**File: Male.mp3
Duration: 0:47:13
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Typist: 727**

START AUDIO

Interviewer: I’m just wondering where to put it. I’ve got quite a loud voice so you can always hear me. I’m just going to write on this as we’re going along. Do you want to start by going over your persona with me? Did you do the persona?

Male: No, I didn’t. I had a look at it several times and I’m not quite sure what I could do here. I notice you’ve put, “This doesn’t need to be you, use your imagination”.

Interviewer: I think we were thinking that maybe if there was a type of person with Parkinson’s and it could be you, for your own case, and if you’d like to use you. For example, Harry did Billy Connolly for his one and Heather had someone in mind who was much younger. They were the types of personas. The reason we use this type of activity is sometimes it gets people to think outside of the box, out of their own experience but, if you want to use yourself as an example, then that would also be absolutely fine.

Male: I think probably it would probably be more accessible if I did it on myself, I think. What is my name? Male. What age are you? 71. How long have you had Parkinson’s? That’s an interesting question. Obviously, it was diagnosed just over a year ago but, looking back over the information I’ve gleaned from various sources, I think it’s been coming on for maybe four or five years. Where do I currently find out information about Parkinson’s? From the services at the local hospital in the elderly medicine section, through the local area group meeting once a month, over the internet. I get the Parkinsonian magazine.

Also, talking with people who are either Parkinson’s people or carers. Harry and Heather, for example, locally. I’ve also found out a lot of information, I had a one-to-one telephone support, the six sessions that you’re able to get through Parkinson’s UK. That was a gentleman who lived, actually, in my old hunting ground of Somerset, and we had six hour-long conversations in the early days of my diagnosis, which I found particularly helpful actually interacting with a real person who was in the same situation.

Interviewer: It was somebody with Parkinson’s?

Male: Yes.

Interviewer: Excellent. Was that before..? Sorry.

Male: A volunteer able to, actually, give that kind of support over the telephone.

Interviewer: What did you find useful about that?

Male: I think, with hindsight, actually being able to talk around all the issues that were emerging for me with someone who, because they’re in the same shoes, understands it from the inside whereas someone like yourself, who clearly hasn’t got Parkinson’s, you cannot fully understand. This is not being disrespectful. You cannot fully understand what it’s like to be dealing with an issue where the electronic circuits are actually closing down.

Interviewer: Of course. That’s why we need to come and talk to people to find things out because we don’t understand at all.

Male: You do.

Interviewer: In terms of the experiences that people have… Did you feel like that was comforting to have somebody who was in the same shoes, as you say?

Male: Yes, definitely. Before the last just over two years, since all came to a head after I had an operation, I had a kidney stone in September 2013 or 2014. It must have been 2014, I think. No, it must have been 2013. It was 2013 and that seemed to trigger both the dystonia and my more obvious Parkinson’s systems started to kick in at that point. Where was I going?

Interviewer: We were talking about the one-to-ones.

Male: It was particularly useful. I had not really thought much about Parkinson’s at all and I think everyone who gets it finds that it was initially quite a shock to have the diagnosis so it was really good to speak to, again, a person’s who’s in the same shoes.

Interviewer: Was this before you started going to the meetings or was it afterwards?

Male: It started before and then it overlapped.

Interviewer: Did it prompt you to go to the sessions? Firstly, who told you about it?

Male: Catherine Jones.

Interviewer: I know Catherine. She’s lovely.

Male: Yes, she is. My own daughter and family were keen for me to, obviously, make connections so there was that as well in the background.

Interviewer: Do you know if many other people have had that one-to-one support thing because it sounds pretty good?

Male: I don’t.

Interviewer: I’m wondering if it’s a fairly new thing. I haven’t heard of anybody else who’s had it.

Male: If you go on the Parkinson’s UK website, it comes up in support. It’s on there somewhere.

Interviewer: I suppose even knowing that that type of thing is available is quite useful because, obviously, Catherine is fantastic. I know Catherine quite well and she’s very switched on but I know for a fact that they don’t have the same kind of thing, list of things to offer people, if you know what I mean. I’m sure she knows about that because she’s pretty switched on.

Male: She is, isn’t she? \_\_\_[0:08:07] facility, I think. Support for you. There it is, “If you have Parkinson’s or if you know someone who has - you can turn to us”. A confidential helpline and, I think, on that particular line, they offer the possibility of a one-to-one.

Interviewer: Excellent. Fantastic. What was it about the back and forth that would be different, for example, than watching a television show where somebody is talking about Parkinson’s?

