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START AUDIO

Interviewer: So, we’ve talked through several different ideas and radio was something that came up as something people would be likely to have in their homes already, be familiar with, be easy to use. And it’s something that we’re already using in a different project, so we have the infrastructure there to support that other project if we wanted to.

We had a chat at the last meeting – I’m not sure if I spoke to you about it – but, Parkinson’s Awareness Week is coming up at the end of April. We were thinking that whatever outcome we have from this, it might be good to try and aim for that as a deadline. Although, we might be pushing it a bit far, but we can try, anyway.

So, what we’re thinking is that- Oh.

Female: That’s the downside of having a tape recording the dogs. (Laughter) We’ve got chickens in one corner and dogs in the other.

Interviewer: So, what we’re thinking is that we would like to attempt to make our own little radio show. It doesn’t have to be as complicated as it sounds. So, there’s ways that we can do it which do not require a recording studio, for example – just simple equipment. And we do have people who do sound and things like that that can make it high quality. We can do that in the back room, for example, of the meeting hall.

What we’re more interested in, though, is that planning around what would go into the show, in terms of content, rather than the actual creation of the show. Which I think is what people are getting confused with the actual creation of the show. We can definitely support that. I think people are like, “Oh, do you want me to host it or anything?” No, no. It’s just the planning that we’re interested in.

So, how do we curate all those questions that are coming in from people that they would like to have answered? How do we even encourage people to ask those questions in the first place? In what format do those questions come in? Who then figures out what goes into the show? What structure should it have? Different things like this.

How do we make it accessible to lots of different people with Parkinson’s? And actually, people with Parkinson’s are the best people to advise on that, because you know what types of things that people want to know, and what type of format will be most successful. And then, things like how do we let people know when the show’s going to be on? So, they can listen in with everyone else.

The way that we’ve done the radio thing in the past has been through telephone. So, you can ring in and listen. You ring in to the show and then the show calls you back, basically. You don’t have to say anything, it just calls you back so you don’t have to pay for the call. And then, actually, you get taken through your press one, press two, press three thing. And you can do things like leave a question, or listen to the show that’s going on, tag it as you’re going along. So, “Oh, I’ll press one, I like this, I want to hear this a bit later,” for example.

There’s different things that we can do that we’ll consider a little bit further. Does that sound scary or confusing?

Female: It doesn’t sound scary. My only concerns are, when you say it’s a radio show, is it going to be something that people can tune into anywhere in the country, and tune into that on that day, because it’s on a certain frequency at a certain time? Or is it something that’s going on, where you need to telephone in and then get a call back?

Interviewer: So, if it was the telephone and get a call back thing, it would still be a similar thing, because it would still play at a set time. The answer to that is, “I’m still looking into it.” Because you can host radio stations on-line, but then it’s on-line and that’s not something that we wanted to do. But actually getting a radio frequency, unless we’re pirates, that’s probably not that feasible. You can definitely host shows and things on the internet, but actually that’s quite complicated to do.

So, the phone-in thing was an example of what this- So, for example, if you register your details, it might call you at 2:00pm on a Wednesday, and then it’ll start the show that you’ve registered your interest for. So, it might be, “Oh, these are the shows that are on this week. Monday, it’s Nick Miller from Speech and Language Therapy, Thursday it’s people talking about their experiences of work and Parkinson’s, Saturday, Billy Connolly’s on. Something like that. You register your interest, by picking one, two or three, and it’ll call you back on the time that it’s supposed to be on. Pick up and listen, basically.

That’s the way it’s worked in the past, doesn’t necessarily have to work that way at the moment. But that’s the way we’re thinking about it, I think. So, it would be a radio show format, but the way you would listen would probably be through the phone.

Female: Okay.

Interviewer: But you could do that from anywhere. And it wouldn’t cost money.

Female: Where’s the money coming from?

Interviewer: We will provide the money.

Female: Oh, right. But for how long?

Interviewer: It would depend how long it would want to be running for. So, if it was something that everybody really enjoyed and wanted to keep on with, then we’d support it probably in terms of long-term research for a while. And then the concept then was perhaps that Parkinson’s UK might take it on, for example, if it was something that was particularly useful.

There’s ways of getting money. We could maybe get a grant from Parkinson’s UK to continue it on for a year and see how many people actually tune in and whatever else. But that’s looking into the long term. For the short term, we’re funding the budget.

Female: And if we’re doing it as a pilot, per se, what’s your time-frame? Not, just starting it, but for how long it will go on?

Interviewer: Normally, if you’re doing a small pilot, you’d do maybe two or three shows in total and then analyse the data that comes in around that. So, how many people tuned in? How easy was it to get people to contribute? What type of feedback did you get from people from that? And then you would evaluate it and see if you could improve it in any way. And then we might re-do it.

But, this project has no real clear ending date, really. But obviously you don’t want me hanging around. Peter was like, “Can you stop doing such long sessions at the end, please. I’m knackered by the end.” Do you know what I mean? You don’t want me hanging around after every session doing an hour long activity with everybody. But, I think once we’ve planned around it, then it’ll be easier to follow it on, if that makes sense.

So, I think maybe one of the outputs, aside from a show, that it would be like a community radio show that was developed together, with some interesting informational content that has been filtered in from people with Parkinson’s in the wider community, hopefully. So, they’re having their questions answered and whatever else. That in itself is an output, because it’s a piece of information in an accessible format.

