2023

# A Proactive Approach To Lymphedema Treatment: A Patient'S Educational Guide

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# A PROACTIVE APPROACH TO LYMPHEDEMA TREATMENT: A PATIENT'S EDUCATIONAL GUIDE

by

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A Scholarly Project

Submitted to the Graduate Faculty

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Occupational Therapy Doctorate

Casper, Wyoming

May
2023

This scholarly project submitted by Bridget Reuss in partial fulfillment of the requirement for the Degree of Occupational Therapy Doctorate from the University of North Dakota, has been read by the Faculty Advisors under whom the work has been done and is hereby approved.

Wanda Lauer

Wanda Lauer

4/10/23

Date

PERMISSION

**Title:** *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide*

**Department:** Occupational Therapy

**Degree:** Occupational Therapy Doctorate

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ACKNOWLEDGEMENTS

My faculty advisor, Dr. Lauer, and my site mentor, Sarah Tanner, were both instrumental in my success during this project. I am grateful for the encouragement and support provided from my family and classmates over the past three years.

## Abstract

**Title:** *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide*

**Background:** Lymphedema affects between 90 and 250 million people worldwide, yet there is little information about it, and it is poorly understood by the medical community (Manrique et al., 2022). This too often results in patients not receiving proactive treatment for their symptoms. Proactive intervention increases the patient's ability to engage in meaningful occupations, socialization, quality of life, mobility, and confidence (Dominick et al., 2014; Lu et al., 2015; Warren et al., 2007; Yarmohammadi et al., 2021).

**Purpose:** The purpose of this scholarly project was to create a guide specific to individuals who are at risk of developing lymphedema or who already have a diagnosis of lymphedema. This guide is intended to help patients manage lymphedema symptoms proactively so that they can remain independent in occupations that are meaningful to them. *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is a paper handout for patients that consists of lymphedema education, preventative handouts, interventions, and safe exercises. The guide addresses proactive lymphedema education for patients who are at risk of developing lymphedema or who have already been diagnosed through an easy-to-use guide that includes best practice interventions for lymphedema treatment. Additionally, this scholarly project is expected to improve patient outcomes and increase awareness of lymphedema conditions.

**Methodology:** An extensive literature review, needs assessment, informal observation, and continuing education courses, were completed during the process of creating the guide. To guide the methodology and development of the guide, theoretical models such as Ecology of Human Performance (EHP) and principles of andragogy were used (Bastable et al., 2020; Dunn et al., 1994).

**Conclusions:** The guide is intended to be viewed by individuals who are at risk or already diagnosed with lymphedema. *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is an easy-to-use guide for patients to be used under the guidance of a healthcare professional. The guide is intended for individuals who are at risk or have already been diagnosed with lymphedema. The projected outcome of the guide is increased participation in daily tasks, health management, increased quality of life, mobility, socialization, and meaningful occupations.

# CHAPTER I

## Introduction

Lymphedema affects approximately 90 million people in the United States (Warren et al., 2007). Lymphedema is a chronic condition associated with progressive swelling due to the lymphatic system not functioning correctly. As a result, lymphedema impacts a person's ability to engage in daily occupations due to negative body image, decreased self-confidence, decreased range of motion, swelling, psychological distress, and sexual difficulties, affecting the patient's overall quality of life (Morgan et al., 2005). Cohen et al. (2001) reports that taking a proactive approach to lymphedema management can help reduce a patient's risk for lymphedema and decrease functional limitations. As a result of not being proactive, patients report more pain, decreased social support, poor coping strategies, psychological distress, sexual dysfunction, and both social and vocational issues (Cohen et al., 2001).

Occupational therapy practitioners have a crucial role in treating lymphedema.

Occupational therapy practitioners can assist patients with modifying or adapting their habits and routines in order to proactively manage their lymphedema symptoms. Additionally, occupational therapy practitioners provide education, safe exercises, manual therapy, and can obtain standard or unstandardized tests to measure the impact lymphedema has on the patient's daily life. In addition to providing education on what lymphedema is, occupational therapy practitioners can assist patients with lymphedema who have limited mobility and decreased range of motion perform of activities daily living (ADLs) and instrumental activities of daily living (IADLs) (Borman, 2018; Morgan et al., 2005; Rubio, 2018; Yildiz et al., 2022).

Patients with lymphedema may not understand their symptoms, diagnoses, treatments, or daily routines, which may adversely affect function (Yildiz et al., 2022). According to Alotaibi et al. (2019), healthcare practitioners do not always explain to patients the purpose or reason for making the referral to occupational therapy; as a result, patients lack the motivation to schedule appointments with an occupational therapy practitioner, and do not seek treatment until symptoms occur (Alotaibi et al., 2019). A proactive approach to lymphedema management reduces the impact on daily occupations and improves the quality of life by reducing the risk of developing later stage lymphedema and empowering patients to self-manage their symptoms (Morgan et al., 2005).

According to researchers (Fu et al., 2014), there is little knowledge of the types of interventions used to treat lymphedema. There is a lack of proactive education and treatment options for those at risk or already diagnosed with lymphedema. To address these needs, a guide titled *A Proactive Approach To Lymphedema Treatment: A Patient's Educational Guide* was created as a result of this scholarly project. The purpose of the guide is to provide education and proactive intervention to individuals who are either at risk or have a diagnosis of lymphedema.

A practitioner providing lymphedema services in a wide range of settings may find this guide useful when implementing the intervention phase of the therapy process. The settings may include hospitals, nursing homes, home health, and outpatient clinics.

**Guiding Theory**

The Ecology of Human Performance theoretical model helped guide the product by recognizing the transactions between the person, context, task, and performance range (Dunn et al., 1994). Additionally, the EHP model aided in intervention strategies for the guide. The guide

is based off of the andragogical theory of teaching and learning, which aims to facilitate greater understanding, retention, and implementation of the guide.

**Ecology of Human Performance**

This guide was developed using the Ecology of Human Performance (EHP) (Dunn et al., 1994). The EHP model was selected as it considers the relationship between the constructs, the *person*, the *context*, and the *task*, as well as the impact on their *performance range*. *Performance range* is the interaction between the person and their context. The terms *task* and *context* are used in the EHP model as opposed to *occupation* and *environment* (Dunn et al., 1994).

**Andragogy Theory of Teaching and Learning**

Andragogy is a teaching and learning theory that is used in adult learning and emphasizes the learner rather than the teacher. Bastable et al. (2020) notes that this method is useful when providing education to adult patients. This method allows the patients to apply the information learned from the occupational therapy practitioner and understand the value of the guide. The andrological theory was applied to the guide as the majority of the partnered facility's patients with lymphedema are adults. Adult patients generally want to apply the information immediately, understand the value of what they are learning, and are eager and prepared to learn (Bastable et al., 2020). Integrating andragogy theory into product development was therefore beneficial.

**Scholarly Project Overview**

Chapter I consists of an introduction to the problem that is addressed throughout the guide. Chapter II contains the literature review of research. Chapter III then contains the methodology that was carried out to develop the scholarly project. Chapter IV contains the

product overview discovered from the literature review and the need for proactive lymphedema intervention. Lastly, Chapter V summarizes the guide, provides strengths and limitations, suggestions for further research, recommendations for use, and a final conclusion. The guide, *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide*, can be found in Appendix A.

# CHAPTER II

## Literature review

Lymphedema is a chronic condition associated with progressive swelling due to the lymphatic system not functioning correctly. In the United States, primary lymphedema affects one out of 100,000 individuals (Sleigh & Manna, 2022). Secondary lymphedema affects approximately one in 1,000 Americans yearly (Sleigh & Manna, 2022). As a result, lymphedema impacts a person's ability to engage in meaningful occupations such as work, leisure, activities of daily living (ADLs), instrumental activities of daily living (IADLs), and social participation. Lack of engagement in occupations may be due to negative body image, decreased self-confidence, decreased range of motion, swelling, psychological distress, and sexual difficulties, affecting the patient's overall quality of life (Donmez et al., 2021; Sleigh & Manna, 2022). Occupational therapy has a unique perspective when it comes to treating individuals with lymphedema. In addition to assisting patients with lymphedema to take proactive steps to prevent chronic lymphedema, occupational therapy practitioners can make home and activity modifications, as well as collaborate with them on occupations that are meaningful to them. (Dominick et al., 2014; Fu et al., 2014).

According to Fu and colleagues (2014), patients who take a proactive approach to lymphedema management reduce their risk for lymphedema and decrease dysfunction. Decreased pain, increased social support, appropriate coping strategies, less psychological distress, decreased sexual dysfunction, and diminished social challenges have been reported by patients who have taken a proactive approach to lymphedema. Research has indicated that when patients receive education regarding their lymphedema risk, their willingness, feelings of

empowerment, and awareness increases significantly. In addition, this approach has been shown to decrease patient anxiety (Fu et al., 2014).

Many patients suffering from lymphedema do not understand what they are experiencing. They may be unaware of the symptoms, diagnosis, treatment options, and daily routines that can be associated with lymphedema. This may cause them to become dependent, less social, lose interest or ability to participate in hobbies/occupations, and have decreased self-esteem (Yildiz et al., 2022). Alotaibi et al. (2019) reported that when healthcare practitioners make a referral to occupational therapy, they do not always fully explain the purpose or reason for the referral to the patient; therefore, the patient lacks the motivation to follow through with the appointment and not to seek treatment until symptoms arise (Alotaibi et al., 2019). Occupational therapy can provide individualized and proactive treatment to patients experiencing lymphedema. As part of lymphedema management, proactive measures can be taken to reduce the impact on daily occupations and improve quality of life for individuals with lymphedema (Sleigh & Manna, 2022; Yarmohammadi et al., 2021).

