**WORK PACKAGE 1 – SESSION 2**

**Individual interview with stakeholder P2**

**22nd March 2021**

Audio File Name: S2 – IdoService – Individual Interview – Other stakeholders – 22 march

Duration: 00:58:45

**KEY:**

Cannot decipher = (unclear + time code)

Sounds like = [s.l + time code]

**R2: = Researcher (Interviewer in bold)**

P2: = Stakeholder

**R2: Thanks a lot for your email confirming you are happy to take part in the study and you consent to take part in the study. So I just have the last time to ask you again to give me your verbal consent about that, so if you can say I consent to take part in the study.**

P2: Yes, no problem. I give you my full consent.

**R2: Perfect, thank you.**

P2: (unclear 00:00:27) wants some commission.

**R2: I will ask you some questions but again, if you have some ideas or if you want to bring in new things, please don’t hesitate too much on that. But my first question is about Springboard. So I think you were part of the people who created that some years ago.**

P2: Correct, yes.

**R2: I was interested in why it was important and necessary for you to have that.**

P2: I came from a situation where I knew the Alzheimer’s Society exists and I knew dementia existed because I’d done some charity work in the past and we used to decide annually where the money was going before we started collecting it. We always seemed to give some money to the Alzheimer’s Society and I never thought any more about it and that was about it. My wife suffered, after about three years of diagnosis, with what they call M.E which in those days was known as yuppie flu back in the early ‘90s. We just carried on as normal. She took the medication. She had her good days and she had her bad days. I wouldn’t say she ever got rid of it but she improved a lot and her stability was okay and things. My son lives 120 miles away. He said to me one day in about 2007, “Have you ever seen my mum’s handwriting, dad? I think it’s deteriorating and things.” I said, “Well not really because she just puts happy birthday in a card and merry Christmas. That’s the only writing I see.” He said, “I think there’s something wrong somewhere, dad.”

Now my son is pretty intelligent. He has got a degree in forensic measurement so he understands a certain amount of what’s going on but he never said to me, “I think mum may have dementia,” or anything like that. Anyway, I retired in 2008 so I was living with her 24 hours a day. I did notice things were slightly different and were going a bit different but what I couldn’t make my mind up whether it was ME or something else. So I swung it in favour of the ME because it was more palatable and there was something wasn’t ringing up. I couldn’t really see a problem. She used to have to go to the doctors about every six weeks, her own GP. I just said to her, “Why don’t you ask your GP if you can have one of these tests relating to your mind because of your age?” because I’ve had one with my GP. (unclear 00:03:47) because we had separate GP practices. Anyway, she came back and she said there’s nothing wrong. Then I was talking to my son. He said, “She’s wrote to me again, dad, and her writing is all spidery.” I got her to write something out, a shopping list or something and she put the paper on the kitchen worktop and it wasn’t a smooth finish. It went all squiggly so I thought that’s what it is.

So I got her to do it again on another piece of paper and it was bad. So I pointed it out to her and she got upset. So we made an appointment for her to go to the doctors. Again, she came back and said there’s nothing wrong. So we made another appointment which was a normal routine one and I said, “Can I come with you?” I went with her and he said there was nothing wrong, I insisted that we got a second opinion. He gave me a list of places where we could go. Obviously you try the nearest hospital to where you live but the nearest one I could get with the earliest appointment was Wythenshawe Manchester so we went down to Wythenshawe which is like 25 miles away for us but you do these things in medical situations, don’t you? So we went down there. Sorry, I’m telling lies. No, I’m not. We didn’t end up at Wythenshawe, we ended up at Withington Hospital under a doctor called [DR] and I think he was a psychologist or something like that. He did various tests on her, took samples and things. After about eighteen months he said to me, she had brain scans and stuff like that, “There is a problem. I don’t think she’s got Alzheimer’s disease but there is a problem.”

