

[Lymphedema](#)

[Compression  
Arm Sleeves](#)

[Touch of  
Courage Breast  
Cancer Support  
Group](#)

[Facts about  
Breast Cancer  
in the United  
States](#)

[Local  
Advocates Meet  
with Iowa  
Senators,  
Representatives](#)

[National Breast  
Cancer  
Coalition  
Fund's  
Legislative  
Priorities](#)

[Relay for Life](#)

[A Survivor's  
Story](#)

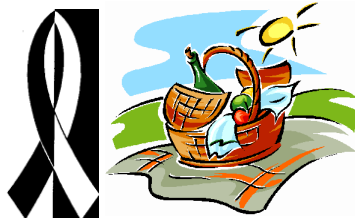
[Iowa Breast  
Cancer Edu-  
Action](#)

[Support and  
Rehabilitation  
Programs](#)

[Resources  
Available](#)

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**Lymphedema**  
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Lymphedema is a chronic condition that involves the swelling of a body part (arm(s), leg(s), trunk, face) due to trauma of the lymphatic system. When lymph channels become blocked and lymph fluid cannot drain properly, protein-rich fluid tends to accumulate in the affected body part. Primary lymphedema can be present at birth or develop from unknown causes later in life. Secondary lymphedema develops because of lymph node removal or damage. Damage or removal of the lymph vessels can occur as a result of surgery (i.e. mastectomy, lumpectomy), radiation, infection or other trauma.

Secondary lymphedema is a risk for a lifetime for anyone who has undergone surgery or radiation for breast cancer. In fact, the average onset of lymphedema for someone who has had breast cancer is 1½ years after surgery. Most often lymphedema will develop in the arm of the affected side, but will also occur in the trunk or breast. It is important to be aware of signs and symptoms of lymphedema so treatment can be started right away. Lymphedema will not go away on its own; it will worsen over time if not properly treated.

Signs and symptoms of lymphedema include the following:

- Increase in limb size
- Feeling of heat in limb
- Puffiness
- Pitting of skin if pressed
- Aching limb
- Inability to pick up fold of skin on a finger
- Decreased sensation of a limb or "pins and needles"
- Redness (although this could also indicate infection)

It is important to see a physician right away if any of these signs or symptoms appears.

A certified lymphedema therapist will provide treatment that includes a specialized massage technique called manual lymph therapy (MLT) or manual lymph drainage (MLD). The gentle massaging action stimulates the lymphatic system and promotes drainage of lymph fluid, toxins, proteins and debris out of the affected areas. The lymph fluid is absorbed back into the system, and the remaining components are excreted from the body through urination or sweating.

A second key component of treatment involves application of low stretch compression bandages (never ace wraps) which allow a

pumping effect when muscles contract, stimulating lymphedema reduction.

Another component to treatment and a key to lymphedema prevention and management is meticulous skin care. Some examples are a daily skin check, including examining your limb for cuts, burns or bites as these are

potential sources for infection. Treat any skin opening with antibiotic cream and protect hangnails or cracked, torn cuticles. Also note the signs of infection (redness, warmth, tenderness, red streaks, or swelling) and contact your doctor if any are present. It is also important to protect your skin from the sun and overheating. Wear sunscreen and avoid saunas or hot tubs. Avoid skin constriction by wearing loose fitting clothing and jewelry. Finally, insist that your affected arm(s) NEVER be used for injections, blood tests or blood pressure measurements.

## **Compression Arm Sleeves** **By Barb Daniels and Jill Roberts**

After receiving MLD treatments and reduction of swelling your therapist will have you wear a gradient compression sleeve. This sleeve is fitted according to arm measurements. The sleeve provides the greatest amount of pressure at the wrist and least at the shoulder. This promotes circulation of fluid and flow to the least resistance, in this case the shoulder. The sleeve may have an attached shoulder extension and or detachable hand gauntlet or glove if needed. Sleeves are worn during all waking hours and removed at night. The sleeve is used to maintain arm reduction after Lymphedema treatment. The compression in the sleeve is guaranteed for four to six months at which time the garment should be replaced. The arm sleeve and a hand gauntlet start at \$98.00. Most private insurance companies allow a sleeve every six months. Medicare will allow a sleeve when a compression pump is required.

