



Thomas's Story

“Know what the rules are, read the rule book, know what the rules are and live within them.”



Thomas's Story

Interviewer: Robby

Robby: As this all about Direct Payments can I ask how did you first hear about Direct Payments?

Thomas: Yeah, well that was when I was on the Carers' Partnership Board.

Robby: Oh, yeah?

Thomas: Presumably or hopefully have heard of William?

Robby: He's how I got my job with The Cambridgeshire Alliance, so...

Thomas: Oh right, well there you go then. Well, when the Partnership Board started I knew William. He and I have become sort of firm friends over the years. William as you well know, is very very knowledgeable in certain fields, just the same as we all are but his speciality really was Direct Payments. He was the one that educated us all and that's where it came from.

Robby: Oh brilliant. So, he spoke to you all at the Carers' Partnership Board about Direct Payments?

Thomas: Yes, yes he did. I seem to recall he probably did it on a couple of occasions, maybe even more. It was a subject that was always coming up because it was new. A lot of people didn't really understand it, as you can appreciate. People in the position of being a primary carer have had so many things turned down and struggled so much to even get as much as somebody to listen to you about your problems. When Direct Payments came in, handling it yourself and doing that sort of thing; there was a lot of scepticism and I was just one of those people, you know? When you've had it hard, you find it hard to engage and believe that anybody's genuinely trying to help you, if you see what I mean? So, that was it but William was well switched on and educated us. Initially I didn't see that there was a need for it but I presume there's another question later on that will fill this bit in. A need did arise and that's when I signed up.

Robby: Okay. So, can you tell me a bit more about the sign-up process?

Thomas: Yeah sure. Well, I got diagnosed with prostate cancer. It was all very, very quick. The information came literally by letter, which I don't think was the best way of doing it but that's how it came. I was told immediately to get in touch with the hospital. The gentleman there that I'd been seeing got me in for immediate admission for surgery. You don't want me to go through the whole

process and things that happened but over the course of a few days I had to get something arranged. At the time the prognosis didn't sound overly cheerful. I had more than 50% belief that I wasn't gonna get through it.

Robby: That sounds quite scary.

Thomas: Well it was.

Robby: And, you're looking after your wife at the same time.

Thomas: Exactly. So, the first thing I had to do was get help for her. Now, had I not been on the Partnership Board or known the people around, I wouldn't know where to go but I was and I did know where to go. I straight away phoned Carers' Trust, spoke to them and said "Help!" Somebody from there came up straight away and, to cut a long story short, by that time my step-daughter had come down from up north. She worked up north doing a similar job for carers to what Carers' Trust do down here, so she had a good idea of how things worked. So, by this time I'd gone into hospital and she was sorting it all out. That's exactly what she ended up doing, sorting it all out, getting cover for my wife, her mum, Mary and getting the Direct Payment set up. She consulted with the people at Cambridge at Cambridgeshire County Council, where it was appropriate. She literally did all that. They did a biopsy on me and then I had to have an operation but I was kept in for a couple of days even with the biopsy. She got this all sorted out in that short time.

Robby: That's good. So, she was there to help take up the slack a bit?

Thomas: Yeah, that's right. She was the one that was on my "What-If-Plan," if you've heard of it? Backup, emergency backup for carers. I've got a son and her, who were both my backup but you know she came down because she's my step-daughter but she was Mary's daughter you see? So, she wanted to make sure that her mum got the right kind of support and that I got the right kind of support.

I was told I hadn't, well no... I wasn't told then that I hadn't gotta do any lifting. This is the whole problem. I then went onto have the operation and within two or three weeks of having the operation I felt fine and right as anything. So, I started going out, as gardening's my hobby. I started doing my gardening again. I was carrying those heavy bags of compost around and then I started having bleeding. I went back to see the doctor and of course he was absolutely furious with us. He told me in no certain circumstances that I was, without using these words; he said "You're an idiot. You've just had major internal surgery, it would take somebody that's trying to get fit for the next Olympics at least a year to get over what you've done. At your age it will take you twice as long at least." And, I said "Well why didn't you tell me that when I was in hospital?" Apparently they did, but they do it all after you've just had

your operation when you're still woozy and you don't know what you're doing, so not a lot of point. So anyway, cut a long story short, I then had to sort of sideline myself from any sort of heavy duties and it did take just over two years to really start bouncing back in that respect. Of course, I could still do my voluntary work because that was straight forward and basic.

Well anyway, Sue that's my step-daughter, got it all sorted. Because she didn't live locally and because I didn't want any extra paperwork, we decided to have it done for us by Cambridgeshire County Council. So, we started doing it that way. The care agency started doing it and we were very very lucky to start off with that. Mary had a lady that turned up who was a not too dissimilar age to what I am now. I think she might've been in her 70's but she was a pocket rocket, she really, really was. People that were a third her age used to get out of breath trying to keep up with her. She and Mary hit it off really, really well and became very good friend's right through to Mary's death.

