Living With Lymphedema

OSF HealthCare Newsroom

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One in 1,000 Americans are affected by secondary lymphedema. It's a chronic disease when there's an increased collection of lymphatic fluid in the body that causes swelling. Those with cancer are known to develop lymphedema, which can lead to skin and tissue changes, according to the National Institutes of Health.

Sometimes those with lymphedema can inherit the disease, known as primary lymphedema, which is much rarer. You can be born with lymphedema, develop it during puberty, or later.

There's no cure for lymphedema. It's a disease, and one like diabetes that you have to manage through treatment. Treva Haney, a supervisor in Rehabilitation Services at OSF HealthCare, says her team works through different treatment plans with patients to meet their specific needs.

"Usually the plan of attack for treating lymphedema is complete congestive therapy," Treva says. "This involves compression bandaging and a special, lymphatic massage."

Along with the massage and bandaging, the plan can include manual lymph drainage, which – like it sounds – is a specialized form of manual therapy used to stimulate the lymph system and promote drainage.

Haney says exercise is a great way to get lymph fluid moving from the part of the body where it has collected.

"We have therapists who will use some of the equipment to get people moving and exercising. We teach the patients how to do the self-massage and how to do the bandages. As we get that limb better under control, we can recommend compression garments that they can wear," Treva says.

Haney says some patients her clinic works with are former cancer patients.

"Our lymph system just builds up and you can get a big arm. We see that a lot with ladies who get breast cancer treatments," Haney says. "They have axillary nodes or armpit nodes removed as part of their treatment and then their arm will swell. We occasionally see it in the legs from other pelvic cancers."

"Stay active, stay mobile!" Is the advice Haney has for those looking to prevent lymphedema.

"If you can maintain a healthy and active lifestyle, that can decrease your risk for lymphedema," Haney says.

People should see an occupational therapist or physical therapist if they've been diagnosed with lymphedema or have swelling due to a post-surgery or post-traumatic injury. You'll need a referral from your physician to set up an initial evaluation.