

9 March 2023

S9(2)(a)



Your Official Information Act request, reference: HNZ00008842

Thank you for your email of 14 December 2022, asking for information about lymphoedema services which has been considered under the Official Information Act 1982 (the Act). Each part of your request is responded to below.

1. Details of which former DHBs provided publicly funded treatment to those suffering from lymphoedema and which did not.

The majority of Te Whatu Ora districts (formerly district health boards (DHBs)) offer services for lymphoedema treatment. Districts that do not currently offer services are detailed below.

Te Whatu Ora Capital, Coast and Hutt Valley (formerly Capital & Coast DHB and Hutt Valley DHB) has the provision to recruit to a 0.6 full-time equivalent (FTE) lymphoedema role, but has been so far unable to recruit to this speciality position. Capital, Coast & Hutt Valley has, however, facilitated access to services for lymphoedema sufferers, as outlined below in the response to question 2.

Te Whatu Ora Te Tai o Poutini West Coast (formerly West Coast DHB) had a specialist physiotherapist lymphoedema service, at 0.2 FTE, until August 2022. This will resume again in August 2023. Currently, referrals requiring specialist care are referred on to Te Whatu Ora Nelson Marlborough or Waitaha Canterbury.

2. Details of the different treatment/services provided to lymphoedema sufferers regionally, and by former DHBs eg "the former Whanganui District Health Board provided lymphoedema sufferers/people at risk of developing lymphoedema with a yearly appointment with a specialist and two compression garments annually. This support for the Whanganui region has not changed since the establishment of Te Whatu Ora".

Te Toka Tumai Auckland

The former Auckland DHB, now Te Whatu Ora Te Toka Tumai Auckland, provides:

- assessment, diagnosis and treatment planning for clients diagnosed with lymphoedema or lipoedema (those at risk of developing lymphoedema)
- exercise prescription to promote lymphatic drainage
- prescription of compression for clients with a lymphoedema diagnosis
- education of modifiable risk factors to reduce the risk of progressive lymphoedema
- annual review; and
- two garments a year.

Hauora a Toi Bay of Plenty

The former Bay of Plenty DHB - Western Bay (now Te Whatu Ora Hauora a Toi) provides lymphoedema treatment to those suffering with lymphoedema, post-surgical breast patients where six or more lymph nodes are removed and some lipoedema patients. The service has not changed with the transition to Te Whatu Ora Hauora a Toi.

Patients can access the lymphoedema service if appropriate by referral from their general practitioner (GP), surgeons (plastics), radio oncologists, medical oncologists, breast care nurses, hospital physiotherapists or community/private physiotherapist. Patients are not able to self-refer into this service.

There are two trained lymphoedema physiotherapists based in the Western Bay with approximately 0.675 FTE between them. Treatment is available at Tauranga Hospital physiotherapy outpatients. The treatment pathway usually consists of an initial assessment, then three to four follow ups as required. Two garments are funded every 6 months (if required). Six months after the final follow up the patient is sent an opt-in letter where they can elect to have a review.

The former Bay of Plenty DHB Eastern Bay (now Te Whatu Ora Hauora a Toi) lymphoedema service accepts referral from health care professionals (GP, specialist, for example radiation, or medical oncologist AH professional, hospice staff or District Nurses) or a self-referral if the patient is previously known to the service for:

- Chronic swelling linked to predisposing risk factors
- Trauma and tissue damage
- Malignant disease
- Infection – re recurrent cellulitis
- Primary – eg hereditary, congenital syndromes
- Obesity; and
- Lipodema.

Referrals are also accepted for pre- and post-op follow ups for breast surgery. Referrals are received from the breast care nurse.

The Service has not changed since the transition to Te Whatu Ora.

Interventions may include:

- Multi-layer bandaging
- Manual lymph drainage and or teaching simple lymphatic drainage
- Exercise
- Education
- Skin care and advice
- Garment provision (2x every 6-8 months or as required); and
- Advice and measuring for prophylactic garments for air travel (purchase privately).

Waitaha Canterbury

Services provided to clients referred to the lymphoedema clinic were, and continue to be: assessment, instruction of self-management, assessment and provision of lymphoedema garments. Where clinically appropriate, clients are reviewed for monitoring on a yearly basis for garment measuring, etc..

In addition, a monthly education session is also provided at Burwood hospital and via online platforms.

