



## Stephanie's Story

“I think for us we're quite a success story in a way that we've got exactly what we wanted from it.”



## Stephanie's Story

**Interviewer: Addison**

**Addison:** How you did you first hear about Direct Payments and what was it about Direct Payments that drew you to them?

**Stephanie:** Originally, we used to have our respite provided by the Continuing Care nursing team. Then once Jack started attending school we wanted our hours to be more flexible so we could have more care in the school holidays and less in term time and they just couldn't accommodate that sort of variation.

Continuous Care are a team of nurses that can do all your case management but they have a team of health care assistants that can-do respite in the home. So, they used to come in once a week and do a session.

**Addison:** How did you get involved with them initially?

**Stephanie:** We were referred to them. So, for any child if they have complex enough health needs then they'll do an assessment and if you have the right criteria then you can fall under their care. So, for Jack it was all his complex case management. All his protocols that need doing, all the training for school. That referral was done by Jack's consultant when he was a baby. So, he's been under the nursing team nearly all his life.

It was probably around when he'd just turned 3 we started to look at other options because we didn't get a lot of care back then. We got about one afternoon a week and there'd been a few problems, like not always gelling with the carers. However, mostly it was not enough flexibility with what they could give us. That prompted conversations with them and from what I remember it was it was the nursing manager there that suggested Direct Payments. I can't remember for sure but I can't think who else would have told me about them.

We had a social worker for a long time so she would probably have come out and talked me through it. I remember very early on meeting someone from Penderel's Trust. They came out and told us more about it as well.

**Addison:** So, a lot of people signposted you to the right information then?

**Stephanie:** Yeah. Also, I knew quite a few other parents that were using Direct Payments. Most of the other families I knew that used them just have a social care budget but the difference with us is we have a joint Social Care and Healthcare budget. I don't really know many other families that are in that sort

of position because most would just use their continuing care as their respite if they qualified for it.

**Addison:** So, you were struggling with not enough respite?

**Stephanie:** Yeah, we weren't getting enough and we weren't getting it when we wanted it. We planned a lot in advance and sometimes we'd get cancellations if they didn't have the right stuff to cover. No choice in carers. There was some that we really liked and some that we didn't but it was quite tricky not having a say. It was just a little bit too structured for us I think.

**Addison:** So, someone told you about Direct Payments and that was the way to go?

**Stephanie:** It was worth a try and it was something different. At a time, we didn't have a very big care package so it didn't seem too crazy an idea. Since we've had it Jack's care needs have changed drastically and our care package has probably quadrupled. So yes, it's become quite a different thing now.

**Addison:** It's good that it's changed as your needs have changed, that's what it's all about really. How did you find the Direct Payments process, all the paperwork and talking to the social worker?

**Stephanie:** Not too bad. I think in the early days getting going was fine and then it all ticked over quite easily. I find paperwork and organisation alright anyway. I'm used to doing it for Jack, so that wasn't really an issue. The only times I've run into trouble has been more recently with all the stuff to do with pensions. That has thrown me a little bit.

Then there was everything with the changeover from Penderel's to Purple. I decided a while back to switch from Penderel's to Purple just so everything was in one place. It wasn't that I wasn't happy with Penderel's it's just everything was getting a bit too confusing. However, that process was more complicated than I thought. I had some paperwork from Penderel's, forms to say, "If you want to switch please fill these forms in," which I did. I didn't hear anything for a long time and eventually chased it up. The problem was that the social worker had to do a referral and that hadn't happened. So, I think there wasn't quite enough information on how to go about the changeover process. But, once I knew that the social worker had to kick it all off, it flowed really smoothly from the get go.

We've had a few other changes in the care package that I'd emailed the social worker about. So, she sent Purple out here a couple of weeks ago. We saw them and they were really helpful and went through everything. They took all the pension stuff off me and is sorting that out. I had a few questions because we've got some night care going on and they were able to talk me through all

of that. They've gone through all the forms again with me and made all that very easy. So, those bits have gone really well now.

**Addison:** That sounds like a nice positive experience, it's good when it all flows quickly and easily. How's your relationship with the social worker?

**Stephanie:** God, we've had a lot of different social workers, they just seem to change a lot. I think we're on our fifth. The one we've got the moment we get on really well with. She's been with us through quite a lot changes now and I find her very helpful. It's just knowing who knows which bits of information. Now I know the people from Purple more. I know what they do and they're going to be my first point of contact because I've got some more queries around the employment bit of it. Before I'd always go to the social worker and they didn't know some of that stuff. So, I think it's just working out who's supposed to know which bit of it. However, generally I've found the social workers really helpful with it all.

I think the biggest difficulty for us has been because Jack's health needs have changed quite quickly over the last few years. We've had to keep going back to panel to be reassessed for changes in our care package. That's been a painful process because we kept running into things, like mix ups with paperwork. So, it was meant to be going to panel but then we'd find out there was a delay in the paperwork so it didn't get to them in time and it wasn't heard at that panel. That means lots of disappointments.

