



Emma's Story

“I need to know what's what and I've got nothing in writing to tell me.”



Emma's Story

Interviewer: Robby

Robby: So, as this is all about Direct Payments I'll start at the very beginning and ask how you find out about Direct Payments and what drew you to them?

Emma: I asked about them because I don't get any help apart from Oscar gets his Independent Payment. I don't take any other help from anybody. My family is good support. I read about it on gov.com or something like that, so I asked.

Robby: So, you found out about them online?

Emma: Yeah and I asked Kate, who was Oscar's care worker, if Oscar would be eligible. Kate is Oscar's care worker.

Robby: Okay. So, she had a bit of knowledge to begin with?

Emma: Yeah, she was doing my carers' assessment. That's what we were doing when I asked her.

Robby: Okay. How did you get in touch with her to begin with if you don't mind me asking?

Emma: There was a lady from the Alzheimer's Society. She first recommended that I get some help from the mental health team because my husband was only in his early 50's. It needed to be the younger people's team and I think Kate was the one who told me I couldn't go direct to her, I had to go to the doctor's and then ask for a referral.

Robby: Sort of like a step by step process?

Emma: Yeah. You have to kind of go through the right process to do it, you can't just ring these people up.

Robby: When you came to her and asked her about Direct Payments, what did she say to you?

Emma: She'd done my carers' assessment and then we chatted in general about them. She said, "There's no guarantee or anything but it's something we can look into and apply for." Kate put all the paperwork in.

Robby: And was that to Adult Social Services?

Emma: Cambridgeshire County Council.

Robby: And, how did you find the application process for Direct Payments?

Emma: Most of it they did with me. I was signing the forms and stuff like that. Kate came down if she had anything. And then Oscar had a succession of social workers. I think he had three in twelve months. So, every time a process was going through he had to see somebody to get them to do an assessment and it changed three times. The process has taken more than a year.

I took Oscar away for a few days to go fishing. A place that you stay on the lakes and sit right on the bank near the cabin so he hasn't got to go anywhere and I can see them. We got back and everything had actually gone through. So, we're sorted now but it took twelve plus months.

Robby: And, that's with you doing three different assessments?

Emma: Yeah, I think we've done three different assessments now.

Robby: I think it would be quite stressful just doing one?

Emma: The stressful bit was the fact that it always takes a few months to sort out but of course with Oscar and the way he is, it's something that becomes a fixation. So, it's like, "Have we heard anything?" "No." "Have we heard anything?" "No." Then it was becoming more of an issue with his illness because the assessments were repeated. So, it was like, "Have we done everything? Have we got to have any more visits?" Obviously he worries that he has people in the house. He doesn't cope with people very well so it just adds to it.

It's gone through now but there's many a time I would have said, "Do you know what? It's just not worth it." Because of the added grief of the thing and because of the anxiety for his part. Then of course the assessment is repeating itself and we're having different people coming over. They were all nice people and they were all very good with Oscar but it takes him a couple of days to get back to normal.

Robby: Did they say why there three assessments?

Emma: 'Cos his social worker had changed three times.

Robby: But, they didn't have the paperwork from the last one?

Emma: They just said that he needed to have another one. They needed to come and see Oscar and do another personal review or whatever they

needed to do to him. The final one I believe this lady had not long joined their team. So, she came out and done it and then it got through very quickly.

However, I still haven't heard anything from them. I got a phone call off Kate saying it had gone through, that's got to be ten weeks ago now. But, I've had nothing from the council or anything in writing. I've only got what Purple sent me. If Purple weren't there I'd have nothing 'cos he's having to email me information, contacts, worksheets, and all that sort of things. But, the actual plan of what Oscar's got, where, when and who or what, I've got nothing from the council still.

Robby: So, it's been a year and you're still having to do more chasing?

Emma: Well Purple are good. Every time I request something they email it across to me. So, all the paperwork was emailed and the employee forms. I've done them on the tablet. I get their information and then just email it across to Purple as an attachment.

