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The Teenage Cancer Trust—advocating a model for teenage cancer services

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In medical practice, the unique characteristics of the age group between childhood and full maturity, have not been as fully acknowledged as in educational circles, the criminal justice system or even the commercial world. In the United Kingdom (UK), all patients, regardless of age, have access to cancer care, but generally speaking, this treatment is not always age-appropriate, especially in the case of teenagers. This lack of 'group identification' has medical, psychological and social ramifications that handicap the patient and may even undermine the efficacy of the treatment given.

This group of patients, who are neither children nor yet fully adult, does not fall easily under one term and may be referred to as 'teenagers' or 'young adults' or 'young people' interchangeably.

Whilst young children are treated in children's wards by those specialising in the field of paediatric oncology and adults are treated in wards with older people in mind, those who are neither children, nor yet fully mature, fall between two stools. The United Kingdom (UK) National Health Service considers 16-year-olds to be 'children', and 17-year-olds to be 'adults'. The UK is not alone in these attitudes. Identification of the specific needs of adolescents as patients was scant, worldwide, right up to the end of the 20th Century. Now, however, the volume of literature that acknowledges the particular issues of treating teenagers and young adults is growing [1–4] and patient's expectations are increasing rapidly in parallel with this growth.

1. Teenage Cancer Trust (TCT)

The TCT was founded in response to our realisation that inequalities existed in the UK health system regarding teenagers with cancer. Our view was reinforced by the findings of the Calman-Hine Report of 1995 [5]. At the time, the Trust did not fully appreciate the seminal changes we were proposing and introducing.

Whilst some sensitive practitioners and forward-thinking hospitals had already realised that the provision of treatment for teenage and young adult cancer patients was not all that it could be, this attitude was the exception rather than the rule. The establishment of paediatric oncology in the 1960s and 1970s, including the formation of the United Kingdom Children's Study Group (UKCCSG) brought many advances in the treatment of cancer in British children. Amongst these, were the creation of specialised teams, and the introduction of clinical trials for all common tumours and the development within them of expertise. The Teenage Cancer Trust felt that these advances should be available for teenagers and young adults too.

Our aim was to design and build a TCT Unit in every Regional Centre, as identified by the Calman-Hine report, so that every young person between the ages of 13 and 25 years, with malignant disease, had access to one of the units (Figs. 1 and 2). To date, there are already eight Units around the UK, with another 12 Units at various stages of planning or development. Teenage Cancer Units not only provide a 'user-friendly' physical environment and a concentration of expertise; but also encourage a philosophy and practice of management which enhances both 'life chances' and the quality of life for patients. In other words, TCT Units go further than any other environment or practice in meeting the varying needs of this particular group of cancer patients.

