see employers proactively doing all they can to support young cancer patients and their parents to return to work when they feel ready. Phased returns, reasonable adjustments, flexible working and effective communication are key.

## Working during and after treatment

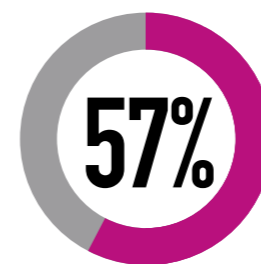
### Young people

For young people who take time off, returning to work can be incredibly challenging. The physical, cognitive, emotional and psychological effects of cancer and treatment can have a long-lasting impact on their ability to work, even after treatment is finished. Without adequate support and adjustments, young cancer patients are at a huge disadvantage in the workplace and may feel unable to fulfil their potential.

Our report, **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.

Nearly three out of five young people (57% n=148) feel they've become **less able to do their job well** because of cancer.



said that cancer has made it harder to keep a job

Over half (57% n=111) of young people said that **cancer has made it harder to keep a job.**

This research has discovered that lots of young people feel their employer is supportive when they are first diagnosed. However, the longer treatment goes on, the less support they feel they receive. Young people told us they don't feel well supported when treatment is over.

One in 10 (9% n=87) young people felt their employer wasn't supportive when they told them about their diagnosis. This increased to 16% during treatment and nearly one in three (30%) once treatment had finished.



"Chemo brain, brain fog and memory problems – it is all very real, but most employers and most people aren't aware"

Young person with cancer



**Employers have a legal duty to make reasonable adjustments so that young people aren't disadvantaged by cancer.** These could include physical alterations such as making the workplace accessible for someone using a wheelchair or crutches, or providing a designated parking space. Or a change to working practices such as time off for treatment or appointments, a phased return to work, or flexible hours. Whether an adjustment is 'reasonable' can depend on practicality, effectiveness, cost, an organisation's size and resources, and the availability of financial support.

However, not enough young people are aware of their employment rights and many aren't accessing them. Worryingly, many young people who have received reasonable adjustments said that they didn't meet their needs.



Nearly three out of four young people (71% n=99) did not know employers have a legal duty to make 'reasonable adjustments' so they aren't disadvantaged because of cancer.

Half (49% n =111) of young people who have been employed during or since their cancer have never received any reasonable adjustments. Of those, nearly three out of four (72% n=54) feel they would have benefited from some.

Of those who have experienced reasonable adjustments, nearly two out of five young people (38% n=55) said these did not fully meet their needs.

"I was made to work from home to meet targets shortly after having my operation. At this point my head was spinning from everything that was happening."

Young person with cancer



It's unacceptable that so many young people are at a disadvantage in the workplace because they aren't able to access the support they are legally entitled to. They may be struggling to cope with their workload and have unreasonable expectations placed on them. They are unlikely to fulfil their short or long-term potential or achieve the promotions and financial rewards that they would otherwise receive.

**Parents**

Parents of children with cancer also face significant challenges in the workplace. They are likely to need time off to care for their child and support other family members. This is all in addition to dealing with the emotional, psychological and financial impact of their child's illness.

Two out of three parents (66% n=160) said they **struggled to manage their child's cancer** and treatment alongside their work.

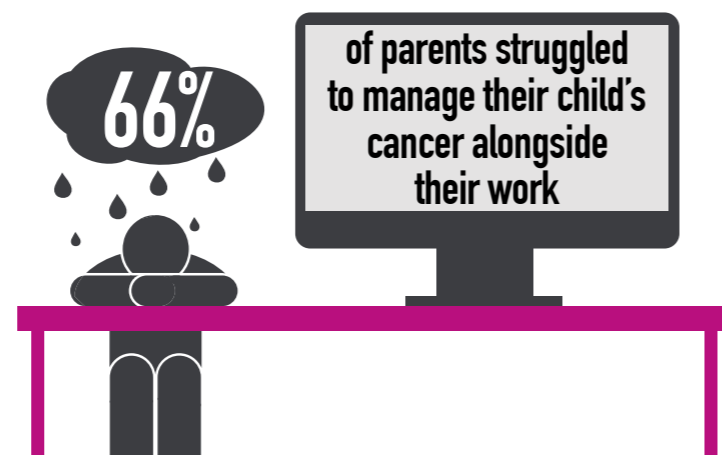
One in 10 (9% n=144) parents felt their **employer wasn't supportive** when they told them about their child's diagnosis. This increased to 16% during treatment and one in four (27%) once treatment was finished. This suggests that **support can be time-limited** and that patience can wear thin.

