



International Alliance of Dermatology Patient Organizations'  
Lichen Sclerosus (LS) Disease Experience Survey  
Select Sample from N=630 replies.

Q61. Do you have anything to share from your personal experience that will help with our understanding of the true impact of LS? (If we can quote your exact words in advocating for this disease – please include your first name and last initial only, or simply your two initials, and we will take that as permission to use your exact words from this question only.)

*My late diagnosis at age 58 was devastating. So much marital heartbreak could have been avoided in my younger years. My husband has passed and I have a new partner, but our sex life is greatly curtailed. If he passes before me, I will NEVER pursue another relationship, all because of LS. —Deb N.*

*I walk around silently dealing with something that people do not even hear about. I have not had any sexual relationships since I found out I have LS and I feel like intimacy is over for me. I know from being part of a support group that I am one of a majority who feel this way. I have neglected to touch myself often, even when showering as feeling the lack of vulva architecture makes me terribly sad. It is grief. I avoid looking at myself, but do, as I have to keep a DAILY eye on what's happening, the symptoms can change you overnight. So not only do I have something that pushes me into depression but also I am forced to look at it daily, in order to retain and protect what is left of my womanhood. Something needs to be done, not knowing what causes this is not good enough, and women should not suffer in silence. We deserve more and better. I brought two children into the world and I deserve better. —Jacqueline. H.*

*A complete shock to the system to be told that you have such a disease, which you have never before heard of. No one around you has ever heard of it. Even doctors seem a bit unclear about the condition and so we sufferers have to go away and do our own research and hunt around for whatever information we can glean from the Internet and support groups. .... It has made my life unhappy and my outlook is no longer youthful and light hearted. I am no longer a woman. I am a freak and I feel isolated. I feel the black cloud of this disease, always hanging over me, will forever impact my whole existence. I have become a shadow of my former self and am unable to free myself from the misery it has brought to my life. — Julia B.*

*This condition has affected me in being a confident woman. I love my husband and want to be with him sexually and when we try, the pain is unbearable. It feels like cut glass is inside of me and that he is ripping my raw skin to shreds (he is actually being very gentle). Please help! —Debra B. Nashville, TN*

*Living with day-to-day burning pain, which I'm forever thinking about when the disease is active. Knowing I can no longer engage in regular sexual relations with my husband without forward planning and hoping I won't be in pain for 2 days afterwards. Not swimming regularly anymore. Just so many issues and I'm considered a mild case. This disease has a massive negative daily impact on all sufferers' lives. Please, please help us. —S.A.*

*... Terrible pain and bleeding, doctor mentioned unusual structure during episiotomy of both babies, never referred for proper treatment 'til I forced doctor to send me to dermatologist who said all damage done, could only give me clob, estrace, send me to LS specialist at age 67, fusing has worsened, vagina almost covered, very tiny, anus is trying to fuse, hood is extensive, can not see urethra at all, no clitoris visible for many, many years, butt crack irritation now even with all the things I use for pain relief, ice packs when throbbing is bad, sharp vulvadynia pain especially at night, how can this be a good life? Feel like skin and bones, not a female, more like an IT... —Patti T.*

*As a mom, watching my daughter suffer (starting at 4 years old) with splits and tears in her skin, being unable to sleep due to intense itching and burning, being terrified to use the restroom because she was afraid of another tear*

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*and more pain, and then having a potent steroid as our main treatment has been heartbreaking. I worry about her happiness in the future and if she will be able to live a "normal" life. I worry that if this disease is not manageable she will see suicide as an option. —C.M.*

*Living with this disease is pure hell. To not be able to go to the bathroom without the horrible burn would be wonderful. It makes me not drink the fluids that my body needs, because I don't want to pee. I have literally screamed when I go. The 1st time the doctor tried to do a pelvic exam after I was diagnosed was horrible. The skin becomes kind of tacky. When the speculum was inserted, my skin adhered to it. At first, neither of us knew that until he tried to remove it. The pain of him trying to pry my skin from it was unbelievable. During a later visit, it was well lubed, but my skin had fused some together. So I was unable to have exam. It's now been 9 years since last exam. I just hope that there is nothing happening in there that isn't being detected. —D.R.*

*I cannot express the amount of emotional pain LS has brought in my life at a time when I expected to be experiencing the most freedom of sexual intimacy with my spouse. The day-to-day pain and fear brought on by this disease has unfortunately affected my joy for life. It's not a disease that you can ignore when something as simple as wiping can tear the skin. —Peggy P.*