The Women's Health and Cancer Act requires all health plans that cover mastectomies to also cover the following services and supplies:

- All stages of reconstructive surgery of the breast on which the mastectomy was performed

- Surgery and reconstruction of the other breast to produce a symmetrical appearance
- Prosthesis
- Treatment of physical complications of mastectomy, including lymphedema

Unfortunately, this legislation does **not** apply to Medicare and Medicaid. Private insurance companies tend to interpret this legislation differently, so it is best to check with your insurer to see what services and supplies are covered by your plan for the treatment of lymphedema due to breast cancer.

There is a lot of discussion on the wearing of a sleeve as a preventative while traveling by plane. Saksia R.J. Thiadens, RN of The National Lymphedema Network comments on wearing compression sleeves as a preventative. "My feeling is that whatever we can do that might possibly help prevent the development of LE, it's a plus. I strongly advise patients who have LE to add a second sleeve or bandage the arm, including the hand, and for the patient who is at risk, to wear a sleeve/glove when flying. Be sure it fits correctly (maybe by wearing it a short period of time for a day or two prior to the flight to test it) since there are patients who developed LE from wearing a poorly fitted sleeve while flying.

On a positive note: I see a number of patients who are flight attendants with LE. They wear their sleeves religiously and their arms have not changed or caused them any trouble." For additional information go to [The National Lymphedema website](http://www.lymphnet.org) at [www.lymphnet.org](http://www.lymphnet.org).

### **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 (unless it's a holiday), with the meetings being held at Covenant Cancer Treatment Center at 200 E. Ridgeway Avenue in Waterloo at 1:30 and 5:30 p.m.

For those of you who are long term survivors, please remember what a critical role you play in the journey of the newly diagnosed.

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.

### **Facts about Breast Cancer in the United States**

The American Cancer Society estimates that a woman in the United States has a 1 in 7 chance of developing invasive breast cancer during her lifetime. This risk was about 1 in 11 in 1975.

All women are at risk for breast cancer. About 90% of women who do develop breast cancer do not have a family history of the disease.

### **Local Advocates Meet with Iowa Senators and Representatives to Discuss Substantive Breast Cancer Legislation**

#### ***Breast Cancer Activists Gather in Washing, D.C., to Demonstrate the Importance of Grassroots Advocacy in the Fight to End Breast Cancer***

On Tuesday, May 24, 2005, in the nation's capitol, *Christine Carpenter, Sue Witwer, Deanna Hughes and Cindy Harris* from the *Cedar Valley Breast Cancer Task Force* joined breast cancer advocates from across the country to lobby Senators Grassley (Republican) and Harkin (Democrat), as well as Representatives Nussle (Rep. – 1<sup>st</sup> District) Leach (Rep 2<sup>nd</sup> District), Boswell (Dem. – 3<sup>rd</sup> District), Latham (Rep. – 4<sup>th</sup> District) and King, (Rep. – 5<sup>th</sup> District), on the National Breast Cancer Coalition (NBCC) 2005 legislative priorities.



*Front row, L to R: Suki Cell (with Iowa Breast Cancer Action) and Cindy Harris  
Back row, L to R: Deanna Hughes, Sue Witwer and Christine Carpenter*

After three days of extensive advocacy training during the National Breast Cancer Coalition Fund's Annual Advocacy Training Conferences from May 21 to 23, members of the Cedar Valley Breast Cancer Task Force joined breast cancer survivors and activists fighting to eradicate this deadly disease. They discussed breast cancer public policy issues with their elected officials on Capitol Hill during NBCC's annual Lobby Day.

The hundreds of dedicated individuals attending this year's conference in Washington, D.C. learned about the latest in breast cancer research and science, explored emerging issues in public policy and medical practice, and built and strengthened their political advocacy skills. Leading experts from scientific and research fields discussed and debated new and often controversial issues in the struggle to diagnose, treat - and ultimately end - breast cancer.

"Almost everyone is sympathetic to the cause of breast cancer. But we need more than sympathy to end the disease. All politicians must be held accountable for their action - or inaction - on substantive breast cancer policy that will make a real difference. All Iowa Representatives and Senator Harkin support the fiscal 2005 Department of Defense Breast Cancer Research Program. After years of support, we are disappointed our own Senator Charles Grassley withdrew his support for this model program," stated Christine Carpenter of the Cedar Valley Breast Cancer Task Force Executive Committee.

