



We Welcome New Members

A Quarterly Publication of the
Lymphoedema Association of Queensland Inc.
ABN 13602 257 202

Find us on

November 2017



Dear Readers

This is our last edition of Node News for 2017 and time to wish you all a happy and safe Festive Season.

You support during the past year has been greatly appreciated and we look forward to continuing to work with you in the New Year as we all continue our lymphoedema journey.

The Lymphoedema register will close at the end of year so if you have not registered yet see the details on page 7 of this edition. The register was opened to assist on collecting numbers of people in the community who have lymphoedema. This data will be of assistance in approaching government with numbers of people needing lymphoedema services. At present is unknown as to how many people are affected. If you know of someone who is not a member of LAQ who is affected, please encourage them to register.

We are pleased to announce the Biannual Australasian Lymphology Conference will be held in Brisbane 17th -19th May 2018.

The Lymphoedema Association of Qld has been invited to host the Public Day on Saturday 19th May.

The event will be held at the Convention Centre at Southbank. We hope you can join us.

There will be overseas and local speakers presenting topics relevant to research, treatment for lymphoedema. Registration costs have been set at \$65.00 for LAQ members and \$75 for non members. This includes morning tea and lunch and access to the Trade Displays of garments, skincare products and other equipment for management of lymphoedema.

Registrations will open in January with information on the full Public Day Program on the ALA conference website. www.ala-conference.com.au

We are seeking sponsorship for the day and would appreciate any contact details of anyone interested in fundraising for us. Please direct them to our website for a copy of the Public Day Sponsorship Prospectus or contact Nerida 0403 782 795 or email info@lymphqld.org

The Health Professional Conference Details can be found at www.ala-conference.com.au.

SAVE THE DATE!

FOR LYMPHOEDEMA PATIENTS AND CARERS

12th ALA Conference
17-19 May 2018

Lymphoedema Public Day
Proudly hosted by the Lymphoedema Association of Queensland
19 May 2018

Brisbane Convention and Exhibition Centre
Stronger Together

www.ala-conference.com.au

I am leaving you with a thought provoking article presented by Mary D'elia Past President of the LAV. This is still relevant today especially with the theme of the upcoming conference.

There is strength in numbers and each one of us is important. If we do not speak up and make our needs known we will never see any progress in access to treatment and garment provision. The organisation can only do so much!



- *Support* for those who live with Lymphoedema.
- *Education* for the general and medical communities of the existence of Lymphoedema.
- *Promotion* of a healthy life management around Lymphoedema.

THE COMMITTEE

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REGIONAL SUPPORT GROUPS

- **BRISBANE:** Nerida 3269 1498 or June 3865 1195
Meeting 4th Wednesday of the month at Noon - 2pm
Library Meeting Room, 1st Floor, Toowong Village
Shopping Centre
- **BUNDABERG:** Olga 4152 8507
Meets Bi-Monthly, 3rd Monday at 10.00am.
Margaret Rose Centre CCQ Bundaberg.312 Bourbong Street.
- **MACKAY:** Heather 0448 823 388
Meeting Quarterly, 1st Friday at 11.30am at Porters Coffee Shop
Phone for details if you plan to attend.
- **MARYBOROUGH/HERVEY BAY /PIALBA (NEW GROUP)**
First Meeting Wednesday March 8 2:30pm-4pm At the Hervey Bay
Cancer Care Centre, Cnr Medical Place and Village Court Pialba
RSVP to Rachael Tassotti or Hayley St Ledger on 07 4325 6300
- **SUNSHINE COAST:**
Margaret 5492 4437 Group Meets socially
- **TOOWOOMBA:**
Contact Cancer Council Queensland if you wish to be informed of
upcoming educational activities on 13 11 20 or Alyce on 4690 5900
- **TOWNSVILLE:** Libby 0439 745 716 or Neradah 4771 6377.
Formal meetings have ceased due to low numbers.

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Please Note

Information Conveyed in any form
(verbal or written) from the
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Queensland Inc, it's Officers or any
Branch or Support Group is for
information only.

It is not intended to be and is not
professional advice and should not
be relied upon by any person
Professional advice should be sought
before any action is taken based on
any information given, other than
that given by Health Professionals in
answer to questions asked.

ARE YOU A MEMBER YET?

Call today for an application form 0403 782 795

General Membership: Initial year \$30 then \$25 per year
July 1 to June 30 yearly

Concession: Health Card holder/Pensioner:
Initial year \$25 then \$20 per year.

