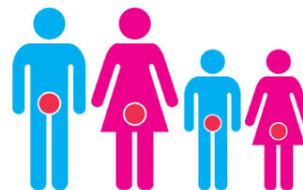


The Association for

Lichen Sclerosus & Vulval Health



LICHEN SCLEROSUS MANIFESTO

Association for Lichen Sclerosus and Vulval Health Date of birth 1994

For the purpose of this Manifesto the Association for Lichen Sclerosus and Vulval Health is abbreviated to ALSVH. World Health Organisation is abbreviated to WHO. Lichen Sclerosus is abbreviated to LS.

WE BELIEVE that men, women and children diagnosed with lichen sclerosus should always be treated by educated, knowledgeable and specialist doctors, who can prove competency by showing a genuine dedicated interest in learning more and keeping their skills up to date by attendance at learning conferences at least every three years. ***(See note below.)

WE BELIEVE that all governments in every nation should instigate education about lichen sclerosus in all medical schools under the obligations and directions of the World Health Organisation (WHO) Right to Health. Education must include recognition of dignity and diversity, must remove health inequality and be gender inclusive.

WE BELIEVE that every person must be given information sufficient to their treatment and care to avoid the destructive process of lichen sclerosus and any subsequent progression to cancer or to loss of sexual function in accordance with the directions and obligations for the Right to Sexual Health defined by the WHO.

Background

Lichen sclerosus (LS) is a chronic, incurable, progressive, destructive inflammatory skin disease of unknown and unproven origin. Men, women and children are affected at any age. First reported in 1887. Real research and randomised clinical trials are limited. Studies display a confusing picture of how this disease can be treated and lived with. It is a Local Community, National and Global concern. Lichen Sclerosus is a Life Sentence.

LS is NOT a sexually transmitted disease. Symptoms range from chronic, intractable itch, soreness, skin fissures, white areas of skin, skin thickening, skin thinning, narrowing of the vaginal opening in women, with clitoral phimosis and phimosis of the foreskin in men. Difficulty in urinating. Symptoms may lead to painful intercourse or inability to engage in intercourse in both men and women.

Impact of Quality of Life in young females

Care by a vulval dermatologist with regular follow up is essential.

Delayed diagnosis and treatment can lead to a child growing up with disfigurement and distorted genitalia, which may include total loss of inner labia and clitoral phimosis when the clitoris hood fuses onto the glans, thus obliterating sensation and for many orgasm is impossible. In untreated cases the inner labia fuse over the urethra making urination a painful problem. Severe psychological and emotional issues occur. On reaching adulthood, dating and social interaction is avoided by many. Those who attempt relationships are often rejected by partners.

**I had this LS thing since being five years old. My mum was afraid to use the steroids and so I grew up with no labia and a clitoris that does not work. Often the itch made me cry and it was sore when I went to the toilet. It was hard to go to school and sit in discomfort all day and doing PE too. My mum just kept putting me on zinc and castor oil cream and that sometimes burned my skin. I am now 21 and I do not date. I do not see my mum now. It destroyed my family. I cannot even talk to a psychosexual doctor because I become so angry and upset that I have to walk away. Why doesn't someone do something to help?*

**My little girl is 9. I finally found ALSVH and got help from them to find a doctor to treat my daughter. I fear for her future. There is no information out there for parents. Why are children so ignored?*

**My daughter was seen by a paediatric dermatologist who told me that if I treated my daughter with steroids she would grow up with deformed genitals. I now know this advice was untrue and completely the reverse. When will someone take responsibility for helping us parents with little children? We want good information for the best possible care.*

Impact of Quality of Life for men and small boys

For men, there is even less information. They suffer the indignation of having to live with a condition that has been widely promoted as a post-menopausal woman's condition. If not diagnosed and treated early, penile phimosis becomes a problem and at a later stage, they may develop difficulty with urination. In the UK at this time, while potent topical steroid ointments are the treatment of choice, the current medical view is that circumcision is the way forward. Many are not keen to take this advice and wish to preserve their foreskin. They suffer body image difficulties regarding this.

**I saw a dermatologist for my penis. I was not given information about how to use the creams or any advice about washing in emollients. I had to have a circumcision due to lack of care. I feel very sad about it and feel I have been let down by doctors. My dermatologist was quite happy to tell me he did not really do LS but here was the cream.*

**I was told I had BXO. I now find out that it is no longer called that. I got penile cancer because my doctor told me that this would clear up on its own. No treatment till too late. Nobody needs this. I am not a man anymore. No longer want to see my penis, let alone show a woman.*

Impact of Quality of Life on adult women

Adult women are subject to one or more of the symptoms mentioned above. There is a high percentage of misdiagnosis in primary care. Some wait in excess of 20 years for a diagnosis. Difficulty with sexual intercourse has been known to destroy marriages and relationships.

