

SCLERODERMA AND SEXUALITY



**SCLERODERMA
FOUNDATION**

SUPPORT • EDUCATION • RESEARCH

INTRODUCTION

If you or your partner has been diagnosed with scleroderma, you may be wondering how this will affect your sexual life. Perhaps you are wondering if you and your partner will continue to find satisfaction and enjoyment through sexuality. If you are single, you may wonder how scleroderma will affect your ability to meet people and to date.

Your sexual life may not change at all. On the other hand, you may experience some sexual changes, but you can make adjustments to ensure a fulfilling sexual life. The purpose of this pamphlet is to provide information and suggestions that will help you continue to enjoy an active, fulfilling sexual life.

LIMITED RANGE OF MOTION

Some people with scleroderma experience pain and stiffness, which could limit their ability to engage in sex with a partner or to masturbate. If this is a problem for you, you and your partner can experiment with sexual positions to find those that are the most comfortable.

Pain can also be alleviated by use of pain medication. (Check with your doctor to make sure it is okay for you to use analgesics.) You can schedule sexual activity for a time when you know that pain will be at a minimum. A warm bath or shower before sexual activity often eases arthritic stiffness. Range of motion exercises before sex may help, but we suggest you stop exercising before reaching the point of pain or fatigue. Extra pillows placed underneath painful joints may be helpful.

If scleroderma has caused the mouth to shrink, kissing or oral sex could become difficult. A physical therapist, occupational therapist, or dentist can teach you exercises to stretch the mouth, which can help retain enough movement to make kissing and oral sex comfortable and enjoyable.

The fingers of a person with scleroderma may become fixed in a bent position. Touching one's partner or masturbating could be difficult. However, these difficulties can be relieved with creativity. Thumbs, wrists, or backs of the hands can be used to touch oneself or one's partner. Use of auxiliary materials such

as vibrators, dildos, creams, and lotions often enhance sexual pleasure. These can be purchased from a store specializing in sexual items or by mail order. (See the products guide at the end of this pamphlet.)

You can make these adjustments a pleasurable part of your lovemaking. For instance, if a warm bath before sexual activity is helpful, you and your partner may enjoy bathing together. Using the lubrication on each other can be enjoyable and part of foreplay. Experimenting can be fun for you both.

FATIGUE

People with scleroderma often feel tired. The scleroderma itself causes fatigue, and it can also be exhausting to cope with a chronic medical condition.

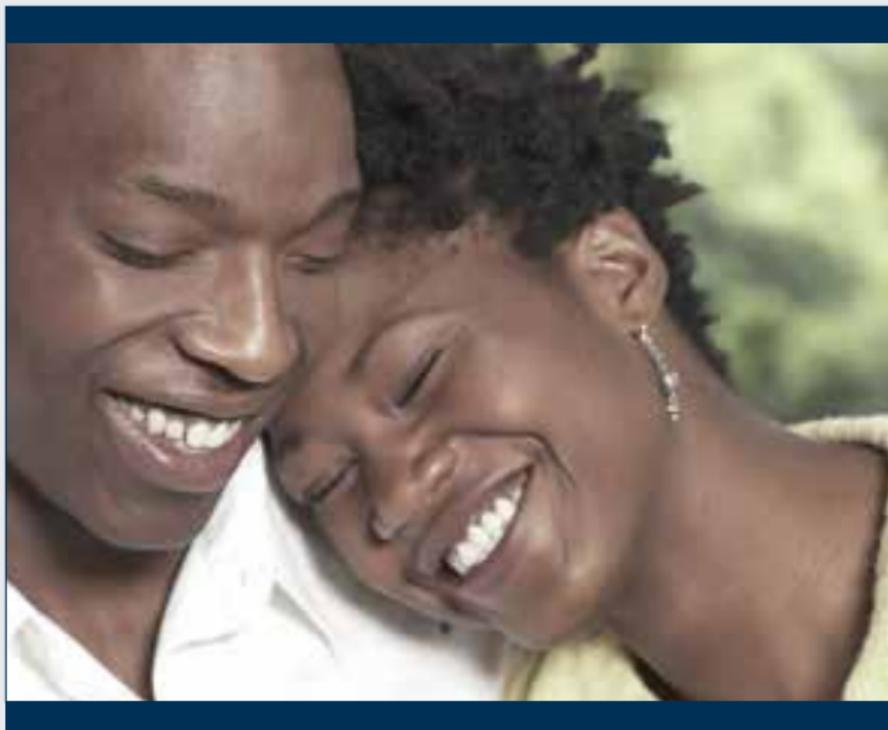
It can be difficult to become sexually aroused when extremely tired. Using time creatively can alleviate this problem. It can be helpful to schedule sexual activity for a time when you both feel energetic—whether morning, afternoon, or early evening, depending on your schedules. Taking regular naps and spacing out activity is recommended for alleviating fatigue.

