



Touch of Courage

Connection Beyond Pink TEAM



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Truncal Lymphedema Amy Kimball, MPT, ATC

By now, most breast cancer patients who undergo a mastectomy or lumpectomy know about arm lymphedema, a common condition involving upper extremity swelling that can occur following surgery, radiation or chemotherapy. Many breast cancer survivors and health care providers falsely believe that as long as their arm does not swell they have avoided the life long condition of lymphedema.

Unfortunately, patients who undergo breast cancer surgery, either lumpectomy or mastectomy, radiation or breast reconstruction are at risk for developing a *similar* condition known as truncal lymphedema. Lung cancer patients are also at risk for truncal lymphedema. This condition involves swelling in the chest or back following one of the above listed procedures. It can present with or without significant involvement of the adjacent upper extremity. Truncal lymphedema often remains undiagnosed or misdiagnosed due to difficulty in accurately and objectively measuring its presence or severity.

Symptoms of truncal lymphedema are similar to that of upper extremity lymphedema. The primary symptom that patients report is pain in the shoulder, chest wall or back. It is usually more severe than the pain patients report with arm lymphedema. Anterior chest wall swelling is commonly

present, especially in the affected breast or chest wall where the breast once was. Some women have swelling collect under the incision from their surgery. Swelling of the back, shoulder blades or involved side of the trunk is also often common. As stated earlier, swelling may or may not occur in the involved arm. If the patient has undergone breast reconstruction, edema may settle around the newly constructed breast and may lead to complaints of fullness, poor shape, breast asymmetry or discomfort. These symptoms persist long after the healing stage of reconstruction and are often accompanied by tissue texture changes such as fibrosis and scar or breast tissue contracture.

Patients can affect the degree of development and progression of truncal lymphedema. Steps taken to avoid increased pressure or the tourniquet effect are the best line of defense. Underwire bras are not recommended for anyone who has breast cancer or is at risk for developing lymphedema. Avoiding a heavy prosthesis which puts added pressure on the chest wall and loads bra straps is recommended. Eliminating narrow bra straps and using wider, padded straps helps to disperse pressure over a greater area, easing the tourniquet effect. It is also a good idea to ensure proper bra fit, especially avoiding constriction around the chest. Choosing a bra with a wide, flexible band decreases

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circumferential chest compression. Experienced certified fitters and breast prosthesis vendors can direct patients to find the right bra for their body type and needs. Patients should also be advised to avoid constriction around the waistline (i.e. belts, tight waistbands) to minimize circumferential compression.

Medical treatment for this condition involves a multidisciplinary approach. Patients should contact their physicians if they notice acute or persistent swelling. Medical workup may be performed to rule out infection or other problems. Physical Therapy is commonly ordered to start complete decongestive therapy (CDT), scar tissue or fibrosis mobilization, therapeutic exercise and compression therapy. CDT includes intensive, hands-on manual lymphatic drainage techniques to be performed by a therapist with specialized training in lymphedema management. A therapist with this training knows specific techniques and patterns for redirecting and removing excess lymphatic fluid. Studies have shown that CDT, in conjunction with scar tissue or fibrosis mobilization can significantly reduce the presence of edema, improve range of motion, and reduce pain. Lymphedema therapists will teach patients how to perform self massage, scar tissue mobilization and exercise at home so that the patient can manage this condition for a lifetime. Many patients do require short or long term use of compression therapy which may include use of specialized bandages, compression pads or custom bras. The specialized bras work to provide

compression where it is needed most while avoiding the tourniquet effect on the chest wall, back or shoulders.

**Pink Ribbon Run
By Pam Dowie**

It is time to sign up for the first annual Pink Ribbon Run in Downtown Cedar Falls. The 5K run/walk race starts at 8:00 a.m. on Saturday, October 6, 2007. It will start and finish in front of the Cedar Falls Library. The cost to enter is \$25, which includes an official Pink Ribbon T-shirt. Several awards will be given out in a variety of age groups. All proceeds from the race will go to the Beyond Pink Fund to benefit women living with breast cancer.

Cedar Falls Community Main Street is sponsoring the race as part of their annual "Girls Night Out" celebration. "Girls Night Out" activities are scheduled for October 4, 5 and 6 in downtown Cedar Falls. I work in a downtown Cedar Falls business and was asked to be on the race committee, as well as my daughter DeeDee. Since the race is in October, they wanted the money raised to go to an organization dealing with breast cancer. I told them about the Beyond Pink TEAM and the Beyond Pink Fund, and they loved the idea of keeping the money local!

