

# WORLD LYMPHEDEMA DAY 2020

**An overview with suggestions on how to celebrate and raise awareness on March 6<sup>th</sup> and beyond**

*A collaboration among patient representatives*



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# Associations

Denmark

**DALYFO**  
Dansk Lymfødem Forening

Dansk Lymfødem Forening

Italy



Lymphido

The Netherlands



Nederlands Netwerk voor  
Lymfoedeemen & Lipoedeem

Portugal



Associação Nacional de Doentes  
Linfáticos

Spain



Asociación Galega de Linfedema,  
Lipedema y Patologías Vasculares  
Periféricas

Sweden



Svenska Ödemförbundet

# OUR GOALS for WORLD LYMPHEDEMA DAY



## **Raise awareness with the public**

-about lymphedema, what is it, how to identify it, what to do if you think you have it, direct to more information. What is World Lymphedema Day?

## **Engage clinicians**

-make sure they know what lymphedema is, signs and symptoms of lymphedema, difference between primary and secondary lymphedema, the risk of secondary lymphedema after cancer treatment, direct patients to patient associations and support groups

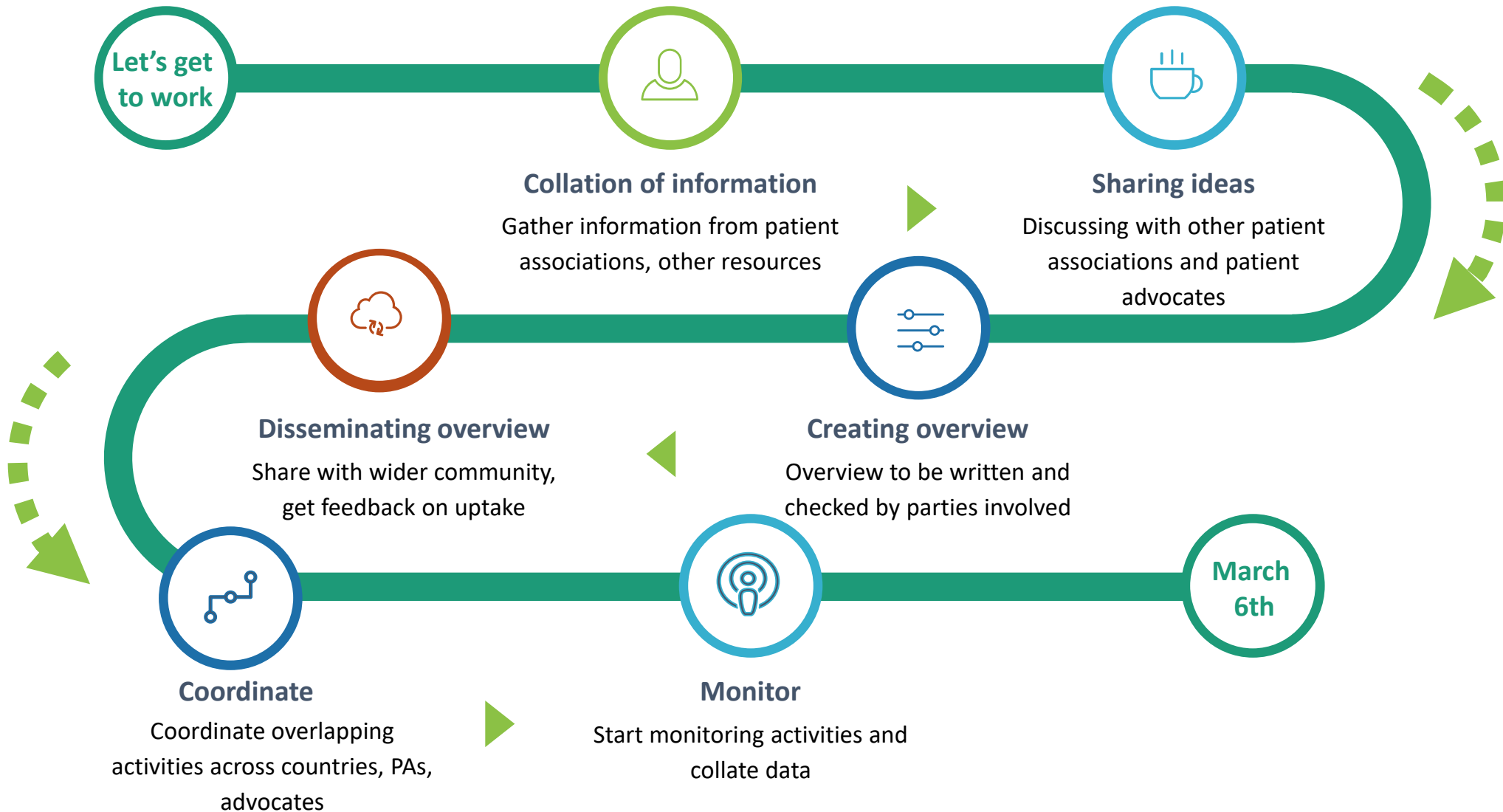
## **Put lymphedema on the radar of politicians**

