~~MEDS & SUGGESTIONS~~ 10/19/08

For Lichen Sclerosis
By Dee Troll
Owner of the LS group at Yahoo

10-19-08

Knowing how confusing and overwhelming all this can be here are some suggestions I've put together over many years that you might ask your physician about and consider trying. Some are for pain, itch, burning and inflammation, basically for symptom relief, others are for rebuilding, unfusing of adhesions, restoring our architecture and getting our tissue healthy and elastic again, using a two tier approach to wellness.

I've gone through hundreds of various treatments with trial and error with the ten years I had this agonizing pain (9+ yrs of being well as of last April '08) and researching through thousands of journals regarding LS and other Vulvar pain issues even longer and these suggestions are what helped me the most and healed me eventually. I sincerely hope by sharing it with you it's of help to you as well and can spare you some pain and the most precious 'time' lost with the myriad of things I too 'hoped' would work but didn't.

One thing before we start, I do want to stress to make certain that 'all' infections of any type whether bacterial, fungal, or viral have been ruled out first! Do not assume it's a yeast infection unless you KNOW absolutely since some medications may excoriate you even further.

It may be a yeast/thrush or bacterial infection or Herpes, or even an atopic dermatitis and not LS. A Herpes problem can quite often feel as severe with the pain as LS can and is often overlooked and often has no typical blisters, and they can co-exist at the same time. One sign of Herpes (often overlooked) might be a particular spot that flares up more so than a general overall pain, so be certain that other things have been ruled out first, even a lichenoid dermatitis resulting from an external source can be a cause that's overlooked.

Big Hugs to all and I hope this helps.

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Your Friendly Owner and Moderator

PS; By the way you do have my permission to show this to your physician (not elsewhere) if you feel it will help, though I'd definitely cut it down, (and we have had some members report their physicians approved) *smile* and also keep in mind these are MY opinions and suggestions as well as 'my' experience and what has worked for me and so many others, though it is considered anecdotal it has worked for so many.

~~MEDS AND SUGGESTIONS~~

Lichen Sclerosis ** **also** spelled with 'sus' ending.*

NOTE* This information is also good for general vulvar pain, (Vulvodynia) as long as all disease or infections have been ruled out or pelvic floor dysfunction and radiating pain and the pain is topical and in the tissue itself and not internal.

Subjects covered:

STEROIDS

PROTOPIC & ELIDEL, ATOPICLAIR

HORMONES

- **Estrace, topical**
- **Testosterone topical**
- **Compounding Pharmacy's**

TEMPORARY RELIEF (long list)

OTHER SUGGESTIONS

DIETS

VULVAR SELF EXAM

BASICS (Common sense)

CONCLUSION *quick synopsis*

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STEROIDS.

Clobetasol, Diprolene, Temovate, Betamethasone, Ultravate, Cormax, Lidex etc. etc. etc. (those are all prescriptions) to be used 'topically'.

All of the above are potent class 1 steroids, for pain, itch, burning and inflammation relief (In other words 'symptoms') to be used 'topically. Usually a steroid is the very first place a physician starts when a patient has vulvar pain or pain with sex, or tampons etc. if it's in the V. tissue itself; After all infections are ruled out of course.

The more potent and class 1 steroids are typically reserved for LS. If one has a dermatitis or other undiagnosed vulvar pain and 'not' LS, a lower strength would be better to use initially. You may even try an OTC (over the counter) very mild hydrocortisone initially if you are not sure of the diagnosis as it may be a simple dermatitis. But "clob", short for clobetasol, a generic, is the steroid most often prescribed for LS and LP (lichen planus). It has been mentioned in many articles that an ointment form is much preferred over a cream form because there are less 'base' ingredients, it's purer and has less of a chance of irritating us or to have something in it that one may be allergic to.

Small amts. only, 'pea size' or just enough to make a 'light' film over the painful/itchy/inflamed/burning area and gently massaged in (as well as the anal area if there) so you can see it depends on the area to be covered as to how much. That part about lightly massaging it in is very important, so don't forget that but please be gentle with yourself. A nice slow gentle count to ten is a suggestion, and a nice warm/hot bath helps the body absorb the medications beforehand.

Name brands are typically suggested as being better than the generic which is clobetasol (clob for short), several excellent reports were from Temovate, Ultravate, Dermovate and Betamethasone and often suggested by physicians if the generic clobetasol doesn't help.

Steroids are the typical first protocol for LS and many other vulvar dermatological pains and those above are the highest potency in class ranking and are the suggested protocol for LS for the simple fact they will penetrate deeper into the tissue than a milder steroid and that is where LS resides in the basement level of the tissue.

As the vulvar pain gets better, I, and some physicians, feel you can downgrade to the midrange steroids like Triamcinolone, Aristocort or Kenalog or eventually even a very weak one like Pramasone or hydrocortisone for maintenance. Some may even 'start' you out on a milder mid level potency depending on your condition. Though generally in the USA they suggest the highest potency ones but I've noticed some other countries will often start with a lower mid-strength one.

Once you are well, from then on it's suggested by some physicians to use on an "as needed" basis if you are in a flare-up with symptoms for a few days, other physicians suggest it must be continued as a maintenance at least once a week for LS, so it's a matter of preference between you and your physician and it is a real variable amongst them as well.

I've read several studies doing what they call 'pulse' dosing where a steroid is used for several days in a row and then halted for several more days to give the tissue time to repair itself since steroids can thin the tissue in a fairly short amt. of time and then continued again in a cyclic pattern as being the better way to use them.

Another suggestion was to use the steroids only on the weekends for 2-3 days but I am assuming that's once one is well and as maintenance, as initially it's often used more often than that.

Potent class I steroids (like those listed in the heading) 'must' be tapered down and not dropped cold turkey, else you may have what is called a 'rebound' effect that can leave you much worse off than the original problem. Too much can be very damaging to the tissue as it can thin the tissue in a fairly short amt. of time and give you the same or even worse symptoms that you're trying to correct. One study shows that thinning effect after only 3 days use of clobetasol (microscopically). I mention that only to show you it’s a potent medication and to not overuse it, but I do not want you to be frightened of it either.

Steroids are wonderful and can be a godsend no doubt, so please don't be afraid of them, just be aware. Generally within 2 -3 weeks and you 'should' be seeing 'some' benefits, if not or if you are even worse, I'd definitely taper down and NOT use more, MORE is NOT better with a steroid! I cannot stress this enough, it's a very potent medicine but used correctly can be a godsend.

If you're doing well and things are improving, a 'typical' recommendation is a PEASIZE amt. OR enough to make a 'light' film over the painful area and gently massaged in, 2 X a day for approx. 3 weeks to a month (some physicians suggest six weeks) then taper down to one time a day for another 3 wks to a month, then go to a maintenance of perhaps 2-3 X a week, down to perhaps once a week, until you find your own level of maintenance.

But again IF you see NO improvement or are getting worse after a few weeks usage of a steroid, please consider what I suggested above. You should see 'some' improvement within a 2 week time frame, if not you may be allergic to it or you may have herpes unbeknownst too (steroids can aggravate herpes and are a real negative with that) or you may need to switch to a different brand, I would definitely call my physician if that happens and let them know.

I would prefer the once a day usage as enough but that's me and have seen that suggested though it's not typical protocol, so don't be afraid if your physician does suggest twice a day since that is more so the standard when 'first' going on the steroids for LS.

Don't be foolish as I was when the physicians and the prescription itself stated to ’’use until symptoms abate'' as I continued to get worse and worse 'waiting' to get well and for the symptoms to abate, but they didn't. That can mean an indefinite time frame, so don't fall into that trap because it 'may' seem beneficial when initially applied (if you find you are getting worse) but indirectly it’s causing more harm without you realizing the very thing you are doing is causing it.

As to the steroids I can only say that I've read thousands upon thousands of pieces of legitimate literature and I've still 'never' come across any that ever stated a steroid itself will restore that architecture, NONE... It’s only purpose as far as 'I' know is to relieve or control the symptoms, things you are feeling. (Which we DO want of course) so don't misunderstand me.

Used correctly they CAN help with the pain, burning, inflammation, swelling, itch (esp. itch) etc. to make it more comfortable to live with, and halt the disease progression where it is hopefully, but to restore the tissue back to it's original condition such as the unfusing of the adhesions or even to give back the color, tone, etc., I've just not seen that in any legitimate studies, most say it is for symptom relief alone and once symptoms are relieved then it allows ones own body to do the healing.

We have to understand this, it may seem so (or you think it does) if ones own immune system is fairly healthy, that in itself is what might do it or if it's an early stage of the disease but it's not the steroid perse but your own body doing it once the symptoms let up, the body 'want's' to heal itself. It's a miraculous machine.

