**Workshop 2**

(PUK-PR-W2a.wav)

**What would you like to ask someone in another PUK group? (7.22)**

Have they learnt anything from their own experience that they would like to share (Male2)

You would need to know about the group, it might be a young person’s group which will be very different to a group with mixed ages like us. It’s important to know who the group are, is it rural, is it urban, do you just drop in to the group or do you see people regularly and have several meetings. If you’re in a rural group there’s the question of transport so you don’t actually see your group all that regularly to build up a relationship. (Female)

And i think it would be very important to know the age group, because people diagnosed with parkinson’s who are very young have a different attitude to those who are older, and have had more life experiences and find it easier to cope with....and i wonder if a sort of bitterness might come in when you’re younger, a sort of frustration, i don’t know. But i think you would need to establish something like that (Female)

Do you think it would be important to exchange experiences, even if people are very different? (Facilitator 1)

Yes, i think what Male2 said ‘have you learnt anything from you own experience’ is very valuable. But i think what i said comes after that and is important (Female)

Anyone else like to ask someone something from another PUK group? (Facilitator 1)

How do you structure your days/week? I think one of the things for me has been getting focuse, trying to build things in that i can work with and actually remind me through the week of wheat was important, getting my priorities and getting through that barrier which i find very strong to not do anything. So that would be useful, to know who other people structure their days and have a purposeful life (Male1)

Do you switch from that to sometimes feeling you’ve got too much to do and you don’t know where to start? It’s the tyoe of thing i never though i would find what i retired (Male2)

>>Male1 discusses a task planning sheet he was recommended to use by his GP to help him write down and prioritise things that are important to tackle through the day >> Female wonders if this is more retirement related than Parkinson’s- she discusses how she felt she also needed structured to her week when she retired- compares retirement to a ‘vaccuum’

>> Facilitator 1 draws o the fact that this could be a learning/ exchange opportunitiy between members- male1 can share his solution and get advice about others

I would want to know how other groups get people to join into things (Male3), people don’t have time, they have busy lives (Male3)

It reminds me of when I found out about the group, I wan’t going to come along because i didn’t want to see people worse than me, i didn’t want to think that’s what I would be like- so that’s a barrier we need to get over i think- because at the very worst it gets a group of people together for a cup of tea and a chat, but it does much more than that. People are obviously losing out who wont take part (Male2)

So what made you come then if you were hesitant? (Facilitator 1)

I was bullied (Male2)

I said, if you don’t want to come that’s fine but i don’t think you should say you won’t come before you know anything about it, I’m going. I came on my own, to get a feel (Female) 15:42

(W2b.wav 15:56) There’s a guys who lives next to me who has parkinson’s and i push him to come to the group but he won’t even admit that he’s got it, he won’t even talk about it. (Male4)

**What would you share with someone newly diagnosed with Parkinson’s?**

I would say Parkinson’s is like a cork (corks are all different). No 2 people are the same with Parkinson’s and that makes it hard because you don’t know what the future is. Everybody is different, no 2 people are quite alike. Each person has symptoms, speech, walking but they’re not the same (Male3)

>> Male4 discusses issues with Freezing

(W2c.wav 3:32) I think one of the things we should be impressing on people is that even though it doesn’t have the same effect on everybody we should eb convincing them that they’re no alone, they should socialise when they can, get out and about, keep moving, i think that’s very important. Keep your mind and body moving and join a club somewhere. I think a lot of PwP don’t want to accept it but they’re not alone. We all accept that its’ incurable but life can still be satisfactory. (4:48) (Male5)

(W2a.wav 19:52) my message would be it’s not the end of the world, most people lead a full life you can help organise your own fight against it and you really should try not to give things up because once you do, you won’t take them up again and ther’ll come a time when you can’t...and contact Parkinson’s UK (Male2)

