



Sexuality
and SCLERODERMA

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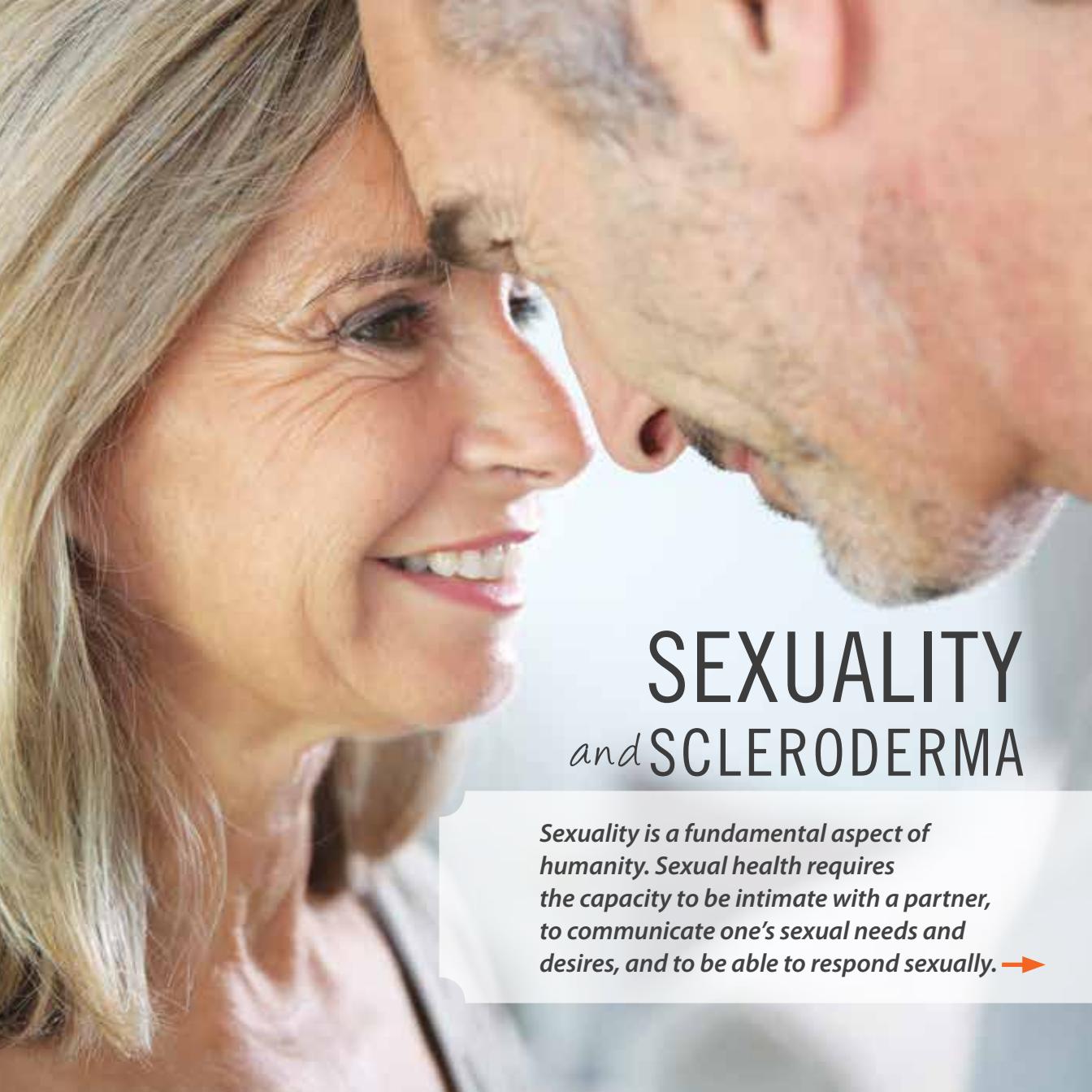
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SEXUALITY *and* SCLERODERMA

Sexuality is a fundamental aspect of humanity. Sexual health requires the capacity to be intimate with a partner, to communicate one's sexual needs and desires, and to be able to respond sexually. →

Sexuality is most often seen from a biological angle, solely in terms of sexual relations and their functions. However, there are many other aspects to sexuality. Its psychological and emotional dimensions include attitudes, emotions, feelings, love and body image. From a relationship standpoint, sexuality is intimately linked to commitment, intimacy, communication and emotions. And of course from a moral and spiritual viewpoint, our beliefs and values guide our sex life. Many of these aspects of sexuality are interrelated, and help shape our view of sexuality.