Membership renewals are sent out early June each year.
Donations to further our work are always welcome.

LOOKING FOR LYMPHOEDEMA TREATMENT SERVICES?

Readers can visit our website www.lymphqld.org for the current
listing.

The updated August 2017 Treatment Directory has been finalised and is
available for downloading and printing from our website.

Hard copies available from LAQ \$5.00 +\$2.00 P&H

If you do not have access to the internet please phone our information
line on 0403 782 795 for direction to services
or phone the Cancer Council Qld Helpline
on 13 11 20

WE NEED NEW LISTINGS!

If your treatment provider is not listed, please encourage them to
contact the office for an application form.

This will assist us to provide a better service to those seeking
treatment.

For a listing of National Lymphoedema Therapists
Visit the ALA Website www.lymphoedema.org.au



Editor: Whilst this is not a recent article much of it rings true today. I do not believe we have come very far in the recognition of the needs of people with lymphoedema nor the numbers. Hence the need for the register and the consumer voice. **We all need to wake up and speak up in 2018.**

Topic: The Importance of the Consumer Voice

The importance of the consumer voice cannot be discounted. Policy changes at the highest levels, funding for research and treatment, staffing for education and advocacy, all of this is possible when we collectively give voice to our lived experience of this chronic condition - Lymphoedema.

We need to band together, to ensure that our voices are heard.

We need to band together so that we don't have to shout alone, get tired alone, work alone, and suffer alone.

We need to band together to give our voices credibility and impact.

The only way that we will get funding for clinics, for education, for research, the only way that we will change government policy, and get the financial and treatment support that we deserve is to speak with one voice and demand it.

You might think that I'm being over the top, or exaggerating, but I'm not. Who actually care's about Lymphoedema? I didn't . . . until I got it!

My friends didn't . . . until I got it!

My work colleagues didn't . . . until I got it!

And, when I think about it, until my mum had cancer, I'm not sure that I really was ever passionate about that either . . . But I am now!

The voices of people who live an illness are vital for our understanding of that illnesses' impact upon their lives. It is their voices that make people sit up and take notice. Their voices give us important information about the treatment and care that they need, (and perhaps don't get?) So, why bother to fund Lymphoedema diagnosis & treatment or services that would improve the daily living experience of sufferers? Because the sufferers tell us in their stories that they would benefit.

Why have a consumer representative on a working party? Because you and I deserve to be able to have a say in the treatment of our condition, and on what funding or research needs to be prioritised for optimum care. Because our experiences can influence and impact the decisions taken.

We are the experts on Lymphoedema management. We do it every day!

Victoria, has had a funded compression garment program for people on low incomes. It wasn't just luck that got u a funded compression garment program, it was good timing & a carefully orchestrated campaign. It involved hours of hard work put in by the consumers who were fed up with the costs involved with this condition.

Part of the process was to convince the government that this financial burden was too much, was unacceptable, on top of the other burdens of disease that we as lymphoedema sufferers carry. They got the the message across that this condition can be debilitating, depressing, and difficult to manage. It puts us at risk of further health complications. It is important that we speak with truth and clarity about the condition.

This is not whinging! However we must also impress upon people who make funding decisions that this is a chronic condition that if left untreated can have dire consequences. It is serious, it needs to be prioritised in the broader health care community, just as other chronic conditions such as asthma, heart disease and diabetes are prioritised for preventative programs, early treatment, and educational \$\$\$.

We need awareness, and it is our voices and stories that will give strength to the awareness campaign.

Awareness means that when they ask for \$\$\$ to continue or start new research, the need for that research is recognised. It has been successful in the past.

The importance of each State Association in providing a unified consumer voice is essential. The Consumer State Associations are where governments, policy makers & funding bodies look to, in informing their understandings of the issues and needs for assistance and support. The State Association is able to prioritise a campaign of action and co-ordinate planning, working diligently and cleverly toward those goals. The State Association is a great advocate for services, and treatment options, and is able to reach out and mobilise their membership whenever campaigning is required. To have a strong voice, though, on the issues of Lymphoedema, State Associations need your membership and that of your family and friends.

Your LAQ membership is important so is your listing of the Lymphoedema Register! Do not delay in registering now as it closes soon! Numbers mean statistics which is so important when lobbying Governments.

Let us fight for change in 2018!

Join us at our planned awareness events in 2018!

- Invite family and friends to a Breakfast Sausage Sizzle and walk at New Farm Park on Saturday 3rd March.
- Gather at Southbank on World Lymphoedema on 6th March for the Victoria Bridge Light up.





