



Carolyn's Story

“I actually know the social workers are gonna cut my Direct Payments when they come in, so I'm off on a defensive start.”



Carolyn's Story

Interviewer: Robby

Robby: We'll start at the very beginning and ask how did you hear about Direct Payments?

Carolyn: Oh, well that is a mystery.

Robby: A mystery?

Carolyn: Yes. There had been a pilot scheme run by a couple who were disabled in South Cambridgeshire. They had run Direct Payments for several months and had got people in to care for them. They paid for them and kept up with the book work, all that stuff. Then they decided to hold a conference based on their experience. They were there and they were speaking up. I think this was more than fifteen years ago.

Out of the blue I got an invitation to this conference. It was held at Ruskin and I thought, "Well who's this invitation from?" And, it didn't say who it was from; it was something that was a total mystery. So, being nosy like I am I thought, "Well, I'll go!" When I went there, there were very few people, so one by one I could go round the room and say, "Did you send me this invite? Did you send me this invite?" And nobody would own up to having sent me this invite so I was there by chance.

The couple talked about their experiences and it was going very well. I thought, "I don't need care at the minute, but I might in the future. I wouldn't mind a respite care element though, that would be quite useful." The respite care element was for my husband to have a break from caring for me.

Anyway I went home and waited for things to happen and it didn't happen. Nothing happened and after 18 months I got someone from Directions Plus to put in a formal complaint. The result of that complaint was amazing. They said they hadn't been able to make me out a cheque because they hadn't got the right cheque book and they didn't know what account to pay the Direct Payment from because nobody else had been interested in just the respite care element. However, eventually it came and we used the respite care element for maybe two or three years.

Then I thought, "I need to go into the care system." A brilliant social worker came along, her name was Deborah Hawkins. She agreed and I think it was about 14 hours a week she allowed me to have. I had the freedom to use it as I wanted but I had to keep the books and I had to have timesheets and I had to have 14 hours on them in total. So, they just left me to get on with it. I kept

my own books. I submitted everything every month and then every financial year ending. Everything was going absolutely perfectly, I had no worries at all, it was the best thing I ever did.

Robby: Oh wow, that's good.

Carolyn: Until about four years ago and now it's turned round into the worst thing I ever did.

Robby: Oh really?

Carolyn: Because this one lady, who was my carer, I had to make her redundant because they cut and cut and cut. Now I've turned from being a very competent employer into feeling wretched about myself. I thought, "How degrading to have to make somebody redundant." It absolutely broke me. It absolutely broke me totally.

Anyway, I've got a very reduced amount of hours now. It was cut again last year. So, now I have just a few hours a week, which just about gets me up in the morning. Other help that I need I have to pay for and it's breaking my bank. But, the demoralisation of me was devastating.

I couldn't do the books any more. So, I found an organisation locally to do the books and I've got a very good relationship with them. I'm so pleased I went to them because one of my carers, it's her second job. So, she has to pay tax and I have to pay that for her.

We've also got this new pension scheme coming in now. Although my three carers don't earn enough to warrant going into a pension scheme, they have all agreed that they won't go into a voluntary system with me. But, I still have to do some work and I have to read up on all the legal aspects. I've just got to the point where I've had to give them a formal letter to say there is a pension scheme and although we're not going to put them into it, they have the option to go into it if they want. However, and fortunately for me, they've decided they earn so little that they'll just keep it like that and not go any further.

I've got a brilliant team of three. I can't tell you how good they are. They are really, really good. Two ladies are personal friends. They've worked very closely together in other jobs and they're best friends. They work together and make sure they don't go on holiday together and things like that, so there's no cross over. They're in their early fifties and then I've got a lady who is of retirement age already. She's well into her sixties but she has decided to carry on working.

One of my main problems is we have an enormous amount of laundry. So, I'm able to get some laundry done on the Direct Payment but everything else,

which is still loads of laundry, cleaning and any work outside the bungalow, I have to pay for. That has to be paid for out of my Attendance Allowance. But, my Attendance Allowance is being quite heavily eaten into.

So, now it's got so bad with the social workers that I don't want them in my house. Last year when they came here, I actually walked out of my own house and left them. I just couldn't be around them anymore and I never ever want to see them again. It's just the cutting. I, as a disabled person have to then pass on those cuts and tell my carers. I get one of them to come every day for an hour a day. They turn out in all weathers and they've never ever, ever let me down. I'm very, very, very fearful of social workers coming again and saying they're cutting.

Robby: Well I'm mean, unless your needs have actually changed, i.e. through reassessment or they felt there were other ways your needs could be met, then they shouldn't be cutting. They do have a legal obligation to make sure that your needs are being met.