Parents who are caring for an unwell child are legally entitled to request flexible working if they have been employed for at least 26 weeks and haven't requested flexible arrangements within the last 12 months.

However, our research showed that nearly half (44% n=181) of parents have **never experienced any flexible working arrangements**. Of these, nearly two out of three (61% n=80) feel they would have benefited from some, with the most popular ones being **reduced hours, working from home, flexible hours and altered responsibilities**.

"People do get sympathy fatigue, especially by the third year."

Parent



"Whilst initially supportive of my son's diagnosis, they were less supportive when I told them my son's treatment plan was going to be three years long. Whilst they were happy for me to reduce hours in the beginning it became apparent that I was more of a burden to the organisation with the amount of hospital appointments and admissions my son had. This was compounded when my mental health declined with the pressure of treatment and work, and I was medically discharged."

Parent

Employers are required by law to support young people with cancer and their parents. Yet it can also bring a range of benefits to employers such as improved staff wellbeing, higher productivity and better staff retention.

We discovered several examples of good practice from employers supporting young people and parents throughout their experience of cancer. However, we know this isn't always the case. In addition, some organisations have excellent Human Resources policies but these aren't always put into practice.



**Recommendation:**

**Better access to reasonable adjustments and flexible working opportunities.** Employers should do all they can to offer a range of tailored support from diagnosis until after treatment finishes, or as long as needed. This should include phased returns, reasonable adjustments, flexible working and effective communication.

The Equality Act 2010 protects the employment rights of young cancer patients, but more needs to be done to ensure that everybody knows this. Young people need to be better equipped to know their rights and employers need to be more aware of the reasonable adjustments they should be making to assist young people and parents in the workplace.

## Facing discrimination

### Young people

Research from YouGov and Macmillan Cancer Support found that one in five (20%) people who returned to work after being diagnosed with cancer say they've faced discrimination from an employer or colleagues (YouGov and Macmillan, 2018).

Employment discrimination can hit young cancer patients particularly hard – they may just be starting out in the world of work or have been at an organisation for a short time, perhaps not yet passing a probationary period. They may lack knowledge about their legal rights and how to raise concerns or seek support. Younger people may also lose out due to power dynamics in the workplace where age and experience can be significant factors.

Not all young people with cancer think of themselves as having a disability. This research has found that **just two out of five survey respondents (40% n=139) considered themselves as having a disability due to cancer or a late effect of cancer treatment.** Some young people just don't feel this description applies to their situation, but others may not be aware of the legal definition of a disabled person or may be put off by the stigma of being labelled 'disabled'.

Nevertheless, young people with cancer automatically meet the legal definition of a disabled person from the day of diagnosis and are covered by equalities legislation. This means employers can't discriminate by, for example, rejecting someone's job application for cancer-related reasons or penalising them for time off sick without taking cancer into account.

Despite qualifying for legal protection, the young people that we spoke to worry that they will miss out on job opportunities because employers might think they'd need time off or wouldn't be as good at the role.

Two out of three (66% n=103) young people said they are **concerned about whether to or how to disclose their diagnosis** to a current or potential employer.

Some organisations automatically offer interviews to disabled applicants (a practice encouraged by the government's Disability Confident scheme), but if young cancer patients are concerned about



disclosing their diagnosis or don't disclose it, they are unable to access these schemes.

"I wasn't sure whether I was disabled or not.... I wasn't sure if I was being a fraud."

A young cancer patient

"I told them after I was accepted [for the job] because I didn't want them to have the opportunity to discriminate, and in the interview I didn't want to feel like a cancer patient."