Capital, Coast and Hutt Valley

The former Capital & Coast and Hutt Valley DHBs provided, and continue to provide under Te Whatu Ora Capital, Coast and Hutt Valley, lymphoedema sufferers with a range of therapy options. This could include accessing therapy through the Cancer Society, private providers (publicly funded); treatment for affected limbs by wound care specialist nurses; or garment or bandage provision by contracted orthotic providers.

Lymphoedema therapy is an important service that Te Whatu Ora Capital, Coast and Hutt Valley wants to be able to provide people in its area. Despite multiple attempts however, the district has unfortunately been unable to recruit to this speciality role. Capital, Coast and Hutt Valley are reviewing the recruitment strategy to support a renewed attempt to recruit a therapist, which they aim to do in early 2023.

Counties Manukau

Te Whatu Ora Counties Manukau provides virtual and face to face appointments under our Lymphoedema service; these clinics are based at Manuaku Health Park (formerly known as Manuaku Super Clinic), Botany Downs and Middlemore.

There are two clinical nurse specialists, one advanced clinician and physiotherapists that make up the outpatient service. We have in our care patients with:

- primary lymphoedema
- at-risk patients due to lymph node dissection
- swelling greater than three months that has been proven by lymphatic dysfunction
- recurrent cellulitis infection with BMI >30.

Frequency of the appointments and provision of pressure garments is based on clinical need.

Te Matau a Māui Hawkes Bay

Te Whatu Ora Te Matau a Māui Hawke's Bay offers a limited Lymphoedema service and treats cancer patients following surgery with lymph node dissection, radiation therapy to lymph nodes, Taxane chemotherapy and lymphatic obstruction caused by trauma.

Lakes

Te Whatu Ora Lakes provides a physiotherapy led surveillance and treatment model of care:

- six-week post-operative all mastectomy and or axillary surgery patients
- physiotherapy review every 6 -12 months
- decongestion therapy (bandaging and massage)
- 1 x compression garments per annum
- education re: skin care and exercise

Lakes has purchased a non-invasive bio impedance spectroscopy (BIS) device which will be primarily used to measure extra cellular fluid (ECF) ratios in oncology patients. By taking baseline measurements of ECF at cancer diagnosis and monitoring measurements over time it is possible to detect the onset of lymphoedema before clinical signs. We plan to start utilising this piece of equipment early 2023.

Te Pae Hauora o Ruahine o Tararua - MidCentral

A lymphoedema practitioner provides services to lymphoedema patients in the MidCentral district. The client base covers those at risk of developing secondary lymphoedema and those with confirmed primary or secondary lymphoedema. Treatment is assessment and goal orientated with

the ability to offer a range of complete decongestive therapy (CDT) in both the intensive and self-management phases. Education is provided to all clients with the goal of prevention of any escalation of lymphoedema by improved self-awareness for 'red flags' and self-management with early bandaging and compression garment use.

All clinically indicated basic compression garments/wraps are provided (usually one prescribed garment annually per patient when indicated), which includes garment glue, donning and doffing devices, etc., as needed. Work & Income may be able to help with funding additional garments as and if required.

Patients with lymphoedema can be re-referred for garment renewal or specialist advice at any time.

Nelson Marlborough

Te Whatu Ora Nelson Marlborough provides a robust, evidence based lymphoedema service pre- and post-transition to Te Whatu Ora.

A well-established network of lymphoedema treatment/service providers ensures a district-wide service for inpatients and outpatients, alongside as-needed community visits including support for aged residential care (ARC).

A multidisciplinary approach to lymphoedema management includes a nurse, occupational therapist, physiotherapists and an experienced Nelson Bays primary health organisation (PHO) lymphoedema therapist working in Golden Bay. Therapists have a positive and collaborative relationship with private providers and hospice lymphoedema practitioners.

The client base covers those at risk of developing secondary lymphoedema and those with confirmed primary or secondary lymphoedema. Treatment is assessment and goal oriented with the ability to offer a range of complete decongestive therapy (CDT) in both the intensive and self-management phases.

All clinically indicated basic compression garments/wraps are provided (averaging two garments per client, per six months), which includes garment glue, donning and doffing devices etc as needed. Work and Income and ACC may be able to help with funding for compression garments, and further fashion garments are self-funded.

