The Financial Hardship of Cancer

By Shelley Pennington, MSW, RSW, BCCA, Cancer Care Resource Social Worker

As the Cancer Care Resource Social Worker for BC Cancer Agency, I hear many stories about the challenges associated with patients living on a reduced income and/or not being able to afford the increased costs that can come with having cancer. If a patient or family has a stable source of income, they may still have trouble paying their monthly bills. However, when a patient is already struggling with financial concerns and is diagnosed with cancer they can easily become overwhelmed. The report, Financial Hardship of Cancer: A Call to Action (pg.4) says there are 3 key factors that are important to consider.

Family income may decline dramatically because of the need to stop working during treatment or while caring for a loved one who is ill. Gaps in our public safety nets leave some people with few financial footholds until they have hit rock bottom.

Expenses may skyrocket at the same time as income is dropping. Gaps and inconsistencies in coverage and services can leave individuals responsible for significant in additional costs.

These issues are compounded by a third factor: A lack of awareness and a false sense of security have left Canadians unprepared to deal with these challenges, both as individuals and as a society. Most Canadians do not know that a cancer diagnosis has caused some people to declare bankruptcy, lose their homes, lose all of their savings, make less than optimal treatment decisions or become dependent on taxpayer-funded programs for the rest of their lives. Until cancer comes into their own lives, they believe the myth that all health care is free. Most never imagine that they could face such difficult challenges at such a vulnerable time of their lives. The reality comes as a shock to many.

It is very important as professionals in cancer care to assess, acknowledge and understand the financial impact of cancer for some patients.

If a patient or family member needs assistance with resources, see our BCCA website Coping with Cancer section or refer them to Patient & Family Counselling Services.
New Patient and Family Counseling (PFC) Practice Leader (PPL) for the Fraser Valley Cancer Centre (FVC)

Sandy Faulks, RSW, joined the BCCA team on May 12th as the new Practice leader for the Fraser Valley Centre Patient and Family Counseling program.

Sandy is well known in the Fraser Health Authority Region. Her most recent position has been as Social Worker, Hospice Palliative Care Consult Team, Abbotsford/Mission Communities and Christine Morrison Hospice since 2012. Prior to that position, for 7 years, she was the Social Work Practice Leader, Chilliwack General Hospital. In addition she has worked in Fraser Health Authority (FHA) hospital settings for 15 years, including Royal Columbian Hospital and Chilliwack General Hospital.

Farewell to Dr. Joanne Stephen

We are sad to announce that Joanne has left the BCCA Psychosocial Oncology Program at the end of May. She was a research and clinician at BCCA since 1998 and as many of you know was instrumental in setting up the CancerChat program as well as a key contributor to other research projects.

Joanne will be moving to Calgary with her family. We wish her well on the next chapter of her life.

The Brain Tumour Foundation of Canada Award in Support of Psychosocial Oncology awarded to Douglas Ozier

Douglas Ozier, PhD (seen here on the left) received this honour at the Canadian Association of Psychosocial Oncology Conference for his poster - Heart Rate Variability Biofeedback for Anxiety and Depression in Primary Malignant Brain Tumor Survivors

The Brain Tumour Foundation of Canada has established an award of excellence to acknowledge the exemplary work of psychosocial oncology professionals, in collaboration with CAPO.

The purpose of this award is to promote the dissemination of information related to the psychosocial care of children/adults/families with brain tumours, and is given to support oncology professionals in continuing education activities.

This annual award is presented to a CAPO member who submits the best abstract, (paper or poster) in the area of neuro-oncology at the annual CAPO conference. The presentation may reflect clinical practice, education or research related to the neuro-oncology population.
WHAT’S NEW AROUND THE PROVINCE

❖ AT THE VANCOUVER CENTRE
Jennifer-Lee Koble joins the team as a new casual staff member after completing her MSW practicum with the VCC program. Jennifer-Lee was awarded the UBC Aboriginal Graduate Fellowship 2103-2014 to complete her MSW. She has had over fourteen years experience working intimately with women and families.

In her previous social work practicums at Aboriginal Wellness Program-Vancouver Coastal Health and at Helping Spirit Lodge Society Jennifer-Lee provided individual support and group facilitation on grief and loss, provided resources and was an advocate to many women.

❖ AT THE CENTRE FOR THE NORTH


❖ WITH THE VANCOUVER ISLAND TEAM

The Vancouver Island PFC team met for two days in April to review and discuss the Gottman DVD series on working with couples. Karen Morrissette, Palliative Care & Oncology Social Worker, Nanaimo Regional Hospital, joined this group for these two days of learning and connection.