A young cancer patient

Unfortunately, this isn't just paranoia. Our survey found that:

nearly one in four young people (24% n=92) have **felt discriminated against at work** or when applying for a job **because of their cancer** or treatment.

### Parents

Parents also told us they worry potential employers will be reluctant to take them on if they're honest about their child's illness, even many years after treatment has finished. Many were concerned that they'd be seen as unreliable or less effective in their role due to needing additional time off to care for their child.

UK legislation protects parents from being treated less fairly by employers because of their child's cancer. This means employers cannot refuse to offer them a job or promotion or give them less favourable employment terms such as lower pay.

Parents and carers are worried though:

Over one in four parents who responded to our survey (27% n=189) have **felt unfairly treated at work** or when applying for a job because of their child's cancer.

Our research also uncovered times when parents faced potentially unfair treatment relating to pay and entitlements such as unfair dismissals, demotions, forced redundancies and docked pay. One mum explained that she took four months off to support her daughter during a particularly intensive part of her treatment; she was subsequently taken back to the bottom of her pay band and lost all rights to enhanced maternity pay. The financial impact of this affected the family for a long period.

### Awareness

Many young people and parents told us their employer didn't understand how long cancer treatment can go on for, its wide range of long-term side effects or the need for medical appointments post-treatment.

Nearly one in four young people (23% n=80) said **their employer didn't understand the impact cancer and treatment had on their ability to work** during treatment; this figure increased to one in three (36% n=80) after treatment.

One in four parents (24% n=138) told us their employer didn't understand the impact their

**child's cancer had on their ability to work during treatment.** This increased to two thirds (39% n=111) once treatment had finished.

"My work were supportive on diagnosis and treatment but now she is in remission, it's like they lack the importance of these check-ups and are making it increasingly difficult to attend... I am a single parent with limited support and so need to work."

Parent of a child with cancer

"Employers don't understand the need for regular hospital appointments...I have no control over the time of the appointment! Also they don't understand that because of my cancer, when I get ill it lasts a lot longer than a normal person and it is a lot worse. They also don't recognise that even six years down the line from treatment you can be exhausted and just need a day to recuperate."

Young person

### Recommendation:

More understanding of the ongoing impact of childhood, teenage and young adult cancer. We want to see improved awareness within the workplace, with appropriate training and resources available to those who are supporting young cancer patients or their families.



# LONG-TERM CAREER IMPACT

We know that cancer has a long-term impact on the employment prospects of young people and their parents.

Our #CancerCosts research in 2016 concluded that for young people, the true costs of cancer may not be realised until years later, due to the impact it can have on their education and employment (CLIC Sargent, 2016).

Our new research found that:

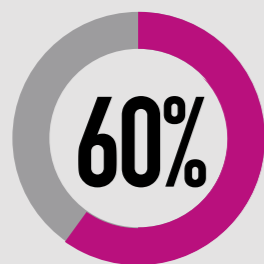
## Work experience and skills

Three out of five young people (60% n=148) feel they have **missed out on an employment opportunity** due to cancer.

Two out of five young people (43% n=157) felt that **cancer has been a barrier to gaining work experience** and employability skills.

"I'm worried about how I will look for work after cancer, with such huge gaps on my CV from last time as well, I feel like I'm years behind everyone else."

Young person with cancer



feel they have missed out on an employment opportunity due to cancer

## Career and ambitions

Nearly half of young people (45% n=50) said that **cancer has had a negative impact on their career progression**.

Two out of five young people (41% n=157) have had to **downgrade their employment ambitions or choice of career due to cancer**.

"I want to become a teacher, which involves working with children. Doctors advised against this for some time after treatment, but weren't clear on what I could do to overcome the issue – it's still ongoing."

Young Person with cancer

"I've tried over the last 12 months to build my career... But it's impossible because I don't physically have enough time and headspace. Even though [my son] has been off treatment for three and a half years all of the stress and everything else means I'm just going to be on a zero-hour contract for the rest of my life, in a job that's fine but not what I wanted for my career at all."

