CanTeen

The Australian Organisation
for Young People Living with Cancer

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

Inquiry Into Services And Treatment Options For Persons With Cancer

Submission from

CanTeen Australia

March 18th 2005

Background: CanTeen Australia's Submission

About CanTeen

CanTeen is the Australian organisation for young people living with cancer. Our Mission statement is to support, develop and empower young people (12-24) living with cancer – they may be cancer patients, their brothers and sisters, or young people with a parent or primary carer with cancer.

Within the broader category of psychosocial support, CanTeen operates using a peer support model. In their words, the best support young people living with cancer can get is from other young people who have "been there, done that."

Started by young people with cancer in 1985, CanTeen's Members are strongly involved in the governance and operation of the organisation. CanTeen is a company limited by guarantee; our Board includes a majority of young people living with cancer. This close involvement of Members is consistent throughout our nine Divisions across Australia.

More information about CanTeen is included as an attachment to this submission.

CanTeen's Submission: A response from young people living with cancer in Australia

Accompanying the release of the Terms of Reference for this Inquiry, Senator Cook's press release called for issues to be examined from the point of view of cancer patients. As advocates for young people who experience cancer, we believe **it is vitally important for the specific needs of young people living with cancer to be addressed** in Australia's cancer treatment and support strategies.

Summary of Recommendations

Primary Recommendation

1. **Establish adolescent/young adult cancer wards in each mainland state capital city.**

Secondary Recommendations

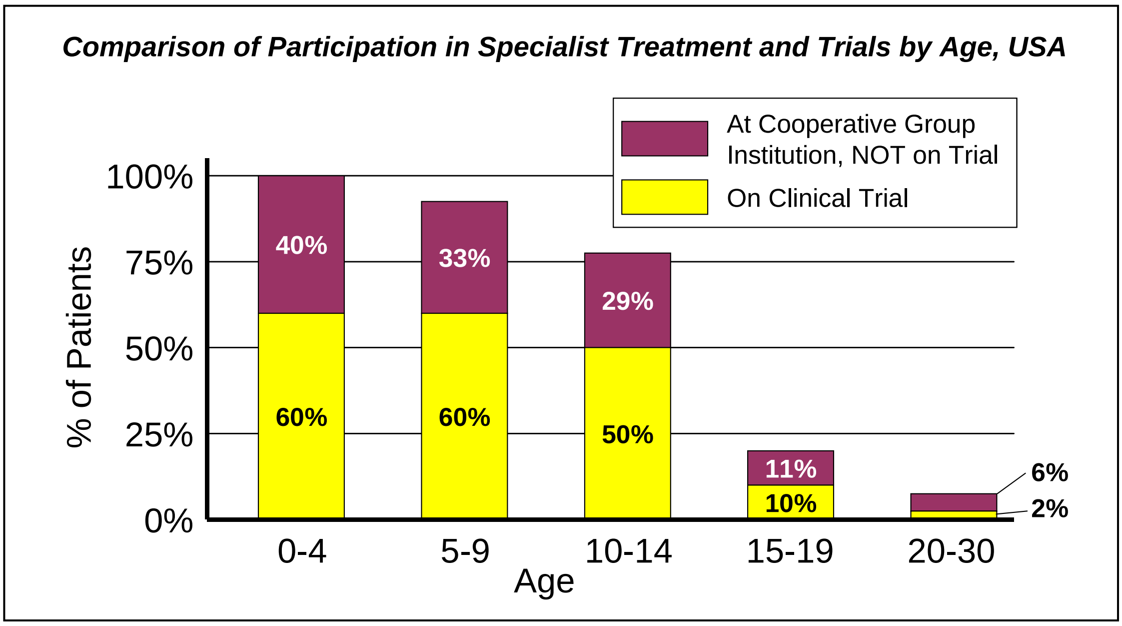
2. **Increase support for research and clinical trials for adolescent/young adult cancers.**
3. **Improve access to support services for adolescents/young adults within existing cancer treatment facilities.**
4. **Provide greater assistance for psychosocial support services in areas of research and delivery.**

Submission Details

The Need for Adolescent/Young Adult Cancer Treatment & Support Services in Australia

Responses to cancer treatment and support can be broadly divided into two categories; pediatric and adult. The forgotten group, with specific needs and characteristics, is adolescents and young adults.

