



## **Your Health in Your Hands**

### *Duchenne's Muscular Dystrophy*

**Catherine:**

This is Your Health In Your Hands, a podcast series for the Open University on PHBs, Personal Health Budgets.

In this case study we hear from Mathew O'Sullivan. He's 25 years old and has a form of muscular dystrophy called Duchenne's. He lives near Reading with his girlfriend Lizzie who has cerebral palsy. They manage their personal health budgets in tandem. Mathew breathes using a respirator and needs 24-hour care.

**Mathew:**

Hello, who is it?

**Paul:**

Hello Matt, it's Paul.

**Mathew:**

Paul?

**Paul:**

Yes.

**Mathew:**

Oh hi Paul. I'll let you in, hold on.

**Paul:**

Thank you.

**Mathew:**

I was diagnosed when I was five years old and basically it's a condition that severely weakens all of your muscles. So as you get older you severely get weaker and weaker and weaker. It means I'm permanently in a wheelchair. I don't really have any kind of weight-bearing abilities, so I can't lift a cup of tea or that sort of thing. I kind of need help with everything.

Hi Paul, are you alright?

**Paul:**

Yes, how are you?

**Mathew:**

Yes, not too bad. How you're doing?

**Paul:**

I'm fine, how have you been? I haven't seen you for a couple of weeks. Hello Lizzie.

**Lizzie:**

Hello.

**Paul:**

How are you?

**Lizzie:**

Fine, thank you.

**Mathew:**

I'm 25 years old. I've just recently moved in with my girlfriend. I enjoy music, any sort of music. I love going to gigs. I also enjoy going to the pub for a couple of drinks at a time.

**Paul:**

How's work going?

**Mathew:**

Yes, I'm alright, getting there.

**Paul:**

Sorted out the last project?

**Mathew:**

Yes, websites getting on alright.

I've done about - three years ago I was off the ventilator but now I'm permanently on a ventilator, which you can probably hear in the background. Basically that's why I need a carer 24/7 just in case something happens to the ventilator or the trachy (tracheostomy) or I need some help. It has failed a couple of times but, touch wood, it hasn't failed recently.

**Paul:**

Lizzie, would you like a cup of tea?

**Lizzie:**

Yes, please.

**Mathew:**

I found out about the personal health project through my social worker at the time. I'd asked her in the past if I could re-jig my budgets and then I decided to go on the first trial run just to see if it works, and it did.

**Paul:**

Lizzie, have you been drinking?

**Lizzie:**

No.

**Paul:**

It sounds a bit like you might have been.

**Mathew:**

I had a two-litre bottle of coke.

We were looking to move in about two years after we started going out, but we couldn't find anywhere. It was just an absolute nightmare to try and find, you know, we applied for the council, they didn't come up with anything. We looked at private rental and there was nowhere that was accessible. So this was the kind of easily adapted property that we found. We moved into a nice little two bed flat which has got all the adaptations we need and automatic front door, ramp, hoist. I mean this computer is my little pet project, I keep tweaking it to make it better.

**Catherine:**

Expensively adding to it?

**Mathew:**

Yes, pretty much. That's where all my profit goes, I need to change that.

**Catherine:**

What care do you have and how do you organise it?

**Mathew:**

I have a mixture of both PAs and agency staff. I use PAs mainly during the day and the weekday nights. We get on with the team and they're really, really good and we wouldn't swap them for the world.

**Catherine:**

You were sort of ahead of the curve a little bit asking about this is my money, is there a way that I can tweak the way that I spend it and, lo, you got your personal health budget. Has it actually lived up to what you wanted?

**Mathew:**

It has, I used to do a lot of Excel programming, so I've gone and got the budget on the screen so that I can change one bit and it'll work it all out. The good thing is that you can save money. So say if you save a couple of hundred quid a week, you can let it build up to go on holiday or something like that.

**Catherine:**

So give me an example, if you had it up on your computer screen, you're working and you're kind of fiddling about on the Excel spreadsheet, how could you jig it to save money? What would you cut back on or add?

**Mathew:**

We've set up our own shared care rate which basically means that my carers could help my partner as well, because she's got cerebral palsy. It basically means they get paid more but I pay less and then Lizzie pays less. Then we also have a few gaps in care where Lizzie is my carer for a couple of hours just so we can just go away together and do stuff.

**Catherine:**

The money that you save you said you could spend on going on holiday or whatever, are you really free to spend it on whatever you like? Could you say, "Lizzie, good news, we've saved £150 this month, we can lash out, get taxis, go out for a nice meal, have a date," whatever or are there jurisdictions on it?

**Mathew:**

I am slightly cheeky about what I claim back for, but as long as you ring up your support broker and ask and just say, "Can I claim back for this?" They usually are okay with it.

**Catherine:**

Mathew O'Sullivan. You're listening to an Open University podcast series called Your Health In Your Hands.