Parent



## Confidence

Two out of three young people (64% n=157) said that **cancer has reduced their confidence** to work or apply for jobs.



"The employer took the risk of employing me and for whatever reason it hasn't worked out... It has really knocked my confidence as to me it was more than just a job, it was me getting my life back to normal again."

Young person



### Recommendation:



More support from the government for employers. We think there needs to be better support for employers to enable them to help young people and parents overcome the employment barriers that cancer brings. The government has a range of schemes aimed at helping people with health conditions, like cancer, or people who have been out of employment for a long time to find or maintain work. These include Access to Work, which provides practical and financial support, and the Disability Confident scheme, which aims to help organisations recruit and retain disabled people. Further research is needed to understand how effective these schemes are.

### Recommendation:



More understanding of the ongoing impact of childhood, teenage and young adult cancer. This research has revealed that many employers simply don't understand the side-effects of cancer treatment and how long-lasting these can be. Nor do they understand the emotional, psychological and financial impact of treatment. We want to see improved awareness within the workplace, with appropriate training and resources available to those who are supporting young cancer patients or their families. It's to everyone's advantage for employers to recognise young people's potential, regardless of circumstance, and help them pursue their career goals.

# CONCLUSION AND RECOMMENDATIONS

We know that cancer costs. It doesn't just limit your physical health, it takes over your whole life. Your ambitions and dreams, your education and career, suddenly seem very far away.

Our new findings, alongside existing research, have shown this is particularly true when it comes to the world of work.

Many young people and parents struggle for years to overcome gaps in their employment or education, even after they have finished treatment. These gaps in experience and skills not only harm their ability to get and maintain jobs, but can also damage their confidence and ambition. Too many young people are forced to downgrade their career aspirations and are unable to fulfil their potential.

## Not enough are able to access adequate government support

Due to the intensity of treatment and its range of long term side effects, most young people and parents need significant time away from work, often unpaid. Not enough are able to access adequate government support, leaving them struggling to cope with mounting cancer costs. Too many are forced to return to work before they have recovered from the physical, emotional and psychological costs of cancer, simply because their financial costs are more pressing. This isn't right, and it isn't fair.

## Many told us their employer wasn't supportive

Once back in the workplace, fresh challenges mount. Many people we spoke to told us their employer wasn't supportive or understanding, and we heard concerning stories of perceived discrimination and unfair treatment. Many young people and parents are unaware of their rights and where to turn for support, leaving them even more vulnerable.

Something that came up again and again was a lack of awareness about the reality of cancer on young lives. Too many employers simply don't understand the physical, emotional, psychological and emotional cost, or how long these last.

We know it can be hard for employers to support young people and parents, often due to financial and Human Resources limitations, or a lack of awareness about childhood, teenage and young adult cancer. However, we also uncovered instances of good practice by employers and a range of great ideas for how support can be further improved. With the right support and awareness, employers can play their part to support young cancer patients and their families. Things will get better for employers too, with improved staff wellbeing, higher productivity and better staff retention.

## With the right support and awareness, cancer need not cost quite so much to employment for young cancer patients and their families

Too many young cancer patients and their families are being let down. On top of cancer – something so overwhelming, isolating and unfair – many are facing devastating financial pressures and challenges relating to work.

But it doesn't have to be like this. With the right support and awareness, cancer need not cost quite so much to employment for young cancer patients and their families.

## As a result of this research we are calling for:



**More support from the government for employees.** The current welfare system doesn't provide adequate employment support for young cancer patients or their families. Statutory Sick Pay is available to too few young cancer patients and their parents, and is inflexible to the modern workplace. All young cancer patients who are in employment when diagnosed should be able to access Statutory Sick Pay to help them manage the costs of cancer and time away from work. Similarly, Carer's Allowance is difficult to access and the amount is too low and inconsistent across the UK. Carer's Allowance should be reviewed to ensure ensure parents are able to support their child throughout cancer treatment and in the aftermath.



