



Essential components of the maintenance phase of complex decongestive therapy

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Abstract

Complex decongestive therapy is the current gold standard for non-surgical clinical lymphedema management and consists of manual therapy, compression exercise, skincare, and education. Complex decongestive therapy involves an intensive volume reduction phase (Phase I) followed by a maintenance phase (Phase II). The aim of the maintenance phase is to promote life-long control of lymphedema through use of self-management strategies and the provision of ongoing reduction therapies as needed. Compression therapies are the mainstay of lymphedema self-management. Poor adherence to self-management practices has been associated with increased volume and progression of lymphedema to more advanced stages, supporting the importance of education and regular monitoring to promote adherence to the Phase II maintenance recommendations. In this editorial, we provide consensus recommendations on the essential components of the maintenance phase, including education, skin care practices, managing infection/cellulitis, compression therapies, health and weight management, exercise, and ongoing follow-up care.

Keywords Cancer · Lymphedema · Compression therapies · Exercise · Healthy life style

Complex Decongestive Therapy (CDT) is one of the most accepted and documented methods for conservative treatment of lymphedema. It consists of two phases: an intensive volume reduction phase (Phase I) followed by a maintenance phase (Phase II) [1]. The aim of the maintenance phase is to

promote life-long self-management of lymphedema through the application of compression therapies and the provision of ongoing reduction treatment as needed.

In October 2023, the American Cancer Society and the Lymphedema Association of North America held a *Lymphedema Summit* to disseminate knowledge and produce consensus documents to guide current practice and future research in lymphology. Our working group was established to identify the essential components of the maintenance phase of lymphedema treatment. Consensus on recommendations was achieved through one face-to-face working group session, a follow-up virtual meeting, and a review of the literature. In this paper, we share the consensus recommendations for the maintenance phase including education, skills, resources, and follow-up care to support self-management and healthy lifestyle behaviors. Although the current research evidence is largely focused on lymphedema secondary to breast cancer, the recommendations are seen as applicable to all forms of lymphedema secondary to cancer.

We identify three guiding principles for the maintenance phase including:

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Principle 1: *Best practices* for maintenance require consideration of the individual beyond a biomedical approach to include cultural, social, economic, and psychological considerations. Best care is interdisciplinary in focus and recognizes that social determinants of health, such as where a person is born, grows, lives, works and ages may influence their perceptions and actions and experience of lymphedema [2].

Principle 2: *Self-management* requires active participation of the individual with lymphedema in their own care [3]. It should be tailored to consider the individual’s needs, goals, and resources. A self-management approach has been shown to foster adherence and result in better control of lymphedema [4].

Principle 3: *Education* requires a focus on individual empowerment and promoting self-efficacy of long-term lymphedema self-management. Educational interventions in preparation for the maintenance phase should focus on increasing knowledge, skills, confidence, and motivation related to self-monitoring and performing needed self-care components [5]. In the following section, we identify the following consensus recommendations as essential components of the maintenance phase (Fig. 1):

Recommendation 1: *Individuals with lymphedema require day and night-time compression garments, as well as supplies to support lymphedema self-management.*

