

# Young adult cancer services in the UK: the journey to a national network

Robert Carr, Myrna Whiteson, Melinda Edwards and Sue Morgan

**Abstract – The past decade has seen the development of a network of specialist teenage and young adult cancer centres across the UK. These provide expertise in treatment across the spectrum of malignancies that occur in young adults, supported by multi-disciplinary teams that are able to provide the psycho-social support so necessary for this age group, and in a hospital environment that encourages social interaction while delivering expert medical care. The development of teenage and young adult (TYA) cancer as a specialty gained establishment backing in 2005, through NICE guidance which mandated that all 16- to 24-year-olds should be referred to specialist TYA cancer centres. The foundation of this achievement was set by a handful of committed individuals and the Teenage Cancer Trust, a charity that has acted as patient advocate and political pressure group, and that has brought to public attention the need for change while providing support for specialist staff and hospitals.**

**KEY WORDS:** Teenage Cancer Trust, teenage and young adult cancer services, transitional care

*‘Now is not a good time’*

*(Steven, diagnosed at 18 with Hodgkin’s Disease)*

## Introduction

In recent years, several initiatives and documents have raised awareness of the special needs of older teenagers and young adults (TYAs) within the National Health Service.<sup>1,2</sup> Nearly all have focussed on transition; the transition of care of children with chronic illness from paediatric to adult services during their late teens. This story is not about transition. It is about provision of care for previously fit and normal young people in their late teens and early twenties who unexpectedly find that they face the possibility of an early death from cancer.

Malignant disease presenting in early adult life, during the decade from age 16 to 25 years, is rare, but malignancy at this age is more frequent than in children.<sup>3</sup> Unlike paediatric oncology,

which has been a recognised specialty with specialist services for three decades, young adult cancer has remained invisible, with the newly diagnosed patient finding themselves referred to either children’s or adult cancer services. Both can be equally inappropriate for individuals who are at a critical stage of their physiological and psychological development into adulthood, and who have tumours that might be biologically distinct from their paediatric or adult counterparts.

Cancer is the most common cause of death, after trauma, in this age group. Among the more common malignancies are the leukaemias and lymphomas, testicular and other germ cell tumours and brain tumours. Some tumours are adult diseases presenting at a young age, most notably some carcinomas; others, for example Hodgkin’s Disease and bone tumours, have an incidence peak in young adults. For tumours that occur both in childhood and in adults there can be real or perceived changes in biology during adolescence. A well-documented example is acute lymphoblastic leukaemia, which a decade ago had a cure rate of 80% in children but only 45% in young adults. This difference in outcome was believed to be the consequence of changing disease biology during adolescence, but recently it has been shown to be the result of using different regimens for treating children and young adults who in reality had the same biological disease.<sup>4</sup> Over a decade or more, improvement of outcomes in young adults across the spectrum of cancer have been poor, while significant advances have been made in younger children and older adults.<sup>5</sup> Yet this is the least-researched cancer age group.

Added to the medical challenges are the consequences of a cancer diagnosis at a time of life when young people are at a critical point in education or starting work, establishing independence from family and forming new relationships.<sup>6</sup>

## The adolescent mind

Adolescence is a time of search for identity and a period of rapid physical, social and emotional development. It is associated with significant remodelling of the neuroplastic adolescent brain. Life experiences and activities during this time determine which synapses flourish and therefore underpin the formation of adult cognitive processes.<sup>7</sup> Developmental tasks include taking responsibility for one’s own behaviour, developing a moral code, establishing an identity including a sexual identity, establishing autonomy from family and forming mature peer relationships, while preparing to live independently and achieving financial and social independence.

Participation in peer groups is necessary to enable an individual to become self-regulating and construct an identity, and a

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Robert Carr,<sup>1</sup> consultant haematologist and lead for young adult cancer; Myrna Whiteson,<sup>2</sup> president and co-founder of Teenage Cancer Trust; Melinda Edwards,<sup>3</sup> consultant clinical psychologist; Sue Morgan,<sup>4</sup> nurse consultant for teenagers and young adults

<sup>1</sup>Guy’s and St Thomas’ Hospital, King’s College London, UK; <sup>2</sup>Teenage Cancer Trust, London, UK; <sup>3</sup>Evelina Children’s Hospital, Guy’s and St Thomas’ Hospital, London, UK; <sup>4</sup>Leeds Teaching Hospitals NHS Trust, Leeds, UK

