



Addenbrooke's Nurses – Wendy, Brenda, Sandra & Jen share their experiences with Direct Payments.



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Interviewers: Robby & Addison

Wendy: My background is a district nurse and I worked with people over the age of 65. My experience was that a lot of people using Direct Payments stuck to care agencies because that was what they were familiar with, even though they weren't often happy with the care packages that they were getting. I would make them familiar with Direct Payments. I'd give them information and could tell them a little bit about what I knew but they would just go, "Oh no, I don't think I could manage doing the admin side. I could manage interviewing and being responsible but I'd feel it would be a bit too responsible managing Personal Assistants." But, at the same time I looked after some young people, usual people with spinal injuries or learning disabilities sometimes and they were much keener on Direct Payments because it gave them freedom. They felt more in charge, more able to do the admin side and it worked very well.

Robby: I've gone to older people groups and I met this one couple where the gentleman was very, very ill. He was on his way out really. They're the just the type of couple that Direct Payments are made for, extremely suitable. I spoke with them about it at some length and they say, "Well we'll get that when we need it." And, I thought, "Well, you need it now!" Obviously it's up to them whether they want to take it or not as it's all about choice at the end of the day. But yeah, it's quite interesting to hear from you that it's predominantly younger people that are interested in it.

Brenda: I think that probably reflects the way that benefits and Social Services has changed because actually the people who have lived with it as just being something that is rolled out and given to you. You don't get much choice about it if you are elderly and are used to a certain type of benefit system. Whereas this is obviously a newer thing that younger people are probably more willing to take hold of it, without wanting to generalise.

Wendy: It's hard to convince some people that they need it. They can't see the need for care sometimes themselves and we sometimes have to do a little talk about it to try and help them see it. We say, "Try and imagine what it would be like to have somebody to do the washing and the dressing and things like that. It gives your primary carer, your husband or wife or whatever, more time and more energy and it gives you, the patient, more time and energy."

Sandra: You meet people that probably do need some sort of care but are not ready for it. They might not be ready for lots and lots of reasons. One is this

sort of idea about letting go and letting an outside agency come in. But, Direct Payments can appeal because you're still in control of the money and who comes in, so it's not being done in the same way as someone else arranging your care for you. I've found that people who have been reluctant to accept care, when they hear about Direct Payments they haven't really heard about it before. Then they might say "Well actually maybe I can begin to think about being an employer rather than being a recipient." They don't want to be just a getter of care because that's not very empowering and it undermines your confidence and everything else.

Jen: It's that feeling of being in control, isn't it?

Sandra: Yeah, as we all would want to be.

Brenda: MS patients are diagnosed typically maybe in their twenties and then have to live with their condition right through to a normal age of dying. They have a long time to have to self-manage their condition and in a sense Direct Payments is something that really suits them very well because that's all part of the self-management process. Having that control over what you're doing in your life is important.

I think the bit that doesn't quite suit so well is possibly because their condition is continuously changing. My experiences have been sometimes finding patients that Direct Payments are not currently appropriate for but they have been left on Direct Payments from a time where they were appropriate. With changing cognitive problems and things like that, people find the Direct Payment side of things really overwhelming and hard to struggling with. I think it would be good to have a regular assessment of the appropriateness of the Direct Payments to reassure people that they're not going to just be left not really knowing who to contact.

Robby: Well that is the general idea already. Social Services should be coming to do a review with you about once a year. Also, if you want to, you should be able to move from having a Direct Payment back to the council arranging all your care for you. That's the idea in theory, but a part of the problem is that the council is very keen on pushing people on to Direct Payment at the moment. I think this is due to a lack of resources mainly.

Brenda: Yeah. I think Social Services see it as an easy fix for them actually. I think sometimes they just think, "Yeah, great we'll get them on Direct Payments and we'll wave them goodbye," and they're quite happy with that. Sometimes patients do get a bit of inappropriate advice from Social Services.

Robby: Yeah, I've spoken to people who literally do not want to be on Direct Payments and are told that they have to be for whatever reason.

Brenda: Yeah. I've had that yeah, experience as well.

Sandra: It isn't right for everybody.

Wendy: No.

Sandra: Then there's dealing with your Purple group, the people who will support people using Direct Payments for a fee? Am I correct in that? They manage money to pay bills and things like that?

