

Patient Education Committee *update!*



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May 2010

Patient Education: A Valued Partner in the Patient's Journey

In this issue we present two excellent articles about the role of patient educators and patient education in improving the cancer experience for patients and families. The first article by Tamara Harth of the Odette Cancer Centre showcases innovative ways that patient education programs are meeting the need for good quality information on such sensitive topics as sexuality. Sexuality can be a difficult subject to broach with those close to us, therefore it is not surprising that health-care providers are often reluctant to raise the topic with their patients. The reasons for this silence are many and varied and can include one's own feelings of embarrassment about talking about sex, to a feeling of inadequacy when it comes to being able to appropriately counsel pa-

tients on such issues (Katz, 2005). Tamara describes the new S.H.A.R.E. (Sexual Health and Rehabilitation) Clinic at the Odette Cancer Centre, the cancer and sexuality presentations to health care professionals and patients at the Juravinski Cancer Centre in Hamilton, and the Canadian Cancer Society's revision of their booklet on sexuality.

The second article, an update on the lung cancer disease pathway management project by Nathalie Assouad of Cancer Care Ontario, illustrates the contributions of both patients and patient advocates to the planning process and the importance of patient-centred care. The Lung Cancer Symposium, which took place in March 2010, included input from a multitude of stakeholders, including

medical professionals, patients, and caregivers. One of the highest ranked projects from the perspective of improving the patient experience was providing comprehensive patient information. Integral to this is the concept of providing the right information to the right person at the right time across the cancer journey, and is a keystone of patient-centred care. The patient, family, and the patient educator are an important part of the cancer patient's health care team and, as CCO is proving, with input from all key players great improvements in the patient's journey can be made.

Contributed by: S. Boyko, K. McGrath, N. Robinson & T. Harth ♦

Special points of interest:

- TWO FEATURE ARTICLES
- REGIONAL UPDATES
- INFORMATION ON THE UPCOMING CPEN CONFERENCE OCTOBER 2010

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Upcoming Event

2010 International Cancer Education Conference - 20th Annual CPEN Meeting

Joint Annual Meeting for AACE, CPEN and EACE

Effectively Translating Cancer Education to our Patients, Practitioners, and the Public

25 - 27 October 2010
Catamaran Resort Hotel & Spa
San Diego, California

<http://www.cancerpatienteducation.org/meeting.cfm>

Patient Education Committee update !

Sexuality and Cancer - The Role of Patient Educators in Helping the Patient

Contributed by:
Tamara Harth, Manager, Patient Education Program, Sunnybrook Odette Cancer Centre

THE S.H.A.R.E. CLINIC (SEXUAL HEALTH AND REHABILITATION CLINIC) AT THE SUNNYBROOK ODETTE CANCER CENTRE IS AN EXAMPLE OF AN INNOVATIVE CLINICAL APPROACH TO HELP CANCER PATIENTS WITH ISSUES RELATED TO SEXUALITY.

A diagnosis of cancer can add a complex new dimension to the sexual side of human relationships. Everything from the emotions around diagnosis to the side effects of treatment can affect sex in a host of different ways. According to the National Cancer Institute, there are a number of sexuality issues that cancer patients worry about. These include infertility resulting from treatment, erectile dysfunction, pain during penetration, body image, early menopause, depression and anxiety and a loss of interest in sex. Clinicians often feel uncomfortable discussing these issues with patients and as a result people can be left on their own to navigate support groups, information and other resources addressing questions about sexuality.

There are some innovative clinical approaches which help cancer patients with issues related to sexuality and acknowledge sexuality as a real and important issue. One such initiative is a clinic based at the Sunnybrook Odette Cancer Centre. **S.H.A.R.E.** the Sexual Health and Rehabilitation Clinic is a clinical service offered to gynecological, breast and gastrointestinal cancer patients that have completed treatment and who are having difficulty with sexuality as a result of treatment. An Obstetrician/Gynecologist who is an expert in women's health and menopause, with an understanding of the side effects of treatment, consults patients about their concerns and works with an Oncology

Nurse who assesses needs, provides information, counseling and follow-up. Social workers, psychiatrists, sexologists and other health professionals are also part of the clinic and are available to patients. The inter-professional team plans care, follow-up appointments and arranges referrals to other specialists when required. This has proven to be an extremely popular service with patients who appreciate formal recognition of sexuality issues by the clinical health care team.

