

Improving mental health of young people with cancer

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More research is urgently needed to improve the mental health of young people during and after cancer treatment and improve their access to clinical trials, concludes a new study published in the journal *BMJ Open*.

In the first study of its kind, involving researchers from the University of Surrey, young people, their friends and family and healthcare professionals identified pressing research priorities for young people with [cancer](#). Funded by charities Children with Cancer UK, CLIC Sargent and Teenage Cancer Trust, and in partnership with the James Lind Alliance, the study calls for funding to be urgently allocated.

Every day, seven young people aged 13 to 24 years old are told that they have cancer, and it is the leading cause of death from disease in people aged 15 to 24 years old. Affected by a different range of cancers than adults, young people often need complex treatment and care to support the unique challenges they face at a time when their peers are leaving home and starting work or university.

Whilst specialist care and support is provided by the NHS and charities, how best to ameliorate the wider emotional and longer-term impact of cancer on young people is not fully understood, especially from the perspective of the person diagnosed and their friends and family.

A research group that included young people, and led by Susie Aldiss and Professor Faith Gibson from the University of Surrey, Dr. Lorna Fern from University College London Hospitals NHS Foundation Trust, and Dr. Robert Phillips from the University of York, conducted a national consultation examining over 800 research questions submitted by young people, family and healthcare professionals to identify priority areas for future research.

Using the James Lind Alliance Priority Setting Partnership method, ten research priorities that encompassed all stages of the cancer journey were agreed. The top three were:

1. What psychological support package improves psychological wellbeing, social functioning and mental health during and after

treatment?

2. What interventions, including self-care, can reduce or reverse adverse short-term and long-term effects of [cancer treatment](#)?
3. What are the best strategies to improve access to clinical trials?

Amy Callaghan, aged 27, was first diagnosed with melanoma in 2013 aged 19 whilst in her 2nd year at university, relapsing two years later. She has undergone surgery numerous times and has been in remission for the past five years. Amy received support from Teenage Cancer Trust throughout her treatment, accessing a Youth Support Co-ordinator and Clinical Nurse Specialist whenever she needed it.

Amy, a politics graduate who now works as an office manager at the Scottish Parliament, took part in the study to help identify research priorities that reflected the needs of young people. She commented:

"I wanted to use my experiences to help other young people facing their own cancer diagnosis. I couldn't allow the time I spent being unwell to go to waste—I had to see something positive come from my diagnosis. It took time for my cancer to be diagnosed: because of my age my symptoms were initially not taken seriously, and this delayed my referral to a specialist. The support I received from Teenage Cancer Trust was invaluable in helping me achieve my university degree.

"I found it really interesting to be involved in the study. Being an advocate for young people with cancer is different to having actual lived experience, and it was fascinating to see the differences in opinion between [healthcare professionals](#) and young people who have had cancer on what should be research priorities.

"Much of the focus of teams supporting a young person can be on how best to treat their cancer. But a person's life after treatment, as they start to rebuild their lives, pick up school or work and live with the long-term

consequences of cancer, is when they need support at least as much. That's precisely why 'psychological support' was identified as the number one priority by the young people who were involved.

Professor Faith Gibson said: "A diagnosis of cancer can have a devastating effect, but for young people it can be even more profound. Not only are they facing a potentially life-shortening disease but they are removed from everything they know, their friends, family, school life/university/workplace. More research needs to be done to support the psychological and emotional wellbeing of young people, to help them cope with what they are facing and to minimize any long term distress."

Dr. Lorna Fern commented: "Young people, families and professionals have identified research priorities reflecting the cancer timeline. The top ten recognise not everything is curable, and the psychological and social impacts of cancer are a priority for young people living with and beyond their cancer diagnosis. Research into support packages that enable young people and their families to lead as healthy a life as possible must be prioritised."

Sasha Daly, Deputy Director of Policy & Influencing at Teenage Cancer Trust, commented: "Cancer can have a long-term effect on a young person's physical and emotional wellbeing. This is especially the case beyond treatment, when many young people tell us that they can feel abandoned. Support as they re-enter education, start work and rebuild their lives is vital."

More information: Susie Aldiss et al. Research priorities for young people with cancer: a UK priority setting partnership with the James Lind Alliance, *BMJ Open* (2019). [DOI: 10.1136/bmjopen-2018-028119](https://doi.org/10.1136/bmjopen-2018-028119)

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