Q OK, so if you would like to start off by telling me why you wanted to take part in this study.

A Oh I thought it was very interesting, it’s something I always refer to, spinning plates. Because being a carer of a child with complex needs we spin an awful lot of plates, plus we’ve got our own issues as well to deal with with families and family issues. And one of my ?concerns? right from the beginning, I mean our disabled son is now 28 our other son is 34, and right from the beginning my concern was that mental health of carers was not being addressed, even though you belong to a carers’ organisation. It was ??? ??? did an expert patient programme course and then became a tutor on it, and it was interesting that the adapted course for carers was 5 minutes relaxation at the beginning and 5 minutes relaxation at the end! Which I thought ‘oh no, we need to….’.

When I first met five carers four of them were on anti-depressants or beta blockers, and I thought oh that’s all very well it does help bring your mood back up but it doesn’t solve the problems that are causing it in the first place, like you can’t access things if people don’t talk to you in a respectful way, especially professionals. And nobody was sort of addressing these, the mental health. And I personally have had to leave work three times because my mental health went down and my brain literally couldn’t not cope with things like ‘what is F’, the alphabet did not exist for me at that time, some of these aspects to file a file. And I thought the mental health of carers is a huge issue. And it’s almost like ‘oh just take a deep breath, breathe in, count to 10, and breathe out – and you’re on your way now’. So it doesn’t help when I sort of look at it that way. It’s the other underlying issues, causes, need to be looked at and addressed.

Q And does your son still live at home with you?

A No he went to live in residential care in 2017. But I still have to be involved because obviously having….he was….oh what’s 2017, three, four, six years ago. The care home wouldn’t have had the background knowledge, and I know for experience that things for example like increasing medication even slightly has a huge impact, so you have to be aware of that and whether you’ve tried it and what happened at the time. And what to do, he’s tube fed as well, so can you actually increase his feed if you….you know even though the nutritionist might think he is underweight there is great difficulty in trying to increase his feed unless you know how to do it or whether you can do it. So it’s having that awareness.

So we try and get involved in any health assessments, attending appointments for the ??? for his epilepsy and so on. So we still get involved in that. And unfortunately, as you will have picked up from the messages I sent, the last two and a half weeks we were in hospital with him all the time because he had a chest infection and pneumonia. And unfortunately, even though they’ve got a learning disabilities unit they don’t really understand what learning disability really means – or at least the staff don’t seem to be aware of it. And he needs high sides, they don’t have high sided beds. And if you ask them to keep an eye on him if you go out somewhere, even for a quick drink or something, you come back and there’s nobody there. So that’s why we have to be there. I think for other families with complex needs they need to be like that as well. And I did meet in the past when we’ve been in hospital in initial assessment stages we did meet another family member who also had a daughter with complex needs and so she was in a similar situation.

But because there’s fewer of us, I don’t know whether it’s 24,500 with more complex needs nationally, we still just seem to be off the list. Or when people do assessments or research it’s like ‘oh well anybody who can talk who has got a learning disability will therefore be aware of the complex needs’. And I don’t think people are and quite often people don’t ask the parents, especially if they’re over 16 or 18, they’re all ‘oh no it’s the person with the learning disability who has to communicate’. And [son] can’t communicate. I will send you a video of him at some point. He just makes sounds ‘a…a…’ so he can’t talk for himself. But I won’t get invited because parents aren’t invited. Therefore 24,500 of us who really aren’t represented.

Time 5:12

And you see that coming out in whatever the government comes up with, or the local government comes up with, that they cater for learning disabilities but not with complex needs and learning disabilities. Like the high sided beds, which I’ve experience in [Hospital 1], [Hospital 2, ] [Hospital 3] [Hospital 4], [City] Hospital, all had the same issues, they didn’t have hoists or they couldn’t find them, or they weren’t charged up, they didn’t know how to use them, weren’t aware of learning disabilities and they weren’t aware of high sided beds. And my son being 28 he looks on the small side, but being 28 he’s on the adult wards but he needs a bed from the children’s ward – but the two don’t communicate somehow, there’s no crossover there.

And that causes such huge stress. You know for both my husband and I spending 12 hours each swapping over, not seeing each other really except for a quick breakfast and a quick tea and then the other one goes home to have rest or bed, or swapping over. But that’s what we’ve had for the last two and half weeks. And it’s just stressful because I also kept hearing people saying ‘oh yes we do one-to-one care’ and I said ‘even if you can provide an hour’, which fortunately our care home did on most of the days, but we just need that extra time for us to be together. Because if [husband]’s working I’m still on my own, I’m on my own for more hours, and just to have just that one hour.

And everybody, the nurse, the clinical… critical care nurse, they’re all saying ‘oh no you can have 24 hours’ – two and a half weeks later nothing’s there. I even checked with the nurse at the desk and said, ‘somebody said, you know the critical care nurse said this is available, can you sort of check’, ‘oh I’ll check for you’ – nothing. And in two and a half weeks. I suppose maybe if I’d been moping and wailing I might have got it. And then somebody said ‘oh well yes we do provide it for dementia care’. Again, well that’s very well but I need a bit more of a break than just an hour, you know. And I need to see my husband as well and we need to discuss things.