But yeah, as far as the council or Kate or the social worker, I haven't had any more contact. It's gone kind of dead again but we're still moving. Me and Purple are moving it forward now. Apparently, Oscar got awarded Direct Payments three months ago. So I said, "Well I haven't been telling people to get receipts and stuff." So, Purple said, "We'll have to do a cover letter for them because at the end of the day it started then." However, I hadn't got any confirmation letter or anything. Still haven't got any confirmation. So, I think Purple are basically a one-man band for Oscar I said to them, "Whatever you get, please send to me," because you don't know do you? I mean, there's this funding letter but I need to know what's what and I've got nothing in writing to tell me. I haven't even had it confirmed from the council that I've got it. He has, obviously. The only thing is it's worrying because you don't know if you're supposed to be doing stuff. As the weeks tick on, are there things I should be doing? Are there things I need to be getting on with? I don't know.

Robby: And I guess you want support in place for your husband?

Emma: Yeah.

Robby: Is that support in place currently?

Emma: Yes, it was because I have put it in place. So, I was already getting him taken out twice a week. This is just where I had to cover the cost with his Independent Payment.

Robby: You were covering the cost of that yourself?

Emma: I was. Now it's being covered by them. It just takes off the financial struggle. You know, sometimes he'd say, "Can I go?" And, I'd go, "Well actually you can't this month or this week because if you get your electric, your gas and your water, the money has gone on other things." There were times when I said, "No, I can't do it this month but we can do it next month." Whereas now it takes that worry away from me because I know now he can go away and do things.

That's just now. We haven't had any money come through yet. We're just doing the paperwork at the moment but I know going forward I haven't got to try and fund it all myself.

Robby: It should be backdated until the date it was awarded to you I think.

Emma: Yeah, Purple said it will be. I did explain to him because I didn't know it started in April, I wasn't getting the people that were taking him to get receipts or stuff like that, because as far as I was aware we still hadn't got the Direct Payments. So, they just said, "We'll have to do a cover letter for that because there's nothing else we can do." I've got the dates when he went out but I haven't got anything else. Now when he goes, I get them to get a receipt for the places they're going.

Robby: You should have really had this information.

Emma: But, I didn't get it. I haven't had anything from the council. That's what I mean, the instruction bit saying what you need to do, what you need to collect.

Robby: Yeah. It sounds like bad communication on the council's part.

Emma: Well no communication, no communication! Kate's been good. She's dropped me the odd phone call or what have you, when she's had an update but I suppose there's only so much she can do really.

Robby: Yes, and with it being called 'Direct Payments' you want the updates to come directly to you, which they're not.

Emma: So, hopefully I'll get the payments. Purple are dealing with all the financial side of it so I'll get these forms filled out tonight. The timesheets, that's what I needed to get printed off. I should get all the timesheets printed out tonight and then email them across to Purple and then hopefully the funding should start coming through.

Robby: Okay well that should be good. I suppose you've already answered this one but I'll ask it anyway. Do you feel that you've had enough help and support through the Direct Payment process?

Emma: I think there's just too big a gap. I think because it's gone on so long... I mean Kate rang me and said I'd got the Direct Payments. They had gone through and been accepted but she didn't say the amount I'd got. I tried to ring Cambridgeshire County Council, 'cos I left it a couple of weeks and I thought, "I still haven't heard anything." They said, "Oh no, it's all had to go through your mental health team." And I went, "Well she don't know anything. She's given me what she knows and she hasn't had anything." And, she still hasn't had anything as far as I'm aware.

It's an added worry because like I say, you don't know what you're supposed to be doing. You don't know what you're supposed to be collecting, there's nothing. But now Purple have sorted out the insurance and they've sorted out the two people that are gonna be taking Oscar So, Purple have kind of given the instructions to me. It is a worry 'cos you don't know what you're supposed to be doing. If you've got no instruction it's the blind leading the blind. It's the stress of dealing with it as well and not knowing what you've got to do.

I mean, I'm really pleased Oscar's got it, 'cos it will take the financial burden away from getting him to do his interests for as long as he is able to. But, the process was very drawn out and long.

Robby: I've not come across someone having to do three different assessments before.

Emma: Well, like I say I've had three different social workers that all had to come out and do a home visit before it could go to panel or something like that.

Robby: Do you feel comfortable getting in contact with Social Services now?

