The speciality of young adult cancer care

Teenagers and young adults with cancer have very different needs to those of adults and children. This is an important time for their development – physical, social, psychological, cognitive – and they need specialist care from a wide variety of professionals to achieve the best outcomes.

Report by: Maria Cable

Cancer is never welcomed at any age but particularly in adolescence when so many life changes are happening on so many levels – physically, cognitively, physiologically and socially. In the UK alone, around 2,200 young people aged between 15 and 24 years develop cancer each year. Around 310 die from it – down from about 580 deaths a year in the mid-1970s.1

It is now well recognised that teenagers and young adults with cancer have needs that are distinct from those of both adults and children. This is now formally acknowledged in the UK National Health Service policy2,3 and by the UK’s Teenage Cancer Trust (TCT) in 2012,4 though internationally some countries (e.g. Australia5) are moving faster on this than others.

There are, however, a growing number of advocates – including young people themselves, representatives of all the health professions, researchers and charities – who continue to champion globally the need to acknowledge and act on this reality.

Traditionally, however, and this is often still the case, these young people have been cared for in either paediatric or adult cancer environments, neither of which necessarily tends well to their specific age-appropriate needs. In 2011, however, young people themselves defined what they believe to be their rights with the launch of the International Charter of Rights for Young People with Cancer.6 Those working with paediatric or older adult patients need only concern themselves with either the upper or lower age ranges. Those working in Teenage/Young Adult (TYA) cancer care, by contrast, need to consider both ends of the spectrum, yet be mindful of all aspects of the specific clinical, physical and psychosocial issues facing this group of patients.

The age limits and language used to define young people’s cancer often cause controversy within the international community (see Table 1).
AGE-SPECIFIC ISSUES

Adolescent development
An understanding of the rapid change that is occurring in the physical, cognitive, psychological, social and existential make-up of adolescents and young adults is essential for all those working with them. This development will continue and evolve despite the diagnosis of a life-threatening illness. Indeed, their lives will be shaped by the cancer experience during adolescence. Therefore, the needs of these patients must be considered in the context of normal development, so that they grow into “functional” adults within society.

A cancer diagnosis will unquestionably have an impact on the developing young person, so the provision of appropriate care and support services can also determine how well the young person is able to cope with the experience.

Clinical trials
Teenagers and young adults with cancer are potentially missing out on life-saving treatments because few clinical trials are open to them. Arbitrary age restrictions mean teenagers are often too young or too old to participate in drug trials. This leaves them at a distinct disadvantage in terms of optimising the best possible clinical outcome, and also means that the development of new treatments has been poor. As a result of a study by Fern et al., Cancer Research UK is one of the first major cancer funders to start asking researchers to justify age restrictions on new studies, in an effort to recruit more teenage cancer patients onto its trials. It is hoped that this practice will be expanded more widely in the UK and internationally.

Multidisciplinary team working
The complexity of providing care to this group of patients mirrors the complexity of the age and stage of life that they are at. Consequently, to meet their age-appropriate needs, multi-faceted holistic care, together with specific clinical care, is needed for improving outcomes. The nature of cancer treatment depends on the tumour type and stage of disease. Therefore, the impact of cancer and its treatments on adolescents, coupled with the challenges that this has on the period of development itself, further challenges the provision of true holistic care. Care pathways may well incorporate several medical consultants and their teams across different hospital sites in order to optimise clinical care. Alongside medical management is the requirement of expert, age-appropriate psychosocial care from a range of professionals.

Table 1. How TYA cancers are described by age and terminology

<table>
<thead>
<tr>
<th>Country/region</th>
<th>Age range (year)</th>
<th>Terminology</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>13-24</td>
<td>Teenagers/Young Adults (TYA)</td>
</tr>
<tr>
<td>Australia</td>
<td>15-24</td>
<td>Adolescents/Young Adults (AYA)</td>
</tr>
<tr>
<td>USA</td>
<td>15-39</td>
<td>Adolescents/Young Adults (AYA)</td>
</tr>
<tr>
<td>Eurocare</td>
<td>15-24</td>
<td>Adolescents/Young Adults (AYA)</td>
</tr>
<tr>
<td>Canada</td>
<td>15-29</td>
<td>Adolescents/Young Adults (AYA)</td>
</tr>
</tbody>
</table>
professionals in nursing, psychology, youth work, education and social work, who understand the issues young people and their families may face, from diagnosis to survivorship or palliative care.

It is likely that the care needed by teenagers and young adults would transcend organisational, institutional and often professional boundaries. Where care works well is through multidisciplinary team meetings that concentrate on clinical and psychosocial aspects where all members appreciate the challenges and benefits of providing age-appropriate care in a variety of care settings.

Care environments and models of care
The approach taken by the UK, with the financial and advocacy support of the charity Teenage Cancer Trust, has seen 28 teenage cancer units/clinical environments developed within NHS Hospitals and clinical environments. Specialist built environments such as these are now emerging across the world, such as in Australia, USA and parts of Europe and Canada, though not in great numbers. Regardless of the built environment, the Teenage Cancer Trust advocates that such clinical areas should encourage the creation of an environment that promotes a sense of familiarity and safety for the young patient. Key recommendations include: bringing personal items such as pillows and photographs to hospital; allowing the use of mobile phones and laptops with internet access; facilitation of flexible visiting so as to promote social engagement with peers; flexible accommodation for families; and flexible ward routines such as later waking times, regarded particularly positively by young people. Developmentally apt recreation and entertainment should be integral to the provision of care and not an add-on, as should be the provision of age-appropriate patient information using a variety of mediums.