So a steroid halts 'symptoms' to give you relief by slowing down the immune system response and hopes your own body does the rest of the healing which it can do especially in mild cases since it helps halt the inflammation, itch, etc..   Just as a topical antibiotic for instance does not heal your skin but prevents infections 'caused' by the bacteria and then lets your own body (or hopes it does) do the healing.

Again I beg you to please just be cautious to not overuse or abuse steroids but also to not be afraid of them. Many physicians are very lax in that and not telling you of the possible side effects especially of thinning the tissue in a fairly short amt. of time... a good one will. One quote from a legitimate medical article by Dr. J. Metts on LS says this.

“Long-term use (of a steroid) may cause an extreme burning sensation that occurs as the steroid is withdrawn. A cycle of vulvar dermatitis can become worse as the patient continues to treat the erythema and discomfort with the very same potent topical steroids that started the problem!’’

Also a nice warm or hot bath before application helps the skin to absorb better and be certain to gently massage it in to a slow count of perhaps ten, this is very important and many forget that part. You don't want to just let it (or any meds) simply lay on the tissue where it may make you more susceptible to a yeast/thrush problem.

I healed without ever using a steroid after my own dire results, just so you know because of extreme side effects from overuse and abuse previously (as told to by several physicians) but I went through hell and pain to get well eventually with using only the hormones Estrace & Testosterone (E & T) alone until the tissue was rebuilt and unfused. (More about E & T below)

Today, I 'probably' would use a steroid or possibly the Protopic/Elidel *immunomodulators* (more about those below too) but sparingly along with the hormone creams E & T. The steroids or Protopic or Elidel are for symptom relief and to put those 'symptoms' at bay and keep them in remission, the others (hormones) are to rebuild the tissue to get it healthy.

There is a new topical medication out called Atopiclair that would most likely take the place of a steroid and the best part is that it (and the Protopic or Elidel) does 'not' thin the tissue as the steroids may with overuse or abuse.

This is what one physician (Dr. L. Mercer) states and I completely agree...

"Lichen sclerosus is an autoimmune process that breaks down the skin by local hypercellular response."

"Treatment therefore should take a 'two-pronged approach':"

1. Stop the inflammatory response and

(We do that with the steroids or Protopic-Elidel or Atopiclair and secondary with antihistamines.)

2. Heal the broken-down tissue.

(We do that with the E & T (estrogen *estradiol* & testosterone) creams as food and nourishment.)"

IMMUNOMODULATORS

PROTOPIC (tacrolimus)

ELIDEL (pimecrolimus)

Both are Prescriptions

This is another form of medication (ointment or cream) similar acting to the Steroids to help stop 'symptoms' but would most likely replace steroid use, although some physicians may use them together varying them. It is somewhat expensive and is usually recommended by a dermatologist. Though some gynecologists 'are' catching on a bit and recent legitimate studies show using it 'off label' to benefit LS, LP, (lichen planus) Vitilago, and other idiopathic vulvar pain if it is in the vulvar skin itself.

(See a lot of information about those in our Home page under Files)

The Protopic or the Elidel have the biggest advantage of NOT damaging or thinning the tissue or skin as a steroid may with 'overuse', and works on halting the histamine and other cytokine inflammatories output from the degranulation of Mast cells 'before' they come out as they are immune system modulators.

Anti-histamines or steroids hopefully work 'after' they're out and have already started causing tissue damage and hopefully those can revert the symptoms.

It's the histamine output from Mast cells and others (TNF, basophils, Sub. P. etc. etc. called cytokines) produced by the body which are inflammatories, that are contributory and causes that skin to react with itch, inflammation, burning, stinging, etc. (also the same thing for example in a person with hives) and we want to halt that ASAP since inflammation and itch can damage the tissue fairly fast and that is what a steroid is supposed to halt and put into remission. We definitely want to stop that 'itch/scratch' cycle as it causes much damage to the tissue. If it continues for length of time (possibly years) it may have the potential to turn cancerous as well.

Protopic or Elidel (very similar products) are not specifically approved for LS or vaginal pain, and are approved for psoriasis/eczema, but many physicians or dermatologists are today using it 'off label' for vulvar problems and it is working with some patients quite well as our excellent poll showed.

UPDATE... Many newer legitimate medical reports tell us of studies with LS, LP, Vulvodynia, and Vitiligo and how Protopic or Elidel usage show it has been proven to work as well if not better than the steroids in 'some' cases. (We knew that!) *smile* and some of those studies are listed at the Home page of our Lichen Sclerosis Group.

The LS group and the Vulvar Disorders group were the first to use Protopic as a group; we were the guinea pigs so to speak. I'd followed Protopic from it's inception long before it was ever approved for those with psoriasis and only a dream, hoping that it would be an answer for those who have Vulvar pain, since they too have to use the steroids as eczema & psoriasis patients do and it has been a godsend for some members who swear by it.

I was well by then so I have not used it but passed on the information excitedly with great hopes & expectations. We also had a gynecologist on our group take a poll I ran to Novartis in the hopes they would do more studies using it for LS and vulvar pain and today we see they have and are continuing to explore that with Elidel by the way.

The Protopic or Elidel ‘may’ severely irritate with initial applications with 'some' patients, so be forewarned and that is mentioned on the insert, (a few members had to go to the emergency room with the pain) and 'not' to frighten you but if you can stick it out and endure it for those first few days it has been very beneficial for some members when nothing else has helped.

Others simply could not use it at all and others had 'no' problems and loved it and it worked miracles for them, hopefully you're one of those. If you do try it, use it on a very small tiny spot initially perhaps even with a Q-tip to see how 'you' react.

For those who may want to see the poll we ran & member’s comments on Protopic usage go to:

http://health.groups.yahoo.com/group/LichenSclerosis/files/PROTOPIC%20POLL%20%26%20ARTICLES%20/

(If that doesn't work go to the LS Home page, sign in with your Yahoo ID and password then go to FILES on the left side,

http://health.groups.yahoo.com/group/LichenSclerosis/files/

Click that and scan down, there is a folder for the Protopic poll. You must be a member of the LS group to see this. (Below near end), If not, please know you are welcome to join.

Some members rejected the Protopic at first but when re-trying it at a later time it worked. Also it's suggested in the literature if one 'already' has Herpes, or Shingles or any type of 'viral' infection like HPV that it 'may' bring an outbreak on. (Just as a steroid may by the way.)

Because steroids and the Protopic or 'Elidel 'are' immune inhibitors and thus may weaken the immune system to 'let out' other diseases so to speak that were previously dormant and held in check, especially things such as Herpes, Measles, Shingles, Chicken Pox or HPV which are all ‘viruses’. That is why you'd definitely want to rule out a Herpes infection since using a steroid may make you much worse.

The theory is that people with LS have an 'overactive' or dysfunctional immune system not under active and it is thought to be genetic and likely hormonally connected.

Just remember that a steroid ointment generally suggested for LS, is the 'first' suggested protocol for LS in most cases and a weaker one for initial Vulvodynia, but a steroid as well as Protopic or Elidel, 'may' also increase a Herpes outbreak as well or any type of a viral infection, (HPV) though not often mentioned in the literature I have seen it reported for steroids too, not only in evidence based literature but also anecdotally with members.

One other quick note about steroids is that 'overuse' can also be systemic if used 'long' term with side effects such as Cushing’s syndrome. It's not likely but can happen and is mentioned in the literature and it did happen to me.

UPDATE Just recently the AMA has suggested that physicians always use a steroid as the first treatment before suggesting the Immunomodulators and then only if a steroid doesn't work. And there have been some recent reports of Protopic or Elidel as being a possible or suspected trigger for cancer, though I've read every single report and to 'me'... Most seem to me to be extreme cases where it was so much overused (whole body as for psoriasis) and not at all like the pea size amt. we’d use.

Some cases blamed it on the immunomodulators when it was used for barely for a week or two so was it that or not? Who knows? Plus we all have to remember that the Protopic or Elidel (and even the steroids to a degree) slow down the immune system and that leaves it weaker to fend off other conditions or illnesses that may have previously been there all along. I myself wouldn't think so using the very small amt. we would, but that is completely up to you of course & your physicians feelings about it. We just know it's helped many when nothing else has but of course leave that totally up to you and your physician.

To read just one expert’s opinion (there are many) counter to the cancer reports click this.

