

10 Things LE



My Family and Friends Can Do to Support Me with My Lymphedema

- 1. Lymphedema (LE) is overwhelming and frightening.** LE is a lifelong disease that will become worse if not diligently managed. Please help lift my spirits when this “new normal” seems unbearable.
- 2. Lymphedema is a debilitating disease that affects every aspect of my life.** Please be patient if I struggle to accomplish daily activities. Offer help with these activities, but realize I may want to accomplish them without help to maintain my independence.
- 3. Lymphedema is not my fault.** LE is not obesity or a “fat disease”; it’s a disease of the lymphatic system. Losing weight may improve lymphedema somewhat, but nothing, including losing weight or exercise, will cure it.
- 4. Lymphedema affects mobility and body image.** Know that I am very aware of these changes when they occur. You can support me best by being sensitive to those body image and mobility issues when inquiring about my health.
- 5. Individuals with lymphedema may need support to stay motivated – to keep wearing compression garments, to stay active, and to eat well.** It can be stressful and depressing to wear compression garments that typically are uncomfortable and unattractive. Please be accepting (or supportive) of how I look and feel.
- 6. Day-to-day life with lymphedema is extremely variable, with both good and difficult days.** Living with the disease is physically and mentally taxing. There will be times that this disease depletes my energy, enthusiasm, and sense of humor. Please be extra supportive on these tough days.
- 7. Lymphedema is burdensome – in addition to physically and emotionally – financially as well.** Living with LE consumes much of my free time and may prevent me from spending discretionary income on things other than lymphedema management.
- 8. If I decline an invitation, it may be because management of my lymphedema must be my priority.** Because it often takes several hours daily, I may not have the energy some days to do anything other than my LE care.
- 9. If my lymphedema is related to cancer treatment, I may find that activities related to management of the disease remind me of my cancer history and the possibility of recurrence.** Thank you for listening when I tell you about my fears of getting cancer again.
- 10. Every person with lymphedema has a unique story and special needs.** I greatly appreciate it when you ask how you can support me. If you are willing to listen, I will share with you my very personal experience as a person living with lymphedema.



Lymphatic Education
& Research Network

For more information: www.LymphaticNetwork.org

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