

Breaking down the social impact of scleroderma



FESCA, Federation of European Scleroderma Associations aisbl, is an umbrella group of scleroderma patient support and advocacy organizations working to increase awareness, and advocate for equitable treatments for people with scleroderma throughout Europe.

What you should know about scleroderma

Scleroderma is a rare chronic autoimmune disease that stiffens the skin and can affect all organs, turning everyday tasks into genuine challenges.

To emphasise the complexity of the patient journey and the burden of scleroderma, FESCA conducted a Europe-wide patient survey translated into 16 languages* and disseminated across 20 countries**. Thanks to feedback provided by 1239 patients, key difficulties faced by people with scleroderma were identified.

Main difficulties faced by people living with scleroderma:

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|  Delays in diagnoses and treatment therapies |  Inadequate access to psychological support and non-drug treatments |  Impact on mental health caused by isolation |  Issues with employment and financial stability |
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Timely and accurate diagnosis remains a priority

Rapid diagnosis is critical in positively impacting patient outcomes.

50%

do not receive an accurate diagnosis within a year of showing symptoms.

Without support, living with scleroderma is an isolating existence

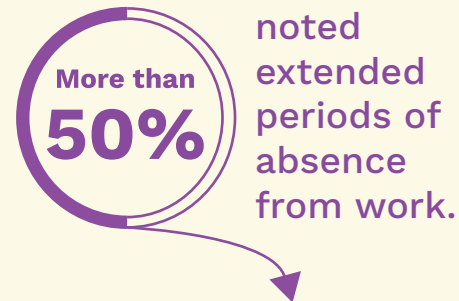
80% indicated that **physical health and emotional difficulties impacted the ability to socialize** with family and friends.

60% **isolate themselves**, reducing time spent at work and other activities. Isolation often arises due to family and friends' lack of understanding and inadequate support from healthcare professionals.

50% **lack of public access to non-drug treatments** including psychological support, resulting in out-of-pocket spending.

Scleroderma impacts performance and independence at work

Employment allows people to be financially independent and contribute to society.



more than **40%** reported that pain interferes with daily tasks.

Addressing unmet needs

FESCA calls upon policymakers

to respond to unmet needs of scleroderma patients and improve their quality of life by taking action to:

1.

Ensure signs and symptoms are recognized early, allowing prompt referrals to specialized care and treatment access.

2.

Prioritize and fund access to psychological support and other non-drug treatments as part of their care plans.

3.

Implement adequate labour market policies, ensuring participation in society and financial independence, whilst preventing work-related issues.

*The survey was disseminated from January to April 2023 and was completed by 1239 patients.

** Austria, Belgium, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Italy, Netherlands, Norway, Portugal, Romania, Spain, Sweden, Switzerland, UK.

