

New: Managing SLE and SSc with non-drug options

This is the lay version of the EULAR recommendations for the non-drug management of people with systemic lupus erythematosus or systemic sclerosis – two conditions that fall under the umbrella definition of rheumatic diseases. The names are often shorted to SLE or just lupus instead of *systemic lupus erythematosus*, and scleroderma or SSc instead of *systemic sclerosis*. The original publication can be downloaded from the EULAR website: www.eular.org.

[Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis *Annals of the Rheumatic Diseases* Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416](#)

Introduction

EULAR – the European Alliance of Associations for Rheumatology – gives advice to doctors, nurses, and patients about the best way to treat and manage diseases. In 2023, EULAR developed new recommendations around non-pharmacological management of SLE and SSc.

Doctors, nurses, other healthcare professionals and patients worked together to develop this advice. The patients in the team ensured that the patient point of view was included.

What do we already know?

Systemic lupus erythematosus (SLE) is an inflammatory autoimmune disease. It can affect all organs or tissues, including skin, joints, kidneys, nervous system, lungs, heart, and blood cells. Drugs have been developed in recent years, but people with SLE still experience poor quality of life caused by their health.

Systemic sclerosis (SSc) is another rheumatic autoimmune disease. It can affect your blood vessels, as well as cause fibrosis or thickening of the skin and visceral organs. SSc also has a major impact on people's quality of life. New therapies are promising, but there is still a need to optimize how the disease is managed.

In both SLE and SSc, there is growing evidence to support the use of non-pharmacological and self-management strategies. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else. They range from patient education and self-management strategies to exercise, lifestyle changes, counseling, treatments such as acupuncture or hydrotherapy, and minor surgical procedures. These non-drug treatments aim to ease disease symptoms and improve quality of life, as well as help prevent disease worsening. Many of these options are helpful, but they are not standardized, and are often underused in current clinical practice.

What do the recommendations say?

In total, there are 4 overarching principles and 12 recommendations. The principles say that non-pharmacological management of SLE and SSc should be tailored to individual people's needs, expectations, and preferences – and be based on a shared-decision with their healthcare team. They also highlight that non-pharmacological management may be made up of one or more interventions. Importantly, non-pharmacological management should not be used instead of drug treatment, especially when such treatment is required, but rather along with drugs to further improve patient care.

The recommendations are split into three groups, looking at general recommendations across both diseases, and those that apply specifically to either SLE or SSc.

Each recommendation is based on the best current knowledge from studies of scientific evidence or expert opinion. The more stars a recommendation has the stronger the evidence is. However, recommendations with

limited scientific evidence may be important, because the experts can have a strong opinion even when the published evidence may for various reasons be lacking.

One star (*) means it is a recommendation with limited scientific evidence.

Two stars (**) means it is a recommendation with some scientific evidence.

Three stars (***) means it is a recommendation with quite a lot of scientific evidence.

Four stars (****) means it is a recommendation supported with a lot of scientific evidence.

Recommendations

For the non-pharmacological management of SLE and SSc

- **Non-pharmacological management should aim to improve health-related quality of life.****
Health can affect people's quality of life and limit their activities. Addressing this health-related quality of life should be the main goal when choosing non-pharmacological strategies in people with SLE or SSc. Evidence shows that physical exercise and psychosocial interventions can improve a person's health-related quality of life.
- **If you have SLE or SSc, you should be offered education about your disease and advice on ways to self-manage.****
Understanding your disease and how it affects you is important in learning to manage it. Patient education can be given in a number of ways – from self-directed internet-based programs to group sessions.
- **Your health team will assess your smoking habits, and try to help you stop smoking.*****
Smoking is a known risk for many diseases, including heart problems and cancer. If you have SLE, an additional risk is that smoking can prevent some drugs from working properly. If you have SSc, smoking can make your disease worse, and increase the chance of having ulcers on your fingers.
- **You may need to consider avoiding cold exposure to help prevent Raynaud's phenomenon.****
Raynaud's phenomenon is a common complication for people with SLE and especially with SSc. This can be triggered by cold exposure and sudden temperature changes. You should try to avoid cold exposure where you can.
- **Physical exercise should be considered for people with SLE or SSc.****
Exercise and physical activity can benefit your health in a number of ways. Choosing the right exercise program should take into account your health, cardiorespiratory status, and any potential risks or medical considerations. But exercise or activity-based strategies such as physiotherapy can help you increase strength, and reduce fatigue.

For the non-pharmacological management of SLE

- **You may be offered education and advice about ways to help improve your ability to exercise, and your quality of life.****
If you have SLE, patient education and self-management support should be considered to help improve your physical exercise outcomes and health-related quality of life. These options might also be considered to help you enhance your self-efficacy. These programs might include supervised aerobic exercise, or web-based education and counselling.
- **Protecting yourself from sunlight can help prevent flares.****
It is well known that UV light can trigger flares in people with SLE. You should use sunscreen, and avoid direct sun exposure by wearing hats and sunglasses, and covering up with long-sleeved clothes. This could mean you also need to supplement your vitamin D levels in another way, since your skin makes this in response to sunlight. Your healthcare team should assess this and offer you advice.
- **You may need psychosocial interventions if your SLE is affecting your quality of life, or causing anxiety or depression.*****

If you have SLE, psychosocial interventions should be considered for improving health-related quality of life, anxiety, and depressive symptoms. This could include cognitive behavioral therapy (CBT), group therapy, or educational programs.

- **Consider taking aerobic exercise to improve your health and help reduce fatigue and depression.*****

In people with SLE, aerobic exercise can help to increase aerobic capacity. Aerobic exercise can also help to reduce fatigue and depressive symptoms.

For the non-pharmacological management of SSc

- **You may be offered education and advice about ways to improve your hand- and mouth-related symptoms, as well as your ability to do everyday activities.****

In people with SSc, patient education and self-management support should be considered for improving hand function, mouth-related outcomes, health-related quality of life, and ability to perform daily activities. This might include home-based exercise, muscular endurance training, or stretching exercises for the hands. Or it could mean seeing a physiotherapist.

- **Mouth, face, and hand movements, as well as aerobic and resistance exercise should be considered.****

People with SSc can suffer from microstomia, which in practical terms means that it is difficult to open their mouth. This and hand function are the major targets of non-pharmacological management for people with SSc. Mouth, face, hand, and aerobic and resistance exercise should be considered.

- **If you have puffy hands, you may be offered manual lymph drainage.*****

If you have SSc, you might get fluid retention or oedema in your hands. If you have puffy or swollen hands, light, skin-stretching massage can help to move lymphatic fluid back out.

Summary

Overall, these recommendations give guidance to healthcare professionals and patients about the management and treatment of people with SLE or SSc. Non-pharmacological options could help you manage your disease and the impact that it has on your life. You should work with your healthcare team to make an informed decision about your disease and its treatment – both for non-pharmacological options and drugs, when required.

Recommendations with just one or two stars are based mainly on expert opinion and not backed up by studies, but these may be as important as those with three or four stars.

If you have any questions or concerns about your disease or your medication, you should speak to a health professional involved in your care.