

SELF-ASSESSMENT FOR LYMPHEDEMA

THE 5th PILLAR OF MAINTENANCE



A GUIDE FOR SELF-CARE

Cathy Burt BScN (Hons), RMT, CDT

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*CONQUERING
LYMPHEDEMA
CHALLENGES WITH
KNOWLEDGE*

DISCLAIMER

This guidebook is for informational and educational purposes only. It is not intended to replace professional medical advice, diagnosis, or treatment. If you have lymphedema or any related condition, consult a qualified healthcare provider or lymphedema specialist before starting any self-care routine, including compression, exercise, skin care, or manual lymphatic drainage (MLD). The information provided is based on current best practices but may not be suitable for every individual. If you experience increased swelling, pain, skin changes, or signs of infection, seek medical attention immediately.

The creators of this guidebook are not responsible for any adverse outcomes resulting from the application of the information presented. Always follow the guidance of your healthcare provider for personalized care.

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A NOTE FROM CATHY

As a lymphedema therapist, I have helped many people manage their condition while balancing busy lives. Research shows that one significant challenge is a lack of education—when people don't have the right information, managing lymphedema becomes much more difficult. However, many research papers use the term 'compliance' when referring to self-care for lymphedema, which, to me, implies simply following a set of rules or expectations set by someone else. I believe that lymphedema self-care is not about compliance; it's about you taking an active, empowered role in your own health. With the right education and guidance to build your confidence, you can engage in self-care practices that work best for you.

Managing lymphedema requires daily attention, and knowing what works for you is essential. That's why I created a series of educational videos to help you:

- Understand the four pillars of self-care
- Learn how to track your progress
- Use simple methods to evaluate if your routine is effective

This guidebook is designed to complement the videos, offering clear steps for self-assessment. My goal is to help you feel confident in your care so you can take charge of your health. I hope these resources make your journey easier and more effective.

Introduction

Lymphedema is a condition of fluid and waste build up in tissues where lymphatic vessels are not working properly. It is a progressive condition that, as yet, has no cure. While managing it can be straight forward at times, fluctuations in both the amount of swelling and the consistency of the fluid are a reality. Complications such as infection, fluid leakage from the skin and changes in mobility over time can decrease quality of life. The key to keeping lymphedema in check lies not only in a good maintenance plan of self-care, but also checking periodically to see if your plan is working. This is called self-assessment. Self-assessment allows you to evaluate the effectiveness of your maintenance routine, which can sometimes feel like hard work with unseen results. The truth is, lymphedema can progress without you noticing for quite some time. By learning how to assess your lymphedema, you can catch changes early and make adjustments as needed. This booklet will be your guide to understanding self-assessment and is a powerful tool to help you manage your lymphedema.



This booklet can be used with the Pillars of Self-Care video series. You can find them on my YouTube channel <https://www.youtube.com/@swellingsolutions>

You have probably already been taught about the 4 pillars of lymphedema maintenance:

1. Compression
2. Skin care
3. Exercise
4. Self-manual lymphatic drainage (SMLD)

There is one key pillar missing:

5. SELF-ASSESSMENT

Even those who practice all four pillars can experience limb changes and increases in size. By learning to self-assess, you transform from a passenger on your health journey to the driver in control.

SELF-ASSESSMENT

Self-assessment involves the evaluation of how your maintenance plan is working for you. It helps you to identify urgent needs and keeps you on track with your lymphedema management plan.

Self-assessment looks at your:

- a) Compression garment(s)
- b) Exercise routine and movement capabilities
- c) Your limb size and shape
- d) Your self lymphatic drainage routine
- e) Evaluates the skin and underlying structures in order to identify any changes that may be occurring due to lymphedema progression

When do I do it?

