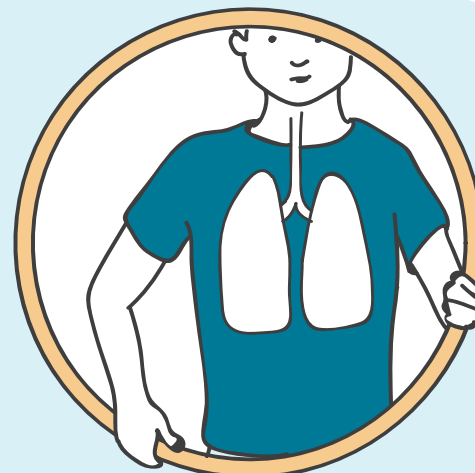


WHAT IS SYSTEMIC SCLEROSIS AND HOW IS IT DIAGNOSED?

Systemic sclerosis (also known as scleroderma) is a disfiguring, disabling and potentially fatal rare disease that causes scarring of the skin, lungs and other organs.^{1,2} Worldwide it is estimated that over two million people have systemic sclerosis² and it affects mostly women in the prime of their lives, between 25 and 55 years of age.³

Systemic sclerosis is a complex rare disease with a variable course. It presents with a range of symptoms involving several different organs; this means it is difficult to recognise and this can delay early and accurate diagnosis.³

"Scleroderma is a serious disease and it can affect all of the internal organs, skin and joints. It can also cause painful ulcers on the fingers and changes to the mouth. This makes it hard to eat and daily activities become challenging."
Patient, Italy



"The symptoms of scleroderma vary for each person and the severity of the disease depends on which parts of the body are affected. It is very unpredictable – it feels like there is a different presentation of scleroderma for every person."
Patient, Denmark



SYSTEMIC SCLEROSIS AND THE LUNGS

Up to 90% of people with systemic sclerosis may develop some degree of scarring in the lungs.¹ When lungs are involved it can be difficult for a person to breathe and perform daily activities.⁴

Scarring in the lung is one of the leading causes of death amongst people with systemic sclerosis.¹ There are no approved treatments that effectively target the underlying scarring in systemic sclerosis or that impact on the course of the disease, leaving many patients in desperate need.⁵

"Lung fibrosis is serious and can change your daily life. It can make everything difficult, from getting dressed in the morning and needing to sit on the bed to get ready, to taking longer to plan and make breakfast."
Patient, Italy

"Currently there is no cure for scleroderma. My ultimate hope? That in the near future we will find one. I have hope, I believe this will happen in my lifetime. I am happy to see that there is more and more research being undertaken in areas of need. For now, it's just important that we all work together and share our learnings across borders."
Patient, Denmark



THE ROLE OF PATIENT ORGANISATIONS FOR SYSTEMIC SCLEROSIS

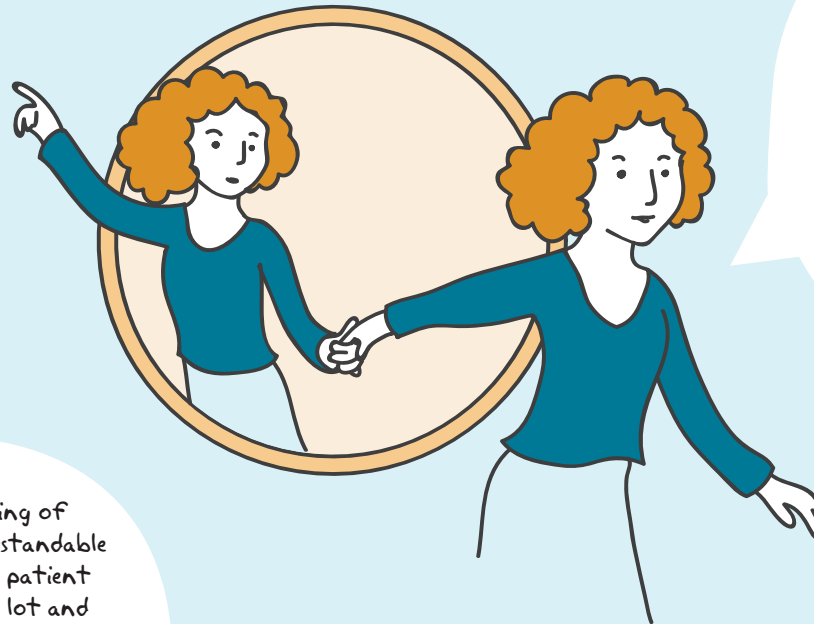
There are a number of advocacy groups which are focused on supporting people with systemic sclerosis, working with doctors to secure earlier diagnosis and better treatments and creating better awareness of the disease amongst the public. One of these groups, FESCA (Federation of European Scleroderma Associations aisbl), acts at a pan-European level to promote and achieve its objectives in alignment with the aims of the national groups it represents. For more information please visit:

www.fesca-scleroderma.eu/



"At the beginning of diagnosis it's understandable to be scared, but patient groups can help a lot and support you. They can explain what scleroderma is and help find the best centre or hospital near to you."
Patient, Italy

LIVING WITH SYSTEMIC SCLEROSIS



"For me, having scleroderma is like having a life-long companion or co-pilot – we are travelling along together but often we pull in different directions. But I've learnt that my companion is not going away so we need to work together and focus on getting the best out of the day. I have learnt how to live with scleroderma and enjoy the small things in life. I feel I now live more in the present and appreciate small things like the sun shining on a cloudy day or friends coming to stay."
Patient, Denmark

"Having scleroderma has changed my point of view. It sounds strange but I believe that I appreciate my life more than I did before. When I was first diagnosed it was devastating and I did wonder 'why me, what did I do to deserve this?' But I changed my point of view and focused my attention on what I can do and what I have – not what I don't. I now know there are many ways to do things – my journey may be different now, but it's not better or worse than anyone else's."
Patient, Italy



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