2023 - World Lymphoedema Day (WLD) &

Lymphoedema Awareness Week (LAW) Campaign

World Lymphoedema Day is an annual advocate-driven celebration, which takes place on March 6, 2023. Lymphoedema Awareness Week runs from 6th-11th March 2023.

LINKS

Video Audio

In 2023, the PhysioPod UK and LWO Community Campaign focusses on the importance of Self/Simple Lymphatic Drainage (SLD) in Lymphoedema Management and the importance of the patient voice.

We are also linking World Lymphoedema Day with International Women's Day which falls on the 8th March 2023, to celebrate all the Lymphoedema Therapists doing a wonderful job according to their patients.



N.B. Survey Limitations

38 Lymphoedema patients and 13 Lymphoedema practitioners completed the survey.

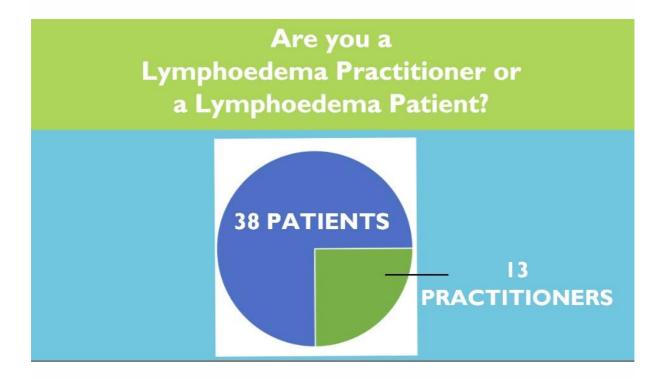
We feel this survey is therefore a good representation of the patient group but limiting with regards to the number of practitioners that engaged.

SURVEY QUESTIONS - Simple/Self Lymphatic Drainage (SLD) in Lymphoedema Management

Results of Survey One which was shared across social media







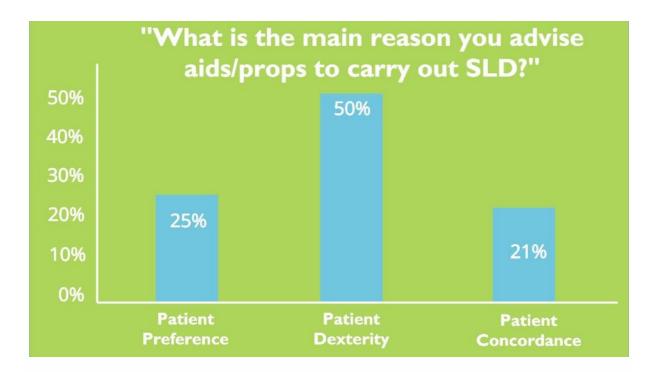
"Did your MLD School teach you SLD for patient self maintenance?"



Do you teach your patients to carry out SLD?

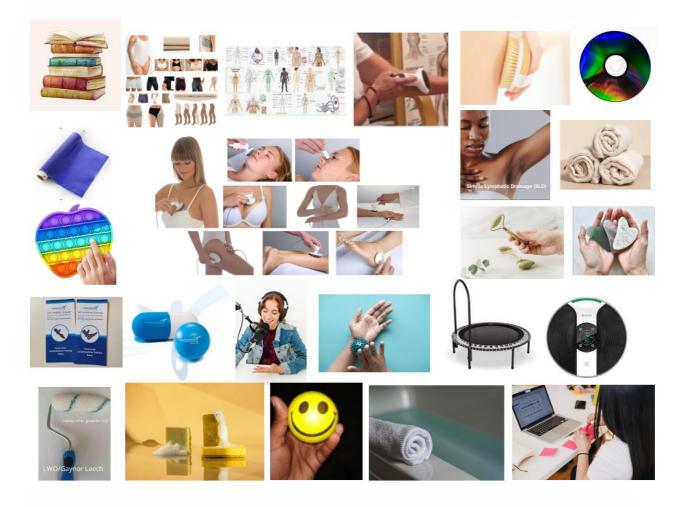


100% YES

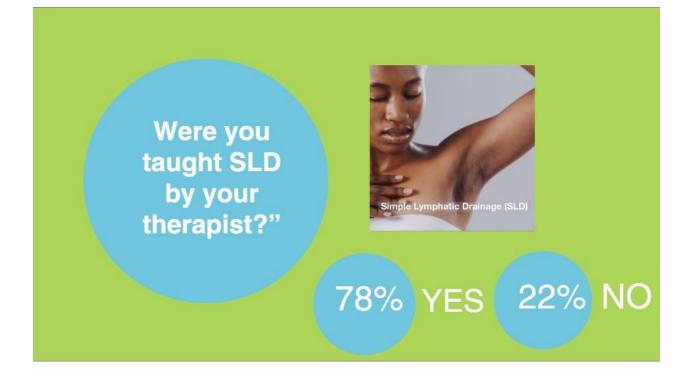


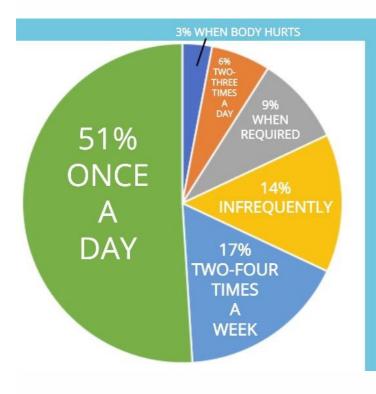
All Lymphoedema Practitioners who completed the survey felt that SLD was as effective as MLD

What aids/props do you recommend/use?



