



**Submission to The Standing Committee on Health:
Inquiry into Chronic Disease Prevention and Management in
Primary Health Care**

**Submission on the prevention and management of
Lymphoedema in Primary Health Care**

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LYMPHOEDEMA ACTION ALLIANCE

Established in October 2014, the Lymphoedema Action Alliance (LAA) is focused on reducing the unnecessary suffering and burden of people living with lymphoedema. The Alliance is made up of a number of organisations that have joined forces to be a more effective voice for improvements in treatment for lymphoedema. The LAA is working to ensure timely and equitable access to affordable lymphoedema services and compression garments regardless of where people live, their financial status and their health situation.



Lymphoedema Action Alliance Member Organisations:

Australian Association of Massage Therapists; Australasian Lymphology Association; Breast Cancer Action Group; Breast Cancer Network Australia; Cancer Council NSW; Cancer Voices NSW; Country Women's Association NSW; International Lymphoedema Framework Australia; Genetic Alliance Australia; Lymphoedema Association of Victoria; Lymphoedema Practitioners Education Group of Victoria; Lymphoedema Support Group of NSW; Lymphoedema Training and Education; Macquarie University Lymphoedema Program; Melanoma Patients Australia; Cancer Action Network Northern Suburbs; Ovarian Cancer Australia; YWCA; Lymphoedema Association of QLD.

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EXECUTIVE SUMMARY

Lymphoedema is a chronic and incurable disease. If untreated, lymphoedema leads to serious and permanent consequences that are costly to treat. In Australia, treatment for lymphoedema that is consistent with internationally accepted best practice is not widely available. Many of the high-cost health consequences from lymphoedema could be prevented by early detection and access to appropriate treatment services.

The adoption of a national model for early detection and best practice management of lymphoedema will reduce the total costs to the Australian health system and improve outcomes for lymphoedema sufferers.

The Lymphoedema Action Alliance (LAA) recommends that the Standing Committee bring forward a proposal in the 2016-17 Budget. This would fund the development and implementation of a national chronic care model for the early detection and management of lymphoedema in the primary health care setting in Australia.

WHAT IS LYMPHOEDEMA?

Lymphoedema is a chronic and debilitating condition caused by the collection of lymph fluid, leading to persistent swelling in the affected body part. It most often affects arms or legs, but the trunk, head, or genital area can also be affected¹. It is caused by poor development or damage to the lymphatics of the body. Lymphoedema is progressive and incurable, so early diagnosis and commencement of best practice treatment methods are critical to improving patient outcomes. (Refer Appendix A: ICD 10 classification codes for lymphoedema.)

CONSEQUENCES OF FAILING TO TREAT LYMPHOEDEMA

Failing to treat lymphoedema puts sufferers at greatly increased risk of developing severe bacterial infection of the skin and underlying tissues, which medical practitioners refer to as *cellulitis*. It can also lead to permanent changes to the skin which reduce its effectiveness at acting as a barrier against infections.² Patients with lymphoedema that has been left untreated are three times as likely as those being actively treated to develop cellulitis requiring hospitalisation and intravenous antibiotics.^{3;4} In a current online survey (www.lymphoedemaregistry.org.au) of

people living with lymphoedema, 43% of the 700 of those answering the questionnaire reported having cellulitis. This was in the lymphoedema-affected area and required the prescription of antibiotics.⁵

These cellulitis cases have a real and significant impact on Australia's health system. In the ACT an average of 336 patients per year (2007-2011) were admitted for lymphoedema related cellulitis.⁶ At just one Sydney hospital, between January and June 2014, 97 patients were admitted for lymphoedema, and their combined length of stay was 975 days.⁷ Accessible best practice management of lymphoedema cases would reduce the 13,400 potentially preventable hospitalisations due to cellulitis in NSW each year.²

“As a doctor I have had patients with recurrent admissions to hospital for leg ulcers and cellulitis because they have not had access to diagnosis and treatment for their lymphoedema or could not afford garments.” (Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote)⁸

While more research is required to understand the cost of lymphoedema to the 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.^{4,9}

Patients living with moderate to severe lymphoedema can suffer a high risk of experiencing cellulitis, lymphorrhoea (leakage) and wounds. These are the high end frequent users of medical and health services. In some cases there is a lack of recognition of the underlying condition which perpetuates the risk of recurrence. Repetitively admitted patients are often inadequately treated, and are provided with intermittent acute care and are not moved into a chronic care program, usually as there is none available.

“If patients have better provision of services for conditions resulting from their cancer treatment e.g. lymphoedema, they will have less hospital admissions for cellulitis and other infections. These infections are a result of poorly managed lymphoedema. Keep the lymphoedema under control and keep people out of hospital.” (Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote)⁸

Other common physical effects from lymphoedema are pain, and loss of range of motion in the affected body part. In addition, recent research has shown lymphoedema can have serious negative effects on a person's mental health¹⁰. For a more detailed exploration of some of the consequences from lymphoedema, please refer to Appendix B.

INCIDENCE OF LYMPHOEDEMA

Clinicians divide lymphoedema into two types, although diagnosis, clinical characteristics and treatment needs for each type is similar.

Primary lymphoedema is the result of a congenital or genetic condition affecting the development of the lymphatic system and has been estimated to affect approximately one in 6,000 people at birth. However the onset can occur throughout life.¹¹

Secondary lymphoedema, which is more common, most often results from cancer treatment.¹² The treatments include removal of lymph nodes and radiotherapy for cancers including breast, melanoma, prostate, ovarian, cervical and other skin cancers. It can also be caused by other health conditions, such as venous hypertension and venous ulceration, immobility and obesity.

International studies have shown a 15.5 per cent incidence rate of secondary lymphoedema following treatment for a number of common cancers, including breast cancer.¹² In Australia, conservative estimates suggest the rate is closer to 20 per cent.¹³ Cases of primary lymphoedema and lymphoedema from other secondary causes will add to the overall incidence of lymphoedema.

The actual number of people diagnosed with lymphoedema each year in Australia is unknown because of varying definitions and poor data collection. However it is reasonable to assume the rate is at least equivalent to that quoted internationally.