Te Tai Tokerau Northland

Te Whatu Ora Te Tai Tokerau Northland provides publicly funded treatment to those suffering from lymphoedema. Education is provided for all referred patients. Other services are provided dependent on individual patient need, for example, manual lymphatic massage, bandaging, taping, compression. This support has not changed since the establishment of Te Whatu Ora.

Southern

Te Whatu Ora Southern provides lymphoedema care for people with a diagnosis of upper limb lymphoedema, as referred by specialists, oncologists, breast care nurses and oncology nurses. All patients are contacted annually for review and garment change if needed. Each patient is entitled up to a maximum of two full sets of graduated compression garments per limb in a 12-month period, depending on the clinical assessment findings. This service is provided by hospital and publicly funded private physiotherapists.

Dunedin Hospital also provides lower limb lymphoedema support/services across the district through the Vascular Service. This includes a 6-8 week programme for each patient. For certain conditions Te Whatu Ora Southern has pneumatic compression therapy (PCT) machines (and 6 funded pumps), compression bandaging and fit patients with hosiery and wraps (for inpatient only).

Patients are measured using the SOZO machine and are scheduled 6-monthly follow ups. Up to two PCT machines can be sent home with patients for a trial – they will then decide whether to buy their own machine. This is a new service, and we are continuing to develop our technology and the service.

Tairāwhiti

Te Whatu Ora Tairāwhiti have a lymphoedema specialist who provides physiotherapy services and compression garments. The standard is two garments every 12 months with the option for patients to self-fund if they require more. The therapist provides preventative therapy for patients to reduce the instances of getting lymphoedema and treating those that have it. The inpatient physiotherapy team assist patients going through a pre- and post-operative journey prior to seeing a community physiotherapist. District Nursing provide appointments for doppler assessments and compression hosiery on the same basis as physiotherapy. However, it should be noted the focus for District Nurses is vascular oedema, not lymphatic oedema.

Taranaki

Te Whatu Ora – Taranaki District continues to provide Lymphoedema services to those patients who meet service criteria. This service provision has not changed since the establishment of Te Whatu Ora.

Te Whatu Ora Taranaki provides:

- assessment and treatment
- ongoing annual and as required review appointments
- 2 daytime garments per year (partial funded)
- screening/prospective surveillance and early intervention for breast cancer patients post axillary node clearance +/- nodal radiation, 3 monthly for 18 months using bio impedance.

Waikato

Te Whatu Ora Waikato - Oncology Outpatient service provide Lymphoedema assessment for patients who have Lymphoedema as a result of their cancer diagnosis or treatment. Post assessment, if the patient requires compression a referral is done to Orthotics (outsourced provider) who provide the initial and subsequent garments for a 5 year period before a new referral is required.

Te Whatu Ora Waikato - Oncology Outpatient service see the patient for First Specialist Assessment (FSA) and the frequency of follow-up is determined by need. Usually a patient will have 1-2 follow-ups and are then discharged if their lymphoedema is well managed. We aim to teach patients to self-manage their Lymphoedema in the community with a combination of massage and compression amongst other things. All oncology related Lymphoedema is provided by the Oncology Outpatient service.

Te Whatu Ora Waikato - Physiotherapy Outpatients service provide Lymphoedema assessment for patients who are referred with non-oncology Lymphoedema. Post assessment, if the patient requires compression a referral is done to Orthotics (outsourced provider) who provide the initial and subsequent garments for a 5 year period before a new referral is required. Following the FSA the ongoing follow-up is determined by need and usually consists of wrapping, massage, self-help techniques and a referral to Orthotics for pressure garment as required. All non-oncology related Lymphoedema is provided by physiotherapy services.

Wairarapa

Te Whatu Ora Wairarapa continues to provide publicly funded assessment and treatment for people with lymphoedema. This is a longstanding service, based at Wairarapa Hospital. Te Whatu

Ora Wairarapa has a monthly outpatient-based lymphoedema clinic for people in the Wairarapa region. This is provided by a registered lymphoedema therapist.

The service is available to those with cancer related and primary lymphoedema, and lymphoedema secondary to other causes.

Referrals are primarily from hospital and community health services (including medical consultants and Community Nursing, eg. Wound Care Clinical Nurse Specialist), and primary care.

Services offered include comprehensive assessment, education, self-management advice and provision of compression garments where indicated. Follow up appointments are provided when clinically indicated.

This service has not changed since the transition from Wairarapa DHB to Te Whatu Ora Wairarapa.

