

Colin and Georgina **Carer and family support**

Georgina

I suppose I'm the unofficial carer, whatever that actually means. It's you just carry on living as you possibly can. And we get through everything. I do an awful lot.

Colin

You do everything.

Georgina

I do everything, yes, but that's how it is. And I think you just carry on. We manage it by escaping the UK in the winter off to warmer climes, which is very good because with Kennedy's disease the cold weather effects his muscles tremendously. Legs, arms and speech. And so we go somewhere where it's warmer and we can carry on living, enjoying it.

Colin

When people say it's your other half, it literally is. She is my other half and that's both meta and physical.

Georgina

There was one, yeah, I don't know how long ago – a few years ago, you came round and said I'll work in the garden and you sat in the garden doing some weeding and you were an absolute -

Colin

I was destroyed afterwards.

Georgina

Wreck by the end of it. And I think I was aware that it, you would say to me, oh, can you just give me a hand with this? Can you just give me a hand with this? I'm thinking I can, but I've also got an awful lot of work I need to do and it'd be much quicker if I was doing it on my own. And I had to wait for you to realise that that was the case. And you did realise and it's now.

Colin

And I can't do anything to help. It's frustration. Major, major part of this syndrome is frustration that you can't do it. Your brain says and your body says something different.

Georgina

I think having a focus, my textiles, having that gives me a focus. Particularly when we go away. As I said, I get things ready and I take it. So I've always got I've got something to do. I think -

Colin

You can't do the tours because that means getting on a big bus. And up and down, up and down and steps.

Georgina

But if I've got my embroidery to do, it gives me focus. And I think that has been a huge outlet, a huge outlet.

I think trying to keep going with as much as you can do and not to get despondent when you hear people say, Oh yes, we did that. We went there and we did this and we did that. And you think, right, yes, you can do, you did that because you can do that. Not to compare your life with how you live your life, with how other people live their lives. And I think that is quite important.

You live your life how you can do so, what's available to you.