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START AUDIO

Roisin: I suppose I was interested, really, in having a chat about your personas first. Did you do the activities?

Female: We looked at them last night. We sat last night, didn’t we, with them. We didn’t get very far.

Male: \_\_\_[0:00:15].

Female: Yes.

Roisin: Do you want to have a little..? There’s this one.

Female: Is that mine?

Roisin: Is this your one here?

Female: That’s yours, Male.

Male: \_\_\_[0:00:49].

Female: No, these are mine. Are they Roisin’s?

Roisin: They’re mine. They’re my driving glasses. Mine barely work on my eyes anymore so I think I need new glasses, definitely. Do you want to take me through your character?

Male: I’m not sure if I quite understood what I was trying to do but I was thinking of a radio show and thought a big name, like Billy Connolly, who has Parkinson’s would be interesting for an audience, if he would do it. Everybody seems interested as to how people are diagnosed so that might be a question. Any way that he could help people with insights and pearls of wisdom. Is he curious to find out more in terms of the science or mechanism or medical aspects because quite a lot of people, I’ve discovered, really don’t want to know.

What does he think the future would hold for him? What is he looking forward to? It’s very hard when you’ve got a degenerative disease and it looks like all the roads lead downhill. What does he think the general population seem to know about Parkinson’s? Where does he find ignorance? That’s about it.

Roisin: Excellent. There are quite a lot of nice questions or themes, I suppose, that maybe might go in to a radio show there. I like the point that you made about focusing on something positive rather than negative. That is quite nice, especially if you’re talking about personal experiences as well, if that was going to be something that we would be looking at.

Male: I’ve had another idea for a person. There’s a jazz musician, she’s got dyskenesis from the Parkinson’s but on the stage people think that’s just movement to the music. She plays two saxophones at once welded together. That is someone who is succeeding in something that you’d think Parkinson’s would make impossible. I’ll find out what she’s called.

Roisin: The double sax.

Female: There are some good YouTube things of her. I’ll have a little look.

Male: Shall I have a look?

Female: I can always get that back to her. I could tell Roisin next week. I wasn’t, actually, listening to what Male said, I’m sorry. Can you just go over what said, Male, very quickly? The points made. It was a celebrity like Billy Connolly?

Roisin: What made you go for a celebrity? That’s an interesting question.

Male: It might interest people, people might be more inclined to listen to a celebrity, rather even than a Parkinson’s expert, giving personal insights that people can identify with.

Female: People are interested. It’s the general thing about celebrity, isn’t it?

Male: Obviously, the scale of it, it couldn’t be afforded to pay somebody on a commercial basis but somebody like Billy Connolly or somebody else, who we all know, might be prepared to do it as a freebee.

Roisin: I’ll just show you what I’m doing here. This is one of the people who might contribute to the radio show, we’re thinking, and what he’d be putting in to the show would be personal insights and there’d be a level of trust from the audience of general people with Parkinson’s. There’s a level of trust from them. What they’d be, then, getting out of that is… I’ll write the trust here, trusted information. One of the concerns might be what will I get paid. We’re going to do a mapping activity here. You said here that another thing would be this level of positivity for the people with Parkinson’s hearing about somebody who’s succeeding with their Parkinson’s.

Female: Well, you hope.

Male: I’m not sure about Billy Connolly.

Female: You don’t know. The person you chose might not…

Male: He had said he wouldn’t take any medication, which I don’t believe him. He maybe might not need any at the beginning but he will.

Female: You’re assuming they’re going to be very positive about their situation but…

Male: What’s been very interesting with the different illnesses is Stephen Fry on bipolar disease and mental illness, how he’s been able to raise the profile.

Female: He’s raised the profile but it doesn’t say that he’s been particularly positive. In raising the profile, I think he maybe frightened the life out of a lot of people. That’s exaggerating a bit but he hasn’t exactly given them hope, has he? I think you’ve got be careful about this. People expect too much from a celebrity. It’s interesting that he can give certain things as a celebrity but be careful. \_\_\_[0:07:39] Male says, I am not \_\_\_.

