



No young person with cancer left out

The impact of cancer on young people's education, employment and training

www.clicsargent.org.uk

Summary

No young person with cancer left out summarises research which shows that cancer can have a significant impact on a young person's education, employment and training. This report aims to raise awareness of the impact of cancer on young people's education, employment and training, highlight existing good practice and suggest ways forward.

About CLIC Sargent

Today, 10 children and young people in the UK will hear the shocking news that they have cancer. Treatment normally starts immediately, is often given many miles from home and can last for up to three years. CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical and emotional support to help them cope with cancer and get the most out of life, from diagnosis onwards.

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Foreword

Being diagnosed with cancer is devastating at any age, but for young people on the brink of adult life a cancer diagnosis and its treatment can have a huge impact. Young people diagnosed with cancer can face emotional, practical and financial difficulties during treatment and beyond. Cancer can also present significant barriers to their studies and their ability to find or maintain a job.

Over two thirds (67%) of young people we spoke to were worried about the impact of cancer on their education.

We undertook this research to better understand the barriers that young people with cancer face in education, employment and training, and we explored these issues with young people who were diagnosed with cancer between the ages of 16 and 24.

Our research found that while there were examples of good practice in colleges, universities and in the workplace, the young people who took part in the research told us that they would have benefited from more support to help them fulfil their potential during and after cancer treatment.

A cancer diagnosis can cause young people to become anxious about their future prospects. Over two thirds (67%) of young people we spoke to were worried about the impact of cancer on their education. This figure rose to nearly three quarters (74%) when young people considered the impact of cancer on their employment.

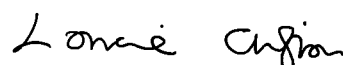
Many of the young people we surveyed and spoke to told us that having cancer inspired them to succeed in education and employment, and gave them renewed focus. But many lacked the confidence they needed to talk about their cancer – they said that this was a barrier to employment and education and that they feared rejection and judgement. Some young people told us that when they disclosed their illness, teachers and employers misunderstood their needs. The majority of young people also wanted more information about what reasonable

adjustments they were entitled to at college or university, and work, because they did not know about their entitlements.

CLIC Sargent believes there is an urgent need for more specialist information available for education providers and employers to help them better understand the impact of cancer and treatment on young people. Using the findings of our research, we will work with others to raise awareness of young people with cancer's rights and entitlements at work, school, college or university. As part of our support for young people with cancer to overcome barriers to education, employment and training opportunities, we will also work directly with young people to enable them to feel confident about sharing their experiences and voicing their needs.

Support for young people is a key component of our services strategy. As part of this strategy we have been testing a model of service for young cancer patients and survivors including face-to-face support in the community. This model has been developed in response to a lack of support available to young people with cancer, particularly those who are treated in adult cancer units close to home rather than at specialist teenage and young adult cancer centres where the majority of our current services for young people are based. As funds allow we'll develop our young people's service in partnership with NHS colleagues to ensure young people have the support they need where and when they need it.

We are extremely grateful to the 205 young people who have contributed to this report. CLIC Sargent is committed to using the findings to raise awareness of the needs of young people with cancer and to further develop the services we provide for young people during and after treatment.



Lorraine Clifton
Chief Executive

November 2013

Introduction

Overview

Each year, around 2,200 16 to 24-year-olds are diagnosed with cancer in the UK. A cancer diagnosis can significantly disrupt a young person's journey towards independence and achieving their goals and aspirations. It can: redefine their life; challenge their sense of identity; threaten their sense of belonging; make them more aware of their body image; as well as impacting on their relationships.¹

Young people in this age range are a diverse and varied group. They may be studying at college for A-levels or technical qualifications, or training as an apprentice. Some will be at university and others could be starting their first job. While some young people will be living at home with the financial support of their parents, others could have their own families and partners, or be studying and living away from home.

Staying in education, employment and training is hugely important for the emotional wellbeing and long-term prospects of young people with cancer. It can help them picture a life after cancer treatment, increase their self-esteem and ensure they have more ability to reach their full potential in life.

Why we undertook this research

Our 2010 research² found that one in three (29%) young people with cancer had to leave education and more than nine out of 10 (93%) said their employment had been affected. Almost half (43%) told us they needed more support with getting or keeping a job.

When we completed further research in 2011,³ we found that just under a third (28%) of young people had a job after their diagnosis compared to half (50%) at the time they were diagnosed. Two thirds (66%) of young people felt less able to do their job and four out of five (86%) had to reduce the number of hours they worked. Half (50%) of those we spoke to had to stop working completely as a result of cancer.

This is why CLIC Sargent decided to carry out further research to:

- Better understand the barriers that young people face in education, employment and training when they have cancer, and what support they feel they need
- Raise awareness of the challenges young people with cancer experience in keeping up with their education and employment
- Highlight ways that education providers and employers already support young people with cancer.

1 Harvey, N and Finch, A 'Supportive care for adolescents and young adults during cancer treatment' in Kelly, D and Gibson, F (2008) *Cancer care for adolescents and young adults*. Blackwell, Oxford

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

3 CLIC Sargent (2011) *Counting the costs of cancer*

What we found

We consulted with young people through focus groups, interviews and a survey to explore their experiences. Our research highlighted the emotional impact of a cancer diagnosis and its treatment, which young people have to cope with alongside often long-lasting and challenging physical and health-related side effects. All of this can have an impact on their studies, training or employment.

Many young people said that not having the confidence to talk about cancer with prospective employers was a barrier to employment. The majority wanted more information about the adjustments that they are entitled to at college, university and work because they did not know enough about their rights.

Communication between young people and their education provider or employer emerged as a key issue, particularly when they needed to be away from work or their studies. Many education providers or employers don't understand that young people may face longer term problems after having cancer, even after treatment has ended. And yet, we found that young people who have had cancer can experience physical changes which have an impact on their studying, working and building the future they imagined for themselves.

Building on what works

Our research found that having access to work experience opportunities can help young people with cancer to gain new skills and a reference, strengthen their CV and develop knowledge of a particular industry – things they might have missed out on as a result of having cancer.

Also, the young people we spoke to said that they wanted to get back to “normal life” as quickly as possible after their treatment. They welcomed meaningful activities such as training courses to help build and maintain their skills, volunteering and work experience opportunities.

Many of the young people we spoke to felt they'd acquired new skills and maturity as a result of having cancer and wanted to use their experiences to motivate them to succeed in education and employment.

Our findings highlight examples of good practice that will help shape the support we provide to young people with cancer. We will use the research to help education providers and employers to improve the support they offer young people after a cancer diagnosis. We will also encourage policy makers across the UK to do more to help with this and ensure the right support is in place for young people affected by cancer. And we will use what young people have told to focus and inspire the future growth of our services for young people.

Key findings

The impact of cancer on young people's education:

- Over two thirds (67%) "agreed" or "strongly agreed" that they worried about the impact that cancer will have on their education
- Three out of five (61%) said that having cancer had presented barriers to their education
- Two out of five (40%) were anxious about keeping up with the pace of their studies after being told they had cancer
- One in five (19%) cited not getting the grades they needed because of cancer to do the course they wanted as a barrier to their overall education
- Over one in 10 (12%) had been bullied, harassed or discriminated against by someone in their current, or most recent, place of education as a result of having cancer

The impact of cancer on young people's employment:

- Almost three quarters (74%) "agreed" or "strongly agreed" that they were worried about the impact that cancer will have on their future employment
- Over one third (37%) said that having cancer presented barriers to finding a job. Of these, three quarters (75%) said their lack of confidence was a barrier to finding a job
- Just under half (46%) had successfully completed voluntary work experience placements. Of these, 15% had done a placement organised by CLIC Sargent
- One in three (33%) said having cancer makes it hard to keep a job

Talking about cancer:

- One in five (22%) felt that not knowing how to disclose their cancer on an application form is a barrier to their education
- Three out of five (61%) were concerned about how to disclose the fact they have cancer on an application form for employment

Identifying and meeting needs:

- Over nine in 10 (96%) young people in education said their education provider was aware that they had cancer
- Just under half (47%) young people in education were not aware of the adjustments they were legally entitled to from their education provider
- Nearly nine in 10 (86%) young people in work said their employer was aware that they have or have had cancer
- One in three (30%) did not know what adjustments they were entitled to at work. A quarter (24%) "disagreed" that their employer made the adjustments they needed at work.

