

Community Cancer Support Network Newsletter

For Health Care Professionals

Volume 4, Issue 2

April 2011

ISSN: 1916-6788



In this issue of the Community Cancer Support Network Newsletter we are pleased to highlight exciting research taking place in radiation therapy, the patient financial assistance program, and some points on when referring to a psychologist may be a helpful. In addition, we are pleased to introduce some new

resources available to you, and tell you about our exciting Community Cancer Support Network pre-conference workshop in June.

If you would like to be added to the network email distribution list or have any questions, concerns, or comments regarding this newsletter please contact Alberta Health Services, Community Cancer Support Network Team; Vivian Collacutt, Provincial Manager, Daena Lamoureux, Provincial Coordinator, and Glenda Armstrong, Program Assistant at acb.ccsn@albertahealthservices.ca



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Patient Journal to Ease Cancer Journey

Submitted by: Phoebe Dey, Communications Manager, Alberta Cancer Foundation



Every year, 16,000 Albertans hear the words, “you have cancer.” That diagnosis often comes with overwhelming feelings of how to cope with the news. To help ease the cancer journey, the Alberta Cancer Foundation has created a journal to help guide patients and families through this difficult process.

“When my daughter was diagnosed with cancer, I saw how confusing it was to navigate through all the information you

are given before, during and after treatment,” says Alberta Cancer Foundation CEO Linda Mickelson. “This gift will help patients access available services and play an active role in their care, benefiting patients, families and care teams. We recognize that each cancer journey is unique and we wanted to allow patients to record important steps along the way.” The journals, which come with a file folder and pen, will be a central place to store medical documents, track side effects, note

any concerns, schedule appointments, monitor emotional and spiritual health, plan a physical activity schedule and maintain good nutrition.

Vivian Collacutt, Manager, Community Cancer Support Services with Alberta Health Services, appreciates the idea of the patient journal as one way to support patients after a cancer diagnosis. "This is, essentially, a 'one-stop shop' where individuals can record all their important appointment information, keep track of their multiple health-care providers and track their own symptoms and

feelings as they are going through treatment and beyond. It can serve as an important tool for individuals with cancer and support them in being an active partner in their cancer care."

The journals will be given to patients on their first visit are expected to arrive at the Tom Baker Cancer Centre, the Cross Cancer Institute, and the four Associate Cancer Centres in May. For more information, contact the Alberta Cancer Foundation at (780) 643-4400 or email acfonline@albertacancerfoundation.ca



From Evidence to Action

Radiation Therapy Clinical Trials

Submitted by **Debbie Mallett, MRT-ACT, Protocol Coordinator, Radiation Oncology, Alberta Health Services, Cancer Care, Cross Cancer Institute**



Recent technological changes enable Radiation Oncologists to customize radiation treatments for patients in ways that we were not able to offer until quite recently. As well, there is a lot of exciting research into how we time the radiation treatments (with and without chemotherapy and surgical treatments) - so it's important to compare all of these promising new treatment methods to the best treatments currently available to test for effectiveness, immediate and long term effects.

Many of these new treatments are currently available only via a clinical trial, until all the information is collected, analyzed and published. If the study is appropriate for the patient, they are given the opportunity to participate.

One study available in Alberta is called "RAPID" - for patients with certain types of breast cancer. Eligible, consenting patients are randomized to conventional treatment (whole breast in either 16 or 25 daily treatments, once daily) or the "experimental partial breast" treatment using a 3 dimensional technique (2 treatments per day, for 5 days total). The effectiveness of the treatments will be judged based on control of the

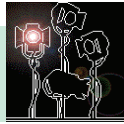
disease and cosmetic results.

Although receiving two treatments per day means they must come in for 2 treatments that are at least 6 hours apart, they complete their treatment in 1 week instead of the usual 4 - 5 weeks! This is very attractive for many patients and their families.

Another study available in Alberta is for patients with certain types of prostate cancer – referred to as the "PROFIT" study. Eligible, consenting patients are randomized to either "standard treatment" which takes 7 – 8 weeks, or the "experimental treatment" which takes only 4 weeks.

In the years to come when the data and follow-up of patients is analyzed, the results of studies such as RAPID and PROFIT will provide more choices for doctors and patients having Radiation Therapy. At this point in time, however, the "experimental" treatment is only available to patients on a study, and only if they are randomized to that treatment option.

