



Deborah & Melissa's Story

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Interviewer: Robby

Robby: How did you hear about Direct Payments and how did you find the process of getting onto them?

Deborah: We heard about it when we were at a conference. Some people that we'd gotten friendly with there had got Direct Payments for their son. They lived in Essex and their son was younger than Melissa. They got it and we were querying with Cambridgeshire County Council as to why we weren't able to get it 'cos we'd heard about it and approached them and said, "Could we have it?" And they'd said, "No because you have to be 18."

So, we did a little bit more digging around, a bit more research and we had to get a solicitor involved from London. She came up to see us, she got in touch with the Council and said, "Look, this family are more than capable and more than willing to do it. You can't actually stop them from doing it if they want to." We then got told we could do Direct Payments. I don't think you were getting much care at the beginning though were you?

Melissa: No, not at the beginning, no.

Deborah: But it did increase, 'cos Melissa had back surgery when she was a child.

Melissa You were pregnant with Daniel.

Deborah: I was pregnant with Daniel that's right. So, when Melissa came home they had to put more care in because I was pregnant at that point. We were living here, weren't we? So we'd got the hoist and everything but basically once Social Services came out and we went through what our needs were, they agreed however many hours a week, I can't even remember now, it wasn't massive. It was basically, "Right, we'll pay the money into your account every four weeks, the rest is up to you." So we were left a bit in the dark.

We weren't given a lot of help back then as to how to go about things. All I was told was we could approach some agencies and see if we can employ agency staff. Then obviously we'd pick which agency staff suited us rather than Social Services just sending agency staff in who were unreliable or actually didn't have the experience that we were told they had. I did ring round the agencies and at that point we were allocated, I think it was £8 an hour to pay the carers.

Robby: When was that sorry?

Deborah: That was about ten, fifteen years ago. The cheapest agency could provide me with a carer for £15 an hour. I said to them, “Well I’ve got £8 to play with. I can’t physically pay you any more.” That was the cheapest one. Melissa was only a child so it was up to me to find ways of advertising, so we put some adverts out in newspapers but that cost money. The cheapest I think was a one by one square box, which was something like £30, to go in one night and that’s it. So, I was hand writing little slips of paper and going round all the local shops, all the noticeboards.

Melissa: ‘Cos she’s not very technical.

Deborah: No, I’m not very technical.

Melissa: She still doesn’t have a clue about Facebook.

Deborah: No, I don’t have a clue about Facebook! I’ll leave it up to Melissa.

Melissa: It’s my job.

Deborah: So, it was very difficult trying to recruit people.

Melissa: Didn’t the Diana Team help out or was that before Direct Payments?

Deborah: Yeah. That was before Direct Payments. We had some help from The Diana Team. They were set up in memory of Princess Diana and they initially sent somebody in for a couple of hours a week just to shower Melissa. As our needs got bigger because I was pregnant, we got a few more hours off them. I don’t think they exist now and I don’t really know where they came from.

But, somewhere along the line when Melissa came out of hospital after having her back done, we had Social Services allocate us one carer overnight a fortnight. Melissa was up several times a night ordinarily and obviously coming out of hospital she was going to be up even more. She’d be in pain and everything else. So, they’d assessed us and originally we started off with one night a fortnight. They provided that night carer and then they provided a second one. When we swapped over to Direct Payments we said to those two ladies, “Would you be happy to come?” So they did. They came and worked for us.

Melissa: One’s still working for us now.

Deborah: Yeah one is still working for us. The other went on to do other things but quite a while ago. So, we were given our budget of X amount an hour and we were just kind of left to work it out. Hopefully it’s a bit different now but we weren’t really given any guidance as to what to do you know?

I had to do all the recruiting people, finding the people and my husband did all the wage slips. So, I would provide him with the hours each month because it was done on a monthly basis at that point and I would say, “So and so worked 10 hours this month and what have you.” Then he would work out how much

tax and national insurance was. We had to make our own payslips up because we had to provide the carers with a payslip but we weren't given a template. I mean they give you templates and stuff now with Penderels Trust because we're now on their payroll.

Robby: I think that's shifting to Purple now.

Deborah: Purple, which is totally confusing so we might go onto that in a minute if that's relevant. But, we didn't have any templates we just had to kind of make up something. Well, once I'd got one printed off it was okay, I could just print off a load of copies each month but it was bit of a headache really.

Melissa: It's an even bigger one now.

Deborah: You need X amount of care a week, here's the money, get on with it.

Robby: Do you feel there was a lot of dialogue between you and Social Services?