We had her, but then, I would probably say less than a year of her caring for Mary, the care agency lost the contract to Cambridgeshire County Council and it was taken over by another care agency. So, what happened is that virtually all of the staff from this one care agency moved over this other care agency. I had heard some not particularly brilliant reports about them nationwide but not necessarily locally but I was still a little bit sceptical. However, within about two or three weeks, literally two or three weeks, some of the carers that had moved over had suddenly said, "No, not staying here," and went back to the original care agency or left. That's how it started happening. It was just run very, very poorly.

We always asked, as I think you will find a lot of people do, we always wanted where possible the same person. Mary had her health conditions amongst which were mental health. She wanted people she knew and felt comfortable with. Would these people do it? No. I mean, the lady concerned lives half a mile down the road and they would send her to all over the place but they would send people, literally, from Chelmsford and Colchester up to see us here in Cambridgeshire. You work that out. And, it was never or hardly ever the same person twice.

They were never on time, sometimes mega early, sometimes mega late. They had an attitude problem. I had a couple of occasions where I had people say, when I opened door and let them in, they'd said more or less the same sort of thing, which was, "I hate this flippin' job." And I said, "Well why do you do it?" "Well I have to do a job because you know, I was on the dole and my time's run out for getting dole money," and things like that.

Robby: That's not the people you want caring for your loved ones.

Thomas: Well exactly, that's right. And I used to say, "Why are you coming all this way?" And they said, "Well, we come all this way because we get expenses on top for travelling and that's what makes our money." And I said, "With that attitude, you're not touching my wife then. Thank you very much, go bye." And they said, "What do you mean?" I said, "You're not looking after my wife. I want somebody who cares you know?" My wife's not a number and I wouldn't have it.

I had quite a few disagreements with the organisation because I asked for our original carer, Carolyn, back but they wouldn't do it. Carolyn wanted to come back this way. Anyway, to cut a long story short, this went on for about three or four months and in the end Carolyn came to my wife one day in floods of tears and said she was gonna leave. We said "Well, we want to change and go to another organisation, perhaps back to the old one." She said, "Well they've approached me and asked if I would go back but I don't want to if I'm not gonna be work in this area, especially with you two."

We then decided that we wanted to go back to original care agency. We phoned up the Council but because the original care agency had lost the contract and were no longer on their list of preferred suppliers, in order to have them, we then had to do it ourselves. So, that's when I started to do all my own administration.

Robby: Yes, so the options are that Cambridge County Council will do all the work for you and then Direct Payments is where you do it yourself.

Thomas: Yeah, that's right.

Robby: I've heard a lot of people actually start off with an agency. They meet someone they really like and then the person has to leave for whatever reason, they say, "Well actually we want to keep you." That's why people tend to go down the Direct Payment route because they want to keep someone that they know and that they trust.

Thomas: Yeah, that's right. Someone we know and trust. Anyway, yes so that's how we did it. I then approached Cambridgeshire County Council and said "We wanted to go back to the original care agency." They said "Well, you will have to do it yourself," which is what we agreed to do. I had somebody come from there to show me how to do the paperwork. We had to open up a new bank account and from there we proceeded forward.

Something else I've haven't mentioned, while we were at this other organisation another woman came along and when Mary was well enough for me to leave for half an hour or an hour, I would take the dog out for a walk or go and see my son and daughter. I would phone her on a regular basis to make sure she was okay. I could do that if she was in a certain kind of

condition but if she wasn't then I couldn't because she had respiratory issues as well. So, I used to have to sort of juggle these things.

Over a period of a few days, I can't say exactly how many, but about six or seven, a carer came got to talking with Mary, this when I didn't realise how bad Mary was. Because of her medication she was quite confused when certain things were asked. To cut a long story short, she could see Mary's credit cards in her wallet and something had come up in a conversation about, you know, "Is that safe to leave them there? I want you to put them somewhere safe," and that sort of thing. Trying to be nice to Mary but what she actually did is take Mary's credit card out. She found out from Mary what her pin number was and she made three or four different visits to the cash machine over the space of four or five days and got out over £1000.

Obviously I became aware of it. I felt as though I'd let Mary down, I blame myself. But anyway, I just hit the roof. I did go straight to Cambridgeshire County Council. They said there was little they could do other than suspend and/or dismiss the person. And I said, "Not good enough."

Robby: No, that's a criminal offense.

Thomas: That's it. I said, "Ah fair enough. I shall be writing to the Care Quality Commission." And anyway, they sort of jumped to attention a bit then. I can't remember all the little bits and pieces leading up to it but the end result was that when they sacked this person, she'd got, with her holiday accruals and all that sort of thing, she'd got about 900-something pounds that was owed to her. Technically and legally they were supposed to pay that to her directly but in the end they somehow must have got her to agree to pay it back to us. So, we got that and she lived local to here, not down in Chelmsford or Colchester. So, luckily enough I got to find out where she lived and I said, "Right, now I know where you live I want that money back and if I don't get it I'm gonna make your life a misery." She had got into drugs and that's where it had all gone. She had a sister who got involved and who wasn't on drugs and she made me the promise that they would pay it me back over a period of, I think it was six months, something like that. She said she would take responsibility for getting me the money back and that's what she did. We got every penny back in the end.