**Better access to reasonable adjustments and flexible working opportunities.** Employers should do all they can to offer a range of tailored support from diagnosis until after treatment finishes, or as long as needed. This should include phased returns, reasonable adjustments, flexible working and effective communication.

The Equality Act 2010 protects the employment rights of young cancer patients, but more needs to be done to ensure that everybody knows this. Young people need to be better equipped to know their rights and employers need to be more aware of the reasonable adjustments they should be making to assist young people and parents in the workplace.



**More understanding of the ongoing impact of childhood, teenage and young adult cancer.** This research has revealed that many employers simply don't understand the side-effects of cancer treatment and how long-lasting these can be. Nor do they understand the emotional, psychological and financial impact of treatment. There needs to be improved awareness within the workplace, with appropriate training and resources available to those who are supporting young cancer patients or their families. It's to everyone's advantage for employers to recognise young people's potential, regardless of circumstance, and help them pursue their career goals.



**More support from the government for employers.** It can be difficult for employers to support a young person with cancer or the parent of a child with cancer. Resources may be limited, or there may be a lack of awareness about the impact of cancer and the needs of young people and parents. There are a range of government schemes available to employers and further research is needed to understand how effective these are.

CLIC Sargent will use the learning from this report to work with government, corporate partners and other charities to ensure that young people with cancer and parents can thrive in the workplace.

We will create and actively promote an Employer's Toolkit to equip HR teams and managers to better support young employees with cancer or a parent or carer whose child has cancer.

By working together we can ensure there is more government support for employees and employers, better access to reasonable adjustments and flexible working, and more understanding of the ongoing impact cancer has on employment for young people and their families.

CLIC Sargent would like to thank everyone who has helped with this research and report including:

All the young people and parents who took part in our scoping workshops and responded to our online surveys

Peter Mills and Mary Strutt who assisted in the creation of the parents' survey

Ben Higgins, Head of Human Resources, UK and Ireland, Societe Generale

Jazz Singh, UK Head of Group Communications, Societe Generale

Lorna Taylor, UK CSR Manager, Societe Generale

Llew Freeman, UK HR Middle Office Assistant, Societe Generale

Erin Craik, UK HR Advisor, Societe Generale

Clare Laxton, previous Associate Director of Policy & Influencing at CLIC Sargent

The HR team at CLIC Sargent

## REFERENCES AND ACKNOWLEDGEMENTS

Carers UK, *Briefing on changes to carer's allowance in Scotland* (2018)

CLIC Sargent, *Are We Nearly There Yet?* (2018)

CLIC Sargent, *Hidden Costs* (2017)

CLIC Sargent, *Cancer Costs* (2016)

De Boer et al, *Adult survivors of childhood cancer and unemployment*, (2006)

House of Commons Library, *Youth Unemployment Statistics: Briefing Paper 587* (2019)

James Lind Alliance, *Teenage and Young Adult Cancer: research priorities* (2018)

Joseph Rowntree Foundation, *UK Poverty 2018: A comprehensive analysis of poverty trends and figures* (2019)

Kirchhoff et al, *Unemployment among adult survivors of childhood cancer: a report from the childhood cancer survivor study* (2010)

Maggie's, Unum & Oxford Economics, *Can Work, Will Work: Valuing the contribution and understanding the needs of people living with cancer in the workforce* (2012)

Money Advice Service, *Over-Indebtedness in the UK* (2017)

Pang et al, *Employment status among adult survivors in the Childhood Cancer Survivor Study* (2008)

Strauser et al, *Career readiness in adult survivors of childhood cancer: a report from the St. Jude Lifetime Cohort Study* (2014)

TUC, *Insecure work: Why the new PM must put decent work at the top of his to-do list* (2019)

TUC, *The Gig Is Up: Trade unions tackling insecure work* (2017)

YouGov and Macmillan Cancer Support, *Working Through Cancer: Surveying experiences of cancer and work* (2018)



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

Registered charity number (1107328) and registered in Scotland (SC039857). 19JW192  
77-85 Fulham Palace Road, London, W6 8JA