Beyond that, potentially, we could look at developing a template that we could give to other groups, perhaps, around developing their own shows with this technology and whatever else. It also would give some good indication of the types of questions that people are asking. And not just those who are on-line. Because the Q&A sessions that Parkinson’s UK do – which they do quite frequently – you submit the questions on-line and then they host the stuff on-line, and then they archive it on-line. So, you can access it, and it’s great information, personalised responses to your questions, but it’s all done on-line. So, it’s hard to access that resource if you’re not on the internet.

Female: So, are you hoping that the questions that come in will be dealt with on that show, on that day?

Interviewer: Ah, okay. So, there’s two different ways we could do it. We could do it live, like a live show, where potentially we would get the questions first and we would get somebody to ask the questions, to pose questions. Or we could do a call-in type thing. But I was wondering whether that would be great for everybody. Some people might not want to actually talk on the thing. So, might then, in that case, not actually ask the questions. So, we wanted to make it as accessible as possible.

Or, the other thing, which is quite an easier option, would be to pre-record the show. So, you get all of the questions in, you get your expert in at whatever time. It’s pre-recorded, especially because everybody’s non-professional, in a sense. If you pre-record it, you can edit out any mistakes, which again we can do. And then you play it at a certain time and whatever else people can access-

Male: That would be a good idea.

Interviewer: Yes, that’s a better idea. I thought that would be, for a starting point, a good way to start. Because I think what we’re more interested in is these types of questions and managing everybody’s points of view in one place, if that makes sense.

Is there a theme to Parkinson’s Awareness Week this year?

Female: Not that I’m aware of. There will be one, but I don’t know what it is.

Interviewer: I thought it was something-

Female: Since they’ve re-hashed it, Parkinson’s UK, I have to say you don’t see as many people coming in. And, there doesn’t seem to be the cohesion that there was, if that makes sense. Because you have- Gosh, the name’s just gone. The lady who was an Information Support Worker, she’s got a different title now.

Interviewer: [Evy 0:11:32]?

Female: No.

Interviewer: Viv? Vivian?

Female: No. Very pretty, dark hair.

Interviewer: Was she there at the last session?

Female: Yes.

Interviewer: I’m not sure I know her very well.

Female: She’s fabulous, absolutely fabulous and very good.

Interviewer: Is it Denise, or something?

Female: No. It’ll come to me in a minute. But even she was saying that that cohesion is gone. That she’s not aware of everything that’s going on. Whereas when it was the ISW and Viv, for example, and the areas were smaller, there was much more cohesion and much more interaction that used to then be to us. So, I’m not sure what the theme is. I’m sure I should do.

Interviewer: Well, last year it was ‘A Walk in Your Shoes’, wasn’t it?

Female: No, that was the year before.

Interviewer: Oh, it was the year before.

Female: Yes, last year it was ‘Take Control’.

Interviewer: Yes. So, last year we did something around Parkinson’s Awareness Week. The Google \_\_\_[0:12:26] was around for Parkinson’s Awareness Week last year. So, in that sense, it was quite nice to have something to how what we were doing for it. But, even if it was just a little discussion of it in the newsletter or whatever else it would be nice to say, “Oh, this is what [Ellington]’s doing for Parkinson’s Awareness Week [crosstalk].

Female: I think- It was something I mentioned to [Linnie 0:12:49]] when we heard- Us and Alnwick met to look at what we would do long-term, and see whether or not the groups – not so much could work together, because we do that in any case (well, not so much with Alnwick, but we do in North Tyneside) – but to look at projects. And I suggested there – which, in a way, goes slightly against the grain, but I think it could work hand in glove – is that we actually had a Facebook page.

And that it became like TripAdvisor with a difference, like Pinterest/TripAdvisor. And that people actually uploaded their comments so that if they had a tip, like the queuing tip, or something like you using your metronome when you’re practising your speech – things that don’t necessarily come from a professional. But it’s something that’s been developed through- You know, like you and your ‘bloody stupid thing’. That’s what I call it.

Interviewer: (Laughter) I tell people that all the time.

Female: I know, that’s what I’m saying. But, you know, things like that that Dad’s invented, they’re things that could go on the Facebook, but also could then transpose into the radio show. So, you’ve actually got a feed-in for those that are able to access it.

If we go somewhere, for example, we had a trip two years ago to Beamish. Now, on paper it looked fantastic.

Interviewer: But it wasn’t.

Female: It wasn’t, because there’s an awful lot of cobbles, which means it’s almost impossible for wheelchair users. Because if they had false teeth, they nearly didn’t when they got back.

Interviewer: (Laughter)

Female: And also, the buses only go to the hill below the visitor’s centre. So trying to push somebody, or for those who are walkers, trying to walk up that zigzag path which is really steep-

Interviewer: Was a nightmare.

Female: It was a nightmare. So, on paper it looked fantastic because you’ve got the buses and this, that and the other-

Interviewer: I’m just worried about your table.

Female: Oh, don’t worry about the table.

It’s doing it that way. And that would be something to say, “We had a good day, but these were the difficulties that we came up with.”

Interviewer: Issues, yes.

Female: And you’re not knocking it, you’re not slagging the place off, because they’ve done a really good job. It meant people could get from A to B. But, actually, there were some little issues that I had not even thought of, until we actually got there and they got the feedback coming back. And we went to the Maritime Museum – fantastic. That worked so well for everybody, on every front. The weather was obviously rubbish.