When it comes to **sexuality**, there is no single ideal model. In the general population, at least one third of men and women experience sexual difficulties. Scleroderma can affect a patient's sexuality. Pain, fatigue, limited joint mobility and medications can obviously have an impact on a person's sex life. The disease itself can also influence sexual function: decreased sexual desire, vaginal dryness in women and erectile dysfunction which is often found in men with scleroderma.

Fatigue and pain

are common symptoms reported by scleroderma patients and have an important impact on a person's sex life. They can cause sadness, anxiety, and frustration, as well as a sense of helplessness and loss of interest in sex. To adapt to the situation physically and psychologically, you must preserve your integrity by respecting your own needs, desires and limits.

Fatigue

Sexual intercourse requires a significant energy expenditure, approximately 200 to 300 calories. That's why it's important to choose the right moment to have sex, preferably when your energy reserves are high, for example in the morning, during the day or after a nap. Before intercourse, you should avoid any strenuous activity that requires a high energy expenditure. Save your energy for moments of pleasure. Talk to your partner about your energy level. Truthful communication allows partners to understand each other, help each other and respect each other's needs.

Pain

Pain during sex is reported by 62% of scleroderma patients. It can be difficult to awaken sexual desire when you suffer from back, joint and muscle pain, contractures and vaginal dryness or erectile difficulties.

Here are some tips to help minimize pain during sexual activity:

- Choose a time of day when the pain is less intense.
- Take a painkiller 1 hour before intercourse or take anti-inflammatory medication, but only if authorized by your doctor.
- Take a warm, soothing bath and do some stretching and relaxation exercises.
- Protect yourself from the cold, to reduce the effects of Raynaud's phenomenon. Raise the thermostat, warm the room and use light, warm blankets if needed.
- Focus on the excitement and feelings of pleasure rather than pain.
- Inform your partner of your painful points and adjust touches and positions accordingly.
- Adopt positions which improve your comfort. Use pillows or cushions to help support painful joints. Avoid positions that cause pain or require you to put pressure on your hands or feet. Tell your partner what causes you pain, and avoid sudden or sharp movements if these are painful. You should not have the full weight of your partner on top of you. Try out different positions and variations to determine which ones suit your needs.



Both partners lie on their sides while facing each other. A pillow can be placed under the knees or head, if needed.



Both partners lie on their sides. The man's stomach is pressed against the woman's back. Pillows can be used, if needed.



The man lies on his back, the woman squats over him while supporting her own weight.



The man lies on top of the woman while supporting his own weight. The woman can place a pillow under her knees to keep them slightly bent. She can also place a pillow under her head.



The woman lies on her back with knees flexed, over her partner's hips. This position can be useful when the woman suffers from contractures in her hips and knees.



The woman lies on her back with knees bent crosswise over the man. Both partners' hands are free, allowing them to caress each other.



The woman lies on her back on the edge of the bed, her knees bent and feet on or near the ground. The man is kneeling. Pillows may be used, if needed.



Both partners stand. The man is behind the woman. Her knees are slightly bent and she leans on some furniture for support. Pillows can be used if needed.

Vaginal dryness

Vaginal dryness is a common symptom in women with scleroderma. It can worsen with menopause because of declining estrogen levels. This disorder can have a significant psychological impact and lead to a decreased libido (sex drive), which in turn can affect the couple's relationship. However, there are solutions that can help address this problem.



Vaginal moisturizers and lubricants are first-line treatments. Hormonal treatments should only be used if recommended by your doctor.