Deborah: They just said get on with it. We had our named social worker who I could refer back to if things were problematic and I think I did go back to her once and say, "Look we just can't get the carers."

We did have one lady who used to come in and help me get Melissa up every morning when I was pregnant. She lived just down the road so that was quite handy.

Melissa: She had to be woken up and come round to look after me when mum went into labour with Daniel at like 4 o'clock in the morning.

Deborah: Yeah, she was really good actually. I gave her a phone call when Daniel decided to come along and she came round and sat with Melissa for the rest of the night. She was very helpful. But yeah, it was just a matter of finding our own people and it was a bit daunting.

Melissa: We're used to it now.

Deborah: Yeah. We've had a lot of people leave recently.

Melissa: Yeah, four carers in five months.

Deborah: We've still got four that have been with us for years. It's not that they don't like the working conditions or the money's crap or whatever. The people that have left, pretty much mostly all of them have said they've just taken too much on and found that they couldn't cope.

Melissa: Yeah and the last lady that left, who I'm still friends with, she said it was because we clashed on some occasions. And, she's taken on too much because she's got two other jobs.

Robby: Wouldn't you naturally clash with people on some occasions?

Deborah: I think if you're working in that close proximity and they're doing those very personal things there are times where you would. I mean, Melissa does get frustrated at times.

Melissa: But wouldn't you?

Deborah: Well yeah, I would. I'd hate it. I hated it when I was pregnant and I had to rely on my husband to do things for me. I didn't like it.

Robby: I clash with my colleagues. Not often but working in an office with people for a long time, you're not going to agree all the time.

Deborah: I think they just took on too much.

Melissa: She was a bit of a 'nana as well though.

Deborah: One lady left because although she worked with us for nearly a year she said the hours weren't very compatible with her children. So, she's gone to find a job that's just more compatible with childcare.

Melissa: And the other one we're not really sure about to be honest. We hear one thing from her and something completely different from all the other carers.

Deborah: We had one lady leave last year after eight and a half years of working for us. She'd gave us no indication until she gave that letter to me that she was leaving. None at all, so that was a bit of a shock.

Melissa: But neither did any of the others.

Deborah: Yeah but when somebody's worked for you for that long and they haven't come to you and said, "Look I'm not very happy. Is there any chance I could have a pay rise? I'm struggling."

Melissa: Yeah that's true.

Deborah: There was just nothing. She just turned up on my door and handed over the letter.

Robby: Did you ask her why at the time?

Deborah: Yeah, she said she hadn't been happy for a while. I said, "Well, I wish you'd have come and spoken to me about it, maybe we could have worked it out." She said, "Well I've done it for a long time now, it doesn't suit me anymore." She did make the excuse it didn't fit in with her children but she had children when she started with us. Her youngest was a baby, so she'd worked through all of that.

Melissa: She used to take me on holidays and stuff. I haven't got that now. The lady that just left recently started taking me out and now she's gone. She said, in her own words, when she feels like all the crap has gone from her head she'll come back and see me. We're going out in a couple of weeks, so hopefully we'll stay in touch.

Robby: So finding people has been problematic?

Deborah: We advertised for a post two weeks ago. Melissa did it on the afternoon on Facebook. We haven't put it round any of the shops or anything. Initially we got loads of people emailing Melissa. Then from that point she said, "Well ring mum. She'll talk you through what days are available." Melissa knows what they are I think, don't you? But you either don't like speaking to them or it always gets passed on to me.

Melissa: Well yeah because I have so many people email me and I have carers coming in and then I don't want them to think like I'm ignoring them. So, I'm like, "Well just call my mum and she'll tell you," but then they never do.

Deborah: If they want to come in for an interview and discuss it further I put all that together because Melissa doesn't really know what I'm doing the rest of day. So, the first week we had quite a few people get in touch. We had two people come for an interview on Thursday, didn't we? Melissa didn't like either of them. One of them was quite well qualified actually but I didn't take to her either. She's not somebody that I'd want because it's on a one-to-one basis and I didn't feel confident.

Melissa: And then the other lady rang up and said she didn't want a place anyway.

Deborah: Yeah, the other lady said she'd been thinking about it over the weekend and it wasn't for her. So, you emailed back the original lot of people that had shown an interest and not got in touch with me didn't you?

Melissa: Yeah. Is there anyone coming from that?

Deborah: Yeah, we've got someone supposedly tonight, tomorrow and Thursday night, we've got three evenings.

Melissa: Tonight? What time?

Deborah: 8 o'clock.

Melissa: Oh. Bollocks, excuse my language.

Deborah: So, you see, this is what we have to do if I can't fit things in during the day...

