



We Welcome New Members

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Lymphoedema Association of Queensland Inc.  
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January 2016

Node News is Good News



We celebrated our 25 years with a Gala Luncheon 24<sup>th</sup> October 2015 which was sponsored by Icon Lymphoedema Clinic.

Those in attendance enjoyed a fine buffet meal and a review of our activities over the years. We were privileged to have the Founding Committee of the Association with us, Mary Stewart, Marilyn Elliot, June Allison, Beverley Mirolo and Dr Ian Bunce. They were presented with certificates of appreciation for their vision and support over the years.

Our guest speaker Dr Debbie Geyer represented the Lymphoedema Action Alliance which was launched in 2015 in NSW to lobby the NSW Government for better access to lymphoedema services in public hospitals and lobby The Federal Government for compression garments in all States. There are many organisations supporting them in this quest. You can follow them on Facebook, Lymphoedema Action Alliance.

As you are probably all too aware, we too have the same problem here in Queensland. Those in attendance were very impressed by what they heard and at the time inspired to do more in lobbying the Queensland Government for better services. Please let us know if you are willing to assist with a campaign or have ideas on what we may do to raise the necessary awareness with our government representatives.

The 2015 Annual General Meeting was held following the luncheon. We welcomed 2 new members to the Committee. Mary Stewart who was the Inaugural President, has joined us as Vice President and taken on the role of Publicity Officer. Avon Mills will serve as a General Committee Member. Morag Mc Gregor and Noelene Kidd have stood down from the Committee to care for their husbands and were given recognition for their Service over the years.

If you have never been to Darwin the following is a reason to visit and learn more about lymphoedema!



2016 Asia Pacific  
Lymphology Conference

integrating the 11th Australasian Lymphology Association Conference  
and the 6th International Lymphoedema Framework Conference

New Networks – New Solutions 26-28 May 2016 Darwin Australia



Lymphoedema Information Day Saturday 28th May 2016 8.30am – 4.00pm  
Darwin Convention Centre | Darwin Waterfront

For people with lymphoedema or at risk of developing it, their family and friends, health professionals or anyone interested in learning more People with lymphatic conditions, their family and friends, and health care workers will be able to hear from international and national experts in the field of lymphology.



- *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

Nerida Smith  
*President*

*Vice President*  
*Publicity/Public Relations*  
Mary Stewart

June Timms  
*Secretary*

Karin Swift  
*Treasurer*

General  
Leila Bourke  
*Pager Coordinator*

Hildegard Reul-Hirche  
Robyn Scheer  
*Education Officers*

Avon Mills

Dr. Di Smith  
*Medical Advisor*

## 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.  
Recreation Room, Mater Hospital, (from Hope St) Bundaberg.
- **MACKAY:** Heather 0448 823 388  
Meeting Quarterly, 1st Friday at Noon at Porters Coffee Shop  
Phone for details if you plan to attend.  
First meeting for 2015 Friday 6<sup>th</sup> February
- **SUNSHINE COAST:**  
Margaret 5492 4437 Bev 5441 4420  
Group will meet socially from April 2014.
- **TOOWOOMBA:**  
Contact Amber or Joan on 4690 5900 at  
The Cancer Council Queensland if you wish to be informed  
of upcoming educational activities
- **TOWNSVILLE:** Libby 0439 745 716 or Neradah 4771 6377.  
Formal meetings have ceased due to low numbers.
- **ROCKHAMPTON:** Meeting Last Thursday Month 2pm at Cancer  
Council Rooms. Contact Jan 07 4928 6852

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### Please Note

Information Conveyed in any  
form (verbal or written) from  
the Lymphoedema Association of  
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 07 3269 1498**

**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](http://www.lymphqld.org) for the current  
listing. The updated Treatment Facilities Directory has been finalised  
and distributed.

If you do not have access to the internet please phone  
our information line on 0403 782 795 for direction to services.

The booklet will be available from the website  
for Health Practitioners to download and print  
or a hard copy will be available upon request from the office on 3269  
1498 or 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](http://www.lymphoedema.org.au)



### Lymphoedema Association of Queensland Incorporated President's Report AGM 24<sup>th</sup> October 2015

It is my pleasure to bring you my Annual Report as we close out our 25<sup>th</sup> year of operation. To the best of our knowledge we have complied with all the legal requirements of a not for profit organisation over the past 12 months and striven to achieve the aims and objectives outlined in our Constitution.