Comments on Compression Garments as Compression Therapy

Robyn Scheer –Occupational Therapist RBWH

Compression therapy in Lymphoedema refers to the use of external compression, often compression garments but can include bandaging and wraps.

Compression therapy is an important component of many treatment protocols for managing chronic swelling such as Lymphoedema. It can be used as an initial treatment with early diagnosis and may be an important part of life long management.

Compression garments are designed to increase the total tissue pressure in the limb and improve transport of fluid in the vessels. This can help maintain the size of the limb particularly after a period of complex treatment where there has been a reduction in size. It is important that the garment is firmer distally (this is furthest from the heart) to encourage the movement of fluid in that direction.

Compression garments are available in a variety of ready to wear sizes, styles and compression levels.

Custom made styles can also be produced for limbs that cannot be accommodated in a ready to wear style. Costs can vary greatly between companies and also with added design features. There are a large range of manufacturers available.

For many patients there is a need to change style or design of the compression garment over time as their needs change.

The prescription of your compression garment is best guided by a trained therapist to ensure safe and comfortable fit. Many therapists are familiar with a variety of compression garment companies and their products which require specific measurements and ordering procedures. If you are concerned that your garment may not be the most appropriate one for your condition it is important to discuss this with your therapist and they may be able to investigate other options. Medical companies generally require a prescription from a qualified therapist to supply compression garments and a prescription may be important to obtain reimbursement from your health fund.

Appropriate compression is essential for effective management of Lymphoedema. The garment should fit firmly but not be so uncomfortable that it causes skin breakdown or tourniquet. Alternatively if the compression is not firm enough the garment will not maintain the size of the limb.

Donning garments (putting them on) can be difficult particularly if you suffer from other medical conditions such as arthritis. A variety of assistive devices such as frames and slides are available but one of the cheapest and most effective aids is a pair of washing up gloves. These assist in gripping and positioning the fabric without the risk of snagging. If all else fails seek assistance!

Regular review of the compression garment and your Lymphoedema is essential as this ensures the continued effectiveness of the compression garment and appropriate modifications to your prescription and wearing regimen can be arranged.

Most people will require two well fitting garments per affected body part at one time to provide effective maintenance of the limb and to adequately launder the garment. One to wash one to wear. These need to be replaced approximately 6 monthly as recommended under the Queensland Government Compression Garment Scheme. The fabrics that are used for manufacturing compression garments have a memory and when they are washed this memory ensures the garment returns close to its original shape and compression. Hygiene and our Queensland climate dictate the need for regular change of compression garment and laundering. Our warm climate can also be a challenge with compression garments. Like many things in life, compression garments can take awhile to adjust to wearing but generally persistence pays.

A compression garment can be the first indication to others that you have Lymphoedema and people may be curious as to its origin this is an issue each individual will need to learn to address out in the community. Think about your response to the question: "What happened to your arm/leg?" Each person will decide how much of their medical information they want to share with others.

If compression has failed in the past, it can be due to some of the following issues:

- Incorrect style of garment
- Inappropriate compression
- Patient unable to don/doff garment
- Inappropriate laundering
- Irregular wear of the garment
- Inadequate replacement of garment
- Inadequate monitoring of the condition

My clinical experience has shown me that compression garments are an appropriate part of the treatment in the management of Lymphoedema, they can be frustrating at times and expensive but the alternative, a large swollen limb, reduced mobility/function and increased infection risk is far more frustrating and expensive.



Importance of the Lymphatic System

A principle I use in my practice is “**what we see and feel happening on the surface tells us largely what is happening below the surface**”. This is true in the diagnosis, management and treatment of Lymphoedema.

Undoubtedly the system of the body that most critically manages Lymphoedema is the LVS (Lymphatic Vessel System). The LVS is prolific in the human body and extends into all areas. It is made up of 600 – 700 nodes and an intricate system of ‘self-pumping’ pipes.

What does the LVS do? All parts of the body are assessed, cleaned and largely defended through the LVS. All large waste, dead tissue, viruses and bacteria move through this fine network of pipes toward an area in the neck near our collar bones where it is finally discharged into the blood stream and processed by our eliminatory organs. The LVS is also responsible for fluid balance in the body.

What is Lymphoedema? Simply put, Lymphoedema occurs when part of the LVS is damaged permanently and the LVS is no longer able to perform its function effectively.

