

## About Teenage Cancer Trust

Teenage Cancer Trust is the only UK charity dedicated to meeting the specialist nursing, care and support needs for young people with cancer aged 13-24. We fund 28 specially designed units across the UK, along with NHS posts including expert Cancer Nurses and Youth Support Coordinators that provide young people the age-appropriate care and support they need.

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*“My Clinical Nurse Specialist couldn’t stress enough that she was always a phone call or an email away if I needed her. She constantly reassured me and reminded me how far I had come. It was great to have someone like her on my side.”*

— Lianne

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## Young people’s experiences with cancer

- Every day, seven young people aged 13-24 hear the words ‘you have cancer’. By 2030 that number will be closer to 10.<sup>1</sup>
- **Cancer kills more teenagers and young adults in the UK than any other disease**, but cancer is still often under-recognised in young people.<sup>2</sup>
- **Cancer is different when you’re young**. The cancers most commonly diagnosed in young people differ from those of older adults. This age group can face delays to diagnosis, and cancer treatments can be less effective for young people.<sup>3</sup>
- **Cancer hits young people hard**. A cancer diagnosis can be hugely disruptive to a young person’s life. It comes at the same time they are undergoing rapid physical, social, psychological, and cognitive changes and can cause significant distress to both them and their families.<sup>4</sup>

## What do young people with cancer need from the incoming government?

Politicians have the power to change the future for young people with cancer. But to achieve this change, young people with cancer need the next Government to:

### 1. Publish a new Long Term Cancer Strategy

Alongside other cancer charities, we are calling for the next Government to publish a new long term cancer strategy in England to improve cancer outcomes in the country. It is vital that any new plan includes a dedicated focus on the unique needs of young people with cancer, such as improving access to clinical trials, faster diagnosis, and addressing the inequalities that young people face when accessing specialist mental health support.

### 2. Take action to ensure more teenagers and young adults are diagnosed faster

Action to improve awareness of the signs and symptoms of cancers amongst young people to drive faster diagnosis and treatment for young people with cancer – with support for public

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<sup>1</sup> (Between 2013-2015). Public Health England, 2018.

<sup>2</sup> Rachel M. Dommert et al., (2019), ‘Achieving a timely diagnosis for teenagers and young adults with cancer: the ACE “too young to get cancer?” study’, *BMC Cancer* 19:616

<sup>3</sup> Yi Feng Wen et al., (2021), ‘The global, regional, and national burden of cancer among adolescents and young adults in 204 countries and territories, 1990–2019: a population-based study’, in *Journal of Hematology & Oncology* 14:89, 2

<sup>4</sup> Teenage Cancer Trust, ‘[The Blueprint of Care: for teenagers and young adults with cancer](#)’ (2016)

awareness campaigns for cancers experienced by young people (building on our 'Best to Check'<sup>5</sup> campaign).

### **3. Ensure that teenagers and young adults with cancer have access to life saving clinical trials**

Investments in, and improvements to, the availability, access and uptake of clinical trials. Teenagers and young adults living with cancer must be included in national initiatives to increase the availability of clinical trials. It needs to be easier for young people to access trials, e.g. through timely financial support, and accessible, age-appropriate information on trials. Additionally, data collection on participation in trials, including young people for whom no trial was available, must be consistent and transparent, as recommended in our report: *Improving Young People's Access to Cancer Clinical Trials*.<sup>6</sup>

### **4. Tackle the crisis in mental health amongst young people with cancer**

This means ensuring that every teenager and young adult with cancer can access expert psychological support from the point they are diagnosed, and for a minimum of two years after their treatment. Funding must be available to increase the number of specialist psychologists in post and accessible for young people with cancer.

### **5. Stop the postcode lottery facing young people with cancer when accessing fertility treatment and preservation**

Further research and investment to ensure young people with cancer can access and obtain funded support for fertility preservation treatment and long-term cryopreservation storage. Fertility treatment and preservation, and funding to support this, should not be a postcode lottery for young people with cancer.

### **6. Address, invest in and improve the NHS workforce pressure**

Since Teenage Cancer Trust was established in 1990, the number of young people in the UK diagnosed with cancer each year has increased by 24%.<sup>7</sup> Future planning for NHS workforce should provide much-needed detail as to how capacity within cancer care will be increased and ensure there are the specialist workforce available to treat the young people who need them.

### **7. Publication of data about teenagers and young adults with cancer**

We want the next government to commit to ensuring that good quality, timely data for teenagers and young adults is readily available, to understand more about the unique issues around diagnosis, treatment and outcomes that young people face.

The data about their experiences, will also ensure that young people and their families receive better support during and after their treatment.

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<sup>5</sup> Teenage Cancer Trust, "[Even if it is nothing, is it not best to check?](#)"

<sup>6</sup> Teenage Cancer Trust, [Improving Young People's Access to Cancer Clinical Trials](#) (April 2024).

<sup>7</sup> Pesola, F., Ferlay, J., Sasieni, P., "[Cancer incidence in English children, adolescents and young people: past trends and projections to 2030](#)" *British Journal of Cancer* (2017), Dec 5; 117(12): 1865–1873

## Further information: key issues for young people with cancer

We are looking forward to meeting with newly elected parliamentarians to discuss the challenges young people with cancer continue to face, and how we can work together to address these challenges.

To support these conversations, we have provided some key information below:

- Just 17% of young people aged 13-24 can identify any of the five most common signs of cancer<sup>8</sup>, and young people have to see their GP more times before diagnosis than any other age group<sup>9</sup>, meaning **many face potentially life-threatening delays to getting their cancer diagnosed and treated.**
- Teenage and young adult cancer patients currently face **barriers to accessing to clinical trials**, despite the potential they have to provide life-saving treatment options for young people.
- There is a **postcode lottery of access to expert psychological support** for teenagers and young adults with cancer. This is particularly concerning the need for this support – when young people we surveyed were asked to describe their mental health in the last 6 months 52% said it had been either very poor or poor.<sup>10</sup>
- **Access to fertility preservation treatment**, and subsequent funding for medium to long-term cryopreservation storage, **is widely inequitable** across the nations for young cancer patients, meaning many do not have the opportunity to preserve their fertility for later in life.
- Young people report better experiences and outcomes when supported by specialist cancer nurses and youth support coordinators<sup>11</sup>, but **high staff turnover and workforce pressures in other areas of the NHS can lead to specialist cancer nurses being stretched thin**, and gaps being met by junior colleagues without a specialist background teenagers and young adult cancer care.

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*“Having cancer at 19 was so isolating. The Teenage Cancer Trust staff on the ward were a godsend.”*

**Rachel, 19, diagnosed with tongue cancer**

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<sup>8</sup> Teenage Cancer Trust, [“New research: Majority 13-24-year-olds don’t know the five main warning signs of cancer”](#)

<sup>9</sup> NHS, [National Cancer Patient Experience Survey](#) (2022)

<sup>10</sup> [Not OK: A cancer and mental health campaign | Teenage Cancer Trust](#)

<sup>11</sup> Clinical pharmacology in the adolescent oncology patient: <https://pubmed.ncbi.nlm.nih.gov/20439647/>