

LYMPHEDEMA – FREQUENTLY ASKED QUESTIONS

What is Lymphedema?

Lymphedema is a protein driven problem. One of the jobs of the lymphatic system is to move large protein molecules that are created when cells make energy. Some of the molecules created are too large to be picked up by the circulation so the lymphatic system moves them from all parts of your body to about the level of your heart. From there the protein molecules get dumped into the circulation and are removed by the kidneys. If the movement of the protein molecules is disrupted, as is the case with lymphedema, they will stay in the tissues and attract fluid, causing swelling.

What are the Causes of lymphedema?

Primary Lymphedema – you are born with some sort of insufficiency that may present itself at birth, around hormonal changes, or later in life

Secondary Lymphedema – The lymphedema is caused by a secondary condition such as cancer treatment (lymph node removal, scarring from surgery, radiation), trauma, blood clots, cellulitis, and obesity.

Will my swelling ever go away?

Under most circumstances, lymphedema is a chronic condition meaning it will typically never go away. We can however, lessen the swelling significantly with treatment. On some occasions, lymphedema can decrease with treatment and not return after healing from a trauma, or with significant weight loss.

How do we treat lymphedema at the MSU Lymphedema Clinic?

Our treatment focuses on management of this chronic condition. If you stop managing your symptoms, your swelling will continue. Typically, we treat patients with arm lymphedema 4x/week x 3 weeks, and leg lymphedema 4x/week x 4 weeks. This may vary depending on the condition of the affected area, the amount out of assistance a patient needs for home management, insurance coverage and out of pocket costs, the willingness of the patient to commit to the program, and transportation to the treatments.

During treatment, we teach patients the following

- 1. How to take care of their skin*
- 2. Educate on some specific lymphedema exercises so the muscles can help move lymphatic fluid*
- 3. Teach self-manual lymphatic drainage (a form of massage) to stimulate the lymphatic vessels*
- 4. Apply compression bandages to the affected area and teach the patient and/or an assistant how to help*
- 5. Fit the patient with compression garments or recommend where fitting can take place.*

What supplies do I need?

If you are committed to the full treatment, you will need to purchase compression-bandaging supplies. Your therapist will tell you what items you will need.

Will insurance cover the cost of the supplies?

Most of the time insurances will not cover the cost of the supplies but on rare occasions, they will. If they are willing to cover the bandaging costs, you will need to get a prescription from your doctor for the bandages to submit to your insurance company. Your therapist will tell you what supplies are needed but she cannot write a prescription for you. The same is true for the compression garments.

What are the expectations for treatment and will I need help?

In order to gain the most benefit we recommend following the prescribed treatment program. This includes daily lymphedema exercises, daily compression bandaging with tolerance for wearing bandages 23 hour/day, 7 days/week, and applying moisturizer to the affected area daily. If you cannot apply bandages yourself, you will need help. Typically, patients are in treatment 4x/week so on the 3 days you are not in treatment, you or an assistant will need to apply the bandages. Once treatment is concluded, we typically recommend that you wear compression garments during the day and bandage at night. Once you reach the management phase, you may not need to apply compression bandages every night. This will depend on how quickly fluid returns to your legs once compression is removed.

Can someone come to my home and help me (like a Home Health Aide?)

Our clinic is unable to supply assist for home. Patients who need assistance are encouraged to seek help from family or friends. If you have a home health aide coming to your home for any reason, typically you do not qualify for outpatient treatment.

What if I don't have help at home and I can't follow the program myself?

You may find some benefit from attending one or two education sessions to learn about a home exercise program, self-massage, and skin care.

I live far away and travel is an issue, OR I have a high copay/deductible and cannot afford to come very often.

Sometimes people who live far away from our clinic or have high copays/deductibles, are understandably unable to attend therapy at the recommended frequency. If either of these scenarios apply to you, we may ask you attend 3-4 sessions so we can teach you how to apply compression bandages, as well as instruct in the performance of the exercises and self-massage. At that point, you would continue at home and return a few weeks later for a check on your progress and possible garment fitting. If you need help, your assistant should also attend a few of the initial sessions so they can learn how to properly apply the compression bandages.

My legs hurt/itch; will treatment help decrease the pain/itchiness?

Anecdotally, we have found that people often report a decrease in pain and/or itchiness with treatment. It could be that decongesting the tissues takes pressure off nerve endings to provide relief from these symptoms. Lymphedema is typically not a painful condition, but people often describe discomfort related to the pressure of the swelling.

What will happen if I don't get treatment?

People with chronic continuous swelling are at risk for infection (cellulitis, lymphangitis). In addition, the longer the swelling remains in the tissues, the more the tissues may change by becoming fibrotic and/or depositing fatty tissue. All these issues may contribute to a worsening of the swelling.

Is there anything else that can help?

If you are overweight and/or inactive, addressing these issues can improve lymphatic flow. Check your medications with your doctor as sometimes a side effect can be swelling (although this would likely be a global body issue and typically not affecting one limb). Poor circulation can contribute to swelling (venous insufficiency) and sometimes specialized testing and treatment is beneficial for this condition.

There are compression wraps and lymphedema pumps, which are typically used as an adjunct to the prescribed therapy above and not a replacement.

What are the benefits of treatment?

With lymphedema treatment at MSU Rehabilitation, wonderful, sometimes life-changing, results can occur including,

- 1. Better fit of shoes and clothing*
- 2. Improved mobility*
- 3. Healthier skin*
- 4. Less discomfort*
- 5. Less risk for infection and further tissue damage*
- 6. Healthier Happier YOU!!!*