

## CHAPTER 1

# A right, not a privilege!

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In 1948, when the National Health Service was established in the UK, we were promised health-care 'from the cradle to the grave'. No-one mentioned much about the in-between years. Here, and in many other countries, health-care is provided separately for children and adults. The age at which one becomes an 'adult' in this context varies from 12 to 18 years, and sometimes appears to be an arbitrary line drawn in the sand. In England and Wales this line divides the men from the boys (and the girls from the women) at 16 years. I am not sure why. We make other divisions about other issues; for instance, we may hold a child over 10 to be criminally responsible. In the field of education we separate infants from juniors, and all of them from the secondary stage at 11 years of age, and may even subdivide the 11 to 17/18 age group. In doing this, it is acknowledged that adolescents or teenagers have specific needs and must be dealt with differently.

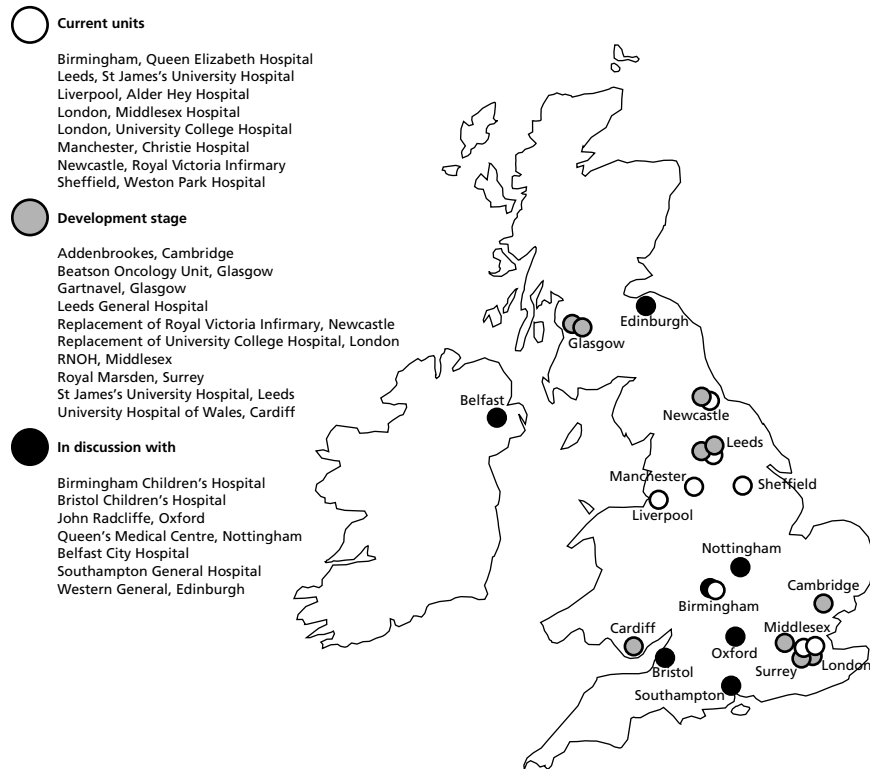
We all know that the commercial world recognizes these 'in-betweens' and makes a great deal of money by meeting their needs. However, in the medical context, teenagers and young adults are a neglected group and suffer as a result. It is their right to have their special needs recognized and satisfied. This should not be seen as a privilege.

The Teenage Cancer Trust (TCT) was established formally in the early 1990s by a small group of charitably minded individuals who, having set up the first specialist unit for young cancer patients at the Middlesex Hospital, London, realized the yawning gap in the provision of treatment and care for this group of patients.

The vision of TCT is to supply a teen-friendly environment in which an expert and highly specialized team of health-care professionals provide their patients with the very best chance of recovery. TCT units are this and more. They espouse a philosophy of putting the patient first. This is not really a new idea, for, as Professor J. B. Murphy (1857–1916, Professor of Surgery, Northwestern University, Chicago, USA) pointed out some 100 years ago, 'The patient is the centre of the medical universe around which all our work revolves, and toward which all our efforts trend.' Within TCT units, the needs of young people are recognized and respected, and not just their needs as cancer patients. The emphasis is on the quality of life as well as its duration.

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### Teenage Cancer Trust Units March 2004



**Fig. 1.1** Distribution of Teenage Cancer Trust units.

We have gone on to establish eight TCT units around the UK and are in the process of developing a further 17 (Fig. 1.1). Setting up these units is a slow process, and it is not the TCT that is causing the delay. Lack of government support, lack of recognition within the medical profession, failure of physicians to cooperate across the age divide, and conservative and unimaginative hospital managements are the main impediments.

