



Transcript:

[Music]

Stephen: (dog barking) Oscar!

Tracey: How are you?

Stephen: Fine, thank you.

Tracey: Oh, good.

Stephen: (bed motor moving bed up) Bingo! (laughter)

Tracey: Okay.

Stephen: I've had a very busy and active life up until this point. I worked as the, erm, education officer for Opera North and the development director for the Scottish Chamber Orchestra. I'm forty-eight. I was forty when I was diagnosed. I actually think I knew that I had MS before any of the medical professionals around me knew. I need support almost with everything because, er, I don't grip with my hands very well. (Tracey drying Stephen's back) Okay, Tracey.

Tracey: Okay.

Stephen: That's good. Lovely. It was only after a couple of years of receiving agency support that I began to, I suppose realise that there were things that I was missing out on. They don't have the time to hang around and look after the, erm, more, you know, the more extensive needs of someone who's far too loquacious for their own good. I'm very lucky in that I can still talk and my cupboards are full of the hind legs of donkeys. When your fingers are less tactile and they don't work to do things like put your hands, your fingers through your hair, it means that I'm no longer a '60s cool. Breakfast.

Tracey: Yes?

Stephen: Er, could you chop an apple for me with some yoghurt and, er, a breakfast bar?

Tracey: Yes.

Stephen: People were coming in and helping me with basic tasks, but outside of those tasks, I wasn't pursuing some of the things which are essential to anyone's life. For example, I wasn't keeping up my somcial circle and widening my social circle, which we're also used to. When I was given the opportunity of managing my own care budget, one of the great things that came with that was the offer of additional hours of care support wrapped up in that budget, which I would be able to use for purely social purposes. There was a recognition, if you like, that my needs had grown, er, and what mustn't be ignored as well is the being able to go out and do things. What managing my own budget has enabled me to do is to continue to attend things like theatre performances, concerts and so on. And I've even gone to the Coliseum to English National Opera with my carer. Not only was I getting out and about and enjoying something, but I was also feeling as if I was still part of a world in which I once belonged. Lisa is my new PA, and I've got two new PAs that have started this week. Pauline started yesterday and Lisa started today. This is the start of my new life really, because Lisa is going to be the person that will enable my independence.

Lisa: (helping with wheelchair and getting ready to go out)

Stephen: Thank you. Lovely. (Lisa and Stephen going along pavement) Erm, just tell me if my speed control is a bit too high.

Lisa: (laughing) That's alright. I'll keep up.

Stephen: It's my plan to make sure you're properly exercised. (laughter)

Lisa: So it's not just poetry you write then? You do a lot of writing?

Stephen: I do a lot of writing really, but increasingly these days it's shorter writing.

Lisa: Yeah. How often does Oscar get walked then? Do you go out a lot?

Stephen: Oscar gets walked every day of the week.

Stephen: Care is a very, erm, intimate thing in some respects. But it's also something you've got to be comfortable and that person that's helping you to do things for you, the closer they are to someone that you like and respect, or have interests in common with, the better.

Lisa: I live in Angmering it's only about ten minutes away, and I've lived here all my life really.

Stephen: A local girl.

Lisa: Yeah. Angmering village all my life. And then my husband's auntie lives over the road, so it's all sort of family. (laughter)

Stephen: Quite a community. Oh, well that's lovely.

Lisa: We, we know everyone.

Stephen: (with Lisa at public library counter) Yeah, I rang ahead and I've got a book kept behind the counter for me. Erm, it's Alfred Watkins, The Old Straight Track.

Librarian: Do you have your library card, please?

Stephen: I do. We know where it is. (Lisa fetching card from Stephen's bag).

Stephen: I don't remember that many of my own poems, which is probably a great saving for the British public, but, erm, one I always can remember and I suppose is a good example of the way in which my poetry has been affected by, erm, my condition: "Café Society Relinquished" (recites poem)

I do not see the faces in a room as once I did.

And then the glances of the youth were seeking something.

Spectacles restore the sight, but nothing can improve the light.

And eyes that see with subtlety see twice the personality.

One of the things that I've become aware of is the way in which I do not have the same faculty to be able to make human contact with people as easily as I once did. And I, you know, I don't spend time worrying about that, or being concerned about it. The fact that I'm aware of it is probably quite helpful because I can perhaps do something about it. Personalisation,

to me, is about enabling me to do the things that I took for granted for so long.

Stephen: (at theatre) Arvo Pärt, the most famous modern Norwegian composer. It's very good.

Lady: You see, where would you be without me and my ignorance? (laughing)

Stephen: He's a great minimalist.

Stephen: It's only recognising something essential in human life, which is that everyone is an individual, like it or lump it.

[End of Recording]