According to a UK community epidemiological study on chronic oedema, the prevalence of lymphoedema was estimated to affect 1.33 people per 1,000 amongst the general population, and 5.4 people per 1000 in the 65+ age group¹. If this ratio holds for the Australian population,¹⁴ there are more than 32,000 people with lymphoedema in Australia, some 19,000 of whom are aged 65 or over. However in the ACT-wide lymphoedema service review (2011) the UK prevalence ratio was shown to significantly under-report the actual “active” lymphoedema patient number under care in the ACT.⁶

BEST PRACTICE TREATMENT METHODS FOR LYMPHOEDEMA

There are multiple areas of lymphoedema treatment and management that already have accepted best practice protocols:

- a) Prevention and early detection of lymphoedema
- b) Treatment and management of lymphoedema
- c) Use of compression in the treatment of lymphoedema

Prevention and early detection of lymphoedema

Preventing lymphoedema or detecting lymphoedema early and managing it when it is mild and potentially reversible, can reduce the long term physical, functional and psychological effects caused by a late diagnosis as well as delayed and less effective management of the condition.¹⁵

“Lymphoedema affects the lives of young and old. Untreated it prevents educated, otherwise healthy individuals from being active members in our workforce and community. We need to embrace the recent research of early intervention. If prevention is better than cure, early intervention saves lives.” (Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote)⁸

The Australasian Lymphology Association (ALA) is the peak professional organisation promoting best practice in lymphoedema management, research and education in Australasia. The ALA has developed a position statement: *Monitoring for the early detection of breast cancer related lymphoedema*.¹⁵ This document has been endorsed by BreastsurgANZ and the Breast Physician Society.

When cancers are managed in specialist cancer teams or services (particularly for breast cancer) monitoring for lymphoedema may be available depending on staffing. Further research is required to determine whether these early detection guidelines can be successfully extrapolated to other types of cancer-related lymphoedema. GPs are not usually involved as part of the cancer services/teams. This means they may not have the experience or opportunity to monitor and detect lymphoedema in its early stages.

Currently, there are guidelines available to assist GPs with identification of established chronic oedema/ lymphoedema in Australia. (Appendix C: GP Education)

Treatment and management of lymphoedema:

Internationally, best practice guidelines have been developed for the management of lymphoedema. The International Lymphoedema Framework (www.lympho.org) developed these guidelines from the success of a UK model in improving

lymphoedema management in Britain. These guidelines have now been adapted in several countries in Europe (France, Netherlands Sweden) and Asia (Japan) and North America (Canada).¹¹ (Appendix E: International Consensus Document).

While therapy will be individualized to the patient the components of the therapy include:

- **Skin care – moisturizing and possible use of low-level laser.**
- **Decongestive lymphatic massage with initial deep breathing and emphasis on training for self massage. Use of intermittent compression pump for selected patients.**
- **Multilayer graduated compression bandaging of the affected limb.**
- **Exercise in compression – ongoing home exercise program.**
- **Prescription of compression garments and education in their care and use.**
- **Review and re-prescription of compression garments six monthly.**

Use of compression in lymphoedema:

In 2014, Queensland Health published a lymphoedema clinical practice guideline; *The use of compression in the management of adults with lymphoedema*.¹⁶ The purpose of this document is to provide lymphoedema practitioners in Queensland with practical, evidence-based recommendations for the use of compression therapy to treat lymphoedema in adults.

Compression therapy involves the use of bandages and specialised compression garments in combination with physical exercise to aid the functioning of the lymphatic system or to move the lymphatic fluid to areas of the body with normal lymphatic function. It has been proven to be effective in helping reduce the amount of fluid in affected parts of lymphoedema patients' bodies.

This clinical practice guideline is a welcome development but needs to be accepted nationally for Australia to have a best practice approach in this area.

CURRENT LYMPHOEDEMA CARE AND SUPPORT IN AUSTRALIA

In 2012, the International Lymphoedema Framework Australia conducted the largest lymphoedema stakeholder survey ever done internationally.¹⁷ It identified the following key issues that need to be addressed to improve the treatment and management of lymphoedema in Australia:

- A need for **education** about lymphoedema, especially for medical professionals, allied health professionals, and the community.

- The **lack of services** to meet patient's needs, including the availability of services, time taken to access services, as well as rural and public services. This included the lack of links between the medical profession and therapists, (referral process and maintenance of patients care), inadequate pathways to service, and limited resources that prevent patients from getting timely and appropriate access to services.
- **High cost of treatment** including lack of government funding of treatments and general cost of accessing appropriate treatment.
- **High cost of compression garments.**

Need for education of health professionals and people at risk

"I think there should be more awareness raising of the possibility of acquiring lymphoedema before or just after surgery. Cancer and lymphoedema are both life changing and women and men need reminding that there is always the risk of lymphoedema in the short term and even years later. I know a lady who contracted it 19 years after surgery!" Marie (Quote from Lymphoedema Stories: The Untold Truth)¹⁸

This anecdote highlights the need to improve awareness and knowledge of lymphoedema in the Australian community generally, as well as the need for more targeted information for medical practitioners and patients undergoing procedures known to be associated with increased risk of developing lymphoedema.

(Appendix C: GP Education)

Lack of services and access to available services

It is estimated that in Australia approximately a third of people with lymphoedema experience difficulty accessing the services they require to manage this chronic condition¹⁹.

In NSW, only 8 of the 35 public hospitals in metropolitan Sydney and 10 of 107 rural hospital offer a lymphoedema treatment service. In addition, access to these is often inequitable, with access being restricted to patients with certain cancer related lymphoedema, or living within the local area, or already being managed by the hospital^{18;19}. Therapy times and services are limited and there are often long waiting times for appointments.^{17;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 is no information available on the NSW Health's website.

“People don't ask to get cancer and when they do issues faced can cause huge family stress not to mention loss of income. They need help with the cost of treatment and also the cost of proper after treatment for lymphoedema, which is a terrible thing to live with.” (Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote)⁸

Lack of access to services via GP

Currently a patient with lymphoedema can receive a Medicare rebate to access an allied health practitioner (item 10958 and 10960) on five occasions in a year, when referred by a General Practitioner under the Chronic Disease Management Plan (GP Management Plan (GPMP) – Item 721). A gap payment of \$40-\$100 per visit still has to be met by the patient. For most patients five standard 30 minute therapy sessions is inadequate to achieve a good outcome.¹⁹

The Department of Veterans Affairs recognises the specialised skills and time required for therapy by providing a payment of \$128.00 per session. This includes lymphoedema therapy provided by an NLPR eligible physiotherapist or occupational therapist.

Best practice dictates that Complex Lymphoedema Therapy (CLT) be implemented by a qualified lymphoedema practitioner. Without lymphoedema management training the lymphoedema therapy is inadequate, or may cause injury. Poorly applied compression can cause vascular injury and further damage to lymphatic vessels.

The Lymphoedema Practitioner (Category 1) is defined as: a health professional with APHRA registration such as physiotherapist, occupational therapist or registered nurse, eligible for registration on the National Lymphoedema Practitioner Register (NLPR). This means that they have completed an ALA accredited lymphoedema management course.²⁰ The Lymphoedema Practitioner is pivotal to breaking the negative cycle of lymphoedema and its complications.