It is an extremely exciting time in Radiation Oncology - these patients and staff are helping to change the way Radiation Therapy is used to treat cancer in the years to come for patients worldwide.



Spotlight

The Patient Financial Assistance Program: a Fund to Reduce Barriers to Treatment of Cancer Patients

Submitted By: Teresa Skarlicki, MSW, RSW, Comprehensive Breast Care Program



While coping with the stress of cancer diagnosis and treatment most cancer patients also experience a loss of income and increased expenses related to accessing treatment. Many cancer patients would not be able to follow through on their treatment due to financial barriers, such as the cost of transportation (often over hundreds

of kilometers), accommodation (often for weeks to months at a time), expensive medications, and meals while away from home. The Patient Financial Assistance Program (PFAP), funded by the Alberta Cancer Foundation, helps to alleviate some of these barriers. It is administered by the social workers in the 2 tertiary cancer sites, the Cross Cancer Institute in Edmonton and the Tom Baker Cancer Centre in Calgary, as well as in the 4 Associate Cancer

Centres (Grande Prairie, Red Deer, Lethbridge and Medicine Hat).

To qualify a patient needs to have a cancer care number (patients are usually assigned a cancer care number once they have a positive pathology). Application forms are completed to include monthly household income, reasonable expenses, and liquid assets (bank accounts, RRSPs). It is important to capture the patient's current financial situation, not just what their income normally would have been before cancer affected their circumstances. This fund is used as a last resort after other sources of funding have been explored. Some social workers in the community (both urban and rural) help patients to access this fund, by completing and submitting the PFAP application to the social worker at the nearest cancer centre. For further information on accessing this fund please call the social work department in the nearest cancer centre.



Education Corner

How a Psychologist Can Help

Submitted by: Garry Last, Psychologist (Hinton, Jasper, Edson, Grande Cache)



For those working with cancer patients sometimes a referral to a psychologist may be beneficial. Psychologists and mental health therapists can help in a number of ways. They can provide ongoing support for the patient and/or family member, as well as an opportunity for them to express their fears and frustrations with what they are going through. On occasion psychologists see patients and their family members to help deal with conflicts between them that have arisen prior to, or since the illness. Patients may also want to discuss issues regarding their own mortality. Denial of one's illness may warrant a referral to a therapist, particularly where treatment may be compromised. On occasion a patient may state that they do not want their family to know about their diagnosis. A psychologist can work with that patient to explore this decision. Although outwardly this may not appear to be a rational choice, it might make sense from the patient's perspective. A

psychologist often has the time and skill to explore with a patient their thoughts and emotions. In working with family members, the psychologist can also advise them on how to deal with the patient either through offering mediation, or by providing insight into how their loved one is coping with their illness. Sometimes post trauma stress may develop after the treatment is completed and a patient may need assistance in getting their life back on track. Psychologists can also provide support to "caregivers" on an individual or a group basis. A "debriefing process" can be particularly helpful to caregivers in dealing with the stress of helping others. A "debriefing" may be warranted when stress has accumulated over a number of years (referred to as "vicarious traumatization") or after a particularly difficult experience in working with a patient.

If you have any questions regarding this article or other issues please feel free to contact me.

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We at the Community Cancer Support Network would like to take this opportunity to remember a valued member of our network who passed away March 10, 2011. Holly Day was a psychologist and mental health worker based in Hinton. Holly was an important professional partner to the staff at the Hinton Community Cancer Centre and was a longstanding Community Cancer Support Network

Advisory Committee member. She believed strongly in the concept of person-centred care and valued the role she played in supporting the psychosocial needs of the people in the Hinton area who were living and dying with cancer. Holly was tragically killed while on vacation in Hawaii. We would like to express our condolences to Holly's family, friends, and colleagues. She will be missed.

CARE ABOUT CANCER PRE-CONFERENCE WORKSHOP

Alberta Health Services - Cancer Care is planning the first integrated and interdisciplinary cancer care conference in Alberta on June 16 - 18, 2011. This conference covers the breadth of cancer control from prevention through to survivorship or palliation including treatment and research. Researchers, oncologists, primary care, those involved in screening and prevention, and care providers from multiple cancer centres and the community will have the opportunity to come together at this event. For more information or to register please visit the conference website at www.careaboutcancer.ca

The Community Cancer Support Network is pleased to be planning a pre-conference workshop on June 16, 2011. Please see the schedule below for more information. To register please visit the conference website.