Melissa: Then we have to do it at night.

Deborah: I hate it. I don't want to come out again at 8 o'clock at night but...

Robby: So, very frustrating then.

Melissa: It is frustrating especially when I've got things to do.

Deborah: See, this is what happens, I'll organise something and then Melissa's like well I was gonna do X, Y, Z!

Robby: Lots of things to sort out.

Deborah: Yeah. Someone has text me earlier today and asked if they can have their shift covered, so that's another thing to sort out.

Robby: Are you on the books of any agencies?

Deborah: No.

Robby: Okay. It's just that another gentlemen said to me when I did an interview with him, "Always make sure you stay on the books of an agency because if there is any last-minute emergency then you can just get in contact with them and tell them to send somebody round."

Deborah: Yeah that's something we've never done. I've never used agency staff.

Melissa: Because we can't afford to.

Deborah: We've not been given enough money so we've never used agency staff and we've never enrolled on it. I mean, at the end of the day, if somebody can't do a shift I have to do it. Whatever I'm doing I have to change. So therefore, if we can't get cover for tonight and someone else can't do it, then I'll end up having to do it which isn't ideal.

Melissa: And dad will have to take both boys to school in the morning.

Deborah: Because in the morning I'd be here all day tomorrow and back in the evening having done a night shift.

Robby: Do you feel able to go back to Social Services and talk to them about this?

Melissa: Well they can't do anything about it.

Deborah: We have a review every year and Melissa's due one so I'm surprised they haven't got in touch. Melissa's care package is very large now. It's twice the size financially of what they like to normally pay out because we have carers coming in four times a day rather than a live-in carer. Part of Melissa's budget is done through the Healthcare side. So her night cover is paid for by the Healthcare budget and her day cover is paid by the social care budget.

Normally it would all come out of social care but they couldn't provide it all for us.

We were told when Melissa moved in here the top they'll pay is X amount per week, which would cover the cost of a live-in carer. But, because Melissa wanted to have as much independence as possible and just have somebody for two hours in the morning, an hour at lunch, two hours in the evening and a night carer, we couldn't get all of that out of the social care budget.

Melissa: I was adamant to keep what I'd got and I said to my mum at one point, I would take them to court to keep it because I wasn't gonna let it go.

Robby: Yeah. It's a bit stressful that you have to think about actually doing things like that. So, are you still in contact with that solicitor you mentioned?

Deborah: No but we'd be able to find legal aid if we needed to. We asked Social Services and they agreed the package anyway in the end. They decided the night care needed to come out of the Healthcare budget because Melissa needs turning over regularly in bed so that's deemed as a pressure sore concern. So, we got the two things sorted out.

When Melissa first moved in here they did another assessment after about six weeks or so. It was the first time she'd lived away from home and it was the first time she was in this situation. They looked at how it was going, how the finances were working out.

Two hours in the morning isn't really long enough for the carers to get a shower done and everything else, they need more like two and a half. So, they looked at it and said, "Well no, we can't pay you any more. If you want them here for two and a half hours then you've got to lose some hours somewhere else in the day. You've got to juggle it yourself." I see where they're coming from but if we needed another half an hour in the morning it would have to come off the evening and that's already tight at two hours.

I pointed out to them, "Well, that's all very well and good but say you've got X working that evening shift. She's not going to be very happy if I tell her, her two-hour evening shift has gone down to an hour and a half to pay this other person. You're taking hours away from somebody that's committed to doing two hours in the evening." Do you see what I mean?

Robby: Yeah, I can see how that might be very problematic. Are Social Services at all sympathetic to this?

Deborah: Well not really. They just said, well you've got the money...

Melissa: Use it.

Deborah: You can use it how you want is what we were told.

Robby: Although I think I remember you saying last time we met they're actually quite rigid with how you can use it.

Deborah: Well we're not allowed to use it for respite any more. We used to be able to use it for respite. There was a certain amount set aside within the budget. Melissa could apply to have up to three weeks paid respite a year. So the social worker said, "Well not many people get three weeks. A lot of people get two." If we ask for three we're more likely to get the two that we want, a couple of weeks away, you know a family holiday. So, we applied for the three weeks and we got the two weeks. This was going back probably ten years or more now. But, they've stopped all that now. I think when you moved in here they said there was some respite money in that package but there isn't now.

Robby: Have they taken the respite money away completely?

Deborah: I mean if we wanted to go on holiday and use the money for respite we could do that but it would then mean me saying to Joe Blogs, "Well I don't need you to work this week." I'd have to work it for nothing to have enough in the pot for respite but then the person that should have worked isn't getting paid.