- **Nearly *twice as many* 12-24 year-olds are diagnosed with cancer in Australia each year as children (0-12).**
    - Data from the Australian Institute of Health & Welfare shows that, between 1995-2000, 5,710 12-24 year-olds were diagnosed with cancer, and 3,102 children (0-12).
- **In spite of this, very few clinical trials address treatment of adolescents and young adults.**
    - Data on clinical trials in Australia is difficult to find, but it is believed that Australia invests no more in clinical trials for the adolescent/young adult age group than the USA or UK.
    - In the USA, most children (0-14 in the graph below) are on clinical trials and/or treated in specialist facilities ("Cooperative Group Institutions"). The difference for adolescents and young adults is dramatic (Bleyer et al, 1997):



Comparison of Participation in Specialist Treatment and Trials by Age, USA

- The experience in the UK is similar:

> *". . . despite evidence that adolescents with cancer fare better when treated on clinical trials, it would appear that adolescents do not have equal access to trials because of the fragmentation of adolescent cancer care between adult and paediatric oncology."*
>
> (McTiernan, 2003)

- As a result, the improvement in cancer survival for adolescents and young adults lags behind improvement in children's and older adults' groups.

> *"Within the last two decades there has been considerable progress in the treatment of paediatric malignancies, and to date nearly two-thirds of paediatric cancers are now cured (Department of Health 2000; United Kingdom Children's Cancer Study Group 2000). However, for those under the age of 20 this reduction in mortality rates is least evident in 15–19 years olds. . ."* (McTiernan, 2003)

> *"Since 1975, young adults and older adolescents have not, in general, benefitted from gains made in cancer outcomes to the same degree as younger and older persons. The Great Divide that they are in appears to be largely explained by a lack of access to, availability of, and participation in, cancer clinical trials . . There is also a lack of psychosocial, financial and physical resources for these patients in the prime of their lives."* (Bleyer, 2004)

- **Treatment and support, as well as research, mostly focuses on children or on older adults, but not on adolescents and young adults.** Australia has pediatric cancer facilities in most capital cities. There are dozens of not-for-profit cancer organisations providing research funding and/or cancer support services for children. Adolescents and young adults are the forgotten group.
- At the same time, it has been repeatedly demonstrated that significantly improved outcomes are possible with **better treatment and support specifically designed for adolescents and young adults.**
  - Many international studies have shown significant improvements in outcomes for adolescents and young adults treated on clinical trials:

    > *"There is substantial evidence to show that adults with cancer treated on clinical trials have a better outcome than those who are not. Similarly, adolescent and paediatric cancer patients also have a better outcome when treated on trial protocols. Children and adolescents with acute lymphocytic leukaemia, non-Hodgkins lymphoma, nephroblastoma,, and medulloblastoma and rhabdomyosarcoma have all shown a significant survival advantage when treated on trial protocols within specialist centres, compared to those who are not."* (McTiernan, 2003)

  - Australian studies have also shown that specific treatment for adolescents improves outcomes; for example, a recent Victorian study showed that treating adolescents with one form of bone tumour in a paediatric regime improved survival rates by 50% (Mitchell et al, 2004).

Adolescent/Young Adult Cancer Units

- In the United Kingdom, the **Teenage Cancer Trust** (TCT) is a not-for-profit group who have established eight adolescent and young adult cancer wards within National Health Service (NHS) hospital facilities:

  > *"<The> Teenage Cancer Trust is an organisation dedicated to changing an NHS system which condemns teenagers with cancer to treatment in wards full of children or old people, a system which fails to give adolescents with cancer an adequate voice to remain in control of their own treatment*." (www.teencancer.org)

  - The TCT wards are designed in collaboration with young people and include some specialist treatment equipment, but also create an environment that helps young people feel comfortable during their treatment.
  - The TCT believes that their wards "**can improve recovery rates by up to 15%**."
- In Australia, the **Princess Margaret Hospital (PMH)** in Western Australia recently received a large donation, enabling it to commence development of Australia's first **adolescent oncology unit**. The donation was made in memory of Johanna Sewell, who died from her cancer, aged 17, in 1989.
  - The Johanna Sewell Adolescent Oncology Unit will have four rooms with two beds and en suite bathrooms, a study area, a kitchen and entertainment space and quiet areas to catch up with parents and friends.

