MARCH IS LYMPHOEDEMA AWARENESS MONTH

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

Welcome New Members

March 2015

Node News is Good News

Dear Readers

Welcome to the first edition of Node News for 2015.

March is Lymphoedema Awareness Month.
The following are the facts we need to make known to government and the general community so those affected can get the help they need.
Lymphoedema is an under diagnosed and underfunded medical condition.
It affects all age groups from infants to adults.
It is characterised by a swelling of a limb or limbs. It can be a congenital condition due to a problem with the lymphatic system sometimes only becoming apparent at puberty or in early adulthood when a further problem arises with the lymphatic flow.
Accidents and Burns can also lead to Lymphoedema.
The majority of the people affected have had surgery for Breast, Gynaecological and Prostate Cancer due to the surgical removal of lymph nodes and radiation.
Lymphoedema does not come under Medicare for the treatment as it is not managed by Doctors. Lymphoedema therapists are specially trained in the management which includes massage, compression and exercise and requires the patient to follow a daily regime.
The cost of Compression Garments which need replacing every 6 months is beyond the means of low income people. People who have had cancer are eligible for more assistance than other sufferers.

Currently it is not known how many people in Australia are affected by the condition. However, this is about to change with the launch of the Lymphoedema Registry, details of which I have included in page 4 of this edition.
We have added our voice to the newly formed Lymphoedema Action Alliance in NSW which I featured in the last edition of the newsletter. The group has a goal to achieve 'Equitable sustainable access to affordable lymphoedema compression garments nationally'

We need to lobby Qld Health to broaden the current scheme for the provision of compression garments for the treatment of malignancy related lymphoedema to include all people on a low income no matter what the cause of their lymphoedema.
Introduce yourself to your new State member and discuss with him/her your needs and give them some information about lymphoedema. Even show them this newsletter.

The ALA which is the Peak Health Professional Body has an Iced Tea Party Campaign to raise awareness and raise funds for research
Details may be found at www.lymphoedema.org.au

Once Again we will be using the Entertainment Book for our Fundraising. It will be available from April. Just $65 (P&H $10.50).Call us on 0403 782 795 to order. Brisbane, Sunshine Coast and Surrounds, Gold Coast and Nthn NSW, Townsville Books available. If you have a business and are willing to assist us with our fundraising Contact Sarah Kirkwood on 0421 619 388 and she will discuss how easy it will be. Thanks.

- *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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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 4959 1383
  Meeting Bi-Monthly, 1st Friday at Noon at Porters Coffee shop
  Phone for details if you plan to attend.
  First meeting for 2015 Friday 6th 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

In This Issue

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

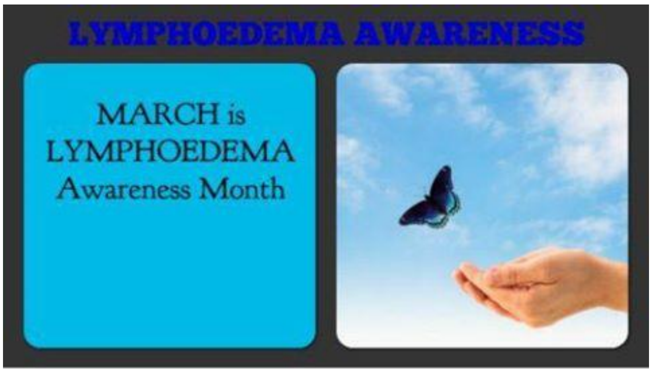
General Membership: Initial year $30 then $25 per year
July1 to June 30 yearly
Concession: Health Card holder/Pensioner:
Initial year $25 then $20 per year.
Membership renewals are sent out early June each year.
Donations to further our work are always welcome.

LOOKING FOR LYMPHOEDEMA TREATMENT SERVICES?

