



Alan and Janet's Story

“My friend asked her if she could define ‘Wellbeing’ because that is at the core of the County Council’s new policy on caring for carers and she couldn’t.”



Alan & Janet's Story

Interviewer: Addison

Addison: As this is all about Direct Payments can we start from the beginning of your story and ask how you found out about Direct Payments?

Janet: Okay. So, about fifteen years ago Alan had an accident where he suffered multiple injuries. The significant one was a spinal fracture, which initially left him paralysed from the waist down i.e. paraplegic. Over a period of time we worked on rehab. I'm an occupational therapist and I work with teams of physios and occupational therapists, so I was in the right place and had connections with the right teams. We did a year's rehab and then somebody said to me, "You ought to be able to get help."

We didn't think we were entitled to help because we didn't want carer agencies to come in and support us. It wouldn't have worked for us because we weren't sleeping at night. Alan was up... well he wasn't up and about because he was in a spinal brace but Alan needed help several times during the night. What used to happen was, I was sleeping downstairs on the settee and we would probably both get to sleep about six o'clock. My experience of care agencies and how they provide care based on my own NHS experience was that they would come anytime between 7 o'clock and 10 o'clock. If I've only just got to sleep I don't want to be woken up at 7 o'clock to let somebody in to do see to Alan

We then found out that it was possible that we could be given money that we could buy our own care, i.e. Direct Payments. If we were buying in the care ourselves we could tailor it to what suited us and what worked for us.

Addison: How did you find that out?

Janet: I knew about it through Social Services, so talking to colleagues and the teams I worked with in the health service and the local teams. Somebody said to me, "You should have an assessment because they might be able to support you." A year after Alan had his accident we had the first assessment. The social worker came out and said "Yes, we can do something to help you but theoretically we can only provide personal care." We said, "Well, we don't want that because Alan wants me to do his personal care." So, she went back to her manager and talked about it and they were very lateral in their thinking and they said "We will give you a budget that you can use to free you up for 7 hours a week to take some of the load off caring for Alan."

We ended up with somebody to help us with the cleaning which is theoretically not what they're supposed to do but they said it was special circumstances. We also had someone come in and do the ironing. It was only those two little things and that rolled on very happily with annual reviews for about four to five years.

Then we had a new social worker assigned to us who came out and said, "You should not be using the money for this!" However, it was on the cusp of the changeover from the fact that you could only use the budget for personal care to the point where Direct Payments became a bit more flexible. So, they were pushing very hard to say that we had to have carers, we had to have people come in to make meals for Alan. That was bonkers because I'm cooking meals for me as well. We said to them, "Look, in 6 months' time, the rules and regulations will change and the Direct Payments can be used on things that support Alan to live independently." Even so they wouldn't play ball at that point so we got out local MP involved. He came and he talked to us. He wrote a letter saying it was ridiculous for the sake of 6 months that they couldn't actually be more flexible in their approach and continue what we had which was working. It was keeping us both afloat and because without the little bit of help we get I don't think I could manage at all.

Alan: There was a time which was maybe a couple of years after my accident when it became evident that I was going to remain in a wheelchair. The sheer workload on Janet was enormous. She was having to do everything and she was working. There was not much I could do apart from phone.

Janet: I was working because of course we'd lost an income in the household.

Alan: Maybe we had a bit in the bank but all that all went and Janet was getting quite near the edge. In fact, the edge was almost touched. That was how the feeling was in the household.

Janet: We were teetering on the brink. There's no two ways about it. So, with our MP's intervention, we got Social Services to come out and do a new assessment. As a result of that new assessment they realized we actually needed a bit more help than we were getting. So, they worked it so we could have a certain number of hours cleaning a week. They funded help with the ironing or for it to be taken away and brought back. They also funded a certain number of hours of gardening so that somebody could keep the grass cut because Alan doesn't get far.

The garden is kind of his only place where he can go where it's different, where he can get fresh air so it's not good if the grass is 6 feet high. So, it was about maintaining that area so it was accessible for Alan. We're not talking about somebody doing all sorts of gardening work. We're talking about

somebody basically keeping the grass cut, keeping the paths clear, so he can access it in his wheelchair. So, that then carried on quite happily for a good few years.

Alan: We were also doing a little bit of swimming down the road.

Janet: Oh yes. We had asked if we could use some of the money to pay for physio for Alan and have somebody come in. The NHS said they wouldn't give him any more physio because he wasn't going to be rehabilitated, it was about maintaining his level of function so he didn't become more dependent on me. We also asked if they would pay for us to go all swimming down the road once a week. We were then asked to have another annual review which was fine and then this lady came out.

Addison: Was this the same social worker?

Janet: This was a different one and this is the lady we had all the problems with. She arrived and I know you shouldn't judge books by their cover but she was very inappropriately dressed. She looked like she was going out for a night on the town, didn't she?

Alan: She did.

Janet: So, that wasn't a good first impression. She sat in the chair where you are and she said, "Oh I've just come back from holiday. I was in Egypt for 2 weeks and it was wonderful, blah, blah, blah." Well, the fact that we haven't had a holiday for nearly 10 years to me made me think that was really was not an appropriate way to start the conversation with us. I felt straight away she wasn't dialled into our situation and it just started there.