- make sure politicians realise the scope of the problem, how many patients are affected, know that lymphedema is a chronic condition, the issues surrounding getting a diagnosis and adequate treatment

## **Increase membership**

- make sure patients know about their national patient association and that they understand the power in numbers, the support we can offer and work we are doing to create changes

# ROADMAP to WORLD LYMPHEDEMA DAY



# ACTIVITIES

Online activities include use of social media and landing page. Use assets and locally generated content for shareability



ONLINE

Events organized/supported by clinicians, health care providers and other organisations



EVENTS – HCP/CLINICIANS

Events organized by the patient associations such as seminars, workshops, “drop-ins”, a table in a hospital/clinic, in the street or at other venues relevant to get into contact with the public or with clinicians, flash mobs, catwalks



EVENTS - PA

“Events” organized by the patients such as a walk, lunch, a fundraiser, patient-to-patient meeting or encounter. Using social media to share content or personal testimonial. Start a blog, an Instagram account, public Facebook profile or Twitter.



EVENTS - PATIENTS

# TARGET areas



## Social Media

Use the outlets of the patient associations to spread awareness. Encourage patients to share content from these to ensure data collection and link back to PA



## Website/e-mails

Landing page on PA website to link to in emails – ensure links to other resources national/international. Use PA emailing list to reach members not on social media



## Patients



Patient collaboration – especially patient advocates with big following, board members, those with access to the press. Get them to tell their story. Organize local events.



## Press

Use PR and contacts to reach the wider public. Circulate stories for higher reach

# USE of POPULAR SOCIAL MEDIA



# EXAMPLES of ACTIVITIES



**Association Vivre Mieux le Lymphoedème (AVML) shared Lymphatic Education & Research Network's post**  
Page · 1K like this · Non-profit organisation

21 hrs ·  · Rejoignez LE&RN Le 6 mars est la Journée mondiale du lymphoedème. Depuis ses débuts en 2016, date de sa création officielle à l'Assemblée législative de l'État de New York et au Sénat américain, la Journée mondiale du lymphoedème, le 6 mars, est devenue un...



Watch the video!

  8

2 shares



ONLINE



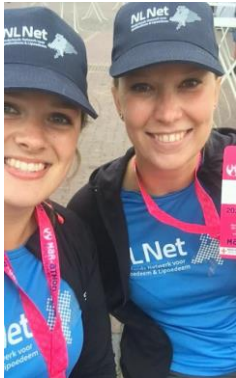
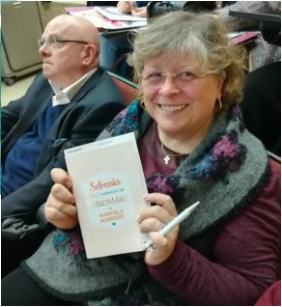
EVENTS – HCP/CLINICIANS



EVENTS - PA



EVENTS - PATIENTS





# ONLINE – PATIENT ASSOCIATIONS

- Create landing page on local patient association website to list ideas for patients and share what patient association is doing to celebrate WLD in local language
- Create event on Facebook page
- Send email to members and direct them to the page, ask them to follow patient association(s) on social media platforms and share the content on public or in private messages to contacts
- Send mail/e-mail to politicians, communities, boards
- Throughout the day or week on social media
  - Post top facts about lymphedema
  - Post testimonials of patients
  - Post information about the difficulty in getting the correct treatment
  - Make sure to tag and use appropriate hashtags
- Link to WHO petition



