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YOUNG LIVES
vs CANCER
CLIC SARGENT

The mental health impact of a
cancer diagnosis on young people

SUMMARY

At CLIC Sargent we know that #Cancercosts. And the cost to young people's mental health is no exception. Undergoing cancer treatment is challenging, isolating and deeply personal. Young people's ability to cope is often seriously affected by the emotional pressures and mental health impact of a diagnosis, and months of gruelling treatment.

Hidden costs aims to bring together existing evidence around the mental health impact of a cancer diagnosis on young people and contributes new data to the conversation. It scopes out young cancer patients' experiences, the key issues and where future research should be focused.

The report shows that young cancer patients are often disproportionately experiencing mental health issues such as anxiety and depression. It aims to raise awareness of the impact of a cancer diagnosis on young people's mental health, as well as their physical health, and makes recommendations for change and future research.

ABOUT CLIC SARGENT

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

Cancer doesn't discriminate. Today, 11 more children and young people will hear the devastating news that they have cancer. From diagnosis, CLIC Sargent's specialist care teams will step in, ready to help, support and guide. They will provide a specialist package of support tailored to each young cancer patient and family.

CLIC Sargent fights 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 work with bereaved families to get them support, to help them cope with their emotional pain.

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FOREWORDS



It's no surprise that a cancer diagnosis can have a devastating impact on a young person. Often we consider this impact to be purely about the effect cancer will

have on their health. In the aftermath of a diagnosis there are a myriad of health professionals to listen to, treatments to understand, short and long-term consequences to absorb, fatigue, nausea, pain and fear.

We know the impact of cancer is far wider than just physical

At CLIC Sargent we know the impact of cancer is far wider than just physical. The damage cancer causes, even in those first few

weeks and months, can spread much further than just physical health. There is college or university attendance and fees to sort, or work to negotiate at a very early stage of a young person's career. We know there is a significant financial burden with additional travel, heating, food, clothing etc, at a time when income is likely to fall or stop, but government benefits have not necessarily kicked in. Our 2016 *Cancer costs* report showed the financial impact of increased costs in excess of £600 a month, often leading to spiralling debt.

What has been less well explored, until now, is the impact this has on the short and long-term mental health of young

people aged 16-24, who are living with cancer or have recently finished treatment. What is the emotional cost of cancer?

We are grateful to the many young people who contributed to this report. They told us in no uncertain terms that cancer has had a devastating impact not only on their physical health, but also on their mental health. It is heartening to hear that many have been supported by statutory mental health services, but worrying that others have not. Our findings show that of significant concern is also the impact a young person's cancer diagnosis can have on the wider family, parents and siblings.

CLIC Sargent welcomes the government's recent focus on the importance of young people's mental health, and the acknowledgement that this is fundamental to ensuring that children and young people go on to achieve their full potential. In the spirit of this change we would like to see greater recognition of the impact of cancer on the mental health of those aged 25 and under, and a drive for improved and consistent support.

Kate Lee
Chief Executive, CLIC Sargent



I am delighted on behalf of the Association for Young People's Health to support this important report from CLIC Sargent. It should not be surprising that a diagnosis

of cancer for a young person is likely to have a significant emotional impact on them and their families. Yet it is alarming that consideration and discussion of young people's mental health needs is not systematically a fundamental part of their care pathway from diagnosis onwards.

We should not forget the links between physical and mental health problems

Young people see their health holistically. The current focus on young people's mental health is extremely encouraging but we should not forget

the links between physical and mental health problems, and the need for a more integrated approach for young people.

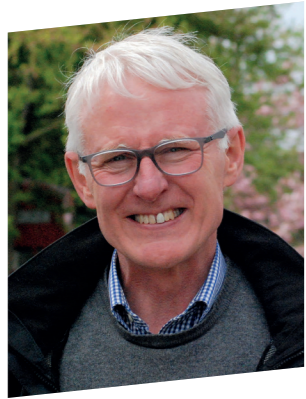
It is also important to highlight the need to discuss how young people would like different parts of their care managed. They may wish their parents to be fully involved in their cancer treatment but prefer to manage their mental health concerns without them present. This may not be the case for all young people but

demonstrates the importance of them being able to see their clinicians on their own, and of clinicians understanding the complexities of information sharing in the transition to adulthood.

Finally, our recent research *There for you* (2015) demonstrated the impact of young people's mental health concerns on their families. Families and carers are central to young people's wellbeing and support for families is fundamental to getting young people's care right.

A continued focus on the mental health needs of young people with cancer is crucial and we support the recommendations in CLIC Sargent's report to take this work forward.

Emma Rigby
Chief Executive, Association for Young People's Health



When I was Minister for Care and Support, I was particularly concerned about the level of support for children and young people experiencing mental health issues. I used my time as Minister

to work on improving the situation, to ensure that young people have access to support and services when they need it.

I was approached to endorse this report by CLIC Sargent with the help of Pete – a young man who has benefited from

CLIC Sargent's support and services. Pete recorded a video message asking me to lend my support to this report. I was impressed by his passion about the

importance of mental health support for young people with cancer and I could not agree with him more.

