The patient's journey: systemic lupus erythematosus

Jane Robinson

38 Percival Street,
Peterborough,
Cambridgeshire
PE3 6AU

Jane Robinson
patient

cambslupus@
ntlworld.com

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Dancing with the wolf

It is fitting that the Latin word for wolf should be "lupus," because the wolf in my life is systemic lupus erythematosus (SLE). My symptoms include rashes, ulcers, fatigue, anaemia, depression, photosensitivity, hair loss, joint and muscle pain, flu-like signs, kidney problems, headaches and migraines, and weight gain and loss. The condition carries increased risks of miscarriage and heart disease. No two people with lupus are alike; their journeys may differ greatly.

I am 37, I was diagnosed with lupus 12 years ago, and I have no idea how my lupus will continue to affect me or what complications I might have.

Watching from the sidelines

From the age of 10, I went to my general practitioner with various symptoms—rashes, joint pain, and mouth ulcers. They were put down to my age, too much sport, not enough sport, and even not being able to sweat properly. The symptoms never presented together nor were they put together to form a potential diagnosis of lupus. I often needed to sleep when I got home from school before I did my homework. It was put down to being a typical teenager and rather lazy. When I was 19 I had trouble climbing the stairs at work. My doctor told me that I would probably go on to have arthritis but was not prepared to take it further and confirm a diagnosis.

Aged 25 I woke up one Sunday morning covered in a rash. On Monday, the doctor suggested that it might be an allergic reaction and said it wasn't contagious. I went to work. By the end of the day I was unable to move. All the joints in my legs and arms had swollen. I managed to get home and went back to the doctor the next morning. I was given a stronger antihistamine and told to go home and rest. I slept for a whole week only to be woken from time to time by friends checking up on me. My general practitioner referred me to an immunology clinic to ensure that it wasn't the start of an anaphylactic reaction. Patch testing proved that I was allergic only to things that I already knew about, such as grass. Blood tests were taken because the symptoms did not match the patch test results.

Learning the steps

Three months later, at the follow-up clinic, I was asked lots of questions, and I found myself saying yes more than no. I was then told "you have SLE and need to see

a rheumatologist. Where would you like to be seen?" Shell shocked, I said, "My local hospital." And I was sent on my way. I had never heard of SLE and didn't know what it was, let alone where I should be treated. My head was spinning, thinking about all the questions that I had been asked and what they meant. I went straight to the local library, where I looked up lupus in a medical textbook. I read that I was probably going to need kidney dialysis and that the likelihood of survival for five years was low. I had promised my parents that I'd telephone and tell them what had happened, but how was I going to tell them all this?

When I finally called, my mother remembered that a friend of my sister had recently received the same diagnosis. I called her and she told me about Lupus UK. She said they had told her not to read any medical textbooks that were more than five years old. (Too late.) It was a huge relief to feel less isolated.

As I found out more about the symptoms of lupus, I started to feel the relief of having a proper diagnosis. I was no longer a lazy kid who slept after school or in crowded rooms, or in my early 20s indolently sleeping away whole weekends. There was a reason for the rash that I got every summer over my nose, shoulders, and forearms. My "unexplained" joint pain was now explained, as were the migraines and regular headaches and the many mouth ulcers. At last there were reasons for all these things, and, in many ways, that was a good thing.

I was in denial for several years. I took hydroxychloroquine every day and the occasional painkiller but tried to carry on my life as though I had never received the diagnosis and there was nothing wrong.

Slowly the wolf began to change my life. I was unable to carry on working hard and also have an active social life. Something had to give. Because of a strong work ethic, my social life was the only choice. I hated letting friends down if I agreed to go out and was not then well enough on the night or fell asleep while we were out, so I stopped going out. Instead, I would fall asleep in front of the television and wake up to go to bed. My weekends were used for sleeping, household chores, and catching up with the few friends I really wanted to keep.

I was not enjoying life, and I was unhappy. It didn't help when new symptoms developed because my doctors were not sure if they were signs of depression, lupus, or something else.

The awkward turns

I needed to learn to make adjustments and not to be constantly disappointed when a flare-up came. I had to learn to think positively and to live with pain and constant overwhelming fatigue. This took time, probably five years or more.

