



## Kristin's Story

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**Interviewer: Robby**

**Robby:** As this is all about Direct Payments lets go back to the beginning and ask how did you first hear about Direct Payments and what drew you to them?

**Kristin:** Well the back story. So, my dad, who has passed away now, he had Lewy body dementia and we got to the point where we needed somebody to help my Mum who was his main carer at home. I was trying to support them from a distance but I had a new baby and all of that. I couldn't actually physically help my Mum out, so we made a referral to adult Social Care. We did that ourselves but also with the support of his neurology nurse because my dad was quite young. He was 57 when he was diagnosed. We always had very good support because, as he was young, he was under the threshold of an older person.

So, we had really good medical support and we had specialist nurses. It was a specialist nurse I spoke to. I was a bit worried about Mum's stress levels and the care that she was giving Dad. I was concerned that the compassion fatigue was kicking in a little bit. So, I chatted with the neurology nurse and said, "I'm thinking about self-referring to adult Social Care," and she agreed it was a good idea. I chatted to Mum and it got to the point where she agreed she needed some help and support. So, Mum referred herself with my support to Social Care and we ended up getting a care manager. It was through the care manager in Social Care that we found out about Direct Payments.

We were told what sort of support Mum needed help with. Dad was waking up at night. Medically they got as far as they could, medicating to try and help with those symptoms but his body clock was starting to switch and Mum was absolutely knackered. It was completely mucking her up, she just couldn't cope with being awake all night. So, we said the priority was for Mum to get some sleep and that she needed some respite care. The care manager brought up about Direct Payments.

She tried to go away and find a package for my Dad with their preferred providers but there was nobody that could fulfill that. I said, "Well is there anything to stop us trying to find a local agency ourselves?" And, she said, "No, not at all. In fact, you could get a Direct Payment for it. If you had a statutory package I wouldn't be able to give you sleep overs but if you took your budget as a payment you could use it how you want."

So, I did some ringing around and I found an appropriate carer agency. We didn't need them coming in on a daily basis with my dad, for example, to help with washing and dressing in the morning because that didn't really help Mum

a great deal and they always needed two carers anyway. We used the money to pay for sleepovers from carers, so my mum could go into our spare room and then the carer could sleep downstairs in the bed next to Dad. So, if my dad woke, the carer was there to do wakeful duty with him. That's how we used the Direct Payment.

It all came through the care manager, before then I'd not heard anything about it. But, in fairness we hadn't had any contact with Adult Social Care at all you know. So, we didn't know anything about what was available to us really.

**Robby:** So, you got a care manager. Was that someone attached to Social Services?

**Kristin:** They were changing the roles of social workers and bringing in care managers instead of social workers because it was cheaper.

**Robby:** How did you find the Direct Payment process?

**Kristin:** I found the process very straightforward. Really straightforward. However, the Direct Payment was in my mum's name, so it was her Direct Payment for her as a carer. If she hadn't had me to manage her Direct Payment for her she wouldn't have been able to do it because she was so stressed, so overworked and so knackered. She didn't want another thing to do. She just did not need that at that time, she just needed somebody to scoop her up and give her the help and support that she needed. She didn't care where it came from, whether it came from Health or Social Care, she just wanted somebody to come to the house so she could get some sleep. End of, you know?

If she didn't have me it wouldn't have happened, which would have meant that Mum wouldn't have got the carers support that she needed. The only reason it happened is because she had me to arrange a bank account for her, check all the statements and get all that information back, to make sure the invoices were right, tally with payments that were going to the bank. All that checking was all down to me. The council knew that they had to give double correspondence, if they sent it to Mum they had to send it to me as well.

**Robby:** Could the care manager not have taken on more of that?

**Kristin:** No, because the whole point of the Direct Payment is that we were doing it ourselves. So, that worked well for years. Then as my dad became more and more terminal, into the last year of his life, that was the hardest time that we've ever gone through. I was getting to the point where I couldn't be bothered with having to deal with a Direct Payment. My dad was terminal. When somebody hits terminal status with dementia and especially with my Dad's type of dementia because it was a sort of mixture of Alzheimer's and

Parkinson's Disease, you've got a double set of challenges. He had a lot of physical health problems that were kicking in. His medications weren't working like they did. He's getting the tail end of his therapeutic medications for his Parkinson's. So, he was falling every day. His bladder was packing up so he's going into bladder spasm and having loads of hospital admissions.

Each time he went into a nursing home for respite care he nearly died, every time. So, we stopped doing that because he was so neglected. He couldn't talk, he couldn't speak, he couldn't communicate, he couldn't make his needs be known. We had some horrendous hospital admissions. It was a very, very stressful time and the last thing that we needed.

My son was just starting school. I was going back to work. The last thing we needed was more Direct Payments paperwork at that point in time. So, for a few years it was brilliant. However, when things were continually hitting crisis the last thing I wanted to do was fucking paperwork quite frankly. I didn't want to do the organising. If the carers didn't turn up I didn't want to be the person who had to keep ringing round, I wanted the care manager to do that.

**Robby:** Did you speak to the care manager about it?

**Kristin:** Oh yes. She was brilliant. She was really good. So, we moved over to a local organisation that was commissioned to provide support for Direct Payments and they picked up the baton from there. That made that small part of our life easier. So, we carried on with the Direct Payments right up until the end, even though my dad went on to continuing Healthcare for a bit. We got a bit more help coming into the house and stuff. But yeah, we still carried on with the Direct Payment.

**Robby:** Do you feel you had enough help through the process? Someone like the care manager?

**Kristin:** Yeah, she was absolutely brilliant, she was a real gem. She worked with our family for years. So, she knew us really well and she's just one of those little gems. Yeah, she was really good and was always on it. She listened to us, she responded and came up with solutions when we needed her to. I cannot fault her at all.