Waitematā

Te Whatu Ora Waitematā delivers lymphoedema services through two specialist trained physiotherapists at North Shore and Waitakere hospitals.

The following is a summary of the typical service provided to lymphoedema patients:

- a full assessment by a lymphoedema physiotherapist
- any of the following treatments, as indicated by the treating clinician:
 - education about lymphoedema
 - advice about management of oedema
 - an exercise prescription
 - advice about skin care
 - advice about elevation
 - advice about management of risk
 - prescription for compression garment, as needed
 - manual lymphatic drainage, if indicated, taught to patients and family/ support people to continue with at home. If patients ask about continued lymphatic drainage they are referred to a website for private clinicians offering this service
 - kinesiology tape, if indicated. If this works well, patients/ support people are taught application technique
- after the initial assessment, patients are reviewed within six months to monitor oedema and prescribe new garments if needed. This assessment can be in-person or virtual
- if the garment is used between one to four days-a-week and oedema is well managed, the next review is at 12 months or if the patient is discharged from physiotherapy review and referred to a compression garment provider with a three-year script and self-referral form
- if the garment is used for between five-to-seven days or the oedema is not well managed, the next review will be at six months by the treating clinician.

Te Tai o Poutini West Coast

Te Whatu Ora Te Tai o Poutini West Coast offers physiotherapy: assessment, instruction of self-management, provision of lymphoedema garments and follow up as required. Garments recommended from the initial appointment are funded.

Whanganui

Te Whatu Ora Whanganui has a lymphoedema service currently consists of a 0.3 FTE designated position.

provided lymphoedema sufferers/people at risk of developing lymphoedema with the following services, which have not changed since the establishment of Te Whatu Ora.

Acute lymphedema management (±1 month)

Covers management strategies listed below with emphasis on self-management (less massage and more emphasis on teaching family/patient lymphoedema massage).

- Lymphoedema education
- Lymphoedema massage (clinician -> teaching patient self-massage)
- Bandaging/Wraps to decrease acute lymphedema
- Education regarding skin care and self-massage (family and patient)
- Exercise prescription
- Issuing compression garments if required when lymphoedema stabilised

Chronic lymphoedema management

- Assessment, measurement, and prescription of appropriate compression garments. Budgeted to issue 1 garment per body part, per year (will fund extra if current garment not managing lymphedema appropriately)
- Lymphoedema reviews done annually

South Canterbury

The former South Canterbury DHB and current Te Whatu Ora South Canterbury provides publicly funded treatment to people suffering from lymphoedema. There has been no change in service since the transition to Te Whatu Ora.

Our physiotherapy service receives referrals from the district nursing team, GPs, and general surgeons for assessment. Prior to a patient receiving their compression garments they are assessed by an experienced physiotherapist with specific knowledge in lymphoedema. They receive 2 pairs of compression garments annually. Our senior physiotherapist maintains regular contact with patients who have been assessed and issued garments. Patients are also provided with a contact number to call if they would like to discuss their garment with the senior therapist. From the phone call discussions, the therapist decides if another appointment is required before receiving another garment.

- clarification of whether data on the number of people suffering from lymphoedema in Wellington and nationally is kept. If so, please provide this data.

Data on the number of diagnoses of lymphoedema in Wellington or at a national level is not held by Te Whatu Ora. Therefore, this part of your request is refused under section 18(g)(i) of the Act, as the information requested is not held by Te Whatu Ora and there is no reason to believe it is held by any other agency subject to the Act.

Te Whatu Ora is able to advise that in the 2019-20 financial year there were 69 publicly-funded hospital discharges due to *lymphoedema, not elsewhere classified* (code 189.0 from the *International Statistical Classification of Diseases and Related Health Problems (ICD-10-AM)*) as a primary diagnosis. This figure does not represent how many people in New Zealand have lymphoedema, it tells you how many people received hospital treatment for the condition.

How to get in contact

If you have any questions, you can contact us at h.nz.OIA@health.govt.nz.

If you are not happy with this response, you have the right to make a complaint to the Ombudsman. Information about how to do this is available at www.ombudsman.parliament.nz or by phoning 0800 802 602.

As this information may be of interest to other members of the public, Te Whatu Ora may proactively release a copy of this response on our website. All requester data, including your name and contact details, will be removed prior to release.

Nāku iti noa, nā

PP 

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Government, Partnership and Risk**