Carolyn: But, when they come I'm so wound up I'm an angry stroppy bitch. I don't want them in my house, I don't want them sitting down in my armchair and whispering between one another if two come. I can't hear their bits that they're whispering, in my room in front of me. I know I've got it to come again but anyway... I thought for my New Year's resolution I will be nice to social workers. I will be so nice they will be totally overwhelmed by me. But, I can feel it in my heart now, I don't want them in the house.

Robby: Fair enough. What do you say to them when they say they're going to cut your funding? Can you say, "Well my needs haven't changed, I still need to do this this and this?"

Carolyn: Well, they came again last year and again they've got worse. Unfortunately I haven't broken out in spots or got a leg in plaster or anything. It's my heart and my heart is giving out. I'm just having that explored. I had an X-Ray and they found out that my heart has been really enlarged and I've had a strange reaction to the medication they put me on. They have to explore putting me on to another drug. That's where I am at the minute, I'm waiting for more tests to be done. But, the social workers can't see that. I can't even show them a scar where a pacemaker's been put in or anything like that.

Robby: Surely there are the medical records that you can use?

Carolyn: Yes, there are medical records if they want to look but I think when they're coming down the drive they've already made the decision about how much cutting they've got to do.

Robby: I do know that everyone's feeling the pinch at the moment, including social workers. They're getting their funding cut all the time.

Carolyn: So, what have your other people been saying? How, are the other disabled people coping with the cuts and having to tell their carers?

Robby: Well, I don't think that I have come across anybody yet who's had their funding cut as severely as you've just described to me. A lot of people describe it as costs of living are going up and up. Carers want more competitive rates and people can't afford to keep up with that. But, their actual Direct Payments haven't been cut as severely as you've just described to me.

Carolyn: Hmm. I suppose in a way, where they left me so long on my own that I just got on with it. I just think it's ever since they've come around on a yearly basis that I live in fear of them coming. I shouldn't be like that, I shouldn't look out my window and see them coming and thinking I don't really wanna be here, I wanna be away.

Robby: Yeah, you shouldn't be scared of your social workers.

Carolyn: I'm terrified of them and I'm terrified of my reaction to them because the person who comes out and presents themselves in this room is not the real me. The real me is really quite a passive person who leads an ordered but interesting life.

Robby: Yeah, you seem like very amiable as we're chatting here but I can imagine if you're worried that someone's coming in and then cutting funds again and again and again that you're not going to be inclined to be that amiable.

Carolyn: When they stopped the respite care element they said, "It was for me, not for my husband to get away or for me to get away. It was for us to be parted to take the pressure off." They turned it round into the fact that it was for me caring for him and the social worker actually sat in that chair over there and she said, "You're not having that money any more Mrs. Smith 'cos you no longer care for your husband." But, I do care for him, we care for one another and we muddle through together. To say I don't care for him anymore is horrible to hear, because I do.

Robby: Yeah, that's fairly shocking. I mean, I can see what she means from a sort of a paperwork standard but that's not how it sounds.

Carolyn: It could have been put in a better way.

Robby: So, how do you cope with all of this?

Carolyn: Well we haven't had a break since then, either of us. I think we would really like to be able to get away. Not only have I lost the respite care element but also, I'm now having to use my Direct Payments to pay for the bits of care that they're saying Direct Payments doesn't cover.

Robby: I can't imagine the social workers would be very happy about that. They always want receipts, receipts are very important.

Carolyn: Yes, well they get all the paperwork. That's fine and in order. Everything's in order and it's always been in order. I took great pride in doing the books. I did them for more than ten years. I used to take great pride at the end of the month in doing my books. When it started to go wrong I lost so much heart I just passed the books all over. Then I found that there was funding to pay for an organisation to do your books and that was included in the Direct Payment. I thought, "Wow, I've been doing this and saving them money for all these years doing it myself."

Robby: Over the course of this project I've been working closely with Purple, who are an organisation that can support you with managing your Direct Payment paperwork. One of the things that people who use Purple have is money actually allocated in their personal budget to pay for Purple's expenses.

Carolyn: So, with Purple, do they literally do everything? Because I write the cheques out and get sent timesheets and the payslips. I send the timesheets in and then they send me the payslips back and then I write the cheques out. So, does Purple make the cheques out?

Robby: Yeah, I think so.

Carolyn: And are they doing everything to do with this pension?

Robby: Yeah, they sort out all the pension schemes, all the holiday pay, all the sick pay, all of that kind of stuff.