That’s so improatnat to know you’re not on your own. It’s such a shock when you get that diagnosis but when you get in touch with PUK, it’s just knowing there’s someone on the end of the phone. I would also want to share practical things like that, you know, say there has been fanastic help Male2 has had from conductive education (Female)

Yes that’s knind of contradicting what i said about when you’ve lost something you won’t get it back because i lost my ability to write and i got it back- it won’t win calligraphy prizes but it’s back (Male2)

Medical professional could gain from being part of this group because they’re the ones who tell people, when they’ve assessed you and come to the decision that you have parkinson’s it can’t be very pleasant for them to tell you but if there’s a whole lot of other things thay could tell you about how best to cope with it ... (Male2)

I my mind, soem people don’t need all the help offered to them, they can go it alone. From a carers point of view, they have the tendncy to keep you safe and it’s not always the best answer. (Male5)

>> Male5 discusses a child with a leg amputee and how he went into Paralympics

>> Male4 discusses ‘something’ i think freezing

So for someone newly diagnosed, experiencing a symptom like that could be distressing, but knowing that it is common and other people experience it could be comforting (Facilitator2)

>> Male5 discusses the importance of being determined and his experience with falls

So how would you usually find out information like this? I use the internet (Facilitator2)

I would ask my wife (Male4)

(W2a 26:30) we’re assuming aren’t we, talking about Parkinson’s UK, that there’s all this support which I shouldn’t have assumed, that everyone will just google PUK and find all of this wonderful information. Not everyboday has access to that, how are they going to find the information? (Heatger)

I suppose you could ring them up (Male2)

It’s not the same thoug is it? (Female)

I think one of the best things is being able to come to groups like this and being able to talk to eachother, what i do could benefit someone else and what they do could benefit me (Male2)

I’ve just had a though about recruitment for PUK, I always promote the groups when i go out to visit people but i often find the whole process a bit facemale3s at times. So you give all this information about these fantastic groups but it’s just very much a clinician’s word at times (Facilitator2)

Yeah, you kind of hear, you don’t really get a sense of the atmosphere (Facilitator 1)

I was at the SLT group recently and told someone about the group and they said they were worried about coming because they cried easily (Male3)

It’s important to know what the other person needs, work out where they’re coming from (Male1)

Yes, it’s relating to what Female was sayin earlier about knowing someone’s background (Facilitator 1)

If you could run the group for the day what would you do?

One of the things i would like is if each member of the group stood up and gave their piece, what they think about Parkinson’s and how it’s affecting their lives. (Male5)

I agree but i wonder if some people would find that difficult. Some people would probably find that terrifying (Male2)

You could overcome that with small groups though. If you were running it for a day you could have some times thorugh the day in little groups, it’s easier with a few people (Female)

Yes, i suppose everyone sits in their usual groups at the moment. What about talking to people in another group?

It’s difficult to say and put yourself in different shoes, it’s easier for us but others might feel uncomfortable (Female)

The medical profession loves clinical trial, before and after, stats test. But exploring the medical social side would suggest to me having semi structured interviews in small goups and not having statistical tsting or hypothesis testing. That would produce different types of data (Male2)

I would have more fun, bingo and singing (Male4)

But keeping it relevant and having more information about Parkinson’s (Male5)

Sometime i have a feeling that it would be nice to try and forget about parkinson’s (Male2)

It’s interesting because you all come to this group because you have this cap of ‘parkinson’s’ but you don’t always necessarily want to be reminded of it. It’s an interesting thing to balanace (Facilitator 1)

>> Male5 discusses a DVD he got about UK Parkinson’s research. Discussion leads to other videos about Parkinson’s

So i suppose if we’re talking about sharing again, all these little stories about research that we picked up on last time was the fact that research is great, but it’s not disseminated ina way that an everyday person with Parkinon’s would know about it (Facilitator2)

Or even researchers with Parkinson’s would know wbout it. There was some interesting thing earlier where kate has had something from someone looking to do some research and she assumed we would know who they were and they would know us, but we didn’t. (Facilitator 1)