And also it’s very stressful because right at the beginning everyone kept saying ‘oh have you thought about DNR’ and then they can’t come up with a leaflet that looks at complex needs and DNR. I need to know what are the realities for those with complex needs if you try to resuscitate them. And I had one doctor who actually explained everything right from the beginning to the end and compared it to somebody else with an adult ??? get you involved anyway for somebody with complex needs, and especially with our son who has got scoliosis, severe scoliosis, this the probabilities and what we would decided, what we would still talk to you as well. It would be everybody involved in it. So sorry for the long answer to the short question!

Q No that’s fine. I’m sorry it’s so difficult for you. You said that really early on you realised that the mental health of carers wasn’t really engaged with.

A No.

Q So did you seek any health for your mental health over the years when your son was younger or…how did you manage it?

A I think I did in a way at the beginning, the first time I left. I seem to leave every 7 years. So I work for 7 years and then I have to leave because obviously it builds up to 7 years. I did go to see a doctor and I asked them if… for me I saw it as severe stress, and to me. I interpreted it as all the same symptoms as depression but without the depression bit, it’s all the anxieties, the worries and frustrations, and the fears and whatever but not the depression really. So I don’t know whether there is something like that because it’s ??? looking at information online and he always goes to sort of the traditional explanations of ‘this is depression – oh no you’re depressed’. But I’m like ‘no I’m not depressed, I’m severely stressed and that makes things happen’. And obviously when we found out later that things that I sort of experience other people experience as well, where my memory goes, I can’t remember things for several days – even a PIN password that I’ve had for 20 years it takes me 3 days to remember it again.

Time 9:50

So I sort of did go to see a doctor. I thought I was stressed, severely stressed and so she offered me anti-depressants and I said ‘well have you got anything else?’ And she said ‘well you know where to come’. A week after I picked up the Patient’s Charter and in there it said the doctor should be able to offer you an alternative – and in fact there was an alternative because prior to going to that GP appointment I’d become a trained Health Walk Leader and I had read about exercise and walking, which is free and you don’t have to pay for it, can help. So I thought I’d use the walking. It took me 6 months to sort myself out.

But I think it would have been nice if they had offered me and sort of said ‘have you tried some health walks? And also perhaps persuading me to sort of take the tablets because that would maybe boost the emotional hormones back up to a more normal level so I could feel better. But sometimes people don’t push things, or people don’t want to sort of explain ‘have a think about it but we do think you would feel much better if you had the tablets as well, but do the health walk’. And unfortunately they’ve redecorated the surgery and taken down my health walk posters, thank you very much! So anything that’s for free where it doesn’t involve money, they don’t really want to know. But that’s being cynical – sorry!

Q So when you said it took you 6 months from starting to walk, was that until you started feeling better, or it took you 6 months to start walking?

A No, no because I was a trained Health Walk Leader, we were already doing health walks. We were leading a group weekly and then I started another informal walk on another day, so we had two walks a week. So I sort of thought ‘well….’ Because on our training we had these information sheets and it talked about depression and exercise, particularly with walking. So I thought, you know this is supposedly research based so I’ll do that, I’ll carry on walking and increase the walking. And I started walking more. And it took me 6 weeks to feel better….er 6 months sorry, to feel better.

Q OK, so it did work.

A It did, yes. But I wish they’d sort of, you know if they’re a bit more involved in what’s available out there. And in fact the Centre was one of the….was it Healthy Living, at the time there was funding available for several years for Healthy Living Networks and Healthy Living centres, and the surgery where I was was actually a Healthy Living, part of a Healthy Living Network. It had a Healthy Living café which they got rid of. It had an information point with computers that people could go access. And it had health walks which they could access, and which they got rid of. So I thought….and now they’re sort of all of a sudden they’re getting social prescribers to find out what’s out in the community. Well they’ve got rid of the healthy café, they could have promoted….you know they encourage patients to eat better. They do have more meetings with the Patient Participation groups.

But there’s no….I don’t know there wasn’t any logical thinking there where they got rid of the café, they got rid of the information point, and then they’re sort of saying ‘what’s out there?’ You’ve lost everything that you had out there and that could provide you with a lot of information. So sometimes I feel that professionals don’t always think straight, they only think about some sort of tunnel thinking. But I’m like why don’t you use my health walks to encourage more people to go on a health walk.

And then what was funny was, one of our health walk people, participants, came back to the Centre, she had to go upstairs. And we have a lift in the building, went to use the lift and one of the doctors came out and said ‘have you thought of using the stairs’, I said ‘well I’ve been on a 3 mile walk today, I think I deserve to….’ Yeah. Never make assumptions.

Q Indeed. And so do you still walk?

A Yes on and off. I have problems with my feet, I’ve had problems with my knees. But I have problems getting to see the GP and I have problems with the GP listening to me when I say ‘I have a problem with my knee’ and they carried on talking about something else. So I sort of gradually started to sort out one thing at a time. I’m trying to get a pace….not a pacemaker, a heart monitor but because I had a rash I had to go and see the doctor, I couldn’t get to see the doctor and all these long complicated thingies. So every so often I seek ???