- CanTeen's Members have a consulting role in the development of this new unit.
- Johanna's story is a good illustration of the issues faced by young people diagnosed with cancer:[1]

> ***Johanna's Story***
>
> <Johanna's mother> Helen said Johanna had had a very difficult time while she was ill, because she had been admitted to Sir Charles Gairdner Hospital (SCGH), an adult hospital.
>
> "She had never been in hospital before - it was a terrifying time for her, especially on her first night in an eight-bed ward," Helen said.
>
> Johanna's illness, osteogenic sarcoma, was classified as a "childhood" cancer, so her treatment was spread between SCGH and PMH.
>
> "The adult hospitals are great but they expect people to behave like adults. Teenagers loose their confidence entirely," Helen said.
>
> "Later on, when Johanna became involved with CanTeen at PMH, we commented how much happier she would have been if she had stayed at PMH instead.
>
> "However, we were both concerned at how teenagers had to reside with younger children at PMH, which was not always practical in terms of bedtime and privacy."
>
> Helen said it was wonderful that out of something so tragic, something good had come.
>
> She said: "I know Johanna would be delighted this has happened.
>
> "She's probably looking down on us now."

The Need for Effective Support Services

Issues faced by young people living with cancer

Social support aims to address key psychological health issues. Concerns most often raised by people with cancer include fear of the disease recurring, fear of death and dying, and fear of social rejection, isolation and stigmatisation.

Cancer can also impact on people's self-esteem, self-image and sense of control over their life and situation. These impacts can lead to psychosocial distress, life disruption in areas of mental health, physical health, sexuality, social and occupational functioning, and anxiety and depression.

Benefits of Psychosocial Support Services

Social support programs provide significant cost benefits to national health systems. **It has been estimated that effective psychosocial support services lower health service use by between 7% and 17%** (Walker et al 2003).

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[1] Johanna's story reprinted from a Princess Margaret Hospital media release.

Another study also showed the “success rates” below for those in social support groups and those not (Meyer & Mark, 1995):

Measure	**Intervention Group (%)**	**Control Group (%)**
Emotional adjustment	56	44
Functional adjustment	55	45
Treatment & disease-related symptoms	57	43
Medical	54	46
Compound & global	57	43

Generally, researchers have confirmed that psychosocial support programs have significant benefits.

> *“… results clearly indicate that psychosocial interventions have positive effects on emotional adjustment, functional adjustment and treatment - and disease-related symptoms . . .”* (Meyer & Mark, 1995)

Recommendations

With reference to the Terms of Reference for the Community Affairs References Committee Inquiry, CanTeen makes the following recommendations for the consideration of the Committee:

Primary Recommendation

1. **Establish adolescent/young adult cancer wards in each mainland state capital city.**
   - Following consultation with young people living with cancer, doctors, social workers and support organisations, we recommend the establishment of at least one adolescent/young adult cancer ward in each mainland state capital city.
   - Pending further consultation, we suggest each of wards operate within an existing hospital in each city, and are run as a collaboration between paediatric and adult oncology departments. The wards should also be used as a base for developing further clinical trials specifically for this target group, with support funding for these trials.
   - The wards should be designed around the needs of young people, and encourage friends and family to visit and to enjoy the space as well as patients.
   - The wards should also facilitate delivery of targeted support services, perhaps including the co-location or near-location of psychosocial support services including peer support services.