Books, compression, Deep Oscillation®, diagrams, dry brushing, DVDs, Dycem Roll®, fidget poppers, flannel (rolled), gua sha, hands, handheld electric massager, jade roller, leaflets, Lymph Ball®, podcasts, prickly massage ball, rebounder, Revitive®, roller, sponge, stress ball, tea towel (rolled for groin) YouTube tutorials.





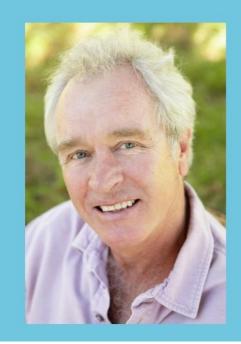
How often do you carry out SLD?

Patient Comments

How often do you carry out SLD?



"Initially it was up to twice a day. Now, 3 years after lymphoedema diagnosis, it's about twice a week - I am able to manage it mainly through lifestyle techniques "

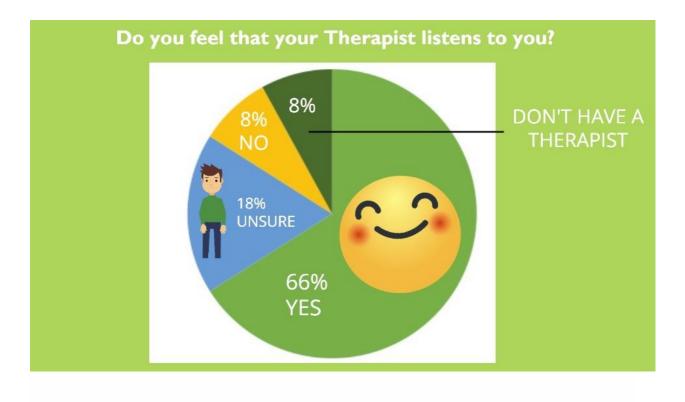


How often do you carry out SLD?

"When I remember or if my lymph nodes are aching, as in my own experience, I personally don't think it makes all that much difference"







Additional Patient responses: Do you feel your therapist listens to you?



"Yes and takes onboard what I say"

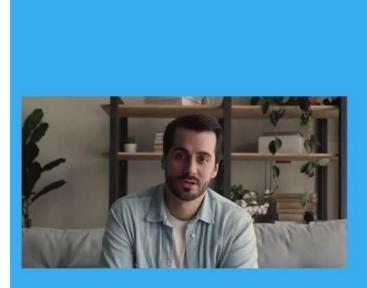


"No, and I think sometimes they just want you to go back so they get money.

No interest in really making the person better "



"No, as I don't see them anymore due to cuts in the services."



"Yes, but there isn't enough time to address all my needs in one appointment. I have to save up concerns until the next appointment, 6 months later. I wanted to get private care to top up my NHS care.

One of my NHS clinics said they would stop seeing me if I got private care. Recently, I enquired about private care but I was informed there was a year waiting list!"



"I don't have a therapist.

Had several lymphoedema nurses over the years and only one has performed MLD.

I purchased a dvd from LSN for how to do SLD"

NB LSN SLD DVDs are no longer available, these have been replaced with the following LSN SLD Tutorials:

Self lymphatic drainage (SLD) for the head, face and neck

Self Lymphatic Drainage (SLD) for the breast or chest wall

Self Lymphatic drainage (SLD) for the arm

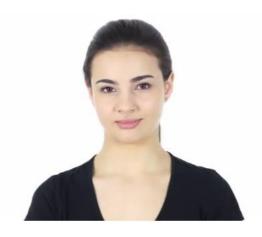
Self Lymphatic drainage (SLD) for the leg



"Yes - she has been excellent, including explaining the what and why of the treatment, as well as giving very helpful advice and practical tips"



"Absolutely, she is amazing"



"They don't have time for anything but measuring for sleeves"



"I don't have a therapist now.

Since the pandemic she retired and I don't want to go to a male therapist.

Also, it is very expensive"



"Absolutely. I have deep oscillation for MLD which is done by my therapist, I would be lost without her support, both emotionally and most importantly, physically, and for introducing me to new up-to-date techniques.

I have had other treatments but the best treatment so far though, has been with regularly using a deep oscillation machine.



... This has totally altered the shape of my leg, and has really softened it, after twenty seven years of being on a constant merry-go-round of bandaging and trialling any sort of new techniques, with very little permanent difference, because it just rebounded.

