

*Not so secret men's  
business:  
An exploration of  
autoimmune illness and its impact on males in our  
community.*

Author: Marline Squance

To acknowledge and support the many men living in our community with autoimmune illness, ARRC sort to give men a voice within the often female dominated world of autoimmunity. The call was made for volunteers to come forward and help us explore autoimmune illness from a male's perspective. Three wonderful men kindly and candidly answered questions regarding their illness, the affect of being diagnosed and the impact placed upon their lives and life decisions.

We could and should subtitle our feature

*3 men & hiccups in the road travelled*

As all three men accepted their diagnosis with courage and saw it as a challenge that may have caused them to stop and think and maybe even change their directions however did not place an insurmountable roadblock. What follows is a brief account of their experience and journey....

A keen gardener, **GC** a man of 75, refuses to let his illness take over. His journey has caused him to make some lifestyle and career changes to allow him to live life to the fullest. Diffuse scleroderma and quite severe Raynauds has been a part of his life for the past 24 years, as has a diagnosis of Cancer 12 years ago. **GC** describes his diagnosis with Scleroderma as "hard at first" and goes on to say his Cancer diagnosis was " a bit of a blow however you just accept it and get treatment and then move on."

A lack of familial history of autoimmune illness has at times caused him to question what influences his career choices may have impacted on his health symptoms and subsequent

diagnosis. The consequences of symptoms certainly has prompted changes with his initial employment with the air force moving from one as a fitter, handling aviation fuel and many chemical solvents, to that as a topographic photo interpreter, which was met with excitement however, realistically, some difficulty. This career was ceased with retirement from the force moving to employment with the reserve bank. Finger and hand symptoms did cause concern with the handling of cash and with an understanding employer GC moved into an administrative position.

GC has over the past years, due to his hands and finger symptoms needed to change work tasks and environments. At times he reports that his fingers would bleed due to the ulcers and cracked skin causing droplets on the photographs he was assessing, this causing him to question why it was happening, (as this was prior to diagnosis) and how to prevent further injury. "With a family to care for, there was a need to be realistic about the changes that were needed to be made so that I could continue to work and provide for my family. You just accept it and move on."

Finger ulceration and injury was GC's first presenting symptom with other scleroderma symptoms of reflux and calcinosis following a few years later. At first his symptoms were put down to the extreme cold. For a couple of years his hand would easily crack and bleed and cause extreme pain, however his diagnosis in Canberra was relatively quick once more symptoms were identified.

GC's specialist did explain that Scleroderma was a chronic condition with no known cure however at first the lack of information was frustrating, "often doctors dismiss the need for information and see their role as just monitoring, your know blood tests etc." As time went on more information was forth coming as medicine learnt more about scleroderma. "Most information was provided in a verbal form from specialists. My sons have also accessed information on the internet as I didn't really use it." "I try to stay optimistic and this has helped me. In the beginning, I did attend a meeting in Canberra however I decided it wasn't for me as I came away feeling pessimistic and never went back."

GC counts his wife and sons as being his greatest support. They all showed interest in understanding the illness including symptoms, management and of course whether there were any heredity aspect to the illness. GC was quite open about his illness with family and friends and work colleagues and for the most part people understood that there were some things that he could not do or needed extra time and/or help with. As his hands were quite visually affected it was "pretty obvious". His family's realistic and pragmatic approach, their support and desire to help on day-to-day tasks has aided management of his symptoms and his overall positive outlook. His sons still actively help even though they are adults and have moved to another city.

GC remarked that his illness has not really interfered with his social life a great deal apart from giving up golf and the need for some hospital visits to dilate his oesophagus every couple of years. He has even managed to travel overseas which has meant that after his cancer treatment the changing of a colostomy bag has been done in many an unusual place. Every day activities have been modified to cope with symptoms with him changing his diet to softer foods, such as casseroles and many foods eaten with gravies and sauces. He learnt to sip drinks in particular carbonated drinks to reduce symptom exacerbation saying that “I just had to accept that I needed to be careful, realised I had to make changes to work and my home life, including what and how I ate and drank.”

