

Equitable access to quality lymphoedema services in NSW

BACKGROUND TO THE LYMPHOEDEMA ACTION ALLIANCE

The Lymphoedema Action Alliance is a group of nineteen organisations representing many thousands of people who are advocating for change so that the unnecessary suffering of people who have lymphoedema can be reduced. Based on evidence, and feedback from people with lymphoedema, the Alliance is pursuing changes in two areas. The first is equitable access to affordable lymphoedema services in NSW. The second is equitable and sustainable access to affordable compression garments nationally. The following document provides evidence to support the first of these goals.

GOAL

People at risk of, or living with, lymphoedema in NSW receive appropriate physical and psychological care within the public health system; and that service information is easily accessible.

PROBLEM

Lymphoedema is commonly defined as a chronic swelling persisting for longer than three months, usually of the limbs, and in some cases the trunk, head, or genital area.¹ It is progressive and incurable.



Primary lymphoedema is the result of a congenital or genetic condition affecting the development of the lymphatic system and is estimated to affect approximately one in 6,000 people.² Secondary lymphoedema, which is more common, most often results from cancer treatment. Secondary lymphoedema is more likely to occur with breast, gynaecological, genito-urinary, melanoma, sarcoma and head and neck cancers, with the risk varying depending on the primary site.³ In Australia, conservative estimates suggest the rate is close to 20% for some of those cancers.⁴

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In NSW,⁵ close to 9,900 people are affected with lymphoedema, with 57% of these affected people being aged 65 or over.⁶ Increasing cancer diagnoses, along with increasing survival rates have resulted in a substantial number of people in NSW needing access to lymphoedema management, now and for the foreseeable future.

A lack of early assessment and treatment has been shown to lead to worsening lymphoedema which increases the risk of poor health outcomes.⁴ Lymphoedema may affect a person's psychological health resulting in negative self-identity, poor body image, emotional disturbances, anxiety and depression, and social isolation.^{4;7-10} It may also cause physical problems such as chronic skin changes, reducing its ability to act as a barrier against infections.¹⁴

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Left untreated, patients with lymphoedema are twice as likely to develop cellulitis requiring hospitalisation and intravenous antibiotics.^{11;12} At Royal North Shore Hospital, 97 patients were admitted for lymphoedema between January and June 2014, and their combined length of stay was 975 days.¹³ It is likely that early intervention can reduce the 13,400 potentially preventable hospitalisations due to cellulitis in NSW each year.¹⁴ While more research is required to understand the cost of lymphoedema to the NSW health system and to model the potential savings, there is evidence that early intervention is significantly less costly than treating advanced lymphoedema encountered in hospital admissions.^{12;15}

Living with chronic lymphoedema can be costly for the individual and their families with practitioner fees (up to \$180 per treatment), in addition to cumulative costs of compression garments and skin and wound care products.^{7;10;16} Patients with lymphoedema also report needing to take time off work or having their employment affected as a result of their illness.^{1;11;17}

It is estimated that in NSW approximately a third of people with lymphoedema experience difficulty accessing the services they require to manage this chronic condition.¹⁶ In metropolitan Sydney only 8 of the 35 public hospitals offer a lymphoedema treatment service and access to these is often inconsistent and restricted to patients living within the local area or already being managed by the hospital.^{7;16} Clinic opening times may be limited and there may be a long wait for appointments.^{7;18} There is no uniform funding for lymphoedema services across Local Health Districts, or policies to guide service planning. In addition it is difficult to obtain information about where lymphoedema services are provided as there are no details available on the NSW Health website.

Currently a patient with lymphoedema, if referred by a General Practitioner under the Enhanced Primary Care Plan, can receive a Medicare rebate to access an allied health practitioner five times in a year. However the care plan is often needed for other allied health services, such as a podiatrist. If using the care plan for a private lymphoedema therapist a gap

payment of \$40-\$80 per visit (depending on how much the individual therapist charges) still has to be met by the patient. Also, for most patients five visits to a lymphoedema therapist is rarely enough particularly during the early treatment phase.¹⁶

SOLUTION

Lymphoedema care may be complex and long term so it is best provided by trained clinicians within a service that is accessible.^{19;20} Indicators from UK suggest that the optimal workforce ratio is one lymphoedema therapist per 150 patients.²¹ Using the generally accepted lymphoedema prevalence estimation of at least 1.33 per 1,000 people,¹ and applying the workforce ratio to the current NSW population, a minimum of 62.5 full time equivalent lymphoedema therapists are required across NSW for our current population. See table 1 for further details.

Table 1: 2014 NSW population projections, estimated lymphoedema prevalence and FTE per patient by LHN

| Local Health Networks (LHN) | NSW population estimate 2014 ²² | Estimated prevalence 1.33/1,000 ¹ | Ratio: 1.0 FTE per 150 patients ²¹ |
|-----------------------------|--|--|---|
| Sydney | 600,000 | 789 | 5 |
| South West Sydney | 900,000 | 1197 | 8 |
| South East Sydney | 850,000 | 1130 | 7.5 |
| Illawarra Shoalhaven | 400,000 | 532 | 4 |
| Western Sydney | 900,000 | 1197 | 8 |
| Nepean Blue Mountain | 350,000 | 466 | 3 |
| Northern Sydney | 850,000 | 1130 | 7.5 |
| Central Coast | 320,000 | 425 | 2.5 |
| Hunter New England | 900,000 | 1197 | 8 |
| Northern NSW | 320,000 | 425 | 2.5 |
| Mid North Coast | 230,000 | 306 | 2 |
| Southern NSW | 210,000 | 280 | 2 |
| Murrumbidgee | 240,000 | 320 | 1.5 |
| Western NSW | 270,000 | 360 | 2.5 |
| Far West | 30,000 | 40 | 0.5 |
| Total | 7,370,000 | 9,870 | 62.5 |

Internationally, experts have agreed on evidence-based principles for best practice to guide lymphoedema clinicians. These are outlined in the International Consensus: Best Practice for the Management of Lymphoedema, and the 2014 Queensland Health guidelines.^{2;19}

POLICY CONTEXT

The NSW State Health Plan Towards 2021,²³ emphasises world-class clinical care, and integrated care which puts the patient first and is organised around their needs. For patients at risk of, or who have developed, lymphoedema their primary need is access to a world-class lymphoedema service which is organised around their need for early intervention and ongoing care. The Plan also discusses service models that deliver 'the right care in the right place' in an effort to keep people out of hospital; and strategies to help patients and their carers navigate the health system. Having information about lymphoedema services readily available on a website is a simple and effective way of alerting patients to available services in their local area.

ACTION

The Lymphoedema Advocacy Alliance recommends that:

- Detailed information about public lymphoedema services (for example staffing, times and referral options) be made available on the NSW Health website and Cancer Institute's CanRefer website.
- The NSW Minister of Health make available adequate funding to ensure 62.5 full time equivalent lymphoedema therapist positions are provided across Local Health Districts on a population basis.

MEMBERS OF THE LYMPHOEDEMA ACTION ALLIANCE



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