Vaginal moisturizers

Applying a hormone-free moisturizer can help restore vaginal moisture and improve the elasticity of the vaginal walls, thus improving comfort. You can buy these products at a pharmacy without a prescription. Typically these moisturizers can be easily applied in the vagina either as a gel, or in liquid form. Regular application every three days can increase their effectiveness. However, used regularly, these products can cause vaginal discharge. Applying the product at bedtime and using panty liners can help reduce discharge. Your pharmacist can tell you more about these products.

Example of vaginal moisturizers

Replens[®], YES[®], Vagisil Intimate Moisturising Lubricant[®], Moist Again[®], Levana[®], Me Again™, Hyalo GYN[®], K-Y[®] - Silk-E[®] - Vaginal Moisturizer

Vaginal lubricants

Unlike vaginal moisturizers, which can be applied every three days, lubricants are only used, if needed, during sexual intercourse. Lubricants facilitate intercourse and also increase comfort. They also enhance sexual pleasure. They are usually applied on genital organs and at the entrance of the vagina before or during sexual activity. Some women use both vaginal moisturizer and lubricant to improve comfort during sexual intercourse.

**There are two types of lubricants:
water-based and silicone-based.**

There are several **water-based lubricants** available on the market. They contain mainly water and most are harmless to your health. Some contain glycerin to extend their duration of action. Others may contain allergenic ingredients. Those with sensitive skin should consider using a product without preservatives (such as methylparaben or butylparaben). Reading the list of ingredients on the packaging will help you make the right choice for you. You can also talk to your pharmacist for more advice and information on water-based lubricants.

Examples of water-based lubricants

YES[®], SLIQUID ORGANICS[®], Astroglide Glycerin and Paraben free personal lubricant[®], KAMASUTRA[®], ASTROGLIDE[®], K-Y[®], SLIPPERY STUFF[®], PLEASE CREAM[®], LIQUID SILK[®], ID GLIDE[®], MAXIMUS[®], PROBE[®]

Silicone-based lubricants have a thinner texture and a longer lasting lubricating effect than water-based ones. They are usually hypoallergenic. However, they are more expensive and more difficult to clean off the bedding. A word of caution: be careful when using these lubricants in the shower as they can make the surface slippery. Check with your pharmacist, as these products are readily available in pharmacies.

Examples of silicone-based or oil-based lubricants

YES[®], PINK[®], EROS[®], ID MILLENIUM[®], WET PLATINUM[®]

If vaginal dryness is caused by menopause, hormonal therapy can be considered. Be sure to discuss this with your doctor.

In addition to using lubricants or moisturizers during sexual intercourse, give yourself more time to achieve natural vaginal lubrication and reach sexual arousal.

Do Kegel exercises regularly. These exercises aimed at strengthening the perineal region can be beneficial to your health and overall comfort, but also allow you to experience more pleasure during sexual activity. They are suitable for women and men of any age. Better muscle tone and increased blood flow in the genital organs enhance sensitivity, improve vaginal lubrication and erections, and promote sexual pleasure in both man and woman.

Contracting the muscles that prevent urination and bowel movement will help you identify your pelvic floor muscles. Tighten these muscles and hold the contraction for 3 to 5 seconds. Do this 10 times. Repeat these exercises 5 times in the course of the day. You can do these exercises discreetly, at anytime and anywhere. If you want to learn more, there are a number of excellent websites that explain how to do Kegel exercises.

SEXUAL DYSFUNCTION IN MEN

Erectile dysfunction (ED)

is the repeated inability to achieve or maintain an erection long enough to perform sexual intercourse.

It is believed that this condition affects 40% of men over 40 and up to 60% of men over 70 years of age.

This condition is found in 80% of men with scleroderma. It is due to vascular problems and fibrosis of the cavernous tissues in the penis (corpora cavernosa) which reduce or obstruct the blood flow needed to achieve an erection.