In summary, those who take a proactive approach to treating their lymphedema conditions often have better outcomes. The Ecology of Human Performance model is an occupation-based model that supports patients' participation in meaningful occupations, social participation, and independence.

**Occupational Therapy Framework**

The Ecology of Human Performance (EHP) was selected as the model used to guide the development of this scholarly project (Dunn et al., 1994). The EHP model focuses on four primary constructs: the *person*, *task*, *context,* and *performance range*. The *person* includes their

experiences, values, interests, and skills (sensorimotor, cognitive, and psychosocial) (Dunn et al., 1994). *Tasks* are observable set of behaviors that allow individuals to complete goals (Dunn et al., 1994). *Context* involves meaningful enviroments to the person, which can include temporal, cultural, social, and physical contexts (Dunn et al., 1994). Once an exhaustive analysis of the constructs has been completed, this will determine the individual's capacity to perform tasks (*performance range*). *Performance range* refers to the interaction between the person and their context. The EHP model also provides five intervention strategies to assist in the development of an increased performance range for individuals: *adapt* or *modify*, *establish* or *restore*, *create*, *prevent*, and *alter* (Dunn et al., 1994).

The assumptions of the EHP model align with this project in various ways. First, for this project, the *person* will be an individual with lymphedema or at risk of developing lymphedema. Second, the *tasks* include health management, garment management, signs of infection, symptoms of lymphedema, referrals, and patient needs. Third, the *context* will be defined by how the person interacts within their environment.

***Person***

In the EHP model, a person is composed of a combination of their past and present experiences, skills, values, and interests (Dunn et al., 1994). Each patient's health care experience is impacted by their skills, experiences, values, and interests. As an example, some patients may have had previous exposure to lymphedema, while others may not. Furthermore, some patients may be able to wrap their extremity independently, whereas others may have limited range of motion, requiring assistance from a caregiver.

### *Tasks*

Dunn et al. (1994) defines *tasks* as behaviors that are observed and help a person complete what they need to do. Tasks can include all activities that are essential to a person's health and well-being (Dunn et al., 1994). Patients with lymphedema who are seeking proactive treatment want to be active and independent in their meaningful occupations. When patients receive proactive lymphedema treatment, this can increase their ability to participate in activities that they want and need to do.

### *Context*

According to Dunn et al. (1994) EHP model, the context consists of the social, temporal, cultural, and enviromental characteristics (Dunn et al., 1994).

#### Temporal

Individuals with lymphedema often have comorbidities such as cancer, congestive heart failure, obesity, and more. When individuals with lymphedema are scheduled for appointments to see a specialist, they may not be included in the planning process.

Having scheduling conflicts affecting a patient's personal life and other appointments can hinder their ability to attend the appointment because of a lack of knowledge and fatigue from other appointments as well as lymphedema treatments (Dominick, 2014).

#### Cultural

The cultural context can support patients with lymphedema by attending support groups, providing familial support, and learning about effective treatment strategies and approaches (Donmez et al., 2021).

**Enviromental**

Examples of the enviromental context for patients with lymphedema include the supplies they need for interventions. This includes foam, tape, bandages, and stockinettes. Additionally, this enviroment could be the setting in which they receive healthcare services.

***Performance Range***

Performance range is the interaction between the person's context and tasks (Dunn et al., 1994). Individuals who are not proactive in treating lymphedema often experience decreased ability to participate in meaningful occupations. Specific occupational challenges include the inability to participate in work, household maintenance, leisure, self-care, sex, limited range of motion, lack of sensation, and pain. Unfortunately, the inability to participate in meaningful occupations leads to decreased quality of life (Dominick et al., 2014). Due to the decreased range of motion, strength, sensation, and other factors associated with lymphedema, patients may not be able to perform meaningful activities, leading to a decrease in their performance range (Dominick et al., 2014). See Table 1 for EHP definitions and application to the guide.

Table 1

*Ecology of Human Performance (EHP) Definitions and Application to Guide*

| EHP Term | Definition | Application to Guide |
|---|---|---|
| **Person** | According to the EHP model, individuals are personified by their experiences, skills (cognitive, sensorimotor, psychosocial), values, and beliefs. | Individuals with a diagnosis of lymphedema or who are at risk of developing lymphedema. |
| **Task** | An objective set of behaviors necessary to accomplish a goal. | Tasks include what the patient wants and needs to do. This guide aims to provide |

| | | |
|---|---|---|
| | | patients with proactive treatment options so patients can perform certain tasks that are important to them. |
| **Context** | Conditions in which the person exists and performs this includes temporal, enviromental, and cultural aspects. | Stage of lymphedema impacts that type of intervention that the occupational therapy practitioner should consider for each patient. |
| **Performance Range** | The transaction between the person and context. | Providing proactive treatment to patients who are either at risk or already diagnosed with lymphedema increases their performance range to participate in tasks that are meaningful to them. |
| **Intervention Types** | | |
| **EHP Term** | **Definition** | **Application to Guide** |
| **Adapt/Modify** | Task demands can also be adapted to enable performance by manipulating and structuring the context. | Using a loofah/shower brush so that patients can independently complete manual lymphatic drainage.<br><br>Use a sock aid, dish gloves, or other donning aids for compression garments. |
| **Alter** | Changing the context in which the person performs. | Occupational therapy practitioner's making a referral to other disciplines, such as wound care or physical therapy to support the patient's needs. |
| **Create** | Creating situations that support patients' performance. | Occupational therapy practitioners should monitor their patient's needs and change the patient's home programming as needed. For example, if the patient only needs upper extremity exercises, the occupational therapy practitioner should |

| | | |
|---|---|---|
| | | only administer the upper extremity exercises from the guide and exclude the lower extremity exercises. |
| **Establish/Restore** | The goal of this intervention strategy is to provide intervention at the individual level. It involves restoring function through improving abilities and skills. | Providing range of motion exercises so patients can independently participate in health maintenance tasks, such as lymphedema bandaging and donning/doffing compression garments. |
| **Prevent** | In this type of intervention preventing maladaptive performance is the main goal of this type of intervention. This is done by addressing factors such as the individual, the task, and the environment that may be responsible for the development of maladaptive behavior. | Teaching patients the purpose of the lymphatic system, how to complete MLD, proactive treatment, such as proper skin care, and compression therapy. |

**General Lymphedema Information**

Patients that are proactive in their approach to lymphedema treatment are more likely to be successful in meaningful occupations and less likely to develop late-stage lymphedema (Lu et al., 2015). Fortunately, there are many formal treatment options certified lymphedema therapists or certified occupational therapy practitioners trained in lymphedema can use to promote healing, such as complete decongestive therapy, manual lymphatic drainage, kinesiotaping, pneumatic compression, and education on self-management that may include bandaging, exercise, and skincare. While these options are effective, it is essential for individuals at risk of getting lymphedema to know the signs and symptoms and ways to be proactive when at risk for lymphedema. A practitioner who does not have any lymphedema experience should familiarize

themselves with this guide prior to administering it, become trained in lymphedema, become a certified lymphedema therapist, or seek a referral to a qualified lymphedema specialist if they wish to administer the guide.

Proactive treatment options include education from a specialist, regular exercise, a healthy diet, avoiding restrictive jewelry/clothing, proper skin care, self-manual lymphatic drainage (MLD), breathing, activity modification, scar tissue massage, and body positioning (Borman, 2018; Cohen et al., 2001; Lu et al., 2015; Yarmohammadi, 2021).

Lymphedema is described as an excess accumulation of protein-rich fluid that causes body tissue to swell due to improper lymphatic system functioning (American Cancer Society, 2021). There are several reasons why a person can become diagnosed with lymphedema. Lymphedema can be caused by a traumatic injury, surgery, radiation therapy, infection, immobility, obesity, or cancer, or it may be congenital or hereditary (American Cancer Society, 2021; Borman, 2018). There are four stages of lymphedema, ranging from stage zero to three (Morgan et al., 2005).

***Evaluation***

At the initial assessment, the occupational therapy practitioner should do the following: review the patient's history, complete an occupational profile, learn how the patient's swelling is impacting their daily occupations, and collaborate with the patient to decide what goals are important to the patient (Borman, 2018; Warren et al., 2007).

The Lymphedema Life Impact Scale version 2 is a tool that practitioners can utilize to better assess the effect and specific areas of life that lymphedema is affecting their patients. The scale is based on a 0 to 4 Likert scale (Weiss & Daniel, 2018).

The Lymphedema Functioning, Disability, and Health Questionnaire for Upper Limb (Lymph-ICF-UL) have high content validity and psychometric properties (Meilani et al., 2022). The Lymph-ICF-UL has sufficient relevance, comprehensiveness, and comprehensibility. The questionnaire is quick and easy for patients and clinicians to understand. The questionnaire takes approximately five to ten minutes to complete and is based on an 11-point numerical scale. The Lymph-ICF-UL is available in various languages. The Lymph-ICF-UL evaluates in close detail what specific daily activities the patient is having difficulty with. The questionnaire has five domains: physical function, mental function, household, mobility, and social activity.

### *Proactive Intervention Approaches*

Occupational therapy practitioners are also trained to use theoretically informed intervention strategies to provide skilled services to their patients. Five intervention strategies are outlined in the EHP model that is designed to support a patient's needs and interests (Dunn et al., 1994).

*Establish/Restore* – focuses on person factors and aims to improve the person's skills. *Alter* – focuses on the context in which the person performs and finding the best match. *Adapt/Modify* – focuses on changing aspects of the context or adjusting task features. *Prevent* – is to preclude the development of performance problems.

*Create* – focuses on creating circumstances that support optimal performance for all persons and populations.

See Table 1 for how EHP intervention strategies were implemented in the product.