Male: Obviously, the television show is set and there’s not the interaction, is there? Whereas with the one-on-one, say, someone like Harry, for example, if I talk with Harry, we’ve had one or two chats together, which has been helpful, you’re responding instantly to the line of questioning and how it develops.

Interviewer: If we think about this is the context of a radio show, I’m starting to add in some of the people that you’ve been talking about. Obviously, this one’s yourself. Will it be interactive is important. That’s just one of the issues that might come up with the show. I’m just going to write down some ideas. We’ll come back to that. This is just me mind-mapping so don’t worry. What’s the next question there on that? Unless there’s anything else you wanted to bring up about the one-to-one support?

Male: No, I think we’ve covered that pretty well. Is there anything that affects your ability to find out information about your Parkinson’s from different sources? The personal thing, is the only thing that comes up for me, it’s actually having the drive to follow things through. It’s motivation, which, again, can be an issue with some folks with Parkinson’s and, clearly, at times I’m battling with motivation.

Interviewer: I suppose in that sense then, listening to a radio show would be pretty easy to do motivation-wise?

Male: Yes. I think that’s where the interaction comes in because once you’ve got the stimulus from another real person, it makes it easier as you’re saying.

Interviewer: What’s the next one there?

Male: What sources of information do you use in everyday life? This doesn’t have to be related to your Parkinson’s, for example, radio, TV, booklets, word of mouth, meetings, internet, mobile phone applications, books from the library, etc. TV to a certain extent, for me, booklets, definitely, word of mouth, meetings, internet and that’s it, I think. I haven’t got a mobile phone although, I suppose, the tablet is equivalent, isn’t it? I’ve got it on there. Tablet applications.

What type of information would you like to have about your Parkinson’s? I think, talking with a councillor friend of mine who’s done some CBT with me and how to, actually, get motivation going. It’s a key thing for me. He was suggesting target-setting, goal-setting and that sort of thing. I’m not quite sure where I got this information from but I’ll show you this. You may well be fully au fait with this. Psychology tools, I find that kind of thing helpful.

Interviewer: Are these the days of the month?

Male: Yes.

Interviewer: These are things that you would set to do, maybe you’ve got something you want to do daily or something you want to do weekly.

Male: Regular exercise, regular social contact, use of internet, phone calls and that kind of thing.

Interviewer: Excellent. I suppose, then, if you want to figure out, maybe you do that once a week so you highlight these down. You might see friends twice a month because people are busy, aren’t they, but you might want to call them.

Male: Yes. It’s a good memory jogger and, obviously, it’s setting a goal.

Interviewer: Fantastic. This is information that you might not have, actually, been able to get through Parkinson’s UK, for example?

Male: Possibly, that’s right.

Interviewer: Fantastic. What about your other wee one there, the other task, which I can see that you’ve done as well? I’ve forgotten my little book again. It’s fine. I did, actually, bring it this time but I left it in the car.

Male: What was that sorry?

Interviewer: My little book but it’s fine.

Male: It was these, was it? Who would you like to have on your radio show? I’ve put down two things under that. First of all, people who have a helpful story to tell. Number two, an experienced Parkinson’s specialist.

Interviewer: Why would you want them on?

Male: The questions I’d like to ask them regarding number one, how have you adapted to you Parkinson’s? What have you found helpful on the way? To the experienced Parkinson’s specialist, obviously, there’s a whole number of things that could go there but please explain some of the common psychological symptoms and support.

I think a lot of the focus, as I’ve found it, with various support groups and specialists and so on is focussing very much on the physical symptoms of the disease and not so much on the psychological side. I feel that, obviously, that’s an issue that everyone is coping with who’s in this particular situation. Excuse me, I’m getting a frog in my throat.

Interviewer: I’m getting coughy as well. I’m not ill as far as I know so I’m not bringing anything in.

Male: On the others, I haven’t actually put anything in. What role do you think you could play? I think partly what we’re doing this morning in a sense, ideas that might come across on the way that might be helpful to others, possibly, to provide those. I don’t know what the mechanism, the actual structure, would be of getting those to the radio station.

Interviewer: Providing what, sorry?

Male: Providing ideas that are helpful.

Interviewer: Ideas for content?

Male: Yes. Obviously, there are things that come with the magazine, Parkinsonian, the latest update on research developments and that sort of thing.

Interviewer: Almost ideas for content and research?

Male: Yes.

