

MANAGING SCLERODERMA

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You have just been diagnosed with scleroderma. Your doctor says that it's a chronic disease that cannot be cured but can be managed. When you are first diagnosed, it is perfectly reasonable to experience a wide range of emotions – fear, sadness, anger. You will feel alone and uncertain. No matter the diagnosis, you can learn to manage.

GET PROFESSIONAL CARE

It is important to have professional care. A chronic condition usually involves contact with one or more medical specialists, but don't abandon your family doctor. That physician probably knows you best and can provide a valuable perspective on what the specialists say. Specialists offer facts, opinions and advice about treatment and products that can make your life easier. Cooperate with medical specialists and work with them to develop a schedule of tests to ensure that scleroderma related complications are diagnosed and treated as early as possible.

BE YOUR OWN ADVOCATE

Learn all you can about scleroderma.

"Knowledge is power and ignorance is not bliss. You need to know what is happening to you and what could happen to you. The well informed patient may not always do well, but he or she will always do better than those who keep themselves in the dark".

- Lee Shapiro. MD, FACP, Scleroderma VOICE 2002 #4 pp 10-13.

Inform yourself about scleroderma and existing treatments, research, and symptom management. It is important to understand your illness so that you are able to:

- Communicate effectively with physicians
- Identify available options
- Alleviate anxieties

It is useful to:

- Keep a notebook for visits with physicians
- Jot down questions, concerns and recent symptoms before visits with physicians
- Write down main points of the discussions
- Keep accurate medical records of:
 - Physicians and specialists
 - Medical conditions
 - Medications – doses and dates
 - Date and description of procedures and tests.

CONSIDER COMPLEMENTARY THERAPIES

Depending on your condition, some complementary therapies may be helpful. Massage therapy, relaxation therapy, and acupuncture are just a few possibilities. Both conventional and alternative (complementary) health practitioners should be made aware of all medical treatments.

LEARN TO CONTROL AND MINIMIZE STRESS

Stress and anxiety tend to exacerbate many symptoms, particularly pain. There are many paths to stress management: exercise, meditation, biofeedback, yoga, tai chi, prayer, and social support from family, friends or a support group. Choose the approaches that appeal to you. Ask your physician, social worker, family, friends or community organizations for referrals.

GET REGULAR, MODERATE EXERCISE AND THERAPY

Exercise is important for many reasons: it improves cardiovascular health, strength, stamina and flexibility, helps to control weight, improves the quality of sleep, and is a natural antidepressant. “Use it or lose it” does apply to scleroderma patients. Exercises may include range of motion, stretching, strengthening and conditioning and/or aerobic exercises. For most people, the easiest exercise program to adopt is walking. Exercises should be performed gently and with due care. It is always important to protect joints to prevent further pain and swelling. Consult your physician or physiotherapist about the types of exercise you can do.

FOLLOW A HEALTHY DIET

It is important for everyone to eat well-balanced meals. In the case of scleroderma patients, antioxidants are essential to help prevent cell damage and to support the immune system. When scleroderma impacts the digestive system, the following may be considered:

- Drink plenty of fluids
- Eat smaller more frequent meals
- Eat slowly and chew foods well
- Eat soft or pureed foods
- Decrease the intake of alcohol, carbonated soft drinks, chocolate and caffeine
- Avoid highly acidic foods
- Avoid fatty and greasy foods
- Sit upright for 1-2 hours after eating so gravity can help move food down
- Raise the head of your bed 4-6 inches (allows gravity to help the digestive process)
- Consider taking a multivitamin, especially if several foods are eliminated from a healthy diet
- Eat food with probiotics

If there are dietary concerns, contact your physician or a registered dietician.

RETHINK YOUR LIMITATIONS WHILE MAINTAINING A BALANCE OF ACTIVITIES

Scleroderma will cause limitations in your life. Changes may mean limitations in diet or activities. It's perfectly normal to miss the things you can't do anymore. Look for alternatives.

ADAPT TO CHANGE

Having scleroderma means that changes in lifestyle will be necessary. Adapting to this is important. You may have to treat pain in different ways (consult your physician). It may become necessary to avoid being chilled. More rest and sleep may be required as energy levels diminish. You must learn to pace yourself.

FIND A SUPPORT GROUP

Most organizations that focus on chronic medical conditions sponsor support groups. Support groups can provide emotional comfort, background information on your disease, opinions about treatments, recommendations about specialists, and support at a time when other friends and family members might not be able to meet your needs. If your condition limits mobility, you can still participate in a support group by joining one online.

REMAIN HOPEFUL

Maintain a positive attitude, but don't expect miracles. It's quite possible that in the not too distant future, a treatment advance may make your life considerably easier. Remember, your life is worth the fight.

We would like to thank **Dr. Margaret Larché, MBChB, MRCP(UK), PhD** for her assistance with this information pamphlet.

DISCLAIMER: This pamphlet is meant to provide information on scleroderma and is not meant to be used as a diagnostic tool or to suggest treatment or medications. Always consult your physician regarding details of symptoms, diagnosis, and treatment.

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