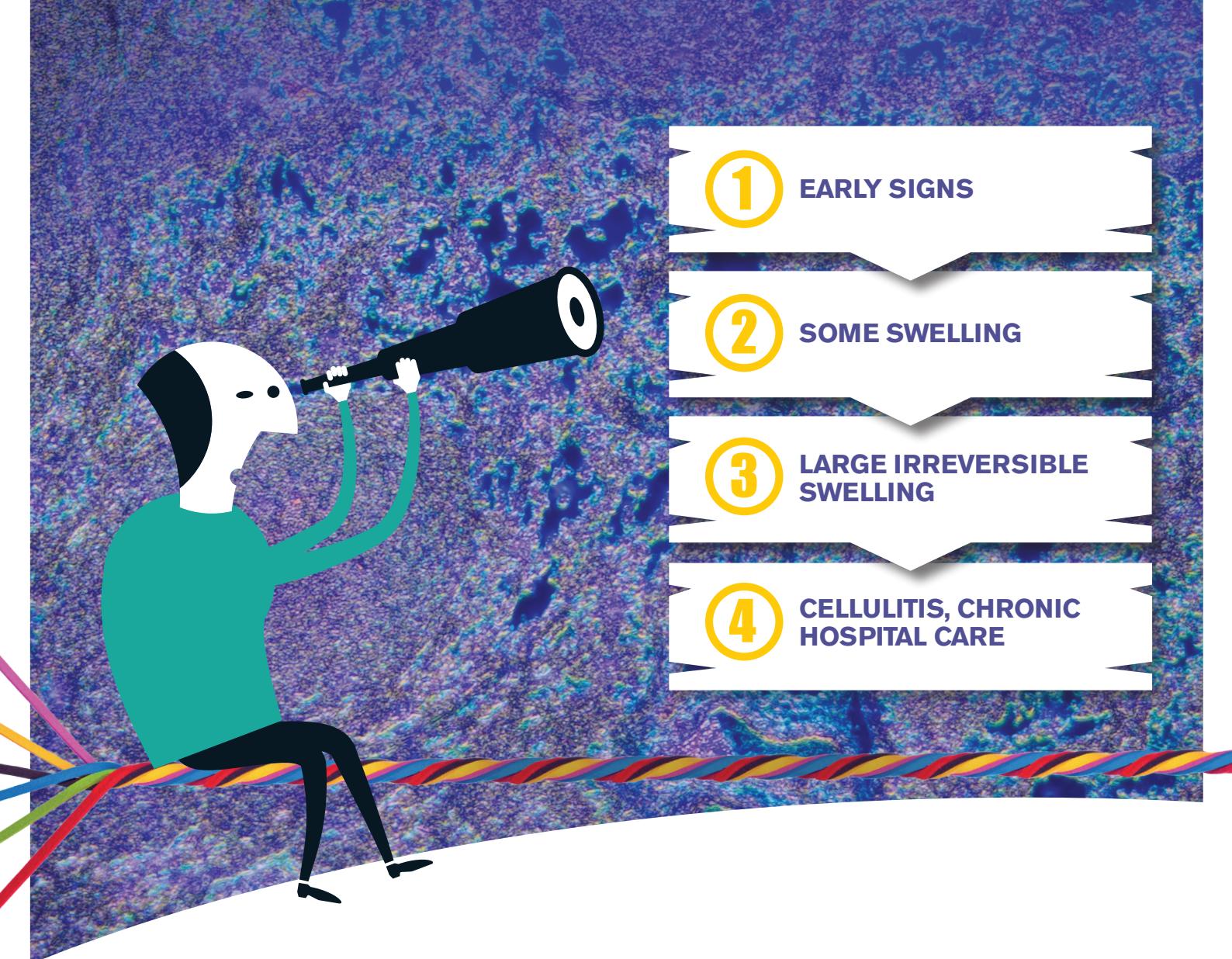


Lymphoedema

Implementation scenarios and frequently asked questions for allied health professionals and managers



Spot the early signs



For more information visit:
[http://heti.nsw.gov.au/allied-health/
lymphoedema/](http://heti.nsw.gov.au/allied-health/lymphoedema/)



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INTRODUCTION

This booklet of implementation scenarios has been developed to support the implementation of the principles outlined in the HETI Online lymphoedema training modules:

- **Lymphoedema Awareness-** for Allied Health Professionals
- **Lymphoedema Early Intervention-** for Occupational Therapists and Physiotherapists.