She started saying things like, "You've been spending money on things you can't be spending money on," and we were saying to her "Well, hang on a minute, it's all been approved by you. It's in our care plan that we're spending money on this." "Well you shouldn't have been. Somebody else has told you that and they shouldn't have told you that. You're not entitled to that. You can't have money to pay for a gardener. You can't have money to pay for a cleaner. You can't have money for the ironing. You can't have money for physio because it's health it's not Social Services. You can't have money for swimming because it's not Social Services, its health." She said that the only thing we can spend the money on is to pay for carers to come in or somebody to cook meals. And, I said to her "Well hang on a minute, under the new regulations of the new Care Act it can be used more flexibly you know?" And, here's this girl saying that we can't use Direct Payments for things that keep us afloat. We're not talking about lot of money here.

Alan: Um, are you including the travel allowance under the same budget? Are there two budgets, they come from two sources, don't they?

Janet: Oh, it's still one budget but Social Services works in such a disorganised way that they can't pay you a monthly amount. There's £60 that's this and there's £20 that's that.

Alan: There about thirty different payments.

Janet: And, different headings to make up the monthly amount. We can't get to the bottom of it. We have asked and asked and asked and we don't need to know which internal budgets they come from but anyway...

So, she said, "If he needs things like physio and to keep fit, then he can go to a day centre." I said, "Well, he can't because he can't tolerate being in his wheelchair for enough time to travel to a day centre." There was not a lot of meeting of minds.

Alan: Basically, she didn't understand my limitations.

Janet: No.

Alan: She seemed to think I can go wherever I wanted and do whatever I wanted, it was extraordinary. I don't know, it was just like she hadn't cottoned on to the fact that I was in a wheelchair and not only was I in a wheelchair I had further problems.

Janet: I believe fundamentally she wasn't listening because she had come here on a cost-cutting exercise.

Alan: Well that's what we both sincerely believe, that she was here on a cost cutting exercise. That's why she kept mentioning that things can be put on the Healthcare budget. Janet at one point did say to her that she was aware that you could apply for a NHS health budget for whatever it was but that you often would expect a 3 or 4 year waiting list if you were lucky.

Janet: No, no, no, you're wrong. You're thinking about what we said to her about having a path put down and she said that's not Social Services funding, that's health and it isn't its Social Services. It's a disabled funding grant for alterations to homes and things.

Alan: Ah, I got it muddled up.

Janet: You needed help because you had pain, therefore you should be being funded by Healthcare. I knew from work that if you had been assessed for Healthcare funding you would have failed miserably because you didn't have

bed sores, you weren't dependent on pressure relieving stuff, you could breathe, you could feed yourself, so you didn't meet any of those criteria.

The social worker said she could do the assessment. She couldn't because respiration has to be done by a consultant in chest medicine, the skin integrity has to be done by a specialist in pressure relief. She thought that she, as a social worker, could complete that assessment and I knew she couldn't because we used to do those at work as a health team. But, she was trying to move as much as possible off the County Council budget onto a health budget. That was her first point. The second point was she was trying to save Social Services as much money as she could. I said, "That whilst I understand that the County Council had received an 8% cut in funding from government why were we being expected to stand a 70% cut in what they were offering us.

This started in at the beginning of the year and it was still going on until the end of the year. Eventually I asked for us to be assigned a new social worker because I felt she was prejudiced against us. I felt she didn't understand where we were coming from. I felt she looked at our house and judged us because of the house we live in. We spent the last 35 years getting this house together, we poured most of our funding into it and I don't think we should be judged on that. We should be judged based on our need. She missed the point that I was having to cut my hours at work because I couldn't cope. I was facing taking early retirement, taking a significant cut in my pension because I couldn't cope. It was starting to affect my health. At one point I said to her I struggle to cope and she said, "Well you need a referral to a psychiatric team then."

So, I asked that she be replaced by somebody else and I was told no but the next meeting her senior manager would come with her. We arranged a meeting and I brought a work colleague in as an advocate for us because I thought we need somebody in our corner trying to help us get our point across. We had the meeting and immediately the social worker was aggressive.

Alan: Yeah, she did have an attitude.

Janet: She came and she sat on the settee and I said to her, "You don't understand the situation and you don't understand the bare bones of the Care Act that you're supposed to be working for." My friend who's also an occupational therapist asked her if she could define 'Wellbeing' because that is at the core of the County Council's new policy on caring for carers, to consider the wellbeing of the carer. That's about physical wellbeing, mental wellbeing, it's the whole shebang and there's a quite specific definition in the Care Act. My friend asked her to define it and she couldn't. She didn't understand the meaning of it so we were going round in circles.

We'd been sitting here for over an hour, we'd both been getting more stressed and then she confirmed our suspicions that she was prejudiced against us. She said, "Do you know, every day of the week I deal with families who are in a far worse situation than you are." My friend put her hand up and she said, "I think you should stop now because you have really spoken out of turn. I think you should just stop now." Her senior social worker was sitting with her mouth agape because she couldn't believe what she had just heard.

So, I just said "Okay we need a resolution to this." So, her senior social worker said, "Would you write a care plan because you seem to know what your needs are." We'd re-written the assessment time and time again because they'd do an assessment, send it out and a lot of it was factually incorrect. I think we got to four drafts of the assessment that I had to be redrafted and sent back to her. It came back and I redrafted it and sent it back. So, we were on the 4th draft of the assessment and the senior social worker said, "Janet would you write the care plan?" I said, "Yes but we're now at the end of the year. I cannot deal with this over Christmas. I will give it my attention at the beginning of next year and not before," and that was fine.