But that’s something that you could write up to say, “Had a lovely day at Beamish, however these were things that we hadn’t considered, that we actually found a problem.” You’re not slagging them off, you’re not saying it’s a bad place to go. You’re just saying for people with Parkinson’s, this could be an issue and it’s something that you need to address if, for example, you’re doing a group trip.

But they’re the sort of things that we could maybe incorporate into the radio show, that you could actually draw from the Facebook page. You know, the tips, hints, things that people have picked up out of magazines, the inspirational quote – a bit like a Pinterest type thing. But those are the sort of things that we could then put into the radio show. So, you could have a quote of the week, an inspirational quote of the week that you’ve found or taken, or your tip of the week, or your hint of the week. And you could actually then perhaps have them going hand in glove.

So, people that aren’t necessarily wanting to ring up and try and speak and put a thing forward, could then actually, if they did have access or had a family member that had access to the internet, that they could then put it onto the Facebook page. And then it could be taken from there, with acknowledgements to say that you’d used the Facebook page. And then you could use it vice versa, in as much as you could use it as an advertising campaign as well. Just a thought.

Interviewer: Okay. I’m getting it for confirmation.

Female: Yes. But, you’ve got far more know-how than I have, I’m just chucking ideas at you.

Interviewer: I think the Facebook page idea is really good. And actually there’s lots of different ways that you can use Facebook. I’m part of a health and fitness group thing, which is a private Facebook page. Obviously, then you have to request access, so it makes the moderation of the page much easier, that there’s not just random people. And that also puts the moderator’s control to kick anybody out if, for example, somebody comes in and starts being negative and everything else. I think constant moderation is the thing. That’s probably more work, because if there’s a thousand people, it’s much more work than others.

There’s also things you can do, like saving things. So, for example – I’m not sure if you can do this on your group page, but certainly on your personal page – if somebody’s put a video on, so say it’s a recipe that I like the look of, I can save that for later. And it brings it up into my saved things. Or there’s a files page that you can add to, on the groups.

So, what I’m thinking is there’s lots of different things. But how do you then structure them so that it’s easy for people to find? Because trawling through a Facebook page which is full of tips, strategies, comments from people, quotes, whatever – all of that is great-

Female: Yes. But I’m not really into Facebook. I do all craft things and I know it just is like a rolling road. But on the Pinterest, which is more-

Interviewer: Pinterest is really good.

Female: It’s folders, isn’t it? Where you go in. I live on that with my craft stuff.

But, I thought if we could somehow do a Facebook page based on a Pinterest idea, where you had folders and you could actually just drop in. So people can upload into it and any person could be part of a folder. So, you’re not asking for one person. On Pinterest – I don’t think I’ve shown you Pinterest-

Male: No.

Female: But Pinterest – it’s like ‘interest’ with a ‘P’ – and basically you pin your ideas into it. And it’s basically like a filing cabinet, with different folders and your ‘bloody stupid thing’ would be a good idea to go into ‘Tips and Ideas’.

Male: Yes.

Female: The TripAdvisor thing would be another folder. So that you would have access to Facebook – which you have – you would go into that site and you would say, “Actually, I wonder if anyone’s thought of how do I…” – I don’t know – “do like that thing that Jenny’s made you. If there’s anything that someone’s found that’s made or manufactured or anything else. If not, I’m going to put that idea forward.” And you could just have a scroll through. You’d be able to have a search engine and just have a look and come up with whatever you wanted to come up with. And if it isn’t, you could then do something and actually post it in and say-

Interviewer: Google Drive is very good for that.

Female: Well, I’m not that techie, sorry.

Interviewer: Google Drive is a shared thing. Actually, with Chrome, if you’ve got Google Chrome, when you just click- There’s something that looks like lots of different coloured circles, if you click on that, you can go to your Drives folder. And that’s something that you share with everybody. You can literally have a folder called ‘Places’, a folder called ‘Tips’, a folder called whatever, and people can just add to a Word document, but collaboratively.

Female: And that way, if we had something like that, then the radio show could be-

Interviewer: Yes, it could link to that.

Female: Linked in. And also, on Pinterest, you do have videos where people can then go off and someone will show you how to do something. You know, so if I’m doing my craft here, it will show you a technique of how to use tissue paper with inks and you get this wonderful sort of collage effect as a background. Well, I’m sure there must be technology where whatever your radio show is, you could then upload your radio show, so if someone didn’t hear it on the day, you could then-

Interviewer: Oh, we can definitely, definitely, definitely do that. Archiving the show is definitely something that we’re really interested in.

Female: Yes. So, someone who doesn’t have, you could then arrange it to say, “Okay, there may only be 25 see it on the day, but actually another 25 have accessed it following that.” It’s like TV Catch-Up or something.

Interviewer: Well, that’s really something worth thinking about as well.

Okay, can we have a little look at the persona things?

Female: Are you staying around to do the persona bit?

Male: \_\_\_[0:22:11]?

Female: It’s in there. Do you want me to go for it?

Interviewer: This one?

Female: Is that it, Dad?

Male: \_\_\_, yes.

Female: That was my bits for \_\_\_.

I came up with George and the Dragon, the Dragon being Parkinson’s disease, George being the one that comes up with various ways and means of holding it back. You might not kill it, but you can take away the fear of the fire. And the other thing I thought of was a little man pushing a car – or a little person, being PC. And in my head I had a little person pushing a car with no help, assistance or anything else and struggling – the car being the Parkinson’s. And then someone, an outsider, medication or other bits, put them in a bag, which gives him the power then to strive to get it to the top of the hill.