Carolyn: I've been amazed by how much I've had to do myself. This organisation I went to said to me, "Legally you must read all of this Carolyn." Then they do their bit of work and they're going to charge me for it of course. But, I'm so pleased I went in to them with it. Still, every month it's me who has to do all the paperwork for the taxman and send a cheque with the tax every month. I look ahead and think, "Well I might not always be able to do this."

Robby: It might be worth your while talking to Purple. They're the primary support service for all issues relating to Direct Payments in Cambridgeshire. They can help out with a lot of different facets of the Direct Payment Process.

Carolyn: I haven't used them before because year by year the contract for Direct Payment support has gone out to new organisations.

Robby: Fair enough. Okay well, I suppose you've actually like answered a lot of my other questions but let's go through one by one anyway to see if there anything else you'd like to add. So, how did you actually find the Direct Payment process?

Carolyn: Well, I quite enjoyed it and I didn't go into it exactly blind because I'd been to this conference. This couple said about keeping their own books. This was far before Purple because it's so many years ago now. I thought at the time, "Oh, that's sad both of them disabled." But, then it's happened to us. My husband's become disabled. It's rather strange because he funds himself, so he's never had to go through the process of being means tested.

I knew when we bought our last vehicle... I was in a Motability car and I had to trade it in because it became unsuitable for me. We decided that we had to have something a lot more complicated to get in the vehicle. I have trouble physically getting in. So, we asked the Motability Scheme if I could go in and they wouldn't take me on my own. They said, "No, your partner has to come in with you." They wanted to do a means testing on him.

Robby: That is usually the case, yes.

Carolyn: But, he wouldn't do it, so I've had to buy instead.

Robby: Oh, how frustrating.

Carolyn: Yes, and terribly expensive, terribly expensive. I'm really lucky that I can still drive an automatic car but I've got a car with a lift in it. It takes me into the car and then the driver's seat comes to meet me. I transfer over to it and then it takes me back under the steering wheel and off I go.

Robby: Sounds handy but is it worth the money?

Carolyn: Yes but I would never ever have dreamt of paying so much for a car as I have this one. It just about drains me every month. I'm very lucky that I've got the Motability component.

Robby: Still, it's not something that you want to pay for if you shouldn't be having to.

Carolyn: Well, it means I can't use that money for anything else. So, that's how it is.

Robby: Sure. Okay, do you feel that you've had enough help and support through the Direct Payment process.

Carolyn: Well I've chosen not to until quite recently. Now, I'm got all the help I want from the people that do my books. My only problem is seeing the social workers and I'm sure they must dread coming here because there's this nasty bitch of a woman who lives in this house. Just for one day I emerge as this nasty bitch, haha! Then I'm drained and think, "Oh, why was I like that?" But, that's what they've done to me.

Robby: Social workers are the people that if you have a problem, you want to be phoning up and saying, "Look, I'm having this problem can you come and help me?" They're not the people that you should be stressing you out because they're causing you more problems.

Carolyn: I just wonder how much and more they're going to cut me. My main carer, she comes in at quarter to eight to do an hour's job. She's supposed to come at eight but she worries so much about getting done in the time that she comes at quarter to eight and she leaves in between quarter past and half past nine. It's because I've lost so much of my mobility now, that I'm really precarious once I'm out of the wheelchair. I mean, I feel very, very vulnerable and I had a lot of falls last year and several this year too. It's just transferring to the shower I can't do quickly. My body doesn't go at a rapid pace any more.

Robby: Sure. And, you said you had to let one of your carers go.

Carolyn: Well, my main carer she did fourteen hours a week for me

Robby: Okay. How long had she been with you for?

Carolyn: Right from the beginning.

Robby: How frustrating and how sad as well.

Carolyn: It's totally demoralised me. You know, I always used to think that I'm a fair employer but I no longer think that about myself now, not after that experience.

Robby: Well, you can only do so much with what you're given

Carolyn: Well, how are other disabled people coping and telling their carers, "I only want you for one hour instead of two hours?" Every time the social workers come they're cutting my Direct Payment, every time. I dread them coming.

Robby: And they come once a year at the moment?

Carolyn: Even that's too often!

Robby: But I think it is meant to be about once a year? You said until recently they didn't come at all?

Carolyn: No. I mean, Deborah Hawkins when she first came on the scene, she said to me, "You amaze me, why are you so settled into being disabled? Why aren't you fighting and angry and bitter about what happened to you?" I said "Well, that wouldn't really be constructive and it wouldn't make me any better would it?" I told her that I'd got a bucket list and when I was 40, I decided to start working through this list. Um how old was when I had that accident? I was in my 50s. By the time I had my accident I'd worked through this list and there was one thing left on it. The thing that was left on it was that I'd never learnt to abseil. I used to do a lot of climbing and potholing but I never did learn to abseil and she said, "Go for it!" And, so I did. I got to an Outward Bound centre down and I learnt to abseil.