Robby: That's good but you don't wanna go through that in the first place.

Thomas: Well of course you don't. The one thing I do know is she will never get a job in a position of trust again and why should she? So, that was a pretty nasty situation but anyway, we moved on from that. The original carer Carolyn came back, we moved back to the original agency, you know the one that we'd been with, we went back to them.

Robby: This was when you'd got the Direct Payments?

Thomas: Yeah that's it.

Robby: How was the process between moving from Cambridgeshire County Council arranging care to arranging it yourself through Direct Payments?

Thomas: Well, in the end it was quite painless actually. I seem to recall, say for argument's sake, I told them that the Saturday the whatever it was, was gonna be the last call for the new care agency and they said we were supposed to give them so much notice and I said, "Tough that's it." And, I said "On the Sunday morning we're starting back with original care agency." Whether they were the days of the week or not I don't know, I can't remember but that was how it was done and it was a smooth process. I have no problems with Cambridge County Council getting it all sorted. In fact they were very, very helpful and I have no misgivings over any of the actions they did.

Robby: So was this through Social Services or was it through talking with the County Council directly?

Thomas: Through the Council directly.

Robby: Okay.

Thomas: Unfortunately, I haven't got the paperwork anymore. I destroyed it literally a few months ago because it's no longer pertinent. The business with them is finished, Mary is gone. I don't want an accumulation of old paperwork so unfortunately I can't give you the dates and specifics now.

Robby: That's fine. It's the story that's important, not the exact dates.

Thomas: Okay. But, the transition was very smooth. I was an auditor by trade, so I do know and understand paperwork well enough. I wouldn't have been good if it had to be done on computer, I have to confess. I've got one but I'm very poor at it. Of course I think if my memory serves me right, about twice a year they used to send me a letter asking for all the statements, telling me which statements they wanted and which period they wanted covered for bank statements, for invoices, for receipts and attendance and that kind of stuff. And, that's how it was.

The only real gripe I ever had is they'd send it in a small envelopes that's what, probably about eight by about five, six or five or something like that but you would have enough to fill a whacking great big one. I would have to buy one of these bigger envelopes but I would stick their prepaid one on the front

of it and send it back. Yet when they sent me the stuff back it always came back in a bigger envelope, which didn't make sense. I mean, I know it's a silly thing but it was the only thing that really used to annoy me. So, that's how that's how it worked. We had them right up until Mary's death. I have to say, over the last 18 months of Mary's life they had started to get very sloppy.

Robby: Is that Cambridgeshire County Council?

Thomas: No, sorry, not Cambridgeshire County Council, the care agency. They were struggling for staff. I've heard nationally with the other voluntary roles I do, most care agency staff don't get paid anything above the minimum wage and they don't get paid for their travel time in between calls. When you live in areas like this... I mean, in the case of Carolyn she always used to go from here over to such and such, which is about three or four miles each way. She would have to come back and go to somebody after that and go to somebody half a mile down the road from us, then she would have to go over to another village which is ten miles away, then she would go somewhere else. She would probably have about five or six calls in our village but she'd have two or three that were miles out and of course they would take her time up. So, by the time she finished her shift she had probably worked, including with the travel time, about six to seven hours but she'd only be paid for something like three to four of them.

So, at the end of the day with the minimum wage, I don't know what it is but let's say it's £7 an hour; with traveling taken off that would only work out at about £3.50. Well, nobody can live at £3.50 and sustain it if they haven't got other means of income or somebody else to help support that. In Carolyn's case, she was okay 'cos she was basically retired anyway and she liked doing it. But, the younger ones couldn't sustain it because it wasn't affordable for them to keep doing that job.

Robby: Well, it is a caring job and you should be doing it primarily to care but with the best will in the world it's still a job and you've still got to make ends meet at the end of it.

Thomas: Well of course you have. I mean, it doesn't really matter whether you're rich or poor, at the end of the day you work to live. I know a lot of people think we should live to work but you don't, you know. The reason we all go to work is because we have to to make a living.

Robby: That's right, yes.

Thomas: Now if you find a job or a career that you absolutely love and it becomes a vocation, like I do with my voluntary work, then that's great. I mean, I don't have to do it but I want to because I absolutely love it and I know I'm making a useful contribution. I'm fortunate that the job I did do I

enjoyed doing but not many people do you know. And, you've got to have a wage that's sustainable.

Robby: That's true.

Thomas: So that's how it had all worked. I mean, I can't particularly break it down much better than that. That bit about the money was the only really bad experience I had.