So he referred us to Wythenshawe Hospital and we saw a consultant called [DR], who ended up being [A POLITICAL ADVISOR] or whatever they call them for dementia. In the small talk we found out he was a caravaner as well so it was a combination of brains and caravans and touring France. So it made it a bit more relaxed and more informative for both parties I think. It was a good experience going down there. So after about a further eighteen months and further tests, he told me that [MY WIFE] had dementia with Lewy bodies. If I just go back. I’m sorry I’m messing you about but just to go back to the Withington experience, [THE DOCTOR] originally thought she probably had Parkinson’s disease so she was given some tablets and depending on the reaction of these tablets would determine whether it was Parkinson’s or not. So she had these tablets and they were horrendous. She had stomach cramps, she was feeling sick and couldn’t be sick, really painful stuff. So because that situation arose, she didn’t have Parkinson’s and that’s why we got referred down to [THE NEXT DOCTOR]. Anyway, they did various tests there, balancing tests and more brain scans and things. They said that she had dementia with Lewy bodies.

He said to me, “Don’t go on the internet looking because you’ll destroy yourself.” He just gave me a leaflet, an A4 leaflet and gave her some medication. So we did that for quite a bit but obviously over time, we had standard tests she used to do, she had to draw clocks and cats and things and answer questions. I could see the deterioration then doing the same thing, I think we used to go quarterly, something like that. This went on and went on and the deterioration got a little bit more but not unpalatably more. What [THE DOCTOR] said to me was, “I’m sorry, [P2], but your [MY WIFE] is getting to the stage where she needs some increased medication and because of the situation, you’re living in Oldham and we’re in South Manchester, I can’t write the prescription for you to have this medication. I can’t deliver it from the hospital to you.” So I said, “Well I can always come down.” He said, “I mean deliver it by writing it on the prescription, I can’t do it.” So sadly he referred us to Oldham. So I think that was on something like a Wednesday or a Thursday. So on the Friday I thought, “I’ll ring Oldham memory services up.” I phoned them up and said, “My wife…” I told them what happened to [MY WIFE]. They said, “We’ll ring you back,” and I thought that’s the end of it.

So this lady phoned me back and said they have what they call a post diagnostic meeting which is about ten or twelve weeks, I can’t remember exactly. It was either ten or twelve weeks where they have different subjects each week, things like power of attorney one week and medication, different topics each and every week. Then I was fortunate enough to get a phone call on the Monday morning saying, “We’ve got a cancellation this afternoon. Can you come down and see us?” So I went down to see them and I saw a psychiatric nurse and the psychologist on my own. I had to go on my own. They explained what it was all about to me and told me it was terminal which I never realised that to be honest with you. That was painful I must admit, (unclear 00:10:06). It’s a moment I’ll never forget. Anyway they said they had these meetings on a Thursday and they’d already started one. I think it was in week six, something like that but I could join now rather than wait for the beginning because each subject is different, it wouldn’t make any difference.

So we did that with great reluctance because I said to her, “If we don’t like it we’re out,” because what I didn’t want to do was put her in an environment where people had dementia and she’d think, “That’s me in x period of time.” I didn’t want to. I didn’t want that for myself, if I’m being selfish about it. So we got to this meeting, very relaxed. There were about 20 people there, a mixture of carers and cared for. I didn’t know any of them. We did that for about four weeks, five weeks and then we got to the last one. It was a summing up session but I knew I still had to catch up on the other ones in time so I wasn’t really bothered. Then something made me say, and it was completely out of character for me, I said, “Really? I appreciate (unclear 00:11:21) to this but are you telling me now that I’ve got to go home and have my tablets and that’s it and get on with it, in the simplest way. You can’t help us in any way shape or form?” and they just said, “Yes.” I said, “Well that’s not right. I’m going to do something about it.” Now there were a couple of guys there, one of them’s mother had dementia. They’d been around quite a bit.

They’d been associated with Alzheimer’s Society who, at that time, withdrew out of Oldham where I lived and centralised in Manchester so the Oldham branch effectively shut down. So this guy was upset because his voluntary work had ceased with a focus on Oldham. The other guy, his wife, she was in a care home and had been in a care home for a long while. They approached me and said, “Do you really mean what you were saying, [P2]?” I said, “Yes.” There was another guy to the side of me and he said, “I agree, it’s wrong this.” I was talking quite (unclear 00:12:34) with this guy. He said he had dementia himself. My reaction was it must be his wife. Anyway, he said, “Shall we get together over a coffee?” so we got together. We were overheard by the psychologist and he said, “Can I join you?” so we all got together and realised that there was nothing, let’s make nothing into something. Through the psychologist, she managed to get a bit of money towards renting a place and things. One of the guys went to church and the church hall was available on the Thursday so we approached the church and they let us have, not rent free but the next best thing to rent free. We just put it out that Springboard existed.

