

# 10 YEAR PLAN TO IMPROVE MENTAL HEALTH



## YOUNG LIVES VS CANCER SUBMISSION

July 2022

### Introduction

Children and young people's cancer comes at a unique time during the developmental stage of one's life. Because of this, young cancer patients needs are different from other young people and adults. At Young Lives vs Cancer we know that cancer costs and the cost to children and young people's mental health is no exception. The impact of cancer goes beyond the physical affecting children and young people's ability to cope with their day to day. Due to children and young cancer patients unique needs, a tailored approach must be taken to ensure that no child or young person is excluded from receiving emotional and mental health support they need.

The government must also ensure that the voices of children and young people with cancer and their families are not excluded in the future of mental health services and provision. We have used our previous research and evidence conducted over the last 8 years to inform our response to the 10 year plan to improve mental health services.

### Key Recommendations

- 1) Evidence-based mental health interventions for young cancer patients should be part of the treatment pathway and after care, and provided consistently across the UK. A collaborative sector approach (such as that outlined in the NHS Psychosocial Task and Finish Group) will help to ensure information, signposting and accessibility of support services provided by the NHS and Third Sector Organisations
- 2) Age appropriate, personalised care should be core to the way young cancer patients receive services – whether they receive treatment at a specialist centre, closer to or at home. The support needed to deliver this care with their unique needs catered for, must be provided consistently.
- 3) Coordinated single point of access follow up services are needed to deliver long term aftercare to address the physical, mental and emotional impact of childhood and young adult cancer.
- 4) To understand and reduce inequalities, tailored and detailed data collection for teenagers and young adults with cancer will support a more accurate understanding of their experiences when accessing mental health and other services.

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# Priorities for the next 10 years of Mental Health services in England

## Access to early mental health support

### Age Appropriate care and support

Current evidence suggests that the rate of probable mental health disorders among children and young people (ages 6-19) has increased to one in six (NHS Digital, 2021). A cancer diagnosis is an extremely traumatic and frightening experience for children, young people and their families. Many will have to navigate cancer treatment alongside different developmental milestones which can bring about different worries and pressures. Young cancer patients often disproportionately experience mental health issues such as anxiety and depression. Our 2017 research found that 70% of young people reported depression, 90% loneliness and 90% experienced anxiety during treatment. Young cancer patients who didn't access emotional support or said that it did not meet their needs, noted that barriers such as accessing treatment, a lack of information, and the appropriate support not being available through traditional pathways or in their local area. We also found that psychological and other services were not tailored to under 18's or were not equipped to deal with the emotional impact of cancer. Service delivery must also take account of developmental age as well as chronological age.

Whilst some parents and young people report excellent emotional and psychological support from a range of services including NHS specialist provision and support by third sector workers like Young Lives vs Cancer Social Workers – access to support services can vary by treatment location and can often feel like a postcode lottery. According to the NICE Supportive and Palliative guidelines, all members of the cancer workforce should hold psychology level 1 skills, this is also echoed in the NHSE Covid recovery taskforce report (CCLG,2022). However, out of 40 organisations who submitted a response to the Children's Cancer Services Workforce and Education Survey only 6 reported provision for this qualification (CCLG,2022). Both reports also encouraged that clinical nurses and advanced and enhanced level practitioners should receive level 2 psychological support training (CCLG,2022). It is important that young cancer patients are able to access appropriate tailored mental health and emotional support to help them face the challenges that come with cancer.

**Recommendation: Age appropriate, personalised care should be the core to the way young cancer patients receive services – whether they receive treatment at a specialist centre, closer to or at home. The support needed to deliver this care with their unique needs catered for, must be provided consistently.**

## Improving the wellbeing and mental health of children and young people with cancer

### Physical support during diagnosis, scans and treatment

The onset of the coronavirus pandemic has exacerbated the emotional impact of cancer on young cancer patients and their families. As a result of hospital visiting restrictions, young cancer patients have had to face treatment alone. Some good practice emerged from this such as offering video calls or remote support with a friend, family member or professional when infection control meant that face to face support could not be accommodated – but this was far from consistent and in some cases is still an ongoing issue.

Despite the easing of coronavirus restrictions, we have found that young people are still having to attend hospital alone without physical or emotional support from family or friends.

**Recommendation: Learnings from the coronavirus pandemic should be considered and implemented – such as looking at the different ways young people with cancer and (other health conditions) can receive support remotely throughout appointments, scans, treatment and beyond, when appropriate.**

### **Access to internet in hospitals**

Going through cancer treatment can be an extremely lonely process. Having access to Wi-Fi can help young cancer patients stay connected to family and friends during their time at hospital. From our research, we learned that young people found keeping in touch with family and friends (80%), talking to others with similar experiences (73%) and access to internet in hospital (72%) helpful during treatment. Having access to internet is a high priority for young cancer patients allowing them to access support online and reliable information about their treatment. Many hospitals do not have Wi-Fi access that is free and of good enough quality to meet the needs of young people in hospital.

### **Improving after-care and support services for cancer patients and their families**

For some children and young people cancer treatment can last up to three years. Once completed, it can have a long-term impact on both the physical and mental health of a young person. The long term impact of cancer includes; disability, fertility problems, emotional and mental health issues. Having to adjust to a new normal can be extremely difficult for young cancer patients and their families as they find themselves worried about relapses and future complications.

In the report of the All-Party Parliamentary Group for Children, Teenagers and Young Adults with Cancer, 73% of parents and young people said that they felt that there was not enough being done to ensure access to post-treatment support.

Sadly, some children and young people may find themselves diagnosed with cancer for the second time. For young cancer patients and their families relapse is extremely traumatic as they have to relive cancer treatment all over again. It is vital that assessment and planning for aftercare and support should be a key part of a treatment plan for children and young people with cancer.

**Recommendation: Coordinated single point of access to aftercare services are needed to deliver long term aftercare to address the physical, mental and emotional impact of childhood cancer and young adult cancer.**

### **Improving data collection**

Access to timely and comprehensive outcomes and patient experience data is essential in ensuring that mental health services meet the needs of children and young people with cancer. Mental health interventions for young cancer patients should be part of the treatment pathway and after care and access to them and effectiveness would be monitored routinely. Outcome data monitoring the impact of mental health support on children and young cancer patients should be carried out.

Data relating to inequalities must be included, which includes age and long term health conditions (such as cancer). This data must record who is accessing services and where, as well as experiences and outcomes.

**Recommendation: A tailored approach should be taken when collecting data for teenagers and young adults to obtain a more accurate understanding of their experiences when accessing mental health and other services.**

## About Young Lives vs Cancer

We fight tirelessly for young cancer patients – individually, locally and nationally. Every year in the UK over 4,000 children and young people under 25 are diagnosed with cancer. That means every day 12 children and young people hear the news they have cancer.

Nine children and young people die from cancer every week in the UK - Cancer is the biggest killer of children and young people by disease in the UK. When cancer strikes young lives we help families limit the damage cancer causes beyond their health. We do this by providing social workers, financial grants and via our Homes from Home.

### References:

NHS Digital (2021) Mental Health of Children and Young People in England 2021 - wave 2 follow up to the 2017 survey

Cancer Costs (2016) Young Lives vs Cancer (As CLIC Sargent)

Hidden Costs (2017) Young Lives vs Cancer

Listen Up ! (2018) All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer

Children's Cancer Services Workforce and Education Survey Report (2022) CCLG (Children's Cancer & Leukaemia Group)

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