The senior social worker said, "You know it's because we're all under pressure and we've got to cut money." I said, "I'm not interested, that's your problem, it's not my problem. That's about how you manage the resources and about how you manage the budgets you're given. That's your problem so don't give it to me." She said, "If you're not happy you can complain," and I said, "You can be rest assured I will be complaining."

I thought about it over Christmas and I thought, "Why should I do their job for them. Why should I write the care plan?" I can't tell you the hours I spent on it and I don't have a lot of free time. I don't have time to stand and daydream and any spare time was spent at the computer trying to sort all of this out.

They say they're there to help us, to support us, to maintain Alan's independence and they were the greatest stress that we've ever had. In fact, if I think back over the last few years, they have been the most significant stress factors for us.

Alan: They have.

Janet: As soon as the phone goes and its Social Services we both get uptight.

Alan: Everything that has happened to improve my otherwise awful lifestyle and make it so that we don't actually jump in front of a bus, we've actually invented ourselves. We've made it possible ourselves by making what they've offered us work for us but not the way they thought it would. It astounds me that they don't seem to have an understanding that people's needs are what

they need, they're not what they invent and they don't come under a category. It's like they've got a whole load of categories and if you don't fit a category they just pull the nearest one out. The problem with that is that I expect that there are... And I'm not being critical of other families who claim on benefits but I know for a fact that there are people who make a lifestyle getting the most money they can out of Social Services. They do it by constructing their lives to do that not because fate has befallen them with a horrible thing like it did me.

Janet: So anyway, because I said we wouldn't look at the care plan until the beginning of the new year, in meantime we decided to make the formal complaint. We said to them, "We are not prepared to progress this any further because there is now going to be a formal complaint. We want that investigated before we can move forward." As a result of the formal complaint they all started jumping up and down.

We then were allocated a new social worker and she came out with her senior manager, a different senior manager. We sat down and they hadn't seen the complaint, so they didn't know what the complaint was about, they just knew that we weren't happy with the assessment. I think that was good because they didn't come out with any preconceived ideas. They came out to do a fresh assessment on us and to move further from where we were. And it was like a breath of fresh air. They said "Well you're not getting much support. If Alan didn't have you we would have to put support in. We would be having to put carers in three times a day, 2 of which would have to be double-ups. In terms of what that would cost us as an organisation as opposed to what it costs us with you with the support it's a no-brainer, we should just support this!"

So, we thrashed it out and they decided to do a joint care plan for me as well because at that point I was getting a small amount of money a year for me as a carer. Because I have my pension I can't get the carer's allowance, so this money was supposedly to be used to give me a break from caring. They looked at that and asked what sort of things do I like doing and in the end, they upped that the money I get for care.

So, that was all done, that was all signed, that was all sealed, that was all delivered. They rang us at the due date for the reassessment and they said, "In view of what's happened in the last two years we'd like to just roll it forward." Fine okay. After that we got a letter saying, "We want to review your agreement, are you happy with a telephone review?" "Yes." They rang us and they talked to Alan, "Has anything changed?" "No." "Are you happy with the existing setup?" "Yes." "Okay, we'll just roll it forward." Alan gets all the paperwork to review and sign off and his Direct Payments continue.

However, they were really tardy in paying me the carer's grant last time it was due. I got it more than three months after I was meant to receive it, so a lot of the things I wanted to do to help support me have already gone. I thought, well as Alan's done his thing they must have done mine as well because it's a joint care plan. Eventually I rang them and said, "What's happening because I've not had any money through." "I think you need a reassessment." "Well, if I need to do a reassessment why wasn't I reassessed when I was meant to be?" "Oh, I don't know. I'll tell you what, why don't we do a telephone assessment?" "Right, fine. Okay, we'll do a telephone assessment."

I was told that they'll send my care plan out and if I can check it, sign it and send it back off then it'll be with me in a couple of weeks. Two weeks go by, then three weeks. I ring them and say, "I haven't got the care plans yet." "Oh, I'm sorry, so and so's not in the office. She's not back till next Thursday. I'll get her to ring you." So, we wait a week till Thursday, Thursday comes and goes and she doesn't ring. I ring again and they say, "Oh she's out of the office till next Thursday we'll get her to ring you." So, you can just see how the time is just disappearing. I got quite cross and I said, "If so and so can't ring me somebody else needs to ring me and tell me what's happening."

Then they send out the care plan and it's the wrong care plan! It's the care plan done with the social worker who we disputed the care plan with. So, they chose to ignore that right care plan and go back to the disputed care plan. So, I rang and I said, "Can I speak to so and so." "She's not back in till Thursday." So, another week goes by. I emailed her and I said "You're working to the wrong care plan, you're working to the care plan that was put together by the previous social worker, it's the disputed one. You should be working to the one you prepared after that." Then I get an email response back saying "Oh, sorry. Yeah, you're right." So, they redo it, send it out and it's still wrong.

So, I actually went into the office. They're not used to having people come into their office. The person dealing with our case said she'd be in the office because she was keen to get it signed off so I could get the money through. I told her I would bring the signed copy in and she wasn't there. They didn't know when she was going to be in. I said, "There must be somebody in the office who can take a message for me. I'll give you this care plan and I'll write what the problem on it but she needs to get it today." You'd think that she would ring the next day but she didn't. I rang and rang and rang and then I found out that nobody had passed the message on. So, then I sent her a message and I got an automated out of office email saying that she was going on holiday for two weeks.