We used to meet on a Thursday morning and we got linked in with Age UK Oldham and they facilitated it through their expertise on managing groups. That was funded for six months and then we took over fully. Over time we got bigger, more involved, realised what we were doing, I could still engage with my wife in it. There was a lot of peer support. That’s how Springboard came about. We used to meet at 11 o’clock to 1 o’clock and then two or three of us would probably go out for lunch as couples afterwards and talk about it. We got known in the town a little bit. We pushed some leaflets out. Then we grew that big that in the Thursday morning session we only had one room available. We established that the whole building was available in the afternoon so we consulted with the members and they were quite happy to come in the afternoon so that gave us three full rooms complete with a kitchen so we could do anything we wanted. We moved to Thursday afternoons, that allowed us to make more use of the memory services. Once a month, well we still do in the real world, in the normal world, we split up and had the cared for in one room, the carers in the other room and those who weren’t interested in the middle room. We had a lot of peer support between ourselves.

The two rooms with the carers and the cared for in separately had the psychologist present. We never knew what was ever said in the cared for room but they always came out with a smile on their face whatever they did or said. The other stipulation we made was that if they thought anybody was at risk out of what had been said, we’d like to know that so we can sort it out with the carers. That never happened. But in a nutshell we grew because there was nothing and we were probably in the right place at the right time. We had a lot of support and support from within. We obviously had upsets, people pass on. The first person who passed away, that was very difficult thinking, “That will be me in a bit. That will be my situation.” But we’ve found that the carers have wanted to come back. They haven’t stopped coming so we must be doing something. We’ve just grown bigger. In due course we became a charity (unclear 00:17:04). So I was founding member if you like. I’m currently chairman of the group and steer the group. Trustees can only be trustees for three years so I wasn’t a trustee last year, I dropped off for three years but I’ve just been re-elected so I’m a trustee so we must be doing something right because we do get vetted by the charity commission every now and again.

We still get the NHS support, not as much as we used to do but I can understand that. I know that the post diagnostic group are starting again by Zoom or Teams or whatever it may be in the very near future so we’ve agreed that I will go along for one of the sessions and give our caring experiences and obviously mention our group as being available. Basically that’s Springboard. I mean we do have trips out. We consider ourselves all-inclusive so if we have a trip somewhere, we make sure we have a coach where people can have access with wheelchairs and things. We only have two people in wheelchairs at the moment but we do that. We have one or two residential holidays Monday to Friday. I didn’t go. I did a day trip once to see them at Blackpool. That was enough. It was good. It was arranged so we do that. We do get guests speakers or guest activities. We’re supported also now by a charitable organisation called Making Space. They’re a national thing. They’re financed through Oldham CCG so they provide a couple of people who come along on a Thursday and help us to deliver it. Sometimes they bring some funding in and pay for somebody.

I lose track of time to be honest with you. Probably about five years ago or six years ago Oldham Council library service wanted to get involved in a new formation, a national formation called Reading Friends but they had to have a charitable type partner with them, they couldn’t do it as a council so they invited us to do it with them which we did and we still get funding now. It’s a good partnership. We’ve had all sorts of different things, actors, different artists, different things to engage from flower arranging, not that I’m good at that. We’ve had I suppose the most extreme one was we had a guy came up from the Midlands somewhere from some animal park and he brought a 20 foot python with him and other bits and pieces. I avoided that like the plague I’ll tell you. Funnily enough, all the people with dementia had their picture taken that day with the python stretched out all over their arms. They were all up for it. So we’ve done lots of things like that.