Roisin: Okay. We also talked about the general public here. I’m sorry that all these stick men are men. They’re gender neutral. Awareness for the general public. What were you going to say there?

Female: That’s where your celebrity comes in, doesn’t it?

Roisin: it raises the profile and increases awareness to the general public. Why do you think the general public would be more likely to listen to a celebrity than, say, people with Parkinson’s? Or do you think they’re all included in the same thread?

Female: I think, in general, people now are very interested in celebrity. You can tell that by the number of these magazines and programmes there are for celebrities. There’s something about a celebrity. You say the name and, this is the impression I get, people will take notice and will listen. They have far more clout than ordinary people but only to a certain extent. Only talking in general terms about it. Obviously not going into the medical side of it, and that side of it because he won’t have that information but just his feelings and how he’s coped with situations and things like that. What do you think, Male?

Male: That would be the bit… If it was about specific details of Parkinson’s then people who are touched by Parkinson’s would be interested but people who are not touched by Parkinson’s need something else.

Female: You’d have to have that. That would be something totally different, wouldn’t it?

Male: In that case, it’s a bigger challenge, which Parkinson’s Awareness week is there to try to do something about.

Roisin: Excellent. I can’t promise you Billy Connolly. I could try, I suppose. I mentioned the medical information there as well, who would be the best person to provide medical information? This is something that came up in the workshops previously as well around trusted information. You mentioned that some people may or may not be interested in the science aspect of Parkinson’s and what’s going on. Who would be the best person to provide that information?

Female: It’s got to be somebody who absolutely knows exactly what’s going on and what medications are available.

Male: Someone like Professor Burn who’s very good at talking to an audience. \_\_\_[0:10:55] Dr Wood but not everybody would…

Roisin: We’ve almost got Parkinson’s celebrities in the science field in Newcastle, actually.

Female: You’ve got Walker, haven’t you?

Roisin: We’ve got Professor Walker. We’ve got Professor Burn. We’ve got Nick Miller who’s an expert in the speech side. We’ve got Lynn Rochester who’s an expert in the movement side. These are the people who are called up time and time again all over the world to present their work. They’re almost our celebs, aren’t they, within the Parkinson’s community? It’s quite interesting in itself. What about yours?

Female: Totally different. A different way I’ve approached it because, obviously, we’re involved in our meetings and looking at the average age of our little group, we’re looking at it from a much older point of view. I know it is a condition where there are more older people than young people, I know that. A lot of what we say about technology, etc. is going to be irrelevant to a lot of people but my little character is, actually, it’s the chap who does the Speedflex with you. They’ve got a young chap doing the Speedflex and, of course, he’s brilliant. He’s young, how old do you think he is? I’ve put mid-forties.

Male: Probably, yes.

Female: This is my little bit…

Roisin: Do you know his name?

Male: John.

Female: Is he the one that’s been a footballer?

Male: Yes.

Female: He’s very fit.

Roisin: He’s not Scottish, is he?

Male: His heart’s behaving like an elite athlete, apparently.

Female: His needs are different and his situation is very different. I’ve got this John, who’s in his mid-40s who, I thought, had been five years and had Parkinson’s but who actually manages to work because this is a big thing, isn’t it? We’ve got time, we can read books and pamphlets and go to meetings but what do these young people who are at work do? This obviously affects them. The internet is the thing for them, isn’t it? Absolutely. Apps on their phone are the thing. The good thing about the radio show is they can get the radio on their mobile.

Roisin: They can still access it.

Male: For them, an internet forum, perhaps.

Roisin: That’s already available through Parkinson’s UK. That’s what I mean, there are fantastic resources and they do this type of Q&A session. They actually have blogs and transcripts written from the Q&A and people can submit their questions online and then they get answered by the expert online and then it’s hosted online.