Interviewer: Very nice.

Female: Hence my very, very poor sketching, because I can’t draw to save my life. It’s a bit scribbly because I did it on the tube.

Interviewer: That’s absolutely fine. Fantastic. So, is this an idea for a character for a show?

Female: Well, I just thought you could bring it in and say, “What sort of things would you put in the bag?” You know, for somebody who’s not within Parkinson’s, who’s a carer or something. A bit like bringing in the ‘Be In My Shoes’, ‘Taking Control’.

Just the thing if you see someone that’s struggling with this, that and the other. They’re not necessarily drunk or they’re not…

Interviewer: So, this is like for the general public?

Female: Yes.

Interviewer: Really an analogy for the general public.

Okay. Well, my stickmen are gender neutral by the way. (Laughter) General public… Okay.

Alright. And what did you get, Les?

Male: \_\_\_[0:24:29]

Interviewer: Go on. Here’s Kevin.

Female: Kevin. (Laughter)

Interviewer: Okay, so Kevin’s-

Male: \_\_\_.

Interviewer: Yes.

Male: In a book that I’ve got, called \_\_\_.

Female: That’s where you got the characters from?

Interviewer: Got the information? Yes. So, information about Parkinson’s…

Is there anything that affects your ability to find information? Except you don’t know where to look. Okay. So that’s a big problem really. So, you know that you want information, but you don’t know where to look for it. Okay.

Female: So, that would be something that you could do as a show, wouldn’t you? Well, as an advertising campaign, to say, “Well, we’ve come up with this, we’ve come up with that, we’ve come up with the other.”

Interviewer: Yes. Sign-posting.

Female: Very good.

Interviewer: To other sources of information. Okay. Fantastic.

So, thinking about Kevin as a person, and the fact that he doesn’t know where to look for his information, how do you think that he would feel about having-? Well, I suppose that we’ve already said that a radio show could signpost. How do you think we would let Kevin know about the radio show? That’s quite a tricky question. Sorry. (Laughter)

Male: Well, yes.

Female: Well, think about going to \_\_\_[0:26:26]. You’ve get all your bits on the \_\_\_, because you always find bits that I never do.

Male: \_\_\_ internet.

Female: That’s through the internet?

Male: Yes. Kevin \_\_\_.

Interviewer: Yes.

Male: Because Kevin is a simple soul.

Interviewer: \_\_\_ dreaming. (Laughter)

Male: A simple soul, is Kevin.

Female: Kevin’s a simple soul. (Laughter)

Interviewer: So Kevin hasn’t quite mastered the internet. And I think that’s the thing that comes up time and time again. So, is there any other way that we could let Kevin know..?

Male: \_\_\_[0:27:12].

Female: You’ll get a real wail in a minute. You’ll get the Hound of the Baskervilles. I’m so sad, I haven’t got a normal animal at all. (Laughter)

Male: \_\_\_ surgery.

Female: In the surgery.

Interviewer: In the surgery, yes.

Male: \_\_\_ them pamphlets. \_\_\_[0:27:33].

Female: Yes. So, almost like a leaflet drop? But within specified…

Male: Yes. We \_\_\_.

Female: I know. I used to do that on the QT, because they wouldn’t-

Male: Yes, exactly. \_\_\_.

Female: I used to do a leaflet drop when we were there.

Interviewer: Oh, at the surgery? Yes, you’re not really supposed to, but- It’s come up again.

Female: So, we’ve tried putting posters in and all sorts, I’ve got absolutely nowhere.

Interviewer: Why-? I don’t understand that at all.

Female: Mainly because I think that the buildings aren’t theirs so they’re reluctant to put anything on the walls. It’s pathetic, but that’s the way it is. We’ve been around and put newsletters down and all sorts.

Male: \_\_\_[0:28:17].

Female: Yes. But that again depends on what time our clinic is, really. Because I don’t want to be going in and dropping them before we’re there, if you know what I mean.

Interviewer: Okay. So, medical staff could be promotors themselves, actually. Couldn’t they, really? Okay.

Female: And also I have to say that the nurse specialists are very good at hearing about things that are going on, and pushing them. Because we were with Louise yesterday and I was telling her about something that Parkinson’s UK has come up with – which I shall email her through – that she’s not heard of, with regards to Speech Therapy. So, she said, “Oh, well please, send it through, and then I can have a look at it. And then I can see what clients might actually benefit from it.”

Interviewer: Word of mouth is a good one.

Female: Yes.

Interviewer: Okay.

Female: Just thinking about your simpleton…

Male: Yes.

Female: If you took your specialists, with regards to your radio show, and we had leaflets – I know that’s going to cost money. But if every group puts some money in, even if it was £30 for some reams of paper and some bits, we could probably knock out some very simple basic type leaflets, just to promote it. If we did it in enough of time. So the month before it started, every PD clinic that was held, all the way around the North East or beyond, could…

Interviewer: Have some leaflets in.

Female: Every patient would come in, and that would cover everybody. Because you look at the numbers that come through the doors, compared to the numbers that actually come to groups – a spit in the ocean really.

Interviewer: Are there many people that you send leaflets to in the Parkinson’s UK, that don’t come to sessions?