Interviewer: Figuring out what is going on at the moment? That was, actually, something that Jack talked about quite a lot. There’s all this stuff going on but…

Male: Yes, he didn’t he?

Interviewer: People don’t really know what it’s about.

Male: He asked for one or two sessions specifically on Parkinson’s, I think, in the group, whereas there was some feeling that people wanted to get away from that as well and have the group as a lighter thing. There’s an issue there but, obviously, that’s different to this.

Interviewer: It is and it isn’t because if we were, for example, to have a regular show, thinking of a blue sky example, say this was to be something that we’ve developed, it was very easy to do and everybody really enjoyed it and doing it and thought it was extremely useful, it might not be supported by us, in the end, but it might be something that Parkinson’s UK would support.

Actually having a list of shows that would be on or having a way to archive show so that people can listen in on different topics, there could be a balance. So the types of things that Jack wants, specific information about Parkinson’s and a chance to ask questions about that but then, also, the more storytelling side of things, as you said, or interesting things that are happening around Parkinson’s but are particularly positive.

Male: I think that’s very important, the positive side and pushing that, isn’t it?

Interviewer: Yes. I suppose the content needs to be, I’ll put that up there, it needs to be balanced. Were there any other questions or is that the end?

Male: Two more questions.

Interviewer: What were they?

Male: How would you let others know about the show? I think, clearly, through the local monthly meeting. Presumably, if this were up and running, Kate would be able to disseminate it through the internet, wouldn’t she, as well to those who were on her list.

Interviewer: Yes.

Male: This is particularly for those who are homebound who don’t get to the local area meeting.

Interviewer: Does she email everybody?

Male: She emails the ones who have, obviously, got computer linkage. When her emails come up, there’s a list of people it goes to. There are about 20, I think.

Interviewer: Does she send it to the rest?

Male: Obviously, there’s the monthly newsletter, which Harry puts together and I think the information is also on there. There’s a hard copy in that sense. In terms of those who’ve not got internet connectivity and who are homebound, I suppose maybe asking at the local area group, people who know others who are homebound, could you pass this information on?

Interviewer: This is word of mouth, isn’t it?

Male: I don’t know. Yes.

Interviewer: What about a little bit wider than the Ellington group, should we just focus on Ellington for now or do you think we should try and promote our show to other people?

Male: If it came out as a radio show, presumably, it would cover Tyneside, Northumberland so I think it would need to be spread across the area, really, to the other groups. I gather from Dr Wood’s information day, or was it from Catherine, one of the two mentioned that there are about 600 people with Parkinson’s in the area that they cover. We’re talking about a big number, aren’t we?

Interviewer: They have access, don’t they? They could also be good promoters of the…

Male: Yes, that’s a point.

Interviewer: If they have a list of people or if they’re going out to see... What was the last question on the list there?

Male: How would you encourage people to contribute questions?

Interviewer: I think the whole concept was that we would be able to collect questions from people and allow them to ask burning questions around a topic but, obviously, we need to… I did forget to mention, there’s two different ways that we could do a show. Obviously, we could do it live, where somebody hosts and whoever the interviewee is answers questions or we could pre-record it.

We could pre-collect the questions from people and then pre-record the responses and then, I suppose, in that way people would still have their questions answered but then there wouldn’t be this phone-in. I think one of the reasons behind that was the fact that quite a lot of people have speech issues so maybe calling in to a live radio show might not necessarily be something that they want to do.

Male: There is a confidence issue, isn’t there, with Parkinson’s as well.

Interviewer: Yes. We thought maybe pre-collecting the questions would gave people the opportunity to still have their questions answered but maybe not in that live scenario.

Male: There’s also, isn’t there, the aspect that there might be some inappropriate questions that come up as well.

Interviewer: Yes.

Male: Pre-record, it looks as though that’s probably, I don’t know what you think, a better option.

Interviewer: It’s certainly easier to do.

Male: Would it be possibly to have both in one show, a pre-recorded bit and then a live bit, as it were.

Interviewer: Certainly. It would still be a live show, if that makes sense, but it would just be recorded in advance and then… Do you mean the call-in aspect? For people to phone in with questions?

Male: Yes. I suppose there’s an issue about filtering there, isn’t there? That could be dealt with, I’m sure. It’s not a major problem.

Interviewer: I’m just trying to think of the people that might be involved. Somebody would need to take call-in questions and then one of the issues might be filtering questions. I suppose, people with Parkinson’s, one of the issues here might be they’re not confident to talk on the radio. I can read this. My handwriting’s awful. You probably can’t really see this here. I can read upside down. Basically, this is our concept of the radio show here.

