Sarcoidosis: Snowflakes, Surviving and Self-Advocacy

By Peter Devonald

Sarcoidosis is known as the ‘snowflake’ disease because patients may have so many different symptoms.

> *“Trust the patient.” – Professor Athol Wells, Consultant Chest Physician, Royal Brompton Hospital*

When you have an undiagnosed chronic illness from an early age you really believe that the way you live your life is the same as everyone else. After playing football or tennis or exercise of any kind, I'd have to sleep - and be in pain for days. Later when going out for nights out I'd have to sleep most of the next day, absolute exhaustion. I thought everyone did this -- and when I heard that people didn't, I presumed I must not be very fit or something else.

So many things in hindsight make sense: how people were able to go school or work - I struggled so much every day. I had a racking cough that started when I was about 5 and never stopped. Endless terrible throat pain was put down to tonsillitis and they were removed - simple cause and effect is so much easier than the complexity of sarcoidosis.

There were more obvious signs of sarcoidosis if anyone really looked. I used to bleed all the time - nosebleeds that never stopped and other places. I hurt everywhere, my breathing was difficult. When I ran it felt like my heart was bursting

out of my chest. I had to sit in the front row seats in class or couldn't read the blackboards.

Later, much later, when I was 18 and at University and finally enjoying life, my right leg stopped working for 5 months. I was in hospital for a barrage of tests, but no one ever came close to an answer. I was in a wheelchair for months - till one day I got up. I felt like such a fake, so baffled and confused. Later when Little Britain had a character that did this, I totally understand. My doctors shrugged and found nothing, life moved on.

Aged 25 the symptoms become far more obvious and debilitating. The exhaustion that had plagued my life meant I couldn't even get out of bed. I was burning and freezing through the night and day, coughing all the time. I lost almost half my weight, my lymph nodes throughout the body were massive, and strange purple spots all over my chest. I was desperately ill. The doctors' tests kept deleting possible causes, till Hodgkin Lymphoma, TB or sarcoidosis were the last on the table. Obviously everyone was scared of the Big C. I remember the biopsy so clearly, the anxiety and worry -- then the longest wait. They said the news was good -- it was sarcoidosis. I had no idea that 25 years later I would still be battling and largely losing this fight.

In 1999 the knowledge most doctors had about sarcoidosis was very limited. I was rather left to it - utterly shameful given everything. I didn't even have a lung function test or cardiac echo/ ECG/ MRI - just left to it. As it happened, after 3 terrible dreadful awful years, sarcoidosis appeared to calm down and I was able to unsteadily return to some sort of life. It frustrates me massively that there wasn't the care, support or help during that time. I tried my best - tried to eat an anti-inflammatory diet, less/ no alcohol, exercise, avoid mould/ pollution and reduce stress -- which really are the keys to a lot of sarcoidosis. But so much was still wrong and so much could have changed what eventually happened. The problem was at the time the considered wisdom (and the lies often still seen on websites) is that sarcoidosis is self-limiting and almost always acute (i.e. lasts under 3 years and can go away on its own). The saddest, most awful reality is the most likely outcome is

recurrent - there might be periods of dormancy, but like chicken pox, sarcoidosis always, always remains in the system.

The first signs of the return of the sarcoidosis were missed by me. I thought I was doing well, but later it turned out others thought I had asthma. I was running a film festival in London, had many films written and produced, I was winning awards and having a fantastic social life. I was living my best life, getting commissions and working with many big TV and movie stars such as Matthew Marsh, David Gyasi, Alexandra Moen, Barbara Keogh, Rik Mayall and Steven Elder. I was developing scripts with film and TV companies such as Neil Morrissey and MTV. My films were showing in competition in festivals all over the world: Venice to New York, London to L.A. There were wins at Houston, Cyprus, Kharkov, Venice, BFi, Branchage, Wood Green, Kyiv and many more. I was senior writer for a Children's Bafta nominated series which won Best Children's Series Award and Winner Children's Choice Award at the British Animation Awards. Another film was top rated on MTV. Formerly I was senior judge/ mentor for The Peter Ustinov Awards (iemmys). Life was good. And then it stopped.

