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HUGS SHOULD NEVER HURT

Lesli Bell, PT/CLT - LANA

Sarah had nowhere else to go for help so she came to me.

After months of painful breast and axillary swelling, following three separate bouts of breast cancer, she was frustrated and depressed when she appeared at my outpatient physical therapy clinic. You would be too if you had endured lumpectomies and radiation on both sides, not to mention four months of still more pain while the abscesses on the right breast healed.

None of the doctors she had seen over several months had an answer for the swelling and the shooting pains on her right chest wall and breast. Sarah hoped that in some way I could help, in part because her daughter in-law trained as a nurse in Germany: in Europe, every breast cancer patient is evaluated by a physical therapist for lymphedema following treatment, and education, physical therapy intervention, and prophylactic training are routine. Her daughter-in-law urged Sarah to be evaluated by a trained physical therapist in the United States to see if there was something to be done about the pain and edema. Unsure where to go, Sarah asked a trainer at a local gym for advice. The trainer suggested our clinic because we were certified lymphedema therapists.

When I examined Sarah, I found severe swelling of the right breast with marked fibrosis in the inferior and lateral aspects. Though lumpectomies were performed on both breasts, the right breast was nearly **double** the size of the left. By her report, after the right lumpectomy and prior to the abscesses, the breasts were about the same size. These conditions were accompanied by an increase in temperature of the same tissue – and extreme pain.

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Sarah complained of heaviness in both arms and fullness in both axillas, with the right side even more painful than the left. Clearly she had some arm edema on the right, and possibly mild arm edema on the left, but her primary problem was severe swelling and pain of the right breast. This condition made wearing a bra awkward and painful. Her activities of daily living were limited, she was having difficulty initiating an exercise program, and in general she was extremely discouraged. With tears in her and her husband's eyes, I could see they were feeling desperate.

I explained to Sarah and her husband that I saw the problem as chest and breast lymphedema. When I told them there is treatment with the potential to greatly decrease her pain, both of them became tearful again. The problem was recognized and validated, and a treatment was available. I look forward to helping Sarah over the next several weeks, and hope I get the same good results that I have with so many other women with similar complaints.

In the last five years, I have seen more and more women with this complaint. Sometimes it is accompanied by arm edema, sometimes not. Constantly and severely painful, it can occur with a mastectomy or a lumpectomy. Traditional Manual Lymph Drainage (MLD) or Complete Decongestive Therapy (CDT) work wonders; self-management also helps if done diligently. The compression needs remain the biggest hurdle to improve self-care.

The question is why haven't we included chest and breast lymphedema in the literature and research we have on lymphedema? Why don't we talk about it? Why aren't we educating the doctors and nurses who care for this population? Lymphedema is a poorly understood condition in this country, with few trained medical experts. It is relatively new to the treatment world of breast cancer in the United States. No, it is not fatal, but it can significantly alter quality of life after breast cancer treatment.

My experience is that unlike arm edema, which is uncomfortable and *sometimes* painful, chest, breast and auxiliary edema is almost always *very* painful. Sometimes the condition resolves itself in a year or two and many times it continues to plague women just like chronic arm edema. The same conditions that exacerbate limb edema exacerbate breast edema. Traditional bras are very uncomfortable and sometimes make the chest wall edema worse. As I have continued to poll my professional colleagues about the incidence of this problem, anecdotally they all validate its existence and the difficulties in managing it.

Research is needed not only in limb edema but the chest wall and breast as well. Objective measurement and documentation needs to be standardized in both instances. As we continue the quest to educate our patients and the professionals who treat them, let us recognize, validate, and treat chest and breast lymphedema as we would any limb. Let us educate women and the caring professionals that treat them in its existence and share with them treatment information. Let's not only celebrate surviving breast cancer, but also concentrate on the quality of life after the fight. A hug should never hurt.

For more information about The Compressure Comfort™ Bra visit www.bellisse.com. Purchase or distribution inquiries may be directed to 1-877-273-1683.

About Bellisse: Bellisse, (www.bellisse.com) inventor and manufacturer of the Compressure Comfort™ Bra, was co-founded by Lesli Bell, PT/CLT-LANA, a certified lymphedema therapist, and Lisa Lindahl, inventor and designer of the original Jogbra®. The company's mission is to provide product that offers support and comfort to the hundreds of thousands of women suffering from chest and breast lymphedema. Bellisse, formed as a play on the founders' names, is derived from words found in the Oxford English Dictionary meaning "beautiful relief from pain."

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