

# The International Charter of Rights for Young People with Cancer

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The International Charter of Rights for Young People with Cancer is a global internet-based initiative set up by five charities from across the world. They are calling on the international community to recognize that access to quality cancer care is a right, not a privilege, and to improve the services and support that young people diagnosed with cancer receive, regardless of geographical location.

## Introduction

CANCER IS A SIGNIFICANT ISSUE worldwide. In 2008, there were 12.7 million new cancer diagnoses worldwide, with nearly 21.4 million new cases annually predicted by 2030.<sup>1</sup>

The International Charter of Rights for Young People with Cancer ([www.cancercharter.org](http://www.cancercharter.org)) is a global initiative set up by five charities from across the world—Teenage Cancer Trust in the United Kingdom, CanTeen Australia, CanTeen New Zealand, and LIVESTRONG and SeventyK in the United States. The term and age range used varies by organization and country, but each organization recognizes the needs of young people diagnosed with cancer and understands that this age group's cancers, symptoms, side effects, and psychosocial needs differ from those of children or older adults. The goal of each organization individually and collectively is to raise awareness of cancer patients that fall between the standard pediatric and young adult groups and to increase access to care and cancer care for these patients worldwide.

## The Founding Charities

### *Teenage Cancer Trust*

Teenage Cancer Trust ([www.teenagecancertrust.org](http://www.teenagecancertrust.org)) is a United Kingdom-based charity dedicated to improving the quality of life and survival chances for teenagers and young people (TYAs, aged 13–24) with cancer. The charity receives no government funding and relies on voluntary donations to design, build, equip, and staff specialist teenage cancer units within National Health Service (NHS) hospitals. Because

young people often feel isolated during their treatment, Teenage Cancer Trust units are not like ordinary cancer wards—they are bright and vibrant and equipped with televisions, pool tables, music, and comfortable furniture. As well as creating a home-away-from-home atmosphere, they allow young people to be treated alongside others their age so that they can support each other. In addition to the specialist units, Teenage Cancer Trust also funds a number of services all with the same goal—to help young people fight cancer. These include clinical and research staff, an education program for schools, family support networks, and an annual conference for young cancer patients.

### *CanTeen Australia*

CanTeen ([www.canteen.org.au](http://www.canteen.org.au)) is the Australian Organisation for Young People Living with Cancer. The touchstone of CanTeen is the belief that young people, through meeting and talking with one another, are better able to cope with the uncertainties of a cancer diagnosis. CanTeen's mission is to support, develop, and empower young people living with cancer. This is accomplished by providing a high-quality Australia-wide peer-support network of adolescents and young adults (AYAs, aged 12–24) living with cancer who share experiences, have fun, offer resources, and promote understanding, well-being, and leadership.

CanTeen is managing the implementation of a US\$30 million Youth Cancer Fund to establish age-specialized youth cancer centers and services throughout Australia, in partnership with the Sony Foundation Australia and the Australian government, and with the support of health professionals (through the

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Clinical Oncology Society of Australia) and other cancer organizations. Including commitments made by Australian State and Territory health systems, more than US\$50 million will be spent on new youth cancer services in the next five years.

#### *CanTeen New Zealand*

CanTeen New Zealand ([www.canteen.org.nz](http://www.canteen.org.nz)) was established to ensure that no young person in New Zealand living with cancer should ever have to feel alone. CanTeen New Zealand's mission is to support, develop, and empower teenagers and young adults (aged 13–24) living with cancer through a national peer-support network and high-quality educational and recreational programs.

#### **LIVESTRONG**

Founded in 1997 by cancer survivor and champion cyclist Lance Armstrong, LIVESTRONG ([www.LIVESTRONG.org](http://www.LIVESTRONG.org)) fights for the 28 million people around the world living with cancer today. LIVESTRONG connects individuals to the support they need, leverages funding and resources to spur innovation, and engages communities and leaders to drive social change. Known for the iconic yellow wristband, LIVESTRONG's mission is to inspire and empower anyone affected by cancer.

#### *SeventyK*

SeventyK ([www.seventyk.org](http://www.seventyk.org)) represents the approximately 70,000 adolescent and young adult cancer patients in the United States diagnosed with cancer each year. With the help of young cancer patients and healthcare professionals, SeventyK created an advocacy and education movement to ensure hospitals, health professionals, and the general public are aware of the unique needs of AYA (aged 15–39) cancer patients.

#### **What is the Charter?**

The five charities first came together at Teenage Cancer Trust's International Conference in London more than 10 years ago. With similar interests, they have continued to support each other on projects and publications. After witnessing the plight of many young cancer patients over the years, Teenage Cancer Trust invited the other charities to come together to help young people fight cancer on an international level. The five organizations collaboratively built upon the efforts of SeventyK's United States-based Bill of Rights ([www.seventyk.org](http://www.seventyk.org)) and adapted the issues to apply to young people worldwide.