Addison: Yeah. They give you advice on how to go about managing Direct Payments. They'll give you templates and interview questions.

Sandra: Yes, that's the interviewing process but Penderels Trust also used to take on the management.

Addison: Yeah they do take on the management stuff, like payroll, national insurance, tax, pensions, all that sort of stuff.

Sandra: Yes, that's being an employer. I had an experience where there was a requirement for them to have power of attorney, it was maybe a particular situation but the person was very reluctant to do that. It did feel a bit extreme.

Robby: I'm not 100% sure about the power of attorney bit. I think it's more of a busy contract but obviously that's not the area where we're working so I'm not fully sure. I've not come across that before in what I've been doing.

Sandra: Okay, I'll look it up.

Robby: For a lot of people being an employer puts them off. The only people using Direct Payments that I've come across that don't also use the services of organisations like Penderels or Purple and do all the management stuff themselves, are people that work in that in similar industry. Some people like accountant's say, "Oh yes, I can do all this, its fine." But, everybody else who doesn't have those natural skills to fall back on actually does want an organisation like Purple to manage all that stuff for them.

Addison: You can also do a combination of Direct Payments and having the County Council mange it for you. That maybe is more appropriate for people who are reluctant to do Direct Payments or whose needs are continually fluctuating. So, people who may need more progressive care if they have a combination, then there's someone regularly coming in who hopefully would have the wherewithal to go, "They need more care now, so the Direct Payments is maybe more appropriate."

Sandra: Direct Payments and a mix of other things works very well with people with slightly changing, fluctuating conditions because they can top up their care with Direct Payments if they need to. It's a sort of safety net having both systems running along if you feel nervous.

There has been an issue with difficulty finding care in Cambridge. If you are the employer and you can't find a carer then that's a problem. The agencies are having enough difficulty getting carers as is. So, that's a very local problem but it makes people very anxious. At least if there's a bit of a shared provision of care there is the feeling that there is going to be something and you're not going to be left completely without care.

Addison: Another thing with agencies as well is that it's generally more expensive.

Sandra: Yes, there are a lot of different rates for care provision.

Robby: It puts a lot of people off. The problem if you can't find someone directly is that sometimes you need to go through an agency but an agency is more expensive which means you'll get less time for a carer to come in.

Brenda: 'Cos your hourly rate for the Direct Payment is often less than the hourly rate for the agency because the agencies who work for Social Services have a special contract.

Jen: Yeah, it boggles my mind.

Sandra: That's a situation that seems very tough. So, somebody is given an assessment for an hourly rate of care, has Direct Payments but actually might spend that on fewer hours because you get what you pay for and they've wanted to spend more money on getting the right care. Then their needs change but Social Services have already given them what they're capped at. So, that person needs more care but is in a catch 22. Actually what they've just got to do is buy cheaper care and that's a very unhappy situation for some people.

Robby: Some people can't even do it. I've spoken to families who've said, "We'd like to be paid for this number of hours but in fact we get a lot less because we can't afford to go anywhere else. We need these specialist carers to come in due to the nature of the condition." So, they've no other choice. Very frustrating.

Addison: I wonder if I could ask you guys something as well. There have been a lot of people that have said about Social Services going, "No this is Healthcare," and Healthcare going "No, this is Social Services." I was wondering how that's managed? I spoke to someone who had all sorts of

issues getting physio to maintain their health because no one wanted to pick the budget up for it.

Brenda: I think even to us it's sometimes not really very clear as to what is deemed to be financed by Healthcare and financed by Social Services. The assessments are really complicated. I think we've got a good level of understanding about them but I wouldn't imagine that patients and relatives would find that easy to understand at all. The assessment takes a long time to carry out if you're going to do an assessment for getting continuing Healthcare funding, so 100% NHS funding for all of your care at home or joint funding. So, some of it is part Healthcare funded and part Social Care funded or whether they feel that nothing is Healthcare fundable. The assessment is huge and takes a long time.

Sandra: And, we do try and do shared assessments when we can or if we think it's tricky.

Brenda: Yeah, we will try and be there.

Sandra: We try to have a good relationship with district nurses who often do the Healthcare one and sometimes mediate between Social Services in our interest. I don't feel we have a foot in the Healthcare budget or Social Services budget.

