



Robin's Story

“It was my lifesaver. I've got no hesitations in recommending them, just get through that initial setting up process.”



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Interviewer: Addison

Addison: As this is about Direct Payments, can I go back to the beginning and ask how did you first hear about Direct Payments?

Robin: My mum lived with me for nine and a half years and I was her sole carer for some time. Then I began to struggle as I had to work part-time as well. I heard about Direct Payments through an Information Event. I attended quite a few years ago. One day I thought, "I really need help." So, I went online, found out where to email, emailed, queried about it, got a response back which put me in touch with an adult social worker, who came to do the assessment and that part was very straightforward. I had heard, I knew about it, but I did look up online to find out who to contact.

They had these annual days for carers, where they'd have some people talking and some activities in the afternoon. There were various stands with options available. So that's where I heard about it from.

Addison: Okay, that's interesting and good to have Information Events.

Robin: There's quite a few support for carers Information Events that they run.

Addison: That's good. So, you got in touch with social worker and you began the Direct Payment process. How did you find the whole process?

Robin: Difficult. I can see why a lot of older people don't take it up with all the forms to fill in. You have to send off bank statements and everything to a financial assessor. There's quite a lot to do and it's a bit mind-boggling. Then of course you sent all the information in that you can use to someone, for me it was Penderel's but I believe it's changed now. Penderel's would do all the wages, income tax and insurance and things like that. You could do it yourself but there was no way I felt I was capable of doing it myself, so I thought, "Well, I'll use Penderel's." I got everything sent off and the finance guy was amazing. He said to me "Your mum is actually entitled to pension credit." So, I phoned up about that and she got six months back pay.

So, with Direct Payments we agreed so many hours. I can't remember how many now but a certain number of hours per week and three weeks a year respite for somebody living with her. I could have used Penderel's to find what they call a Personal Assistant, I call them carers, but I had a friend whose mum had a carer who I liked. So, she came and did it and once it had set up it was very straightforward.

You do have to keep a time sheet with how many hours the carers have done each day and add it up. Then they get holiday leave, so when you add it up you then have to do this complicated sum to find out how many hours holiday pay they have, multiply that by the hourly rate and then add that to your

original number. Then you either have to post it off by a certain date or you scan it and email it. Not everybody can cope with that I don't think. Some people might need help filling it in and working it out. It's done four weekly, those four weeks come about very quickly and you have to second-guess the fourth week because you send it in at the end of the third week and any changes you have to amend that on the next time sheet. I think the actual process, finding a social worker and the social worker coming out here was fantastic.

Not long after I started Direct Payments I was diagnosed with breast cancer and need chemotherapy and radiotherapy. I hadn't used up any of the three weeks respite, so I did contact the social worker and said, "Is it alright to use those hours for extra sessions because I was having the carer for breakfast and lunch but I needed the evening as well." They said, "Yes that's absolutely fine and if you do run short and we'll have an interim review meeting, an emergency one, so you will be covered." I was too ill to do much for mum at the time. So, for me that year became invaluable.

Then she passed away, so she only actually had Direct Payments for just over a year. She could have had them for a long, long time before that. That was me wanting to be her carer and not wanting anybody else, it was just my pride. I liked caring for her, I didn't want strangers coming in and doing it.

You do get an option with the Direct Payments of how you do it. You can use an agency but I said, "No I don't want different people coming in. Mum needs to have the same person for continuity of care." I said I'd use my own person. Mum couldn't remember me and at this point she'd been bed-bound for three and a half years. So, it was personal care as well, she needed feeding, needed having drinks given to her, she had a catheter but she needed changing when she had a bowel movement. So, it needed to be somebody who could cope with that and that I'd trust to do that.

That was the easiest part care-wise because you know, she couldn't go anywhere. The hardest part was waiting the years before that, when she'd wet the bed every morning, you'd have to strip the bed and remake it. I managed all of that and it was hard but as soon as I got the Direct Payment and had a carer in it was such a weight off my mind. It was such a relief to think, "I don't have to do her breakfast and feed her before I do anything else, somebody will come in and do that." It was brilliant.