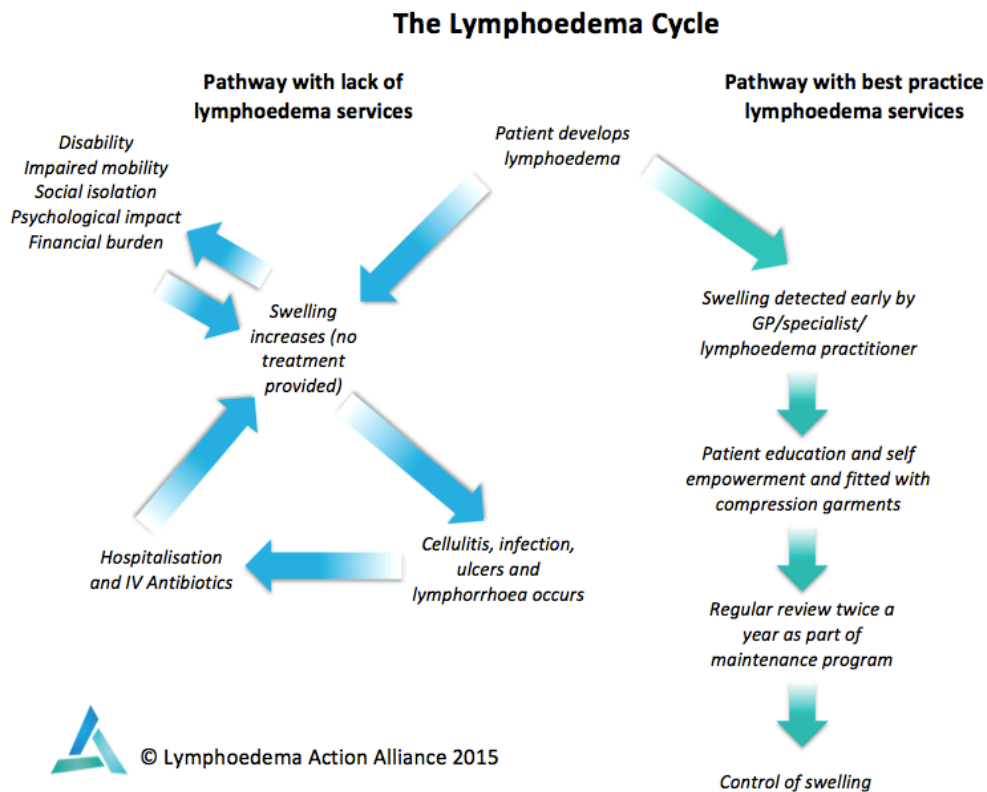


Figure 1. The Lymphoedema Cycle. Poorly treated lymphoedema leads to poor outcomes physically, psychologically, economically and socially. The Lymphoedema Practitioner is pivotal to breaking this cycle.

Cost of compression garments and treatment

Compression garments form part of the long-term management of lymphoedema, usually following a period of intensive therapy. Compression garments are also used for prophylaxis or as part of initial treatment.¹¹ Lymphoedema sufferers without private health insurance struggle to pay for garments (they can cost in excess of \$1,000 per year). Whilst there are programs, such as ENABLE in NSW, they are rarely sufficient for the majority of people, as it is means tested and capped. (In Queensland the compression garments scheme is only available for malignancy related lymphoedema). For further information See Appendix F: Estimates for cost of treating lymphoedema.

“I have suffered from primary lymphedema for 7 years & have discovered there is no support from the government to cover cost of garments or any lymphatic massage therapy. I have a massage every 4 weeks & require a new pair of garments every 3 months @ \$90/pair. As I am retired I find I can't afford to purchase garments every 3 months so tend to use the garments beyond their practical use by date which means my leg is not getting the recommended care which leads to further complications such as cellulitis for which I have already spent a 12 day period in hospital. I believe it would be more cost effective for the government to offer financial support for both garments &

Lymphatic massage therapy rather than to have to support patients during long hospital stays. (Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote)⁸

LYMPHOEDEMA ACTION ALLIANCE RECOMMENDATIONS

The LAA makes the following recommendations for best practice and quality improvement in lymphoedema prevention and management.

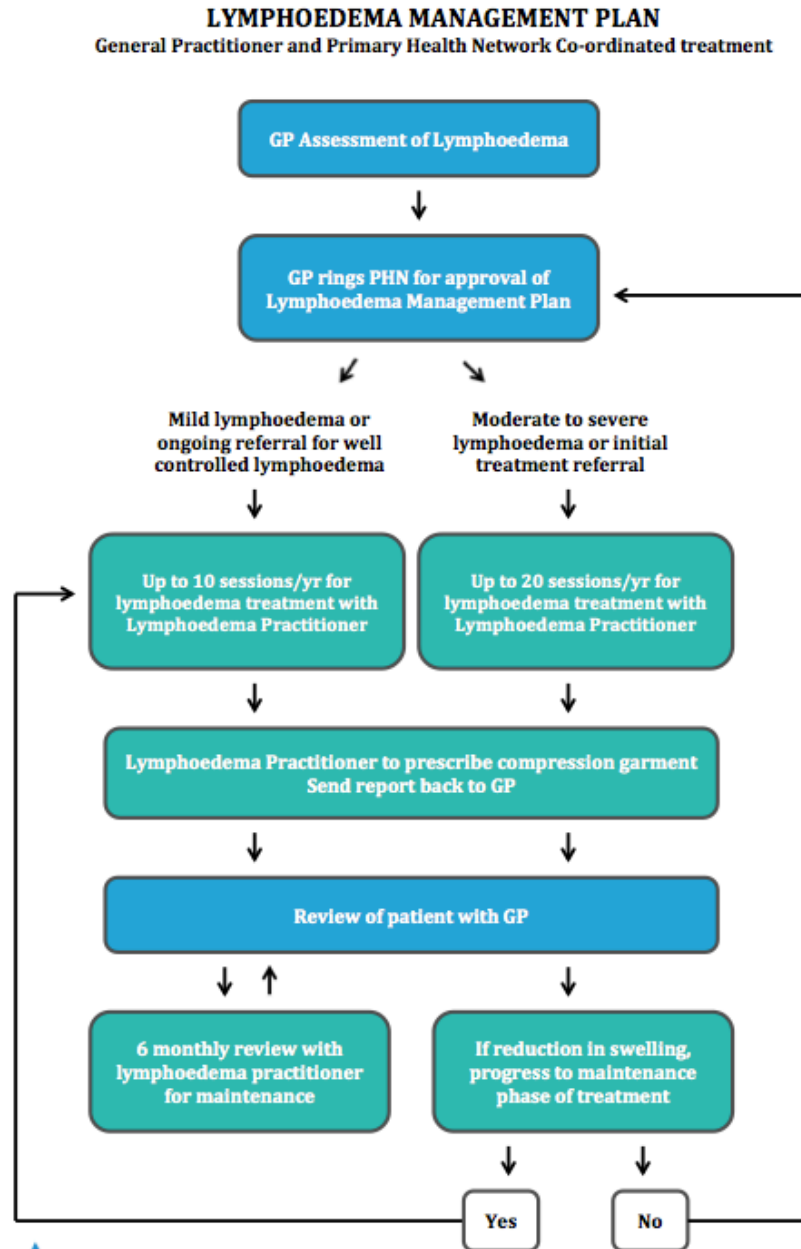
1. A new *Lymphoedema Management Plan* to provide both the incentive to medical practitioners and a structured best practice methodology for the patients' treatment and ongoing care.