Today it is widely recognized that erectile dysfunction often has multifactorial causes, and in many instances physiological causes are compounded by psychological ones. Commonly held stereotypes of virility according to which the male asserts his masculinity by his capacity to have an erection, may further exacerbate this difficulty and contribute to a loss of sexual desire.



Treatments for erectile dysfunction are very effective.

Several drugs are available in tablet form, to be taken as needed before sexual intercourse. They work by increasing blood flow to the penis, helping the man achieve and maintain an erection. These treatments, called phosphodiesterase type 5 (PDE-5) inhibitors, require a medical prescription. Sildenafil (Viagra®), vardenafil (Levitra®), tadalafil (Cialis®) and avanafil (Spedra®) fall in this category. These drugs are sometimes used to treat other symptoms of scleroderma such as pulmonary hypertension and complications associated with Raynaud's phenomenon.

There are alternatives for when PDE-5 inhibitors are ineffective or their use is contraindicated.

- A urethral **suppository** (MUSE®) or cream (Vitaros®) containing a vasoactive agent called alprostadil relaxes certain muscles in the erectile tissue and increases blood flow to the penis. The drug is introduced into the urethra 5 to 30 minutes before sexual activity.
- A **penile injection** is the process whereby a vasoactive substance (e.g. alprostadil) is injected directly into the corpus cavernosum of the penis. Self-injection is carried out on the side of the penis for an erection that lasts 30 minutes to 1 hour.

- **Penile constriction rings** are devices placed at the base of the penis to maintain an erection. Essentially, they trap blood in the penis, making for a stronger and longer erection. When the penile ring is not sufficient, a **vacuum erection device** (VED) or vacuum pump can be used in conjunction with a penile ring. It involves a cylindrical device placed over the penis to create a vacuum that triggers an erection, which is maintained by a penile ring.
- When all other treatment options have failed, a penile implant may be considered. A **penile implant** is an inflatable device with flexible stems which is inserted in the penis. A pump is used to produce an erection. This permanent solution requires surgery.
- In addition to conventional medical treatment addressing physical health problems, psychotherapy and behavioral therapy can be beneficial to sexual well-being.

Body image

If your physical appearance has changed during the course of the disease, you may suffer from low self-esteem, which in turn can affect your sex life. Here are some tips to improve your self-confidence.

Share your fears and feelings with your partner or someone you trust and who will reassure you. Beauty is subjective and, you might be pleasantly surprised by how others see you.

Focus on what you believe are your best features.

Take care of yourself. Pamper yourself and get a new hairstyle, clothing or a massage. Whatever it is that makes you feel good.

Dim the lights during sex or turn them off completely if this reassures you.

To help you get through this period of adjustment in your life, use your sense of **humour**, give yourself **time** to find what works for you and **engage** your partner in the process. Overall, this will greatly improve your sex life!

Loss of sexual desire

A person's sexual desire will fluctuate throughout their life. It's intensity highly depends on the state of the person's relationship, physical health and state of mind, as well as life's many ups and downs. Lack of desire can affect both men and women.

Scleroderma greatly affects one's energy, physical and psychological health, and lifestyle habits. All these changes can impact a person's sex drive. In addition, some drugs have adverse side effects on sexual health.

If you think your medication is affecting your libido and your sex life, talk it over with your physician, who might be able to recommend some adjustments.

Communication

Here is some advice to promote sexual desire and increase pleasure:

- Maintain **effective communication** with your partner. Effective communication allows for the expression of feelings, inclinations, preferences and desires. A mutual understanding of each other's needs and desires will do a great deal toward promoting a satisfactory relationship.

- **Tell your partner how you feel and listen to him or her.**
 - Clearly communicate how and where you like to be touched.
 - Remember that the **way you communicate** affects your relationship with your partner.
 - Choose the right time to talk and listen to each other.
 - Communicate your preferences and be open to those of your partner.
 - Tell your partner what you like, not just what you don't like.
 - Deal with only one issue at a time instead of venting your spleen all at once. This will allow your partner to make adjustments.
 - Write down your expectations to help start the discussion and facilitate communication.
- Indulge your desire for **fantasy, romance and inventiveness.**
 - The brain is a sex organ. Ultimately, all signals stem from our head and play a fundamental role in facilitating sexual arousal. Spark your imagination and allow yourself to fantasize. You don't have to carry out all of your sexual fantasies. What gives us pleasure in our imagination will not necessarily have the same effect in real life. That being said,

carrying out some fantasies can bring novelty in one's sex life, provided the fantasy is shared and you know to what extent your partner is ready to go along for the ride.

