

**Table 1: Obstacles faced by sarcoidosis patients**

<b>Fatigue</b>
“According to the medical examiner, extreme fatigue due to sarcoidosis is not a sufficient argument for declaring me largely unfit for work. You’re supposed to spend whatever energy you have on work. How you cope at home is not their problem.” “Fortunately, I got, during those years, more and more physical complaints, she spoke cynically...”
The impact of sarcoidosis fatigue may not be dissimilar to cancer-related fatigue and should not be underestimated in terms of both physical and psychological impact. “There’s sometimes, where, like I said I wasn’t even getting out of bed, and I could not tell if it was because I just fatigued or you know just mentally, because I know breathing is so difficult....”
<b>Cognitive failure</b>
“Since I suffer from sarcoidosis, I have difficulty concentrating and I also suffer from memory loss, this brain fog makes it almost impossible to do my job properly”.
<b>Psychological and emotional problems</b>
“I have been diagnosed with anxiety and depression, and I also feel my cognitive functions have been affected.”
“The mood swings. It was affecting everything, affecting my family life. It was affecting my wife and my children, you know I felt like I was blowing up easier because, I just felt so aggravated. I’m, I’m angry about it (sarcoidosis). I’m very angry about it. So, this is why I referred myself to talking therapy”.
“I felt that in order to fix other people’s problems, I need to fix myself and with all the medication and all the struggles. I’m a single mom as well, all of that and flare-ups and everything, I had to be a bit selfish. I do feel useless right now because I’m not working. I feel like I’m not important anymore.”
“I did a baseline (memory test) about a year and a half ago, and did one about two months ago, and my memory definitely has gotten worse, .....my short-term memory is worse.....the long-term wasn’t too bad, but the short-term it’s definitely like it dropped percentage-wise.”
<b>Physical limitations</b>
“The medical examiner made light of my symptoms, as my lung function is still good. Why don’t they rely on my story? My personal situation should be the starting point and not the outcome of a lung function test alone.”
<b>Not taken seriously; not believing what the patient says</b>
“Why is it always thought that we sick people are out to abuse the compensation system for the sick? Every sarcoidosis patient is unique and has their own problems in daily life in dealing with this condition.”
“Why do you have to defend yourself again and again when you are sick and have little energy?”
“Because I don’t look ill, the medical examiners don’t believe I have any issues with my work-related and other daily life activities.”
“There’s a need for better explanation of the pathway that will be followed, better understanding of the complexity of sarcoidosis, the great variability in clinical presentation and disabilities. Each personal situation should be considered in the evaluation of work ability.”
“What I failed to find was a humane attitude. I felt I was being dismissed as the umpteenth person who came to claim benefit.”
“The entire process took many years; years of great tension and not being taken seriously.”
<b>Drug-induced side effects</b>
“Although I am constantly very tired, I could not sleep due to the prednisone.”
‘I was really like almost manic on the prednisolone like I was really high and then in between I would get really like anxious and like doing a lot of stuff and I could walk a mile a minute, but then there was other times, where I was so low I didn’t want to get out of bed.’
“I have chronic depression and that’s been from the prednisolone and everything else that’s gone wrong because I think one of the things about having sarcoidosis is that my health crumples and I have to be dependent on these tablets that they eat my mind...”
<b>Travel time to and from work, and issues during work</b>
“I have to travel an hour and a half to get to work, so I’m already exhausted when I get to work and would like to go home straight away.”

**Table 1: Obstacles faced by sarcoidosis patients.** To be continued.

Knowledge gap
<p>“Company doctors and medical examiners should know more about sarcoidosis, so they understand us better. The problem with sarcoidosis is that you never know when it’s going to strike: the fatigue and dyspnoea are always just around the corner and that’s what makes the future so insecure”.</p>
<p>“Since my lung function is normal, the medical examiner thinks there is nothing wrong with me and that I can work as usual. He has no idea what tiredness does to you... He considers sarcoidosis solely as a pulmonary disease.”</p>
<p>Many people encounter secondary challenges due to medication side-effects. Medications to treat diseases are just that, treatment, not necessarily curative. Cancer is perhaps better understood as it appears to be accepted that chemotherapy and radiotherapy treatments are debilitating treatments, but in other conditions the side-effects of therapies such as high dose cortico-steroids and immune suppression appear to be less well appreciated.”</p>
<p>“There’s a whole emotional component that comes along with that. So, you have now an emotional piece going on while your body's falling apart. And then you have this doctor sitting across from you, not only telling you something that you never heard of before that you can't pronounce. But then, it can be progressive and there is no known cure. So, you're going through what I call the ‘trading places life’, you know you have to really lose your old self and then learn how to adapt with your new physical self and yeah, get strong with your mental self.”</p>

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\* Representatives of the sarcoidosis community, who are listed in appendix 2, endorsed and coauthored this Comment. Breaking barriers: holistic assessment of ability to work in patients with sarcoidosis. Lancet Respir Med 2024; [https://doi.org/10.1016/S2213-2600\(24\)00297-2](https://doi.org/10.1016/S2213-2600(24)00297-2).

