

Lymphoedema Stories

The Untold Truth



Patients' voices highlight the vital need to improve lymphoedema care.

Lymphoedema Stories: The Untold Truth

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Note to Reader

The views expressed in this book are the opinions of those who were interviewed, and do not necessarily reflect the opinion and policy of the Cancer Action Network, Cancer Council NSW or the Lymphoedema Support Group NSW.

You should not use the information in this booklet for diagnosis or treatment of your condition. Treatment should always be discussed with and practised under the supervision of a qualified lymphoedema healthcare professional and/or your doctor. Products or companies mentioned in this booklet are not to be taken as an endorsement of that product.



Acknowledgements

Thank you to the members of the Lymphoedema Support Group NSW who responded to the survey. We appreciate their willingness to share their personal experiences with lymphoedema so that other consumers may benefit.

We also thank Cancer Council NSW for funding the design and production of this booklet.

Foreword

This book brings to life the experiences of people living with lymphoedema.

It is their voices we must listen to, hear and understand to establish the important priorities for support, care and benefits.

The health community and policymakers need to appreciate the lifelong impact of lymphoedema, which is so well elucidated in the conversations written in this booklet.

Improvements in cancer care have made the quality of these survived years increasingly important, and fulfilling the expectation of returning to a full life of love, work and sports is now increasingly a real probability. Lymphoedema emerging during this recovery can be devastating.

I am sure that this book will make the advocacy for improved lymphoedema care more immediate and that readers will understand the ongoing struggle and courage of those living with the daily reality of lymphoedema.

Dr Helen Mackie
President, Australasian Lymphology Association

Who We Are & Why We Wrote This Booklet

The Cancer Action Network (CAN) Northern Sydney is a cancer awareness and advocacy group. The group members are passionate volunteers who are interested in reducing both the prevalence and impact of cancer in the community.

The Lymphoedema Support Group NSW (LSGNSW) aims to increase awareness of lymphoedema among health professionals and the community, and to empower those with lymphoedema to become advocates themselves. LSGNSW encourages members to share their experiences with other people living with lymphoedema.

In early 2012, the CAN and LSGNSW joined forces to raise

awareness and improve services for people with lymphoedema in their local area. Consumers and health professionals were responsive to initial conversations with the CAN and LSGNSW regarding the need for better access to lymphoedema therapy and personalised garments for the long-term treatment and/or prevention of lymphoedema.

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 booklet has been compiled to share the experiences and challenges of those living with lymphoedema in the hope that it will benefit people who feel isolated by their experience.

Furthermore, this booklet is intended to highlight the need for improved awareness and early diagnosis of lymphoedema, as well as the need for greater access to treatment.

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What is Lym

Lymphoedema is the accumulation of excess fluid within the body resulting from failures of the lymphatic system.⁽¹⁾ The lymphatic vessels transport lymph fluid, which is made up of proteins and infection-fighting cells. The lymph nodes filter the fluid to remove invading organisms and dead or abnormal cells which assists immune function.

Lymphoedema can occur as a result of trauma to the body, notably trauma caused by radiotherapy during cancer treatment or the removal of lymph nodes. When the demand for lymphatic drainage exceeds the capacity of the lymphatic circulation,⁽¹⁾ severe and painful swelling can develop, affecting movement and increasing the risk of infections.

Lymphoedema may present soon after trauma has occurred or months

to years later. This progressive, chronic disorder can lead to a sense of heaviness caused by the swelling that can harden and in some cases even become painful and debilitating. Because lymphoedema can result in loss of mobility and infection, prevention strategies are paramount.

Primary Lymphoedema

Primary lymphoedema is the less common form of lymphoedema. It is usually the result of a genetic condition that affects the development of the lymphatic system:

- Lymphoedema congenita is present from birth.
- Lymphoedema praecox develops at puberty.
- Lymphoedema tarda occurs later in life.

These conditions can occasionally be associated with other syndromes.

lymphoedema?

One in 6,000 people will develop primary lymphoedema at birth.⁽²⁾

Secondary Lymphoedema

The majority of lymphoedema cases occur as a result of trauma to the body. Trauma can include surgical removal of lymph nodes, radiotherapy treatment, burns or injury. Venous disease, cellulitis and other infections may also cause secondary lymphoedema.

Lymphoedema and Cancer

Secondary lymphoedema is not limited to cancer patients, however, it often follows cancer treatment. Conservative estimates suggest that 20 percent of breast, genitourinary, gynaecological or melanoma cancer survivors will experience some form of secondary lymphoedema.⁽³⁾

As secondary lymphoedema does not necessarily occur immediately after treatment, it is recommended that cancer patients be aware of their body and be advised of the possibility of localised swelling. Acknowledging early warning signs and symptoms of lymphoedema is key to preventing or managing the condition.