In June 2010, the International Charter of Rights for Young People with Cancer launched in London. It is an internet-based campaign identifying 10 key rights for young people with cancer, and relates to each step of a cancer journey from early diagnosis and fertility issues to employment and education post-treatment. The five charities are calling on the international community to recognize these rights to improve the care received by young people with cancer, underpinned by the principle that "access to quality cancer care is a right, not a privilege." As of March 2011, more than 10,000 people have signed the Charter.

The International Charter of Rights for Young People with Cancer states that young people with cancer have the right to:

#### *1. Receive education about cancer and its prevention including early detection*

Many cancers that develop later in life are due to health risk behaviors, including tobacco use, poor diet and physical inactivity leading to obesity, and sexually transmitted infections, as well as being influenced by environmental carcinogens. Young people deserve to be educated about these issues and empowered to look after themselves and their bodies. Young people experience some of the most rare and aggressive cancers, making the earliest possible detection of cancer in a young person critical.

*I knew nothing about cancer when I became ill. I didn't realise that teenagers could get cancer, I thought it was just babies and old people. It would have helped me if I knew what to look out for and what to expect. (Allister, 19, brain tumor)*

#### *2. Be taken seriously when seeking medical attention and receive the earliest possible diagnosis and speedy referral for suspected cancer*

Young people may delay seeking a medical opinion because they feel invincible and commonly lack regular medical attention.<sup>2</sup> Additionally, medical professionals often miss the signs of cancer in this age group. A study in the United Kingdom showed that young people with cancer revisit their general practitioner an average of five times before symptoms are recognized or taken seriously. Delays can be weeks, months, and in some cases, years. Their complaints are often disregarded and attributed to growing pains, sports injuries, or not wanting to attend school or college.<sup>3</sup> The combination of these factors results in young people carrying a higher risk for delay in diagnosis or misdiagnosis, which adversely affects survival rates.

*I started feeling really breathless when I was 13, but my Doctor said it was asthma. It got worse to the point where I had a constant stabbing pain in my chest yet they still told me it was just asthma. Five years later I got really ill and spent four months visiting my doctor every week until he eventually gave in to my pestering and sent me for a chest x-ray. The x-ray showed that my right lung had collapsed, and by the time I saw a consultant the collapsed part had died. All this time I had a large cancerous tumour growing on my lung, and as a result I've had two thirds of it removed. (Hannah, 25, carcinoid tumor in right lung)*

#### *3. Have access to suitably qualified multi-disciplinary medical specialists with significant experience in treating cancer in this age group*

The biology of cancer in young people is not fully understood. As a result, there should be open access to physicians familiar with this unique age group and consultation across medical disciplines.

#### *4. Information about and reasonable access to clinical trials and treatment that has been clinically trialled with people in their age group*

Young people are the least represented age group in clinical trials. The gap in participation results from many factors, in-

cluding a lack of available trials, lack of information given to people about clinical trials, inability or reluctance of the patient to participate in a trial, and financial limitations for both the patient and family care providers.<sup>4</sup>

A recent study in the United Kingdom found that between 2005 and 2009, 70% of children (under the age of 14) diagnosed with cancer were entered into clinical trials. However, during that same time period, only 28% of patients aged 15 to 19 and just 11% of those aged 20 to 24 were enrolled on trials.<sup>5</sup> With only four children but six teenagers and young adults being diagnosed with cancer in the United Kingdom each day,<sup>6</sup> there is a clear inequality.

Cancer biology and patient tolerance for chemotherapy change during adolescence, affecting both the ability to deliver effective therapy and the likelihood of treatment response. In order to ensure the most appropriate treatment protocols, there also needs to be a better understanding of how a drug is used in the body, how it is broken down, the potential side effects, and which of these side effects are manageable and which are dangerous.

Seeking out trials that may be available in other treatment centers (e.g., an adult trial for a young person being treated in a pediatric setting) and providing education and support to facilitate adherence to trial requirements can contribute to greater enrollment rates.

**5. Receive age-appropriate support including, but not limited to, psychosocial, community and palliative support services**

The spectrum of adolescent cancer is unique and diverse. It is a difficult process to navigate through and professional assistance throughout is crucial. The psychosocial needs of young people are unique, broader in scope, and often misunderstood in comparison to other age groups. Specialized services and resources to assist with peer relationships, body image, isolation, dating and sexuality, and interruptions in school and career are critical to the success of these survivors.

*If it weren't for June [one of Teenage Cancer Trust's Youth Support Coordinators] I don't think a lot of us would've got out of bed in the morning whilst we were on the unit. She always had stuff planned for us to do and she was brilliant at introducing us to each other and listening if I was feeling a bit low. Thanks to June I made four best friends for life who I love and adore. (Jo, 15, osteosarcoma)*

**6. Empowerment in making decisions supported by full and detailed explanation of all treatment options and long-term effects of the disease enabling them to actively influence their care**

A thorough understanding of both treatment side effects and the post-treatment rehabilitation options available plays an important role in the psychosocial issues faced by young people with cancer. Building trust between healthcare providers and survivors is an important step in empowering young people to navigate the healthcare system and take an active role in their own care.