Addison: You mention that the person coming in doing care was doing care for another of your friends.

Robin: Yes. I started off with Wendy and then her back-up carer, Sue, who had done bits for me. She moved and then I had Emma. They're all people that cared for my friend's mum. If you employ your own PA, you do need to have a back-up.

I was told Penderel's Trust that they will come to the house and go through things with me but it's pretty mind-boggling. They show you how to fill in the

form and the timesheet and they leave one with you. The number of times I had to refer back to it to make sure I was doing it right and I was filling in the right columns. I think Penderel's don't do it now, it's been handed over to another company.

Addison: Purple.

Robin: Purple, that's right. I believe a lot of its done online now so you don't have to post them in. So, it needs to be somebody who is capable. If you can't do it, then the carer can't do it, the Personal Assistant can't do it, because you don't know what they're going to put down.

Addison: And, you're the employer, so the responsibility rests on you.

Robin: If it's somebody elderly who really can't do things like that then they need a family member who can do it, sign it and have the Personal Assistant sign it. You can send it in without the Personal Assistants signature. Then of course you have to add up all the hours well. Its point 0.75 for three-quarters of an hour and 1.5 for an hour and a half so its adding all of those up. The amount of times I used to do it, I used to do it mentally and then use a calculator and got a different answer every time. Then I'd always get the carer to check it after I'd done it. I'd always say, "Can you just check I've done that right." However, if the employer doesn't sign it they won't accept it. So, I think to do it online which is the way it's going, they do need a family member to be able to do it but not everybody has one.

Addison: That's very true. I know some people are very much looking forward to it going more online.

Robin: I'd have preferred it but then you have to scan it in, you know, the old way you have to fill it in on paper and scan it in. I should think done online it would automatically add it up for you. Which is a plus.

Addison: Anything that makes things easier I think that's the point. Do you feel that you had the right amount of help and support through the process?

Robin: Well I had a social worker, a very young Australian one to start with and she was very by the book. She insisted on introducing herself to my mum and my mum wasn't fit. She had severe dementia and was also profoundly deaf, so she couldn't even hear what you said but she responded to smiles and things like that. The social worker insisted on introducing herself and I said, "You can do but she's not gonna hear you and she's not gonna understand you even if she could hear you." "But, I have to do it, I have to tell her why I'm here because after all we are talking about her." And I thought, "Oh yes, you're young, you're doing it by the book."

When the second social worker came out, he was lovely, he wasn't like that at all, I thought "Yeah, you're more my school." So, he was very good and once you've got the Direct Payments, that's it you're left on your own pretty well.

Addison: Did you feel that if something came up or if you had a problem you'd be able go back to them quite easily?

Robin: The social worker? Well, yes because when I was diagnosed with cancer and I was having chemotherapy I did phone him to say can I do this and he said yes, so he was very helpful in that respect. Penderel's do work out the hourly rate and how it all fits in with your budget because there is an initial fee for setting it up. However, that's by far the easiest way. Well it's Purple now.

Addison: Okay, what would be some of the problems you've found using Direct Payments and how did you go about resolving them? Did you manage to resolve them?

Robin: The only problem I had was the initial set-up. Once it was set-up no problems whatsoever. There was a lot to think about but once it was set-up, apart from the odd time... There was one time the payslips didn't arrive; mum's carer hadn't been paid. So, I did phone up and they missed the email and they rectified it very quickly. I said, "She's going on holiday and she needs her money. You can't make her wait until next month. That was only the once because they were changing their system and they did say there might be a few little hiccups while they were changing over to a new system.