Context

Overview

Young people face complex issues as they grow up. This stage of development, during which an individual transitions from being a child to a young adult, is characterised by biological, psychological and social changes. Having cancer can create even more uncertainty, as well as additional challenges due to the physical, emotional and social changes a diagnosis can bring.⁴

Unfortunately, a cancer diagnosis means that young people often experience significant disruption to their family life, learning and employment, with treatment sometimes lasting as long as three years. Even before they are diagnosed, some experience symptoms which have an effect on their education or employment.

If treatment is successful and the young person goes into remission, they may still experience long-lasting effects of cancer, including chronic fatigue, attention and concentration difficulties and psychological and emotional problems. This can be as a result of the treatment, as well as of the cancer itself. Those young people who had been diagnosed with a brain tumour often have an increased risk of long-term cognitive effects because of their illness and the aggressive nature of treatment.

All of this has an effect on their learning and employment.

Previous research

Previous CLIC Sargent studies have shown that cancer can have a significant impact on a young person's education, employment and training.

*More than my illness*⁵ found that keeping up with education, employment and training is important for a young person's emotional wellbeing, increased self-esteem and long-term job opportunities. We found that just under two thirds (64%) of 16 to 18-year-olds fell behind with their studies or did not do as well as they thought they could have. Just under one in three (29%) young people had to leave education and more than two in five (41%) had to leave their job.

In 2011 our report, *Counting the costs of cancer*,⁶ found that two in three young people had to reduce their school, college or university hours because of cancer. Around two in five young people (39%) who took part in this research felt that cancer had limited their future work prospects.

No child with cancer left out, published in 2012, looked at the impact cancer has on children's primary school education, and *No teenager with cancer left out* (2013) explored the impact on secondary school education. Both reports found that communication and information are vital for a pupil to feel supported and for those around them to fully understand the impact that cancer might have on their ability to learn and fulfil their potential. We also found that cancer can quickly take away a child or young person's independence and that they may experience significant emotional and social consequences of missing out on education.

4 Harvey, N and Finch, A 'Supportive care for adolescents and young adults during cancer treatment' in Kelly, D and Gibson, F (2008) *Cancer care for adolescents and young adults*. Blackwell, Oxford

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

6 CLIC Sargent (2011) *Counting the costs of cancer*

Research from the charity Macmillan Cancer Support looked at the importance of employment, both to working age adults (18 to 64 years) with cancer and the economy. Macmillan's 2013 report⁷ concluded that lack of vocational rehabilitation services is a key reason people struggle to remain in, or return, to work. The research found that less than 2% of people with cancer access specialist return-to-work services, and over three-quarters do not access any support service related to work or employment. Macmillan proposes that UK policy makers take responsibility for improving access and availability to specialist vocational rehabilitation services for people with cancer and other complex health problems.

Current economic climate

It can be difficult for all young people looking for work at the moment because:

- Youth unemployment is high, with almost one million young people unemployed in the UK.⁸ Unemployment rates are nearly twice as high for people with no qualifications – this group of people are also likely to earn 10% less than others.⁹
- Young people aged 18 to 24 are 10% less likely to be in work today, compared to the eve of the recession in February 2008.¹⁰
- Young people often feel pressured to achieve academically, and exam success is an important feature in how they feel about their future prospects. Those with few qualifications are almost twice as likely as their peers to believe that they will “never amount to anything”. One in five young people (20%) say they’ve “abandoned their ambitions” because of their poor qualifications.¹¹

Policy

Additional support in education

The Children and Families Bill, going through parliament at time of writing, will make a number of changes to the support available for young people with special educational needs (SEN) in England. The proposals have the potential to improve coordination between the various agencies involved in supporting young people with SEN and to smooth transition into post-16 education and training.

However, we think more needs to be done to ensure young people with cancer get the support they need when they leave school and as they become young adults. We also believe that local authorities and education providers must work closely together to make sure young people receive the range of support they need to access learning opportunities.

In Scotland, the Children and Young People (Scotland) Bill, which proposes a more holistic approach to children's services, could improve the support that young people with cancer are entitled to. We are ensuring the findings of our past research are put before policy makers in all parts of the UK.

7 Macmillan Cancer Support (2013) *Making the shift: Providing specialist work support to people with cancer*

8 For latest figures see www.ons.gov.uk

9 UK Commission (2011) *The youth inquiry evidence base*

10 TUC (2013) “UK has a shortfall of 395,000 jobs for young adults, says TUC”.

Available at www.tuc.org.uk/economy/tuc-22207-f0.cfm (Accessed: 20 May 2013)

11 The Prince's Trust (2013) *Abandoned ambitions? The need to support struggling school leavers*

Changes to the welfare system

Personal Independence Payment (PIP), which is replacing Disability Living Allowance (DLA) for new claims for 16 to 65-year-olds, is being brought in gradually for people who are already receiving DLA. CLIC Sargent and other charities have worked with the Department for Work and Pensions to help make sure changes meet the needs of young people with cancer and we will continue to monitor the impact of the new benefit.

There have also been a number of changes to Employment and Support Allowance (ESA) which ill or disabled young people can claim if they are too sick to work. We address some of the issues that young people with cancer experience when they claim ESA on page 16.

Protection under equality legislation

CLIC Sargent recognises that not all young people with cancer see themselves as disabled. For this report, nearly two out of five young people (37%) surveyed said they had a disability and just over a third (34%) of all respondents felt this was due to their cancer.

However, young people who have had a cancer diagnosis are covered by the Equality Act 2010 in England, Scotland and Wales¹² and by the Special Educational Needs and Disability Order 2005 (SENDO) and the Disability Discrimination Act 1995 (DDA) in Northern Ireland. Under these pieces of legislation individuals with cancer have ongoing legal protection from diagnosis onwards.

According to the legislation, disabled people should be treated equally, including in their access to education and employment. Education providers have a duty not to discriminate against potential, current or former students. Employers have a duty not to discriminate against job applicants or employees, including all paid staff and apprentices.

The Equality Act, SENDO and DDA all emphasise the legal duty on education providers and employers to make 'reasonable adjustments' so disabled people can take part in education, use services and work. However, Macmillan Cancer Support research¹³ has found that employees lack knowledge about their legal rights, while employers lack awareness about their responsibilities.

A **reasonable adjustment** is a change an education provider or employer can make so that a disabled person is not disadvantaged. This could be a change to practice, for example allowing them to have extra time in exams. Or, a physical adjustment, such as installing a ramp for a wheelchair user or providing extra equipment like a screen reader. Whether an adjustment is 'reasonable' is based on factors such as whether it is practical, effective, what the costs are, the organisation's size and resources, and the availability of financial support for the adjustment.

¹² Cancer is listed within the Act as a 'certain medical condition' which classifies it as a disability

¹³ Macmillan Cancer Support (2010) *Making it work: How supporting people to work after cancer is good for business, good for the economy, good for people with cancer*

Careers guidance

Given the economy and jobs market, access to high quality careers guidance is essential to support young people as they navigate their way from education to their first jobs.¹⁴ Cuts in public funding have affected careers services across the UK with staffing levels in careers services in both Scotland and Wales being reduced, and significant changes being made to services in England which may reduce the face-to-face guidance which some young people receive.¹⁵



¹⁴ The Work Foundation (2012) *Raising aspirations and smoothing transitions*

¹⁵ In September 2012 the statutory duty to provide careers advice moved from local authorities to schools. Schools have not been given additional funds to secure services and do not have to provide face-to-face guidance to meet their responsibilities

Our research methodology

This research looks at the experiences of young people across the UK who were diagnosed with cancer between the ages of 16 and 24.