Robby: Which I can't imagine makes them very happy.

Deborah: Exactly. And, we haven't heard from the social worker this year. Normally she gets in touch quite early because she has to get the other lady from the Healthcare sector to come at the same time and trying to marry them both up and get them both here on the same day is normally a nightmare.

Robby: That's interesting you say that actually. I've heard from other people that their social worker's not been in touch for their annual review. So, other people will sometimes say "I'm happy with the way things are going so I don't want to see Social Services." I don't know if you feel the sort of same way? Perhaps things are going well enough that you don't want to see them and don't want shake the boat at the moment. I think things like funding is getting tighter and tighter.

Deborah: Yeah, I know. We have always been relatively lucky with the amount we've got 'cos the lady that's been with us for all these years she used to come to ours and say that another family she'd worked with had got their funding cut or she'd heard about a lot of it being cut all over the place. So, we've always kind of been waiting for it to happen and touch wood, we've been lucky that we've kept what we've originally started with, which is a bonus.

Melissa: I mean people who've been here five, ten, fifteen years should be getting a pay rise but they can't because we haven't got the funds to do that.

Deborah: We don't get given any extra money.

Robby: If you don't get given it, you can't pass that on.

Melissa: But, they should be getting it.

Deborah: We did ask one year for a pay rise.

Melissa: Three years ago we had to take their pay roll down, when we moved to Penderels and we shouldn't, we definitely shouldn't be taking it down. I mean everyone lost... however much it was.

Deborah: It was a pound an hour.

Robby: That's quite a lot.

Deborah: What happened was, from the original £8 an hour that we were allocated I just couldn't get anybody to do any of the shifts. So, I went back to Social Services and I said, "Look, nobody's interested in working here for an hour for £8. By the time they've spent a quarter of an hour or whatever getting here, a quarter of an hour getting home, that's an hour and a half of their time for £8. And they said, "Oh yeah, we see what you mean." We are apparently classed as semi-rural out here. There's not a very good bus service. We're not as easy to get to as, for example, if you lived in the middle of Cambridge. So they upped it to £9 an hour.

We did find it a bit easier, didn't we? We did manage to recruit some people. Oh no, not £9, £10 an hour. So we managed to get some people on £10 an hour, did that for two or three years and then my husband actually approached them and said, "Look come on, everybody else gets a pay rise, these girls don't." I wasn't working as a paid carer 'cos Melissa still lived at home. They did reluctantly give us more money so we could up everybody's wages to £12.

But, then we had to switch over our payroll services to Penderels Trust and our independent living advisor looked at our budget and looked at what we had to have still in the bank. We then had to have enough money for annual leave cover, etc. We had to have enough money for sick pay because there's five ladies that would be entitled to sick pay, money for the payroll services, because every timesheet I put in each month cost X amount per person. All of this had to come out of our original budget and we couldn't still do that paying everybody £12 an hour. So, everybody had to take a pay cut of £1 an hour to do that. The ladies that were working nights have been worst off, because when Melissa was living at home they were given £140 for a ten-hour shift. They now get £120 for an eleven-hour shift. But, that's still quite a lot of money. If they went to work for an agency they wouldn't get £11 an hour. They wouldn't get £120 for a night shift. So, its swings and roundabouts but it has been difficult.

Now we get these letters saying all the support, guidance, information is now coming from Purple. Payroll at the moment is staying as Penderels Trust although we have the option to switch over to Purple. But, I'm still waiting to get the letter that I was told that I would get from Purple detailing their costs

for payroll etc. I've actually got to get in touch with both of them this week because I'm waiting for a contract form I still haven't got.

I've got no annual leave entitlement forms sent out in the post, last year Penderels Trust did all of that. What I had to do in the past was email Penderels Trust. I don't know where to send that email now. I don't know whether I'd have to send it to Penderels or if I send it to Purple. I don't know. It's all very up in the air. The original letter we got saying it was all changing gave a link on it. So I clicked on that link and it basically gives you the Purple website, which all looks very wonderful but I actually wanted to speak to somebody or email or whatever.

So, there was an email address on there so I sent them an email. This is going back a bit now. Two weeks later I still hadn't got a response from that email so I thought, "Right I'm going to ring them up." So, I rang up, spoke to somebody and she's said, "We had a problem with our computers about that time, would you mind sending it in again? What address are you sending it in to?" I'd got the right address so I sent it in again. Now I had a reply a couple of weeks ago which I still haven't sorted out but I must do. They didn't answer any of the queries in there, about the annual leave forms, about my contracts; they didn't answer any of it. So, I'm no further forward. I've still got to ring them up again. I need to speak to somebody. I'm not going to email them, there's no point. The number they give, you get through to a switchboard and it gives you various options and one of the options is if you live in Cambridgeshire, I forget how they worded it but you click on that option.