There are various different types of people who are contributing or listening to our show at the minute. We’ve got people from Parkinson’s UK meeting who might be listeners of the show. The Parkinson’s team who might promote that to others. People with Parkinson’s in the wider community who would be listeners and, hopefully, also contributors of the show. Experienced Parkinson’s specialists who could be on the show.

We’ve got this production team who make it work. We have somebody who thinks up the ideas for content, somebody who researches current research. Again, I suppose these two are together really, aren’t they? It’s almost a research team, I suppose, for the content. We’ve got somebody who promotes it, who takes charge of that and somebody who answers the call-ins. You’re here thinking about whether or not it will be interactive, that was something that was important to you.

We’ve had other people with Parkinson’s themselves, who could, actually, be contributors to the show, who could interviewees to help with the content. These are people who are putting in to it as well, aren’t they? Let’s section these people up for a minute. The way that I like to think about it is we have consumers of the show, contributors to the show and then producers of the show.

If you think about consumers as being the people who are just listening in. They get all the information about when the show is on, they tune in and they listen and consume the information. Would there be anything that we would need to consider for them as just listeners? Would there be any issues of just being a listener? That question is probably not framed very well.

Male: I can’t think of anything particularly. Maybe to have a safety net if something that’s discussed on the radio triggers, for an individual, maybe, how would I put it?

Interviewer: I know exactly what you mean.

Male: Some sort of telephone support line linked in with the show so that people could, if necessary, get a fairly quick response to an issue that, maybe, has been raised in the show that, for them, in a personal way is maybe a bit distressing or whatever. Hopefully they wouldn’t be distressing but…

Interviewer: That’s a really good point. What if I need support? These issues apply to me personally, I feel distressed. Fantastic. I suppose the Parkinson’s UK helpline would probably be a good thing to provide. Maybe saying the helpline at the end. I suppose it’s what they do when you watch soap operas on TV, isn’t it? If you’ve been affected by any of the issues in this, call us.

Male: Again, for people who’ve got computers, there is a, I think it’s in 48 hours, helpline, which you send an email to and one of the professionals… You probably know all this, do you?

Interviewer: No, not really.

Male: One of the professionals at Parkinson’s UK will send an email response back. I’ve used that a couple of times in the past. I think it’s 48 hours. It might be 24, actually.

Interviewer: How about the contributors to the show? We first had people contributing questions. I suppose the way of thinking there is what might be the issues with contributing questions, people with Parkinson’s. Say, for example, I’m just thinking of a question and answer thing that Parkinson’s UK have with Nick Miller.

Nick Miller is a speech and language professor from Newcastle University, he does this, this and this, he’s going to be answering some questions around speech and Parkinson’s, what would your questions be? These were submitted online but, obviously, for people who don’t have the internet, what might be some of the issues there? How might we do that? How might people then contribute their questions if it wasn’t going to be online?

Male: Presumably some sort of telephone recording system, do you think? I’m just going to get one of my supplements. I’ll bring it through, if you don’t mind me drinking it while…

Interviewer: No, of course.

Male: This is from the dietician. Just over a month ago on these. Trying to boost the weight and it’s gone up by a couple of pounds in the last month, which is brilliant.

Interviewer: Yes.

Male: Sorry, where were we?

Interviewer: No, you work away. We were just talking about contributing questions to the show and we suggested telephone. Would there be any other ways that we could do that? Would there be any issues for anybody who’s contributing by telephone or do you think that’s generally a good way to do it?

Male: I suppose, if they didn’t have an issue with speech, they’d, hopefully, go through their carer. Their carer could, actually, telephone the question.

Interviewer: Yes. What would we do with the questions? How would we then get that? Say we were pre-recording it, how would we filter those questions and translate that to the show?

Male: Good question.

Interviewer: This might be a job for the production team.

Male: Yes.

Interviewer: Here’s the scenario, you tell people what the show’s going to be about and you get 125 questions back and you need to make that something that you can give to, say, Nick who’s coming on to the show to do his thing about speech. Do you think that’s a job for one man or is it maybe a job for more people?

Male: I would imagine, if you’ve got 125, it would take a couple anyway, I would imagine. I really don’t know because I’ve not had to deal with kind of issue.

Interviewer: There’s different ways, I suppose, that we could do it. Maybe that’s something that we talk about at the next session with the team, what do you think?

