



Touch of Courage

Connection Beyond Pink TEAM

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Lymphedema

By Katie Boaldin, PT, DPT

Lymphedema is the abnormal accumulation of lymphatic fluid in the tissues¹. It can occur when there has been trauma to the lymphatic system, such as surgery or radiation for cancer. Symptoms may occur immediately following surgery or may present a few months or even years later. Lymphedema is a condition that can worsen without treatment. At this time there is no cure, however it can be managed successfully with collaboration between the patient and medical team (physician, therapist, and certified garment fitter). The earlier treatment begins, the more successful the management. The goal of treating lymphedema is to decrease the swelling and keep it down¹.

There are a variety of causes of lymphedema. As stated above, a common cause is surgery or radiation for cancer. This can result in lymph nodes being removed or damaged, which decreases the ability for that area of the body to transport fluid. Other possible causes of lymphedema include: infection, injury (such as a burn causing scar tissue), venous insufficiency (veins unable to pump sufficient fluid back to the heart), and developmental abnormality¹.

Signs and symptoms of lymphedema include: swelling in the affected area, skin tightness, a sensation of fullness, or tight clothing/jewelry (that was not previously tight). It is important to contact your doctor if you feel you

have symptoms of lymphedema so that the necessary treatment can be initiated.

A person at-risk for developing lymphedema should be aware of certain precautions to decrease the likelihood of developing the condition:¹

- *Avoid strenuous or repetitive activity/exercise.*
- *Avoid extreme heat or too much sun.*
- *Avoid injuries to the skin as this provides an area for bacteria to enter and increases the chance for infection. For example, avoid injections and IVs in the affected arm, avoid bug bites, wear gloves when gardening, and use an electric razor to shave in the underarm area.*
- *Avoid blood pressure tests in the affected arm.*
- *Avoid constrictive clothing.*
- *Practice good skin care techniques including keeping skin clean and moist (use fragrance-free alcohol-free lotion).*
- *Wear your compression garment while traveling, particularly long distances or on an airplane.*

Remember, lymphedema is a very manageable condition in which early detection and treatment leads to the best outcomes. The first step is education and awareness. If you think lymphedema is affecting you, please consult your physician.

Bibliography

¹Zuther. JE. Lymphedema Management. The Comprehensive Guide for Practitioners. 2nd ed. New York: Thieme, 2009.

Lymphedema Garments By Jill Roberts, Certified Mastectomy Fitter

Removal of lymph nodes can cause lymph drainage to become interrupted, causing lymph drainage from the arm to become impaired. In some cases, the body will find a way of compensating for this damage; however, 50% of breast cancer patients are affected by lymphedema. Once you have lymphedema it will never go away but it can be managed. MLD (manual lymph drainage) therapy is a very important part of the treatment plan. The therapist will work on complete decongestive therapy (massage, wraps and training to manage lymphedema).

As a Certified Mastectomy Fitter, my role is to properly fit the correct compression garment when it is needed. I assess the patient, talk to them about their symptoms, discuss any MLD therapy treatments and supply the item prescribed by their physician. Once the patient has finished or is in the final stages of

completing their MLD therapy, they may be referred back to me to be fitted with a compression garment. Circumference measurements of the limb are taken, assessment of the lymphedema and fitting of the garment compression according to the physician's prescription are made.

Compression garments are available in different "knit" styles but each "knit" style serves a different purpose. Part of my assessment includes choosing the proper "knit". Garments that are a "circular knit" provide a two way stretch to the fabric. This style of garment is used for preventative measures or for very mild lymphedema. A patient with a more aggressive amount of lymphedema will need a denser weave that is "circular knit" and also "vertical knit". This allows for less stretch to the fabric and allows the garment to better hold the fluid out of the affected area. In more severe cases a custom made or "flat knit" fabric containing very little stretch is used. This type of garment will hold the

fluid out and give the compression to the veins to help with blood flow in turn helping the lymph system by carrying more of the fluid.