In developing these units, we have learned that physically appropriate environments – where architecture and interior design not only provide pleasant surroundings but also add constructively to the well-being of the patient – really make a difference to the quality of patients' lives. In 2003 the TCT unit at Weston Park Hospital, Sheffield, received a commendation from the Commission for Health Improvement for its innovative design and for meeting patients' needs. Additionally, in 2003 the TCT unit at St James's University Hospital, Leeds, was the winner of one of the Department of Health's Health and Social Care Awards – the Cancer New Hope Award.

The growth of a network of units is beginning to allow specialization (and so expertise) within adolescent cancer medicine. There is a definite growth of interest in the field which can only benefit our patients.

We have also extended our sphere of work to support the basic concept of specialized units for youthful cancer patients. We sponsor the Teenage Cancer Trust Multidisciplinary Forum, organize conferences such as the International Conference on Cancer and the Adolescent, and also Find Your Sense of Tumour – a conference for young cancer patients. We are setting up a Family Support service, run an Education and Awareness team for schools and universities – and hope to be appointing the first Chair in Adolescent Cancer Medicine in the world, very shortly.

We consider we have played a considerable part in focusing attention on the needs of this hitherto neglected group of patients, world-wide. Attendance at our international conference has increased from the involvement of five countries to 18 countries, indicating the massive growth in interest. This is one field where the UK (and TCT) is showing the way!

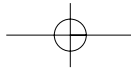
World-wide, cancer service provision for those at such a sensitive and crucial stage of life appears generally inadequate and fails to meet all the needs of the patient. Cancer service provision, we would argue, is about more than treatment: it is also about the quality of care and life both during and after treatment. As in other social structures, this transitional stage of development of young people has to be recognized and our state health services have to make provision built upon good information and must be available to all who require them. Within the UK we appeal to our government and our National Health Service to work with TCT to meet that need.

Some people question whether there is a need for specialized care for adolescent and young adult cancer patients and ask whether teenagers get cancer. The common perception – not only among the general public but sometimes also among professional and political decision-makers – is that children get cancer and adults get cancer, but teenage cancer numbers are insignificant. Yet cancer is the commonest cause of non-accidental death in teens and young adults in both the USA<sup>1</sup> and the UK.<sup>2</sup> In the UK we are just below the European average for 5-year survival rates for children and teenagers with cancer, which leaves much room for improvement.<sup>3</sup>

### **What are the issues?**

Cancer services are delivered by an out-of-date infrastructure that, by and large, fails teenagers and young adults.

- There are difficulties in obtaining reliable statistics.
- Teens and young adults are often subject to late diagnosis.
- Levels of skill and expertise vary between and within treatment centres and we need to know the effect of these variations on outcome.
- Young people have low enrolment in clinical trials.



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- They are placed at the crossover between adult and childhood cancers and experience a different distribution of cancers from other age groups.
- This complexity is exacerbated by the usual division of child and adult services. In the UK (and elsewhere, too) the approach to children is generic, across the board, whereas for adults it is specific to the cancer site.
- Different protocols are used by adult and paediatric practitioners for the same diseases – the relative success of these needs to be evaluated.

Cancer patients in their teens and early adulthood tend to be disadvantaged at every stage.

#### **Do we have the information?**

Although statistics for this age group are still difficult to obtain, we are beginning to appreciate, contrary to common perception, that there are more young people with cancer in the 15–24 age group than in children aged 0–14 years. It is estimated that around 2000 new diagnoses are made per annum in the teenage and young adult (TYA) group in the UK. Some of those treated successfully for cancer during childhood go on to relapse during adolescence. About 75% of children with cancer are cured, but many continue to require physical and emotional follow-up in the long term. Because of the way we gather information in the UK and other countries, we do not actually know how many young people nationwide will be calling upon our cancer services.

In England and Wales the National Institute for Clinical Excellence is currently studying cancer services for children and young people. The National Public Health Service for Wales<sup>4</sup> has data which suggest that the falling birth rate will result in a change in the population's demographic profile, with increasing numbers in the older age groups projected to 2011. Since the incidence rate of cancer is higher in the 15–24 age group (214 per million) than the 0–14 age group (134 per million), increased survival and a changing demography are likely to result in an increase in absolute numbers of incident and prevalent cancer patients aged 15–24. This suggests an increased need for services both in the short and longer term for the TYA group.