There have been many collaborators in this clinic and Patient Education has taken a lead in developing and facilitating educational interventions that are specific to this area of interest. A comprehensive list of credible materials and resources has been developed in close consultation with the clinicians. Where a gap in resources existed, these were developed in house to complete the sexuality collection. A bookmark for gynecological cancer patients has been created to point people to credible and helpful web sites. Plans are underway to identify experts in this area and offer speaker sessions that are focused on issues related to sexuality. Other cancer centre patient education programs that are participating in bringing knowledge and raising awareness about sexuality and cancer include the Juravinski Cancer Centre in Hamilton. During the month of May the Juravinski Cancer Centre hosted a session for

clinicians on sexuality by renowned expert **Dr. Anne Katz, RN, PhD** Clinical Nurse Specialist and Sexuality Counselor from Cancer Care Manitoba. Dr. Katz described the extent of sexual issues with patients, identified resources for health care providers and patients and barriers to providing sexuality assessment to patients with cancer.

Other efforts where patient educators are contributing to creating a path through the maze of sexuality and cancer includes advising in the revision of the Canadian Cancer Society's (CCS) book on sexuality. The Canadian chapter of the Cancer Patient Education Network has started to pull together a working group to review the current CCS guide to sexuality and provide feedback gathered from both clinicians and patients in an effort to contribute to a comprehensive and "user friendly" resource.

The issue of sexuality and cancer is often seen as taboo by both patients and clinicians. Innovative clinical approaches, awareness raising and the provision of credible, current and accessible patient education interventions related to sexuality are starting to emerge in a more consistent way which will help in making this area an easier road to navigate for patients across the province. ◇

Lung Cancer Disease Pathway Management: An Update

Overview of DPM

Disease Pathway Management (DPM) is a new approach to examining the cancer journey for a specific disease site, with the objective of identifying areas for improvement along the dimensions of quality of care, processes and the patient experience. This program uses a multidisciplinary approach by bringing together experts for a given type of cancer including clinicians, patients and patient advocates. Together, these teams work to:

- develop pathways of the patient journey and identify any gaps;
- brainstorm improvement projects to address these areas;
- present the project ideas to a wider community for feedback and sponsorship; and
- help implement these projects to improve the cancer journey.

What Took Place

Year one of the lung cancer DPM work saw a team of 50 lung-related clinicians, patients and patient advocates forming five working groups representing each phase of the cancer journey. Over the course of 50 hours of working meetings in 2009, the teams arrived at a total of 17 improvement project concepts and four recommendations.

Eight of the project concepts were selected for discussion at the Lung Cancer Symposium, held on March 5th, 2010 at the Toronto Public Library.

Over 110 people, ranging from RVPs to oncologists, patients and caregivers, attended the event. The event was a forum for a wider group of stakeholders in the lung cancer community to discuss the projects and share their feedback. In breakout groups led by DPM team members, attendees discussed content and implementation considerations of the proposed projects and then presented their findings to the larger group in a rapid-fire feedback session. The suggestions and ideas put forward at this Symposium will be used by the DPM team at CCO to help implement these projects.

Outside of the Symposium, work is underway on a few other projects generated by the lung DPM team. The recently launched patient navigation pilot project at CCO requires navigators to assess patients in Diagnostic Assessment Programs using Edmonton Symptom Assessment Scale. Additionally, the DPM team at CCO was recently able to fund a one-year pilot program for Dyspnea (Breathlessness) Management, targeted at lung cancer patients.

Next: Regional Engagement

In fiscal year 2010/11, the lung cancer DPM team will look towards regional engagement as a next step. A

Lung Cancer Priorities for Action document will be created and circulated. The DPM team at CCO will then organize a series of regional roadshows, designed to bring the issues and ideas to the local level for discussion and adoption. Finally, the pilot Dyspnea Management Programs will be implemented and evaluated throughout the year, with formal recommendations resulting from the pilot work expected in May 2011.

