



Victoria



Me and my goddaughter Keira



At work



**Victoria Garratt  
United Kingdom**

My name is Victoria, I am 30 years old.

I live in Wolverhampton in the UK and my profession is branch manager. I heard about the Edgar Stene prize from the Scleroderma Society, which emailed me the details. The title of, "Working with a rheumatic disease, my daily reality", appealed to me immediately as my work is very important to me and I recently had to take time off work. I had lots of initial ideas but I knew I had to go into hospital a few days before the deadline and so I took my laptop in and wrote my essay whilst I was there. This generated lots of questions from the doctors and nurses; my consultant was really impressed! I chose to enter because I knew that this was my chance to explain what my daily working life was like, I found writing it cathartic and reading my essay back I feel proud of what I achieve. I've also been able to share my essay with friends and family, which I think has been enlightening for them, as I don't often talk about how my scleroderma affects me.

# Working with a Rheumatic Disease: My daily reality

**I am a branch manager responsible for a retail outlet that turns over twenty million pounds a year and employs one hundred and forty people.**

I am thirty years old and have scleroderma of the lung. I hope to give you an insight into my working life and how my scleroderma affects me on a daily basis.

I start the day by convincing my joints that getting out of bed and heading to work really is a better idea than staying in bed a little longer. I enjoy what I do and look forward to my journey to work, except when my car needs de-icing. I don't know anyone who enjoys this job, but trying to de-ice your car when the circulation and feeling has gone from your fingers is quite a challenge.

My day at work begins with a walk across the shop floor. I say hello to all of my staff and check in with my managers that we will be ready to open. I then read emails, check sales figures and open the doors for another day's trading to begin. I enjoy this time of day as there is often

so much information to take in, the whole shop floor to check over and a morning meeting to hold – I like it because by the time I take a break my joints agree with me that coming to work and walking around was absolutely the right thing to do.

I often welcome visitors to my branch, from other shops and from the local community. If you were to visit me at my branch, I would meet you at the customer service desk and you might notice that I'm wearing gloves that match my suit; you might also notice how cold my hands are when I take off my gloves to shake your hand. Our visit might start with a brief tour of the shop floor. I would be careful to set the pace of walking to a slow speed, which means I can conceal my breathlessness. I hate people to see me breathless, I worry that it makes me look like someone who isn't well, or worse, someone who can't cope. I might take a quick break and go to the bathroom, I would check my reflection in the mirror, I'm not checking to see if my mascara has run or lipstick smudged, I'm checking that my red rash is concealed. I'm looking to see if I look like a girl with scleroderma or a leader of a business; I always hope it's the latter.

**"I'm looking to see if I look like a girl with scleroderma or a leader of a business; I always hope it's the latter."**

Possibly the greatest challenge in my day to day life is managing people. I make time every day to walk the shop floor and ask my employees how they are, how their families are and how life outside work is. I believe that having scleroderma makes me a better manager, although it has taken me some time to arrive at this view. My initial feelings towards my scleroderma were to see how it limited me, how it interfered in my day to day life, how it always seemed to misbehave when I really needed to have a good day. I now believe that my scleroderma gives me empathy. A supermarket is like a microcosm, all of human life is here. Over the years I have encountered employees who are dealing with marital



Enjoying a night out with my friends



My colleagues

break-ups, ill children, domestic violence and serious health diagnoses. I think that my own experiences with my health help me to empathise with those facing difficult times. Let me be clear: I don't openly talk about my medical condition at work, I prefer people to regard me as the boss, as a capable manager rather than someone who has a rare medical complaint. That said, there are times when in order to allow someone to talk it helps to give something of yourself. I relate to them how I felt when I was first diagnosed, how I cope and how I maintain that a positive attitude is the only option when facing life's inevitable challenges.

After spending time in the warm sanctuary of my ground floor office, I head out to the shop floor for a final check around. Scleroderma has taught me the power of delegation. I am a perfectionist and prior to my diagnosis I would try and do everything myself. I've learnt that this is often to the detriment of my team; my managers will not learn if I do not allow them to make their own mistakes. I've learnt that I have to trust the people around me. I hand over to my duty manager, pick up some shopping and leave the branch. I've learnt that if I work excessive

hours one day I won't be able to do my best the next day.

### **"Can I inspire and lead a team of people when I'm too breathless to speak?"**

As I climb into my car a wave of fatigue creeps over me. As I drive home I reflect on the day I've had and I realise how lucky I am. I work for a business that has always supported me, that has promoted me in spite of my medical background, that has given me my own branch that has no stairs. My employer has a holistic approach to business, where the happiness and welfare of the people who work for the business are as important as commercial success. I recognise that not everyone is so fortunate. And yet it is not the physical manifestations of scleroderma that pose the greatest challenges to me in the workplace. It is how scleroderma can make me feel. It causes me to ask questions, Can I do this job? Can I physically run around a shop and do a job I love with less

than fifty percent lung capacity? Can I inspire and lead a team of people when I'm too breathless to speak?

### **"It causes me to ask questions, Can I do this job?"**

I am a proud person. I take pride in what I do; my job is a central part of my identity. It gives me purpose and satisfaction and it is one of the reasons that I will continue to tenaciously manage my scleroderma in the same way I want to continue to manage my branch, irrespective of the hurdles and challenges that I anticipate my scleroderma will place in front of me.

For now though, as is often the case, my joints have the last word, and on this occasion they are absolutely right, a hot bath and an early night are exactly what I need.

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