1. Whenever you feel or see a change (limb size, new pain or swelling or even increased feeling of heaviness)
2. Just before you get a new garment

When to see your doctor

- Any new or sudden swelling, pain or changes in skin texture (new rash, skin weeping, lumps or bumps)
- Any signs of infection: Redness, Increased tissue warmth, swelling or pain in the area of swelling
- Before beginning a new exercise routine

Compression

Compression has been used in various forms since ancient Rome, but modern science has refined its role in supporting lymph and blood circulation, promoting wound healing, and softening hardened, fibrotic tissue. Today, compression garments come in a wide range of styles, pressure levels, and fabrics. However, what looks appealing may not always be the best choice for managing lymphedema. Because each person's condition is unique, it's essential to choose a garment that matches your specific stage of lymphedema, mobility, and ability to apply and remove it. A properly fitted garment with the right compression level and fabric can significantly improve both comfort and effectiveness, supporting better long-term management

What are the benefits of compression for lymphedema?

- Encourages fluid return out of the tissues and into the lymphatic vessels
- Graduated compression helps to bring fluid from areas that are congested to other areas that are working better
- Improves lymphatic function by stimulating contraction of the lymph vessels
- Helps calf muscle pump that helps lymph flow
- Helps to reduce inflammation
- Helps deter complications of lymphedema and its progression

see Pillars of Self-Care videos series at:
<https://www.youtube.com/@swellingsolutions>



Compression is Medicine for Lymphedema

Diabetes and high blood pressure are just a couple of examples of chronic conditions that require medicine for their control. As of yet, there is no medication for lymphedema, but compression garments, worn daily, can be considered medicine for lymphedema.

Compression

Maintenance vs Reduction Compression

Compression is used not only to reduce swelling in a limb but also to maintain its size. Compression therapy occurs in two phases: the reduction phase and the maintenance phase. The key difference between them lies in the type of compression used and the length of time it is worn.

Reduction Phase

- goals include decreasing limb size, soften hardened tissues, stop fluid leakage from tissue, improvement of mobility and pain or discomfort
- Compression bandages or velcro-style garments are used 23 of 24 hours a day in an intensive attempt to meet the goals of reduction
- Initial treatment length varies and continues until the maintenance garment is received

Maintenance Phase

- Compression in this phase is meant to maintain the goals of the reduction phase
- Various styles of knitted garments or velcro-style garments are used based on the size, shape and tissue characteristics of your area of swelling
- Maintenance garments are worn from within an hour of waking until bedtime
- Special night garments are available to help soften and control lymphedema while you sleep

Our bodies are constantly influenced by factors that can cause lymphedema to progress, leading to increased swelling, tissue hardening, and a higher risk of infection. These changes often happen gradually and can go unnoticed. Regularly assessing your compression garment and asking a few key questions can help ensure it continues to support your lymphedema management effectively.

It's essential that your compression garment meets your current swelling needs. The garment you start with may not be the same one you need years down the line. By tracking changes in your condition over time, you can make sure your compression remains the right fit for you.

Compression Check

THE RIGHT GARMENT

1. My garment does not cover all swollen areas
2. I have had more than one infection (cellulitis) in my swollen limb in the past year
3. My skin is hard/lumpy/bumpy
4. My limb is not a uniform shape
5. My swelling gets worse as the day goes on
6. My garment cuts in/hurts
7. I have trouble putting on or taking off my garment

THE RIGHT COMPRESSION

1. My garment is older than five months
2. My garment is loose and easy to put on
3. My garment is out of shape, has runs, tears or holes
4. I wash my garment daily/regularly
5. My swelling increases as the day goes on
6. I cannot put my garment on or have great difficulty doing it

THE RIGHT TIMING

1. My finger leaves an indent when I press into my skin
2. My clothes/shoes/jewelry feel tighter than usual
3. My self-measurement showed that my limb has increased since I measured last
4. My swelling increases or does not go down overnight
5. I have new or worsening swelling

EXERCISE

BENEFITS OF EXERCISE

- Improvements seen with fatigue, sleep quality and mood
- Helps to restore range of motion
- Helps with weight management (a BMI greater than 30 is associated with lymphedema progression)
- Increases immune cell activity and reduces inflammation
- Increases blood flow in the body
- Shown not to make lymphedema worse, but through muscle contractions, helps promote lymph flow

