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# Meeting the needs of teenagers and young adults with cancer

## Age-appropriate cancer care – the story so far

The last 25 years has seen a radical shift in how the medical profession view and treat cancer patients aged 13-24. Teenage Cancer Trust has worked with the NHS and health professionals to ensure this patient group is recognised, and Teenage and Young Adult (TYA) cancer care has been established as a speciality in its own right.

Specialist and age-appropriate care is crucial to patient wellbeing. TYA cancer professionals acknowledge that teenagers and young adults tend to cope with the experience of cancer differently from older adults or children; they are in a rapid phase of development, changing physically and in cognitive, psychological and social behaviour.

Treatment at this age can have significant psychosocial and physical impact on wellbeing, from the point of diagnosis and often well beyond active treatment. Undergoing cancer treatment disrupts school life, career and educational plans, as well as relationships and social networks.

In an experience that can be bewildering, it is important that young people understand what is happening to them and feel involved in their treatment. Effective communication can help empower TYA cancer patients through their experience. When effective, TYA cancer care allows a young person to mature through their illness, while developing coping strategies and a sense of self.

Teenage Cancer Trust has so far addressed the needs of this patient group by providing specialist care within dedicated cancer units in NHS hospitals. The charity has 28 units in Principal Treatment Centres across the UK, where young people can be treated in an environment designed specifically for them. The charity also funds specialist nursing staff and Youth Support Coordinators who have specific expertise and experience in TYA cancer care.

The result is that young people receive specialist age-appropriate care and the opportunity to gain peer support through meeting other young people with cancer. In 2005, the National Institute for Clinical Excellence endorsed Teenage Cancer Trust's philosophy of care as best practice [1].

## A gap in provision

The model of care based on Teenage Cancer Trust units has been crucial in developing the specialism and allowing age-appropriate services to evolve, and the model has begun to be adopted in other countries. However, across the

UK, ~50% of young people do not have access to this specialist support. This is because in some regions fewer than half of young people diagnosed with cancer are notified to a Principal Treatment Centre [2]. Many teenagers and young adults are therefore treated only in local designated hospitals, where doctors and nurses are unable to offer age-appropriate support.

This gap in provision matters, especially given a current discrepancy in the care received by teenagers and young adults compared to older patients. This has been highlighted in all four National Cancer Patient Experience Surveys (NCPES). Particularly notable are the findings on how well treatments, tests and different types of cancer are explained – with young people significantly more likely to be left feeling uncertain or excluded [3]:

- 49% of 16-25 year-olds said they completely understood what was wrong with them when it was first explained to them, compared to an average among all patients of 74%;
- 7% of young people did not understand the explanation, compared to an average of 2%;
- 58% of young people felt involved in decisions about their treatment, compared to an average of 71%.

In 2014, the Teenage Cancer Trust commissioned patient experience experts, Experience Engineers, to analyse the unmet needs of a representative sample of young people with cancer. Building on the NCPES findings, this research identified a number of key priorities for young people:

- Support to keep life as normal as possible;
- Treatment from a consistent team of people, collaborating effectively;
- Honest, straightforward communication and information;
- Acknowledgement that young people need tailored care;
- Help to feel in control and clear about what to expect.

In order to meet these needs, regardless of where young people receive their cancer treatment, we have had to develop and extend the support we offer and our methods of working with the NHS. The resulting Nursing & Support Service model extends our current services beyond our units.

## Reaching all patients with the new Nursing & Support Service

The Nursing & Support Service model involves Teenage Cancer Trust nursing staff and Patient Pathway Coordinators working within individual



Teenage Cancer Trust funds specialist nurses who give young people with cancer expert care, support and advice.

regions – at Principal Treatment Centres and local designated hospitals. Within the Nursing & Support Service model, staff seek to identify all young people with cancer locally. They then offer individual age-appropriate care and support across all hospitals and at young people's homes from the point of diagnosis.

The Teenage Cancer Trust experts who make up our Nursing & Support Service teams include:

- **Clinical Nurse Specialists**, who establish our outreach services, provide direct nursing support to young people and help to minimise the disruption of cancer treatment;
- **Lead Nurses**, who lead, develop and coordinate cancer services for young people within Principal Treatment Centres and local hospitals;
- **Nurse Consultants**, who help provide senior nursing expertise and support nationally and provide mentorship to our nursing workforce;
- **Head of Nursing and Clinical Services**, who provides professional leadership to all the national funded nurses and is responsible for the development of nursing for the organisation;
- **Multi-disciplinary/Patient Pathway Coordinators**, who work with NHS staff to identify young people who had been diagnosed with cancer outside Principal Treatment Centres, then put those young people in touch with our specialist staff;
- **Youth Support Coordinators**, who ensure young people with cancer can meet other teenagers and young

adults who have the disease. They also organise social activities, offer emotional support and practical advice, and help young people to stay active and socialise.

We piloted the Nursing & Support Service in the North West of England, including the Principal Treatment Centre in Manchester (The Christie Hospital) and 18 designated hospitals across the region. A range of specialist staff were put in place to support young people wherever they were treated, both at hospital and at home. These staff included one Lead Nurse, two Clinical Nurse Specialists, two Youth Support Coordinators and a Multi-disciplinary Team Coordinator

The pilot was independently evaluated by the Centre for Children and Families Research at Coventry University, led by Professor Jane Coad. Evaluation of the new service model found that it increased collaboration between the hospitals, and entirely changed the culture and understanding of young people's support and care needs.

We estimate that close to 100% of all young people newly diagnosed in the region are being reached. In addition to the reach of this pilot, we have also addressed the needs outlined by Experience Engineers, with the result that the right age-appropriate holistic care is now available to all young people with cancer in the region. The new service was recognised in 2015 by winning the Nursing Times HRH Prince of Wales Award for Integrated Care.

## What is next for TYA cancer care?

To reach every young person diagnosed with cancer in the UK, Teenage Cancer Trust now needs to extend their networks right across the country. The Nursing & Support Service puts young people and their families at the heart of their care – and its success depends on strong relationships with NHS partners nationwide.

Over the coming years, we will be working with hospitals and regions across the whole of the UK to roll out the Nursing & Support Service. We are already working to raise the £80 million estimate we will need to make this happen by 2020, whilst maintaining our current services.

These plans fit well with NHS England's Five Year Forward View for the NHS [4]; core to this is a commitment to give patients more control of their own care. Similarly, the service also closely reflects the Independent Cancer Taskforce's 'Strategy for England 2015-2020', and in particular that strategy's focus on informed choice, patient-centred, holistic care and post-treatment support [5]. These principles are at the heart of Teenage Cancer Trust's new model of care, and pave the way for a future where patient-centred care is at the heart of our healthcare system.

*Sam Smith will be hosting the 1st Adolescent and Young Adult (AYA) Global Cancer Congress at the Assembly Rooms in the centre of Edinburgh from 5 to 7 December, 2016. To register for a place and download the programme, please visit [www.teenagecancertrust.org/conference](http://www.teenagecancertrust.org/conference).*

### References

1. National Institute for Health and Clinical Excellence (2005), *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer*.
2. 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?*
3. Department of Health (2010, 2012, 2013, 2014), *National Cancer Patient Experience Survey*.
4. NHS England (2014), *Five Year Forward View*.
5. Independent Cancer Taskforce (2015), *Achieving world-class cancer outcomes: a strategy for England 2015-20*.