It has been a bitter/sweet year for me and several others on the committee with the loss of my husband to Cancer on 20<sup>th</sup> November last and Morag and Noelene having to devote more time to the care and support of their husbands. Personally, having the Association matters to attend to has given me a purpose in helping others, and served as a diversion from the void in my life.

Lawrie was very supportive of me in my role as President as many will have witnessed over the years. He attended meetings, took photos and most important of all fed me when I had a deadline to meet with the newsletter or reports for the AGM.

As a Committee we have remained mindful of the needs of members and those affected by lymphoedema and have been part of the consultative forums for Projects and where possible advocated for better services.

We updated the **Treatment Facilities and Resources Directory for Qld and Northern NSW** which we aim to update Bi Annually. It lists the Lymphoedema Service Providers both in hard copy and on our website. Our aim is to ensure that those listed are suitably trained to provide the Service. This takes considerable time and data entry. I wish to thank Jeanine Mewburn for the hours she put in assisting me with the project which was completed in March this year. There is also a listing on the ALA website of all Australian lymphoedema Therapists [www.lymphoedema.org.au](http://www.lymphoedema.org.au) Glenda Crew our webmaster has updated the web page.

In my last report I informed you of the **Metro North Hospital Health Service Lymphoedema Service Review** which was set up as a result of a Letter to the then Health Minister, Lawrence Springborg re the access to services in the Redcliffe Caboolture area. A Pathway was to be planned with the aim of improving access to services closer to home for those at risk, those needing treatment and or/ monitoring. The pathway has now been developed and it is planned patients post surgery will be directed in a certain pathway according to their needs for monitoring or treatment for lymphoedema by either a Non Government Organisation such as Blue care, Private Practice Physiotherapists and OT's or the Public Hospital system.

At present funding has been granted to set up a trial and A Project Officer has been appointed to introduce the concept to stakeholders. Further funding is needed for the Service to be implemented. The initial pathways are for cancer related lymphoedema, however we are in favour of the broadening of the scope to include all lymphoedema and have expressed our desire for consideration to this matter.

#### RESEARCH

Over the past 12 months we have been several requests for participation in research for lymphoedema. This we are happy to do once it has been passed by the Ethics Committee.

Urgently needed current research participation comes as a result of Anna Finnane's PhD. Research in 2011 '**Patient's experiences of lymphoedema treatments**' the outcomes of the research highlighted the difficulties people were facing in trying to access adequate lymphoedema care. To address this problem, she is now, as a Postdoctoral Research Fellow School of Medicine at Qld University, exploring the possibility of supporting lymphoedema self-management with a specialised lymphoedema telehealth service.

So we have been approached to ask members to participate in a phone interview which will take 30 - 40 minutes to ensure they fully understand the needs of people with lymphoedema and health professionals treating lymphoedema prior to developing this telehealth program.

Thank you to the members who are willing to give of their time to participate in these research activities.

#### LAUNCH OF THE LYMPHOEDEMA ACTION ALLIANCE

In the 2014 report we announced the launch of the Lymphoedema Action Alliance in October 2014.

The Alliance is working to reduce the unnecessary suffering of people who have lymphoedema, by ensuring timely access to affordable lymphoedema services and compression garments regardless of where people live, their financial status and their health situation.

Late last year a publication 'Lymphoedema Stories' The Untold Truth' was Published by the NSW Cancer Action Network Northern Suburbs Members of the LSGNSW were surveyed about their



experiences with lymphoedema. The key issues highlighted by the respondents suggest that services are severely understaffed and underfunded, and there is limited understanding of lymphoedema among health professionals. This would be true in most Australian states and many overseas countries. As it is a NSW based group we have joined to add a voice to their Action to achieve 'Equitable sustainable access to affordable lymphoedema compression garments nationally'

### ASSOCIATED ACTIVITIES WITH THE ALA.

We continue to support the ALA where appropriate to assist in furthering their aims of educating the Health Professionals and Consumers at Seminars and advocating for better services for lymphoedema.