**R2: It’s really impressive.**

P2: We tried to keep that going as best we can on Zoom. I mean the only thing that’s wrong with the group, and it’s not of our making, is we have only got one black face in the group. She’s a lady who was a nurse and she’s been in the UK since the year dot. I think her parents came over as part of the [s.l. boom thing 00:21:10]. She’s a very nice lady. She’s the only [BAME MEMBER] we’ve got, if that’s the right way of putting it. We were aware of that. We were asked if we could try and extend… although it’s a diverse community, quite a large Pakistani community, Bangladeshi community and one of our members lived on the edge of a large Pakistani community. They were well known in the area this couple. They started making enquiries about informing people about dementia. So we opened up like a coffee morning and put leaflets out in the area saying come and talk to us and nobody came. Nobody wanted to know. So we had a word with a couple of the people from a couple of mosques that we’re aware of and they didn’t want to know. I phoned a friend of mine up who I used to work with who is Asian and he was telling me, he said, “It doesn’t work like that, [P2]. The community always look after their elders.”

So we carried on doing that. We had quite a few coffee mornings. Then one particular morning, the last one, we decided it was going to be the last one, this young couple came in, I don’t know if they were a man and a wife or partners or just two friendly people, they were male and female of a similar age group and they were talking very positively. I thought (unclear 00:23:01),” and then they said, “How much do you get paid for doing this?” I said, “It’s voluntary,” “Oh right,” and they were off like a rocket. That was the end of our direct Springboard trying to extend ourselves into the Asian area. It didn’t work.

**R2: It seems really challenging to access this community, black community, Asian communities. Have you some support in Manchester, I don’t know, from Oldham Council, someone helping you, giving you some addresses or you do it by yourself?**

P2: What, within the Asian community?

**R2: Yes.**

P2: We do, yes. I’m on the Oldham CCG board as a carer or ex-carer and Springboard representative. There is a chap on there who’s on the payroll of CCG and it’s his job to work within those communities and to enlighten them as to what’s going on. I know Oldham Memory Service are doing a similar thing as well. They are aware of our acceptance of them. We appear to be a white organisation but we’re not. We’re multicultural which you have to be in a charity commission as well. I just completed our return for the charity commission and one of the questions relates to equality. We just had to put in that we just have one Caribbean descent lady and that’s it. Well if you look at Caribbean people in Oldham, yes they’re there but there’s not that many there. If you (unclear 00:25:08) Pakistani and Bangladeshi and do we try to… the answer is no.

**R2: Do you think it’s because they prefer to take care of their parents and only people in their community? It’s maybe also because dementia is more taboo or stigma and they think dementia is not an illness, it’s just normal ageing so we have nothing to do?**

P2: Yes, that’s what I think it is, yes. My children, I wouldn’t say they’ve abandoned me, I do get phone calls and things. I think if I was Asian now being on my own after [MY WIFE] died, I think I’d be living with one of my kids whether I wanted to or not. I think that’s how they do it. I am not aware of any other scenario other than that. Having said that, I haven’t looked. I haven’t directly tried to engage in that. I mean I have spoken to my GP, who was Indian, because he knew what I was up to. I always think of the Indian community and there is quite a few Indian people in Oldham as well. He was saying, “These communities look after themselves, [P2], and we do as Indians but I think there’s more chance of Indian people joining your group than the others because they get a bit more westernised in their approaches.” So we then got an invite to the Indian ladies group. It was on the edge of the area where we’d done our coffee mornings. Being a male I couldn’t go. A few of the ladies went and they had a good time and what have you but they just weren’t interested in what we were doing. It’s nice to know what you’re doing and they gave a donation to the group which was kind of them, “We know you exist. Here’s some money but we’re not joining. We look ourselves.” I think that were it in a nutshell which is sad really. I don’t think that will change. It probably won’t change in my lifetime.

**R2: I hope you will have a very long life of course but it’s a very long process to change mentality. It’s also very… I have to say, it’s why I was really interested to go in the UK because in France, I was living in Luxemburg the last year so very close to France and I think dementia, we talk about that and we have training session and support groups but not that much so I really think it’s fantastic to have groups like Springboard because to be a support group is really, really impressive and something really great.**

P2: Really the only thing I would say about France is that there’s campsites well I still go to. I didn’t go last year and I won’t be going this year but over time it’s a family site and the guy who owns it, he obviously got to know me and my wife and things and he understood her problem. He catered for it. He always used to say, “If you’ve got any problems, [P2], let me know and I’ll help you out. If you want to go out somewhere, I will come or my wife will come and look after your wife or take her for a walk round or something.” So that support was there and that recognition was there and there was no need for it to be there, personally there. Yes, so that was reassuring.

