Over the past 5 years, the Oncology/Bone Marrow Transplant Follow-up program at BC Children's Hospital has transferred approximately 140 survivors of childhood cancer to adult healthcare services. The usual transfer will be to the young adult’s family physician. This new responsibility for the family physician can be daunting, due to the comprehensive medical care that is needed for these survivors.

The remarkable success in treating childhood cancer has resulted in a high increase in the number of survivors. Now more than ever, there is a compelling need to focus attention on education, advocacy, and the allocation of new resources for this unique population. Survivors need assistance and guidance from their pediatric caregivers to enable them to articulate their needs and thoughts about survivorship and to make these known to others, especially primary care physicians who for the majority of survivors, will be their caregivers in the adult healthcare world. Survivors also need to be empowered so they can identify their abilities, skills and knowledge from their experiences to use for their benefit in navigating the adult healthcare world (Wiard & Jogal, 2000). A gap in healthcare services could result in serious consequences for survivors as they are at risk for late effects and secondary malignancies.

It is important for the survivor to be empowered to assume responsibility for their own healthcare. The process of achieving this is through the transition process. According to Blum and colleagues (1993), transition is defined as “the purposeful, planned movement of adolescents from pediatric healthcare to adult healthcare” (p.570). It is also defined as a process, not an event, that begins on an individualized basis and occurs, in stages, over an extended period of time (Lewis-Gary, 2001).

These definitions express the essence of what transition is to survivors of childhood cancer. The purposeful planned movement fits with the movement from pediatric healthcare overseen by parents and pediatric oncologists to a more self-designed and self-monitored adult healthcare world (Keene, Hobbie, & Ruccione, 2000). The universal goal of “this movement from pediatric healthcare to adult healthcare is to ensure that it is uninterrupted, coordinated, developmentally suited, psychosocially sound, and comprehensive” (Blum et al, 1993, p.570). The goal of transition planning and preparation is to assure that survivors seek follow-up care to ultimately reduce the incidence of them dropping out of the healthcare system (Nasr, Campbell, & Howatt, 1992).

Survivors of childhood cancer need to be cognizant of their unique medical history and be able to share their medical journey. The internet web site www.kidscancer.bc.ca was launched in January 2004 to serve the needs of both patients and families and all health care providers. The web site is still in an expansion mode with additional sections in development. The Network welcomes comments and suggestions regarding revisions or additions to this web site. Please direct correspondence to Dr Chris Fryer: cfryer@cw.bc.ca or Grace Chan: gchan@cw.bc.ca

Courtney diagnosed at six weeks of age with leukemia (ALL). Relapsed at one year of age and received a bone marrow transplant. High School Graduate 2003.
Victoria Pediatric Oncology Program

The Victoria pediatric oncology program is located at the Victoria General Hospital in Victoria, the capital city of B.C. and the heart of the Banana Belt of Canada. We have a large bright treatment room where all the outpatient chemotherapy and other special procedures take place. There are three nurses certified in pediatric chemotherapy: Anita Breiland, Susanne Bourgh, and Eleanor Shambrook. These nurses also are responsible for other outpatient programs and clinics. Eleanor also sits on the Provincial Pediatric Oncology/Hematology Network Steering Committee and is involved in a number of Network initiatives. Our oncology medical director is Dr. F. Jagdis who is a local pediatrician with an interest in oncology. Other members of the team include Delane Peters (nutritionist), Dr. Laila Thaiss (psychologist), Michael Blades (social worker), Dr. Greg McKelvie (pharmacist), and Theresa Low and Diane Edwards (child life specialists). Our local chapter of Help Fill A Dream provides much appreciated help to families when needed.

We service the southern part of Vancouver Island and the Gulf islands, sometimes as far north as Nanaimo. Our level of care is between levels two and three. Currently we follow about 15 active patients. Patients are most often seen individually with time spent tailoring the care to the needs of the child and family.

Many of the families choose to have most of their treatments in Victoria as commuting can be difficult. The Victoria nurses are in frequent contact with nurses and oncologists at BC Children’s Hospital when questions or concerns arise.