Readers can visit our website www.lymphqld.org for the current listing. The updated Treatment Facilities Directory will be finalised for March 2015
If you do not have access to the internet please phone our information line on 38334376 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



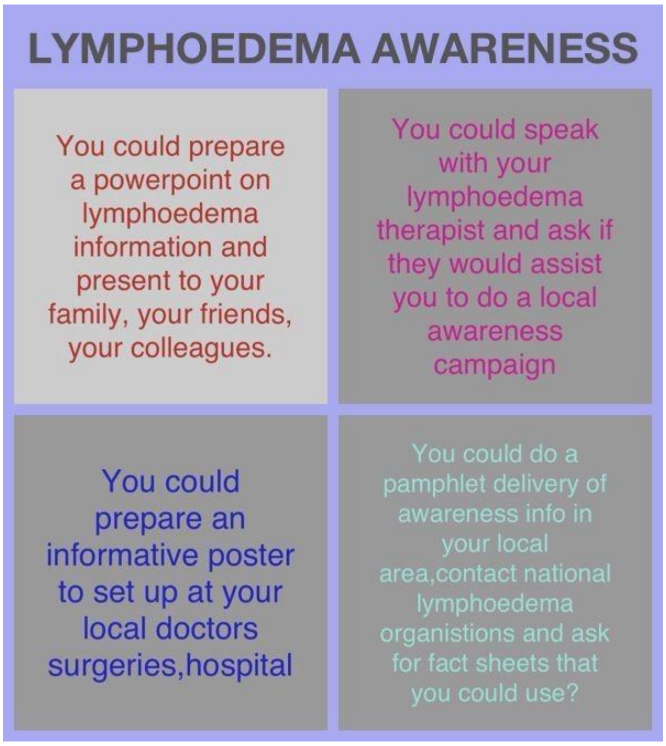

Value LYMPHOEDEMA, it could happen to YOU!

Lymphoedema is NOT an invisible condition physically!

Then why is it we feel so invisible

I value me, my family values me, so why can't our condition be valued the same as others

Lymphoedema Awareness is important, can you hear us?


LYMPHOEDEMA AWARENESS

You could prepare a powerpoint on lymphoedema information and present to your family, your friends, your colleagues.

You could speak with your lymphoedema therapist and ask if they would assist you to do a local awareness campaign

You could prepare an informative poster to set up at your local doctors surgeries,hospital

You could do a pamphlet delivery of awareness info in your local area,contact national lymphoedema organistions and ask for fact sheets that you could use?

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A Post from New Zealand

Just to remind you all that March is Lymphoedema Awareness Month, if any of you who are involved in local awareness groups or national ones, please share with us what and how you are planning to bring further awareness, if not maybe some of you have ideas that you feel could be positive in giving Lymphoedema a local voice. The posts I have been making up, maybe some of these could be printed or you could make your own to put up at your local doctors surgeries, I encourage you to begin thinking about this and what each one of you could do to action some form of awareness where you live, maybe by contacting your national bodies, they may have posters or info made up that could be shared and used, put your thinking caps on and be part of the change we all want, need and deserve. Editor: We would love to hear from fellow Queenslanders on your activities.


Be part of the change Lymphoedema needs

Diabetes, Heart disease, Breast Cancer, Epilepsy, Autism, Cerebral Palsy, Cancer, Downs Syndrome

Were all conditions along with many more that were under recognised in society

It took people with these conditions to become motivated, frustrated, determined, focussed at giving these conditions a VOICE of there own

This required Strength, Commitment, Focus, Belief, and most importantly a vision of improved services in the community

Lymphoedema can become this in each of our countries!