Otherwise payslips arrived bang on time. You had to pay for each payslip but I believe Penderel's were going down the route of having their payslips sent by email. Mum's stand-in carer didn't have the internet so she didn't have an email address but I think each payslip was £7.95. We'd got two carers doing that for four weeks, you know, with one on holiday and the other ones covering. That's £15 out of your budget just gone on payslips. But, that's all factored in when they work out your personal budget.

And, you have to open a separate bank account for Direct Payments. You cannot have it paid in to your mum's own account, it had to be a completely separate account. So, the Direct Payments go into that and the payments to Penderel's come out of that. You have to take out employer's liability insurance or something like that. Penderel's give you a pack and it was in that pack.

Every three months you send off the copies of bank statements for Direct Payments and the invoices from Penderel's for the wages. They do send this form that you have to fill in each payment which I did and it was really time consuming. Then you get them all back a bit later. It's just the council end looking at it to make sure you're not overspending and you're not using the money for what you shouldn't be. Because that account only ever had the council's Direct Payments going in and the Penderel's money coming out, we didn't need to do that. Paying a carer was all the money was used for, it wasn't used to pay a gardener a couple of hours or something like that.

So, you do have to send that in every three months and that's something to think about. You think, "Oh gosh is it that three months up yet?" because

when you get your things back you get a letter and the form giving you the date it has to be received by. You don't get a reminder the week before its due.

Addison: Do you think a reminder would have helped?

Robin: Yes. Because when you're doing everything else, it's something that's three months away and it's a long time to remember it.

Addison: They're changing this from separate bank accounts to a pre-pay card now.

Robin: Are they?

Addison: Yeah, so the Direct Payment will be loaded onto one card.

Robin: How does that work with paying a carer then?

Addison: I'm not a 100% sure but I think if you due to pay an organisation like Purple then it'll be loaded up to give money specifically to Purple.

Robin: Well, Direct Debit's easy enough.

Addison: Some people really like this idea; some people think it's just another waste of money. I remain undecided.

Robin: The thing has to be whatever's easiest for the carer and for the person that's being cared for. But, mostly the family member that's having to do the caring because the person whose being cared for doesn't have to fill in all the things, if they've got Alzheimer's. If it's a physical reason and they're all there, then they can do it themselves. However, if they have dementia they're not able to do anything, so you do need somebody to do it.

Also, to open an account, well mum wasn't able to open an account. I had go into the bank with a copy of the power of attorney before they would even open the account in her name. You have think about that, opening an account for your mum just for Direct Payments. It's a bit of a minefield to start with. I was actually granted it in at the end of the year but I didn't get it set up and start using it until the beginning of the next year. I needed to get my head round everything. So, she had a little while when I wasn't using it.

It's tricky to get a bank account open or even to get an appointment to go in and do it because they could never see you straight away. You have to take all these things in and even then, they wanted something else. I said, "Well, I'm sorry!" If you phone up and talk about anything to do with the person you're caring for they want to speak to the person you're caring for. I said, "Well she's got severe dementia and she's profoundly deaf, it's not possible."

One time the nurse came to do a blood test when mum was much more with it and she said, "I need your mum's permission to take this blood test." I said,

“You are joking.” She said “No.” I said, “Of course she’s not going to agree to have a needle stuck in her arm. She has dementia.” Apparently, they just need to hear her say “Yes.” So, I said, “Would you like a cup of tea mum?” She said, “Yes.” So, I said, “There you go she’s said yes get on and do it.”

Addison: Goodness, I suppose that’s one way around it. It sounds overly complicated.

Robin: Yes, yes it was.

Addison: Okay. Did you feel like you had enough help at the time?

Robin: I had all the information, it was just getting my head round it and organising things, opening the bank account and finding a carer. I’m reasonably intelligent and got all my marbles but I personally found it quite daunting to set up, in all honesty. Once its set up then it’s all easy.

Addison: How easy did you find it to use the Direct Payments for the things you wanted to use it for?

Robin: It was a doddle because it was only for care. I’m glad I did it, really glad I did it and it ended up being a lifesaver for me. I think part of me wishes maybe I’d done it a bit sooner but then obviously no because I managed.