Lipoedema

Lipoedema usually occurs in women and results in excessive subcutaneous fat deposition at times of hormonal change, such as puberty or pregnancy. There is often a family history. Lipoedema can progress on to develop an oedematous component, known as lipolymphoedema.⁽²⁾

References:

- (1) Australasian Lymphology Association: www.lymphoedema.org.au
- (2) Christine Moffatt, *Best Practice for the Management of Lymphoedema: International Consensus*, Medical Education Partnership (MEP) Ltd, London, UK, 2006.
- (3) *Review of research evidence on secondary lymphoedema: Incidence, prevention, risk factors and treatment*, National Breast and Ovarian Cancer Centre (NBOCC), Sydney, Australia, 2008.

Diagnosis

Early and accurate diagnosis can minimise the severity of lymphoedema. Warning signs are often misdiagnosed or simply dismissed as swelling due to standing on one's feet all day or being overweight. Early diagnosis requires the general practitioner (GP) to be aware of lymphoedema and to exclude other causes of swelling.

Diagnosis can be a long and confusing process for people with lymphoedema. Lymphoscintigraphy uses radioactive material to image the lymphatic system. This can be used to diagnose the condition. However, the majority of lymphoedema cases can be diagnosed clinically by assessing symptoms, signs and history.

We wanted to hear from patients about the pathway to their diagnosis and any issues they experienced along the way.



It took five different specialists before I was diagnosed with lymphoedema in 2001.

Susan

'My lymphoedema appeared at age 64, ten years after a mastectomy. My general practitioner diagnosed me, but I didn't have a lymphoscintigraphy.'

Margaret

'Nineteen years ago, a rheumatologist confirmed my primary lymphoedema diagnosis by performing a lymphoscintigraphy. I had to wait three weeks for a custom-made stocking for my right leg, and in this time I received massages and bandaging to see me through. Lymphoedema then developed in my left leg eight years ago.'

Lesley



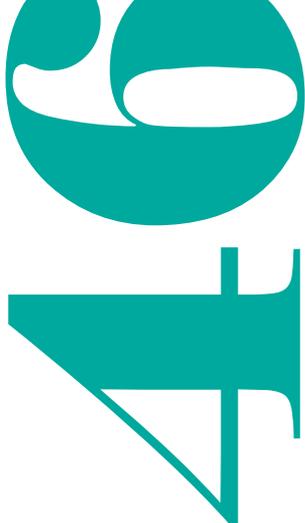
How long did it take to diagnose your lymphoedema?

'I was diagnosed in February 1992 after having cervical cancer and a hysterectomy in June 1990. My surgeon at the time didn't mention the potential for any swelling or the word lymphoedema. In 1991, I noticed slight groin and inner thigh swelling, but it wasn't until I took a flight to Canada that I started to panic. During the flight I presented with severe swelling and a hot limb. On return to Australia, I was diagnosed with lymphoedema and immediately started four weeks of complex physical therapy and had garments fitted.'

Robyn

'It took five different specialists before I was diagnosed with lymphoedema in 2001. The diagnosis was confirmed with a lymphoscintigraphy, and I was told to just live with it and that there was nothing that could be done.'

Susan



'I was 46 years old when I was diagnosed with lymphoedema in 1999. It appeared after I underwent a radical hysterectomy for cervical cancer. The surgeon did explain that surgery could result in lymphoedema and he checked for signs of this at each check-up. Six months after surgery and after an extended car trip, he diagnosed and sent me for an ultrasound of the veins in my leg to rule out other causes for the swelling. I visited therapists at a private hospital who confirmed my lymphoedema.' **Marilyn**

'I was diagnosed at 49, but I didn't have a lymphoscintigraphy to confirm the diagnosis until a few years later.'

Bonnie

'My swelling began gradually, and the first doctor I saw didn't know what it was. A home visiting nurse thought it was lymphoedema and I believe I did have lymphoscintigraphy to confirm the diagnosis.' **Ruth**

'I was diagnosed at 51 with lymphoedema. My kidney specialist didn't know that the side effects of a particular anti-rejection drug he prescribed for me caused lymphoedema to present. For four months I told him that one foot was swelling, and then my cellulitis began recurring. My entire leg swelled, then my other leg, then my trunk and pelvis. At this time he did some research into the drug and found that it was all caused by the particular drug. Nine months after I initially complained about the swelling, my doctor took me off the drug. I had cellulitis from my trunk to my toes on both legs in February 2010, and since then I have had it six times. I am now on antibiotics continuously.' **Richard**

'At age 58, I was diagnosed with lymphoedema after having treatment for breast cancer. My physiotherapist diagnosed my condition and has been looking after me ever since. She is a trained lymphoedema specialist physiotherapist and has been great.' **Judy**

Treatment

Lymphoedema cannot be cured. However, with appropriate intervention the symptoms can be reduced and managed, improving quality of life. Treatment varies with the severity and location of the lymphoedema. Best-practice management generally includes initial intensive treatment performed by a qualified lymphoedema practitioner, followed by a self-management program for the patient.

The components of treatment include:

- education
- good skin care
- gentle exercises
- lymphatic massage
- compression bandaging and/or garments.