![Image of the Vancouver Island PFC team](image)

Left to Right – Catherine Traer-Martinez, Karen Morrissette (NRH Social Worker), Helen Wong, Marita Poll, Josie Hessels. Missing: Nancy Payeur (photographer!)

❖ WITH COMMUNITY ONCOLOGY

We wish the best to Cheryl Jolliffe who recently retired after many years as the Professional Practice Leader for Social Work at Providence Health.

Harvey Bosma is now accountable for the overall delivery of professional, clinical and academic Social Work services across PHC and for fostering interdisciplinary approaches to patient/resident care.

❖ WITH THE PROVINCIAL TEAM

A few of the Provincial Psychosocial team members are seen here, welcoming a visit from Reuben Prins Hankinson, the son of Sara, Art Therapist, BCCA.

![Image of the Provincial Psychosocial team](image)

(left to right: Vickie Mattimoe, Gina MacKenzie, Shelley Pennington holding Reuben and Elaine Shearer)
Tools for Living Well: Clinical Program Research
Catherine Traer-Martinez, Registered Clinical Counsellor
Patient & Family Counselling Services, Vancouver Island Centre (VIC)

This is the second offering of this group program, which was well received and positively evaluated by participants in a pilot in May-August 2012.

This project is will evaluate the impact of teaching somatic coping skills within a group format to post-treatment cancer patients. The group is intended to serve the needs of post-treatment cancer patients who continue to struggle with the shock of diagnosis and recovery from complex cancer treatments. The content and structure of the group will address unresolved post-treatment emotional shock and distress for patients aged 35-65. The focus will be learning about "emotional self-regulation" and "somatic awareness" to resolve shock and distress, and cope with fears of recurrence. This group integrates a new clinical approach, informed by neuroscience research, that recognizes cancer as a traumatic stressor requiring body-based ways of processing traumatic stress to create emotional stabilization and resiliency.

Extensive literature exists on the unmet needs and struggles faced by many cancer patients. For adults under age 65, generally the age of retirement, functioning well in the "prime of life", a cancer diagnosis often presents many challenges and many stresses. Integrating the shock of diagnosis, and recovering from treatments frequently results in a variety of losses and distressing changes:

- inability to return to previous work,
- loss of income,
- loss of relationships,
- loss of previous good health status,
- changes in body image,
- adapting to physical deficits, as well as
- coping with fears of recurrence.

Literature also exists regarding the efficacy of somatic methods for clients, although not specifically related to the post treatment cancer patient population.

While Vancouver Island Centre (VIC) offers Cancer Transitions approximately three times per year, this brief (two days plus follow-up calls and booster session) and psycho-educational program is geared to providing wellness information, tools and support within a very limited time frame. Anecdotally, our counselling team - and others within the Centre - continue to hear from certain patients that they struggle to adapt and cope post-treatment, well beyond what is typically seen. Our perception is that for certain patients, a more intensive program that intentionally addresses coping strategies, would fill an on-going gap in our services to patients.

Report back about highlights from CAPO 2014

From Sarah Sample, PPL, Vancouver Centre:

Roshi Joan Halifax, a Buddhist nun was one of the keynote speakers. She spoke about values, ethical stance, moral grace and what is nourishing to the calling of working with death and dying. She compared research on Empathy and Compassion. Compassion was said to be something that can’t be taught but can be supported by training in attention, ethical intention and insight, embodiment and engagement. Empathy was described as leaning towards the feelings of empathic concern and compassion.

Another Keynote speaker was David Kuhl from the Health Care Provider Renewal Center who talked about relationship centered health care rather than patient centre care. He talked about healthy teams needed healthy relationships and that civility is an authentic respect for others that requires time, presence, willingness to engage in discourse.
A workshop called Psychosocial Oncology Clinical Rounds: Peer supervision in action on the Prairies by Jill Taylor-Brown, Tom Roche, Bunty Anderson, Rejeanne Dorge, Lindsay Drabiuk, Miriam Duff, Patti Findlay, Katherine Gottzmann, Elizabeth Payne, Irene Shapira. For well over a decade, the psychosocial oncology clinicians at CancerCare Manitoba have come together monthly for consultation with one another about challenging clinical situations, to reflect on observations made and wondered about in clinical practice, insights gained from clinical work, and more.

From Melanie MacDonald, Counselor, Vancouver Centre

Another keynote speaker was Harvey Chokinov, Canadian Chair in Palliative Care, Director Manitoba Cancer Care. This talk explored Health Care vs. Caring stating that caring is the gateway to disclosure. Patients who feel caring will more likely be open to share goals/values making the “Care Tenor” or “tone of care” key to patients dignity.

