SAVING LIFE 2019
FAQs: Lymphoedema

Q: What is lymphoedema?
A: Lymphoedema is a chronic, incurable condition involving swelling, usually in an arm or leg, but it can also affect other parts of the body such as the neck, breasts or genitals. It happens when lymph fluid, which transports immune cells, bacteria and viruses, can’t flow through the lymph vessels and nodes properly. This may happen if they’ve been damaged during cancer surgery or radiation therapy. A blockage can result in symptoms of lymphoedema such as persistent swelling, heaviness, pain, aching or tightness. Not all people treated for cancer will get lymphoedema, however it occurs in approximately 20% of people treated for melanomas, gynaecological, breast, or prostate cancers. More information about lymphoedema can be found in the ‘Understanding Lymphoedema’ pamphlet https://www.cancercouncil.com.au/wp-content/uploads/2017/06/UC-Pub-Lymphoedema-CAN6478-lores-June-2017.pdf

Q: Why is lymphoedema a problem?
A: Lymphoedema can be painful and cause problems with limb function and overall mobility, which causes difficulties with getting dressed and other activities such as driving or going to work. Lymphoedema also increases the risk of poor body image, anxiety, depression, and social isolation. The build-up of lymph fluid can damage the tissues and skin which means there’s a higher risk of getting an acute infection in the skin, called cellulitis, requiring hospitalisation for intravenous (IV) antibiotic treatment. While lymphoedema starts as a fluid build-up, it can progress to hardened fat and/or fibrous tissue in the affected area which further increases the risk of infection, and ulcers.

Q: Why is living with lymphoedema so expensive?
A: Lymphoedema is a chronic condition so treatment costs may be incurred over many years. This includes the cost of seeing a specialist lymphoedema practitioner, skin and wound care, and GP appointments. Employment can also be impacted, affecting a person’s finances and work opportunities. In moderate or severe lymphoedema an intensive treatment period, with three to six appointments per week over 4 weeks, may be necessary. Access to public lymphoedema services is limited. For some people getting quality care requires paying to see a private specialist lymphoedema practitioner. For those with private health insurance the level of reimbursement varies. For others who can’t afford the out of pocket cost, they may have to go without lymphoedema care altogether.

Almost everyone with lymphoedema requires compression garments for ongoing management. Customised garments cost up to $500 and at least 2 sets at a time, replaced 6 monthly, are needed. Once compression garments have been fitted and shown to be effective, some patients are eligible for funding through EnableNSW. If so, the cost is means tested and the patient also pays a yearly co-payment. If not eligible for this funding, the cost of compression garments is borne by the patient. Even with private health insurance, the cost of the garments are never fully reimbursed.
Q: What does timely access to care mean?
A: For someone who is diagnosed with a cancer that carries a higher risk of lymphoedema, timely access means having an expert assessment before symptoms emerge. This includes objectively measuring the limb before and after surgery or radiation therapy, and follow-up 3 monthly for two years to observe any changes and intervene early if necessary. This also allows for the patient and/or their carer to learn how to identify the first signs of lymphoedema and what to do to lessen the risk of it worsening. If someone is experiencing mild swelling in the early stages, timely access means seeing a specialist lymphoedema practitioner so that the condition doesn’t develop further, and the severity of the condition long-term is significantly reduced. If obvious symptoms such as persistent swelling, heaviness, pain, aching or tightness already exist, timely access means seeing a specialist lymphoedema practitioner quickly for treatment as soon as possible. The NSW Government’s Agency for Clinical Innovation says that this should be within 4 weeks of the symptoms appearing.

Q: What does evidence-based lymphoedema care mean?
A: It means caring for a person who is at risk of, or who already has, lymphoedema in a way that aligns with the best quality evidence from peer-reviewed literature. The current consensus among experts worldwide says that evidence-based lymphoedema care is: identifying people at risk of developing lymphoedema early; having appropriately trained health professional who can identify, assess and diagnose lymphoedema; providing education to enable patients/carers to self-manage lymphoedema; tailoring treatments to the patient’s needs; and managing the lymphoedema to prevent cellulitis.

Q: What is a lymphoedema service and what does a model of care mean?
A: A quality lymphoedema service is one where there is a specialist lymphoedema practitioner who can provide education and advice, assess symptoms, develop a treatment plan, and prescribe compression garments. The specialist lymphoedema practitioner needs access to resources including: bandages; equipment such as a bioimpedance spectroscopy to measure objectively; equipment such as pneumatic pumps and low level laser to treat the lymphoedema; and a budget for trialling compression garments.

A model of care describes how an LHD will deliver lymphoedema services to their community. To develop their model of care an LHD needs to understand how many people are likely to access the service. There is no clear picture of how widespread the problem is in Australia, however international data suggests that approximately 1.53 per 1,000 people are affected by lymphoedema. In addition, there’s evidence that approximately 20% of people who’ve had breast, gynaecological and prostate cancer, or melanoma, are likely to get lymphoedema, and prevalence data about these types of cancers are available for each LHD. This will add to the picture of need, as will reviewing current waiting lists and consulting with patients about their experience when seeking access. Staffing is also a significant part of developing a model of care. While there’s no Australian benchmarks for staffing ratios for lymphoedema, there are some guides from the United Kingdom. With administrative support, and access to bandages and compression garments, a ratio of one full time lymphoedema practitioner with a caseload of 150 patients, or 200 patients per year, is considered appropriate.
Q: How many LHDs have lymphoedema services?
A: In 2010, research showed that only 8 of the 35 public hospitals in greater metropolitan Sydney offered a lymphoedema treatment service. However there is no current data about lymphoedema service provision in NSW and availability of information about lymphoedema services on LHD websites is inconsistent.

Q: Is it only specialist trained practitioners who should provide lymphoedema care?
A: No matter where they work, allied health professionals, doctors and nurses should be able to identify if a person they are caring for has signs of lymphoedema, so that they can refer them to a specialist lymphoedema practitioner in a timely manner. However, it is only with comprehensive training that a practitioner can accurately identify, assess and diagnose lymphoedema early and provide quality evidence-based care. This includes prescribing compression garments and providing targeted treatment at all stages of the condition.

Q: What is an appropriate qualification for a practitioner?
A: The Australian Lymphology Association (ALA) accredited training course is for physiotherapists, occupational therapists, doctors or registered nurses. Level 1 of the course, which provides basic skills/knowledge to assess and treat uncomplicated lymphoedema, is one full week of pre-learning online and 8-9 days training. Level 2 of the course, which results in the practitioner being able to assess and treat all forms of lymphoedema including complex presentations, is a further 6 days training.

NSW Health’s Health Education and Training (HETI) offers an online training module for generalist allied health staff to help them recognise lymphoedema when they are providing their own patients with care. Another module for physiotherapists and occupational therapists only, focuses on early intervention and referral to specialist practitioners. Undertaking a HETI course does not result in registration as a lymphoedema practitioner. Registration as a lymphoedema practitioner, which is necessary to coordinate patient applications for EnableNSW funding, requires a minimum of level 1 ALA accredited training.

Q: Will the new way of doing cancer surgery reduce the number of people with lymphoedema?
A: Changes in surgical techniques for cancer, which take less of the lymph nodes than was previously possible, have reduced the number of people who are at risk of lymphoedema. However, there are still approximately 22,000 people living with lymphoedema in NSW, many of whom will need life-long management of their condition.