

22 April 2005

Inquiry into services and treatment options for persons with cancer
Senate Community Affairs Committee
Committee Secretary
Community Affairs Committee
Department of the Senate
Parliament House
Canberra ACT 2600
Via e-mail community.affairs.sen@aph.gov.au

Dear Senator Cook and Committee Members,

Joint submission from Westmead Hospital, Sydney NSW and The Children's Hospital at Westmead, Sydney NSW on services and treatment options for young people with cancer

This submission is made on behalf of young people throughout Australia with leukaemia or cancer, to bring to your committee's attention needs of young people with cancer and their families, referring to the following terms of reference: *'the delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:*

- *the efficacy of a multi-disciplinary approach to cancer treatment;*
- *best practice for addressing psycho/social factors in patient care;*
- *current barriers to the implementation of best practice.'*

Survival improved with appropriate therapy

Reliable evidence from various countries is available to show that survival rates after treatment for young people with cancer or leukaemia aged 15-25 years can be improved by ensuring that those patients who have cancers of childhood type (eg acute lymphoblastic leukaemia, acute myeloid leukaemia, non-Hodgkin's lymphoma, rhabdomyosarcoma, Ewing's tumour) are treated with paediatric cancer trial protocols, and are enrolled, if eligible, on clinical trials conducted by international paediatric cooperative groups (e.g. the USA-based Children's Oncology Group.)

For example,

i) a retrospective comparison of paediatric and adult therapeutic practices in the treatment of acute lymphoblastic leukaemia in young people aged 16 – 21 was made jointly by representatives of US-based major paediatric and adult cooperative leukaemia groups. Outcomes were compared for 103 patients aged 16-20 who were enrolled on an adult therapy trial between 1988 and 1998, and 196 patients aged 16-21 who were enrolled on a paediatric therapy trial between 1989 and 1995. The results, published in 2000, showed that patients with ALL aged 16-21 years appeared to have a better outcome when treated on a paediatric cooperative group trial protocol compared to an adult cooperative group trial protocol. The investigators recommended that as adult and paediatric groups design new risk-adapted treatment regimens, consideration should be given to combining efforts and treating all young adults on the same protocols, perhaps using one of the intensive paediatric regimens as a backbone to which novel strategies could be added.¹

ii) a comparison of paediatric and adult therapeutic practices in the treatment of acute lymphoblastic leukaemia (ALL) in young people aged 15 – 20 years was made prospectively over a 15 month period by a group of twelve hospitals in France in 1993. The outcome for 77 consecutive patients who were treated with a contemporary paediatric ALL treatment protocol was compared to the outcome for 100 consecutive patients who were enrolled on a contemporary adult ALL treatment protocol. The results, published in 2003, showed a better outcome for the group treated with the paediatric protocol. The investigators recommended that adolescents should be treated in paediatric protocols and that new trials inspired by paediatric protocols should be designed for treating young adults.²

.../2

iii) a retrospective comparison of paediatric and adult therapeutic practices in the treatment of ALL in young people was made in the Netherlands. The outcome was compared for 47 young people with ALL aged 15-18 years treated with contemporary Dutch Childhood Oncology Group protocols and 73 young people aged 15-20 treated with contemporary adult Dutch-Belgian Hemato-Oncology Cooperative Study Group protocols. The results, published in 2004, showed that the young people who received paediatric protocol therapy had approximately a 35% higher probability of survival at 5 years compared to those treated on the adult protocols. For 15-18 year-old patients, the 5-year event free survival when treated on paediatric protocols was 69%, compared to 34% when treated on adult protocols.³

Survival improved by appropriate referral

Survival rates for children with leukaemia or cancer are higher when treatment is supervised by a tertiary paediatric cancer centre, where treatment is planned and supervised by a multidisciplinary team comprising both medical, surgical and radiation oncological disciplines, and where treatment utilises active trials conducted by international paediatric cooperative groups. It is very likely that the same referral practice will benefit young adults with cancers of childhood type. Young people with cancers of adult type are most appropriately treated by medical oncologists and radiation oncologists expert in the treatment of cancers of adult type.

We are concerned that many young people with cancers of childhood type are not receiving optimal treatment because they are not being treated with paediatric cancer protocols, and in some cases, not even being referred to a tertiary cancer unit. In one study of young people aged 14 – 29 years with acute leukaemia, only 39 per cent of patients with acute lymphoblastic leukaemia, and 46 per cent of patients with acute non-lymphoblastic leukaemia, entered the relevant national treatment trial.⁴

At the outset, young people with cancer should be referred to a major tertiary level healthcare campus in preference to receiving treatment in a less comprehensive setting, for example, the private rooms of an adult oncologist or adult haematologist. This alteration to existing patterns of referral will require the awareness and cooperation of general practitioners and physicians nationally. Further, the physician supervising the treatment of the subgroup of young people who have cancers of childhood type should be an oncologist with expertise in the management of young people with cancers of childhood type. Young people with cancers of adult type should be managed by medical oncologists and radiation oncologists.