At that point I threw my toys out the pram and I demanded to speak to a senior social worker. The social worker I got was the one who investigated the complaint. I recognised her name but she obviously didn't recognise mine. I said, "Somebody needs to sort this out otherwise I'll be doing another

complaint that you have to deal with.” I think some little lights started to go off and she said, “Well you can’t just assume you’ll get the same money every year.” I said, “I’m not. It’s been reviewed my situation has not changed therefore it was agreed that the funding would not change.” She said, “Well you’ll have to have a review next year.” I said, “Well I hope so but I hope it happens in when it is supposed to happen and three months down the line!”

But, the other thing, is that you always feel that they suspect you’re spending the money incorrectly. I mean, my carers grant still isn’t a lot of money. What could I do with that money other than fund my art classes and go for a facial at the local beauticians in the village. That’s what my money is spent for a year. However, you always get the feeling that they suspect that you’re abusing the money, you never feel there’s any trust.

We produce receipts, we produce accounts, we send them in every year, but there’s still this undercurrent of, “You are abusing.” It’s as if they think we’ve got money that we’re not declaring. However, as Alan told you we were surviving on no income from him and a reduced income from me. Where do they think the rest of the money to live was coming from? There is always this suspicion isn’t there?

The social worker we had the problem with said she thought we needed a new financial assessment. We said, “Fine okay, send the papers out.” Alan did all the papers and it was most interesting that because our savings had been eroded, our contributions towards our Direct Payment services went down. Her own finance department indicated that our financial situation was much worse than it had been at the start but she still wasn’t prepared to accept it. But, it frustrates me that they cause us major stress. It frustrates me that it takes them so long to do the simplest things. The new year comes along, “Oh the Woodward’s need reassessing. Right, we’ll get out there in a timely manner. We will reassess them. If nothing’s changed, we’ll rewrite the care plan, revise the dates on it and set the finance department in motion.” It’s not rocket science.

Alan: I mean, right now how many months are we behind?

Janet: Well, I got my money at the end of February and I should have had it at the beginning of August. What I’ve done is, I’ve been spending the money on things I’m meant to spend it on and now the money’s come in I’ve just taken the money out to fund it. In effect I have made my budget go from August by funding those things myself and actually billing them back for those services. However, somebody else might not be able to do that. It is wrong that the single biggest factor is the stress and the hassle. We operate at such high-level stress anyway that it doesn’t take very much more to start tipping us over the edge.

Alan: No, it doesn't.

Janet: And, I feel quite strongly that we do save the organisation a lot of money. I could say said, "Right I don't want to be Alan's carer, I want to be his wife and friend again. I'm not prepared to do all the things I do for him." I don't know what the current rates are for care staff.

Alan: I mean if I wanted a shower...

Janet: They'd have 2 people.

Alan: To help me into the shower?

Janet: They'd have to. They'd have to have 2 people. They wouldn't do what I do.

Alan: Okay, so they'd have to send 2 people out. Do they send people out when I want a shower?

Janet: No.

Alan: Or do they send them out when I'm in the middle of breakfast or when we've got visitors or when whatever?

Janet: Yeah. I think the other thing about Alan's needs are that Alan can't always get up at 9 o'clock or 8 o'clock in the morning. It depends how much pain he's had during the night. It may be he needs to stay in bed for a couple of extra hours and get up at 11 o'clock and have his breakfast at 11 o'clock. If the carers have been and gone that's no use to us.

The whole point of Direct Payments is to facilitate what works for us. To maintain Alan's independence and to reduce the burden on me really. I mean it's a burden I embrace and a burden I'm more than happy to accept because that's how we work as a couple because we're a partnership, we're a team and that's how it works for us.

I think when they set out to offer help and support but instead they offer stress, harassment and suspicion, that's the thing I don't like because I'm the kind of person who's always been dead straight. I would never do anything corrupt. I even have a problem stealing pencils from the NHS, that's the kind of person I am. And, to be met with this undercurrent of suspicion, that I'm misusing government funds, I really have a problem with that. I don't know what the answer is. I don't think it's just about resources, I think it's about the way they use their resources, I think it's about the way they train the staff. How can you possibly get anybody to understand what it's like to be a carer if you go on a course for a day. Before I left work, we used to do in-service

training on a regular basis about career development and broadening your perspectives.

Once I was asked to do a lunchtime talk about what it's like to be a carer and the guys all knew Alan, they knew what life was all about. Some had actually been in and treated Alan and at the end of the hour two of the girls were crying. They said, "You've put it across in such a way that we feel for you, we feel we understand what's happening." I said to them, "You know I'm relatively young, so think about if you've got a situation where you've got somebody in their mid-80s caring for somebody else in their mid-90s. How the hell do they do it? They've got no time left over to talk to people like you or to write formal complaints." I just feel strongly that half of me doing the complaint was fighting the corner for all those people who couldn't.

Alan: What about couples who don't have this background, who don't know the ropes. The reason we got on this far is partially because Janet understood the system and knew, well not everything about it but when everything started to go wrong we knew what the right thing was to do. A lot of people would feel lost and the social system doesn't do anything positive to say to individuals, "Wait this is what you have to do to sort this out." They sweep this under the carpet.

