

## **Colin and Georgina Managing symptoms**

### **Colin**

When you've Kennedy's and you can just about walk, how do you get your heart beating? So I swim 15 metres underwater every time I do my forward stroke. I try every stroke I can think of, so every muscle gets a go. I do balancing exercises while standing in the water because they support the weight and stretching. So it is enormously beneficial physically and mentally and I would recommend it to everybody. But I do understand not all pools are accessible.

### **Georgina**

I think the accessibility of pools is quite interesting. I think some of these clubs think their pool is accessible, but in reality they're not. So I'd look from a distance and yes, it had steps going down, but the risers was too high it was too wide to hold the handles. So they think they're ticking the boxes, but no, they're not.

### **Colin**

And funny enough, you have to look at the changing room and you've got to make sure that the benches are not too low, that once you sat on them you can't get off. I went to push off the bench and the bench shot out from under me.

I can't go swimming every day or I would be wrecked because there is only so much strength I've got and swimming takes a big lump of it. But the on the off days that I'm not, I, well, I've got an exercise bike. 100 of them, just on a low rate, 100 of them.

Then I sit on the bed and I've run. Close your eyes and you are running. Try it. You can run on the bed. Going back and forth, abdomen holding, so I do a hundred of them. Then I've got a hand bicycle thing. Guess what number? 100 of them. Then I have a pair of push together, it's like a chicken bone thing. If I'm really doing well 50, but generally 40 of them. Put it under your arm.

Do lifting weights and I do the weights and the chicken bone standing up, trying to keep the balance while I'm doing that. And after that I'm absolutely knackered but it's safe.

At the moment, I'm very concerned the amount of walking I'm doing is going down. Walking for me is unpleasant, anxious. My right leg which is the weak one gets tired, just doesn't lift enough, catches the ground. I'm really good at falling.

Anybody who wants any lessons in falling and not breaking a wrist, come and see me. I have Nordic sticks.

**Georgina**

Going down the garden he uses them as well.

**Colin**

Well, the grounds aren't even. Nordic sticks take 45% more power in your arms to take your weight off your legs. They help you, no end of times, I've gone to fall and the stick's been there to help me stay upright. Gives me confidence, gives me an extended range that I can walk and gives my upper body exercise. So rather than just the legs working, I've got core and I've got arms that are working.

**Georgina**

The other thing they do is they alert people around him that he struggles and not to push past.

**Colin**

Most people.

**Georgina**

Most people.

**Colin**

In fact, if you've got on an airplane, there is a depletion in oxygen. That's a fact. Kennedy's sufferings should not go anaerobic, that is, should not go beyond the oxygen that's in their body.

When I swim, I go beyond it. I have to. When you're in an aeroplane for two or three hours and you come out, you are destroyed and it will take you a day or maybe two days to get over it.

**Georgina**

We did some research and that's when we realised the oxygen levels with flying. And we think, ahhh. So having the knowledge you then, you fly but you don't do anything – you fly and you get there, and you just chill.

**Colin**

Even though, as it was pointed out, you have so much energy for the whole day, it's up to you how you use it.

I wrote my father's life history, I started writing mine. This spike in my neck, I stopped doing it. I was doing wood working in the garage. Can't do that.

So in the end, you got everything I think of doing, somehow my body stops. I've said it before, Kennedy's is bespoke. We met someone at Kennedy's event and unless he told me he had it and he's older than me, I wouldn't have known. Okay.

And then you get other people, like my cousin in a wheelchair at 30 years of age, and we don't know why.

**Georgina**

No, you can't work out.

**Colin**

I don't even know why I'm up one day and down the other. Why? What did I do the day? What did I eat? Too many variables in there for you to decide why your body does this, why your body does that. And that's for many diseases, not just Kennedys.