To be effective, treatment needs to be developed individually for each patient, and regular visits to a lymphoedema practitioner are required. Long-term needs are then assessed through response to treatment.

Patients told us about the treatments they have used and how frequently they access services.



Every eight weeks, I have lymphatic drainage massage. I'd have it more often if I could afford it.

Bonnie



Can you tell us about your lymphoedema treatment?

'I should have lymphoedema therapy every six months, but the process of getting a referral from the GP then the specialist referral to the lymphoedema practitioner takes a lot of time, and that's just to get on the waiting list. It's necessary that I have physiotherapy and bandaging, but it means I can't do much else each time I have treatment. My advice would be to keep up the massage, the exercises and wear the stockings when they are prescribed. Also, see a very good therapist who specialises in complex therapy for lymphoedema.' **Ruth**

'I have had bandaging two or three times now. The first time was when I was diagnosed, the second, when I moved house, and the third, after a large amount of gardening one afternoon. That day, I carried rocks, dug out trees and other physical things I shouldn't do, but sometimes you just need to do those jobs yourself. Every eight weeks, I have lymphatic drainage massage. I'd have it more often if I could afford it.' **Bonnie**

MY

experience with treatment has been positive. I have a good treatment plan and integrate the use of alternative therapies. In 2011, I was hospitalised for nearly four weeks in total where I had hydrotherapy, physiotherapy and lymphatic drainage, as well as bandaging. I have a hydrotherapy session every week, as well as massage, laser or acupuncture to work on my lymph drainage.'

Lucy

‘Over a period of five weeks, I was hospitalised to reduce leg swelling. This was followed by compression garments (50mm Hg). Since that time, I wear them daily along with carrying out a light massage.’

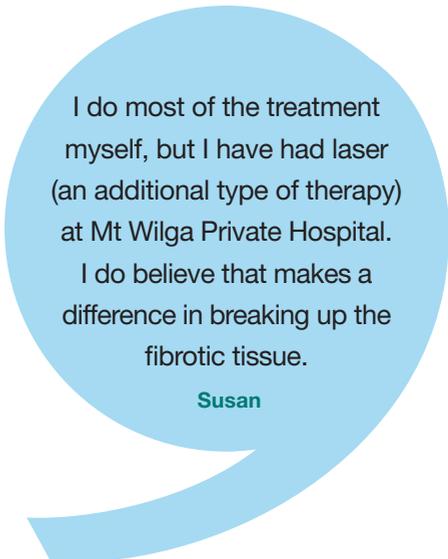
Graham

‘My treatment began as an outpatient at the local hospital by the occupational therapist who runs a lymphoedema clinic. She was the only therapist so she was overwhelmed by demand. I then visited Mt Wilga Private Hospital and underwent intensive physiotherapy treatment. I am sure this is the reason my arm is so good now, five years on. At present, I visit a local therapist when I feel I need to, and at my own expense.’ **Anne**

Lymphatic drainage massage

is the only treatment I’ve had. For my condition it is very effective, and I have massages monthly in the cooler months and more frequently in summer.’ **Elizabeth**

‘I visited the occupational therapist who provided me with off-the-shelf gloves and sleeves, and I had occasional lymphatic massages during my chemotherapy. As my swelling worsened, I wore bandages for three weeks plus I had a daily massage performed by my husband. I have since used custom-made garments, my husband continues the daily massage, and I have three-monthly visits to a therapist to get measured for garments and to discuss ongoing management of my lymphoedema.’ **Denise**



I do most of the treatment myself, but I have had laser (an additional type of therapy) at Mt Wilga Private Hospital.

I do believe that makes a difference in breaking up the fibrotic tissue.

Susan

Compression Garments

Compression garments are an integral part of lymphoedema treatment and ongoing management. They improve the functioning of the lymphatic system by ensuring pressure to swollen regions to improve drainage. Compression garments are used by the majority of lymphoedema patients. The type of garment required depends on the type and severity of the lymphoedema.

Purchasing compression garments can be costly, and they need to be replaced and refitted every six months because they lose elasticity. Custom-made garments are particularly expensive, and patients are often on long waiting lists to be fitted due to a lack of services.

Our respondents reported varying experiences with compression garments, however most noted comfort, fit and cost as the key issues.



*I have mainly worn
off-the-shelf garments,
which work well
enough for me.*

Mary



What have been your experiences with compression garments?

'I found my made-to-measure sleeve and glove difficult to wear when I was using my hands/arms for other activities. I wear them when I am less energetic, i.e. travelling in the car or watching television. I use my off-the-shelf sleeves mostly and have my arm in a sleeve

24
hours.'