Over the years when Carolyn wasn't here there were some carers that came that weren't brilliant. The problem we had was Carolyn had very high standards. She was an ex-paramedic so she was well trained and of course most of the others weren't anything like that, so they never had those kinds of standards or outlooks. It was hard for them to follow in her footsteps. There were many, in the whole experience with the two agencies over all the years, there were many people that came to fill in for Carolyn who we just didn't want back again. I was often phoning up and saying, "Can you not send so-and-so to us again." And if they'd said, "Why?" I said, "My wife wasn't comfortable with them, or I wasn't comfortable with them." That happened quite a few times.

The only other issues we used to have was with timing. With Carolyn it was always okay and in fact there were a couple of other ones that if they were running late they would phone us and say, "I'm gonna be a bit late." But, there were equally a lot that if they were running late just didn't bother phoning at all. So Mary's first call in the morning was for 8 o'clock. Carolyn always used to get here at ten to but the others experienced ones were always here at 8 o'clock. But, then you'd get some of the new ones that'd suddenly turn up at half past 8, quarter to 9 even, things like that. By that time I needed Mary up, I needed her showered, dressed, changed, in her chair and having her breakfast. If I was going somewhere like The Partnership Board and I'd got somebody coming in for her at 9 o'clock, something like that, then I wanted her to be at a certain point before I left because a lot of her medication had to be delivered at a certain period of time either before a meal or after a meal if you see what I mean.

We found out over the years, with the amount of pills and tablets Mary was on, that if you did 'em too close together sometimes there was too much of a certain kind of tablet in her system at once. You know these time release ones, things like morphine and that kind of thing; if they were 12-hour ones, if I give them her at 10-hour intervals then there would be an overload, which for people like Mary was quite damaging. Equally, if it was 12-hour release she didn't want to be left 14 hours because the pain that it was trying to cure would be starting to come back again. So, it was critical to have all those things in place.

The breakfast ones generally speaking we were okay with because we had Carolyn doing them. Lunchtime ones it was always between 12 and half past and I was quite flexible on that because there were no tablets around that period of time. The teatime one we used to have been at 4 o'clock and the evening one was 7 o'clock. It got to a point where the teatime ones, that wouldn't be Carolyn most of the time; were always late. Sometimes, literally, it could be half past five, quarter to six, an hour, nearly two hours late. That person would go out the door and sometimes the 7 o'clock one might come at half past six, so you had two calls within three quarters of an hour.

It was a waste of time and the problem was, why I wanted them at 4 and 7 o'clock is because between those times I wanted to cook our evening meals. I wanted to get things ready so that they fitted in with Mary's tablet times, so it was very, very irritating. It puts more pressure on the carer but at the end of the day the organisations providing that care are getting their boxes ticked and the people providing the care are getting their money. They're all happy but the people, the users and the primary carers are the ones that are getting the stress.

When things aren't kept to a certain pattern, the pattern that you've asked for when you've had your assessment and expect to have it delivered; you're always getting one excuse after another. "Oh they got hold up here," or "They got held up there," and there's nobody to back it up you know. So it was pretty frustrating a lot of the time.

Robby: Did you chase this up with people?

Thomas: Oh many a time, many a time. But, you see it got to the point where it didn't make a lot of difference. If they hadn't got the staff then we just had to go with what there was.

Eventually I cancelled the 4 o'clock one because there was no point. I couldn't go out with Mary because I'd always want to be back at quarter to four in time for them to come but if they didn't come 'til quarter to six then it was pretty frustrating. I was expecting them to come at 4 o'clock, be finished with her by half past, quarter to five and during that time I would be preparing dinner so we would have our meal around about 5 o'clock. It would be eaten, digested and I would have had things washed up before the 7 o'clock people came here. But, when those two visits were crammed together I couldn't do either or any of those things, so that would put me behind. It would mean Mary's tablet taking was compromised.

It's just the little things. Well when I say these sort of things to you, they might sound like minor issues. They are when you're sat behind a desk delivering the stuff but when you're the person receiving it and when you've got lots of other things to do, you know as the carer with patients who've got time

controlled constraints on their medication, it is not little it is serious and it is stressful.

Robby: And when it's happening all the time as well.

Thomas: Well that's right. And, the lack of communication! I've never had worse communication in my life than I've had in this last 20 years. We've got computers, mobile phones and all other new ways of getting in touch with people but nobody ever really bothers. In the old days when there was just a telephone box on the corner or a landline or letter, everything used to work properly because people were organised. They had respect for one's time and that sort of thing. Yes of course there would be delays here and there but, you know, nowadays nobody really bothers. It's not just with care, it's anywhere in life. Nobody really respects time any more and it really does get very, very frustrating. As I say, I don't mean that applied to yourselves this morning.

Robby: Haha. Yeah, I was just thinking "Oh dear, I arrived half an hour late!"

Thomas: Yeah I knew in your case public transport would be difficult but as I said to you today I am not doing anything. If I'd have had something on then I'd have had to say, well if you're not here at 10 o'clock tough.

