

your confidence for the “real thing”. They come in a series of sizes, to enable you to improve things gradually. These are called “Amielle Trainers” and you may find it helpful to look at the manufacturer’s website: [www.owenmumford.com](http://www.owenmumford.com).

Most larger hospital gynaecology departments will have a "Vulval Clinic" with facilities to look at the skin of the vulval lips (at the entrance to the vagina) in particular detail, including taking small biopsies (skin samples) for more specific analysis. You should ask to be referred to a Vulval Clinic if the simple remedies have not proved helpful, so that the possibilities such as using steroid ointments can be considered by expert gynaecologists who are used to looking at chronic problems of the vulva.

Most women with vulval and vaginal problems do not tend to talk about them to others because they find them embarrassing to discuss. However, these difficulties are more common than you think, and you are certainly not alone! Remember also to be patient. If you have a problem which has been building up over a period of a few years, it will need a fair bit of time and care to correct this and to achieve improvements. However, there are always ways of making things better.



**The Scleroderma Society** supports people with scleroderma and their families by providing:

- educational literature
- a telephone helpline
- a comprehensive website & forum
- a newsletter with research information
- member contact
- informal group meetings
- an annual conference

We also work to promote awareness of scleroderma among the medical profession and general public in order to improve early diagnosis and prognosis. We fund medical & scientific research in the UK and are a founder member of FESCA (Federation of European Scleroderma Associations), working to forward the cause of people with scleroderma throughout Europe.

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## Sexual Problems in Women with Scleroderma

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# Sexual Problems in Women With Scleroderma

## Introduction

Scleroderma is an umbrella term used to indicate a spectrum of disorders. Often medical professionals use the term "scleroderma" when they talk about systemic sclerosis.

Both women and men suffering from systemic sclerosis may find it has a significant effect on their sex life, and may lead to a lasting effect on their sexuality. The purpose of this leaflet is to highlight some of the sexual problems you may have and discuss a number of solutions to them. Not all of these problems will apply to you. It is important to remember that everyone's sexual needs and attitudes are different and vary with age and experience, regardless of whether you have scleroderma or not.

## Why do women with scleroderma get sexual problems?

As a person with scleroderma you will be experiencing a variety of problems, among them pain, stiffness, tight skin, dryness of the mucous membranes, tiredness, lack of sexual desire and a change in body image.

The extent of your illness will determine the effect it has on your sex life. Changes to your body may be disabling and make you feel unattractive and depressed. As a result, sexual activity may well decrease or stop, which could be harmful to your self-esteem and in turn have a severe impact on your partner's sex life also.

## What sorts of problems occur?

### Fatigue

Fatigue is a common symptom of scleroderma. Many patients find it hard enough to cope with a job and family life much less with an active sexual relationship. Fatigue is a difficult problem to treat but often as the disease begins to stabilise the fatigue improves. It helps if patients and their partners recognise this is part of the illness and try to pace their days accordingly. If sex is an important part of your relationship then resting up and planning for it may become necessary even though you may feel it lacks spontaneity!

### Vaginal dryness

Sjogrens syndrome frequently accompanies systemic sclerosis. This causes dryness of the mucous membranes, typically leading to symptoms of dry eyes and dry mouth. The vagina can also become dry, with less lubrication during arousal, making sex uncomfortable, or even painful. Vaginal lubricants, which can be purchased in most chemists, are very helpful. However, it is important to exclude other causes of vaginal dryness such as the menopause, for which different treatments are helpful.

### Joint Problems

Many people with scleroderma have painful or stiff joints and you may not be able to move your limbs easily. Drug treatments can help with joint pains but the real answer is imagination, a sense of humour and an understanding partner!

### Emotional Problems

Scleroderma can be a very distressing disease and the resulting anxiety and depression may reduce sexual enjoyment.. Changes in body image and anxiety about sex being painful may also cause problems. Communi-

cation with your partner is of paramount importance but you may feel that you would both benefit by seeing a doctor with particular expertise in psychosexual counselling. (Your GP may be able to help or contact the Institute of Psychosexual Medicine, 11, Chandos Street, London W1 (Tel 020 7580 0631) for information on appropriate doctors working near to you).

## Treatment

Unfortunately, operations on the vaginal entrance are not usually helpful for scleroderma sufferers, as the scar tissue from operation wounds is often more uncomfortable than things were before. However, it is sometimes appropriate, and you should ask to be referred to a gynaecologist if you want advice on this. (Doctors trained in Psychosexual Medicine- see above- would also be able to advise you on this).

If there are additional reasons for vaginal dryness or soreness, such as local infection or the menopause, these each have relevant treatments which your GP or your local Well Woman Clinic or Sexual Health Clinic could arrange for you. Vaginal lubricants, such as KY jelly, Aquagel, Replens or Senselle, are completely harmless, and can be bought without prescription at any chemist. Remember that if you are expecting intercourse to be painful, your vaginal muscles will instinctively tense up and intercourse will then be even more difficult. Therefore you need to try to relax, with music or soft lights or whatever works for you! It can also be helpful to apply some local anaesthetic jelly to the vaginal entrance about ten minutes before intercourse so that you can feel confident that it will not be painful. 2% lignocaine antiseptic gel comes in single-use sachets (on prescription) and is safe to use - although it will make your vagina feel tingly for a couple of hours!

Sometimes it is helpful to use smooth plastic dilators to open up the vaginal entrance and to help you to regain