For me i would like to have a group session theme around ways to increase motivation (Male1)

>> Facilitator2 brings conversation round to research aims (technology)

We’ve talked a lot about sharing with other groups and enticing people into coming into the PUK groups

>> Male5 discusses a medication study at RVI

In relations to finding information about the group, info is usually put on the internet and that is often the assumed way that people access it and a lot of people don’t use the internet, so there seems to be an issues there that this group are dealing with a bit aswell because at least half don’t use the internet (Facilitator 1)

Well we have to produce a newsletter because so many people aren’t on the internet, otherwise we would send it electronically (Female)

 So it would be interesting to think about how tchnology could help share information, without being something that people necessarily had to have in their homes (Facilitator 1)

Video newsletter from PUK, where someone is the presenter and interviews peope taking part in the studies, because we’re not going to go and read medical journals and extract bits to put on the newsletter. Livening it up by seing people’s expressions and hearing about the work could be an idea- but that would have to be something done by PUK because that’s too much for a branch to run (Male2)

How would you present that? What would you use (Female)

It could be part of an obscure television channel (Male2)

That would cost a fortune (Female)

Yes, I suppose so (Male2)

You could do a radio show- we did a project recently which was partly in Scotland and partly in india around diabetes management. A group of people interested in diabetes put together a short broadcast. People can either listen on their radio or dial into a freephone number to listen. That’s an example of an existing technology that could help get into peopl’e homes (Facilitator 1)

Or an intstallation in a place in the community (post office, hospital, local meeting), a technology that could be static but present information, rather than something people would have in their homes. (Facilitator2)

For the question about what you would like to talk about with your MP, i wou;d have increase information and awareness about Parkinson’s, it think generally there’s not enough awareness about the condition and that can only be helped if it’s more publicised, through the MP and possibly through the clinician (Male1)

A lot of the big things that people know about like stroke, heart attacks, cancer, a lot of them have television adverts so it get’s really widely spread through the TV. PUK have some really excellent campaigns but i haven’t seen anything on the tele (Facilitator2)

Is it to do with money? Because i expect these ads are very expensive (Female)

But there are some chanels with tiny audiences compared with years ago when there were only 5 chanel. I mean there are some thing selling make up and kitchen things that are very crude, they can’t have lots of money (Male2)

I think it’s during the day isn’t it, the ads tend to be a lot of those infomercials advertising a mop or something. I often think these are the types of companies that can’t have a lot of money. Or even the UK TV chanels on Sky, the ads are almost repeated every 5 minutes (Facilitator 1)

Our GP has a tv in the waitin room and they have medical video on a loop. I’ve never seen a Parkinson’s thing on it but that wouldn’t be that expensive (Female(

No and that would be exactly the type of place where you might catch someone who needs the info (Facilitator2)

And you’ve got a captive audience because they’re all waitin (Female)

I was at Gateshead metro recently and there was an advert for a specific type of cancer to do with the throat and gut and in it’s imagery it used a goose. All i really remember from it is this goose and the massive honk from and i thought that was a strage thing to do but it struck me that that was a very specific kind of charity that i’d never heard of but it’s plastered across all the metro stations. Yeah, i hadn’t thought of it before but Parkinson’s doesn’t have that same sort of awareness- apart from Michael J Fox (Facilitator 1)

>> group discuss Michael J Fox

Someone like Billy Connely, who’s got Parkinson’s, could increase awareness if he wanted. That would creat a lot of awareness (Male2)

Iv’e put out in front of you some project ideas, these are completely based upon this people said at the last meeting (Facilitator 1)

Sharing experience is most important to me- how could people share their experiences of living with and managing their parkinson’s to others (Male5)

There are some ideas there around even just having some little group sessions in the actual sessions already, and you said also the 15 mintues space (Male5’s thing around tlaking for 15 minutes) (Facilitator 1)

Yes, i think a lot of people don’t understand that Male2’s medication could be differtent from mine witht eh same results (Male5)