RAYNAUD PHENOMENON

Most people with scleroderma also have Raynaud phenomenon, causing sensitivity to the cold, especially in the fingers and toes. If you or your partner has Raynaud, there are many ways to ensure comfort during sexual activity. Turn up the thermostat, leave some clothes on, take a warm bath or shower, or use extra blankets. It is important to keep the entire body warm as a Raynaud episode can occur if any part of the body is chilly.

RENAL PROBLEMS

In rare cases, scleroderma causes kidney disease, which can affect sexual desire and orgasm. Sometimes sexual difficulties are caused by the medications used to treat kidney problems, rather than by the kidney problems themselves. Men may not be able to have erections, and women may stop menstruating. People of both genders can experience low sexual desire.



In such cases, you and your partner may enjoy exploring sexual options that do not include intercourse. You may wish to stimulate each other's bodies with your hands, give massages, cuddle, or other enjoyable physical activities. You might try using vibrators or other sex toys. If you are not interested in intercourse itself, you can be physically close by holding or caressing one another.

If you believe medications may be inhibiting your sexual desire, talk to your doctor about the possibility of switching medications. It may be possible to substitute alternative medications with fewer side effects. Do not make changes without your physician's approval.

VAGINAL DRYNESS

Women with scleroderma may experience vaginal dryness, which could make vaginal penetration painful. This problem can be addressed by the use of a water-based lubricant, which you can buy at a drug store or a store specializing in sexual aids.

Vaginal dryness could result from the medications used to treat scleroderma. If you suspect that this is the case, talk with your physician about possible alternative medications or medicated creams.

If penetration is painful, you and your partner can explore alternatives to intercourse. Because the clitoris (not the vagina) is the primary source of sexual

pleasure in many women, they often find clitoral stimulation with hand or mouth more enjoyable than intercourse. Both you and your partner may find oral sex or touching with hands or sex toys an enjoyable alternative.

ERECTILE DYSFUNCTION & PEYRONIE DISEASE

Some men with scleroderma experience changes in the penis. A man with scleroderma may have difficulty getting an erection. Some men with scleroderma experience Peyronie disease, in which the penis may become inflamed and uncomfortable. In rare cases, blockage of penile tissue may cause the penis to develop a bent appearance as blood flow is inhibited.

There are several treatments for both erectile dysfunction and Peyronie disease, which you and your urologist can explore. These treatments include oral medications, penile implants, and injections. You and your partner can also experience pleasure with alternatives to intercourse such as massage, cuddling, and oral sex.

CONTRACEPTION

If you are concerned about contraception or protection from sexually transmitted infections, you and your partner will want to consider which form of contraception is best for you. Work with your physician to make an informed decision, taking into account the effects of some forms of contraception on your scleroderma.

PREGNANCY

In most cases, scleroderma will not affect your ability to bear children. However, it is recommended that you delay pregnancy until your scleroderma has stabilized. Pregnancy should also be avoided if there is a chance you might have renal failure. Many women with scleroderma experience premature births. If you do decide to become pregnant, we suggest you develop a good relationship with an obstetrician who

is experienced with scleroderma and who can advise you about how your scleroderma might affect your pregnancy and how pregnancy might affect your scleroderma. Your obstetrician should work with your rheumatologist and the rest of your health team to monitor you closely both during and after pregnancy.

MENOPAUSE

Women with scleroderma sometimes undergo early menopause. If you wish to bear children, discuss this possibility with your gynecologist. Most women cannot become pregnant after the onset of menopause.

Menopause can also cause vaginal dryness, which can be relieved by the use of a water-based lubricant. Please note that many causes of vaginal dryness are unrelated to menopause. Vaginal dryness can be associated with hormone changes; your provider can recommend creams made especially for this condition.

IF FURTHER HELP IS NEEDED

Remember that your physician can be an excellent resource. You may feel shy about discussing sexual matters with your physician, but we urge you to find a physician with whom you are comfortable. If your physician does not bring up sexual issues, you may have to raise these questions yourself. This can be easier to do if you rehearse what you are going to say before seeing the physician. Bringing a written list of your questions to the appointment may also help to organize the discussion.

