



PATHWAYS

A Study of Breast Cancer Survivorship

A NEWSLETTER FOR STUDY PARTICIPANTS

SPRING 2008



Lymphedema after Breast Cancer

Marilyn Kwan, PhD

Women who have been treated for breast cancer may be at risk for lymphedema, a irregular swelling of the arm or hand that can occur days, months, or years after surgery or radiation therapy of the lymph nodes. The swelling can range from mild to severe and be acute or chronic depending on the extent of breast cancer treatment. Lymphedema can cause limitation in range of motion, pain, weakness, or stiffness in the affected arm. In addition, patients with lymphedema can experience anxiety and depression as well as social avoidance related to the condition. The true incidence of lymphedema among breast cancer survivors has not been definitively established in research studies. The Pathways Study is one of the first studies attempting to characterize the development of lymphedema by asking newly diagnosed breast cancer patients to periodically answer a questionnaire on symptoms and to take arm measurements using a specialized tape measure. By collecting this important information at various times after breast cancer treatment, Pathways will be able to determine the risk of developing lymphedema during the survivorship period.

The National Lymphedema Network, a nationally recognized organization which promotes awareness of lymphedema through education, has made available risk reduction guidelines for lymphedema (see below). Once lymphedema occurs, it cannot be cured, but early and careful management can reduce symptoms and keep the condition from getting worse. Current therapies available for lymphedema treatment are mainly rehabilitative and managed by physical therapists. For more information on lymphedema, go to the National Lymphedema Network (www.lymphnet.org) and American Cancer Society (www.cancer.org) websites.

Lymphedema Risk Reduction Practices

1. Skin Care

- Keep arm and/or hand clean and dry
- Apply moisturizer daily to prevent chapping/chaffing of skin
- Attention to nail care
- Protect exposed skin with sunscreen and insect repellent
- Use care with razors
- Avoid punctures such as injections and blood draws
- Wear gloves while doing activities that may cause skin injury

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Here is a photo of all the wonderful women who introduce you to Pathways during your first interview (taken in November 2007).

Left to right: Janet Thiessen (Sonoma), Laura Beth Jones (Sacramento), Virginia Pozo (San Francisco), Veronica Ting (San Francisco), Yvonne Quevedo (San Jose), Paula Partee (San Rafael), Kalliope Bellesis (Fremont/Hayward), Judy Jensen (Oakland), Sandra Wolter (Vallejo), Elinette Nicolas-Hearn (Carmichael/Sacramento), Nancy Wittels (San Jose), Cynthia Perry-Baker (Antelope/Sacramento), Althea Crichlow (Stockton), Socorro Ramirez-Caglia (San Jose).

How Pathways Study Participants Contribute to Research on Complementary and Alternative Medicine



*Heather Greenlee, ND, PhD,
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Epidemiology*



*Christine Bonnell, MA,
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California, Division of Research*

Pathways is currently one of the few pioneering studies looking at nutrition, herbal therapies, naturopathic medicine, and mind-body therapies as it relates to cancer survivorship. These therapies are collectively known as Complementary and Alternative Medicines (CAM). CAM is broadly defined as those diverse medical and health care practices and products that are not presently considered to be part of conventional medicine.

All Pathways study participants are being asked about their CAM use over time, so that researchers can begin to identify some of the products and practices that may be the most useful to breast cancer survivors. The questionnaires ask you about five different categories:

- ⌚ Herbal or botanical therapies
- ⌚ Dietary supplements
- ⌚ Special diets
- ⌚ Mind-body therapies
- ⌚ Energy-based therapies

If you would like to learn more about CAM and dietary supplements, you can visit the following websites:

- ⌚ www.cancer.gov/cam
- ⌚ www.nccam.nih.gov
- ⌚ www.naturalstandard.com

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The Role of Breast Care Coordinators at Kaiser Permanente

*Beth Arvidson, RN
Breast Care Coordinator,
Kaiser Santa Rosa*



*Rachel Whalen, RDMS
Manager, Kaiser Permanente
Breast Care Services Oakland*



The Kaiser Breast Care Coordinators represent a diverse group of individuals including health educators, registered nurses, nurse practitioners, physician assistants and social workers. Coordinators are located in Radiology departments to work with patients during the diagnostic phase, Surgery departments for primarily newly diagnosed patients, and Health Education and Oncology departments. The role of the Breast Care Coordinator may vary by facility, but all coordinators share the same goal: to improve psycho-social and educational support for members and patients in order to enhance the experience of care and the ability to cope with the disease.

