Peer support in action

[music plays]

Damian: **Welcome to this, I think which is the sec... no, the third, maybe, of 21 sort of anniversary festival events we're holding this week. This is on day one, it's 10 years of the DEEP network – how fantastic. So, throughout the year we've put on... as well as this sort of week's virtual festival, we thought we'd just need a bit more than just virtual stuff, we've had 17 sort of physical gatherings in all sorts of shapes and sizes, whether it's conferences, get-togethers,—**

Monica: Mm, well done.

Damian: **—bike rides, outings, so this is a culmination of all those, so we've hopefully tried to sort of get everyone right across the country really involved in celebrating the 10 years of the DEEP network, which is just phenomenal really.**

Monica: 10 years.

Damian: **10 years, Monica, yeah.**

Monica: Did you start it off?

Damian: **Not me, no, but my colleagues did,—**

Monica: Yeah.

Damian: **—and now it's made up of about 80-odd groups of peers living with dementia. And [Jasper's? 01:09] joined in, and it's great to see the ban... Jasper's one of our film crew who made a film [unclear 01:14]—**

Participant?: [unclear 01:14].

Damian: **—and very shortly. But welcome to this session, which is essentially 'what happens in a DEEP group',**

Monica: [unclear 01:22].

Damian: **—is the title today, and yeah, that's a question a lot of people might wanna ask, and we made a film recording of... we allegedly called it 'a typical DEEP group meeting'. Every group's unique, we know that, but I think those of you who know the DEEP movement will recognise a lot of the values in there, and a lot of the fun and the smiles, and the serious debate, and the hard work, and the fun, and the food, and the welcome, and the belonging and all that sort of stuff in a short video we're gonna share shortly. And so, yeah, a typical DEEP group, if you want, that was the meeting that was filmed so beautifully last week, and it's a real treat in store just to share the video coming up.**

Without more ado, let's introduce ourselves, and if I go round the screen, I'll start: I'm Damian, Damian Murphy, as well as being a director of Innovations in Dementia, I also help facilitate York Minds and Voices, which is a DEEP group in York, funnily enough. And alongside me I've got Monica. Are you gonna say hello?

Monica: Hello everybody. Nice to meet you all, and I'm always amazed at the willingness of people who can use these screens and filters, and so on, on modern technology.

Damian: **That's great, Monica, so thanks, Monica, welcome, and you haven't got the computer yourself, have you?**

Monica: No, I've never needed one.

Damian: **Yeah, so in lockdown, Monica and I, we managed to pair up with Monica, and so Monica was able to come our house, when Minds and Voices would meet over lockdown, and she would play us out**

on the piano, which may well happen again today – you never know. So, Monica, fantastic to have you with us.

Can I go below now, and I've got Eddy.

Eddy: Hi everybody.

Damian: Do you want to introduce yourself, Eddy.

Eddy: I'm part of Minds and Voices, which I'm very thankful of, wouldn't... and we'd be lost without it: it's so friendly and happy, so it's nice to be talking to everybody.

Damian: Thanks very much, Eddy, and the cheque's in the post.

Eddy: [laughs]

Damian: Great, and we'll hear more from Eddy as... over the next hour. So, we're here for another hour, so plenty of time on our hands.

And I'm also delighted to introduce you... I don't know where you're coming from today, Alun, but I'm delighted to introduce you. Alun, where are you? And say hello and who you are.

Alun: I'm in Porto today. Yes, so I've just moved to Porto in Portugal. So, I'm an artist, and I live in... lived in York until very recently, and it's almost five years ago when I first started looking for some people living with dementia to help me work on an art project, and by luck I found Minds and Voices and just kept going back. The project finished about four years ago and I kept going back and finding more excuses to do more work with them, and so I'm very pleased to be here and very pleased to still be involved with Minds and Voices.

Eddy: Well done.

Damian: Thanks, thanks, Alun. And yeah, Alun became a huge friend to Minds and Voices – he just kept turning up, but... which was great fun really, and he completely surprised with a magnific piece of

work, which we'll talk about in more detail shortly, and it's sort of hanging behind us. We've pinned it up in our backroom in our house, but... which is a magnificent banner, and let me just... with our hands on, I've got... me and Monica have locked ourselves in the room, look it's covering the door, but that's our... that's our Minds and Voices banner that was brilliantly made and put together by Alun using the words of people with dementia, but we'll talk about that later on.

Yeah, so that's really sort of where we are, and people often say, "Well, what happens in Minds and Voices?" and I suppose the question... you know, what happens in a typical DEEP group is the challenge laid down for today's session: for me, I suppose it's really hard to capture the magic of Minds and Voices, and I often call it the magic of Minds and Voices—

Monica: If I make an exit, it's to the loo.

Damian: OK, Monica.

