



Polly Lysen-Halpern, a nurse practitioner in the Hutchinson Center's Survivorship Program, examines breast-cancer survivor Nancy Edwards of Edmonds.

Moving Beyond Cancer

PROGRAM OFFERS CANCER SURVIVORS A MUCH-NEEDED LIFELINE TO IMPROVE THEIR HEALTH AND ENHANCE THEIR LIVES.

It's a chilly yet sunny February morning and Nancy Edwards is meeting up with nurse practitioner Polly Lysen-Halpern of the Fred Hutchinson Cancer Research Center Survivorship Program.

A breast-cancer survivor, Edwards has been cancer-free since 1993. The meeting is a follow-up from an appointment a year earlier when Edwards first experienced an inflammatory condition that she thought might have been a long-term effect of her cancer treatment. Like many of the approximately 270 people who have taken advantage of the program's services, she heard about the Survivorship Program by word of mouth.

"I wasn't aware that the Survivorship Program actually existed until someone

recommended that I make an appointment," Edwards says.

On this day, the two sit down in an exam room in the Seattle Cancer Care Alliance outpatient clinic, located on the Hutchinson Center campus, and begin the session by discussing health issues or concerns Edwards has had during the past 12 months. Although the two haven't seen each other in more than a year, they are clearly comfortable with each other. Edwards is forthright about any concerns she's had while Lysen-Halpern listens closely.

Lysen-Halpern questions Edwards about everything from which supplements she's taking to her sleep patterns and exercise habits. In response to some of Edwards' answers, Lysen-Halpern

recommends alternative therapies like acupuncture in addition to more traditional preventive care such as breast self-exams. She even suggests wearing more supportive shoes while at home to reduce physical stress—practical advice one won't find on a prescription pad but no less useful.

A UNIQUE EXPERTISE

It's this kind of in-depth knowledge and sincere compassion that has been drawing cancer survivors to the program since it opened its doors in June 2006, thanks to initial funding from the Lance Armstrong Foundation. The program merged pre-existing survivorship programs geared for adult and pediatric transplant and medical-oncology patients, as well

as a prostate-cancer research program and a Women's Wellness Center, to become a member of the LiveStrong Survivorship Center of Excellence Network. The Hutchinson Center program is one of only eight in the nation and the only one in the Pacific Northwest.

The Survivorship Program takes into account a survivor's body, mind and spirit. Patients are given a thorough screening and health evaluation by health care professionals who have dedicated themselves to learning about, and dealing with, survivorship issues.

Individuals interested in participating first contact the program's coordinator who requests that they send their oncology records prior to scheduling an appointment. They are also asked to complete a comprehensive survey that covers a variety of topics, including depression, sleep habits and any pain they may be experiencing.

"Prior to meeting with the patients, we review the survey and their medical records so that we can arrange for any

labs or scans as well as face-to-face appointments with nutritionists, psychiatrists or social workers," says Dr. Scott Baker, director of the Survivorship Program along with co-director Dr. Karen Syrjala. Meetings can last up to several hours depending on the services set up throughout the day.

Patients are provided with a Survivorship Care Plan that lists therapy and medical information related to their diagnosis and any potential long-term problems. The summary may include test results, support services, and dates of treatment while the follow-up care could consist of recommended health and wellness screenings, monitoring for long-term effects of treatment, therapy for possible psychological effects, recommended lifestyle changes and a list of local resources. Copies of the Survivorship Care Plan are then provided to the cancer survivor's medical oncologist and primary-care physician.

The clinical evaluations are generally covered by most third-party payers, and

Dr. Scott Baker, director of the Survivorship Program.



On a Mission

The mission of Fred Hutchinson Cancer Research Center is the elimination of cancer and related diseases as causes of human suffering and death. The Center conducts research of the highest standards to improve prevention and treatment of cancer and related diseases.

But the dedicated researchers and caregivers at the Hutchinson Center recognize that the effects of cancer go far beyond the physical, touching every aspect of a patient's life. So research is not limited to helping patients survive—it extends into helping them thrive in every area of their lives.

To that end, Dr. Marc Chamberlain, a neurologist and oncologist with the Center, conducted research that examined how spousal relationships are affected by cancer. The research was conducted in

conjunction with Dr. Michael Glantz at the University of Massachusetts and Dr. Larry Recht at Stanford University.

"As part of the research, we compared divorce or separation rates among 300 patients of primary brain cancer, 200 patients with solid cancers and 120 with multiple sclerosis. We found that if the cancer patient was a woman, the likelihood of divorce or abandonment was significantly higher," says Chamberlain, director of the Brain Tumor Program at the Hutchinson Center and University of Washington.