Apart from changing jobs, the greatest modification he has made is that he now thinks about everything before he does it no matter how simple the task. He needs to plan how he will go about the task and plan how to protect his hands and reduce injury and pain to his fingers. “For most things I need to wear two pairs of gloves, two pairs for driving, two pairs for gardening, and even two pairs for opening drawers. If I directly touch something I feel pain and my skin can split.” GC also has to keep warm and rug up whenever I go out regardless of the weather.

Each of our participating men was asked to share a single piece of advice they would give other men diagnosed with autoimmune illness. GC offered the following;

“Accept what you’ve got whether it is cancer or scleroderma, that’s the way the cookie crumbled, accept it, make the necessary changes & get on with it, there is no one panacea and there is no use hiding behind the door”.

VT aged 53, is an active and fit man that use to play competitive soccer. He was diagnosed with lupus five years ago and describes his illness onset as “one week I was a star player the next week I had no energy. It was frustrating it never had the same pattern. Some days I found that that during the day I needed to stop, other days were fine. It was so sporadic.”

VT’s main symptoms include muscle and joint pains and fatigue. The first sign of illness showed itself in his early twenties with him experiencing a lot of pain and fatigue. A long history of seeing many different specialists that did the best they could with suggesting different treatments and plans. Finally, one specialist many years later put all the different puzzle pieces together, allowing him to find peace of mind and relief in being diagnosed with lupus.

This diagnosis allowed him to access the most appropriate treatment and allowed him to understand the illness and the symptoms. Explaining the roller coaster of waxing and waning symptoms he had experienced over the past years. “Some men think they are superhuman, invincible, it was a welcome relief when you know the symptoms and you know how to handle it.”

VT was offered ARRC factsheet information and an appointment with the ARRC educator nurse to discuss his diagnosis and management, as soon as he was diagnosed. This allowed him to quickly understand the overall illness and to a certain extent some of his symptoms, however, not all of his symptoms. More clarification of his individual symptoms was needed and obtained directly from discussing them with his specialist. "I listened to the doctor and the nurse and my ex-wife did a lot of internet searching for information, but I didn't really want to know everything about it. I just wanted to know about my symptoms so I asked the specialist and just got on".

Management of pain and stress has been the greatest impact upon VT's life style, however medications and modifying his lifestyle has positively impacted upon his symptom frequency and severity. VT recounts that before medication he use to think he would just have to live with the pain "suck it in and get on" understanding that stress can bring on symptoms and taking medications at the right time has helped and allowed him to continue to play sport occasionally. The greatest improvements have been seen with "getting fit, living a more healthy life and regular eating of good food". This has been problematic in the past due to unknown allergies and his job as a salesman on the road, eating a lot of junk food and not being able to organise his life and lifestyle.

VT also credits health improvements to "getting on top of stress management, going to the gym regularly and playing golf occasionally, giving up the cigarettes and most importantly having a supportive partner". VT's partner also has lupus therefore she understands the illness symptoms and has encouraged him to be more organised. His partner makes sure he takes his medication and eats properly and together they manage their illnesses well and he definitely feels better. Living between different homes, one in the central coast and one in the Blue Mountains and needing to spend time on the road means he has a travel bag pack with all he needs, including his medications with him always.

I asked how he explains his illness to family and work colleagues, VT simply responds "I just tell them. At first they asked questions. Once I have explained that medication helps to keep it at bay and that it come and go. They just accept it. It also helps that my work knows and are supportive". His greatest supports have been his partner, family (children and grandchildren) and his medical team in particular, his specialist.