My daughter, Michelle, lost her battle with breast cancer at the age of 33. Michelle knew how fortunate she was to have good insurance and a strong support system to help her and her family with a myriad of problems that came up. Her wish was to start a foundation to help other women

with breast cancer and their needs. The Beyond Pink Fund can help with those problems. So the Beyond Pink Fund is special to us, and we are thrilled to be working on a project to promote it.

Sign up now, and encourage family, friends, neighbors and co-workers to join you. It will be a fun event, helping a great cause. For race information, contact the Cedar Falls Community Main Street office at 319-277-0213.

**Touch of Courage
Breast Cancer
Support Group**

The Touch of Courage Breast Cancer Support Group continues to meet on the first Monday of every month at the **Kimball Ridge Center on 2101 Kimball Avenue**. The meetings are held at 1:30 and 5:30 p.m.

The Support Group invites any woman or man who is dealing with breast cancer to attend the support group meetings. Spouses and significant others are also welcome.

On November 5th, Mark Wikner will report at both meetings on the book, *The Most Comprehensive Study of Nutrition Ever Conducted: THE CHINA STUDY, Startling Implications for Diet, Weight Loss and Long-Term Health*.



Plant It Pink: Hope Blooms for Breast Cancer

Thank you to all who ordered pink tulip bulbs from the Beyond Pink TEAM. We are pleased to announce that we sold more than 4,500 tulip bulbs and can't wait to see them all blooming throughout the Cedar Valley next spring. Many of our orders came from the readers of this newsletter, and we appreciate your support.

We look forward to seeing you on October 13, 2007 when you pick up your tulip bulbs at the Covenant Cancer Treatment Center on 200 E. Ridgeway Avenue (Waterloo). Bulbs can be picked up between 9:00 a.m. and 1:00 p.m.

Chemical Free Lawn Care by Cindy Harris

Here we are coming up on fall again. What a beautiful time of year, all these colors. But we all know where the colorful leaves end up - in our yard. Remember not to burn or bag them. Instead, start a compost pile. You won't need a specific container; you can just make a pile or place fencing around a small area into which you place the leaves. If you make only a pile, be sure to keep it wet so the leaves won't blow away. By spring you will have freshly composted material as good as any fertilizer to spread around your plants.

Fall is the time to apply corn gluten for weed control. Doing so will help you have a nice thick, green lawn next year. Try to apply the corn gluten when there is little chance of rain for 48 hours. If you have thin or bare spots in your lawn, this is a good time to reseed.

Many perennials need to be cut back at this time so they have less of a chance for the freeze to go down to the roots. For instance, my daisies, cone flowers, black eyed susans, mini roses and hardy hibiscus are cut down to about 5 or 6 inches tall. I then cover them with leaves. In the spring I add these leaves to the ones I put in the compost pile in the fall.

Nature gives us a beautiful fall show of color and then lets us use it to benefit our flowers and gardens for the next season. Remember to put everything to rest for winter so you are ready for spring.



Do Something Besides Worry! By Christine Carpenter

When I was diagnosed with breast cancer at age 45, I was afraid I would not live to see my 14-year-old daughter graduate from high school. That was 14 years ago; yet, not a day goes by that I don't fear a recurrence. After treatment, I started thinking about my daughter's future and about the many women in the area who get breast cancer. I realized I must work on ending this disease.

The exact causes of breast cancer are unknown but exposure to certain environmental pollutants is a key suspect. Those of us coping with cancer do everything we can to prevent unnecessary exposure to hazardous substances.

I joined the Cedar Valley Cancer Committee's Beyond Pink Team (BPT) and a group of us began studying the pesticide and cancer connection. We learned that many lawn care products and insecticides pose serious health risks to children, pregnant women, the elderly, and those of us already living with cancer. The labels for several insecticides applied by pest control companies state, "Hazard to humans and domestic animals." It also says, "This pesticide is extremely toxic to fish and aquatic invertebrates . . ." The County and the State Health Departments recommend against routinely spraying.

We also learned hospitals, clinics and schools routinely spray insecticides, often when patients, staff and students are in the buildings. We are working to reduce the use of pesticides in hospitals, clinics, and schools.

We have a chance to make the Cedar Valley a healthier environment. Join BPT's Iowa Breast Cancer Edu-action Pesticide Reduction Working Group as we urge city, school and hospital officials to adopt healthy practices and stop spraying cancer-causing insecticides where we walk, sit, eat, crawl, and play. We meet at 8:00 p.m. at Area Education Agency 267, Child Find Room in the Special Education Building, 2706 Cedar Heights Drive, Cedar Falls. We meet the 4th Thursday of every month except November when we meet the 3rd Thursday. We do not meet in December. Need more information? Contact Christine Carpenter (319) 266-0194 or email christine.carpenter@cfu.net.

