

CANCER AND CORONAVIRUS AS TOUGH AS IT GETS?

The psychosocial impact of the Covid-19 pandemic
on young cancer patients and their families



SUMMARY

The coronavirus pandemic has been a particularly difficult time for young cancer patients and their families, dealing with the emotional, financial and practical impact of cancer whilst the country has had to adapt to changes in how we live, work, and receive health care.

Our survey of young people and parents found that:

- 52% of young people felt they were not coping with the situation
- Around half of parents felt that they were not coping (53% of parents of young people, and 46% of parents of children with cancer)
- Nearly half (46%) of respondents said their finances were affected by the current situation
- Over half (54%) of people who completed the survey felt the most difficult thing about the coronavirus pandemic was the additional stress and worry
- Around a third (36%) of parents felt they were not meeting the needs of their families
- Almost one in 10 young people (9%) felt that their treatment had been impacted in some way, and around one in 10 parents felt their child's treatment had been impacted in some way (12% parents of young people, and 13% of parents of children).

We are calling for:

- Access to emotional support being made a priority as the health system moves into the recovery phase and beyond
- Analysis of the impact of coronavirus on cancer diagnosis and treatment experiences of children and young people
- The government and NHS should work with the children and young people's cancer charity sector to understand the gaps in support that have arisen due to coronavirus, and how we can work together to make sure everyone has the support they need.

INTRODUCTION

In spring 2020, coronavirus was declared a worldwide pandemic. The UK went into 'lockdown' with travel and services across sectors restricted to stop the spread of the virus. Workplaces, shops, schools and education, social care and health services radically disrupted and altered. The UK has had to adapt to living, working and receiving health care differently.

This has been a particularly anxious and challenging time for young cancer patients and their families, who have been dealing with the huge emotional, financial and practical impact of cancer whilst navigating these uncertain times.

As we move out of the initial crisis stage of the pandemic, this research briefing reflects on how young cancer patients and their families have found this difficult time, and considers what we must learn from how health, social care and other services have adapted.

Previous and other research

CLIC Sargent knows that there is a huge emotional and financial impact of cancer. Cancer costs £600 extra per month on average, and it can cost £180 per week just to travel to treatment (CLIC Sargent 2016, 2018). It impacts on education, employment, and mental wellbeing (CLIC Sargent 2012, 2013, 2017, 2020).

A picture is starting to build on the impact of coronavirus on cancer. Evidence from the adult cancer sector suggests that cancer services were disrupted during the UK lockdown; with referral and treatment numbers down, there is concern about the impact of these delays (Macmillan, June 2020). Teenage Cancer Trust research reported that young people with cancer found it difficult to manage issues including seeing friends and family, accessing work or education, mental and physical health (Teenage Cancer Trust, 2020).

CLIC Sargent wanted to understand the impact of these unprecedented times to better support young cancer patients and their families to navigate the new environment and ensure their needs are met.

METHODS

CLIC Sargent conducted two short online surveys with young people and parents. The goal of the surveys was to explore the practical, emotional and other impact on young cancer patients on their families. In total 273 people completed the surveys; 114 parents of children with cancer, 70 parents of young people with cancer, and 80 young people. The surveys were live in the second week of April (survey one), and the second week of July 2020 (survey two). 115 people completed survey one and 158 completed survey two. They were promoted via CLIC Sargent's Twitter, closed Facebook groups, emailed to potential service users and promoted via other charities' networks.

Comparison between the surveys

Surveying twice meant we could capture experiences at the beginning and the end of some of the national lockdown. Responses are comparable with few notable significant differences. Therefore survey two is mostly referred to in these findings as it had a bigger response size - except where there was something notable about the comparison, and this has been highlighted.

Cautions and data limitations

The survey provides a snapshot of experiences at this time. Participants were self-selecting and are therefore not necessarily representative of all young cancer patients and their families or all CLIC Sargent service users, but this data provides valuable insight into the experiences of children and young people with cancer and their parents, at this difficult time.

FINDINGS

Financial impact

Research by Citizens Advice Bureau (2020) shows that six million people in the UK have fallen behind on a household bill due to coronavirus. They found that carers, people who were shielding and key workers are at least twice as likely to be behind on their bills.

Nearly half (46%) of respondents to our survey said their finances were affected by the current situation. Around a quarter (26%) said making sure they had enough money was one of the things they were finding most difficult. Factors impacting on finances included 'not working because they were shielding' (29%) and being put on furlough (24%). Around a quarter (26%) were self-employed and had less or no work due to coronavirus.

CLIC Sargent's emergency hardship grants were crucial during this time for families in crisis who were struggling to afford the essentials such as food, and paying bills.

Emotional impact

Coronavirus has had a huge impact on the mental wellbeing of parents and young people.

Over half (54%) of people who completed the survey felt the most difficult thing about the coronavirus pandemic was the additional stress and worry.

Young people

Research is beginning to show how difficult the situation has been for young people already going through a difficult time. Young Minds (2020) found that 80% of young people already experiencing mental health issues felt the coronavirus pandemic had made their mental health worse.

Our survey found that **52% of young people felt they were not coping with the situation** (this was down from 61% who felt this way in our April survey).

// I've been isolated and not been able to have my day-to-day normal life meaning it's been harder to cope. Obviously if I was having my normal routine, I'd have many more distractions. //

Young person with cancer

Our previous research shows that young people struggle with their mental health during cancer; 79% of young people felt cancer had a serious impact on their emotional wellbeing, and 83% of young people experienced loneliness during their cancer treatment (CLIC Sargent, 2017). They've now had to cope with the added isolation that lockdown has brought for many.