Being diagnosed with cancer affects almost every single part of your life

There is no denying that a cancer diagnosis can be devastating for anyone, including young people. Being diagnosed with cancer and undertaking treatment affects almost every single part of your life. Much attention has been paid to the physical effects of a cancer diagnosis. However, there has been relatively little focus on the mental health impact of the diagnosis and treatment of cancer, and even less on how it affects young people.

With around 11 children and young people being diagnosed with cancer every day, it is clear that a significant number of them will need ongoing mental health support alongside the medical treatment they receive.

A staggering 41% of young people with a cancer diagnosis did not receive mental health support during treatment, even though 79% felt that cancer had a serious impact on their emotional wellbeing according to the findings of this report. Clearly, much more needs to be done to improve support for the mental health impact of this terrible disease.

I would like to thank CLIC Sargent, and Pete, for bringing this to my attention. I am delighted to endorse this report and its recommendations, and hope that it will lead to more young people living with cancer getting all of the support they need throughout their cancer journey.

Rt Hon Norman Lamb MP

Former Minister for Care and Support

EXECUTIVE SUMMARY

At CLIC Sargent we know that **#Cancercosts**. And the cost to young people's mental health is no exception. Undergoing cancer treatment is challenging, isolating and deeply personal. Young people's ability to cope is often seriously affected by the emotional pressures and mental health impact of a diagnosis, and months of treatment.

Every day across the UK, our frontline care teams are working with young people and families who are dealing with the mental health impact of a cancer diagnosis. We wanted to bring together their experiences, give them a voice and make recommendations for change to ensure that their mental health needs are recognised.

Our scoping report aims to bring together existing evidence around the mental health impact of a cancer diagnosis on young people, and contributes our new data to the conversation. It scopes out young cancer patients' experiences, the key issues and where future research should be focused.

Our report shows that young cancer patients are often disproportionately experiencing mental health issues such as anxiety and depression, and aims to raise awareness of the impact of a cancer diagnosis on young people's mental health, as well as their physical health.

We asked 149 young cancer patients about the mental health impact their cancer diagnosis had on their lives. Our research shows that the mental health impact of cancer should be given equal consideration alongside young people's physical health needs, and makes recommendations for change and future research.

This report is part of CLIC Sargent's **#Cancercosts** campaign highlighting the range of costs a cancer diagnosis has on young cancer patients and their families.

Summary of findings: young cancer patients' mental health

We asked young people what mental health impact they felt their cancer diagnosis and treatment had on them:

Key findings included:

- **Emotional wellbeing**
79% of young people felt cancer had a serious impact on their emotional wellbeing
- **Depression**
70% of young people experienced depression during their cancer treatment
- **Anxiety**
90% of young people experienced anxiety during their cancer treatment
- **Loneliness**
83% of young people experienced loneliness during their cancer treatment
- **Panic attacks**
42% of young people experienced panic attacks during treatment.

Summary of findings: support needed by young cancer patients

We asked young people about the support they accessed during treatment and whether it met their needs.

Key findings included:

- **41%** of young people did not access support for the mental health impact of their cancer diagnosis and treatment
- Where they did access support, the top three types were CLIC Sargent social workers, counsellors or psychologists, or online support
- **73%** of young people said talking to others with similar experiences helped them.

Conclusions and recommendations

The young people we spoke to reported high levels of mental health issues due to their cancer diagnosis and treatment. Many young people were able to access support but a significant minority were not. Reasons for this included a lack of available and appropriate services, the costs involved in accessing private treatment and a lack of information around the support on offer.

Our report aims to raise awareness of young cancer patients' mental health needs and contributes to the evidence base in this area. We hope

this particularly raises awareness of the issue among young cancer patients and encourages them to seek help if they feel they need it. We want to ensure that all young cancer patients across the UK get the mental health support they need.

Our recommendations for change include:

- Access to evidence-based mental health interventions for young cancer patients should be part of the treatment pathway if needed, and provided consistently across the UK
- All UK hospitals should provide free Wi-Fi access to support young cancer patients to maintain the connections that are important to them
- Further research is needed on how young cancer patients are accessing services locally and the emotional and mental health impact of a cancer diagnosis on the wider family, particularly siblings.

INTRODUCTION

At CLIC Sargent we understand it takes a team of professionals to minimise the disruption cancer has on the education, social life and future prospects of young people. We know this support is needed from the start, to limit the long-term damage by stopping problems that might become real barriers for them later on. Our care teams support young cancer patients emotionally – building their resilience so they can continue to learn, regain their confidence and self-belief and be inspired to think beyond cancer.

We also know that mental health is a major part of young people's general wellbeing, and is also closely bound up with their physical health (AYPH, 2015). There are strong links between physical and mental health problems. Research has found that 30% of people with a long-term physical health problem also have a mental health problem, and 46% of people with a mental health problem also had a long-term physical health problem (The King's Fund, 2012).

Previous CLIC Sargent research on psychosocial and emotional wellbeing revealed the impact of cancer on children's relationships with school friends (CLIC Sargent, 2012), young people's fears of being left behind by peers going on to college, university or work (CLIC Sargent, 2013), and what it means to be resilient (CLIC Sargent, 2014). CLIC Sargent's report *Cancer costs* (2016) highlighted the financial impact of treatment on young cancer patients and their families and the emotional burden of these costs. The report found that on average parents spend £600 extra a month during treatment and 54% of young people felt that managing their finances during treatment caused them additional stress and anxiety.