The latest time we went to panel, because Healthcare and Social Care fund our budget jointly, they came away from panel with slightly different conclusions. So, Social Care were funding us for something that was going to last for about 18 months and Healthcare were only funding it for 12 months. We'd been given all the money until he was going to be 10. However, Healthcare said, "No we want this trial to end after twelve months and then we're going to review it." So, there's been confusion over that but that's all to do with the panel and whoever sits on panel. That's been the most frustrating for us.

**Addison:** Were you able to talk to your social worker about this?

**Stephanie:** Yeah. I still find the Social Care and Healthcare don't really talk to each other enough. I'm going to the social worker saying, "This is a problem, you've got different things going on causing a lot of confusion." However, they just don't seem to want to connect in the middle. It seems quite obvious they need to get together and say, "All right let's just decide on one outcome." But, getting them to do that is just impossible. So, I'm just rolling with it and going more with Healthcare because they put the shortest time-frame on it. So, we're just working to that and it's frustrating.

**Addison:** Have you got a separate contact in Healthcare?

**Stephanie:** Yes. So, all the Healthcare side is managed by the Continuing Care team. They've got a nurse that will sometimes sit on the panels as well. So, the Healthcare team is their side and the social worker is the Social Care side.

**Addison:** It sounds like a lot of people to talk to.

**Stephanie:** Yeah, it does. I think in terms of extra work Direct Payments is definitely more because you're an employer. Obviously, you're managing people and working with the payroll company and then you have all the stuff going on with the actual budget. There's stuff around the care package you'd be having anyway whatever you were doing. If my care was being provided by someone else that would all still be there. However, I think the benefits for us definitely outweigh the downsides. Once you get used to paperwork it's not that hard. You just get into a routine with it and it's not been a problem at all.

**Addison:** Do feel like you have enough help and support the paperwork or if you were confused by something, could go and say, "I'm confused with this?"

**Stephanie:** Yes, I think so. Especially now I have been a bit more in touch with Purple. They just seem to know everything and they've been so useful. But, even before I've always found Penderel's sorted stuff out quite easily. Like anything, there's always a few little bits and bobs that take bit of chasing up but we've never had too much of an issue just yet.

**Addison:** That's good. So, what are some of the problems you've had with Direct Payments and how did you resolve them if you've resolved them?

**Stephanie:** I think the biggest thing has just been getting my head around just some of the ins and outs of being an employer I guess. Like the pensions stuff, that's been quite confusing because if an employee earns a certain amount then we have to pay into the pension but I have employees that earn different amounts every month. So, that was all a bit confusing. When it first came out you had to appoint someone who could deal with it, so I appointed someone from Penderel's as Penderel's told me to but then nothing seemed to happen with them. It all seemed to still come to me and it's not until now that I've switched over to Purple that they've stepped in and someone's gone, "That's okay we can sort this out." That's really helpful because I've been so stressed about it. I think we've swapped just at the right time. Yes, it's been very helpful.

We've had this addition on to our care package recently that's quite unusual. That's because it involves some night care, which involves different rates of pay and that all threw me quite a bit. However, again Purple have been

around to explained all that and answered all my problems with that. So, Purple has come to my rescue really because I was very confused.

**Addison:** Fantastic. Okay, how easy do you find it to do the things you want to do using Direct Payments?

**Stephanie:** Given our situation and how we tend to use the Direct Payment, I don't really think of it as respite. It's just that we need another pair of hands because Jack needs constant medical care. We use most of our payments in the evening after school. When he gets in from school he has a solid three-hour routine before he can go to bed because of all the medical stuff we've got to do. So, me and my husband are out doing that but then we've got another child. Someone's got to make tea and it's just crazy. So, it kind of allows us to live a normal life.

We do use it in the holidays to have people in, say if I wanted to take my daughter somewhere. We do occasionally use it for going out for a treat but that's a lot rarer. A lot of that's just because Jack's needs are so complex, us going further or far afield isn't that straightforward. But yeah, without Direct Payments we'd be I do not know where. We would not cope.

**Addison:** How have you found hiring carers?

**Stephanie:** That's one of the bits where we've been really lucky. When we first got Direct Payments, I approached a TA who I'd met through school and who I could see was really good with Jack I wrote a letter to her because at that point I'd got really no idea how to go about hiring someone so I thought I'll just try. I wrote to her and said, "I can see that you're really good with Jack. We're looking for people to work with him at home, are you interested?" And, she was. So, she's worked with us since the start.

I took on another lady around the same time who was the school nurse. She knew that I was moving to Direct Payments and offered herself, she said that she'd like to do some work. So, she worked with us for a period but because of health and other stuff she doesn't now.