Emma: This is the only contact I have with them because I don't have anything else from them. They come in and visit Oscar when they need to. But, as in other support, I do it myself or family helps.

Robby: I was just thinking if there ever an issue or a problem?

Emma: I have the contact numbers for these people if there's anything ever wrong, which I carry. So, if there is anything ever wrong, then I know I can call Kate and leave her a message with their office. Then what they do is they send an email to her.

Robby: Which team is Kate from again sorry?

Emma: She's from the mental health team. She's been with me for just over a year. The first two years I was on my own.

Robby: You said she was doing the carers' assessment with you?

Emma: Yeah, that's why I went to see her. We've been in here a while but it took me some time before I got in touch with the mental health team. You just don't know who to get in touch with. I ended up going to Citizens' Advice and Citizens' Advice put me in touch with the Alzheimer's Society. They were the ones that really put the ball rolling. They pointed me in the right direction 'cos there weren't nobody that I knew to get in touch with.

The Alzheimer's Society did a six-week course with me about dementia as well. It was about what to expect and explained it a little bit better. So we did one day a week for six weeks. So, that was good as well because obviously I'd literally just packed up work then to care for Oscar full time. But, I did find it really hard finding the right people for information and guidance.

Robby: I guess it would have been better to have something like that sooner.

Emma: Yeah but there isn't anything in my doctor's practice. There doesn't seem to be a lot of leaflets or information about anything. When you go onto gov.com it tells you your local thingy, which is Cambridgeshire County Council, but then they'll say you need referring. You can't refer yourself or I can't refer Oscar I'll need to get him referred.

Robby: For Direct Payments?

Emma: No, for any support. I mean even getting in touch with Kate to get the Adults Mental Health Team people took about 18 months. But, it's sorted now. Again, it's like this big black hole. Who am I supposed to be having coming in checking him? Who am I supposed to be keeping in contact with? Surely there's some team or support network in place for the communication but it just seemed to take an awful long time to sort it. It's sorted now but it was a long while getting it.

You end up in this loop. "Who do you want? Do you want social workers?" "Well, I don't know 'cos I don't know if I want social workers or if I want an actual mental health group or whatever." You don't know. You don't have the information and you don't know where to be referred to. So, it's a bit frustrating for them as well I suppose. I would say, "I need to talk to someone about my husband." "Yeah, okay what's the matter with him?" "He's got dementia." "Right, but who is it you actually want? What department do you want to go through to?" "Well, I don't know! I don't know what department I need."

But, we got there eventually. Like I say, it was just trial and error and being persistent. I found it online to be honest, gov.com was the easiest one but

then again sometimes they just direct you to Cambridgeshire County Council. That again can still leave hurdles and walls that you can't actually get over.

Robby: One of the points of Direct Payments is that it's about reducing hurdles to make life a bit easier and to put you in the driver's seat.

Emma: I think it was just the long periods of time we're not hearing nothing. I know their workload, like Kate's workload's already high. So, I don't want to be ringing her saying, "Well, have we heard anything of it?" Because, if she'd heard anything surely, she'll get in touch and tell me.

But, like I say, Purple have given me everything now. I've printed it all off today. It's about 30 sheets or 40 sheets there. So, I've got the contracts of employments. I've read read through them myself because again there's nobody there to explain it to you.

Robby: Will Purple not sit down and explain it with you?

Emma: Yes, they've put on the email if there's any questions I've got just contact them, so that's what I'll do. However, like I say if you haven't got anybody... Well, I guess if you've been doing it a long while I suppose you're used to it but when you're first doing it, it's like that black hole. Should I be doing this, should I be doing that? It's quite difficult.

Robby: I suppose you want your social worker to come and sit down and do it with you? That should be your main point of contact.

Emma: Yeah. I don't want to be sending stuff in and getting it wrong but we're getting there anyway.

Robby: Okay. Well, you've already answered this next quest but can you think of any other problems that you've had with the Direct Payment process and how you resolved them, if you resolved them?

Emma: I think it was just that the time delays and the long periods with no communication. Like I say, it's still a long time and I still haven't had confirmation yet from the people who have issued the funding. It's just the time spans that is too big to be giving people direction or instruction.