The various drugs offered to reduce symptoms have side effects, and there is always a dilemma as to whether you want the possible side effects as well as the potential benefits. I currently take prednisolone, azathioprine, amitriptyline, pizotifen and rizatriptan (for my migraines), lisinopril (for my high blood pressure), and artificial tears, as well as the hydroxy-chloroquine.

The wolf is a demanding taskmaster. The daily grind of living with him is hard, he's there every day and never goes away. My lupus may wax and wane, but it is always there. When it flares up I feel really down and disappointed. I have to learn to live with the more unpleasant aspects of lupus all over again; acquaint myself with pain management techniques and cancel arrangements; and slow down and rest more, which is not easy when you like to be busy. But on the positive side, it's a great reminder that you have lupus and that there's a reason for taking the drugs and maintaining a healthy lifestyle.

New symptoms have to be dealt with. Are they because of your lupus or are they something else? Sometimes, if the symptom is unusual, I find myself discussing it with a doctor who isn't used to seeing people with lupus.

Lack of psychological support has been a particular problem. I struggled for several years to come to terms with my diagnosis and the affect lupus was having on my life. During the early stages, I didn't really have anyone with whom I could discuss the condition. I knew my doctors had little time to see me, and specialist rheumatology nurses, especially those familiar with lupus, were few and far between. I lacked the confidence to talk to my line manager about my workload and the pressure I was feeling. Although I knew in my heart that I could talk to my family and friends about the frustrations of feeling poorly day in day out, I lacked the confidence to do so.

I met someone else with lupus, and it helped to talk with her about my feelings, frustrations, and anxieties. But there were some things I didn't want to discuss with her. Eventually I was referred for counselling. Although it was difficult, it was beneficial and made me think about my lupus and its effects. Eventually I came to the conclusion that I was not going to allow lupus to run my life. I was going to run it myself, as I wanted it. It was up to me to make the change. I also found support from others with the condition and soon learnt the benefit of being involved and helping others with similar problems.

Eventually the wolf began to get the upper hand. The standard of my work started to slip. My concentration levels were falling, I needed increasingly to rely on my colleagues, and I hated letting them and my customers down. A very helpful occupational health doctor, seeing me struggling with my work, helped me to apply for early retirement, with the intention of returning to work on a part time basis after a break. I was in my 30s. It was an extremely difficult decision and

took two years to make, but once I had made it I felt an overwhelming sense of relief. In hindsight, I wish I had been strong enough to make the decision earlier. Since then, I have been able to return to work part time, leaving me with the energy to do other things I enjoy.

Forgetting the steps

All this was made more difficult by memory loss, possibly due to my lupus. Learning to live with memory loss is difficult, but I think it was easier for me because I had already learnt how to live with lupus. Learning new techniques to help me remember my own telephone number, where I live, and when I am seeing friends was not easy, especially when my memory, particularly for numbers and dates, used to be very good. But perseverance pays, and I have become much better at it.

Becoming the dance teacher

I would not claim to be able to teach others how to live with their illness, but the adage, that "it takes one to know one" is never truer than with lupus. Being able to give newly diagnosed people the support that I felt I needed when I was newly diagnosed, helping them not to trip up or have their toes trodden on as I did, and helping them to see how they can really help themselves are all very rewarding. Not only did I want to help others learn about their lupus; I also wanted to help people with other long term conditions. So, I participated and then became a volunteer tutor for the Expert Patient Programme, an NHS self management programme to give people the skills, confidence, and knowledge to manage their conditions better and to be more in control of their lives.

Before I became involved with the programme, I had a positive attitude and thought I was managing life with my wolf quite well. During the course I learnt so

