

Neither child nor adult

Catering for the needs of Europe's teenage cancer patients

→ Claire Laurent

Should teenager cancer patients be treated as children or as adults? The answer is surely that they should be treated as teenagers – but that's not an option available to many of them.

The teenager is a peculiarly human phenomenon. This phase between childhood and adulthood is not found in other animals. Given to odd sleeping patterns, awkward growth spurts and monumental untidiness, adolescents swing from vulnerable to reckless, funny to infuriating, as they find their way from childhood to maturity.

The teenage generation is now the biggest the world has ever seen: according to a 2003 United Nations report, one in five of us is aged between 10 and 19. And yet in many walks of life, there is scant recognition that teenagers are a defined group of people who need to be understood and supported – and nowhere more so than in the field of cancer care.

Cancer is not seen as a disease of the teenage years. However, incidence rates are in fact higher for teenagers and young adults than for children. For every one million teenagers between the ages of 15 and 19, around 185 received a cancer diagnosis in Europe according to data covering the period 1988–1997, compared to 131 for children

aged 0–14. And the problem is growing, as the incidence rate appears to be rising by around 2% a year, according to data presented by the Automated Childhood Cancer Information System (ACCIS), a collaborative project of the European cancer registries (*Lancet* vol 364, pp 2097–2105).

Teenage cancer patients have poorer average survival than both their older and their younger counterparts. One reason may be that diagnosis tends to be more delayed in adolescent patients. Quite why this should be is unclear, but Tim Eden, who holds the post of the recently created Chair in Teenage and Young Adult Cancer, at the University of Manchester, UK, says “the biggest delay is getting professionals to recognise that there might be cancer and doing something about it.” Adolescent belief in their own invincibility may also play a role.

There are no cancers specific to teenagers. Some tumours such as the bone neoplasms and Hodgkin's disease peak around these years, accounting for around 30% of cancers in teenagers and young adults. The majority, around 60%, are early onset of adult cancers. The remaining 10% are the tail end of what is found in children.



TEENAGE CANCER TRUST

Teenagers together. This music workshop, organised by the UK Teenage Cancer Trust, is a great way to help break the isolation faced by many young cancer patients

Most tumours in children are embryonal – tumours of the developmental tissues – and tend to have a relatively good prognosis. “[They] are much more responsive to treatment, so you actually expect to do well with them,” says Eden. However, teenagers seem to be more resistant to treatment, probably because of differences in their biology. “They occur in the first four, five or six years of life, so if you get one when you are thirteen or fourteen it may be subtly different to the children’s one, even though down the microscope it looks remarkably similar.”

He adds, however, that outcomes are improving as more is being learned about the best way to treat this age group, citing acute lymphoblastic leukaemia – the most common leukaemia of childhood – as a case in point. “What has been exciting

is that if you treat teenagers and young adults with the children’s type protocol you get better results than if you treat them with the older age leukaemia treatment – the difference may be 30%.”

The very nature of adolescence – growth spurts and hormone turmoil – may also play a role in the development of the cancer. “It is far from clear,” says Eden, but “some of the causation of the tumours might be related to growth. It is likely that you have abnormalities which may carry over in cells in your bone from early on, and then you grow and make it more likely than an abnormal cell may proliferate and divide and become a cancer.”

Given how much is still unknown about teenage cancers, it is of particular concern that this age group is far less likely to be recruited into a clinical trial than younger patients. In the UK,

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where enrolment in clinical trials is relatively high by European or US standards, around 12%–15% of teenagers are part of a trial; the figure for children aged between one and five is 70%–80%. It is known that the best outcomes occur in those patients in a trial, and this too may impact on the poorer survival rates. It is not clear why the enrolment rate is so low, but Eden suggests that it may be linked to the delay in diagnosis that many teenagers experience.

So, even before their cancer is diagnosed, teenagers seem to be up against the odds. When it is diagnosed they are caught, literally, between childhood and adulthood. They are often in a transitional period between school and college, college and university or university and a job. They are beginning to put some distance between themselves and their parents and starting to make lifestyle decisions for themselves when they find themselves back at home needing parental support and help.

BREAKING THE ISOLATION

Jeunes Solidarité Cancer is an Internet-based group set up to help break the isolation of young French cancer patients, survivors and those close to them (www.jeunes-solidarite-cancer.org). It hosts a popular discussion forum, and provides online information packs tailored to specific groups (patients, survivors, friends and family, professionals). It also lobbies for greater social and employment security for young patients and survivors and campaigns to raise awareness and break the taboo surrounding the disease. JSC traces its origins back to the first États Généraux, or ‘parliament’, of cancer patients, held in on 22 November 1998, where cancer patients gathered for the first time to speak out in public. Among the voices heard that day were some powerful contributions by young cancer patients.

One told of having to battle for social security benefits, because he had not been earning a wage for long enough. Another told of her fight to get home help to enable her to continue to live inde-

pendently. Yet another about the isolation of being the only one on the ward under the age of 65.

These young people did not want to revert to dependence in the family home, but nor were they able to start to build their own futures, extend their education, start a career, find long-term relationships, as their peers were doing. And as teenage cancer remains relatively rare, many found themselves cut off from their peer group. Luckily, they were the online generation, and the JSC chat room has proved a popular forum.

Eden recognises the problems from his experience in the UK. “It is a time of great physical and emotional development and during that time clearly it’s very often difficult to cope with a life-threatening situation. Many patients who are threatened with a serious illness at this age regress back into a dependent status again. That causes tensions to the young person and the parents and family. Of course, individual patients, personality and the way they function and the way a family functions does determine tremendously how that works.”

Once diagnosed, young teenagers (below 16 years) are usually treated on a paediatric ward whilst older teenagers and young adults are admitted to older age wards. Neither environment is suitable, says Eden. In the UK, pioneering teenage and young adult cancer units have been established. There are seven provided by the Teenage Cancer Trust, with plans to build another 15. The units provide top-quality medical facilities at some of the UK’s largest hospitals, but more specifically they provide day rooms, kitchens and space for teenagers to relax in, for their families to spend time with them and for them to make friends with their peers on the unit. There are computers with Internet access, pool tables, Play Stations, satellite TV and music equipment.

Some units have activity coordinators to help patients cope with the long hours in hospital away from their friends. One such is Lorraine Case, based at the Christie Hospital in Manchester. Peer support is a key factor for teenagers. “We cover a huge area and



CHRISTIE HOSPITAL

The Oasis room. Patients at Manchester's Christie hospital aged between 12 and 25 have a room of their own, away from the ward, where they can pass the time of day and bring their friends and siblings. With a pool/air hockey table, TV, laptops with Internet access, DVDs, games consoles, art equipment, books and board games, there is plenty to do

we find that a lot of friends can't visit – it's too far – so we find a lot of peer relationships are impacted."

Once diagnosed with cancer, teenage patients have to take out at least six months of their life receiving treatment at what is developmentally a crucial time. As a result they can get left behind by friends who move onto the next stage and they can no longer identify with their peers or they with them. "We find their friends stand by them completely or unfortunately they back off – they can't deal with the situation, they don't know how to, they are not developmentally equipped to deal with it. Their existing relationships are so fragile at that point they quite often disappear and young people find themselves very isolated," says Case.

"We recognise that and we try and encourage pre-existing friends to take part in things with them at the hospital or we might go out to the theatre, a concert or a football match. We also have an extensive support group system here." There's a support group for people going through treatment and for up to two years out of treatment – they meet monthly and go out for meals and other social outings. "People two years out of treatment may still require that support because they have become so isolated from their peers that they are

not spending any time with any of their friends, or they feel that what they went through was such a significant part of their life that they want to remain in the group," says Case.

These sort of specialist facilities are still rare in most of Europe. Damien Dubois, the president of Jeunes Solidarité Cancer, says they have been following developments in the UK and are calling for similar specialist facilities to be developed in France. Currently only the Institut Gustave Roussy has a special unit for teenagers, though other hospitals – he mentions Lille and Lyon – are trying to adapt their paediatric wards to take on board the needs of adolescents. A study into the therapeutic benefits of specialist teenage and young adult wards currently being carried out by the Ligue contre le cancer may provide the evidence needed to move forward on this front.