For more information on Disease Pathway Management, please contact Nathalie Assouad, Program Manager at

Nathalie.Assouad@cancercare.on.ca
◇

Contributed by:

Nathalie Assouad, Manager, Disease Pathway Management Program, Cancer Care Ontario

One of the projects discussed at the Lung Forum was

Comprehensive Patient Information.

The purpose of this idea is to ensure that all lung cancer patients across Ontario receive the right type of information from the right person at the right time across their cancer journey. Symposium participants ranked this as one of the top-rated projects from the perspective of improving the patient experience.

This project could take the form of a provincial standardized tool, customizable for each ICP, that encompasses the cancer journey and can be tailored to both patient and provider needs. It could contain disease-related, psychosocial and practical information. Possible champions for such a project may include Canadian Cancer Society, Lung Cancer Canada, the Ontario Lung Association and the

Patient Education Committee update !

Regional Update: Simcoe Muskoka Regional Cancer Program

Contributed by:
Lesley MacInnis

The Simcoe Muskoka Regional Cancer Program recently created a Regional Education Lead position within their team. This role will be integral in facilitating valuable patient and staff education initiatives across the LHIN. The initial goal to streamline an educational approach, involving key

regional stakeholders, will enable valuable services and programs to be developed. Future work will complement current initiatives, such as the Chemotherapy Education Classes for new patients and families, supportive services, and the annual Updates in Oncology Conference in May.

The Simcoe Muskoka Regional Cancer Program values patient satisfaction and will continually enhance this through patient and provider education. ◇



CREDIT VALLEY
THE CREDIT VALLEY HOSPITAL

Contributed by:
Krista McGrath

Regional Update: Carlo Fidani Peel Regional Cancer Centre

The Psychology department at the Peel Regional Cancer Centre (PRCC) has recently launched a group psycho-educational program for oncology patients, called “**Minding the Body**”. This program consists of three modules, “Managing the Stress of Living with Cancer”, “The Emotional Effects of Cancer”, and “Living with Advanced Cancer.” Each module is comprised of three sessions. The first two modules discuss topics such as the causes of stress, relationship between stress and physical illness, techniques to manage stress, benefits of emotions, and understanding and relieving feelings of depression, anxiety, and anger. The third module is more suited to palliative patients and delves into a deeper exploration of what makes life meaningful for the individual, how to remain in control of the experience, and how to continue to live in hope and with joy as one faces life with advanced cancer.

As part of a patient and family centred care initiative, a series of evidence-based,

educational pamphlets for patients undergoing radiation therapy at the PRCC have been developed and are scheduled for implementation in June 2010. The pamphlets are designed to provide patients with information on how to manage their radiation therapy induced side effects as well as instructions on when to seek further medical attention. The **series of 11 pamphlets** are symptom based to allow for customizable education and information for each patient based on their treatment area and the side effects they personally are experiencing. Pamphlets will be provided to patients on an “as needed” basis to help minimize information overload. The patient pamphlets, which have received multidisciplinary input, were developed based on a similar series of guideline documents created for staff use only. This initiative will help standardize the information that our patients receive throughout their cancer journey. The pamphlets are intended to be companion documents to the recently developed general information

booklets for therapy.

PRCC is set to disseminate our new “**Breast Cancer Surgery**” and “**Breast Cancer and Lymphedema**” booklets. The development of these resources was a multidisciplinary effort involving oncology and surgical nurses, nurse educators, surgeons, oncologists, and physiotherapists. The Breast Cancer Surgery booklet is intended to provide general information to patients who are undergoing surgery for breast cancer in our hospital and more broadly in our LHIN. The Breast Cancer and Lymphedema booklet provides information on what lymphedema is, why it occurs, and how to manage symptoms should they occur. These resources will help our breast cancer patients navigate the system and better prepare them for what is ahead in helping formulate any questions they may have as they meet with their healthcare providers. ◇

A SERIES OF
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BE EXPERIENCING.