To achieve equitable and timely lymphoedema management in the community, in particular in the Primary Health setting and in collaborative PHN (Primary Health Network) structure, the LAA recommends:

- A referral pathway with assistance of Primary Health Networks, similar to that of the current Mental Health Care Plan and Access to Allied Psychological services (ATAPS) pathway. This could be called the Lymphoedema Management Plan. (Figure 2)
- GPs can refer to a prepared list of lymphoedema practitioners listed as service providers by the Primary Health Network.
- Severe lymphoedema usually requires an intensive therapy and would require up to 20 one hour sessions per year. This would allow for bandaging to reduce the swelling, and then fitting of garments to maintain it and prevent exacerbations.
- Mild lymphoedema (or lymphoedema in the maintenance phase) would likely only require up to a maximum of 10 one hour sessions per year.

This Lymphoedema Management Plan would operate separately to the current GPMP pathway, so that patients can still access other allied health services such as dietician, podiatrist and diabetes educator to manage their other co-morbidities.

*“Lymphoedema treatment needs specific Medicare rebates/EPCP number to cover 1hr treatment for a course of 20 sessions to bring it under control. Then compression garments ought to be fully funded, as PBS prescription to control the condition. No garment means no control. Lymphoedema if neglected leads to life threatening infection and intensive care admission costing a fortune. It is cost effective to treat early and control and prevent the deterioration into chronic disease.”
(Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote)⁸*




 © Lymphoedema Action Alliance 2015

Figure 2. Lymphoedema Management Plan. Based on current Mental Health Care Plan & ATAPS Pathway. (See Appendix G).

“Treatment should be automatically accessible to patients – say each six months. This would prevent deterioration of the condition, and probably would require less work to control the swelling, resulting in fewer sessions.” Ruth (Quote from *Lymphoedema Stories: The Untold Truth*)¹⁸

2. Improved role of private health insurers in lymphoedema prevention and management

2.1 Reimbursement for treatment sessions that are either through private lymphoedema practitioners or via private hospital based admissions.

Effective management of lymphoedema is through treatment such as bandaging and compression, performed or prescribed by a lymphoedema practitioner, as per best practice guidelines discussed above. Currently, patients with private health insurance receive anywhere from \$20-\$40 back per allied health visit with a physiotherapist or occupational therapist. Often these sessions cost the patient anywhere from \$100-\$180 per session. The patient may require daily or intensive treatment to get the condition under control and be able to be self-managed to prevent complications. This could mean anywhere from 10 to 20 sessions over a 4 week period.

In only one instance in Australia is a comprehensive internationally accredited Lymphoedema program funded by Private health funds as a rehabilitation program (Mt Wilga Private Hospital, Hornsby NSW). This program provided therapy to interstate and rural patients who have private health cover. Inconsistent and variable restrictions to service provision and to the development of new private health insurers funded units continue to be set by the individual health funds.

“Once you have lymphoedema you have it for life and the impact on the sufferers' life in general and their financial standing is highly affected and many are unable to afford treatments, therapies and bandaging and compression garments that keep this insidious condition under control.” (Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote)⁸

The LAA advocates for higher private health insurance rebates for lymphoedema practitioners. We would advocate that this could be determined by the GP or specialist depending on severity, and indicated in a referral to the health insurer at the onset of treatment. It is also recommended that the private health insurers create a special category for Lymphoedema Practitioners, which would include NLPR eligible practitioners.²⁰

2.2 Reimbursement of compression garments

Patients who have private health insurance, still struggle to receive rebates for their garments. Most private health insurers give around 15% reimbursement for the cost of compression garments. Many private health insurers are requiring a letter from a medical practitioner each time a new garment is ordered, which is a further cost for the patient and Medicare.

Currently, many patients who can afford private health insurance cannot afford to pay the additional gap for garments, and as a result their health is suffering and they are placing themselves at risk of cellulitis and hospitalisation.

“I have met people who have been on a cancer journey and have been cured, only to find that they were left with a life-long problem of lymphoedema. They were supported during their cancer journey by the health system but their lives have been greatly affected by the lack of knowledge of health professionals, lack of access to treatment and cost of treatment of lymphoedema. It is imperative that these people receive funding for compression garments just as diabetics get funding for insulin and needles.” (Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote) ⁸

If Private health insurers appropriately reimburse their clients for compression garments this would be an incentive to enable patient compliance with compression garments and ultimately reduce health care costs.

The LAA is currently working on research of the private health insurance market to establish better statistics to support the above claims. Early surveys of patients and therapists done by the International Lymphoedema Framework Australia¹⁷ and The Lymphoedema Support Group NSW¹⁸ supported the need for this further research.

“Lymphoedema post cancer affects my grandmother and mother. They both experience significant limitations in their day-to-day life. They have lived with this for years with times where driving, working or leaving the house were not possible due to their symptoms. My mother has had to return to work to pay for her garments and therapy. As a family every birthday we raise money to help pay for their garments. I cannot imagine how others manage the costs of managing this life long condition.” (Cancer Council NSW Saving Life 2015 Campaign Community Survey Quote) ⁸

The LAA would advocate a 75% rebate on properly prescribed compression garments from private health insurers.

3. Improved linkage with State and Territory Government services in lymphoedema prevention and management

Lymphoedema prevention and effective management can be achieved by State and Territory government health departments implementing a pre-emptive surveillance strategy for the at-risk cancer patients so that there is integration of lymphoedema education, monitoring and networking to community service by the public hospital cancer services in all states. The public hospitals have special clinics such as vascular and wound clinics and infectious diseases consultative practices which can provide specialized care to community lymphoedema patients as part of a multidisciplinary

chronic care network. Lymphoedema complements The Chronic Care Model well. (See Appendix H for further information on the Chronic Care Model).²⁵

Patients with severe lymphoedema may not be able to access public hospitals as elective patients due to their high care (often bariatric) needs, lack of lymphoedema practitioner resources and potential for long stay hospital admissions. They are then reliant on the community health, which is also unable to provide the care needed resulting in an almost inevitable emergency admission sometimes into the intensive care units.

