

Committee Secretary
Standing Committee on Health
PO Box 6021
Parliament House
Canberra ACT 2600

PO Box 197
Rose Bay 2029

21st July 2015

Attn: Minister for Health, The Hon Sussan Ley MP, Committee Secretary, and other members of the Standing Committee on Health

I would like to submit some thoughts ahead of your inquiry into Chronic Disease Prevention and Management in Primary Health Care. Specifically, I would like to address the care and management of lymphoedema.

I have been affected by secondary lymphoedema following my treatment for breast cancer. I would not change a thing about my treatment – not only was it life saving, but it was given to me through an excellent care system where I was treated with professionalism and compassion. However, I am left with a lifelong condition to manage.

There is no cure for lymphedema and the treatment – to the layperson – seems a little inadequate. All that I can be offered to reduce my swelling are massage and compression garments. And to keep cool, which in an Australian summer is virtually impossible.

I would like to take this opportunity to request a scheme – similar to the [External Breast Prosthesis Reimbursement Program](#) – wherein lymphoedema patients can be reimbursed for compression garments.

Here are some quick facts to support this:

- Compression garments are the recommended treatment, but they wear out after 3 months and need replacing.
- Patients need at least 2 pairs at a time, for hygiene reasons. One needs to be worn while the other is being washed.
- Many patients – myself included – require customised garments to allow for the correct measurements and compression strength. This brings the cost to at least \$250 per garment per quarter.

Wearing a sleeve is uncomfortable and they're also pretty ugly. Add expensive to the mix, and many women just can't manage the treatment. Unfortunately, this frequently leads to further problems, which, due to the lack of knowledge of lymphoedema in both the medical and the general community, are often diagnosed much later than the recommended guidelines would recommend.

I would welcome any improvements in care for lymphoedema patients, and I would like to take this opportunity to thank you for considering my views. I would also be delighted to speak further with you on this, or any aspect of my treatment. I have written both a book and a blog, which gives me access to feedback from many women, and I would be pleased to share this with you, too.

Kind regards,

Yvonne Hughes
Author of *One Piece of Advice*