The research is important because when combined with a life-threatening illness, marital discord can have a large impact on a patient's treatment, quality of life and even survival. "Patients faced with marital abandonment are less likely to receive

multiple treatments. They're less likely to complete prescribed therapy. They're more likely to take anti-depressants. And they're less likely to die at home—which is a quality-of-life issue," he says.

"It suggests that as physicians, we need to be particularly sensitive and empathetic to marital stress and provide intervention early on," he adds.

Research such as this can help the Survivorship Program educate oncologists and primary-care physicians, as well as provide much-needed resources for cancer survivors.

For information on additional research conducted at the Hutchinson Center or to learn about opportunities to participate in a research study, go to www.fhccr.org and click on "How You Can Help."

Strength Building

YMCA AND THE HUTCHINSON CENTER TEAM UP TO HELP CANCER SURVIVORS EXERCISE THEIR WAY BACK TO HEALTH.

The Fred Hutchinson Cancer Research Center Survivorship Program and the YMCA of Greater Seattle have teamed up to offer cancer survivors the “Exercise and Thrive” program. Currently available at five locations—the Downtown Seattle YMCA, Meredith Mathews East Madison YMCA, Northshore YMCA, Bellevue Family YMCA and West Seattle & Fautleroy YMCA—the free, 10-week program features two 90-minute workout sessions each week.

“Research has shown that a side effect of cancer treatment is a loss in muscle mass, so one of the key objectives of ‘Exercise and Thrive’ is to regain strength,” says Amy White, director of Total Health for the Downtown Seattle YMCA.

Groups range in size from seven to 14 people. Each person meets with a personal trainer who has been trained by the team at the Hutchinson Center. The trainer develops an individual program for the survivor based on his or her needs and abilities.

“The whole group comes in at the same time, but they each do their own program at various workout stations. At the end of each session is a 20-minute discussion surrounding a question of the day, which allows participants to open up and connect,” White says.

Therese Billings is the director of cancer survivorship at the YMCA of Greater Seattle. A seven-time breast-cancer survivor, she was also a participant last fall in the very first session of the program.

“I was first diagnosed with breast cancer 13 years ago and had my last surgery in February 2008. Your muscles atrophy in treatment. I never had time to fully recover physically between the fifth and sixth treatments. You’re so impacted emotionally and spiritually,” she says.

Her motivation to participate in the program was her grandchildren.

“I have eight grandchildren and I wanted to hold them but found that I didn’t have the strength,” she says. “I also wanted to get back in shape. I had gained 20 pounds in chemotherapy.”

In addition to the physical benefits, Billings appreciated the social and emotional support the program offers. “I was first diagnosed with cancer when I was 45 years old. I’ve been through so much that I feel like I can help others because I understand what they’re going through. It felt good to come together. There were some ‘aha’ moments. Friendships develop—I still keep in touch with people from my class,” she says.

Currently, all five locations are at capacity, although plans are in the works to add three more programs at new locations as more qualified instructors are trained. Participants receive a free YMCA membership for their family (two adults and all dependents) for the duration of the program.

Response to “Exercise and Thrive” has been overwhelmingly positive.

“The most significant comment we get from patients is that when you complete your treatment, you kind of feel like you get dropped. You’ve had your life structured around cancer treatments and then there’s this weird feeling that you’re now all by yourself. We’ve heard from a lot of people that it’s nice to have some accountability [through ‘Exercise and Thrive’] in helping to take steps to prevent cancer from recurring,” White says.

For more information on “Exercise and Thrive”, phone Billings at 206.382.7893 or e-mail her at tbillings@seattleyymca.org.



Seven-time breast-cancer survivor Therese Billings directs the cancer survivorship program at YMCA of Greater Seattle.

financial counseling is available for those with concerns about their ability to pay.

“We serve as a bridge from the oncologist to the primary-care physician,” Baker says. “Our specialized knowledge of the short- and long-term concerns that result from having cancer and going through the treatments allows us to red-flag any possible issues that may arise down the road. As a result we can let primary-care physicians know what to look and test for in the future.”

Dr. Patricia Read-Williams is one of those primary-care physicians who not only appreciates the information offered by the program, but she’s been a recipient of its services. Six years ago, Read-Williams underwent treatment for chondrosarcoma, a type of bone cancer. Four years after her last treatment, she signed up for the Survivorship Program.

