



# Towards an estimate of the prevalence of lymphoedema in Australia

## What is lymphoedema?

Lymphoedema is a condition where the accumulation of excessive amounts of protein-rich fluid in the tissue results in swelling of one or more regions of the body.

Lymphoedema occurs when the demand for lymphatic drainage exceeds the capacity of the lymphatic system and may develop due to a congenital malformation in the lymphatic system (primary lymphoedema), or due to damage to the lymphatic vessels or nodes (secondary lymphoedema). Secondary lymphoedema can be classified into cancer treatment-related and non-cancer treatment-related lymphoedema.



Lymphoedema is a chronic, progressive condition that left unmanaged will cause increasing morbidity for the individual. Whilst the condition can be managed, it requires significant time, effort and cost to prevent symptoms from worsening. Lymphoedema can often cause pain and decreased limb movement and mobility, which can impact on activities of daily living. If left untreated, people with lymphoedema are twice as likely to develop cellulitis requiring hospitalisation and intravenous antibiotic therapy.

## How many Australians have lymphoedema?

There is currently no population-level prevalence estimate for the number of people in Australia living with lymphoedema.

However, available data shows that in 2020–21, the age-standardised rate of hospitalisations for lymphoedema as the principal or additional diagnosis was 30 per 100,000 population (9,400 hospitalisations), with the rate higher for females (6,500; 40 per 100,000 population) compared with males (2,900; 20 per 100,000 population).

Some types of lymphoedema are related to cancer treatment and based on projected new cancer cases for 2022, around 4,100 people with breast cancer and between 1,600 and 5,100 people with melanoma of the skin will go on to develop secondary lymphoedema.

Note, more work is needed to understand the prevalence of Indigenous population.

## How is lymphoedema diagnosed?

A critical issue when investigating the prevalence of lymphoedema is the misdiagnosis, or missing diagnosis of the condition due to lack of understanding and awareness of its presentation.

In addition, there is a lack of awareness of lymphoedema among medical practitioners, leading to under-diagnosis of the condition. Appropriate training and the provision of resources will help to facilitate early detection of the condition and improve outcomes for people living with lymphoedema.

## How is lymphoedema treated?

While there is currently no cure for lymphoedema, it can be managed with appropriate care – often from a range of health professionals. With early intervention being the primary means of limiting the impact lymphoedema has on patients, identifying those at risk and early detection is important.

The aims of lymphoedema treatment are to prevent progression of the condition, to reduce oedema and then maintain the improvement. This includes the alleviation of associated symptoms, prevention of infection and improvement of function and quality of life.

Treatments offered in complex lymphoedema therapy (CLT) vary depending on the stage of lymphoedema and include compression therapy, skin care, exercise, and massage therapy.

## What data sources are there for lymphoedema?

There is no single data source which is able to provide a holistic estimate of the prevalence of lymphoedema, however there are a number of data sources which provide health information in Australia. These include administrative data sources, linked data sources, survey-based data sources, longitudinal surveys, registry-based data sources, General practice clinic information system (CIS) data extraction data sources and other data sources.

A thorough assessment each of these data sources, outlining their benefits and limitations is included in the full report *Towards an estimate of the prevalence of lymphoedema in Australia*.

The early warning signs of lymphoedema can be intermittent and may include:

- transient swelling of a limb or other region of the body
- recurrent cellulitis
- feelings of aching, heaviness, stiffness in the affected body part
- decreased range of movement in the affected body part
- tightness of the affected body part

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