Why has this not been sufficiently considered by the medical profession? Failure to do so has hindered the reorganization of service delivery. Why has the National Health Service not made the necessary infrastructure changes to care appropriately for young cancer patients? Surely this is negligence! In the UK, it has taken a charity – TCT – to show the way and inspire change.

#### **The numbers game**

The problems of gathering statistics are, in part, due to the division of TYAs between child and adult services. This is a serious problem and an obstacle to the provision of sound information. It undermines the establishment of appropriate standards and systems of service delivery to the complex group of patients that make up the TYA sector. The work of Birch and colleagues<sup>5</sup>

highlights the value of detailed data in assessing the needs of and the provision of services to the hitherto neglected youth with cancer.

In order to fulfil our duty to young cancer patients, both as a profession and as a society, we need more focused information-gathering. The sector of the population with whom we are concerned presents many problems that would be addressed by more reliable information, and this information would also enable us to build structured approaches to treatment and help resolve the unique issues.

It may be too cynical to suggest that failure to identify this group of patients – so that true figures and information are not available – has resulted in the absence of demand for special facilities, treatment, research and funding. Defining this group out of existence might save governments, the National Health Service and the health trusts a great deal of money. You don't have to spend on what doesn't exist.

### **Late diagnosis**

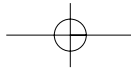
There is much anecdotal evidence and some factual indication regarding the issue of general practitioner delay. Many factors contribute to this impediment to speedy diagnosis and treatment.

- Teenagers themselves! Often they are hesitant or even reluctant to visit the doctor. In the USA it is observed that young adults have the lowest rate of primary care use.<sup>1</sup>
- Young people are under-educated regarding their own health.
- Parents are less involved in their children's personal care at this stage of life.
- Few general practitioners have experience of adolescent and young adult cancers.
- Few general practitioners have cancer in their lexicon of possible diagnoses for young patients (the low profile of teenage cancer may contribute to this).
- There is not a clear pathway of referral, as there is for children. As a result, the locus of referral is something of a lottery. In turn, this influences the levels of experience and expertise that patients will find. We need to know how this affects the outcome.

### **Clinical trials**

Relatively few teenagers and young adults with cancer are enlisted in clinical trials. Overall, the outcome for patients involved in trials tends to be more favourable. Results of clinical trials provide the information base for future treatment. They are the foundation upon which treatment can be improved and standardized. Therefore, once again young cancer patients are disadvantaged.

It is accepted that few TYAs are included in trials. The following factors contribute to their exclusion.



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- The pharmaceutical industry dominates in this field. Pharmaceutical companies work on numbers, and we are talking about a relatively small group of patients. It is accepted that within each country the numbers are proportionally small, but world-wide there is a considerable total, enough to justify research. The pharmaceutical industry appears to show little interest in this age group.
- Governments, who are sizeable customers of the pharmaceutical companies, should place requirements on these organizations to test drugs to benefit young people. In the USA the Food and Drug Administration requires drug companies to evaluate their products for children in order to obtain a paediatric licence. This is an encouraging move.
- While eminent clinicians advocate clinical trials for young cancer patients, we in Europe are concerned about a European Union directive, due to come into force in May 2004, which will make clinical trials for children, adolescents and even young adults even less likely than they are now. If implemented, this directive will make trials more costly and the outcome will be that only the pharmaceutical companies will be able to afford to set up trials, and academic trials will be severely curtailed as a result. This can only further limit the involvement of young cancer patients in such research.
- Some of the cancers which TYAs experience are rare and so do not inspire trials.
- Clinicians often see young people as non-compliant, and there may be some validity in this argument – but insufficient to justify not involving them. A concentration of young people in specialist centres such as TCT units would assist in the setting up and management of clinical trials and help mitigate patient resistance.

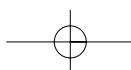
It is vital that young people with cancer are actively involved in clinical trials, in order to ensure a consistent and enhanced standard of care.

### **Range of cancer services**

The variety of cancers affecting the age group in question includes childhood and adult cancers. Imposing this diversity upon the rigid structure of childhood or adult centres and protocols raises further problems.

It is common practice in the UK for the approach to childhood cancer treatment to be generic while that for adult cancer is site-specific. These systems do not mesh well. As a result, those on the cusp may not get the appropriate approach to treatment. This is often exacerbated by a lack of cooperation between adult and paediatric practitioners. Unfortunately, this is sometimes my experience when working with hospitals in the UK, and having conducted a straw poll via nurses from a number of other countries I conclude that this glass wall exists in those countries too.