But, I'm really confused because Penderels is meant to be doing payroll and Purple's meant to be doing the guidance and the support. So, who does the annual leave forms because that's not either? Who does the contracts because that's not either? I don't know.

Robby: Would this be something that you'd want to talk to the social worker about?

Deborah: It did say on that original letter, if you have any problems get in touch with your social worker. Or there was a number there or something so I thought I would when we see her.

The other thing I want to bring up is we had a letter, it was on quite thick-ish paper, quite posh, from Penderels Trust. Last year we had to, by law, do pensions. So, we had to have all that set up. Now that's all very well and good, so whatever our ladies pay towards pension we as employers have to match. It's not a lot but that's coming out of Melissa's budget. This letter was detailing the pension costs to us, so per year we've got to pay X pounds on top. So effectively, if they're gonna say we've got to pay that out of her budget we're 9 hours short a year. That has to come out of the budget. That's taken out of the account.

Melissa: Out of my care budget.

Deborah: When Penderels do the payroll and I send the timesheets in, we get a standard letter where they break down what's come out: wages, national insurance, tax, pension costs, and payroll services. They give you a total of what's been taken out of your account. So, they do all that and we have no say over that at all. But, at some point, if 9 hours a year are coming out just to pay that one payment, we're going to go over what's in the bank.

Robby: Then would you have to subsidise that with your own funds?

Deborah: Well I don't know.

Melissa: It would have to come out of my sick bit, wouldn't it? That's where it would have to come out of because there's a little bit in there.

Deborah: We've got a buffer. With the sick pay, you have to have some money sitting in bank in case your employees go off sick. Now we've only have one lady who's gone off sick and used that. They don't get a lot, whether you work 2 hours or 20 hours it's the same amount but it sits there. So I said, "Well if that doesn't get used up then what happens to that money?" We lose it. It doesn't get carried over so I've been told. But, at the moment we've got that buffer because nobody's using that so I guess if the money comes out for the pension costs then it will get taken out of that. We're not gonna see an immediate disadvantage to that.

Robby: That sounds like a lot of juggling and a lot of paperwork?

Deborah: I do most of that now. I do the timesheets.

Melissa: And I have to send them off via email.

Deborah: Melissa sends them off. I photograph them on her iPod, she sends them off. We had a problem; you can only put so many documents on each email, so most of the time it goes off in twos. The time before last they only received one email so only three of the care staff got paid when they should've done. So, then I'm ringing up saying "Look, why haven't the other ladies got paid?" "Well, we've only received one email." There's no confirmation from them at their end to say they've received all the timesheets. When I spoke to our payroll officer she said she doesn't know how many employees each individual service user has. So, if she gets an email in for just three timesheets nothing sparks off in her head thinking, "Oh Melissa is meant to have more than that, I wonder why I've only got three?" And then, for her to get in touch with us and say, "Where are the others?" There's nothing. So, what I'm doing now is I've gone back to ringing them up every month. After the emails go off I ring them up the next day and say, "Have you got them?"

Robby: Which is obviously more work.

Deborah: Which is a pain in the neck, I shouldn't have to do that. We normally get paid on the Friday, so those five ladies that didn't get paid, got paid the following Wednesday. But, one lady was relying on that money, so I actually

lent her money out of my own pocket to keep her going over the weekend, which she then paid me back on payday. It isn't what I want. I offered it to all of them, I said, "Look, there's been a cock-up at our end somehow or Penderels Trust's end. We don't quite know how the cock-up happened. The email was sent off but they had no record of it. If it's going to leave you short let me know and I'll take money out of my savings to give it to you for the short term." There was only one lady that took me up on it so I gave her, her wages out of my pocket, which I got back. But, then it was going through my mind, "Well should I have done a little note and got her to sign it? I have lent you X amount." 'Cos I'm thinking, "Well, what happens if she doesn't pay me that back on payday?" But she did, so it was all fine.

Melissa: Well you would have lost it, wouldn't you? You wouldn't have a leg to stand on.

Deborah: You run that risk. There's nothing to say I'd lent her it.

Melissa: If it ever happens again you need to write a note.

Deborah: I will probably, yeah.

Robby: I suppose they should have been really getting in touch with you to say this if it's on their books?