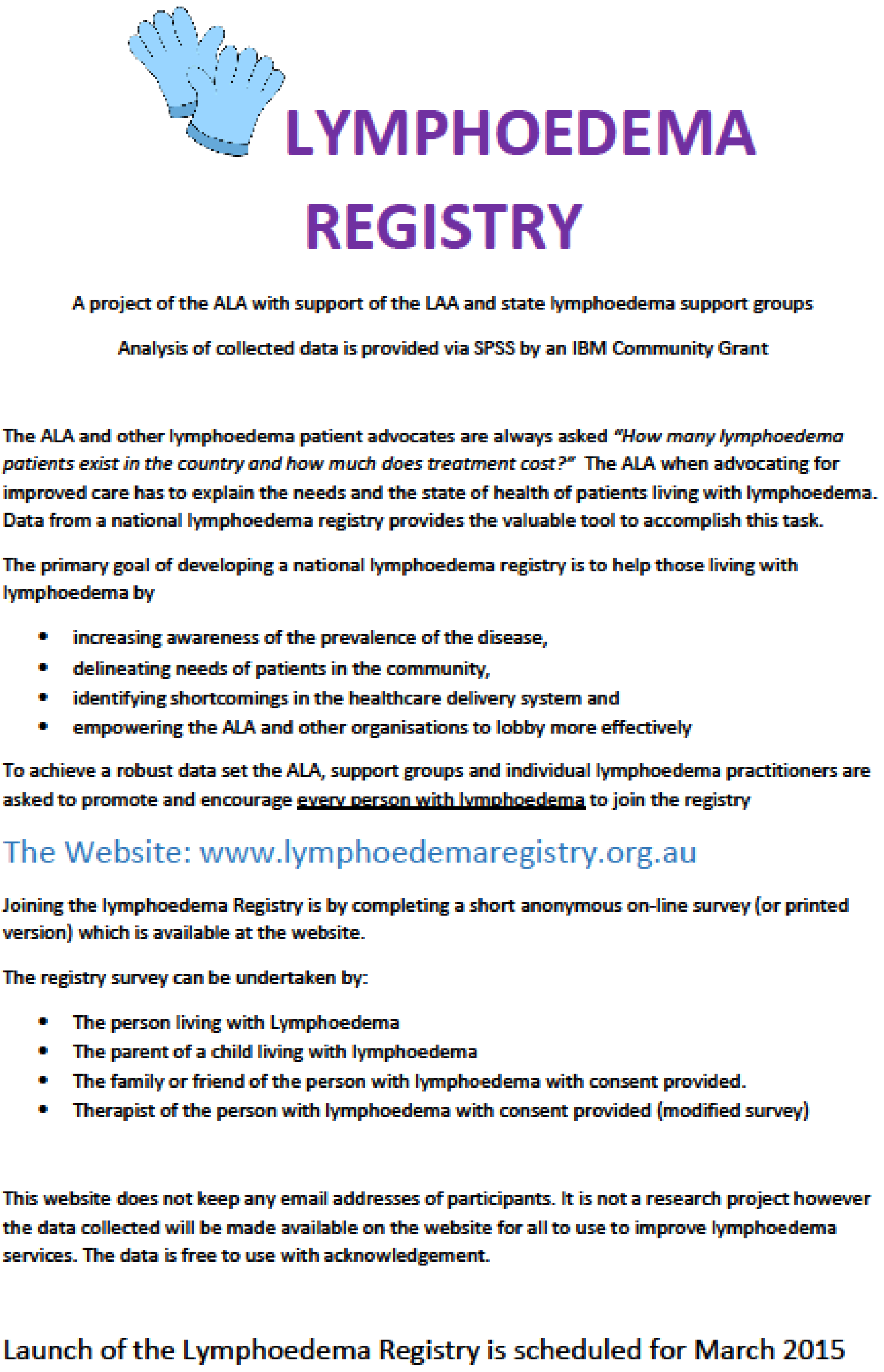
If we have the desire, the guts to step out of our Comfort zones and make our voices heard together!

Lucie the lymphoedema lizard

Wearing "Lucie the Lymphoedema Lizard" is a great way to support and promote awareness of Lymphoedema in the wider community. This small lapel pin is green and gold, and features bandages on the paw and tail to represent the bandaging that people with Lymphoedema commonly undergo to control their condition. Wear "Lucie Lizard" and show your support for Lymphoedema!

We have badges on hand if you wish to purchase one for $5.40 including postage please contact the June O 07 3865 1195 or email info@lymphqld.org A Bulk order can be obtained from the Lymphoedema Association of Victoria for $4 each plus postage by email info@lav.org.au or phone the LAV office on 1300852850

The Lymphoedema Registry has been launched.
I would encourage all members to participate.
Health Professionals will share the message with their clients.
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.
As a courtesy to members we have included a hard copy with your newsletter.