But TYA cancer patients should not be limited to either paediatric or adult services – there is another alternative. There is the transitional facility – such as TCT units – where the skills and expertise are focused on their specific needs.



Too many young people with cancer do not have the benefit of access to a specialized teenage unit – this is true abroad, and also here in the UK. We look forward to the day when TCT units and services are the norm, as paediatric services are now. Until then we need to call upon consultants to exhibit a generous degree of cooperation and flexibility and to bridge the discipline and age boundaries.

Generally, service provision for TYAs is supplied in two self-contained structures, with children in the paediatric box and all the rest in the adult box. For some, where there is a TCT unit, an alternative to the rigid two-box system is offered and this works best where practitioners show an elasticity of approach.

In declaring that we offer care from the cradle to the grave, we must ensure that needs are met at all ages. No-one questions paediatric medicine today – nor do they question geriatric medicine – so why do we fail to meet the needs of those at the most sensitive, transitional stage of life?

For teenagers and young people with cancer the appropriate situation is to have specialized staff with specific training in the management of the cancers affecting this age group, and nurses and other staff who have a particular interest in young people who are trained to deal with the medical and psychosocial issues affecting this group of patients.

Ideally (Fig. 1.2), genuinely concerned practitioners will endeavour to accommodate the needs of these patients by blurring the delivery edges. Keeping the patients central, the consultants will bring their particular expertise to the

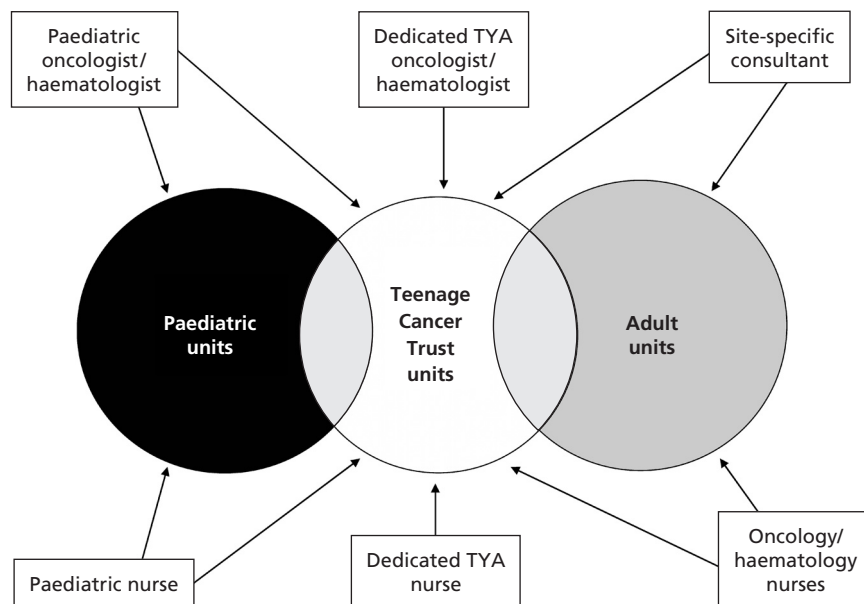
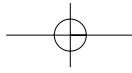


Fig. 1.2 Diagram of professional practitioner flow.



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patients, and I envisage that, in all probability, there will always be a need for consultants in certain cancer types to be involved. Nurses specializing in adolescents with cancer will be supplemented by paediatric oncology nurses with an interest in the age group. This will be demanding, particularly where facilities for the very young and for the elderly are miles apart, but some movement in that direction must take place until a critical mass of practitioners specializing in adolescent cancer medicine is built up and we can provide every young person with cancer access to a specialized, age-appropriate facility and team.

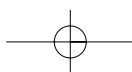
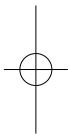
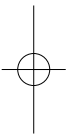
### Why is this group so special?

I have indicated already some of the particular issues complicating the diagnosis and treatment of young people with cancer. These people are going through a great many changes aside from the impact of their cancer: physical, psychological, emotional, educational and lifestyle alterations.