"There is still more work to do on the federal and state levels. We must continue our activism until women no longer fear this devastating disease."

This is the ninth time members of the Cedar Valley Breast Cancer Task Force have participated in NBCC's Lobby Day and discussed substantive breast cancer public policy issues with members of Congress.

The National Breast Cancer Coalition is a grassroots organization dedicated to ending breast cancer through the power of action and advocacy. NBCC has hundreds of member organizations (including Cedar Valley Breast Cancer Task Force) and tens of thousands of individual members. For more information about NBCC, go to their website [www.stopbreastcancer.org](http://www.stopbreastcancer.org).

### **National Breast Cancer Coalition Fund's 2005 Legislative Priorities**

**Priority 1:** Guaranteed access to quality health care for all.

**Priority 2:** \$150 million appropriation (level funding) for the Department of Defense (DOD) peer-reviewed.

**Priority 3:** Enactment of the Breast Cancer and Environmental Research Act. It is generally believed that the environment plays a role in the development of breast cancer, but the extent of that role is not understood. The National Breast Cancer Coalition believes that this critical issue must be approached thoughtfully and methodically and that a national strategy for increasing knowledge in this area must be developed.

**Priority 4:** Preservation of the Medicaid Breast and Cervical Cancer Treatment Program (BCCTP). In 2000, after years of NBCC grassroots lobbying and influence, Congress enacted a Medicaid expansion to treat women with breast cancer. This expansion, the BCCTP, provides enhanced matching funds to states to provide Medicaid coverage for treatment of breast and cervical cancer to low income women screened and diagnosed through a federal program - expanding access to care for thousands of underserved women.

**Priority 5:** Enactment of legislation to mandate registration of clinical trials. NBCC supports legislative proposals to mandate clinical trial registration and public disclosure of research.

## **Relay for Life**

Marie Iverson had another outstanding year as Team Captain for the Cedar Valley Breast Cancer Task Force's Relay for Life team. Besides being captain of our team, Marie has two other teams for Peace Lutheran Church.



*While Senator Grassley did not sign the letter of support for the DOD Breast Cancer Research Program, he attended the Relay for Life and offered support for breast cancer research in Appropriations Committee decisions. He's shown here with Cindy Harris.*

The American Cancer Society recognized Marie's dedication to the Relay for Life by asking her to share in carrying the banner in the survivor lap.





*Survivor Lap (Marie in center wearing cap)*

This is the 16<sup>th</sup> year that the American Cancer Society has held the Relay for Life. Ninety-five teams participated and raised more than \$154,000. In this fourth year of participating in the Relay for Life, the Breast Cancer Task Force Team had 20 members walking and raised \$3,252 for cancer research. To find out more about our team, [visit our website](#).



*Marie Iverson, Deanna Hughes and Kathy Boeckmann at the Relay for Life*

**A Survivor's Story**  
**Hope, Bravery, Courage & Endurance**  
**By Kim Luebbers**

I was 35 and working as a radiation therapist, giving treatments for cancer, when I was diagnosed with breast cancer. I had a husband and three children ages 7, 3, and 2. My breasts were very fibrocystic and I had a large area in my breast that had always troubled me but now appeared to be changing. I had aspirations and a biopsy before. The first biopsy in 1995 showed only fibrocystic disease. In September of 2001, I went to the doctor and a fine needle aspiration showed atypical cells, suspicious for malignancy.

Two weeks later an open biopsy was performed which showed ductal carcinoma insitu and a 5mm tubular carcinoma. After talking to my surgeon, medical oncologist and radiation oncologist, I decided to have a double mastectomy. To some, this treatment choice may have seemed too aggressive but I knew that breast cancer in younger women tends to act more aggressively, and I had lots of other lumps in my breasts. My tumor had not shown up on mammogram and I didn't want to have to worry about what kind of cells were in those lumps.

I also consulted with a plastic surgeon to discuss options for reconstruction. I opted for immediate reconstruction and my surgeon and plastic surgeon performed the operation together. My tumor was small, I had no positive lymph nodes and I had very little breast tissue left after surgery. For all these reasons the doctors agreed I did not need any radiation or chemotherapy. The reconstruction was very helpful to me in dealing with the loss of my breasts.