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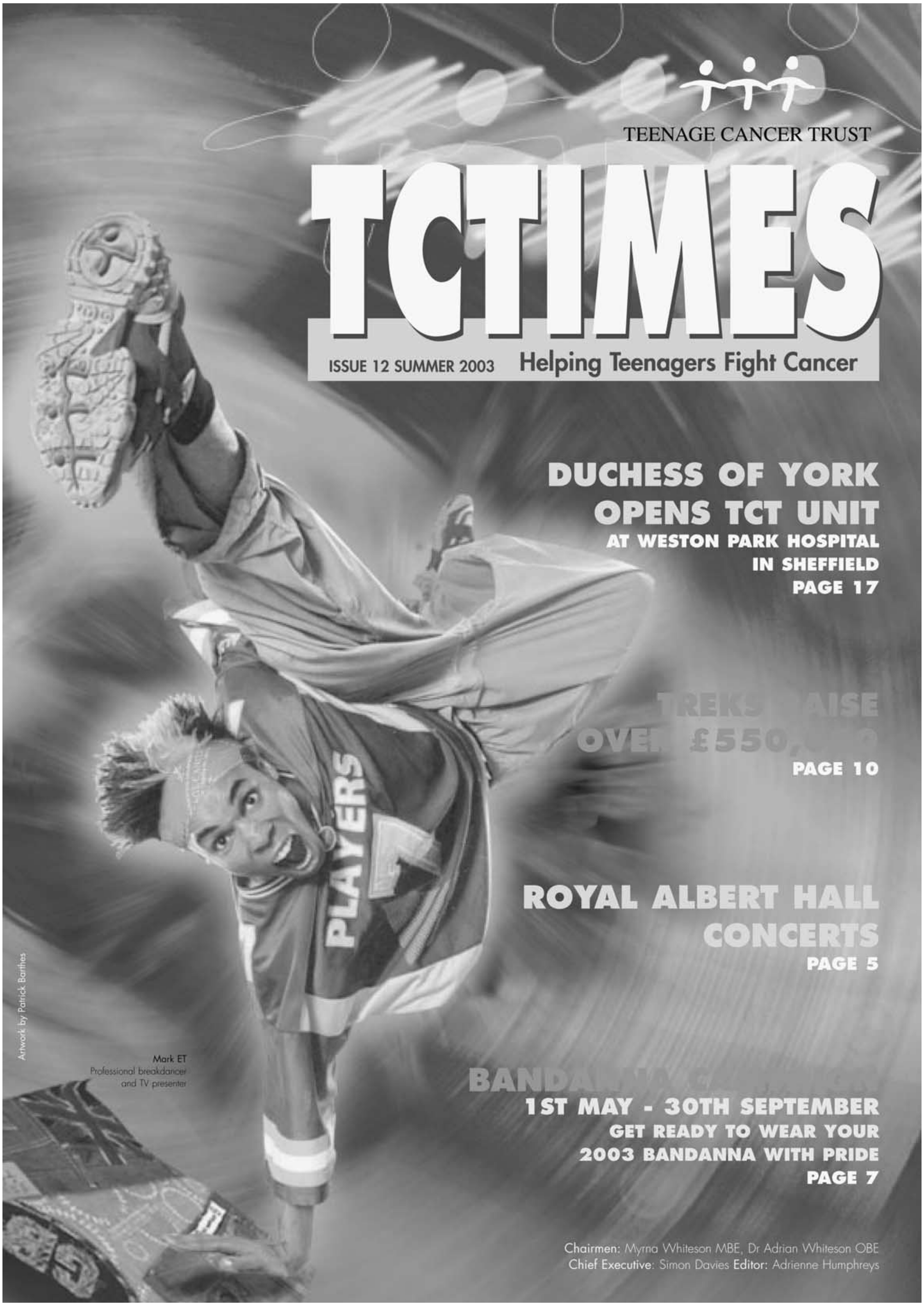

TEENAGE CANCER TRUST

TCTIMES

ISSUE 12 SUMMER 2003 Helping Teenagers Fight Cancer

DUCHESS OF YORK
OPENS TCT UNIT
AT WESTON PARK HOSPITAL
IN SHEFFIELD
PAGE 17

TREKS RAISE
OVER £550,000
PAGE 10

ROYAL ALBERT HALL
CONCERTS
PAGE 5

BANDANNA [illegible]
1ST MAY - 30TH SEPTEMBER
GET READY TO WEAR YOUR
2003 BANDANNA WITH PRIDE
PAGE 7

Mark ET
Professional breakdancer
and TV presenter

Artwork by Patrick Barthes

Chairmen: Myrna Whiteson MBE, Dr Adrian Whiteson OBE
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Fig. 1. Front cover of *TC Times*, Summer 2003. Reproduced with kind permission of Teenage Cancer Trust.

Fig. 2. Neil Smith in the Teenage Cancer Trust Sheffield Unit. Reproduced with kind permission of RVI, Newcastle Department of Paediatric and Adolescent Referral Patterns.

2. Challenges

At times we have been met with unanticipated resistance to the establishment of a specialist Unit from some members of the medical profession, National Health Service (NHS) Trusts, managers and administrators. Our view—that specialist facilities, combined with the development of medical expertise in the field and involvement in clinical trials was the appropriate way to proceed to achieve advances—challenged established practice. Initially, it was the most radical-thinking consultants, nurses and hospital managers who embraced our philosophy. Pressure of work, traditional practices and the constraints of the system in which nurses, doctors and their managers operate can discourage innovation. Possibly, only an independent organisation, such as ours, can challenge systems and encourage radical changes.

Quality of life issues and patients' views are often given insufficient weight. Many patients within this vulnerable age group do not survive, so both time and the need for a degree of 'control' during treatment becomes increasingly precious to the patients. Patients as well as parents wish to be involved in decision-making [6,7].

Some young patients may be denied treatment in the most appropriate and supportive setting due to reluctance by some consultants to refer them to an adolescent Unit. In addition, the transition from a paediatric milieu to an adult environment may be delayed because of an unwillingness to refer onwards. Transfer to the very different atmosphere of an adult ward is likely to cause a 'culture shock' for the vulnerable young patient. TCT Units, by contrast, provide support in an appropriate environment with suitable trained and experienced staff.