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

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

To achieve a robust data set the ALA, support groups and individual lymphoedema practitioners are asked to promote and encourage every person with lymphoedema to join the registry

The Website: www.lymphoedemaregistry.org.au

Joining the lymphoedema Registry is by completing a short anonymous on-line survey (or printed version) which is available at the website.

The registry survey can be undertaken by:

- The person living with Lymphoedema
- The parent of a child living with lymphoedema
- The family or friend of the person with lymphoedema with consent provided.
- Therapist of the person with lymphoedema with consent provided (modified survey)

This website does not keep any email addresses of participants. It is not a research project however the data collected will be made available on the website for all to use to improve lymphoedema services. The data is free to use with acknowledgement.

Launch of the Lymphoedema Registry is scheduled for March 2015

On Tuesday March 3 at the cancer Council Brisbane we attended the Public lymphoedema awareness event. We were treated to 2 presentations by guest speakers
Ms Louise Koelmeyer OT from the Macquarie University who spoke on the Advanced Lymphoedema Surgical Program.

The Macquarie University Cancer Institute has introduced an advanced lymphoedema Clinic where people may be assessed for surgical intervention as a treatment for their lymphoedema

In the past people living with lymphoedema had to undergo a combination of intensive lymphatic therapies to reduce and control their symptoms. Lymphatic drainage (massage), compression therapy, skin care and exercises have provided little or no relief for some people and have impacted on their day-to-day living.

At the Macquarie University Cancer Institute (MCI), we have access to the latest technology including MRI scanning to effectively determine the best treatment for individuals suffering with lymphoedema. With the use of MRI we focus on exploring why lymphatic fluid can stimulate fat production in the arm or leg - a process that can make compression therapy ineffective - then decide on the best course of action as a result.

New hope for relief

Our lymphoedema intervention surgeries include liposuction and lymph node transfer.

Liposuction

Liposuction is providing hope for people with longstanding lymphoedema and persistent large limbs for which conservative therapy is providing no further benefit despite compliance.

It is now known that advanced lymphoedema is often an accumulation of fatty tissue in the limb and not just fluid.

Our plastic surgeons can effectively remove this fatty tissue and fluid.

Liposuction is not a cure for lymphoedema - to be effective it requires a compression garment to be worn post-surgery 24 hours a day.

Liposuction will however immediately reduce the weight and girth of the affected limb, which will increase an individual's comfort while living with lymphoedema, and will potentially benefit them both emotionally and socially.

Lymph node transfer

Lymph node transfer is a surgical option aimed at reducing and controlling the symptoms people living with early lymphoedema experience.

This procedure is best done in the first five years of lymphoedema developing.

Our surgeons surgically remove lymph nodes from one area in the body and complete microsurgery to attach them into the lymphatic system of the affected limb.

The theory behind this surgery is that these new lymph nodes will start to act as the body's natural pump, in order to move the existing lymph fluid.

While the ultimate goal of this surgery is to reduce the time a compression garment needs to be worn long term, the technique is still very new and experimental.

As such, there is no guarantee that physical changes of the lymphoedema limb will be completely reversed.

Louise Stressed that this type of intervention is not suitable for every lymphoedema and if you are interested you could contact the unit and organise to fly to Sydney for an assessment.

Contact Macquarie Cancer Institute (MCI)
Hotline 02 9887 8887
www.mqci.org.au

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Quote from Jan Rice

‘If children gave up when they fell for the first time, they would never learn to walk’

The battle with LYMPHOEDEMA will continue- I wish you all well- take care of your skin and it will take care of you.

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Jan Rice Registered Nurse
Director Jan Rice Wound Care Services
Coordinator Wound Education, La Trobe University

Treated us to an informative presentation which challenged the views of wound management and healing that many of us had held.

Jan explained that it has been discovered that it has been discovered that cells do better in a moist environment and there are many dressings now available to promote this concept.
In the past wounds were left to form a scab/crust and painted with lotions to aid drying up

There are several causes of lower leg oedema namely Venous disease, Immobility, Heart disease, Kidney disease and Lymphoedema.