This report aims to bring together existing evidence around the mental health impact of a cancer diagnosis on young people, and contributes new data to the policy area. It aims to:

- Look into the mental health impact of a cancer diagnosis and treatment on young people
- Find out more about what helps and what further support is needed
- Scope where future research needs to focus.

Current evidence demonstrates young people in the UK are experiencing a range of mental health issues which require different services and support, and young cancer patients are no exception. In fact they are disproportionately experiencing mental health issues such as anxiety and depression and should be receiving the services they need to support them.

This report ensures that young cancer patients are not forgotten in the debate around the mental health needs of young people. It clearly highlights the fact that a cancer diagnosis can often have an impact on their mental as well as their physical health and that this can be an invisible impact, but still requires support, both formal and informal.

METHODOLOGY

In 2016 CLIC Sargent carried out research as part of our #Cancercosts campaign. We used a mixed methods approach to collect data from young people and their families about the costs of cancer. *Cancer costs*, published in September 2016, revealed the devastating financial impact of cancer (CLIC Sargent, 2016). Our new report, *Hidden costs*, draws out the data collected relating to the mental health costs of cancer on young people.

Literature review and scoping

A literature review was carried out to understand the existing evidence base using a number of sources such as CLIC Sargent's internal evidence base, journal articles, reports from charitable and other organisations, government reports and guidelines.

Workshop discussions were held with CLIC Sargent's Young People's Reference Group to scope out what young people felt were the key issues. CLIC Sargent young people's social and community workers took part in workshop discussions and interviews to help shape interview schedules and survey questionnaires.

Qualitative research

Telephone and Skype interviews were conducted with five young people from around the UK. The interviews were semi-structured, based on the key issues and questions arising during the scoping work. They lasted between 30-60 minutes. The transcripts and notes from the interviews, workshops and discussions were analysed for key themes. Quotes from the transcripts are included throughout the report.

Quantitative research

The design of the survey was based on the literature review and workshop sessions with young people and CLIC Sargent staff. Staff, young people and parents were consulted on the survey. The survey was designed in two parts. Part one focused on the financial costs of cancer and this data formed the basis of our *Cancer costs* report. The second part of the survey focused on emotional costs and impact. This data is presented throughout our report.

The survey respondents

A total of 149 young people completed the survey, recruited through CLIC Sargent's networks, our care teams and social media.

The majority of young people who responded to the survey identified as female and had finished treatment at the time of completing the survey. Most had finished treatment between two to four years ago and were 22 to 24-years-old. They had a range of diagnoses, with Hodgkin's lymphoma and leukaemia the most common.

All percentages reported throughout this report are drawn from the number of people who answered each question, not the total sample size.

Young people

- **Gender:**
Female 79% | Male 21%
- **Treatment:**
On treatment 20%
Finished treatment 76%
Other 4%
- **Time since finishing treatment:**
Less than 6 months 17.5%
6 months–1 year 28%
2–4 years 38.5%
5 years or more 16%
- **Current age:**
16–18 years old 15%
19–21 years old 27%
22–24 years old 39%
25–30 years old 19%
- **Country of residence:**
England 79%
Scotland 9%
Wales 5%
Northern Ireland 5%
Other 2%
- **Diagnosis:**
Hodgkin's lymphoma 26%
Leukaemia 19%
Non-Hodgkin's lymphoma 9%
All other cancers 46%

Limitations of our research

Our surveys provide a snapshot of experiences. Participants were self-selecting and reached through existing CLIC Sargent networks. Our sample is not representative of all young cancer patients as the demographic spread above shows in terms of gender, diagnosis and treatment stage. However, given the rarity of teenage and young adult cancer, we believe we have consulted with a significant proportion of this population.

CONTEXT

Young cancer patients' mental health – what do we already know?

Every year around 2,400 16 to 24-year-olds are diagnosed with cancer in the UK (CRUK, 2017). We know a cancer diagnosis has a huge impact on a young person and can significantly disrupt their journey into adulthood. CLIC Sargent's 2014 report *Coping with cancer* highlighted that a cancer diagnosis can also affect their future. As well as the potential long-lasting physical effects of treatment, research has shown that a cancer diagnosis can impact on long-term emotional wellbeing, and education and employment prospects. There are ways to alleviate this, for example, by providing young cancer patients with the information and support to help them manage their illness and its associated challenges (CLIC Sargent, 2014).

We know that the costs of cancer to young cancer patients and their families are wide-ranging and include impacts on financial, social, physical, educational and emotional wellbeing, both in the short and long-term. We know that young cancer survivors have an increased risk of developing chronic health conditions and cancer can disrupt social, psychological and educational development both during and beyond the cancer journey (Lancashire, 2010; Robinson, 2011; Zebrack, 2012). We know that young cancer patients and their families need support and guidance to understand the emotional and mental health impact of treatment, and not feel ashamed to ask for help.