**I am a breast cancer survivor but I feel that living with lichen sclerosus is much worse. At least my cancer got better and I could talk about it to friends and family. Nobody wants me to talk to them about lichen sclerosus and I feel isolated.*

**I lost my thirty year marriage. It has meant that I have gone into old age and retirement alone, financially impoverished and I live on benefits. I lost my health and my home and my socio-economic status reduced drastically. In rented accommodation now I no longer enjoy other benefits of my marriage, such as a garden or the ability to own pets, let alone the challenges of dating and being rejected time and again.*

**I am in my forties. I have given up dating because when the time comes for sex, I do not know how to tell my partner that I cannot function like a normal woman. My life has been destroyed by this disease.*

**I am only in my thirties. My clitoris is buried and I have never had an orgasm. Sometimes my new boyfriends tell me that I am frigid because I cannot orgasm, they are unkind and desert me. I have tried through the NHS to get help and have been sent in circles of referrals that never lead to me getting help. It is hard to know I will spend the rest of my life like this and I wish someone would do something to make it better for me and for other women. Even doctors from a vulva group have told me. 'We do not do surgery in the UK for this, there is no help, you have to live with it.' On the internet forums and social media, I see others getting surgery on the NHS that I seem unable to find. I know some doctors can do surgery privately but I do not have the money. I long to be able to have an orgasm like other women.*

**I saw my GP at first I had a nice woman who helped and examined me but she went on maternity leave. I asked the men doctors at the surgery to examine me and help me. They refused and said I had to wait till the woman doctor returned. It took a year for her to come back, during that time, I lost all my labia and my clitoris fused, its sore to have sex now. I feel I have been violated and abused and why has this happened to me?*

**I was seeing a dermatologist, have had this for a long time. Suddenly they told me I did not need follow up. All I needed to do was keep using the cream. I was to go to my GP. Well, my GP did not want to know. After a while, I had a real problem and I went to a sexual health clinic. Was shocked to find out I had vulval cancer. I feel so betrayed by the services and my dermatologist was a member of a vulval team of doctors who say they promote learning and improve standards. If so, then why did this happen to me? I had a wide excision and there is nothing left of me. My poor husband but he is so kind.*

Impact of lack of Education and Services

Lichen sclerosus is probably the only dermatology condition that is not exclusively cared for by dermatologists in the UK (and other countries). Primary care doctors have little or no knowledge or training in skin disease and even less in genital skin disease. Women are routinely referred to gynaecologists, who have no training whatsoever in skin disease, its function or treatment. Men are seen by a variety of doctors. Subsequently many situations arise that are dangerously detrimental to both genders. Not only physically but on a psychological level when they are given no clear instruction about how often and where to apply treatment.

*** A CPD accreditation and a certificate of attendance to prove an interest in further education can often be obtained by attendance at vulva conferences given by the bodies listed at the end of the document. Read more about CPD accreditation at The CPD Certification Service – Continuing Professional Development www.cpduk.co.uk

Impact of failure to educate on Clitoral Phimosis in adult women.

There is disagreement amongst the medical profession regarding remedial treatment for clitoral phimosis. In the UK conversations with dermatology organisations, vulval societies and with the Royal College of Obstetrics and Gynaecology reveal a reluctance to make standards and provide any relief. There is no information given regarding prevention. Women are told they have to learn to live with it. However, men are able to receive surgery for phimosis and this begs the question as to whether there needs to be an inquiry under the Equality Act.

One society produces a statement for doctors to say that only selected people can go forward for surgery but there is no information on the selection process or who would be eligible. Doctors are left with no real guidance.

Letters from ALSVH asking for equality of care to various leading doctors have been ignored. There is a reluctance from many health bodies to take responsibility for improving standards across all genders.

Conclusion

ALSVH has aimed to show that lichen sclerosus is a very neglected area of health. Neglectful attitudes among those in a position of power to make change are the root of much suffering.

Neglect is a failure to exercise the appropriate and or ethical ruled care expected to be exercised amongst specified circumstances. The core concept of neglect is that people should exercise reasonable care in their actions, by taking account of the potential harm that they might foreseeably cause to others. ^[3]

ALSVH, has discovered that at no time, has any treatment been devised specifically for lichen sclerosus. Dermatologists over 30 years ago, borrowed treatment ideas and regimes from other skin disease such as Eczema and Psoriasis to treat lichen sclerosus.

ALSVH believes intervention and constructive, positive action by Governments in all countries is needed to achieve the rights set out by WHO.

“The human right to health means that everyone has the right to the highest standard of physical and mental health, which includes access to all medical services.”

On sexual health the World Health Organisation states “Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality.” “For sexual health to be attained and maintained, the sexual rights of all persons MUST be respected, protected and fulfilled.” “The responsible exercise of human rights requires that all persons respect the rights of others.”

What can you do to help?

Here is a list of organisations you can either email or write to and use this Manifesto and other documents featured at lichensclerosus.org under ‘Awareness.’ You will be able to identify organisations in your own locality that you can write to. You can share on Facebook and Twitter, send to Medial Professionals, Politicians, Government Health Agencies, friends and family.

***International Society for Vulvovaginal Disease (www.issvd.org)

***European College for the Study of Vulval Disease (www.ecsvd.eu)

***European Academy of Dermatology and Venereology (www.eadv.org)

British Association of Dermatologists (www.bad.org.uk)

Royal College of Obstetrics and Gynaecology (UK) (www.rcog.org.uk)

British Society for Paediatric Dermatology (bspd.org)

Royal College of Paediatrics and Child Health (www.rcpch.ac.uk)

Royal College of General Practitioners (UK) (rcgp.org.uk)

BSSVD (bssvd.org)

American Academy of Dermatologists (www.aad.org)

American Association of Gynaecology (www.acog.org)

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*‘The idea that some lives matter less is the root of all that is wrong in the world’
Dr Paul Farmer. Medical Anthropologist.*