Dancing partners

- My general practitioner at the time of the diagnosis had little knowledge of lupus but was willing to learn, was very supportive, and enabled me to acquire some of the basic steps
- My family have been by my side throughout. It has been difficult for my parents, who feel guilty, fearing that it their fault. My mother knows me better than anyone else and can always see through my "fine, thank you" response when I don't really mean it
- Close friends I have made over the years, several of whom helped me through my period of denial, can all be relied upon in times of poor health. Two of them also have lupus
- My drugs and my pharmacist are important. I take many drugs so interactions need to be watched out for
- Lupus UK has been a key partner, providing me with information when I most needed it and, more recently, with opportunities to help others by being part of the local group's committee, being a contact, and writing their newsletter
- Finally, there are my current general practitioner and a very patient consultant rheumatologist, who has let me get angry and upset and hopefully is now seeing the pay-off. A good doctor-patient relationship is key to the successful management of a condition like lupus

much more and found that through simple action planning I was able to start making the changes that improved my life and my health. I learnt pain management techniques and was able to improve my pain relief. I increased my exercise levels, improved my eating habits, and drank more water. I was able to maintain these improvements after completing the course and now, if they do slip, I notice straight away, feeling more fatigue and more pain. Living this healthy lifestyle also helps me to feel in control.

The judge's score

Although I do get frustrated quite often, and I am occasionally fearful for the future, I no longer have any anger. I am a very optimistic person and keeping up to date with current research helps reassure me. I hope that the self management techniques I have learnt through the volunteer programme and through over a decade of living with lupus has meant that I have a better relationship with my clinicians (I think it has) and feeling better and improved self esteem have improved my prognosis.

And, strangely, there have been benefits in having lupus. Without it, I would not have learnt so much about myself and about life in general; I would not have met some of the people I have met and become friends

Websites

- Lupus UK (www.lupusuk.org.uk)—the only British national charity that supports people with systemic lupus and discoid lupus and helps people approaching diagnosis
- Lupus UK's site for healthcare professionals (www.medical.lupusuk.org.uk)—provides information on the diagnosis of lupus and the treatment and support of patients with lupus and related connective tissue diseases
- The LUPUS Journal, published by Hodder Arnold in the United States (www.ingentaconnect.com/content/arn/lu)
- Lupus Patients Understanding & Support (LUPUS): for free information and free psychological support (www.lupus-support.org.uk; www.lupus-forums.org.uk; LuPUSMB)

with; and I would not have become involved with the Expert Patient Programme. I am genuinely grateful for all these things. With support from friends, family, and clinicians, dancing with the wolf is not all doom and gloom.

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Lesson of the week

New football boots and toxic shock syndrome

C M Taylor, F A I Riordan, C Graham

Consider toxic shock syndrome in a child with rash, fever, and hypotension

Birmingham
Children's Hospital,
Birmingham

C M Taylor
consultant
nephrologist

C Graham
consultant
microbiologist

Heartlands
Hospital,
Birmingham

F A I Riordan
consultant
paediatrician

Correspondence to:
C M Taylor,
Department of
Nephrology,
Birmingham
Children's Hospital,
Birmingham
B4 6NH
cm.taylor@bch.nhs.uk

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Toxic shock syndrome is unusual in childhood. Although it is easily recognised by those who have seen it before—and is an important diagnosis to make—few clinicians will have encountered a case. We present two similar cases. Both patients developed friction blisters over the area of calcaneal insertion of their Achilles tendons—the result of wearing new football boots. The blisters contained *Staphylococcus aureus*, which in one case was found to express the toxic shock syndrome gene TSS1. Both had a secondary rash during recovery.

Case reports

Case 1

A 13 year old girl played a competitive game of football in new boots and developed friction blisters over both heels. The next day she developed fever, lethargy, and vomiting but remained alert and oriented. Within a few hours, she had developed an erythematous, macular, coalescent rash over the trunk, back, and all limbs (figure). Twenty four hours later she developed diarrhoea, which lasted a few hours, and abdominal pain.

She was admitted to her local hospital, where the rash was recorded as having spread to the hands and feet, with oedema of the fingers. The buccal and labial

Case 1: Erythematous rash on patient's arm and trunk

mucosae were erythematous and the conjunctivae injected. On arrival at hospital her blood pressure was 106/46 mm Hg. She had no anaemia, lymphadenopathy, or hepatosplenomegaly and no abnormalities in the respiratory or central nervous systems. Her last menstrual period had been 10 days previously and she never used vaginal tampons.

She was treated empirically with intravenous ceftriaxone 3.2 g daily (she weighed 64 kg). A blood culture taken before she started taking antibiotics proved sterile. Over the next 48 hours she deteriorated and