In particular, we know that psychosocial wellbeing¹ is an issue that spans the whole cancer journey (Taylor et al, 2013). This also extends beyond treatment, as some survivors of childhood and young people's cancer have been found to have symptoms related to post-traumatic stress disorder (PTSD), depression and anxiety (Bagur et al, 2015). The disruption of the normal developmental pathway of a child or young person due to cancer contributes to psychological issues such as depression, anxiety, loss of self-esteem and distortion of body image (von Essen et al, 2000).

We know that there is an understanding of the mental health impact of cancer. NICE guidance recommends that children and young people with cancer, their families and carers have their psychological needs assessed at key points of their cancer journey and receive support based on their identified needs (NICE, 2014).

Across the general population, one in four people in the UK will experience a mental health problem in any given year (NICE, 2011). For adolescents aged 11–16 years, the rate of mental health problems is 13% for boys and 10% for girls (ONS, 2004, as cited in Mental Health Foundation, 2015). 21% of 16 to 24-year-olds experienced depression or anxiety in 2013 (ONS, 2015).

Organisations across the UK have highlighted that many young people are already struggling with issues such as isolation, unhappiness, eating disorders, self-harm and suicidal feelings amongst others (YoungMinds, 2017; Prince's Trust, 2017). The 2017 Prince's Trust Macquarie Youth Index recorded the lowest levels to date of happiness amongst young people, with emotional health receiving the lowest score for

happiness (Prince's Trust, 2017). Access to mental health support is also an issue, as the average maximum waiting time for a first appointment with CAMHS (Child and Adolescent Mental Health Services) is now six months and then nearly 10 months until treatment begins (YoungMinds, 2017). In terms of risk factors for children and young people developing mental health issues, having a long-term physical illness is considered one of them (Mental Health Foundation, 2017). It is therefore possible that a cancer diagnosis could increase the risk of young people developing mental health problems.

Young people's mental health — what is being done about it?

England

In March 2015, the Children and Young People's Mental Health and Wellbeing Taskforce published *Future in Mind*, outlining recommendations for improving mental health services for children and young people by focusing on prevention and early intervention. These recommendations included facilitating greater access and standards for CAMHS and promoting positive mental health and wellbeing (Department of Health, 2015).

The Independent Mental Health Taskforce published the *Five Year Forward View for Mental Health* in February 2016 with specific objectives for children and young people. This includes a recommendation that by 2021, 70,000 more children and young people should have access to high quality mental healthcare when they need it. The Taskforce also highlighted the need to meet the needs of those particularly vulnerable to developing mental health conditions. This includes

those with disabilities or long-term conditions such as cancer. They called for the Department of Health and the Department for Education to establish an expert group to examine the complex needs of this group and identify how they should be best met (NHS England, 2016). The Taskforce additionally called for the recommendations from *Future in Mind* to be implemented in full.

The government has pledged an additional £1.4 billion over five years for CAMHS. However, research shows that in the first year of funding (2015/16) nearly two-thirds (66%) of Clinical Commissioning Groups used some or all of the additional money to either backfill cuts or to spend on other priorities (YoungMinds, 2016).

In January 2017, Prime Minister Theresa May reaffirmed the government's commitment to transform mental health support by announcing a series of measures designed to help children and young people. While the announcement was largely welcomed, many criticised the lack of ring-fenced funding available to deliver such a transformation of services.

Scotland

The Scottish Government has described improving the mental health of the population in Scotland as a national priority (Scottish Government, 2012), and has developed a set of national mental health indicators for children and young people. Analysis of these indicators from 2013 (NHS Health Scotland, 2013) demonstrates that while the mental health of children and young people in Scotland has improved, or stayed constant over the past decade, there are substantial opportunities to improve.

The Scottish Government's mental health strategy committed to improving access

to specialist CAMHS and has set an 18-week waiting time target for children and young people. A number of charities have criticised the 18-week wait period as being excessively long. Recent figures (Information Services Division, 2017) indicate that NHS Scotland is failing to meet these targets in five out of 14 health boards, highlighting disparities in access to treatment.

Wales

The Welsh Government's 10-year strategy, *Together for Mental Health*, was launched in 2012 and aims to provide a long-term commitment to improving mental health and wellbeing. The strategy highlighted that around 50% of individuals with enduring mental health problems will have symptoms by the time they are 14, with many experiencing problems from an even younger age. It emphasised the need to promote resilience and self-esteem among children and young people and to identify signs of mental health issues at the earliest stage (Welsh Government, 2012).

In 2014, the Welsh Assembly's Children, Young People and Education Committee's inquiry into CAMHS reported that specialist services in Wales were under more pressure than ever before, with a 100% increase in demand from 2010 to 2014.

Northern Ireland

Northern Ireland is reported to have worse levels of mental health problems than any other part of the UK, with a 25% higher overall prevalence of mental health problems than England (Department of Health, Social Services and Public Safety, 2014). It is estimated that more than 20% of young people in Northern Ireland suffer significant mental health problems by the time they reach 18.