### *Proactive Signs/Symptoms*

When a person's lymphatic system is not functioning correctly, some of the signs that may indicate a person needs to seek medical attention include changes to their skin, such as thickened skin, heaviness in the limbs, pain when they palpate the skin, and a slowed wound healing (Borman, 2018). Depending on the person, the effects of lymphedema may appear differently. A patient with lymphedema symptoms should consult an occupational therapy practitioner to learn about proactive treatment options.

## Occupational Therapy's Role

Occupational therapy practitioners have a unique role when it comes to providing treatment to individuals with lymphedema. Occupational therapy combines the medical model and holistic care in order to provide patients with a balanced lifestyle, satisfaction in occupations, and intervention for lymphedema. An occupational therapy practitioner's most valuable skill is the ability to use therapeutic use of self. To achieve therapeutic use of self, practitioners must demonstrate empathy, personal understanding, and professional reasoning.

The goal of occupational therapy is to approach treatment from a holistic perspective. When occupational therapy practitioners use a holistic approach, it involves considering the person and their context to achieve a balance between play, rest, and daily responsibilities (Rubio, 2018).

## Statement of need

An essential aspect of managing lymphedema on a long-term basis is self-care. Managing one's health and treating lymphedema conditions proactively can be a challenge for many patients, especially those who find it difficult to adhere to a self-management program.

patient’s quality of life can be improved by providing patient education and risk reduction strategies. According to research, proactively treating lymphedema will improve health outcomes (Fu et al., 2014). Occupational therapy practitioners are skilled practitioners who provide intervention to support patients' independence in everyday occupations. However, currently, there is limited research and programming in occupational therapy practice for proactive lymphedema treatment.

# CHAPTER III

## Methodology

Chapter III Methodology includes the motivation for development, theory, literature review steps, and the need for programming. This includes the literature review process and how the EHP model (Dunn et al., 1994) and andragogy teaching and learning theory (Bastable et al., 2020) were incorporated into the guide. *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is for individuals at risk or who already have a diagnosis of lymphedema. The guide originated from the author's desire to work with the population and noticing a gap in the care that individuals with lymphedema were receiving.

### Motivation for Development

It has been one of the author's greatest passions during my time at the University of North Dakota to study lymphedema. As the author completed level II fieldwork at the partnered agency, the author noticed that the facility and patients would benefit from patient education material on how to self-manage lymphedema. A few months later the author returned to the partnered agency and the site mentor and author collaborated closely on what the product should look like. The author and site mentor decided that it should be for the adult population as that is the majority of their caseload, paper format, large and simple text for ease of use, and limited jargon. *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* seeks to integrate proactive treatment into patients' treatment plans and daily routines (Appendix A).

### Theoretical Framework

The Ecology of Human Performance (EHP) model (Dunn et al., 1994) was used to develop the guide, *A Proactive Approach to Lymphedema Treatment: A Patient's Educational*

*Guide.* The author created research questions for the literature review using constructs and sub-constructs of the model to ensure *person*, *contextual*, *task*, and *performance range* factors were accounted for throughout the development of the guide. The EHP model was also used in the final product design. How the person interacts within their context will determine their *performance range* (Dunn et al., 1994). EHP defines the *person* as a complex individual, including their past and present experiences, values and interests, and numerous personal factors (sensorimotor, cognitive, and psychosocial). Depending on the resources available to the individual, the *task* varies, but it does impact the individual's overall *performance range* depending on the relationship between the person and their contextual variables.

EHP has five intervention approaches that assist in meeting the patient's needs: alter, adapt/modify, create, establish/restore, and prevent (Dunn et al., 1994). See table 1.0 for definitions and application to the guide. To assist occupational therapy practitioners with the patient's home programming, the EHP intervention approaches were applied to the guide. For example, if the patient has concerns about completing the suggested exercises, the occupational therapy practitioner should adapt the exercises by having the patient do them in sitting.

A secondary theory used in the product development process was the andragogy theory (Bastable et al., 2020). Using andragogical principles, the guide focuses on the learner rather than the teacher. Educating adults who are eager, prepared to learn, and capable of applying the information immediately is useful using this theory. As a result, the integration of andragogy teaching and learning theory was an effective tool for developing the product.

**Literature Review**

First identifying what information was available related to lymphedema treatment, interventions, importance of being proactive, treatment techniques, and role of occupational therapy was completed in creating *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide*. Next, analyzing what best practices are for lymphedema treatment and interventions were reviewed. An analysis of the barriers and supports faced by individuals with lymphedema was conducted following my research into best practices in lymphedema therapy. A few examples of search terms used include: "(lymphedema) AND (occupations OR activities)" and "(lymphedema) AND (health management)" and "(lymphedema) AND (proactive OR effective). Inclusion and exclusion criteria were then developed for each combination of search terms. Inclusion criteria included for the searches included: in English, related to lymphedema, swelling, edema, breast cancer related lymphedema, and articles published in 2000 or after. Exclusion criteria for the searches included: languages other than English and articles published before 2000. A literature review was conducted using databases deemed appropriate for the type of data being collected (i.e. health sciences databases for allied health research). The literature review was conducted using a variety of electronic databases and professional organizations. A variety of databases were used to gather information: American Journal of Occupational Therapy, CINAHL, University of North Dakota Scholarly Commons, and PubMed.

Through mentored treatment sessions, the author had the opportunity to learn what some of the patient's concerns were. Patients had common concerns about remembering how to bandage their extremities independently so the author provided a notes page within the guide. Another concern was that the patient didn't feel safe while exercising or that the exercises would

be too difficult, so the author provided modifications for the occupational therapy practitioner to suggest and demonstrate.

### Need for Proactive Lymphedema Intervention

After the literature was collected and analyzed, the author realized that there was a significant need for proactive intervention resources for individuals who are at risk or already have a diagnosis of lymphedema. A guide was developed to provide simple directions with pictures on how to bandage arms and legs, exercises, how to perform self-massage, and basic education on lymphedema. It is important for patients to receive proper education prior to receiving the guide, this will allow the patient to complete the interventions correctly and increase patient outcomes. To reach a wide range of patients and learning styles, the product was developed using eighth grade reading level. This allowed for the guide to potentially reach a broader range of patients and abilities (Bastable et al., 2020). To ensure greater retention and self-directed learning, the product included photos and clear colors and fonts (e.g., pictures of manual lymphatic drainage techniques, exercises, and compression bandaging), and was simplified into specific contexts to facilitate easy integration. The pictures are large and simple for ease of integration, with supplemental description of how to complete exercises and bandaging. The format was decided on based on collaboration between the author and site mentor.

### Summary

Chapter III described the development process for the guide, the literature review process, and how theory was incorporated into the guide. Chapter IV Product provides an

introduction and description of the guide. *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is located in Appendix A.

# CHAPTER IV

## Product

In the United States, nearly 90 million people suffer from lymphedema, a chronic condition that causes progressive swelling (Warren et al., 2007). Proactive lymphedema education and intervention is needed since lymphedema negatively impacts individuals' self-esteem, self-confidence, socialization, quality of life (QOL), as well as physical aspects like decreased range of motion and mobility. It is common for healthcare practitioners to overlook lymphedema as a chronic condition. Those undergoing surgery, injury, cancer radiation, or trauma should seek an evaluation for lymphedema. As a result of trauma, radiation, wounds, burns, injuries, and more, can cause the lymphatic system to become compromised and need to be treated accordingly (American Cancer Society, 2021; Borman, 2018). Additionally, individuals with a history of cancer in their family or who will undergo surgery and seek early education and proactive exercises have better outcomes. Outcomes could include increased mobility, decreased limb circumference, and improved range of motion (Fu et al., 2014). Among the benefits and importance of proactive lymphedema interventions are early limb measurements and patient education. As a result of receiving home exercise training during the early stages of their diagnosis, patients have a greater range of motion, a greater understanding of lymphedema signs and symptoms, greater confidence, awareness, empowerment, and less anxiety (Cohen et al., 2005).

**Product Goal and Objectives**

Based on the research gathered from a literature review on proactive interventions for individuals with lymphedema, the product goal and objectives were developed in collaboration with the occupational therapy practitioner at the partnered agency. The overarching goal of the guide is to educate and treat those at risk of developing lymphedema or who have already been diagnosed so patients affected by lymphedema can continue to be active and independent in meaningful occupations. With the use of *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide*, patients will be able to (Bastable et al., 2020):

- Patients will be able to **verbalize** three lymphedema symptoms within two weeks of receiving the guide.
- Patients will **demonstrate** the ability to complete self-manual lymphatic massage.
- Patients will **integrate** at least two proactive lymphedema interventions into their daily routine.

*A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide*, aims to provide patients with interventions to treat lymphedema proactively. The guide is intended to be used in outpatient, inpatient, and home health settings with patients receiving intervention pre- or post-surgery, post-injury, or at risk of developing lymphedema. Adults at risk of lymphedema or diagnosed with this condition will benefit from this guide. However, therapy practitioners should modify this guide according to the patient's needs and abilities. In addition, the practitioner would thoroughly explain the guide to the patient. The practitioner should provide each patient with a guide and modify the guide based on the patient's needs. The guide includes the following sections, instructions on pre- and post-surgery or injury actions steps, skin

care, intervention techniques, self-massage directions, and general lymphedema information. The

complete guide: *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide,* is included in Appendix A.

**Product Overview**

This guide provides a detailed overview of the different types of lymphedema therapy, safe exercise, and interventions. To help patients make informed decisions about their proactive treatment options, practitioners should print off and distribute the guide to patients. The guide includes basic information about lymphedema, self-massage steps, exercises, and skin care recommendations. It is important for practitioners to modify the guide to fit the needs and abilities of their patients. Practitioners can modify the guide by explaining lymphedema in a way that the patient will understand. Lymphedema can be explained in multiple ways. One way to adapt or modify the guide is for the practitioner to provide the patient with the guide and handouts that are relevant to the patient's situation and diagnosis. The practitioner should collaborate with the patient to determine what learning style is best for the patient. To make it easier for the patients to read, they can change the font size or color, and create an exercise program tailored to their needs.