Quality of life improved by having psycho-social needs met professionally

Provision of the highly specialised medical and nursing care needed for cancer treatment must go alongside meeting the specific needs associated with this age group, an age of transition from childhood to adulthood. Care provision for young people must, therefore, address the treatment, information, educational, social, and other support requirements of young people and their families.⁵ The psychosocial characteristics and needs of well young people, and of young people suffering from chronic life-threatening illnesses such as cancer or leukaemia, are already well described and accepted.^{6, 7} The implication from this body of knowledge is that young people with cancer fare better if they are managed in a purpose-designed environment that is sympathetic to the special needs of sick young people, and treated by a multidisciplinary healthcare team with expertise in the medical and nursing management, and the psychosocial support of young people, and their families and partners.

Recommendation pertaining to New South Wales sought from this enquiry

A best-practice model of care for young people with cancer or leukaemia throughout Australia needs to incorporate these principles in each state of Australia. For example, to assist the development and adoption of a best-practice model of care for young people with cancer or leukaemia in New South Wales, an appropriate course of action would be for the Senate Community Affairs References Committee to make a recommendation to NSW Health and to Cancer Institute NSW that a New South Wales Adolescent Cancer Management Working Party be appointed to advise Cancer Institute NSW (and NSW Health) on this issue, with a view to developing and recommending a detailed plan for the adoption of a

.../3.

suitable model of care for young people with cancer or leukaemia aged 15-25 from throughout New South Wales, utilising the two major healthcare campuses in Western and Eastern Sydney. Similar processes would be adopted for each of the other states of Australia.

For New South Wales, the Westmead and Randwick healthcare campuses are suggested because the principles mentioned above are already well-established at both centres, so that the state-wide workload can be effectively shared between the two campuses.

Implementing the Committee's recommendation at the Western Sydney Campus

We suggest that a suitable model for the Western Sydney campus would involve jointly the Oncology and Radiation Therapy Departments of Westmead Hospital, the Oncology Unit of the Children's Hospital at Westmead, and the Adolescent Medical Units of both institutions. Inpatients could be managed in the adolescent ward of either hospital, with nursing and allied staff with a skill-mix appropriate for adolescent and young adult patients with cancer. A purpose-built amenity would likely improve the standard of care above that available currently at either hospital. Medical supervision of the patients would be determined by the type of cancer. Patients with cancers of adult type would be managed by members of the adult oncology, haematology and radiation oncology departments of Westmead Hospital. Patients with cancers of childhood type would be managed by a physician holding a joint appointment to both hospitals, with expertise in the medical treatment of cancer and leukaemia in young people.

We commend these suggestions to the Committee on behalf of young people with cancer throughout Australia, and look forward to positive outcomes from your inquiry.

Yours sincerely,

A/Prof Paul R Harnett
Network Director
Cancer Services
Sydney West Cancer Network
Southwest Area Health Service
Westmead Hospital
Westmead, Sydney NSW

Dr Colin Bull
Director
Dept of Radiation Oncology
Westmead Hospital
Westmead, Sydney NSW

Dr Luciano Dalla-Pozza
Snr Staff Specialist & Head
Oncology Unit
The Children's Hospital
at Westmead
Westmead, Sydney NSW

References

¹ Stock, W, Sather R *et al.* Outcome of adolescents and young adults with ALL: a comparison of Children's Cancer Group (CCG) and Cancer & Leukemia Group B (CALGB) regimens. Abstract no. 2009, Proceedings 42nd Annual Scientific Meeting, American Society of Hematology 1-5 Dec 2000, *Blood* 2000 (96) 467a.

² Boissel N, Auclerc M-F *et al.* Should adolescents with acute lymphoblastic leukaemia be treated as old children or young adults? Comparison of the French FRALLE-93 and LALA-94 trials. *Journal of Clinical Oncology*, 2003; (21) 774-80.

³ de Bont JM, van der Holt B *et al.* Significant difference in outcome for adolescents with acute lymphoblastic leukemia treated on pediatric vs adult protocols in the Netherlands. *Leukemia* 2004 (18) 2032-53.

⁴ Benjamin S, Kroll ME *et al.* Haematologists' approaches to the management of adolescents and young adults with acute lymphoblastic leukaemia. *British Journal of Haematology* 2000 (111) 1045-50.

.../4.

References, cont.

⁵ Whelan, J. Where should teenagers with cancer be treated? *European Journal of Cancer* 2003 (39) 2573.

⁶ Stevens MM & Dunsmore JC. Adolescents who are living with a life-threatening illness. In: Corr CA, Balk DE (eds) *Handbook of Adolescent Death and Bereavement*, Springer Publishing Company, NY. 1996, 107-35.

⁷ Stevens MM & Dunsmore JC. Helping adolescents who are coping with a life-threatening illness, along with their siblings, parents, and peers. In: Corr CA, Balk DE (eds) *Handbook of Adolescent Death and Bereavement*, Springer Publishing Company. NY. 1996, 329-53.