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Teenage Cancer Trust response to Health Select Committee Inquiry into Palliative and End of Life Care

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Introduction to Teenage Cancer Trust

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them.

Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we work to significantly improve their diagnosis experience. And through our own research and working with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people.

Young people with cancer and palliative and end of life care

There are around 2,500 teenagers and young adults diagnosed with cancer each year across the UK¹, while 295 young people aged 15-24 die from the disease annually^{2,3,4}. Cancer is the most common cause of non-accidental death in young people, and five-year survival rates remain lower in teenagers than in children⁵. While survival rates for cancer in this age group have been increasing in recent years, they vary widely by cancer type from 96% in germ cell tumours to 56% in bone tumours⁶. For these reasons, it's really important that the NHS considers the palliative and end of life care needs of young people with cancer. We welcome the Health Select Committee's inquiry into this area and the opportunity to respond to highlight the needs of teenagers and young adults with cancer.

Research into the experiences of young people with cancer at the end of their lives has identified a range of challenges in providing appropriate support⁷, including:

- Transition problems from hospital to community-based care
- Lack of specialist paediatric palliative care services

¹ North West Cancer Intelligence Service (2013)

² Office for National Statistics (2011), Cancer mortality by age England and Wales

³ Information Services Division Scotland, <http://www.isdscotland.org/Health-Topics/Cancer/Publications/index.asp?ID=903> (Accessed September 2013)

⁴ Northern Ireland Statistics and Research Agency, http://www.nisra.gov.uk/archive/demography/publications/annual_reports/2011/Table6.4_2011.xls (Accessed September 2013)

⁵ Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer

⁶ Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer

⁷ Grinyer and Barbarachild (2011), Teenage and young adult palliative and end of life care service evaluation

- Lack of agreement between staff about allowing teenagers and young adults to die in specialist units
- The need to establish better communications between Principal Treatment Centres and community-based services
- Insufficient teenage and young adult specific hospice care
- Gaps in services for 16-18 year olds
- A range of services resulting in a lack of clarity about the 'best' option

Specific comments on the terms of reference of the Inquiry

- **Why so many people die in hospital when the majority of people say that they wish to be cared for and die at home or in a hospice**

52% of teenagers and young adults with cancer die in hospital, 32% in their own home, 13% in a hospice and 3% in a care home or other place. This compares to 48%, 25% and 16% respectively for cancer patients of all ages⁸. The greater proportion of young people who die in hospital may be related to the complex symptoms patients have at the end of their life which require more specialist input. It can also be linked to a lack of teenage and young adult specific hospice care and a particular gap in provision for 16-18 year olds who may fall between paediatric and adult care services.

- **The impact of geography and demographic characteristics on access to, and quality of, 24/7 specialist palliative and end of life care**

Cancer in young people is rare, accounting for less than 1% of the total cancer population⁹. We estimate that each Clinical Commissioning Group in England has an average of only seven new diagnoses in 13-24 year olds each year. For these reasons it's really important to have a national standard of specialist care for young people with cancer during treatment, into survivorship and for those who need palliative and end of life care.

After diagnosis, young people with cancer should be notified to the Teenage and Young Adult Multi-Disciplinary Team (TYAMDT) at their nearest Principal Treatment Centre, where Teenage Cancer Trust units are based, in order to ensure they can access the best possible treatments and specialist support¹⁰. TYAMDTs are also best placed to develop a plan for end of life care in partnership with the patient and family. Yet currently this notification only happens for 62% of 15-18 year olds and 34% of 19-24 year olds¹¹. It is critical that this referral pathway continues to be secure in the NHS and 100% of young people are notified to the service as part of standard cancer care. To achieve this, it's important that teenage and young adult cancer services remain a nationally commissioned specialised service, supported by the Teenage and Young Adult Cancer Clinical Reference Group in NHS England.