Dianne

'It is essential that you are professionally assessed for your sleeve or garments, as the wrong garment causes a lot of problems.' **Lila**

'I have always worn an elastic stocking (compression garment), however, I found custom-made stockings very uncomfortable – especially behind the knee and around the ankle. I have mainly got by with off-the-shelf garments that work well enough for me and are not as expensive. The most challenging aspect, I find, is getting them on and off, particularly on hot days, and more so as I age and osteoarthritis becomes more of an issue.' **Mary**

'My legs feel supported with compression garments. It has taken a number of years to have the garments fitted correctly. The lymphoedema clinic is much better than public hospitals. Even though my garments fit much better now, I still have days where the pressure is uncomfortable. I wear a made-to-measure toe piece and thigh high stockings, with varying compression on my toes, foot and each leg.' **Janet**

‘My experience with compression garments has been good. I do not feel they are hot to wear or uncomfortable. My advice would be to wear your compression garments as recommended and exercise as much as you can.’ **Alison**

‘My garments are essential in reducing the swelling and I always use a double layer when flying. I wear made-to-measure thigh-high garments. The only problem I have had is a reaction to the silicone band which gives me a rash in hot weather.’ **Adrienne**

‘My compression garments work fairly well. I’m not fond of them so one puts up with the inconvenience of wearing them

18
hours or more

a day. The alternatives would be worse for me. I wear off-the-shelf garments including chaps, ready-wrap for foot, calf and thigh.’ **Marilyn**

6 Compression garments are expensive and take a long time to receive. The turn-around time from ordering the garments – a company in Germany making them; sending them to Australia; waiting time in Customs; and finally arriving back at my local private hospital – is about three weeks. This is too long; by the time treatment has finished, and the new garments arrive to be worn, the limb would have swollen again.’ **Helga**

‘The off-the-shelf garments do not quite fit properly and do not work well for decreasing my lymphoedema swelling. The made-to-measure garments work great.’ **Robbie**

‘I need assistance from my husband to put on my compression garments. I have worn them now for about a year and a half with very little change in the swelling. I have also noticed that my arm feels heavy most of the time, regardless of whether I am wearing my garment.’ **Toni**

Finances & Funding

There is no uniform financial assistance program for lymphoedema treatment. Garments for lymphoedema are expensive, and patients may not always be able to afford them. Therapy can be provided by lymphoedema-trained physiotherapists, occupational therapists, massage therapists and nurses. However, these treatments are not adequately covered by Medicare or private insurance companies. In addition, access to these treatments is often limited by a lack of services or availability.

Currently, Medicare does not cover garments for lymphoedema. Limited access to physiotherapy and occupational therapy is available via the Medicare Enhanced Primary Care Program. However, it is barely enough to cover the first week of treatment, let alone the long-term management. The EnableNSW initiative provides some subsidies for lymphoedema compression garments depending on the individual's income and the cost of the garment. For more information see www.enable.health.nsw.gov.au. Some private health funds may provide limited subsidy for some therapies and garments. This can vary, and not all patients can afford private health insurance.



In total, my garments cost \$2,000 over two years and the rebate I received from my health fund was \$200.

Lucy

'In 2011, I had a lot of treatments. Doctors, podiatrists and tests took me over the Medicare Safety Net by August. This did not include any hospital lymphoedema treatments, which were covered by my private health fund. For private massage therapy in 2011, I claimed \$5,500 and received a rebate from my health fund of \$100. Now that I am well managed, I require less frequent massage. In total, my garments cost \$2,000 over two years and the rebate I received from my health fund was \$200.' **Lucy**

'Treatment for four weeks at Mt Wilga Private Hospital costs about \$5,000, which was covered by my private health cover. I have two garments every six months, which in total cost about **\$3,200** a year. I only get 15 percent back on private health cover.' **Robbie**



How much does your lymphoedema cost you each year?

'My fund is now covering most of my garments and I have minimum out-of-pocket expenses, which are approximately \$150 this year. It's hard for me to gauge costs, as I have multiple recurring melanomas and am on a clinical trial and cannot always wear my compression garment.' **Judith**

'I have just started with EnableNSW, and I have been told that the made-to-measure sleeves are around \$300-\$400 each. Without EnableNSW it would be very hard to keep buying the right garments, as it is ongoing every year. Until recently I have paid with no help.' **Lila**

\$900

'I am in the top bracket for rebates with my health fund, so when it cost me over \$900 for my wraps, I got \$690 which was 75 percent back.' **Susan**

‘I was paying \$400 plus per sleeve, for four sleeves each year. Now I pay \$100 each year through EnableNSW.’

Megan

‘I have approximately four monitoring and treatment visits per year, at \$100 each time, and receive about \$40 back from my health fund. I need one compression garment per year, which costs \$500, and receive around \$350 back from my health fund.’ **Denise**

‘In 2011, I had 21 physiotherapy sessions at \$100 each, for which my health society refunds up to \$800, or \$30 per visit. I need three sleeves, at \$250 each. Buying them three times a year means it adds up to

\$2,250

Bandaging between garments requires daily visits for two to three weeks, although last time I trialled bandaging that lasted four days.’

Annette

‘Private massage costs me \$90 a week for a single session, and I get a \$25 rebate from my health fund. I get some money back from the garments.’