ATOPICLAIR

This medication is fairly new out and a nice handful of our members have tried it and truly seem to love it and most are using it in place of the steroids to help with itch, inflammation etc. Atopiclair nonsteroidal cream is indicated to manage and relieve the itching, burning, and pain experienced with various types of dermatoses, including atopic dermatitis and allergic contact dermatitis.

Atopiclair nonsteroidal cream helps to relieve dry, waxy skin by maintaining a moist skin environment, which is quite beneficial to the healing process. Apply Atopiclair nonsteroidal cream to the affected skin areas 2 to 3 times a day (or as needed) and doesn't seem to have any side effects least of all the thinning tissue that can be associated with steroid overuse.

Heads up WARNING: Atopiclair nonsteroidal cream contains nut oil, and patients with a known allergy to nuts or nut oils should consult their physician before using this topical preparation. It contains no dyes or fragrances and is well tolerated and safe for patients of all ages. Atopiclair nonsteroidal cream does not contain milk, wheat or animal derivatives and is supplied in a 100gm tube.   So this would be something to consider almost in place of a steroid but it has not been approved for LS but for general dermatitis conditions but as I mentioned some members have used it and swear by it and may well be worth a try for you as well.

HORMONES (E & T)

(E) ESTRACE CREAM (17b Estradiol)

(A prescription) "USED TOPICALLY":

***Note this is used on 'top' of the vulvar tissue, not inside the vagina.**

Estrace is the 'name brand' of a female estrogen cream (17b Estradiol). To be used topically for restoration of tissue to give it back it's elastin, & collagen, it's stretch ability, it's 'give', it's tone, color, resiliency, elasticity, and plumpness and overall healthiness, and hopefully for 'unfusing' the adhesions that may go along with LS and restoring the architecture of the vulva.

It completely unfused me after three solid years of being like that out of the ten I had that severe pain, and even if it doesn't, (If one has true atrophy) it will definitely will make that tissue healthier. The steroids won't do that!

Estrogen (17b estradiol) or E2, is known to have many wound healing benefits for the skin, not only for the genitals and is considered an anti-inflammatory agent as well by virtue of healing that tissue, plus estrogen helps the nerve endings so they feel less pain.

The medical community knows this and why an estrogen used topically or intravaginally is so often suggested for menopausal women to restore that genital tissue. It's definitely been found in the medical literature used topically to unfuse labial adhesions in children, but apparently no studies with adults assuming it won't work, and it certainly can and does!! I'm living proof and many others (hundreds of testimonies) on our groups have as well.   Check out just a handful of the testimonies I've put in the File section of our Home page.

Also for information you may want to check out this link....

http://www.ajog.org/article/PIIS000293780300365X/abstract

It talks about how 50% of the women with 'Vestibulitis' in a study did not express 'any' Estrogen 'receptors'. It's the 'receptors' that are the active & working part of our cells like keys that open locked doors. Often those receptors can be blocked by things such as progestin/progesterone, phytoestrogens, soy, yeast, and esp. birth control pills.

For another good read about how BC's (birth control *contraceptives*) particularly those high in progestin may affect V. pain with vestibulitis check out this article from the American Journal of Epidemiology. I believe a big part of that is because progestins in birth control 'block' those E. receptors.

That is also why often in a test the blood serum levels of estrogen may be fine and normal so a physician may be reluctant to give you estrogen (Estrace) especially if you are younger, stating your E levels are fine, but it does not necessarily mean the E. 'Receptors' are receiving it, they may be defunct or deficient. They are two totally separate & distinct things, and why using the estrogen even topically can work so well as it fills those receptors from an external source.

http://www.ajog.org/article/PIIS000293780300365X/abstract

This is another recent article (of so many) that talks about labial unfusing (adhesions) using estrogen and yes just 'topically'. Even though this one speaks about infants and children I cannot stress enough that it can absolutely work for many adults as well.

Not everyone of course if it's true atrophy but in many it has. I've seen physicians make mistakes and diagnose atrophy when it wasn't but it was truly the fusing or adhesions of LS.

http://www.rednova.com/news/display/?id=145666

(This may be a fee charged site now, I'm sorry if so)

To see a piece I wrote on 'Fusing vs. Atrophy' and to understand the differences go to: the LS Home site, go to Files and scroll down to the F's.

http://health.groups.yahoo.com/group/LichenSclerosis/files/

Estrace cream too must be gently massaged in (that's important for all of these medications) you do NOT want to just let any of them lay on the tissue. Generally a pea size amt. or enough to make a light film over the area 'once' a night before bedtime I feel is the best time to use the hormone creams (Steroids daytime) because nature does our best healing during sleep. (It has to do with our circadian rhythms.)

But keep this in mind: Estrace cream is 'not' used for it's soothing qualities perse' nor to be used in a flare up typically, so if it irritates just back off for a few days (or more) and then return to it, it takes time and patience to rebuild that tissue, just as it takes time for our hair to grow out or our nails to grow long. Others have no irritation and can use it more often. Once you are well you definitely should taper down to a maintenance dosage. (For me it's was twice a week for a few years and now I can get away with once a week, and sometimes twice.) *smile*

Initially it took me approx. six full months of use (topically only) to see the full effects although the unfusing took place probably by the end of the 3rd month or so but I used 'very little' initially because I was so bad I often could only use it every 3rd or 4th day as it irritated me quite a bit and my tissue was extremely excoriated. Some it won't bother at all. But I always returned to it no matter how little I used, I 'knew' it would work and knew of its tremendous benefits and it did so I beg you to not get discouraged.

Estrace is a brand name and only comes in one strength and is available at all local drugstores in the USA via prescription. The main ingredient is called '17b Estradiol' our mother hormone and what we produce our whole lives and lose as we go into menopause and is what the skin lives and thrives on and is nourished and fed by.

It can also be compounded at a compounding pharmacy with just the 17b Estradiol (estrogen) *the main ingredient in the name brand Estrace* to leave out some of the irritating bases in the name brand Estrace. Some compounders may use Olive oil as a base or Acquafor, or esp. Liquigel. Another good one suggested is Emu oil for those who may be extra sensitive. I wasn't aware of compounding pharmacies 9 yrs ago unfortunately but am well versed today.

(More info on compounding pharmacies further down)

If Estrace is not available in your country, you might ask to have ESTRIOL compounded, (Estriol is one of 3 estrogens we produce) and considered a milder one than estradiol. One name is Ovestin, another is Ortho-Gynest *not available in the USA* from my understanding, that can work as well for tissue restoration even if it might be slower process it can be very effective as well.

You most likely have Premarin, (name brand of an estrogen cream) which can be used, though not preferred since it's simply not natural to us at all but better than nothing if you can't get Estrace which is exactly bio-identical to our own hormones. I would insist on the Estrace if it were ‘me’ and is available in the USA.

Estrace (estradiol) cream can be used topically 'once' a night if you can, (bedtime is best). If it irritates you, (and it may) just back off for a few days and go back to it. If it doesn't irritate then twice a day, (pea size) for a short while may be even more beneficial and would speed up the healing but don't be a martyr or think you have to use it and suffer or endure. Take it easy on yourself. ;)

It has very little if any systemic absorption used topically and usually can be used by all ages, even children. There are many legitimate studies that show it absolutely can work to unfuse labial adhesions in children as the above link shows it's benefits and if small children can use it without fear or side effects. I myself wouldn't be concerned at all with the small dab we use topically... and 'I've' been using it for more than 9 yrs with no side effects at all.

By the way I've seen several legitimate studies where they've used it in 'male' children as well who have BXO (a male version of LS) but not long term and it also helped them. Here's just one link:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10701883&dopt=Abstract

Be certain to tell your physician you want to use it 'topically' as most will assume it's to be used 'intravaginally' and rarely do they think of it for topical use, most aren't even aware that it can work topically. If you don't they may hesitate to give it to you, esp. if you are younger. (Just toss the applicator that comes automatically with it.)

As I mentioned above, it doesn't really matter in ‘my’ opinion and from studies I've seen even if the estrogen blood levels are fine, it’s likely to be a problem with the E. (and T) 'receptors' themselves . Many physicians aren't even aware that E can work used topically.

If menopausal, Estrace cream can be used 'intravaginally' (inserted with that applicator) otherwise just throw it away. Talk to your doctor of course, as most physicians automatically 'assume' it's to be used intravaginally (inside the vagina) but topical alone works very well to restore that genital tissue even if menopausal.

So be certain to mention that to your physician as to how you'll be using it, (topically) esp. if younger & not menopausal since most have never heard of nor are aware of using it topically alone. If one is menopausal then it can be used intravaginally but please talk to your physician about dosages etc. as there are other products available too made with estradiol for that such as Vagifem or E-string.