The greatest thing that VT has reported to learn about himself since diagnosis is that he needs to take better care of his health, he needs to know and understand his symptoms how to avoid making them worse and how to prevent them coming back. "It would have been easier if I had known earlier. I spent a lot of years with a lot of pain, not knowing what was happening. Lacking sleep due to pain or worry. I have learnt to be proactive when symptoms returned".

His final piece of advice to other men is, “See a physician, make sure you explain **all** the symptoms in one sitting so it can be put together. Most importantly, take the advice you are given.”

**SY** is a man of 39 with a young family and a busy career as a paramedic. He was diagnosed 3 years ago with primary Sjogrens Syndrome, however **SY** suspects that symptoms of the illness were showing as early as in 1992, 16 years earlier. **SY**'s autoimmune road is one that has a discovered familial history of his father having blocked ducts and calcifications; his own unresolving and lasting symptoms of dryness and gland swelling after glandular fever; and a history of repeated episodes of face swelling and gland blockages after exposure to cold wet conditions.

**SY** reports that he was “always dry” even as a child, always needing to drink. As an adult he unsuccessfully tried to wear contact lenses, however the dryness of his eyes prevented comfortably wearing them finally succumbing to his optometrist's advice of not to wear them. **SY**, has thought back to when symptoms first began to be noticed and remembers that when he had glandular fever he underwent a biopsy of his submandibular gland (salivary gland) that showed signs of Sjogrens however, the changes were put down to the glandular fever, therefore missing an opportunity to diagnose early. The following year he recounts that he was in a RAAF parade and needing to stand for a long time, he remembers his discomfort when he couldn't moisten his mouth and numerous other times that his activities prevented him getting adequate moisture causing pain a return of this discomfort.

His symptoms progressed and became more extreme in presentation with his whole face swelling due to a suspected infection when needing to be in a cold and wet environment for a long period of time in Griffith, 2003. This episode caused him to go to hospital and seek treatment for pain relief and the unusual swelling. Antibiotics were administered and the symptoms subsided only to present themselves again six months later. The pattern of face swelling and pain continued to occur whenever **SY** was in cold and wet weather conditions, whether they were for social activities or as a necessary consequence of attending scenes of accidents or environmental incidents for his work.

The Newcastle floods, a very cold and very wet large storm event in June 2007, required that **SY** was needed to provide assistance to community members in difficult weather conditions and for long periods. As a result his symptoms flared again and he sought help from his general practitioner (GP) and was referred to see an ears nose and throat specialist (ENT). This event and a subsequent cold and wet fishing trip and 'symptom flare' allowed **SY** to put the pattern together of “exposure to cold for a long period and then flare of symptoms”. However, each flare event and symptoms subsided with antibiotics and pain medication and because of the symptoms going away the initial specialist referral was not followed up. Sadly it took another flare and a second referral from his RAAF doctor to an ENT specialist before **SY**'s symptoms were more thoroughly assessed and a suggested diagnosis of

Sjogrens was made. Confirmation was made with immunological blood tests, Schirmer's test; contrast CT of the salivary glands, although even then, not conclusively confirmed.

After the diagnosis SY says that he received Sjogren's medical support information from his specialist, he also purchased and read a book about Sjogren's and attended an ARRC seminar. At first he didn't rely too heavily on accessing the internet for information "learning the hard way about 'diagnosis Google' in the past. Realising that it can rake fear and anxiety, and in some cases misinformation. My initial thought had been that I had diabetes due to my need to drink and the large number of toilet stops. This led to me having a reactive bladder". For the most part SY reports that the information was relevant and practical however it did focus upon women and the older generation. This confirmed his belief that his condition and presentation was usual, confirmed that "he had a rare diagnosis, it was obvious that he was a minority being under 70 and male".