Male: Do you think that folks generally would have..? Some might have been involved in it. I wouldn’t want to cut off suggestions if someone’s been involved in that kind of situation themselves. For myself, I haven’t been involved in that so I wouldn’t know quite what the way ahead on that particular one was. Yes, maybe the group.

Interviewer: I suppose, if you get 125 questions, 50 of those might be duplicate questions and then another 25 of them might be very similar theme-wise but slightly different. There are ways you can cut it down, I suppose. The best way would be coming up with a plan of how you would do that and then translating that into the show, I think, is the other thing.

We have all of our questions and then we need to come up with a show around that, I suppose. Any other issues in relation to producing the show? Bearing in mind that it would probably be us, i.e. us, the research team, including you guys, very heavily supported by myself and John, bearing in mind that we’ve done this before.

Male: You’ve done it before?

Interviewer: Yes. We have the background to it. Forgetting about the actual, I suppose, it’s more the planning than the execution, if that makes sense.

Male: So you have actually delivered radio shows in the past?

Interviewer: Not personally, but the group has. We’ve got experts in the field who can deliver. I might bring [Delvin 0:40:17] with me in the next session, who is the person who’s been doing the radio health \_\_\_. I’ll ask him if he can come along and answer some questions.

Male: Where would the recording be done?

Interviewer: We, actually, have a radio-recording studio at Culture Lab but we also have people who are sound experts and, actually, you can probably record it in a small room at the meeting, for example, in the therapy room, and still get a pretty good sound sample. That’s a discussion that we need to have and figure that out, what the best way we’d do that would be. It depends how much people feel that they would like to contribute, I suppose.

Whether the group feel that they’d like to see it through form the beginning to the end or whether it’s just the planning stages. We’re only really planning on doing one or two, I think, just as a little pilot to see how it works. Don’t think that we’re expecting to develop this production team and then leave you for months on end to try and do radio shows. That’s definitely not what’s going to happen. It’s more of exploring how this actually could be used to help promote information to the wider community of Parkinson’s people in the area.

Maybe starting with Ellington as a pilot group would be a good deal and trying to reach all the members of the pilot group and seeing who tunes in. it could be interesting. I’m trying to think if we had anything else.

Male: To be honest with you, I don’t see this as my forte, for want of better words. Obviously, I’ve not been in that situation in the past. I don’t want to put a negative on it but that’s my own perspective at the moment. I was going to ask you how is this funded and who’s going to be doing it?

Interviewer: It’s funded by us and we will be doing it. If you think about these roles that we’ve thought about…

Male: You’ve got access to funds?

Interviewer: Yes, we’ve got lots of access to funds. If you think about the roles we’ve already considered, we’ve got one person who thinks of some ideas, we’ve got one person who researches the research so, if everybody joins together, these little jobs make up the bigger job of what we’re doing and all are equally as important. Do you understand? It’s not necessarily hosting a radio show. That doesn’t need to be anybody. That can be me or whatever. Myself and John are members of the research team too so we have jobs to do as well.

As I said, it’s not going to be a monster undertaking… What we’re more interested in finding out is how do we get the type of information that we need to find out what people actually want to know about. How do we curate these questions from the wider community of people with Parkinson’s? How do we translate that to a sensible, accessible piece of information? If you talk about it like that, that’s where our research interests lie and the mode of doing it is through the radio show. Everybody seems a bit scared. I promise it will be fun.

Male: That’s good.

Interviewer: Was there anything else? I’m just trying to think. Any other jobs that you think would be important?

Male: I suppose the production team, obviously, will give feedback and that kind of thing and it goes into a plan, do, review cycle sort of thing so it’s on-going in developing.

Interviewer: How would you get that feedback?

Male: I think maybe ask folks who had actually heard the show, if one or two people wanted to perhaps phone in and give responses.

Interviewer: Excellent. We’re already starting to think of ideas of what we might do for next week. This has been very useful. Any other issues that you can foresee?

Male: I can’t think of anything. Obviously you’ve got a major job if you’re going round seeing folks like you’re doing at the moment and putting it all together because, I would imagine, the amount of information you’re getting would be quite significant, quite substantial. Just looking at that now, there’s a lot of stuff on there. That’s my perspective anyway, I don’t know if it’s yours.

Interviewer: There’s definitely a lot of information but I’m highly skilled.

Male: Yes.

Interviewer: No, of course. It’s just the way we do things and it, actually, helps me to figure out what we’re doing. If you don’t have anything else to add, maybe we can leave it there.

Male: Okay.

Interviewer: I’ll switch off my recorder here.

END AUDIO

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