Time 15:13

But at the moment I’ve got breathing problems, which I’m trying to sort out with a cardiologist. So it’s not like the children’s side where you’ve got a pediatrician who deals with everything and refers you to this, refers you to that, or refer you to that for that. You know with our son it was we’ll refer you to a wheelchair service, we’ll refer you to orthotics for his shoes, we’ll refer you to the back specialist to make sure his back’s OK because he has scoliosis, and tube feeding so we need the nutritionist. So we juggled an awful lot of things.

And then sort of whilst [son] was in hospital for two and a half weeks I had to get a heart monitor. Cardiologist said ‘you’ve got a rash, it might make it worse, go back to your doctor’. I said ‘can you refer me to the skin specialist to get rid of the rash’. And so unfortunately she couldn’t refer me. You’d think as somebody who is a consultant can do something simpler like do a referral, but for some reason she couldn’t. Went to the GP surgery, the receptionist said ‘you’ll have to phone tomorrow morning, we can’t do anything here, all appointments are booked’. And this was on a day when they do all the emergency stuff, and I’m going ‘well I need to have my monitor’ but she didn’t understand. Phoned on the Tuesday, I was 29th in line, came to place 5 and the phone rang me off. Phoned in again and they said you’ll have to phone tomorrow.

So my husband said ‘well we’re in a hospital, there’s an urgent treatment centre here, let’s go to the treatment centre’. So I tried the next day, couldn’t do it, I just ended up driving round the car park, round and round like everybody else at lunchtime, we were all driving round. So [husband] says, my husband says to me ‘we’ll try in the morning, there’s hardly anybody in there in the mornings’ so I went at 7.30. There was only 2 or 3 of us there. I got seen by the GP who was there. And again she couldn’t refer me to a specialist. So it’s head banging stuff this.

And then also she could do…she gave me a prescription for some emollients and, I can’t remember what it’s called, Betanovate. She gave me a prescription for something to sort of help me sort of…I’d developed eczema on my hands, she sort of gave me some cream to sort of keep me going while I sort of worked through all the systems and saw the doctor again. And it turns out that what she’d prescribed me hadn’t been available for 3 months and was going to be discontinued. And you think I’ve had this situation before with my son as well where you get prescribed something that’s out of date, isn’t being reinstated and is carcinogenic. So ??? in the past was found to be carcinogenic so they stopped providing that and he is now on Omeprazole. But I’ve had them try to prescribe him Ranitidine and I kept going back to the pharmacist who sort of kept saying ‘oh no it’s out of date, you need to…’ you know.

So all the things, I’m sorry, it’s like a factory of ??? but all these things happening, you ask one question and it’s like ‘agh’. It just gets so complicated. We were juggling [son] and his chest infection and pneumonia. The worrying situation of Do Not Resuscitate, do we sort of do that again. My having to get ‘I can’t breathe very well’ and discover that our family have got this breathing thing that must be genetic. So I’m finding it difficult to walk because I can’t breathe if I try to walk faster. So I want to find out, if I exercise what happens and what is it that’s stopping me doing it.

So I’ve noticed over the past….so I’m juggling all these things and then trying to do some babysitting in [city] while we’re in the [region]. So currently we’re actually having a break from just having done some babysitting and ??? with our older son who has got a 4 year old now. So there you go. I’m sorry.

Q So is there a story that stands out for you about being a family carer and your mental health. Or is there sort of like something that just comes to mind when you think about it?

Time 19:50

A I don’t know I keep thinking about it all the time. I think well if I’ve had severe stress and the way it makes my brain go….I mean the worst situation was the first time I had to leave work after 7 years was that my manager gave me a folder to file. All I know it was something beginning with F. And I thought ‘I don’t know what to do with this’. I mean if you now gave me 100 envelopes with names on I would happily just put them into, in a couple minutes, and I’d have them in alphabetical order whether by name or address or town or whatever, I would happily do that. But at that point my brain went ‘I don’t know what F is’. I said I’m ever so sorry, I don’t know what to do with this. My brain just completely shut down. And I didn’t understand that this was possible. And I didn’t know what to do with it.

And I found it difficult to cope with other things and do things. Listening to somebody else, and especially some members of my family keep putting me down for things or saying ‘well you do that yourself’, ‘I want some help mum and dad’, ‘no you can do it yourself’. But when I’m asking for help I want the help. And my brain just went ‘OK, shut down’ and it felt like a goldfish bowl on my head. I could see my sister talking to me but I said ‘I’m sorry I can’t hear a thing you are saying’ my hearing went. All I could see was her mouth going but I have no idea what she was saying to me. I said ‘I’m ever so sorry, you’re going to have to stop because I can’t hear a word you are saying and there’s no point in carrying on really’. And so it took….you know.

