



Imogen's Story

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Interviewer: Robby

Robby: Let's go right back to the beginning and ask you how you initially heard about Direct Payments?

Imogen: Initially it would have been through the Alzheimer's meetings that we go to. My husband's got Alzheimer's dementia. It was quite a while ago now but I went to them for help and advice. Initially they put me in touch with Carer's Trust. They came and did an assessment and the process started there. So, then it went from them I think to Social Services.

Robby: So, you had to deal with quite a few different organisations?

Imogen: Masses.

Robby: So, the Alzheimer's group initially suggested it and you thought that it was quite a good idea?

Imogen: Yes, that there could be something there, that it'd be worth me investigating and taking a bit further to see what help and support we could get.

Robby: How did you find the whole process of getting Direct Payments?

Imogen: A bit painful, rather a lot of paperwork. I mean, I do it myself and I can stand it but it takes a bit of working though. Also, there's not knowing who you should speak to find out for clarification.

Robby: So, do you feel that you had enough help throughout the process?

Imogen: Not really no. I think it could have been easier and more direct if I'd had somebody sitting opposite me.

Robby: Did the social workers not come and visit?

Imogen: No. Initially I received things through the post and had forms to fill in. That went back to whoever it goes back to, I can't remember now. Some Social Services department. They then decide if you're worthy of a visit. You then get the visit and it is then discussed with you. However, by then you are two or three months down the line and because obviously they're overloaded and nothing is quick.

Robby: That sounds quite stressful?

Imogen: Well it is because you don't know if you're going to get anything or if what you're going to get will be worth it. Initially, after the first little bit you think "Is this worth bothering about? Is it worth more trouble than its worth?"

Robby: So, did you feel like you had to chase people quite a lot?

Imogen: It was not knowing who to chase. There was no, "If you've got a problem ring me." It didn't work like that. It was, "Do this, send it in, then somebody will contact you." But, you didn't know who, when or where and the time lag is leaving you in limbo. You're waiting and waiting and you think, "Well, obviously we're not important enough or needy enough or whatever phrase you want to use; we're not enough to be on the high priority list." I mean perhaps we're not high priority? There are a lot of people with probably more stressful situations than us. However, if somebody says, "Lets, go through this now and then we'll go through the process which might take three months," then you just park it until they get back to you.

Robby: Yes, I suppose it would be good to know extract timeframes. Unfortunately I'm not sure anybody can give you those.

Imogen: Because you don't know what their workload is.

Robby: That's it. Did you try ringing up Social Services?

Imogen: Yes, but the initial person that we had contact with then went off on sick leave for six months. However, that didn't mean we have to wait six months. Was there was no easy way of passing from A to B back to us.

Robby: What is it like now?

Imogen: Well the Direct Payment eventually came through. I got a call from the original lady and she's back at work. She's been off for six months or whatever and she is ringing just to make sure everything is okay, that we have received the payments, to give her name again and a number to ring should I need to talk to her about anything. So, actually, we've got that but we should have had it seven, eight, nine months ago or whenever it might have been.

Robby: Any other problems?

Imogen: Well, it's not being sure who to ask. Let's say, we may eventually need to see if we can get the bath changed for a shower. Who do I talk to about that? Do I go back to our contact at Social Services or is it somebody else that I should be in contact with? There's too much unknown organisations who you should talk to about things.

Robby: Social Services should have an idea, if not them specifically then they should pass you on to another organisation that deals more specifically with home adaptations.

Imogen: Well perhaps I don't use them enough because I've never been used to having to use Social Services. I'm perhaps a bit reticent in actually contacting them. I tend to sort things out, I wouldn't go as far as to sorting out a shower myself but lesser things I will research and find out and sort it out for myself. I guess I'm not used to having things done for me. Until we've needed help and support with Shane's illness we've never actually used any outside bodies. So, Direct Payments was so totally new and strange to me, the fact that I've actually got to go to somebody and ask for help and support.

