



Equitable access to quality lymphoedema services in NSW

BACKGROUND TO THE LYMPHOEDEMA ACTION ALLIANCE

The Lymphoedema Action Alliance is a group of twenty organisations representing many thousands of people who are advocating for changes to reduce the unnecessary suffering of people who have lymphoedema. Based on evidence, and feedback from people with lymphoedema, the Alliance focuses on a) equitable access to affordable lymphoedema services in NSW and b) equitable and sustainable access to affordable compression garments nationally. The following provides evidence to support the first of these.

GOAL

That people at risk of, or living with, lymphoedema in NSW receive equitable access to appropriate physical and psychological care; and information about lymphoedema services is easily accessible.

POLICY CONTEXT

Currently there is no funding allocated to NSW local health districts for lymphoedema services, nor government policies to guide local health districts in planning them.

The NSW State Health Plan Towards 2021, emphasises the importance of world-class clinical care, and integrated care, organised around patients' needs with service models that deliver 'the right care in the right place' in an effort to keep people out of hospital.¹ For people with lymphoedema this means a lymphoedema service that provides world-class early intervention and ongoing care that is geographically accessible. The NSW State Health Plan Towards 2021 also emphasises the need to help patients and their carers navigate the health system.¹

Currently, there are no NSW Health policies or clinical directives about the prevention and management of lymphoedema. NSW Agency for Clinical Innovation is developing a document outlining the key principles of the management of people with, or at risk of, lymphoedema, which will be available to local health district staff.

Evidence-based clinical practice guidelines from interstate or overseas, that can be accessed by local health district staff, include *Lymphoedema Framework: Best Practice for the Management of Lymphoedema*,² and *Queensland Health lymphoedema clinical practice guidelines 2014*.³

PROBLEM

Lymphoedema is swelling (oedema) that occurs when lymph fluid builds up in the tissues under the skin, as a result of the lymphatic system not working as it should in that part of the body. It usually occurs in an arm or leg, but in some cases the trunk, head, or genital area.⁴ It is progressive and incurable.



Lymphoedema can be primary or secondary, or a combination of both. Primary lymphoedema is the result of a congenital or genetic condition affecting the development of the lymphatic system. It is estimated to affect approximately one in 6,000 people.² Secondary lymphoedema, is the more common of the two and most often results from cancer treatment, in particular, breast, gynaecological, genito-urinary, melanoma, sarcoma and head and neck cancers. The risk of lymphoedema with these cancers varies depending on the primary site.⁵ Conservative estimates suggest that, in Australia, the rate is close to 20% for some of those cancers.⁶ With more people being diagnosed with cancer and surviving longer, it is likely that there will be an increase in the number of people with cancer needing access to lymphoedema services in NSW.

**In NSW, close to 12,000 people are living
with lymphoedema and this number will
increase**

Approximately 1.53 per 1,000 people are affected by lymphoedema.⁷ With a current population of 7.7 million people in NSW,⁸ there are now close to 12,000 people living with lymphoedema in this state. By 2021, the population of NSW is estimated to grow to 8.3 million people,⁸ which means that approximately 12,700 people will be living with lymphoedema in NSW by then.

Left untreated, patients with lymphoedema are twice as likely to develop cellulitis requiring hospitalisation.

A lack of early assessment and treatment has been shown to lead to worsening lymphoedema which increases the risk of poor psychological and physical health outcomes.⁶ For example, lymphoedema may result in negative self-identity, poor body image, emotional disturbances, anxiety and depression, and social isolation.^{6;9-12} It may also cause chronic changes to the skin which reduces its ability to be a barrier against infections.¹⁴ As a result, bacteria can cause cellulitis, resulting in the skin and tissue under the skin becoming inflamed and causing pain, swelling and redness. Cellulitis can occur suddenly or take several weeks to become obvious. Left untreated, patients with lymphoedema are twice as likely to develop cellulitis requiring hospitalisation and intravenous antibiotics.^{13;14} In NSW in 2014-15 there were 18,340 potentially preventable hospitalisations due to cellulitis.¹⁵ While more research is required to understand the cost of lymphoedema to the NSW health system there is evidence that early intervention is significantly less costly than treating advanced lymphoedema encountered in hospital admissions.^{14;16}