Community Cancer Support Network: "Support Through the Cancer Journey" <i>June 16, 2011</i>	
9:00 - 10:00	Topic Coming Soon Dr. Eduardo Bruera, MD, The University of Texas M. D. Anderson Cancer Center, Houston, TX
10:00 - 10:15	Break & Refreshments
10:15 - 11:15	<i>The Impact of Death and Dying on Health Care Professionals: Death and Dying May Not Be as Morbid as You Think</i> Dr. Shane Sinclair, Spiritual Care Coordinator, Tom Baker Cancer Centre, Calgary
11:15 - 12:00	<i>CancerChat Canada - Professionally Led Online Support for Canadians Affected by Cancer</i> Dr. Jill Turner, Psychologist, Cross Cancer Institute, Edmonton
12:00 - 12:45	Lunch
12:45 - 1:45	<i>Supporting the Patient, Supporting Each Other - Lessons from an Interdisciplinary Cancer Team</i> Karmen Schmidt NP, Anna Sytsanko SLP, Patty Tachynski RD, Cross Cancer Institute, Edmonton
1:45 - 2:45	<i>Ethical Issues in Nutrition Support of the Cancer Patient</i> Shirley Hobenshield RD, BC Cancer Agency, Vancouver Victoria Kletas MSc Pharm, BC Cancer Agency, Vancouver Al-Noor Nenshi Nathoo, MA, Executive Director, Provincial Health Ethics Network, Calgary
2:45 - 3:00	Break & Refreshments
3:00 - 4:15	<i>Searching for Superheroes - A Journey of Discovery</i> Roland Majeau, Singer & Song Writer, St. Albert
4:15 - 4:30	<i>Wrap Up and Evaluation</i>

Please Join Us In Welcoming Pam Barnaby, Transition Nurse, Cross Cancer Institute



Pam is thrilled to have begun her new role as of Dec.6, 2010. She works with the Community Cancer Network for Community Oncology. Her title is Transition Nurse, and her role is three-fold:

- Transitioning with Community Cancer Centres so patients can receive their chemotherapy treatments as

close to home as possible.

- Covering for the Alberta Cancer Line, and
- Components of navigation

Pam has extensive years of experience as a Registered Nurse. Areas of practice include: Internal Medicine, ENT, Urology, General Surgery, Obstetrics and Gynecology, more recently at the Cross Cancer Institute in Clinical trials, and currently as a Transition Nurse for Community Oncology.

She has been married for 38 years (same man), and is a mother of 3 children and one fur-child (cat – they never grow up). In her spare time, she enjoys getting away to their cabin in Saskatchewan. Just to keep the wrinkles in check – she provides Laughter Yoga sessions to different interest groups.

She looks forward to a long & happy working relationship with all of you. Welcome Pam!

Contact info:

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Articles of Interest

- Brisbois, T.D., et al (2011) Delta-9-tetrahydrocannabinol may palliate altered chemosensory perception in cancer patients: results of a randomized, double-blind, placebo-controlled pilot trial. *Annals of Oncology Advance Access*.
- Martin., L., et al (2010) Prognostic Factors in Patients With Advanced Cancer: Use of the Patient-Generated Subjective Global Assessment in Survival Prediction. *Journal of Clinical Oncology*. 28: 4376-4384
- Stephen., J., et al (2010) Facilitating online support groups for cancer patients: the learning experience of psycho-oncology clinicians. *Psycho-Oncology*
- Frederic, A., et al (2010) Breast cancer in pregnancy: Recommendations of a international consensus meeting. *European Journal of Cancer*. 46: 3158-3168

Available Resources

The following presentations are available on disc for your use. To receive a copy email

glenda.armstrong@albertahealthservices.ca

- **Screening for Distress: Getting from Here to There** presented by Deborah McLeod, PhD, Capital Health Cancer Care Program, Dalhousie University, Nova Scotia
- **Knowing What to Say – Speaking with Patients About Spirituality and Exploring Verbal Responses to Spiritual Pain** presented by Oceanna Hall, B.Sc., M.Div., M.Ed., CPE Specialist.
- **Lowering cancer risk through nutrition: recommendations for your clients** presented by Teresa Fung, ScD, RD, Associate Professor of Nutrition at Simmons College (Boston, USA) and Adjunct Associate Professor at the Harvard School of Public Health
- **Radiation Therapy: Answering Some Burning Questions** presented by Brian Chwyl, RT(T), B.Sc, Clinical Educator, Radiation Therapy, Cross Cancer Institute