We also have a busy post treatment follow up clinic which is held every two months. At each of these clinics one of the oncologists from BC Children’s Hospital attends. About 60 childhood survivors of cancer are seen at these clinics, often into their twenties as currently there is no adult follow up provided.

When we asked our patients how they felt about our program, one young person replied that it was fine as all the nurses were old and knew what they were doing.

Pediatric Oncology at Prince George Regional Hospital

In July of 2002, after months of development and planning, the Pediatric Ambulatory and Oncology Care Clinic was up and running. Although children in our region were able to receive their chemotherapy treatments through the Regional Cancer Care Unit, the transfer of these children to our service allowed them to come to a ‘kid friendly’ pediatric outpatient clinic setting.

At present we have four nurses who are Level 1 Chemotherapy Certified. Kristine Brownscombe and Nicole Kish are employed as the clinic nurses and share the responsibility of ensuring that the clinic is open every day of the week. They also coordinate the activities of the Oncology service ensuring that parents, children, pharmacy and the pediatrics all receive information in a timely manner.

Corrine Reich is our casual nurse who fills any gaps in our coverage. Lael Cole acts as a resource nurse and supports the activities of the Oncology service by being available throughout the week. She also sits on the Provincial Pediatric Oncology/Hematology Network Steering Committee and its working groups, representing the Northern Health Authority. Teresa Kozjak acts as our clerical support - keeping the physicians' offices, parents, and clinic nurses organized with appointment times. All of us communicate with the primary nurses in Vancouver in order to provide seamless care to the children and families we serve.

Our pediatricians are all involved in caring for the children in our service. Dr. Simon Earl is the director of the clinic and has been very active in ensuring that we maintain a high standard of care by supplying us with opportunities to attend conferences and establishing monthly meetings to review all of our patients. Dr. Earl is also a source of great entertainment for the kids, families, and staff in Pediatrics as he regularly runs races through the ward with our cancer kids following their treatments. Both Dr. Abelson and Dr. Hay also care for oncology patients in our clinic setting. Prince George has been lucky to recruit two additional pediatricians who will take a role in caring for these patients. At present, we provide Level II care to our oncology kids.

Our clinical pharmacists, Joyce Totten, Rob Watt, and Carey-Ann Lawson, have an active role in our clinic, ensuring that the roadmaps are correctly interpreted and followed in collaboration with the physicians and nurses. They also participate in our monthly meetings.
Most of the work of the group has centered around the data gathering and assessment stage. A pilot telephone survey was conducted to assess the health care needs of adult survivors of childhood cancer. An attempt was made to contact 10 adult survivors of childhood cancer who were discharged from the BCCH clinic 5 to 10 years ago. Four replies were received and all were interested in attending a specialized clinic. None were aware of the specific details of their therapy nor of subsequent health risks. Plans are in progress to conduct a more extensive study to find out what kind of long term follow-up care adult survivors are receiving.

The Network has identified that establishing a comprehensive long term follow-up care plan is a priority. Key activities will be to develop evidence-based criteria for long term follow-up care and to establish a risk-based model of long term follow-up and transitional care to adulthood. The model of care will then be tested as a pilot project in selected communities. A database for childhood cancer survivors (started and funded by the CIHR) is to be completed and maintained to ensure that there is adequate surveillance data collected in keeping with provincial and Canadian cancer control strategy.

Network Key Initiatives for 2004/2005

- Support the health care professionals in the four major referral sites (Surrey, Victoria, Kelowna, Prince George) by assisting with educational resources
- Formulate the psychosocial and palliative care working groups
- Conduct a pilot project for an electronic health record for ALL patients
- Implement an electronic health record system
- Maintain and enhance the content of the web site as the major information resource.
- Develop and implement risk based management guidelines, including surveillance data collection, for a province wide cancer control system for survivors of childhood cancer that meets provincial and national requirements.
- Participate in the Family Practice Oncology Preceptorship Program
- Collect data for evaluating the impact of the Network.

Transitioning Survivors of Childhood Cancer to Adult Healthcare

Continued from page 1

it with all future doctors who will care for them after the pediatric experience. Empowering these survivors with the knowledge of their diagnosis, past medical treatment, recommended follow-up tests, and information on living a healthy lifestyle will not only benefit survivors but also the physicians who will be looking after them.

