# **RESEARCH BRIEFING:**



# The continued psychosocial impact of the COVID-19 pandemic on young cancer patients and their families

August 2021

# INTRODUCTION

This research briefing follows the report *Cancer and Coronavirus:* As tough as it gets?, our initial look at the impact of coronavirus on children and young people with cancer published in May 2020. The pandemic continues to be a particularly difficult time for young cancer patients and their families, dealing with the emotional, financial and practical impact of cancer.

1,216 people completed the online survey (486 young people and 730 parents) at the end of February. This is the third survey over the last year and the results were comparable to our previous surveys: the impact of coronavirus did not significantly lessen over the course of the year. Families with cancer are still finding things tough emotionally, practically and financially.

### **FINDINGS**



# Emotional and mental health impact of the pandemic

- 52% (n=464) of respondents felt they were not coping well with the ongoing pandemic
- 38% (n=293) of respondents felt they were not meeting the needs of their families

"The biggest impact has been on my child's mental health. Her mental health suffered whilst on treatment, but since the pandemic restrictions hit it's had an even greater impact on their mental health and that of the whole family. That feeling of never quite being able to get back on track. They have recently been referred to a psychologist by their oncologist."

Parent of a child with cancer



#### **Finances**

- 43% (n=380) of respondents felt coronavirus had or was likely to negatively impact their employment or finances
- 53% (n=197) felt they needed more financial help to manage their day-to-day living costs



## **Treatment impact**

- 39% (n=69) of young people experienced some aspect of their cancer care alone
- 19% (n=95) said an aspect of their treatment had been delayed in some way.
  - Of those: 26% were delayed getting through to their GP, 17% experienced delays getting prescriptions and 11% had delays getting prescriptions delivered. 44% had a delay to a planned scan, 24% experienced delays to blood or other tests. 24% experienced delays to planned chemotherapy or immunotherapy and 4% delays to radiotherapy. 49% had delays to planned hospital visits and 24% had surgery delayed.



#### Support

Charities like Young Lives vs Cancer (formerly CLIC Sargent) have been supporting children and young people with cancer and their families throughout the pandemic:

 95% of respondents (n=856) said that the support of Young Lives vs Cancer made a positive difference

The top three services used during the pandemic were:

- Social workers (31%)
- Grants (18%)
- Information (10%)

"Even in the darkest times [Young Lives vs Cancer] has provided us with sources of joy and reasons to be positive and excited about the future – not just the end of treatment, but the long journey to full recovery. Our social worker helped us come to terms with our situation and anticipate some of the challenges. This really helped us cope." Survey respondent

Because of Young Lives vs Cancer's support during the pandemic respondents felt:

- Informed about how the pandemic relates to their circumstances (69%, n=323)
- Able to manage their emotional and mental health (63%, n=302)
- Less isolated (53%, n=253)
- Able to manage their day-to-day life (72%, n=343)
- Able to maintain positive relationships with family (75%, n=360)
- Able to manage financial challenges (67%, n=320)
- Able to manage their work situation (58%, n=240).

# **CONCLUSION**

As outlined in our previous report Cancer and Coronavirus: As tough as it gets? (May 2020) we believe it is vital that:

- Access to mental support be made a priority as the health system moves into the recovery phase and beyond
- Analysis is done to understand the impact of coronavirus on cancer diagnosis and treatment experiences of children and young people so that any potential ongoing impact can be tackled
- Gaps in support that have arisen due to coronavirus are understood, so that charities, the NHS and others can work together to make sure that children and young people with cancer have the support they need.

After the impact of the last year, like many in the sector, we are turning our thoughts to mental health and what is needed for those we support to thrive. A combination of services and support structures are needed to ensure that children and young people with cancer and their families have the support they need – from early intervention, crisis support, peer support and listening services to specialised and acute psychological services. All these services play their part and Young Lives vs Cancer will continue to be there to provide mental health support to those who need us and to advocate for other services and changes needed. By working together with the NHS, charities and other organisations, we can be part of a system which truly supports the mental health of children and young people with cancer and their families.

For more information contact campaigns@younglivesvscancer.org.uk

# About Young Lives vs Cancer

When a child is diagnosed with cancer life becomes full of fear, for them and their family. Fear of treatment, but also of families being torn apart, overwhelming money worries, of having nowhere to turn, no one to talk to.

At Young Lives vs Cancer, we help families find the strength to face whatever cancer throws at them. We'll face it all, together.