¹ wellbeing related to the interaction of social factors, thought and behaviour

The Bamford Review of Mental Health and Learning Disability published *A Vision of a Comprehensive Child and Adolescent Mental Health Service* in July 2006, which recommended that mental health services be provided to children with physical and sensory disabilities and illnesses. However, the 2011 Regulation and Quality Improvement Authority (RQIA) *Independent Review of Child and Adolescent Mental Health Services in Northern Ireland* found that this recommendation had only been 'partially achieved'.

In October 2011, the *Service Framework for Mental Health and Wellbeing* was published, setting out standards for the prevention, assessment, diagnosis, treatment, care and rehabilitation of people who have a mental illness. Whilst none of these standards refer to the mental health needs of young people with cancer or other long-term health conditions, the framework does recommend that children and young people experiencing depression are referred to mental health specialists and that information and support is offered to the individual and the family.

KEY FINDINGS

Young cancer patients' mental health

EMOTIONAL WELLBEING

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

DEPRESSION

70% of young people experienced depression during their cancer treatment

LONELINESS

83% of young people experienced loneliness during their cancer treatment

ANXIETY

90% of young people experienced anxiety during their cancer treatment

PANIC ATTACKS

42% of young people experienced panic attacks during their treatment.

"Cancer and its treatment strips you back to nothing [and] you become weak... so issues of mental health are bound to show through."

Young person with cancer

For young people, the impact of a cancer diagnosis cannot be underestimated. Often, there are immediate concerns about the physical effects of cancer and its treatment, as well as how they will carry on with their day-to-day lives and focus on their survival. The mental health impact of a cancer diagnosis may not be felt by young people straight away, or is often not experienced until after treatment has ended. Young people may not be prepared for the impact on their mental health, may not know who to tell about it or be aware of information and services to support them.

However, the vast majority of young people we spoke to (79%, n=119) said their cancer diagnosis impacted on their overall emotional wellbeing. More worryingly, 70% [n=98] of young people said they experienced depression during treatment. Treatment had an impact on the mental health of almost all the young people we spoke to with 99% [n=143] experiencing 'low mood'.

"I've been overly depressed, confused and freaked out by it but everybody has been as supportive as they could be."

Young person with cancer

90% of young people experienced anxiety during treatment

We also found that 90% [n=128] of young people we spoke to experienced anxiety during treatment. Shockingly, 42% [n=58] of young people experienced panic attacks during treatment.

Depression and anxiety

Treatment can be lonely for young people. They are often away from school and friends for an extended period of time, sometimes physically isolated due to infection risk, or away from home in unfamiliar surroundings. 83% [n=117] of young people told us they experienced loneliness during treatment.

"A lot of friends I had before I was diagnosed I don't speak to anymore because a lot of them just ran away... I told these friends 'oh I've just been diagnosed with leukaemia' and then all of a sudden they just vanished."

Young person with cancer

70% of young people experienced depression during treatment

"After I was diagnosed with cancer I became isolated from society."

Young person with cancer

Our research findings show staggering levels of mental health needs among young cancer patients, ranging from 'low mood' to panic attacks and depression. When compared with ONS figures for young people's mental health overall they show a stark picture for young people with cancer. ONS figures report 21% of 16 to 24-year-olds experienced depression or anxiety, compared with our data reporting 70% of young cancer patients experiencing depression and 90% experiencing anxiety. Compared with their peers, the young people we spoke to were far more likely to

experience depression or anxiety. Given that the Mental Health Foundation cites a long-term physical illness such as cancer as a risk factor for developing mental health issues, it is unsurprising that we noted higher than average levels of conditions such as depression and anxiety.

Support available to young cancer patients

- 41% of young people did not access support for the mental health impact of their cancer diagnosis and treatment
- Where they did access support, the top three types were CLIC Sargent social workers, counsellors or psychologists, or online support
- 73% of young people said talking to others with similar experiences helped them.

Access to emotional and practical support at the right time can be a lifeline

Access to emotional and practical support can be a lifeline for young people

for young people with cancer and their families. Support needs will vary but can include help and advice with welfare, education or employment rights, referral for specialist emotional support, or just having someone to talk to. This support can be provided by CLIC Sargent social workers, tailored to individual needs, and has been found to deliver positive outcomes for young people (Insley Consulting, 2015).

NICE guidance on improving outcomes for children and young people with cancer states that, "There should be access to expert psychological support with clear routes of referral in principal treatment centres and other treatment settings. This should include identified psychologists or other members of psychological services with expertise in the care of children and young people with cancer. It is important that use is made of existing services and that access to these is facilitated." (NICE, 2005).

41% [n=59] of young people we surveyed did not access emotional support for the mental health impact of their cancer diagnosis or treatment. It is concerning that there is a significant minority who did not access emotional support, or have their mental health needs met by the health system. Of the young people who experienced certain symptoms, 39% [n=37] of those who reported depression and 38% [n=49] of those who reported anxiety said they did not access any support. This increases to 40% [n=53] for those who reported 'low mood'. Our data therefore shows that a significant minority of young cancer patients experiencing mental health issues were not accessing any support at all.

For young people who did access support, the most common were CLIC Sargent social workers, counsellors, psychologists and online support. The majority of those young people (87% [n=72]) said the support they accessed met their needs. Counselling, in particular, was an important form of support for the young people we spoke to.