Janet: It's easy to think that if people aren't shouting at me it must be alright. I think if you work under heavy caseloads like social workers do, then I think it's all too easy to say, "Okay they're not shouting, I can park them and get on with the ones that are shouting."

The social worker we had the problem with didn't know what she was biting off. I mean at one point she was saying Alan should be getting a DGF to sort out the garden path. I said, "A DGF, what's a DGF? I think you mean a DFG." So, then she stopped and looked at me but she hadn't found out that I was an occupational therapist. She was spouting forth rehab things that she didn't know the first thing about. Well I bloody certainly did. That's why I started to question her and she said to me, "Well, I know all about what it's like to be a carer believe you me." I say, "Oh, who have you been a carer for?" She says "Well I've been on a course. A day course." I said, "You haven't got a clue what it's like to be a carer."

I think they should put people out here for 24 hours. It's what they should do. They should put a social worker with us for 24 hours and I'll sit here and have a cup of coffee and watch the telly and she can just get on with it. They should have to spent time with a couple where one is the fulltime carer for the other They should actually spend a full 24 hours, not 9 till 5 not 10 till 3. 24 hours, so they go through the night with them and understand what it's like to have disturbances in the night and try to catch up.

And, being ill, that's the other thing. When you're ill you still have to be the carer, you can't stop 'cos you're ill. This is priceless, I managed to fall down stairs. We had the paramedics out and I was taken to Addenbrooke's because they thought I'd broke things and goodness knows what else. I came home and I could just about get on the settee. The phone goes the next day and it was one of the social workers saying, "Oh there's something I need to check with the paperwork." Alan said, "Oh, it's a bit difficult now because Janet has fallen downstairs and all the paperwork's up in the office. Janet can't get upstairs." So, the social worker said, "Oh, alright well I'll ring you again in a couple of weeks." Wouldn't you think they would have gone, "Oh my god, they might need some help?" Now we have a good circle of friends and they just rallied round. I think I had broken a rib and for the social worker not to pick up on the fact that here we were in crisis and do something about it. "Oh, well I'll give you a ring in a couple of weeks then."

The first three social workers we had were really good, really understood the dimensions of us and understood that we were prepared to bridge the gap that they couldn't fill if they gave us a bit of funding to take pressure off. I could do the personal care and I could do the physio.

When Alan first had his accident, the physios wanted him to go to the gym and we went but he was carsick all the way there. He was sick all the time we were at the gym and then he had the journey home to make. It just didn't work but the equipment we needed was in the gym. I went and got in touch with the chief executive and we said, "We need the equipment at home. I'll find out where I can hire it from, will you pick up the hire fees for the equipment so that your physio can come up and treat him here?" Which they did. But, that's about knowing which buttons to press. It's about how to persuade and encourage them to meet you halfway.

So, they paid for that equipment to be in our home for 6 months by which time Alan was stronger and could then go to the gym. We went to the gym three times a week for I don't know how long. They were prepared to meet us and say, "Okay you're doing something. You can't do it within our facilities so let's use your facilities." But, I don't feel there's any meeting of minds anymore with Social Services. I don't know what their call philosophy is anymore. I think if you ask the staff they wouldn't know either.

Addison: Well, obviously funding is the big issue for everyone. Social Services are especially underfunded these days.

Janet: Then it makes more sense, in my mind, to grasp onto a situation like ours because of what I'm doing. I'm saving them money. Double-up carers twice a day, a single carer in the middle of the day for a meal. It must cost them about £17-20 an hour for a carer, so I think it would cost them a lot more

than the money they're paying us a year. If I was the manager that's the way I would look at it.

Alan: In your case it's more like £120 pounds a day.

Janet: Well it's certainly not the amount we get. It's probably about £20-30,000 a year. However, they can't look at the bigger picture because I think the guys who come up don't understand the cost to Social Services to putting carers in here. They probably know what the carers are paid an hour but that's different to the cost of providing that service. If I could not care and if my own health problems became an issue for me then they might end up supporting us both. So, I feel that they're getting a good deal out of us but they're inefficient and they lack insight.

Addison: Is there anyone that you feel you can turn to for support?

Alan: There isn't anyone I feel you can just pick up the phone and say, "Hey look!" You know?

Janet: No, there's nobody. We've got an emergency care plan in place and that's with a carer's organisation where 2 couples would support us. They've got a plan so that if anything happened to me and they need to put care in in a hurry, they would send somebody here and that person would sleep in for 24 hours if necessary. That would give Social Services time to get other things into place like carers coming in or whatever. We've got named friends on that care plan so we have that in place.

But, in terms of somebody to pick up the phone and say, "We've got a problem here can we have some help?" I would not turn to Social Services or our social worker because I know if I rang on a Monday I'd be told she was not back in the office till Thursday. If we have a crisis it would be picking up the phone and talking to mum. My family are all in the northeast so they can't run round. Mum can get a train that takes her 15 hours because it's Virgin but there is nobody within the organisation. Our private physio who comes in once a week, he would drop everything and help if I asked him, I know he would. My friends from my time as an OT would help us. However, you can see our support network is an informal friend's support network it's not an organisational support network.