Secondary Recommendations

2. **Increase support for research and clinical trials for adolescent/young adult cancers.**
3. **Improve access to support services for adolescents/young adults within existing cancer treatment facilities.**
   - Increase training and support for medical and support staff so they better understand the (psychosocial and other) issues for young people with cancer, and can better communicate with these young people.
   - Coordinate more seamless information provision and referral for support services in cancer treatment facilities (oncology wards, skin clinics, selected surgeries).
4. **Provide greater assistance for psychosocial support services in areas of research and delivery.** Greater funding is well spent – studies have shown that effective psychosocial support services can reduce the burden on health services by between 7 and 17% (Walker et al 2003).
   - Research is needed to better understand the effectiveness of different support options, develop services, and direct services at the appropriate point of need.
   - Ongoing funding for service delivery is needed, especially in support of services covering rural and regional Australia, and for services covering needs groups not commonly covered (eg older young adults).

References

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Attachments

1. **About CanTeen** – an overview of the organisation's work with young people living with cancer.
2. **Personal Statements.** CanTeen is an organisation run for and governed by young people living with cancer. This submission is representative of their views.

   Attached to the submission are stories in the words of some CanTeen Members who are now leaders in various roles with CanTeen.

About CanTeen

What is CanTeen?

> **'This was so good for me! I have regained my sanity, my love for life and my confidence in my own strengths and abilities…thanks!'**
>
> **QLD Member**

CanTeen's Mission Statement is ***supporting, developing and empowering young people living with cancer***. We do this by providing a high quality Australia-wide peer support network of young people living with cancer – who share experiences, have fun, offer resources and promote understanding, well-being and leadership.

The touchstone of CanTeen is the belief that young people, through meeting and talking with one another, would be better able to cope with the uncertainties of a cancer diagnosis.

Who are CanTeen Members?

Members are adolescents and young adults in the 12-24 age range living with the impact of cancer. This includes cancer patients, their brothers and sisters, and young people who have a parent or primary carer with cancer.

CanTeen Philosophy

We believe that no young person should live through their cancer experience alone.

Our primary role is to support, develop and empower 12-24 year-olds living with the impact of cancer. Secondly, we seek to reduce negative impacts of cancer on their family, friends and community.

We help support the young person so they can best deal with their cancer experience. In the longer term, we help young people work through the impact of their experience and continue on their journey.

Our work centres on models of **youth empowerment** and **peer support.**

What does CanTeen DO?

Support, Develop, Empower

CanTeen uses a **peer support** model. In practice, much of our work is to facilitate support and networks through a range of camps (including general and specialised programs) and one-day activities. Some examples are:

- *Division and National Camps* –provide the opportunity for Members to meet others from around the country and establish caring and supportive friendships.
- *Patient, Sibling and Offspring Weekends* –separate weekend programs catering specifically for patients, siblings and offspring Member categories, designed around issues faced by each group.
- *Good Grief* – a weekend program which raises the issues of grief and loss and provides Members with an opportunity to develop skills which enable them to work through a number of these issues.
- *Recreation Activities and "Café Crawls"* – one-day activities throughout the year provide regular opportunities to develop and maintain relationships with other young people with similar experiences.
- *TeenLink* – a peer support program in which we train Members so that they can provide newly diagnosed young people and their siblings with the support of a young person who has 'been there, done that'.

> **'It's great to be able to help others by sharing your experiences and being there for them.'**
>
> **WA Member**

Youth Participation

CanTeen's philosophy is to inv**olve young people in the decision-making process** and empower them to take responsibility for their organisation. In practice, this happens at every level:

- CanTeen is a company limited by guarantee. Our **Board** consists of nine Directors; by constitution, the majority (five) of these are Members – ie young people living with cancer. The other four Directors are specifically chosen for their skills in relevant fields.
- Our Member Directors are elected from a national committee, the **Member Advisory Council**, with representatives from each of our nine Divisions.
- Our Divisions throughout Australia also have Member **Committees** that consult with staff on program implementation at the local level. For particular activities, camps and conferences, sub-committees are often formed.

We are committed to developing the skills of our Members and supporting them in these roles. Our strong youth participation focus ensures that Members' views are represented in our strategy, development and operation, and is also an important part of our role in developing Members' skills and abilities.