Regional Update: Juravinski Cancer Centre



Juravinski Cancer Centre
A Cancer Care Ontario regional partner

Over the past year a tremendous number of accomplishments have been achieved at the Juravinski Cancer Centre (JCC) and Regional Cancer Program. Here are just a few of the many highlights:

New Website and Virtual Tour Launched November 2009

Our new enhanced web site at <http://www.jcc.hhsc.ca> is constantly evolving. Key areas include our new interactive virtual tour, podcasts and a link to the Hamilton Health Sciences patient library hosting a wealth of patient education resources. The website provides patients and visitors to the cancer centre with a welcoming tour. The cancer centre's services and supports are designed to provide comfort to patients through difficult times, and is reflected through the virtual tour featuring a compelling "TV-like" interactive experience.

The **Community Services Locator**, a partnership of the JCC and the Cancer Information Service of the Canadian Cancer Society, is a new tool to help patients and families locate services close to home. Unlike other searches, the Community Services Locator generates results in the area of the postal code entered facilitating easy access of LHIN services.

Patient Education Resource Development

Many new valuable patient education materials based on the principles of patient health literacy and the most current evidence can be accessed through the JCC web site. A

recent Google search on one of our popular new booklets called "Getting the air you need: A practical guide to coping with and managing shortness of breath" showed more than 264,000 hits. Our patient education materials have a new branded look. With enthusiastic support from the family of Conrad Furey, a well known Canadian artist and former patient of JCC, an image of Conrad's 35 foot mural in the JCC entitled *Riding the Dragon* has been incorporated into our patient education branding guidelines.

Orientation for New Patients

The 1st JCC handbook for new patients was recently created. Each new patient receives a tote bag filled with the new handbook and other patient education material on their first visit. Many staff, managers, volunteers, patients and family members invested their time and expertise to develop this practical handbook which can also be found on the JCC web site.

Staff of the St. Catherine's General Hospital community oncology clinic completed a very comprehensive orientation binder for each one of their new patients to introduce them to care provided in Niagara.

Hamilton Fire Fighters Award of Distinction for Excellence in Oncology Patient Education

In May 2009 the inaugural Hamilton Firefighters Award of Distinction for Excellence in Oncology Patient Education was announced at a special rounds presentation. Linda

Learn, Social Worker at the JCC and colleagues, Karen Biggs, Jennifer Wiernikowski and Dr. Richard Tozer were selected as recipients of the award for developing "Out of the Shadows - Challenging Post Treatment Monsters". This is a psycho-educational wellness program for patients of the JCC who are completing treatment for early stage breast cancer. The recipients of the 2010 award will be announced in June.

RNAO Best Practice Guideline

Theresa Harper, Patient Education Specialist of Hamilton Health Sciences who works in collaboration with the JCC Oncology Program has been appointed by the RNAO to co-facilitate a team mandated to develop a new best practice guideline on patient education. Theresa shares this role with Audrey Friedman, the Director of Patient Education for PMH and CCO. For more information about the Guideline Development Project of the RNAO see the website at <http://www.rnao.org>.

Lymphoma Workshop

On Thursday June 24, 2010 the JCC and Lymphoma Foundation Canada will host a workshop for patients and healthcare professionals located at the JCC from 2 – 5 pm. Details can be found at <http://www.lymphoma.ca>.

For more details please contact: Cathy Bennett, Patient Education Coordinator, JCC at cathy.bennett@jcc.hhsc.ca. ♦

Contributed by:
Cathy Bennett

On Tuesday May 4, 2010, **Dr. Anne Katz** RN PhD, a sexuality counselor at Cancer Care Manitoba visited the JCC. Dr. Katz is also an adjunct professor at the University of Manitoba and the author of five books; the award-winning text *Breaking the Silence on Cancer and Sexuality*; three books for consumers (*Woman Cancer Sex*; *Man Cancer Sex*; and *Sex When You're Sick*) as well as a book for teens called *Girl in the Know*. Dr. Katz generously provided three presentations in our JCC lecture theatre about cancer and sexuality including: Regional Oncology Rounds, a workshop for healthcare professionals and trained volunteer leaders, and a presentation for patients, family members and the public. The busy day was a huge success.