The aim is to enable allied health professionals and managers, in particular occupational therapy and physiotherapy staff, to think about how they might translate the concepts outlined in the above HETI Online training modules into practice. This resource is particularly focused on enhancing the knowledge of clinical staff on what to do if they think a patient has lymphoedema. It also models practice to investigate a number of avenues which can be explored to connect patients at risk of, or with, early stage lymphoedema with the required support and services that they need.

The scenarios are by no means exhaustive however it is hoped they will provoke thought and discussion amongst allied health professionals within NSW Health to improve services for patients at risk of, or with, lymphoedema.

At the end of the booklet is a list of frequently asked questions to clarify issues and the purpose of the training program.

SCENARIO 1:

Enabling patients to access public services for lymphoedema

After completing the HETI Online lymphoedema modules, a conversation starts between colleagues at a team meeting acknowledging they weren't aware of the benefits of early intervention for patients with lymphoedema. They think that they can make a difference, and acknowledge there are gaps in current practice. The following questions are raised:



Questions:

- Is there anyone that is able to assess and treat patients with lymphoedema in our hospital/ health service or local health district/speciality network (LHDN)?
- Where do we refer patients to?
- What is the process and criteria for referral?

Someone is tasked with the role of investigating these questions through their clinical networks and getting back to the team at the next meeting.

The staff member finds out that there is no public service available in the LHDN and considers what else can be done for the patients. Discussion about the following options occur with the team:

Options for consideration:

1. Referral to another public service in a neighbouring LHDN.
2. Investigation of neighbouring services, their criteria and process for referral.
3. Determining how staff will know what advice to provide to patients about available options.
4. Compile an information leaflet for staff/patients re where to refer patients to if deemed at risk of, or with, early stage lymphoedema.

*go to scenario 2 on page 4 for when all public options have been exhausted

Outcome:

Patients are provided with information to ensure they have access to services to meet their needs as outlined in the Australian Charter of Health Care Rights (Australian Commission of Safety and Quality in Health Care (ACSQHC), 2008)

SCENARIO 2:

Public services not available for patients with lymphoedema

At the physiotherapy (PT) staff meeting it is noted that fairly an extensive investigation has been undertaken in relation to public services for patients with lymphoedema, in particular for those patients who require specialist treatment beyond early intervention and education in the LHDN and surrounding areas. As a result it is determined that public services are not available for the majority of patients with lymphoedema who require specialist intervention. The team discusses the following questions:

Questions:

- Are there alternatives outside of the public system?
- Can patients access support from Medicare to access private services?
- What information can we provide to patients and how?



The PT manager decides they will investigate and seek further advice to ensure that information provided to patients is accurate and within the scope of public health staff.

The PT manager investigates and advises the team of the following options:

Options for consideration:

1. Referral of patient back to their GP to consider if they are eligible for Medicare funded allied health services – this may assist with the costs of visits to a private practitioner.
2. Provide patient with the weblink/print out of the National Lymphoedema Practitioners Register (<http://www.lymphoedema.org.au/the-register/find-a-practitioner/>) maintained by the Australasian Lymphology Association (ALA). This is so they may self refer or obtain a referral from their GP to see their practitioner of choice.
5. Compile an information leaflet for staff/patients re where to refer patients to if deemed at risk of, or with, early stage lymphoedema including public and private pathways.

Outcome:

Patients are informed about services, treatment, options and costs in a clear and open way (ACSQHC, 2008)

SCENARIO 3:

Increasing knowledge and awareness of referrers to enable patients with lymphoedema to access public services

An Occupational Therapy (OT) manager was approached by one of the oncology specialists wanting to find out where they could refer a patient who had some early signs of lymphoedema. The OT manager provided the oncologist with the information about the OT in the outpatient department who sees patients with lymphoedema as part of their overall caseload. The oncologist was thankful to the OT manager for the information and asked whether this information is available anywhere, so that other staff in the health service and external to the service, can access this service for patients. The OT Manager asks the lymphoedema specialist the following information:



Questions:

- How do people know you offer a service for patients at risk of, or with, lymphoedema (either through a specialist service or within existing case loads)?
- Is the information made available on the intranet/internet?
- What is the criteria for referral?
- What's the process for referral?

Upon discussion with the lymphoedema specialist it is revealed that referrals to the service are mainly through word of mouth and there is criteria however it is not published. Referrals generally come from regular referral sources however the lymphoedema specialist acknowledges that a wider variety of patients could be seen.