You know, I was talking to another social worker about getting my care grant. I said, "If I want to go to my art class I have to pay for it on the set date. If I can't pay I lose my place and there's a waiting list for places. If I lose my place I can't just pick up again when I get my care grant, I'll have to go on the waiting list and wait and I don't want to have to do that. I really need you guys to pull out your finger and do something about this. These things are supposed to support me, they're supposed to help keep me buoyed up and

keep me going. You're not providing them and you don't understand how critical these are to me." The social worker said, "We'll do what we can." There's no sense of urgency.

Again, it comes back to I don't think they understand how important these things are to me. Sometimes I go to art and I don't even paint, I just sit and talk to the girls and have a cup of coffee. But, that is something I can't otherwise do. Everybody comes to us, we can't go out for meals, we can't go out for coffee.

Alan: Last time we went out for coffee was about 2 years ago wasn't it?

Janet: Yeah and that wasn't a great success.

Alan: "I don't have much pain today, can we try it?" We're lucky that we managed to get a settee at a place we went to. We sat there for an hour and a half before I had to move, so it is possible. However, it is very much a question of what I feel capable of doing on the day.

Janet: It has to be spontaneous. But as I say, I don't feel if things went wrong today, god forbid, touch wood, who would I ring? Well, I wouldn't know who to ring, Social Services? I don't think our own social worker would be of any use. I actually think if I carry the card around with me to say that I'm a carer for somebody and if there's a problem please ring this number, then I have trust and faith in the carer's organisation to actually respond immediately.

I don't have any trust in Social Services to actually act and put something in place. If something happened on a Saturday, well our social worker isn't there. There's a duty team there. I've had experience of the duty team as an occupational therapist working in this area and we've had crisis happen with patients. The duty team have not come forward with any support whatsoever. I as an occupational therapist, have gone out with other occupational therapists taking heaters out to patients, taking food out to patients. That's not really our job but we knew that the social workers wouldn't pick it up till Monday morning and here it was Friday night. So, we dealt with it because what mattered most to us was the individual at risk. I don't think they have a sense of risk, I don't think they have a sense of urgency. I'm very damning really but it's based on a lot of experience. And experience of how good it can be.

Addison: You would think as time goes on things would get better not worse.

Janet: They don't learn from their experience. Social Services have never had a lot of money to throw around. There have always been budget constraints, there'll always be budget constraints. You can't help thinking that if they use what resources they have more wisely then they'd get better value out of it but

they're not using it wisely. If the social worker can send me the wrong care plan three times that's wasting their time just as much as it's wasting mine. If she hadn't got it wrong the first time then she wouldn't have had to ring me, she wouldn't have had to email me, she wouldn't have had to rewrite it and the same for the second occasion she did that. It's about good use of their own resources as well. I don't know what the answer is. I could think of a few things.

Addison: Sure. You mentioned them asking you to write the assessment before. How you do find things like doing paperwork?

Janet: Well it leads me to think they're not capable of writing it.

Alan: It was not only the fact that the assessment was inaccurate and not only did it not reflect our needs but it was the wording was so poor. I mean, I don't expect them to be all like George Bernard Shaw but you expect it to be reasonably grammatically correct, don't you?

Janet: She put double negatives in the assessment. Well a double negative is a positive, so she was not saying what she thought she was saying. Do you see what I mean? The last time the senior social worker was here she said to me, "Who wrote the assessment?" And, I said, "Well, I did." She said, "I could do with you coming to do some training sessions with my staff on how to write an assessment."

Alan: There must be people who are trained to do that sort of thing, how to write an assessment, how to write something about something else. It doesn't necessarily have to be a health service thing, it could be related to something else. But, they have the skill to write in such a way that conveys the information correctly. That can be taught now, why aren't they doing that? Why haven't they got someone in to train them? They have trainers presumably to train their staff, they don't just employ them off the streets, do they?

Janet: They have their own their own internal training. But its very interesting because I said to the social worker who investigated the complaint, "I question your training about what it's like to be a carer. I am very happy to come into your training courses and do a session on what it's like to be a carer." She said, "Thank you very much we really appreciate that and we'll pass that information along to our training department." Here we are now and have I had any answers?

Alan: No of course not. They'd be embarrassed to have their deficiencies shown up.

Janet: No, it's not about that. It's about somebody who has relevant experience sharing it with them to help them understand it better.

Alan: Yeah, but what I meant was they don't want someone coming in and exposing what they've done wrong in the past.

Janet: The people sat in that training session wouldn't know what had happened in the past because they're new to that training. What you're doing is enhancing the experience for those new social workers who need to understand what it's like.

Alan: Oh, I see what you mean.

Janet: You know, when I used to train my staff if I had anybody volunteer like that I'd take their hand off. However Social Service use their own trainers and their own trainers don't have on the ground experience. It's like me going to talk to somebody about building a rocket engine. I haven't built a rocket engine, I don't know what the problems are.

Addison: Training is very important. Interestingly that's something we've covered a lot on this project. We've run events throughout the county about Direct Payments. They were events specifically geared up towards informing the public about Direct Payments. What I thought was interesting was that instead of Joe public, predominantly it was professionals who came to these events to find out more about Direct Payments.

Janet: Which is sad isn't it?

Alan: It is sad. I'm happy that they were prepared to do it but it is sad that they felt they needed to.

Janet: Well fortunately or unfortunately, I'm the kind of person who if I hear about something I'll find every document I can about it. In the complaint we made you can see there are examples of how people use Direct Payments that were far more outlandish than ours. There was a total lack of understanding. It's taken us a long time to get out little support network with the people we use. It works and it doesn't need tweaking and it doesn't need changing. It took us 18 months to sort out a cleaner!