Patient Education Committee update !



Contributed by:
Christine Black

THE PATIENT EDUCATION
DVD FOR SYSTEMIC
THERAPY IS NOW
AVAILABLE AT: [HTTP://
WWW.LAKERIDGEHEALTH.
ON.CA/CHEMOTHERAPY/
PLAYER.HTML](http://www.lakeridgehealth.on.ca/chemotherapy/player.html)

Regional Update: Durham Regional Cancer Centre

The Patient Education Program at R.S. McLaughlin Durham Regional Cancer Centre (MDRCC) continues to develop in its second year. The highlights of the program's accomplishments for the past months include:

- The availability of the patient education DVD for systemic therapy on the website. A specific version was made for MDRCC and Peterborough Regional Health Centre (PRHC) Cancer Clinic. Hard copies will also be made available for patients to take home. The DVD provides information about chemotherapy, the treatment process, potential side effects

and their management, safety precautions and how to prepare for treatment. The DVD will be used in combination with teaching in the clinic. The production of the DVD was done in partnership with Grand River Regional Cancer Centre.

- The Patient Education Advisory Committee continues to build momentum in its second year. The group is investigating group teaching practices throughout the province for cancer patients.
- A standard package of material for new patients that provides general information on cancer,

nutrition, the psychosocial impact of cancer and local supports has been in use at MDRCC and PRHC. A centre specific orientation guide is now included to provide information and contact information about available services. A survey is included to encourage patients to provide their feedback about the package. The survey is a first step in the development of the program to focus on gaining patient feedback and input to drive patient education services and resources. ◇



Contributed by:
Nicole Robinson

WRCC PARTICIPATING
IN CANADIAN
PARTNERSHIP AGAINST
CANCER'S ONCOLOGY
INTERACTIVE
NAVIGATOR (OIN) PILOT
PROJECT. OIN IS AN
INNOVATIVE,
INTERACTIVE PATIENT
AND FAMILY INTERNET-
BASED SUPPORT TOOL.

Regional Update: Erie St. Clair Regional Cancer Program

New Patient Referral

The Windsor Regional Cancer Centre (WRCC) is working to provide a great first impression to patients and their families. Launched in April, all new patients referred to the WRCC will be mailed a revamped information package. The package contains important and helpful links to support programs and services within the cancer centre and the community. The branded package has an enhanced look and feel that is inviting, warm and welcoming.

Patient Education

WRCC has been selected to pilot an innovative and interactive patient and family internet-based support tool called, *Oncology Interactive Navigator* (OIN) with all newly

diagnosed colorectal and melanoma patients. The pilot launched in April 2010, and is being funded by the Canadian Partnership Against Cancer. OIN provides a wealth of information for patients, family members, care givers and health care providers. Help and support will be offered to patients *before* coming to the cancer centre through the inclusion of the OIN Patient Summary Form and system log-on information in the New Patient Referral package for melanoma or colorectal cancers. OIN will help enhance efforts toward patient-centered care within the Windsor Regional Hospital Cancer Program.

Patient Education

The Erie St. Clair Regional Cancer Program (ESC RCP) developed and launched a

comprehensive patient satisfaction strategy in 2009. This initiative involved gathering information from patients and families through focus groups as well as the internal development of a patient satisfaction survey. The survey was designed to build on the Ontario Hospital Report Card Patient Satisfaction Survey implemented by NRC Picker and was intended to help specifically identify program strengths and opportunities for improvement.

A communication strategy is currently being developed in order to provide the focus group and survey results to patient care teams throughout the cancer program. The next step will be for the teams to use the information to develop strategic and evidence-based goals for improvement within the next year. ◇

Regional Update: Regional Cancer Care—Northwest

As part of Cancer Awareness month, Regional Cancer Care hosted its first Open House to the general public on April 21st. The event offered tours of the centre, guided by Canadian Cancer Society volunteers with specific departments showcased by respective staff members. Individuals were encouraged to attend Dr. Vergidis, Chief of Oncology's presentation titled 'Lifestyle and Cancer... Making Choices to Modify the Risks' which attracted more than 100 people.