And I have met a couple of other people who have been in that kind of situation and had those kind of symptoms, but finding that on the NHS choices websites or anything, because they only give you the basics, you know you’re stressed, you’re out, ???, you’re worried, they don’t tell you about all these other little symptoms that you can have. You know it always seems to be just the general basic symptoms without saying ‘here are other possibilities’. A bit like you could do with having leaflets which are like what you get with the tablets, like boxes of tablets where it says ‘here are the…’ you know most people will experience this, a few less people will experience this, and a very small number of people experience this. Well I’m the small plus. I experienced really weird things like tunnel vision, where I literally can’t see. I tried to go through the doorway and I’d bump into….because I can’t see where the door and the wall is on the side. It’s very weird.

But I have met other people who have the same, but that doesn’t seem to be written down generally so it would be nice if the health professionals were a little bit more honest and explained a little bit more. Because then I keep finding reports that say ‘GPs and the patients aren’t very educated’. But that’s another thing actually, I’m sorry, but they’ll say ‘oh your blood pressure’s high’, ‘yes – and?’ So you have to say ‘well what’s my blood pressure and what should it be and how do I get it down?’ ‘Oh eat a healthy diet’. ‘What do you mean by healthy diet?’, it’s different for me and my husband, my husband is diabetic. We were both in the same meeting ‘eat a healthy diet’. What does that mean? There’s no explanation. Professionals don’t give you that explanation.

So everything impacts on everything else you know, and I want to be there for my children and I want to be there to support my son, but I want some help as well. And that’s what caused me stress when you ask for things and you don’t get given them, or you sort of get treated like a child, or sort of when you get accused of something that you haven’t done or anything. But that’s the one thing that stands out, the first time I left when my brain just shut down and I couldn’t cope with anything.

Q So what did you do? Left work? And then did you feel less stressed because you weren’t working?

A Yes because I didn’t have to worry about whether I was doing something right. Because if my brain was shutting down and I couldn’t sort of work out how to file things, where does F come in the alphabet, how to file things. It’s stuff that I usually love doing, I love sort of doing things and making things in order and doing the statistics and charts and things. But when your brain then sort of suddenly stops you doing that, I can’t do work because it was an admin post. It was one I really enjoyed because it was to do with Arts, it was ??? Youth Arts and they had a graffiti artist, they had a music artist, and you used to work with 14 to 25 year olds who might have been excluded from school, or who needed some extra skills which maybe they wouldn’t get from school perhaps. And I really enjoyed that work and got to see what they did. And we juggled with 100 projects a year, so we had to look for funding and do the applications for it. So it involved a lot of writing and thinking and re-jigging things. And I had to do the book-keeping as well. I had to keep looking in books to see what the National Insurance was for different artists if they were doing another job. So there was a lot of juggling involved.

Time 25:21

And there was a lot of juggling involved with the caring, so I had to just step back out of that so I only had to juggle the caring bit, but even that was complicated. Because with [son], he’s got….when he was born he had epilepsy the first day, got put on Barbitrips? I think it was but it’s taken off, but stayed in Special Care for a week. Then I think he was over the next 6 months, towards the end, the health visitor found he was failing to thrive. And it was very tiring because it was feeding on demand, so you didn’t know what you were doing really, you just carried on doing that without realising what’s going on. She realised. Saw the GP and she had no notes in front of her and said ‘next time breast feed’, in other words blaming me. I don’t think you can do that. You shouldn’t do that. It’s something ‘well what was your hospital experience’ they caused me to have a cyst on my breast so I couldn’t breast feed. Because somebody had had….there was broken equipment that they tried to use at the hospital but nobody put a sign on it to say that it was broken, so I used it and caused a cyst.

So communication is the biggest factor in anything, any jobs, anywhere you go, anybody you talk to. The communication, well if it’s not there or you’re not communicating or it’s communicated to one person but not to the five other people who are relevant, you know. So it’s a very stressful situation. But [son] also has epilepsy which developed again at 6 months. His scoliosis started to develop over those months and over the next few years, so we get to see a back specialist. And then it was only at 14 years that they decided to give the diagnosis of cerebral palsy, but no specific type of cerebral palsy. So it took a long time.

And then we did try the geneticist 4 or 5 years ago and they came up with 17 Q12 micro duplication. But it doesn’t really explain why [son] is like that. It was only 4 or 5 people in the world with the same thing at the time. I think there’s a lot more now, there’s a lot of people coming round the world and going online saying ‘oh I hear you’ve got this’. And apparently my husband’s got this, but he’s nothing like my husband. So having a diagnosis doesn’t necessary help. It helps get you somewhere else, it helps you know ‘I’ve got a disability’, ‘oh OK well you can have this equipment, you can maybe have this equipment, you may get some discounts’ but it doesn’t always necessarily provide an whole answer. I think there are solutions, and they’re not perfect but there are other solutions that you have to look for really.

Q OK, thank you for that. So thinking about….so you left work which sort of reduced the stress at that point. Is there anything else that would have helped….is there something that would have helped you not get to the point where you couldn’t work out what F was? What would have helped you?