When asked about what could have been given or offered that may have made his early diagnosis experience more understandable and manageable, SY suggests that a focussed workshop on Sjogren's presenting both the primary illness aspect as well as the secondary aspect when Sjogren's presents with scleroderma or lupus would have been of benefit. Additionally, SY offered his perspective as a young male seeking information, and the challenges faced by some men diagnosed with an autoimmune illness, saying that, "it would be good if there was a young persons' workshop. I mean, I'm grown up enough to feel comfortable with older groups of people and women but younger males may not. A young persons program would be good." He added that "there are issues that may be of great importance to young people such as single issues, trying to form a relationship, sexuality and such, life goal challenges, all these things. Although these are issues for everyone, but young people may have a different need and approach required".

Having an autoimmune illness can greatly impact on our lifestyles, life choices, our goals and aspirations. SY's greatest fear was that his diagnosis would interfere with his military service and that he would be medically downgraded. In reality his diagnosis did not impact greatly, only really needing extra precautions (eye drops) when flying on long flights. He has adopted some changes to his lifestyle more so in the beginning, now he is a little more relaxed. He regularly chews gum to keep salivary glands flowing and is more conscientious about oral hygiene in particular flossing in between his teeth. He is more aware of his individual symptoms of thrush and flares and proactively takes things to lessen impact. He takes medication, (plaquenil) and now uses help to stop mouth breathing at night, which reduces dryness (Beconase). He has actively reduced his alcohol intake and is happy to share with friends the reason for not over indulging.

His drinking of water has also required some retraining as he needs to keep hydrated. SY reports that after the diagnosis he adopted the practise of increasing his water intake however his drinking regime did cause some concern as he reports that he "used to drink a

large amount of water to keep moist, although I drank large amounts in one sitting, but I think way too much as I kept on going to the toilet. Now I've learnt to take smaller quantities but more frequently. I manage the water intake better."

Learning about your illness, it's symptoms and importantly how they present within himself, including triggers to flares has been SY's greatest managing strategy. He reports that the illness has not impacted too greatly on his ability to do things nor on his family life and lifestyle as long as he looks after himself, takes his medications and recognises the signs of being run down which he reports as being a vital lesson learnt.

"Tired & run down affects mental ability and ability to function. I need to take breaks to recuperate. Sometimes my head tells me I'm mentally fatigued while my body is telling me otherwise. I am still learning to listen to my head".

SY also has become more relaxed about his illness and symptoms and as a medically trained person does not take an over interest in all his test results by reporting that he

"Looks at results, I try not to take it too seriously. I look at them for my own interest and as long as I feel well, I don't worry too much. I allow others to manage and guide me about complications."

His illness experience and learning to accommodate his illness has been met with a positive approach that allows him to live well and happy despite the symptoms, his flares and the need to modify slightly his lifestyle. His advice to other men is to "Get your symptoms, understand them and get on top of it early. Don't deny your symptoms when they come. Hit it hard and try and be sensible. Don't focus on the negative side of things."

A positive outlook and acceptance of having been diagnosed with an autoimmune illness has allowed each of our men interviewed to move through their lives confronting their illness and its different symptoms. Each has accommodated their illness by being proactive in making the changes necessary to ward off or lesson the impact of symptom exacerbation. We often hear that men tend to ignore health symptoms and with bravado fail to modify their lifestyle even if modification would help them to maintain good health. This has not been exemplified in the stories presented today and I hope these stories give some support and encouragement to other men living with autoimmune illness allowing them to see that it is possible to live well with autoimmune illness.

ARRC greatly appreciates GC, VT and SY for giving us their time to explore and share their experiences. Thank you for being so open in retelling us your autoimmune story and the road you have travelled.

Marline

Post note: There are only a few resources focussing on men's autoimmune health issues available, ARRC will endeavour to develop and include more factsheets focussing on this neglected area of autoimmune illness.

Some male specific resources can be found at the following sites:

<http://www.lupus.org>

1. 15 questions with Dr Robert Lahita – Men and Lupus
2. How lupus differs in men
3. Men and Lupus

[www.sclerodermasociety.co.uk](http://www.sclerodermasociety.co.uk)

1. Sexual health in men with Scleroderma