*LS has ruined my marriage, and left me feeling alone and unlovable. It came out of the blue. And no one seems to have heard of it. —Holly M.*

*This is an "unspoken", "woman's" disease and there are too many women now suffering from it. No one seems to be studying it - we have almost zero data on the numbers i.e. is it increasing? What are the real causes? Etc. When it's severe, it consumes your life. It's painful to sit and to walk. I can't wear underwear without pain and I'm fearful that in 5 years, I will not longer have any sexual function. —Sandy K.*

*LS destroys your marriage. There is no way a partner can comprehend the pain you experience and the impossibility of trying to have intercourse to preserve your marriage, when you simply can't bear the pain. They think you don't like them or you are having an affair or something. It is horrifying to go from being a normal sexual human being to someone who can't have sex anymore, for no understandable reason. You don't know what is happening to you. It is absurd. It is a secretive disease that no one wants to talk about and all the GP's reel off the same explanations and treatments and in fact, they know nothing. —J.W.*

*I feel like I am fighting an uphill battle to prevent the loss of my female parts as I see them disappearing a bit at a time. I am also terrified at the thought that something could happen in my life that puts me in a medical situation where I am unable to speak for or advocate for myself, and those who are caring for me won't take proper care and will physically hurt me every time they tend to me. —J.K.*

*This disease is socially isolating, painful, and devastating. Sexual relationships are impossible most of the time. So many doctors are ill informed about the disease and poorly prepared to help with setting up a treatment plan. —H.S.*

*As a single person, I feel very lonely and unable to motivate myself to get out there and go on a date or meet someone due to effect of LS on spontaneous, pain free sexual relations. Forecast is very bleak. —Y.K.*

*Sexuality is a huge part of most peoples' lives. This disease disfigures sexual organs and can make a sexual relationship impossible. It isolates you. It's the disease no one talks about. The mental anguish, the physical pain*

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*and not knowing what health care provider to see/how to treat LS makes living with LS almost unbearable at times. It's progressive and no treatment exists to stop it or reverse the effects. —V.A.*

*A flare-up of Lichen can be extremely painful and has caused me to take to bed for days with ice packs on my genital area. The pain is unbearable and it is increased when urinating or defecating. When such a flare-up occurs, I eat and drink minimally to avoid voiding in any way. Sex is not in my vocabulary any more. —D.D.*

*I believe the most urgent issue is to find some kind of treatment that can stop the progression of LS. I can deal with a certain amount of pain, but sometimes I start thinking about my future (I am a young woman) and I worry a lot because I'm afraid my LS will prevent me from having a normal and happy life. It is a disease that makes you feel vulnerable and less "woman". —C. C., 21 year old*

*I hate this hidden disease! HATE IT! Why did it appear in the first place!? What did I do to get this disease?! And then when I got it I went to our "home Doctor" who treated me against vaginal fungal infection/vaginal candidiasis. The itching and white spots were still there. Came to gynecologist WHO KEPT TREATING ME FOR vaginal candies is! 27 weeks and my vagina changed! I have almost no clit! No labia!! Then I changed to another gynecologist who right away, just talking to me (!) knew I had VLS!!!! —C.M.*

*If I wasn't a part of the LS group here in Denmark I would be completely lost because my doctor didn't give me the necessary information about this disease and all the tips and suggestions I get from all the woman around me are truly priceless. This disease sucks less because of those many advice and support through the years. —Karen H.*

*I was diagnosed at 22 years old and by then the LS was severe. I was still a virgin; the nurse asked me if I was abused as a child because my vaginal opening was so small, I was basically raped with dilators at a hospital. I had to have a C-section to have my daughter. I won't enter a relationship because intercourse hurts too much. I am petrified my daughter will suffer the same fate with LS. —Emma N.*

*LS means... coming home from work and having to go immediately to the bathtub in order to urinate in the bathwater due to the pain. Then having to soak and gingerly dry off in order to rub in the cream - not easy to get that time when having to be "mommy". Also risk of UTIs because you don't want to urinate. The embarrassment of peeing on your hand as you try to shield the raw spots. Waking yourself up at night from scratching and knowing you are going to be sore because of it. Not being g able to go to sleep due to the pain during a flare up. —S.L.R.*

*I have not been with my husband in over 18 years. He doesn't understand. Sometimes I feel so alone. —A.S.*

*The guilt of always being in pain during sex and either pretending all is ok to avoid upsetting my husband, or telling him and having him feel guilty is heartbreaking. As is having to say that it will not get better if we just stop having sex for a few weeks my life is adversely effected forever. —M.M.*

