

INTRODUCTION

You or your partner have been diagnosed with scleroderma, and 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. 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.

RAYNAUD'S PHENOMENON

Most people with scleroderma also have Raynaud's phenomenon, causing sensitivity to the cold, especially in the fingers and toes. If you or your partner has Raynaud's, there are many ways to ensure comfort during sexual activity. Turn up the thermostat, leave some clothes on, or use extra blankets. It is important to keep the entire body warm as a Raynaud's 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 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 inter-



course. You may wish to stimulate each other's bodies with your hands or mouths. You might try using vibrators or other sex toys. If you are not interested in sex, 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.

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'S 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's 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's 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 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 pre-term

BECOME A MEMBER OF THE SCLERODERMA FOUNDATION

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



- funding over \$1 million in original research grants awarded to investigators annually
- helping patients and their families cope with scleroderma through mutual support groups, peer counseling and physician referrals
- promoting public education of the disease through patient literature, health professional seminars, and publicity campaigns.

Your membership gives you the following benefits:

- our quarterly magazine, the *Scleroderma Voice*. The magazine includes updates on the latest scleroderma research and treatments, profiles of patients who are overcoming their condition to live productive lives; tips on how to manage your disease
- newsletters and informational and educational offerings from your local chapter
- discounted registration fees to the Foundation's National Conference

Please consider joining the 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.

- 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: _____

E-mail: _____

Credit Card: _____

Credit Card #: _____

Exp. Date: _____

Name on Card: _____

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 monitor you closely during 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.

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)

P.O. Box 1960
Ashland, VA 23005
Phone: 804-752-0026
Email: aasect@aasect.org
www.aasect.org

Sexuality Information and Education Council of the United States

130 West 42nd Street, Suite 350
New York, NY 10036-7802
Phone: 212-819-9770
Email: siecus@siecus.org
www.siecus.org

The First Year: Scleroderma by Karen Gottesman, pp. 192–197

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

www.arthritis.org/resources/relationships/intimacy/intimacy_home.asp

PRODUCTS

Vagisil Womens Health Center
800-431-2610
www.vagisil.com

K-Y Brand Personal Lubricants
877-KY BRAND
www.k-y.com

Good Vibrations
800-289-8423
www.goodvibes.com

Eve's Garden
800-848-3837
www.evesgarden.com

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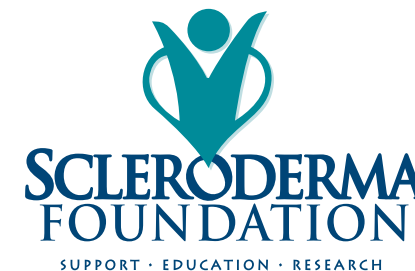
OUR THREE-FOLD MISSION IS SUPPORT, EDUCATION AND RESEARCH



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.



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SCLERODERMA AND SEXUALITY