Breast Care Coordinators work collaboratively with internal and external resources to streamline, personalize, and standardize breast care for patients in the Northern California Region.

Breast Care Coordinators provide a wide range of supportive services at their medical centers, including:

- ⌚ Provide education and support to patients through support groups and individual appointments with patients and their families
- ⌚ Coordinate the patient's movement through the continuum of care by arranging second opinions and referrals and facilitating communication among health care team members
- ⌚ Advocate for patient's needs by participating in Tumor Board and Breast Care Committees and working closely with the patient's multidisciplinary team

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How Pathways Study Participants Contribute to Research on Complementary and Alternative Medicine Continued from page 2

You can also check the Natural Medicines Comprehensive Database in the drop down menu at: www.kp.org □ “health and wellness” □ “drugs and natural medicines.” This database will help you identify the different ingredients in natural products, so you can better grasp how they may interact with other medications and supplements you may be taking.

Kaiser also offers discounts on various CAM services. To find these discounts on www.kp.org, go to “health plans and services” □ “member discount programs” □ “complementary health and fitness programs.”



Thank you for participating in the Pathways Study and for answering questions on your CAM use! You are providing valuable information to help cancer researchers understand more about the relationship between CAM and breast cancer. ☺

The Role of Breast Care Coordinators at Kaiser Permanente Continued from page 2

- ⌚ Counsel patients to help them examine their values and make decisions that are right for them, and to cope with the effects of treatment
- ⌚ Provide appropriate resources within KP and in the community including health fairs, American Cancer Society programs, shared leadership of support groups, and breast cancer awareness activities
- ⌚ Be a resource for breast care education to the medical center and the community.

The Breast Care Coordinators have had a profound effect on the consistency of counseling and education regarding treatment options and psycho-social support for recently diagnosed women and their families. They have improved the coordination of care between the specialties, and have worked diligently to provide consistent access and coverage for reconstruction, prostheses, lymphedema, and all other areas concerning breast cancer services. ☺

Lymphedema after Breast Cancer Continued from page 1

2. Activity/Lifestyle

- If scratches/punctures to skin occur, wash with soap and water, apply antibiotics
- If a rash, itching, redness, pain, increased skin temperature, fever or flu-like symptoms occur, contact your physician immediately

3. Limb Constriction

- If possible, avoid having blood pressure taken on the at risk arm
- Wear loose fitting jewelry and clothing

4. Compression Garments

- Gradually build up the duration and intensity of any activity or exercise
- Take frequent rest periods during activity to allow for limb recovery
- Monitor the arm and/or hand during and after activity for any physical change
- Maintain optimal weight

5. Extremes of Temperature

- Avoid exposure to extreme cold
- Avoid prolonged (>15 minutes) of exposure to heat, especially hot tubs and saunas
- Avoid immersing limb in water temperatures above 102°F (39°C)

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New Contact Information?

Please get in touch with us if you have recently changed your contact information, including new phone number(s) and/or home address. You can reach us by calling our toll-free number, **1-866-206-2979**. ☞



Japanese Garden at the Washington Park Arboretum © 2006 by Larry Kushi

Pathways Update – Who Is Participating?

Pathways began in January 2006 and as of April 2008 has over 1750 participants drawn from across Northern California.

Over 1200 participants have passed the six month mark since the baseline interview; about 700 participants have been with the study at least 12 months.

The flow chart to the right shows participation in the follow-up portion of the study.

Your continued participation in the Pathways Study is valued by our research team. All of you add significance and unique perspective to the wealth of knowledge about breast cancer.

Thank you for participating. ☞

Completed 6-month
follow-up packet:
72% of eligible participants.



Completed 12-month
follow-up interview:
91% of eligible participants.



24-month follow-up packet:
started mailing late
February 2008.