*This condition robs you of parts you didn't realise made you feel like a 'whole' woman, until those parts are gone. Then we have to deal with the daily pain and loss in silence, because we are all taught a woman's private area is embarrassing and shameful to talk about. The one place you are able to discuss your vulva in detail is with your doctor... but an unsympathetic doctor will shatter what little confidence you had. I know my body better than anyone, but I wasn't listened to. I was told, "you just have to learn to live with pain, women aren't very good at dealing with pain. So you'll always be whinging about pain anyway for the rest of your life!" That dismissive attitude from my doctor has damaged me more than my LS ever has. Because it told me I wasn't worth listening to, And my suffering wasn't worthy enough. —Poppy J.*



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*For 10 years I was able to integrate pain into my sexual life...but now as I attempt to find a mate in my late 50s I am realizing that no amount of courage and optimism is going to help me over the hurdles ahead. I need an act of God. I'm fusing shut and I have had sensations of water bubbling through a straw when I pee so the urethra is getting involved. I'm looking at a bad end. —Mally S.*

*Its a debilitating condition that effects every aspect of your daily life, 24/7 Pain that is forefront in your mind, it's never-ending. —M.S.*

*It's a horrible disease and many people no nothing about. It has impacted my whole life. I have to watch what kind of toilet paper to use, creams, can't have sex or go swimming for fear of a flare and tearing. I feel like my freedom of life is gone. —E.S.*

*Doctors don't seem to realize how horrible it is nor how it affects your entire life. Treated as a minor annoyance when in fact it is major! If it was a man's genitals affected, I honestly believe they would realize the significance and the impact on our daily life! ... This is unacceptable and should be given the attention it deserves. —S.M.*

*LS has affected my whole life. I am unable to travel long distances to visit friends or go away due to the pain caused by sitting for long periods and the increased pain the next day. Difficult to explain the problem to people as they often become embarrassed by references to genital area and it is not a condition that is well known. It even influences the clothes that I'm able or unable to wear. I am so sensitive that I can't wear underwear or trousers. —Susan B.*

*With all of my autoimmune diseases, and I have three, LS has impacted my relationship with my spouse in a devastating way and is life changing. My doctor had no clue and never spoke to me about this aspect of this disease. He said it was no big deal. —J.M.*

*LS is soul destroying, it is debilitating, painful, exhausting, destroys relationships, causes depression & anxiety. It is Life Changing. —Diane C.*

*This condition has stopped my sex life with my husband. It's not normal anymore but we work around it. Luckily, he is understanding. I hate going to the toilet because I am scared I will see blood or it hurts. I hate that LS is always on my mind and I hate how it has consumed my life. I am scared of the future and how this condition will progress. —Sonya O.*

*The psychological impact of being deemed incurable and only going to get worse has been severe speaking personally. I feel broken and damaged. The constant fear of making a mistake and causing things to progress, which cannot be reversed, feeling like I'm doing things wrong and blaming myself for the condition when in reality there is nothing more I could be doing. This condition has affected me in all aspects of life, not just sexually, because of the constant stress and blame towards myself, and the feeling of inadequacy. —G.W.*

*There's a devastating loss of femininity made worse by no one talking about it. This is a very lonely disease. —J.E.*

*Intimacy with my husband stopped after 2 years of marriage (second marriage). I worry about the risk of cancer and the damage the steroid is doing to the surrounding tissue. I feel helpless and inadequate. —Debbie J.*

*This is a silent illness that many people feel ashamed of or unable to talk about. It feels like the medical profession*

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*does not understand the impact that LS can have on our lives and our relationships. —L.W.*

*My life changed since I've had LS... I was afraid to have sex because of the tearing and pain... from a vibrant woman I turned into a woman who couldn't stand the touch of my husband there and froze, and although I loved him so much we divorced because he couldn't stand it anymore... Now, I'm single and I think I will be for the rest of my life because I don't want to go through this again... now it's just me, no one has to touch me there anymore, no more fear... and I'm only 48... —Jacky S.*

*The physiological & psychological toll of this condition is unending. It is a constant issue that wears you down like nothing else I've experienced. The constant blow to your masculinity is never ending...having to constantly adjust your underwear because of pain, shifting uncomfortable after urination because it stings, loss of sexual prowess, loss of ability to EFFECTIVELY satisfy my wife, the self-esteem issues, the feeling of skin tearing after a hopeful period of treatment trying something else to see if it works. It's a never-ending blow to your manhood. Yes, you can use my name. You can call me. You can email me. Whatever it takes to get info to the right people. —Dustin L.*