It is always a pleasure to have the Qld ALA Representative to join us at meetings and update us on recent or upcoming events. We were recently advised that due to the cost of promoting the Iced Tea Parties and the limited funds raised they will no longer be a major fundraiser; however it could still be used to raise awareness.

We are planning to be involved as a Consumer Group with the next Conference which will be held in Darwin.

**2016 Asia Pacific Lymphology Conference 26 May 2016 - 28 May 2016**

### NEW NETWORKS - NEW SOLUTIONS

### LYMPHOEDEMA REGISTRY LAUNCHED IN APRIL 2015

A project of the ALA with support of the LAA and state lymphoedema support groups.

The ALA and other lymphoedema patient advocates are always asked "*How many lymphoedema patients exist in the country and how much does treatment cost?*" The ALA when advocating for improved care has to explain the needs and the state of health of patients living with lymphoedema. Data from a national lymphoedema registry provides the valuable tool to accomplish this task.

The primary goal of developing a national lymphoedema registry is to help those living with lymphoedema by

- increasing awareness of the prevalence of the disease,
- delineating needs of patients in the community,
- identifying shortcomings in the healthcare delivery system and
- empowering the ALA and other organisations to lobby more effectively

Analysis of collected data is provided via SPSS by an IBM Community Grant

We have advised members of their need to register in order to achieve a robust data set.

People do not necessarily need to belong to the Association to be on the register.

### AWARENESS

**March Cancer Council Public Awareness Event**- an update on Lymphoedema research and treatment for consumers and interested Health Professionals.

This was part of their Health Professional Education and Engagement in collaboration with the Qld Health Allied Professionals Group.

This was well attended with Jan Rice - A wound Care Specialist and Louise Koelmeyer OT.

We heard about the latest on Wound Care and the Advanced Lymphoedema Surgical Program being undertaken at the Macquarie University Cancer Institute - Liposuction for lymphoedema.

Earlier this year we were contacted by the **State Library of Qld and the National Library of Australia** for licence under the Copyright act 1968 to add the Queensland Lymphoedema Website: <http://www.lymphqld.org/> to PANDORA i.e. Preserving and Accessing networked Documentary Resources of Australia to which we agreed.

### FACEBOOK

This is a recent attempt to raise awareness. I have set up 2 Face book Accounts.

A page for the Association on which to post articles of interest <https://www.facebook.com/lymphoedemaqueensland>

There is also a public group you can ask to join Lymphoedema Queensland. I plan to review this account to allow input from members in the future.

### TECHNOLOGY

The availability of refurbished computers and discounted software at low cost and a price we could afford, from Connecting Up a group who supply to Not for Profit groups, allowed us to obtain a Laptop Computer to be used for presentations and awareness without having to put in a submission for funds.



**FINANCIAL**

We have continued our endeavours despite the fact we do not receive any additional funding from Government and rely on the voluntary support of the executive committee, the financial support of members and donors.

I wish to thank Karin who so ably keeps our financial records on MYOB. The records are able to be printed off for the auditor which provides clarity of transactions and makes his work a lot easier.

The generosity of the Brisbane City Council in the free use of meeting room at Toowong Library and seminars to assist with board decisions. The Cancer Council Qld. Rockhampton, the Bribie Anglican Church BACS group and the Mater Hospital in Bundaberg has assisted us to spread our funds further.

**THE FUTURE**

I recently attended a seminar run by the Brisbane City Council re the **Future Sustainability of Not for Profit Groups**. This was a very interesting meeting and we heard how groups such as some bowls clubs who lease council facilities have been able to continue through the letting of other groups use the facilities for meetings, thus obtaining the income to assist in the survival of the group.

Another interesting idea was that of **Porous Boundaries** where groups give up their autonomy and join together with similar groups to achieve their goals.

This may have to be our direction in the future as Support group numbers are dwindling and there is little interest in serving on the Committees, both here and in other States.

There have been discussions over many years for a National Association with perhaps a change of name to a Foundation which seems to be more appealing to some. This would cut costs of Insurance and other running costs of maintaining individual State Associations.