**R2: That was great. You mentioned for Springboard, you said you have some groups where people living with dementia and their carers are together but sometimes it’s also quite separate so it can be, I don’t know, people with dementia having some activities and carers having different activities. My question, I suppose it’s very different for people but do you think it’s important to give some time to carers, some respite so they can have time for themselves to do other things? Are they also looking for activities to do together and to find support or talk about new things or learn new things?**

P2: I think there may be a misunderstanding between us. I think I answered part of that question about Springboard. There’s no real split in activity. Our physical activities are always together. There’s no split that way. The only split is round an educational way if you like where we have these two groups once a month or six weeks, whenever we can fit it in with the memory service where we get peer support by the carers being together, the psychologists. Sometimes the psychologist cringes at what we’re doing because it may not be in the good code of practice but the bottom line is it gets (unclear 00:31:06). I mean the classic example of that was, and it’s not a sexist remark in any respect, it’s reality, there’s a particular guy who was getting a little bit shabby. He was a real smart guy when he started with us. He was in his mid-70s and he started looking a bit shabby and he started putting more clothes on. Even in the summer he’d have three waistcoats on and a jacket and an overcoat on, things like that. His hair was growing longer and he was unshaven. His wife was a little dapper lady. She just said, “Can I have a word with you, [P2]?” so we go round the corner and she just burst out crying. I said, “What’s up?”

She said, “Look at the state of him. I’ve been trying this and I’ve been trying that.” It was one of the Thursdays when the memory service people were coming. So I said, “Let’s try and sort it then. If we can share it, let’s do it that way. If not, we’ll sort something out but we’ll probably have to have a chat after the meeting because I’ve got something to do at the moment.” Anyway, we got in the room and the memory service were there so there was about twelve or thirteen carers there, some of them were new-ish carers, some of them had been carers with great experience and time. She told us this tale and this lady said, “Well I had a similar thing. He wouldn’t got to the barbers or anything like that. He wouldn’t get dressed properly,” and what have you. “I went and had my hair cut and they did men’s hair cut in there and there was a couple of young ladies who looked pretty good,” the young blonde type with a pair of scissors. So she took him along there, she dragged him along and said, “Can you come with me when I have my hair cut?” She said to me, “This young lady here will cut your hair if you want,” “Oh yes, great. I’m having that.”

So he got his hair cut and he wanted to go for his hair cut every day this guy after that. He smartened himself up. So it’s simple things like that. Now that’s not on any national health leaflet. It’s not on any Alzheimer’s Society leaflet. It’s all about peer knowledge, isn’t it? So that guy became one of the smartest in the group just by a simple comment. Sadly he has passed away now. She was better, he was better just from one simple thing that came out of the Thursday group. There are other things like that and things have been said and the psychologist is like, “Tell me,” and I said, “Well this is what we do and this is how it works.” There’s no danger to anybody. As a carer you get frustrated sometimes. You feel like forgetting it all but you can’t do that. You’ve got to care for the one you’ve got. No two scenarios are the same, are they? It moves as the hour. It’s very difficult but a lot of peer support goes on. So yes, we do have the two groups but they are educational groups limited by time. We just have an hour once every four to six weeks but the main activities are all shared activities.

**R2: Okay. I thought maybe in France we have this idea carers have a lot of things to look after and they maybe want to have some time for them so we offer some activities just for people living with dementia. Often people are not coming. Carers say, “Oh no, he or she will not like that,” but maybe it’s a mistake. Maybe we need to have more activities together because they want to be together. Sorry, I’m probably not very clear when I want to say that.**

