



## Ethan's Story

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**Interviewer: Robby**

**Robby:** So, when did you find out about Direct Payments and how did you find out about them?

**Ethan:** My social worker suggested it about three months ago and I said, "Oh, yes that sounds good, I'd like to go ahead with that." She just didn't get around to it or whatever. I kept prompting her and it still didn't happen. I can't believe that it was only very, very last minute. We were desperate and I said to her, "You still haven't done it yet!" Later that day the man from Purple rang me, so obviously she only did it there and then. Yeah, I was disappointed because I needed to get it going.

**Robby:** So, only three months ago that you found out about Direct Payments. What were you doing before then?

**Ethan:** Social Services were just getting my carers.

**Robby:** So, they were doing it through the County Council then? What do you think it was that prompted your social worker to bring up Direct Payments with you?

**Ethan:** Well they were struggling to get me care so they wanted to pass off the responsibility off on me. But, you know the saying you get what you pay for? The main thing was I was getting a lot of bad care. It was only when I got recommended a certain company and I told them how much they charge that they brought it up. One of the social workers, I think she's a manager with Social Services, she said, "Oh, no we can't do that!" She actually said the money was too high and that you get what you pay for. That explains why I was getting the bad care because they were employing cheap companies and it was accordingly bad. So, to get the care I needed it cost more money, more than they were prepared to pay. That's why they wanted to go down the Direct Payment route.

**Robby:** Yeah, the County Council are trying to push more and more people into Direct Payments, as they have limited resources and they prefer people to sort things out for themselves.

**Ethan:** I can understand why.

**Robby:** And you say it's taken three months? That seems surprisingly quick for it.

**Ethan:** Really? I thought it was a long time. Once it got going it was very quick

**Robby:** How did you find the whole process of actually getting the Direct Payment?

**Ethan:** Well, to be honest pretty smooth. It hadn't been finalized. I was still under the continuing Healthcare department and they couldn't find anybody to look after me, so they found me a care home. I was there for 9 days until I found a care company. I thought I was finding this care company to carry on under their payment and then I had this Direct Payment thrust upon me. I wanted to be out and they got me to sign something in the care home, not explaining what it was. The manager came afterwards, later in the day and told me I was signing to initiate Direct Payments. If I hadn't signed it I wouldn't have been able to go. So, I signed it without reading it because it was that or nothing really.

The amount of Direct Payment is not enough to cover the cost of the situation. It's not financially viable the way it is at the moment. So, I don't know, I need to speak to somebody. The money going in is wrong and doesn't meet the money going out.

**Robby:** Are you having to pay out of your personal finances?

**Ethan:** I haven't as my personal balance is down all the bloody time anyway. I wouldn't be able to afford it for long. So, I don't know what to do?

**Robby:** Have you spoken about this to your social worker?

**Ethan:** I haven't, no.

**Robby:** How often do you see social worker?

**Ethan:** Not for quite a long time but I speak to her on the phone fairly regularly, although not for the last couple of weeks at least. I was meaning to do it all last week but didn't get around to it.

**Robby:** How easy do you find it to approach Social Services or Purple with issues like this?

**Ethan:** I think I should probably speak to Purple first.

**Robby:** Quite possibly, they are a good source of advice and support. Yeah, it sounds like it's all set up but it's not quite functioning as it should. And, obviously from your perspective three months is quite a long time.

**Ethan:** I've had to jump in at the last minute really, into a new set up. The person who's here now is a carer from a company, that's why it costs more than I'm getting.

**Robby:** Are you going to try looking for your own PAs?

**Ethan:** Yeah. I'd rather go down that route rather than the companies because the companies got to make their money.

**Robby:** Yeah, the agencies charge quite a lot. They've got to make a profit and pay competitive wages. However, that doesn't help you out when you're here just try to try to get by.

**Ethan:** It's possible that Pat, she's quite good, could leave the company. Then I would be compensating them for her leaving the company, like poaching her. I know it can be done officially but then the company would want compensation.

**Robby:** I'm not sure about that, that a bit outside of my experience. I'm sure Purple can give you advice on whether that's a good option. One of the options of Direct Payments is to talk to people that you like and actually have them come in and do the work.