Teenage Cancer Trust is delivering a pioneering Nursing and Support service model in the North West of England, providing age appropriate outreach services in line with NICE Guidance to reach 100% of local young people with cancer. This model of care helps to tackle the geographic and demographic challenges in delivering specialist care to young people with cancer and will also help ensure that the needs of all young people with cancer are met throughout their cancer journey, including at the end of life.

⁸ Gao et al (2013), Changing patterns in place of cancer death in England: a population based study. PLoS Med 10 (3)

⁹ Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer

¹⁰ National Institute for Health and Clinical Excellence (2005), Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer

¹¹ O'Hara C, Khan S, Flatt G, North West Cancer Intelligence Service (2011), How many teenagers and young adults with cancer are being referred to specialist care in England?

- **The competence and capacity of the workforce: What changes may be needed in staff numbers, skills and training to enable generalist health and social care staff to improve their skills and confidence in supporting people at the end of life?**

Palliative and end of life care is part of a wider cancer journey for many teenagers and young adults with cancer, and their families. It's important that sufficient numbers of specialist staff, who are skilled at communicating with young people, are available at every stage of the cancer pathway. Yet we know that this isn't always the case; for example the National Cancer Patient Experience Survey has repeatedly found that 16-25 year olds report worse experiences with GPs, have less confidence in doctors, and report lower understanding of their condition and treatment¹².

Teenage Cancer Trust has been working with Coventry University since 2006 to develop and deliver specialist accredited courses for health care professionals working with this unique group of patients so that teenagers and young adults with cancer are cared for by well-informed staff commensurate with the specific needs of young people in their care. Many of the courses can be completed online, while some are taught at a London campus. Teenage Cancer Trust offers funding to health care professionals working in the specialty to enable them to complete these modules, and more details can be found online [here](#).

Teenage and young adult cancer care services are rapidly evolving and it is therefore crucial that care and services are delivered by a skilled and appropriately trained workforce with access to continuing professional development. Teenage Cancer Trust is working with the Royal College of Nursing to develop a competency framework for this area, to capture and describe the knowledge, skills and competencies which are the cornerstone for specialist age appropriate care delivery.

We also fund specialist staff across the UK, currently comprising 25 funded or adopted nurses and 24 funded or adopted Youth Support Coordinators. Our nurses are responsible for developing and providing excellent clinical care for young people with cancer and their families throughout their cancer journey, and make sure that care is joined up across different services. Youth Support Coordinators help young people share their experiences and fears with each other and encourage socialising and peer support.

Specialist staff play a vital role in addressing the particular psychosocial needs which young people may have at the end of their life. These can comprise wanting to control the depth of information they receive about their condition, managing what information is shared with the young person or their families, and respecting confidentiality issues between older young adults and parents¹³.

It is me that is the one who has been diagnosed with cancer so I wanted to know everything that the doctors needed to say, good or bad. However I did want my mum to be there to make sure she understood everything in case I missed anything. I wanted to know everything there was to know about my diagnosis even the statistics because even though you knew some things were going to sound terrifying, I just didn't want to be lied to."

Nicole, 17, diagnosed with medulloblastoma

¹² Department of Health (2010, 2012, 2013, 2014), National Cancer Patient Experience Survey

¹³ Smith et al (2012), A Blueprint of Care for Teenagers and Young Adults with Cancer

Recommendations

- **Data**

NICE have highlighted the lack of data available on young people's use of palliative care services¹⁴. In order to improve service provision it's important that more and better data is collected and available. We have wider concerns regarding the lack of data available regarding teenagers and young adults with cancer, and cancer registries as a whole, and would urge the Health Select Committee to review this in a future inquiry.

- **Recognising the unique needs of young people**

Young people with cancer are "a distinct group with special needs"¹⁵ and therefore end of life and palliative care services for this age group must reflect this. In order to meet their needs it's important that teenage and young adult cancer services remain a nationally commissioned service within NHS England, and that all young people have access to these services. Staff delivering care along the pathway must receive appropriate training and be supported to deliver care in line with best practice.

¹⁴ National Institute for Health and Clinical Excellence (2005), Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer

¹⁵ National Institute for Health and Clinical Excellence (2005), Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer