

The lost generation

Cancer treatment is better than ever, but experts say teenagers have been overlooked – and a Senate inquiry agrees.

The Australian, September 03, 2005 (Front page of Health Feature, p30 of newspaper)
Journalist: Lynnette Hoffman

Text:

WITHIN a week Lauren Michels went from being an active 14-year-old on a family holiday - riding roller-coasters and snorkelling at the Great Barrier Reef - to a cancer patient in a room full of much younger children, surrounded by giant murals of fairies, clowns and under-the-sea themes.

Her treatment succeeded in improving her condition, but when she suffered her first relapse aged 17 and had to return for hospital care, the institution she went back to was even less suited to her needs.

In particular, the isolation and fear of being ostracised hit Michels hard. "I was crushed. Being 17, the opposite sex was now a greater issue in life, and I was devastated thinking that no boys would ever want to go out with the girl with cancer," she says. "My hair fell out and I looked different, and I was asked on many occasions if I was a boy."

She hadn't felt comfortable with the older, male psychologist at the children's hospital, and at the adult hospital, patients had to seek out such services on their own - something Michels, along with many of her peers, didn't do.

Michels's frustrating experience is far from unique. Treatment for teens and young adults with cancer is a tale of two extremes. As if the uncertainty and trauma of being diagnosed with cancer aren't enough to cope with, they have to deal with the reality of their illness and treatment in a system not set up to accommodate them.

Adolescents are the odd ones out, and not only is it making their road to recovery tougher from an emotional point of view, it's literally holding them back from the vast improvements other groups are making.

A recent Senate inquiry recommended that state and federal governments "examine the feasibility of establishing specialised adolescent cancer care units in public hospitals".

The report by the Senate Community Affairs References Committee, *The cancer journey - informing choice*, also noted the importance of social support and the specific difficulties young people with cancer face. It recommended such factors be taken into account when referring them for treatment.

Andrew Young, CEO of CanTeen, an organisation for young people living with cancer, says adolescents and young adults "are the forgotten group in cancer research, treatment and support, not only in Australia but internationally".

And while survival rates for other groups are improving dramatically, adolescents haven't caught up. Tracey O'Brien, acting director of the Centre for Children's Cancer and Blood Disorders at Sydney Children's Hospital, agrees adolescents and young adults "are slipping through the cracks" and says "improvements in cure rates for adolescents are the worst, and are falling at least 50 per cent behind that of all other age groups."

And cancer is increasing more rapidly in adolescents and young adults than in any other age group. In the past decade, the number of new cancer cases rose 30 per cent in 10 to 24-year-olds.

Nearly twice as many 12 to 24-year-olds are diagnosed with cancer as are children under 12. Yet they are far less likely to have access to clinical trials or specialist services which can significantly

Media Article

The Australian, Sept 3rd 2005

improve the odds of survival by finding the most appropriate treatments, and dosages with the least toxicity for a particular cancer.

Data on clinical trials in Australia is difficult to find, but anecdotally Young, O'Brien and others say Australia doesn't invest any more in clinical trials for adolescents than the US or UK does.

An American study in the Journal of Adolescent Health found that while 60 per cent of children aged nine and under are enrolled in a clinical trial, along with 50 per cent of those aged 10 to 14, the figure plummets to 10 per cent for those aged 15 to 19, and just 2 per cent for 20 to 30-year-olds. (1997;21:366-373).

Part of the problem may be that there is not enough collaboration between paediatric and adult cancer specialists, O'Brien says. Some cancers that occur in adolescents are more common in children, while others are more common in adults - but often young people are assigned to either an adult or children's hospital based on their age, regardless of how much more experience the doctors at either place may have in dealing with their particular cancer.

But when young people do get tailored treatment and support, outcomes improve.

Studies in the US, France, the Netherlands and Italy have all shown that survival rates are significantly higher when adolescents with acute lymphoblastic leukaemia, a cancer more common in children, are treated on paediatric clinical trials. A study in the Journal of Clinical Oncology found survival almost doubled when French adolescents with leukaemia were treated on a paediatric leukaemia trial as opposed to an adult trial (2003;21:774-780).

Another study in the Medical Journal of Australia showed that when adolescents in Victoria with one form of bone tumour were treated in a paediatric regime their survival rates improved by 50 per cent (2004;180(2):59-62).

"There are so many more trials being done for older adults and children and this middle group really misses out," Young says. "The result has been improved survival rates for children and adults while teens have lagged behind, and that doesn't make a lot of sense. If they're younger they should be improving at a bigger rate because their bodies should be able to adapt better, but that's not happening."

In the UK the not-for-profit Teenage Cancer Trust has built eight dedicated wards around the country, complete with top medical facilities, funky furnishings, TVs and computers and even pool tables. They say they expect chances for recovery to improve by 15 per cent.

So far there's only one such ward being developed in Australia, thanks to a \$3 million donation from the mother of a cancer patient who died in 1989 at age 17. The ward, at Princess Margaret Hospital in Perth, will be especially designed for adolescents, but it won't be as extensive as its UK counterparts with their specialised clinical expertise.

"But it's a start," Young says.

Still, that's just one piece of the puzzle.

Versions of Michels's story have been told by other young cancer patients over and over again across Australia. They feel isolated from their peers, fearful of their future, and confused. Often they aren't getting the right specialised support.

And it's not just making them unhappy, it is also hampering their recoveries. Studies have shown cancer patients in social support groups not only adjust better emotionally, but are also more likely to have successful treatment outcomes.

"Psychological state can make a huge difference to physical wellbeing," Young says. "One study showed that access to good support services lowered

‘Studies have shown cancer patients in social support groups not only adjust better emotionally, but are also more likely to have successful treatment outcomes’

Media Article

The Australian, Sept 3rd 2005

health service use by between 7 and 17 per cent. There's dramatic evidence that good psychological state can make a difference."

Dealing with issues of self-worth, identity, independence and peer pressure are challenges for all teenagers, but when cancer enters the mix it can be overwhelming.

Adolescents are less likely to follow their doctor's advice and treatment regimes than other groups. They don't have their parents controlling everything they do the way an infant would, and they don't have the maturity and responsibility of an adult.

So without adequate support, Young says, it's easy to see why, for example, a teenager might stop taking medications that have side effects they don't like.

Often hospital staff aren't experienced in dealing with some of the more specific concerns that affect teenagers.

"Adolescents are going through rapid body changes and the hardest social times," Young says. "A 17-year-old boy has to think about donating sperm, because cancer treatments often make you sterile. These are issues that children's hospitals don't deal with and adult hospitals don't often think about. An 80-year-old doesn't need to think about putting sperm aside to start a family."

But donating sperm or worrying about how their friends may react when radiotherapy causes their hair to fall out can cause enormous stress for teens and young adults.

In her own case, Michels says an adolescent ward would have been invaluable in providing the support and friendships she so desperately needed.

Young says two hospitals, in Melbourne and Sydney, are looking into building specialised wards for young people, but more than two months since the Senate committee issued its recommendations, nothing has yet been done by any state governments.

He says CanTeen plans to use the recommendations to lobby them in the months to come. "We have a long, long way to go," he says.

Table:

TEENAGE CANCER

About 1000 12 to 24-year-olds are diagnosed with cancer in Australia every year

They are almost twice as likely to be diagnosed with cancer as those under 12

Survival rates of teens with cancer have fallen 50 per cent behind other age groups

Sources: CanTeen, Australian Institute of Health & Welfare

Picture:



Isolated: Lauren Michels, 17, found adolescents' needs fell between children's and adult hospitals
Picture: Sam Mooy