Female: To be able to speak to somebody one-to-one and actually speak but you could do that on your phone on the radio. Presumably, if it happens at work time, you could just get it later on. There’d be facilities, wouldn’t there? You wouldn’t have to listen to it there and then.

Roisin: No, that’s what we thought the…

Female: You can ask the questions. It couldn’t be interactive if they’re going to listen to it later on but you could certainly hear the programme. It depends what your job is, of course, but if you knew what time it was on, you could maybe just put their phone on, like they do with You and Yours on the radio, when they get a phone-in. People must know it’s 12 till 1, that’s my lunch break, I can ring in now, I can email to You and Yours and talk to them before one o’clock. That’s doable, isn’t it?

Roisin: Definitely. I think the general idea was that perhaps we would let people know what the topic of the show was going to be and who it was going to be in advance and then they could submit questions in advance.

Female: The other thing is who would you want to talk apart from the celebrities. Perhaps they don’t just want to hear older people. It would be quite difficult to get younger people. Obviously, you want the professionals still. Would this chap, John, really be interested in hearing about Billy Connolly’s Parkinson’s because he’s an old man to him?

Male: I don’t know.

Female: I don’t know because I’m not that age. I’m not young but, trying to think back, you’re more interested in young people than you are in older people. You would need a mixture, not just older people talking about it.

Roisin: I think what you’re trying to say is that you’d need people who are going to speak to other people’s shared experiences. Obviously, the work element, family life is going to be different for somebody who is much younger than somebody who is retirement age, for example.

Female: You’re going to have to have a range, for example, to be able to call on a range of different backgrounds and different types.

Roisin: Do you think that he, in himself, would make an interesting person for the show?

Female: Well, I’ve never met him, I’ve just heard about him and I find him quite fascinating.

Roisin: Somebody who’s a little bit younger, active, still at work, to talk about some of the issues that maybe other people are experiencing. I suppose, if we’re thinking about sharing experiences, maybe he’d be quite a good person to think about.

Female: Yes, because you wonder how does he find out? Yes, obviously, you use the internet but he can’t go on information days if he’s at work, like we go. There are meetings, I know there are evening meetings for young people who are working and they are good.

Male: Like everybody, they struggle to get a work-life balance. It’s a work-life balance with a complication and ill health.

Female: We know a lot of people who have had to give up work and it’s a huge thing to have to give up… They probably want to hear from people, like the chap who’s doing the Speedflex, he runs his own company.

Male: He hasn’t turned up.

Female: No, he hasn’t turned up but, at least, he’s running his company, isn’t he? He’s still working. With that sort of thing, how do they manage to keep working and keep their job going?

Male: Another topic for one week or whatever it might be would be if there’s work and there’s benefits to understand Parkinson’s, given that we fluctuate a lot. When people are examined, how fit are they to work etc. medically? They might be fit on the time that they’re looked at and not fit another time.

Female: Roisin, that’s a great one anyway. Honestly, it’s a minefield to work out anything about the benefits at the moment because they just seem to be changing so quickly. Lisa is very good and we’re lucky that we’ve got Lisa but if you haven’t got access to Lisa…

Roisin: What’s Lisa’s surname?

Female: Watson.

Roisin: Actually, she might be a good person to have.

Male: Very good. So maybe we don’t need a celebrity so much.

Roisin: If we think about celebrities and experts, celebrities, obviously, do have that familiarity factor but experts are the people that really know what they’re talking about, I suppose.

Female: There’s Lisa for that. There’s diet. Does diet affect..? Because they’re all losing weight, a terrific amount, and you’ve got to be so careful because you want to keep your weight up but you don’t want to start eating masses of fat and affecting your heart. You need somebody who could give advice about how to get over this problem of the weight loss.

Male: Parkinson’s UK, one of the leaflets is diet and Parkinson’s and gives an example of a recommended diet, which, actually, is not very demanding and is the sort of thing that lots of people might do. You could have diet and Parkinson’s, exercise and Parkinson’s, people who are running this…

Female: What do they call them? Steve, he’s called. He gave a presentation at the Parkinson’s information day. He’s very tall.

