

Lymphedema: The Life-long Aftereffect of Breast Cancer

For Thousands of Survivors, Breast Cancer is Only Half the Battle

Washington, D.C., Oct. 24, 2014—Imagine getting a breast cancer diagnosis, battling and surviving the disease, and then learning the very treatment you received has caused a new life-long health problem—lymphedema—a chronic condition that causes swelling, pain, and increased exposure to infection and deformity.

That's exactly what happened to Elaine Eigeman, a Seattle resident who underwent treatment for stage-three bilateral breast cancer in 1998. In her case, and for thousands of others, the removal of lymph nodes caused lymphedema.

"The first sign of lymphedema may be a feeling of heaviness, aching, weakness, tension under the skin, or numbness in the arm or chest. Often these feelings occur before seeing swelling," said Dr. Nancy Hutchison, certified lymphedema therapist with the Lymphology Association of North America and Medical Director for Cancer Rehabilitation and Survivorship at the Sister Kenny Cancer Rehabilitation Program in Minneapolis, Minn.

"Early treatment is very important. Some early lymphedema may be reversible and may only require a compression sleeve. Breast cancer survivors should not delay in having an examination by medical professional with knowledge of lymphedema at the first sign or symptom of swelling or change in sensation."

Out of the estimated 232,670 women and 2,360 men who will get breast cancer this year, up to 40 percent may end up with lymphedema at some point after treatment. Many will struggle to access treatment for their lymphedema.

"The Women's Health and Cancer Rights Act of 1998 requires any private insurance plan that covers mastectomy to also cover treatment for breast-cancer-related lymphedema, including compression garments," said Founder and Executive Director of the Lymphedema Advocacy Group, Heather Ferguson. "However, this law does not apply to Medicare, nor does it provide coverage for men affected by breast cancer. Medicare beneficiaries—especially women who had coverage through a private plan previously—are shocked to learn that they now have no coverage for the doctor-prescribed, medically necessary compression garments they need to manage this disease."

That's exactly what happened to Eigeman.

"I am now without coverage for my essential compression garments," she said.

When she first began to experience symptoms, she sought not only treatment, but support from others. "We met every week to process our own anguish over having lymphedema. We would bring devices that helped alleviate swelling, listen to people and help them," she said.

Eigeman decided to join the Lymphedema Advocacy Group because she was frustrated and angry to see so many elderly and disabled patients whose conditions had worsened because they didn't have coverage for their compression supplies. She is now the chair of the group, and lobbies for-improved insurance coverage for lymphedema treatment. The disease is devastating for thousands, which is why Eigeman and Ferguson have gotten involved in advocating for coverage.

"Many patients have expressed to me that their lymphedema has been harder to deal with than their cancer," Ferguson said. "Cancer had an end, lymphedema is forever. That disease was covered by insurance; this disease (largely) is not. They had a wealth of support when battling cancer, yet feel alone to deal with the physical, psychological and emotional consequences of lymphedema."

The Lymphedema Advocacy Group is working to pass the Lymphedema Treatment Act—a federal bill that would enable Medicare to cover the compression supplies that are the cornerstone of lymphedema treatment. Although this legislation relates specifically to a change in Medicare law, it would set a precedent for Medicaid and private insurers to follow, thereby benefitting lymphedema patients nationwide.

To learn more about lymphedema, the Lymphedema Advocacy Group and the Lymphedema Treatment Act, visit http://lymphedematreatmentact.org.

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About Lymphedema

Lymphedema is an incurable medical condition caused by injury, trauma or congenital defects in the lymphatic system. This chronic but treatable disease results in an accumulation of lymph fluid or swelling in parts of the body where lymph nodes or lymphatic vessels are damaged or inadequate. Compromised immune function puts patients at high risk for serious infections and other complications. Among the many causes, damage from cancer treatment is the most common, making lymphedema one of the most prevalent and significant survivorship issues.

About Lymphedema Advocacy Group

The Lymphedema Advocacy Group (LAG) is an all-volunteer nationwide organization of patients, caregivers, healthcare professionals and industry partners. Its mission is to advance lymphedema care in the United States by advocating for improved insurance coverage for the diagnosis and treatment of the disease. For this purpose the organization works to increase awareness of and education about lymphedema amongst lawmakers, insurance providers and other relevant entities. LAG supports attempts to improve coverage at both the state and federal levels and encourages all members of the lymphedema community to become active participants in this process.