**Box 1 . Web-links.**

- Teenage Cancer Trust: [www.teenagecancertrust.org](http://www.teenagecancertrust.org)
- Teenagers and Young Adults with Cancer (TYAC): [www.tyac.org](http://www.tyac.org)
- North West Cancer Intelligence Service, TYA Cancer Registry: [www.nwcis.nhs.uk/tya/](http://www.nwcis.nhs.uk/tya/)
- Coventry University courses on teenage or young adult cancer care: [www.coventry.ac.uk/life-on-campus/faculties-and-schools/faculty-of-health-and-life-sciences/teenage-cancer-care/?theme=main](http://www.coventry.ac.uk/life-on-campus/faculties-and-schools/faculty-of-health-and-life-sciences/teenage-cancer-care/?theme=main)
- jimmyteens.tv: <http://jimmyteens.tv/>
- International Charter of Rights for Young Adults with Cancer video: [www.teenagecancertrust.org/what-we-do/international-charter-of-rights/](http://www.teenagecancertrust.org/what-we-do/international-charter-of-rights/)
- Teen Info on Cancer (TIC): [www.macmillan.org.uk/Cancerinformation/teensandyoungadults/Infoforteensandyoungadults.aspx](http://www.macmillan.org.uk/Cancerinformation/teensandyoungadults/Infoforteensandyoungadults.aspx)



**Fig 1. Photographs from two TCT-funded Teenage and Young Adult Cancer Units.** (a) Common room in a unit providing care for teenage patients from age 13 years. (b) Personal space in a unit providing care for patients aged 16 to 24 years.

supportive peer group enables a sense of belonging and provides an opportunity to try out new roles that further mould identity formation.

Acute serious illness can profoundly affect this process and potential adult functioning. The development of independence from parents is compromised as patients have to rely on their care once more, while dependence on doctors and other authority figures is matched by ambivalence about their involvement and the restrictions this places on newfound autonomy. These factors disrupt the development of social relationships with peers, as can a loss of self-confidence arising from bodily changes or physical limitations. Aspirations for the future can be overwhelmed by concerns about fertility, sustaining relationships and fulfilling academic or career plans, with confidence, self-esteem and self-efficacy significantly undermined as a result. A diagnosis of cancer and its treatment in these early adult years has a well-documented long-lasting effect on survivors, even if cured without medical sequelae.<sup>8</sup>

## Creating a national teenage and young adult service

### *Teenage Cancer Trust — a force for change*

Through the work of the Teenage Cancer Trust (TCT) and committed local advocates championing the special needs of adolescent cancer patients, the UK has become a world leader in the provision of specialist cancer care for young people.

For 22 years, the Teenage Cancer Trust has been the national advocate, campaigning to raise awareness of teenage and young adult cancer. Historically, the doctors who treated this minority patient group in their adult or paediatric service were aware of the added problems that a cancer diagnosis created at this age, but individually they had neither the time nor the organisational structure required to bring about a systemic change.

The beginnings were small: a single ‘teenage cancer unit’ at the Middlesex Hospital in central London, established in 1990. But the ethos behind this was visionary: a hospital unit capable of treating sometimes critically ill patients, but in an environment unlike a normal hospital ward; a layout that brought the patients together and encouraged social interaction rather than isolation (Fig 1); and a place where the patients could have some control over their environment (it was one of the first to be equipped with electronic beds) at time when they had lost control of their lives.

Since that time, and particularly since the need to provide specialist TYA cancer care was embraced by the establishment, TCT has raised funds for and engaged in the design of bespoke units. There are now 25 such units in ‘Principal’ and ‘Designated’ Treatment Centres across the UK. These units are supported by dedicated medical staff with skills in the speciality and experience of working with young adults. But to achieve this, political decision-makers have been wooed and lobbied, relationships built with hospital administrators, and partnerships developed with architects and allied professions in order to create a tailor-made service in each location.

While the growing number of Teenage Cancer Trust Units (as they have become known) have been the visible marker of

progress, the charity has done much more to change the landscape. They have promoted and provided funding for specialist staff, including senior specialist nurses and youth support coordinators; driven professional education through sponsorship of meetings, an international conference and a training course for professionals led by Coventry University; promoted research by funding the first national professorial Chair of Teenage and Young adult Cancer; and developed a schools education programme to raise awareness of cancer in young people as a way of encouraging earlier diagnosis. But above all, the charity has brought the problem to public, professional and institutional attention, and has then worked hard to provide solutions.

