I Want My Physician to Know about Lymphedema (LE)

1. Lymphedema (LE) must be diagnosed early. Often, LE is not diagnosed in its early stages when treatment is most effective. Referral to a Certified Lymphedema Therapist (CLT) is essential to manage the disease before serious complications occur.

2. Lymphedema may initially present as chronic swelling. LE should be suspected and screened for in individuals with chronic swelling. Referral to a vascular specialist with expertise in lymphedema diagnosis and treatment also should be considered.

3. Lymphedema as a potential outcome requires patient education, especially before surgery that will affect lymph nodes. LE should be discussed with individuals prior to recommending they undergo an invasive procedure or surgery in which lymph nodes/vessels may be damaged or removed—not to discourage patients from agreeing to surgery, but to educate them about the risks.

4. Lymphedema has both physical and psychological effects. LE changes the individual’s sense of body image and mobility.

5. Lymphedema often causes individuals to feel unsupported and isolated. Individuals may feel they are part of an invisible population—many physicians do not even recognize the condition.

6. Lymphedema patients often need psychological support. LE has an effect on the individual’s emotional health that should not be overlooked. Referral to a mental health professional should be offered.

7. Lymphedema is exhausting and disabling. LE 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.

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

9. Lymphedema management is 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. Physicians and therapists must understand the condition and exhibit compassion for people struggling with the disease. Most insurance does not cover garment costs, which are higher if the lymphedema is more severe and custom-made compression garments are required.

10. Lymphedema is different in every individual. LE manifests with different signs and symptoms in each individual. Thus, like pain, lymphedema is what the patient says it is.