Options for consideration:

1. Placement of information on the intra/internet of the LHDN so that both internal staff and clinicians such as GPs can make referrals to the service.
2. Ensuring referral criteria is clear i.e. primary and secondary, all cancer related, specific cancer related, non cancer related, all lymphoedema, obesity, diabetes etc.
3. Ensuring scope of services offered are clear.
4. Consider how information could be communicated to staff who are likely to refer to the service.

Outcome:

Agreed and documented clinical guidelines and/or pathways are available to the clinical workforce (ACSQHC, September 2011)

SCENARIO 4:

Establishing a local peer network/community of practice for lymphoedema

An OT and PT are chatting in the tea room about the recent online training and its relevance to their patients. They also discuss the benefits of early intervention and that they could actually make a difference. They admit neither of them previously felt confident to discuss lymphoedema with patients or provide advice or information despite their extensive experience in other areas of practice. They reflect on the following questions:

Questions:

- How do we raise awareness of lymphoedema amongst our colleagues?
- OT and PT have an important role to play within our existing practice, how do we enhance this?
- It's important to share knowledge and experience between our peers, how do we best facilitate this?



After some further discussion with various colleagues they come up with the following options to further facilitate translation of this new knowledge into practice.

Options for consideration:

1. Establishing an interest group in the LHDN for lymphoedema.
2. Contacting lymphoedema specialists who work in the LHDN and starting a conversation about how OT and PT can better work with them.
3. Sharing of knowledge, research and best practice examples between peers either in person, via email, in-services, forums etc.

Outcome:

A culture of learning, teaching and professional development is embedded within organisational values (HETI, 2014)

SCENARIO 5:

Enhancing social workers knowledge about services to support patients with lymphoedema

A social worker in the community has come across a number of patients in the last few months who are struggling to cope with symptoms of lymphoedema. They are recovering from cancer treatment and don't seem to know where to go to get help. The social worker wants to learn more about lymphoedema and phones the PT manager at the local hospital to find out about whether any help is available for the patients to be assessed/treated.



Questions:

- What services are available for patients with lymphoedema?
- How do I refer patients?
- What information is needed?
- What is the criteria for referral?
- Is there a waiting list?
- Are there support groups?

Following discussion with the PT manager, the social worker discovers there is a lymphoedema specialist service available. Whilst there is a waiting list, the patients who they have in mind are eligible for assessment by outpatient/community PT with a view to referral on to the lymphoedema specialist if required. The social worker seeks to link the patient in with available support groups.

Options for consideration:

1. Passing information on to other colleagues about available services for lymphoedema patients through email communication, forums and team meetings
2. Familiarising self and colleagues with the Lymphoedema Support Group of NSW www.lymphoedemasupport.com to provide information to patients

Outcome:

Agreed and documented clinical guidelines and/or pathways are available to the clinical workforce (ACSQHC, September 2011)

FREQUENTLY ASKED QUESTIONS

Why has HETI developed online training for lymphoedema for all allied health professionals (AHPs) rather than just occupational therapists (OTs) and physiotherapists (PTs)?

The thing most complained about by patients with lymphoedema is the lack of knowledge and awareness amongst all health professionals in general about lymphoedema, its early signs and where to get help. Everyone has a role to play in being able to recognise whether a patient is presenting with or describing symptoms of lymphoedema. If it is thought this might be what the patient is experiencing, then any one should at least be able to point the patient in the right direction to get help as early intervention is critical.

The first HETI Online module on Lymphoedema Awareness is targeted at all AHPs (including OTs and PTs). This is to raise awareness amongst the general therapy population in NSW Health of lymphoedema, oedema and cellulitis. Each of these conditions can present at any time and can be easily missed, particularly when the person is living in the community with minimal contact with the healthcare system. Paying attention, talking to patients and referring appropriately can make an important impact.

But I am a speech pathologist, how is this relevant to me?

Whilst you may not be involved in providing hands on treatment to patients who may be at risk of/or with lymphoedema, you have an important role in being able to recognise some of the signs and symptoms of lymphoedema which patients may talk to you about during your other interactions with them. It is important that if this occurs you feel confident to ask further questions and then refer the patient to another health professional with expertise in the area. Doing nothing will delay the patient from accessing basic treatment which may prevent progression of their condition, from one that is easily manageable, to a chronic and irreversible situation.

What role does OT and PT play?