Brenda: It does feel a lot of the time with the people doing the assessments that they're the gatekeepers of their own organisation's finances. But, then there might be a big gap in the middle that neither is going to want to admit to funding.

Sandra: It's a lot of discussion about unpredictability Healthcare needs and predictable Social Care needs. There are very clear checklists, it's just when people disagree about what the words on the checklists are and the language used.

Wendy: Usually for Healthcare funding you need quite a lot of health, nursing-type needs and also mental health needs. If you've got problems with mental health, for example dementia, you score much higher so you will be looking at more Healthcare funding but if it's more social caring needs and stuff like that then you just won't really.

Sandra: It's very tough. I mean, the assessment's very tough. They don't speak from the heart! So say with your person who needed physio to maintain their health, I'm immediately thinking, "Nobody gets ongoing physio."

Jen: Well doesn't it have to be based on an attainable goal that ends in improvement?

Sandra: A goal yeah, but for something like ongoing physio to maintain health there isn't one.

Jen: But if you're trying to keep somebody's health maintained isn't that considered an improvement?

Sandra: That's wouldn't be physio, that's a stretching programme, passive exercises. So, the physio therapist would set the pattern but wouldn't do it with you. The idea would be you would you would train your carers and you'd train your family to do it with you.

Brenda: You can get Social Care to do that but it's less and less.

Sandra: No, I think that was stopped but you can get carers via Direct Payment who will do stretches. Agencies don't. That stopped a while ago. So, it becomes a huge problem. I mean, everybody knows a limb needs to be stretched. You need to stretch it, it needs to be done.

Addison: Prevention of bed sores and all these other things as well.

Sandra: All of that stuff you need to do it, so you have to have an argument about who does what. It is very, very frustrating.

Robby: Yeah, there seems to be a lot of arguments.

Sandra: It must feel very depressing from the patients or family point of view.

Addison: A lot of people say, "Well why can't these organisations just communicate with one another better to make all of this easier." And, it's not just from between Health and Social Care, it's everybody. It's Social Care and the County Council, the County Council and Purple.

Robby: Yeah, everyone seems to be saying, "Well why can't we all just communicate with one another better to get things moving forward easier and faster."

Jen: But everybody comes with a hidden agenda I suppose?

Wendy: At the end of the day it's political and that's where it needs to be sorted out. The way these were all set up traditionally was that health was free at point of care from cradle to grave and social care has to be paid for in England. If you're in Scotland it doesn't have to be.

Sandra: So, the hope is that we're going to join Health and Social Care together one day. I mean, that is what we're supposed to be doing.

Wendy: We are trying to move forward into working in a much more integrated way and I think the people on the frontline are doing that really quite well, but I think the organisationally they are still struggling to sort things out.

Brenda: As soon as you have separate budgets you're always going to going to have a smaller budget than you actually would like and you're always going to get that conflict.

Wendy: For us to get caught up in those conversations with people can take so much time and it's not something that we can even do a lot about. I think one of the things I'd say I don't know a huge amount about is when a patient asks me about Direct Payments, I can only kind of give a little smidgeon of information. I know where to send somebody off too but it'd be good for us to be able to say to a patient, "Look this is what other people's experience has been. Read this and see what you think." Something, we could post out to them or give them and then they can have a chance to make an informed decision would be more useful.

Addison: Sort of try before you buy. Well, not really trying but knowing how it is.

Jen: Yeah because with a medication you would ask, "What does it do? How does it work? How many times a day? What are the side effects?" It's weighing that up, isn't it?

Wendy: I know as a health professional there are three of us here who work in the community. We would all probably say, "If I was a patient I'd know what I'd like, I'd like Direct Payments."

Brenda: Yes I'd like Direct Payments if I were a patient.

Wendy: But we're not really allowed to recommend agencies and I don't know if we're even allowed to say, "Actually if it was me I'd go for Direct Payments." I don't know if we're allowed to say that so I don't say it. I just say, "There is this and there that but I think what you're doing is a good idea."

