

**Cancer Enquiry Senate
Submission from
Jane Ewing**

Parent of young adult cancer victim, youth health advocate & student researcher
18 March 2005

Dear Senator Hon Peter Cook, Committee Secretary & Members of the Senator
Community Affairs Reference Committee

Congratulations on the initiative to request submissions from stakeholders about targeting the control of cancer. Since I am a NZ youth health advocate living in NSW I reflect more on concerns I have about what is happening here in NSW.

I understand the Cancer Institute NSW, was established by the Cancer Institute (NSW) Act, and "is charged with substantially improving cancer control in NSW" ...and have "the broad purpose of guiding the cancer control effort in NSW and enhancing its effectiveness".

My concern is that there is no mention or apparent concern in this State document for the population of adolescent and young adult cancer patients.

The population of young people in NSW

This is sizeable. At the time of the 1996 Census:

There were 2 134 017 people under 25 living in NSW;

52% or 1 105 310 were aged between 12 and 24. ...

almost one in five people (18%) living in NSW are aged between 12 and 24...

One third of Australia's population of people under 25 live in NSW.

[Focus on Young People, NSW Youth Health Policy, NSW Government October 1998]

How many young people get cancer?

Each year, approximately 1000 Australian young people are diagnosed with Cancer [AIHW]. This is in addition to those who were diagnosed last year, the year before and so on....

A thousand young people means 1000 families usually consisting of siblings, parents, aunts, uncles and extended family, plus the effect on the peers of all the above. Hence the effect and shock of the cancer diagnosis and subsequent treatment of one young person has a far-reaching ripple effect, which impacts on a huge number of people. It is estimated that 1 adult per 900 is a cancer survivor.

What about survival?

More than 70% of children and adolescents diagnosed with cancer survive their primary disease [Cotterill et al 2000, Viner 2003]. After surviving the initial disease these people need survivorship skills in emotional support, financial advice and support, and long-term follow-up (LTF) to keep them well while checking for early signs of relapse or other health problems caused by the cancer treatment itself.

The problems of physical, emotional and financial stress continues on for patient, siblings and parents. Since around 70% survive, this means that about 30% of cases don't survive. These stresses continue for those left behind.

Appropriate, well co-ordinated, and timely support is needed for the family group (whatever that may comprise) from the time of diagnosis right through and beyond 'cure' or bereavement.

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Adolescents and young adult cancer patients are considered a challenge:

The Governing Committee of the Cancer Control Network acknowledges that adolescents with cancer “present a challenge that is not adequately addressed by current systems or models of care in Australia.” [White2002]. This situation is likely to have occurred because the care of adolescent patients is often seen as neither the preserve of paediatric or adult services [Leonard et al 1995], and consequently these people fall into the void between. Unfortunately, the lack of data about the adolescent and young adult patient group due to this split between the paediatric and adult services makes it difficult to measure and monitor their QOL, needs, satisfaction, survival, entry into clinical trials etc.

Some of the difficulties inherent in caring for the adolescent and young adult cancer patient is touched on in the following paragraph about responding to young patients with cancer:

“Health Professionals tend to cope by avoiding or distancing themselves in situations where they expect that they themselves will experience anxiety and distress. However, there is evidence that younger patients are more vulnerable to psychosocial distress in the context of cancer, and in a setting where health professionals avoid discussion of emotionally charged issues, there is the risk that this distress in younger patients is not detected, or is responded to inadequately. Participation in communication skills training is a powerful way of improving the ability to respond to the specific needs of younger patients, as is access to specialized health professionals who can assist in supporting staff, and treating disorder in patients.”

[Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer, Section 5.2, P118]

International recognition for young people with Cancer

There is growing concern internationally for the adolescent and young adult cancer population and mounting evidence for targeting improvements for this patient group, so much so, that an entire issue (Vol.39 issue 18. December 2003) of the European Journal of Cancer (listed below) was dedicated to this specific cancer group. Issues include breast cancer in adolescents and young adults, the special needs of young people with cancer, their survival, treatment, clinical care, and palliative care etc. (I've listed these articles below the references)

What's happening in NZ?

In comparison with NZ, the New Zealand Cancer Control Strategy Action Plan: 2005-2010 (NZCCSAP) is a comprehensive and co-ordinated programme to control cancer for **all** New Zealanders.

Firstly, NZ backs up its overall claim to target cancer firstly, by acknowledging in policy that the needs of all population groups are important. This includes the special needs of adolescents and young adults as well as paediatric, adult and aged patients. Among other Outcomes/Results, please check out in particular, Goal 3 objective 4

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Parent of young adult cancer victim, youth health advocate & student researcher (p60) and goal 4 objective 3 (p75) of the NZCCSAP which can be found at www.moh.govt.nz/cancercontrol NZ also is targeting educational and vocational needs of young people on treatment and long-term follow-up care and provision of developmentally appropriate hospital and hospice facilities, and the training of health providers in adolescent health, and data collection which doesn't lose young people in the gap between paediatric and adult services.

