

Facing Your Fears & 'The Big Freeze'

Judy Flack, 67 from Derby tells us how she came to realise she is in charge of managing her Raynaud's and how with rigorous planning and preparation, she travelled to one of the coldest parts of the world!



For as long as I can remember, I have wanted to see the Northern Lights. I also wanted to whale watch and walk on a glacier. As it is for most people, it was something I had planned for retirement, and then around 10 years ago, Raynaud's kicked in with a vengeance.

Until I could control the episodes, I decided to put the idea on the back burner. My feet and toes are the most affected and I always feel cold in winter. My fingers are affected less so, but can be bad at times. Firstly, I needed a good diagnosis and my GP and local hospital, (Derby Royal), were brilliant.

I was already on medication for osteoarthritis and high blood pressure and so the experts had a medication balancing act to do; keeping my blood pressure at a healthy level without dropping too much and controlling acute and chronic pain effectively without turning me into a zombie. The only treatment I had before medication was self-medication of rum and coffee, when necessary! A wonderful, but not recommended vaso-dilator.

I was referred to Rheumatology and Cardiology and continued to see my GP when necessary, especially when I had infected chilblains...ouch! I had ultra sound and echo testing on the blood vessels in my legs and repeated blood tests, Raynaud's Phenomenon was diagnosed. I was given open access to hospital for iloprost infusions when necessary and after tweaking, my medication was adjusted to suit all conditions. My local health services have been brilliant in my diagnosis and treatment, but I soon realised that the control of the condition is largely down to me.

My husband and I decided to book a holiday to Iceland called, 'Orcas, Auroras and Icebergs'. Everything we wanted. We had planned it over a couple of years before we went and we picked the last week of the season to avoid the coldest of winter weather, but a week before we travelled, Iceland had the heaviest snowfall of the winter and a big freeze.



Judy layered up for her trip

For the previous 2 winters, I had to hibernate so when we booked, I had expected I would have to opt out of some activities if I was too much at risk and stay in the hotel whilst everyone else went out. However, I decided to look carefully at clothing and footwear to keep me warm and protected and give me every chance of living my dream. I had to use all the information I had been given and plan to make sure I got the best out of this 'bucket list' trip.

Over a couple of years, I went to outdoor activities shops and bought some 'all-leather-uppers' Berghaus walking boots and pairs of Heatholders thermal socks. I also bought winter jacket with a detachable fleece lining, thermal vests, waterproof/windproof/lined trousers, long-johns, hat, silk glove liners and thermal gloves also went into the basket. An initial expensive outlay for me, but they will all last for years.

We went, and dressed in 5 layers every day. I saw the Northern Lights 4 nights running, went whale watching on a boat, (dressed in a waterproof baby grow over everything else), walked on a glacier, saw icebergs, sat in a hot tub on the side of a fjord, while it was snowing and walked across an ice cap. We swam in an outdoor thermal pool and watched geysers blow. The snow was still deep when we arrived there and it stayed. We were treated to a storm with winds blowing at a constant and freezing 106mph.

Through trial and error, and with good professional help, I learned to manage Raynaud's. I went into 'arctic training', and on the coldest days, went walking in the Peak District to try out my clothing and attitude. Raynaud's is still there and is still as aggressive as ever, but I will not allow those awful symptoms to wreck my dreams.



Judy saw wonderful sights in Iceland: Geysers, the Northern Lights & Orca Wales swimming in the Arctic sea

With a lot of thought, and careful planning I had the very best holiday. I kept snug and warm throughout the trip and had no episodes to hands or feet. Toasty! I have clothes that will serve me for winters to come and allow me to go out more in the winter months. I looked a bit like Michelin woman, but so what! I had a fabulous time with memories that will last the rest of my life.

I loved it. I did everything I wanted to do and much, much more. When I was working, I was a nurse working in a school for severely disabled children. In my treatment room, I had a notice which said, 'Stop telling me what I can't do. Give me the time and I'll show you what I can do'. 2 years ago, I decided to apply that message to me.

If you have Raynaud's, you should accept it. Work with the professionals and listen to advice. Go back if your medication is not working or is giving you unwanted side effects. Work with them to get the balance spot on. However, you must remember it is **your** condition and ultimately it is down to you to manage and control it. I used my Personal Independence Payments for exactly its purpose, i.e., to keep me independent and give me a good quality of life. I have bad osteoarthritis, and if I want to stay mobile, **I must walk and be active.** If the weather is very cold, I must still do it, even if it is just walking twice around my local park. Just doing this, I invite Raynaud's episodes. Wear the right clothing, copies of brands just do not work. I must have bought 4 pairs of copy Ugg boots and thrown them away, the real Ugg Bots have lasted me 3 winters, so far.