- *Staff* need different skills when dealing with these patients and also with their parents. Negotiations are far more complex when dealing with TYAs than with small children or fully independent adults. Who makes the decisions – patient or parent? What if they disagree?
- *Physical changes*. While any cancer patient will struggle with physical changes, these are so much more painful for the TYA patient. In our surveys, patients identify their appearance as of more concern than the possibility of death.
- *Fertility* is a vitally important concern for young people. It is a significant possibility that fertility will be impaired or lost as a result of treatment. This can cause major psychological and social damage. When young people are treated in a paediatric setting they are deemed to be children and are not offered advice on fertility. But even in adult centres patients are failed by a lack of fertility counselling.
- *Social relationships*. Peer groups are of primary importance during this period of life. Cancer diagnosis singles out and isolates the young patient. Youth can be a difficult stage to handle without the added complication of cancer. Lack of confidence (despite an often brash image) is not uncommon during the ‘in between’ years. Both self-perception and expectations can deteriorate. Life-threatening disease, change of image, loss of contact with contemporaries and possible loss of fertility can all undermine the fragile self-assurance of the young patient.

Many of our patients who have been treated in either children’s or adult wards have complained that their friends would not visit them – highlighting their sense of being different – and of isolation. In TCT units, friends are considered important and welcomed into the user-friendly surroundings.

- *Education*. It is the norm within the UK for education to be provided for children in hospital – that is, up to 16 years of age – but it is from that age that education and examinations become more serious and achievements at the 16 to early 20s stage can dictate future life work and lifestyle. There is





rarely any educational provision for 17-year-olds and over who are being treated in adult facilities.

- *Independence*. For this age group generally and for our patients in particular, family issues are complex to handle. Many of our patients will just be gaining independence and their illness will throw them back into dependency. Instead of becoming financially self-supporting, or even a contributor to the family coffers, they become a burden. The equilibrium of normal separation, both emotional and financial, will be unbalanced to the detriment of both parents and youngster.
- *Palliative care* too requires very special expertise when dealing with adolescents and young adults. The issues differ considerably from those relevant to other age groups with cancer, and appropriately trained staff for both patients and their families are necessary.
- *Long-term effects* for young people may be more far-reaching than for older cancer patients. Impaired image, fertility loss, neurological and psychological damage, loss of education and life chances, loss of independence and the sword of Damocles effect can all severely affect their future. Will having had cancer always affect their personal relationships, as it may their financial ones? Will potential partners be deterred from long-term relationships? Many insurers are unwilling to provide insurance (sometimes even holiday insurance) or mortgages for people they see as a risk. Or if they do, the premiums are unaffordable. In the USA it has been noted that the young adult age group is the least likely sector to have medical insurance anyway – they are not able to afford it and are too old to be included under their parents' policies. Having cancer when young can determine a survivor's pattern of life.

### **And now?**

We cannot in all honesty say that cancer services, anywhere, are offering the very best to young people with cancer. There is much that is within our power to do and much that we have yet to learn. We know that having cancer at any age is tough, and to combine it with adolescence and young adulthood makes things even harder. We *can* do something about this – and to fail to do so is to fail our young citizens.

Within the UK we have a great advantage. We have the TCT, which for over 10 years has been highlighting the needs, showing the way, lobbying and bringing about change to reduce the disadvantage experienced by many young cancer patients – while successive governments have done nothing!

Although our government has given lip service to the needs of TYA cancer patients, what have they done? In discussion with colleagues from other countries the same or a worse situation seems to exist for them.

We are not even asking the British government for money. This has to be a first! We will continue, as we have over the years, raising money in pennies and pounds to fund our activities – but we *are* asking them for something!

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It is hard to believe, but health trusts can take years to see the needs of their TYA cancer patients as any sort of priority. There are hospitals which, after 10 years of discussions, are still deliberating and denying their young patients the service they need and deserve. These institutions need the push that only the state can give. We are willing to go on providing specialized units, to develop expertise, to work on prevention, to encourage research, to provide staff and to continue many of the support services required, but without the backing of the government – without their requirement that health trusts make appropriate provision for young people with cancer – our work will continue to be uphill and slow.

Is the UK government going to sit on its hands and watch while young people with cancer continue to fall behind in the cancer lottery? There may have been some recent improvement overall in cancer death rates, but not necessarily in the young people with whom we are concerned. Funds have been given to support cancer services, but how much has this benefited TYA patients?

Our patients are dying for government recognition and support. It must be remembered that these young people are citizens of the UK; they are the future and current voters, taxpayers, workers, politicians and parents (as are their families) and cannot continue to be ignored.

The government has a responsibility here – one that it has an obligation to meet. It is time that our work was endorsed by the government. This would help accelerate the development of TCT units and services and hopefully improve patients' quality and chance of life.

Remember, it is our young patients' *right* – not just their *privilege* – to receive the best treatment, care and chance of recovery.

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