“From my own experience, one component that I noticed was really missing was a lack of follow-up after the cancer therapy. After I completed my treatments, I was told what diet to follow for the short-term, but I wanted

Get Involved

EDUCATION

MOVING BEYOND CANCER TO WELLNESS

June 13

Learn more about the Survivorship Program at this free educational event, featuring breakout sessions with experts on topics such as nutrition, alternative medicine, physical therapy, relationships, insurance rights and research. This year's event features keynote speaker Dan Shapiro, Ph.D., a psychologist and cancer survivor from Penn State College of Medicine. *For more information, visit www.fhccr.org/survivorship or call 206.667.2814.*

CANCER SURVIVORSHIP FOR THE PRIMARY-CARE CLINICIAN

June 12

Cancer is now a disease that most people diagnosed can expect to survive. Roughly 12 million Americans are now living more than five years after a diagnosis of invasive cancer. Although cured from their cancer, survivors may have elevated risk for other cancers as well as fatigue, musculoskeletal symptoms, memory problems, sexual dysfunction, infertility and other health-related issues. Survivors lose muscle mass, gain weight and are more sedentary than before their diagnoses. These physical and behavior changes increase their risks for cancer recurrence and development of second cancers as well as other chronic illnesses. Primary-care clinicians are an essential part of a patient's access to appropriate cancer survivorship care and will benefit from the latest information surrounding the management of cancer survivorship issues. This conference is designed for primary-care physicians, mid-level providers, as well as ancillary health care professionals involved in management of cancer survivors. This will also be of interest to oncologists, researchers, psychiatrists, psychologists, occupational therapists, social workers, genetic counselors, registered dietitians,

educators, vocational rehabilitation counselors and other interested health care professionals who work with cancer survivors or cancer survivorship issues. *For more information, visit www.fhccr.org/survivorship or call 206.667.2814.*

FUNDRAISING

TRAVEL & LEISURE AUCTION

May 2

Make a difference and take home some fun travel and leisure items at this live and silent auction. Tickets are \$125/person or \$1,500/table of 12. *For more information, contact Emma Croston at 206.667.5492 or ecroston@fhccr.org.*

PREMIER CHEFS DINNER

May 17

Sample some Northwest wines and hors d'oeuvres before enjoying a six-course dinner prepared by some of the region's top chefs. Tickets are \$250/person or \$300/patron (includes preferred seating and valet parking). *For more information, contact Brooke Stabbert at 206.667.6680 or bstabber@fhccr.org.*

LIVESTRONG CHALLENGE

June 21-22

Raise funds for the Lance Armstrong Foundation at this 5K walk and run or 70- to 100-mile bike ride. *For more information, visit www.livestrongchallenge.com.*

SHORE RUN/WALK

June 28

Lace up those running shoes for the 32nd annual Shore Run/Walk. The event features a 6.7 mile run from Seward Park and a 5K run and walk from Leschi to Madison Park. The little ones can participate as well in a 1K Kids Run in Madison Park. *For more information, contact shorerun@fhccr.org.*

For additional events as well as information on how to contribute time and funds to support research at the Hutchinson Center, visit www.fhccr.org/donating.

to know what I should be eating now, years later, to stay healthy," she says.

And the lasting effects of cancer treatment are not just physical. Fears of recurrence can be emotionally draining not just for survivors, but for their loved ones as well. "Cancer has a ripple effect that goes through your entire family and affects everything in your life. I see it affecting my children, my parents. This is an ongoing issue that the program helps you deal with by providing resources and information," she says.

Read-Williams has recommended that a number of her own patients sign up for the program as well. "I tell them that this is information that will help me help you," she says.

ONGOING SUPPORT

Patients come from around the region and across the nation to participate in the Hutchinson Center Survivorship Program. Taking into account distances traveled to access the program's services, about half of the patients will return for a follow-up, something Baker recommends.

"With ongoing follow-ups we can continue to build on our knowledge of the future effects of cancer treatments and share this information with our patients," Baker says.

Following her meeting with Lysen-Halpern, Edwards will receive a bone-density test and meet with a nutritionist. Before she leaves for her next appointment, Lysen-Halpern reminds Edwards to take time to pat herself on the back for the steps she's taking to improve her health, no matter how small.

"We like to look at the whole picture—how we can make you as well as possible," Lysen-Halpern explains. "The small changes are those that can sustain you. Be sure to reward yourself for those."

For information on how you or a loved one can participate in the Hutchinson Center Survivorship Program, contact 206.667.2814 or visit www.fhccr.org/survivorship.