GENERAL RECOMMENDATIONS

- Build up to a program of 30 minutes three times a week of moderately intense exercise plus two muscle strengthening exercise sessions per week
- If starting a new program it is best to take a class to prevent injury
- End goal is 150 minutes per week of exercises that include a balance of strength, flexibility, aerobic and restoration and relaxation
- CAUTION: Seek the advice of your doctor or physiotherapist before beginning any new exercise regimen

Examples

AEROBIC	STRENGTH	STRETCH	LYMPHATIC
Cycling	Weights	Yoga	ALL EXERCISE
Dancing	Pilates	Qi Gong	
Walking	Resistance Bands	Water Yoga	Deep Breathing
Swimming	Yoga	Essentrics	
Aqua-fit	Essentrics		
Sports	Aqua-fit		

Exercise Check

Is your routine helpful?

EXERCISE INVENTORY

1. What are my exercise goals?
2. Do I have any exercise restrictions?
3. What exercises am I doing and how often am I doing them?
4. Do I Incorporate a variety of forms of exercise?
5. Make a list of your exercises under each category.
6. Do I include lymph specific exercises in my routine?
7. Do I like what I am doing?
8. If I stopped an exercise, why did I stop it?
9. Should I make a new plan that incorporates other forms of exercise?
10. Do I need help?

Whatever exercise routine you choose:

*DO WHAT MAKES
YOU SMILE!*



POST-EXERCISE CHECK

- Is my swelling reduced or stable? (No increased heaviness or tightness)
- Is my skin soft and pliable? (No hardening or thickening)
- Can I move my arm/leg/shoulder easily? (Better flexibility, less stiffness)
- Is my pain level low or improving? (No new aches, sharp pain, or discomfort)
- Do I feel energized after exercise? (Not overly fatigued)
- Has my urinary output increased? (A sign of better fluid movement. Note: not everyone will notice this after exercise)

Movement Check

Is your routine helpful?

Is a Plan Change Needed?

Consider changing your exercise plan if:

1. You are bored with what you are doing
2. You do not enjoy what you are doing
3. The exercises you are doing cause you discomfort, make your swelling worse or you find a form of exercise too difficult
4. You think you need a more challenging routine
5. You answer no to your post-exercise check



Who can you talk to about this?

Your doctor, physiotherapist, exercise specialist

Functional Movements That Can Be More Difficult After Cancer Treatment

After surgery, lymph node removal, and radiation for cancer treatment, scar tissue, muscle tightness, tissue restrictions, and lymphedema can develop. These changes may lead to joint stiffness, weakness, and reduced mobility, making everyday activities—especially those involving the shoulders, arms, and lower body—more challenging.

Note:

- Increased swelling can cause difficulty with movement.
- Decreased movement can occur with other health states.
- Decreased function of joints can impede lymph flow



Mobility Check

Is your routine helpful?

Mobility Check: Upper Body

These movements are often impacted due to tightness, pain, and swelling in the shoulders, chest, and arms:

1. Reaching Overhead – Difficulty lifting arms to put items on high shelves or getting dressed
2. Reaching Behind the Back – Trouble fastening a bra, scratching the back, or tucking in a shirt
3. Lifting & Carrying – Struggle with lifting grocery bags, picking up a child, or carrying laundry
4. Pushing & Pulling – Difficulty opening heavy doors or pushing a shopping cart
5. Fine Motor Tasks – Swelling in the hands or arms making it hard to button clothes, use utensils, or write



Mobility of The Lower Body

Lymphedema and stiffness in the hips, knees, and ankles can make movements harder, especially when standing, walking, or balancing.

Squatting & Bending – Struggle to pick up objects from the floor or get in/out of a chair

Climbing Stairs – Feeling weak, heavy, or unsteady going up/down stairs

Walking Long Distances – Fatigue, swelling, or stiffness making walking more difficult

Standing for Long Periods – Increased discomfort in the legs or feet when cooking or waiting in line

Balancing & Stepping Sideways – Feeling unstable when stepping sideways or turning quickly



Mobility Check

Is your routine helpful?



Mobility Check: Lower Body

Lower Body Mobility

- Can I squat down and stand up without knee or hip stiffness?
- Can I go up and down stairs without feeling weak or unsteady?
- Can I walk for 10-15 minutes without needing to stop due to discomfort?
- Can I stand for at least 10 minutes without swelling or pain?

