



Scleroderma Society of Ontario
136 Kenilworth Avenue North, Hamilton, Ontario, L8H 4R8
Toll Free: 1-888-776-7776
www.sclerodermaontario.ca

Ada's Story

My name is Ada, I am 53 years old and I am married for 33 years to a wonderful man who always was beside me and gave me hope and reason to fight no matter how bad I felt. I also have a son who was quite disturbed by my health situation and was very hard for me to see him so upset.

My whole life I worked as a dental technician and I loved my job. It was very rewarding for me to be able to make people smile with confidence again, after years of hiding their mouth. Unfortunately my career had a big impact on my health, because I was exposed to a lot of silica and metal dust and last December, after my lung biopsy, my career came to a halt .

I was diagnosed with systemic scleroderma last summer but my first symptoms started about 3 years ago with swelling hands during the night, numbness in my fingers, and a lot of pain in my shoulders. After I complain to my family doctor about all those symptoms, she sent me to do some physiotherapy for my shoulders, but she didn't take the swelling of my hands too seriously telling me that this could be a menopausal symptom. When I realized that my symptoms are getting worse, I insisted to be sent for a carpal tunnel test and I surely enough was diagnosed with carpal tunnel on my both hands. I was wearing those uncomfortable splints at night for a while but they didn't help me at all.

In the spring of 2006 every evening I started to feel almost like I had the flu. I had chills, a low grade fever, I felt very fatigued and I also started to have shortness of breath. At this point my family doctor became more concern and sent me to a cardiologist. The appointment was too far, like with any specialist, so I had to go to the ER. After I had a CT-scan, I was told that my chest lymph nodes are enlarged, I had pericardial effusion,



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and my base of my lungs showed some opacity. That's how my ordeal started! I was now in the attention of a pulmonologist who was almost convinced that I had Sarcoidosis or Lymphoma, so he did a bronchoscopy but the result was no diagnosis. He decided to put me on 50mg Prednisone. The Prednisone did help me with my joint pain but not with my breathing. Next step was to have a Diasthenoscopy which had the same result again (no diagnosis). At this point my Doctor was very confused and told me that the only way to find out what kind of lung disease I have, was to have a lung biopsy. I was very reluctant of having this procedure because I knew that my immune system was compromised from Prednisone and I could get complications. The pulmonologist and the surgeon tried to convince me that I shouldn't be concern about that but they couldn't convince me and I refused to have it done at that time.

Unfortunately my condition stated to deteriorate more. I felt more fatigued, chills, my breathing got worse and my Doctor refused to give me any treatment unless I had a diagnosis. In the mine time, because of my shoulder pain, I was also send to a rheumatologist who happened to be also a Scleroderma specialist, but because at that time I didn't have very obvious skin symptoms, after all kinds of blood tests he still couldn't give me any diagnostic. So, on the 15th of December 2006, I was on the operation table, and the next day I was almost put on a ventilator because I had gotten pneumonia in my other lung. With my both lungs collapsed, I wished that I would have never done the biopsy, but now was too late to change my mind. Those 10 days in the hospital where the most horrific days of my life and every time I opened my eyes I wished that the reality was just a bad dream .I was on 5l oxygen 24 hours, I lost 20lb, I could hardly move few steps and even talking was too strenuous for me.

After I got home, I had a better environment, but my family was under more pressure and I was terrified to be left alone. My pulse was jumping to 120-135 in the morning



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when my husband had to go to work. As the time went by I started to feel better. For my pulse I was given Metropolol and my breathing and strength starting to improve quite a bit. When I had the 2nd follow up X-Ray, my Pulmonogist was very pleasantly surprised by my progress because my lung biopsy result which was UIP (Usual interstitial pneumonia) had the worst prognosis from all the lung diseases (only 2-3 years of survival). After few more follow ups, my Doctor told me that my lung fibrosis didn't progress for about 9 months. Right now I am on 2l oxygen at exertion and I don't have to used it at rest.

My medication was again Prednisone (20mg) and Imuran. Because I had so many other problems with my lungs nobody had paid any attention to my skin symptoms that I had for a long time like a rash on my inner tights, redness at the base of my finger nails and between my fingers etc. These small details would of lead to the real diagnosis and spared me from so much suffering. I finally wanted to know why I have all this changes of my skin, so I asked my family Doctor to send me to a dermatologist. The moment the dermatologist touched my arms and cheeked my fingers he told me that he is almost sure that I had Scleroderma. From then on, I stated to research about this disease and everything started to make sense even for my lung Doctor. I learned that this is a very unpredictable disease but I was somehow encouraged by the fact that after few years is a possibility that the skin condition could go into remission and the lung fibrosis could stabilize. It seems that now I am at that stage with my lungs, but not with my skin that started to change very rapidly after 1 year from having my lung problems. In effect my skin symptoms right now are so bad that I am almost desperate and it seems that any of my doctors know how to treat my condition. I have read about some treatments like UVA-1 light therapy, euricine, minocycline etc. but I don't know which one really works.

At present I am staying home trying to be as useful as possible taking care of my family



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(my son is living temporarily with us). I am also enrolled in a volunteer program called Friendly Visiting, which would give me a chance to keep company to an old, lonely person, 2-3 hours a day, once a week. I would also like to be involved in a Scleroderma support group because I realized how much lack of knowledge is there about this disease, and I think that at least we can help each other by sharing our own experiences and by supporting Scleroderma Society with their research and their awareness programs for the medical professionals.

I would like to end my story thanking everybody for letting me sharing it with you and I hope that rather sooner than later the medical science will be able to conquer this terrible disease!