A I think not having to juggle everything. I mean my husband, we were both working but I worked part-time. My husband worked full-time and he was an optician. I sort of took on the main carer role, which I sort of objected to really because there was three of us, because there was me, my husband – we both looked after [son] – and our older son, so there were three of us and I worked out the hours. Both my husband and I were doing at least 50 hours each, and my younger son was actually doing 37 hours. If somebody had sat down and said ‘well actually…’ he did eventually join a young carer’s group which was absolutely fantastic, but initially it was ‘oh well he’s not doing the tube feeding’ or ‘he’s not setting up syringes or anything’. But I used to get him to check the pump when it was bleeping, and see if [son] was happy, or ‘can you just keep an eye on [son] while I just nip to the shops’. Which was like, oh that was like very difficult sort of saying to my son who was absolutely brilliant, and he’s a very caring person.

Time 30::00

So I think there’s a lot of things that would have felt really. It’s people’s attitudes primarily. It’s like being, when you go in, treated like adults, don’t accuse us. So for example [son] had orthotics so he couldn’t stand. He can’t stand, he can’t walk either. Can’t talk but I could see a little bit of communication there. But he had different types of shoes, piedro boots, and he had like sort of this moulded thing, like a thing to go into his shoes and up the back of his leg to support his leg in the correct position. And we sort of had an appointment straight after school and as soon as we came through the door the orthoticist said ‘oh don’t you know how to put these shoes on’. Well excuse me but before you accuse anybody let’s sort of go….why not say ‘hello, we’ve got a bit of a problem here, are you OK’ sort of the shoes aren’t quite…. I could have said ‘well we’ve just come from school, he’s just had a swimming lesson and the staff had put his clothes and shoes back on so they obviously….’ ‘Oh right so they haven’t put the shoes on correctly, right’. Well don’t accuse me of….

And that’s sort of one of the things that really sort of hurts is when professionals say ‘don’t you know how to do that’, ‘don’t you know how to do that’, ‘why did you do this, why did you do that’. And we didn’t necessarily do that, and we didn’t necessarily think that. You know please don’t accuse people, don’t sort of say straightaway ‘did you do this?’ And anyway if somebody had some something wrong surely you say to them ‘oh let me just check this for you, do you know that this works this way’ or that way or… Because that really upsets me – amongst several other things.

I mean there’s some fantastic people out there, they do some fantastic stuff and basic stuff and things, they go out of their way to do things, and yet others just seem to sort of….you know I’m a bit more sensitive as well, which doesn’t help. But it’s not nice when you know that there are other carers who are in that same kind of situation who get accused of things. So…anyway.

Q So things that would make it better is being listened to I suppose is what you are saying?

A Yes. Yes primarily listened to, and then sort of working together really. It’s the teamwork. And I always talk about partnership, working in partnership with everybody and we’re all a team. You know you are the professionals, you know your technical side of things, I know my son, I know that he’s not happy. I don’t jump to conclusions, I will know. After 5 times I think ‘no this isn’t right, this shouldn’t be happening like this, I need to go and see somebody and do something with it’. It’s the partnership working that’s really important. And with the councils and social services and everybody really to just sort of sit down and work out.

And then also working at solutions. Some of the things, like sort of….like because I used to go to work, my son needing transporting to school from home. But then I finished work after he finished school so I managed to arrange the transport, well I paid for the extra transport for them to sort of drive him to work for me or to nursery. And it’s finding those solutions that really work. That’s the wonderful thing. That you can talk to people and they’ll say ‘well I can’t do that but I can do this’. Because they were saying ‘well we can only take from home to home, from home to school and back to home again’ and I said ‘well I am working at that point, are you going to leave him homeless and without a parent’, you know it would be your fault for doing it, it’s not me, I’m having to work, I have to still pay bills. And they said well OK, you’ve got to provide the transport. So they provided part of the transport that was already booked and then I paid for the rest of the way to drive up to either work or to a nursery for me. So it’s fantastic.

One other thing I found, what enabled me to go to work especially in the ??? Youth Arts at the [name] place was, there was a nursery. At 6 months old he had been admitted to sort of see what was the problem, that’s when he had started having fits again. And I left after 5 weeks with him in hospital and the first Monday I was starting…he was going straight to nursery. I’d had to negotiate that because normally you have to do a 2 weeks beforehand, one hour or two and then a couple more hours the following week. I had to negotiate to go straight in with him. And also during that 5 weeks we’d learned to do the tube feeding.

Time 35:20

It’s strange, I think sometimes people, professionals, don’t always tell you everything, they’re just….it’s almost like ‘well hope you ??? to say anything’. And I was thinking well shouldn’t we be going home with him having no fits and him not being tube fed? And it’s like he’s still tube fed, he wouldn’t be here if it wasn’t for the tube feeding. He’s got a peg? in his stomach now. But it’s the silence sometimes, that they don’t tell you. It’s the things like, and also I found with my mother and I found a useful leaflet about this, not the DNR but the bereavement, going up to bereavement. There was a little….I think the hospices have provided a little booklet and in there there are lists. But I think the doctors need to be honest, to say ‘this is the process of when somebody is dying, this is what’s happening’.