The Northern Cancer Question & Answer is a community cancer education speaker series offered by Regional Cancer Care. This is a monthly series of presentations open to the general community, cancer patients, survivors, caregivers, families, and health care professionals. Recent presentations include:

- 'Clinical Trials: Offering Tomorrow's Treatment Today' by Dr. Adrian Chan
- 'After Illness Strikes: Protecting your financial health' by Shannon Gothard Ramirez.

The **Chronic Disease Self-Management Program (CDSMP)** is a six week program with weekly sessions offered to people throughout Northwestern Ontario. Participants are adults experiencing chronic health conditions such as cancer, arthritis, heart disease, stroke, lung disease, diabetes, etc, as well as their family members, friends and caregivers. The program provides information and teaches practical skills on managing chronic health problems. Most

importantly, the CDSMP gives people the confidence and motivation they need to manage the challenges of living with a chronic health condition.

The **'Surgical Breast Bag'** has been implemented to ensure all breast cancer patients who have surgery are given consistent information prior to their surgery. Developed by a committee of breast cancer patients and staff at Regional Cancer Care, the bag contains education resources to guide women through their breast cancer diagnosis. The Surgical Breast Bag includes such information as what questions to ask, understanding treatment, lymphedema, supportive care services, exercises and activities in a reusable, cotton tote bag. Through a recent partnership with a local business woman and support from community volunteers, bags and pillows are now being sewn by high school students as part of their course work, and by volunteers.

Through partnership with the Keewatinook Okimakinak (KO) Network, Regional Cancer Care provides an education speaker series via video-conference to remote northern communities in Northwestern Ontario. The audience includes Community Health Representatives (CHR) and other specified target audiences. Presentations cover a range of topics from cancer prevention, screening and treatment, and are given by health care providers and patients who share their cancer experience.

Digital picture frames that provide information about

cancer education programs and event updates, CCS services, supportive care, and photos of the centre have been installed in the Radiation Therapy waiting room and the Main Reception waiting room at Regional Cancer Care.

Patient & Family Centred Care (PFCC) is a new corporate initiative for Regional Cancer Care and Thunder Bay Regional Health Sciences. Full-day retreats for staff ensured that the key concepts of PFCC are part of the organization. We have had 100% compliance in the program and very good feedback from staff. Strategies have been developed and implemented in each department. A PFCC Leadership team has been established to ensure continuity and further development of the program. An annual PFCC competency course is included in Medworxx. Patient Family Advisors have been integrated into individualized action plans. Most exciting are the practical tools which have been implemented to improve the patient experience such as bedside whiteboards with detailed patient information; Ticket to Home indicating the patient's readiness for discharge; and Rocket Rounds, improving communication & inter-professional collaboration. A custom PFCC curriculum has been developed for specific areas of care including, DI/Cardio Respiratory staff and laboratory staff. ◇



Contributed by:
Kelly-Jo Pfaff

PFCC IS A PARTNERSHIP INVOLVING PATIENTS, FAMILIES AND HEALTHCARE PROVIDERS THAT RESULTS IN SAFE QUALITY CARE. INFORMATION IS CLEAR, COMPLETE, TIMELY, ACCURATE AND USEFUL IN HELPING PATIENTS AND FAMILIES EFFECTIVELY PARTICIPATE IN CARE AND DECISION-MAKING.

Patient Education Committee update !



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Sue Boyko (Sudbury RCC)
Tamara Harth (Odette CC)
Krista McGrath (Peel RCC)
Nicole Robinson (Windsor RCC)

Patient Education Guidelines Available on the CCO website:

**“Effective Teaching Strategies and Methods of Delivery for Patient Education:
Guideline Recommendations”**

**“Establishing Comprehensive Cancer Patient Education Services.
A Framework to Guide Ontario Cancer Education Services: Executive Summary”**

<http://www.cancercare.on.ca/cms/one.aspx?pagelId=8727>