Balance & Stability

- Can I balance on one foot for at least 5 seconds without wobbling?
- Do I feel stable when stepping sideways or turning quickly?

REMEMBER: Other health conditions also play a role in your mobility. It is good to look at the **BIG PICTURE** when doing your self-assessment. **IF YOU ARE FINDING YOUR MOBILITY A CHALLENGE, CONSULT YOUR MEDICAL PROFESSIONAL FOR ADVICE.**

Professionals to consider seeking advice from:

- Doctor
- Physiotherapist
- Lymphedema therapist
- see Pillars of Self-Care videos series at: <https://www.youtube.com/@swellingsolutions>

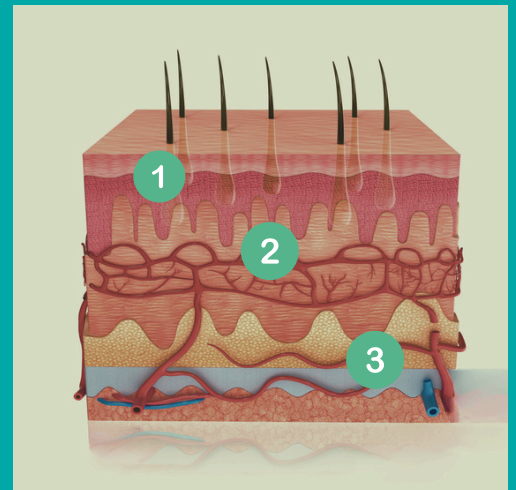
Skin Care

The skin is the body's largest organ, made up of three distinct layers. The outer layer consists of tightly packed cells held together by a natural "glue" that helps retain moisture. This layer also forms the acid mantle—a slightly acidic barrier that protects against infection and inflammation. Skin cells continuously renew, with old cells shedding as new ones form. Beneath the surface, a network of lymphatic and blood vessels, immune cells, oil and sweat glands, hair follicles, and nerve endings function within a framework of elastin and collagen fibers, which provide strength and flexibility. Deeper still, a layer of fat cushions and insulates the body, helping to regulate temperature and protect underlying structures.

see video explainer, Skin Care, at: <https://www.youtube.com/@swellingsolutions>

FUNCTIONS OF THE SKIN RELATED TO LYMPHEDEMA

- Barrier from environmental irritants
- Protection from infection
- Temperature regulation
- Sensation of vibration, temperature, pain or pressure



WHAT CAN HAPPEN WITH CHRONIC SWELLING?

- **Layer 1, the epidermis:** pH increases and moisture factors decrease making it more dry and more susceptible to infection.
- **Layer 2, the dermis:** The collagen-elastin component is gradually replaced by fibrous tissue making skin and underlying tissue less flexible and feel firm or hard when touched.
- **Both layers have lowered immune function** making an environment that is more susceptible to bacterial growth and infection.
- **Layer 3, the hypodermis:** Chronic inflammation stimulates increased fat cell production

Skin Care



As a result of hardening of tissue under the skin, tissue becomes less pliable and more difficult to pick up between two fingers



With changes in the skin's layers and its protective mechanisms, infection can occur.

SEE YOUR DOCTOR IF YOU EXPERIENCE:

1. A new rash
2. Increased swelling
3. Red coloured skin
4. Increased heat in the swollen area
5. Pain
6. Accompanying flu-like symptoms (fever or a feeling of being unwell)

Skin, Edema and Tissue Check

Self Measurement

ARM	LEG
<ul style="list-style-type: none">• Hand• Wrist• 4 fingers below elbow• Elbow• 4 fingers above elbow• Top of arm	<ul style="list-style-type: none">• Mid foot• Ankle• Hand width below knee• Knee• Hand width above knee• Hand width below groin crease

Other things to keep in mind is swelling in your hips, buttocks, back or under your armpits and sides. Check in a mirror to see if one side looks different from the other. See measurement trackers at the end of this guidebook.