Sarcoidosis returned with a terrible vengeance. The same symptoms before, spectacular weight loss, illness, exhaustion, coughing all the time, temperature, night sweats, so much pain and also dreadful skin sarcoidosis that covered my whole body, sarcoidosis in the bone marrow, lymphatic and systemic sarcoidosis. Sarcoidosis is called "the great mimic" because it presents in such a similar way to other conditions: even with the previous diagnosis, you have to go through the whole process again of biopsies towards certainty.

Some doctors were appallingly slow and inept - even when they realised what was happening. I was only treated because of the marvellous dermatologist Dr Adam Friedmann at the Whittington hospital, but by then my lungs had significant fibrosis - capacity down to nearly 30%. Though the staging system is more a diagnostic tool, I was stage 4 systemic sarcoidosis. My old world collapsed. Everything that had been happening so spectacularly, stopped. I still had a couple of films made but I couldn't take meetings let alone network or go to festivals. Over the years I have won many script competitions through my old scripts, but life changed almost overnight.

I am so thankful for the NHS in the UK – we are so incredibly lucky to have this marvellous free service. Over the years I have seen some of the very best sarcoidosis specialists – Doctor Amit Patel now at Kings College Hospital was a total life saver. Knowledgeable, caring, supportive, helpful and kind, he helped nurture back my lungs and well-being: now my lungs are around 55% on most lung function tests. He also saved my sight: I had terrible pain around my eyes, assumed it was skin sarcoidosis which at the time was extensive. He ordered me to go to A and E – and was frustrated I didn't get an ambulance. A and E refused to treat me because they were sure it was sarcoid, when Dr Patel marched in and demanded treatment. As it turned out it was very severe shingles and without treatment I would have been blind within 24 hours.

Professor Athol Wells at the Royal Brompton was another brilliant, life affirming and life changing specialist. Professor Wells has devoted so much of his life to helping those with sarcoidosis, and trained so many of the very best specialists throughout the world, including Dr Patel. He is the most generous, kind and brilliant doctor, so full of empathy and kindness. His view of sarcoidosis is always "trust the patient". Even though he knows more about sarcoidosis than anyone, he still listens, learns and responds. I urge you to watch/ participate in the sarcoidosisuk patient days – videos on their website and interactive yearly. Also great youtube videos. It is because of him and a 3 hour session where we looked back through my history/ medical records and worked out the sarcoidosis is almost certainly active from the age of 11, perhaps earlier.

I have battled sarcoidosis for the last 40 years. I still struggle, still rage and rail against all that has happened, still baffled and broken, sometimes. I have sarcoidosis arthritis and also in the bone marrow – so it is systemic and reactive. My lymph nodes are forever swollen throughout my body, causing cracking nails, pain and an inability to fight infection. Though sarcoidosis is an inflammation disease, it is also an immune mediating condition, which means that we are prone to catch any illness going.

Covid times added another layer of difficulty. Covid vaccines are unlikely to be as effective -- and also they flared my gout and shingles. Once our bodies are out of balance we catch other illnesses. I have had terrible issues with pleural effusions, coeliac, high cholesterol and so many others. As I fight through one thing, something else goes wrong. For many years I was collapsing and passing out because of sudden BP drops --- the 'solution' from the doctors was to have Lucozade in the morning. It worked, but now I am diabetic and fighting that too.

Much of the last decade I have spent increasing the general awareness of sarcoidosis and helping others with this condition. I have set up facebook groups and helped out in a dozen groups. I have created massive file databases with all the best information, available all for free: from symptoms to treatment plans, best doctor lists to secondary illnesses, benefits advice to travel insurance. Developing everyone's ability to self-advocate is central for positive outcomes. I have been extremely active with sarcoidosisuk in particular, helping rewrite texts and creating new pages. Also providing my voice in making information more accurate, more relevant and more helpful. It is a long process but slowly the information online/ for doctors is improving. I never wish anyone to have the terrible level of care I received in the early days.