Deborah: They say they don't know how many carers each individual has. They are reliant on us putting the timesheets in. I mean ours does vary. We were down to six timesheets at one point and then last time it was ten because we'd taken on more people to do the part time stuff at the weekend.

Robby: I seem to remember when we spoke last time you said had a similar sort of problem with paying in for pensions?

Deborah: There was the problem 'cos my husband set the account up with Nest. When it should have started the money came out of my wages because I earn enough to pay pension and so do the four other ladies. We got a letter from Penderels Trust saying we can't pay it into where it needs to go because you haven't set it up properly. So there was, I think, two months running where we had that. We had to keep going back and sorting it out and I said to the woman on the phone, "Well, you've taken the money off us so where is that money now?" She said, "It's kind of in limbo at the moment. We've got it, but when the account is set up properly we can then put it in." So we had that two months running. We had the same letter saying they couldn't pay it in. They'd paid the first one in by that point. Second one goes to go in, they can't pay it in. It does seem bizarre. It's fine now. We haven't had any letters like that since. It's all going in.

So, Penderels are still doing the payroll. We can switch over to Purple, but until I know the costings of how much they're gonna charge us, I'm not doing it.

The other thing Penderels cocked up was tax. This was a while ago, when we switched to Penderels. So, half of that year was before we used Penderels and half of it was after. Penderels Trust put the first half in twice figure-wise. So they've got five of us. For example myself, I can't remember the exact figures but for example we'll say ten grand. So, I earned about £5,000 before enrolling with Penderels and about £5,000 after enrolling with Penderels. So, it gives me a total yearly income of £10,000-something and effectively I shouldn't pay any tax on that. What they did was put the first £5,000 before enrolling with Penderels on twice and added that onto the second £5,000 after enrolling with Penderels. So, they've got me down as earning £15,000. So I'm marked as underpaying nearly £1,000 tax when I shouldn't be.

They've done this for four other of our ladies. We've got one lady who owes over £1,000. We all owe money and what they've done is they've now cut our tax codes in half to recoup that money. But, it's a cock-up on Penderels' behalf. They're saying it's tax people, the tax people are saying it's Penderels and we've all been docked. I mean, I've had tax taken away from me this week. So that's something else I've got to go and sort out, I've got to ring the tax people. I had those four ladies moaning at me. I said "Oh, it's a cock-up and I can't sort it out. I can give you the Penderels number. You've got to ring Penderels Trust."

At the end of the day, what the woman at Penderels Trust wanted was the individual figures on our tax form that came through. Once she'd got all five of those she sent the whole thing off again but she was still adamant that she'd sent the details off correctly in the first place. Now, I got my P60 last week and I've got to go through it and get all my payslips out and add up what I've earned over that year to make sure that they've got that figure right before I ring them. That's something else I've got to do this week.

Robby: So, more things to do.

Deborah: Yep, so it's not easy. And, as Melissa pointed out, nothing like this happened when her dad did it. He had to do end of year summaries and end of year figures. That was more than 10 years ago and in all that time we didn't have any of these tax problems. So, it's annoying. He worked in an industry with mortgages and finance and pensions and all of that but he didn't know how to do the tax side of it or the national insurance. He had to learn that from all the guidance booklets that come through from the tax people. He got this booklet saying, "This is what you need to write down, this is how you need to do it, this is how you work out a certain calculation." He had to do it and he did it very well but they've cocked up!

Robby: Oh dear. So, could you tell me about some of the benefits of Direct Payments?

Deborah: Haha!

Melissa: Is there any?

Deborah: Well you employ the people you want.

Melissa: Apart from I employ the people that I wanna employ.

Deborah: You employ the people you want to employ, that you're happy to have in your home.

Melissa: That's about it, innit?

Deborah: Yep I think so. This other chap you mentioned. I'm presuming because he's still on the agency's books he doesn't have family to support him? Because, I often wonder about Melissa and the people that come for an interview. Somebody said to me, "Oh you'll just employ anybody." I said, "Well no, I wouldn't employ anybody if I didn't want them looking after Melissa because they're in the house together on their own." I'm here as backup but if you've got somebody who's on their own, doesn't have a family support network or whatever and they have to try to look for carers, they might employ somebody that they don't really like or they don't really want to be there just because there's nobody else.

Robby: The gentleman I mentioned does find it a bit tricky finding carers.

Deborah: Yeah. If he hasn't got somebody that could step in in the short term, it must be really difficult. I don't think we've ever employed anybody we haven't liked just because we had to, have we?

Melissa: No.

Deborah: We've obviously employed some unsuitable people. We've had people leave, there was a personality clash with one carer when you lived at home but she had some health issues herself.