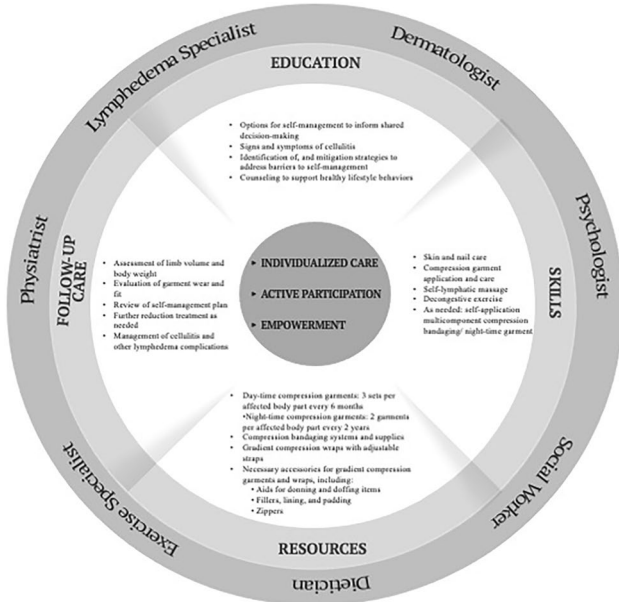


Fig. 1 Essential components of the maintenance phase of lymphedema treatment

Compression garments are essential to the maintenance phase and are used to promote circulatory and lymphatic function, reduce pain, and prevent re-accumulation of edema [1]. During the maintenance phase, compression garments are preferred for daytime wear over compression bandages due to their reduced bulkiness—providing greater freedom for daily activities. The types prescribed may be circular knit, flat knit, or hook-and-loop wraps. Effective compression therapy requires matching the garment type and compression level to the individual’s presentation, tolerance, abilities, and preferences. Garments may be ready-made (off the shelf) or custom made, with the custom garment option recommended for individuals with a misshapen limb or those who find the ready-made garment uncomfortable or ineffective [1]. As per the Lymphedema Treatment Act, individuals with lymphedema should be supplied with a minimum of three garment sets per body part for each 6-month period [1, 3], along with the necessary accessories (e.g., fillers, lining, padding, and zippers) and donning aids to support proper self-application [6].

Individuals may need both day- and night-time compression to stabilize the lymphedema and prevent symptom relapse [1]. If day compression garments alone do not adequately control the lymphedema, supplies to support inelastic compression strategies, such as multilayered short-stretch bandaging or night-time garments should be provided [1]. Night-time compression can be achieved with a night-time compression garment or application of short-stretch compression bandaging. Night-time garments are non-elastic and provide low resting pressure on the limb, making them safe to wear at night when resting. These garments are easy to use, reducing the time burden associated with application. Consistent with the Lymphedema Treatment Act, individuals with lymphedema should be supplied with two night-time garments per affected body part every 2 years [6].

Recommendation 2: *Individuals with lymphedema require education to support successful long-term self-management.*

Poor adherence to self-management practices has been associated with progression of lymphedema to more advanced stages. Education and regular monitoring to promote adherence to maintenance recommendations. Barriers to self-management include complexities of treatment regimens, symptom burden, chronicity of the disease, challenges of balancing time for treatment and life demands, and lack of education and support [5]. Individuals who understand and feel confident in managing their lymphedema are more likely to be consistent with recommendations. Goal setting, informed decision-making, and satisfaction with outcomes related to lymphedema volume have been shown to result in

better adherence [5]. To identify factors related to non-adherence, strategies such as motivational interviewing (i.e., a counseling method to enhance an individual's motivation) and solution-focused therapy (i.e., a strength-based approach to solution building) are recommended [5].

Recommendation 3: *Individuals with lymphedema require skills to support successful long-term self-management.*

Individuals with lymphedema require skills and confidence in following self-management regimens for skin and nail hygiene, garment application and care, self-bandaging, self-lymphatic massage, and decongestive exercises. Proper skin and nail care are essential for lymphedema management and in preventing cellulitis. Due to impaired lymphatic function, meticulous hygiene, skin monitoring, avoiding damage and trauma, and using emollients for skin moisturize are vital [1]. Precautions such as protective clothing, gloves, or creams (e.g., gardening gloves, oven mitts, sunscreen) may be necessary for those at risk of skin damage or infection. Dermatological consult is recommended to address specific skin problems [1, 3].

Instruction should cover the proper application, daily wear time, and care of compression garments. Clinicians should demonstrate the correct donning and doffing procedures of the garment, including, where needed, the use of limb butlers and foot slippers for donning, and ensure that individuals with lymphedema and their caregivers are able to perform these tasks accurately [1]. Education should include garment application aids (e.g., use of donning gloves to smooth out creases) and strategies to prevent slippage. Compression garments are advised for all waking hours, and care should follow manufacturer's instructions, including daily washing and, for some garment types, avoiding oil-based moisturizers before application [1].