P2: I think you could be creating isolation, couldn’t it? I think as a carer I was never too keen to leave [MY WIFE]. I wanted to be with her. I wanted to care for her. I think I’m about 99% certain that most carers who I know are in that similar position. I remember leaving [MY WIFE]… well part of the CCG group at that time, I got friendly with a guy who ran a care home and we got talking and what have you. He said to me, “You need a break, [P2]. Why don’t you try bringing your [WIFE] to our place for an afternoon. We’ll keep her busy, we’ll keep her safe.” I said, “Alright, I’ll give it a try.” So I took her and I felt really guilty. I just came home and cried. I was going to do this and do that because I was on my own. All I did, I just fretted for her. It just didn’t seem right. So I picked her up. I never said anything. She was happy. The only thing wrong was they painted her fingernails with some red nail polish. Well she never used makeup, very rarely had makeup and certainly never painted her nails. She looked totally out of character so we spent that night getting that stuff off. I ended up getting some paraffin or something out of the garage because we didn’t have the proprietary stuff to do it. Anyway we sorted that.

But as she deteriorated, she did end up going there a full day each week which I made good time with it. It allowed me to do all the domestic things, shopping, washing and cleaning the house and what have you. That was great support. Obviously, well probably not obviously to you because you’re from France but it’s something you have to pay for. There’s no central government support for it or local government support for it. That costs you money. In terms of respite, Age UK in Oldham own a respite service. Again, you have to pay for it. I don’t really know how much it is but I think it’s certainly not a commercial free. It’s something like £10 or £12 which is nothing for a day but you have to have the transport which I think is about £6. Somebody left them a big bungalow in her will and they’ve done that and made it dementia friendly. People go there. I think it only allows about twenty people so that affords the respite. Age UK Oldham could tell you more about that. The home is called […]. What they do when they get there I do not know. I should imagine they just keep them occupied and obviously feed them and take care of the personal requirements while they’re there.

That’s the only respite I’m aware of. There’s no national health or local authority respite. If you wanted respite, you’d have to go to an age persons home or something like that and ask them if they do it and pay whatever they want to charge you.

**R2: You are living in Oldham for a long time now?**

P2: [MY WHOLE LIFE]

**R2: I suppose it’s a long time. We mentioned that during the focus group that there can be some differences between boroughs so for example between Oldham, Salford, [s.l. Stakeford 00:40:11] or Manchester centre. Have you observed these kind of differences? Is it a problem for you? In a perfect world, what would you like to improve in the current situation?**

P2: I think there should be more recognition for the support that carers require. I think it should be recognised that the stresses and strains of carers health is most important, more important than the person with dementia because the carer looks after the cared for by definition. I must admit, when my carer role finished, I felt, although I was bereaved, I felt a lot stronger in myself and people said I looked a lot better in that respect. I still miss my wife every minute of every day. There’s no doubt about that. But you physically… I mean I can remember [MY WIFE] ended up in a home for the last eighteen days of her life and I can remember the night before she was going in this home, she thought she was going somewhere to get better. She soiled herself in the living room and I had to sort all that out. I were absolutely wringing wet, my clothes were wet throughout, I was sweating and what have you, probably about midnight time and I thought, “That’s why [MY WIFE] is going in this home because I’m getting to a point now where it’s breaking me.” That’s never happened to me since but it’s happened to me a few times when we were together. So I think it’s about personal carer support. There’s all the talk about carers.

Oldham Council are doing a strategy for carers. It’s the 2020 strategy for five years. I wrote the forward to it and it never got published and they’re redoing it again so it will never get published. It’s something I think everybody knows. I don’t think it’s unique to Oldham. I think it’s something everybody knows is there but nobody’s doing anything about it. I don’t know what the current rate is but I think it’s about £70 a week. If you look at that, it works out about 5p an hour or something like that over a week. It’s something silly. So if it were a paid job, it wouldn’t be one you’d apply for. It’s 24/7 for nothing really. I think the other thing I think is difficult is that as a carer, from my personal experience and one or two others, as soon as you lose that caring role, it’s a big change on your life. It’s very difficult. There’s no support there for you. I did try and seek some support and it was a case of well we’ve got a waiting list of six months which isn’t good enough. But I was fortunate enough, I am a school governor as well. I was at a governor’s meeting and one of the governor’s came to me afterwards, this lady, she was a lot younger than me, she just said, “Are you alright, [P2]?” I said, “Well no, not really.”