Robby: Sure. Fair enough.

Thomas: I didn't mind today but what I'm trying to say is that this is something that happened time and time and time again. I know with every other carer that I mixed with that we all have the same issues. People don't care. It's the same with the government. They don't care about carers really because they can't afford to admit how valuable we are to them. That's the attitude all the way through. When you see the figures of how much the percentage of stress-related illnesses there are in primary carers, it is because of build-up of things like this that adds to it.

Robby: Yeah, I can believe it. Did you ever go back to Cambridgeshire County Council to express your concerns?

Thomas: I did once or twice 'cos as I say I was lucky in knowing Linda. She's got another title now and I don't know what it is but basically Linda was Head of Adult Services amongst her many roles several years ago. When I started with the Carers' Partnership Board that was where I met Linda. So, I got to know her quite well and then when I joined the Partnership Board she used to come to that and I got to know her very well. Luckily enough she got to know that if I had a reason to complain there would be some construction behind it. It wasn't just me wanting to throw my toys out of the pram and just create a fuss. It would be something that I had a genuine concern over. So, Linda

would always find out who was responsible for dealing with my case and I would get the service that I needed to get things sorted.

So, in my case, in that respect, I was quite lucky. But of course, had I not known those people then my life would have been considerably harder. That is why it is essential for carers to have a helpline-type thing where there's a real person they can speak to in one call about these sorts of worries and get them sorted out.

Robby: You mentioned doing the paperwork. Did you do that that all yourself?

Thomas: Yeah. Well in actual fact no I didn't. All I used to do is collect the bank statements. Every month the invoice would come in, itemising that month's calls and how much the bill would be. I had a Direct Debit set up so that whatever it came to, the care agency could get it out of the bank account straight away. But there was always an upper limit because the money that used to come from Cambridgeshire County Council was paid directly into that account. That's how it used to work and so I used to just keep the paperwork. The bank statements from that account, the invoices from that account and the receipts that used to come back to say they'd got it because I always used to ask for a receipt. I would keep them in the folder and then when the Council phoned me up or sent me a letter rather, and asked me for information, let's say from the 30th June to 30th December, it was there. I used to just grab the lot, shove it in the envelope, send it off to them and they used to do whatever they needed to do, you know.

Robby: That's good, so not too stressful in that respect.

Thomas: Well no because you see just after I had my cancer... and bearing in mind I've skipped over it because once I started having that bleeding then there was about two or three months when I had do nothing more than lift a cup. So, Carolyn and some of the carers that we knew well would look after me by helping get the dinner ready and things like that. You know, they would do things like that just voluntarily to help us out.

Robby: Ah that's good.

Thomas: Yes, it was a fantastic rapport we all had. I understand that everybody used to like coming here. When Carolyn wasn't on duty they apparently used to fight, in a friendly way from what I understand, to come here because Mary was the most loving, endearing woman you could ever meet. It appears that I wasn't unpleasant either so they used to quite enjoy coming here, so there you go.

The only issues we had from a financial point of view is that once they started that new organisation and a lot of people that had gone over to the new

organisation did the same as us and went back. So the old organisation that had suddenly lost a lot of customers then gained them back again. They would always put their costs up on an annual basis and sometimes more than on an annual basis. The problem was because they weren't appointed by Cambridgeshire County Council, the County Council wouldn't fund the difference if there was a difference. It got to a point where I was gonna have X pounds shortfall a month, which I couldn't afford.

I mean, if you're on income support and all the state benefits they don't give you money to burn. So, what I had to do is cut out the tea time one and then later on I started cutting out the lunchtime one on a Saturday and Sunday so that would help to give us the surplus within the money that we were getting from Cambridgeshire County Council to fit the rest of the services. Strangely enough, not long before Mary died, we'd got to the point where I'd started saying to her "We're gonna have to cut another day, another lunchtime one out," or something like that.

Robby: That's not what you want, not when needs are increasing. You don't want to be cutting out services.

Thomas: Yeah that's right but that's how you had to do it. So, as I say that is another issue we used to have.

Robby: Did you feel able to go back to Cambridgeshire County Council and say "Look this is problematic?"

Thomas: Well yes I did but they used to sort of say "No." I mean, we did get somebody come to see us on an annual visit on one or two occasions and I think the money did increase a bit but not by as much as what the agency were putting it up if you see what I mean. So, there were always discrepancies, so cutting services is how we got round it. I couldn't afford it, you know, the increase. We didn't have the money, so that's how we had to manage.

As I say, not long before she died, we'd had the conversation about having to cut out another lunchtime one somewhere and I was trying to see which was the most suitable day of the week. Obviously the agency were going to want us to give them clear instructions well ahead of time. So, I was gonna have to pick another day. I don't know which one it would have been because we didn't get that far.

You know at the group you were saying you can only do certain things with the Direct Payments?

Robby: Yeah.