OTs and PTs in particular have an important role in early intervention. Whilst there are specialist lymphoedema therapists working across NSW Health in the disciplines of OT, PT and nursing, the general OT and PT population have the necessary background knowledge and skills to be able to provide early intervention to patients with lymphoedema and if required refer to specialist therapists. The second HETI Online module – Lymphoedema Early Intervention is targeted specifically at OTs and PTs. The skills described in this module are in line with normal therapy interventions for these two groups of AHPs. OTs and PTs are recognised as key providers of services to the lymphoedema population.

Isn't lymphoedema only relevant to people who have had cancer?

No. Whilst cancer and its treatment is one of the main causes of secondary lymphoedema, it is also caused by complications of conditions rapidly increasing in the Australian population such as diabetes and obesity and through damage to the lymphatic system such as through trauma or surgery. It can also occur due to an underdeveloped lymphatic system (primary lymphoedema) which is a lifelong condition, originates at birth and needs to be managed on an ongoing basis to minimise progression and development of recurrent cellulitis infections. If left untreated it can be costly and has a significant impact on the physical, psychological and social function of individuals.

Which OTs and PTs should do the early intervention module?

All OTs and PTs should do the module as lymphoedema is not currently covered in undergraduate training programs and hence this knowledge gap exists with many therapists. In particular, it has been determined the priority groups would be those therapists seeing patients in the following clinical areas across acute, subacute and community settings.

- Vascular
- Oncology
- Cancer services
- Palliative care
- Orthopaedics
- Paediatrics
- General surgery
- General medical
- Women's health
- Rehabilitation

But can't patients with lymphoedema only be seen by specialist lymphoedema therapists?

No. The research and evidence clearly shows that early identification and patient education are the most critical factors in preventing the onset of chronic lymphoedema and minimising the progression of the condition. Lymphoedema specialists have a critical role to play in the assessment and treatment of patients with lymphoedema however in the early stages there are many things that non lymphoedema specialist OTs and PTs can do. This includes providing early intervention, educating the patient and empowering them to commence self management of their condition. This is a critical component of prevention which is well supported by the current body of evidence on lymphoedema treatment and management.

Why is cellulitis important?

People with lymphoedema are at a much higher risk of developing cellulitis than the general population. Cellulitis is painful and debilitating for patients and also costs the NSW Health System lots of money. The costs to NSW Health in the 2013/14 year for admissions alone for all cellulitis was \$66 million dollars. Even if only 10-20% of this cost was due to lymphoedema related cellulitis, this is a very large and potentially preventable expense for patients and the health care budget.

What is the role of AHPs in preventing cellulitis?

Everyone has a role in prevention, so whilst for example, a dietitian may not provide intervention to patients with lymphoedema they may suspect a patient has lymphoedema or be developing a condition such as cellulitis. They then should be able to refer the patient promptly to the required professionals such as a Doctor in their clinical team or a General Practitioner. One of the biggest issues for patients with cellulitis is delays in receiving treatment. This has a negative impact on patients and takes money away from other areas of service delivery. This condition is largely preventable, and at least much more manageable in its early phases, and hence there is an opportunity to save money, relieve pressure on acute services and keep patients out of hospital.

Who are specialist lymphoedema practitioners?

Clinicians can become specialised in treating patients with lymphoedema through skills and experience obtained on the job and attendance at various training courses. The Australian Lymphology Association (ALA) formally identifies lymphoedema practitioners as those that have completed training courses accredited by them. The ALA accredits training providers to run Level 1 and Level 2 courses which provide health practitioners from defined groups (in NSW Health, OTs, PTs, Nurses and Doctors) with the ability to provide full scope lymphoedema treatment.

What is a lymphoedema service?

A lymphoedema service is provided by a health professional specialised in lymphoedema. Depending on the resourcing of the service it may provide full scope lymphoedema treatment to patients with lymphoedema from all causes or may be restricted in its service provision based on diagnostic groups such as cancer or types of lymphoedema such as primary vs secondary. It is important for lymphoedema services to make it clear what their referral criteria and processes are and equally important for health professionals to be aware of what is available for patients in their LHDN.

But I don't want to advertise our services as demand is too high?

Patients have a right to access services in the public system as outlined in the Australian Charter of Health Care Rights (2008). Whilst it is expected that referrals may increase as a result of making the service availability better known, it is important that this information is available to patients and referrers. Information about increasing demands and waiting lists should be captured and collected by local services to continually highlight the ongoing need for this service provision to relevant service managers and executives.