*LS is like a slow vulvectomy - with pain and itch and bleeding - no one wants to talk about it because it affects genitals and largely affects women and girls. We need help. —C.J.*

*This is a life changing disease that no one understands. It's hideous and explaining it is hard because no one can grasp the impact of such pain and disfigurement. If I could, I'd happily give ANYTHING to not have this disease and to feel happy about my vulva. Every day is different. Pain levels, itching, burning, tearing, everything. It's an emotional rollercoaster and mental health care is needed as much as physical health care. —R.D.*

*I don't think people realize the daily pain and discomfort of living with LS. Sometimes all I could do was sit home with baggy clothes on and go back and forth from sitz baths to ice packs trying to get relief. It has destroyed my sex life at 36 and my marriage is suffering. It is not something you want to discuss which leaves you feeling alone, helpless, and depressed. —Kassie K.*

*LS has stolen my identity as a female. —K.B.*

*I have never been able to orgasm with a partner due to the restructuring of my vulva / clitoris. I've seen doctors and all they said was some women can't. No one has ever looked/ examined me until I was diagnosed at age 51. I've always suffered from an early age with soreness and no diagnosis; this is not acceptable. —D.Y.*

*I was born in Malta. I find that my life is over. To tell you the truth i hate myself. Not sure how to cope with it all. —Ann B.*

*It destroys you as a person, physically and mentally. It is a very difficult condition to live with. —E.N.*

*LS has stolen any chance I had for a normal life. —Laura W.*

*Unbelievable that medical profession has no idea of its existence. —J.S.*

*This disease has destroyed my quality of life. I have to put on a fake smile at work and with family and friends and I cannot concentrate on tasks. I have wanted to just put a bullet in my head so many times to end my suffering but the doctors do not get it. —T.H.*

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*Lack of intimacy makes you feel dead inside. —D.W.*

*A mother of a child with LS, you feel hopeless, you grieve, you find you have a constant fear for them. You want to desperately help but can't as doctors just simply don't know what to do. Doctors ignore you, say 'she's too young', and prescribe thrush creams for months. Nobody should be left to suffer like this. —J.M.*

*It steals your life and everything that makes you a woman. —Jane S.*

*This disease is such a painful and debilitating disease. It changes everything about you and limits you because you are so afraid of a flare up. It can happen at the blink of an eye. There are children that have this horrible disease that can't go out and play like the other kids. It has definitely changed my life and the life of others and makes me sad. —D.D.*

*Treatment options for LS is based on data from 20 or more years ago. Ignoring this disorder (and this is the only way to interpret this) is causing greater harm to women (mostly). I personally feel ignored by the scientific medical community. Loss of the vulvular tissue and sexual health with the increased chance of cancer should be enough to warrant better treatment options. —M.B.*

*As a breast cancer survivor, I can honestly say this disease has been more devastating than cancer. —Katie W.*

*Doctors don't seem to understand how devastating this disease is to your sexuality and identity as a woman. —V.G.*

*The itching, burning and pain from this disease are unbelievable. I have spent weeks just sitting undressed from the waist down using lidocaine so I can tolerate an ice pack for the burning, itching and pain. It truly is just too much. And I say that already accustomed to dealing with difficult, painful, demoralizing diseases and conditions. —Julie S.*

*It's difficult to hear that steroids are the main treatment and 'sorry about that' attitude. I'm always curious if more men got this disease if there would be more support for figuring it out. Food for thought... —L.S.*

*LS alongside menopause has made me feel less like a women. I am very worried about sex with my partner of 31 years even though he is very understanding because if pain and splitting which has put pressure in us both. My job involves standing all day and very often I am uncomfortable the whole time. The creams/gel I use is messy and I can't use pads as they irritate so I am often aware that they make leak onto my clothes and they have marked car seats in the past. Living with LS along with all the horrible physical symptoms is very mentally debilitating. —Lynn B.*

*I am newly single after being in a long-term relationship and recently diagnosed with LS. I'm scared about what my future looks like and how this will affect future relationships. —Anna O.*

*Due to the location of the disease, it's often not taken seriously. It's also extremely lonely - you don't feel like you can share it with anyone the way you could with back pain. It affects every area of your life from your self esteem, sex, clothing you can tolerate, sitting, walking, having to plan things for outings (bring special toilet paper/wipes, figuring out where I can apply my creams, wondering if the seating will be soft enough, how much walking will I have to do, etc.) I feel like acid is being poured over my skin 24/7. I wouldn't wish this on anyone. —J.W.*