Richard

‘The sleeves cost me \$250 out-of-pocket every two years. I am out of pocket \$50 for each physiotherapy visit.’ **Toni**

‘Each year I pay

\$1,500

for stockings,

\$30

for moisturising cream,

\$600

for special shoes.’

Graham

‘My treatment is at a hospital and therefore paid by my health fund. Garments are around \$90 each (\$180-190 p.a.), partly reimbursed.’ **Melanie**

Cellulitis

Cellulitis is an acute infection of the skin that often occurs with lymphoedema swelling. The protein-rich fluid within a lymphoedematous region provides an ideal environment for bacterial growth. Lymph nodes help to filter and remove microorganisms from the body.

Patients with cellulitis should receive prompt treatment with antibiotics from their general practitioner. Unfortunately,

cellulitis can become life threatening and may require hospitalisation for intravenous antibiotics. Maintaining a good skin regimen with moisturisers and protective precautions will help prevent the development of cellulitis. More information on treatment can be found on the Australasian Lymphology Association position statement, *Management of Cellulitis in Lymphoedema*: www.lymphoedema.org.au.



*I have always caught
my cellulitis early since
the first outbreak.*

Audrey

'I have had cellulitis twice, and in both instances was hospitalised. One of these times, I was overseas and it was thought to have been caused by an insect bite. Another time was in Sydney following a cat scratch.' **Mary**

'In the last ten years, I haven't had a case of cellulitis. However, within the six years prior, I had cellulitis on four different occasions. On one occasion I was bed-ridden for four days and was nearly hospitalised. Instead, I visited the doctor's surgery daily for antibiotic injections.'

Robyn

'Over the years I've had cellulitis about two or three times. I was hospitalised early on to try and bring down the swelling, and then was able to hire a pump for treatment use for home. I was hospitalised as a half-day patient at Mt Wilga.' **Ruth**

Have you experienced cellulitis as a result of your lymphoedema?



'I have always caught my cellulitis early since the first outbreak. I now limit what I do to avoid skin damage, worry about leeches, etc., and have not yet been hospitalised. I recently took an over-the-weekend antibiotic as I felt a problem coming on. My general practitioner agreed that the condition looked suspicious and an outbreak was averted.'

Audrey

'I had cellulitis in April 2012. I never considered the idea that I would get cellulitis. I didn't have any cuts or injuries to my leg, but it became red so I was given a double course of antibiotics.'

Helga

'I had cellulitis once after breast cancer surgery but I wasn't hospitalised.' **Virginia**

Everyday Life

Lymphoedema has a profound impact on daily activities. Managing lymphoedema often requires regular visits to therapists for lymphoedema massage, and buying expensive off-the-shelf and made-to-measure compression garments. Skin care, self-massage and exercise are also key in day-to-day management.

Our respondents described a number of strategies to prevent swelling, cellulitis and infections. For some, it has meant giving up or adapting activities such as cooking, gardening, holidays and trips to the beach.

Pain & Discomfort This can at times accompany lymphoedema and limit people's activities. However, after diagnosis and appropriate treatment, many people with lymphoedema felt they had less pain and greater freedom.

Work Lymphoedema also has an effect on work life. Some of our respondents found ways to adapt to the new challenges.

Travel & Holidays Long trips frequently came up as a problem, and many respondents avoid travelling to protect their health.

Shoes Lymphoedema affecting legs and feet can have a particular effect on footwear. Our respondents felt the impact on their style, comfort and their hip pockets.

Clothes & Self-image Lymphoedema can also become a source of anxiety and poor self-image. Many people use clothing to hide their stockings. Some clothes may cause discomfort because of the lymphoedema swelling. Finding clothes that fit different sized limbs can be a problem.



It takes time for me to put the compression stockings on and off. I also need to wash and dry them each day.

Robbie

Daily Life

'I wear disposable gloves for food preparation and am careful with implements – same goes with cleaning and gardening. I never sunbake and always keep antibiotics in the first aid kit. Holidays don't bother me, I make sure I wear garments all the time, but drying them can be difficult sometimes. My friends accept my condition but strangers can be more upfront than I like, but I'm aware that with garments on I look a bit different and I don't always feel at my best.'

Bronwyn

'My treatment experience has been positive, but as I get older bandaging gets harder to put on, and the results aren't as positive as for other people with the condition. I have to do manual work around the house alone and do not have the whole morning to do care, exercise, hydrotherapy, massage as well as property and vegetable garden work. I wouldn't want to move into a home in the city – at least here I can walk, enjoy surroundings and have peace of mind.'

Audrey

'At first it was hard.'

For at least eight years I wore a glove, and this was exceptionally difficult for hygiene. It was very inconvenient for cooking, changing babies' nappies and I was especially conscious of it when handling food for others. I feel the need to wear long sleeves when out because of the constant queries about the sleeve – especially from strangers (often three queries in half an hour). Wearing a compression glove can lead to loss of feeling and if a rubber glove is added over the garment, there is even less feeling and possible accidents can occur, like dropping things or slipping when holding a rail on the steps in a train that may stop suddenly.'

