

Sjogren's Solutions - Module One – Bev's History

<https://youtu.be/WswPisLpa6g>

There are videos and extracted audio of all the Sjogren's Solutions videos on the TASSA website

<http://www.sjogrens.org.au/solutions.htm>

Continue reading the text below from the first video module transcribed by Marion. Please contact jay@sjogrens.org.au to volunteer to transcribe a module.

In my case I was totally independent, living on my own, going to work 60 hours a week and overnight I became totally dependent. I had to have a carer. I already had 2nd stage Sjogrens when I got a cold and flu virus that started my immune system killing off my peripheral nervous system. That was 13 years ago.

The Doctors had no idea how to treat it and by the time they had worked it out I was a complete vegetable. I've had to learn how to walk, talk and eat and everything all over again.

Now what I'm going to tell you is a little bit about my history. I was diagnosed with Rheumatoid Arthritis when I was 18. I had all sorts of medication and I also had gold injections. I was allergic to the gold injections. So they nearly killed me with the gold injections.

I had various other medications that I used to have. My knees used to swell up and I used to have cortisone injections in my knees. I found I was getting sicker and sicker and sicker. So I decided that the medication they were giving me just wasn't working. I needed to look at alternative therapies.

So I looked at vitamins and supplements and I went to naturopaths and things like that.

On an average of every 6 years I would have some sort of trauma. A cold and flu virus or something like that which would then set my immune system going again and I would end up with either Lupus or Scleroderma. I had Vasculitis. I had Raynaud's and I also had Sjogrens.

It made it very difficult to work but I still worked and also I

discovered that my Mother ended up having Sjogrens as well. She had primary Sjogrens and secondary Sjogrens and she was one to take a lot of medication that the Doctors gave her. She ended up dying from the medications they gave her. It caused a buildup of the medications in her kidneys and caused renal failure.

So very early on I decided there was no medication for me and I controlled the Sjogrens with Acupuncture, massage and diet. When I say diet I ate lots of raw foods. Salads, vegetables and shoots like bean sprouts, alfalfa shoots. The more raw vegetables you can get into your diet if you can swallow them the better because there is more nutrients. The nutrients go straight into the cells.

So what I did was used myself as a guinea pig with all sorts of vitamins, supplements, therapies and things to keep myself going. At different times I would have flare ups from cold and flu viruses or some sort of bacterial infections. I would then take Prednisone until the inflammation had gone. I would then get the Doctor to wean me off it.

I had an overactive thyroid because Sjogrens affects your hormonal system and it can affect your thyroid. This could be why you get really, really tired.

So that was how I controlled it until the year 2000 when I had a virus that started my immune system to killing off my peripheral nervous system. Then I became, as I said, a complete vegetable and I've had to learn how to walk and talk and eat all over again. The doctors only gave me about 3 months to live.

I moved to Byron Bay to spend my last days with my daughter and I embarked on a spiritual journey which opened up a lot of alternative therapies which is the reason why I am still alive today - which I will cover in another module.

It's very daunting and it's very depressing, it's a lot to get your head around not knowing how to cope with Sjogrens and what to do. Getting no information to help. It had just been trial and error that has brought me to this point where I now know how to cope with all facets of second and third stage Sjogrens.

Many questions that I get asked from phone calls and over the internet is where do I find a doctor and what type of doctor do I go to?

Usually it is diagnosed by a GP. Sjogrens usually has 6, 8 or 10 years before there is a diagnosis. The doctors are only as good as the results of the blood test. They have no idea how it affects your digestive system, your connective tissues, your organs, your capillaries and it affects the whole of your body, your eyes, your lungs so, when you are diagnosed, what you need to do is build your body up with exercise and really good food.

A disease like this is a warning to say what you have always done is not working anymore. You have to change your lifestyle. You have to change your eating patterns. You have to change your sleeping patterns. If you work there is a lot of coping mechanisms I can give you to cope with air-conditioning and light etc. Your eyes become very sensitive to light which can be very depressing.

Everything you are experiencing now I have already been through, so I know exactly what you are going through, the feelings that you are expressing and also the reaction from the people around you because it's just as hard for them - because on the outside we look ok when on the inside we are self-destructing.

They do refer to Sjogrens as the silent disease and it is on the unusual diseases list.

So together I'm hoping these modules will help you cope with living with Sjogrens and I hope I can give you the mechanisms to cope on a daily basis. Everybody is individual, everybody is different so if you're having any problems I am just a phone call away so I can help you through whatever you are experiencing.

If you wish to call Bev and discuss your case in detail then please sign up as a TASSA Lifetime member for just \$60.

<http://www.sjogrens.org.au/join.htm>