**Table 2: Summary of organisations who have endorsed this initiative**

Organisation	Website	Country
European Association of Patients Organizations of Sarcoidosis and other Granulomatous Disorders (EPOS)	<a href="http://www.sarcoidosis.biz">www.sarcoidosis.biz</a>	Europe
European Respiratory Society (ERS) Assembly on Sarcoidosis	<a href="http://www.ersnet.org">www.ersnet.org</a>	Europe
ERS Assembly 12 Interstitial Lung Diseases	<a href="http://www.ersnet.org/the-society/assemblies-and-groups/interstitial-lung-diseases">www.ersnet.org/the-society/assemblies-and-groups/interstitial-lung-diseases</a>	Europe
The Sarcoidosis Patients Advisory Group of Europe	<a href="https://europeanlung.org/en/people-and-partners/patient-advisory-groups/sarcoidosis">https://europeanlung.org/en/people-and-partners/patient-advisory-groups/sarcoidosis</a>	Europe
European Lung Foundation (ELF); Sarcoidosis Patient Advisory Group	<a href="http://www.sarkoidose.de/epos">www.sarkoidose.de/epos</a>	Europe
Lung Fibrosis Forum Austria	<a href="http://www.lungenfibroseforum.at">www.lungenfibroseforum.at</a>	Austria
Danish Patient Organization for Pulmonary Diseases		Denmark
The Danish Lung Association	<a href="http://www.lunge.dk/sarkoidose/sektion-sarkoidose">www.lunge.dk/sarkoidose/sektion-sarkoidose</a>	Denmark
French Sarcoidosis Society		France
German Sarcoidosis patients' association: Deutsche Sarkoidose-Vereinigung	<a href="https://sarkoidose.de">https://sarkoidose.de</a>	Germany
Irish sarcoidosis patient community; Sarcoidosis Ireland		Ireland
ASCI: National Association for Sarcoidosis Integrated Research and Assistance of Italy (Amici Contro la Sarcoidosi Italia ets)	<a href="http://www.sarcoidosi.org">www.sarcoidosi.org</a>	Italy
ild care foundation	<a href="http://www.ildcare.nl">www.ildcare.nl</a>	Netherlands
Lung Foundation Netherlands (Longfonds), the leading not-for-profit lung health organization and patients' association in the Netherlands	<a href="http://www.longfonds.nl">www.longfonds.nl</a>	Netherlands
Dutch Pulmonary Fibrosis Patients Society	<a href="http://www.longfibrose.nl">www.longfibrose.nl</a>	Netherlands
Dutch Sarcoidosis Patient Association: Sarkoidose.nl	<a href="http://www.sarkoidose.nl">www.sarkoidose.nl</a>	Netherlands
Association of Sarcoidosis Patients in Poland, Sarko Stowarzyszenie Poland	<a href="http://www.sarkoidoza.eu.org">www.sarkoidoza.eu.org</a>	Poland
ANES (Asociación Nacional de Enfermos de Sarcoidosis), Spanish Association of Patients with Sarcoidosis	<a href="https://anes.org.es">https://anes.org.es</a>	Spain
Sarcoidosis patient group Sweden		Sweden
Pulmonary Hypertension and Scleroderma Patient Association, Turkey	<a href="https://ph-ksp.com/">https://ph-ksp.com/</a>	Turkey
Sarcoidosis UK – Information, Support, Research & Awareness, UK	<a href="http://www.sarcoidosisuk.org">www.sarcoidosisuk.org</a>	United Kingdom
Canadian Pulmonary Fibrosis Foundation (CPFF)	<a href="https://cpff.ca">https://cpff.ca</a>	Canada
JSSOG (Japan Society of Sarcoidosis and other Granulomatous Disorders)	<a href="http://www.jssog.com/">www.jssog.com/</a>	Japan