I recognised that in my mother. Nobody else in the family had been told that she was dying and it was just….I read a book by a foster carer who wrote, based on true experiences, but it was like more fictionalized. But that was the ??? And I thought this is just wearying. And it was wearying. And it’s understanding that and somebody telling you this is what it’s really like, or what it can be like, it can be better, it can be worse. And it’s having that honesty and having those leaflets with that information. Again it’s sort of coming up again, having that honest description ‘this is what it can be like’ and please if you are a nurse, if you’re a doctor, a consultant, please give us a leaflet that explains things – especially with complex needs.

So it’s having that honesty. But it’s partnership working and finding those solutions and going ‘right, this is what life is like’ or it can be like ‘and this is how it can be better’. Trying to get things like ceiling hoists so we don’t have to lift our son. And you know we don’t expect all singing all dancing, we don’t want everything, but we want some solutions to get around. So the ?HG?? managed to get a ceiling track and things like that. But it’s always a battle it seems.

And I’ve actually worked as an Information Officer as well for a disabled children’s charity for kids, and you know in the sort of various jobs that I’ve had sometimes the health professionals say ‘well don’t tell the parents that, they’ll all want it and we haven’t got enough money’. Well you know you have to know how many people out there really need things because we’re all struggling and our mental health goes down because we’re not told about these things. And sometimes we assume we have to sit and wait, and sometimes we don’t realise, it took me 6 months to realise – just ask. They can say no but they can also say ‘yes you can have this’ or ‘we can’t give you this but something simpler or cheaper or something, we can give you something’. You know it’s just working together and finding a solution really that sort of always helps.

But definitely with the medication, it’s not just a case of just giving anti-depressants or beta blockers, it’s finding solutions or helping find solutions, or signposting people to where do you get those extra continence pads, how do you get the ceiling tracks or hoists or what are the alternatives. You can get portable hoists, you know why not try and get a portable hoist so you can then sort of, if you need to move it into a different room you can then move it into a different room it’s not fixed to the ceiling. You know there are always solutions.

I have actually found a seating system for [son]. I can’t remember how old he was – a couple of years old – and they offered this black and grey metallic chair. And I just burst into tears. It was gloomy enough, it’s almost like a bereavement every day because your child’s not going to do what you thought he was going to do, you know jump up and down and do things and tell you things, or not tell you things, and be awful and whatever. And they offered us this….I mean you know when you’re….you can almost see like a black cloud hanging over you and then they offer you yet another black cloud, it’s like ‘I can’t cope with this’.

Time 40:11

And I went to the NAID? Exhibition that year fortunately and found him a beautiful chair with red frame, blue seating with little flecks on it and a yellow tray, and when my son sat in it he just patted it because he loved the colour of the yellow and he associated it with teddy bears. He just loved it and patted it. And that cost £200 less than what they were offering that was black and grey and depressing. You know so everybody working together to come up with some kind of solution.

And my boss was fantastic at ??? Youth Arts, he kept sort of saying ‘well my sister’s a physiotherapist, would you like her to come and help you out’, you know so he was brilliant and he understood that you were sort of….you know they had children themselves so they understand, and he sort of kept almost throwing…like go ‘no, no go and sort him out, if you’ve got to go, leave work, go now’, which is what you want people to do really.

Q And did you have any mental health issues before you had children?

A I don’t know because of not having looked at it. But one of the things that’s come about is I’ve got hoarding issues. I thought ‘oh I’ve had enough of this’. I did ??? pre COVID and I didn’t have any kind of diagnosis whatsoever of anything, not even anxieties – and I did have some anxieties about going back to work and ‘am I good enough?’ self-esteem and all this. So again that’s something I was ??? to go and find out about job clubs with the carer support, and that unfortunately ??? carer organisation fell through. But there were things there. There have always been things there. And I like to help people.

And I don’t ask for help very often because from my family background it’s like ‘oh you’re old enough, you know how to do it, go and do it yourself’, so even when I ask for help I don’t get the help because ‘well you can do it yourself anyway’. But when you want help you want help, you know, you need somebody to hold your hand. So I haven’t found enough in the past and I’ve tended to be sort of….I don’t know, it’s ??? continue I’d be either out-going or very shy, so I joined a dramatic society when I was younger ???. And yet at other times I sort of don’t really like mixing with people. I do sometimes but not always. So I think I’ve had issues.

And they came to the forefront I think when my son started head-banging, complex needs, couldn’t walk, rolled around the floor and started head-banging on the floor. It was because the schools in the summer were reorganizing and they were going to get rid of most of the special schools and most of the pupils would go into mainstream. But there’s not much understanding in mainstream schools of what all the disabilities are. And I didn’t realise but a lot of teachers were leaving to go to work at….you know so they knew the work would be there. And apparently they didn’t know….their jobs only existed until Christmas and then they didn’t know what was going to happen after that. So obviously a lot of them were going off on long term sick leave. A lot of the autistic kids were sort of going….sort of really sort of struggling, and I didn’t realise my disabled son also started struggling as well and he started head-banging, just sit on the floor and just bang his head on the floor. So obviously I knew there was something there. So he felt frustrated with everybody else around him feeling frustrated, so I did notice that.