In order to improve patient outcomes, patients should meet with an occupational therapy practitioner who has training in lymphedema therapy, or is a certified lymphedema therapist (CLT). As long as the occupational therapy practitioner has determined that the guide is appropriate for the patient, they should demonstrate and explain all appropriate interventions. In order to determine if any modifications need to be made to the patient's home programming, the occupational therapy practitioner should suggest a follow up appointment once the guide has been administered.

The practitioner must allow the patient to ask questions after demonstrating and explaining the guide in a one-to-one teaching setting. Delivery of information from the practitioner is intended to be informal and conversational while allowing for a mutual oral exchange of ideas. The practitioner is urged to use demonstration and return demonstration while explaining the guide to patients (Fitzgerald & Jacobs, 2020) to ensure they have understood everything the practitioner explained. As an example, the practitioner should demonstrate on themselves how to perform self-manual lymphatic drainage. Patients should then perform a return demonstration of self-manual lymphatic drainage. This will boost their confidence and skills. It is important that the practitioner explains the guide at a slow pace, exaggerates some of the steps, keeps it simple, uses repetition, and engages the patient at all times (Fitzgerald & Jacobs, 2020). Designed visually with content adapted to the patient's learning style, the guide helps the patient understand and retain the treatment plan (Bastable et al., 2020). The practitioner can determine the patient's learning style and preferences by evaluating the following questions (Kitchie & Arnaud, 2020):

- What are the patient's needs and wants?
- Is the patient ready to learn?
- How does the patient best learn?

Patient information regarding their learning needs should be collected by the practitioner. The patient and their family may identify what learning supports they have used before, which learning supports have been or have not been beneficial, and which context the patient thrives in (Kitchie & Arnaud, 2020).

## Application of Theoretical Framework

The Ecology of Human Performance (EHP) model (Dunn et al., 1994) and the andragogy theory of teaching and learning (Bastable et al., 2020) were used to develop the educational guide. EHP aimed to determine how to increase the performance range of individuals with lymphedema through proactive intervention. The model was selected because it provides patient-centered interventions and increases occupational performance. Throughout the creation of the guide, EHP intervention strategies were used, including establish/restore, adapt/modify, alter, create, and prevent (Dunn et al., 1994). Refer to Table 1.0 for EHP intervention strategies and application to the guide.

# CHAPTER V

## Summary

This chapter discusses strengths and limitations of the guide, as well as suggestions for further development and research for future students or practitioners. Recommendations are discussed, including implementation of the guide in an outpatient setting.

The purpose of this guide is to treat and educate patients on lymphedema proactively so that they can continue to actively participate in their meaningful occupations. When lymphedema is addressed proactively it decreases the likelihood of chronic lymphedema and later stage lymphedema, keeps lymph fluid flowing, reduces infection risk, increases mobility and range of motion, self-confidence, and self-esteem. The guide was designed to be easy to use, and useful when read either in parts or as a whole. This will allow the product to be useful either in its entirety or in short sections. This chapter consists of an overview of *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide*. The purpose of this guide is to proactively treat individuals who are either at risk or already have a diagnosis of lymphedema.

### Strengths

In spite of the fact that the guide was developed in an outpatient clinic, the guide has the strength of being suitable for multiple settings. Furthermore, the author was intentional about where the page breaks where places and how the guide was organized so that occupational therapy practitioners who have experience treating patients can clearly present information in the guide or modify it as necessary. A strong point of the guide is its application of andragogy theory of teaching and learning. To broaden the performance range of most patients served by the partnered agency, the author wrote descriptions of interventions and education about

lymphedema at an eighth grade reading level. The guide was edited using a large font, adequate white space, appropriate coloring, and photos for demonstrations to ensure thorough implementation and use by all patients. It is expected that the interventions within the guide will cost a minimal amount for patients with lymphedema, since the partnering facility already supplies bandages, foam, tape, and stockinettes. Implementation of the guide is extremely cost effective, only the cost of printing the guide for the patient would be necessary. Finally, the guide was developed in collaboration with a certified lymphedema therapist (CLT) who has been treating lymphedema for 15+ years.

**Limitations**

The limitations of the current product are that it has not been implemented in a clinical setting, and there is limited research supporting the target population. There is also the limitation that a patient must seek a healthcare professional's referral to obtain the guide from the partnered agency. For the guide to be implemented, there are no expected costs. The partnering agency already supplies bandages, foam, tape, and stockinettes to patients. The facility would be responsible for printing the guide. Occupational therapy practitioners or other healthcare professionals with knowledge in lymphedema looking to implement the guide were not given funding options or suggestions as there is no expected costs to implement the guide.

**Further Research**

A future recommendation for this guide is to implement it in an outpatient setting. In order to measure effectiveness, the practitioner should monitor outcomes and adjust the guide based on results. For example, the practitioner could administer a client satisfaction survey

regarding lymphedema symptoms, create pre – post lymphedema education surveys, or base outcomes on practitioner reflections and semi formal interviews with patients.

Another recommendation would be that this guide is able to be shared with patients electronically with videos embedded within in it so that it is user friendly. Lastly, the author recommends that a future student could create an educational in-service for healthcare providers that provides education on lymphedema and specific interventions.

**Recommendations for Use**

This guide promotes evidence-based interventions that can be used by multiple professionals who have experience treating lymphedema. The purpose of the guide is to encourage individuals with lymphedema to be proactive in managing their condition so that they can remain active in occupations. The recommendation for the use of this guide is the implementation for individuals who are at risk or have a diagnosis of lymphedema. The guide can be implemented if the individual is presenting signs or symptoms of lymphedema, expects to undergo surgery or radiation, has a family history of cancer, or has experienced an injury.

**Conclusion**

*A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is an evidence-based solution to proactively treating lymphedema in a variety of settings. It is anticipated that through implementation of this guide, patients will experience an increased performance range though proactive intervention. Overall, it is concluded that with the implementation of this guide, individuals with lymphedema or who are at risk of developing lymphedema will be able to continue to participate in occupations that are important to them and

promote occupational engagement. It is the author's hope that this guide can be implemented in a wide variety of settings.

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# Appendix A

## Implementation Plan

## Implementation Plan

### Purpose

The purpose of *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is to provide individuals at risk or already diagnosed with lymphedema proactive treatment options so that they can remain active in meaningful occupations. Lymphedema is poorly understood and there is a lack of scientific research regarding the condition. The author intends that with the development of this guide, patients will be able to understand lymphedema, increase their confidence, have a greater quality of life, and implement proactive lymphedema interventions into their daily routines.

### Prior to using the Patient's Educational Guide

Prior to using the guide, either healthcare professionals or support staff will administer the Lymphedema Life Impact Scale version 2 with the patient (Weiss & Daniel, 2018). LLIS version 2 is a questionnaire that consists of 18 questions that assess' a patient's physical, psychosocial, and functional areas. The results of the scale will be entered into the patient's chart for future reference. Additionally, the results of the scale should be discussed with the patient. For a patient to be a candidate for the lymphedema guide, the patient should either score greater than 10% impairment on the LLIS version 2 or self-report a personal or family history of cancer, lymph node removal, injury, or other disruption to the lymphatic system (Weiss & Daniel, 2018).

### Goal

The overarching goal of the guide, *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is to provide individuals with the tools to manage their lymphedema

before it progresses into later stages or becomes problematic so patients affected by lymphedema can continue active and independent in meaningful occupations.

**Objectives**

- Patients will be able to **verbalize** three lymphedema symptoms within two weeks of receiving the guide.
- Patients will **demonstrate** the ability to complete self-manual lymphatic massage.
- Patients will **integrate** at least two proactive lymphedema interventions into their daily routine.

**Operational Plan**

The guide is a resource for patients who are at risk of developing or who already have a diagnosis of lymphedema to use. If necessary, the guide could be emailed to the patient in a PDF format. The guide includes basic education about lymphedema, proactive resources for skin protection, risk reduction, self-care, healthy lifestyle, safe exercises, and interventions. The purpose of the guide is to proactively treat lymphedema so patients can actively participate in activities that are meaningful to them. This product is expected to be implemented at the partnered agency, which is an outpatient clinic in rural MN.

**Facility Times of Operation**

- Monday – Friday: 7AM – 6PM CST
- Saturday – Sunday: Closed

**Staff Responsibilities**

Occupational therapy practitioners (OTP) will complete an initial evaluation and administer the Lymphedema Life Impact Scale (LLIS) 2. The OTP will re-administer the LLIS 2

every 10th session, if necessary. Next, the OTP will gather the patient's history and collaborate with the patient to decide if proactive lymphedema treatment is required. From there the OTP should use clinical judgement and decide if the guide should be administered or not. At the end of each session the OTP will document progress and anything else that they feel should go into the patient's chart.

### Financial Plan

There are no expected costs for the patient to use this guide. However, there are minimal expenses for the facility to administer the guide. Expected expenses include costs for paper and ink. These prices vary dependent on the type of printer and paper used for printing.

### Marketing Plan

The target market for this guide is individuals who are at risk of developing or already diagnosed with lymphedema. It is recommended that patients first be evaluated by an occupational therapy practitioner to see if the guide is appropriate for their condition.

## Assessment Plan

### Evaluation Method

A certified lymphedema therapist or healthcare provider will conduct the non-standardized Lymphedema Life Impact Scale version 2 with patients during their initial evaluation and at discharge. Depending on the patient's pre – post scores, and how well they are self-managing their symptoms, the therapist and patient will collaborate on what is best for the patient's plan of care.

**Plan for Managing Adversity**

Problems with the assessment or intervention that may arise will be addressed by the health care practitioner providing the guide or services associated with the guide.