Body changes during Lymphoedema. Below the skins surface the fluid that bathes all of our cells and tissue becomes stagnant and syrupy. Fat is drawn to the area and this attracts more fluid and a vicious cycle of ‘fat-fluid attraction’ begins to manifest in the affected area. Collagen fibers multiply beneath the skin and the skin thickens. The area becomes ‘swampy’ and low in oxygen. Our defence systems now find it difficult to enter and work in these areas. Our skin now begins to break down not able to protect us as well. Rashes and discoloration on the skins surface accompany the changes happening below the skin. All of these changes are referred to as ‘Remodelling’.

What can be done to help?

The patient should consider their diet and a tailored exercise program. Self-stimulation helps increase the function of the LVS slowing the progress of the Lymphoedema and ensuring the health of the affected areas. Appropriate skin cream should be applied regularly to help the struggling skin barrier.

A good **therapist** will become part of the patients ‘team’ and work to reduce any edema through MLD (Manual Lymphatic Drainage), compression bandaging, Lymph taping, LLT (Low level Laser Therapy) and if required compression garments.

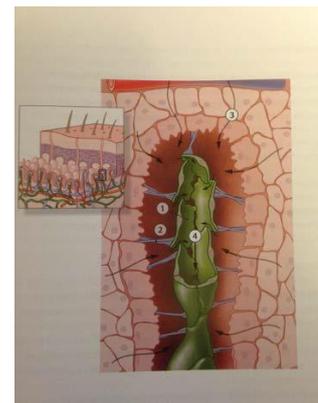
Stimulating the LVS. The LVS normally operates at 5-10% of its potential capacity. There are three ways to increase the ‘metabolism’ of the LVS;

1) **The Skeletal Muscle pump;** When muscle rubs against the surrounding tissue it alters the position of the tissue pulling on collagen fibers that open the small doors allowing waste material to enter the LVS pipes (see 1:1). This occurs when we move or have MLD performed.

2) **Temperature change;** When we move from normal temperature to cooler temperature the LVS is encouraged to increase in its operation.

3) **Pressure change;** As pressure is placed upon the LVS it is encouraged to increase in its operation. This can occur during submersion in water or in the chest area as we ‘Deep yoga breath’.

- 1:1 Lymph collector; 1-Pipe,
- 2-collagen fiber,
- 3-Direction of pre-lymphatic fluid
- 4- Direction of Lymph flow



For further information contact Tony Van der Niet
Clinic: 1 Seib Road Eumundi, Qld, 4562 0411129759



Cancer, Lymphoedema and Physical Activity

Physical activity is any movement that uses muscles and energy. Exercise is a subset of physical activity that is planned, repetitive and designed to improve or maintain fitness.

Physical activity during and after cancer treatment has been shown to be safe and feasible. Evidence suggests that being active can reduce the number and severity of side effects such as nausea, fatigue, pain, weight gain and development of other comorbidities.

Australian Physical activity guidelines encourage everyone to be as active as possible. Aim for 150 min or more physical activity per week (30 min per day). The greatest health benefits can be gained with moderate to vigorous intensity exercise. Exercise intensity is individualised according to each person – how they feel at the time or how heavily they are puffing. Aim to do cardiovascular exercise daily as well as muscle strengthening activities at least twice per week.

Being physically active can assist with lymphoedema management by the pump action caused by movement of muscles and joints and assists by managing weight and should not cause pain or worsen the condition.

Individualised and gradually progressive strength exercise has been proven to be beneficial for lymphoedema management and does not in fact exacerbate symptoms.

support@fluidep.com.au
T: 0408 006 086
W: fluidep.com.au
F: (07) 3036 5875

"BRIDGING THE GAP BETWEEN TREATMENT AND LIFE"





SUPPORT GROUP NEWS



BRISBANE

Meeting Monthly 4th Wednesday except Sept& Dec.
Toowong Library Meeting Room, 1st flr. Toowong Village
We begin with a shared lunch and general discussion.
Phone June 07 3865 1195
Gold Coin Donation

SEE PAGE 2 FOR ALL OTHER GROUP MEETING TIMES AND CONTACT DETAILS

Kooks Corner



SMISSVEGIEFRITTERS Serves: 4



INGREDIENTS

- 2 zucchini, grated
1 parsnip, peeled and grated
1 carrot, peeled and grated
1 red capsicum, de-seeded and finely chopped
1/2 cup grated Australian Swiss-style Cheese
1/2 cup grated Australian Parmesan Cheese
1 tablespoon parsley, chopped
2 eggs, lightly beaten
1 cup cornflake crumbs or dry breadcrumbs
salt and pepper, to taste
50g Australian Ghee (clarified butter), for frying

METHOD

Combine vegetables, swiss and parmesan cheese, parsley, eggs, cornflake crumbs and season to taste.
Shape into patties .Fry in hot ghee for 2 minutes on each side until golden brown.
Drain on absorbent paper.