**Ethan:** I don't know If she wants to do that, she may want to carry on with the company.

**Robby:** Is there anybody else that you can think of that you might want to approach?

**Ethan:** The man from Purple sent me some templates for doing adverts for attracting carers. I've got to go through and look at them. Go down that route. I think he said that he would come round and help with doing that. Are they a local company or national?

**Robby:** Purple are predominantly based in Essex I think. They've just come into Cambridgeshire as the preferred provider for Direct Payment Support. Before it was Penderel's Trust doing the support for Direct Payments, Purple have just taken over the contract from the County Council.

**Ethan:** Yeah, I remember Penderel's because we were going to go with them a year ago. It was all sorted and it was going to happen when we finally got a good carer from one of the care companies, so we just carried on with him. That was okay, so we just stuck with that and then he left. We all know that obviously nothing is forever is it?

**Robby:** People do struggle to find people to do the work. I think there is quite a high percentage of people that struggle actually finding people to do the work especially out in more rural areas, although everybody is struggling. Did you feel like you had enough support through the Direct Payment process?

**Ethan:** Possibly not. The trouble is my memory is very weak and given that it was quite a while ago no when I spoke to Purple, I'm not sure. I wouldn't remember how in depth we went into it or not. They may well have given me plenty of help on that score. I can't think back to that point but if I wasn't happy I think they would have been involved. So, I think everything must have been okay.

**Robby:** Do you feel that you know where to go for some help and support now?

**Ethan:** No, apart from I'd speak to Purple first I guess and then the social worker.  
So, I see how what they were paying for was considerably lower. The social worker said they would give more if necessary.

**Robby:** Sounds very frustrating. No, easy answers. What are some of the problems that you've found with Direct Payments?

**Ethan:** Probably just switching from them taking care of everything to me now being responsible for everything. My wife is dead against it, very much so. She's worried that it will not work because she knows how hard it's been getting care, or getting good care, for so long. She thinks that they're just passing the buck, so that before it was someone else's problem and now it's going to be ours. She's very worried about that.

**Robby:** Yes, it's a big responsibility, just even finding people to begin with.

**Ethan:** Although I've proved my point in a way. This company I've found is only the second good carer, well the third good carer I've had in 6 years. So, I'd like to hope that that's a pattern and that I will find better carers. I don't know.

**Robby:** Part of the thing with Direct Payments is that you can get people in and talk to them to see if you get along with them and see if they know their stuff.

**Ethan:** Which is a big part of it

**Robby:** I suppose although there's no paperwork to do there's still pay slips and holiday pay, sick pay, which Purple do cover.

**Ethan:** This is what is a great relief to me because I don't think I would be able to do it if I had to do it. I'm not a paperwork person. Even on just every day

home stuff, I just can't cope with it. To start employing people I wouldn't even have been able to consider it without Purple, it wouldn't happen.

**Robby:** Okay. So, what if any are the benefits of using Direct Payments?

**Ethan:** Too early to say that really. Just hopefully the potential of finding my own carers pays off. So far though, I've been worryingly disappointed. I've looked on the internet the whole day and there are so many websites where you think you'll find carers on there but all it is care companies asking for carers. They're on the wrong website really. They should be on ones where companies are recruiting and another one where they are offering their services. So, it's not looking good so far.

**Robby:** Purple is talking about a matching making website to pair PAs with clients.

**Ethan:** That sounds good.

**Robby:** I'm not sure how far they've got with it but it might be worth asking them about the next time you speak to them. What would be the benefits that you would hope to achieve by using Direct Payments? What were you hoping?

**Ethan:** The choice of seeing who's coming rather than just a stranger turning up. As you said before, speaking to them and interview them. Having more control would suit me. As I say my wife does not like that idea but I do.

**Robby:** You're optimistic about it?

**Ethan:** Yes. It obviously it's more involved but it should be advantageous.

**Robby:** What advice would you have for other people looking to use Direct Payments?

**Ethan:** Don't do it, ha-ha! Err, just get everything clear in your mind and get cracking with it. But, not before I've got my carers picked!