I pay privately to have the treatment approximately every three weeks and I firmly believe that this is what has made the most difference to my well-established lymphoedema.

PhysioPod and LWO Community WLD2023 Campaign Survey

World Lymphoedema Day - an annual advocate-driven celebration,

March 6th 2023

In 2021, our campaign featured video support messages from the healthcare community and covered many topics with simple, easy-to-digest, information, graphics and videos, including:

- the lymphatic system and primary and secondary lymphoedema,
- lowering lymphoedema risk, signs and symptoms.
- Newly diagnosed, self-care tips, hydration, compression and compression pumps
- Deep Oscillation, electrostatic lymph drainage the LWO Community and lymphoedema and #GetMoving.

In 2022, our detailed campaign lymphoedema from top-totoe included self-care tips from UK Lymphoedema experts Christine Talbot, head and neck Lymphoedema, Sue Hansard, breast/axilla/chest wall Lymphoedema. Jane Wigg, arm lymphoedema, Dr. Rhian Noble-Jones, genital lymphoedema, Catherine Groom leg lymphoedema. In 2023, we focus on the importance of SLD in lymphoedema management and the importance of the patient voice.

Results of survey one which was shared across social media simple/self-lymphatic drainage

in lymphoedema management

<u>MailChimp survey design by Sue Hansard of First Lymph</u> <u>Care, Gaynor Leech of LWO Community</u>

and Mary Fickling of PhysioPod UK.

Are you a Lymphoedema practitioner or a Lymphoedema patient?

38 patients and 13 practitioners completed the survey.

Did your MLD school teach you SLD for patient selfmaintenance?

100% Yes.

Do you teach your patients to carry out SLD?

100% Yes.

What is the main reason you advise aids/props to carry out SLD?

- 31% patient preference
- 54% patient dexterity
- 15% patient concordance

All lymphoedema practitioners who completed the survey felt that SLD was as effective as MLD.

A to Z props/aids used:

- Books
- Compression
- Deep Oscillation
- Diagrams
- Dry brushing
- DVDs
- Dycem
- Fidget poppers
- Flannel
- Gua Sha
- Hands
- Handheld electric massager
- Jade roller
- Leaflets
- Lymph Ball
- Podcasts
- Prickly massage ball
- Rebounder
- Revitive
- Roller

- Sponge
- Stress ball
- Tea towel rolled for groin
- YouTube SLD tutorials

Were you taught SLD by your therapist?

- 78% Yes
- 22% No

How often do you carry out SLD?

- 3% when body hurts
- 6% 2 to 3 times a day
- 9% when required
- 14% infrequently
- 17% 2 to 4 times a week
- 51% once a day

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Initially, it was up to twice a day now three years after lymphoedema diagnosis, it's about twice a week. I am able to manage it mainly through lifestyle techniques.

How often do you carry out SLD?

When I remember or if my lymph node are aching as in my own experience, I personally don't think it makes all that much difference.

Do you use Deep Oscillation Therapy for SLD?

- 35% Yes
- 43% No
- 10% never heard of it
- 46% of therapists use

Has your therapist completed an holistic needs assessment that any of your appointments?

- 62% Yes
- 38% No

Do you feel that your therapist listens to you?

- 8% Don't have a therapist
- 8% No
- 18% unsure
- 66% Yes

The following are patient responses to the question:

Do you feel your therapist listens to you?

"Yes and takes on board what I say"

"No, and I think sometimes they just want you to go back so they get money. No interest in really making the person better."

"No, as I don't see them anymore due to cuts in the services"

"Yes, but there isn't enough time to address all my needs in one appointment"

"No, as I don't see them anymore due to cuts in the services"

"Yes, but there isn't enough time to address all my needs in one appointment. I have to save up concerns until the next appointment six months later. I wanted to get private care to top up my NHS care. One of my NHS clinics said they would stop seeing me if I got private care recently. I inquired about private care, but I was informed there was a year waiting list"

"I don't have a therapist had several lymphoedema nurses over the years and only one has performed MLD. I purchased a DVD from LSN for how to do SLD"

"Yes, she has been excellent including explaining the what and why of the treatment, as well as giving very helpful advice and practical tips" "Absolutely. She is amazing"

"They don't have time for anything but measuring for sleeves"

"I don't have a therapist now since the pandemic she retired and I don't want to go to a male therapist. Also, it is very expensive"

"Absolutely. I have deep oscillation for MLD which is done by my therapist. I would be lost without her support both emotionally and most importantly, physically and for introducing me to new up-to-date techniques. I have had other treatments, but the best treatment so far though has been with regularly using a deep oscillation machine. This has totally altered the shape of my leg and has really softened it after 27 years of being on the constant merrygo-round of bandaging and trialling any sort of new techniques with very little permanent difference because it just rebounded. I pay privately to have the treatment approximately every three weeks and I firmly believe that this is what has made the most difference to my wellestablished lymphoedema"

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Thank you for reading and watching and please do join us on Wednesday, March 8th, International Women's Day where we showcase some pretty special lymphoedema therapists as nominated by their patients.



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