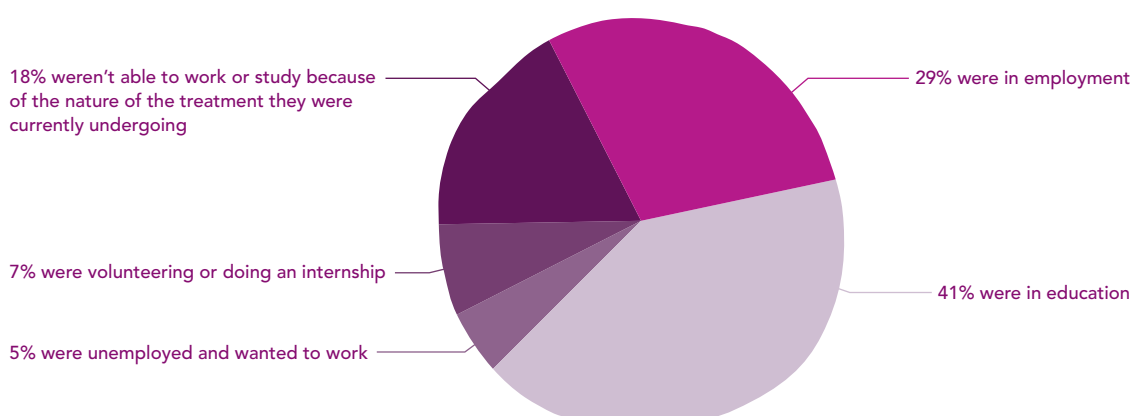
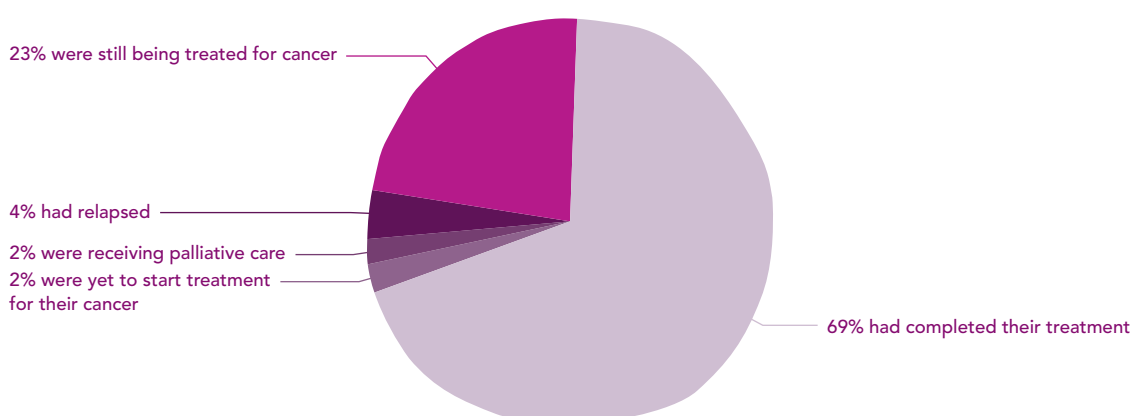
We talked to 205 young people – 169 responded to our survey, 33 took part in focus groups and three in face-to-face interviews.

Young people were involved in the design and testing of the survey which asked them about the impact of cancer on their education, work experience, and employment and training experiences and opportunities. In particular, we asked whether their cancer diagnosis and treatment presented any barriers to accessing or maintaining these opportunities, what additional support they may have needed and whether they adequately received this.

Our semi-structured interviews and focus groups were designed around the key themes identified in the survey.

Of the young people who completed the survey, 19% were aged between 16 and 19, 67% were in the 19 to 24 age group and 14% were now aged 25 to 30. The 36 young people who took part in focus groups and interviews were all aged between 19 and 24.

Of the 169 survey responses from young people who had cancer when they were 16 to 24:



The impact of cancer on young people's education

Overview

Some young people with cancer go through treatment with relatively minor disruption to their education. Others have to cope with years of aggressive and debilitating treatment, which may lead to significant gaps in their learning and impact on their potential future prospects.

Young people with cancer can face a number of challenges in keeping up with their studies, maintaining friendships and feeling included in school, college or university life. Some who go back to education after treatment need significant additional support and some may not achieve as much as they would have done if they hadn't been diagnosed with cancer.

Our 2011 research¹⁶ found that nearly two thirds (64%) of 16 to 18-year-olds with cancer fell behind with their studies or did not do as well as they thought they could have. Five out of six (83%) young people missed their friends at college and university when they couldn't see them. Nearly one in three (29%) said they left education altogether.

In July 2013, our research¹⁷ exploring the impact of cancer on teenagers in secondary school found that young people with cancer feared retaking the academic year and being left behind.

Almost two thirds (64%) of the young people we spoke to for this report had been in some form of post-16 education since their cancer diagnosis. Around three in five (61%) said that cancer created barriers to their education. And over two thirds (67%) "agreed" or "strongly agreed" that they worried about the impact cancer has had or will have on their education.

"I still need extra time off. I get tired a lot and my concentration is awful. Because of that, I feel like I don't know when I'm going to be better and when it is all going to be normal."

Feeling left behind

Often young people with cancer experience difficulties catching up with learning they missed when they were absent. For this research, 40% of the people we spoke to told us they were anxious about keeping up with the pace of work at college or university.

Around one in five (19%) said not getting the grades they needed to do the course they wanted to do was a barrier to their overall education. Some struggled because of the side effects or long-term impact of treatment. "I was really ill and picked up an infection at college so I decided not to go. I just got work sent home for me," said one young person. Another added:

"At times I struggled a bit in the last semester, when I had lots of deadlines. I got tired quicker, couldn't work until late, would get headaches and couldn't focus for long periods."

The idea of being left behind as peers progressed was an issue for many. One young person told us: "I think that there were about 19 of us that did the foundation degree all over the UK and all of them were ahead and I got stuck behind." Another commented:

"Some of my friends have finished masters now. They're qualified teachers and are moving on and getting married, getting a house. I thought it wasn't ever going to happen for me."

With more support, some respondents felt that they could have done better in their exams and this left them feeling frustrated.

Some of the young people we spoke to who were at university felt that deferring for a year, rather than stopping completely, was the best option. This represented a temporary break from study and the opportunity to return to their "normal life" as quickly as possible:

"I don't want to be defined by cancer. Deferring university was a small break, it was a detour, but I was always going to go back to what I wanted to do. Going back to my normal life was the main thing."

Others could not defer, or carry over credits when they changed to a university closer to home, which could be frustrating for those who had to repeat a year or start from scratch.

Other responses confirmed findings in our *No teenager with cancer left out*¹⁸ research which found that retaking a year was seen by young people as the "worst case scenario". Participants in our focus groups described the negative emotional and social impact of watching their friends' progress and seeing them move on without them. Their responses suggested that they felt there was a stigma to being put back a year.

Relationships with peers

Our respondents told us that their confidence was affected following their cancer diagnosis and treatment, and this could cause anxiety when they went back to college or university:

"My confidence just went. I was just starting in the second year and I didn't like putting myself out there in a big group of people who all knew each other. They'd already made their friendship groups and I was just nudging my way into it."

A quarter (25%) were concerned about how other students would treat them. This was particularly the case for those who'd been absent for a while and were returning to a different year group, or had repeated a year at college or university. The way the college handled telling people was important:

"I realised that I had to repeat a year if I wanted to get onto the university course I wanted to do. But I was dreading going back because people had heard little bits about me. But all they really knew was 'There's this sick girl coming into our year because she didn't do her exams last year'. They didn't even know my name - they just knew I'd been ill."

In terms of fitting back into their former social relationships, many young people we spoke to said that their illness had had an impact on their friendships. One told us:

"All my friends want to do is to go drinking and try new things. Maybe I would've been a bit different before this happened but now I think 'No, I don't want to be involved, I'll just let you do that'. I guess it's putting a barrier between me and my friends a little bit."

For others, having cancer drew their friends closer to them. One respondent told us that their university friends were like their parents since they cooked for them, put them to bed, and made sure they were alright. "I didn't realise that I didn't have a normal friendship with them like other students had with their housemates because I wasn't ever involved in any arguments over bills and petty things that happened. I was left out of that," they said.

For a minority, this social aspect was a big enough issue that they decided to change to a distance learning course:

"I wanted to go to the Open University because it's less hassle than having to explain to everyone. I won't be able to be involved as much and go out as much as people do in university, like I used to do in first year. I think I'm just trying to stay away from that and do my own thing."

"Up until then I wanted to be in with everybody and go out and do things. I feel that I've become a lot older in my ways because of the things that have gone on in the past. I've missed out on my youth, missed out on a lot of the things young people do."

Attitudes to cancer

Worryingly, more than one in 10 (12%) respondents said they were bullied, harassed or discriminated against by someone in their current or most recent place of education as a result of having cancer. One said that a dean at their university was unwilling to let them return to their course after learning about their diagnosis. "They insisted I take a year out despite having never met me and evidence from my doctors citing my ability to study long-distance," they said.