Secondly, there is a special task force to ensure the implementation of the action required with priority given as directed by stakeholders (at the implementation workshop held at the end of 2003).

NZ's plan to target adolescents and young adult cancer patients is well documented. http://www.cancercontrol.org.nz/pdf/2003_Cancer_Control_Workshop.pdf and <http://www.cancercontrol.org.nz/publications.html> <<http://www.moh.govt.nz/>>

Funding the Policy

It is interesting to note that the NZCCS 2003 was partially funded by the NZ Child Cancer Foundation. Does this mean that unless the policy development is funded by an organisation whose mission is to promote the needs of adolescents and young adult patients, that their voices are not heard?

The NSW Cancer Plan is not representative of all population groups by age

The NSW Cancer Plan cannot truly claim to target cancer for all cancer patients in NSW because it overlooks the needs, issues and concerns of young people, and children.

“Young people” are defined as aged between 12 and 24 by the Youth Advisory Council Act 1989.

What is the problem for young people?

- ◆ The gap between paediatric and adult services
- ◆ No significant improvement in health status since 1960 (Watson 2001)
- ◆ Least improvement in survival over the last 25 years (Bleyer 2002)
- ◆ Cancer incidence is higher and increasing at a faster rate in 15-19 year olds than younger paediatric patients (NCI 1999)
- ◆ Not adequately addressed by current systems or models of care (White 2002)
- ◆ Many health professionals caring for adolescents have little or no formal training in adolescent health (Hein 1994) This is a main barrier for adolescents accessing health care (Gordon 1996)
- ◆ Improvements in outcomes may require... questions specific to the 16-24year age group. (Bleyer 2002, Newburger 2002, Barr 1999)
- ◆ Their right to developmentally appropriate healthcare information, support and care is breached (Ewing 2003)

The impact of cancer on the patient and families of a person of any age is fairly well documented. Why is the impact on the child/adolescent and young adult cancer patient relatively overlooked? Their lives should be just unfolding, and as they face

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Parent of young adult cancer victim, youth health advocate & student researcher the usual turbulence of adolescence a cancer diagnosis is devastating. The impact on the siblings and parents is profound, and appropriate psychosocial support is rarely available. In many families it can impair or destroy the educational potential of the young patient and their adolescent aged siblings, particularly if the diagnosis and treatment and/or bereavement occur during their crucial school years. It can also ruin the financial stability of families and wreck career paths not only of the patient but those of the adolescent aged siblings, and the parents through emotional and psychological exhaustion and posttraumatic stress.

Recommendations:

The appointment of a specific board member or representative assigned to the issues, needs and concerns of adolescents and young adults with cancer and their families, plus one designated to represent children.

Make it mandatory that adolescents and young adults are included in all appropriate clinical trials, and make it easier for oncologists to access appropriate trials for the inclusion of their patients (Mitchell 2004, White 2004)

CanTeen and Camp Quality be fully engaged in any future research and policy developments in support services for young people.

Understand and provide appropriate well co-ordinated and timely support throughout the full range of the disease continuum and beyond i.e. from diagnosis – through treatment – remission – relapse – bereavement.

There needs to be better understanding of:

- ◆ The process and delivery of support services for young people with cancer;
- ◆ Current support services and the extent to which they meet the needs of young people and their families.

Since there is little systematic documentation of support services and an urgent need for rigorous research. My team and I are currently validating instruments to measure HRQOL, Preferences for different types of support service, Satisfaction, and an Impact report for use with adolescents and young adults. (Analysis of the data collected at three hospitals in SESAHS is currently occurring). Our research is about:

- ◆ Adequacy of current support services in terms of patient and family needs and preferences;
- ◆ Patient quality of life, patient and family satisfaction and unmet needs and service preferences; for gathering
- ◆ Baseline data to support the development of appropriate support and evaluation of the impact of subsequent change in support services.

This should:

- ◆ Facilitate the development of better planning and delivery of support services to this group;
- ◆ Provide an essential step towards developmentally appropriate and well-coordinated support services and better health outcomes for these young people.

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Please ensure the following organizations are included in the consultation process:
Australia New Zealand Child Cancer Study Group (ANZCCSG),
Greater Metropolitan Clinical Taskforce (GMCT)'s special sub-group,
Transitional Care for Young People with Chronic Childhood Illness,
CanTeen Australia (The Australian Organisation for Young People Living with Cancer), and CanTeen NZ
Cancer Control Network;
NSW Government Action Plan for Health; Young People's Health: Our Future 1999;
The Ministerial Youth Health Task Force;
NSW Youth Health Policy 1991 (currently being updated).
AWCH – Association for the Welfare of Child Health, Director - Dr David Bennett
CHiPS - Chronic Illness Peer Support program for young people living with chronic illness
Centre for the Advancement of Adolescent Health (CAAH);
NSW Association for Adolescent Health (NAAH);

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