And, where do I go, who do I talk to? Social Services to me, until we got involved with them, were not an organisation that I would have thought that I needed to talk to. To me, they were a body that worked with people that needed housing or were unemployed or on really hard times. Well, we found our own housing. When we needed to move back up here because of Shane's illness, I didn't go to them and say "I've got to move back up here, I need somewhere to live near my family." We found our own place. So, if you've never in your life had any contact with an official body of that type you really are down a blind alley. Whereas, people who have been supported by Social Services for whatever reason, children, housing, whatever it might be, would automatically know who to talk to.

Robby: Sure. And. have you had quite a lot of contact with other organisations like the Alzheimer's Society or Carers' Trust?

Imogen: Yes, all of whom I found myself by using the internet.

Robby: And, I suppose what if you don't know how to use the internet?

Imogen: Yes! I know a couple at the moment, they don't use the internet, an elderly couple, and they've got no other way of finding out information that I find out for them. Because, I will search and search until I find something.

Robby: That's something I hear a lot, "How do we find the information?" Okay, so how easy do you find it to do the things you want to do on Direct Payments?

Imogen: Well I just use it really for respite, that's what it's for. That's what they've said it's for. I'm not aware that it can be used for anything else.

Robby: There are actually quite a lot of things that Direct Payments can potentially be used for. It can be used to hire Personal Assistants, travel to and from the community, arranging activities to meet your social, leisure or

occupational needs. The list of things that it potentially can be used for is very, very large.

Imogen: Right how do I find that out? From Social Services?

Robby: Yeah, from Social Services. Direct Payments are for anything that you are struggling with in your day to day life. If there's something that you're struggling with, I always use the example of people who are struggling to get out of bed, struggling to get themselves washed, struggling to make themselves a meal, then it can be used to hire a Personal Assistant. However, it can be used for when you're struggling access services in the community. It's all about your own personal needs.

Imogen: I understood I could use it for respite and care. So, if I need a carer to come and sit-in, I can go and do something and use Direct Payments for that. Or, I can use it to pay for Shane to go into a care home for a day or a week. We just had a week's respite so I use it for that.

However, the amount that you get, the annual amount that you get, well it's quite reasonable I suppose. However, it doesn't go far when you're paying X pounds a week or Y pounds an hour. You have to look at the year and think, "Right I need so many days for this or I'm going to need so many hours for that." And, care isn't cheap. I don't expect it to be cheap, I know carers don't get paid very much and I appreciate what they do.

Robby: Is getting carers in something you've thought about then?

Imogen: We have carers that come in every morning to shower and dress Shane now. I've got health problems so it was affecting me. We just have them in the mornings, I do the day and evening. They come in and shower him now because he's incapable of doing that.

Robby: Is that through an agency?

Imogen: Yes, that is through an agency and that is through Social Services. However, if I need somebody to sit in while I go to a hospital appointment I have to pay for that and that comes out of the Direct Payments.

Robby: So how do you find the agency carers?

Imogen: Very good the ones we have, very good. I'm really, really happy with them, they are good. We're very lucky we have the same girl probably four days a week. The other three days we will get a mixture of people but they are the ones that come quite frequently so we know them now and they all work well with Shane We've only had a problem with one and we don't have her anymore.

Robby: Okay do you mind telling me about this problem and how you resolved it?

Imogen: I rang the company and said I wouldn't have her back in the house. She wasn't capable of doing the job. She really wasn't. She came twice and when she went away he wasn't clean. She was not capable of actually persuading him to do what you have to persuade him to do. How she could see what she was doing through her curtain of hair I've no idea. She just didn't do the job properly.

I just rang the company up afterwards and said, "In my opinion, she's not capable of doing the job." I know they train them and I know what training she had because I asked her, so I knew what level NVQ was. I am an ex-NVQ external verifier, not in home care but I've got a lot of experience in NVQs so I know what they have to go through. Anyway, we don't have her anymore and they never sent her again.

Robby: So, one bad experience but lots of good experiences.