In NSW it is estimated that a third of people with lymphoedema have difficulty accessing services needed to manage the condition.¹⁷ This exceeds the 2.6% of patients overall who have difficulty accessing health services.¹⁸ The main barriers for people with lymphoedema are the costs associated with ongoing treatment, and access to a clinician.¹⁷ In metropolitan Sydney only 8 of the 35 public hospitals offer a lymphoedema treatment service, often with long wait times for appointments. Public clinics may also restrict access to patients living within the local area or to those already being managed by the hospital.^{9;17}

Visits to a lymphoedema therapist in the private sector can be expensive, even when partially reimbursed to those who have private health insurance. With the addition of the cumulative costs of non-reimbursed compression garments and products for skin and wound care, the out-of-pocket costs for people with lymphoedema can be high.^{9;12;17} If someone has a GP Management Plan for their chronic disease they have access to five appointments with a private allied health practitioner per year, the cost of which is only partially reimbursed through Medicare. However five appointments has to cover all allied health services, potentially leaving an inadequate number remaining for a lymphoedema therapist specifically.¹⁷ Any of these barriers may result in someone having neither access to appropriate care nor an adequate amount of therapy, or having to pay significant out-of-pocket costs for the care they do receive. Patients with lymphoedema also report needing to take time off work or having their employment affected as a result of their illness which adds to their financial burden.^{4;13;19}

It is difficult to obtain information about lymphoedema services in NSW. The Australasian Lymphology Association (ALA) has a national directory of trained therapists, however it's voluntary. The list includes only a few working in local health districts in NSW. Where public lymphoedema services do exist, they are often part of physiotherapy or occupational therapy clinics so specific details are not included on websites. Neither the NSW Health website, nor individual local health district websites, nor the Cancer Institute's website include information about where to find a lymphoedema therapist in the public health system.

SOLUTION

Lymphoedema care may be complex and long term so it is best provided by trained clinicians.^{3:20} Evidence suggests that this should be at a ratio of one lymphoedema therapist per 150 patients.²¹ Applying this ratio to the estimated 12,700 people with lymphoedema in NSW by 2021, a minimum of 84.5 full time equivalent lymphoedema therapists will be needed, across both the public and private sectors. See Table 1 for further details.

Table 1: 2021 NSW population projections, estimated lymphoedema prevalence and FTE required per 150 patients, by LHD

LHD	LHD population projected 2021 ⁸	Lymphoedema Prevalence 1.53/1,000	FTE therapists required per 150 patients
South West Sydney	1,057,080	1617	10.8
Western Sydney	1,079,650	1652	11
Hunter New England	962,390	1472	9.8
Northern Sydney	966,340	1478	9.9
South Eastern Sydney	970,370	1485	9.9
Sydney	706,850	1081	7.2
Illawarra / Shoalhaven	423,130	647	4.3
Nepean Blue Mountains	396,790	607	4
Central Coast	357,250	547	3.6
Northern NSW	313,820	480	3.2
Western NSW	286,410	438	2.9
Murrumbidgee	244,870	375	2.5
Mid North Coast	227,980	349	2.3
Southern NSW	220,020	337	2.2
Albury Wondonga Health Authority , NSW part	54,470	83	0.6
Far West	30,220	46	0.3
Totals	8,297,640	12,694	84.5

A review of the number of practitioners providing lymphoedema services in each public health service will allow the NSW Government to develop an increased understanding of the need in each local health district. A calculation will then be needed to determine how many extra lymphoedema therapists are required per local health district, to bring the lymphoedema therapist workforce up to 84.5 FTE across both the public and private sectors by 2021.

To improve equitable access to affordable lymphoedema services across NSW detailed information, for example the number of lymphoedema therapists available, appointment times and referral options, is needed on relevant websites. This includes websites managed by each local health district, the NSW Health website and CanRefer, the online cancer services directory managed by the Cancer Institute NSW.

ACTION

The Lymphoedema Action Alliance recommends that:

- The NSW Minister for Health advise how many therapists (full time equivalent) are currently funded by NSW Health to provide lymphoedema services in local health districts
- The NSW Minister for Health make available funding to bring the number of lymphoedema therapists in NSW up to 84.5 FTE, across the public and private sectors, to meet projected needs
- Detailed information about public lymphoedema services, for example the number of lymphoedema therapist available, times and referral options, be added to local health district websites, the NSW Health website and the Cancer Institute's CanRefer website.