As the care package has increased over the years I've taken on more people. So, I took on another girl maybe a year after, who's here today. She's another TA from school and again I'd met her through school. She was in Jack's class. With people I just get a feel for who I think is good with him. You need to be quite confident to work with him because of his medical need. He's also got a multisensory impact and he's very profoundly disabled. So, people have to have that right ability to be able to communicate with him. I can just sort of see it in people. So, I took this TA on next and then another year or so later I took on another girl from school. Each one of them I have just approached them. It's always the people that have already been working with him.

The final girl that I took on, the most recently, she was working with him in school as a TA but was quite new to caring for children like him. She lacked some confidence; all the skills were there but she just needed her confidence building. So, I took her on at home, partly to just build her confidence at school as well. Now she's just part of the normal team and it's done her the world of good. It's also been good for us to get together.

So now we have four girls. They all work at school with him and so two of them are his regular TAs that work with him day-to-day. One of them is a back-up and works with him one half a day a week. Then the other one is again a backup but she does all his transport into school. He couldn't go on normal transport because of his health needs. School now provides transport for him. They have a rota of drivers that drive the school minibus to pick them up and then one of the girls acts as his escort to school. That's all paid for by the council, not the Direct Payments but because they work with him at home as well, we've got all this crossover.

As his health needs have changed over the years they've been along for the journey and I've just picked it up as we've gone along. At the start of the journey he was not too complex medically and now he's really quiet extreme. However, because they done it a bit at a time alongside us it's not been too crazy for them to pick up. It's just worked so well that we've got that crossover with home and school. I'm not sure without it if he'd still be able to go to school because of his health needs. So actually, there's a much bigger picture to our package than just us having a break it's actually enabling him to go to school and to be safe and to do things at ours.

**Addison:** That's good to hear. Okay, so what would be some of the benefits that you've found with using Direct Payments?

**Stephanie:** I think firstly having that crossover with school, having that continuity. We've been able to have that because of choosing who we take on. That we've been able to choose who we employ, that we've been able to get to know the people first. So, rather than having to have an agency or anything where it's just somebody who's never met Jack coming in and worked with him, we've headhunted and picked people that we've seen.

We have a lot more flexibility. So, we have quite a set structure through the week but school holidays are a lot more flexible. We've got a team of four and we all work round each other quite a bit. If somebody's away someone else fills in a bit more. If one of the girls can't do their shift one week another one tries to swap in. The cover is better because it's more of a team and there's a lot more room to change things.

I think probably one of the biggest things for me, because we have so much care, is it's a lot to always have somebody in your house, especially when we do still have respite. It's such a different feel when you've got people coming in that you don't know you very well or you might not be too sure about. However, the way we've got it, having the girls in every week, we know them really well they've become really good friends. Now they don't feel like carers coming in, they just feel like friends coming in to help us or family. We often give them tea because they're here over teatime and I think that's a good thing to do if they're here at teatime. So, we've got this really informal structure to it. We've obviously got the formal side with the payments and the time sheet and the contracts and the insurance but actually the day to day running of how it works is very informal. It's just nice. It's as far away from feeling like we have carers in that it could be, while still having care.

Also, because we've got that informality and because we're friends it does mean if there's something Jack's doing that's a bit different we can talk to each other easily about it. We've got a Whatsapp chat group so we're messaging each other. It keeps everyone up to date with everything all the time, with little things that change with his health needs. If he's at school and they're trying to communicate with me about something, because we've got communication going all the time, it's pretty easy to sort things out. So, it's that whole picture that it's built and I think of us like a team. Between all of us we keep Jack going. I don't think it could work much better.

**Addison:** It sounds like Direct Payments are doing everything they're meant to be doing for you.

**Stephanie:** I think for us we're quite a success story in a way that we've got exactly what we wanted from it. I think a lot of people will say to us, "It's because of how you are, that's why you've made it such a success." But, the way I see it is, I've always been quite of a strong opinion that we treat the carers like they're friends and if it was us how would we want to be treated? So, although they're employees, I don't think of them as employees. I don't ask them to do stuff that I would want to be asked to do in terms of the working hours and stuff. Very rarely will we ask for weekends and I'm very aware that's it for good reason that I don't want to take advantage. The job for them is a second job, they don't need this job. They don't do it because they want the money they do it because they want to help us.

People are going to want to help you as long as you're a nice person and nice to be around. So, I think it's just being mindful of that. I think that's what's really worked because I think in general they like being here. I guess because it's so relaxed and they don't feel like they're working. I think that's some of the differences I see with other families. Sometimes it's like people have unrealistic expectations of what their carer might agree to do in terms of hours. I mean, we expect a lot from them in that there's a lot for them to do.

However, I think we have a very open conversation and I always say to them, "If there's anything you're not happy with or anything you're not sure about, then talk to me." We've always got that open dialogue.

**Addison:** That's good. What advice would you have for other people using Direct Payments?

**Stephanie:** I think I'd say, don't be overwhelmed to start with because the paperwork does seem a little bit confusing initially but it gets a lot easier. So, don't be worried about that stuff. Speak to Purple because they'll help you. And, I think just be mindful of your attitude towards your carers. Value them as if you would want to be treated.