Several states have provided lymphoedema management training to allied health practitioners, however consistent long term funding for hospital based lymphoedema clinics has been difficult.

The LAA advocates for timely and equitable access to affordable lymphoedema services in NSW and increasingly has been joined by other state members with similar aims in other states.

“I would like to see more public lymphoedema clinics, especially for those who have no private health insurance. The garments need to be more accessible to those who can’t afford them.” Lucy (Quote from *Lymphoedema Stories: The Untold Truth*)¹⁸



The LAA was launched by the Hon. Anna Bligh in NSW Parliament on 15th Oct 2014.

Left to right: Kerryn Tutt (International Lymphoedema Framework Australia), Kate Guthrey (YWCA), The Hon. Anna Bligh (YWCA), David Elliott MP, Dr Debbie Geyer (Lymphoedema Support Group NSW), Nicholette Conway (Health Economist), Dr Helen Mackie (Australasian Lymphology Association), Dr Andrew McDonald MP.

“I am not someone whom has personally experienced lymphoedema. But during my time as premier, one of my members of parliament on my side of the chamber, did experience breast cancer. And post her cancer, she did develop very, very severe lymphoedema, and it is

something that she continues to live with. If she had the choice between breast cancer and lymphoedema, I know which one she would pick. But actually, prior to entering parliament, she was an oncology nurse for about 15 years. Lymphoedema still came as a terrible surprise and shock to her and her family. I know the physical difficulties that it has continued to pose for her life. So that tells me that if an oncology nurse was still surprised when this happened to her, there is a lot of work to be done out there in understanding, awareness and education around lymphoedema." The Hon. Anna Bligh, Former QLD Premier.

SUMMARY

The LAA advocates that Lymphoedema be recognized as a chronic disease, which should be managed in the primary health setting using a pathway similar to that of the current Mental Health Care Plan and ATAPS pathway. The lymphoedema sufferer should be empowered, educated to self manage and proactively supported. They need to be followed up with strategic funding for skilled therapy and compression garmenting, which will ensure maximum control of swelling. This will reduce the risk of cellulitis as well as the impact on physical, functional and psychological care. This can be provided by an integrated multidisciplinary care network in the public, private and hospital and primary health care setting.

Appendix A

ICD-10 AM (2010) Condition Classifications

Lymphoedema:

- 189.0 Lymphoedema, not elsewhere classified
 - Lymphoedema – praecox
 - Lymphoedema – secondary
- 182.0 Lymphoedema – hereditary
- 197.2 Lymphoedema – post mastectomy
 - Lymphoedema – post mastectomy (syndrome)
- 197.8 Lymphoedema – surgical, not elsewhere classified
- 189.8 Other specified non-infective disorders of lymphatic vessels & lymph nodes
- 189.9 Non-infective disorder of lymphatic vessels and lymph nodes, unspecified

Appendix B

Effects of lymphoedema on health outcomes (physical, psychological, economic and social)

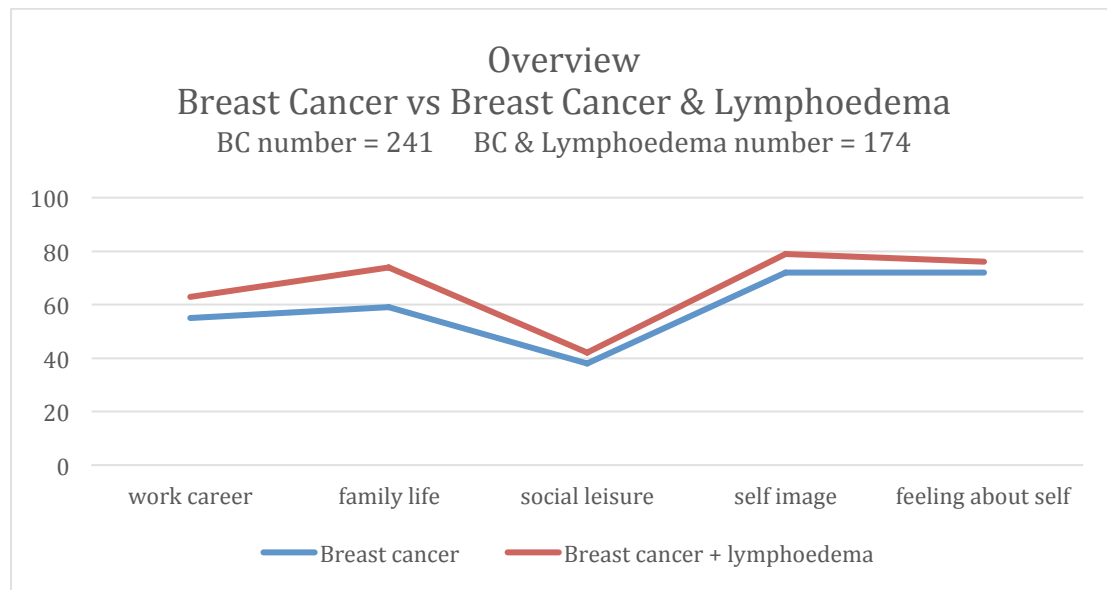
Physical effects of lymphoedema: pain, decreased mobility, infections.

Lymphoedema can cause pain, decreased movement and mobility of limb, increased risk of poor wound management and infection (cellulitis). It may also cause physical problems such as chronic skin changes, reducing its ability to act as a barrier against infections.² Left untreated, patients with lymphoedema are twice as likely to develop cellulitis requiring hospitalisation and intravenous antibiotics.^{3;4}

Psychological effects of lymphoedema: depression, anxiety, low self-esteem.

Lymphoedema may affect a person's psychological health resulting in negative self-identity, poor body image, emotional disturbances, anxiety and depression, and social isolation. Recent research at Macquarie University has identified the additional socio-economic impact of the development of lymphoedema following breast cancer (Figure 3 and 4). In a national survey, supported by the Breast Cancer Network Australia, a diagnosis of lymphoedema impacted on work, family life, self-image and feelings about oneself. This impact was significantly higher than for those with a diagnosis of breast cancer without lymphoedema.¹⁰ It was also shown that the greater the severity of lymphoedema the higher the impact.