From Amy Rappaport Counselor, Vancouver Centre

Assessing Distress and well-being in palliative care
Tom Hack addressed Quality of Life Assessments at end-of-life. The study showed discordance between distress levels reported by patient/caregiver. A subset of caregivers routinely report the distress of the patient as higher than the patient self-reports. This points to a possible role for the counselor to address issues of discordance between patient/caregiver (i.e. supporting families to bring the perspective of patient and caregiver closer together so that they have more insight into each other’s experiences).

Palliative Care Transition Project (Winnipeg) Tara Carpenter-Kellett provided ideas for supporting transition to palliative care: offering tumour-site specific resources, pain/symptom informational resources, letter to primary care provider, info-sharing with palliative care team (advocating for a nurse in community to attend appointment at the cancer agency).

Depression scores for patients who have undergone a palliative rehabilitation program (Ottawa) Andrea Feldstain provided insight into the role of rehabilitation at end-of-life. The presentation inspired considerations for advocacy to improve care, addressing dignity right up until end-of-life through rehab interventions.

Living with Advanced Cancer: Living the Questions Glen Horst (Spiritual Care Advisor) – Canadian Virtual Hospice — a resource that we can refer patients to but also use ourselves to support us in the difficult work. Sections on website include: recommended books & links, asked and answered, a section to ask questions privately, programs/services, and articles on various topics.

From Dr. Douglas Ozier, research clinician, Provincial Psychosocial Oncology program

A workshop I attended called “Dignity conservation and the best and worst aspects of palliative care” had two parts.

The first part gave background on the Dignity Therapy model and briefly reported on the results of larger study that these specific results are a subcomponent of. Keith Wilson presented the first part. The points that stood out strongly for me in the first part were:

· That a relatively small number of people in palliative care report experiencing strong problems related to loss of dignity. I will recall that about 80 percent of people said this was not an issue for them, around 10% of people said that they had a lessening of dignity but this was not a serious problem for them, and only about 10% people said that they had a problematic lessening of dignity.

· The second main point was that overall these patients were very satisfied with the palliative care they received.

· He then covered the Dignity Therapy model; I recommend that you go to the URL: http://dignityincare.ca/en for many practical resources to promote dignity in the clients we work for.

In the second half Sara Beattie presented results of an analysis of the best and worst aspects of palliative care. The main thing I remember was that over all it was the tenor of care which influenced the quality of people's experience. The presenters repeatedly stated that patients often don’t know what is medically appropriate so the thing that most strongly determines the quality of their experience is whether their care team treats them as individual human beings or as numbers/ problems to be managed.
JUNE 19, noon -1pm
Parents Living with Cancer: Bringing hope with compassion, honesty and creativity
Speakers:
- Amy Lai, MSW. Counselor, BCCA Fraser Valley Centre
- Melanie McDonald, MSW, Counselor, BCCA Vancouver Centre

SEPTEMBER 18, noon-1pm
Sexual Health Clinic Research Project
Research findings from a pilot research project ran at the Cancer Centre in Kelowna will be shared during this presentation. The last patient was seen in 2012.

Speaker: Myrna Tracy, PPL, Patient & Family Counseling, Sindi Ahluwalia Hawkins Centre for the Southern Interior

OCTOBER 16, noon-1pm
Questions about Employment Insurance
This presentation will give a general overview of EI information and access to benefits and answer specific questions that have been submitted by staff.

Speaker: Brenda Giesbrecht, Service Canada
Moderator: Shelley Pennington, Resource Social Worker, BCCA

As many of you know, you can download a free electronic copy of the second edition from the Coping with Cancer section of the BC Cancer Agency website. Hard copies are on sale now at the Online Bookstore www.bookstore.cw.bc.ca for $20.

The workbook was created by Maureen Parkinson, M.Ed, CCRC, Vocational Rehabilitation Counsellor, Psychosocial Oncology Program, BC Cancer Agency and incorporates feedback from physicians, insurance providers, lawyers and employer/employer representatives as well as patients.

It could be useful as well to patients suffering from other chronic illnesses who are considering returning to work.

Coming soon –
New online tools for palliative care
Virtual Hospice with the support of Canadian Partnership Against Cancer (CPAC) is developing new online tools to support people living with advanced illness, loss and grief, and also for health care providers. Stay tuned for more information about the videos and interactive apps and web tools for dying people and grieving families who don't have access to any other counselling or support.

If you would like to contribute to this quarterly newsletter contact Elaine Shearer, Community Education Coordinator, Psychosocial Oncology Program - eshearer@bccancer.bca.ca Deadline for submissions to the fall newsletter is September 4.