Female: I try and hear of people and get an email address and bang it out. I do it off my own back, because I’m never sure with Parkinson’s UK, as much as they say they hit all the community, I’m always a little bit reticent to have people’s emails and accounts and x, y and z, that aren’t necessarily registered with them.

Interviewer: Yes, okay. So, you think maybe they don’t have the contact details that they think that they have?

Female: No.

Interviewer: Because they post things out as well, is the other thing. So maybe Parkinson’s UK would be a good person to promote stuff like that.

Female: But that’s only going to go to the people that joined up with Parkinson’s UK.

Interviewer: Yes, exactly.

Female: There’s quite a few that haven’t even done that, because they’re worried that they’ll have to join the group or do something. You know, if we hear of someone, we say, “You know, you don’t have to come to group, but join Parkinson’s UK just for the information.”

Interviewer: Yes, okay.

Female: And our group ethos is that if anyone meets anyone that’s got Parkinson’s that don’t want to be part of the group, that they let us have some details so that we can just push the information their way-

Interviewer: Yes, even without joining.

Female: For people without joining or doing anything else.

Interviewer: Okay, I got it. So, there’s probably quite a lot of consumers of information from that email that you give out to people, that maybe might not be very vocal in opinions or anything, but they actually might be sitting down and reading that information and getting quite a lot from that. Okay. Do you post anything out?

Female: I post to people that aren’t on email.

Interviewer: Yes, okay.

Female: So, you’ve got quite a mix of those that are and those that aren’t. Sadly, it’s a nuisance for those that aren’t, because it’s so much cheaper just to- that. But, every meeting, anything that I’ve sent through by email, I print off so that every table’s got a pile of the information that’s gone out by email. I print it off and…

Interviewer: Okay. So, who else might be listeners of our show, do you think? Apart from people in the Parkinson’s UK group.

I suppose we’ve talked about that already, so we’ve got the people in the Parkinson’s UK group, the people who you have contact details for but who aren’t at the meetings. Do you think that this should be something that’s available just to the Ellington group, or should we try and include other people in listening to it?

Female: Oh God, if it’s going to go, it’s got to go. There’s no point in doing it just for our group, without being unkind.

Male: Yes.

Interviewer: So, other Parkinson’s UK groups?

Female: Well, I think if you can pump it out, you pump it out.

Interviewer: Okay. So these are our listeners.

Female: Because if you’re just doing it for people within Parkinson’s UK, you might as well just stick to a paper format and have it put in the magazine and sent through. I think that would defeat what you’re trying to do and what information has come out.

I think it’s got to be somehow advertised that it’s for anybody that has an interest or a connection with Parkinson’s disease, as opposed to Parkinson’s UK. Otherwise it defeats the object, because you’re talking to a committed audience if you’re just talking about our group, for example. And a very small section of the society.

Interviewer: So, we’ve got the general public there as well.

Female: And I think everybody that’s in a group, whether it’s our group, Alnwick, North Tyneside.

The minute you know that you’ve got a connection with Parkinson’s, it’s amazing how many more people you hear of. We could probably reel off half a dozen that we know, that don’t want to be part of any group – just get on with it and the rest of it. And they might listen in. So, you’ve got the potential for a wider audience, who don’t necessarily want to publically connect themselves with anything to do with Parkinson’s. They’ve got it, they go to the clinics and that’s it. They don’t want to know. They don’t want to meet with people with Parkinson’s because they don’t want to see what they’re going to become. It might never happen, but that’s how they perceive it.

So, I think word of mouth, from, say, the six people that we know, if they know another six, even if they don’t listen, you’ve got the potential of passing the information on.

Interviewer: Yes. Excellent. Okay.

So, we’ve talked about the kind of people who might consume the information, I suppose, or listen to the information. What about people who might contribute to the radio show? So, that could be people who might be on the radio show or, I suppose, any of these people here listening, what they might be able to contribute in terms of questions and comments.

Male: \_\_\_[0:35:59]. A regular host.

Interviewer: A regular host? Do you think it’s important to have the same person all the time?

Male: I think so. A regular host \_\_\_ celebrity \_\_\_.

Interviewer: Say that again, slowly.

Male: \_\_\_ celebrity \_\_\_-

Interviewer: Celebrity?

Female: Celebrity. Try to get someone who you’d know that’s acting as a supporter?

Male: \_\_\_[0:36:20] experience \_\_\_.

Female: Oh, that’s a good point. Somebody who’s experienced in hosting a radio style show. Because you’re basically talking to yourself, aren’t you, at the end of the day?

Interviewer: Okay.

Female: You are, aren’t you? Because you’re not having a conversation with someone, you’re trying to hold a conversation with someone that you’re not seeing.

Interviewer: Oh, well, I think we would have the conversation and then record that conversation.

Female: Yes. But if you’re talking about hosting the show and looking at bits, even if the show was only for half an hour, basically you’ve got someone who’s almost holding it together as a DJ and talking to themselves, as well as having a conversation. So, I think you’re suggesting that you need someone who perhaps is experienced in that side of things-

Male: Yes.

Female: As your mainstay and then other people bouncing off them. Yes.

Interviewer: Okay.

Female: So, if we could get someone who, perhaps, was known, but would be willing to support it for half an hour a week, say, for four weeks or something, and see where it goes from there. It’s like all things, once you’ve got an audience, providing you can maintain the standards, you can change the host, can’t you?

Interviewer: Yes. Okay.

Female: Once you’ve got them kicked off.