Awaken your sensuality

Make use of all of your senses to be in touch with the world around you so that you might experience things more intensely, building a connection with your partner through sensuality, developing a new sense of closeness and intimacy. Your goal should not be to achieve arousal or an orgasm. The objective is to become fully aware and enjoy the sensations perceived through your senses. Be creative and use whatever works for you: movies, an erotic or romantic ambiance, music, flowers, pleasing smells, caresses, a massage with soothing cream or essential oils, light touches, sex toys, food, candles, wine, soft bedding, sex shops, etc.

In the absence of desire, gentle touches, hugs, cuddles and kisses can help foster intimacy. Take advantage of these opportunities to experience closeness and pleasure with your partner.

Maintaining sexual health throughout the course of the disease might often requires adjusting your expectations.

Physical intimacy is not limited to sexual intercourse. It can take many forms; hugging, kissing, masturbation, taking long walks, talking, and using stimulation and massage can all contribute to the expression of sexual intimacy.

Follow those recommendations which you believe will have a positive effect on your physical and sexual health. Save your energy to be able to enjoy fulfilling moments with your partner.

Despite the changes brought upon by the disease, remember that you remain in control of your renewed sexual life and intimacy.

References

- Brooke Levis; Marie Hudson, MD; Ruby Knafo, MSc; Murray Baron, MD; Warren R. Nielson, PhD; Marilyn Hill, PhD; Brett D. Thombs, PhD; Canadian Scleroderma Research Group (CSRG). *Sexual Activity and Impairment in Women with Systemic Sclerosis Compared to Women from a General Population Sample*. December 2012.
- Canadian Cancer Society. *Sexuality and cancer*. 2012.
- Centre Intégré de cancérologie de la Montérégie. "Traitement de la sécheresse vaginale : les options qui s'offrent à vous". *Petit guide de santé sexuelle*. 2015.
- A.J. Impens, J. Rothman, E. Schiopu, J.C. Cole, J. Dang, N. Gendrano, R.C. Rosen, J.R. Seibold, *Sexual activity and functioning in female scleroderma patients*. 2009.
- Furst, Elaine, RN. *Sexuality and scleroderma*. MA Scleroderma Foundation, San Francisco, July 2011.
- Knafo R, Thombs B, Wigley F, Heinberg L, Haythornthwaite JA. "The association of body image dissatisfaction and pain with reduced sexual function in women with Systemic Sclerosis". *Rheumatology* (Oxford), 2011 Jun; 50(6): 1125–1130.
- Knafo R, Jewett LR, Bassel M, Thombs BD. "Sexual function in women with systemic sclerosis: A comment on Schouffoer et al". *Arthritis & Rheumatism*, Vol. 62, No. 8, August 2010, pp. 1200–1202.
- Malcarne, Vanessa, PhD. *Sexuality and scleroderma*. Montreal, Quebec, Canada, October, 14, 2010.
- A. Schouffoer, J. Van Der Marel, M. M. Terkuile, P. T. M. Weijenburg, A. Voskuyl, C. W. Vliet Vlieland, J. M. Van Laar, and T. P. M. Vliet Vlieland. "Impaired Sexual Function in Women With Systemic Sclerosis: A Cross-Sectional Study". *Arthritis & Rheumatism* (Arthritis Care & Research) Vol. 61, No. 11, November 15, 2009, pp. 1601-1608.
- PasseportSante.net. "La dysfonction sexuelle féminine". August 2010.
- PasseportSante.net. "La dysfonction sexuelle masculine". February 2016.
- The Arthritis Society. *Intimacy and Arthritis*. April 2009.



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