Beth

'I need to have time to do my exercises in the morning and put on my garments. This takes approximately one hour. At night I also exercise. Sometimes I find it extra hard to walk up stairs. Bending and crouching are also difficult.'

Richard

‘Lymphoedema has had an impact on the quality of my life.’

I have to wear a full sleeve and a fingered glove that goes up to my elbow. I find that I cannot find clothes that will go over my arm and compression garment, particularly during bandaging. Cooking, cleaning and gardening are difficult, and I have to remove the glove to attend to these chores. I get upset when I am out shopping and socialising and people ask, “What have you done to your arm?”. I have to be careful of the sun and heat as they cause my arm to get hot and swell.’ **Marie**

‘My lymphoedema is very well managed and controlled and adversely affects me only slightly. If I stand in the one position for any length of time, for example ironing or cooking, I get tightness in my feet and ankles. Stop-start walking, such as in an art gallery, is uncomfortable. I used to love walking along the beach and water’s edge but cannot do so now, due to not being able to go without stockings.’ **Lesley**

‘I have trouble with any job that requires me to squat or be on my knees, etc., like cleaning the shower or finding objects in low cupboards.’ **Janet**

 I am reasonably active for my age. I have made a conscious effort to keep the lymphoedema under control. I use my hands a great deal – I cook a lot, clean when needed, garden, embroider and knit. Lymphoedema has not stopped me doing these things but my arm “tightens up” so I know to leave off and do some massage.’ **Dianne**

‘It prevents gardening, limits travelling, and makes it difficult to walk.’ **Graham**

Helga's Story

'My everyday life is affected 24 hours a day, seven days a week, 365 days a year. There is never a moment when any decision I make isn't governed by my leg.

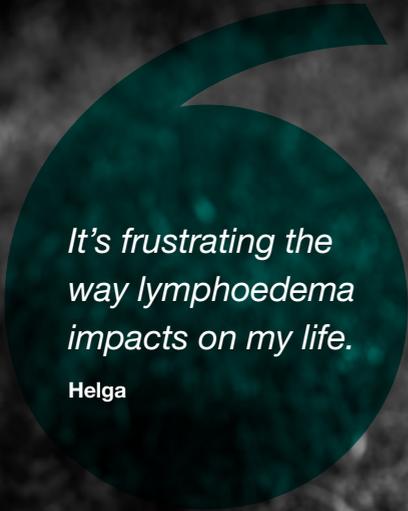
Yes, I am very lucky that I am healthy and well, and I never forget that. My skin is in excellent condition, my general health is excellent and having lymphoedema doesn't prevent me from doing most things. But it does affect my life.

When I was first diagnosed, I regret not knowing earlier that my leg swelling was lymphoedema. If I had treated it sooner and with more respect, then perhaps it might not be as bad. Now as arthritis has started to affect my fingers, it is very painful to put my stockings on. I have been used to just dragging the rotten thing on, but now I am trying to use rubber gloves (pretty useless) and a material aid. I haven't used a metal aid, as I understand they stretch the stocking, which leads to the stocking wearing out faster. I worry about being in my seventies, eighties, nineties. How am I going to be able to put my stocking on then?



In respect to work, I can't have a job where I sit for eight hours, and I can't have a job where I'm on my feet for eight hours. I am lucky that my job means that I am up and down, and moving around for most of the shift. On the rare occasions that I have a "night off", I don't want to go out and do anything.

My leg and I just want to do nothing. So, I do find that my social life is impacted. If there is a dinner organised, visiting friends or family,



It's frustrating the way lymphoedema impacts on my life.

Helga

my heart always sinks, and I think, "Do I have to go? Can't I just do nothing?"

Clothes, I hear you ask? Dresses? Forget it! I could count on one hand, the number of times I've worn a dress in the past few years. Pants cover up both legs, and it's easier to have them covered rather than explain why one leg is bigger than the other. It's not that I am particularly self-conscious about "showing off" my leg, as it's always a good opportunity to explain to anyone who asks why my leg is swollen or

bigger, that I have lymphoedema, and to raise awareness. Going out for a special event? Uh oh ... will I be able to get just one pair of shoes, or will I have to buy two – a different shoe for each foot? So far, joggers and work shoes are okay. I buy shoes to fit my big leg and foot and manage with padded inserts in the other shoe.

Going to the beach? Hmm, what will I do? The options are to swim with my stocking on, and leave it on – soaking wet, sandy and uncomfortable until I get home; or to take it off, have a swim, and then try to drag a stocking on over a wet leg. In the end I conclude: "Nah, don't worry – I'll just sit here on the sand – yes, I'm okay, you go for a swim, I'm happy sitting here ..."