Melissa: Yeah, I missed her now.

Deborah: But yeah, that's probably the only benefit to be honest.

Robby: How about living independently in this apartment?

Melissa: Well yeah, there is that but then, I don't know.

Deborah: Its good Melissa lives here on her own.

Melissa: But it's also a pain in the arse.

Deborah: But, it is also a pain in the arse. Like yesterday I didn't come round at all. Bank holiday, I took my sons to the cinema with their friends and it was lovely to go out with them. Melissa wants to see the film as well but when we go with Melissa she has to sit near the front and they like to sit right at the back. It was nice to go out and you know, just do stuff with them. But, then

when I come here today, things that I might have done yesterday had I been here, I've now got to do today. Things build up that other carers don't necessarily see, or have time to do or just aren't within their job description, you know.

Like, I do all the washing. So, on a Tuesday I normally go round and I get all the towels together and I'll wash them tonight at home and then tomorrow I'll bring them and put them in the tumble dryer over the road. There's a community thing over the road and there's a washing machine and tumble dryer in there. Well, if I don't come here on a Tuesday, that doesn't get done.

So, there are benefits and there are disadvantages of Melissa living independently because you run your own household. We've got everything set up and we've got Direct Debits for all her bills. Melissa's pretty good with getting on the phone to the GP if she need something or if the hoist breaks down. The other day I rang up here and a carer answered the phone who I wasn't expecting to be here. That was because another carer had rung in sick, so Melissa had done that without my knowing. She's very good at doing a lot of stuff, but there are some things, like ringing the electricity board, you won't do that, will you? They wanted to put her electricity up by quite a bit. It was a big jump for one property. So, I had to ring them up ring up on her behalf and sort that out. So, it does have its disadvantages.

My eldest son, he's got autism. The school he's in at the moment, we're looking to get him out of because he's not doing well there. He's not happy. There's a lot of other children in the same position at that school. I've been to a school meeting this morning to go through his EHCP paperwork. My youngest son's got anxiety issues, so sometimes things crop up with school with him. Although he's, touch wood, 100 times better than he was this time last year. It's juggling the whole time. This afternoon we've got to go back to the vets because your cat's not been well. Then when I get back from the vets I'll go home for a couple of hours, cook tea and then I'll come back here to do the interview at 8 o'clock.

Melissa: And it looks like the night.

Deborah: And possibly the night shift as well.

Robby: At some point you're going to want to be taking a step back as well.

Deborah: Well, yeah. I mean that's the one thing I picked up from that meeting where we met. That lady that came in and did the talk, she was kind of handing the reigns over for management of her child's care to someone else for when she's not there all the time. Yeah, I mean I'd like to do that. I'm in my 50's now so I've still got a long while to go. I'll always be around but I don't really want to be the main person all the time. I've got too much else going on but I have no choice at the moment. It's just something I have to do.

I've looked at cutting my hours down here, not working as much here and seeing if I can claim Carers' Allowance. I can't claim Carers' Allowance at the

moment because I earn too much. You're allowed to earn so much a week a week and anything over that you can't claim Carers' Allowance. Well I earn more than that here. So, I can't claim, even though I've got my autistic son at home who I care for as well.

Melissa: Three children.

Deborah: Three children if you include my other son. I still can't claim it.

Melissa: Four if you include Dad.

Deborah: Yeah, four if I include my husband. He has depression and he's got Asperger's and OCD as well. I think even cutting down my hours here, even if I could find somebody to do them, I'm not going to get the sort of money that I need, you know. I'm in one of those catch-22 situations I think. You're damned if you do and you're damned if you don't sort of thing. Then there are things like getting that text through today asking us to cover a carer's shift, which then put pressure on us the rest of the day.

Robby: Bit of a, bit of a stressful situation.

Deborah: Definitely.

Robby: Coming back to respite and you said you're not able to do that as much anymore.

Deborah: Well we have got one break booked.

Melissa: Yeah but I have one free night like a year and it's not enough. My mum takes me on that so she's getting no respite.

Deborah: I now take her on that because the lady that used to take her on holidays last year said she didn't want to do it anymore and then she left. So, I am now the only person that can and will take Melissa on holiday. That causes, not upset at home, but my eldest son doesn't talk to his dad. Something happened that we still can't really get to the bottom of. My son said dad ignored him all afternoon and 'cos of his autism... I don't know, it's just got worse and worse and he just won't speak to dad. So, knowing I'm going away Friday to Monday and they're all at home, you know? I do enjoy going away but it is tiring because I'm doing all day, all night, all the driving there, back and everything else. But, then I wonder what's going on at home. So, it's really not respite for me. Respite for me would be when Melissa goes on holiday with somebody else and I get to stay here.