Sandra: I think I probably take more risks than you. I just think if I see somebody who I do think Direct Payments would appropriate for I would recommend it. I mean, obviously it's got to be their decision and they're going to manage it. I don't suppose I get involved once it's been suggested. The route to doing that is usually getting the Social Services involved. Actually, it's one way of getting a Social Service assessment, is the promise that it could lead Direct Payments. I can see that works for a lot of people and its great.

Wendy: So can I. That's why started off at the beginning saying to you, "What have you heard about carers." In my experience I feel very sorry for an awful

lot of people who have to rely on carers because there are some very good ones out there but there are some I've seen who rush about in 15 minutes, throw the salad at you and go.

Brenda: Do you mean agency carers?

Wendy: Yes. There's nobody actually monitoring what goes on behind closed doors. You could say the exact same thing for Personal Assistant but at least that person has the control to say, "This isn't working, we're not getting, can you go?"

Robby: It's not quite that easy because it's an employment contract and it comes under employment law. If you're letting somebody go then there has to be legitimate reason otherwise potentially your employee can take you to court.

Wendy: I know it's not easy. I was being a little bit kind of tongue in cheek.

Robby: Sure, but I've run into people who've had those kind of problems. It's been very difficult because they've really not gotten on with their carers but they've not had the grounds to remove them. It's very difficult.

Sandra: But, there has to be ground to remove them?

Brenda: I suppose just because they personally don't like them isn't enough.

Wendy: So, that would be a negative of employing your own carers I guess. Whereas if you've got agency carers you can keep complaining to the management.

Robby: Yes exactly. One gentleman had agency carers come in and this carer said, "Well, I'm only really here for the money." So the gentleman said, "Right well you can leave if that's your attitude." He phoned up the agency and said, "They're not coming back to my home". And that was that, sorted.

Wendy: So you've got more protection from that point of view with the agency. However, I think to be able to have some way of describing to people the differences would be useful.

Brenda: Yeah definitely.

Sandra: What I don't think we have discussed and I think is important is the staff training element. If you're the employer you are obligated to keep your employees updated. If you're an employer you do have to make sure people know how to use lifting equipment and all of that side of things. I think sometimes that can be difficult. Especially if people don't acknowledge that

their mobility needs have changed and then the carer's are put under more and more strain to be performing moving and handling manoeuvres that they haven't been trained to do properly. But, where you get training from can be a bit of an issue.

One family I was involved with, they started to use a mobile hoist. Who was going to train the carers hired via Direct Payments? An agency would get training in moving and handling but who was going to train these carers not with an agency? So, we got the OT but it wasn't very straight forward. The family needed a lot of guidance about protecting the carers and it was not necessarily given by Social Services. That came from our side of things.

Addison: The law is not very accessible in and of itself on that and other things, which is also an issue.

Sandra: I don't know all those work employer regulations and I'm not absolutely convinced that everybody completely understand the legal requirements when they take Direct Payments on.

Robby: I think it's difficult to understand. I remember when all the pensions stuff came in. I remember thinking, "My goodness this is so complicated!" That's just one aspect of it to try and wrap your head around but there are so many other things to try and wrap your head around as well. I can see why some people would rather go another route and have the County Council look after it for you. It's sad that some people are actually being forced onto the Direct Payment route seemingly against their will.

Sandra: That's reminded me of a family that I was involved with and all of their needs would have been so much better met by Direct Payments just on every level but they were whispering, "No don't let them put us on Direct Payments, we don't want to be on them." They were capable but they just didn't want to do it. So, even though they could have had support to do it, their lives were so full of problems that they just couldn't take on another thing.

Brenda: Yeah. People are just overwhelmed, aren't they?

Jen: It's just another thing, isn't it?

Sandra: Yeah. And, they had the kids in the house you know. It was just another thing that the family couldn't deal with. But that's fine, you work round it.

Wendy: People like Personal Assistants, is there anybody to monitor them? What if the relationship either breaks down or becomes too close that there's the problem of maybe leaving something to somebody in their will or those kinds of things. Is any of that ever a problem?

Robby: I haven't personally come across that but that doesn't mean that it's not an issue in some cases.

Addison: Anyone working with children has to be DBS checked but I know that with adults employing people then they don't have to be DBS checked.

Wendy: Do they not?

Addison: Nope. If someone's going through Purple then I know Purple very strongly would recommend that people are DBS checked and obviously if I was talking to anyone I would very strongly recommend a DBS check but it's not actually a legal requirement to do so.