Young Survivors Annual Conference

Annual Conference for Young Women Affected by Breast Cancer

The Young Survival Coalition and Living Beyond Breast Cancer's Annual Conference for Young Women Affected by Breast Cancer is the only international event focused on the unique needs and issues faced by young women who are diagnosed with breast cancer.

The 2008 conference is scheduled for February 22-24 at the Hyatt Regency Jacksonville Riverfront, Jacksonville, Florida. Scholarships are available to help with costs. Visit the conference website at www.youngsurvivorsconference.org to get more information, register for the event as well as view the 2007 conference archives.

This one-of-a-kind event features educational programming focused on every phase of a young woman's breast cancer journey: from recent diagnosis, to treatment, to living with advanced breast cancer to post-treatment - and years beyond!

The Young Survivors Conference is specially designed for:

- Young women affected by breast cancer
- Long-term breast cancer survivors diagnosed prior to age 45
- Caregivers of young women affected by breast cancer, including partners, family and friends
- Young women with a strong family history of breast cancer

Join those at the conference and:

- Hear updates relevant to young women from leading professional who care for them
- Learn what's in the pipeline in scientific research and clinical care for young women affected by or at increased risk for developing breast cancer
- Empower yourself to make informed choices with up-to-the-minute and age-appropriate information about your treatment and well-being
- Gather the resources you need to help you navigated your breast cancer journey
- Network with peers who relate to your experience

Panera Bread Partners with Beyond Pink TEAM

The Panera Bread bakery/cafes have partnered with the Beyond Pink TEAM in their efforts to promote breast cancer awareness and raise money to help women locally. For each Pink Ribbon Bagel sold, 25 cents will be donated to the Beyond Pink TEAM.

The Pink Ribbon Bagel is baked fresh daily and features cherry chips and real bits of Bing cherries and cranberries. The bakers form the bagels into awareness ribbon shape before baking. Sue Stees, of Panera Bread's first franchise and a breast cancer survivor, developed the idea for the Pink Ribbon Bagel in 2001 as a way to support the cause. As part of the campaign, Panera donates 25 cents from every Pink Ribbon Bagel sold to our partner groups. The total donation depends on the number sold at the bakery-cafes in the partner group's city. Panera promotes the bagel sale a number of ways including in-store signage and posters, on their website, through press releases, and by sampling the bagels at local events.

The Beyond Pink TEAM is pleased to be selected as the partner group for the Waterloo and Cedar Falls bakeries. Panera is furnishing bite size pieces for sampling at several of our events this October.

Try one of these Pink Ribbon Bagels soon. It will be a tasty treat for you, and you will also be helping raise money for the Beyond Pink TEAM's projects.



October is Breast Cancer Awareness Month

- 1 out of 8 women will have breast cancer in her lifetime.
- *80% of women diagnosed with breast cancer have no family history.
- 10% of all breast cancers can not be seen on a mammogram, so you must see a healthcare provider once a year for an exam and also check your breasts monthly

A Survivor's Story

By Paula Pecenka

It was July 6, 2005 and the biopsy results were in. Everyone had assured me that I had nothing to worry about; turns out they were wrong. There I was sitting in the doctor's office with my mother when I was told the news: I had breast cancer at age 25.

I didn't even know that this could happen to a young person like me. I didn't know what to do. From the get-go I knew that this was going to be a rough road. But in the end I knew I was not going anywhere. I still had too much to accomplish in my life. My son was 2 years old. I wanted to see him grow up and live his life. My husband and I had just started our life together. All these thoughts kept going through my mind for the first month.

I had a lumpectomy one week after the diagnosis. The twenty strenuous weeks of chemo started one month after surgery. I always kept positive no matter how bad it got. For example, I started to lose my hair so my sister gave me a Mohawk. I couldn't go out so my friends would come over to sit with me through the tired days. My husband was always there for me and, of course, always took good care of our son. I had such a good support group, family, friends and work family. My mom and dad were always there for me. My sister came and lived with me for three months. While she was there, she helped take care of my family and cleaned my house.

I also had a great job. Allen Home Health Services is the best place to work. I have never had supervisors that cared so much

about their employees. I couldn't have gotten through this period of my life without my 50 work-mothers.

After chemo was finished, I discovered another lump in the same breast in December of 2005. I felt that the only way I would feel safe would be to have a bilateral mastectomy. That was the best decision I could have made. I have since had a total breast reconstruction and am doing great. I appreciate life so much. I don't regret any decisions that I have made.