> **'Being on a committee is an opportunity to be part of a team and to voice your opinion. Not only that, in CanTeen what we (the Members) say is important and acted upon'.**
>
> **Sydney & Central Member**

What CanTeen means to me?

Dayna Swiatek - Sibling Member & National President,
Member of Victoria Division

I wish to tell you about my personal experience with cancer as well as a particular CanTeen program, the Good Grief weekend, and how it changed my life. A couple of months prior to me joining CanTeen it was discovered that my younger sister Aylla relapsed, meaning the leukaemia we thought she had beaten 5 years before had returned. This threw my sister's life, my family's life and my life into chaos. The only way Aylla had a chance of beating the cancer once again was to have a bone marrow transplant. This meant that they would have to destroy her immune system with massive amounts of chemotherapy and radiation and then revive her system with the bone marrow from a compatible donor. It turned out that I was the only compatible family member. There were no choices necessary; it was the obvious thing for me to do.

As proud as I am today at being able to save my sisters life, as a 15-year-old I struggled at the time coming to terms with the idea. What if she died, would it be my fault? Would the operation hurt and what does it actually do? What will happen to me? What will happen to my sister? Basically I was scared. It was not until I attended my first CanTeen event nine years ago that I understood that I was not alone, and that all my fears were normal. I was able to talk with health professionals who knew the medical implications involved, and I also got the chance to talk with another sibling who was about to do the same thing for her brother.

The Good Grief weekend is not necessarily about death and dying, which is normally associated with grief and loss, but rather the loss of many different things. These include loss of independence, loss of friends, loss of hair or limbs, and loss of time from being a 'normal' young person. After attending the weekend I gained so many skills on how to cope in times of crisis and deal with stress, but most importantly I knew that I was not alone. Even though each Member's experience is unique, we are all linked together by a common bond of cancer. Whether or not I can say, "yes that happened to me as well", or "I never thought about it that way before", I now know what my sister might have been going through. Every time I talk to a CanTeen Member I gain something special. And likewise I get to share something special with them.

Without the support of other CanTeen Members who had been there and done that and who could genuinely understand what I was going through, there were times I don't think I would have been able to continue. The catalyst for me joining CanTeen was that I had attempted 'running away from home'. I was lost, confused and scared, with no one to talk to. My friends at school couldn't grasp what I was going through, and my parents, not surprisingly, were focused on my sister's health and well being I didn't feel I could talk to them either. In retrospect I think my attempted getaway was a cry for attention. I was lucky that my parents recognised this and arranged an interview with the hospital social worker, who promptly introduced me to CanTeen.

One week later I had attended my first CanTeen camp. I was still scared but I wasn't confused anymore. I understood what was going to happen to my sister and me, at least in a medical sense. This gave me courage and strength to continue with the challenge that lay ahead. More valuable though I had met other young people who I could share my greatest hopes with, but also my darkest fears, despite just meeting these people two days earlier. At that weekend I remembered what it was like to be a teenager and just have fun. Getting thrown in the river and playing 'Pictionary', rather than running a household because mum was at hospital and dad was at work.

Often in the public eye, the focus of cancer is on searching for a cure and identifying risk factors. However it is just as important that we continue to support in whatever way we can all those who are impacted by cancer. The programs and services that CanTeen provides are vital to help other young people face up to the challenge of living with cancer, just like I was able to many years ago. It scares me to think about what the consequences would be if cancer support networks for young people don't exist in the future. No young person should have to live through the journey of cancer alone.

What CanTeen means to me?

David Gregory - Patient Member & National Vice-President
Member of South Australia/Northern Territory Division

The impact cancer can have on a young person's life is profound, presenting a challenge to be overcome by not just the young person, but also their family and friends. I was diagnosed at the age of 10 with a Non-Hodgkin's Lymphoma. The diagnosis was sudden and my world was turned upside down in the space of 24hrs.