More recently, TCT has looked internationally, collaborating with charities in Australia, New Zealand and the USA to launch, in 2010, The International Charter of Rights for Young People with Cancer.<sup>9</sup>

At the outset, the founders of the Teenage Cancer Trust did not envisage the influence for change that the charity would become. Their success has been based on the premise that the patients are teenagers first and patients with cancer second. This vision of placing the young person at the centre of everything that they have done has remained crucial.

In retrospect, it was TCT's independence and single-minded advocacy that was prepared both to take on the political establishment and to challenge accepted medical practice that has helped put teenage and young adult cancer care in the UK ahead of the rest of the world.

### *Becoming part of the establishment*

Fifteen years after that first unit was opened, teenage and young adult cancer services were put on a national footing in 2005 with the publication, by NICE, of *Guidance on Improving Outcomes in Children and Young People with Cancer*.<sup>10</sup> This had started as an extension of children's cancer services to cover adolescents up to 19th birthday, but the expert group, influenced by TCT, young people and a handful of expert TYA professionals, recognised that young adults in their early 20s need the same specialist support, and the age was extended to cover patients until their 25th birthday. With the publication of Peer Review Standards for TYA Cancer in 2011 against which service providers could be assessed, the structure was in place for a national network of regional Principal Treatment Centres, with more local affiliated TYA Designated Hospitals, providing specialist cancer treatment and age-appropriate psycho-social support.

### **Building communities**

Much of the success of the UK's young adult cancer network has stemmed from the creation of communities. This is a vital and obvious function of centralised care in dedicated treatment units, which provide a community of shared experience and peer support for the patients. Less obvious but equally important has been the development of the medical community, as many professionals were previously working in isolation to develop these

services locally. Fundamental to this has been the creation of Teenagers and Young Adults with Cancer (TYAC), a multidisciplinary health professional organisation founded in 2004. It was formed 'to help all professionals involved in the care of young people with cancer to work together to improve knowledge and services'. It genuinely embraces all, whether doctors or nurses, social workers or youth workers, clinical researchers or laboratory scientists. It organises national educational meetings and smaller subgroups focussed on professional education, service development, research, communications and a multi-disciplinary forum. Its genius is to bring all together to share experience and learn from each other in what is still a very new specialty. The professional network spreads internationally through the biannual Teenage Cancer Trust International Conference on Teenage and Young Adult Cancer Medicine.

For the patients, peer support is pivotal. Anne Grinyer's interviews with young cancer patients revealed that treatment in a setting where there were no other patients of similar age added a sense of isolation to the uncertainties of the cancer diagnosis. A 26-year-old described her sense of feeling an out-of-place curiosity when attending for treatment in an adult oncology unit and wondering 'is there nobody just like me?' Another, much younger, patient felt similar isolation compounded by a lack of dignity and privacy in a children's unit.<sup>6</sup>

A specialist age-specific unit for older teenagers and young adults, where both inpatients and outpatients can meet, creates a community in itself. But even in the absence of a physical unit, facilitating patient contact through support groups, social evenings (eg bowling trips) and a closed, moderated Facebook page (as we recently established in partnership with Guy's & St Thomas' Trust Information Governance department), can dispel isolation and create a community in which patients can make friends and support each other.

At Guy's & St Thomas' Hospital, the designated TYA Cancer Centre for south-east London, more than 60 new patients aged 16 to 24 years are referred for treatment each year. Before 2009, they were managed by fourteen separate tumour groups across seven hospitals, and most patients were unaware that there were others of their age being treated for malignancy within the same regional cancer network. The creation of a bespoke TYA service has brought young people together to provide peer group support, alongside the oncology expertise needed to treat them. Over the past decade, several such services have been developed, providing the blueprint of care that is replicated across the country in both Designated Hospitals and Principal Treatment Centres.

A virtual but powerful national TYA community is provided by a filming company called jimmyteens.tv, a project for TYAs who have been affected by cancer. All aspects of the media are used to enable young people to explore and express their feelings and to document them on film. It helps them to make sense of, and share, their very personal journeys. A dedicated team of young staff, all of whom have been affected by TYA cancer, support any young person wishing to make a film, managing the website ([www.jimmyteens.tv](http://www.jimmyteens.tv)) as well as editing the films and posting them online. The site now hosts over 1,000 films and

attracts 2,000–4,000 views a week from around the world. These films are not only viewed by patients but also used as an educational resource by health professionals.