Even in the UK, not all teenagers and young adults are treated in dedicated units; some continue to receive care in generalist settings. Choice of place of care may not be an option when more local care is preferred. Young people with cancer nonetheless have a right to specialist care. Various models of care exist, from centralised designated care units to hub-and-spoke and outreach models. Technology can be used to harness age-appropriate care for patients and their families.

In 2011, a pilot scheme successfully tested a new role, the young people’s community worker, who would provide flexible and personalised support to young people treated in a local adult cancer ward nearer home who did not currently have access to this help. This initiative came from CLIC Sargent, another UK charity for children and young people with cancer and was based on findings from a study of members of TYA cancer multidisciplinary teams throughout the UK, and on feedback from over 200 young people with cancer, who said they needed more non-clinical support to help them through their treatment. The study concluded that high-quality, community-based services were needed to improve young people’s experience of cancer treatment and their long-term outcomes.

Through strong advocacy and financial support from charities such as the Teenage Cancer Trust and CLIC Sargent in the UK, CanTeen in Australia and TeenCancer USA, services that are age-specific for teenagers and young adults with cancer can be developed alongside mainstream cancer care, though there is much yet to be done. In the UK in 2014, we witnessed a remarkable awareness-raising campaign that was led by a young man with cancer. Stephen Sutton, a young man with progressive bowel cancer, started a national campaign to raise £1 million for the Teenage Cancer Trust. He garnered support from a plethora of celebrities, including the Prime Minister, and the country as a whole, amazing everyone with his aspirations and ambitions in the face of adversity. Sadly, he passed away in September 2014, but his fundraising campaign continues and has raised more than £4 million. Even more impressive is the way in which he heightened general awareness of teenagers and young adults with cancer, reminding us that young people do get cancer and that their needs are different.

Professional development in TYA cancer care
Multiprofessional care of teenagers and young adults with cancer is the foundation on which this specialist field of cancer care is built. Specific learning to care for this patient group has evolved significantly in the last 10-15 years as health professionals, young people and charities worked together to determine the specifics of age-appropriate care gaining a greater understanding of age-specific cancers, treatments and the impact this has on the young person and family as a whole.

The importance of specialised training and education is now established by authors, policies and organisations such as TYAC (www.tyac.org.uk) and ENCCA (www.encca.eu/Pages/TYA-Welcome.aspx) all of whom recognise that advances in the care of teenagers and young adults with cancer will be enhanced by improving the knowledge and skills of health professionals. Much of this learning and education is underpinned by a multiprofessional approach, where professionals
Teenagers and young adults with cancer are potentially missing out on life-saving treatments because few clinical trials are open to them.

As with any specialist area of care, how professionals are educated varies. Conferences focused on cancer in this age group are increasing in number, such as the Teenage Cancer Trust, TYAC, and ENCA2C, a European Research and Innovation Network bringing together nurses and young adults with cancer.

In parallel to study days and conferences, specific TYA-cancer-accredited educational programmes are delivered by two universities – Coventry University, UK, and the University of Melbourne, Australia – both of which offer online post-graduate programmes. Coventry University complements the workforce development work of the Teenage Cancer Trust and delivers further accredited face-to-face and non-accredited learning events. The University of Melbourne works in tandem with PeterMac hospital in Melbourne and CanTeen, the Australian charity, in delivering additional non-accredited online learning opportunities.

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Learn alongside each other.

Some of the core elements of the education required for health professionals caring for young people facing the challenge of cancer include:

1. Understanding the unique needs of teenagers and young adults.
2. Developing skills in the use of age-appropriate communication tools.
3. Creating strong relationships between the pediatric and adult sectors.
4. Developing an understanding of the importance of inclusion into age-appropriate clinical trials.
5. Enhancing the awareness and training in the use of developmentally sensitive assessments and psychosocial tools.

These educational initiatives can lead to improved outcomes for this population of young people. As more general health professionals appreciate that this group of patients have unique needs, we are seeing greater demand for specific learning opportunities in this field through the use of technology.
The role of nurses

Throughout the development of this cancer speciality, nurses have played a significant role and championed excellence in caring for teenagers and young adults with cancer as well as sharing, teaching and developing cancer nursing practice for this age group in a number of ways. A significant development for nurses in this emergent field is the launch of ‘A Competence and Career Framework’ by Sam Smith, Head of Nursing at the Teenage Cancer Trust. This document is endorsed by the UK’s Royal College of Nursing and is designed to complement any existing frameworks of nursing and also draw on the specific needs of caring for teenagers and young adults with cancer. A robust and methodical process, through leadership from said expert nurses, was key in its development, alongside the opinion and guidance of others with expertise in the fields of practice, education and research. This work is transferable across the professions, and indeed internationally, and is freely available to download at www.teenagecancertrust.org/sites/default/files/Nursing-framework.pdf. Additionally, in the past year, EONS and Teenage Cancer Trust jointly held two events that brought together senior nurse leaders in this field of cancer, to harness a European nursing network that shares mutual interest in improving services and nursing care for this group of young people in their countries.

CONCLUSION

Beyond those with specialist interest in the care of teenagers and young adults with cancer, a momentum across the professions, the general oncology community and the world has been fostered and continues to develop. Young people themselves are recognising that they have unique and specialist needs, as are policy makers. Multiprofessional working and learning is key to the development of this movement, and we now see that some professions such as nursing have begun to document what is unique about the approach to care for these patients. Such advocacy and professionalism amongst the nursing profession is welcomed for the benefit of care for young people with cancer, their families and cancer nursing in general.

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Details of the references cited in this article can be accessed at www.cancernurse.eu/magazine

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