There have been many advances in the fabrics and textiles used to make compression arm sleeves. They are now made of softer materials and able to be machine washed and dried. They may also have aloe vera encapsulated into the fabric or contain moisture wicking materials. There are also many color options available from the basic beige, black or brown to the more adventurous hot pink and blue. You can also make a fashion statement with unique and fun designs including black lace, tie dye, paisley, stripes or a denim look. Most importantly is you receive proper treatment to manage your lymphedema and are fitted with the proper compression garment by a Certified Fitter.

If you suspect or question you have lymphedema or some symptoms of lymphedema, please contact your health care professional right away. The sooner it is diagnosed and treatments are started, the easier it is to manage.

Living Green By Cindy Harris



Many people have allergies. Dust mites in pillows are one of the main causes of allergy symptoms. Instead of buying the products that claim to kill the mites try something natural.

In the summer you can put the pillows outside in the warm, direct sun during a low humidity day for about 4 hours to kill them. Don't do this on high pollen days. During the winter months put the pillows

(or children's stuffed animals) in a large plastic, sealable bag and freeze them. Either way it is best to wash the items afterward as some people will still have a reaction to the residue left behind by the now deceased dust mites.

Remember it always helps to use natural cleaners to decrease symptoms. Peroxide, Borax, white vinegar, baking soda – all mixed with water – work as well as any cleaner you purchase and there will be no chemical build up to cause

symptoms with all the windows closed.

Just a little side note, you might want to keep covered those tulips and early spring flowers with leaves, if you have any around. With this warm weather, they are coming up too early. Since we have a good chance for a freeze yet it is best to try to keep them from exposure as long as possible. Also, those pesky bunnies will find them a delightful juicy meal if left unprotected. Not too early to put hair or blood meal down for them.

Fight Back



at Relay For Life!
By Marty Mullnix

Relay For Life events are life-changing cancer events that help communities across the globe fight back against cancer. In the Cedar Valley Relay For Life events are happening. Check out any of the following Relay For Life events or go to www.relayforlife.org to find an event close to you.

April 13 – University of Northern Iowa – McLeod Center, Cedar Falls

June 8 – Grundy County – Grundy Center Community Schools, Grundy Center

June 9 – Buchanan County – City of Independence-River Walk Park

June 15 – Black Hawk County – Hawkeye Community College, Waterloo

June 15 – Fayette County – Oelwein High School, Oelwein

June 20 – Bremer County – Waverly-Shell Rock High School, Waverly

July 6 – Butler County – Butler County Fairgrounds, Allison

Show your support in **Fighting Back** against cancer by forming, joining, or donating to a team.



HOPE is blooming this spring!

Thank You to Area Public Service Groups



The Cedar Falls Police Department presented a check to BPT from the proceeds from the sales of their "Bustin' Breast Cancer" t-shirts.



A check was received from the Cedar Falls Fire Department from the sales of their "Check 'Em Monthly" t-shirts sold.

A Survivor's Story by Jane Clark

During my yearly mammogram a lump was found in one of my breasts. EARLY DETECTION saved my life!

April 2005 I had a lumpectomy. The surgery went well. I went back to work. Because of the very aggressive cancer I had and the results of an Oncotype test, I had to decide about chemotherapy.

My chemotherapy started in June 2005 with 8 treatments of very strong chemotherapy given every other week. After each treatment I slept 4 to 6 hours. I did lose my hair, didn't have much of an appetite, but didn't get sick.

After a month off I began my second round of chemotherapy plus

herceptin (her2neu drug) which was not nearly as strong as the first round. In November, I developed heart valve damage on my left upper chamber. All chemotherapy and herceptin treatments were stopped. I was on 2 different blood pressure medicines to keep stress off my heart, had several CT scans, bone scans and echocardiograms to make sure the cancer was not spreading and/or caused heart problems.

In December I began radiation treatments (33) which were given every day, Monday through Friday. Saturday and Sundays I had off. The treatments did not burn my skin, but I was very, very fatigued. The 2 types of chemo put my body

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Beyond Pink TEAM Joins National Breast Cancer Coalition to End Breast Cancer by 2020!

