

Lympho-Logical Thinking in self-management of primary lymphoedema and other rare diseases involving lymphoedema

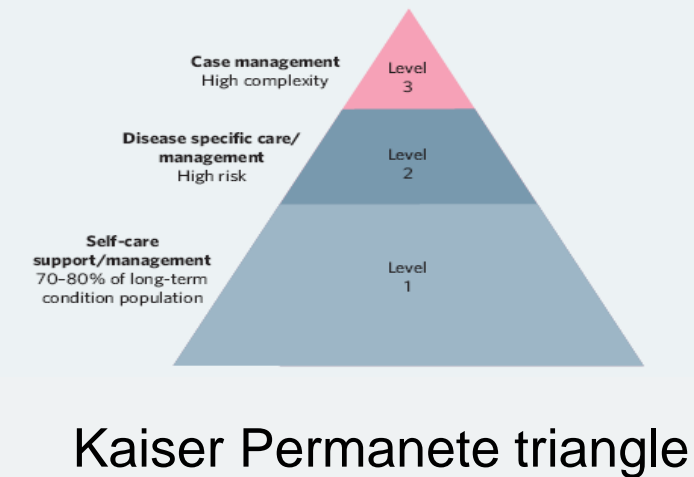
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Background

Many patients benefit from knowledge

Primary lymphoedema is a progressive diagnosis. 70-80% suffering from chronic conditions such as lymphoedema can control their disease with supported self care according to the Kaiser Permanente triangle model.



Aims

Understanding self care of lymphoedema

Answer to the important questions:

- How is self care taught?
- What is understood?
- How obtain adherence?

Methodology

Surveys and experiences from SÖF and 20 years of clinical experience of a lymph therapist.

Result

Works

Guidance through the 4 steps of learning in the areas of:

- Anatomy and physiology of the lymphatic system
- Deep breathing
- Self Manual Lymph Drainage (SLD)
- Skin care
- Compression techniques
- Physical exercise
- Factors affecting the swelling
- Emotional issues

Does not work

- Hand out a film with repulsive pictures of lymphoedema
- Hand out a picture with arrows how to massage
- Compression garments, rubber gloves and instructions sent home by mail
- Impatient and demanding therapists
- Compression as sole remedy

References

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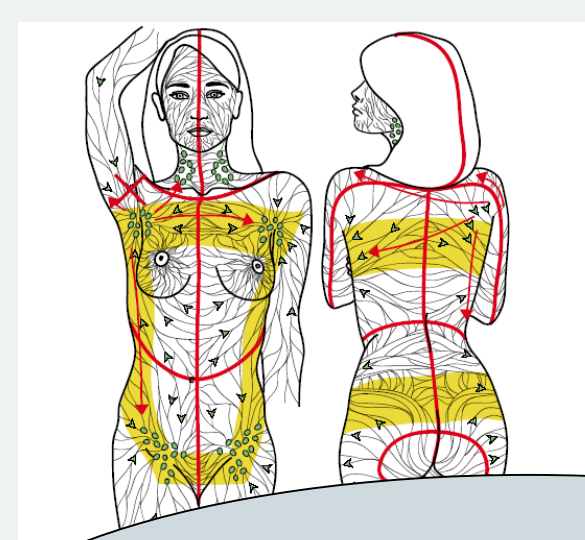
The 4 steps of learning – for lymphoedema patients

1. **Unconscious incompetence** – no knowledge of the existence of lymphoedema management
2. **Conscious incompetence** – knowledge of the fact that lymphoedema can be managed
3. **Conscious competence** – knowledge of how to manage lymphoedema
4. **Unconscious competence** – managing lymphoedema unconsciously

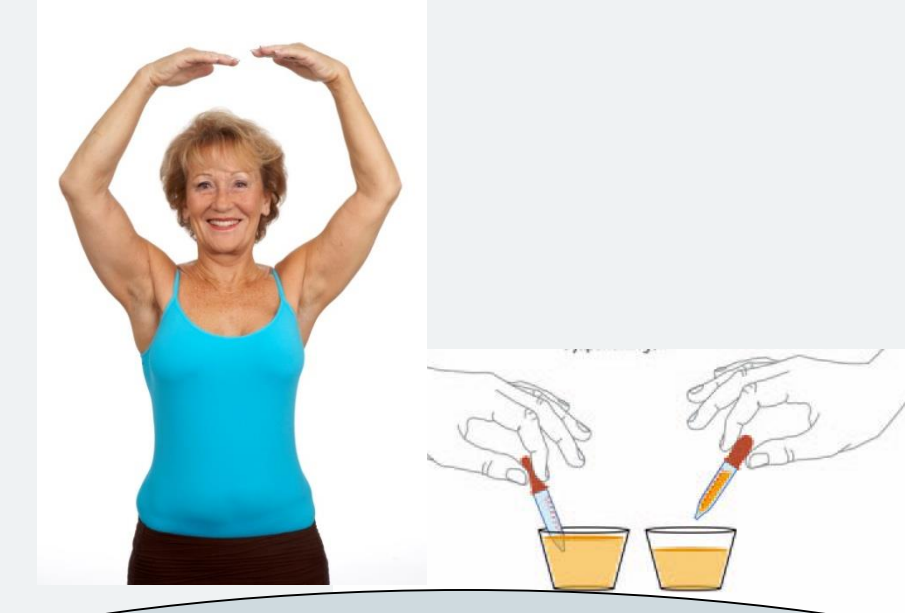
Result

What is important to learn and teach

Suggestions of how to simplify and use metaphors in understanding self-management of lymphoedema



