Shared clinical decision-making for managing lymphedema for patients in the post-cancer stage

Lymphedema is a long-term condition, and different people can manage it in different ways. The right plan is the one that works best for you and your daily routine. After cancer surgery or radiation, the lymph system may not drain properly, leading to swelling in an arm or leg.[1] Treatment can usually keep the swelling under control and reduce infections.

Use shared clinical decision-making (SCDM) to make collaborative decisions with patients for managing lymphedema in their post-cancer stage.

Use this guide to:

- Frame a **structured, empathetic conversation** with patients.
- Help patients understand their **treatment options.**
- Align treatment with **daily function, goals and capacity to achieve goals.**
- Support **documented SCDM.**

Key points about lymphedema for patients in the post-cancer stage[1]

- Lymphedema can appear **months or even years after cancer treatment.**
- Lymphedema is **long-term**, but **manageable.**
- **Early and consistent** care improves health outcomes.

Table 1. Management paths for lymphedema: home-based versus professional[2-4]

Options	Home-based: conservative management	Professional: complete decongestive therapy (CDT)
Actions and treatment	• Wear compression sleeves or stockings during the day • Daily self-care routine (i.e., skin care, simplified self-massage) • Ongoing monitoring over time	• Short-term, frequent visits with a certified lymphedema therapist (CLT) • Specialized massage and compression bandaging • Transition later to home maintenance
Framing for primary care providers	• Emphasize the stabilization and prevention of progression; this is appropriate for mild disease or when intensive therapy is not feasible	• Emphasize the rapid volume reduction and tissue softening via therapist-led CDT; transition to home maintenance once the patient is stable
Benefits	• Fewer clinic visits • Easier to fit into daily routines • Less disruption to work or for caregiving responsibilities	• Faster reduction in limb size • Hands-on professional support at the start
Challenges	• Requires hand strength and flexibility to put garments on • Needs daily consistency • Changes happen gradually	• Time commitment (multiple visits per week for several weeks) • Bulky bandages during treatment • Higher short-term costs depending on insurance

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Three questions to ask the patient and/or caregiver

1. **Schedule and logistics:** "Do you currently have the time and transportation to attend therapy sessions several times a week?"
2. **Daily function:** "Do you feel comfortable putting on a tight compression garment by yourself (or do you have assistance available) every day?"
3. **Priorities:** "Is your main goal to reduce the swelling as much as possible right now? What treatment will fit in with your current daily routine?"

Reinforce with patients and/or caregivers[1,5,6]

- Compression is **not started during active infection**.
- **Skin care** is essential to prevent cellulitis.
- **Swelling may fluctuate** over time.
- Compression sleeves and garments typically need replacement approximately every **three to six months.**

PCP summary (for charting)

- **Document:** stage/severity (i.e., measurements), current management path (i.e., home-based versus CDT) and barriers (e.g., dexterity, transport, cost)
- **Counsel:** chronicity, infection prevention and red flags prompting urgent intervention
- **Plan:** referral to CLT when indicated, follow-up interval and criteria for re-referral.
- **Prescription logistics:** anticipate garment replacement and refit approximately every three to six months and renew prescriptions, as required.

Resources

The Lymphoedema Framework. International consensus. Best practice for the management of lymphoedema. https://www.lympho.org/uploads/files/files/Best_practice.pdf

National Lymphedema Network. Position statement of the National Lymphedema Network. https://cdn.ymaws.com/lymphnet.org/resource/collection/2EE8AF2F-DE0C-458B-99C0-1B7600362542/WITH_References_-_Lymph_Diagnosis_and_Treatmen.pdf

National Lymphedema Network. Patient resources. https://lymphnet.org/page/patient-resources

A Celerian Group Company. Lymphedema compression treatment items – Correct coding and billing – revised. https://www.cgsmedicare.com/jc/pubs/news/2023/12/cope147943.html

Science Insights. What is the best compression for lymphedema? https://scienceinsights.org/what-is-the-best-compression-for-lymphedema/

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2. Bergmann A, Baiocchi JMT, Carvalho de Andrade MF. Conservative treatment of lymphedema: the state of the art. *J Vasc Bras*. 2021;20:e20200091.
3. Karaca-Mandic P, Solid CA, Armer JM, et al. Lymphedema self-care: economic cost savings and opportunities to improve adherence. *Cost Eff Resour Alloc.* 2023;21:47.
4. Gultekin SC, Karadibak D, Cakir AB, et al. Self-administered versus lymphedema therapist-administered complex decongestive therapy protocol in breast cancer-related lymphedema: a non-inferiority randomized controlled trial with three-month follow-up. *Breast Cancer Res Treat.* 2025;212(1):123-138.
5. Schaverien MV, Moeller JA, Cleveland SD. Nonoperative treatment of lymphedema. *Semin Plast Surg*. 2018;32(1):17-21.
6. Beck M. Compression sleeves and garments for lymphedema. March 7, 2024. Accessed May 11, 2026. https://www.breastcancer.org/treatment-side-effects/lymphedema/treatments/compression-sleeves

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