Beyond Pink Team has been a member

organization of the National Breast Cancer Coalition (NBCC) for over a decade and as a result of NBCC's work and Beyond Pink TEAM (BPT) advocate's help, the worldwide scientific community has received more than \$2.8 billion in federal appropriations for innovative breast cancer research through the defense budget alone. NBCC, including BPT advocates, continue to oversee how those dollars are spent. As a result of NBCC's work and BPT's help, legislation was designed and passed to ensure that uninsured women diagnosed through the CDC Breast and Cervical Cancer Screening Act have access to treatment. BPT's work with NBCC has had a mighty impact.

In September 2010, the National Breast Cancer Coalition again launched a revolution in breast cancer with a new weapon: a deadline. Breast Cancer Deadline 2020® - the end of breast cancer by January 1, 2020. Because BPT is committed to ending breast cancer, we applied to join the NBCC Board of Directors in order to play a larger role in ending breast cancer.

What does this mean for Beyond Pink TEAM and our community?

♦ It means BPT members, Christine Carpenter and Anne Doyle, go to Washington DC to attend three NBCC Board meetings where they represent you and other Cedar Valley individuals touched by breast cancer.

♦ It means BPT advocates will be working locally to change the conversation from breast cancer awareness to breast cancer PREVENTION and ENDING breast cancer.

♦ It means all of us, including you, your friends and your family need to sign the Breast Cancer Deadline 2020® petition to the President. We need to show the President there are millions of us who want to end breast cancer.

♦ It means BPT is asking local organizations, medical offices, businesses, and governments to endorse Breast Cancer Deadline 2020®. We want the President, organizations, and individuals behind the deadline because we need a national focus and a national commitment to make it happen.

When America decided to end polio and when we decided to put a man on the moon, we did it in less than ten years. We can do the same to end breast cancer. Are you with us?

Please SIGN the petition by scanning this with your Smartphone!



OR

Go to:
www.breastcancerdeadline.org.

Meet our NBCC Representatives!



Pictured are Christine Carpenter, BPT Representative; Fran Visco, NBCC President; Sharon Ford Watkins, Field Director; Anne Doyle, BPT Representative.

Reach to Recovery Volunteers Needed!

Remember the first few days after your diagnosis? How about the months that followed? There were so many changes in your life, the way you felt, the effects of the treatments, wondering about the surgery you were going to have or already had.

Did you have someone to walk with you through all of this, someone who really understood because she has been down that road already? Did you have someone who could listen, really listen and truly understand what you were trying to say?

This is what a Reach To Recovery volunteer does. You can be that person for a woman who wants a 'sidekick' to walk alongside her on this same journey you have traveled. You have something to share that only a survivor can share with that woman.

What is involved in being a RTR Volunteer? You must be a breast cancer survivor. You do not have to have been visited by a volunteer when you had your new diagnosis, surgeries and treatment. You are not responsible for giving medical advice or directing decision making. You are there to encourage, be a listening ear, and provide guidance to resources for questions they may have. One recent example of a volunteer's help: *"A new newly diagnosed person was struggling about treatment decisions wondering if they should get a second opinion. I*

(the volunteer) reminded her of the book she had received, "Breast Cancer, Clear & Simple" by the American Cancer Society, pages 20-22, which explains how to get a second opinion. She was reminded to also check with her doctor and the insurance company to see if this would be covered."

Does this sound like something you want to do for someone newly diagnosed with breast cancer? You can become a volunteer. Let us know by calling Cindy Harris – 319-230-1200 or Trish Pedersen – 319-277-5930. To apply to be a Reach to Recovery volunteer, contact Teresa.Allen@cancer.org for an application form and she will communicate with you to schedule a two-hour training course. Her phone is 515-727-0075 or 800-688-0147, Ext. 223.