Others felt the impact of a lack of understanding of cancer treatment from their peers:

"The students at the university I attend do not fully understand cancer or its treatment and side effects. I have faced ignorant comments, physical discrimination and have been ostracised. This has led to me feeling isolated."

Some young people rethought their future plans in light of the effects of their cancer treatment and worried about its long-term influence on their ability to work:

"I've had to change my career, because my cancer made me physically disabled. I'd done my dance course and I am qualified to do that. But now I have to do something else because I am not able to do my dream job."

Financial impact

University fees

In England, students who started higher education courses from 2012 were charged more for tuition fees than in previous years. Universities can now charge up to £9,000 per year for full-time undergraduate courses.

Students can apply for a loan from the Student Loan Company which will cover the total cost of the fees and this is paid directly to the university, although it must eventually be paid back.

In Wales, education providers can also charge up to £9,000 for their courses. If students are from Wales, they can get a tuition fee loan of up to £3,465 to cover some of the cost and they can apply for a grant for the rest. The grant does not have to be repaid.

If students live in Scotland, as long as they meet certain residence criteria, they won't be charged tuition fees to complete their first degree.

If they live in Northern Ireland, the maximum tuition fee for students is £3,465. This does not have to be paid at the start of the course as in the rest of the UK.

Some young people we spoke to in England who had to delay the start of their university course were charged the new higher fee, even though they'd been accepted onto a course before 2012. For some, this meant changing their plans and not going to university at all:

"I got accepted in July 2010 and then I got ill and they kept my place for two years. I was prepared to go in September 2012 and I contacted them about the fees. They wanted to charge me £9,000 a year. I was going to study policing but I took the opportunity to just join the police, cut out the middleman, even though I was worried I might struggle going straight in. So I have saved myself about £18,000."

Other young people had to defer a year because of their illness. Those in England, who had started their course but then had to defer a year, were still charged the original lower fee. However, if they deferred, young people were not able to access Employment and Support Allowance (ESA). Those affected also had no access to any student loan during this time out, leaving them with potentially little financial support during the time they had deferred.

The young people we spoke to who chose to officially leave their course when taking a break for treatment were able to claim ESA. But that meant that if they returned to university, they had to pay the new higher fees:

“Because I deferred my university rather than finished it, they wouldn’t allow me to have any benefits. There is no incentive to return to normal life, the incentive is certainly just to give up.”

In Scotland, the Student Awards Agency can extend the number of years a student qualifies for support if study is interrupted due to an underlying medical condition. However, some young people in Scotland found that where they needed to change courses due to their illness (for example, because their course was no longer appropriate or they couldn’t continue due to a physical disability) they struggled to secure funding. This put them at a financial disadvantage in comparison with their peers.

Added to these difficulties, some of our respondents found that communication between student finance and the university was non-existent. They had to explain the situation and provide documentation about their cancer to student finance, even though they had already provided this to their university. Respondents suggested that having support to liaise with student finance would be very helpful:

“I told student finance I was deferring the year and they said ‘Okay’. Then, when it came back round to the next year, they said ‘But you’ve already done your second year’. I had to complain before they finally took it seriously.”

In terms of benefits, the young people we spoke to were confused about what they were or weren’t entitled to, particularly when they took a break from study. Many said that their CLIC Sargent Social Worker, or other support services, helped them access benefits.

There are a number of benefits which could be available to students affected by cancer, including ESA and Disability Living Allowance (DLA). In many cases, full-time students can only claim ESA if they are receiving DLA or have paid enough national insurance contributions to receive the contributory type, rather than the income-related benefit. But part-time students do not have to be receiving DLA in order to claim ESA.



The impact of cancer on young people's employment

Overview

We know that adults of working age who have had a cancer diagnosis are nearly one and a half times more likely to be unemployed than those who have not.¹⁹ Research from Macmillan Cancer Support shows that the long-lasting physical, emotional and practical impact of cancer can cause significant disruption to people's employment.²⁰ This includes fatigue, depression and time off for medical appointments and check-ups.

We believe that young people may be further disadvantaged at work. They are unlikely to be established in their career, or to have been working with a company or organisation for any length of time. They may not have previous work experience or may have to alter their career plans, for example because they have ongoing health issues or lack the grades they need for certain professions as a result of their cancer diagnosis and treatment. They may also be unaware of what support or legal protection they are entitled to and some may have little experience of dealing with employers.

Almost three quarters (74%) of the young people we spoke to for this report told us that they "strongly agreed" (38%) or "agreed" (36%) that they worried about the impact that cancer will have on their future employment.

Finding work after cancer

One in four (26%) of the young people who took part in our survey were looking for a job. Of these:

- ◉ Almost one in five (17%) had searched for more than seven months
- ◉ Almost one in 10 (7%) had been job hunting for 12 months or longer
- ◉ Three out of five (58%) had not had an interview
- ◉ Less than one in 10 (8%) had taken part in three or more interviews.

Almost two in five (37%) of the young people we talked to said that cancer presented barriers to finding a job. Of these:

- ◉ Half (51%) told us that lack of work experience was a barrier
- ◉ One in five (21%) said they lacked CV or application writing skills and the right qualifications
- ◉ Three in five (61%) were concerned about how to disclose cancer on an application form
- ◉ Three quarters (75%) said their lack of confidence was a barrier to finding a job.

19 De Buer AG et al (2009) Cancer survivors and unemployment: a meta analysis and meta regression. *The Journal of the American Association*, 301:753-762

20 Macmillan Cancer Support (2010) *Making it work: How supporting people to work after cancer is good for business, good for the economy, good for people with cancer*

Looking for employment when our respondents were receiving palliative care was another barrier. One young person who had terminal cancer told us that they were concerned that, after learning about their cancer diagnosis, their employer would presume they were going to get better, and they wouldn't.

Gaining work experience

Some young people with cancer are forced to miss out on opportunities to take up paid or unpaid work experience. This might be because the side effects of their cancer treatment make them too unwell to work, or because their treatment means they must attend multiple hospital appointments (and travel to/from the hospital) which makes work experience placements impractical.

It is encouraging that nearly two thirds (64%) of the young people we surveyed were "quite" or "very" confident that they'd get work experience. But 16% were "not at all confident" and 20% were only "a little" confident.

Just under half (46%) of respondents had had successful (unpaid) work experience placements. Of these, 15% had either volunteered with CLIC Sargent or been on a placement organised by CLIC Sargent:

"CLIC Sargent managed to organise a work placement at a Sheffield publishing company which lasted for two weeks. The placement was a great success, and gave me the confidence I needed for going into the world of employment following my graduation."

However, almost one in 10 (9%) respondents had unsuccessfully tried to find work experience. Just over a quarter (27%) had not done any work experience but would really like to, with over three in five (63%) hoping to gain new skills from doing so. Other reasons to get a placement were for a reference (41%), to make contacts (43%) or develop knowledge of a specific industry (50%) and to get some experience of being in a work environment (47%):

"I would really like to gain experience as I know that this will help me get a job. However, having developed M.E [myalgic encephalomyelitis or chronic fatigue syndrome] as a result of treatment, I am severely fatigued and suffer many physical and mental issues that prevent me from seeking or undertaking any work experience."

Those who had done some work experience said that taking part in meaningful activity when they were having treatment helped them feel ready for work. It also helped their personal development:

"That year became a really positive part of my life. As well as being sick, I got help to go to work, get new skills and improve my CV."

Others became ill during a placement and worried that this meant they would have less experience and find it more difficult to get a job in the future.

Indeed, treatment that a young person receives for cancer can have an impact on their mobility and ability to get around easily at work. They might have muscle weakness, be physically disabled or have vision or hearing problems. Many worried about explaining this to employers or that these effects of cancer treatment would become barriers to working in the future.

Katie's story

At the end of her first year of studying law at Nottingham University, Katie was diagnosed with non-Hodgkin lymphoma and was unable to return for her second year of studies. Her treatment finished in January 2012 and she went back to university that September.

Katie's CLIC Sargent Social Worker, Rachel, organised a week's work experience with Chester-based solicitors Walker Smith Way in April 2012. It became a four month placement, followed by six weeks shadowing a top criminal barrister. Katie, now 21, shares her story.