Robby: Yay!

Carolyn: So that's my bucket list!

Robby: Ah that's really good. So, a few questions left.

Carolyn: Fire away.

Robby: How easy do you find it to do the things you want to be doing using Direct Payments?

Carolyn: Well I've only got the Direct Payment to get me up in the morning and to get to bed at night. I'm supposed to have half an hour to get to bed at night, which isn't working well because I'm having trouble finding anybody who will come out in the winter for half an hour. When the social worker does come again I shall ask her about employing an agency.

Robby: That is actually a very common problem for a lot of people, finding the PAs. Most PAs won't come out for anything less than an hour because obviously with the best will in the world it is still a job and it has to be worth their while.

Carolyn: Well at the moment, what happens is the one who comes in the morning just comes back and so they all take their share of it. Over the wall at the bottom of my garden is a residential home and I thought, "I wonder if they have a staff noticeboard that I can put a notice on, when you're leaving duty will you just pop into our house to do a check?" I did think about that but I haven't put that in motion yet. So, we're fiddling about with that at the

moment but I will get it sorted because I'll be able to get an agency to do that if I think that there's enough money in the scheme to do it.

Robby: One of things that someone told me was that it's always worth staying on the books of an agency 'cos you never know what's going to happen. Just in case it's worth being known to an agency so you can just give them a ring and say, "Look, such and such has happened, I need you to come out."

Carolyn: There was a lady. She's just gone into a care home now but one of my neighbours uses her agency because they call in at her house. I need to look for somebody local who's having care at night and see if I can latch onto their visit so that the agency isn't just sending somebody out to me.

Robby: That's not a bad idea. If someone can come and do lots of different visits in the same area that would be a very smart way of doing it.

Carolyn: I'm in the process of looking into that at the moment.

Robby: How easy are you finding it?

Carolyn: Well, when I started with Direct Payments right at the very beginning I put a little advert up in the post office. That was amazing because that note went on the noticeboard and the very week I put it there, the shirt factory in area finished. All these women were made redundant and I was bombarded by people! Anyway, I had my choice and I made a very, very good choice.

Since I had to make one of my carers redundant, I've kept three ladies on just doing a little each so that they can fit in with one another at times of sickness or holidays.

Robby: Are you still in contact with this one who you made redundant?

Carolyn: Yes, I am. She's one of my friends, she comes and visits me every month and we go out together. You don't have anybody in your house for all those years without being friendly with them, do you?

Robby: Yeah, that's very true. That's, that's really nice.

Carolyn: Yeah.

Robby: Okay. So, what are some of the benefits that you've found of using Direct Payments?

Carolyn: Well financially I wouldn't be able afford to have carers without the Direct Payment, so the money side of it's very important. I do love having the people in that I've chosen to work here, and they've been good choices.

Robby: That's good. Did you go through an of interview process with them?

Carolyn: Yes. That was fine because I'd done that at the organisation where I work, I had to interview people for jobs. Although I was on a board of people doing it where I work, that set me up for doing it on my own. So, I never looked for help there and it's worked really well.

Robby: Fantastic. Any other, any other benefits you can think of?

Carolyn: Well it is nice having somebody in at the time that I want them to be in. Years ago I needed care and Cambridge County Council's had their own carers then. They would come in and get me up at 11 o'clock. Then somebody on this carer's list would die and then I'd be put down to half past ten and then somebody else would die and I'd get up at 10 o'clock. The day that I got to 8 o'clock my carer, who was only one girl doing this, she had a really severe mental health breakdown. That very day, that very day! So guess where I got put? Back to 11 o'clock. So, it was at that point that I thought, "Oh no, this is when Direct Payments has got to come in!"

Robby: Yeah, you want to be able to get up when you want to get up, not when they tell you to.

Carolyn: Yeah exactly. So, that side of it, employing people, I've never been short of people. One of my carers lives opposite me. I used to go round there with her post and she used to come round here with my post, so we got to know one another. I met her in the street with my little card for the post office thinking that I was going to employ another person. When I met her I said, "Would you like to have a look at this piece of paper? Take it home and give me a ring later today to tell me what you think about it. Would like to come and work here?" I knew she worked at one of the local nursing homes as well. Anyway, she said to me there and then in the street, "Oh yes, I'd love to!" The fact that I'd got to know her beforehand was nice.