Consistency Counts

- Try to measure in the morning when your at your lowest
- Use the same tape measure and tension when measuring
- Try to measure at consistent points: you can use body landmarks such as ankle/wrist bones, moles or freckles or even use specific measurements that you mark with a washable pencil like an eye liner pencil before measuring around you limb.
- You may need someone to help with your measurements

Fluctuations do occur

- Certain foods, illness, other chronic conditions, hormone changes, humidity, increases in weight and muscle mass and some medications can influence body fluid levels
- If you notice your limb size is up or down with this measurement, try again over the next few days to get a better idea AND look at your other assessment results to see if your measurements correspond with your other checklists

Self-Measurement

Measuring Checklist

1. Preparing for Measurement

- Are you measuring your limb at the same time of day each time (preferably in the morning before activity and fluid accumulation)?
- Are you using the same measuring tape each time (flexible, non-stretch, and marked in centimeters or inches)?
- **Are you in the same position each time you measure (seated or standing, with the limb relaxed)?**

2. Measurement Technique

- Are you measuring at consistent landmarks (e.g., wrist, mid-forearm, elbow, mid-upper arm for an arm, or ankle, mid-calf, knee, mid-thigh for a leg)?
- Are you keeping the tape snug against the skin without pressing too tightly or leaving gaps?
- Are you recording circumference measurements at consistent points?
- Tracking & Comparing Measurements
- Are you recording your measurements in a journal or digital tracker to compare trends over time?
- Do your measurements remain stable or show a decrease over time with consistent self-care?
- Are there sudden increases (2 cm or more) in one or more areas that may indicate fluid buildup?

Suggested Actions Based On Assessment Results:

- Stable or decreasing measurements: Your self-care plan is working well. Keep tracking regularly.
- Mild increase in some areas: Adjust your routine—ensure proper compression use, increase self-MLD, and monitor closely.
- Significant or persistent increase: Contact your lymphedema therapist for evaluation and guidance.



Tissue Assessment

See Assessment checklist at the end of this guidebook



LOOK

Visual inspection is likely something you already do regularly. Infection is a common complication of lymphedema, and early detection is key to managing it effectively. When swelling accumulates, the skin of the affected limb may take on a pinkish hue—an indication of chronic fluid and waste buildup beneath the skin, leading to inflammation.

By performing regular assessments, you'll begin to notice patterns in your skin's color and be better equipped to identify changes that aren't normal for you.

As you assess your skin, take note of the following:

1. Skin Condition

- ☐ Is your skin free from cracks, dryness, or flaking?
- ☐ Does your skin feel soft and well-moisturized, not tight or rough?
- ☐ Are there any areas of redness, irritation, or sensitivity?

2. Signs of Infection

- Is your skin free from any unusual warmth, swelling, or tenderness?
- Are there any cuts, scratches, or sores that are slow to heal?
- Do you have any red streaks, fever, or chills (which could indicate an infection like cellulitis)?

3. Hydration & Moisturization

- Are you applying a fragrance-free, hypoallergenic moisturizer daily?
- Is your moisturizer being applied immediately after bathing to lock in moisture?
- Does your skin feel properly hydrated throughout the day (not excessively dry or oily)?



See your
lymphedema
therapist if you see
or feel these
changes



Tissue Assessment

See Assessment checklist at the end of this guidebook

LOOK



4. Cleansing Routine

- Are you using a mild, non-irritating, fragrance-free cleanser?
- Are you avoiding hot water and harsh scrubbing when washing?
- Is your skin completely dry before applying moisturizer or compression garments?

5. Skin Protection & Prevention

- Are you protecting your skin from insect bites, cuts, and scratches?
- Do you wear protective gloves when gardening or cleaning?
- Are you avoiding sunburn by using sunscreen and protective clothing?

6. Compression Garments & Skin Health

- Are your compression garments clean and free of rough seams or worn areas that could irritate your skin?
- Do you check your skin after removing garments for any indentations, redness, or irritation?
- Are you wearing compression consistently without discomfort or excessive tightness?