And I sort of…we saw somebody from CAMHS, eventually we managed to get to see somebody, and we were sort of talking about what was going on. And then sort of he turned to me, because I was so upset because my sister was trying to tell me that ‘I was doing that’, ‘I wasn’t do that right’, ‘I wasn’t doing that right’, ‘I could have done that ???’ ‘I could have done that better’, ‘should have done this, should have done that’. And I just burst into tears and I ended up having the counselling. So there were issues there because of the way we sort of interacted or didn’t interact. And then we had problems on my husband’s side of the family, which I can’t really talk about. Let me sort of re-word that bit. There were other problems and issues that we had to deal with.

Time 45:30

But I think it was always a case of like ‘put up or shut up’ sort of thing, you know the traditional kind of thing, or stiff upper lip, even though of my parents were [Eastern European] so we had got sort of that slightly different culture. But in this country it’s sort of like, you know, don’t mention anything if you can help it, or sort it out yourself, and that’s not necessarily my philosophy but that’s what I tend to do. I tend to sort of struggle through things without realising that I haven’t asked for help when I could have asked for help. So that’s one of my problems. And I sort of try to avoid the mental health side of things. And I know it’s not been very well supported the mental health side of things, there could have been a lot more for me gone into it and a lot more support to everybody who works in that sector really. So yeah.

Q Do you get support from other people outside of your husband or your son?

A Sorry?

Q Do you get any support outside of your husband or your son?

A Erm….the difficulty was, play schemes. Mainstream school children sometimes would get 6 weeks of play scheme. If you have a disabled child you’re lucky if you get one week or two weeks, and even then it’s short and it’s between 10 and 2, whereas the schools they get support from 9 til 6. And the school around the corner from where we live, they had funding – this was when they had…I can’t remember what the local funding was called, you could apply for funding, and they managed to get 6 weeks of funding 9 til 6 with the coaches all paid for and everything. And I sort of phoned them and said ‘well….’ And they said we haven’t got access for a wheelchair. I said ‘well you’ve got different rooms haven’t you, and if you need to sort of change them you can use one of your extra classrooms because you won’t be using them all through the school holidays’. ‘Oh we haven’t thought of that’. They had one wheelchair user that year when I asked. And I think people, again people don’t think out of the box sort of looking at things like that and sort of making it better.

We did have some respite care we got through social services, which was brilliant. And eventually we got a sitting service as well. We started off with 2 hours a week and then eventually had 3 hours a week, which was brilliant. But the difficulty with the things like that, it’s sometimes parents want to bunch up the hours, so they want a whole day off and you’re being told by social services or by the council ‘oh we can’t do that, it has to be 2 hours per week’. We have sort of requested that in the past. But I do know that other parents, sometimes these things aren’t very flexible for some of us and it sort of just causes stress because you think you need just a whole day just to sort of refresh and come back, and then you can carry on. But it’s difficult.

There’s direct payments as well sometimes. I found it very stressful trying to go for the direct payments to fund things yourself, because I had to sit for 6 weeks listening to this person reading the notes in front of me and I found that very stressful, it was almost like a controlling situation I think, just thinking now. I don’t know why I found it very stressful but you have somebody sort of sitting there reading the notes and going ‘right, this is the rules? about direct payments, this is what we do’ blah, blah, blah. And I had to sit there for 2 hours listening to them. I assume that was to make sure that people had heard the notes, because maybe on their own they hadn’t had time to read the information. But then afterwards I sort of backed out, I said I can’t cope with this, having to sit in front of somebody. So I didn’t get the funding. But I did hear about other parents who, yeah couldn’t do it for what they needed to, and yet it was to do with their disabled child and to help their disabled child. So sometimes things become inflexible either intentionally or unintentionally.

Time 50:00

But there have been some fantastic people along the way, and sometimes just the staff that you meet and the health staff that you meet as well, when they approach you in the right way that always helps.

Q When they approach you….you said when staff approach you ‘something’ that always helps – what was it?

A I’ve forgotten now. It’s just gone out of my head.

Q And then your sister you were saying.

A There are very helpful people out there that will sort of come along. We had a very good social worker for one year. I mean pretty much…. well they’re pretty good most of the time, for one year we had one that had come from adult services so she didn’t understand children’s service much but she would look up information and phone me and say ‘I’ve got this, I’ve got this’ and then we would talk about ‘do you know about this as well’. And she got really excited and it was so brilliant to have that kind of relationship where we could share information with each other and pass it on. And then one of the stresses for us as carers is when the social workers and the professionals disappear and you’re not told that they’ve gone, and then 6 months down the line you suddenly find out ‘oh well where’s my social worker’, ‘oh she’s gone’. You know it’s nice to say thank you to them to say goodbye rather than just have them disappear.