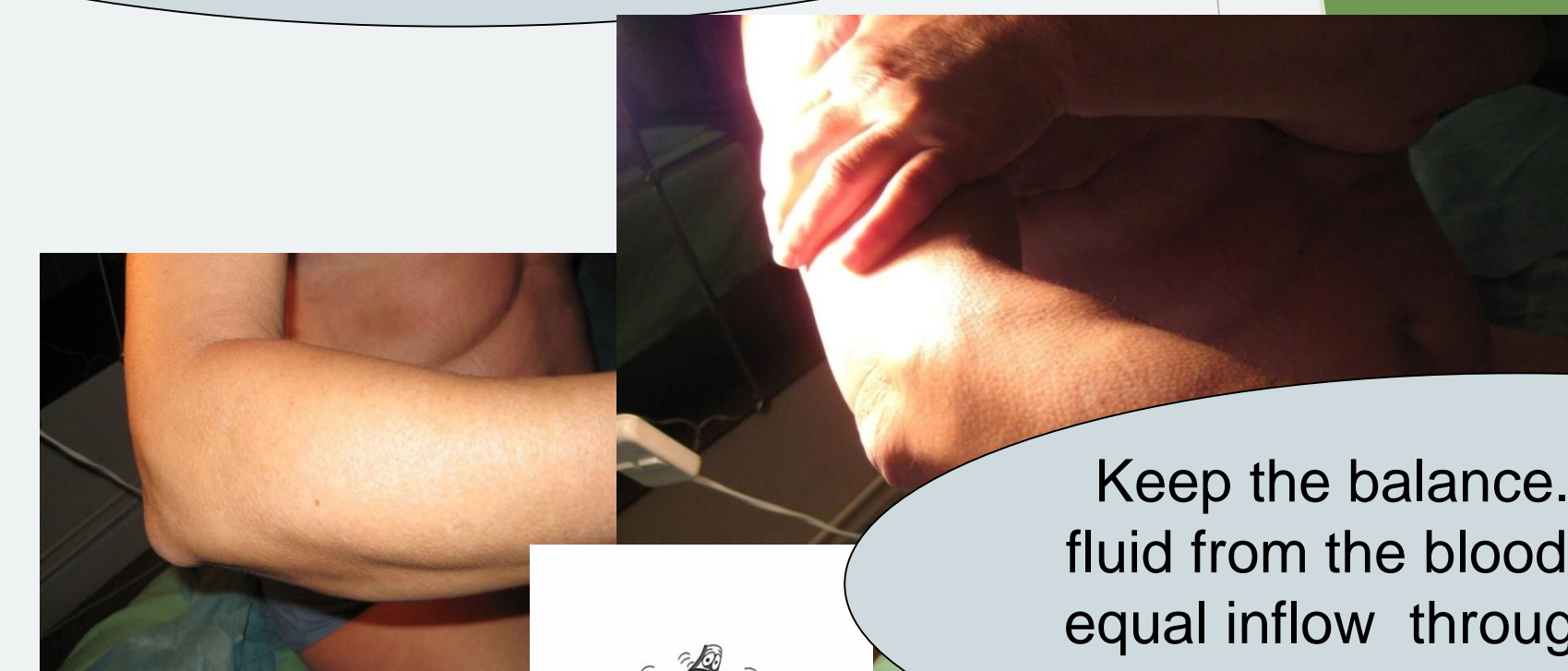
The lymphatic system is the "sewage system" from the tissues and can be activated



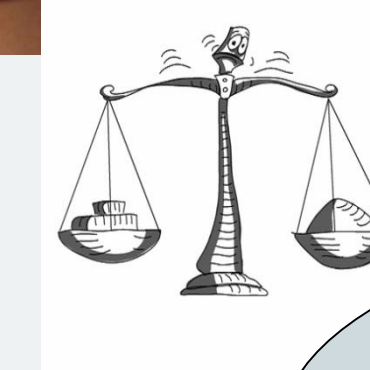
Deep breathing. The expansion of the chest has an effect on the lymphatic system that can be compared to sucking up water in a syringe



Neither clothes nor garments or bandages should cut off the lymphatic flow.