Male: The nurse.

Roisin: Has he got grey hair?

Male: Yes, I think so.

Roisin: I think I know who you’re talking about but I can’t quite remember what his name is.

Male: There’s Eilish.

Roisin: I know who you mean. Yes, mid-40s, early-50s. I know who that is. I can’t remember his surname. And Eilish Callaghan, I know Eilish.

Female: As far as exercise is concerned, they’re, actually, spot on with the effects of exercise and Parkinson’s at the moment, nobody more so I would think.

Roisin: Obviously you know Eilish and Steve but how would we let other people know that these guys are experts in their field? What do you think we would need to do to let the wider community of Parkinson’s people, who might be listening to this show, know what the show’s about to get them interested?

Female: That’s a biggie, isn’t it? Actually, that’s the big one. That’s been easy. You could do it the slow way. You could…

Roisin: I suppose, if we want to get people to contribute questions, they may need to know who they’re asking questions to. How will people know who I am, I’ll put that as a concern.

Female: You’d have to use your groups, wouldn’t you? All your local support groups. You might have to go…

Roisin: That’s another one, then. Maybe we need to collaborate with people in other groups.

Female: Other groups because there’s North Tyneside, there’s Alnwick, there’s Newcastle, there’s one in the Tyne Valley, all the Durham groups and South Shields, etc. Then somebody could give a little chat and could ask the secretary, because some of these big groups, most of the people, I won’t say most of them but those that are on email, just a general email dropped.

Roisin: You’ll have almost a representative of each group to be responsible for sharing information about what show’s going to be on and who’s going to be on it. Would they also then be responsible for getting people’s questions and things or would that be somebody who’s organising the show.

Female: You’re asking a lot, I think, of your secretary then and there. They need to have a number, don’t they, to phone or an email. It must be so frustrating for you to realise how many people are not on email.

Roisin: I do realise that. I think telephone is always the best way to get in contact with people. I, actually, don’t email people ever. I don’t even ask for email address unless it’s offered as the preferred way to get in contact with somebody. I just assume that telephone will be the best way to make contact, usually.

Female: When you’ve got a big group…

Male: I think there’s \_\_\_[0:24:39] go off on a tangent but there’s a group like my daughters who are now so hardened to having a plague of emails at work that they routinely don’t open them, don’t look at them unless they see it’s something that’s very relevant to them. For work, ten years ago now, I was getting something like 50 or 60 emails a day and I would get no work done at all if I’d given them all attention.

The lazy thing is you always send it to everyone and you can’t always tell, when you see it on the screen, do I need to look at that or not? Whereas the telephone, some people don’t answer the telephone either but it’s a bit harder to ignore and it’s much more personal, I think.

Roisin: I suppose, then, if you had a question to ask and you could telephone the question in then you know that you want to ask the question already so you make that active decision to call in a question. What about people who might have speech problems? Because we’ve talked about this a bit as well.

Female: Can I just go back a couple of steps? The information, so that you’re letting people know, the Parkinson’s clinics.

Roisin: Yes. Excuse my drawing. That looks like a church not a hospital.

Female: You would need posters for that. If the Parkinson’s nurses knew, like Catherine and Louise, they could tell the people visiting the clinic.

Male: It’s all right for people who know they’ve got a speech problem but some people have a speech problem…

Female: Sorry, that’s going back.

Male: Have a speech problem and are not necessarily aware of it. That’s a bit harder. People who know could get somebody else to actually be on the telephone on their behalf but people who don’t know…

Female: Do you think people like Alan and Les realise how bad their speech really is?

Roisin: Les does but he still tries. Alan only notices when he loses breath, I think. I can, actually, understand them both most of the time but that’s because I know them both quite well. I’ve known both of them for years.

Female: I cannot understand Les.