My experience with cancer left me socially isolated from my friends, who had little understanding of what I was going through, nor of how they could help me. I was forced to miss several months of school, most of which time was spent either travelling into hospital for chemotherapy and radiotherapy, or at home, where I was visited by a district nurse. The treatment, and the sedentary lifestyle that it enforced meant that throughout these months I lost physical strength to the point that I required assistance to walk. I also lost my hair twice and gained weight. These physical changes had a large impact on my self-confidence and body image, as well as my ability to play sport with my friends, both during and in the years following treatment, as I tried to restore my body to its former healthy state.

The impact of my experience was also felt by my family. My mother went from working full-time to part time in order to drive me to treatment in the city, and look after me at home. With all the attention I was receiving from my parents, my younger sister became intensely jealous of the attention I was receiving from both my mother and father, and this severely altered the dynamics of our family.

Throughout my two years of treatment, I received support from my family at home and my friends at school. As such, I was comfortable in both of these environments. The nurses and my doctor were also supportive, ensuring that I had a movie or video game to pass the long periods of time in hospital.

However, the experience of repeatedly travelling to the hospital to endure the pain and overall unpleasantness of treatment was an overpowering element. My anxiety towards treatment meant that simply the mention of the word 'hospital' caused me to feel nauseous, and I would often throw up as we neared the building. I ended up seeing a psychologist about this problem, which was of minimal benefit.

The greatest support I have received through my experience of cancer has been from my peers in CanTeen (which I joined after finishing treatment), all of whom have also experienced cancer in their lives. This connection and understanding, and simply the opportunity to share experiences was something I was never given during the two years of my treatment, whether at hospital or at school, and it made all the difference, enabling me to move beyond my cancer experience and the issues it created. I am now heavily involved in CanTeen so that others may be able to better cope with their cancer experience too. My sister also joined CanTeen, and I attribute the strengthening of our relationship, and the mending of our family's dynamics to the peer-support and understanding she received from this involvement.

What CanTeen means to me?

Josh Hogan - Sibling Member and Patient Member,
Member Advisory Council Member, Western Australia Division

In January of 1996, my older sister, Jess, was diagnosed with cancer. For 12 months Jess underwent a course of chemotherapy and radiotherapy. The different treatment drugs that Jess was given had a range of brutal side effects, which in conjunction with the disease, left her constantly nauseous, lethargic and in pain. This was incredibly difficult to watch, not being able to do anything except try to make life as enjoyable as possible for her.

Throughout that year I had to spend a considerable amount of time away from home, either at the hospital to help support Jess through the aggressive cancer treatment or, at a friends house because my parents had to be at the hospital. This, in addition to always worrying about Jess's health, disrupted life for our family.

Being at school was also difficult because although I had the support of my friends it was difficult to talk to them because they didn't understand the levels of stress that this brings into someone's life.

Being a CanTeen Member was very helpful for me. I could attend the programs to meet other CanTeen Members, and have some fun, away from the stressful environments at home and at the hospital. Through meeting other young people who were experiencing similar issues to me I was able to be myself and not put up a 'strong front' all the time. Another important thing for me was having contact with past and present patient Members in CanTeen from whom I could learn more about the different issues cancer brings to the patient and what the experience was like for my sister.

Jess passed away six months after she finished treatment and the support I received from my friends within CanTeen assisted me immensely in dealing with the grief. Being able to talk to and spend time with people who understand what these experiences are like made coping a lot easier.

In 2001 I also was diagnosed with cancer. I underwent a course of chemotherapy and radiotherapy and there has been no sign of my tumour for three years. While I was in hospital and sick at home it was great to have CanTeen Members, including ones I didn't know, come in and talk with me just to take my mind off what was going on. It was really uplifting for me because they could appreciate what the experience was like and I felt like they were sharing the load.

What CanTeen means to me?

Melanie Brown - Sibling Member & Division President,
South Australia/Northern Territory Division)

My name is Melanie Brown and I am 20 years of age. Just over 3½ years ago (I was 16), my older brother Gareth started to get sick. What started as a bad cold, ended up as an unknown illness hospital admission for a biopsy and numerous tests a few months later. For me, this was the worst time, because of the uncertainty. I knew that there was something seriously wrong but no idea what, how serious, and how to fix it. Fortunately, in a way, the diagnosis was made relatively quickly.