Figure 3: Social and Work Impact of Lymphoedema (Source Macquarie University Lymphoedema Program and Faculty of Business & Economics).¹⁰



Economic and Societal effects: financial hardship and disability

There is a significant social and economic impact of lymphoedema. 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. Patients with lymphoedema also report needing to take time off work or having their employment affected as a result of their illness.¹⁰

Lymphoedema also impacts on the patient’s ability to work, and in some cases, long-term disability. This has flow on effects of decreased income. Taking care of lymphoedema is costly and this further results in financial hardship for the patient and poor treatments, as they are predominantly self-funded.¹⁰

Appendix C

GP Education – Opportunities for the PHNs to coordinate and support lymphoedema prevention and management in primary health care.

Lymphoedema suffers from lack of funding, and awareness within medical professions and the wider community. The condition is not well diagnosed, and many patients, especially those with non-cancer related lymphoedema, struggle to access services and treatment. General Practitioners (GPs) are often the first port of call for patients presenting with lymphoedema. Too often they are turned away without a diagnosis and told to lose weight as they are too fat, or worse still, given a diagnosis of lymphoedema, but told there is no treatment and to 'just live with it'. There is a significant lack of education amongst GPs, and they are notoriously a difficult group of professionals to target. Their workload is huge and ever increasing, and our expectations of them are vast.²²

“None of us chose to have lymphoedema, but the lack of support – medical, financial, therapeutic – suggests we are to be penalised and that we just don’t matter. I would particularly like to see more doctors; both in general practice and in specialties, become informed about lymphoedema. I think there are many people in the community who are not diagnosed and not treated.” Mary (Quote from *Lymphoedema Stories: The Untold Truth*)¹⁸

A general practice based approach for the management of lymphoedema was recommended as the most feasible, long term delivery strategy as it encouraged continuity of care. This was evidenced in the review of current practices and future directions in the diagnosis, prevention and treatment of lymphoedema in Australia February 2004. Report to the Australian Health Ministers’ Advisory Council.²³

In order to implement the suggestions made regarding *Lymphoedema Management Plans* (referred to above), the Primary Health Networks (PHN) would need to facilitate education of GPs. The PHN would need to provide a strategy for coordinating care between allied health and community services as well as hospital services and private clinics for improved outcomes for patients.

“By aligning PHNs with state Local Hospital Networks we also aim to reduce the merry-go-round for many patients with chronic or complex conditions between primary care and hospital treatment.”
Minister for Health Sussan Ley. Proposal for GP education by Primary Health Network.

GP Online learning modules:

Primary Health Networks are in a prime position to work with GPs to increase their knowledge of lymphoedema. In the UK, the Lymphoedema Support Network joined

forces with the British Medical Journal (BMJ) Learning to create a GP online module on lymphoedema.²² The cartoon postcard below was used to promote the module, with patients distributing them to their GPs to encourage them to take part. The program was a success with over 3,700 healthcare professionals from over 80 countries (mostly in the UK though) completing the module. It proved the 10th most popular module that year (out of 1,000).²²

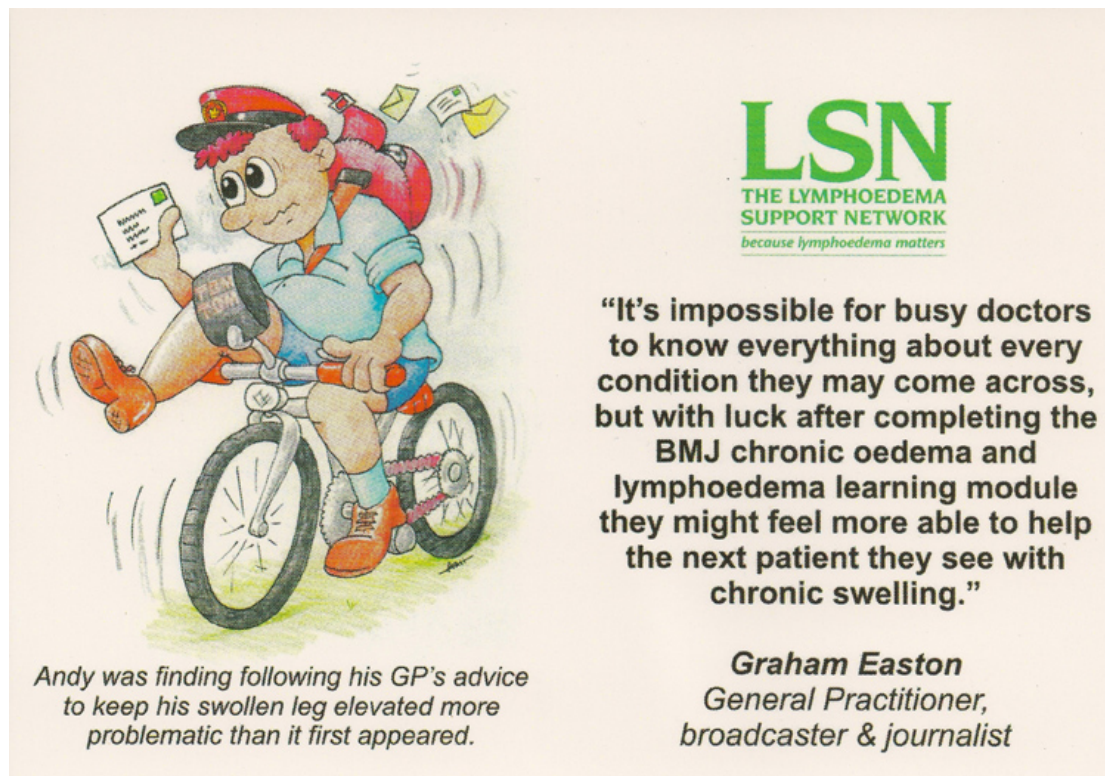


Figure 5. Postcard used in the UK to promote the online lymphoedema modules for GPs.²²

A similar program as that in the UK could easily be initiated, potentially in collaboration with the Royal Australian College of General Practitioners (RACGP). The RACGP have an online learning module, called 'check', which is part of GP ongoing education, and attracts continuing professional development points for part of the health professional's registration. These 'check' are available on a monthly basis and are a prime opportunity to increase the knowledge of GPs.

Supportive literature for GPs:

2009 Lymphoedema - Guide for diagnosis and management in general practice
Funded by the Dept. Human Services Victoria.²¹

This was initially a Victorian based initiative of a GP educational scheme for the awareness and diagnosis of lymphoedema. It has since been adopted by other states. Supportive literature such as the one below, could be adapted for Australia wide usage to accompany Lymphoedema Management Plans in the Primary Healthcare setting.