We've got a team of three and very often my husband and I share, we share the whole team. We maybe have two carers who come in round about 8ish. But on days when it's hospital appointments, maybe somebody'll do us both. Then we've got to see who goes first and who goes second depending on what we're doing the rest of the day. He pays his independently and I go through the Direct Payment.

Robby: Okay. How's he finding it paying it independently?

Carolyn: Well, he has this thing where he won't do a financial means testing. So, nothing will make him go into the Direct Payment scheme. He pays for all his care with his Attendance Allowance.

Robby: Okay. I guess there's very little left after that?

Carolyn: There isn't anything left, he uses it all. He does his own books and sorts that out.

Robby: Fair enough. I think that's a very valid way of doing it. Everybody who wants to should be in control of their own care and support.

Carolyn: Yes, and given the choice of what they want to do.

Robby: Yeah exactly, it's all about choice all. Last question, what advice would you have for other people using Direct Payments?

Carolyn: Well, I would say make a friend of your social worker. I had a really good rapport with my first social worker and I really liked her. It was a pleasure to have her in my home and I've lost that. I would say, appreciate your social worker.

Robby: I suppose that a big problem with that is the high turnover. A lot of people I've spoken to, from one year to the next they've got a different social worker.

Carolyn: I'm sure that I've got a blacklist on my book at the social workers' office. I'm sure they must toss up the coin and say, "Who's going to see this dreadful woman?"

Robby: I suppose making friends with your social worker would be great if you can but it must be very difficult when they're coming here saying that they're going to give you less money.

Carolyn: Yes. Also, if you don't feel able to do your books, there is plenty of people out there that can do them for you. You should be able to pay for that out of the Direct Payment.

Robby: Yes, that's true.

Carolyn: So, on the whole the system has worked really well for me. It's just that I have this issue with them cutting. At the time that I got a Sam, my Canine Partner, lots of Canine Partners get funding for their dog. I've got to a point where I wouldn't even dare ask. Sam really is my main carer in the daytime and at night too. He's on duty all night. I can't speak highly enough of him. Get on the Canine Partners' waiting list if you can. I think it's closed at the minute but that's been the single best thing I did.

They take two people at once into the training kennels and you have to stay for a fortnight and learn how to look after you dog. You have to learn your responsibilities and the dog's responsibilities. You have to work out a programme of work and teach your dog to do it.

I worked with a young girl who had 24-hour care. They even they cut her care. She's left alone for two hours a day, just her and her dog. She is literally locked in her wheelchair with her hands crossed in front of her. She drives with her left hand on the right-hand side of the chair. With the right-hand side she has a tube of cheese put on her armrest. You know, the cheese spread in a tube? Every time her dog does something to her she can just reach the tube and press it so he gets a smidgeon of cheese. I've got a bag on the side of my wheelchair for Sam but she couldn't reach the bag. So, she just has this smidgeon of cheese that she can squeeze out and she has to manage on her own. She finds that quite frightening. But, of course the dog knows how to use the alarm system and knows when to use the alarm system. Her alarm has gone off many, many times and her mum has to come out, which is about a 15-minute drive. Her mum never knows what's going to meet her at the end when she opens her daughter's door. She doesn't know what she's going to find. So, she's the only other person that I've found that's been really severely affected by the cuts. I don't know what other people were saying, were they saying that they'd been cut when you had your meetings?

Robby: Not as much I don't think. I think the bigger problems were people finding that wages increase, inflation increases, PA's need to be paid more but their amount of Direct Payment has stayed the same. This is obviously problematic because they want the same amount of support with essentially less money. I haven't really heard stories where someone's Direct Payment has been cut as much as yours has, although that's not to say it doesn't happen.

Carolyn: I find it really frightening. I'm due now for a call from the social workers and I'm thinking, "Please forget me for another year."

Robby: That's not good really. Like you said, "Be friends with your social worker." It's nice to be able to approach them when you feel you need support or you need someone to talk about doing certain things. It's not good when you're scared of them.

Carolyn: Well, I actually know the social workers are gonna cut my Direct Payments when they come in, so I'm off on a defensive start. I'm never open and welcoming. I'm fine as long as they don't come and as long as they don't come with more cuts.

Robby: Oh dear. Um, is there anything else about Direct Payments that you'd like to share with me?

Carolyn: Well really, I think I wanted to share with you the fact that I was in at the beginning. Mentally I've always been able to cope and organise things myself. I like the fact that you have the freedom to do that. You think you're doing really well and managing really well in the community, living a fruitful life, a busy life and then somebody comes along and takes the rug from underneath your feet.