Self-bandaging and self-lymphatic massage may be helpful strategies to control the edema and improve quality of life [1, 4]. Instruction and demonstration should be provided by a lymphedema therapist along with the provision of bandaging supplies and evidence-based written and online resources [4].

Evidence supports the continuation of the lymphedema decongestive exercise regimen and deep breathing exercises (prescribed in the intensive reduction phase) to help manage symptoms and reduce limb volume [4]. These exercises can be easily incorporated into daily activities or as part of an overall exercise program in the maintenance phase.

Recommendation 4: *Individuals with lymphedema require counseling and resources to support healthy lifestyle behaviors.*

Healthy eating and regular physical activity help to maintain a healthy body composition and reduce the risks of other chronic diseases, such as heart disease and Type II diabetes. Following a healthy diet to maintain an optimal body weight range is essential for lymphedema management, as excessive body fat is closely linked to lymphedema progression and increased risk of cellulitis [1]. Referral to nutrition counseling interventions is recommended for individuals with high body fat/body mass index; a focus on health as the primary motivator is recommended rather than emphasizing weight loss [7].

The individual's preferences for physical activity will largely drive recommendations, which may range from guidance to simply 'move more' to prescribed exercise fitness regimens. Physical exercise benefits lymphedema symptoms, tissue composition, range of motion, muscular strength, and quality of life. Resistance exercise training, specifically, has shown benefit in reducing lymphedema volume [1]. Ideally, individuals with lymphedema should be physically active and aim to, at minimum, meet public health recommendations for physical activity.

Recommendation 5: *Individuals with lymphedema need to be able to identify the signs and symptoms of cellulitis infection and understand the importance of seeking immediate medical attention and follow-up care.*

Cellulitis often occurs without a preceding event; thus, early detection and timely intervention help prevent further damage to lymphatic function and worsening of lymphedema [5]. Signs and symptoms of infection may include presence of high fever, rash, itching, redness, pain, and increased skin temperature. Infection may progress systemically to fever and flu-like symptoms. If an infection is suspected, the individual needs to seek immediate medical attention [1].

Poorly managed lymphedema increases the risk of cellulitis, potentially resulting in hospital stays and higher medical costs [1]. Provision of emergency antibiotics for those at high risk, especially when traveling abroad, may allow for early self-treatment—stopping bacterial replication and minimizing lymphatic system damage. For individuals with two or more cellulitis episodes per year, consideration should be given to antibiotic prophylaxis.

Recommendation 6: *Ongoing follow-up care, at least annually, performed by a lymphedema healthcare professional is recommended to monitor for changes and adjust the lymphedema treatment plan as needed.*

To ensure optimal lymphedema management, it is advised that individuals receive ongoing follow-up care by a lymphedema healthcare professional. Regular assessments enable timely intervention (including the need

for further reduction treatment) and modification to the self-management treatment plan to support long-term disease control. Follow-up visits should be scheduled at minimum annually, and include discussion on adherence to self-management and assessment of lymphedema size/volume, occurrence of cellulitis or other lymphedema complications, and body weight [3]. The need for replacement garments should be reviewed, ensuring the fit, compression level, and response are adequate [1]. Referral to a physical medicine and rehabilitation specialist may benefit symptom management; and referral to psychosocial services may be needed to address body image disturbance, sexual concerns, treatment costs, and social support, as well as any emotional distress arising from the burden of lymphedema and the need for life-long self-management [5, 8].

In summary, our working group recommendations aim to support best care through a focus on education and tailored self-management with consideration given to the broad range of personal, social, economic, and environmental factors among individuals with lymphedema secondary to cancer.

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Declarations

Conflict of interest The authors declare no competing interests.

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