**VOTE OF THANKS**

- Teresa for your attendance today and the interest and support you give to the Lymphoedema Association of Qld.
- Veronica for your services as Minutes Secretary for our AGM each year. It is very much appreciated.
- Noelene for her service on the Committee over the past years
- June Timms as Secretary and assistant Support group Co-ordinator
- Leila Bourke who takes the calls on the Enquiry Line. 0403 782 795
- Members who have supported and encouraged me throughout the year
- Members who have taken the time to attend today to show your support for our efforts.

Nerida Smith, October 24, 2015

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COMMITTEE MEMBER PROFILE- Mary Stewart Vice President/ Publicity Officer

I am very excited to be involved once again with the LAQ after having a considerable number of years off the executive committee due to my work commitments. I was one of the original people who started the LAQ and I am so impressed with all the inroads the Association has made over the years due to the dedicated people who work tirelessly for the association, I hope that I can contribute some new energy and ideas to the association moving forward.

I originally got lymphoedema of my right leg at the age of 24 and was a flight attendant at that time and I found out after many years this was a congenital condition. I was heavily into sport and this I found helped elevate the severity of my condition. I was ranked within the top 10 in Qld for squash and then I took up kayaking and won several gold medals in the world masters over a number of years. I still kayak a few times a week and also ride a road bike a few times a week and this keeps me very fit and also keeps my leg healthy.

I look forward to meeting you all throughout this coming year.

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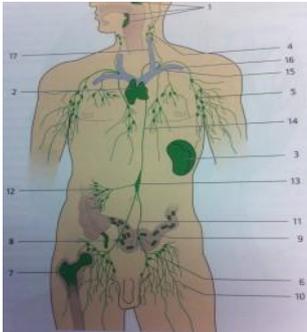


# The Benefits of Abdominal Breathing Exercises in the Management of Lymphedema

BY JOACHIM ZUTHER, ON DECEMBER 30TH, 2015

Unlike the heart in the blood circulatory system, the lymphatic system does not have an active pump to propel lymphatic fluid back to the bloodstream. Effective lymph flow depends on sufficient muscle and joint activity, especially if the functionality of the lymphatic system is compromised.

### The Deep Lymphatic System



Abdominal (diaphragmatic) breathing exercises are a valuable tool in stimulating deep lymphatic structures, such as the cisterna chyli (13), the abdominal part of the thoracic duct (14), lumbar trunks (11) and lumbar lymph nodes, pelvic lymph nodes, and certain organ systems. Stimulation of these deep lymphatic structures, in particular the thoracic duct (the largest lymph vessel in the body), accelerates the transport of lymph fluid toward the venous angles (15), through which the lymph fluid is returned into the blood circulatory system.

Lymph fluid from the lower extremities passes through these deep lymphatic structures and an increased flow of lymph, particularly in the thoracic duct, results in improved lymphatic drainage from the lower extremities. Individuals affected by lymphedema of the leg greatly benefit from diaphragmatic breathing exercises, especially when combined with a comprehensive decongestive exercise regimen.

The downward and upward movement of the diaphragm in deep abdominal breathing not only is an essential component for the sufficient return of lymphatic fluid back to the bloodstream; movement of the diaphragm, combined with the outward and inward movements of the abdomen, ribcage, and lower back, also promotes general well-being, relaxation, peristalsis and return of venous blood back to the heart.

The considerable decongestive effects on the lymphatic and venous systems in combination with these additional benefits make abdominal breathing exercises also a valuable tool for the treatment of upper extremity lymphedema.

Diaphragmatic breathing exercises with the primary goal of decongestion is best performed lying on your back (supine) with the knees bent and your head supported with a pillow; however, they may also be performed sitting on a stool or chair without leaning back.

Abdominal breathing exercises should never cause dizziness, pain or discomfort. Please consult with your physician especially if you are experiencing pain and discomfort.

How to perform abdominal breathing in the supine position:

(Here is a link to a video demonstrating abdominal breathing exercise: <https://www.youtube.com/watch?v=kgTL5G1ibIo>)

**1. Lie on your back on a flat surface (or in bed), with your knees bent and your head supported. You may use a pillow under your knees to support your legs. Place one hand on your upper chest and the other on your belly. This will allow you to feel your diaphragm move as you breathe.**

**2. Breathe in slowly through your nose so that you feel your stomach moving out against your hand. The hand on your chest should remain as still as possible.**

**3. Tighten your stomach muscles, letting them fall inward as you exhale. The hand on your upper chest must remain as still as possible. To pronounce the exhaling you may let the exhaled air flow through pursed lips.**

It is recommended to first practice abdominal breathing exercises 5-10 minutes about 3-4 times per day. If no dizziness or discomfort is noted, you may gradually increase the amount of time you spend doing this exercise.