"[Counselling gave me] somebody to talk to, somebody to talk to who doesn't judge."

Young person with cancer

Those who didn't access emotional support, or said that it didn't meet their needs, reported barriers such as delays in accessing treatment, a lack of information, and the appropriate support not being available through traditional pathways or in their local area. As a result, some of these young people had no option but to pay for private services and treatment.

"The TYA psychologist wasn't able to help me as I was too complex. Despite presenting as an emergency case I had to wait 2-3 months to get referred and start cognitive behavioural therapy. During this time I was... advised to access private services but it cost me £40 per session... The mental health consultant wasn't use [d] to dealing with young people especially those diagnosed with cancer – he often made me feel worse rather than better."

Young person with cancer

"It would have been helpful to have had someone asking me how I'm dealing with things without my parents being there – I didn't want to admit in front of my mum how difficult I was finding things as I didn't want to upset her even more."

Young person with cancer

Impact on families

A cancer diagnosis affects more than the individual. As well as the impact of cancer on themselves, the young people we spoke to were acutely aware of the effect their cancer had on their families. A third of the young people [n=47] felt that their cancer diagnosis had a negative impact on their family relationships and a similar number [n=40] felt that it had a direct impact on the health and wellbeing of their siblings.

"I think the emotional impact on the families of young people with cancer can never be overstated... initially I felt very alienated from the people I love the most."

Young person with cancer

While it is obviously important to provide mental health support to young people with cancer, it is clear that those closest to them may need support as well. Currently, there is very little research into this area and it would be beneficial to explore more about the emotional impact cancer has on the wider family.

What impact this has: Harry's story



"I thought my toughest time came when I was diagnosed with testicular cancer at the age of 20. I went through two bouts of surgery as well as intense chemotherapy. However, it was only a couple of weeks after I received the all-clear that I found myself falling into depression. That was the beginning of a battle that was always on top of me, something I just couldn't shake off – no matter how much I tried to ignore it.

I masked my depression for two and a half years. I was in a long-term relationship and my partner was barely aware of it. I wanted people to see me as the happy, easy-going guy I normally am so I kept my feelings repressed.

I felt incredibly ungrateful and selfish for feeling the way I did. Why should I feel this way when I'd been handed this new lease of life? I tried to force myself to be happy, but that just made things worse. It was a never ending cycle fuelled by guilt and pessimism.

I even developed quite severe OCD. I tried cognitive behavioural therapy, but it was quite the ordeal. Eventually, over time, I was able to change my thinking, to turn the situation I was in upside down. I had believed that in order to truly be grateful for what I'd been given I had to show the world that I was happy and living life to the fullest.

I was just putting too much pressure on myself. It took years but I finally came to the realisation that I didn't have to be doing something all of the time. Instead I concentrated

on the fact that those little things you do in life are special themselves. Just playing and listening to music, or talking nonsense with family and friends. Those moments are so precious.

I still can't believe it took me this long to realise it but I've shown how strong I am now and I just feel the best I ever have done."

Harry

What helps

We asked young people what they found helpful during treatment. The top three priorities were keeping in touch with family and friends (80% [n=102]), talking to others with similar experiences (73% [n=93]), and access to the internet in hospital (72% [n=92]).

"It can be quite a lonely disease if you feel you're the only one fighting it. So to have those connections and have people who are like 'I've been through that as well, you'll be fine.'"

Young person with cancer

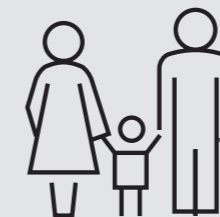
It is unsurprising that access to the internet came up so highly as a priority, as it can enable young people to keep

in touch with family and friends, talk to others with similar experiences and access reliable information about their treatment. Of the young people who wanted to talk to others with similar experiences, more than half (60% [n=54]) said they wanted to do so online. For those who found access to reliable information helpful, the most popular way to access this was online with 80% [n=51] preferring this.

Ensuring free access to reliable Wi-Fi in hospital should be a relatively simple way of supporting young people in hospital. However, we discovered that provision of Wi-Fi in hospitals is not universal (see next page).

TOP 3 PRIORITIES

for young people during treatment



1. Keeping in touch with family and friends



2. Talking to others with similar experiences



3. Access to the internet in hospital

ACCESS TO WI-FI IN HOSPITAL

■ 72% [n=92] of young people said that access to the internet in hospital was helpful during treatment

■ 80% [n=102] of young people said keeping in touch with friends and family helped. Using apps such as Skype, WhatsApp, and social media sites like Facebook, Twitter and Instagram can be a vital way of doing this but require internet access

■ In 2016 CLIC Sargent made a Freedom of Information (FOI) request to all hospital trusts and health boards in the UK that provide any cancer or related services to children and young people to ask if they provided access to Wi-Fi, and if there was a charge for this. We found that England has the lowest availability of Wi-Fi in hospitals at 74%. Of these 14% charge a fee, making access to free Wi-Fi in England significantly lower than other UK countries.