Appendix D

GP Education – Diagnosis and Assessment of Chronic Oedema

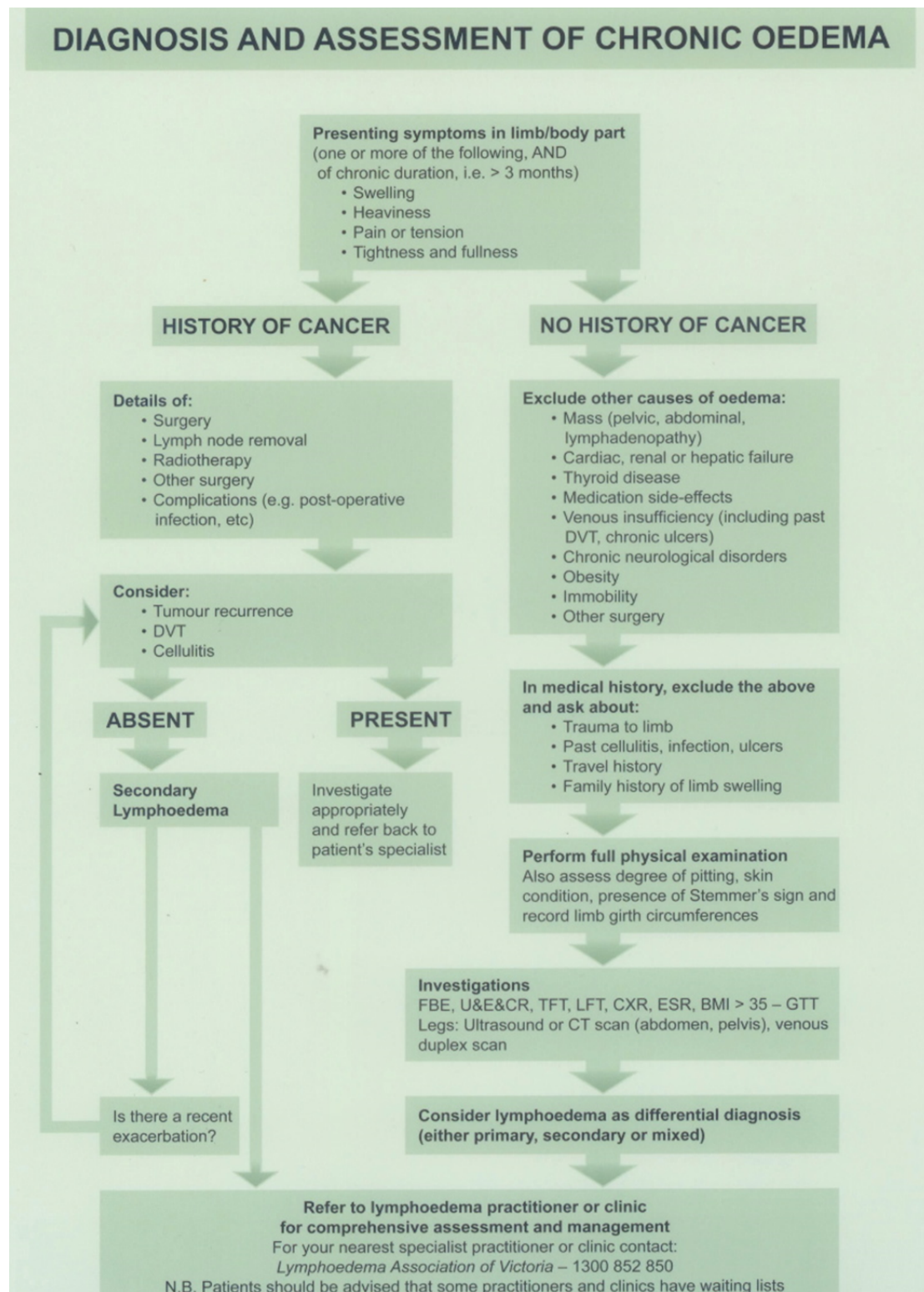


Figure 6. Diagnosis and Assessment of Chronic Lymphoedema.²¹

Appendix E

International Consensus Document: Best Practice for the Management of Lymphoedema.

Standards of practice for lymphoedema services:¹¹

1. Identification of people at risk of or with lymphoedema.
2. Empowerment of people at risk of or with lymphoedema.
3. Provision of lymphoedema services that deliver high quality clinical care that is subject to continuous improvement and integrates community, hospital and hospice based services.
4. Provision of high quality clinical care for people with cellulitis.
5. Provision of compression garments for people with lymphoedema.
6. Provision of multi-agency health and social care.

BOX 1 Standards of practice for lymphoedema services, adapted from⁵

Standard 1: Identification of people at risk of or with lymphoedema

Systems to identify people at risk of or with lymphoedema, regardless of cause, will be implemented and monitored to ensure that patients receive high quality education and lifelong care.

Standard 2: Empowerment of people at risk of or with lymphoedema

Individual plans of care that foster self-management will be developed in partnership with patients at risk of or with lymphoedema (involving relatives and carers where appropriate), in an agreed format and language.

Standard 3: Provision of lymphoedema services that deliver high quality clinical care that is subject to continuous improvement and integrates community, hospital and hospice based services

All people at risk of or with lymphoedema will have access to trained healthcare professionals, including lymphoedema specialists, who will work to agreed standards for comprehensive ongoing assessment, planning, education, advice, treatment and monitoring. Care will be of a high standard and subject to continuous quality improvement.

Standard 4: Provision of high quality clinical care for people with cellulitis/erysipelas

Agreed protocols for the rapid and effective treatment of cellulitis/erysipelas, including prevention of recurrent episodes, will be implemented and monitored by healthcare professionals who have completed recognised training in this subject.

Standard 5: Provision of compression garments for people with lymphoedema

Agreed protocols for assessment for and the provision of compression garments for people with lymphoedema, or where warranted, those at risk of lymphoedema, will be implemented and monitored.

Standard 6: Provision of multi-agency health and social care

Following comprehensive assessment, any patient at risk of or with lymphoedema who requires multiagency support will have access to and receive care appropriate to their needs from health and social services.