Continued medical follow-up of childhood cancer survivors into their adult years is important for several reasons. Early diagnosis and the application of interventions can improve the quality of life for these survivors (Hudson, 2000). Also, the appearance of late effects of treatment may not become evident until the survivor is well into his/her adult years and long gone from the pediatric treatment centre (Hudson, 2000).

The crucial element in the transition process is the ability of the adult healthcare providers to obtain the knowledge about childhood cancer and its late effects. Factors that may increase the availability of this knowledge for adult healthcare providers are the survivors and their families sharing their vast knowledge of their cancer experience and information regarding the need for life-long follow-up, the pediatric oncology treatment team taking an active role in the education of the community primary care physician and the provincial pediatric oncology/hematology network helping to support this effort by provincial conferences, print and video materials, education workshops and traveling consultants.

A successful transfer to adult healthcare will ensure that the survivor’s healthcare needs will continue to be met as adults in an age appropriate setting and by knowledgeable primary healthcare providers. This will ultimately decrease the chance of survivors feeling frustrated, feeling lost and dropping out of medical follow-up care. Overall, this will enable the survivors to make wise healthcare decisions to attain an enriched quality of life and be able to look forward to their future with strength, hope and courage built from their cancer experience.

References


Parent & Survivor Corner

Going through cancer treatment was the hardest thing I ever had to do. But I turned the experience into a huge, positive one. In the hospital, you get to meet a number of amazing people: doctors and nurses who truly care about their patients and all the other patients from across the province.

Having gone through surgeries, chemotherapy, and radiation, I have fully recovered from the brain tumor that I was diagnosed with. I go back to the hospital to share my experiences with other patients who are going through their treatments. I am so blessed to hear about amazing success stories from other kids who have beaten the odds and are still here to talk about their experiences. The most important piece of advice that I can give to anyone going through cancer treatment is to keep a positive outlook and know that you are in the hands of people who truly care and will stop at almost nothing to keep you here with us. — Jared

Jared (right) with Kristina Jackson (Child Life Specialist) at Balding for Dollars.

Education and Communication Working Group Report

The Education and Communication Working Group has been very busy in the last months organizing activities to support education and improve communication among caregivers around the province.

The Pediatric Cancer Education Day held in conjunction with the BCCA Annual Cancer Conference in November 2003 was very well attended by over 70 delegates from many regions in the province. We received excellent feedback on the content and the speakers. The discussion during the working lunch pointed to 3 major areas of need:

1. The need for an electronic health record system for timely information transmission.
2. The need for a province wide long term follow up program for survivors of childhood cancer
3. The need for educational resources for caregivers in the communities.

The feedback obtained was invaluable as we make plans for the next year.

As a start to addressing the educational needs, the Network will be partnering with Royal Inland Hospital in Kamloops and Prince George Regional Hospital to provide training in chemotherapy administration for pediatric nurses on March 1-2 and March 22-25 respectively.

To help address the educational needs of physicians, we are offering a pediatric oncology preceptor module as part of the BCCA's Family Practice Oncology Preceptor Program. For more information on this continuing education opportunity, visit www.bccancer.bc.ca/HPI/FPON.

To improve communication among health care professionals around the province, we are in the process of gathering contact information from the community care centres and BCCH. This information will be on the website by April 2004.

If you are a teenager/young adult with cancer or cancer survivor, check out this excellent website: www.planetcancer.org

For more information

To learn more about the Provincial Pediatric Oncology/Hematology Network or to submit articles or stories to this newsletter, please contact:

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The Provincial Pediatric Oncology/Hematology Network

The Network is an interdisciplinary organization whose goal is to ensure appropriate diagnosis, management, follow-up, and end-of-life care for pediatric patients with malignancies and blood disorders. The Network supports community hospitals and practitioners and develops partnerships with other health facilities to enable seamless and integrated care for patients and families on treatment and off treatment. It will further develop and enhance the research programs of basic, translational, and clinical research to better childhood cancer control and improve outcomes for these patients and their families.

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