# ACTIVITIES

- Organise a run/walk
- Set up in local hospital or on streets
  - Table, flyers, registration forms, banner, volunteers to talk
- Support the manifesto (local language), share it and read it in public areas
  - Send to/Invite press, engage a spokesperson or public figure
- Flash mobs or catwalks in public places
- Support publication of articles or dissemination of surveys for research
- Submit abstracts to conferences
- Seminars
  - Inviting patients, clinicians, politicians, public service workers
- Workshops/hands-on/coffee meeting for patients
- Send mail to politicians, communities, boards
- Ask patients to sign WHO petition
- Log your event on the website
  - <https://lymphaticnetwork.org/wld/create/>



EVENTS - PA



Reading the manifesto in Spain



The Netherlands: Photo shot with patients with lymphedema



Italy: Left and right patients with secondary and primary lymphedema. Centre patient with congenital melanocytic nevus



Out on the streets with banners and flyers in Norway

# ACTIVITIES

- Organise a run/walk/coffee morning/lunch among friends and family.
- Bring cake to work and ask co-workers to read a flyer to get one
- Consider raising funds for patient association or ask friends and family to become members to show support
- Start a blog or instagram account about their life as a patient with lymphedema – follow others!
- Share their story on other outlets like LE&RN, in forums like Rareconnect or via the patient associations website or social media accounts
  - <https://lymphaticnetwork.org/living-with-lymphedema/your-stories/>
  - <https://www.rareconnect.org>
- Attend events – get out and meet other patients
- Visit local hospitals and GP practices and hand out flyers
- Volunteer skills and time to the patient association
- Wear blue, a teal/blue ribbon, a specially made t-shirt
- Create business cards with your instahandle or other social media profile
- #flauntyourcompression – show the world your compression and remember to use hashtags
- Decorate your profile pictures with a twibbon. <https://twibbon.com/Support/world-lymphedema-day>
- Sign the petition
  - <https://www.change.org/p/world-health-organization-who-designate-ld-awareness-cures-as-the-world-health-day-campaign-for-who>



EVENTS - PATIENTS



# SOCIAL MEDIA

## What can the patients do online?



### Facebook personal profile

- Add profile frame
- Change profile picture/cover picture
- Write a personal testimonial
- Share content from patient associations



### Twitter & YouTube

- Write post
- Share content



### Patients groups and forums



- Patients should be encouraged to share their tips on how to manage their lymphedema, living with lymphedema
- Answer questions, encourage other patients
- Invite other patients to the patient groups
- Join Rareconnect (for primary patients)



### Instagram

- If patient has a profile dedicated to lymphedema then share testimonial, content and other patient stories
- If patient has non-lymphedema related profile consider to add a post on March 6
- A patient can consider to create their own Instagram profile sharing their life with lymphedema



**PATIENT  
engagement**

# HASHTAGS



## International

#worldlymphedemaday, #wld2020, #lymphedema  
#lymphoedema #lymphedemaawareness  
#nevergiveup #flauntyourcompression #rockthesock  
#primarylymphedema #secondarylymphedema

## National

Local language words for lymphedema, local  
language words for lymphedema day or world  
lymphedema day etc. Check other patients use of  
commonly used hashtags in your country

## Tagging

Don't forget to tag associations, organisations,  
clinicians and companies, tag each other

## Share

Make sure content can be shared in public

# Clinicians and Researchers

How to engage them?



## Patients

- Ask to leave flyers/leaflets/factsheet in the GP practice
- Make sure you discuss your lymphedema at the visit...even just to say all is well – make sure they remember how it looks!
- Take the time to speak to the receptionist and nurse practitioner – use a leaflet to start the conversation and explain why you have lymphedema. Tell them to refer patients to the patient associations or Facebook patient groups – help a fellow patient

## Patient associations

- Email contacts about your activities for WLD and ask for their support in sharing and celebrating the day
- Tag organisations/societies/key opinion leaders on posts on social media
- Make sure they know you as a patient association so they can refer patients to you
- Support research and dissemination of surveys

# ASSETS

The national and international websites are packed with information which can be shared and used.