In February of 2006 I went to the Young Survivor Breast Cancer Conference in Denver, CO. It was a three day conference with over 400 young survivors attending. There were many workshops for us to attend. I went to the "fertilization after chemotherapy workshop", the "nutrition workshop", and many others. I met people from all over the country. It was great! I was not able to attend in 2007 but would love to go in 2008. The conference usually changes locations every year.

Having cancer is a lot to cope with at 25 or any other age - losing your hair, feeling tired all the time, stomach upsets and low blood counts. If I could tell all the young people in the world one thing it would be "don't give up". You need to do everything in your power to keep on living.

My faith was also a big part of my recuperation and recovery. God has always been there for me. He helps me be strong for my family.

It has now been 2+ years since my diagnosis. My son is now 4

and is in preschool. My husband and I just celebrated our 6 year anniversary. Everything is going great. I still think about cancer going into the future but I know that I am strong and will be able to handle anything.

I would also like to encourage people to talk and be open about your experiences – good or bad. I believe that we need to get more young survivors involved in the Cedar Valley area. It would have been very helpful to me if I had had another survivor to talk with which is why I would like to be there for someone else in need of support.

OCTOBER Upcoming Events

October 13:
Tulip Bulb Pick Up
Covenant Cancer Treatment Ctr.
200 E. Ridgeway Avenue, Wlooc

October 19:
Beyond Pink TEAM Annual Luncheon
Contact Dee Hughes at
319-235-3179 for reservations

October 20:
Black Hawk Hockey
Breast Cancer Awareness Night
Young Arena, Waterloo

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Medical Compression Garments

Iowa Breast Cancer Edu-Action

Iowa Breast Cancer Edu-Action includes breast cancer survivors and their supporters. We are members of the Beyond Pink TEAM. **Our mission** is to: take Action, Educate, Advocate, Make a difference (TEAM).

What We've Done

For the last ten years we have:

- ❖ Visited with Iowa congressmen to secure their commitment to breast cancer research.
- ❖ Participated in email and phone call campaigns to Congress to secure guaranteed access to quality care for all.
- ❖ Created the Iowa Breast Cancer Resource Guide, secured funding, and distributed 9000+ free copies
- ❖ Translated the ACS Guide "For Women Facing Breast Cancer" into Serbo-Croatian for the Bosnians in Iowa

We Meet:

When: 6:30 p.m. on the 4th Thursday of each month, except November when we meet the 3rd Thursday, and December when we do not meet.

Where: Area Education Agency 267, 3706 Cedar Heights Drive, Cedar Falls, Special Education Building, Child Find Room

Need more Information?

Email or call:

Christine.carpenter@cfu.net

(319) 266-0194

Support and Rehabilitation Programs

- | | |
|-------------------------|---|
| Care and Share | Support group for anyone dealing with cancer. Meets the 1 st Tuesday of every month at 1:30 p.m. |
| Touch of Courage | Breast cancer support group. Meets the 1 st Monday of every month at 1:30 p.m. and 5:30 p.m. |
| Reach to Recovery | Provides information and support for women who are faced with breast cancer. Visits available before and after surgery. |
| Look Good...Feel Better | Consultation with a trained cosmetologist to help a cancer patient feel more comfortable with the physical changes that occur during treatment. |

For more information call the American Cancer Society at 319-272-2880 or 888-266-2064.

Resources Available:

Information, support, counseling, and educational materials are available from the following:

Allen College of Nursing
Library and Media Center
1825 Logan Avenue
Waterloo, IA 50703
(319) 235-2005

American Cancer Society
2101 Kimball Avenue, Suite 130
Waterloo, IA 50702
319-272-2880 or 888-266-2064
1-800-ACS-2345 (available 24 hrs)

Breast Care Center
at United Medical Park
1753 West Ridgeway
Waterloo, IA 50701
319-833-6100

Covenant Cancer Treatment Center
200 E. Ridgeway Avenue
Waterloo, IA 50702
319-272-2800
Include Cancer Information Library

National Cancer Institute
1-800-4CANCER

National Coalition for Cancer Survivorship 1-505-764-9956

National Lymphedema Network
1-415-923-3680

Y-Me
1-800-986-8228

Covenant Lymphedema Therapy
319-272-7894

Physical Therapy Partners
Lymphedema Therapy
319-233-6995

Connect with us...

A donation for Touch of Courage is both needed and appreciated. All donations go to support the services of the Cedar Valley Cancer Committee and are tax deductible.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

\$_____ amount of donation

General Donation Newsletter Donation NBCC Scholarship Fund

Make checks payable to the Cedar Valley Cancer Committee and send to 1607 Heath Street, Waterloo, IA 50703