**Data Collection**

The guide will be introduced to the patient in the first session, if appropriate. It is based on the health care practitioner's judgement and patient's readiness when the guide should be administered. During follow up sessions, the health care practitioner should discuss the patient's progress and attitude with the guide. Every ten follow up visits and during the discharge evaluation, the healthcare practitioner should re-administer the Lymphedema Life Impact Scale 2 and discuss the patient's changes in score. If the patient's LLIS version 2 score improves more than seven points from the pre-treatment score, there has been clinically significant improvement. The patient's score can be easily calculated using the LLIS Impairment Calculator.

**Data Reporting**

Data reporting for *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* will be done after administration of the assessment and will be recorded in the healthcare professionals daily note within the documentation system that the facility uses. After each follow up session, a progress note will be documented.

**Data Analysis**

If *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is successful, it is expected that patients associated with lymphedema will be able to better self-manage their lymphedema, actively participate in meaningful occupations, and have increased knowledge of their symptoms. However, if the guide is not successful and patients are unable to

self-manage their lymphedema symptoms, actively participate in meaningful occupations, and have increased knowledge of their symptoms, changes to the guide can be made under the discretion of healthcare providers that have knowledge in the area of lymphedema or certified lymphedema therapists.

**Reviewing Process**

Appropriate healthcare personnel will complete a yearly reviewing process of *A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide*. Based on the results, appropriate changes will be made to the guide to continue to provide best practice and meet the needs of the patients.

**Sustainability**

*A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide* is a low-cost guide to implement because the facility already has all of the necessary materials for the guide. There are minimal materials needed for interventions for this guide, such as stockinette's, short stretch bandages, compression foam, tape, and a model of a compression garment. All of the listed materials are already at the facility. The toolkit includes interventions that are easy to leave with the patient and they can engage with them when they would like to. Finally, the toolkit is accessible to all OT practitioners and healthcare providers through the facility's shared file folder.

## Conclusion

Once the guide is completed, it will be available to all disciplines at the partnered agency to distribute to their patients via an online database. In the future, additional outcome measures may be utilized such as patient surveys or interviews.

# Appendix B

## Release Forms

Information and Picture Release Form

I, Sarah Tanner, grant permission to Bridget Reuss and the Occupational Therapy Department at the University of North Dakota School of Medicine and Health Sciences to use my information and pictures for educational, promotional, operational purposes, or other conditions that may arise. I understand that information and pictures may be published in scholarly work through Scholarly Commons, a repository service of the University of North Dakota libraries, which may be accessed around the world.

Signature: *Sarah Tanner* OTR/L LANA CHT Date: 03/27/2023

Information and Picture Release Form

I, Ross Grussing, grant permission to Bridget Reuss and the Occupational Therapy Department at the University of North Dakota School of Medicine and Health Sciences to use my information and pictures for educational, promotional, operational purposes, or other conditions that may arise. I understand that information and pictures may be published in scholarly work through Scholarly Commons, a repository service of the University of North Dakota libraries, which may be accessed around the world.

Signature: *Ross Grussing* Date: 03-27-2023

# Appendix C

## Patient Guide

# A Proactive Approach to Lymphedema Treatment: A Patient's Educational Guide

**By: Bridget Reuss, OTDS**

**Advisor: Wanda Lauer, OTD, OTR/L, CLT**

**Site Mentor: Sarah Tanner, OTR/L, LANA, CHT**

**University of North Dakota Doctoral Experiential Capstone Project**

**2023**

Staple occupational therapy practitioners contact card here!

## Seek medical attention <u>immediately</u> if you are experiencing:

- Swelling
- Redness
- Area of redness spreading
- Skin that is warm or hot to the touch
- Tender or painful
- Fever
- Flu-like symptoms

*Knowing the signs of an infection is an important part of your lymphedema care.*

# Table of Contents

# The Ecology of Human Performance (EHP)

The Ecology of Human Performance (EHP) was selected as the model used to guide the development of this scholarly project (Dunn et al., 1994). The EHP model focuses on four primary constructs: the person, task, context, and performance range. EHP also describes five intervention types that were considered during the development of the product. See Table 1 for definitions and application to the guide.

Table 1

*Ecology of Human Performance (EHP) Definitions and Application to Guide*

| EHP Term | Definition | Application to Guide |
|---|---|---|
| **Person** | According to the EHP model, individuals are personified by their experiences, skills (cognitive, sensorimotor, psychosocial), values, and beliefs. | Individuals with a diagnosis of lymphedema or who are at risk of developing lymphedema. |
| **Task** | An objective set of behaviors necessary to accomplish a goal. | Tasks include what the patient wants and needs to do. This guide aims to provide patients with proactive treatment options so patients can perform certain tasks that are important to them. |
| **Context** | Conditions in which the person exists and performs this includes temporal, enviromental, and cultural aspects. | Stage of lymphedema impacts that type of intervention that the occupational therapy practitioner should consider for each patient. |
| **Performance Range** | The transaction between the person and context. | Providing proactive treatment to patients who are either at risk or already diagnosed with lymphedema increases their performance range to participate in tasks |

| | | |
|---|---|---|
| | | that are meaningful to them. |
| **Intervention Types** | | |
| **EHP Term** | **Definition** | **Application to Guide** |
| **Adapt/Modify** | Task demands can also be adapted to enable performance by manipulating and structuring the context. | Using a loofah/shower brush so that patients can independently complete manual lymphatic drainage.<br><br>Use a sock aid, dish gloves, or other donning aids for compression garments. |
| **Alter** | Changing the context in which the person performs. | Occupational therapy practitioner's making a referral to other disciplines, such as wound care or physical therapy to support the patient's needs. |
| **Create** | Creating situations that support patients' performance. | Occupational therapy practitioners should monitor their patient's needs and change the patient's home programming as needed. For example, if the patient only needs upper extremity exercises, the occupational therapy practitioner should only administer the upper extremity exercises from the guide and exclude the lower extremity exercises. |
| **Establish/Restore** | The goal of this intervention strategy is to provide intervention at the individual level. It | Providing range of motion exercises so patients can independently |

| | | |
|---|---|---|
| | involves restoring function through improving abilities and skills. | participate in health maintenance tasks, such as lymphedema bandaging and donning/doffing compression garments. |
| **Prevent** | In this type of intervention preventing maladaptive performance is the main goal of this type of intervention. This is done by addressing factors such as the individual, the task, and the environment that may be responsible for the development of maladaptive behavior. | Teaching patients the purpose of the lymphatic system, how to complete MLD, proactive treatment, such as proper skin care, and compression therapy. |

Blue rectangles with EHP intervention tips are integrated throughout the guide and are intended for occupational therapy practitioners (OTP).

# Introduction to Lymphedema

Lymphedema affects between 90 and 250 million people worldwide (Manrique et al., 2022). Yet, there is limited scientific research on the importance of proactive lymphedema treatment. This guide was created for individuals who are at risk or already diagnosed with lymphedema, so they can receive proactive lymphedema treatment and participate in meaningful occupations.

If lymphedema is left untreated, patients can experience heaviness, itching, immobility, infection, fibrosis, skin papillomas, and other skin changes. A lack of treatment can result in psychological morbidities like anxiety, depression, social isolation, and diminished quality of life.

According to the National Lymphedema Network (NLN), individuals at risk of lymphedema do not display signs and symptoms of lymphedema but have an insufficiency of their lymphatic system. Those individuals include, but are not limited to, those who have had lymph nodes removed, received radiation therapy for cancer, or have family members with hereditary lymphedema.

(National Lymphedema Network, 2021)

# Lymphedema Basics

## What is Lymphedema?

Lymphedema is a condition that can get worse over time without proper care. Lymphedema self-care can help reduce the symptoms you feel and prevent problems from happening or getting worse.

Lymphedema refers to tissue swelling caused by an accumulation of protein-rich fluids that is drained through the lymphatic system.

The lymphatic system plays a role in circulation and immune functions. It carries fluid, waste products, bacteria, and protein molecules from the tissues through a series of vessels and nodes.

The lymph nodes break down and eliminate the waste products and protein-rich fluid is brough back to the heart to rejoin the circulatory system.

If the lymph vessels are unable to transport lymph fluid, it begins to accumulate in the tissue and cause swelling.

Lymphedema occurs when your lymph vessels are unable to adequately drain lymph fluid, usually from an arm or leg. Lymphedema can be either primary or secondary. Lymphedema can occur on its own (primary lymphedema) or it can be caused by another disease or condition (secondary lymphedema). Secondary lymphedema is far more common than primary lymphedema.

## How the lymphatic system works:

The lymphatic system is the body's drainage system, it works around the clock to clean up and properly dispose of waste left behind by other body systems. A healthy lymphatic system contributes to many other functions including:

- Drains fluid back into the bloodstream
- Filters lymph
- Removes impurities from the body
- Fights infection

## Types of Lymphedema

*Primary Lymphedema*

- May be the result of a lymphatic malformation
- May be present at birth but more often develops later in life without an obvious cause

*Secondary Lymphedema* (most common)

- Secondary forms also can occur from injury, scarring, trauma, or infection of the lymphatic system.
- Is a result of damage or trauma to lymphatic system from surgery or radiation, especially with lymph node dissection. This can result in a change of the normal flow of the lymph fluid throughout the lymphatic system.

## What Areas Can Be Affected?

If you had treatment for cancer in your upper body (breast cancer, melanoma, sarcoma), lymphedema may occur in your:

- Hand
- Arm
- Shoulder
- Breast
- Chest
- Trunk
- Back

If you had treatment for cancer in your lower body (melanoma, sarcoma, ovarian, cervical, prostate, testicular, or anal cancer) lymphedema may occur in your:

- Feet
- Legs
- Groin
- Genitals
- Abdomen

If you had treatment for head and neck cancer, lymphedema may occur in your

- Face
- Neck
- Mouth

(Borman, 2018; Manrique et al., 2022)

# Stages of Lymphedema

## Stage Zero (subclinical)

- At risk to develop lymphedema
- Post procedure swelling (lymph node dissection)
- No visible edema
- Difficult to diagnose/detect
- May be triggered by an illness, injury, surgery, or combination.