In our experience, in cases where hospitals and medical staff adopt an open approach to these issues, so much more can be achieved for the patients. Hospitals such as the Teenage Cancer Trust Unit at St James's University Hospital, Leeds, provide an example to be followed.

Obtaining reliable statistics of adolescent patient 'numbers' is problematic. In the UK, statistics referring to the teenage cohort are potentially duplicated on adult and paediatric data-sets or are inconsistent across regions. Teenagers access cancer care via adult networks, paediatric networks or both, hence data capture can be unreliable. However, what is known is that the numbers of young people with cancer are significant [8]. Many of the needs of these patients are unique to their age group and it is their right to have these recognised and met. With the capital costs of the TCT Unit development met by the charity, only the revenue costs generated have to be found by hospitals and can be creatively achieved. The success of the eight Units already established in the UK justifies the investment required and is inspiring other charities, and even governments abroad.

3. Towards specialisation

The years between childhood and adulthood are the years of change and vulnerability, crucial for a rounded development into maturity. The onset of cancer and the need for treatment is traumatic at any age, but possibly even more so during adolescence and early adulthood. The psychosocial issues, the shift from dependency to independence, the sensitive period for education as well as the medical challenges of treating rapidly developing young bodies, require a special expertise. Units like those provided by the TCT provide an appropriate environment in which to enable and encourage the development of specialisation in adolescent oncology. There are fundamental differences in the needs and treatment of teenage and young adult cancer patients compared with those in other age groups and these differences are shared between countries and continents. These issues govern the TCT's philosophy and practice is geared to these requirements.

3.1. Medical

- Many patients in this age group experience late diagnosis. It may be rare for general practitioners (GPs) to see young people with cancer, but referrals months after initial presentation at the GP surgery are not infrequent and are a significant cause for concern.[1]

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[1] 13–17 year olds: Time to diagnosis 3–6 months 26.3%, over 6 months 15.8%. 18+ years: Time to diagnosis 3–6 months 40%, over 6 months 20% (Department of Paediatric and Adolescent Referral Patterns, RVI, Newcastle).

- The range of cancers affecting the 13 to early twenties age group includes both childhood and adult cancers. Successful management of these conditions, require special medical training and expertise, and possibly complex management.
- Fertility is a significant issue for teens and young adults, and both the cancer and its treatment can damage the chances of future parenthood. Recent changes in the law and in medical technology have widened the range of options that can now be considered. The issue of fertility also involves ethical, psychological and social considerations.
- Few young people are involved in clinical trials either in the UK or worldwide. Outcomes, including rates of cure for patients involved in clinical trials tend to be better than those who are not.
- A reducing amount of data is available as the age of the patient increases.[2]

3.2. Psycho-social

- For normal development in the postpubertal to pre-adult years, association with the peer group is vital. Teenagers are shifting from being family-centred towards peer involvement. Identification with and acceptance by friends is essential, but is damaged by cancer diagnosis and treatment.
- These young people experience both 'accelerated maturity' as a result of their life-threatening disease and 'delayed youth', whereby they are unable to participate in their friends' activities.
- Patients and their families often feel isolated in children's and adult wards, where they have no contact with peers—patients prefer to be with their own age groups and with other young cancer patients [9].
- Adolescence is a period of self-questioning and insecurity; cancer diagnosis and treatment further undermines the confidence of the individual.
- Survivorship is an issue for all cancer patients. However, for some, cancer treatment in the teenage years may be 'second time round' (or more), having previously been treated during childhood.
- Image and self-image may be physically and emotionally damaged.

3.3. Family issues

- Parents of teenagers with cancer will feel as desperate about their 'child' as parents of small children. This is particularly pertinent for parents of older teens and young adults.
- Parents can experience conflicts, isolation and/or rejection when their son or daughter wants to manage 'their' disease and its treatment.
- Teenagers and young adults sometimes overprotect their parents.
- Formerly highly personal issues, such as sexuality and fertility, become 'public' topics, challenging adolescent and parental sensitivities.
- The 'almost independent' member of the family becomes dependent once again, to the dismay of both parent and youngster.
- Family life is disrupted and problems arise with siblings, many of whom are also at a vulnerable teenage stage.