All my efforts were focused on getting well physically, trying to eat and sleep well and not let the pain get to me. I was dealing with the physical part of my cancer, not doing too badly, handling things well, or so I (and everyone) thought.

You might think that this would be the end of my journey; however, this is when the toughest part began. When I finally began to deal with the emotional part of having a cancer diagnosis and losing my breasts, it became extremely difficult for me to give radiation treatments to my patients. I knew we were facing the same monster. Everyone's story was different, yet similar, different diagnosis and tests, yet similar emotions. I found it difficult to be grateful for my prognosis.

I was physically tired having all these emotions of anger, sadness and despair while also trying to keep up with working full-time, the housework, being a wife, and being a mother to three small

children. It put a strain on my relationship with my husband. I felt indifferent about a lot of things and felt joy in nothing.

At a yearly appointment with my gynecologist, I finally broke down sobbing. She asked me if I thought I needed an antidepressant and I said, "No." Why couldn't I be as strong emotionally as I was physically? I felt like a failure.

Because I was so depressed I agreed to take the medicine prescribed. Slowly my mood began to improve and I was able to get beyond the depression and start to find joy again. My work was not as hard for me emotionally. I was able to empathize with my patients, understand how they were feeling and encourage them.

It is difficult to deal with a cancer diagnosis, to have check-ups and worry about the possibility of the cancer coming back or spreading. For me, it was scary to have to deal with my own mortality at my age. Some of the most difficult days for someone with cancer may be after the treatments are finished, just when everyone thinks you're fine.

Within a week of celebrating my third year of being cancer free, I had a scare. I had to have one of my implants removed due to an infection. This doesn't happen very often, but leave it to me to have a low risk complication. After three months of healing I was able to begin the reconstruction over again. After two more surgeries and about six more months, I will be back to my "new" normal self.

I am grateful no cancer was found when my implant was removed. I am completely satisfied with the decision my doctors and I have made so far. I would not change anything except for having cancer in the first place.

It is important to have a support system during and after cancer treatment. I personally believe that the emotional side of cancer is the most difficult to deal with. I encourage people to reach out to others for support; people in our churches, co-workers, friends and family. Most often people are willing to help. As survivors, we need to let others know when we need the help. In asking for help we display our strength.

**Iowa Breast Cancer Edu-Action**

### **Who Are We?**

Iowa Breast Cancer Edu-Action includes breast cancer survivors and their supporters. We are members of the Cedar Valley Cancer Committee. **Our mission** is to serve as a catalyst for the prevention and cure of breast cancer.

### **What We've Done**

- Visited with our congressional representatives to secure their commitment to breast cancer research.
- Participated in fax and letter campaigns o Congress for a commitment to a national strategy for the fight against breast cancer.
- Created the Iowa Breast Cancer Resource Guide, secured funding and distributed 4000+ copies
- Iowa Breast Cancer Edu-Action is a subcommittee of the Cedar Valley Cancer Committee

### **We Meet:**

When: 7:00 p.m. on the 4<sup>th</sup> Thursday of each month.

Where: Area Education Agency 7 Special Education Building  
Conference Room 5

### **Need more information?**

Call Christine Carpenter 319-266-0194

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<b>Support and Rehabilitation Programs</b>	
Care and Share	Support group for anyone dealing with cancer. Meets the 1st Tuesday of every month at 1:30 p.m.
Touch of Courage	Breast cancer support group. Meets the 1st 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 50702 (319) 235-2005	American Cancer Society 2101 Kimball Avenue, Suite 130 Waterloo, IA 50703 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 50702 319-272-2800	Covenant Cancer Treatment Center 200 E. Ridgeway Avenue Waterloo, IA 50701 319-833-6100 Includes Cancer Information Library
National Cancer Institute 1-800-4CANCER	National Coalition for Cancer Survivorship 1-505-764-9956
National Lymphedema 1-415-923-3680	Network Y-Me 1-800-986-8228
Covenant Lymphedema Therapy 319-272-7894	Physical Therapy Partners Lymphedema Therapy 319-233-6995

<p><b>Connect with us...</b>          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.</p>
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:  
1067 Heath Street, Waterloo, IA 50703