An important annual patient event is a TCT sponsored ‘conference’ for young people with cancer, ‘Find Your Sense of Tumour’. Held over a long weekend at Centreparcs Nottingham, it comprises educational lectures, workshops, questions to an expert panel and evening parties; above all, it provides comradeship and fun. This event has also proved an important vehicle for gathering information from the patients themselves to inform service developments, for example, on experiences of delays in diagnosis and opinions on research recruitment. But central to these weekends is the idea of the patient community, and it provides, on a grand scale, the peer group support that is so vital in TYA cancer care. Other useful resources are shown in Box 1.

## Organisational challenges

### *Delivering care*

Although the provision of specialist care has undergone a transformation in the UK during the past 6 years, many challenges remain for both the young patients and the health professionals, and there are hurdles to negotiate to get into the system. There is lack of awareness of malignant disease in young adults and this can lead to delays in diagnosis.<sup>11</sup> Once diagnosed, the referral pathways are not yet fully established and it can take time for patients to be referred into the appropriate TYA cancer service.

Within the designated TYA treatment centres, the challenge is establishing how delivery of cancer treatment by the tumour group multi-disciplinary team (MDT) fits with delivery of supportive care by the TYA MDT. Unlike paediatric oncology services, in which the medical team cover all paediatric cancers in an environment used to a holistic approach to care, the tumours occurring in young adults mostly need treating by adult oncologists who are specialist in an individual tumour type. The psychosocial support, so necessary for patients in this age group and their families, is provided by a MDT headed by a lead clinician and lead nurse, with specialist allied health professionals including a psychologist, a social worker, a youth worker, a dietician and others as appropriate. In reality, once established, different teams providing treatment for the cancer and supportive care for patients and family can work well but this arrangement does require commitment, negotiation and good communication on both sides.

### *Research*

There is a lack of historical, detailed diagnostic and incidence data for individual malignancies in 16- to 24-year-olds. Birch *et al*<sup>12</sup> have worked to address this retrospectively, and going forward, the North West Cancer Information Service is developing a centralised national Teenage and Young Adult Cancer registry, with TCT funding support.

In 2005, the National Cancer Research Institute (NCRI) created a separate cross-cutting Clinical Studies Group for Teenage and Young Adult Cancer. This has developed three main themes: increasing therapeutic clinical trial availability, health service research and, more recently, promoting disease biology research.

There has been some progress in closing the gap between paediatric trials, which end at patients’ 16th birthday, and adult cancer trials, which tend to have a lower age limit of 18. A recently launched study (Brightlight) aims to measure the qualitative benefits of treatment in specialist TYA centres; benefits have been assumed but have not yet been quantified. Age-specific disease biology studies are underway or planned for testicular tumours and across the spectrum of non-Hodgkin lymphomas, but recruitment to treatment trials, and even observational research, remains difficult.<sup>13</sup> Many newly diagnosed young adults (and their families) are too traumatised by a cancer diagnosis to contemplate research participation. Likewise, many adult oncologists themselves admit to finding talking to young patients about research difficult.

Study recruitment could potentially be increased by making the consent process easier. Making a positive decision to opt in to a study is difficult for a newly diagnosed cancer patient at any age, and particularly for young adults and their anxious parents. The opt-in process also has the effect of making the research seem more complex and contentious than it might be. The possibility of adopting the position of trial entry as the default, with the facility to opt out then or at any time in the future, was explored at the 2012 International Conference. The 200 or more delegates, all of whom work with young adult cancer patients, voted 75% to 25% in favour of informed opt-out consent for peer-reviewed, research ethics approved studies involving just data collection or entry into therapeutic trials that did not influence the treatment given during the early stages of therapy. This approach would remove the pressure of a one-off decision and allow time for further discussion and consideration.

The need for more research to be undertaken in young people across the fields of disease biology, therapeutic trials and health service research has been highlighted by a recent wide-ranging policy initiative from the Royal College of Paediatrics and Child Health.<sup>14</sup>

## Lessons for other hospital specialties

The past two decades have shown that establishing hospital provision for teenagers and young adults needs local ambassadors and champions, regardless of specialty.<sup>15,16</sup> What is important for the patients is support from a team of professionals who understand their needs and can create a peer-group community, help with the disruption that illness brings to financial independence, housing, education and employment, and provide access to experienced psychological support to address the emotional and developmental impact of illness and treatment.

The lesson from TYA cancer services in the UK is that investment in age-appropriate support brings real dividends.

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## Conflicts of interest

Myrna Whiteson is President of Teenage Cancer Trust. The authors have no competing financial interests.

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**Address for correspondence: Dr R Carr,  
Department of Haematology, Guy's Hospital,  
Great Maze Pond, London SE1 9RT.  
Email: [robtcarr@gmail.com](mailto:robtcarr@gmail.com)**


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