Again just a small pea size dab or to make a light film over the affected area and gently massaged in. One can also use what I've named the "Q-tip 'twirl' in the clitoral shaft if pain in that area or a fused clitoral shaft. (I also put the Testosterone cream on the Q-tip as well) *see below*. Also once healed we do have to taper down and go only on a maintenance dosage. Do not overuse it.

REGARDING HORMONE REPLACEMENT FOR MENOPAUSE

A study in a recent excellent cont. Med. Ed 4 hr class on hormones for physicians showed that oral or patches of estrogen as in HRT (hormone replacement) generally does not help restore the vaginal tissue directly. It 'must' be applied locally and be 'site-specific'.

That's why even if the E. blood levels are fine it doesn't necessarily mean it's working for the vag. tissue because the E. 'receptors' may be blocked by such things as progesterone, birth control pills, soy, or even yeast or they may be simply lost as with age.

The Estrace cream is used to rebuild, nourish, and feed the tissue to bring back it's tone, color, and resiliency (stretchiness), it's 'give', by direct local application and thus lessens the effects of the LS to where often a physician would not ever know one ever had LS.

Also it's used topically to hopefully help unfuse those smaller labial lips or release the clitoral shaft if one has that area fused as well. It has in many cases as well as me. I literally watched it happen with me as it reversed after I was solidly fused for the last three yrs of the ten I had this and I 'only' used it 'topically' not inserted.

Generally only menopausal women would use the ' Estrace cream' 'inserted' for HRT. If Estrace cream is used inside the vagina for any length of time, (depending on usage) then a progestin or progesterone is likely needed if one has their uterus. Not as likely with E-String or Vagifem or if using Estriol. It's a debatable issue with physicians though but studies I have show no or very little proliferation of the lining of the uterus with those products.

Definitely speak to your physician about using anything intravaginally. But using it 'topically' and rimming a bit inside around the opening of the vestibule, say up to the first knuckle, all ages can use it to rebuild the tissue since very little if any is absorbed systemically and has very little risk from all I've read and know, especially being it's the bio-identical estrogen we ourselves produce.

One quote from a CME cont. med. ed. class I took states this...

"Topical estrogen is generally considered a safe treatment for labial agglutination, (fusing) even over prolonged periods of time (2 to 3 months), with minimal if any side effects." (And in that study they used it daily)

I have seen very few women out of thousands over these many years that did have mild tender breasts using an estrogen cream even topically but it may be like birth control pills when initially started and usually will pass as the body adjusts, but again we're all different or if someone 'overuses' it that may happen.

One might also have a minimal break through bleed but again it's fairly uncommon and usually not a big deal. It's rare that I've seen it in thousands of members who've tried it. A typical reason is that the body has often been 'without' its necessary estrogen that it may wonder 'what's up? Why the change? *smile* but that isn't typical and if it does happen simply use less or back off of it for a bit as it may mean you are using too much and each of us are so very different and no one knows your complete health history so that is a generalization.

Estrace can/may irritate (generally it's the base it's in) so must be used slowly and if in a flare up it's not used for it's soothing qualities, so just let things 'simmer down' a bit and back off but do consider going back to it.

Others may have no problems with it irritating. Again, do NOT overuse any of these meds. Patience is a real virtue here. Also once healed please remember to taper down to a maintenance level, don't continue the constant every day usage. Whether it's a steroid OR the hormone creams. Mine is now twice a week average of the E & T. topically to 'keep' me well as it has for the last 9 plus yrs and no steroid usage needed at all and no flare ups. (After suffering horribly for 10 long years).

(T) **TESTOSTERONE** cream 2%

(natural bioidential T)

Used topically

T. cream is a prescription that 'must' be compounded and I suggest a natural form only, not a methyl form. It's not as likely to have any side effects with the natural as opposed to the Methyl form, although usually the Methyl form is oral and was usually used where you read those stories of side effects, but I've not seen it using the small dab topically.

I swear by the Testosterone cream as well as the Estrace cream. And have used it for 9 years as well. It's to be used for rebuilding the tissue and getting it well; seemingly making the newer skin rebuilt by the Estrace stronger or tougher and has been recommended for rebuilding and strengthening the genital skin by many articles.

UPDATE **

A new medical article is out specifically mentioning that some women with V. pain (Vulvodynia & Vestibulitis) may have less or no T. receptors, a deficiency in T. 'receptors' as well as those with LS ('that' is already well known with LS) and it may be a big part of their pain as well. Read it here at Medscape and how the lack of it may contribute to V pain. (Note the T. 'receptors' mentioned).

http://www.medscape.com/viewarticle/492121?src=mp

(''Androgen insufficiency and genital pain'') You may have to be a member but sign up; it's free, and then click that link.

One other 'very' important note is recently it was discovered that when one adds the Testosterone topically it helps to restore the damaged or lost 'estrogen' receptors as well and why the TWO used in combination (E & T) are so much 'more' beneficial than either used alone. See a FILE I have on that in our FILE section at our Home Page.

The Estrace brought the tissue back and even unfused me but I was 'still' somewhat tender & 'ouchy' after four months of E use alone, (used 'very' slowly & minimally) and I then added the T and it put 'me' totally over the edge to full wellness when I added it to the Estrace for the next two months. (Total of six months)

Keep in mind though that I truly was a 'worse' case scenario, raw bloody hamburger and totally fused as well doesn't begin to describe me and we may all be at different stages so it may not take you that long at all.

In fact approx. 15% of women with LS have no symptoms of pain like many of us do, although it will often evolve to a worse stage with time if it's not treated. LS is not something you ignore even without symptoms, it 'must' be treated with something so it doesn't evolve into a worse case condition. Either minimally with the Steroids-Protopic-Elidel or Atopiclair to keep it at bay.... or by keeping the tissue so healthy and nourished with the E & T it stays in remission and has for me for these last 9+ years and since no flare ups, there hasn't been a need to use a steroid.

Also statistics say that patients with LS have a 3-5% higher risk of vulvar cancer so we do want to be very aware of any types of changes going on, it doesn't mean it will happen to 'you' but be aware. Especially of a specific lesion or spot or sore that just will not seem to heal. GET A BIOPSY!, do not fool around with that esp. if it's chronic.

It took a total of six full months to complete restoration for 'me' after ten years of pure agony and hell, so just a reminder that it's not an immediate 'fix' and it does take time and patience. Patience, Patience, Patience, and then Persistence much as I hate saying that it simply does. As skin has it's own rate of renewal and can't be rushed.

You likely will continue with flare ups (you would anyway) but as time goes on they get further and further apart in between cycles until hopefully there are none as the tissue rebuilds. So please don't be discouraged and have patience, and it's better to know that going in so you don't get frustrated or ready to give up. ;) Just let up, but don't give up!

I used a ratio of about 3X's usage of the E to 1 X of the (T) testosterone or on every 3rd day I'd add the T to the E regimen right on top of each other. By the way when I say 'day' I do mean bedtime at night as that is when we heal the best.

So it was more Estrace (estradiol) than testosterone cream but I feel that both were a huge part of my own healing. Now that I'm well I 'still' continue with both hormone creams (E & T) a small dab once or twice a week topically for maintenance only and it was nine years as of April '08, of being well and with no side effects at all and I have never had to use a steroid again. IF a flare up were to happen I would but gingerly and sparingly.

The T. was the old standby for many years for LS until the steroids became available and the sweetheart of drugs and 'to me' the T. still of great benefit and I do see some doctors are returning to it. It is known to give strength to vag. tissue whether it's Vulvodynia or LS.

Just a small pea size dab is all that is needed applied directly to the affected area (though I rub it all over the vulvar area) and I also do a dab of both the E & T on a Q-tip for something I named called the 'Q-tip twirl' * (see write up in the Home page under FILES) in the clitoral shaft to keep that healthy as well.

I've seen many have release of the clitoral shaft by gently 'twirling' that Q-tip with the meds, in, up and over the clitoris inside of the hood/shaft. It may only be a dimple if severely fused, but just try to 'gently' do that, you may be surprised as many others have been.

I've had NO side effects, no growth or enlargement of the clitoris no unwanted side effects at all even after all these 9 years of a minimum of once or twice a week use of the E. & T. for maintenance. But be aware I do not know YOUR medical status and this would be for someone who basically is overall healthy except for the LS tissue.