Thomas: There was one woman I used to know that used to go round and say “If you use your loaf there’s other ways and means.” She used to go to various carers’ meetings and say this is what she’d done. Don’t ask me specifics because I can’t remember, I mean I am going back a while. I was pretty annoyed with her and I said, “So basically what you’re doing is you’re getting extra money to help you and while you’re doing that there are people here that are needy that can’t have it ‘cos the budget’s run dry.” I was pretty peeved about that, you know and always will be.

To cut a long story short, I did mention this to somebody, I won’t say who, in Cambridgeshire County Council ‘cos I don’t think that’s how it should be done. It’s sort of like fiddling you know. What they did with that information I don’t know. Whether it got changed or not I’m not in a position to say. I just sort of said, “I’m on the Partnership Board and I’m here trying to help carers universally throughout the county to get the best we can for them.” We were always, obviously, trying to fight to get better deals. So equally, if we found somebody that seemed, as I did in that case, to be openly saying that they were misusing it, then I felt I wanted that person dealt with, you know?

I’m an auditor by trade as I say. The whole concept of an auditor is that you find out where mistakes are being made and you put them right. That’s all part of my upbringing or rather my adult life upbringing and I stick by those rules. I still do now and I’m proud of it you know. I loathe anybody that tries to do that sort of thing because it’s always the innocents that suffer as a result of it.

Robby: Sure. Well, you’re not generally allowed to hire someone to come and do the cleaning for you with Direct Payments for example but then you could have someone who will just clean the bathroom after you’ve finished in there. That’s sort of tidying up but you would have tidied up after yourselves anyway, which I thought was not a bad way of doing it if you’re struggling with that sort of thing.

Thomas: Yes, that’s right. Yeah. I understand that one but this particular person was on about helping to fund holidays and things like that.

Robby: Oh no.

Thomas: You know! So, that’s what I mean by that. There were other things but I specifically remember holidays.

Robby: No, it shouldn’t be used to fund holidays. Respite certainly but that’s not the same thing.

Thomas: Yeah, so there you go. So yeah, what next?

Robby: You've sort of answered the problems question and gone quite into detail into that so that's okay.

Thomas: Right.

Robby: So, how easy did you find it to do the things that you wanted to do on Direct Payments?

Thomas: Well the things that I was allowed to do. I didn't really explore things like respite and that kind of thing because Mary didn't want it and to be perfectly honest I didn't want it. It is the one situation where I always said to her, "I married you and yes, I need a little break when I go and do my voluntary work and things like that." I used to see that as my respite but there was always somebody that used to come in and look after her, keep an eye on her, that sort of thing.

I didn't want to have breaks from her and I certainly didn't want her going into a care home. She'd had very very bad experiences in the beginning when she had her nervous breakdown. And, I'd always promised her that I would never let her out of my sight as long as I had breath in my body to do it. I like to hope and I strongly believe I managed to do that, certainly to the best of my ability.

So, help caring was really the only thing I sought. We did try having somebody cleaning but we funded that ourselves. For about a year we had somebody coming in once a week to Hoover and clean. She was meticulous when she started but by the time she'd been settled in, after a few months, she became sort of, flick of the duster here and flick the duster there. You could always see things that niggled you if you know what I mean. And, because Mary had respiratory issues, I needed the place to be dust-free and clean. I often used to have to go round after her. I used to say to her now and again, "Can you do this or can you do that?" If I asked her she'd do these things but she wouldn't without being asked. It got to the point where, once I enough strength back to be able to do it, I said "Thanks, I can manage now you know." She wasn't very happy with that but that was it.

Robby: That's what you've gotta do.

Thomas: That's right. So yeah that's how we got round it. But no, I didn't use them for anything else. I know the option was there to apply for it but I just never took it up.

Robby: But that's what you wanted to do, so it worked out quite well for you in that regard.

Thomas: Yeah, that's right.

Robby: Are there any other benefits of using Direct Payments that you can think of for yourself?

Thomas: Well I can't actually because as I say, I never had the reason to do it, to need them. I had a sit-in service with Carers' Trust which wasn't part of Direct Payments but that was provided by them. I used to have somebody come in for 3 hours once a week but I could get that person in at other times. That was if I was doing voluntary work for them and I was gonna be out of the picture and I needed somebody for Mary. They would always provide me with the same people where possible for Mary. We got it down to about three people that Mary got to know and between those three they would cover things when I was out. Same as if I had to go to hospital for my benefit.

There's nothing else that I know of through Direct Payments. I think in answer to your question, I knew all the things that it was possible to apply for with Direct Payments but help caring was the only thing that I chose to ask for.

Robby: Sure. Well it's good that you've had the information at your fingertips.

Thomas: Yeah. Well the thing is, going right back to the very very beginning, I would be having conversations with William you see. I'd be saying to him little bits and pieces and he would tell me whether I could or couldn't get this kind of thing if it was needed. I was quite happy with what I had in that respect. As I say, the problems that we did have were with the girl taking the money and these various different people coming in that really weren't qualified.

