*Genital Lymphoedema

* Rhian Noble-Jones, PhD, PgD (PT), MCSP
* Shelley Smith DiCecco, PT, PhD, CLT-LANA
Rhian’s History

Dr Rhian Noble-Jones, a physiotherapist who has been working with lymphoedema patients for 25 years now. I’m national lymphoedema research specialist in Wales, UK, and a lecturer at university of Glasgow, Scotland. I’m on the scientific committee of the British Lymphology Society and part of Casley-Smith International Lymphoedema Instructors.

* Started researching genital lymphedema topic 9 years ago
* The self report tool for men took 2 years to develop with patients and professionals
* Further research found the tool helped by providing a voice for the patient but health prof still not confident enough to bring up the subject and then to treat.
* So I’m now working with Dr DiCecco and others internationally find out what education lymph professionals need.
*Dr Shelley Smith DiCecco, a physical therapist in the US who has been working with lymphoedema patients for almost 20 years now. I am also a pelvic floor PT and due to this, I specialize in genital lymphedema.

*I am an assistant professor with PCOM in the PT department and am working on lymph node cadaver research at the school.

*I am part of Casley-Smith International Lymphoedema Instructors and own LymphEd - a lymphedema educational company; including an advanced course for lymphedema professionals on evaluation and treatment of genital lymphedema.

*My dissertation involved research on females with genital lymphedema and new treatment techniques to improve quality of life and reduction of symptoms.
Genital Lymphedema

* The true incidence of genital lymphedema has not been studied in depth for an accurate number.

* Males- can involve the scrotum and/or penis

* Females- can involve internal and/or external genitals

* Can occur in individuals from infant to adult
*Causes*

*Primary:* The person is born with an underlying cause or dysfunction, such as Noonans & Milroy’s

*Secondary:* The person acquires the dysfunction

- Filariasis; Lower abdomen/genital surgeries; Obesity; Trauma; Hormone therapy; Pregnancy; Long distance cyclists; Repeated infections; Endometriosis-male & female; Digestive disorders; and many others.
Possible Symptoms

* Pain: dragging, bursting, achy, stabbing, pressure, or heavy sensations
* Edema: entire or portion of genitals
* Bowel/Bladder dysfunction: any leakage of bowel/bladder and/or constipation
* Sexual dysfunction- to include impotency, pain with erections, decreased libido, and/or pain with/post intercourse
* Frequent infections: UTIs, yeast, bacterial, viral, etc
* So, as a patient, you need to speak up about any of these symptoms with all of your health care providers, especially your lymphedema professional.
* You also need to ask your lymphedema professional about his/her experience with treating genital involvement, for not all are confident in this area. Children especially need a therapist also experienced in the pediatric population.
Treatment may involve...

* The lymph professional needs to fully evaluate the genitals and trunk and make accurate records

* Manual Lymphatic Drainage (MLD) is vital to the trunk and genitals- no one specific technique for the genitals. Training is available for lymph professionals.

* Compression- needs to compress AND support the genitals. May take time and multiple attempts to find the perfect garments- must be in some form 23 hours a day. These may need to be custom made - the main deciding factor is the fit of the garment.

* Exercises often need to involve the pelvic floor muscles and other trunk muscles (glutes, abdominals, hips, back)

* Skin care- check daily, watch moisture/lotion, clean frequently

* The personalized home program of these 4 aspects are vital and need to be done daily!
**Other treatment options**

* Pumps - only to be used if the main 4 components are being implemented daily... or may contribute to worsening of the involvement.

* Surgery - may be required for some individuals - your lymph professional should help navigate this route. Even if surgery is suggested, the person must continue with the 4 components of a home program for prolonged success.

* Taping - can be useful, especially on the trunk portion. It is not recommended on the actual genitals due to skin breakdown and infection risks.

* Additional padding may assist with compression to move fluid in desired directions, soften hard tissue, and/or provide additional support.
Sexuality with Lymphedema

• Decline in sexuality
  * Decreased libido
  * Decreased sexual response or feeling
  * Psychological for both person and his/her partner
  * Difficulty from symptoms of lymphedema

• Methods to improve intimacy
  * Use it or loose it- increased sexual activity will increase libido (self or with partner)
  * Psychological- may need to speak with a professional
  * Lubrication- see handout
  * Positions and techniques that do not cause pain or increased friction. Try to avoid dependent positions of the swollen genitals
  * Hygiene- clean participants prior and post to reduce infections
    * Urinate post to also reduce infections
  * Use proper barrier if infection or open areas are present
*Other Answers to questions....

* Papillomas- should reduce with proper compression and MLD.

* The emotional impact or stigma with this can be significant- speak with your lymph professional about this to help identify ways to reduce this stress. Can involve changing type of outer clothing, education to school children/friends, counseling, group support with others in similar situations.... Don’t just hide it.

* To reduce cellulitis- hygiene and compliance with the 4 components of the home program is key. Some may be more prone due to other factors- and this should be discussed with a knowledgeable lymph professionals. It is recommended to also seek a dermatologist.
*Other Answers to questions....*

*Pregnancy can increase genital lymphedema. Compression will need to be adapted to address the changing body. The swelling will not hinder the delivery; yet, can impact healing post. Your entire medical team involving the pregnancy need to be aware of your lymphedema and may need to speak to your lymph professional for guidance. Need to really address hygiene and skin care*

*The best way to prevent progression and to have the best outcomes with reduction in your swelling is really compliance with the 4 components of your home program daily!!! Also, addressing any changes sooner rather than later with your health team.*
**Final Thoughts....**

* Remember you are part of your healthcare team and you must speak up about your concerns, symptoms, emotional impact, and any changes in your status!

* If you feel your concerns or comments are not being properly addressed, your health team may need to broaden to include a pelvic floor specialist, a dermatologist, pediatrician, psychologist, or sex therapist.

* Please feel free to contact us for any concerns or questions:
  * Dr. Rhian Noble-Jones: rhian.noble-jones@wales.nhs.uk
  * Dr. Shelley Smith DiCecco: shelleydicecco@LymphEd.com

* Thank you again to Lymphie Strong!