Gareth was diagnosed with Hodgkin's Disease, a cancer of the lymphatic system. Although this was really scary, I felt relieved- now that it had a name, it also had options for treatment. Overall the prognosis looked good, because as Gareth was young and diagnosed in a relatively early stage, the survival rate was really high. Soon after this that Gareth started his course of chemotherapy, which would go for 8 months.

It was an interesting time in my life, I was 16 and in year 11 at school. I remember sitting with my friends at lunchtime and listening to a conversation about boys, parties etc. and getting incredibly frustrated. Here was my family that was going through such a tough time while my friends remained preoccupied by the pathetic. Although my friends were supportive, there was still a level I felt they couldn't understand. I noticed that my perspective on life had really changed, things that would have been important for me a week or so ago, now didn't even rate close.

I was lucky to have a supportive family, having my parents as well as my other younger brother and my older sister still at home. All the same, being the sister of a cancer patient, I often felt left out and that I didn't really know what was going on.

It was around this time that I got involved with CanTeen. My first event was a ski camp to Falls Creek, and although the activities were absolutely amazing, the people and the friendships were even better. Finally, here were people who had gone through similar things to me, and who recognised that even though, I didn't have cancer, I was still living with cancer and therefore had needs of my own.

Three and a half years later, I don't need the same support anymore, Gareth has been in remission for three years and I'm past my own experience. However, through CanTeen, I am now able to give the support to others that I once received myself, and have been given so many opportunities, including leadership on our programs, helping organise events, public speaking, and being elected into the role of President in my Division of CanTeen 2005. CanTeen has been a really positive thing in my life, and has helped me both during my cancer experience and now, giving me support and skills that have helped me to grow as a person. For that I am very thankful.

What CanTeen means to me?

Damien Heywood – Patient Member & Division President,
Victoria Division

In April 1999 I was diagnosed with a bone cancer called Osteosarcoma, in my left knee. At the time I was 15 years old and was treated at the Royal Children's Hospital in Melbourne for 9 months.

When I was diagnosed I was a typical 15 year old. I was very fit and healthy and had no history of cancer in my family. I didn't know anything about cancer or any of the treatments for it. It was something I had never come across before.

From the time 'something showed up on the x-ray' until the time I finished my treatment I wasn't at school. This meant that I didn't get the opportunity to spend time with my friends like a 'normal' teenager would. Even outside of school my friends didn't come and visit me. I assume because they didn't know what to say. This meant that I didn't have anyone who was my age that I could talk to about what was happening to me. Even within the hospital there were very few teenagers of my age due to that fact, I was being treated at a children's hospital.

When I started my treatment, I signed up to be a Member of CanTeen – The Australian Organisation for Young People Living with Cancer, however I didn't feel well enough to attend their activities until the end of my treatment.

Soon after I finished my treatment, I attended a camp for Patient Members of CanTeen. This was the first opportunity I had had to talk to people my age about what had happened in the last 9 months of my life and how it would effect the rest of my life. I got to meet people who had 'been there and done that' and see how they had continued with their lives.

Approximately a month later I attended CanTeen's Summer Camp where I got the chance to meet other Patient Members and their Siblings. I was able to continue that had started during Patient's Camp, as well as talk to siblings and see cancer from their perspective.

Two of my sisters are CanTeen Members and have had the opportunity to talk to other young people in similar situations. They found out they weren't they only ones who had to run a household while Mum and Dad were with me in hospital. They have also gained an understanding of what I went through during those 9 months.

I believe it is hard enough for a young person to grow up and cope with the normal changes that happen in their life. Throw in a diagnosis of cancer, and it throws the young person out of their normal life, and into hospital. Being able to talk to people my age that had been through similar experiences was able to bring back some kind of 'normalness' into my life.

What CanTeen means to me?