"I was the first member of my family to go to university and it was really hard to find out that I couldn't do things on my terms when I was diagnosed with cancer. The university have been very good in that they said I could defer for the year or two I thought I might need.

It was awful moving back home. I was completely reliant on my parents and sister when I should have been living independently. I was left temporarily paralysed by a bad reaction to the medication and I couldn't do anything.

One of the hardest things I had to face through the whole thing was the loss of my independence. It was hard knowing that everyone else's lives were continuing while mine was standing still. I had to delete my Facebook page as it was too painful seeing the life I couldn't have. I just wanted to live the life I'd planned and worked for.

Building confidence

My CLIC Sargent Social Worker, Rachel, recognised that I needed her help to become intellectually challenged again, more than I needed emotional support.

The work experience at Walker Smith Way did a huge amount for my confidence. Being told you can do something by people who are already doing it and at the top of their profession is an amazing thing to hear. It was exactly what I needed at the time.

Now I'm back at university and I've made a new group of friends. I honestly feel things have turned out for the best. I am using so much of what I was told and observed during my work experience – I am realising now how much I got from them. The skills I learnt are invaluable.

I used to fear what people thought but I don't anymore. I feel I'm capable of anything now."

Maintaining work

More than half (53%) of the young people we spoke to were in paid work or had been since they had cancer. Nearly a third (31%) were in full-time work and just under half (48%) were part-time.

One in three (33%) said that having cancer made it difficult to keep a job. Reasons for this included:

- ◉ Lack of confidence (38%)
- ◉ Lack of support from colleagues (15%)
- ◉ Lack of support from managers (23%)
- ◉ Money (17%), as earnings weren't enough to support them because of the extra expenses they had as a result of having cancer, such as travel to hospital
- ◉ Other issues (6%), including fatigue, needing time away from work for check-ups and work being too physically demanding.

Job security was an important issue for those we talked to. "It's not the job I always wanted to do but I feel secure there so that's the main thing," said one respondent. Another added:

"The first thing that my manager said to my mum and dad was 'Don't worry about his job, his job's safe and he can slowly get back into it and do as many shifts as he wants to.' That was quite a weight off my shoulders because you don't want to be going through cancer and worrying if you're still going to be employed after you've made your recovery."

Financial impact of not working

Some young people we spoke to who were in employment had received statutory sick pay for the period they were entitled to. However, many who were not able to missed earning their own money and the independence that this brings.

A number of those who took part in our focus groups said that they felt there was a stigma to claiming benefits. "I feel guilty because I get Disability Living Allowance," said one young person. Some young people told us they couldn't claim benefits, particularly if they were working and not living with their parents, and this brought increased worry and problems:

"I couldn't claim any sort of benefits to help pay my mortgage or any of my bills. So whilst I was ill, I had to go for a job and was on a temporary contract for six months. I was having chemo and stuff and not telling them why I wasn't going in."

Impact on relationships with colleagues

We found that people who had supportive colleagues felt this helped them to cope at work:

“They’ve been great. They always say: ‘Text me to let me know how your appointment has gone’. Whether it’s a scan or just a general check-up, they want to know. If I want to get out of work for a chat they’re supportive. Some more than others, but all in all they’ve been really good.”

However, not all young people reported having this support with 15% saying that lack of support from colleagues was a barrier to maintaining employment.

Attitudes to cancer

A small number (4%) of the young people we spoke to felt that they had been bullied, harassed or discriminated against by someone in their current or most recent organisation as a result of having cancer:

“I was once really offended by someone getting annoyed with me and telling me that they don’t see why I should be allowed time off to go to my check-ups without having to repay the time.”

Some, again a minority, felt that they were dismissed from work because they were ill, or that they had no choice but to leave. “I had to leave the job that I was in,” said one respondent. “I got diagnosed and they sacked me because I was poorly.”

Others felt they missed out on promotions or development opportunities:

“I said I wanted to train to be management but that was put on hold because of my diagnosis. Then, in the past month or so, I’ve been doing well. I can do more things, so I’ve asked them to give me the responsibility and they’re still not doing so. It really irritates me because the new starters are getting the responsibility that I should have and I feel that it’s because of my illness that I’m not getting it.”

Talking about cancer

Overview

Thankfully, cancer is rare in young people. However, this means many education providers or employers will have little or no experience of supporting a young person with cancer, and their understanding and awareness of what support to offer and how to go about it may be limited.

Our previous research²¹ found that regular communication and effective information on the impact of cancer helps education professionals to provide the best support to a child or young person with cancer.

However, for this report, young people told us that talking about cancer can be difficult.

Keeping in touch

...In education

Some young people who took time out from their education as a result of their cancer diagnosis experienced excellent communication from their teachers or tutors. Regular emails from a member of staff helped young people to feel supported and part of things. This meant it was easier to go back to their school, college or university when they were ready to:

“It was nice to know that someone was keeping in touch with you. And that you are not forgotten or left out. Having someone that knows about it helps you integrate, especially if you are at university and are away from home.”

Others had a less positive experience and, in many cases, this contributed to them not returning to education. One young person said:

“When I rang they were quite understanding but I haven’t had any communication since. They haven’t asked me how I’m doing or if I’m going to go back. My personal tutor hasn’t emailed me or anything. I just feel that I could have had more support and that’s one of the reasons why I’m not going back.”

Keeping in touch also helps young people keep up with work they are missing. Some colleges or universities were better at this than others. One respondent told us that their teachers didn’t mind explaining things and helping them catch up in time for exams. Another said: “If I wanted work to carry on revising I had to email my teachers, but they never emailed back.”

...At work

Communication was also important for young people who worked. Those who took part in our focus groups said that regular communication from their employer when they were absent helped them feel supported:

"They've been really good. They said that they'd like me to phone every fortnight to keep in touch with them. They said: 'We know that you're tired and you may not have a lot to say but we'd like to keep you informed about updates and things.'"

We believe it's important that employers have sufficient information about how cancer might affect a young person at work. Many young people told us that the way an employer handled telling colleagues about their illness was vital:

"I expected the whole department to know that I was not well but they've been very professional and I was able to tell people myself."

Hanifa's story

Hanifa was on maternity leave when she was diagnosed with leukaemia. Her apprenticeship job was terminated before she returned to work and now, at 24, she is looking for work.

"When the letter arrived confirming my employer was terminating my contract, the envelope had a stamp on it which said: 'We support cancer charities'.

There'd been a big reshuffle in the office and I wasn't given a new manager. When I called I didn't know who to ask for, and I ended up having to speak directly to the centre manager. It was really intimidating.

At a meeting I was called in for with the centre manager, I explained my treatment plan and it was agreed that I should come back when it had finished. Even if I hadn't been on maternity leave, I couldn't work because the side effects were horrendous.

But at another meeting, they put a lot of pressure on me to say I could come back sooner. I had to put my foot down and say 'No' because I was still having lumbar punctures and was in and out of hospital. That's when I got my termination letter.

Knock on effect

I appealed the decision, explaining the benefits they would have got from keeping me on, but they still rejected it. It had a huge knock on effect on my mental and physical state. I felt completely hopeless and didn't have the energy to take it to tribunal.

I was on partially-paid sick leave, so I was used to having a bit of money coming in, even if it wasn't much. My CLIC Sargent Social Worker, Tricia, helped me apply for a CLIC Sargent grant and find funding from other charities. Tricia is helping me with my confidence too. We've talked about me getting back on track, and she has helped me apply for a few courses, and tried to help me to get some work experience.

Facing fears

I feel scared of even approaching the subject of applying for jobs and going for interviews. My apprenticeship was to become a manager or centre manager. Now, I'm right at the bottom again. I feel like no one is going to accept someone who is applying for a job with cancer. But before this happened, I kept on thinking that I just had to get better, get back to normal, and that I could inspire people to show that it was possible.

I do want to go back to work in the future. I really enjoy management and I'm good at it. It's just that I'm scared of getting a job and not being able to live up to the expectations."



Disclosing cancer on an application form or CV

...In education

Young people applying for a college or university place can choose to tell the education provider about their cancer diagnosis and treatment in an application form. However, we found that many young people were unsure about their rights and what level of information to disclose. We found that one in five (21%) respondents felt that not knowing how to disclose the fact that they have or have had cancer on the application was a barrier to their education.