Brenda: It's surprising, isn't it?

Sandra: I suppose, at the end of the day, it's an agreement between the person and the person they're employing. If I'm happy with you coming into my house and looking after me then that's my decision.

Wendy: Yeah, they're given the choice.

Brenda: Which makes it all very unofficial!

Wendy: But, it also makes it very reliant on trust, doesn't it? These people are vulnerable and can really end up building a very trusting relationship with someone they don't necessarily know very well.

Robby: I think the local authority is responsible for doing some check-ups on people to make sure that everything is running smoothly. They're meant to review people on Direct Payments annually.

Wendy: A year is a long time. As an ex-district nurse some of the problems we had were not being recognised quickly enough. Things like the starting of a pressure sore, a patient with MS wouldn't necessarily feel it or know they had it. A Personal Assistant may not recognise what it is or report it quickly enough and then who's responsible? So, that can be quite a tricky one. Usually the district nurse ended up being responsible for some reason.

Sandra: It's your fault!

Brenda: Yeah of course. You're the registered person.

Wendy: It's always our fault because we should have known. There are tricky things about it but generally I would say Direct Payments are very good. They work very well from what I've seen.

Robby: That's good. How about yourselves, would you say it works well?

Sandra: Yeah.

Brenda: Yeah. I think when it works well it's brilliant. It really does change people's lives because they really can be more independent and that's what we're aiming for really, to help people self-manage. So, the idea of Direct Payments for our patients is great.

Wendy: It's the whole aspect of being able to get out as well. If they have an adapted car and their Personal Assistants can drive, it means their husband or wife can go back to work. So, instead of being isolated and waiting three times a day for the carers to come in, they can go out. That's lovely because their quality of life's a lot better.

Addison: Yes. Being housebound is also an issue for carers. I heard recently a case where a couple of carers complained to Social Services. They complained that they, as spouses, were not allowed respite payment if they wanted to go away with the person they cared for. The respite was only there if they were going alone. But, that's even more stressful because their leaving their loved one in the house with a care agency and they don't want that for their wife or husband.

Brenda: Yeah, the care agency's not going to do it as well as they are doing it. That is something that does come up quite a lot when we talk to relatives the phone. They get frustrated about it as well.

Addison: And, language that people use to classify themselves as well, 'cos if they have to say exactly the right words in order to get the right sort of care that can be very tricky.

Brenda: We do have quite a lot of complex situations where there are these ambiguous relationships with people. So, they will always call themselves the carer but actually it may be that they're a girlfriend or boyfriend and things like that and you know? Those are probably the ones who know the system and know what they need to say to continue to be getting what they're getting. It's a bit of a minefield really I think.

Addison: So, just a couple of last questions then if we may? What advice would you have for people looking to get into Direct Payments?

Wendy: I would probably say, use Purple. Use the support of someone behind you. It is quite daunting to do it all on your own. That's probably what I would say.

Brenda: Yeah and I think I would say the same. I think that I'd say it can really enhance your quality of life but I think that probably there is a lot of work that has to be put into it. Using the support services is obviously going to help you but there's a lot of responsibility to be taken on with it but then again that can pay off.

Robby: And just finally, what recommendations would you as professionals say to us to take back to the County Council?

Sandra: Don't push people into it who don't want to do it. It's a rough old world. We've all got problems but actually, sometimes living with a disability is a job enough.

Brenda: Yeah.

Jen: Listen to people.

Sandra: It's a full-time job to manage your life and to put carers into that as well, it's a lot of work and isn't for everybody for whatever reason. There shouldn't be one brush from everybody.

Brenda: I think they should be really careful counselling for people to make the decision about Direct Payments or not. If they want to then they can involve people like us in that conversation. You know, they want to involve somebody who's known that person longer and sometimes that would maybe make the assessment more accurate. We may be able to advise the patient and little bit more appropriately.

Sandra: Yeah and that's being sort of realistic both ways.

Jen: And, if they're pushing people towards Direct Payments, do they not have a responsibility to actually give them more information? Be signposting them and making sure that they're facilitating the best options, rather than just because the local authority would like to?

Robby: That's very useful information. Thank you very much for your time.