**WEBSITES**

Factsheets are available and could be translated into local language for easier usage



**FACT SHEETS**

We lack press release material to copy and translate in local language



**PRESS MATERIAL**

Many excellent videos are already available on YouTube or websites.



**VISUAL CONTENT**

# ASSETS- WEBSITES

English language



WEBSITES

Organisation/Association (English)	Web address
LE&RN	<a href="https://lymphaticnetwork.org/">https://lymphaticnetwork.org/</a>
LE&RN WLD	<a href="https://lymphaticnetwork.org/wld/get-involved/">https://lymphaticnetwork.org/wld/get-involved/</a>
Canadian Lymphedema Framework	<a href="https://canadalymph.ca/">https://canadalymph.ca/</a>
International Lymphoedema Framework	<a href="https://www.lympho.org/">https://www.lympho.org/</a>
Lymphoedema Support Network	<a href="https://www.lymphoedema.org/">https://www.lymphoedema.org/</a>
Lymphoedema Ireland	<a href="https://www.lymphireland.com/">https://www.lymphireland.com/</a>
L-W-O	<a href="https://lymph-what-oedema.com/">https://lymph-what-oedema.com/</a>
Macmillan	<a href="https://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/lymphoedema">https://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/lymphoedema</a>



# ASSETS- WEBSITES

Local language

Patient Association	Language	Web address
andLINFA	Portuguese	<a href="http://www.andlinfa.pt">www.andlinfa.pt</a>
AGL	Spanish	<a href="http://www.linfedemagalicia.com">www.linfedemagalicia.com</a>
AVML	French	<a href="http://www.avml.fr">www.avml.fr</a>
DALYFO	Danish	<a href="http://www.dalyfo.dk">www.dalyfo.dk</a>
KIF11	German	<a href="http://www.kif11kids.com">www.kif11kids.com</a>
Lymphido	Italian	<a href="http://www.lymphido.it">www.lymphido.it</a>
NINet	Dutch	<a href="http://www.nlnet.nl">www.nlnet.nl</a>
NLF	Norwegian	<a href="http://www.nllf.no">www.nllf.no</a>
SOF	Swedish	<a href="http://www.svenskaodemforbundet.se">www.svenskaodemforbundet.se</a>

*Your own local language resources!*

Web address



WEBSITES

# ASSETS- VISUAL CONTENT

Video	Link
Lymphedema from a child's perspective	<a href="https://youtu.be/CrzyAaj655U">https://youtu.be/CrzyAaj655U</a>
An Overview of Pediatric and Primary Lymphedema	<a href="https://youtu.be/zcYSmxX_RPc">https://youtu.be/zcYSmxX_RPc</a>
My lymphedema in a few words	<a href="https://youtu.be/lf75ueX-2aI">https://youtu.be/lf75ueX-2aI</a>
The lymphatic system and lymphedema: how it works	<a href="https://youtu.be/HEiW0bE2OwI">https://youtu.be/HEiW0bE2OwI</a>
LE&RN WLD 2020	<a href="https://youtu.be/PMZw0N9p2Nk">https://youtu.be/PMZw0N9p2Nk</a>
You are never alone – Lymphedema and Lipedema Community message	<a href="https://youtu.be/zRWfViRp6dY">https://youtu.be/zRWfViRp6dY</a>
What is lymphoedema (with Denise Hardy)	<a href="https://youtu.be/6nzvPEqLn8E">https://youtu.be/6nzvPEqLn8E</a>
A collection of patient stories with challenges and top tips	<a href="https://www.youtube.com/playlist?list=PLekVty32TyUms2d2rWi4WejrgbdB7Rk6w">https://www.youtube.com/playlist?list=PLekVty32TyUms2d2rWi4WejrgbdB7Rk6w</a>
What is Lymphoedema	<a href="https://vimeopro.com/ehdm/ltn-18/video/299859108">https://vimeopro.com/ehdm/ltn-18/video/299859108</a>

