Cancer’s dirty little secret: The Lymphedema Treatment Act can help millions suffering from this little known condition

The need to pass the Lymphedema Treatment Act has become increasingly urgent with the pandemic limiting lymphedema patients' access to care, Carter writes. (Tom Williams/CQ Roll Call file photo)

Posted November 17, 2020 at 5:30am

If having cancer wasn’t bad enough, those undergoing treatment to beat the dreaded disease often face an aftershot of debilitating life-long swelling that can be painful and impede activities of daily living.

Lymphedema can be caused by surgeries, infections, other physical traumas or congenital defects. The most common cause in the United States is cancer treatments that remove or damage lymph nodes and vessels, or cause blockages in the lymphatic system. This results in an accumulation of lymph fluid, or swelling, that is chronic and, if untreated, progressive, putting the patient at high risk for infections and other complications.
Lymphedema affects up to 40 percent of women who have undergone surgery or received radiation for breast cancer. Men who have undergone prostate cancer surgery often experience it as well, as do survivors of other types of cancer. Yet doctors rarely discuss the condition; it is sometimes ignored and frequently misdiagnosed, and it routinely goes untreated. That’s why cancer patients refer to it as “cancer’s dirty little secret.”

As a health care professional, the only pharmacist serving in Congress and co-chairman of the Congressional Cancer Survivors Caucus, I came to Washington to make a difference and help those suffering. Lymphedema affects 3 million to 5 million people nationwide, and anywhere from 1.5 million to 3 million Medicare beneficiaries. There is no cure for lymphedema, but the disease can be effectively managed if patients have access to the compression garments and supplies that are the long-standing cornerstone of treatment for this chronic condition.

These prescription medical compression garments are much different from what can be purchased at your local drug store. These are highly specialized compression stockings, sleeves, gloves and other items, all of which must be custom-fit by trained providers, and in the case of more advanced disease or complex cases, sometimes must be custom-made.

Such medically necessary supplies, which must be replaced about every six months, should be covered by insurance. Unfortunately, Medicare cannot currently provide coverage for lymphedema compression supplies because they do not fit into an existing benefit category. As a result, Medicare patients often suffer from recurrent infections, progressive degradation in their condition and eventual disability. Medicare’s failure to cover compression supplies cannot continue. We need to invest in preventing complications instead of spending money to treat avoidable complications of disease.

That’s why I joined my colleagues to introduce the Lymphedema Treatment Act. This legislation will provide Medicare Part B coverage of compression garments by including certain lymphedema treatment items as durable medical equipment. The legislation currently has tremendous bipartisan backing, with over 380 House and 70 Senate co-sponsors, making it the most supported health care bill in Congress by a large margin. The bill also has broad support from a large number of patient advocacy, health provider and health industry groups.

The need to pass the Lymphedema Treatment Act has become increasingly urgent. The pandemic has further limited lymphedema patients’ access to care, which increases their risk for hospitalization and exposure to COVID-19. All lymphedema patients have permanently impaired immune systems, making them vulnerable to suffering from more severe cases of COVID-19 and placing them in a high-risk category.

Especially at this time, we should be doing all we can to make sure lymphedema patients have the medical supplies they need to safely manage their condition at home and stay out of the hospital. Now is the time for Congress to come together to pass this widely supported legislation that will ease the pain of those suffering from cancer’s dirty little secret.

Rep. Earl L. “Buddy” Carter is a Republican representing Georgia’s 1st District. He serves on the Energy and Commerce Committee, including its Health Subcommittee.