



SCLERODERMA AND INTIMACY

A helpful guide and resource for people
with scleroderma to discuss with
their doctor or partner



scleroderma **australia**

Introduction

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

Your sex life may not change at all. On the other hand, you may experience some changes, but there may be adjustments you can make to ensure you and your partner feel fulfilled. The purpose of this booklet is to provide information and suggestions that may help you continue to enjoy an active, fulfilling sex life.

Scleroderma may limit your 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 with pain medication (check with your doctor to make sure it is okay for you to use analgesics), or you can schedule sexual activity for a time when you know that pain will be at a minimum. Taking a warm bath or shower before sex may help to ease arthritic stiffness, and range of motion exercises before sex may also help, but we suggest you stop exercising before reaching the point of pain or fatigue. Extra pillows placed underneath painful joints may also 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.

Scleroderma Australia has published an exercise guide developed by a team of specialist doctors to help maintain normal mouth movement and range of motion. The guide can be accessed and downloaded at the following link:

<https://www.sclerodermaaustralia.com.au/wp-content/uploads/2021/11/SA-Scleroderma-and-Oral-Health-Brochure-web.pdf>

The fingers of a person with scleroderma may become fixed in a bent position, which could make touching one's partner or masturbating more 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. You may also find using things like vibrators, dildos, creams, and lotions can help to enhance sexual pleasure. These can be purchased from a store specialising in sexual items or by ordering online (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 sex is helpful, you and your partner may enjoy bathing together. Using the lubrication on each other can be enjoyable and part of

foreplay – experimenting with one another and finding out what you both like can be fun!

Fatigue may affect the amount of energy you have

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 but using time creatively can alleviate this problem. It can be helpful to make time for sex when you both feel energetic – whether morning, afternoon, or early evening, depending on your schedules and energy levels throughout the day. Taking regular naps and spacing out activity is recommended for alleviating fatigue.

Raynaud's phenomenon may make you feel colder than usual

Most people with scleroderma also suffer from 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, take a warm bath or shower before sex, 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 and treatments may affect your ability to have sex

In rare cases, scleroderma can cause kidney disease, which may affect sexual desire and the

ability to orgasm. It's also important to be aware that 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 achieve an erection and women may stop menstruating. People of both genders can experience low sexual desire.

In these instances, 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 treatments. It may be possible to substitute alternative medications with fewer side effects. Do not stop or change your treatment without talking to your doctor first.

Vaginal dryness may make sexual intercourse uncomfortable

Women with scleroderma may experience vaginal dryness, which could make penetrative sex painful. This problem can be addressed by using water-based lubricant, which you can buy at your local pharmacist or a store specialising in sexual aids. In addition, general skin care measures such as washing with a soap substitute (such as QV, Cetaphil or similar) and liberally applying a good quality cream or ointment-based moisturiser each day, can help keep the vulval area as well hydrated as possible.

Vaginal dryness could result from the medications used to treat scleroderma. If you suspect that this is the case, talk with your doctor 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 and Peyronie's disease may affect men

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

There are several treatments for both erectile dysfunction and Peyronie's disease, which you and your doctor can explore. These treatments include oral medications, penile implants, and injections. For example, sildenafil (Viagra) can be helpful for males with early erectile dysfunction but will not always be effective if fibrosis has occurred. Some patients with pulmonary arterial hypertension (PAH) or digital ulcers may already be taking sildenafil. In addition to medical treatments, sometimes low mood, anxiety, or other psychological factors may contribute

to erectile dysfunction and should also be addressed.

It's important to remember that you and your partner can also experience pleasure with alternatives to intercourse such as massage, cuddling, and oral sex.


Gastrointestinal problems can be quite common

Most people with scleroderma will have some symptoms that affect the gastrointestinal tract (or digestive system), which runs from the mouth, through the stomach and bowels to the anus. Any part of the gastrointestinal tract can be affected by scleroderma, but the most common areas are the oesophagus (throat) and rectum.

When scleroderma affects the mouth or oesophagus, it may make oral sex uncomfortable or not possible due to problems such as tightening of the skin around the mouth, 'dry mouth', nausea and heartburn. If the anus is affected, you may find anal sex too painful or no longer possible due to tightening of the skin in this area.