Roisin: Have you ever heard Les meter himself and slow down?

Female: No.

Roisin: It’s perfect. Have you heard him do his exercises?

Male: Kate says that he’s sometimes quite clear but when he’s bad even she can’t…

Female: Peter Santer can. Have you noticed? I don’t know if you’ve noticed in the meetings, Peter will often sit beside Les and he can communicate with Les. He says. I just can’t.

Roisin: The speech problems, I’ll do this as an issue even though a telephone can’t talk.

Female: Then they could be emailed in, couldn’t they?

Roisin: Or written. This is for the questions. The other thing would be to have a selection of questions that you could vote for but, I suppose, people then wouldn’t have the chance to ask their own. What do you think about that idea?

Female: I suppose there are only a set number of questions that can be asked about anything, aren’t there? The chances are, if you’ve got a variety of questions, yours may well be there.

Male: An alternative, just as a possibility, is that you don’t have people phoning in but you have an interviewer interviewing an expert with questions that the specialist Parkinson’s staff will see as coming up again and again. Like with the other things we’ve mentioned…

Female: A lot of the radio programmes do that now, Male, don’t they?

Roisin: Something like frequently asked questions? I think that would be useful for working with the experts but what if we were, for example, doing that with the younger person with Parkinson’s who is talking about work?

Female: You mean, not have a list? Not have frequently asked..?

Roisin: How would we come up with those frequently asked questions, I suppose?

Female: Just getting hold of somebody who is young and who does work and, within a general chat, pick up the things that are relevant, the things they’re worried about and the things they want to know about.

Roisin: I suppose the other thing, I’ve noted this down and then I didn’t really talk about it, have you heard of human-interest stories? They do them in magazines or on the news.

Female: They do them in the Parkinson’s UK magazine.

Roisin: Yes. Where you, rather than asking people lots of different questions, you get them to explain their…

Female: I thought of that anyway. I thought that was… With this chap, he’d be talking about his life and Billy Connolly would talk about his life and how he’s coping with what he does and those sorts of things.

Male: Just talking to the taxi driver, whichever day it was, he’d seen Billy Connolly on a chat show or something and he’s still working but, as a comedian, he’s apparently lost, like a lot of Parkinson’s people, he’s lost his facial expressions. Something that might have been quite important in his act has gone. He seemed to be a pretty good actor but, again, acting, with losing the ability to make facial expressions, means that’s gone.

I suppose that’s a human-interest story where all the outcomes are not necessarily positive. On balance, the outcomes are not going to be positive but it’s nice to show some things are positive and how people cope with something or other.

Roisin: I suppose, with my science hat on, we’re concerned about the fact that… We’ve said what hope do I have, this is negativity related to the human-interest stories. How would we make sure that the content that we’re giving to people is not damaging in any way?

Female: I think we’ve said, we’ve talked about it before, I think you have to be very careful about this. That’s why you need experts. I do think that’s…

Roisin: What would you do if you heard something and it upset you? What would you do yourself?

Female: That you thought was wrong? That the information was wrong, in that respect? Upsetting in that way? I think you’d have to say so that’s it’s not repeated.

Roisin: Maybe we may need some level of feedback from the audience.

Female: Actually, Roisin, we met this, haven’t we? I won’t go into it but we went to an art exhibition and it was for Parkinson’s friends and it was at one of these places that sell incense and they do aromatherapy.

Male: Mindfulness.

Female: They do all of that. They do they’re own courses. You know the kind of place I mean. They give talks. The lady in charge, it was an awful assumption that Male had Parkinson’s but she seemed to assume we knew nothing about it when, in fact, the opposite is true. Not only was she incredibly patronising but she said things that were totally wrong, weren’t they, Male? About the condition and then what they could do to help. I don’t mean help in the quality of life but the actual condition, Roisin. It’s rubbish and, actually, it’s dangerous.

Male: There are people, charlatans, who are very well aware and it’s a money-making scheme and then there’s the edge of it where it’s ignorance.