She phoned me up later on that night and she said, “I’ve spoken to a bereavement counsellor who will have a word with you.” He’s associated with the school doing counselling work with the kids. She was that link. So I went to see this guy. I went for six weeks and he just completely… [MY WIFE] died at the end of August so I had a few sessions with this guy before Christmas. So I had a good Christmas out of it and was refocused but that was purely by luck and chance. The system didn’t do it for me. It’s still like that I’m afraid. So it’s alright saying these services are there, it’s how can you get to them. I think at the moment, sadly, when you try and engage with any services, they’re going to say, “Well we’re busy with COVID.” So they are or it’s an excuse. I think they are busy rather than it being an excuse but I doubt it.

**R2: Maybe it will be an excuse for a long time because I don’t know if the situation will improve but we’ll see. We are close to the end. Do you want maybe to add something? We already talked a lot about a lot of things but maybe something that’s very important for you on this topic of activities, access to activities, support.**

P2: You mean support for the group?

**R2: Yes.**

P2: Well I think the group are well supported because we’re recognised. You’ve got to get to that point. That’s the difficult bit. Like any organisation, we need funding to keep going and keep it reasonable. We never charged anybody for turning up for our meeting. We managed to scrounge some money to pay for the church hall as a commitment so we got that for nothing. If we had a coach trip somewhere, we worked it how much per head and did it like that. So it was never charged. We did get some money when Age Concern run it at first, they brought a bit of money with them for their activities. When we got involved with Making Space and Reading Friends, they were bringing money with them as well and still are. Our biggest problem is they’ll not be able to bring that money because the background of all that money is local and national government funding. So if ever that gets drawn in, which it could do because they’re that much in debt, we probably would have a problem. But we haven’t put our heads in the sand. Quite remarkably about three years ago at our AGM, one lady stood up and she said, “How do we pay for all these things, [P2]? It’s been going on and on and on.”

So we said, “Well we keep telling you every year this is…” and she said, “I think we should all pay £5 a year to be a member.” She just turned round to the people who were there and she said, “Put your hands up if you agree with me.” So they all put their hands up and they’re getting their wallets out and their purses out to give us £5. It was incredible. So we charge £5 a year now for that. The next AGM she said, “I think we should all pay £1 to come and build this money up.” So we get £1 a head now and £5 a year. Okay, we’re not meeting now so we’re not charging but we have got a little bit of money in the bank. Our masterplan is that when we can all get together again, there’s a restaurant in Rochdale about seven miles away, they’ve always been good to us and we’ve had Christmas meals there and a couple of afternoon teas so we’re all going to descend on that. They’ve told us they will accommodate us on a Thursday. So we’ll look forward to that to celebrate being together again.

**R2: Yes. I’m sure you are really looking forward to that because it was very frustrating, all these months with just Zoom meetings. As you said last time, it’s not convenient for all members. Some of them can attend and not the other ones.**

P2: Yes. I think we have a Zoom meeting every Thursday at 1 o’clock. We’ve got a membership of about 80 to 90. I think there’s only about five or six couples who turn up on Zoom which is not good. We’ve sent newsletters out telling them how easy it is to get on to Zoom. We’ve put together guides on how to get on to Zoom. We phone everybody up every week and have a chat. The final line is before we say goodbye, “Are you going to get yourself on Zoom so we can physically see you?” “It’s not that easy.” So one thing we are going to do when we do get back together again, we’re going to push out our IT. We’re going to have a purge on IT. Should we ever get a similar situation, we won’t find ourselves frustrated by the lack of attendance and (unclear 00:50:44) because they can’t see their friends. There’s no doubt about it, dementia is a lonely world to be in and people who see one another every Thursday, you can see the pleasure they got out of being there and that’s been denied now for a year. We need to make sure we can do that. It’s not the same on Zoom. I’m sure our conversation would have been something different if we’d been sharing a table together.

**R2: Exactly.**

P2: But it’s the next best thing, isn’t it? I can’t always connect. I was struggling to do it to be honest with you. I knew I had an email with the link but I couldn’t find the thing could I. I got it at the last minute. But if you weren’t that committed to it, you could all think, “Oh forget it.” I think that happens as well with people with dementia. Most people are over 70, the younger end tend to be the ones who use Zoom. So we need to plug that gap. That’s a commitment we’ve got. I’m suggesting everybody gets some form of tablet or apparatus for their birthday or for Christmas next year.

