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Ian and Deanne
Equipment and adaptations

Ian
Well, the car is very important for my mobility and independence, and I was having trouble changing gear long before I was diagnosed, so I'd already got an automatic car.

The thing that I found difficult was putting my seat belt on because the seat belt housing is in with all the upholstery and I couldn't hold the seat belt fastener to buckle it in. So I sent for an adaptation that buckles into your existing seat belt and it makes it longer so that I can hold the housing to put the seat belt in.

And with adapted things in the house, I can't reach things and my reach is getting worse. So obviously we'll have to adapt things. I'm using what were the grandchildren's cutlery.

Deanne
And that's been a step, hasn't it, for you, Like with other things, with clothing where you can't reach up to, for your hat example, for example. If it's a sunny day and it's hot and you need your hat on then and you're on your own, you need to ask someone, please, could you help me? And, and people are very good.

Ian
Or zipping my coat up.

Deanne
Yeah, but we got some adaptations for that.

Ian
You can get little tugs that you put on your zip to so that you can zip it up.

Deanne
The zips are quite small and fiddly. But also Ian's sister has been, she's really good with her sewing machine and she's adapted a lot of his trousers so that they’re velcro rather than zips and belts. If you're out somewhere and there aren't any accessible toilets, then it's quite useful to have something that's easier to work.

Ian
And I've adapted the way I move sometimes, because if I can't lift my glasses up to my face, I take my face to the glasses. It does look strange, but that's what I do.

Deanne
And the same with toothbrushes, you know, have to go down to the sink to get the toothbrush to your mouth. But, and, and again with toothbrushes, you've – we've got a variety in our bathroom because sometimes Ian can use more of a normal sized one, but other times needs a smaller one depending on how he's can move his hands.

So lots of adaptations really. And I think we're planning, you know, thinking about the future, about adaptations.

Ian
Also someone's coming again from the enablement team to talk about motorised wheelchairs and also we've got the physios coming to talk about a seat that tips up.

Deanne
In the shower.

Ian
And, and also a shower seat. So there's lots of things that I've been offered but my stock answer is normally I want to find out about it but not action everything at the moment because I don't want to give in.

I want to go on holiday, we've got assisted travel, but I've not thought about walking.

And I'm now coming to the realisation it's not that I need an aid for walking, but I need something portable-like, that I can sit down. And like, for years I've gone to a beach, sat on a wall and read a book, and that's something I will not be able to do. So the next best thing is taking a portable seat.

Deanne
So, yeah, getting a four-wheel wheeler with a seat and then we can go further because Ian can keep stopping.

It's coming to those decisions and I don't think we've left it till the last minute. I mean, that would be awful. Some things you can sort of think, right, I need that, I need it now. And you can get other things you need to plan ahead for.

Ian
I know what's in store further down the line and I don't want to think about it. So I know I must, but I have to think about it when I'm comfortable in my mind.

Deanne
The occupational therapist says, look, I'm here all this journey, I'll be here with you for this journey. She's trying to see what our priorities are and how what we will need to reach those priorities or to live with those priorities. And that's helped us to make decisions.

Ian
It takes a lot of planning. So you can't do things spontaneously, like say it's a nice day today, let's go. Because first of all, you've got to know what place is suitable, has it got accessible facilities? Is it relatively flat? Things like that. Also what I'm wearing.

Deanne
Taking, taking lots of things like paper towels. I think we've got shares in paper towels now because if Ian starts to cough or choke or sneeze, and also because you can be a bit more messy and so you need paper towels to sort of wipe. But we have to take perhaps a supplement. It might even be that we've got spare pants.

There's lots of things that oh – and if you're taking a supplement, a cup as well, because you can't just drink out of the bottle or you need a lightweight cup and, and it's time issues, isn't it as well, making sure you get up in plenty of time. Give yourself a couple of hours to make sure you can do – flushing the tube, having breakfast, having supplements.