Female: You don’t know whether, well, she didn’t have the background. It was her business. She wanted to make money. She’s selling stuff and it’s wrong.

Male: Selling treatments.

Female: All right, fine to help you improve your quality but these things, when you think they can do nothing to cure.

Male: Then you get areas that are, maybe, on the fringe because something like conductive education is not mainstream. It doesn’t have double-blind controlled trials to fall back on. You’re reliant on anecdotal evidence and people’s experiences to say that it’s effective. Whereas Levodopa, you can say what it’ll do, what it won’t do. I suppose, if it’s something like that, if it’s controversial for some people, you could have pros and cons, which would add interest to the programme if you balance it.

Roisin: There was a singing group thing as well, which doesn’t have any evidence and, actually, was... I saw Sheila White, who does the Lee Silverman, give a talk and people were asking about the singing gym because they’d been and it helped them loads and helped them with their speech volume and she was like, “It’s just rubbish, there’s nothing behind it”. She was trying to get me to back her up and I was like, “To be honest, people think it’s helping”.

Female: They think it’s helping. It’s like a placebo, isn’t it?

Roisin: Actually, Lee Silverman works in a very similar vein. If you’re spending some level of time increasing your volume, taking deeper breaths, thinking about your breathing more carefully, thinking about your loud voice, it’s what Lee Silverman is but just much more high intensity. It is just think loud, it’s nothing else. You don’t do anything. You’re just training yourself to think in a loud voice because it’s all about perception. Actually, practicing at the singing gym is probably very helpful to lots of people but it’s anecdotal, it doesn’t have the evidence.

Female: To rubbish it and all the people who are doing it…

Roisin: People are going, “I think it’s fantastic”.

Female: If they do get something out of it, it’s worthwhile, isn’t it? You’d do anything, wouldn’t you? You’d clutch at straws to improve your quality of life.

Roisin: That’s interesting. We can talk about these, as you said, double-blind, placebo-trialled, proven aids and medication and whatever else but then, actually, there’s lot of other things that probably would be people with Parkinson’s themselves, I’m not doing a very good job at these, who would provide the anecdotal evidence. Maybe the facilitators of the activities, like Aggie.

Female: She might frighten them off.

Roisin: She’s quite nice in a chatty atmosphere. I’ve chatted to her before. I was like, “You’re Aggie”. It seems like we’ve got lots of ideas for things that we could talk about on the show. One of my interests now is thinking about what would go into that in terms of translating it from the idea to being on the show. I gave you this little card and I think we can think about this together, just the questions. We’ve already talked about the types of people that we might have on the show and, I suppose, the types of questions you might ask them and the types of things they might contribute.

I’m interested in thinking about the roles of the different people who might be involved. We’ve talked about the consumers of the information, the people who might benefit from it, the general public, people with Parkinson’s. That’s it. The celebrities themselves and the people that are providing the information, the interviewees, the interests of the stories. There’s another thing that we haven’t quite talked about, which is the production of the show. I’m interested in thinking what you think might need to go into the show in terms of manpower, I suppose.

We did talk about this a little bit. People provide their questions to the show and how, then, would we curate all those questions and translate them into something that could be used on the radio show? I was talking to Male before about the idea that maybe we wouldn’t do something live, it would be pre-planned. We would know who was coming on. It would be pre-recorded with a script to make it a little bit easier and we’d spend some time before then collecting questions and things from people and then writing that into a script, if that makes sense.

Here’s the scenario, you let everybody in all of the different Parkinson’s UK meetings know that this is going to be on and they spread far and wide. There’s lot of different avenues where people can email or write or phone in their questions and you have 125 questions. What do you think that we would need to do?

Male: Somebody’s got to be responsible for editing and choosing…

Female: You’d have it headed, it couldn’t be one person, could it?

Roisin: You’d need an editing team.