And by the way, Yes, I do know of a few studies that says T. is not as good as a steroid or it's a placebo effect (I say NOT SO). In a study I have, the statistics 'did' show a considerable improvement but not as high a percentage as the steroids. Unfortunately most of the studies after that one rejecting testosterone usually refer to that study as it's proof, but many 'many' other earlier studies do show of it's benefits as well. So please DO check out that link dated Oct. 26, 2004 that talks about androgen insufficiency & V. pain.

http://www.medscape.com/viewarticle/492121?src=mp

To 'me' the T. must be properly compounded, some I've used didn't seem to do much or irritated me or had an odd odor, until I found a specific compounding pharmacy that did a great job in 'my' opinion.

COMPOUNDING PHARMACYS

(Note these are also listed in our Home page under database)

I use Bellevue Solutions because Pete Hueseman R.Ph, P.D, (or his son Paul) is very knowledgeable pharmacists with Pete being one for over 30 yrs. He's quite knowledgeable and was very instrumental in developing a formula for the T, cream which is vastly different than most T. prescriptions with the base ingredients and different than the typical 'Propionate T'. Which he doesn't use (the propionate form) though he still uses the standard 2% T. strength which is typical. Although the propionate form is still ok I'm sure, but 'I' really liked his formula so much better.

My formula or prescription for T. states:

"Testosterone Cream 2% in "Liquigel", titrate as needed for topical use".

But.....that's for the Bellevue compounding company and Pete knows what is needed for LS since it's applied directly to the genital area to leave out the irritating base ingredients and I've no idea if others have the T. Liquigel, I doubt it. I found it quite soothing as well, that has never irritated me, and NO negative effects even after 9 yrs of usage. It's somewhat like an opaque whiteish lotion consistency.

Also be certain to ask to have ask to have it put into a tube like toothpaste, it keeps it sanitary, easy to use, and keeps it's shelf life a lot longer as well. Have your physician write that on the script or call and talk to them yourself, which you need to do anyway to set up an account plus he or his crew are more than willing to talk to your physician as well. By the way he does take most prescription plans as well.

That phone number for Pete Heuseman is:

800-728-0288 or 314-727-8787 and located in Missouri, feel free to call him at any time, you might mention my name (Dee Troll) as he is aware of me and our LS group and quite a few women from there have gone to him.

No connection at all, believe me, just a very satisfied user and he'll know it's for LS or vulvar pain in order to leave out those irritating base ingredients. (Though you will want to mention that to them just in case). You can have your 17b Estradiol (Estrace brand name so you can’t ask for Estrace) compounded there if the Estrace brand irritates you, as well as your testosterone cream.

I'm also adding someone new, the name of Mark H. Mandel R.Ph. Another compounding specialist that I've not used but one member has and I too am impressed after speaking with him with his knowledge but have never used him. He's at Mark Drugs and located outside of Chicago, ILL. (Roselle)

Tel: 1- 800- 776-4378 or (630) 529-3400

Just remember you can send or have your prescription filled wherever 'you' want to, yes, even across country. I've used local ones and just have not gotten the quality, consistency or performance that I did from Pete at Bellevue pharmacy.

So I make no claims about other testosterones except that Bellevue’s was quite beneficial to me. They use a different base than most and not usually the propionate form of T. The choice of where to go is always up to you and I hope you can discuss it with your physician as well as them.

Some women mix the two hormone creams together in the palm of their hands, (the T & E)... or apply on top of one another (as I do) together the same night. Someone mentioned she had the 2 compounded together into one cream. My only hesitation is that more of the T would be used than what I did in the beginning of my healing since I used more E than T then, but may work as well and be a good idea but I like to adjust mine and wouldn't be able to if compounded together.

TIP...be certain to wash your hands afterwards if using a steroid or the hormone creams and I'd definitely suggest to 'not' use any of them before sex. You don't want those products on your partner and for heavens sake do NOT use those as lubrication. I recall one member who did and that's a real NO NO...

Again I'd use Bellevue Pharmacy for this but that's 'my' personal choice after having tried many others and interviewing over a dozen by phone across the country and felt Pete definitely ‘knew his stuff’ much better than most.

Also one can also use the steroids to help with the pain at the same time as using the E & T but generally I found it best to use the Steroids in the morning when we're more active and need pain relief & more bathroom usage, TP wiping, walking, sitting, etc., and the hormone creams at bedtime since we heal best at night and that's when we want that restoration. If a bad itch at bedtime of course add the steroid too, but don't be afraid of testosterone, just be cautious and don't abuse or overuse any meds.

By the way I also use a compounded 'natural' Testosterone tablet that I take sublingually every day too with my HRT replacement and have NO side effects. (Also from Bellevue) I've used the T cream twice a week for 'maintenance' and E & T in my ‘’sublingual’’ HRT every day (365) for nine years and have NO side effects at all, no enlarged clitoris, no voice changes, no hairiness, or hair loss, no aggressiveness, etc.etc. Definitely only benefits, *wink* but I do keep track of my hormone levels with blood tests as well. (And know where those levels should be) But please do not be afraid of today’s testosterone; remember we women produce it too.

Keep in mind that it is a 'natural' bio-identical form of T. made with soy/yams as is the Estrace (pure 17b estradiol) and both are bio-identical to what we produce ourselves our whole lives, and NOT a Methyl form of T nor a synthetic form such as the Premarin for estrogen.

NOTE * IF one has had a previous breast cancer that was estrogen positive then you might want to use an oral methyl form of Testosterone since the Methyl T. won't convert to E, (as T does normally) but it can easily be much too potent since it won't increase the T blood levels no matter how high a dosage one takes & and why there are often more side effects with a methyl form of testosterone since you can't measure that but that would be for an oral form, it's not likely to be a methyl form in the cream.

Of course we're all different as well and I've no other health problems but that's 'my' experience. I'll stick with the natural bio-identical every time, especially since that's the least likely to have side effects.

Again, please remember that MORE IS NOT BETTER for any of these medications!

By the way even though the E & T are made from soy/yams they are NOT anything at all that you may see that is SOY related as in those OTC soy or progesterone (P) creams, in fact those P. creams may make you worse since they 'block' our needed estrogen (those 'E-receptors) and are anti-estrogenic which we so desperately need. And most birth control pills have a high progestin content and that too may contribute to our V. pain for the same reasons. (As well as lower the libido)

So don't confuse the E & T with the fact it's made from soy/yams. It's in the processing of it that makes it 'exactly' bio-identical to our own hormones that we've produced all our lives. In fact one it is my understanding that one is unable to tell the difference biologically & microscopically from what I've learned. You do want the bio-identical hormones indeed whether it's the Estrace (estradiol) or the nat. testosterone as far as I'm concerned.

TEMPORARY RELIEF:

Not a real 'cure' perse' but certainly can help with those flare ups for quick relief (hopefully)

Antihistamines:

Over the counter antihistamines can help combat inflammation like Actifed, or Sudafed, (orals) or Benedyrl oral OR the gel especially, can be a great help when applied topically or even Nasalcrom nose spray but sprayed on the genital area. A prescription like Atarax (oral) is an antihistamine and great for hives and itchies as well as inflammation but can make you sleepy, but may really help in a severe flare up and besides we heal when we sleep.

I even used an Atarax (prescription antihistamine) when left with severe inflammation with a bad yeast infection and it helped tremendously to calm things down. The yeast/thrush infection itself was gone but I still was left with that inflammation.

Not that the yeast wasn't cleared up, it definitely was but I find too often we 'think' we still have a yeast infection but it's the inflammation that won't stop (because of an overactive immune system) and we assume that yeast is the problem when it isn't far too often and we mistakenly treat over and over again for yeast.

I recently found this out... The most effective are those older type antihistamines that DO make you sleepy for some reason, so keep that in mind.

Another one that can be quite beneficial is Doxepin cream, brand names of ZONALON OR PRUDOXIN. (Both are prescriptions). I have a study that states this.....

"Doxepin cream has been found to control the pruritus (itchiness) inflammation and pain of atopic dermatitis, eczema, and urticaria - (all histamine, *cytokine; etc. induced) - with results ''superior'' to the use of any steroid cream or oral antihistamines." (In fact 10 X's better)

"Topical Doxepin provided as a five-percent cream has been shown to be extremely effective in controlling the itch, burning pain and inflammation caused by a number of types of dermatitis"

Some newer recent studies (Drs. Ledger, Witkins, Willems, Nyjersey, etc) suggest that over 52% of us 'may' have an autoimmune genetic trigger (gene) that can set off vulvar pain by over producing too much histamine and other inflammatory cytokines,(basophiles TNF etc.) Without us ever knowing the 'trigger' or cause, it's idiopathic, no known cause, sometimes yes, sometimes no, that's why the antihistamines can really help to reduce that inflammation, pain and itch.