COUNSELING

In some cases, people with scleroderma may benefit from individual counseling, couples therapy, or sex therapy. Your physician or AASECT (see the information resources section at the end of this pamphlet) can help you find a competent therapist.

CONCLUSION

Scleroderma may not alter your sex life at all. If there are changes, adapting to them can be an enjoyable opportunity to experiment and explore. You can still experience pleasure and be close to your partner.

ADDITIONAL INFORMATION

American Association of Sexuality Educators, Counselors, and Therapists (AASECT)

1444 I Street NW, Suite 700

Washington, DC 20005

Phone: 202-449-1099

Fax: 202-216-9646

Email: info@aasect.org

www.aasect.org

Sexuality Information and Education Council of the United States

90 John Street, Suite 402

New York, NY 10038

Phone: 212-819-9770

Fax: 212-819-9776

Email: siecus@siecus.org

www.siecus.org

The Scleroderma Book by Dr. Maureen Mayes, 2nd edition

[http://www.arthritistoday.org/daily-living/
relationships/index.php](http://www.arthritistoday.org/daily-living/relationships/index.php)

PRODUCTS

Vagisil Womens Health Center

800-431-2610

www.vagisil.com

Good Vibrations

800-289-8423

www.goodvibes.com

K-Y Brand Personal

Lubricants

877-KY BRAND

www.k-y.com

Eve's Garden

800-848-3837

www.evesgarden.com

Y.E.S. Lubricant

USA/Can: 1-888-777-0125

<http://www.yesyesyes.org>

Luvena Vaginal Moisturizer

877-522-5333

www.luvenacare.com

(The Scleroderma Foundation thanks Elaine Furst, R.N., B.S.N., M.A., of Los Angeles, California and JoAnna Harper, Pharm.D., R.Ph., of Minnesota, for their assistance in preparation of this brochure.)

BECOME A MEMBER OF THE SCLERODERMA FOUNDATION

When you become a member of the Scleroderma Foundation, you support the organization's mission of support, education and research. Your donation helps pay for programs in each of those three areas, including:



- We budget at least \$1 million annually for research.
- Helping patients and their families cope with scleroderma through mutual support groups, physician referrals and the National Patient Education Conference.
- Promoting public education of the disease through publications, seminars, patient education events and awareness activities.

As a member of the Scleroderma Foundation, you will receive:

- Our quarterly magazine, the "Scleroderma VOICE." The magazine includes updates on the latest scleroderma research and treatments, positive and uplifting stories from patients living with the disease; and tips about how to manage living with scleroderma.
- Information and educational offerings from your local chapter.
- Discounted registration fees to the annual National Patient Education Conference.

Please consider joining the Scleroderma Foundation today. A membership form is attached on the reverse side of this panel.

To become a member of the Scleroderma Foundation, fill out this form, tear at perforation and send with your check or credit card information to:

Scleroderma Foundation
Attn: Donations
300 Rosewood Drive, Suite 105
Danvers, MA 01923

I would like to become a member and help support the Scleroderma Foundation's efforts to improve the lives of those with scleroderma, and to assist in the search for a cause and cure. Enclosed please find my check (or credit card information) in the amount of \$_____.

Donations of \$25 or more can be acknowledged as members (\$35 or more for international members).

- I am not interested in members benefits.
 However, I would like to make a contribution in the amount of \$_____.

Name: _____

Address: _____

City: _____

State/ZIP: _____

Country: _____

Telephone: _____

Email: _____

Credit Card: _____

Credit Card No.: _____

(Circle One:    )

Exp. Date: _____ CVV Code: _____

Name on Card: _____

OUR THREE-FOLD MISSION IS SUPPORT, EDUCATION AND RESEARCH

Support: To help patients and their families cope with scleroderma through mutual support programs, peer counseling, physician referrals, and educational information.

Education: To promote public awareness and education through patient and health professional seminars, literature, and publicity campaigns.

Research: To stimulate and support research to improve treatment and ultimately find the cause of and cure for scleroderma and related diseases.



Funding for this brochure was provided by an unrestricted educational grant from Actelion Pharmaceuticals USA, Inc.



January 2019

A publication of
Scleroderma Foundation
300 Rosewood Drive, Suite 105, Danvers, MA 01923
800-722-HOPE (4673) www.scleroderma.org

 www.facebook.com/sclerodermaUS

 www.twitter.com/scleroderma

 www.youtube.com/sclerodermaUS