**Robby:** Was she the one who suggested you move on to this agency that does all the paperwork?

**Kristin:** Yeah, and she wasn't aware that there was a Direct Payments support service. So, I said, "Well, can we get any help or support, could somebody else to manage this for us?" She had to go away and find out that information and then came back. She said, "I think these people do it." So, then I rang them but this is a while ago. I mean, my dad's been dead for a number of

years now, so we're talking 10 plus years ago when they first came in. So, our care manger was probably learning as much as any service user. I couldn't fault her though, she was a real solution-focused sort of person.

**Robby:** She was the primary person that you went to?

**Kristin:** Yeah. Well, we had two. Mum always says that she would never have been able to get through it without Julie, the care manager and without Dennis, the neurology nurse. They were both really kind, if they were passing by my mum's they'd give her a knock and pop in for a cup of tea and check-in, even though my mum and dad weren't due any reviews of any sort. I think that was the nature of it. My dad was a young man when he was diagnosed. Mum was sweet and they could see how hard she was working.

My brother Matt is on the autistic spectrum and he has quite a lot of secondary mental health problems because he wasn't diagnosed until late into adulthood. When my dad was terminal, Matt could not cope with what was going on. He lives in the house with Mum and Dad and he was developing very bizarre challenging behaviors. Mum had all that to deal with on top of all the grief that she was going through, the hard work she was having to do, the lack of sleep, no freedom, you know?

There was a lot going on in the house and I think that's probably why the neurology nurse and the care manager gave my mum a little bit of extra attention and TLC. In fairness I had raised with them that I had some concerns because I could see that compassion fatigue was kicking in with Mum, that it was really stressful and I was concerned. I'd raise those concerns with Julie, the care manager and I felt comfortable with doing that. We kept it completely private between us.

**Robby:** So, she was quite good at responding to you?

**Kristin:** Yes, brilliant. She was good, we were really lucky I think.

**Robby:** That's good. So, what were some of the problems that you found and did you find a way to resolve these problems?

**Kristin:** We didn't really have any problems. The problems came from my mum really because she can be quite ditzy and disorganised. She didn't understand the system and didn't want to. Like I say, she just wanted somebody to scoop her up and make her life a little bit better. Nothing ever went wrong from the County Council's end of things. The admin was flawless, I was doing things correctly. It had just been my mum that would mess things up. She'd get an invoice then she'd pay it out of her personal account. "No Mum! I've explained..." No matter how many times I'd say, "This is my responsibility."

She never quite got all of that. From a caring for the carer point of view it was hard from a distance to keep my mum in check if that makes sense?

**Robby:** I guess this is when the sort of agency that deals with the process would have been a bit more handy?

**Kristin:** Well, no. When it went over to them she would still muck things up for them. Of course, because they were still sending a copy of an invoice to my mum and the copy to the support service, Mum would do something and the support service would ring me and say, "We've gone to pay this but they said it's already been paid, what's going on?" My mum would try to ring up but she was a carer under immense stress. There was nothing wrong with the system, the system was really good. We didn't have any problems with that.

**Robby:** What would be some of the benefits about Direct Payments from your perspective?

**Kristin:** Like I said, if we'd gone with the statutory package they would never have been able to provide sleepovers for my mum. That was the bottom line. And so, taking on the personal budget through self-directed support meant we could use it how we wanted to because it was meeting that care need. The statutory preferred providers wouldn't do and couldn't do that. Whatever their reasons I don't remember now but it couldn't be done that way. The only way we could achieve that was through Direct Payments. If we hadn't had that payment I think my dad would have gone into a nursing home maybe five years before his death. Whereas, with the Direct Payments and when he went into continuing Healthcare as well, he stayed at home until he died, albeit for a few days. So that was the impact.

Mum got some sleep. How can you care for somebody if you can't sleep, it just does not make sense, it's ridiculous, you know? If someone's got severe sleep deprivation they're going to crumble very quickly. That's what was happening. So, having that Direct Payment and being able to get that solution for our family worked really well.

**Robby:** Okay. So, what would be some advice you would have for other people using Direct Payments?

**Kristin:** I don't know really because it's so individual. For us it was being able to get Mum some sleep. It depends what you need it for. Going back to whoever's arranged it for you if you're struggling or any problems. Social workers and people who work in support services. Anybody that's monitoring your accounts and stuff. They're there for a reason, they're not in those jobs for the money, they're not in those jobs to drive profits for companies. They are in those roles because they work in the public sector. They're in those roles for a reason because they actually care about your situation. So, I

suppose the best bit of advice I could ever give anybody is just use them. That's what they're there for. They want to help.

**Robby:** It's very good that you had the same person for the entire time.

**Kristin:** Yes, we were really lucky.

**Robby:** A lot of people say that every year its somebody different. There's a massive turnover of staff in Social Survives right now.

**Kristin:** But, this is 10 plus years ago when the public sector wasn't underfunded. It was funded properly so people were happier in their jobs and so they were going to stay.

**Robby:** Sure. Is there anything else you'd like to share with me?

**Kristin:** Just it had a huge impact on our life in a positive way. I'm a real advocate of it. However, if you looked at the data for my mum you would think that she had been managing the account herself but in fact I was doing so.

**Robby:** I wonder how many other people have done the same?

**Kristin:** Exactly. I always say I was the carer for the carer.

**Robby:** Which is obviously an important role in and of itself.

**Kristin:** A lot of people under those circumstances, can't manage without that support, it's really difficult, you know. So, it was really good for us, really good.