Applications for most full-time undergraduate degrees are done online through the Universities and Colleges Admissions Service (UCAS). An important part of the application process is writing a personal statement, to persuade universities and colleges to accept an applicant and set out why they are right for the course. A young person with cancer might use this as an opportunity to tell the universities they are applying to about their situation.

Those who found that it was straightforward to disclose their cancer on a UCAS form were still confused about how to approach the subject in their personal statement. Some explained their experience in detail and others chose not to focus on it:

“You sell yourself when you write your personal statement and then your tutor writes their statement. ‘Do you mention it, or not?’ was the big question. Do I say anything? Do I talk about it? Do I not talk about it? I didn’t want to sound like I was asking for sympathy.”

...For a job

Similarly, respondents weren’t sure how to approach their illness on their CV or job applications. Around two out of five (43%) said they were “not at all” or only “a little” confident about writing their CV. “I’m terrified I’ll never get a degree or job either because my general health is so unstable or people will look at a CV with ‘cancer’ on it and decide I’m too big a risk to hire,” said one young person.

Many were worried what a potential employer might think about gaps in their employment history, or if they had taken longer to complete their university degree:

“It will look as though I just stopped studying for some reason and haven’t finished my degree. It feels like it’s going to be a gap where they’re just going to think I gave up.”

A minority of young people felt that they had to hide their illness from employers completely. One young person told us that they didn’t tell their employer they had cancer because they were on a temporary contract. Then they got a permanent contract and when they told the employer they had cancer “they were not impressed at all”.

Talking about cancer in an interview

Under the Equality Act 2010, employers can't ask questions about a candidate's health during the recruitment process. This includes asking whether or not a candidate has a disability.

However, an employer can ask for information about someone's medical circumstances after they have offered a position. If, on the basis of this information, they decide to withdraw the job offer, the reason they do so can't be discriminatory.

Only in certain circumstances is it lawful for an employer to withdraw an offer of employment on the basis of medical information provided, for example, if the reasons for withdrawal are related to the person's ability to do the job after having considered reasonable adjustments. Employers who don't meet their duties under the Equality Act could face discrimination claims in the civil courts, along with damage to their reputation and legal fees.

Despite this legal protection, the young people we spoke to still worried about job interviews. Over half (54%) of the people we surveyed told us that they were "not at all" confident or only "a little" confident about preparing for an interview. Almost two thirds (65%) were "quite" or "very" confident about searching for jobs.

Many were worried about talking about cancer in an interview. However, those who had, often had positive experiences:

"I always felt employers wouldn't be very supportive. I had two interviews and got two jobs so it worked out that it didn't affect anything but, at the time, I was very nervous."

Some people chose to talk about their cancer in a way that showed what they'd learned from the experience:

"I tried not to make it the main part of the interview but I did want to put a bit of a positive spin on it to say that I have been through cancer and didn't just sit at home doing nothing."

Other respondents had to complete a medical questionnaire and/or have a medical test as part of their application process to jobs, such as the police, or courses, including nursing:

"After they offered me the position I had a meeting with a company nurse and I wasn't sure what was going to be expected of me. I was thinking 'Do they expect me to do press-ups and stuff like that?' But nothing like that happened so it was fine."

Identifying and meeting needs

Overview

Even if a young person has been successfully treated for cancer they may experience significant and long-lasting late effects. These could occur months, or even years, after the initial treatment period and can range from mild to severe.

Studies show that survivors of childhood cancer may perform less well in education compared to their peers. Those who achieve less tend to have had particular cancers, including brain tumours and leukemia, or received cranial radiation during their treatment.²²

As cancer in 16 to 24-year-olds is rare, education providers and employers may have little or no experience of supporting a young person who has cancer. This issue is exacerbated by the fact that often a young person's needs are not immediately apparent.

Our previous education research²³ found that parents would like a formal needs assessment when their child returns to school. We also found that some education providers struggle to accommodate the individual needs of young people with cancer who have returned after a period of absence. This can contribute to them achieving less than their peers in education.

Under the Equality Act 2010, education and training providers in England, Wales and Scotland, as well as employers, have a duty to make reasonable adjustments for young cancer patients so that they are not placed at a substantial disadvantage compared to non-disabled students. The Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO) also imposes a "reasonable adjustments duty".²⁴ Also, in Northern Ireland, the Disability Discrimination Act 1995 prohibits discrimination in the workplace and places a duty on employers to make reasonable adjustments.

A college or university will have disability support services and larger institutions should have support staff on campus. One of the roles of staff who work in these services is delivering the university's equalities duties by making sure reasonable adjustments are in place. Disability officers should be trained professionals who have experience of working with students with all kinds of needs.

Understanding cancer and raising awareness

Our research has shown that lack of awareness about the impact of cancer in colleges, university and workplaces can be a problem for young people.

Many of the young people we talked to felt that employers and universities didn't understand the impact of their treatment - their tutors expected them to be back to full fitness as soon as they finished treatment. One in five (21%) were concerned that they wouldn't receive the support they needed:

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

23 CLIC Sargent (2012) *No child with cancer left out*

24 Equality Commission Northern Ireland (2006) *A practical briefing guide for teaching staff in the further and higher education sectors*. Available at www.equalityni.org/archive/pdf/SENDOBrief10.pdf (Accessed: 20 September 2013)

"It's not the actual illness that's the problem – it's the side effects and knowing about them, the fatigue and things like that. They hear the word 'remission' and think it's fine."

Uncertainty about how long a young person might be off work was also an issue:

"They said to me as soon as I got the all clear: 'So you'll be available all the time to work now won't you?' And I said: 'I'll be available all the time but I won't be able to work all the time.' They just didn't understand that at all."

"I had to do a 12-hour shift and by the end I was just close to tears. I couldn't walk around that much and I don't think they understood that was because of the cancer. I think they thought I was being grumpy."

Awareness of entitlements

Almost all of the young people we spoke to (96%) told us that their education provider was aware that they had had cancer. However, under half (47%) of those in education were not aware of the adjustments they were legally entitled to from their education provider.

Young people also expressed a need for colleges and universities to show a greater understanding of the impact of cancer: "Staff in education need to be more aware of the impact cancer can have not just physically but emotionally too, such as lack of confidence and how it can affect concentration if you're worried."

Nearly nine out of 10 (86%) of those in work had told their employer that they'd had cancer. However, only one in three (30%) knew what adjustments they were entitled to at work. Many of those who did know what help they were entitled to had support from CLIC Sargent.

"My CLIC Sargent Social Worker helped me to claim ESA when I was out of university and not working. She gave me all the information I needed."

Identifying new needs

Our research shows that some education providers had processes in place to assess student's needs, and this worked well. This was particularly the case with universities who identified that a student might need support through the UCAS application, and then followed this up through the disability support department:

"I declared it formally on my UCAS form, then I got a form from the various disability support departments and they all outlined what they do. I got an email saying that I could have preference of accommodation with regards to certain needs, like an en-suite or closest to campus. When I did go to the university, it was already on my file, and they already knew I existed."

Conversely, not getting support with things like mobility issues was a barrier for some in accessing education. One young person said that things “got bad” with the support from their college when they were in a wheelchair and couldn’t get to college anymore:

“When that happened basically they just said it’s not my problem.”

At work, it is good practice for employers to assess an employee’s new needs when they return to or begin a job after having treatment for cancer. Most public sector organisations, and many large private companies, provide a workplace occupational health service to support people returning to work after long absences. However, employers do not have to provide this service for staff meaning not all young cancer patients can access this support.

Making adjustments

...In education

More than four in five (83%) young people told us that their education provider gave them sufficient extra allowances and flexibility because of their cancer, such as extra time in exams. The rest, 17%, did not think that they were given enough allowances.

Almost half (48%) “strongly agreed” that they had adequate support. Of those who received extra allowances:

- 33% had more time for coursework or exams
- 14% had time out for appointments or fatigue, if they needed it
- 14% had flexible assessment arrangements
- 10% had extra support with lessons, for example a scribe or opportunities to catch up on work they missed.

One young person said:

“I applied for two universities and both got back to me saying they’ll offer me voice recorders for my lectures to help if my concentration is flagging a bit. They’ll give me a lift key for the library so I don’t have to walk up and down the stairs. And if I have to miss any lectures for medical reasons and appointments, I can have a one-on-one catch up so I don’t miss any work. So, they’re really understanding.”