Cleaning, driving, gardening are no problem – I do them all. I never liked cooking and it's a running joke that I don't cook anymore – too much standing. Before, instead of sitting down, resting, relaxing and doing nothing, I'd be up cooking, washing and cleaning. Now my leg and I don't want to! It is frustrating the way lymphoedema impacts on my life, every aspect. At times I hate it. But it is part of me now.'

Pain & Discomfort

'It affects my cleaning because of limited use, tiredness and, sometimes, pain. I'm always aware of hurting the affected arm and hand.' **Lila**

'The garments hurt the crook of my arm whenever I bend it, for example when I apply make-up. My arm aches when doing housework, for example cleaning windows and mirrors. It aches when I am at the gym, so I alternate exercises, for example one upper body, one lower body. My arm goes to sleep easily if I lay on it. It aches regularly after gardening and any activity I do with my arms above my head.'

Bonnie

'My legs feel heavy at the end of the day. Before I started regular treatment, my legs felt like cement blocks at the end of each day. Even now, while it is not as bad, there are days that I still have this feeling. Most exercise is difficult. It's hard to get out to meet new people.'

Maria

Shoes

'Until now shoes were not expensive. But now I may need handmade shoes and I would like assistance to buy better fitting shoes.'

Jenny

'It is difficult to find stylish shoes, so my choices are then limited and boring. Occasionally, I win!' **Mary**

'I couldn't find a decent pair of shoes for my daughter's wedding.'

Richard

'I have to get size 11 or 12, which are hard to find and not very attractive.'

Maria

'I seem to be paying about \$300 per pair.'

I need to be able to fit fairly deep orthotics in them, but I am fortunate that my toes don't swell (only my ankles). I have found two specialist shoe shops to access my shoes.'

Lucy

'I took a flight to Rome, and my symptoms worsened despite staying overnight in Hong Kong. I never slept on either flight. I got up and exercised as much as I could and wore my compression stockings.' **Alison**

'I fear travelling since it is always found to increase the swelling.' **Marie**

'Aeroplane travel is always worrying – I keep the arm elevated and massage regularly on planes.'

Bonnie

'For vehicular travel we need to have many more frequent stops, as sitting exacerbates the swelling.' **Elizabeth**



'Overseas travel and camping trips (outback) have continued. I do, however, pace myself. I also write lots of letters – my arm doesn't like that!' **Dianne**

'At home I was an active mum with three small children. I continued my gym exercise and also was passionate about the outdoors and snow skiing. My part-time job involves under five-year olds, so bending, kneeling and standing for a whole day takes its toll. I will get more swelling and, occasionally, blocked nodes. I need to rest more the following day and elevate the leg. Hence, I always have a day between work days.' **Robyn**

'I try to stay out of the sun at the school where I teach – I am given an indoor sport because I have a letter from a skin specialist.' **Kathleen**



'It's a mild inconvenience as it becomes swollen every day, particularly after physical work – gardening, car washing, rubbish removal or bush regeneration.' **Douglas**

Clothes & Self-image

'In summer, clothes are more of a problem. I never wear sleeveless tops any more. I'm very conscious of trying to choose clothes that will cover the compression garment.' **Denise**

'A lot of people stare or make comments.'

Maria

'As my lymphoedema is very well managed, I have no self-image problems, just frustration from time to time when it's hot or when I'd like to go without stockings to enjoy the beach and sand in my toes!'

Lesley

'Pants are a chore to buy. I hate it, especially as the slim leg is "in". When wanting to stay with fashion, I find I compromise. Stretch fabrics are great. Dark colours too. I don't wear dresses and skirts very much, and not often shorts. I feel self-conscious.' **Robyn**

'I hate it – but I try to forget about it. Whenever I am having a photograph taken, I try to remember to have my left side showing to hide my fat arm. I resent the fact that I will have this condition for the rest of my life. I hate spending a fortune on garments. I hate having to wear long-sleeved clothing, especially in summer, but if I don't, someone always asks, "what have you done to your arm?"'

Bonnie

'I usually wear slacks so people do not see my legs.'

However, my self-consciousness has diminished over the last year.' **Miriam**

'It affects me very much. I try to buy clothes with a looser sleeve, be it long or elbow length. Most summer ladies' clothes have either no sleeves or very short ones. I try to be blasé about my arm but it doesn't always work. I feel embarrassed by it and the attention it receives.' **Marie**

'I make a lot of my clothes. I had to abandon suit jackets when the swelling occurred. It is a problem I have to be aware of when buying ready-mades.' **Kathleen**

'I have had lymphoedema for years so it is hard to remember life without it. Sometimes I am aware how ugly my leg looks but I just get on with it. I realise, particularly in other countries, people focus on my leg whereas, at home, people will often know me for some time before they are even aware of the lymphoedema.' **Mary**

'I do feel emotional about my lymphoedema

and the state of my body – now I'm 75 and not what I used to be. I feel worried that my husband and I will run out of our money and be unable to afford compression garments when I am older – then what will I do? I'm not sure what I'll do when our money runs out. I have been trying to get my physiotherapist to fill in an application for EnableNSW but she told me she would have to give EnableNSW a measurement and quote for the garments. As it takes EnableNSW two to three months to process the applications, the sleeve and gloves may not fit when the approval is given to go ahead with the order – my arm may have gone up or down in that time and then the garments would be useless.' **Marie**

'I buy long-sleeved shirts. Also, for a long time the swelling on my ribs prevented me wearing a bra (for about eight years). Therefore I had to buy oversized shirts to disguise the fact that I had no support. I also have other physical problems that limit my clothes choice, and the result is that I always feel dowdy.'