Addison: I suppose you’ve got to do it at the time that’s right for you.

Robin: Yes. It’s that admitting that you need help, that’s the hardest part.

Addison: Any other benefits that you can think of about having Direct Payments?

Robin: For me the only benefit was having somebody I trusted and who loved mum and mum was very comfortable with her. She’d often give her a big smile when she walked in the room. I was a bit jealous actually as she got more smiles than I did. That was because she did more with her, especially when I was ill. It was relief that there was somebody coming in, they had a key so they could let themselves in, somebody that I trusted, somebody that mum liked. she loved my mum. She’d lost her own mum and she wished she could have still had her mum to look after. Just peace of mind knowing that someone was looking after my mum. I knew she was in good safe hands.

I got lay-ins again, at weekends, because she comes in and does her breakfast. I’d have a lie-in, especially when I was having all my treatment. I slept the morning and most of the day, on and off. So, it was just nice knowing there was somebody coming in.

Addison: And, did they work well with you when you were having your chemo?

Robin: Oh yes, they were brilliant, very understanding. She’d been through the same, she didn’t have chemo she just had radiotherapy but she was very

understanding. If she came in to do her lunch she'd tiptoe around and try not to make a noise.

You wouldn't have that with agency nurses because there's always two, you have to have two if its agency and its dearer having agency. Also, you might get two in for breakfast, you might get a different two in for lunch, and then the next day might be two other different people. There's not that continuity and they don't get to know mum. She's my mum at the end of the day, who I love dearly and they don't get that. If there's two carers it's just a job to them. With Wendy it was devotion as well. You want someone who is devoted. I just didn't want different people in and out.

Addison: Sure, and it really good that you found that. Okay, what advice would you have for other people using Direct Payments?

Robin: Don't be put off by the initial set-up because it is daunting. Don't be put off by it. Just get help if you need it. Social workers are brilliant, I'm sure if you need extra help they'd be there. Penderel came out to the house and you could always phone them if you had a query. My advice is it is daunting, but don't be daunted, don't be put off, go for it, get help to fill it in.

Age UK I'm sure would come and help you fill them in because that's the sort of things they do. Get Age UK in to help you fill them in if you need that help but don't get put off.

Addison: Is there anything else about Direct Payments that you'd like to share with me today?

Robin: No. Just that it was my lifesaver, that it was my absolute lifesaver. The carer's all came to mum's funeral. I've got no hesitations in recommending them, just get through that initial setting up process. A lot of these benefits that are around people don't apply for. It's like pension credit, half of pensioners aren't claiming that. It's the thought of filling in forms and having people look at your bank account.

Addison: This is it. It's all very daunting and if you don't have the information about it anyway, how are you going to know?

Robin: Yes, because the only reason I knew about it was by going to these Alzheimer get-together events and carer support meetings. Otherwise I wouldn't have known about it.

I would say to anybody who's family member has dementia, go these support groups, you don't have to go every time. However, you get so much information and they then put you in the system so you get a carer's assessment.

I hadn't claimed for that for 4 or 5 years, as I didn't know about it. When I did find out and they did it was a small amount of money a year for you to spend on yourself, whatever you wanted. You could buy a dishwasher if you wanted

or a laptop to do online shopping, whatever you wanted. I put mine towards a holiday. They send somebody rounds from the Alzheimer's Society who fills in the assessment, discusses with you what you do as a carer, and that's something I didn't know about, so that's something else for the carer.

I think there needs to be some sort of system as soon as somebody is diagnosed with dementia. You are diagnosed by a consultant and the adult mental health team, at the end of the day. I think there should be something put together so it signposts you in all the different things available, like the carer's assessments, the Direct Payments, all the support that's out there, just all together on one page. One leaflet which is simple, easy to follow and you know exactly what you can claim, what you can go for support should you want it. Not everybody knows, but it's there.