3.4. Relationships

- Isolation from peers at such a socially crucial stage of life may retard or undermine a patient's ability to form long-term relationships.
- Young partners may be unable to cope with the stresses placed upon the relationship by cancer and its treatment, leading to breakdown of relationships.
- Changes in body image can lower self-esteem and may also discourage friends and partners.
- Sexual drive and function may be adversely affected during treatment.
- The damage caused by treatment, e.g. fertility, may deter would-be partners.

3.5. Financial

- Not only might one or both parents have to relinquish their employment to care for their sick son or daughter, but illness creates additional financial burdens—for transport, laundry, special foods, for example.
- The teenager or young adult may well be contributing to the family finances, or even be financially independent. The diagnosis of cancer usually returns this responsibility to the family purse.
- Benefit systems provide little or no support for this age group.

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[2] Charles Stiller, Childhood Cancer Research Group, Oxford (Multidisciplinary Consultation Day, 16 January 2003).

3.6. Education

- Teens and those in their early twenties are at a crucial time with regard to education. Interference by the cancer treatment can disrupt education and future career prospects permanently.
- Whilst there is educational provision for children in hospital, it is normally directed towards young children.
- Education facilities for study or exams is vital.
- Adult wards rarely provide technology to assist with education, in fact there are usually no educational facilities at all.

3.7. Employment and insurance

- Cancer and its treatment may well frustrate the employment hopes and plans of the young person, and mitigate against employment opportunity, closing some options completely.
- Difficulties are experienced by young cancer patients seeking mortgages, holiday and life insurance.

4. Achievements and aims of the Teenage Cancer Trust

The TCT has established a network of Units in the UK, and has influenced other nations (Australia, Canada and France) to begin to work along the same lines. The UK network of TCT Units may well have implications for treatment options for other European Union (EU) countries and their citizens, as well as for those further afield. There is a programme of expansion and upgrading of these Units to ensure that all UK teenage cancer patients have access to a TCT Unit. Our Units provide an environment for the development of professional expertise, and offer opportunities for sub-specialist career development in the field. It is through these specialist centres that young people are more likely to be involved in clinical trials from which patients are known to benefit [10].

Through the pioneering work of the TCT, the patients and healthcare communities are now much more aware of the very sensitive medical and psychosocial issues, surrounding teenagers and young adults with cancer. We are taking this ‘awareness’ to Government via lobbying, seeking to influence NHS decision-makers and sharing our expertise and information with other voluntary organisations in the UK and elsewhere. Delayed diagnosis, which is common in this age group, is a cause for concern [11,12]. So the TCT is working to ensure speedy referrals to specialist centres.

We listen to our patients, and provide them with a voice by sponsoring ‘Find your Sense of Tumour’ (a conference for the teenagers themselves) (Fig. 3). The TCT Multidisciplinary Forum gives an opportunity for professionals to meet quarterly to discuss issues pertinent to treating young cancer patients. On the international stage, the TCT’s International Conferences on ‘Cancer and the Adolescent’ provide an opportunity to present advances and to debate and face common concerns in the field of cancers affecting young people. The TCT also provides an information service for schools, encouraging young people to be aware of their own health, advising on healthy lifestyles, and to be sensitive to their peers coping with cancer.

5. Conclusions

The TCT has been both a catalyst for change for young people with cancer, and an instrument of that change. The Trust’s influence has permeated practice within the UK and is gradually encouraging and enabling change for young cancer patients elsewhere in the world. The path that we have forged provides a blueprint that other countries may wish to follow.

The ‘model of good practice’ that the TCT advocates has highlighted the needs of teenagers and young people with cancer, and contributes to meeting them.

We are proud that the TCT’s initiative has been a UK ‘first’ and that other countries are now following in our footsteps. Indeed, the Trust’s focus on life- threatening disease in adolescence has inspired those working in other medical specialities to examine the ‘standard of care’ they provide for their own young patients.[3]

Fig. 3. Teens signing the ‘make your mark’ graffiti wall at the teen conference, Find Your Sense of Tumour, October 2002. Reproduced with kind permission of Sigh Jones, RVI, Newcastle Department of Paediatric and Adolescent Referral Patterns.

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[3] TCT sponsored: Third International Conference on Cancer and the Adolescent, Monday 1st and Tuesday 2nd March 2004, Royal College of Physicians, 11 St Andrews Place, London, NW1 4LE, UK.

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