Robby: What about getting carers in? How have you found that?

Emma: I don't have carers, I just have my friends and family. I don't have outside carers come in. Oscar's got dementia where it's a behavioral thing, so he gets really stressed, like really bad anxiety. So, people that he's familiar with he's happy with. People that he's not familiar with it just creates other issues. So, I've got family and friends that are really good. 90%, of the time

they usually take him out once a week. So, I get a couple of days where I get caught up, if I need to go shopping or I need to go to town or I need to do something, I'll have that to go.

Robby: How easy do you find it to do the things you want to do with the Direct Payments?

Emma: It'll be better for him. Well it will have no effect on him to a degree because I've been doing this anyway. Since I've packed up work, I've been doing this. Always encourage him out, not to be in, because this ends up being like a prison cell. You know what I mean? But, at least now it's in place so that when I need to go shopping I've got someone that'll take him and do something and I can get out and go and get what I need done without it feeling like I've got to get someone to sit in or someone to come round and visit. So, it takes the stress out of it for me because I can get out and get my bills paid, get my shopping done, just get the normal stuff that you do but without having to think, "I've got to rush back." I've got this period of time he's going to be with this person, I can just go on and blitz it.

Robby: I'm sure it's good for him as well.

Emma: He gets his time out of the house given to him, otherwise he'd be in here all the time, wouldn't go outside. I've got CCTV around the garden and the house where he goes so I can watch him. I've had another team of people in that put door alarms and stuff like that on so that I'm more relaxed. I haven't got to feel that I've gotta be watching 24/7, but I do watch him 24/7! I know if he's outside I can put the monitor on and I've got a camera in the shed, I've got cameras in the garden, I've a camera on that gate so I know if he goes through anywhere. I know he's within the boundaries without him wandering off.

However, I've put that in myself. My son fitted it all for me. It just felt like I shouldn't have to. It felt like I was invading his privacy if I'm all the while going, "Oh, you alright?" Popping out every ten minutes. It was frustrating for me but it must have been worse for him 'cos it's like, "Oh god, I can't even go to the loo if you like without her asking me, 'where've you gone and what you are doing?'"

So, it takes that away and I can just literally just flick it and have a look to see what he's doing. If he's been in the garden for a couple of hours or in the shed, then I can just flick and go, "Yeah he's alright." A lot of stuff I've put in place myself just so that he feels more relaxed going out and about doing stuff and I feel more comfortable knowing that I can keep an eye on him without standing up and being behind him.

Robby: Big benefits for both of you then. Any other benefits you can think of?

Emma: I've had assistive technology people come in. They came and put indoor alarms on the back door and front door so at night I can flick them on. We've got the tablet there that tells us appointments and stuff like that. I'm programming it to tell him days of the week and the roundabout time of the day, like afternoon, morning or evening. So, that kind of help 'cos it's not something he's repeatedly asking me. So, I've got a few bits like that have been really good. He wears two hearing aids, they come and put a vibrate plate under the pillow. He has a loop there so that we don't have to have the telly full blast, it feeds into his hearing aid. Little gadgets that have made life a little bit easier.

Robby: So quite a few useful bits and bobs then, that's good. Okay, so what advice would you have for other people using Direct Payments?

Emma: I would seek out any information that you can get prior to starting the process because I think you need to be aware that things aren't always straight forward and they don't always go to plan. I mean, people say it'll take a few months to get it all sorted out but in some cases it can become a bit of a stressful process.

I'm grateful that we've got it and that it's gone through. It's just, I think the process can be made easier, both the information and the keeping of the information. Communication is really key I think for people that are sat here worrying if you're doing what you should be doing or is there anything you're not doing. Am I making it longer because I've not done something? It really needs to be opened up, even if it's a letter saying we've received it, it's going through, it's gone to review or whatever. You know it's just keeping that flow of information going instead of having no communication. Sometimes you don't know where the process is or if it's even been forgotten about. On a few occasions I thought, "Well it's just not gonna happen anyway so..." You know what I mean? You're not talking a few weeks, you're talking twelve plus months.

Robby: Yeah that's a long old while.

