

Scleroderma & sexuality

Scleroderma may affect the genitals of both men and women. Sexuality involves the physiological and the psychological, the body and the mind. These two features are always intertwined in human behaviour, but they are particularly so in the realm of sexuality.

Men's problems

Scleroderma unfortunately is one of the disease groups associated with erection problems. Studies have demonstrated that approximately 1 in 10 of all men have a problem obtaining or maintaining an erection. This can be a very distressing problem for any man.

There are several reasons why men with scleroderma may have a problem. One of these can be caused by tissue changes. During erection the erectile tissue has to relax to let it fill with blood. Scleroderma can cause a thickening (fibrosis) of the erectile tissue reducing its ability to relax. As a consequence the erectile tissue cannot fill to form an erection. Other reasons could be associated with anxiety and distress from scleroderma itself.

What help is available?

Problems with erections can be treated and many men return to satisfactory sexual activity. The problem should first be discussed with your partner, as an understanding between the couple may remove some of the anxieties and distress. Talk to your GP so that a referral can be made to an appropriate specialist for treatment.

A blood test can check if there is a normal level of the male hormone testosterone in the circulation. Any deficiency may then be helped by tablets, patches or injections. Psychological problems contributing to erection difficulties can be helped by psychotherapy.

Treatment of any underlying anxiety or depression can restore erectile function. Mechanical erection aids are available and these options together with medical intervention should be discussed with your consultant.

Women's problems

In women, genital effects can be emotionally upsetting but are less incapacitating in terms of sexual functioning than in the male. Physical problems for women with scleroderma include fatigue, dryness of the vagina (as part of Sjögren's syndrome) and physical discomfort during sex, as a result of decreased mobility of joints, sometimes associated with joint pain. Symptoms of reflux (heartburn) can be worsened by lying flat and by having the weight of a body on top.

Vaginal dryness

Vaginal dryness or itching makes intercourse uncomfortable but can be remedied with vaginal lubricants and cream. Vaginal ulcers until healed, (or calcium deposits), can make sexual intercourse painful but do not restrict other sexually satisfying activities.

Sjögren's syndrome frequently accompanies scleroderma, causing dryness of the mucous membranes. This typically leads to symptoms of dry eyes, dry mouth and dryness of the vagina. With less lubrication during arousal, sex can be uncomfortable or even painful.

Before you blame scleroderma and Sjögren's syndrome, it is important to realise that vaginal dryness can also occur with the menopause and the drop of female hormones that accompanies it. If this is the case, either oestrogen replacement hormones in pill form or an oestrogen-containing vaginal cream can be useful.

Joint discomfort

Some women find sex painful because they have trouble finding a comfortable position. Joints are stiff and sore, or ribs just don't move the way they used to. A warm bath may help to loosen up joints. The real resolution to this problem is imagination, creativity, a sense of humour, and a loving partner.

Psychological issues

In general, sexual interest is diminished by the emotional distress and mental preoccupations related to living with scleroderma. Psychological issues get in the way of sexual enjoyment. These include depression, which typically decreases sex drive, changes in body image leading to the fear that you are not as attractive as before, and anxiety that sex will be painful.

Male partners of women with scleroderma can be affected by this attitude of heightened anxiety and retreat from sex for fear of causing pain and discomfort in the women they love. In the absence of good communication, both partners can fall into a world of silence that fosters isolation and loneliness.

A woman may be angry at what has happened to her body, she may feel guilty about being a burden to her partner and frightened by what the future may hold. This is an area where counselling can be tremendously helpful for both partners. However, if one of the partners is reluctant to talk about such personal issues in the presence of a stranger, the other partner can go alone and talk about their fears of the illness and what it means for both partners and their future.

The real issue is communication, more so than the technical aspects of sexual intercourse. Once communication is re-established, the rest will follow.

Sexual desire

The willingness to overcome physical changes are related to sexual desire. In scleroderma not only may sexual function be diminished but also desire. Some drugs used to dilate blood vessels, relieve joint inflammation or curtail stomach acidity, are known to depress sexuality. In addition, as a couple grows older, the aging process lessens sexual interest, independent of any effects from scleroderma.

Sex can still be enjoyed comfortably if a couple take advantage of the 'feeling good times' and by making whatever adaptations are necessary to relieve physical aches and pains.

Fatigue

Fatigue is a common problem in the general population. Sometimes it is difficult to distinguish the fatigue that is associated with depression or hopelessness, from the fatigue that commonly accompanies a connective tissue disease. Often people say that it is all they can do to go to work each day, much less have extra energy to devote to their families in the evening. What frequently goes unmentioned, is that this level of fatigue also means there is not enough energy to enjoy an active sexual relationship with their partner. Women seldom bring up this issue due to embarrassment. Fatigue is considered a personal problem, a fault, a failing. Fatigued people are thought of as 'lazy' or simply as lacking the motivation to get things done.

Fatigue or exhaustion compete for attention with sexual impulses. Feeling unwell can stand in the way of sexual desire. Aching muscles, itchy skin or painful ulcers can take over and sexual inclinations are ousted even further away. When sexual needs do take precedence over physical discomfort, the sexual experience may be unexpectedly disrupted by a muscle spasm or heartburn.