As humans if we spend too long stationary on our legs, we get swelling because our legs are our pumps- -the heart pumps the oxygenated blood around the body and the legs are the pumps that return the blood for re-oxygenation. Swelling is not good.

As we age Skin Cells are slower to multiply Our skin has a delayed response to injury, this along with our poorer immune system so more prone to infection. The skin Layers separate more easily and there are less blood vessels and nerves
Combine these effects with Oedema and we have very real problems with ulcers and infections

We need to care for our skin by keeping well hydrated, from the inside and the outside especially as we age.
We need to protect delicate skin against trauma and reduce swelling whenever possible

If you get a wound seek help early. All wounds should be progressing well within one month of injury
If no progress ask for a second opinion or ask the doctor to consider taking a sample to see if there something else going on

The use of dressings in wound care is to protect the tissue, absorb fluid and yet prevent drying out, assist the body to clean the wounded area. Dressings assist the body to grow more tissue and assist the body to grow skin.

There are many types of dressings available which are chosen according to the type of wound.
Film Dressings -Sheet of plastic with adhesive - waterproof, has no ability to manage fluid and should not be used on infected wounds
Foam dressings -There are many of these types of dressings on the market and they are excellent for soaking up fluid or wound ooze.
Honey dressings- These also are very good for infected wounds. Must use medical honey specifically for wound care NOT from the pantry.

In the past. .....
Absorbent dressings- There are a number of absorbent dressing that look like thick 'pads' these are very good for soaking up excess wound ooze.
Ideally if the swelling/oedema is managed the leaking will slow down and become manageable.
Recommended- Zetuvit Plus- Paul Hartmann brand.
Seaweed, Iodine and strong salt dressings are also available.
Ideally your pharmacy will have the products which met your needs, however sometimes they may not have stocks of what you require.
Independence Australia a medical distributor will deliver to your home usually within 24 hours of your ordering.

We need to be aware if our lymphoedema leaks a lot that The fluid which leaks out of a wound contains **protein** and this needs to be replaced.
If the protein levels are too low then you will leak even more
ALWAYS eat a healthy well balanced nutritious diet rich in protein and vitamins.
A Mini-nutritional assessment scale is available from www.mna-elderly.com. Another patient using the product Arginaid extra “Support wound healing from the inside out” is avaible by phoning 1800 671 628.
A patient with wounds may need up to 3 times the recommended daily allowance of some nutrients.

Some controversies remain in wound care range from how to initially treat the wound to the frequency of changing a dressing.

Jan recommends washing and cleaning most wounds in the shower under warm tap water.
Antiseptics may be used but if they are they are then washed off after a few minutes.
Larger people need to clean skin folds carefully as this is where bacteria like to grow.

If the wound is not too dirty then changing dressings regularly disrupts the new tissue so ideally dressings are changed twice per week. If leaking and it looks ‘yucky’ then change more frequently

Cellulitis is an Infection in tissue -painful, causes swelling and redness and some people become very unwell.
Treatment involves antibiotics, antiseptic washes and antimicrobial dressings on an open wound
Often there is no visible wound--check between toes/feet- this is often an entry portal

Recommendations to enable you to remain healthy
Eat a healthy well balanced fresh diet-minimal pre-prepared foods
Exercise --it may be difficult but you must try--USE it or LOSE it, this is very true
Rest, in order to be able to exercise
Work on your mind, have the power of positive thinking.

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REMEMBERING 1950's Australia, is what Brisbane Seniors magazine did recently.
It revealed that "Pasta was not eaten in Australia.
Curry was a surname.
A takeaway was a mathematical problem.
A pizza was something to do with a leaning tower.
All potato chips were plain: the only choice we had was whether to put salt on them or not.
Rice was only eaten as a rice pudding.
Calamari was called squid and we used it for fish-bait.
A Big Mac was what we wore when it was raining.
Brown bread was something that only poor people ate.
Oil was for lubricating, fat was for cooking.
Tea was made in a teapot using tea leaves and never green.
Sugar enjoyed good press in those days and was regarded as white gold. Cubed sugar was regarded as posh.
Fish didn't have fingers in those days.
Eating raw fish was called poverty and not sushi. None of us had heard of yogurt.
Healthy food consisted of anything edible.
People who didn't peel potatoes were regarded as lazy.
Cooking outside was called camping.
Seaweed was not a recognised food.
Kebab was not even a word let alone a food.
Prunes were medicinal.
Surprisingly, muesli was readily available - mostly cattle feed.
Water came out of a tap. If someone had suggested bottling it and charging more than petrol for it, they would have been a laughing stock.