Interviewer: Okay. With a link to Parkinson’s maybe.

Female: Well, not necessarily. Because if you had somebody who’s a newsreader or somebody locally who might be prepared to give a bit of time as a freebie. Because that’s the other thing, you don’t want to be paying. That again, is publicity in itself, because they’ll plug it out on whatever they’re doing.

Interviewer: Okay. So, publicity seems to be coming up time and time again as well. And what about the person who’s answering all the questions, I suppose?

Male: \_\_\_[0:38:21] massive experience.

Interviewer: Yes, so you have the medical professionals and then the people with Parkinson’s, who’ve got direct experience.

Male: Yes, all of those. They have to speak.

Interviewer: Yes, they’ve got the ability to speak. So, somebody with experience that can hold themselves a little bit. Yes, I’ve got you – I understand.

Female: You wouldn’t feel comfortable, I know you wouldn’t, to actually offer to be the questioner or the respondent. But you could actually be given questions that were put in before the thingy, and you could actually respond to those. And someone could speak on your behalf and say, “Les Brown, who has this problem, actually sadly it’s affected his speech, so he’s not happy to do it. However, from his own experiences, this is what he’s put forward.” So, it’s all inclusive, it’s just somebody else is putting something forward.

Male: Yes.

Interviewer: So, I would say- I’m going to do this. So, person with Par- Excuse my shortening, it’s not very good. With experience of an issue. And then I’m just going to do as a little- Because these are my issues. What if I can’t speak?

Female: You see, even- That would be a good topic, because we’ve learned through your speech thing, and your dexterity, the thing about speech things for your computer and x, y and z. There are a lot of things that we’ve learned that have developed.

Interviewer: And cause response by proxy. Excellent. This is the messiest one I’ve done so far. (Laughter)

Female: (Laughter) Is it? That’s because we talk too much.

Interviewer: That’s good. Okay. Would there be any issues that might go around the experienced host? What do you think some of the issues might be in terms of getting somebody for that? Or what they might think, in terms of being an issue?

Female: Sorry, say that again slowly.

Interviewer: Yes, I often don’t really make any sense.

Female: (Laughter)

Interviewer: So, we talked about having an experienced host for the show. Would there be any issues, do you think, with getting them to be involved? Or might they have any issues with being involved on the show?

Female: That’s something you’d have to discuss with them, wouldn’t they? It would be helpful if you had someone that had a connection with Parkinson’s, without necessarily having Parkinson’s themselves. But, somebody that’s actually perhaps slightly in the public eye.

I mean, we’re not going to get Connolly or any of those there. But there may be somebody locally. Carol \_\_\_[0:41:38], well, she’s called Malia. It may be that her uncle has Parkinson’s and we might be able to call on her better nature. Somebody that has a connection would be good, but actually I think Dad’s right, somebody that’s recognised, that is throwing support into it, that has other people to bounce off.

Interviewer: Okay.

Female: And maybe the personal experience isn’t the be all and end all, but having that ability to be able to interrogate and bring forward what needs to be brought forward, you know, the salient points. If someone clams up on the other side, as it were. And that would probably be better than having…

Interviewer: So, talking about bringing forward the important points, how would we go about figuring out what they are? I suppose, that’s a good question. Because we talked about getting questions from people-

Female: Well, could you come up with subject ideas?

Interviewer: Yes.

Female: So, like ‘mobility issues’, ‘dexterity issues’, ‘swallowing’, ‘speech’.

Interviewer: And who should come up with those ideas?

Female: Well, hopefully you’d have them pumped in, but if you had a few that were the obvious ones to start with… You know, research what’s going on. And that also adds as an advertising campaign.

Interviewer: Okay. So, goes into the show. So, this is an example of production, I suppose-

Female: You see, where you may get advertising, you might be able to get somebody to be prepared. So, maybe I’m getting ahead of myself but, say, for example, Disability North, that helps out with bits and pieces. But they might put somebody in to help us on our way, to get more advertising done. If it comes to doing papers or leaflet drops or something for those that aren’t aware. I know we just put things up on walls and what have you, but what about a swizzler, when you swizzle in the car. You know, you sit down and it’s a bit like a cake stand, a Lazy Daisy, and then you swoop in. Or other little things like that that would be help, or \_\_\_[0:44:05] coming up with that thing for you, to do with your dexterity – an extra-large speaking, whatever you call it? Card reader thing.

Interviewer: Okay.

Female: So, things are around that may come into their own.

Interviewer: So, you’re talking about maybe advertising products-?

Female: Yes, without going over the top. But that might \_\_\_[0:44:33], you can come in and spread your name and say that you’ve got this, that and the other. However, we would like you to make a donation so that we can actually do a leaflet drop or…

Interviewer: Excellent. So that’s a two way thing really, isn’t it? Because they would get something out of it.

Female: Yes.

Interviewer: Okay. So, who would be the person to go and find people like that? We talked about one area of production, which was getting these ideas from people with Parkinson’s and coming up with ‘themes’ I suppose from their ideas. So, what I’m interested in thinking is the roles and responsibilities that might go into the planning of a radio show. So, we talked about advertising, we talked about publicity, these leaflets…

Female: Is this all-

Interviewer: Facebook page…

Female: Just a thought, having come up with all these ideas, because I’m thinking, “Oh God, it’s all going to come my way.”

Interviewer: Well, no, it needs to not come your way, that’s the thing.