MEMBERS OF THE LYMPHOEDEMA ACTION ALLIANCE



References

- (1) NSW Ministry of Health. NSW State Health Plan:Towards 2021. 2014 [cited 2017 Aug 31]; Available from: <http://www.health.nsw.gov.au/statehealthplan/Pages/NSW-State-Health-Plan-Towards-2021.aspx>
- (2) Lymphoedema Framework. Best Practice for the Management of Lymphoedema. International consensus. London: Medical Education Partnership; 2006.
- (3) Queensland Health. Queensland Health lymphoedema clinical practice guidelines 2014. Queensland Health; 2014 Mar.
- (4) Moffat C, Franks P, Doherty D, Williams A, Badger C, Jeffs E, et al. Lymphoedema: an underestimated health problem. Q J Med 2003; 96:731-8.
- (5) Cormier JN, Askew RL, Mungovan KS, Xing Y, Ross MI, Armer JM. Lymphedema beyond breast cancer: a systematic review and meta-analysis of cancer-related secondary lymphedema. Cancer 2010; 116(22):5138-49.
- (6) National Breast and Ovarian Cancer Centre. Review of research evidence on secondary lymphoedema: Incidence, prevention, risk factors and treatment. Sydney: NBOCC; 2008.
- (7) Cooper G. Lymphoedema prevalence in the West Midlands region. Journal of Lymphoedema 2013; 8(1):17-20.
- (8) NSW Ministry of Health. Population by Local Health District_2016 and 2021 projections. 2017 March 14 [cited 2017 Jul 31]; Available from: http://www.healthstats.nsw.gov.au/Indicator/dem_pop_lhnmap/dem_pop_lhn_snap
- (9) Cancer Action Network. Lymphoedema stories: The untold truth. Sydney; 2013.
- (10) Fu M, Ridner S, Hu S, Stewart B, Cormier J, Armer J. Psychological impact of lymphoedema: a systematic review of literature from 2004 to 2011. Psycho-Oncology 2013 Jul 22; 22:1466-84.
- (11) Pusic A, Cemal Y, Albornoz C, Klassen A, Cano S, Sulimanoff I, et al. Quality of life among breast cancer patients with lymphedema: a systematic review of patient-reported outcome instruments and outcomes. J Cancer Surviv 2013 Mar; 7(1):83-92.
- (12) Stout N, Weiss R, Feldman J., Stewart B, Armer J, Cormier J, et al. A systematic review of care delivery models and economic analyses in lymphedema: health policy impact (2004-2011). Lymphology 2013 Mar; 46(1):27-41.
- (13) Vignes S, Arrault M, Dupuy A. Factors associated with increased breast cancer-related lymphoedema volume. Acta Oncol 2007; 46:1138-42.
- (14) Shih Y, Xu Y, Cormier JN, Giordano S, Ridner SH, Buchholz TA, et al. Incidence, treatment costs and complications of lymphedema after breast cancer among women of working age: a 2-year follow-up study. J Clin Oncol 2009 Apr; 27(12):2007-14.
- (15) Australian Institute of Health and Welfare. Admitted patient care 2014-15: Australian Hospital Statistics. Table 4.22. 2016 [cited 2017 Aug 2]; Available from: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129554729>

- (16) Stout NL, Pfalzer LA, Springer B, Levy E, McGarvey CL, Danoff JV, et al. Breast cancer-related lymphoedema: comparing direct costs of a prospective surveillance lymphoedema model and a traditional model of care. *Physical Therapy* 2012; 92(1):152-63.
- (17) Sierla R, Black D, Lee T., Kilbreath S. Access to treatment for breast cancer-related lymphoedema in Australia. *Australian Family Physician* 2013 Dec; 42(12):892-5.
- (18) Australian Bureau of Statistics. 2012 Year book Australia; Chapter 11 Health; health service usage and experience of health care. 2012 [cited 2017 Aug 28]; Available from: [http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/LookupAttach/1301.0Publication24.05.121/\\$file/13010_2012.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/LookupAttach/1301.0Publication24.05.121/$file/13010_2012.pdf)
- (19) McGilvray S. Lymphoedema and cellulitis: a narrative review. *Wound Pract Res* 2013 Jun; 21(2):56-60.
- (20) International Society of Lymphology. The diagnosis and treatment of peripheral lymphedema: 2013 consensus document of the International Society of Lymphology. *Lymphology* 2013 Mar; 46(1):1-11.
- (21) Welsh Assembly Government. Strategy for Lymphoedema in Wales. Wales UK: Welsh Assembly Government; 2009.