Female: You need a team and, again, who have some Parkinson’s background, I think. When they see the questions, they don’t seem stupid or irrelevant or anything like that.

Roisin: They would field and collect and look through all of the questions?

Female: Actually, that’s not fair, is it? If anybody wants a question answered, it doesn’t really matter whether it’s relevant or not. If they’ve gone to all the trouble of putting a question forward they deserve to have it answered even if it’s…

Male: There might not be time to do them all.

Female: Yes, that’s true.

Roisin: Say, out of those 125, 50 are duplicates.

Female: That’s fine.

Roisin: People are asking the same questions, which is to be expected, really. I suppose you would need somebody to go through those questions and decide which ones are the same. There might be some that are worded slightly different but could be combined into one question for the expert. We need some way of analysing the questions and putting them into themes, really. Who do you think would be on this editing team?

Female: I do think somebody with a Parkinson’s background. I’m going back to that.

Roisin: What about somebody with Parkinson’s?

Male: That’s a good idea.

Female: Yes.

Male: I don’t think consultants would have the time.

Female: No, you can’t ask…

Male: Somebody with Parkinson’s, you’d have to be somebody you could, in a way, I’d use the word trust not to…

Female: If you had a team. If you’ve got a team, you’ve got back up, haven’t you? It’s not just what one person thinks.

Male: You don’t want someone who’s going to say something slanderous.

Female: I think you’ve got that as well, haven’t you? You want someone with Parkinson’s, who’s got it, who’s been a solicitor.

Male: Not many of those.

Roisin: Maybe a couple of people to field the questions would definitely \_\_\_[0:44:23]. Is there any other editing that needs to go on aside from just the themes? I suppose we need to figure out, once you’ve got those themes, how do you put that into the script? What goes in to the show? How do you structure the show?

Female: Yes, you can’t just have questions, can you? You’d need to have a case history or something general. It would be nice to have a live forum with that person but I don’t think it’s going to be possible, is it?

Roisin: We could do it live.

Female: If somebody’s giving a case history, something might crop up and somebody else who’s listening thinks, “Gosh, I would love to ask him about that because that relates to me or somebody else” but then, of course, it’s pre-recorded.

Roisin: It doesn’t have to be pre-recorded. Pre-recording is just easier. If we were going to do this call-in, what would we need to do to translate that into the show?

Male: It would need to be live, wouldn’t it? To know whether to accept a call or not because you might have somebody uttering obscenities or whatever.

Female: Yes, you can’t just put anybody on, can you?

Roisin: Somebody needs to receive the calls and then pass them to the show. That could be done by just listening in to the phone conversation and, I suppose, passing it as a piece of paper.

Female: Or you ring them back. You say, “We’ll ring you back in a couple of minutes” or not.

Roisin: That’s something, actually, that, originally, the radio show did do. It was a live show and people called in with questions and we could do that. It’s just it would have been a little bit easier to do the other way round.

Male: I think a couple of times I did interviews on radio for the council, it was live but it was only live-ish because their questions were scripted and they let me know pretty well what we were going to talk about in advance so there weren’t any shocks. The only thing is I was aware that there might have been branches of questions that were asked that would have lead on to quite interesting things, which they didn’t, they just stuck to the script.

It probably sounded a lot more wooden than it needed to. It would be the same thing here but if there’s an amount of risk you’re prepared to take. If it’s absolutely live and there’s no filtering, god knows what you’re going to get. It might be brilliant or it might be terrible.

Female: No disrespect to who’s doing it but live radio programmes, these are experts who have been doing it for years and are very experienced. Somebody who’s not very experienced, it can be very daunting. There’d be an absolute skill in handling this, wouldn’t there?

Roisin: Here you’re talking about the host and I think that’s probably a good person to identify as a key person who’s going to be involved in the radio show.

Female: It’s got to be somebody who’s got nerves of steel, who isn’t going to flap.

Roisin: I think that’s maybe why I was thinking about the pre-recording.