Patient-provider relationships should facilitate open communication and balance a young person's needs for both autonomy and independence. Concurrently, continued en-

agement in education about their cancer can contribute to better outcomes. The highest quality of care results from a strong relationship and mutual respect between patients and their providers.

**7. Fertility preservation, as well as information and counselling concerning short-term and long-term effects of cancer and treatment which affect fertility**

Fertility is a primary concern for young cancer survivors. Full disclosure about the impact of treatment on fertility and access to fertility preservation options at the time of diagnosis is imperative for all young people. The information and support needs to be consistent so that all young people have the same opportunities internationally.

*When I was first diagnosed I was told about my treatment plan and possible side effects. No one spoke to me about fertility preservation and at the time it didn't even cross my mind. By the time it was mentioned it to me, I had already started treatment and it was too late. But if I had been given the option, I definitely would have taken it. I don't know if I am fertile now, and I don't really want to know until I'm ready to think about children. (Peter, 22, brain tumor)*

**8. Have access to specialised treatment and services in age-appropriate facilities alongside their peers**

Young people can fall into a "no-man's land" between pediatric and adult hospitals. Specialized facilities can provide an environment tailored to young adult needs. Dedicated units allow young adults to be treated alongside their peers, rather than in a child's room or sitting next to an older adult, and provide access to staff focused on developing expertise related to young cancer survivors.

New research commissioned by the Teenage Cancer Trust showed that its innovative specialist units create significant benefits, including a sense of normality, for young people with cancer. The study, the first of its kind investigating the hospital environment's impact on this age group, showed that the dedicated units enable teenagers to continue being teenagers, making them feel at ease and more likely to complete treatment than if they are treated alongside children or older adults. Findings from the study, carried out by The Futures Company, clearly demonstrate that the hospital environment plays an integral role in providing a sense of normality by delivering five key areas of benefit to patients: control, connectivity, comfort, stimulation, and personalization. These include being able to keep in touch with friends and family, engaging patients through activities and equipment, a comfortable space where patients can personalize their own area, and the ability to have control over aspects from lighting and meal times to visiting hours and sleep time.<sup>7</sup>

*The thought of having to face my battle with cancer alone, without my friends around me really scared me...the Teenage Cancer Trust unit made such a difference to me; without it I would have been lost. Just knowing that there was a room full of people my age who had been through cancer put a great deal of hope back into my life. (Fiona, 17, non-Hodgkin lymphoma)*



### 9. Financial and practical support to minimise the burden of the disease during treatment

Many young people are in the early stages of financial and professional development when they are diagnosed with cancer. They are not likely to have established substantial savings and as a result are vulnerable to financial hardship from their cancer diagnosis and subsequent treatments. Young people are most likely to be under- or uninsured compared with other age groups.<sup>8</sup> In addition to facing the prospect of bankruptcy due to medical costs and lost income, a lack of insurance is often a barrier to obtaining appropriate referrals, second opinions, and receiving the best possible care.

### 10. Elimination of all forms of discrimination, during and beyond treatment, in education, vocation and insurance, or in the community

Young people affected by cancer experience great phases of transition surrounding diagnosis, initiation of therapy, school or job re-entry, post-treatment follow-up, and during transfer from pediatric to adult care. Increasing cancer awareness and reducing cancer-related stigmas, myths, and misperceptions in the community are just as important as personal planning and stress management. A careful balance can facilitate coping and provide a smooth transition for young people after completing their treatment.

*I returned to school during my treatment and there was naturally a big gap that separated me from my peers. I felt incredibly isolated. But then my head of year arranged for Nigel from Teenage Cancer Trust to come to my school and give a talk about teenage cancer to my year group. When he started talking, everyone looked genuinely interested. He was direct, straight to the point and held our attention. By opening up the issue of cancer, he really highlighted the isolation that I felt. As a result of the talk, I received a lot more support and understanding from my friends and teachers. (Clare, 18, Ewing sarcoma)*

### Conclusion

In recent years, the specific needs of young people with cancer have been increasingly formally recognized in reports by several countries, including the United Kingdom,<sup>9</sup> the United States,<sup>10</sup> and Australia.<sup>11</sup> These guidelines, reports, and recommendations are a result of collaboration between governments, cancer clinicians, young people with cancer, and non-profit organizations concerned with outcomes for young people with cancer. Achieving the outcomes in the International Charter of Rights will similarly need the resources, efforts, and passion of governments, health professionals, young cancer patients, and community organizations.

The International Charter of Rights for Young People with Cancer provides a mechanism to grow the base of support for change. Organizations in many countries will use it to advocate for change locally. Even more importantly, youth cancer is an international issue—by working together we can do far more to achieve outcomes across the globe.

### Disclosure Statement

No competing financial interests exist.

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