Tracy and Iain
Social care

Iain
Social care, yeah, it's a minefield. It really is. To be honest, the first carers that we had were horrendous. Now, the way the system works, from what I've gathered – because we had a really big battle getting the continued healthcare – we started in the March and come the October, on the third attempt, they'd finally given it. And by the third attempt I was basically, how disabled would you need to be? You know, this is just ridiculous.

Anyway, we've got the full funding, but then they give you the ones that they've given the contract to. The problem with these companies is they do, because they're all generally bigger companies and they're going in at the lowest price and it's, they're just like lightning. You never get the time with them, you never get a set time.

Their idea of care was some time between 7:00 and 11:00 in the morning. So if they rock up at 11, it's like, how is that a morning call? You know, so I ended up giving her meds at 8:00 in the morning. Otherwise, it would affect the meds in the afternoon, which would then affect the meds at night.

And you try and say to these people, that's not a morning call. And all they say is, well, that's our morning call. And then at night they're ringing at 6:15, come to put Tracy to bed. No, you're not. You know, she's like, she's not like 95 ready to go to bed. You know, 10:30 would be great, but it was a battle to get the fully funded.

So they basically pay us and it was up to us then to find our own carers, which we did. Get to that stage as quick as you can. And the carers you use now are great.

They're pretty much bang on 8:30 in the morning, couple hours at night, 9:00 at night. And in general, I think we've got about six or seven different girls that come, whereas the original well Tracy's got a list.

I think we had 44 carers in two months. But the problem is every time they came, they didn't know Tracy's needs. So I'm having to show them what to do. So it's like I may as well do it myself. Well, I think they got sick of us complaining because they weren't meeting our needs. Yeah.

And in the end they said that, you know, we can't meet your needs anymore, find somebody else. So we did.

But even that was a battle getting the self – I can't remember what they call it now, self payment or whatever it's called – because everything's got to go to a panel all the time. They don't agree to this. So that took another couple of months.

Tracy
Direct payment.

Iain
Direct payment. There you go. Told you the boss would know. She knows everything. Yeah. So, it works well now.

Tracy
Now I need my carers to respect me and my home. I hate it when I have been spoken to like a child or asking questions about me instead of asking me. I just ask them to get to know me and what I like.

Iain
That's not just carers, though. People, you know, people, visitors come in and they'll end up saying to me, how is she? Is she all right? She's there. You ask her, You know, there's nothing wrong with her brain. It's just the muscles don't work anymore. And that used to be really frustrating for her. Really, really frustrating. It's like, that's me, you know? Ask the boss. Yeah.

Tracy
If you have been newly diagnosed with MND and are thinking about care even for the future, do your research. I never thought that I could cope with carers and although I don't like the idea of having to be washed, dressed and fed by others, you need them. And if you get the right ones, you will build relationships with them.

Iain
Say if you're female and you want female only carers, don't let them fob you off with male carers. You know you. They've got a duty care look after you. You stick with what you want. If you're a male and you want male carers, you make sure you get male carers. They can't supply that, then try and get them to change it.

And keep going with the continued healthcare because they will turn you down the first time and the second time and possibly the third time, unless you get a little bit grumpy with them. That's pretty much it really. And then be strong. You're going to need it. You've got to keep smiling.