If you still want to engage in oral or anal sex, using a generous amount of water-based lubricant can help (you can even buy flavoured lubricant designed especially for oral sex), but the most important thing is making sure you and your partner are aware of any limitations, and you stop if it becomes uncomfortable.

In some instances, it may be unsafe to engage in anal sex or to use anal sex toys as people with complications in this area may be prone



to bacterial infections, obstruction or pseudo-obstruction. If you're unsure, talk to your doctor before you try anal sex.

Pulmonary arterial hypertension (PAH) can make you feel out of breath

Around 10% of people living with scleroderma may develop PAH, a serious condition that affects the heart's ability to pump blood through the lungs and around the body, causing shortness of breath, fatigue, weakness, dizziness or fainting, chest pain and heart palpitations.

The degree to which PAH may affect your sex life will depend on how serious it is; however, most people with PAH notice that they have sex less than before their diagnosis.

PAH can make you feel out of breath or dizzy even after a small amount of exercise, which can happen during sex. So, you may find it helpful to change positions to reduce breathlessness – it's important to find a position that is comfortable for you and doesn't make you worry.

Some treatments for PAH may also make having sex more challenging. Depending on what your PAH specialist prescribes, you may need to be fitted with a continuous infusion pump that delivers your PAH treatment 24 hours per day, or you may need oxygen. If this is the case, it is important to talk with your doctor about how to maintain a healthy sex life without disrupting your treatment or damaging your infusion device. There may also be other treatment options available.

Sjogren's syndrome can make you have a dry mouth

Many people living with scleroderma may also be diagnosed with Sjogren's syndrome, which affects nine times more women than it does men. Symptoms typical of Sjogren's syndrome include dry eyes, dry mouth as a result of changes in the saliva and how much your body is able to produce, and vaginal dryness.

Dry mouth may affect your ability to perform oral sex comfortably, so having a glass of water on hand or a specially designed lubricant suitable for oral use may be helpful and/or necessary. Vaginal dryness caused by Sjogren's may also be relieved by the use of a water-based lubricant; however, some women may still find this too painful. It's important to communicate your comfort levels with your partner if this is the case and stop intercourse if it becomes too sore.

Discuss any attempts at becoming pregnant with your doctor

In most cases, scleroderma will not affect your ability to have children. However, it is recommended that you delay pregnancy until your scleroderma has stabilised. If you are a woman of childbearing age, you should discuss contraception and any pregnancy plans as early as possible with your rheumatologist and obstetrician to ensure your wellbeing and to make a plan that takes into account your safety and that of your baby.

Many major hospitals have foetal maternal clinics, so it may be useful to seek referral to a specialist at one of these clinics for planning.

It will be important to discuss which medications can continue and which (if any) need to be stopped before conception and pregnancy, or whether an attempt at having children should be delayed.

Pregnancy should be deferred or avoided in cases of scleroderma-related renal disease and PAH, as it may be unsafe, and these conditions may worsen during pregnancy. Some important treatments for these conditions may not be safe for the baby if used during pregnancy. It is best to discuss whether it is safe to proceed with pregnancy with your treating physician. Equally, some of the treatments used for interstitial lung disease can be harmful to the foetus, so it's always important to discuss any attempt at having children with your rheumatologist before trying to conceive.

Another thing to think about is that 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 may start early in scleroderma

Women with scleroderma sometimes undergo early menopause. If having children is something you want to do, you should discuss this

possibility with your gynaecologist. Most women cannot become pregnant after the onset of menopause. Menopause can also cause vaginal dryness, which can be relieved by using 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 doctor can recommend creams made especially for this condition.

Remember that your doctor and wider health team can be an excellent resource. You may feel shy about discussing sexual matters, 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 them. Bringing a written list of your questions and a copy of this booklet to the appointment may also help to organise the discussion.

Counselling

In some cases, people with scleroderma may benefit from individual counselling, couples therapy, or sex therapy. Your physician or the Society of Australian Sexologists can help you find a competent therapist (see the information resources section at the back of this booklet).

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

Authors

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Products

Vagisil Australia:

<https://au.vagisil.com/>

Toys:

<https://itsnormal.com/>

<https://joyforwomen.com.au>

<https://Pleasurechest.com.au/>

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