*Your own local language resources!*

Link



**VISUAL CONTENT**

# ASSETS- PRESS RELEASE MATERIAL




PRESS MATERIAL

- There is not much easy to use or copy press release material available
  - An example from Sweden
    - <https://www.svenskaodemforbundet.se/wp-content/uploads/2019/03/PM-Världsdagen-för-lymfödem-Pressmeddelande-2019-1.pdf>
  - LE&RN website
    - <https://lymphaticnetwork.org/news-events/category/press>



Please share what you do with other patient associations



## FACT SHEETS



Fact Sheet	Website
Do's and Don'ts Fact Sheet for clinicians	<a href="http://www.vascern.eu">www.vascern.eu</a>
Teenage Lymphoedema, Early Childhood Lymphoedema	<a href="http://www.lymphoedema.org">www.lymphoedema.org</a>
10 Things....a range of Fact Sheets	<a href="https://lymphaticnetwork.org/resource-downloads">https://lymphaticnetwork.org/resource-downloads</a>
Swelling – Lymphoedema	<a href="https://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/lymphoedema">https://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/lymphoedema</a>

lymphaticnetwork.org. Card 03: How Do I Stop LE From Getting Worse? A CLT will design a treatment program which includes education, reduction in swelling (bandaging, massage, special exercises), and prescription of compression garments/tubing. If required to help you manage your LE. See a CLT every six to twelve months to make sure you are doing everything you can to stay healthy and to learn new ways to manage your disease. Card 04: Are There Support Groups for LE? Facebook has several LE support groups. LANA sponsors an online support group on [www.facebook.com/LREN](\"http://www.facebook.com/LREN\") provides a service, 'Ask the Experts,' so you can contact physicians and therapists directly. Your CLT is likely to know about support groups in your area. Card 05: Why Did LE Happen to Me? Everyone has a lymphatic system—some people have a system that is more prone to developing LE. LE can be triggered by cancer treatment, lymph node removal during surgery, trauma or infection (bacterial lymphedema), or you can be born with an imperfect lymphatic system (primary lymphedema). Card 06: What Are the Dos and Don'ts of LE? Do: Be normally, but take some extra precautions to stay to managing your LE. Avoid activities that can risk of infection such as extreme heat (hot tubs, hot showers, saunas, avoid really hot or steamy environments). Look after your skin, and seek medical advice for infection, such as cellulitis, in the LE limb(s). Card 07: What Are the Symptoms of Cellulitis? 'Symptoms of cellulitis include flu-like feelings, fever, and joint aches. Cellulitis causes immediate damage lymphatic system—early treatment is essential. Seek immediately even if you're not sure it's cellulitis.' Card 08: Are There Special Diets, Lotions or Medicines? While a dietitian you have specific questions about you. Ask your CLT about skin care as many lotions can dry your skin. Find something that works for you, it may not work for you but information sharing is a good thing. Just find what works for you. Card 09: Can LE Be Cured? There is no known cure for LE at present. Surgical approaches available, but not everyone is a suitable candidate for surgery. Drug trials are underway to find medication to improve the function of lymphatic vessels. In the meantime, practice vigilant LE care—prevent and nourish your skin, avoid infections, wear compression, and exercise regularly. Card 10: How Can I Learn More About LE? Physicians and healthcare practitioners often have little training in diagnosing and treating LE. Seek out trusted sources for information on the Internet. LREN ([www.lymphaticnetwork.org](\"http://www.lymphaticnetwork.org\")) has many LE educational programs and links to a variety of resource organizations. NIA Qeiosmatters4all has position papers on key issues affecting people with LE. LE is different for each individual. Check with your CLT about what might work for you."/>

**01**

### WHAT IS LYMPHEDEMA (LE)?

Lymphedema is chronic swelling, most commonly in arms or legs, that can affect other areas of the body, such as the trunk, head, or neck. Lymph can be very serious as the affected area can increase in size over time if the swelling is not controlled, and you are more susceptible to infections. Lymphedema often drains, weeps products from your tissues, trapped lymph fluid is not healthy fluid.

