Feeling OK about it all

It is not always easy to have something that nobody has heard of. Frequently there is a period of frustration until you get used to it, and obviously there is a certain amount of anxiety and depression when you cannot join in sports or if you have a visible disability. Adjusting to having any condition is a very personal process, and each person learns to cope in their own way. Sometimes you may feel very angry. This is ok. Depression is also a natural reaction and it is important that you seek appropriate support for this. Talking about it openly can help your family and friends understand any physical and psychological problems you have. Often this can help them to support you when you most need it.

Disease can change the way you look or what you can do. It doesn’t change who you are.

Raynaud’s & Scleroderma Ireland

Raynaud’s & Scleroderma Ireland is a registered charity founded in 1988 to spread awareness and information, promote understanding, support research, administer relief and improve communication between doctors and patients. It receives no core government funding, and is reliant upon the generosity of volunteer effort and sponsorship.

An Annual Conference is held each April in Dublin for patients and their families, at which top specialists give talks and answer questions. June 29 is World Scleroderma Day, created to tell people what it means to have this disabling disease.

Scleroderma

Some young people develop a related, very rare disease called scleroderma. If you have this, it may take a long time before the correct diagnosis is made and you are referred to a specialist who knows about scleroderma in young people. This is because it is so rare.

Tell your doctor about any difficulties you are having eating or digesting, if your joints feel stiff, if your fingers are swollen, or if you have any other strange symptoms. This will help Doctor’s to find out what is wrong.

We have prepared this leaflet to help teenagers understand this annoying condition and to take care of themselves sensibly while continuing to enjoy a normal life.

Acknowledgement

We are grateful to the Raynaud’s and Scleroderma Association and the Scleroderma Society UK for permission to reproduce information.
Is Raynaud’s a common condition?

If you have Raynaud’s, you are not alone. One tenth of the people in your school have it, even if they don’t have it as badly as you do. (If you have 200 students in your school, probably 20 of them have Raynaud’s sometimes, though only a few will not be able to do sports outside).

It can vary from very mild (occasional attacks) to pretty bad (attacks several times a day), and it is important to stop it from happening, so that there are no long-term effects.

What is Raynaud’s?

When you get cold or are under stress, your body over-reacts (we don’t know why) and stops sending the blood to the tips of your fingers and toes. In effect, it is trying to save you from the cold and conserve your warm blood in your organs. First, some of your fingers go very white and numb, then blue, and then red when things finally get going again. That is usually the stage that hurts, like pins and needles when the feeling comes back. All through the attack, your hands feel useless and you cannot hold a pencil, do up buttons, or type properly.

Who gets it?

Actually, everyone can get it, even babies, though it is most common in women. Luckily, if you get it as a teenager, it is usually a fairly mild form and in most cases it disappears during your twenties. It is more than a nuisance, however, and should be taken seriously. Any cuts or scrapes you may have on your hands and feet will heal much more slowly than in other people and may become infected.

At school and with friends

You may find it difficult to explain to your friends why you can’t join in all their activities, and they may be frightened when they see your “dead” hands. But don’t give up on outdoor activities entirely; just choose those that do not make you so cold. Sometimes it is not only cold weather that brings on attacks, but air conditioning in a restaurant, a cold wind on a hot day, or wearing the wrong clothes. Be prepared!

Take the time and trouble to explain to your teachers and friends about your condition. Take in this leaflet or others from the RSI to your teacher or school nurse to help them understand. Permission may be needed to stay indoors at break times in the winter, or to wear fingerless gloves in all classes. If you need to be excused from outdoor games once in a while, you will need to have told your teacher ahead of time that you have Raynaud’s, or s/he will think it is just another excuse! Explain that you have to wear tights under your shorts, or track-suit bottoms under a skirt, or two pairs of socks and larger trainers for sports.

DO NOT BE TEMPTED TO SMOKE! SMOKING WILL MAKE YOUR RAYNAUD’S WORSE

Watch Out!

• When you take cookery, chemistry, or metalwork classes, you may be more likely to drop things
• When your fingers are numb, you may not be able to tell if a surface is too hot, and burn them
• When you climb apparatus in gym, you may lose your grip easily

Quick ways to get your fingers back

• Put your hands under the warm-air hand-dryers in toilets
• Put your hands in lukewarm (never hot) water
• Put your hands around a baked potato, a hot mug of tea, in your armpits, or under your knees

What to eat and drink

There is no special diet for Raynaud’s. Be sure to eat a balanced diet with all the proper nutrients in it. Eat often; being hungry makes you cold. It is important to beware of remedies that you read about on the web and to discuss anything you take with your doctor. Drinking a mug of anything hot will always increase your body temperature. Hot ginger and chilli are good if you like them!

Medications

There is no known drug which cures Raynaud’s, but appropriate care will do a great deal to help in controlling your condition and keeping you in the normal stream of school and college life. Your doctor can prescribe drugs called “vasodilators” if your condition gets worse; these open up the blood vessels however, they can cause headaches.

How to dress

Lots of ways to keep warm can now be used without looking bundled up. Obviously hooded jackets are great and these can be layered over sweathirts and T-shirts with a body-warmer over the top. The key is to get thick warm ones made of a natural fabric, not polyester or nylon. Boots are better than shoes, the thicker-soled the better. Uggs are best of all. There are even cheaper sheepskin boots on the market now that look just like Uggs.

The trick is to leave no gaps—no gaps at your waist (something you are wearing must luck in), no gaps at your ankles or wrists, no low necklines. You may think that if Raynaud’s is in your fingers and toes, these are the parts that need to be kept warm, but specialists agree that keeping your core body temperature up stops you having Raynaud’s attacks.

Other Tips:

• Wear tights under your trousers. Choose long jackets, not waist-length ones
• Do not wear thin socks, and wear a couple of pairs at once
• Always wear a t-shirt or a vest under your school shirt
• Wear a scarf - make it your trademark - it doesn’t matter what kind
• Put your clothes on a radiator overnight so that your coat is warm when you go out
• Find a hat that you really like and wear it all the time. It conserves 20% of your body heat
• Of course you hate raincoats and umbrellas, but keep dry one way or another. Damp is worse than cold.
• Get gloves with long wristwarmers, either with or without fingers
• Use handwarmers inside your gloves (buy them from www.irishraynauds.com)