

**Welcome to the very first international online breast cancer rehabilitation summit. My name is Denise Stewart – I am your host from Brisbane Australia.**

**Today we have Karin Josenhan online. Karin lives and breathes lymphoedema she is a very experienced Lymphoedema specialist - an Associate Professor and a practicing therapist.**

A Registered physiotherapist (RPT), Lymphedema specialist, Department of Oncology, Division of Cancer Rehabilitation, Lymphedema Unit, Skåne University Hospital, Lund, Sweden. PhD, Associate professor, Dept of Health Sciences, Division of Physiotherapy, Lund University, Lund, Sweden. Member of the Board of International Society of Lymphology (ISL), European Society of Lymphology (ESL) and Swedish Society of Lymphology.

Specialist advisor for the National Guidelines for Breast Cancer Care in Sweden. Editor of the National Lymphedema Guidelines in Sweden.

Recent research focus on early diagnosis as well as physical activity for prevention and treatment of arm lymphedema following breast cancer treatment, and measurement of health related quality of life for lymphedema patients.

My question to you Karin is what got you as a physiotherapist into this field of practice?

K: Nearly 25 yrs ago, my aunt had treatment for breast cancer and a year later developed lymphoedema. I had absolutely no idea what to do to help her. I started to search for knowledge in this area and found there was not much done in that area. So that is why I started in this area - my aunt is still alive and still has lymphoedema unfortunately. However...

D: It is a very different place- 25 years ago we used to see many women with very big arms and today we do not see that as much.

K: That is what I am going to talk about today- how to prevent lymphoedema. So arms do not get that large.

K: Today I am going to talk about prevention and early management of breast cancer related lymphedema.

It is important to define prevention:

**Primary prevention** - not to damage the lymph system. This is impossible because of the nature of medical treatment today for cancer . I am particularly talking about the patients at risk who have both axillary node surgery and radiotherapy to that region.

**Secondary Prevention**- not to develop lymphedema after cancer treatment. That is to have some treatment or regime during or at a fixed time after to support the lymph system. To maintain normal weight may be such a regime.

**Tertiary prevention:** not to worsen already established lymphedema.

This picture of the lymphatic system of the arm- it works parallel with the venous system to transport fluid from the arm towards the center parts of the body.

As I mentioned breast cancer patients at particularly high risk of developing arm lymphedema - are those who have:

1. **Axillary surgery**- mostly at level 1-2 of lymph nodes beneath axillary vein
2. **Axillary radiotherapy** may increase the risk evenmore
3. BMI > 30 are evidence based risk factors

I will talk about which treatment could be applied. I heard a Swedish doctor give a talk on the radio some time ago and she very wisely said: " when a new medicine is introduced it has to be tested step by step on animals and healthy subjects before it is allowed on the market. But advice and recommendations are never tested that way and are most often not even evidence based. That is the use of control groups and for large groups of patients to get the statistical power for the position - this is hard to accomplish and can explain the lack of studies.

However a systematic review was published in 2011:

1. Avoid extreme temperatures: False
2. Avoid vigorous exercise False
3. Avoid pressure Probably false
4. Avoid air travel / preventative compression Probably false
5. Avoid needle sticks Not determined
6. Leg limb precautions Not determined
7. Maintain a normal body weight **FACT**

Manual lymph drainage is a massage technique believed to stimulate the lymph system.

Two randomized studies have done done using massage for prevention and they show totally contradictory results.

Preventative ability of lymph massage is Not determined.

There are no studies found that evaluate compression sleeves for prevention but we do know from systematic reviews and meta analysis where the effect on the limb can not be questioned.

If the lymphedema can be diagnosed at the early stage- most of the patients will not develop large lymphedema. To detect early lymphedema - you need a strategy- you need to advise the patient of early signs and then have them call back at the slightest sign of lymphedema. Or you can apply a follow up program for the patients at risk.

The information to the patients concerning early signs should include:

Patients experience of tightness in the tissue

Circumferential measurement at identified spots

Visible swelling

If you apply a program across these symptoms then simple objective measures can be made:

Volume measures using circumferential measure or water displacement method.

These measures can identify small and early changes in lymphedema- which is less than 10% volume difference between each arm. By comparing skin tissue thickness between the operated side to the operated side- an increased thickness can be detected.

The patient may also feel tightness as mentioned previously and these can be measured using a visual analogue scale.

**More advanced methods of lymphedema measurement:**

- BIS- Bioimpedance spectroscopy
- TDC Tissue dielectric constant ( to identify surface changes) using a Moisture Meter

However the combination of water displacement and TDC have been found to be the most sufficient.

I will give you one example of what the program of breast cancer at risk may do for prevention .

This is the program of the lymphedema unit at Skane University hospital and Lund university since the mid 1990's.:

1. At 1 month postoperatively the patient is measured and provided LE prevention advice. Already at this point some LE patients are identified.
2. 3-4 months check up after radiotherapy is completed
3. At any time in between some patients call themselves or they may be diagnosed by someone else in the healthcare system.

So when you can diagnose LE in the first year after surgery- very few cases will show up.

An evaluation at 10 years:

Included: 292 BC patients axillary dissection and RT  
BCRL 111 ( 38.7%) during follow up 1-10 yrs post op.

Exclusion: 13 pts

N= 98 with arm LE

The mean volume difference at diagnosis: 8,+ - 3, 6%

At follow up mean 4 years after diagnosis 9,+ - 6, 7%

Some other findings from this study:

80-90% can be kept on a mild or moderate level for at least 10 years = prevention

10% need individually adjusted motivation / treatment with careful monitoring with measurements

Some may not need treatment at all.

The challenge for the future is to determine what variables that we will be able to settle to question of the best treatment for each individual. And should everyone be treated - is there some post breast cancer edema that will resolve itself without LE ( lymphedema) treatment. Some may actually not need any treatment at all and to find these patients is another challenge. So I hope that this presentation has been helpful for you to understand how to prevent lymphoedema

Thank you.

D: What is the main intervention used in Sweden for LE when it is detected early?

K: We use a good fitting comfortable compression sleeve. Then you get the patient back to the clinic after 1 month to see that the increase in LE has stopped. The best outcome being that the LE has reduced. If the LE is less than 10% it is important to stop treatment . In some patients the LE has resolved and they do not need a compression sleeve any more.

D: That is very exciting - to get that early intervention.

K: That is what needs to be done- when you know that there are patients who are at risk - then they can be followup - give them good information about how to detect LE themselves. Then if you do the program- with follow up - then there is objective measures.

We still have women in 50-60yrs age who have seen their aunt or another women from many years ago with a very large arm and they are frightened of LE. What you are saying is that this is not the same anymore.

K: Yes we never ever see those big arms any more. I saw them in the 1990s - but not now.

So as health professionals we need to be sharing that information - if LE is detected early then the intervention is short- eg 1 year or less- to allay that fear of LE.

K: I think that is very important.

Thank you Karin!