Remember that the Protopic or Elidel (the immunomodulators) also halt that output of histamine, mast cells, basophils, etc. (cytokines) hopefully 'before' they can come out (degranulation) they suppress the immune system, and antihistamines and steroids can help afterwards to revert those back. (Hopefully)

Vinegar:.......

On a damp cloth held in the area, to restore pH levels, or a vinegar soak. Helps with the sting and itch, especially helps with inflammation from a yeast infection. (Remember how we put vinegar on a bad sunburn as a kid? That's why, and it doesn't usually sting... didn't me anyway but it may someone else.

CORN STARCH........

In a sitz soak of warm water or on a dampened cloth, I always found soothing. Remember moms using it on babies for bad diaper rash? I don't have a specific sitz bath or pan, but using a large basin I used to sit on the floor with towels and then set it in front of the TV while I sit in it, legs akimbo outside, I lived alone then so it was easy. There are some made that sit on the commode and relatively inexpensive.. I used about a cup in a small basin. I've seen some soak a menstrual pad in it to hold against themselves for relief.

HONEY:*Update*.....You'll never think of it as 'just honey' again as it does have healing powers. To read of it's many benefits.

try this link.

http://www.healthliesexposed.com/articles/article_2006_07_14_2651.shtml

Honey has been known to help with yeast/thrush infections and is an excellent wound healer. "Raw honey is exceptionally effective internally against bacteria and parasites. Plus, raw honey contains natural antibiotics, which help kill microbes directly. Raw honey, when applied topically, speeds the healing of tissues damaged by infection and/or trauma. It contains vitamins, minerals and enzymes, as well as sugars, all of which aid in the healing of wounds."

BAKING SODA..... Sitz or a bath-soak, some have luck with that, but it burned and irritated me severely. It has a higher pH level which may irritate us as does sperm and blood which also have higher pH levels in case you didn't know that and why that can irritate. Again, we're all different but some find it soothing.

BALNEOL LOTION: This was recently mentioned as excellent for itch and is available OTC. I've not used it but it had high reviews.

THE 'CAINES' ....like Lidocaine, EMLA, ELA-MAX, benzocaine, prilocaine etc. used topically. From several technical studies that I've seen, those 'caine's' also help reduce histamine, cytokines, basophils etc. from the Mast cells (as mentioned above and why we use antihistamines) which causes that inflammation or itch, as well as it's a numbing agent for help with that pain. A recent report of using Lidocaine on a cotton ball at night, set into the vestibule for up to 7 weeks nightly has shown some improvement with women with Vulvodynia (painful vulva).

A clip from one report.....

CONCLUSIONS: "Our results indicate that lidocaine directly inhibits histamine release from both rodent mast cells and human basophils in vitro, an allergic reaction caused by direct effect of lidocaine seems to be impossible."

Not saying it's a cure perse' but for possible relief but I have seen some few women say they were allergic to it so be careful of not overusing it. Listen to your body and initially I would only try one tiny small spot to see how YOU react, in fact that's so with any of these meds.

EPSOM SALTS ....soaks or sitz bath for soothing and healing also great for drawing infections out. To use in the tub I'd suggest a couple of cups full, (maybe half a cup in a small basin or sitz) great for aching muscles too as it adds Magnesium < click> to our bodies.

Also I try to take extra Magnesium < click…. It's a different site> orally as well up to 800-1,000 mgs a day. Magnesium also reduces histamine. It's wonderful for how good it is for us in many ways and Magnesium helps reduce inflammation and pain as does estrogen help quell those painful nerve endings called nociceptors or pain pathway . Don't use Epsom salt soaks too often or it may dry the tissue. Ocean salt water and Sea Salt works well too.

CHAMOMILE.... tea bags soaked and then pressed on the vulva may help for pain relief as it's supposed to soothe but I've not tried that personally but some members claimed relief.

ALMOND & PEPPERMINT OIL .....We've had several members approve of this and they claim it works quite well for a pleasant cooling relief.

1oz. of almond oil with 2 to 3 drops (ONLY) of peppermint oil.

Be sure to mix it up and keep in a dark container to keep its strength. Don't use more than those 'few' drops, it did severely irritate one member but others really like it. It may feel a little warm initially I hear. Beware of Tea tree oil, that has been reported to extremely irritate unless hugely diluted but apparently also good for a yeast infection.

EMU OIL... More' than a few members really liked this product (OTC) often ordered 'on line' claiming it helped quite a bit for the itch and was very soothing. It supposedly has no taste or odor (some do, some don't) and can be used even as a lubricant. Suggested use is 4X's a day. A full list of resources is available the LS Home page suggested by our own members under LINKS. One of the more often mentioned brands & well researched by one of our members is by Laid in Montana

It may also be very helpful for burns, cuts, arthritis, Fibromyalgia, joint paint, thickens the skin and so much more from the sites I've seen. (With some legitimate studies) and even used for burn or radiation patients.

I ordered some (not that I need it now with being well) as I wanted to know about it, and it's an extremely light type of oil and very gentle, only a few drops are needed and it may be an excellent compounding 'base' to use with some compounded meds as a carrier for deeper penetration of the main medication. But do be careful of using it 'with' a steroid as it may penetrate the steroid too deeply, some 'few' members have been bothered with that combination others have no problem.

AQUAFORE .... Another topical for soothing, some swear by this as an aid for relief. I tried this myself just recently for chapped hands & lips and it's very similar to Vaseline but I like it better, BUT..... Nothing is more pure than plain ol' Vaseline as far as not having other ingredients that may irritate.

EGG WHITES ? Yes, someone suggested this as it was suggested by her physician to give it a try and she said it truly helped with her flare up, I doubt it would hurt you and might be soothing. ;)

BABY DIAPER RASH CREAMS.... like A & D or Desitin, or Balmex, used for soothing. It's suggested that the more Zinc in them the better as zinc is good for tissue healing. I believe Desitin has the highest amt. of zinc at 40%.

BURTS BEES DIAPER OINTMENT ...A member suggests Burts Bee's Diaper Ointment and says this... "it's wonderful stuff, it's all natural, has healing herbs, is a powerful barrier, smooth as silk and smells GREAT to boot".

CRISCO or a vegetable type of oil, especially Olive oil and another is Coconut oil:

Those have been suggested by some physicians as well as in some articles and definitely by patients to be very soothing or to even use as lubrication and this too can be used as compounding 'base' Careful though if using a condom they may weaken it.

VASELINE... Is always a good standby for severe irritation, especially in those cheeky butt cracks or to protect the vulva from urine or blood irritation. Sometimes we just need to take a break from all of those chemicals and protect the inflamed tissue without using anything that might be 'harsher'. Most Physicians agree with using it, a few others don't, so it's a matter of opinion, but I've used it quite successfully and never had a problem.

VANICREAM... This is available OTC, (Wal-Mart's) and fairly inexpensive even by the tub. I've seen some patients rave about this as a soothing type cream. Not a real 'fix', but when we need daily relief they claim it truly helps and is suggested by some dermatologists as well. I've not tried it myself and a few said it irritated but others seem to love it.

VICKS ...Diluted with Vaseline has helped some as well. 3-4 to 1 ratio. (Less Vicks) I know of one woman who swears by Noxzema as well for relief of itching. It was a little too 'stingy' for me though and it may act similar to the 'Almond & Peppermint oil mixture' with that menthol cooling effect. One member used ONLY the Vicks and it helps her tremendously. As for me I personally don't like that menthol effect it feels too 'burny' for 'me'.

MILK... Soaks or compresses I've also seen recommended as soothing. So did Cleopatra. *smile* and milk truly can take the sting out of things. Recently I suggested it to a member who was in a severe flare up and she was amazed it gave her almost instant relief when nothing else did. *smile* Try it on a menstrual pad and hold against yourself for one idea, or perhaps sit in a small sitz bath with some.

BUTT PASTE http://www.buttpaste.com/ Yes that's its name, and some members claim this is great for soothing relief as well.

UDDER CREAM... is another & used for cows’ teats but works for us as well. :)

AVEENO SOAKS, ...or creams, lotions, or a compress made with it purchase that OTC, or you can make up your own by grinding up Oatmeal or Mothers oats, (same ingredient) some find this very soothing but might clog up your tub if you use it there for a soak if you don't put it in a nylon sock. *smile*

ICE PACKS ...Try a bag of Frozen Peas, it's malleable. This can give some relief. Wrap carefully in a cloth to not freeze or damage the tissue, the peas move easily to form.

A recipe a member gave is: 2 cups water 1/3 cup (80%) alcohol - rubbing alcohol, vodka, etc. combine ingredients & pour into a vacuum Seal Bag or Ziploc baggie, just seal & freeze & then double bag. The alcohol keeps it from freezing solid and creates a gel-like ice pack.