Here is another link to video tutorial providing a 3-D view of the diaphragm during abdominal/diaphragmatic breathing: <https://www.youtube.com/watch?v=hp-gCvW8PRY>

More articles on exercises for lymphedema:

1. [Decongestive and Breathing Exercises for Lymphedema](#)
2. [Resistive Exercises for Lymphedema](#)
3. [Aerobic Exercises for Lymphedema](#)
4. [Aquatic Exercises for Lymphedema](#)

**Do you need more information on other topics on lymphedema? Join [Lymphedema Guru](#), a Facebook page solely dedicated to inform about all things related to lymphedema**

**This is an American Site so the information on treatment centres and support groups is not relevant to Australia**

**Go to our website [www.lymphoid.org](http://www.lymphoid.org) for information and links to other sites.**



This lovely article was contributed by Rene Pezy for the Lymphoedema Support Group of South Australia December 2015 Newsletter.

**The Lighthouse**

Let your life be as a lighthouse that pierces the darkness of the storms of life to bring others to safety. Allow your spirit to be a harbor of peace and tranquillity amidst the turbulence and chaos. Let your heart be a refuge....a sanctuary of calm.



Reach out and embrace the heart of a child...bring companionship to the loneliness of the old....share a tear and bring comfort to those who mourn....bring joy to those who know sorrow....and bring hope to those who know only the black futility of despair.

A lighthouse never focuses in on itself...but always, selflessly reaches out to guide and help....Let your light so shine, that others are drawn to you....not by mere words....but by your life and the richness of your spirit. Remember - Life is meant to be a celebration of the things we can do, not a requiem for this things we cannot do."

The great Native American chief Tecumseh once said, "When you arise in the morning, give thanks for the morning light, for your life and strength. Give thanks for your food and the joy of living. If you see no reason for giving thanks, the fault lives in yourself."

*Extracted from web page Step Up-Speak Out*

<http://www.stepup-speakout.org/patoconnorcopng.htm>

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**WHAT IS A SUPPORT GROUP ?**



A support group involves a small number of people who come together- either in person, on the phone or through the internet - to share feelings and exchange information in a supportive atmosphere.

Groups give people the chance to talk about their feelings with others who have had similar experiences and understand how they are feeling. Many groups have regular guest speakers, with meetings held in two main types of places: community setting or hospital/health care venues.

**Why people join?** Most people join groups to learn about cancer and treatments and deal with the emotional effects. They are looking for encouragement and optimism, inspiration and hope for survival and quality of life, and advice about how to get the best outcome.

**Why people stay:** Once people join a group, certain factors encourage them to stay.

- 1. **A sense of belonging:** Group members feel they are not alone.
- 2. **Reducing isolation:** Groups develop a sense of community through shared feelings and experiences.
- 3. **Empathy:** People outside a support group may not understand the experiences of people who experience living with lymphoedema.
- 4. **Feeling safe:** Inside the group people feel protected and safe to express their feelings.
- 5 **Humour:** People feel comfortable to have a good laugh, to relax and feel at ease.

The LAQ has affiliated support groups listed on page 2.

Why not check out your local group or start a group in your area? Contact Nerida 07 3269 1498 or info@lymphqld.org for information on starting a group or request to join our facebook page lymphoedema queensland.

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**Looking for a Compression Pump to assist in managing your lymphoedema?**

Flowtron Hydroven 3 compact lightweight 26cm long by 13cm wide.  
Plus arm Sleeve 79 long and 30cm wide to plug into the machine plus user manual.

Original cost \$1200, asking \$570 for the machine and \$50 for the sleeve.  
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Located on Brisbane's North, and offers quality, comprehensive treatments for people living with lymphoedema and venous insufficiency.

Our range of services includes:

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"It would be more cost effective for the government to offer financial support for both garments and lymphatic massage therapy rather than to have to support patients during long hospital stays."