Tissue Assessment

See Assessment checklist at the end of this guidebook

FEEL



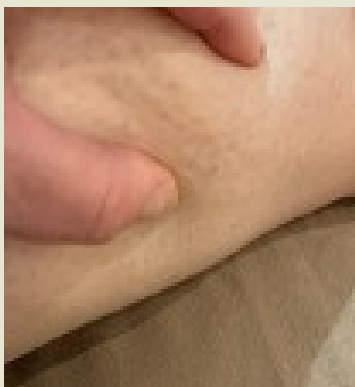
1. Tissue Texture & Firmness

- Does your skin feel soft and pliable rather than firm, fibrotic, or hardened?
- Can you gently pinch the skin without feeling excessive tightness or resistance?
- Do you notice any areas of thickened, leathery, or bumpy skin that may indicate fibrosis?

2. Pitting & Fluid Retention

- When you press on your skin for a few seconds, does the indentation disappear quickly?
- Do you notice persistent pitting (a dent that remains after pressing), which may suggest fluid buildup?

NOTE: Any new or sudden signs of swelling should be assessed by your doctor



Fluid/Fibrosis in tissues



No fluid in Tissues

See your
lymphedema
therapist if you see
or feel these
changes

Self- MLD

Manual lymphatic drainage (MLD) is a specialized technique that involves gentle, rhythmic hand movements, much lighter than traditional massage. Since the peripheral lymphatics are located close to the surface of the skin, the goal of MLD is to guide fluid away from congested areas toward regions with better drainage.

However, MLD is more than just light massage strokes—it also includes what can be described as tissue remodeling techniques. These techniques help soften hardened tissue, break down adhesions, and improve mobility in areas affected by fibrosis or scar tissue. A lymphedema therapist can teach you how to incorporate these methods into your self-care routine.

Because every person's lymphedema is unique, MLD should be tailored to individual needs. The techniques you use may differ from those of someone else, and over time, your self-MLD routine may need to change. What works for you in the early stages may not be what you need months or years later. This is why it's essential to have your drainage patterns assessed periodically by a lymphedema therapist, who can adjust your self-care plan as needed.

If, during your self-assessment, you notice any tissue changes—such as increased firmness, thickening, or new restrictions—reach out to your lymphedema therapist. They can guide you on modifications to your routine that may help soften these areas and improve your overall lymphatic function.

Tissue assessment may feel challenging at first, but with time and practice, you'll become more confident in your ability to recognize changes. When you see your lymphedema therapist, get involved—ask them what they're feeling and feel for yourself. Compare your own findings with theirs to develop a better understanding. After all, you are an essential part of your lymphedema care team.

If you notice changes in your tissue, your therapist can help adjust your self-care routine. Additionally, your fitter may recommend a different compression garment that provides a gentle micro-massage effect, helping to soften the tissue as you wear it.

Self- MLD Check

1. Changes in Swelling & Limb Size

- Do you notice a reduction in swelling in the treated area?
- Are your clothes, jewelry, or shoes fitting more comfortably?
- If you use measurements, has the circumference of your limb decreased?



2. Skin & Tissue Changes

- Does your skin feel softer and less tight?
- Are any previous areas of pitting edema improving?
- Do you notice a reduction in fibrotic (hard) areas?

3. Sensation & Comfort

- Do you feel a lightness or relief in the treated area after self-MLD?
- Has any aching, heaviness, or discomfort decreased?
- Do you feel a mild warmth or tingling, suggesting improved circulation?

4. Function & Mobility

- Are you able to move more easily with less restriction?
- Do your joints feel less stiff in the affected limb?