Female: I know, but are we looking at Ellington only, doing these bits and pieces?

Interviewer: Not necessarily. And let’s think about it this way, also. Let’s think about this as a one-time thing. So, let’s come up with the idea, let’s do one show. And let’s see how it was. And then we can re-evaluate whether we want to do more or not. So, very much supported by myself and John, let’s do one.

So, if we can think about what the roles and responsibilities are, then we might be able to get people to volunteer to be involved. There might even be people in the group who aren’t coming to these sessions, who would actually quite like to be involved in something like this.

The whole point is that it doesn’t come your way, because it’s supposed to be a community radio station. But, let’s not think about this as something that might be happening a year down the line, think about it as a one-time thing and it might be easier to process. Does that make sense?

Female: Well, we can go and find some advertising, can’t we? We can try. Do you know anybody from your old days that is slightly more in the public field?

The person who’s coming in my head at the moment is Andrew Tebbutt, who’s a local councillor.

Male: Yes.

Female: Because he had a very good friend who had Parkinson’s who was also a councillor.

Interviewer: Tebbutt? E-B-B-O-T?

Male: E-B-double-U-double-T.

Interviewer: T-W-E-?

Male: T-E-double-B-U-double-T, I think.

Interviewer: U-double-T – I got it. Tebbutt, got it.

Male: Where is-?

Female: I don’t know. She’s in here. Because I think he’s currently the…

Interviewer: Because to be honest, I’m just getting ideas here, and I will come up with something more concrete next week. Maybe we could have a go at trying out some of the different roles and what they might feel like?

Female: Yes.

Interviewer: So, I might mock up some data, like 125 questions, for example, like you might get from people. Or ideas, or feedback, or whatever else. And see what it might be like, what it might look like, trying to put that together.

The other thing is that we wouldn’t be saying, “Oh, here’s your role, just go off and do it.” John and I are there to make sure that everything’s going okay and that there’s some kind of a template and instruction to follow. I think it’s just important to figure out what the important things are and I think definitely, the advertisement is very important.

I mean publicity in terms of advertisement, less about funding at the minute, actually, because we can provide the funding, that’s all done. But making sure that other people actually know about it, getting the other Parkinson’s UK groups involved, and making sure that their people are aware.

What about people getting their ideas to us for what the show might be? What would be the best way to do that, do you think? The most inclusive, because the best is email, obviously.

Female: Yeah, I know. It’s amazing how when you’re on it and you’re used to running your life through email, how…

I mean, I can act as a central point, if you want a central point. I can put my mobile number out.

Interviewer: So, phone. So, the other thing is that we could curate and then come with the finalised list, if that makes sense. We could do that. Email is easiest. I think just saying that there’s multiple different ways that people could-

Female: If you want to appoint a contact, I’ll be your contact for that. Can’t we?

Male: Yes.

Female: We’ll do that jointly, Dad and I – if that helps.

Interviewer: So, that’s definitely a role. That’s definitely a responsibility. Would there be any issues with that? Any concerns with being the point of contact for that?

Female: No, because my number’s publicised all over the shop in any case. And that’s something that Dad can do a lot with, because he can look at something, we can tape it and then he can write it up either on his word processor or type it up.

Interviewer: Excellent, yes.

Female: It’ll be slow time, without being unkind, won’t it? But that’s something that Dad can help out with.

Interviewer: I suppose if you’re getting emails and stuff as well-

Female: You might do that.

Interviewer: You might get hundreds of emails, you never know.

Female: My email address is out there as well. If it comes in to me then I can pump it to Dad, and then he can sort it, if I’m out and about and doing.

Interviewer: So, what might you need to..? Would you just put that into a spreadsheet, or what do you think?

Female: Excel? I’m not that brilliant at Excel.

Interviewer: What do you normally use? Just a word processor?

Female: You use Word.

Male: \_\_\_[0:51:18].

Female: You normally do Word, don’t you?

Male: Yes, that’s right.

Female: We don’t tend to use Excel, do we?

Male: \_\_\_.

Interviewer: Well, you see the good thing about Word is that if you’ve got lots of different questions, you can actually cut them out into strips and that’ll make it really easy to move them around and say, “Well, actually, all these questions are exactly the same.” Put them in one pile and then you can stick them on walls and things. Well, that’s the way my mind works, anyway.

Okay, I’m trying to think. Are there any other concerns that you might have? Any other jobs that might be important for other people to do?

Female: My only concern is that people want to be involved, but not.

Interviewer: Okay. So, people saying they want to be involved, but they don’t actually do anything.

Female: Yes.

Interviewer: Slackers, I’ll call it. Nice, ‘slackers’. Okay.

Female: I’m just talking from experience at the group. You’ve got the same people who do all the work. You’ve got others that come along and support it, but don’t necessarily want to be in the forefront.

Interviewer: So, actually if in the session next week we were to figure out what the roles and responsibilities exactly might be, and then assigned them to people within the group and maybe beyond, then that’s quite clear, voluntary-

Female: I don’t know whether you’re able to say, but people like Peter, who are very poorly, but if he could do something that was home-based, for example, he would be brill.

Interviewer: So, Peter actually said that his favourite role would be an ideas generator – thinking up some ideas and researching what’s going on in Parkinson’s at the minute.

So, that’s already two really quite clear jobs we’ve got.

Female: And Harry and he can work together on that, because of Harry being in the research bod.