Figure 7. International Lymphoedema Framework: Best Practice for the Management of Lymphoedema.¹¹

Appendix F

Estimates of costs for treating lymphoedema

The Macquarie University study found that for patients with moderate or severe breast cancer related lymphoedema the average yearly cost of complex lymphoedema care was approximately \$1400.²⁴

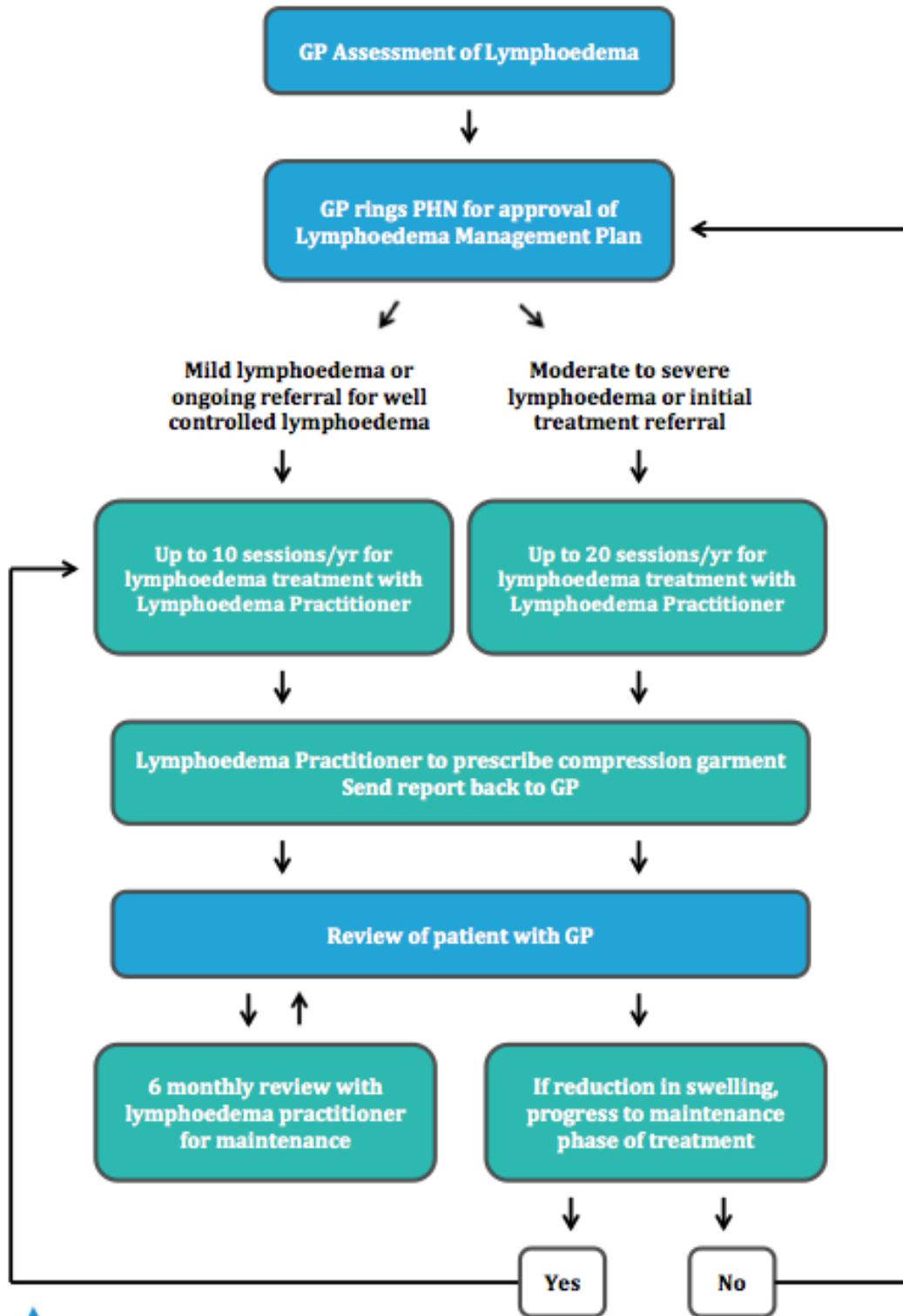
	Severity subgroups					
	all		none	mild	moderate	severe
number	152		14 *	77	55	6 *
Visits to Therapist						
Number of visits per year	5.8		1.9	4.5	8.8	3.5
Cost of each visit	\$86		\$65	\$97	\$77	\$78
Compression garments						
How many garments each year	2.2		0.5	2.0	2.6	4.3
Cost of garments each year	\$392		\$98	\$268	\$574	\$1000
Overall cost in last year						
Mean	\$977		\$207	\$755	\$1433	\$1442
Median	\$525		\$80	\$500	\$800	\$1100

*Note: Very small sample size, interpret with care.

Figure 4: Socio-economic impact of breast cancer related lymphoedema. Financial costs of breast cancer related lymphoedema.²⁴

Appendix G

LYMPHOEDEMA MANAGEMENT PLAN General Practitioner and Primary Health Network Co-ordinated treatment



Appendix H

Chronic Care Model – Best practice of multidisciplinary teams in lymphoedema management in primary health care and hospitals

Multidisciplinary teams are a component of the Chronic Care Model, which makes a difference to the patient outcome. The PHN can act to provide the framework for gathering many health disciplines who can contribute to a positive care program centered on the patient.

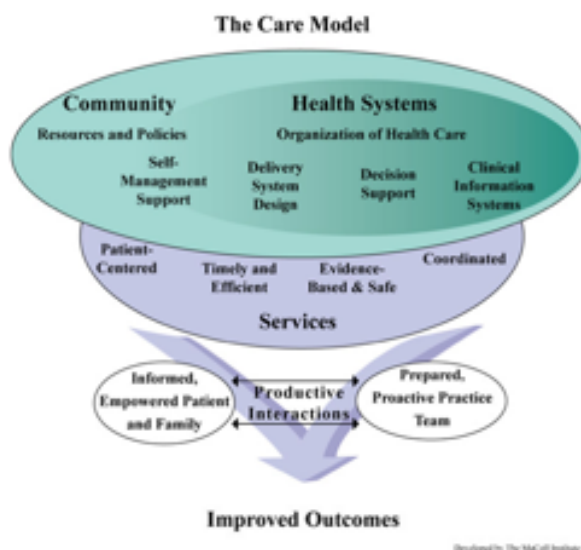


Figure 8. Chronic Care Model. Developed by The MacColl Institute.²⁵

The delivery system design would incorporate a multidisciplinary team or network, which would include the GP, medical specialists, lymphoedema practitioners, wound care and breast care nurses, podiatrists, psychologists, exercise physiologists, garment suppliers and others. Proactive follow up is also a component of service delivery.

The Chronic Care Model requires linkages centrally to the patient and carers to ensure education and motivation to assume self-management as the cornerstone to a long term positive outcome. The education to both the patient and health service staff must be based on evidence based guidelines. Support groups can provide a special source of patient support.

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ABBREVIATIONS:

- LAA – Lymphoedema Action Alliance
- ALA – Australasian Lymphology Association
- ATAPS – Access to Allied Psychological Services
- NLPR – National Lymphoedema Practitioner Register
- GPMP – General Practice Management Plan
- CLT – Complex Lymphoedema Therapy (Treatment)
- AHPRA – Australian Health Practitioner Regulation Agency
- GP – General Practitioner
- PHN – Primary Health Network
- ACT – Australian Capital Territory