Trying to Prevent Lymphedema After Breast Cancer

Hospitals in about a dozen states are testing whether some simple steps, such as arm-strengthening exercises, could reduce the risk of one of breast cancer's troubling legacies — the painful and sometimes severe arm swelling called lymphedema. Lymphedema has long been a neglected side effect of cancer surgery and radiation: Many women say they never were warned, even though spotting this problem early improves outcomes.

And while less invasive surgical techniques mean fewer breast cancer patients today than just a few years ago should face lymphedema, it’s a lingering threat for tens of thousands of survivors because it can strike two decades after their tumor was treated. "I have ladies tell me the lymphedema is much worse than their cancer because the cancer's cured," says Dr. Electra Paskett, an epidemiologist at Ohio State University who is leading the first-of-its-kind research into possible protective steps.

Among them: Wearing elastic sleeves to counter temporary swelling during things like airplane flight or heavy lifting, and doing special exercises with light weights designed to help keep open the lymph channels that allow fluid to drain through the body.

"The theory is building up muscles in your arm acts as a natural pneumatic pump to move the fluid," explains Paskett, herself a breast cancer survivor who developed lymphedema.

When lymph nodes under a breast cancer patient’s arm are removed or damaged by biopsy, surgery or radiation, lymph fluid can build up and cause anything from mild swelling to a ballooning of the arm. Lymphedema isn’t just a legacy of breast cancer treatment. The leg can swell if groin nodes are damaged from other cancers, including
gynecologic cancer. Melanoma treatment left former presidential candidate John McCain with facial swelling. Occasionally, rare diseases can trigger a different form of lymphedema.

But lymphedema among breast cancer survivors may be most common. It's been estimated to affect between 20 percent and 30 percent of patients who have 10 or more under-the-arm nodes examined, called an "axillary lymph node dissection."

A surprising study published in November's Journal of Clinical Oncology suggests few such women may be diagnosed. University of Minnesota researchers analyzed records from the huge Iowa Women's Health study, to cull more than 1,200 patients who'd had breast cancer between 1986 and 2003. Eight percent had been formally diagnosed with lymphedema yet another 37 percent of the women suffered persistent lymphedema symptoms, including a swollen arm.

Today, some women have far fewer nodes examined in a "sentinel node biopsy," and separate research suggests those women are far less likely to get later lymphedema — possibly as low as 5 percent, Paskett notes — although many don't qualify for the smaller surgery because of large tumors or other factors.

But perhaps most concerning from the Iowa data, only 40 percent of the women with swollen arms but no diagnosis had heard of lymphedema and less than 2 percent had sought care for their arm symptoms.

Yet early care is key, as Anne Holman of Washington, D.C., can attest. In 2006, doctors found cancer in eight of 18 lymph nodes. She was undergoing chemotherapy to shrink her tumor before an eventual mastectomy when one day her arm turned red and itchy. Come in right away, said Minna Manalo, a nurse practitioner at Georgetown University Hospital's breast cancer unit.

Along with a skin inflammation, Manalo diagnosed lymphedema — Holman's arm was just starting to swell. Daily for two weeks, she
underwent what's called complete decongestive therapy, where a machine massaged fluid from her arm and it then was tightly bandaged to counter swelling. Once her arm shrank, Holman was prescribed a lifelong therapy: A tight elastic sleeve and fingerless glove to wear regularly, especially during her job as an international flight attendant, plus arm exercises to help push out returning fluid. "I'm trying to stay ahead of the game," says Holman, 61. "You can't cure this, but you can manage it."

Paskett's study — now recruiting participants at Ohio State, Georgetown and a growing number of other hospitals — tests whether milder versions of those techniques could prevent lymphedema in the first place. Women recovering from a large node removal are randomly assigned to either a regimen including personalized arm exercises, or just lymphedema education. Results aren't due until 2012.

Meanwhile, cancer groups advise:

Be alert for subtle swelling. Don't ignore a tight ring or watch, or clothes suddenly not fitting.

See a certified lymphedema specialist, who has proper training in fitting compression garments and proper use of decongestive therapy. Improper use of either can worsen the condition.

Obesity and arm injuries are additional risk factors. So watch your weight; avoid injections in the affected arm; clean cuts and seek care for infections promptly; wear gardening gloves and oven mitts; and avoid temperature extremes, such as hot tubs.