Emma: Yeah and especially when they said, "Well it's gone from the beginning of April," and I only found out a few weeks ago that we've got it. That's quite a long while isn't it? But, like I say I'm grateful we've got it because it will help us, it'll help him and myself out.

The process needs to be made a lot simpler. The communication definitely needs to be coming through a bit more regularly. You've the social workers in, you've got your support workers but they obviously have a lot of people to deal with. You're not a one-off client, are you? You're in a pack of many and they can only spread themselves so far. But, the people that are dealing with

it at the council, they should be able to give you regular contact even if it's a once a month update. You know it's not like you're asking them for a letter once a week.

I haven't had anything from them yet still. When I explained it Purple they said, "Oh, I can get in touch with people and I'll find out for you and whatever information I have I'll pass on." If it weren't for Purple I wouldn't have heard nothing.

Robby: Purple are really good but you want to be receiving your information directly from your social worker really.

Emma: Well, it's more of a worry if you don't know what you're doing or what you're supposed to be doing or what you're supposed to be gathering. Purple told me to get a receipt book. They told me I need a receipt book, I need receipts collecting. I need payment forms filling in.

They've dummy filled one in so I've got an idea of how to do it, because when you've done it a while you're alright with it but when you've never done it... Chuck me a timesheet and say, "Fill it in." You know what I mean? What am I putting? It's easy enough to say that they've done so many hours. Well where do I put the hours? So, Purple did a dummy one for me and sent it across so that I've got something to give me an idea of what to do. But, like I say, if it weren't for them I think I'd still be sitting here twiddling my thumbs because I wouldn't have been notified.

Robby: Do you think you can give them a ring?

Emma: I tried to ring but you need to know who you're actually talking to.

Robby: And you don't know who your social worker is.

Emma: I can find out from Kate I suppose but then again, it's contacting them to email her. You have to go through probably three different lots of people to get her, then a phone call back in probably in two or three days.

You should have a point of contact where if you've got a query or a question. You should be able to pick up the phone and have it answered. Most places have a customer service that you know is reliable but again when you ring the council you're not sure who you need to talk to. If you can't give the person on the end of the line who or what section or what department then you waste time making the call in the first place because you've got no information to give them. But, if you had a letter or a confirmation saying, "You've got this," then it'd have someone's name, it would have their email address, it would have information for you to contact them if you had a query. I haven't received that yet.

Robby: That's not what you want and you can't rely on Purple for everything.

Emma: No, I can't. They've been really good to be honest. I wouldn't have known any of the information or what to do, it's only 'cos they've forwarded it to me that we've got things moving. It's moving slowly but we'll get there by the end of today hopefully. The paperwork side should all be finished.

Of course, that was the other thing because they used to be a different company. Penderels Trust and that's who I originally signed all my paperwork with. Then nothing. When they said about going to panel they said, "Oh well, it's not Penderels Trust any more Emma, it's Purple." And I went, "Well, who do I get in touch with? So, when I rung a contact number they put me through to a department that wasn't anything to do with Purple. I had to leave three or four messages for Purple to get hold of me. They rung me and they said they needed to come out and change all the paperwork because Oscar's all under Penderels and he's not under Purple. They'd actually changed company in the twelve plus months but again no information telling me that the company had changed. So, it's just the communication really.

Robby: It sounds like a constant battle with the communication. Is there anything else that you'd like to tell me?

Emma: I just think that sometimes the council have to put themselves in the situation of the person who's sitting here waiting for the postman every day thinking, "You're gonna get something, you're gonna get something," but nothing appears.

When I packed up It was like, "Now what do I do?" Because I've worked all my life and I've always been the main breadwinner. Then it got to where I couldn't work. Again, it was Citizens' Advice telling me to make an appointment with the Job Centre.

There's no information from Doctors. You'd think doctors and libraries would carry some sort of leaflet, booklets or something. I didn't know about Carers' Trust till I'd been here a year and that was just on the off chance of the doctor saying, "Have you had a carers' assessment?" "No, what's one of them?" It's like everything's always on a back foot. Information's not readily available. People say, "Well you can go on gov.com they tell you all about it." But, someone needs to be telling you to go to gov.com to find the information out. So, Citizens' advice really is the key! If you want to know anything they will try and put you in the right direction.