Imogen: Yes, they're very good with him. They're really nice and they're all age ranges. They all manage him very well.

Robby: So, you're generally happy with how everything's going?

Imogen: Yeah.

Robby: Fantastic. Okay, what would you say are the benefits that you've found with using Direct Payments?

Imogen: Well, because I know what my budget is I can decide how I spend it within the framework he has. Obviously it can be used in other ways than I thought it could but it does give me a budget to use. I'm quite happy with it. I do my own paperwork, all online.

Robby: You've not thought about using an agency like Purple?

Imogen: No. They did come and see us before it was Purple, when it was Penderels Trust. They did come and they were very informative but why should I pay somebody to do something that I can do myself? I couldn't see any benefit of having an agency do it for me. I don't want to employ anybody so how we do it is fine. I couldn't see any benefit at all in an agency doing it for me.

Robby: Fair enough. So, sometimes agency's fall off Social Services' books for whatever reason and the County Council is trying to push more Direct

Payments on people to do less work with agencies. Would you mind becoming an employer to retain a person from the agency if they were to fall off Social Services books?

Imogen: I would be very loath to go down that route because I don't want to get involved in paying somebody's NI and being responsible for other things, you know? Presumably you'd have to do health and safety checks, etc. You'd need to know everything that's involved. I would not want to do that. Now if it was the difference between getting a Direct Payment and not getting a Direct Payment I would think about it because I have been an employer so I know that I could do it. However, I really do think that it is just too time-consuming and too much faffing.

Then you've got to find somebody to cover the person your employing's holiday. So, it's not just employing one person, you've got to employ two people so that they can have their days off, they can have their holidays. What happens if they're sick? It is too much I think for us generally to do ourselves. And, I don't just mean Shane and me, I think in a general sense that the majority of people would struggle to go down that route.

If you were lucky you could employ one of the people that you've been in contact with regularly. That would help but there's no certainty that you could do that. You've perhaps got to find somebody, you've got to interview these people, you've got to have them DBS checked. There's an awful lot.

Robby: Well, as long as it is working for you then that is good and that's the main thing. Okay, what advice for other people using Direct Payments would you have?

Imogen: Probably try and get a little bit more clearer information at the beginning of what you can actually use it for. I guess because I was grateful to get it I said, "Yes that's fantastic." I never thought I could get it. I can use it for respite, that is what I was initially interested in because prior to that I'd been paying privately for somebody through another agency to come two hours a week so that I could go out for a while. That was before I knew that I could get anything.

So, more information at the beginning. That comes from the carer's groups that we go to, which now would be the place where you would go to get that sort of information from because of the speakers. It also comes from the Alzheimer's Society group that we go to once a month. They're the sort of places where you can gather this information.

However, you've got to know they're there. I had no idea there was a carer's group at the library and I use the library. I have masses of books from the library but I've never seen a notice telling me that there was a carers group.

Robby: How did you find out about the carer's group?

Imogen: Somebody actually at the Alzheimer's morning said, "Oh, do you go to the carer's group?" I said, "I've never heard of it." That is I think because, initially, the group at the library had been set up more for people that were carers for people that had had strokes and that sort of thing, not people with dementia.

I don't know who knows, but there's two camps of carer. There's those that are long term, that have been going for a long time, carers for people with long-term disabilities. Then there's just a few of us who started going who are carers for people with Alzheimer's and dementia. We take our partners with us because we have nobody to leave them with and they're not capable of being left on their own. I can never leave Shane on his own. If you've got Alzheimer's and dementia you can't leave them. They're not safe to be left, they might go off or wander. Whereas, the other group of carers, the people they care for can be left for an hour or two.

Robby: Okay. Is there anything else about your experience of Direct Payments that you'd like to share with me?

Imogen: It does work well and I'm pleased with what we get and I'm pleased with how it works. I will probably look into what else I can use it for but then it works at the moment how I do use it. It does give Shane respite and I get time-off time. And, that to me is what keeps you sane.