Another thing I haven't mentioned is that there were a good many occasions when Carolyn would be given any trainees that came from this area. They would be assigned to Carolyn because even the agency she worked for knew that Carolyn was the best trained of the lot. So, she would put them through their paces, so to speak. I know of more than a handful of occasions over the years where somebody has started, say on a Monday and they've been with Carolyn three or four days, come the weekend they'd had to go out on their own. We've had one or two that have come here to Carolyn and they really haven't got a clue. The three or four days isn't enough.

Robby: No you would have thought at least two weeks.

Thomas: Well certainly because the same argument applies with primary carers as well, like I've just sort of said. I say in my story when I tell it at the hospitals and with Carers' Trust. When Mary had her breakdown, they got her home, they sedated her and the doctor give me a box of pills. He said, "Read what I've written on the side and not inside." And, that was my training to be Mary's mental health carer; I never ever ever had anything else. So I had to sort of work things out myself.

What did I know about mental health? I didn't know a thing. I hadn't come from a family where it had been evident, although I could probably look back and say I'd got a couple of mad brothers and that sort of thing but that's being a bit flippant I suppose. The point is, I didn't know anything about anything. I could stick a plaster on my hand and take a cold remedy when I'd got one and that was just about the only knowledge I had of anything to do with health.

When we went to see the specialists at the hospital, they were satisfied with everything. They just accepted that that was what it was. Nobody ever said, "Well done," "Thank you," "Good work," or anything like that. But, if I did something that wasn't quite right they'd give me such a bollocking you know. The difference was that I wasn't one that would stand there and take it. I would have a go back.

I had to stop doing that after a while because the problem was that Mary felt that she was the problem as these people do. So, it really, really didn't unify the whole area of treatment and the people providing it. There was always a certain amount of animosity and that made it hard.

But as I say, the lack of training for carers and the lack of training for family carers, and the lack of proper training for professional carers is sadly only too evident, you know?

Robby: Yeah that's true.

Thomas: As is the attitude for a lot of people providing care because at the end of the day they are not getting paid a decent wage. As I say, the fact that they don't get paid for travel time is absolutely criminal.

Robby: Yeah. I wonder how are you going to keep up a workforce like that? People need to live.

Thomas: Well that's right, yes they do and it's got to be better addressed. I mean, I know and everybody knows that, at the end of the day, the NHS is struggling. One of their biggest issues is bed blockers in hospitals and in care homes. The only way those things are going to get properly addressed is if you can find carers for the people who are doing the bed blocking. But, nobody's going to rush to give up a job and become a carer for somebody when the treatment they get, plus all these other issues that we've discussed keep throwing themselves at you and you haven't got anybody you can turn to who can sort it out you know, straight away.

Robby: Yeah. These things always seem to take an inordinate amount of time unfortunately.

Thomas: Yeah absolutely, this is it you know. It's so badly managed and that starts right at the beginning with the government. The fact that they don't give us the money... I better stop there because I'll get too political and you probably don't want this.

Robby: Well, I'm not allowed to share my political views although I definitely have some!

Thomas: Sure. Yeah, that's right.

Robby: We're nearly finished this. Next, penultimate question would be, what advice do you have for other people who are looking to use Direct Payments?

Thomas: Well without a doubt I would be saying first of all write down what it is you want and why you need it. Ensure that when you are assessed that you get your provisions made available or if they can't be, be clear why it can't be provided. Know where you need to go to in one single phone call if it's possible when you've got a problem. If you've got a problem, it shouldn't be that you've got to chase around to find out who's responsible for it and be getting passed from one person to another. I would always say to be prepared, get your facts right and write everything down. Get names of people, don't leave anything to memory and just cover your own back at all times.

I will say now what I used to say to my managers and staff where I used to work. I used to say to them, "Know what the rules are, read the rule book, know what the rules are and live within them. If you make a mistake within them I will support you all the way. If you go outside and use a cavalier approach and you make a mistake, you are on your own." I would say the same here, know what your parameters are and work within them.

If they're not enough to fulfil your issues then go back to the County Council or find somebody that you can take it to the Carers' Partnership Board where it can be discussed openly. There are ways and means because that's the whole point of having the Carers' Partnership Board, to get these issues raised.

Robby: Yeah. I've spoken to quite a few people and it's not just the Carers' Partnership Board it's any of different the boards. I was chatting to someone with physical disabilities about all of her issues and said, "This would be great for the Physical Disabilities Board." Something to actually chat about, bring forward and try to resolve it there.

Thomas: Yeah. So, if I may ask then, is with what you're doing here, this piece of work on and all the issues that are coming from it; is this something that has

been to the Partnership Board to be discussed yet or is it going to be fed back to them at some point in the future? Because if not, why not?