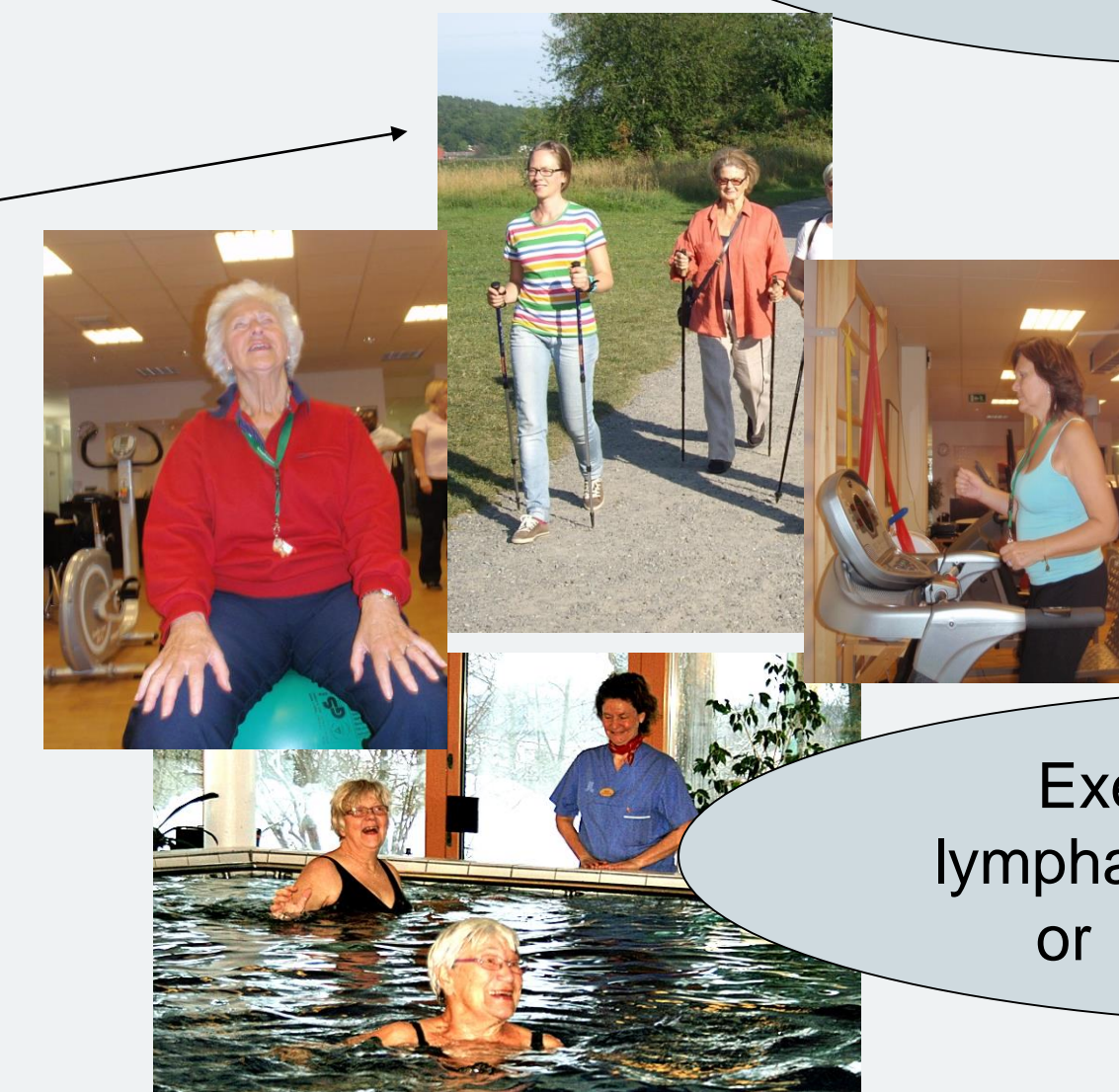
Keep the balance. The outflow of fluid from the blood vessels should equal inflow through the lymphatic system – every day



The skin is your armour. Skin care is important not to overload the lymphatic system, a part of your immune defense.

Listen to your body. Observe what makes the lymphoedema better/worse.

To accept life with a chronic condition. Allow for a mourning process.



Exercise enhances the lymphatic flow. It has to be fun or it doesn't get done.

What it takes to learn and teach

Patient

Goal: To gain best possible control of the lymphoedema

What is needed: Motivation

How obtain motivation: Knowledge

Therapist

Goal: To assist the patient in gaining best possible control of the lymphoedema

What is needed: To motivate the patient

What motivates the patient? Knowledge

Teamwork - Turning knowledge into practice

Conclusion

To understand and apply self care the patient needs:

- To accept the diagnosis lymphoedema
- Simple explanations
- Coaching until the patient is sure of the "know-hows"
- Feedback - experiencing a result

To teach self care the therapist needs:

- To use simple explanations
- To use metaphors if needed
- Patience with the patient
- To listen to the patient's part of the story
- A pedagogic approach
- Make sure that the patient can reason and act Lympho-Logically when swelling occurs