## Stage One (spontaneously reversible)

- Symptoms are more noticeable, but are still likely reversible with proper intervention
- Compression therapy is likely most effective
- Swelling reduces with elevation
- Protein-rich fluid build up
- Pitting skin/indents with pressure and hold the indentation
- Swelling may not be present all the time
- Swelling can come and go intermittently
- Skin is soft

## Stage Two (spontaneously irreversible)

- Irreversible lymphedema
- Skin becomes fibrotic (thick & hardens)
- Firmer tissue, less signs of pitting

## Stage Three (elephantiasis)

- Final stage
- High risk of skin lesion, non-healing wounds, hardened fibrosis, and papillomas
- High risk of secondary infection and sepsis
- Swelling increased significantly
- Permanent skin changes (dense, thick, fibrotic)

(Fu et al., 2014; Manrique et al., 2022)

# Lymphedema Symptoms

## Symptoms of Lymphedema

- Swelling
- A feeling of tightness, fullness or heaviness
- Aching, stiffness or pain
- Reduced movement in the affected area of your body
- Recurring infections
- Fibrosis or hardening and thickening of the skin
- Aching or discomfort
- Clothes, bras, jewelry, shoes, etc. feel tight

## Can Lymphedema be Prevented?

While there is currently no cure for lymphedema, there are things you can do to reduce your risk of developing lymphedema. The risk of lymphedema is life-long. Following these proactive steps will greatly reduce the possibility that you will develop lymphedema.

EHP Intervention Tip for OTPs:
The occupational therapy practitioner could create a plan with the patient in the event the patient begins to experience signs of lymphedema or infection. Creating a plan prior to the situation occurring will likely increase the patient's outcomes and decrease dysfunction.

(Manrique et al., 2022)

# Proactive Treatment

## Why is Proactive Treatment Necessary?

The best way to treat lymphedema is early on or before a diagnosis is made. Practitioners can provide baseline measurements, education, and home programs before a diagnosis is made.

## Ways to be Proactive

- Protect your skin (refer to page 13)
- Know your risk
- Reduce your risk (refer to page 14)
- Participate in self-care (refer to page 15)
- Wear properly fitting clothes and jewelry
- Maintain a healthy diet (refer to page 16)
- Exercise (refer to page 19-21)
- Be active
- Wear proper fitting compression
- Be evaluated by a certified lymphedema therapist
- Post-mastectomy or lumpectomy: no injections, acupuncture or blood draws on the involved arm

## Who is at Risk?

Individuals who have or expect to experience the following:

- Lymph node dissection
- Cancer
- Obesity
- Radiation
- Surgery
- Infection
- Injury
- Immobility
- Tumor

(Manrique et al., 2022)

# Skin Protection

## Skin Care

- Low pH moisturizer to avoid dry and cracked skin
- Daily application of moisturizer to avoid chapping/chafing of skin
- Use insect repellent to avoid bites and stings
- Use caution when using razors to avoid nicks and skin irritation

## Limb Constriction

Do not overly compress the affected area or tighten in a way that restricts lymph flow or causes tissue damage.

*Avoid:*

- Improperly fitting compression garments
- Tight socks that cause indents around the ankles or toes
- Tight bras or underwire that binds or causes indents in the stomach or chest

*Recommendations:*

- While gardening, it is suggested to wear gloves to prevent infection and cuts to the skin
- While cleaning it is important to wear protective gloves to prevent cuts to the skin and take frequent breaks
- Avoid carrying heavy bags, purses, or groceries over the at-risk limb
- If possible, get blood draws and blood pressure readings taken on the non-affected limb

## Infections

- Signs of infection: rash, itching, redness, pain, skin that is hot/warm to the touch, fever, flu-like symptoms, and increased swelling
- If you are experiencing any of the above symptoms, contact a healthcare professional immediately
- If you scratch or cut your skin, wash the area with soap and water, apply a topical antibiotic, and observe for signs of infection.

(National Lymphedema Network, 2021)

# Risk Reduction and Awareness

## Surgical risk

If surgery is necessary on an area at risk for lymphedema, inform your surgeon about your concerns of developing lymphedema. It is important to ask your surgeon how long it usually takes for swelling to subside after your surgery. After surgery, if you are experiencing excessive or prolonged swelling, contact your surgeon and request a referral to a lymphedema specialist.

If you are at risk for lymphedema, refer to page 34 for proactive self-MLD to stimulate your lymphatic system before surgery.

*Pre-Surgical Risks*

- Lymph node removal
- Radiation therapy
- Any surgical procedure
- Before surgery, measurements should be taken of both limbs (affected and unaffected) to get a baseline measurement for future reference.

*Post-Surgical Risks*

- Lymph node removal with or without radiation
- Excessive swelling
- Prolonged swelling
- In the event of prolonged or excessive post-operative swelling, you may wish to meet with a lymphedema specialist prior to your surgery.

## Reporting changes

Report to your occupational therapy practitioner or medical provider of any of the following changes:

- Sensation, color, temperature, or skin condition

## Air Travel

- The National Lymphedema Network highly recommends that individuals with lymphedema wear their compression garment that has been measured by a specialist during air travel. Individuals who plan to travel should also wear their compression garment a day or so prior to flying to ensure their garment fits properly and will not cause skin irritation.
- During air travel, it is important to move around, drink water to ensure hydration, and attempt to do seated exercises (ankle pumps, circles, wrist bends, shoulder circles, etc.). Refer to pages 19-21 for safe exercises for lymphedema.

(National Lymphedema Network, 2021)

# Self-Care Strategies

## Nail care

- *Lower extremity lymphedema*
  - Consider getting your toenails trimmed by a podiatrist
- *Arm lymphedema*
  - Maintain good hand hygiene
  - Soften the cuticles using warm soapy water
  - Use a proper moisturizer (low pH)

## Skin care

- Maintaining good skin condition with proper hygiene and applying a low pH moisturizer is important to avoid skin cracking.

## Exercise

- Follow the recommendations of the guide and your occupational therapy practitioner for safe exercises for lymphedema. Incorrect form or unsafe exercise may exacerbate swelling.
- Exercise that promotes lymphatic flow gentle stretching and muscle contractions to help move excess fluid.

## Manual lymphatic massage (MLD)

- Refer to page 34 for proactive MLD
- Refer to page 35 for upper extremity MLD
- Refer to page 36 for lower extremity MLD
- Refer to page 37 for left breast and arm MLD
- Refer to page 38 for right breast and arm MLD

(National Lymphedema Network, 2021)

# Healthy Lifestyle

## Stasis

- Avoid prolonged sitting or inactivity, especially if you are at risk for leg lymphedema
- Change positions and exercise daily (refer to pages 19-21)
- Take frequent rest breaks

## Diet

- Eat a balanced diet (fruit, protein, vegetables)
- Maintain proper hydration, 8-10 glasses per day
- Avoid excess sugar and sodium intake

(Cavezzi et al., 2019; Manrique et al., 2022; National Lymphedema Network, 2021)

# Patient Guidelines

## Keep the affected area clean by:

- Washing the skin thoroughly and frequently
- Keeping the skin moist to avoid drying and cracking
- Use a low pH lotion to protect the skin

## Avoid injury to the skin as this may lead to infection:

- Avoid animal scratches and bites
- Avoid insect bites and stings
- Unnecessary skin punctures (acupuncture, piercings, etc.)
- Avoid nail biting

## During activity:

- Stay hydrated
- Avoid injury to the skin (blisters, cuts, scratches)
- Wear compression garment/bandaging
- Avoid excessive strain during exercise
- Avoid restrictive or binding clothing, bras, watches, rings, etc.

## Other lifestyle changes:

- When traveling by air, use compression garments or low-stretch bandaging (those who do not have lymphedema but are at risk should seek the advice of a lymphedema specialist).
- Keep active and exercise regularly
- Maintain a healthy diet
- Seek medical assistance immediately if infection occurs

(National Lymphedema Network, 2021)

### Is exercise safe if I have lymphedema or am at risk?

Yes, it is safe to exercise if you have lymphedema. Follow the guidance of your occupational therapy practitioner.

- Always wear your compression garment or bandages while exercising.
- Compression garments/bandages do not need to be worn while swimming as water provides similar compression/pressure

### Deep Breathing prior to Exercising

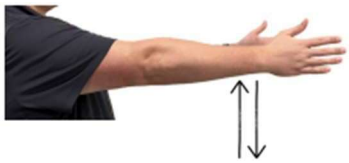
Breath in through your mouth to make your stomach rise. Breathe out through your mouth. Do not hold your breath. Complete as taught by your occupational therapy practitioner.