Robby: Well, I think some of the issues that have come up have definitely been raised in various Partnership Boards. I think sometimes its problematic because you think, "These are the same issues that were coming up years ago, why haven't they been resolved?" But yeah, certainly some of the things that people have told me are definitely getting fed back into the Partnership Boards. Also, there is definitely going to be a report at the end of this project highlighting the issues and common themes that people have told us regarding Direct Payments. That report is going to the County Council.

Thomas: Right, so who are the professional organisations that you're going to feed back to?

Robby: In terms of care agencies? I haven't got any care agencies in mind. I can certainly make a note of some if you think like that's worth my while doing so?

Thomas: Well, I believe I'm right in saying that the care agency we used after our original one ceased to trade, certainly under that label. Whether they've been reinvented under another label or whether that one's disbanded and same people that were running that are running something else I don't know. But again, you see, if that's what is happening, basically it is corrupt, isn't it? It certainly is from our point of view and it shouldn't be allowed to happen. If people have failed to live up to what they need to do when they set up a business, then they shouldn't be allowed a second chance because lives are at risk all the time. That would be my view but whether that's what happens or not, or any part of it is what happens I don't know.

I have no other experience outside that, not at first hand. I've heard a few people say, oh they're rubbish or these are great and that sort of thing but I couldn't back it up either way and it would be unfair to make comments because they are third party.

Robby: Sure. I've got very little experience of actual specific care agencies. I've heard about good and bad things about various agencies. Like Penderels Trust, that was one that came up the other day. I've heard good and bad stories about them. I actually had a lady said the other day that she was not very happy with them but I've heard other people say "Oh they were wonderful, everything was smooth sailing." So, I guess its people's personal experience.

Thomas: Yeah that's right. Well again, I haven't had dealings with them but yes, I have heard a lot of primary carers say their rubbish and I believe I've heard it said by some of the members on the Board. I've now obviously stopped being

a Board member 'cos now I'm no longer a carer. You're allowed to stay on it for up to a year afterwards and my year finished. I had missed several during that last year after losing Mary 'cos I just wasn't up to doing it. So yeah, I'm out of that now but I do do the work for Carers' Trust. I know, where appropriate, they fed through to Cambridgeshire County Council because they're obviously contracted by Cambridgeshire County Council to do certain things. I still keep in touch in that respect but I don't know the inner workings any more of the Partnership Board.

Robby: Well it's good to keep in touch.

Thomas: And, I do beg your pardon when say, "Does it get fed back to the Partnership Board." I forget that you represent lots of Boards.

Robby: Well I work in my own little bubble. I do know about them and I do attend them now and again but I don't really work within the Partnership Board branch for the Alliance.

Thomas: Yeah well, I didn't mean it to sound as though the Carers Board was the only one but it is as far as I'm concerned as that's the one that I associated with.

Robby: Yeah, it's the one that's the most pertinent to you, which is fair enough.

Thomas: Yeah that's right. You said penultimate question, so do you have one more?

Robby: Yes, my one last question would be, do you have anything else you would like to talk about with regards to Direct Payments?

Thomas: I can't think of anything that I haven't already said. I mean, can you think of anything that's been said by others that jogs the memory at all?

Robby: No, we've talked about quite a lot I think, which is good. A lot of information.

Thomas: Yeah. Is what I've said useful to you?

Robby: Very much so. I think like it's good to gather both good and bad experience, like you've had. Good experiences highlight things that have gone well; bad experiences highlight things that need to be improved. Both of those are very useful for professionals and other people coming in looking at Direct Payments. What are the benefits, what are the curves, what are the pitfalls? I also think the things you've said will be very useful in our final report that we will feedback to the County Council at the end of the project.

Thomas: I have just had something come to mind thinking about it, while you said that. You know when I said about we wanted to come away from second care agency and we wanted to go back to our original people which meant having to have Direct Payments ourselves because they weren't on Cambridgeshire County Council's preferred list?

Robby: Sure.

Thomas: What nobody in Cambridgeshire County Council ever told me that Care UK wouldn't have been the only care provider that they were contracted to use. I could have chosen another one on a preferred list. That was never made clear to me. That is why I said I wanted to go back to the original care agency because I knew what we'd be getting and who we would be getting. But, I was never told, when Care UK had the contract, that they were only one of however many and that I could've asked for another one.

Robby: Well, Cambridgeshire County Council, they're very keen on pushing people onto Direct Payments. Certainly at the moment it's a big thing, they want to get people off their books and managing themselves.

Thomas: Yes, that's right, which I understand. But as I say, if they have got three or four different preferred care organisations, when you ask them to manage it for you they should at least give you that information and give you the option of looking at one or two.

Robby: Yeah, that's a good point. They do say "It's all about choice and control," and if it's all about that then they should be making you aware of what your choices are from the get go.

Thomas: Yeah, that's right. Well that was never made clear. Whether it's changed or not obviously I don't know. But, at that time at least to us, it was never made clear there was more than one provider on their books that we could choose from, so there you go. Okay?

Robby: Sure. Yep. That's great, thank you very much.