And I know of somebody else at the moment whose social worker and physiotherapist and occupational therapist have come in and said ‘you can have this’ and disappeared and she’s not got anything and they’re not there any more. So it’s things like that that you don’t want to happen really. If somebody’s going to go, if somebody is going to leave or on long term sick leave, will you please let us know and say ‘you’re not out there on your own, there is someone, you can always phone back in to this number’ or whatever. But not just to have people leave, people just suddenly leave, especially in the social services, they just suddenly leave, nobody tells the carers out there that their social workers have gone. Yeah.

Q OK well thanks for that [name], I mean I’ve asked all the questions that I’ve got. Is there anything that we haven’t talked about that you think is relevant?

A I don’t know, I could send you some notes if I think of anything I haven’t sort of mentioned. It’s just that there’s an awful lot of juggling. The one year I….because…oh yes the hoarding issue. I thought ‘I need to sort it out’. I joined a ??? college at the beginning of 2019 and then we had to go on Zoom, which was brilliant that we had Zoom, and I sort of realised that I had hoarding issues. And I picked up there were sort of people out there as well had hoarding issues. And pre-COVID I had started going to a group as well because we’d got so much stuff and I realised that it was an issue. I don’t know all the reason, I want to work out, I mean that’s psychology kind of. I do realise that some of the things I like sort of having [son] with these disabilities, it’s that loss, and sometimes you feel like a bereavement every so often. And I know that’s sort of affected me, so I keep a lot of his notes. And I keep picking up notes about Direct Payments and Lasting Power of Attorney, and I go ‘it doesn’t cater for complex needs’. And so I sort of file things in alphabetical order and stuff. And so I thought ‘well I need to get this sorted out because I just can’t cope and I don’t want ??? inheritance’.

And so we managed to keep a group going on What’s App and then finally persuaded the local charity called [name] to keep on the support group. Because through COVID we had managers coming and going and disappearing and saying unfortunately it wasn’t their remit, they didn’t have enough funding. So I thought right, I’m going to push for this. So last June I went for a diagnosis. I have heard there is this hoarding diagnosis, and I know that through Megan at [name of charity], and she sort of mentioned about sort of training courses and things. And she was talking about the diagnosis being available for the last 10 years. But people still don’t understand, there aren’t enough professionals who understand, even on the mental health side of things.

Time 54:50

So I said right I’m going to push. As it’s possible to have a diagnosis I pushed for it. I finally got it in January this year, so it took 6 months to get the diagnosis. And even then it was on…well I thought 6 months later, I thought ‘well…’ I know I was in contact with some of the psychiatrists and psychologists and one of the nurses who said ‘well we’ll take this information to whoever we can and see what we can get for you’. I did have a doctor come round who sort of specializes in that sort of area. And in January I got the diagnosis. But the doctors haven’t told me, they haven’t phoned me, it just went online on to my notes and that was it. And I think 2 months later my husband said ‘what’s happened with the diagnosis, have you got one’, so we had a look online and found it there. And you’re thinking ‘well if you’re going to find a diagnosis you could at least tell the people that you’ve got the diagnosis’.

And since then I’ve pushed for a support group to be there. So it’s brilliant because we’ve got a counsellor who has taken on the support group and wants to meet once a month. And I want to sort of encourage the local authority to sort of take on this because I just can’t cope with having all this stuff around me. I know everybody’s got different reasons but people aren’t trained to understand, not even…I think sort of professional development should….CPD should be available in Hoarding. You know a one day’s training to understand, and especially for psychologists and psychiatrists, because they sort of kept saying ‘oh we can talk about it generally around anxieties, worries, depression’ and you think ‘well I want to know what’s behind the hoarding though so that I don’t keep doing it over and over again.

So we’re heading in the right direction. I’ve got the clinical permission group on board, and I’ve got my local MP who sent me a nice letter from Parliament. So it just shows you that if you communicate with people they are aware of things and hopefully in some way they can push for things. So yes unfortunately hoarding is one of the things I want to get sorted. And I presume there will be other people who are carers as well. It’s difficult because you don’t know unless you talk to somebody else. There’s a couple of us now have started invited each other to each other’s houses, but it’s not generally, it’s difficult inviting anybody or having service people coming in, that’s very, very stressful.

And it’s like, oh my husband gets shouted at, going ‘put that there’ because we have to move things out of the way obviously, and it’s like ‘oh leave that over there, no don’t touch that’. I don’t mean it, my husband sort of understands, but it’s very difficult for me. So you know so there’s a lot of other things going on in our lives, but it’s interesting the impact some things have on you.

Q Well thank you very much for sharing that, I very much appreciate it. I will downloaded the two files now and delete the video file for you.

A Thank you.

Q [husband]a will be in touch to sort out your voucher and she’ll be asking you to fill in a form that’s got some demographic details. And she’ll also explain the digital story telling part of the project.

A OK, yes. If you don’t get a reply just ask her to sort of…I don’t mind you hassling me. In a nice way. But you know just in case you don’t, because sometimes it takes a bit of time to do things, but I will.

Q OK well thank you Teresa, it was really fine. And thank you for sharing all of that, which is really interesting and important and will make a good contribution to our analysis.

A Thank you for your listening ear. OK thank you.

Q Have a nice rest of the day. Thank you.

A Thank you, bye.