Plans are afoot in Ireland to develop a teenage unit in Crumlin at Our Lady's Hospital for Sick Children. Evelyn Griffith, group coordinator for the young people's cancer support group in Ireland, CANteen, said the unit would be a welcome development in meeting the needs of young people. CANteen itself provides peer support through its website and chat rooms and its activity

weekends which bring youngsters together.

In rural Ireland many children may be quite isolated and CANteen gives them an opportunity to meet others of the same age with similar problems. Griffith says young people often express concerns about the longer-term implications of their treatment, many of which were not discussed with them when they first became ill – issues such as fertility, future health problems as a result of chemotherapy and the implications when seeking out mortgages and insurance. All things that health professionals need to think about if care is to be holistic for young people and not just about the cancer.

A difficult juggling act

Seventeen-year-old Lucia Pasqualino lives in Blackpool in the UK. She was diagnosed with acute lymphoblastic leukaemia when she was 15.

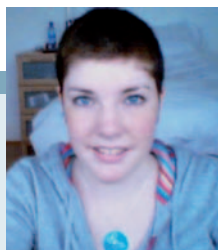
“I’m still on chemotherapy and don’t finish until August this year. It’s hard to describe how you feel when you are diagnosed. I was upset and shocked but it wasn’t the illness that made me like this, it was more grieving for the life I was giving up than being scared with what I was faced with.

“I was completely honest with my family and friends and they all knew the day I was diagnosed. I wanted everyone to know straightaway so they could be there for me when I needed them.

“I have always been able to make decisions about my care and everything about my treatment has been discussed with me since the beginning. I’ve always had the opportunity to ask questions and a good relationship with staff is vital.

“Teenagers are one of the most important groups in society – we have school work, exams, social lives, interests and family – it’s a lot of pressure and people don’t often recognise this. And the other young people I have met also have cancer to cope with and it’s hard to juggle it all.

Everyone should have a basic understanding of cancer, people are scared to talk about it and so they victimise patients and I find it patronising. I like to be admired for the things that I do that aren’t about the disease alone.”



SPECIALIST TRAINING

Until now, there have been no specific training courses for health professionals working with adolescents with cancer. Most are paediatric trained and the numbers involved in any one area or even any one country mean that providing taught courses is not economically viable. However, in February this year, the world’s first course on caring for teenagers and young adults was launched via the Internet by the Teenager Cancer Trust in conjunction with the Paediatric Oncology Nurse Education group of the UK’s Royal College of Nursing and Coventry University.

The course uses voice tools, web conferencing, podcasts and an online chat forum to deliver educational materials. Aimed at nurses and other health professionals, the course leads to a postgraduate certificate in cancer care for teenagers and young adults. Sixteen students worldwide have signed up to the first course, which will take them through two theory modules and a work-based learning module. Much of the material has been put together with teenagers and young adults with cancer.

Helen Langton, dean of the Faculty of Health and Sciences, University of Derby, UK, was the driving force behind the course, which was compiled by an international curriculum development group. She says, “The course offers specific insights into what it is like to be a teenager or young adult in today’s society with cancer. And because it’s masters level we expect students to bring some critical thinking to this and consider what it means in relation to service delivery, organisation of care and how we actually manage what we provide.”

She says that the UK appears to be leading the way in the field of cancer care for teenagers and young adults, but New Zealand and Australia are catching up. “I think that some countries have not got to the stage of recognising that this is a neglected group and therefore don’t see the need to do something specific for them.”

Eden says, “Understanding young people and knowing how you can handle them and how they can handle you and manipulate you is a great art. Getting the best support for these young patients is incredibly important and while it is very difficult to prove real benefit of the TYAC [teenage and young adult cancer] units, we believe in it. Once you have been in one you don’t want to be treated anywhere else.”