**Do x____reps of deep breathing prior to exercising**

(Fu et al., 2014; Lu et al., 2015)

# Upper Extremity Lymphedema Exercises

| | |
|---|---|
| **Neck Movements:**<br>Bend your neck forward, chin to chest<br><br># of reps:_____<br># of times per day:_____ |  |
| **Neck Movements:**<br>Tilt your head toward each shoulder<br><br># of reps:_____<br># of times per day:_____ |  |
| **Neck Movements:**<br>Gently look over each shoulder<br><br># of reps:_____<br># of times per day:_____ |  |
| **Shoulder Blade Squeeze:**<br>Gently squeeze shoulder blades down and back toward your spine<br><br># of reps:_____<br># of times per day:_____ |  |
| **Shoulder Rolls:**<br>Shrug shoulders and roll shoulders back to complete a circle<br><br># of reps:_____<br># of times per day:_____ |  |

| | |
|---|---|
| **Overhead Reach:**<br>Raise arms in front of you as far as able and return to your side in thumbs up position<br><br># of reps:_____<br># of times per day:_____ |  |
| **Elbow Bends:**<br>Bend your elbow, bringing your hand to your shoulder, and then straightening<br><br># of reps:_____<br># of times per day:_____ |  |
| **Side Movement:**<br>Lift arms out to side and return to your side with thumbs in up position<br><br># of reps:_____<br># of times per day:_____ |  |
| **Wrist Bends:**<br>Bend your wrist up and down<br><br># of reps:_____<br># of times per day:_____ |  |
| **Forearm Rotation:**<br>Turn your palms up and down slowly keeping your elbows close to your side<br><br># of reps:_____<br># of times per day:_____ |  |
| **Hand Grasp:**<br>Open and close your hand<br><br># of reps:_____<br># of times per day:_____ |  |

# Lower Extremity Lymphedema Exercises

| | |
|---|---|
| **Seated Knee Flexion/Extension**<br>Raise your foot, straighten your knee as far as comfortable, then bend your knee back as far as comfortable.<br><br># of reps:_____<br># of times per day:_____ |  |
| **Seated or Standing Marching**<br>Bring your knee up toward your chest, then back down, as if you are marching in place.<br><br># of reps:_____<br># of times per day:_____ |  |
| **Seated Toe Scrunches**<br>Curl your toes down as far as comfortable, then pull them up as far as comfortable.<br><br># of reps:_____<br># of times per day:_____ |  |
| **Seated Ankle Pumps**<br>Pull your foot/toes up toward you as far as comfortable, then point them down.<br><br># of reps:_____<br># of times per day:_____ |  |

# Treatment Options for Lymphedema

## Complete Decongestive Therapy (CDT)

CDT is an intensive two-phase treatment program.

*Phase 1*

The goal is to reduce swelling and improve tissue health. Patients may be expected to wear compression bandages for 20-22 hours daily between sessions. This phase continues until the affected extremities or areas are decongested, and the volume is stabilized.

*Phase 2*

The goal is to maintain gains and manage swelling with a home program. This phase focuses on long-term lymphedema self-management. This phase includes:

- Day time compression garment
- Nighttime compression bandages
- Exercise
- Skincare
- Manual lymphatic drainage

## Manual Lymphatic Drainage (MLD)

A gentle lymphatic therapy technique that activates the lymphatic system. MLD outcomes are best when coupled with compression or similar interventions. Refer to page 32-38

## Compression Bandaging

Short stretch bandages support the tissue without squeezing it. The multi-layering of the bandages and foam prevents the refilling of lymph fluid. Refer to page 24-30

## Compression Garments

Compression garments are necessary for effective lymphedema management. A single-layer support system that provides graduated compression allows for an overall decrease in compression at the trunk and more compression at the ends of the extremity.

## Pneumatic Compression Pumps

A mechanical device that "milks" the lymph fluid out of the swollen extremity. It may be used for home programming. Not appropriate for everyone.

## Medications

Diuretics are often prescribed, and they can actually make lymphedema worse. Diuretics pull the water content off of the edema while the protein molecules remain in the tissue spaces, this can lead to the tissue becoming higher concentrated in protein and leaving the skin more fibrotic. In addition, diuretics are needed to manage other health concerns such as keeping fluid off the heart or lungs. DO NOT STOP TAKING MEDICATION WITHOUT TALKING TO A PHYSICAN.

(Manrique et al., 2022)

# Compression Garments

Compression garments allow for non-bulky and natural limb shape/contour while maintaining limb size. It is important that a medical professional fits the compression garment to ensure appropriate sizing and compression.

## Wearing Schedule

Compression garments have a very high resting pressure, so it is not recommended to wear them at nighttime. It is recommended to wear compression garments:

- During the daytime
- During phase 2 of complete decongestive therapy (CDT)
- While exercising
- While on an airplane

## Can I wash my garments?

Yes, your garment should be washed after each use so that it maintains its compression and elasticity. Refer to page 25.

## How long will they last?

6 - 9 months

## Signs your garment needs to be replaced

It is important that your compression garment fit properly. Your garment should fit snugly but it should not pinch, bind, roll, or cause pain.

- If your compression garment slides on too easily, it may be a sign that it has lost its elasticity
- Worn/thin fibers
- If you have gained/lost weight or your limb has reduced in size
    - Compression garments will only work properly if your measurements are the same as when you purchased them.

# Compression Bandaging

## Purpose of Bandaging and Foam

To prevent fluid from returning back into the skin, it is necessary to apply external compression to the affected area. Compression bandages (not ace bandages), and/or compression garments provide gradient pressure to allow for lymphatic flow.

### Why should I wear compression?

- Prevents hardening of the skin
- Promotes fluid uptake from the skin into the lymph vessels, keeping swelling out of the limb

### When to wear the Bandages and Foam

Ask your provider about your specific wearing schedule. During phase 1 of complete decongestive therapy (CDT) bandages are worn 20-22 hours a day between sessions. During phase 2 bandages are typically worn only at night and compression garment is worn during the day.

## Supplies for Compression Bandage Wrapping

* It is best to gather all your supplies before wrapping

1. Stockinette **2.** Bandage **3.** Foam **4.** Tape (refer to page 26)

Supplies may differ based on your specific needs. Check with your provider/therapist if you have questions.

## General Bandaging Guidelines

- Wash and dry your skin with water and soap, and apply lotion before putting wraps on.
- Check your skin for cuts or redness
    - If you notice infection, do NOT wrap with compression bandages
- Overlap the foam by half the width of each wrap
- Do NOT throw your supplies away. They can be washed! (refer to page 25)
- Do not put tape on white foam
- Overlap the short stretch bandage by half the width of each wrap
- While applying foam and bandages, use even pressure and give a **gentle** pull
- Always start foam and bandage in the same direction for consistent pressure

# How to wash your supplies

- Place foam and bandages in a laundry bag to avoid the supplies from knotting up
- Wash the foam and bandages with other items if needed
- Use a gentle detergent
    - No bleach
    - No softening agents
    - No fragrance
- Wash and dry on regular settings
    - No dryer sheets
    - Low heat

# Supplies for Compression Bandaging

Stockinette

Compression foam


Tape

Short stretch compression bandage

# How to Apply Arm Compression Bandages

| | |
|---|---|
| Put stockintette on arm to protect skin |  |
| Using the foam, fold the foam in half<br><br>Wrap 2-3x around hand |  |
| Continue the foam up the arm in single layer, overlapping by ½ width each time<br><br>Tuck to foam ends in, avoid using tape on foam<br><br>Easier to wrap with foam is unrolled |  |
| Continue with foam up the arm<br><br>Stop just below the armpit (about two fingers widths) |  |
| Begin wrapping bandage around the base of the hand 2-3x<br><br>Tape end of roll |  |
| Continue to wrap bandage up the arm |  |
| Start bandage #2 at wrist<br>Start bandage #3 at mid forearm<br><br>Continue wrapping overlap ½ width.<br>While wrapping, pressure should be firm, but not too tight. Wrap should not cause pain. |  |

| | |
|---|---|
| Put stockinette on foot and leg to protect skin |  |
| Wrap foam around the base of the toes 2-3x, ½ width overlap each time<br><br>Try to keep the foot at 90 degree angle so it is easier to walk once you are finished wrapping<br><br>Tuck foam ends in, avoid using tape |  |
| Continue across the top of the foot toward the back of the ankle<br><br>Follow your providers instructions for how high to wrap |  |
| Wrap the bandage around the base of the toes 2-3x, overlap ½ width each time<br><br>Try to keep the foot at a 90 degree angle<br><br>Tape end of roll |  |
| Continue across the top of the foot toward the back of the ankle<br><br>Follow your providers instructions for how high to wrap |  |
| Keep all bandages going the going the same direction<br><br>Start bandage #2 at ankle<br>Start bandage #3 at mid-calf<br><br>Use firm pressure, but it shouldn't cause pain |  |

EHP Intervention Tip for OTPs:

*Prevent*

- Have a caregiver assist with applying compression garment.
- Have a caregiver assist with applying foam wrap and bandaging.

*Adapt/Modify*

- Label the bandages to make application easier.

To increase the patient's performance range during self-care or health maintenance tasks, the occupational therapy practitioner could suggest that the patient incorporate rest breaks while they are wrapping to prevent fatigue and increase safety.

# Manual Lymphatic Drainage (MLD)

## How does MLD help?

Manual lymphatic drainage (MLD), gently stretches the skin and helps move fluid away from an area that is swollen to areas of the body where the lymphatic system has not been affected by radiation, surgery, injury, etc.

This method stimulates the weakened lymphatic system and decongests tissues adjacent to the swollen area; this facilitates lymph flow along alternate pathways to reduce swelling.

MLD is very different from deep muscle massage. MLD uses light pressure and gentle, rhythmic strokes such as the pressure that gives you goosebumps. Deep pressure will increase fluid to the area and cause further damage to the lymphatic system.

## Why should you do MLD daily?

- MLD relaxes your heart rate, blood flow, and respiratory rate
- MLD promotes the movement of fluid and waste products, which assists with decreasing swelling and decrease hardening of skin
- MLD stimulates the growth of new lymphatic capillaries

## If you are associated with the following, ask your provider/therapist prior to completing MLD

- Major organ failure
- Hypotension
- Fever/acute inflammation
- Influenza
- Deep vein thrombosis within 2 years
- Blood thinners (depends on the integrity of the skin)
- Infection (must be on antibiotics for at least 48 hours)
- Recent asthma attack
- First trimester of pregnancy
- Any trimester of pregnancy when still experiencing morning sickness
- Those undergoing active oncology treatments would need permission from their treatment team

(Borman, 2018; Fu et al., 2014)

# Guidelines for Manual Lymphatic Drainage

- Use light pressure
- Keep your hands soft and relaxed
- Apply just enough pressure to gently stretch the skin as far as it naturally goes and then release the pressure and let your skin come back as it was
- Use the flats of your hand instead of your fingertips for more contact with the skin
- Self-massage can be done while seated, standing, or lying down. Choose the position that is most comfortable and safe for you.