Alan: Well, you've got to be able to trust them apart from anything else. They've got to be able to come at a semi-convenient time.

Janet: We went, we went to agencies and they just didn't turn up. Eventually I found somebody because I talked to a lady who had somebody who cleaned for her and she said that she'd ask her. It's that networking again which sorted it out.

We accepted that by taking the Direct Payment we were going to manage all that out ourselves. We didn't have a problem with organising all that ourselves. Having to pay them ourselves and having to do all the accounts for Social Services every year, that was fine and we were happy to do that. That was the choice we made.

But as I say, I think the system is broken fundamentally. I think because I've worked in the health service for more than 30 years I see inside the system. I know what's possible and what's not possible and I know what's achievable and they just disappoint me really. But, we're happy enough aren't we?

Alan: Well we cope very well. We try and be positive but I keep forgetting things. I'm reading on the internet that if you keep forgetting things you've got this and you've got that and you're gonna die, so I try to do new things. I tell you what I started yesterday. Origami! I thought I'll try origami so I made a rabbit. There's my first attempt at it.

Addison: That's pretty good for a first attempt.

Alan: I tell you have to be so precise with it. To make it decent you have to be so precise. Apparently if you learn really new things, things that you don't rely on past experience or your memory of having done thing before, then it creates new bridges in your brain. As I was telling you earlier about synapses and thingies to talk to each other. It actually creates new ones, which is good 'cos the new ones aren't like the old ones, all lazy and don't do anything and are forgetful. They're quite bright new thingies. So, I thought "Yeah new things are worth doing."

Janet: I love the rabbit. I think the rabbit's really nice. Is there anything else? We seem to have given you a huge amount already.

Addison: We've run through most of my questions in your story but let's go through the last couple. How easy do you find it to do the things that you want to do using Direct Payments?

Janet: I think that the things we use the Direct Payments for works for us.

Alan: They run quite well.

Janet: We've got our framework established. If we can keep it ticking over its fine.

Alan: If we can keep the same cleaner, the same guy who does the grass.

Janet: Initially setting them up was difficult because it was finding people to do what we wanted. But, we did find people, although we found them ourselves and we didn't get any help from anybody to do that. It was a question of trial and error. Trying agencies and other things.

Addison: And did you say you hadn't had any carers coming in?

Janet: No, we haven't. Right from the word go we didn't have anybody coming in to do care. Someone suggested to give me a night off we got somebody to come in and bring us a hot meal or come and cook us a meal. We did find somebody to bring us in a hot meal.

Alan: But, it didn't really work. The first meal that we chose somehow got changed.

Janet: Or, they morphed into the cheapest.

Alan: And sometimes she rang up and said she was gonna be late and sometimes this had happened and this happened...

Janet: She was a great talker so by the time she'd finished talking and the food was cold.

Alan: There was a lot wrong with it. Had that been forced upon us, in other words if it was essential that we had that, then I guess we would have had the same struggles as we had with other things. It didn't fit well with what we were doing.

Janet: The knock-on effect of that is if we have somebody come in and cook a meal for us I've got to have all the ingredients for them, which means I've got to go and shop for the ingredients. I'm a bit of an intuitive cooker. I'll go, "What's in the fridge, what shall I make?" It's much easier and simpler if I just cook and if I want a night off I buy an instant meal.

However, the cleaner who we have, the ironer who comes and gets our laundry and takes it away and the gardener who comes and does the garden; that all works for us. In terms of using the Direct Payments and using my carers grant for my art classes and having my facials, that work well for us and it's the right use of that money for us. We get things tailored to our needs. By using the hours, we get in the way we do that frees me up to do all the things for Alan that we don't have carers come in to do.

It means that if Alan wants to get up at 11 o'clock, Alan can get up at 11 o'clock and have his breakfast at 11 o'clock instead of between 7 and 10. If carers come and he'd had a bad night and couldn't get downstairs, it would be

a wasted visit for them and a wasted visit for us. So, the benefit of it is that we can tailor it absolutely to what we need.

It's about things happening at the right place at the right time for Alan and because I'm here that can happen because Direct Payments frees me up from other things. I've then got the capacity to be able to do that but it works, it's just getting the mechanism in place that doesn't work.

Addison: Well I'm glad to hear that there are at least some benefits for you.

Janet: Yeah there are some positives. I mean, it does really work for us.

Addison: That's good. I guess it's just everything else is a bit stressful.

Janet: I know, but the end result is a plus, it's just getting to the end result that has been painful.

Addison: Okay. So, what advice do you have for other people using Direct Payments?

Janet: I would say that they need to sit down and think about the things that matter to them as individuals. What I'm trying to say is that they need to sit down and think about the things that you only want your carer to do for you because they are the priorities. So, for instance Alan wants me to do his personal care. In order for me to do his personal care what can somebody else do for me to free me up for that? By having somebody clean once a week and by having somebody cut the grass once a week and by having somebody take the washing away and ironing it, that means that I can do the things that Alan wants me to do for him.

So, I would say to somebody sit down and think about what it is you don't want somebody else doing for you and then look at the other things you need doing that your quite happy for somebody else to do for you and buy in the services to do that. You have to put your own priorities first and just decide. Having somebody do your personal care, I would find that quite invasive, I would find that was it a crowd.