**02**

### HOW DO I TREAT LE?

Find a Certified Lymphatic Therapist (CLT) to help you with a management program. The Lymphedema Association of North America (LANA) has a network of CLTs who are dedicated to supporting people with LE. The Lymphatic Research and Education Network (LREN) provides a link to "Find a Lymphedema Therapist" on its website [lymphaticnetwork.org](http://lymphaticnetwork.org).

**03**

### HOW DO I STOP LE FROM GETTING WORSE?

A CLT will design a treatment program which includes education, reduction in swelling (bandaging, massage, special exercises), and prescription of compression garments/tubing. If required to help you manage your LE. See a CLT every six to twelve months to make sure you are doing everything you can to stay healthy and to learn new ways to manage your disease.

**04**

### ARE THERE SUPPORT GROUPS FOR LE?

Facebook has several LE support groups. LANA sponsors an online support group on [www.facebook.com/LREN](http://www.facebook.com/LREN) provides a service, "Ask the Experts," so you can contact physicians and therapists directly. Your CLT is likely to know about support groups in your area.

**05**

### WHY DID LE HAPPEN TO ME?

Everyone has a lymphatic system—some people have a system that is more prone to developing LE. LE can be triggered by cancer treatment, lymph node removal during surgery, trauma or infection (bacterial lymphedema), or you can be born with an imperfect lymphatic system (primary lymphedema).

**06**

### WHAT ARE THE DOS AND DON'TS OF LE?

Do: Be normally, but take some extra precautions to stay to managing your LE. Avoid activities that can risk of infection such as extreme heat (hot tubs, hot showers, saunas, avoid really hot or steamy environments). Look after your skin, and seek medical advice for infection, such as cellulitis, in the LE limb(s).

**07**

### WHAT ARE THE SYMPTOMS OF CELLULITIS?

"Symptoms of cellulitis include flu-like feelings, fever, and joint aches. Cellulitis causes immediate damage lymphatic system—early treatment is essential. Seek immediately even if you're not sure it's cellulitis."

**08**

### ARE THERE SPECIAL DIETS, LOTIONS OR MEDICINES?

While a dietitian you have specific questions about you. Ask your CLT about skin care as many lotions can dry your skin. Find something that works for you, it may not work for you but information sharing is a good thing. Just find what works for you.

**09**

### CAN LE BE CURED?

There is no known cure for LE at present. Surgical approaches available, but not everyone is a suitable candidate for surgery. Drug trials are underway to find medication to improve the function of lymphatic vessels. In the meantime, practice vigilant LE care—prevent and nourish your skin, avoid infections, wear compression, and exercise regularly.

**10**

### HOW CAN I LEARN MORE ABOUT LE?

Physicians and healthcare practitioners often have little training in diagnosing and treating LE. Seek out trusted sources for information on the Internet. LREN ([www.lymphaticnetwork.org](http://www.lymphaticnetwork.org)) has many LE educational programs and links to a variety of resource organizations. NIA Qeiosmatters4all has position papers on key issues affecting people with LE. LE is different for each individual. Check with your CLT about what might work for you.

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 **Lymphatic Education  
& Research Network**  
LE&RN is a 501(c)(3) nonprofit organization located at 261 Madison Avenue,  
9th Floor, New York, NY 10016. For more information: [www.lymphaticNetwork.org](http://www.lymphaticNetwork.org)

**10ThingsLE**  
For more information: [www.10ThingsLE.info](http://www.10ThingsLE.info)

# DATA which can be COLLECTED



## GOALS

#patients, clinicians, public reached  
#of new members in your association



## AWARENESS

#PR uptake, press attendance at event



## EMAILS/WLD LANDING PAGE

#emails send to members, clinicians,  
public sector, politicians.  
#visits to landing page



## COST

Cost for events, gadgets, flyers, etc.



## ACTIVITIES

#volunteers engaged in supporting  
the work of the patient associations.  
#activities done, #attendance



## SOCIAL MEDIA

#posts/content shared, likes, shares,  
comments, visits, click-throughs, new  
followers, downloads, tags, testimonials

# THANK YOU



We hope you liked our suggestions and ideas. Please share with us what you do so we can exchange best practice across Europe.

We wish you all the best for a successful  
World Lymphedema Day!