Beth

'It is a constant reminder that I had breast cancer.' **Marie**

Taking Action

Lymphoedema patients know first-hand the assistance required to improve their quality of life. They recognise that good management reduces acute exacerbations and allows them to maintain a more active and less dependent life. Structured policy and social change in the areas of cost; access to

treatment; and education of the community and health professionals would help to address the inequities felt by people with lymphoedema. These interventions would support lymphoedema patients in living fulfilled, functional lives with greater mobility, less financial burden and reduced stigma.



*I'd recommend
visiting an approved
lymphoedema facility
as soon as you can.*

Annette

Rebates for Garments & Treatment

‘Costs for treatment, including garments and specialist visits, should be claimable under Medicare. I have private health insurance but this does not cover all the costs. I plan to continue having preventative treatment, so ultimately this will be very expensive with monthly visits.’ **Virginia**

‘I would like to see more public lymphoedema clinics, especially for those who have no private health insurance. The garments need to be more accessible to those who can’t afford them.’ **Lucy**

‘Garments should be less expensive. Also, if your condition is stable, then you should be able to order your own garment without the cost of a physiotherapist visit added on.’ **Beth**

More Informed Healthcare Practitioners

‘Doctors need to know a lot more about lymphoedema – where to send us and what to tell us to do. My wife and I fumbled through the first 12 months of this condition before finding the generous care and continuous support needed from my lymphoedema treatment team.’ **Richard**

‘None of us chose to have lymphoedema, but the lack of support – medical, financial, therapeutic – suggests we are to be penalised and that we just don’t matter. I would particularly like to see more doctors, both in general practice and in specialities, become informed about lymphoedema. I think there are many people in the community who are not diagnosed and not treated.’ **Mary**

‘Firstly, we need more information and understanding of the condition, especially among healthcare professionals. Secondly, we need more trained lymphatic massage therapists. Thirdly (but most importantly), we need Medicare rebates on bandages, garments and therapy. It is terribly wrong that poorer people don’t have access to appropriate treatment if they can’t afford it.’ **Denise**

Prevention & Early Detection

‘Lymphoedema patients need access to more therapists trained in proper lymphoedema massage. I also think education should be available for people undertaking surgery or radiotherapy.’ **Alison**

‘I recommend obtaining as much information as you can on your condition. Ask questions and find answers from your doctor and educate yourself. Your family and friends can support you, so ask them to be there.’ **Miriam**

‘I think there should be more awareness raising of the possibility of acquiring lymphoedema before or just after surgery. Cancer and lymphoedema are both life changing and women and men need reminding that there is always the risk of lymphoedema in the short term and even years later. I know a lady who contracted it 19 years after surgery!’ **Marie**

‘More information should be made available to general practitioners as well as more therapists available so people do not have to travel long distances. This information should be relayed to patients so they are aware of the risk of potentially developing lymphoedema after certain procedures. You need to be in control of your body. What I did when I found out I had breast cancer was read all the information I could find, which included lymphoedema. I was aware of it and was able to begin medical treatment promptly and keep up the massaging. Some people refuse to read up on health problems, which delays treatment.’ **Megan**

Better Access to Services

‘Treatment should be automatically accessible to patients – say each six months. This would prevent deterioration of the condition, and probably would require less work to control the swelling, resulting in fewer sessions.’ **Ruth**

‘I would like to see all public hospitals have lymphoedema clinics.’ **Susan**

Summary

Lymphoedema can be a challenging condition to live with, and it impacts on patients' lives in a multitude of ways.

We hope that consumers who are currently living with lymphoedema or those who may be at risk can identify with the stories in this booklet and feel comforted that they are not alone.

We want health professionals to become more highly skilled in recognising early warning signs and symptoms of lymphoedema and to be able to connect their patients with the appropriate services and therapists.

Finally, we hope that the government and health providers will recognise the need for better access to lymphoedema treatment, therapy and garments, and take action to ease the physical and financial burden on patients.

Contacts

- Cancer Action Network, Northern Sydney
c/o Cancer Council NSW, 02 9334 1900
- To find a Cancer Action Network or
Cancer Council office in your local area,
call Cancer Council Helpline 13 11 20.

Websites

- Lymphoedema Support Group NSW
www.lymphoedemasupport.com
A list of support group contacts for regions
in NSW is available on the website.
- Australasian Lymphology Association
www.lymphoedema.org.au

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