Popcorn Kernels are another suggestion since those mold to the shape. Just put in a cloth bag and pop into the freezer (definitely not the microwave *chuckle*).

DERMOPLAST: Is a pain relieving spray with benzocaine (a numbing agent) and menthol in it. When in a severe flare up this may help. It's also been suggested to use after having a biopsy done for pain relief. I read of a woman whose doctor told her to spray Dermoplast on her pad after the delivery of her baby or apply it with a cotton ball and said it really helped with her burning & itching. One woman said the ‘red’ can (an antibacterial spray) was devastating to her, so be careful not to get that one. Always try the smallest amt. of anything first to see how 'you' react.

I want to sincerely thank all of the members who contributed some of these suggestions *smile* to be cont. I'll add more here with time (or space) ....

OTHER SUGGESTIONS

1. It's best to NOT use 'any' soaps to cleanse the vaginal area even if it sounds unusual, it's true. Use mild soaps always for the rest of the body as eventually some soap residue will end up there, shower or baths. If you do feel you need to use soaps, one suggestion is Dove recommended by several physicians and in articles, or Neutrogena or Cetaphil if you feel you must (try not to though). Natural Beauty Cleansing bar by Natures Plus with Vit. E and allantoin has also been suggested for those who don't feel clean without soaping.

We just had a new suggestion from a member who loves this and finds it excellent. Soaps by Blue Heron http://www.blueheronsoap.com is a 100% food grade olive oil, palm oil, and coconut oil as the base, with the powerful essential oils. She says it has a surprisingly rich, thick lather even in hard water and will last 2-3 times longer than regular soaps because of their density. They use no animal products and are environmentally friendly but it isn't an antibacterial soap if that's important to you yet quite gentle on the vulvar tissue.

Remember we can't 'wash' this disease away and the vagina is self cleansing. Do not think your normal feminine odors or even normal discharge is something else or unclean or unhealthy. ☺

2. Some suggest wearing white 100% cotton underwear which I tried but to no avail. Be sure to thoroughly rinse well when washing them. (Though personally that didn't make any difference for me either) It's best to wear NO panties if you can or pantyhose the least amount of time you can especially at night as air circulation is important. Wear loose fitting clothes, skirts, baggy pants, etc. so that nothing is close to the vulvar area to irritate it even more such as panties or tight jeans.

3. Some have done this for relief: Rinse the vulvar skin with warm water after urinating using a spray bottle. Use water poured over the area while urinating. Pat, don't rub, gently with toilet paper, or try softer facial tissues instead. Some women use a hair dryer set to 'cool' afterwards to be sure the area is dry to make one less likely to get a yeast infection.

Take a warm/hot bath 'before' applying your meds, it helps them to absorb better. If in a severe flare up, some have sat in the tub with water to urinate to dilute it. Some have suggested using a funnel type appliance (or even a paper cup) to hold against the urethra to direct the urine stream away.

4. Use a lubricant to make sex more comfortable if needed. Some suggestions are Astroglide, Liquid Silk, and Slippery Stuff <--*my favorite* and to me is the most natural, no odor or taste or stickiness, rather than KY or Astroglide, which can irritate some people. Many lubricants contain glucose (sugar) and that 'might' trigger a yeast infection. (Look for that ingredient) I have just heard recently of one woman who was irritated by the Slippery Stuff, so again we're all different but for me it was the most natural and like me.

One member suggests Emerita Personal Lubricant, she says not for the lubricating properties, but because of its ingredients: Aloe Vera Gel, Calendula, Vitamin E, Ginseng and Black Walnut Leaf. She applies it 5 times a day and claims it is absolutely fantastic. This is NOT the Emerita product that is progesterone based, so please do NOT confuse it with that. Progesterone creams & progestins, Soy, birth control pills, and even yeast 'blocks' our E. receptors and we 'do not' want that.

Many fine lubricants can be purchased on line if you can't find them OTC. Olive oil and even Crisco has been recommended by physicians and is excellent as well.

BEWARE and Use NOTHING with non-oxynol 9 in it!!

5. Avoid all lubricated condoms, lubrications or spermacides that contain the ingredient NONOXYNOL # 9 or derivatives of it in them!! It's extremely irritating and suggested to not use even if one is healthy. Check those ingredients!! It has been banned already in some countries and they're working on it in the USA as well and is before the FDA right now for consideration or at least to have warnings on it. It can increase ones risk for STD's and even AIDS because of the little tears and fissures it can cause in the tissue. (Feels like asbestos)

6. Use 100% cotton menstrual pads or tampons, do *'NOT'* use the *ALWAYS* brand, it's been found in medical journals to cause even more irritation. A full article about this is at the LS home site under Files. Do not use pads or tampons that are scented. If you use tampons you may find those with the 'plastic' inserts easier to use as they glide easier esp. if wetted first. There is also a cup type that is inserted to collect the menstrual blood.

7. Do not use feminine sprays or talc's or bubble baths.

8. Avoid sex that hurts and never 'make' yourself perform.

DIETS

Last, but certainly not least to consider are diet possibilities for some of you. I've tried them all over the 10 years with a good trial run, and for 'me' they made no changes or differences at all and luckily I can eat anything, but we've had some report good results by eliminating basics such as Wheat, (grains) Diary, and Sugar and within a short time they can see a difference, especially with eliminating the grains or Glutens. No doubt at all if one has Celiac or if you have a lot of 'gut' problems like Irritable Bowel or problems with constipation or diarrhea.

Some take the Omega 3 oils, (I do) that can be wonderful for its many benefits for the whole body for anyone it's an excellent addition for overall health. EPO (Evening Primrose Oil), and Flaxseed have also been recommended. By the way the EMU oil is high in Omega 3 and can also be purchased in capsules for internal usage.

Some have tried the Guaifenesin & Low Oxalate diets, (I did both and they made no difference) and the low oxalate one hasn't been proven scientifically according to the literature, but eating certain foods, like greens, chocolate, berries, jello, beans and nuts, may produce oxalates in the urine that are irritating as the urine flows over that damaged tissue.

Eating less of these foods may help but remember it's the tissue that's damaged and not necessarily the food you are eating if it never bothered you before, when even water or air flowing over it can irritate. Just as holding salt in your hand wouldn't burn or irritate but if you had a cut or wound of course it would. But the salt isn't the problem, the broken excoriated skin is.

By the way many of those same foods I just mentioned might trigger a Herpes outbreak in case you didn't know that since many are high in Arginine. (That is a real 'no no' for Herpes).

Herpes can often be contained quite well by the way with taking the amino acid Lysine (also found in foods) to counter that breakout (avail. OTC).

It's worked for me for well over 15 or more yrs as I was prone to Herpes 1 (cold sores) on my facial lips, but haven't had one in years IF I take Lysine immediately within seconds of feeling that 'tingle'. Recently on vacation (wouldn't you know it) I didn't have any with me on the beach, felt the tingle and sure enough I had an outbreak. I was so upset with myself but it also proved how good the Lysine really is and works if it's taken immediately upon feeling that odd or weird tingle, so I always carry a few with me in my purse. ☺

VULVAR SELF EXAM

It's very important that we ourselves keep an eye on our bodies as well. Never leave your health in someone else's hands completely. Know your own body! You might want to check out this info as to how to examine the vulva from the U. of Michigan.

Just as you would examine your breasts or skin for changes, you should examine your vulva. Many diseases of the vulva have similar symptoms. This vulvar self-exam will help you to be aware of any changes in the vulvar area that may need ongoing evaluation. Some changes in the vulva may mean cancer. Learning how to do a vulvar self-exam can best accomplish this. "Your private area should remain private but not to YOU," as one author, Dr.E.Stewart, quotes from her excellent book, 'The V Book'.

1. Wash your hands carefully before you begin.

Lie or sit up in a comfortable position with good lighting and a hand mirror (a magnifying mirror may work best). It may help to prop up your back with pillows, or you can squat or kneel. Finding a comfortable position is important so you can clearly see the vulvar area, perineum, and anus. First, just look and learn. Things may appear different from what you expect, and that does not necessarily mean they are abnormal.

2. Gently separate the outer lips of the vulva. Look for any redness, swelling, dark or light spots, blisters, bumps or other unusual colors. (Be especially aware of fusing or adhesions of the smaller labial lips that look like they're 'melting' or disappearing. Dee t)

3. Next, separate the inner lips and look carefully at the area between them for the same changes. Also, look at the entrance of the vagina.