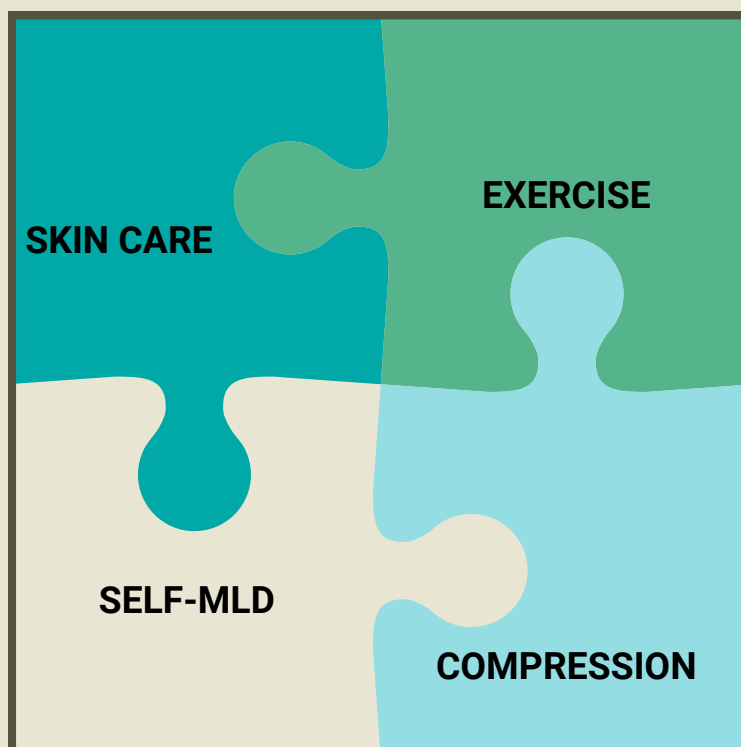
5. Consistency & Adaptation

- Are you performing MLD regularly (as recommended by your therapist)?
- Have you adjusted your technique or routine based on how your body responds?
- Do you combine MLD with compression, exercise, and skincare for best results?

PUTTING IT ALL TOGETHER

SUMMARY

Lymphedema is a chronic condition of swelling that can affect any body region. Because lymphedema does not resolve on its own, ongoing self-care is essential to manage and prevent its progression. The four key pillars of self-care—exercise, self-MLD, skin care, and compression—play a crucial role in controlling lymphedema. However, to know if your routine is truly working, regular self-assessment is key. Tracking changes in swelling, mobility, and how your body feels over time helps you identify patterns and make necessary adjustments. By monitoring all four areas of self-care together, you gain a clearer picture of what's effective and where improvements may be needed.



1. Ensure you limb is in a relaxed position. Maintain consistency by measuring in the same position each time you measure.
2. Use a flexible tape measure. The tape measure should not cause bulging of tissue. Tension should be taught, but not constricting.
3. Measurements should be done in the morning.
4. Write down your measurements in the chart and then add the total measurements. This is an easy and effective way to catch flare-ups if there is a spike in total measurements seen.
5. When entering the intensive phase, measurements should be completed at least weekly. In the maintenance phase, measurements can be done monthly or when you feel a change (increased heaviness, tightness or a change in fit of clothing).
6. The hand is measured across the knuckles. The wrist should be measured just before the wrist bone. The largest forearm is usually about 3 fingers below the elbow crease. The largest upper arm can be measured at the level of the armpit or where your compression sleeve ends.

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MEASUREMENT TRACKER

LEG

Instructions & Tips

1. Ensure your limb is in a relaxed position. Maintain consistency by measuring in the same position each time you measure.
2. Use a flexible tape measure. The tape measure should not cause bulging of tissue. Tension should be taught, but not constricting.
3. Measurements should be done in the morning.
4. Write down your measurements in the chart and then add the total measurements. This is an easy and effective way to catch flare-ups if there is a spike in total measurements seen. Fluctuations occur. Allow for 1/2 differences in each measurement spot. If you find increases, measure again the next day and compare.
5. When entering the intensive phase, measurements should be completed at least weekly. In the maintenance phase, measurements can be done monthly, before your next garment purchase or when you feel a change (increased heaviness, tightness or a change in fit of clothing).
6. The foot is measured about four to five finger widths below the tip of the big toe. The ankle, just above the bones. Measure the calf about a hand's width below the knee crease. Choose a point mid-way between the knee and the groin for the thigh measurement. You can use two measurements on your thigh if you wish. It is up to you.

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NOTES FOR FITTER OR LYMPHEDEMA THERAPIST

Take this guide with you to your appointment. Use this page for any questions you may have for your fitter or lymphedema therapist. Write down their answers beside your question or any important information they may give you during your appointment.

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