Robby: Yeah. I suppose that is important as well. I mean, that's part of being independent.

Melissa: I was going to ask that lady that left if she'd take me next year but she's left so... She might still do it, when she's sorted all her crap out, she might come back and be happy to do it but...

Deborah: Trouble is, when we interview people, we can't always say to them... well we could say to them, "Are you able to take Melissa on holiday?" But that's not the main thing that we need. We need somebody to provide the care in the home. We just hope at some point that they get on well enough they want to go on holiday together and maybe that other person could take her. But, that's not a requirement of us interviewing people. Do you see what I mean?

Robby: Yeah, I suppose it can't be. I suppose that would be a bit too picky, which is difficult when you're trying to find people. I have heard it's become increasingly harder and harder to find people at the moment.

Deborah: Yeah. And, we've had so many people ring up who actually don't even drive. So, I'm like, "Well how are you going to get here?" "Oh, well I'll come on the bus," and I'm like "Well there's five buses a day. I don't think so, you know." One lady was going to get a train. I said, "Well you've got to get from the train station to our village then. It just doesn't work" If I was applying for a job, I would go on AA route finder and see how far away it was and ask, "Is that feasible?" I'd do that before I rang up but a lot of people don't bother.

We had one lady ring up from across the county and it would have been an hour each way in the car. She was like, "Oh yeah, I'll still come for the interview." I said, "But do you realise how far away you are? You're at least an hour." And then, when she looked she said, "Oh yeah it is a bit far, I won't come then!" That's so frustrating when they've rung up and they're experienced or qualified, you know, seemingly suitable but they live too far away or they don't drive.

Ideally you need to drive to get here but we'd like to find somebody who will drive and take Melissa out of an evening. She has an evening once a week where she can go out and have a long night. We have the evening and the night shift go back to back, so basically somebody's here from six in the evening through to the next morning. It gives her the opportunity to go out. But, the only lady that did that has left now, so we've lost that for the time being.

Robby: Hopefully you can find someone to do those things.

Deborah: Well we hope so yeah. We've had a couple of ladies ring up who are interested in the nights but don't want the evening shifts so then we don't get that long night as well.

Robby: Oh dear. So it's problematic trying to actually find the people that do this.

Melissa: Those nights are fourteen hours. That's how you do it, starts at six and finishes at eight.

Deborah: Yeah I know but that but that one lady couldn't get here before 8 o'clock.

Melissa: Then she's not suitable then, is she?

Deborah: She could be highly suitable but she's not what you want.

Melissa: She's not what I need.

Deborah: So, until we find somebody else I've got to do it. I had a list up on the board. I've got to go through the book when you're gone and put another list up on the door to get our regular carers doing these shifts or I end up having to do them. It's a headache and lots of work.

Robby: I guess it's difficult to talk to Social Services about this if they're not getting in touch with you?

Deborah: Well I can ring them and in fact I think I probably will ring them up at some point. Normally they've got in touch by now. At the beginning of the year I had a phone call from somebody who wanted to come round and do an assessment. I said, "But we're not due any assessments." Turned out it was the Healthcare assessment but normally that's done after a social worker review. Melissa has to pay a certain amount in Healthcare contributions. However, it didn't get done last summer, so they wanted to come round and do it in at the beginning of the year. I said, "Well there's no point because the social worker hasn't been yet." So they postponed it but that's all looming.

Melissa: They better not make me pay any more 'cos I can't afford it.

Deborah: No. Melissa's gone through all her budget. We've been helping her out with the contributions. We pretty much pay the majority of that but we're in a position where that's going to change soon. So Melissa's going to have to pay some of that herself.

Robby: A lot of money to find which is not something you want to have to be doing. Finally, is there anything you'd like to say to people like who want to get onto Direct Payments?

Deborah: It is a good thing, I mean, it would help I would hope.

Melissa: Haha!

Deborah: What?

Melissa: Sorry. I laugh at that, "It's a good thing."

Deborah: Well it is because you get the people you want and you can do it how you want to do it. I would just hope that there would be more support for somebody setting up. You know, somebody that was given Direct Payments

today would hopefully get more help with setting up everything because we weren't and it was hard.

Robby: That's unfortunate. One of the other things I'm doing is feedback to the County Council. So, something like support setting is very important and is something that they should be told.

Deborah: Yeah. So that's it I think really.

Robby: Thank you very much. That's very appreciated. Thank you for seeing me again.

Deborah: That's okay.