Know your absolute limitations. In Iceland, I knew that if I walked up the side of a volcano, I would very likely trigger an arthritic episode which could take weeks to sort out. In balance, it was better not to do that, and so I waved the others farewell and went for a nosey around with my camera instead. My next trip is into the mountains of Crete. It will be spring and warm, but I will take some of my 'arctic kit', because it could be chilly up there. After that? It will take us a couple of years to save for it, but we really want to go and see the big boys, (whales) next. Now Alaska, hmmm.....

Thanks to Judy for sharing her story and providing the wonderful photos, if you have a personal story you would like to share, we would love to hear from you. Please get in touch with tracey.spray@sruk.co.uk or visit www.sruk.co.uk/shareyourstory Read and watch other personal stories on living with Scleroderma and Raynaud's here www.sruk.co.uk/stories

Wish You Were Here!

Photo Credit: Captinzz



The Summer holiday season is creeping up, which should be an exciting time for everyone, however for those who have a condition such as Scleroderma and/or Raynaud's, the thought of going away on holiday, or even deciding where to go in the first place, can be daunting. This need not be the case with a bit of careful planning, many people living with chronic conditions manage to take overseas trips and holidays very successfully.

Before doing anything else, it would be advisable to speak to your specialist about your plans. They will be able to give you an expert opinion on whether you should travel. If necessary, your specialist may recommend that you wait until your condition settles.

Once you have the all clear for your travels, it's time to start planning. With regard to your health condition, it would be wise to take some special measures. To start with, as well as a wallet containing your passport and travel documents, it is a good idea to include some other vital items:

- ☀ Prescription list
- ☀ List of all conditions and treatment for them
- ☀ List of any allergies
- ☀ Medical insurance contact details and hospital contact details (in case you need to check anything or medical staff who treat you whilst away)
- ☀ Any hospital letters to cover certain medications or fitness to fly/travel

To be on the safe side, take a couple of copies of each, keeping one in your hand luggage and one in your luggage.

Another priority should be your holiday insurance, ensure this is up to date and will cover you for the area you are travelling to. If any health conditions have changed since you obtained your current cover you will need to inform your insurers.

This needs to be set in motion in plenty of time as it may mean a new cover note is needed. You may even require a 'fit to fly' letter from your doctor (for which there is usually a charge).

Once you have your insurance, make sure that your next of kin has contact details of your insurance company and make sure that you take a copy of your policy document, leaving it with a friend or family member. You could also take a photograph of it yourself, to make sure that you have some proof, in case the original copy is stolen or misplaced.

Photo Credit: Taokenisis



There is some useful information about travel insurance on our website:

You may be on medication for your condition, so remember to pack enough to cover you for the duration of your trip, and in case of delays.

Keep all pills and medicines secure and easily accessible in your hand luggage, with a copy of each prescription for clearance with customs, and in case of emergency.

If you're taking immunosuppressants, extra care should be taken to reduce infection, particularly gastroenteritis that can be linked with some foods. Only drink bottled water, avoid unpasteurised foods and keep your hands clean. Consider asking your doctor for a course of antibiotics, which you could take if needed for infection or digital ulcers which may develop.

If you are usually affected by travel sickness, check with your doctor well in advance to source suitable anti-sickness medication that works with your drugs.

Lastly, if you are going somewhere hot, try to book a room that has a fridge or a mini bar in and store your medication in there. Consider also bringing a small cool bag so you can take your medication out

Almost there...

Once your travel arrangements have been finalised, make sure that the airline/train company has been notified if you might need any extra assistance during your journey. Likewise, book extra assistance at airports/railway stations in plenty of time.

Make sure you do not book plane seats in emergency exits if your mobility/health condition is a problem as you need to be fit to open doors etc. in an emergency.

And we're off!

When you're making the final preparations for your travels, a few last bits to think about are of course the clothes you're bringing with you, as well as anything extra that might be particularly useful to you. This might include plenty of layers, comfy shoes and socks, gloves, scarves and headwear, as well as things like your Blue Badge and any adapted cutlery you might use (packed in your hold luggage)...and last, but not least of course, sun-cream, sunglasses, your camera and a good book! You should now be set for a holiday to remember!

with you during the day (any ice packs will need to go in your hold luggage).

Do consult the 'Travel' section on our website for more details about travel insurance and travelling information. www.sruk.co.uk/travelling



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