There is a publication for PUK which tells you about all the different classes of medication and what they do, but how many people send for that and read it and even so does it tell you enough about all the individual differences (Male2)

They have an amazing range of booklets, and they’re all free (Female)

It’s the most unbelievable resource but unmale3s you are egaged with what Parkinosn’s and what you want to know exactly, and for some people they don’t know exactly what they want to know, they just know that they’re having this problem and they don’t know why, then it’s not always that easy to access (Facilitator2)

Exactly, you open the booklet and it’s written in a fairly clear style, but it would say things like, this class of drug is a dopamine agonist, they work in ths way and there are list of drugs that fall into this category but that might not help the person wondering if they up their dose of sinamet or the doctor has said this, what’s the significance of this to them (male2)

Do you understand that now after you’ve experienced it for a few years and what all the terms mean? (facilitator 1)

I understand some of it, others i’ve forgotten (Male2)

But this type of litereature, you’ve been looking at this type of things for a very logn time now. It’s people who are newly diagnosed, getting it to them in a way that they can understand. Help them to calm down in the situation a bit and figure out what these drugs are and what they’re doing if helping them (Female)

And i bet when you have a short period of time with the doctor or nurse who might explain that, they might explain it in a different wany, which isn’t always very helpful (Facilitator 1)

So what’s the easiest way to learn something like that, i don’t know (Facilitator2)

It could be like someone being interviewed, and that appearing on youtube or something (Male2)

Yes, i find visual things much easier to learn from, videos or cartoons which are basic information in a short period of time- you can take quite a lot in visually. Or even those type of infographs where you can see how things connect (Facilitator2)

Text would suit me most of the time because it’s quicker. I presume you could read in 5 minutes what would take 30mins of video to get across but on the other hand the video images might stick more (Male2)

By video you mean a video of someone who understands the material discussing it, or a video of a person who is struggling to make sense of it? (Facilitator 1)

Who’s stuggling. Or an actor that appears to be struggling. It could be something like- the major cause of symptoms on parkinson’s is lack o f dopamine- so what’s dopamine, what does it do? (male2)

You mean Q&A, 2 people (Female)

Yes, so tyring to avoid saying it’s a neurotransmitter and here is a nerve ending, and a synapse here (Male2)

So, question 2 was How could we help people understand their medication intake better so that they can make informaed decisions. This came from something Male5 was saying about how sometimes he didn’t see why he was put on a medication and then taken off it, and you didn’t see any effect. But also there was discussion about how you were often consulted to make decisions around what you should be taking, and you think i don’t know, you tell me (Facilitator 1)

The nurse or doctor will ask you what you want to do and i don’t think we understand enough (Male5)

It’s almost suggesting that there is a lack of medical knowledge- we don’t have a cure, we don’t know the cause, we can’t slow it down, so all we can do is alleviate the symptoms which sometimes works well and sometimes doesn’t. For all the effort, to be able to understand the underlying condition or why the person next to me hasn’t got it but i’ve got it is beyond us. (Male2)

There’s this idea aroundthe quantified self which is basically people who count nd track things in their lives, it’s been used a lot for people monitriing their weight or diabetes over time. I suppose it would be good o see how different things affect parkinosn’s, although there are so many variabmale3 (Facilitator 1)

Yes, it requires a lot of input from the person themselves too. I suppose if the doctor wanted to find something out he would get you to keep a diary. (facilitator2)

Most of us have tried ina male3s structured way to think about why did i have a terrible few meeks a month a go and i’m feeling finenow, what’s different. We all think, did i drink too much, did i not do enough exercise, was it cold? And i don’t seem to get anything out of that (Male2)

Yes, there are lots of things going on looking at making Parkinson’s better but it’s really hard to find a cure (Facilitator2)

There’s a questions here ‘how do we share the latest research between people’ does it give hope? Is that why you’re interested in it? (Facilitator 1)

yes (male5)

>> wraps up