MICROWAVE METHOD -

Prepare patties as above. Coat in extra cornflake crumbs.
Cook 6 patties at a time, uncovered on High(100%) for 2 minutes.

Nutrient Analysis Per Serve

Carbohydrate: 18g Calcium: 262mg Energy: 1121KJ Protein: 14g Fat: 16

LYMPHOEDEMA ASSOCIATION OF QLD

T SHIRTS FOR SALE.

Create Awareness by wearing one of these custom designed T-Shirts

Sizes Small to XXL

Cost \$15each + P&H\$8.50

(Aust Post Satchel)

Order today! Phone 040378275

Email: lymphqld@gmail.com



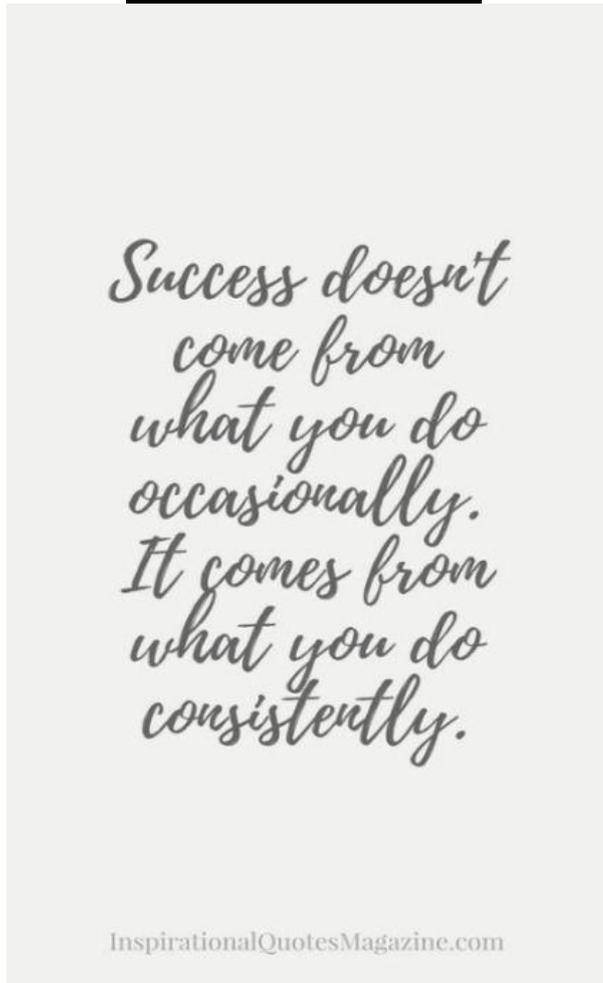
LYMPHOEDEMA REGISTRY

A project of the ALA with support of the LAA and state lymphoedema support groups
Analysis of collected data is provided via SPSS by an IBM Community Grant

Closing Soon!

The Lymphoedema Registry is closing soon!
Register now before it is too late!
I would encourage all members to participate.
If you do not have access to a computer encourage friends or family to assist you to register.
It is simple and easy to register.
You will remain anonymous.
www.lymphoedemaregistry.org.au
The data base will help to identify the prevalence of lymphoedema in Aust and NZ.

THOUGHT FOR THE DAY



InspirationalQuotesMagazine.com



This is Lucie the Lizard. She was designed to raise awareness of lymphoedema by the Victorian Association. We have a few on hand at \$5.00 each.



Paid Advertising

JM REMEDIAL THERAPY & LYMPHOEDEMA CLINIC

Located on Brisbane's North, and offers quality, comprehensive treatments for people living with lymphoedema and venous insufficiency.

Our range of services includes:

- manual lymphatic drainage,
- compression therapy ie. fitting and supplying compression garments as well as bandaging for severe swelling.
- kinesiotaping
- education for long-term self-managing program.
- Bioimpedence Analysis for Lymphoedema measurement and early detection.
- Onsite Private Health Fund rebates

Early treatment means low cost – act now!



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 10 % discount off first treatment
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- MLD - (Manual Lymphatic Drainage Massage)
- CDT - bandaging of limbs and tailored garments
- Lymph Taping - Kinesiology taping working 24 hrs day
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- Laser therapy for scar reduction

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