The last 3 years I have focussed on writing a novel and now poetry. I have had 100 poems selected and also Winner of the Waltham Forest Poetry Competition 2022, one of the winners of FofHCS Poetry Award 2023 (work printed at Heaton Chapel Station) and Heart Of Heatons Poetry Competition winner 2021. I am poet in residence at Haus-a-rest and had work shown in 7 galleries.

Learning to accept the new normal is hard and painful, but writing gives new insights for me every day. Things have been extremely difficult, and there are always new pains and new challenges. I have had hundreds of tests and retests – so many lung function tests, bloods, x-rays, CT scans, ECG's, MRI's, ultrasounds and everything in between. It is exhausting and draining and awful. The list of illnesses keeps growing… And over the years I have lost many friends who have died of sarcoidosis. It is a cruel and punishing condition, made all the worse from the lack of knowledge most people have of it.

But I also feel blessed and lucky. I have one amazing friend in Alison who has supported me throughout all of this, went to countless hospital appointments, A and E and so much more. You really learn your true friends when things go bad, and I really am so lucky to know her.

I am thankful for all the friendships, love and support of fellow sarcoidosis patients, and I do really feel blessed to have met so many wonderful people. It has been great to do many projects that increase awareness of sarcoidosis including the sarcoidosis postcard website that became a calendar and cards sold through SarcoidosisUK. The generosity and talent of Joanne Cudmore and Daniela Cruz is an inspiration.

I also have been involved in so many projects for sarcoidosis with the wonderful Jacqui Newton and others. We are fortunate to have so many brilliant, articulate and intelligent people with sarcoidosis who can advocate and help push awareness forward. SarcoidosisUK is doing so much marvellous work, especially through the hard work and insights of Leo Casimo and Brogan Fricker. They have a fantastic free service in the UK to talk to sarcoidosis nurses - Jo, Jenny and Rachel - who are absolutely the best.

If you have sarcoidosis I urge you to join the facebook group SarcoidosisUK Facebook Group. There is so much information that can help every aspect of the condition. Alone this disease is terrifying - together we have strength and power. Also excellent leaflets and information available at https://www.sarcoidosisuk.org/

Though life can be hard with a lifetime of sarcoidosis, we have to be thankful for all the positives, the kindness, the awareness and the good times. My life hasn't turned out how I hoped, and I still sometimes regret all that has been lost – but every day is an adventure, a miracle and an opportunity. And for that I am forever thankful.

MY ADVICE FOR PEOPLE WITH SARCOIDOSIS

1) Eat lots of fruit and veg - Mediterranean diet is best. Avoid sugar and processed food, alcohol and smoking

2) Improve your gut health. Maybe reduce carbs, red meat and gluten?

3) Be very careful with vitamin D and calcium supplements (check PTH with bloods)

4) Similar to 3 - avoid long exposure to sun; use high factor sun cream

5) Avoid living or working in polluted places, especially black mould

6) Try to exercise but don't overdo it. Swimming is best – less pressure on body

7) Make sure you find the best specialist you can – ask nicely for their email!

8) Learn about sarcoidosis - be your own advocate

9) Count your blessings - we are still so lucky

10) Take each day as it comes - stay positive– things will turn out ok

WEB LINKS:

Great leaflets and information - https://www.sarcoidosisuk.org/

Excellent general info - https://www.rbht.nhs.uk/our-services/sarcoidosis-treatment

Brilliant summary - https://my.clevelandclinic.org/health/diseases/11863-sarcoidosis

SarcoidosisUK Postcards: https://store.sarcoidosisuk.org/product/postcards-pack-of-12/?fbclid=IwAR3PoKsaeNzGuCsS1mTDdq9TJRTmmO4ydQgMMfinRmoLWCnqdmOzPNHEcoQ

Global sarcoidosis postcards: https://photosarcoid.wixsite.com/sarcoidosis

Interview: https://tetedepunk.wixsite.com/theunconcourier/post/interview-with-peter-devonald?fbclid=IwAR2SbF41sCVwcu3qahpVY3XfviUt2VSAdw7l0N0VO-cxz5n8RpHyM97ZMRA