Kooks Korner

Fillets of Fish Mandalay

4 fish fillets e.q. sea perch, flake
2/3 cup Australian light Sour Cream
2 teaspoons curry powder
6 spring onions, sliced
2 bananas, sliced on the angle
1 tablespoon shredded coconut, toasted

Cook fish in a non-stick frypan for 5-7 minutes on each side or until cooked.
Remove to serving plates and keep warm.
Place sour cream, curry powder and spring onions in the pan.
Slowly bring to simmering point.
Add bananas, cook for 2 minutes.
Spoon over fish and garnish with coconut.
Serve with saffron rice, broccoli and carrot. Serves 4.

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Dear Friends and Colleagues,
On 20th December, Lawrie Smith, husband of our president Nerida Smith, lost his fight with cancer.
During the eulogy everyone present learned a lot of the background of this quietly spoken man. A shy country boy who came to the city to embark on a career in the aircraft industry in which he worked for 44 years. His work ethic learnt as a child on the dairy farm helped him to rise to the top as a Senior licensed aircraft engineer. Husband to Nerida, the land ladies daughter, for 48 years and proud father of Kathryn, Linda, Geoffrey and Robert and grandad to 4 girls and 3 boys.
Friends enjoyed his company and the interesting pearls of wisdom he shared with them.
His wit and humour came to the fore when he was relaxed and at ease. He was known for his generosity and willingness to help out neighbours and friends wherever he could.
The old saying "Behind every successful man stands a woman" can be changed to the opposite gender. Because behind the successful Nerida was always her husband Lawrie quietly supporting her! In many ways he helped out when there was a task to be completed, but also gave Nerida the space and time to complete her important work. He will be deeply missed!

LAQ executive committee

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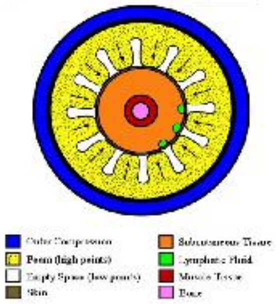
Reid Sleeve Compression Garments

Developed by a Physician, Replaces Nightly Bandaging,
Reduces Limb Swelling, Easy to Don and Doff, Latest Technology



Contact Kristin Osborn at Newcastle Lymphoedema Clinic Reid Sleeve Australasian Distributor
www.newlymphclinic.com.au or newlymphclinic@bigpond.com or (02) 49207010

Printed Book
$35
AUD
+ Postage

Now available
in eBook
$18
AUD

Winter Book

Lymphatic
Friendly©

AN EDUCATIONAL COOKBOOK
1st Edition "Hearty and Humble"

Written & Photographed by
Kristin Osborn
(A Lymphatic Therapist and Lipoedema Sufferer)
Recipes by David Osborn

Summer Book

Lymphatic
Friendly©

AN EDUCATIONAL COOKBOOK
2nd Edition "Lovely and Light"

Written & Photographed by
Kristin Osborn
(A Lymphatic Therapist and Lipoedema Sufferer)
Recipes by David Osborn

This is the first and second known Lymphatic Cookbook which teaches what foods to cook and eat to assist in reducing your weight, limb size and creating a Healthy Lymphatic System.
Written by a Lymphatic sufferer and a Lymphatic Therapist , this book will take you on Kristin's personal journey through her weight issues over the years to how she presents today, keeping the weight permanently off, reducing her limb size and "Pausing The Progression" of her condition.
Enjoy recipes for delicious Pizzas, Burgers, Desserts, Snacks, Breakfast, Lunch and Dinner Meals, Salads and Entertaining Ideas.
Combining helpful information and digitally photographed recipes you will be learning a new set of skills for a new way of living.
If you have a Lymphatic System, you can benefit from this book.