Internet access is important to young people who may be away from home during cancer treatment, as social media and messaging apps like WhatsApp offer a vital channel of communication with family and friends. While it is encouraging that the majority of hospitals in the UK offer free Wi-Fi on their wards, the provision of Wi-Fi that is of reasonable speed, free of charge and permits the use of social media platforms should be a priority for all trusts across the UK.

Other findings of the FOI requests were:

In England only 60% of Trusts provided free Wi-Fi

74% of Trusts in England said they provide Wi-Fi on the wards

86% of Health Boards in Scotland said they provide free Wi-Fi on the wards

75% of Trusts in Northern Ireland said they provide free Wi-Fi on the wards

83% of Health Boards in Wales said they provide free Wi-Fi on the wards.

Internet access is not just a 'nice to have', it can be vital lifeline for young cancer patients

Why young people are not accessing support

It is reassuring that more than 50% [n=85] of young people we spoke to were able to access services to support their emotional and mental health needs during treatment. However, a significant minority did not access these services due to poor availability of local services (particularly for those who lived in rural areas), lack of awareness about the

A number of young people said that may psychological and other services were not tailored to under 18's

the school day). A number of young people said that many psychological and other services were not tailored to under 18's, or were not equipped to deal with the emotional impact of cancer. Additionally, a number of young people who did access services reported that there was a lack of suitable long-term emotional support.

support on offer, financial implications of having to access private treatment and support services not being tailored to young people's routines (e.g. appointments only being available during

It is vital that support services and care pathways exist to ensure that young cancer patients, wherever they are in the UK, are made aware of and are able to access services to help them with their mental health. It is important that both TYA psychologists, and those working with the general population, are made aware of some of the specific issues facing young people with cancer. It is also important to acknowledge that many young people are dealing with a number of different mental and physical health issues alongside their cancer. These needs should be taken into account when considering appropriate services.

CONCLUSIONS

The existing evidence around the emotional and mental health impact of a cancer diagnosis and treatment on young people, combined with CLIC Sargent's new research, demonstrates high levels of mental health needs of young cancer patients.

With 70% [n=98] of young people reporting they experienced depression during their treatment and 90% [n=128] reporting experiencing anxiety, it is clear that a cancer diagnosis is extremely likely to have an adverse impact on young people's mental health. From our analysis, it is evident that young cancer patients are disproportionately experiencing mental health issues compared to their peers. It also appears that a significant minority do not access support services to help them deal with the mental health impact of their diagnosis and treatment.

Our research highlights a number of areas for improvement where access to emotional support is concerned:

- Information about appropriate services needs to be provided to young cancer patients early on in the treatment journey so they can make an informed decision about what, if any, support they access and mitigate against any delays
- Young cancer patients should be supported in accessing appropriate and timely support for their emotional and mental health needs
- Psychologists working with young cancer patients should ensure they understand their needs and provide tailored and appropriate support.

On a positive note the fact that many young people accessed support such as a CLIC Sargent social worker or counselling, demonstrates that there are services that can meet their needs. Young people reported that being in touch with friends and family, and talking to people with a similar experience, helped them. That is why access to fast and free Wi-Fi in hospitals is so important. Young people were also aware of the impact their diagnosis had on their families, even affecting the wellbeing of their siblings.

Despite some of the positive stories we heard, we know there are many more young cancer patients that need to be reached and supported. The long-term impact on young cancer patients living with untreated mental health conditions as a result of their cancer is a serious concern.