4. Gently pull back the skin or the hood covering the clitoris and examine the area under the hood at the tip of the clitoris. (That can fuse as well as the smaller labial lips. Dee T)

5. Be sure also to inspect the area around the urethra, the perineum, the anus, the outside of the labia majora and the mons pubis. (The Urethra can narrow occasionally as well, and you may find yourself 'spraying' all over when you urinate. Several women had to be catheterized regularly and the Estrace cream definitely helped eliminate that. Dee T)

BASICS and common sense....of course,

Along with good nutrition, and perhaps a good 'One a Day' Vitamin-mineral supplement, regular exercise, drinking plenty of water and getting some fresh air is a good place to start.

One of the most important I think is a sound, restful sleep and is a basic requirement for overall good health and sleep is truly when we do heal best. (It has to do with our circadian rhythms).

As the demands of modern life contribute to increasing levels of stress, try to eliminate as much STRESS as you can as stress appears to be a big component in many flare ups, most especially in autoimmune diseases.

CONCLUSION

We have to keep in mind there are basically several prongs in the approach to LS or Vulvar pain in general and one formula doesn't work for everyone of course, but over the many years (18+) I've studied this and 10 years of suffering and now with 9+ years of being well, these suggestions above have been the most beneficial for myself and so many others.

We have to first eliminate symptoms, get relief as soon as possible & and then work on rebuilding the tissue.

1... Prescription medications for pain, itch, burning, and inflammation, are for symptom relief, such as the Steroids or Protopic or Elidel or the milder steroids for general Vulvar pain. A newer product on the market is Atopiclair (prescription) and some members are using that to replace the steroids for symptom relief such as the itch or inflammation and it doesn't thin the tissue as steroids may and is apparently very soothing & healing as well.

2... Other minor suggestions like the antihistamines, milk, Ice or Over the Counter baby type creams for quick help and relief in a bad flare up but not a cure perse'... are for hopefully 'quick' symptom relief.

3.... Then we have the prescription Hormone creams like the Estrace and Testosterone (E & T) for rebuilding the tissue to full healthiness, stretchiness, color & tone and even hopefully unfusing of the labial & clitoral adhesions, but it takes longer to work as skin has it's own rate of renewal but are definitely effective whether it's LS or Vulvar pain if the tissue needs healed to regain it's elasticity, tone, color, etc. to prevent that tearing, or razor like cuts or splits (fissures) and E can even soften up old scar tissue.

So we have different reasons for each medication and quite often why both a steroid 'and' the hormone creams are needed.

4... We also have our diets to consider which may contribute to pain in some cases and definitely worth checking out or giving one a good trial run but if foods did not bother you previously its not likely to affect your LS afterwards either.

5.... Lastly just some common sense things to avoid, like tight clothing, jeans, no panties, no soaps, eating and sleeping right and trying to eliminate stress.

Those are just quickly off the top of my head, even though it took forever to type or you to read, *smile* please forgive any redundancy's. I will be adding more as time allows.... (Or space) plus once again, make absolutely sure you have ruled out all infections. If you have an infection whatever you do will be temporary and must be fixed and taken care of first. Keep in mind that they can co-exist along with the LS so do not mistake a yeast infection assuming it’s your LS flaring up.

Rule out bacterial infections, yeast infections and viral ones, especially Herpes!! Herpes is quite often overlooked and may not ever show blisters or typical symptoms, it may be a simply tiny red spot or like a brush burn, or just a tiny rough spot that consistently irritates you and it may be worth trying a Herpes oral medication, it just 'may' help.

I've seen that happen FAR too often with more than a few members over the years and unfortunately because the 'thought' of having Herpes is so taboo and shouldn't be, when at least that can be contained and controlled. It is much more common than one would suspect and often with NO visible symptoms either, many studies say that most have no idea they carry it, so please be doubly sure it's not that and worth a blood test to double check and rule it out. PLUS using a steroid if it is herpes will only aggravate it even more and it can become a terrible vicious cycle of pain.

NOT CONTAGIOUS:

Last but certainly not least my dear friends know that this disease is NOT contagious, nor is it a sexually transmitted disease, nor generally associated with cancer. Though there may be a slight risk increase of 3 - 5% with LS with a long term itch & scratch cycle or a sore or lesion that is chronic and simply won't heal and most cases of V. cancer connected with LS are in over 50% that have not been treated.

So please don't hesitate to have a biopsy if that's the case if only to rule out cancer. I personally think cancer is the 'main' reason for a biopsy myself especially is one has a lesion or sore that hasn't healed for a long time. Do not second guess here! Many physicians feel treating LS or Vulvodynia with a steroid as the first course of action, and if that doesn't help then of course a biopsy would be suggested.

Quote* “If a patient presents with what appears to be lichen sclerosus of the vulva, it is often a good idea to treat her with clobetasol propionate before attempting to biopsy any lesions unless an obvious carcinoma is present.” Dr. C. Paul Morrow.

It has nothing to do with poor hygiene, it was nothing you did nor did anyone give you this! You are not a bad person nor deserved this. (Think of the poor little infants with it)

Most theories are saying LS is autoimmune and likely hormonally connected and probably passed on genetically or a 'tendency' to it, and to males as well, although it's called BXO *(Balanitis xerotica obliterans)* in males, it's the same disease. The foreskin may adhere or fuse to the head of the penis.

So you 'moms' out there, be aware for your little sons as well as daughters. Treatments are likely be the same with usage of a steroid and as I mentioned above possibly the Estrogen creams even for males as well. Also a circumcision is often suggested if one hasn't had that done and LS (BXO) rarely reaches the anal area in males because of the scrotal sack where it does with women.

LS is likely to be hormonally connected as well since it seems to be more prevalent in pre-pubescent youngsters and menopausal women (both are lacking or have less Estrogen) though on the LS group I can assure you are many ages in between that.

Know most of all that you can be made well!

Never ever give up that hope and yes, setbacks or flare ups may occur but you 'will' find the right 'key' for you and that is when you mustn’t give up or give in. Consider surgery only as a very last resort and it's rarely recommended for LS and if it is LS, it may return anyway. Healthy tissue in grafts has turned to LS in many cases and LS tissue turned healthy grafted to a leg, so it's vice versa.

In some few cases of other vulvar pain, like Vestibulitis, surgery may help but I'd most definitely consider that only as a last resort. Surgery cannot be 'undone' and I've seen far too many unsuccessful stories unfortunately, and yes some few good ones, but rarely is surgery suggested with LS.

Discuss how you're feeling with your partner, get support from friends and groups such as ours as the frustration and futility let alone the pain, can be overwhelming at times and not only physically but emotionally devastating as well.

If you'd care to join the Lichen Sclerosis support group, we'd welcome you. This is the address: http://groups.yahoo.com/group/LichenSclerosis

We discuss many various kinds of genital problems and there is so much medical information there as well as photos in the archives with many links, polls, and even physician recommendations.

Another I am the owner of is the Vulvar Disorders list, more varied and not as focused on one specific thing but collective vulvar pain from many causes: http://groups.yahoo.com/group/VulvarDisorders

If I got well (using the E & T hormone creams) after ten years of excruciating pain and I was truly a worse case scenario, YOU can/may as well, *smile* so hang in there my dear friends. I sincerely hope from the bottom of my heart, some of these suggestions I've made can help you as I wish I had known of them nineteen years ago to have spared me the agony and pain of this as well as the precious time lost trying the myriad of things out there and even going thru a broken relationship as the emotional toll this can take can be as bad as the physical pain.

Big BIG hugs and healing thoughts out to one and all and again these are just 'my' opinions and suggestions and my experience and I am one of the healed as far as I'm concerned. (Nine yrs. as of April '08) Others may say I'm in remission, to me it doesn't matter I've no pain and life is normal and happy once again and I even got remarried a few years ago, *smile* (after yrs of forced celibacy because of this pain) but I do make certain I continue my maintenance of both hormone creams (E & T) once or twice a week to keep me well.

Love to all, and wishing you too, healthy days ahead!

Dee DTroll@cboss.com

Owner of the LS group at Yahoo~ ;)

Note....All of the information from the above, is meant for general health information purposes only, and is not intended to be medical or pharmaceutical advice or otherwise take the place of your doctor's orders, or to diagnose or treat your specific health problems. These recommendations are not a substitute for professional medical advice, diagnosis or treatment and are 'my' opinions only and based on 'my' experience and research of many years as well as much anecdotal evidence of members with over 11 years with my LS group.

This article is for personal use ONLY for the person to whom it was sent and not to be distributed to anyone outside of to whom it was sent personally by me without my express permission, excepting your physician which is fine to show it to.   (Though I'd certainly shorten it) *smile*

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