“My college said ‘If you can’t be here then don’t worry about it, we’ll just catch you up at a later stage’. When I went back, they’d laid on extra helpers to help me catch up. We had core subjects we had to pass, so I had extra people to help me and make sure I got through what I needed to. It was almost like one-to-one.”

However, over two in five (41%) young people wished that they had received more support from their education provider with the additional needs they had because of cancer. And more than one in four (27%) young people did not feel that they were able to discuss problems they were experiencing because of having cancer with their college or university.

“My college wasn’t very good when I had appointments for x-rays and check-ups. They told me I should be more committed to my college course which I was, but I still had to attend appointments.”

Some young people felt that they received more support when their cancer had a physical impact on them:

“This time last year, I was still using a walking stick so I was obviously disabled at that point. Now it’s harder for people to understand, because I look normal now.”

Lack of flexibility and understanding from education providers meant that some young people felt they had to stop their studies. Because of its flexibility, and accessibility, a number of people were studying or planning to study through a distance learning course:

“The qualifications that I have aren’t relevant at all to what I’d like to study now. At 24, I feel like it’s too late for me to be taking a step backwards and be doing A-levels in order to be able to go to university and study. At the Open University, as a mature learner, you don’t need the A-Levels or equivalent qualifications so you can join no matter what your background.”

...At work

Over two thirds (69%) of young people told us that their employer made the adjustments that they needed at work. The majority (86%) “strongly agreed” (38%) or “agreed” (48%) that their employer understood their situation. Likewise, four out of five (82%) said colleagues were understanding.

Some people told us that their employer paid their full wages through their cancer treatment, even though they weren’t always able to attend work. “They allowed me to go back to work, once I felt ready, at hours that suited me and not necessarily suited them,” said one respondent.

Many could have regular breaks, if they needed them, when they went back to work, or their employer gave them different work to do:

“If I’m quiet then they’ll ask if I’m alright and I’ll just say ‘I’m having a bad day’ and that’s it, they don’t badger me. If I feel like I can’t be on the shop floor they give me something to do out the back. They will find something specifically for me so I’m not under that pressure of facing customers even if it’s for five to 10 minutes or half a day. They give me the time I need.”

Employers were often flexible, giving time off for appointments, or if the young person did not feel up to working. Although some struggled initially:

"At the beginning they didn't understand because there was a lot of moving about in the company and we were really busy. They'd say 'Can you not have a day off?' or 'Can you change it'. Now I say I need to finish early or have a day off or swap a day and they're fine with it. It's 'Yes' straightaway."

Some were given a phased transition back into work, which generally worked well. "They said 'When you come back, there will be a phased return for you' and they really reassured me," said one young person.

However, almost one in 10 (9%) "strongly disagreed" that their employer was understanding:

"I felt let down as I had worked for the company for six years and they ironically supported several cancer charities. Therefore, when they terminated my contract due to cancer I felt disappointed."

A quarter (24%) "disagreed" and 8% "strongly disagreed" that their employer made the adjustments that they needed at work. And almost one third (31%) did not feel they have had adequate allowances made for them at work.

Some felt that because of this lack of flexibility and understanding, they were unable to continue with their employment.



Reassessing the future

Overview

Young people have lots of important decisions to make between the ages of 16 and 24 which may affect their future; from choosing college or university courses that will have an impact on the career they pursue for the rest of their life, to applying for their first job.

If they go through school from GCSEs to A-levels and then straight into university, or from GCSEs to an apprenticeship or other vocational qualifications, these decisions may be part of a fast-paced period of their life. They may not have been able to take time out to reflect on them.

Taking time out from education or employment, and instead spending time in hospital, interacting with nurses, doctors or others with cancer, can give young people this space to reflect. They can think about the decisions they are making, what they want for their future and how they can turn their experience of being unwell into something more positive.

A different approach

This was the experience of many of the young people we spoke to for this report. They told us that through having cancer, they'd done things they would not have thought of doing before, and had gained a different perspective or new skills. "You're more understanding of other people's situations once you've been through something that's traumatic," said one young person. Another said:

"Because of dealing with certain issues, I've found that I've got compassion towards people, particularly with working in the care home now. I've got a real empathy towards them because I realise that they've got an illness."

This new perspective helped some young people to reassess their future career goals, and choose something that they really wanted to do. "I've had a bit of a personality adjustment, having gone through what I've gone through, like nothing's going to stop me ever again," said one young person. For some, this was going back into education or trying a new course:

"I didn't know what I wanted to do and because I took tons of time off while I was getting better, I had more of a chance to think about what I wanted to do."

Many respondents who had been supported by CLIC Sargent said that their care professional provided them with the support they needed to reflect on their own future.

Jack's story

Jack was diagnosed with acute lymphoblastic leukaemia shortly after finishing secondary school and before he was going to start a course in bricklaying. He finished his treatment in December 2012 and now, at 20, is studying at college.

"Being diagnosed with cancer as a teenager is one of the hardest times to get the illness. You've just begun to taste adult life and then it is all taken away from you. Your friends are off to parties, going on dates or starting jobs, and you're stuck at home, googling what is wrong with you.

When I first received the diagnosis, I think I was in denial about what was going to happen. At first there's no time to think. It's full steam ahead into treatment. It's only after the initial treatment stage that the emotions start to come out.

That's when CLIC Sargent is really important. CLIC Sargent has been there to make me emotionally better. The doctors and nurses are there to get you physically better, but actually looking after your emotional health can be more of a task. I am not one for asking for help but Anita, my CLIC Sargent Young People's Community Worker, could sense when I needed support and found ways to get me to talk. She didn't barge in, she built my trust over time.

Change of direction

Before I had cancer I was going out doing what lads did at the weekend. But my attitude totally changed after being ill. After leaving school, I went for the easy option. Lots of my friends had gone into the building trade, so I started a bricklaying course.

Cancer made me realise life is too short to just breeze through it. It made me want to strive to achieve something, and do something more challenging that I'd enjoy – something that would work the brain.

Support to make decisions

Anita helped me think about life after cancer. Although I carried on with my course, I realised I was more interested in electrical engineering. Anita encouraged me to pursue what I most wanted to do. So I did a course in electrical installation and have now got a job with a power company.

But now that I am where I am, it is good to think back about what I've been through and how far I have come. I have already lived through a fair bit and I think I could take what life throws at me on the chin now.

Something like cancer makes you really want to achieve your ambitions. I'd never wish cancer upon anyone. But I'm glad I had it because it's helped me turn my life around."



CLIC Sargent support

Overview

Just under half (46%) of the young people we spoke to had worked with a CLIC Sargent care professional, such as a CLIC Sargent Young People's Social Worker or Young People's Community Worker, to access or maintain education, employment or training opportunities.

CLIC Sargent supported them to:

- Access work and education. Four out of five (86%) young people felt that CLIC Sargent had helped them to find education and work opportunities
- Feel more confident about their abilities. More than nine out of 10 (95%) young people who had worked with CLIC Sargent felt that we had helped to increase their confidence, supporting them to take control of their own lives
- Secure work experience. Nearly three out of five (57%) young people said CLIC Sargent helped them feel ready for job interviews
- Make plans for their future. More than three quarters (78%) of young people said we helped them develop their goals.

"CLIC Sargent does an amazing job and the support I received whilst going through treatment and post treatment has been incredible."

Support to stay in work or education

The emotional support our care professionals provided helped many young people to maintain their education or employment. One young person said:

"I couldn't have done it without people to talk to, without friends, without my CLIC Sargent Social Worker, without the counselling and the university support. It wouldn't have happened because I would have got swallowed up in the small things, they get bigger and bigger, you don't know what it's like to be in a normal place anymore."

Our support also helped young people to maintain communication with their employer or education provider:

"I couldn't explain to my employer how I was feeling and what I was going through so they weren't very supportive. But then I spoke to my CLIC Sargent Social Worker and my nurses and they helped me tell them a bit more about it. That helped them understand. Now most of my work are really supportive."

Accessing benefits

Young people said their CLIC Sargent care professional was invaluable in helping them apply for and access benefits:

"It was quite easy because my CLIC Sargent Social Worker helped me understand how to apply for financial support. I got a letter back about two months later saying I could have DLA."

"CLIC Sargent has been a great help to me in getting back on track with my life. I now have the confidence to go out and do volunteer work, something I had never considered before, which will improve my skills and understanding of the workforce."

