

## **Colin and Georgina** **Social care**

### **Colin**

They would come out, they'd be able to fill out the bathroom, be able to sort out something in terms of stairs, but we haven't needed it. So we haven't experienced it.

### **Georgina**

I think they make an assessment. They make an assessment as to how you're coping and what you can do. It is very difficult. Everyone is different and I think we know how to manage it. The other thing is because it is, they keep saying it's very slow developing. Yes, it is.

And that is good. So you're, each stage, you're building up to each stage, each development and you have to do things differently. You don't, you can't do things in the same way that people who have no disability does.

I did find it very frustrating during COVID when it was all done over the phone and it was on the phone, it wasn't like a video call. And I think I found, I personally found that very difficult that I couldn't interject into, into what they're talking about. And I think that was a mistake. It should have been done.

### **Colin**

Georgina says I'm too optimistic.

### **Georgina**

Yes, there are times, yes, you tend to in certain situations like that when you're being asked, you play it down. Well, of course you do, you have to, but you play it down. And as I said it, you can be disabled by a very small amount, but it still has a big impact on your life.

And I think this is, it's very hard for people to actually understand that, if they're not encountering it themselves. I think it's been very hard to actually access things. I think it's geographical. I think we know from other people with Kennedy's disease in the UK, they get a huge – seem to get a huge amount of support. And I think it is based on where they live.

### **Colin**

Perhaps it's how pushy they are.

**Georgina**

I think it's also they are pretty much pushy. I don't think we're pushy. I don't think we've felt the need to be pushy yet. I think at times you do feel quite isolated by it. But then you have to think, well, what do I want? What do we need?

I mean, the answer is just to carry on as we are for the moment. It's a very difficult one. I think it's, we got a friend with motor neurone disease and she's a member of her motor neurone disease local group. There's nothing like that for here.

**Colin**

You mean MS.

**Georgina**

No, I mean.

**Colin**

Dystrophy, muscular dystrophy.

**Georgina**

Sorry, muscular dystrophy. And she's a member of a local group, but there's nothing like that for Kennedy's because it's so widespread.

**Colin**

There's only three of us in the county.

**Georgina**

That we know of, but I think there's probably more that they are looking at misdiagnosis with various things. And so I think it's very difficult to know.

I think it's nice to know though that there is an organisation out there that when you need the help you can contact them. And I think we do have that with a local disability group. They cover lots of different things and they come out once every...

**Colin**

Year.

**Georgina**

Year, 18 months.