We are excited about this new possibility for you to help others as a Reach to Recovery Volunteer! The reward you will feel in your heart is more than you could ever imagine.

Survivor Story, *continued from page 3*

in a fake menopause mode. The hot flashes and not sleeping at night were the worst!

My last radiation treatment was in January 2006. I lost my hair a total of 2 different times during this journey, but when it grew back for good, it was thicker, darker and with a little curl.

In February 2006, I began taking tamoxifen. Then in November I went to Dr. Singh in regards to some pain in my lower right calf. It was a blood clot. Within 2 weeks I had 8 more blood clots. Immediately I stopped the tamoxifen (one of the side- affects) and began taking a blood thinner. In February 2007 I had a hysterectomy due to blood clot complications. I have been released from taking the blood pressure medicine and blood thinner

I continue having 6-month checkups with Dr. Singh and 6-month checkups (mammogram once a year and MRI once a year) with Dr. Duven, my surgeon. All is A-ok. I feel great and LIVING A HEALTHY LONG LIFE!

Save the Date!

April 2 1:30 p.m.
Touch of Courage
Breast Cancer Support Group
2101 Kimball Avenue, Waterloo
Dawn Colbert 415-6430

April 3 1:30 p.m.
Care & Share Support Group
Covenant Cancer Treatment Center
200 E Ridgeway, Waterloo

April 9 1:30-3:30 p.m.
Look Good, Feel Better
Covenant Cancer Treatment Center
Conference Room
RSVP to American Cancer Society
At 866-460-6550

April 17 4:30-7:00 p.m
Meet, Mingle and Learn – Young Cancer Survivors
Unitarian Universalist Church
3912 Cedar Heights Dr, CF
Emily Hodgins 239-8118

May 1 1:30 p.m.
Care & Share Support Group

May 7 1:30 p.m.
Touch of Courage

May 7 4:45-6:45 p.m.
Grundy Area Breast Cancer Support Group
Kristi Barnet 3199-824-4129

May 10 5:00-7:00 p.m.
Splash of Color Event
Waterloo Public Library
Cathy 319-493-8857

June 4 1:30 p.m.
Touch of Courage
Breast Cancer Support Group

June 5 1:30 p.m.
Care & Share Support Group

June 11 1:30-3:30 p.m.
Look Good...Feel Better

July 2 1:30 p.m.
Touch of Courage
Breast Cancer Support Group

July 3 1:30 p.m.
Care & Share Support Group

July 14 Time TBA
Pretty in Pink Horse Show
Silver Spur Saddle Shop Arena

July 17 4:30-7:00 p.m
Meet, Mingle and Learn – Young Survivors Group



Resources

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

Beyond Pink TEAM is a local breast cancer organization providing a variety of services. Our website lists services we provide as well as other services available in the Cedar Valley. www.cedarvalleybreastcancer.org

Iowa Breast Cancer Edu-Action is a local advocacy group taking action against breast cancer. www.iowabreastcancer.org

Living Beyond Breast Cancer includes a helpline, newsletter and information. Survivors Helpline: 888-753-5222 www.LBBC.org

Young Survival Coalition connects with other young women diagnosed with breast cancer. www.youngsurvival.org

Cancer Care is a national nonprofit organization offering counseling, support, financial assistance and education to individuals with cancer and their families. www.cancercare.org

Iowa Cancer Consortium offers cancer information and links to resources in Iowa. www.canceriowa.org

American Cancer Society offers cancer information and services. www.cancer.org.

National Breast Cancer Coalition The NBCC’s mission is to eradicate breast cancer by focusing the government, research institutions and consumer advocates on breast cancer. It encourages advocacy for action and change. www.stopbreastcancer.org

M.D. Anderson Cancer Center, University of Texas offers patient and cancer information. www.mdanderson.org

Susan G. Komen for the Cure website offers cancer and social networking information and a newsletter on their website. www.komen.org

Iowa Breast Resource Guide is available on the Iowa Breast Cancer Education website. www.iowabreastcancer.org

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