// It's making it a lot harder to be social...I have no one who knows me well in a social support bubble near me to talk to. //

Young person with cancer

CLIC Sargent social care staff saw an increase in demand for support from families they work with, and in the intensity of emotional support required, as families struggled to manage the mental health impact and anxiety surrounding the coronavirus pandemic.

Parents

Research from the Disabled Children's Partnership (2020) found that between 70 and 80% of parent carers reported worsening emotional and mental health for both their children and themselves during lockdown.

Around half of parents who responded to our survey felt that they were not coping (53% of parents of young people; 46% of parents of children).

Coronavirus has meant that many parents have been navigating difficult experiences alone, as infection control measures in many hospitals are only allowing one parent in with their child. Some young people were not able to have anyone with them at all. This restriction is easing in some areas, but still affects many of our families.

// Not being allowed family support in times of being diagnosed, having to be told all alone in a room with just a doctor, not being able to have support when [your] child is having treatments... just having a cuddle from family or friends helps //

Parent of a child with cancer

// The one parent at bedside policy has been the most difficult of the situation. It is very difficult to take in complicated information on your own and try to relay it. Also for bad news not having the support around you. The impact on this has been very upsetting... this has been a truly horrendous time and with the current situation has made it even harder. //

Parent of a child with cancer

Practical issues

Around a third (36%) of parents felt they were not meeting the needs of their families.

At the beginning of lockdown, over a third (35%) said that not getting enough or the right food was the most difficult thing they were dealing with, however by July this did not seem to be a significant issue for families. Initiatives such as CLIC Sargent and Morrisons working together to prioritise food deliveries for our service users and the most vulnerable, were useful during the period where access to food was a particular issue.

Treatment

Evidence from the adult cancer sector suggests that diagnoses and treatment of adults was impacted, with growing concern about the impact of delayed cancer diagnoses during the pandemic. The picture is less clear for young cancer patients. Teenage Cancer Trust found that 46% of young people with cancer (aged 13-30 years old) experienced changes to their treatment or support. This included a change in how often they were able to access or contact physiotherapists, psychologists, or their consultant or other doctor (Teenage Cancer Trust, 2020).

Our survey found that for young people, at the start of lockdown, around one fifth felt that their treatment had been impacted (23% young people, 22% parents of young people). When the survey was repeated in July, this had gone down to around one in 10 (9% young people, 12% parents of young people). 13% of parents of children said that their child's treatment had been impacted.

The positives

Some young people and families have felt that they were well equipped from their cancer experience to deal with the isolation of lockdown. Some patients have appreciated being able to talk to their doctor over the phone rather than a face to face appointment before going in to hospital for treatment. There are positives and lessons that can be learnt from the resilience of this community and their experiences over the last six months.

CONCLUSION

The coronavirus pandemic, and lockdown measures have been difficult for young cancer patients and their families, adding an additional strain to the challenges they already face. The emotional wellbeing and mental health of young people in particular has been under tremendous strain. Social care professionals, such as CLIC Sargent Social Workers, play a vital role in supporting the mental health of young people.

Children's cancer data is a key part of the picture – detailed analysis of the incidence, referral pathways, and outcomes would help to determine the impact of the pandemic. Evaluation of some of the new ways of working and changes to treatment protocols, such as delaying 'routine' scans, and remote consultations is necessary to understand the benefits and pitfalls of these changes. Some of this work has already started, for example, the UK Paediatric Oncology Coronavirus Cancer Monitoring Project (a clinician-led reporting project to enable tracking of paediatric oncology patients who have had Covid-19) and the SHARE study by University of Southampton (2020).

The charity sector is vital in providing support to young cancer patients, and relieving pressure off the NHS. CLIC Sargent, along with others in the sector, has experienced a massive reduction in income during this crisis, and this will be felt for a long time to come. Organisations have had to restructure and make redundancies to survive. Urgent mapping of the services provided and the gaps that may come to exist is needed so that charities, government and the NHS working together can make sure that every young cancer patient receives the support that they need. CLIC Sargent is actively working with others to make this happen, and call on the government to use the outcome of this work as part of their cancer and charity sector recovery plans.

RECOMMENDATIONS

- Access to emotional support from an appropriate professional should be made a priority as the impact of coronavirus continues to be felt. Services should still be accessible even if, for example, further lockdown restrictions are imposed
- Data collection and analysis is needed to understand the impact of the pandemic on diagnosis and outcomes – we call on the government to work with us, alongside colleagues in the sector, to make sure that we have robust data on the impact of coronavirus
- Evaluation of ways of 'new' working in the health system and their impact on cancer treatment experience – a review of adaptations to ways of working such as remote/digital clinics, delayed 'routine' scans or other alterations to treatment pathways
- The government should make it a priority to look at the sector mapping work that is happening and commit to funding charities who are best placed to fill the gaps in support for young cancer patients as a result of coronavirus.

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ABOUT CLIC SARGENT

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

PROJECT TEAM

For more information contact campaigns@clicsargent.org.uk

Helen Gravestock, Associate Director – Policy, Influencing and Voice

Sonia Malik, Head of Research, Policy and Campaigning

Angus Kerr, Head of Strategy and Insight

Jeanette Hawkins, Chief Nurse

Sarah Gilbert, Policy and Public Affairs Officer