



10 THINGS TO KNOW ABOUT OVARIAN AND OTHER GYNECOLOGIC CANCERS AND LYMPHEDEMA (LE)

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SOME STATISTICS

While survival rates among patients with gynecologic cancers have steadily improved, it comes with the risk of a secondary disease—lymphedema. Up to 10 million Americans, and over 250 million worldwide, suffer from lymphedema (LE) and lymphatic diseases (LD). More people in the U.S. suffer from LE/LD than from multiple sclerosis, muscular dystrophy, ALS, Parkinson's disease and AIDS—combined.

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WHAT IS LYMPHEDEMA (LE)?

Lymphedema is a lifelong, chronic, and incurable disease. Lymphedema most commonly involves swelling in arms or legs and can affect the head, neck, trunk, and genital area. It occurs after cancer treatments, non-cancer related surgery or trauma to the lymph nodes (secondary LE), while some people are born with it or develop it later in life (primary LE).

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WHY ARE GYNECOLOGICAL CANCER PATIENTS AT RISK?

Treatment plans such as cytoreductive surgery, extensive node dissection, lymph node removal, and radiation can all cause a disruption to the lymphatic system running the risk of lymphedema. With the surgeon's goal of eliminating cancer, development of LE is often not even discussed with patients.

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PATIENT EDUCATION IS CRUCIAL

Patients must be educated about lymphedema risk from the inception of treatment, particularly before undergoing an invasive procedure or surgery in which lymph nodes may be damaged or removed. Educating patients about LE signs/symptoms to be aware of post-operatively should not discourage them from agreeing to surgery or other treatments.

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IS THERE FURTHER RISK AFTER SURGERY?

Lymphedema can occur months to years following surgery or treatment for gynecological cancer with lymph node involvement. Reoccurrence of the tumor or metastasis of gynecological cancers increase the risk of lymphedema by further impairing lymph drainage.

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SHOULD MY DOCTOR BE DOING ANYTHING PRE- AND POST-SURGERY?

Measurements of the affected area (ie pelvis, lower or upper limbs) are needed both pre and post-operatively. Referral to a Certified Lymphedema Therapist (CLT) as soon as changes are detected is essential to manage the disease before serious complications occur.

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LYMPHEDEMA MANAGEMENT CAN BE COMPLEX AND EXPENSIVE

Compression garments can be difficult to put on and wear and only last from 4 to 6 months; ongoing treatment is expensive. Most insurance does not cover garment costs, which are higher if the lymphedema is more severe and custom-made compression garments are required.

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LYMPHEDEMA CAN BE EXHAUSTING AND DISABLING

Lymphedema alters the individual's ability to participate in activities of daily living; chronic pain and discomfort associated with the disease can be debilitating, exhausting, and depressive.

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LYMPHEDEMA MAY DECREASE QUALITY OF LIFE

Lymphedema robs affected individuals of the sense of joy in life; it is incredibly time consuming and expensive to manage on a daily basis.

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LYMPHEDEMA MAY CAUSE INDIVIDUALS TO FEEL UNSUPPORTED AND ISOLATED

Individuals may feel they are part of an invisible population since physicians and medical practitioners often fail to correctly diagnose and treat the disease. Although treatment centers are currently few, there are a variety of resources available on the LE&RN website; e.g., a current list of LE/LD treatment centers, resources to help you find a therapist, stories of others living with LE/LD, free symposium videos, and LE&RN's social media connecting you to the LE community.