CLIC Sargent's work experience programme

As our research findings show, many young people who have had cancer miss significant amounts of their school or university education, and need to take time out from their career as a result of their treatment.

Our work experience programme supports young people aged 16 to 24, who have been supported by CLIC Sargent, to gain skills and experience in the workplace. It's a structured first step back into, or towards, employment, and has an impact on a young person's employability and confidence.

Feedback from young people who have attended placements has been overwhelmingly positive. They've said that they gained confidence, self-esteem, new skills and insight into the industry of their choice. One young person was even offered further experience and an interview with their placement provider:

"It did me so much good getting away from home, having structure in my day and feeling like I had a project I could get my teeth into."

Many of the young people we spoke to for this report had accessed work experience through our programme or with the assistance of their CLIC Sargent care professional. Those who had done some work experience found the experience invaluable:

"I came to the firm through CLIC Sargent. So right from the beginning, they understood. They'd say 'Take the day off; you work for us when you want to'. I don't think any other employer would have been so good about it, especially if they'd not had knowledge of my history."

CLIC Sargent is committed to helping more young people access work experience opportunities and to increase their prospects of finding work through a CV support scheme and by providing job hunting and interview skills information. We will also pilot a Young Ambassadors Programme which will provide opportunities for young people affected by cancer to gain new skills, increase their confidence and boost their employability.

Supporting young people in the community

In 2011 our Services strategy included a commitment to expand our young people's service in order to reach our ambition of being able to fully support every young person with cancer who needs us.

As part of this work we looked at a model of service which recognised that our care professionals (based in specialist teenage and young adult cancer centres) may not be able to provide the community outreach that is necessary to support young people being treated in adult cancer units near where they live, or who are only attending hospital as an outpatient.

So, we developed a two-year pilot project to test a new role – the CLIC Sargent Young People's Community Worker.

We employed five young people's community workers in Birmingham, Southampton, Cambridge, Glasgow and Nottingham. In 2012/13, they supported 220 young people, providing practical and emotional support in the community with a particular emphasis on:

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- ◉ Emotional wellbeing and resilience
 - ◉ Social isolation
 - ◉ Education, employment and training issues.
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We commissioned an independent evaluation of the impact of the project, which was completed in March 2013. The evaluation concluded that this model has the potential to transform the support available to 16 to 24-year-olds with cancer, particularly those being treated close to home rather than at a specialist teenage and young adult cancer centre. The evaluation demonstrated that Young People's Community Workers would play an effective part in filling the current gap in support for young people with cancer and their families, as part of the social care support the charity offers.

This is why we are committed to expanding the service throughout the UK so that practical and emotional support is available to every young person with cancer who needs it.

To provide the right support to every 16 to 24-year-old with cancer, we need to significantly increase the number of care professionals we have to support them. To fund this, we need to raise at least £3 million of additional funds, every year.

Conclusion and ways forward

Our research found that young people with cancer feel they face a number of barriers to their education and employment following a cancer diagnosis and treatment.

It highlights the social and emotional impact of cancer on young people, including their worries about social exclusion, and about fulfilling their potential.

We've discovered that lack of awareness about cancer in education or the workplace can be a problem. Employers may need more support to understand, identify and meet the needs of young people with cancer. In particular, young people identified the importance of ensuring employers are aware that the physical impact of cancer can last long after treatment and that they may still be struggling even when they appear well.

Many of the young people we surveyed and spoke to told us that having cancer inspired them to succeed in education and employment, and gave them renewed focus. But all too often, they needed more information to better understand the adjustments they were entitled to. They also needed more information and support so that they could talk confidently about having cancer with prospective education providers and employers.

This research is a valuable addition to CLIC Sargent's research portfolio but also offers a focus on young people aged 16 to 24 which we hope will be a useful addition to the significant body of expertise and evidence on work and cancer gathered and disseminated by Macmillan Cancer Support.



These findings complement those from our previous reports *No child with cancer left out* and *No teenager with cancer left out*. We will use them to:

- ◉ **Develop specialist information for post-16 education providers and employers.** Our research shows that these organisations need better information to understand the impact of cancer and cancer treatment on young people. Providing this to education providers and employers will allow them to better support young people
- ◉ **Raise awareness of the rights of young people with cancer at work, school, college or university.** We will produce information that describes what young people are entitled to so they are better supported to stay in work or education
- ◉ **Inspire our influencing.** We will continue to campaign with governments and policy makers across the UK to ensure young cancer patients and survivors receive the support they need to access education and employment opportunities
- ◉ **Help more young people access work experience opportunities.** This can help give young people purpose when they're having treatment and improve their job opportunities when it's finished. We will also provide more CV writing and interview advice for young people
- ◉ **Inform the development of our services for young people, in particular support in the community.** We will support young people to access education, employment and training opportunities by expanding our young people's community worker programme, continuing to help build young people's confidence to fulfil their potential and shape their future
- ◉ **Inspire future research and data gathering.** We want to find out more about how we can help young people to feel confident talking about having had a cancer diagnosis
- ◉ **Help employers and education providers support young people with cancer.** This will help enable employers to fulfil their duties under the Equality Act 2010 and other disability legislation, and help young people to access the support they need to stay in education or work.

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- ◉ Other health and social care professionals who helped arrange the focus groups with young people.

Glossary

Disability Living Allowance (DLA)

A benefit that helps with the extra costs that disabled people face as a result of their disability or illness. DLA is being replaced by Personal Independence Payment for all new claims and is being brought in gradually for people who are already receiving DLA (except in Northern Ireland).

Education provider

An organisation that provides education for young people, which could be a school, college, further education college or university.

Employment and Support Allowance (ESA)

A benefit for people under state pension age who have a disability or illness which affects their ability to work. There are two types: one based on national insurance contributions (contributory) and another that depends on your income and savings (income-related).

Lumbar puncture

A medical procedure where a needle is inserted into the lower part of the spine to look for evidence of conditions affecting the brain, spinal cord or other parts of the nervous system. Common, but usually short-lived, side effects of the procedure can include back pain and headaches.

Palliative care

Palliative care usually begins when curative treatment is no longer an option.

Personal Independence Payment (PIP)

Introduced in April 2013, PIP is replacing DLA as the government benefit for working age adults with a disability or illness.

Reasonable adjustment

A change an education provider or employer can make so that a young person with cancer is not disadvantaged. This could be a change to practice, for example allowing them to have extra time in exams. Or, a physical adjustment, such as installing a ramp for a wheelchair user or providing extra equipment, like a screen reader.

Universities and Colleges Admissions Service (UCAS)

UCAS is the organisation responsible for managing applications to higher education courses in the UK.

How CLIC Sargent helps

Hearing they have cancer is probably one of the most difficult things young people will ever have to deal with. We understand the huge impact cancer and its treatment can have on a young person, and their partner, family and friends.

CLIC Sargent provides vital practical, financial and emotional support to young people with cancer across the UK to help them cope with the impact of a cancer diagnosis and its treatment.

We provide:

- A wide range of **information** on cancer and its impact on all aspects of life
- **Financial support**, including grants and referral to a specialist CLIC Sargent welfare rights advice service, to help young people deal with the financial difficulties a cancer diagnosis can bring
- Advice to young people about keeping up with their **education** if they are at school or college, and their jobs if they are in **employment**. Our work experience and volunteering programmes can also offer young people the opportunity to broaden their skills
- **Free accommodation** at our eight Homes from Home – close to specialist hospitals where families can stay during treatment, and patients too when treatment allows, so that long journeys for hospital visits and paying for overnight stays can be avoided
- **Free holidays and specialist short breaks** away from the everyday challenges of cancer, with the support of our care professionals and with medical support close by
- **Practical and emotional support**, including face-to-face support where this is available, to help young people cope with the impact of a cancer diagnosis and its treatment.

Committed to supporting young people with cancer

We want to reach all young people aged 16 to 24 diagnosed with cancer and provide them with the support they, and their families, need to cope with cancer and get the most out of life.

That's why we're planning to grow the support we can offer to young people as soon as funding allows, and achieve our goal of helping all young people with cancer who need us across the UK.

We can't provide our vital services without our supporters. If you would like to donate to CLIC Sargent, you can do so easily online at www.clicsargent.org.uk/donate



Supporting
children and
young people
with
cancer

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