Annie Schmitz – Sibling Member & Division President,
Western Australia Division

In 1999, I was in my final year of primary school. My brother had been complaining of aching bones and muscles for weeks and we had finally got an appointment with a specialist. No medical staff knew what was wrong with him and for a while everyone thought it was arthritis. It was only then when we saw the specialist that it hit hard on our small family. The doctor was shocked that my brother wasn't dead already because he was sure close. Rushed to hospital to have tests, we found out what was wrong with my brother. My brother, Alex was diagnosed with cancer of the blood - leukemia.

Treatment began immediately at Princess Margaret Hospital (PMH) in Perth, Western Australia. As I was only eleven at the time, my thoughts on cancer were extreme and limited. When I was told, I kept gulping back the tears and sobbing " He's going to die" repeatedly, which looking back now, would not of helped the matter at the time.

Looking back at his treatment, it is all really a blur. Mum was never really at home to care for me, whilst family and friends all had to look after me night after night. My father was also never around as my parents split when I was four. As I never had a permanent adult around, I had to care for myself and became very independent. I starved for attention and my mum, Margaret found it hard to try and balance between my brother and I.

I used to go into hospital a lot and see my brother. It was shocking to see my brother so frail and brittle, when only a few months before, he was wrestling with me on the lounge room floor. Alex didn't have a smooth treatment. He was always catching viruses because the therapy had annihilated his immune system. He was bed ridden for months and if he did try to walk, he would fall and bruise severely. Alex didn't react well with the treatment and was put in ICU - the intensive care unit. I was shocked and distraught with seeing my brother so sick and me so healthy. I always wished that I could've swapped places with him. I would've gone through all the hardships just for him to have experienced being a teenager. Going to parties, hanging out on weekends and just generally having a good time. He never was healthy until he finished school in year twelve.

CanTeen contacted me whilst I was in PMH with my brother. It was a godsend. Being a bit scared and didn't know what to expect, the members at CanTeen welcomed me warmly. I learnt to deal with my experience through the many discussion groups and remembrance events at the programs. We all got along spectacularly because all had that special link of been there and done that. CanTeen provided me with the support I needed through the wonderful caring members and the ethos of support, develop and empower. Now being the president of Western Australia for CanTeen I have recognized that there are others that need the support that I gained whilst being a new member. I have realized that I need to give back to this wonderful organization that has helped so many people that have been touched by cancer.

What CanTeen means to me?

Peter Hancock – Patient Member & Division President,
Queensland Division

I was diagnosed with a rare form of childhood cancer in October 2003; the 3 letters which spelled the change of a lifetime were A.L.L. This stands for acute lymphoblastic leukaemia. At the age of 17 I had now been given a life challenge.

Straight away they started my surgery for the placement of my central line and after which I started my main course of chemotherapy. I was still numb from the shock of this diagnosis along with my brothers and sisters we tried to deny the fact for nearly 2 weeks. It only sank in after I met my first "Treatment Buddy" a young girl by the name of Anna. We did a lot of things while in the hospital, for example just sitting in each others rooms talking, putting the best spin on things, and making bets on who would be in remission first. In many ways it is just the same as the peer support aspect of CanTeen.

Sadly after I left for Australia, Anna passed on from an infection. At this stage I was just finished my main treatment cycle and joined CanTeen. I was extremely upset as was the normal, but when I first met other teenagers like me from CanTeen it was great - I was able to speak out about these feelings of guilt and helplessness and was amazed to find that each and everyone who was part of this organisation have been there before and knew exactly how I felt. It was an unbelievable feeling.

I also drew immensely on CanTeen when another one my best friends passed away and once again the warmth and understanding of the members, and the emphasis of supporting developing and empowering each member, really goes miles toward getting you through the emotional turmoil of a diagnosis and the major emotions such as regret, anger, helplessness and complete numbness. I can guarantee that without the CanTeen support system I myself and my brothers and sisters would not have coped so well with what had happened.

From there I have become extremely active in this organisation as I want to help others who are just going through what I have gone through and who have yet to get through the uncertainty of a diagnosis. Also I want to give back to CanTeen as the help I received from other members has been invaluable.