Fatigue also tends to develop gradually and is sometimes unnoticed until either medication is given or the disease begins to stabilise. Patients will then comment that they are feeling better and suddenly have their energy back again. Fatigue is a difficult symptom for a doctor to treat.

There is no medication that will magically make it go away and restore energy. The advice is to stop beating yourself up over it! Too often it happens that constant fatigue can nudge people into depression. Fatigue and depression are closely interrelated - fatigue can lead to depression, just as depression is usually associated with fatigue. Depressed individuals are unable to see the whole picture. They are blocked from enjoyment, and no amount of arguing will convince them otherwise. Persistent depression may require professional help.

If sex is important to your relationship (as it usually is), then resting up for it or planning for it may become necessary. Although this may take away some of the spontaneity, the rewards of having an active sex life will make up for this.

Talk about it

We would urge patients to talk to their doctors on this issue which affects many people. Treatment is available, so don't be embarrassed to ask for help.

Physical changes

Physical changes caused by scleroderma, unrelated to the genitals, also affect sexual functioning. Muscle and joint stiffness limits sexual movement and position. Stiff and puffy fingers are clumsy and insensitive. When the fingers are curled or bent, fondling and caressing may not even be possible. Thin lips, small mouth or protruding teeth make kissing less pleasurable.

Self-consciousness about changes in skin texture and body contours inhibit sexual relatedness. A woman whose skin has become hard and tight continues to experience sensual pleasure when caressed, but may be self-conscious about being touched. If the tightened skin alters breast contours, or if weight loss makes one less shapely, her appearance may be of concern to her.

A woman wants her partner to find her physically attractive and sexually desirable, therefore if she feels unattractive, sexually undesirable and personally unlovable, she will sustain little sexual interest. If her partner is worried and depressed about her illness, his mind may be too preoccupied with her problems and therefore may conceal his desire for sex.

To maintain sexuality in a relationship, it is important to convey sexual feelings whenever they do occur, even if only expressed in affection. A decrease in sexual attraction does not mean a decrease in love.



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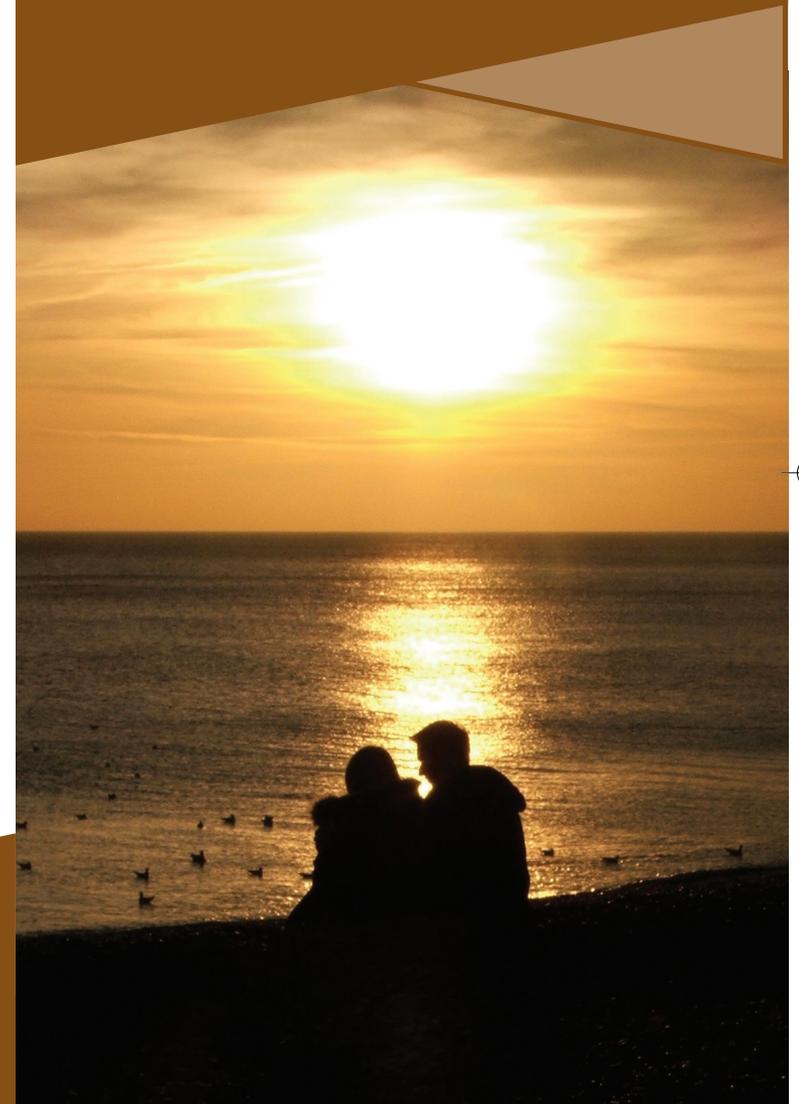
112 Crewe Road, Alsager, Cheshire ST7 2JA
Tel: 01270 872776 Fax: 01270 883556

Email: info@raynauds.org.uk
Website: www.raynauds.org.uk

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