3 out of 5 childhood cancer survivors struggle with long-term impact

Monday 11 September, 2023

A recent public survey has found that nearly 60% of childhood cancer survivors are faced with a range of health challenges, with the biggest impact on emotional and mental health.

Research carried out by leading UK charity, CCLG (Children's Cancer and Leukaemia Group), has found that survivors of childhood cancer are living with a wide range of physical issues such as fatigue, heart failure, nerve damage, hearing loss, slow growth in height and bones, and infertility. These 'late effects' need lifelong follow-up care and management.

Nearly 3 out of 5 (57%) survivors reported an effect on emotional health and wellbeing, with patients describing a range of mental health issues, including depression, trauma-related conditions such as PTSD and self-esteem issues. The fear of cancer returning, or of managing health conditions as a result of treatment, meant that health anxiety was prevalent, with 77% of survivors worried about future health needs and 65% said to be scared about what might happen in the future.

Parents are also hugely affected and are left feeling worried that their child's cancer will come back (95%), scared of not knowing what might happen to their child in the future (87%), feeling anxious around scans and follow-up (86%), and feeling abandoned and lost after treatment.

This Childhood Cancer Awareness Month (September 2023), CCLG is highlighting the long-term impact of childhood cancer and its treatments, by sharing the stories of those affected, such as that of Ellen Bisci 27, from Harrow, north-west London.

Ellen was diagnosed with a form of acute myeloid leukaemia (AML) in 2005, before relapsing three years later when she also suffered a stroke. As a result of the treatment she received, Ellen suffers from a long list of late effects, including chronic migraines and fatigue, urinary dysfunction, and thyroid issues. She also has focal epilepsy, problems with her memory and facial recognition from the stroke, and intracranial hypertension - for which she's had 13 brain surgeries, including having a shunt put in.

On top of all these longer-standing health issues, Ellen was diagnosed with heart failure in September 2019, describing it as "a massive blow" coming so long after her cancer treatment. These struggles have impacted all aspects of her life – not just her health, but everything from her education and relationships to finances and day-to-day activities. This, she said, has taken her a "huge amount of time to come to terms with".

She explained: "There's a perception that once treatment finishes, your life returns to normal, but for many of us, this isn't the case. Most people, if not physically but emotionally, are impacted in some way from their cancer.

"It's taken a mental toll and I think it took me so many years not to compare myself to peers I'd been at school with, dwelling on things like I haven't been to university, or I haven't done this or that.

"It's deflating when you know you're not able to do what others are able to. Even now, I have to pace myself if I'm out and then make sure I have two days of rest after because of the fatigue. And, because the stroke, I've got issues with my memory and that's where I struggled with education and taking exams.

"So, my life is very different to others, and I think that's difficult to navigate as a young person. I'm stronger now, but it's taken me 15 years to get to this point."

Another possible consequence of children's cancer and its treatment is the development of further cancers later in life. Kimberley Hattersley-Barton, 25, from Halifax, was originally diagnosed with rhabdomyosarcoma in 1999 when 13 months old. After undergoing emergency surgery, followed by several rounds of chemotherapy and radiotherapy, she was given the all-clear at two-and-a-half years old.

Since then, however, she's been diagnosed with cancer a further three times – twice with squamous cell

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carcinoma and most recently, when surveillance scans picked up a thyroid mutation last year. Though now in remission for all four cancers, she suffers from a raft of late effects because of the treatment she received as a child, including kidney, heart and ovarian failure, the latter of which led to her being told she was infertile last year.

She said: “The main thing I suffer from is kidney failure. This condition impacts my energy levels, leaves me with extreme fatigue and affects my breathing, and I’m susceptible to water infections as well.

“I also have ovarian failure and I'm infertile, which was only really properly diagnosed last year. Because of the ovarian failure, I haven't had puberty naturally. I’ve never had monthly periods and had to start hormone replacement therapy in my early teens.

“I was injected with growth hormones every night for eight years, to basically do everything that my body should have been doing but couldn't because of the damage the treatment had done.

“When I was told I was infertile that had quite an emotional impact. I was always aware I couldn't have carried a baby, but the full issue of fertility was never properly addressed.”

Ashley Ball-Gamble, CEO CCLG, said: “This Childhood Cancer Awareness Month, we want to share these findings in the hope that the public and professional bodies are more aware of the long-term challenges children with cancer face after treatment.

“As the professional network for those involved in the treatment and care of children with cancer, we are in a unique position to feed back our findings to our members. These invaluable insights will help us influence positive change through our network of national experts, who are working hard to understand the full extent of childhood cancer’s impact, which will, in turn, help implement improvements in care and resources.

“There’s lots more to do to develop appropriate support for survivors, but we’re working hard to make it happen.”

Ellen believes there’s hope for a brighter future thanks to charities like CCLG funding research into finding kinder, more effective treatments that will result in less long-term impacts for the patient.

She said: “I’m extremely hopeful that with the newer treatments that are available now and that continue to be modified and found, late effects won’t be so impactful for childhood survivors in the future. It would be great to get to a stage where all children not only survive but do so without all these side effects.

“We also need research looking at support for people with late effects, and that’s why the work of CCLG, which funds research across the whole cancer journey, is so important. Hopefully, by speaking out about my experiences, people might want to donate and help fund such research.”

Mr Ball-Gamble added: “One of the best ways we can mitigate the impact of late effects is to continue to find or refine treatments so that they’re less harmful to patients in both the short- and long-term, and the only way to do that is through research.”

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