Female: Yes. That’s asking a lot of somebody who’s got no background, or you might be able to find somebody who has got some background but they’re few and far between. It’s asking them to go live and coordinate what’s happening.

Roisin: For example, actually, I don’t know whether you could think of anybody good from our group. Do you think anybody would be interested in being a host from Ellington group? You can say if you don’t think so. Kate might do it.

Female: Kate might do it except she is so pushed for time. You know what she’s like but she would be brilliant.

Roisin: The other thing would be opening it up to other Parkinson’s UK groups because there might be other ones.

Female: You’ve got Newcastle, that’s a huge group.

Roisin: I’m trying to think if there’s anybody in the Newcastle group who would actually do it.

Female: Do you know people?

Roisin: I used to be the chair or the vice chair for the Newcastle branch but I couldn’t keep up with all the daytime meetings when I started my new job so I moved on after two years. The Active Person’s branch, certainly, there are a couple of people I could think of off the top of my head who’ve done television work for me.

Female: That’s what you need, somebody with a little bit of experience.

Roisin: That could, potentially, be something we open up to the wider groups or we do a little pilot maybe with Kate as our host and we open it up to interest and see if anybody else wants to host a show, for example. We’re thinking about the processes that go into it and maybe what we’re creating here is a structure where people can host their own shows in the end. We’ll have a think about it. I’m going to go in ten minutes.

Female: I’ve got to be in Monmouth for twelve.

Roisin: Do you?

Female: Yes, and I’ll have to get changed and put some make-up on. I’m not rushing you. I can do it.

Roisin: We’ve got the host and we’ve got the editing team who field the questions, how do we find all these celebrities? I suppose we need a finder as part of our team as well. Is that a role for somebody or is that something that could be…

Male: There’s a hell of a lot of work involved. If this is an idea, whether it’s handing over to a radio station and it becomes a programme on a radio station where they’ve got people who are not experts on Parkinson’s but who are researchers and used to organising and could provide somebody who could host it.

Roisin: That’s what we’re here to support, really. We’re not expecting everybody to fill all these roles, by the way, we’re just scoping it as an idea. I know, for example, that might be a role fro me. I have access to all these people. You might not have access to all these people, I do and wider and beyond so maybe that’s something that, if you didn’t feel like you were able to do… As I said at the beginning, this is a co-research project so we’re all co-researchers. Myself and John have a role also in supporting.

We’ve got a finder/researcher. Male looks really scared now. That might be Roisin and John/someone who has access. Next week, probably, what we’ll do… I’ll leave it for now. We’ll go through some of the ideas that have come from everybody and think about how we plan and structure a show. Who do we want to interview? What might that interview look like? How are we going to get the questions from different people? In the next session, we’ll bring the technology in for the show and stuff like that and let you see it.

We do, actually, have some pretty simple ways of doing it and we’ve got a sound recorder, a sound guy, basically. We’re pretty well resourced, actually, in terms of the different things. I’ll let you go because I can see that you’re actually busy. Thank you very much. Have you got anything else that you want to add?

Male: Just the thought that it was probably the vision that we’ve had of something that’s a regular event but maybe somebody like Radio Newcastle would be interested as a one-off. Parkinson’s today and somebody to host it and interviewing people for half an hour.

Female: What about other parts of the university? You know how Sunderland University are doing this Tyne and Wear thing, aren’t they, on the television regularly? They’ve obviously got a very vibrant media department and they put lots on, you know. Have you ever seen it?

Roisin: No.

Female: It’s ghastly. It’s awful.

Roisin: Tyne and Wear TV?

Female: It’s called Tyne and Wear TV or something.

Roisin: I don’t really watch television.

Female: It’s on in the evenings. It’s on Freeview and they have programmes. Some are local and some, obviously, are bought in but they do have what’s on and they have bits about what’s coming up and interviews and things.

Roisin: I’ll check it out.

Female: That might be specialist.

Roisin: Okay.

END AUDIO

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