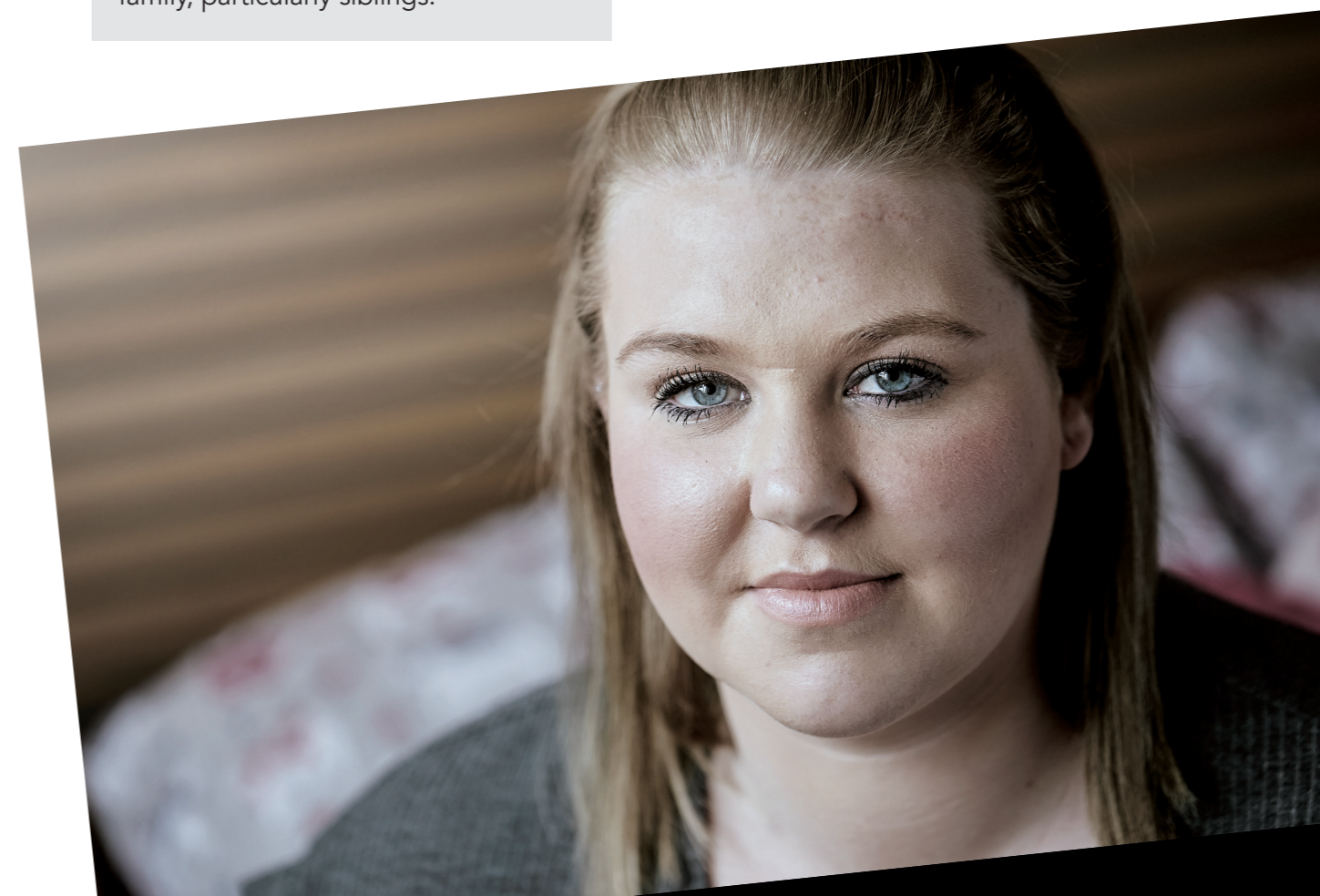
Young people need support with all aspects of their cancer diagnosis, with a greater focus on the mental health impacts. This is why CLIC Sargent supports young people and their families across the UK with the emotional and mental health impact of a cancer diagnosis.

This report contributes to the evidence base on the mental health impact of a cancer diagnosis and treatment on young people in the UK. We also want to raise awareness of the issue, not only among professionals, but also among young cancer patients. We want them to know not only that they may experience mental health issues, but that they should not be afraid to ask for support to help them thrive, not just survive.

RECOMMENDATIONS

We make three key recommendations for change to ensure that the mental health needs of young cancer patients are better recognised and appropriately supported.

- Access to evidence-based mental health interventions for young cancer patients should be part of the treatment pathway if needed, and provided consistently across the UK
- All UK hospitals should provide free Wi-Fi access to support young cancer patients to maintain the connections that are important to them
- Further research is needed on how young cancer patients are accessing services locally and the emotional and mental health impact of a cancer diagnosis on the wider family, particularly siblings.



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- The CLIC Sargent care teams who shared their experiences in interviews

- The Association for Young People's Health

- Rt Hon Norman Lamb MP

- The CLIC Sargent staff who helped to promote our surveys, arrange our interviews, and create the report.

HOW CLIC SARGENT HELPS

When the doctor says cancer

CLIC Sargent is there to help families after their world has been devastated by the news their child has cancer. Our team of care professionals tailor support to a family's needs during this time, providing vital emotional, practical and financial support so that young cancer patients and their families will always have someone to turn to when the doctor says cancer.

There's no place like home

What every child and young person diagnosed with cancer, and their family, so desperately want is to try and get life back to normal. CLIC Sargent nursing teams provide personal care and support at home, allowing families to avoid travel and stay together where possible. CLIC Sargent Homes from Home are havens for patients and families during treatment, alleviating the financial cost and emotional strain of cancer so that families can stay together during the toughest times.

Helping young lives thrive, not just survive

Our CLIC Sargent care teams liaise with schools on behalf of children and families. We speak to fellow pupils and teachers about their condition. We help inform individual school health care plans tailored to their individual needs. Our social workers and community workers support young people with job interviews after treatment and encourage their self-confidence during the long process of recovery. Our team of professionals support young cancer patients so they can continue to learn, regain their confidence and self-belief and be inspired to think beyond cancer.

Cancer costs

CLIC Sargent grants and our welfare advice service help families and young people deal with the debilitating financial consequences of cancer. We award grants and help them secure the benefits they are entitled to. We offer this support so that families can care for their children, and young people can care for themselves, without having to worry about the financial impact of cancer.

When a child dies

Tragically, 10 children and young people die from cancer every week in the UK. We help children, young people and families to prepare, we encourage them to think about how they want to be remembered and help manage their anxiety. Our care teams provide bereavement support through home visits, local support groups and memory days. We provide this support so that children, young people and their families can cope as best as they can when the worst happens.

Making change happen

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



**YOUNG LIVES
vs CANCER
CLIC SARGENT**

**“CANCER AND
ITS TREATMENT
STRIPS YOU BACK
TO NOTHING.”**

clicsargent.org.uk

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