Alan: However even if you got a good one you know and you don't know that you would...

Janet: It's still a stranger seeing you in the bath and all the rest of it...

Alan: If I'm gonna take a shower I can't just shut the door and take a shower. I have to be helped into the shower because we have a special seat there with a special cushion I can sit on for a little while. But, they'd have to help me in, help me out and they'd have to help me to the settee there.

Janet: But, there's no dignity in that.

Alan: No, there isn't really. I guess if there is someone who was exactly the right kind of person then it wouldn't be too bad but you can't determine who that's going to be.

Janet: It could be a different person every day.

Alan: It could be a very invasive procedure.

Janet: Yeah, it could be a man if you're woman or a woman if you're a man. Nine times out of ten if you're a man you get female carers.

Alan: And the other thing is when the hell does it happen? When you need a shower or when you don't?

Janet: And, then you'd have to wait 2 years to be assessed for a level access shower, then it takes 6 months to get it in because it was the wrong time of year for the budget and all the money had run out.

Addison: Yeah. Is there anything else you would like to share with me?

Alan: I think we've been through everything. I guess there's a lot of people wandering around and they look at people in wheelchairs. I think, they think they're just people who are sitting down but they're not. They're don't want to be in a wheelchair but because they're there because they have to be. I'm not saying everyone should now suddenly step back and usher people through but I don't think people understand quite what it means to be in a wheelchair you know?

Janet: A perfect example is in our complaint. The bones of the complaint were that on the day the senior social worker came Alan had a onesie on and it was 11 o'clock. He really does have an issue with clothes.

Alan: Yeah, that's why I've got a skirt on.

Janet: She said "Oh, you're still dressed you're in your pyjamas." And, he just looked at me and I just looked at him. We just chose not to make any comment in response but you see, she didn't go, "I wonder why he's in a onesie. Is that because that's all he can wear because he gets pain wearing ordinary trousers?" That made us feel as if she was criticizing us, as if we were slovenly and not dressed in time for their visit and all the rest of it. So, its perception again.

Alan: I understand it's a bit strange to come in and there's a bloke sitting there in a skirt but there's a reason for everything. Either I'm a bit weird or there's a good reason for it. I tried to give you an idea why to stop you being embarrassed 'cos sitting there interviewing a guy in the skirt you know...

Addison: I've done personal care before and I've seen stranger things.

Janet: I met a lady at on a mobility scooter.

Alan: Yes, and Janet said, "Why do people always shout at you?"

Janet: She said, "If you're in a wheelchair or a mobility scooter you are therefore you're deaf."

Alan: Of course, that is the assumption.

Janet: She said, "If you're with another person, they'll talk to the other person about you instead." It's the, "Does he take sugar routine isn't it." That's about society and society's perception of people.

Alan: Yeah, people see people in wheelchairs and they'll talk to the guy who's pushing you or the woman who's pushing you.

Janet: It's like when we used to go to the dentist and the reception desk was lean on height for the girls used to. They'd pass the board over to me with a pen, to pass to Alan to sign it. I thought, "Sod, it I'm not doing this anymore." So, I just used to walk away and stand out of arms reach so they had to get off their chairs and walk right round the end of the thing and come to him in his wheelchair.

Alan: There are lots of people who have problems which make things difficult for them to do. Things which people without problems can do so easily, they don't think twice. People in shops who can't read properly or can't hear properly or can't see properly. I don't think people ever stop to think what it really means. I guess we're protecting ourselves not wanting to know about these things in case they happen to us.

Janet: In regard to Direct Payments, I think the other thing is that people shouldn't give up easily. I know it takes energy not to give up easily. But, it is a right to be supported and I think they shouldn't take "No," for an answer. I mean we were told we wouldn't get any help and we wouldn't be eligible for anything.

Alan: You have to be sometimes darn right pesky about it as the Americans say.

Janet: The whole idea of my making a complaint is so the system changes and so it gets better. However, if they deal with a complaint and go, “Oh god, it’s just another complaint,” and then pacify the people who’ve complained... I kind of felt we’d been brushed off in terms of the complaint and I didn’t feel that the issues we had raised had been properly addressed. I think we’d been pushed aside ‘cos this girl was no longer working for Social Service. We had no sense of satisfaction with that. The outcome for us was that we got a good assessment and we moved forward and we got the issues resolved. However, looking at the broader picture I didn’t feel anything changed.

I don’t think the things we complained about were minor issues, they were significant issues. If I’d had a complaint about my member of my staff about the headings we had put the complaints under I would have been really worried about that person and I would have done appraisal with them. I would have shared the complaint with them and I would have helped them to learn and move on so they were a better social worker as a result of that.

I don’t feel that as a result of our complaint any procedural or systemic change happened at Cambridgeshire Social Services and it should have done, it would have been a superb learning objective. They could have taken our case and used it as a presentation of, “These are the things that can happen, these are the things we want to prevent.” But, no they haven’t they’ve dealt with the complaint. They’ve just shut the book on it and put it in the filing cupboard and it’s a lost opportunity. I don’t think they took any learning out of that process at all.

I did. I learned not to trust them, I learned that I have to be on their backs all the time to get it right. I just feel it is a lost opportunity to modify the process and make the process better. I’m more than happy to engage in things like this because we’ve been through that experience. If we can help change things then we’re more than happy to get involved.