**R2: Exactly. We need to anticipate because probably in the future it will be something again and it can be interesting for some aspects too. I don’t know if people are not feeling great, if they want to stay at home, it’s also a way to have some contact.**

P2: I mean what I thought of but I haven’t mentioned it to anybody yet so you’re the first. I thought that if we could have some form of Zoom connection, we could possibly, with everybody’s agreement, have a fixed camera in the main hall where we meet so if somebody is bed ridden or whatever, they could see what’s going on.

**R2: Fingers crossed everything will be right. It was really, really nice to talk with you and thanks a lot. For your voucher, what do you prefer? I think for the university I can for example do a voucher for Amazon or something like that so you can have your 40 Euros to use them on Amazon or maybe, I don’t know if you have maybe another idea because Amazon, some people are not very happy with Amazon. Or it’s also possible as I say to do a donation. It seems it’s possible. So what do you prefer?**

P2: I think the donation to Springboard would be better. If you’ve got a voucher, we’d have to raffle it or something like that, wouldn’t we?

**R2: As you want. I can totally understand if you want the money for you. I don’t want to put pressure on you.**

P2: I don’t want any money at all. If you make the cheque out to Springboard, that will be nice.

**R2: I suppose I can find all the information on your website, the bank account and this kind of thing?**

P2: No, that won’t be on the website.

**R2: So can you send me by email the bank account details and I will contact the university. The last time they said to me it’s okay to do a transfer so I suppose it will be okay. I will let you know. If that’s okay for you.**

P2: I mean I haven’t got them. I’ll have to ask [ANOTHER VOLUNTEER] for them. I think I may have one for an email for something else I did a while ago. I’ll send you an email on that one.

**R2: Okay, right. Just to give you some information about this research, so we made a focus group with you and two other people and we had also two other focus groups. It was eleven people. Now I am doing interviews with people in the focus group and I will begin soon interviews with people living with dementia. So maybe I will contact you again if you know people interested in participating in research. It’s an individual interview like this one by Teams. I can send you information and you can share it if you think someone in your group can be interested in…**

P2: Yes. We’d be more than happy to do that. There’s no problem with that. We are committed to getting this sorted out once and for all.

**R2: That’s very kind of you so great. I will let you know. If it’s okay for you maybe I will try I suppose to send some email just to give some information about the project because for the moment our website is still not online. It’s still the beginning of the project. We want to let our participants have information of course about the project and know what’s going on.**

P2: What I can also do is once we do get back together, you’re more than welcome to join us for one of our sessions if you like.

**R2: Yes, I would like.**

P2: Either to give a talk or just sit there and have a drink with us, whatever you want. You’d be more than welcome on that.

**R2: I will be very happy. You know what? When I arrived in Manchester five months ago I made my quarantine because as I come from France I had to do that and I made it in Oldham but as it was quarantine, I never had the occasion to visit the city so I will be happy to come back and have a better overview of the city. That’s very kind.**

P2: Where did you stay in Oldham?

**R2: Sorry?**

P2: Where did you stay in Oldham?

**R2: I think it was quite in the city centre but… I’m very bad with street names but I was quite in the city centre with all the shops around. I think quite in a poor area of Oldham but it was nice. I was inside during two weeks so it was not a welcome to the UK as I thought it would be.**

P2: You’re picking your words very carefully there but I understand. Somewhere in the centre of Oldham.

**R2: I saw some very nice parks around and this kind of thing.**

P2: Okay then.

**R2: Perfect. So yes if you can send me bank details for Springboard and I will forward that to the university to have your voucher.**

P2: Thank you very much. Nice to meet you and best of luck with what you’re trying. I’ll probably go up to France one day.

**R2: Perfect. Thanks a lot. I will contact you soon. Thank you.**

P2: Thank you. Bye, bye.

**R2: Bye, bye.**

P2: Au revoir.

**R2: Au revoir.**

P2: Bye.

**[End of Recording]**