Try to put self-massage into your life in a way that works best for you.

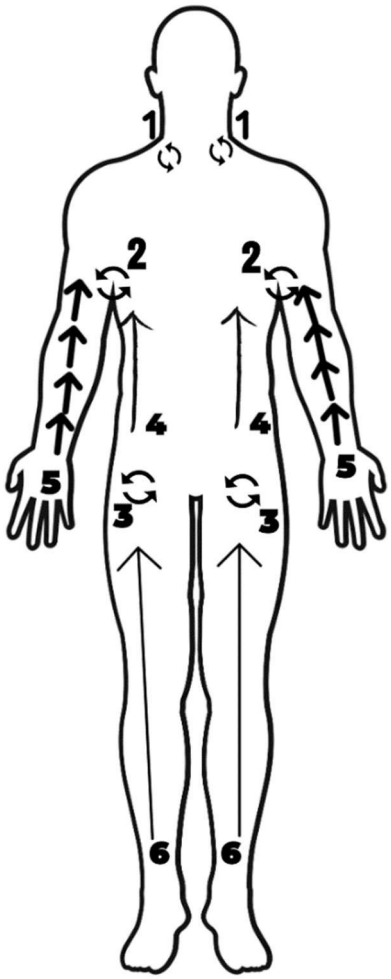
EHP Intervention Tip for OTPs:

*Adapt/Modify:* If the patient has limited ROM or pain in hands/shoulders when completed MLD, suggest they complete MLD using long-handled dry shower brush/loofah.

- To increase the patient's performance range during self-care or health maintenance tasks, the occupational therapy practitioner could suggest that the patient use a long-handled loofah or shower brush to complete MLD independently. Additionally, the occupational therapy practitioner could suggest that the patient completes MLD while they are drying off from the shower or prior to getting in the shower, this incorporates MLD into the patient's daily tasks.

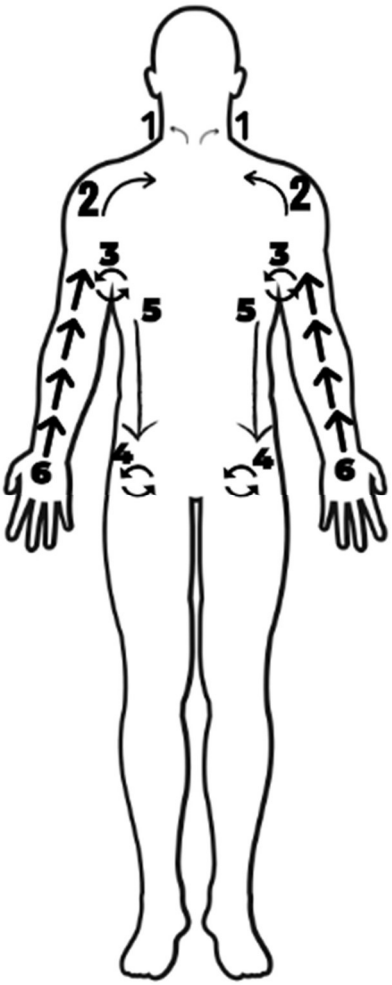
# Proactive Manual Lymphatic Drainage

1. Place hands on neck, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
2. Place hands at the armpit, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
3. Place hands just below the hip crease, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
4. Lightly sweep from right armpit down towards the right hip. Then lightly sweep across the chest from the right armpit to the left armpit. Repeat 5 times.
5. Lightly sweep with fingertips up the right arm 5-10 times.
6. Lightly sweep from the feet to the hip crease, only going in one direction.
    a. Start at hip and work your way down to feet



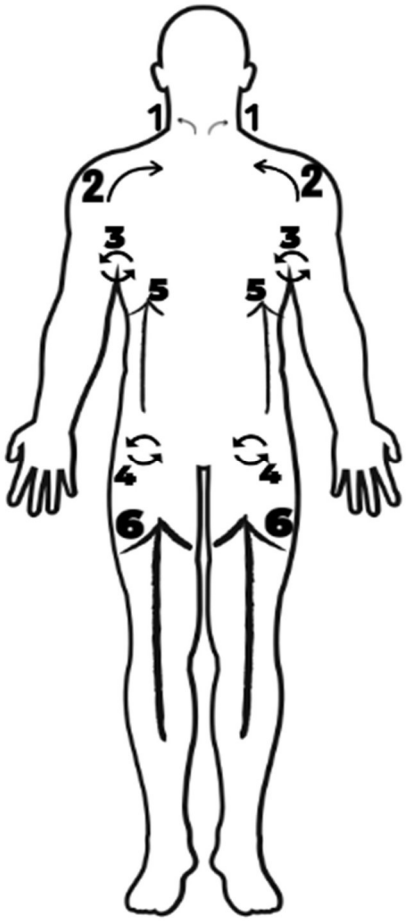
# Bilateral Arm Manual Lymphatic Drainage

1. Place hands on neck, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
2. Place hands at the collarbone, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
3. Place hands at the armpit, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
4. Place hands just below the hip crease, gently stretch skin, and make counterclockwise circles, repeat 5 times.
5. Lightly sweep with fingertips from armpits down towards hips, repeat 10 times.
6. Lightly sweep with fingertips up each arm 5-10 times.



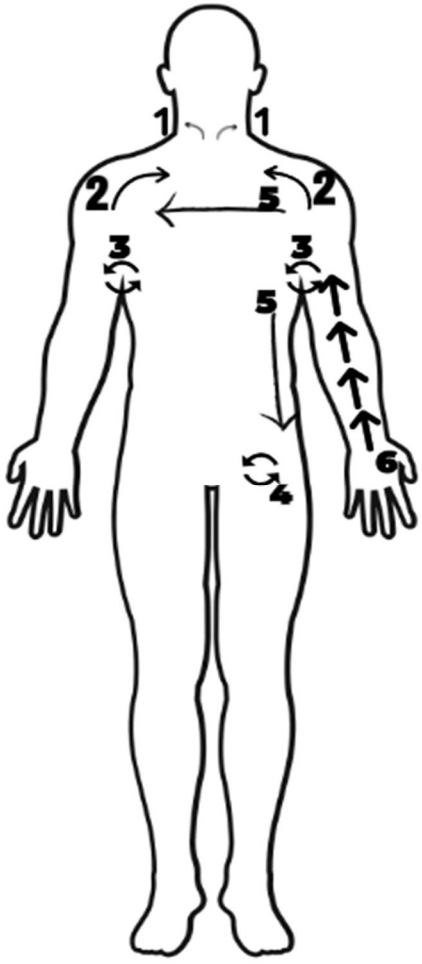
# Bilateral Leg Manual Lymphatic Drainage

1. Place hands on neck, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
2. Place hands at the collarbone, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
3. Place hands at the armpit, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
4. Place hands just below the hip crease, gently stretch skin, and make counterclockwise circles, repeat 5 times.
5. Lightly sweep from the thighs up to the armpits, only going in one direction
6. Lightly sweep from the feet to the hip crease, only going in one direction
    a. Start at hip and work your way down to feet



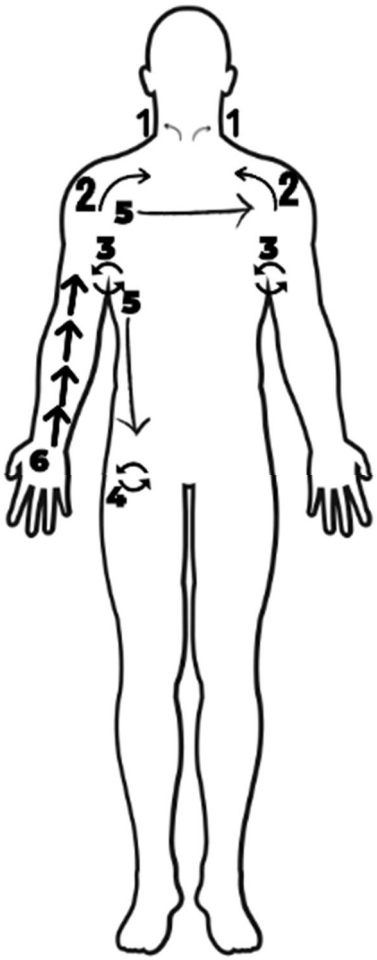
# Left Breast and Arm Manual Lymphatic Drainage

1. Place hands on neck, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
2. Place hands at the collarbone, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
3. Place hands at the armpit, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
4. Place hands just below the hip crease, gently stretch skin, and make counterclockwise circles, repeat 5 times.
5. Lightly sweep from left armpit down towards the left hip. Then lightly sweep across the chest from the left armpit to the right armpit. Repeat 5 times.
6. Lightly sweep with fingertips up the left arm 5-10 times.



# Right Breast and Arm Manual Lymphatic Drainage

1. Place hands on neck, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
2. Place hands at the collarbone, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
3. Place hands at the armpit, gently stretch the skin, and make counterclockwise circles, repeat 5 times.
4. Place hands just below the hip crease, gently stretch skin, and make counterclockwise circles, repeat 5 times.
5. Lightly sweep from right armpit down towards the right hip. Then lightly sweep across the chest from the right armpit to the left armpit. Repeat 5 times.
6. Lightly sweep with fingertips up the right arm 5-10 times.



# Notes

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