I already have an established functioning lymphoedema service. Why should I get involved?

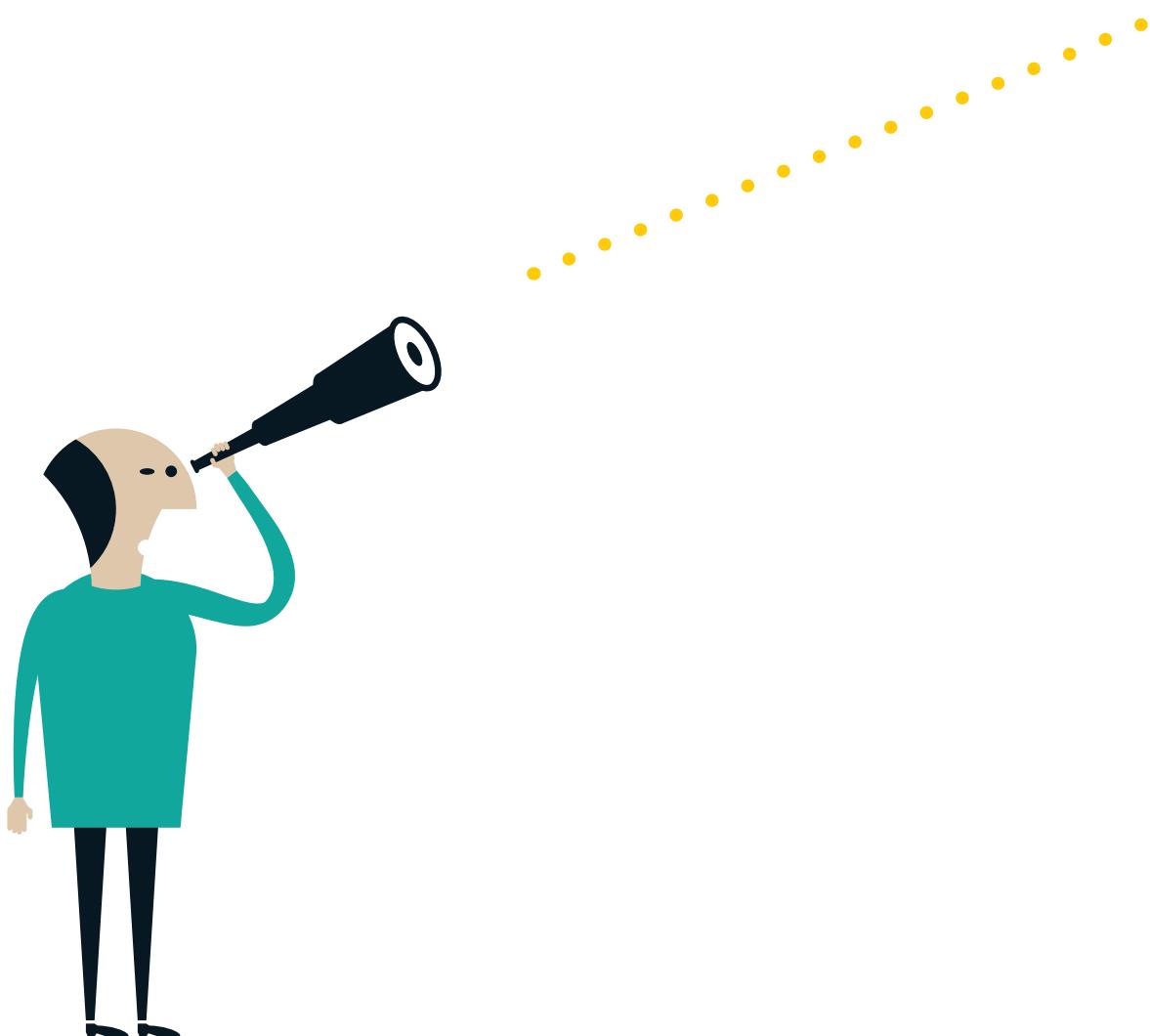
You have an important role in raising awareness and supporting local OTs and PTs to start the conversation with patients early. This is particularly important if they are waiting to see a specialist so that early intervention can commence. You will also be able to redirect staff, who may be referring to you, to complete the HETI Online modules to increase their knowledge and awareness about lymphoedema.

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1 EARLY SIGNS



2 SOME SWELLING



3 LARGE IRREVERSIBLE
SWELLING



4 CELLULITIS, CHRONIC
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