Interviewer: Yes. There’s definitely things that people are already interested in. So, I think maybe what we do, we have the meeting, obviously. We could call it our editorial meeting, because actually that’s what we are doing. And then I suppose people will do what they need to do for that meeting, once a month probably wouldn’t be that bad. So, even if it was going to be a regular type of thing, every couple of months, you’ve got a planning meeting and recording session every couple of months. Probably wouldn’t actually take up that much time.

So, we need clear roles and responsibilities. Okay. Anything else?

Female: No, not that I can think of.

Interviewer: No?

Male: No.

Female: Have you got any?

Interviewer: I’m not really supposed to say.

I have thought about it, in terms of the production team, the editorial team, as we say. So, you need, from the forefront, somebody that’s going to pump out these, somebody that’s got to make sure that all the information is out for people to give their questions and ideas in. And then when the questions and ideas come in, somebody needs to curate that and then organise it into themes, so there’s no duplicate questions, or whatever.

Then there’s the writing process, or the idea formation process, around what might actually go into the show. So, there are ten sets of questions, how can we maybe link them up into one question, which will answer both, blah, blah, blah. You know, that kind of thing. And then which questions should come first. So, “Oh, this one’s definitely about work and this one’s about pension, and this one’s about benefits…” So, then, well the next one is about actually day-to-day tips and strategies, blah, blah, blah. So, that’s kind of themes, if you know what I mean.

And there’s somebody to find somebody to be on the show – find your expert-

Female: Well, I know who’ll do the bit on benefits, because I work at CAB. My CAB Manager might come out and play.

Interviewer: That would be brilliant, because that actually came up in the last interview I had as well. We talked about benefits as like a really important thing. But it’s that type of thing, and that’s quite specific that you can say, “We have an expert coming out about benefits – what are your questions? It’s completely anonymous.” And then people can really ask some quite tricky things.

And then the show is done, the show is recorded and then we put it out and maybe have some feedback afterwards. So, that’s kind of my perception of how it would go. And then what we’d be looking to do is really just do one and see how it goes, see what the issues are. And if it’s actually really useful and pretty good fun, we’ll maybe do another one, and get everybody else involved.

So, I think when I was up with Harry and Heather, they had slightly different ideas actually. They thought that maybe a good host might be somebody from the Active Persons’ Branch in Newcastle, because they’re all quite bubbly and up for talking on TV and things like that. Which I thought was quite a nice idea and the fact that it would be pre-recorded might be quite good. And then they could ask their own questions as well, which was quite a nice idea.

But I also do agree with this, having somebody experienced is quite important. And actually, I think that’s kind of- You were talking about the kind of celebrity- They also thought of celebrity as well, as a way to get more of the general public to get involved with listening and stuff-

Female: Yes, and also it makes it- It’s going to sound silly. I was thinking about hospital radio. The hospital radio is to an audience that is captive. So, if you had something that gave it slightly more credibility at the beginning…

Interviewer: Yes, for like the starter one?

Female: Yes.

Interviewer: And then you could get people to-

Female: And then you can move. Because I agree with you, I think the Active Group, I thought of them and I thought of getting them involved to try and do my Facebook page-

Interviewer: Yes, well, they do have a Facebook page.

Female: Yes.

Interviewer: I’ll help you do your Facebook page.

Female: Well, not necessarily Facebook page, but you know our Pinterest type thing-

Interviewer: Yes.

Female: Because I think that would be really good nationally. You know, not just for Ellington, nationally it would be really good. So, I think if we could get someone just to start it off, to show that it’s a serious venture, rather than it be a bit of a- Well, I was going to say ‘amateurish’. If you know what I mean? You need to put that stance down I think.

Male: Yes.

Interviewer: So, I’ll have a little look around and see if we can find anybody who might be interested. Because I think, especially local radio stations, we could definitely say it’s like a pre-

Female: I’ll tell you who else we might tackle for that – Becky. Becky might know someone who would help us out.

Male: Yes.

Female: Becky is not one to write down, but Becky is a friend of ours. She’s just started her own company, one of her clients is Kenneth Branagh.

Interviewer: Is he on local radio?

Female: No. He is Kenneth Branagh, the actor, director…

Interviewer: Oh. Okay.

Female: That’s the sort of clientele she mixes with.

Interviewer: Oh right, okay.

Female: And she’s just in a perfect-

Male: Michael Flatley.

Female: Yes, Michael Flatfoot – Michael Flatley she’s been with. She deals with big, big names. And she’s just gone out on her own and started, and she deals with musical theatre and productions and what have you, and doing the publicity for them. Now Becky may come up with some ideas as to whether or not she can get someone local that she may work with or got involved that might just come and help us out. Because if it’s a one-off, you’re committing someone-

Interviewer: Yes, exactly. And it would probably literally take them 20 minutes, because it should only really be one take and we can give them all the information beforehand. And it would be a conversation maybe with an expert. The other thing I was thinking about, around your hints and tips thing- And actually everybody has said people who have experience with an issue with Parkinson’s is actually just as vital as an expert. Is that we could collect, as you said, almost similar to this, people who are very experienced in the issue, could maybe write in or could do a little phone snippet of a recording. And then we could play them in a different way as well.

There’s lots of different ideas today. Okay, anything else to add?

Female: No.

Interviewer: Just the last question. I’ve probably been here for about three and a half hours, so I do apologise.

Male: No.

Female: Not at all.

Interviewer: Okay.

END AUDIO

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