Eddy: [chuckles]

Monica: Is it upstairs or [unclear 05:50]?

Damian: It's... you can go upstairs or to the end at the back of the kitchen.

Pat: [unclear 05:55].

Damian: I'm pointing you in the right direction.

Monica: And that's it.

Damian: We've also got [Nelly? 05:58] the dog here with us, who might...

Eddy: [chuckles]

Damian: Right, what I'll do is... yeah, so, you know, to show that magic and to capture that magic... "Anyone else need to go?" Yeah, as my mother, she'd say, "Do you wanna try?" To capture that magic of

Minds and Voices, you know, I can talk about it all the time, and that's really boring and me droning on: we got a film crew in, and I think one of the cameramen, Jasper's here on... in the audience today, but... so I wanna share this film. It's a lovely little film, it's... I think it's really warm, and feel free to make some notes, pop some comments in the chat box, during or after. As I say, it'll be made available publicly anyway, if not already on our website, and obviously this session as well. Ouu, we haven't... ouu, it is recorded, it's being recorded, this session will be recorded and we'll tweak it and tidy it up and take out a lot of my waffle, and put it out there once the festival's done and dusted, but without more ado, I'm gonna cue up the video, the beautiful film...

//[film clip starts: 07:11]

Damian: **Welcome everyone.**

Alice?: Thank you.

Damian: **Another Minds and Voices, only 20 minutes of faffing today, that's quite a record, I think,—**

[laughter]

Participant?: You're doing well.

Damian: **—or less; we're not doing so badly, and we're not doing so bad.**

OK, I'm Damian Murphy. I live here in York, and some years ago a colleague and I decided since York was supposed to be a... what they call a 'dementia-friendly city', that there should be a forum, or a platform, for people with dementia to get together, so we tried to facilitate that, and that was about eight years ago.

When we started, there were about four or five people with dementia that we knew, that we got together, and we just started having conversations and discussions, and when you get people together,

they start asking questions and maybe recommending it to other people they know. We had a good relationship with some of the consultants who would refer people newly diagnosed, so we would grow over the time, and there used to be about five or six, then it grew to about eight to 10, and now it's about 15, and obviously there's been quite a turnover of people in that time, over the eight years, yeah.

Welcome, Alice.

Alice: Thank you, [and Paul? 08:32].

Damian: Good to see you.

Alice: Thank you.

Damian: And Ron, and Helen.

Helen: Yes, thank you.

Damian: Good to see you again. Welcome, Julia.

Wendy?: Mm.

Damian: Good to see you.

Wendy?: Mm.

Damian: Eddy and Pat – trouble.

[chuckles]

Damian: Welcome.

Eddy: Yeah, my name is Eddy Flory. I've had dementia for seven years, and I've been coming to Minds and Voices for about the same time. Minds and Voices to me is a lifeline. I got diagnosed with dementia and basically told, 'you've got dementia, now scram,' and then I come to Minds and Voices and it's just a new family. It... friendly, we're always

laughing and joking with everybody, and we travel around the country to different groups, which when you see other people has got the same thing as you – it doesn't worry you at all, you just carry on your life as normal.

Damian: **And, Sue, you joined us when we were all in lockdown, didn't you?**

Sue: It was quite a long time...

Damian: **And it was all on the internet, wasn't it, when you joined, Sue. So, why do you still keep coming back?**

Sue: Why? Because you walk through the door and everybody's laughing and it's great, and it's a sort of... it cheers you up and, you know, that sort of thing is... I'm so lucky, you know, that's what I feel is [unclear 09:50]—

Roland: I'm Roland [Blackdown? 09:51], Sue's my wife, and we've been coming to Minds and Voices for about a year and a half, since Sue's diagnosis with Alzheimer's.

Sue: It's made a big, big difference to me because when you have this sort of problem, it's very difficult not to sort of think about it all the time: 'are you doing something which is going to affect my husband,' you know, all sorts of things have cropped up, and then Damian came to talk to me in our own home, and saw what a super chap he is, and sort of immediately it's calmed it all down. I feel sort of quite happy about it because there's nothing to sort of alter things or make things worse.

Roland: Having come to Minds and Voices, it's clear that one thing that it gives you is much more confidence to speak about what you've got with others, and you're with a peer group who've got the same situation, and you can compare notes, and even the care partners, like myself, could compare notes with other people who are in a caring situation, so it's been good for both of us actually.

Sue: Mm.

Damian: **What's the message? Maybe we can ask you now, all of you now: what's the message that you wanna give to someone who's been diagnosed with dementia recently? What would you say, Paul?**

Paul: Carry on as normal and enjoy life, and make the most of it, and just keep on going.

Damian: **Brilliant.**

Eddy: Don't hide it. Get yourself out and go to groups and just live a normal life. I have a friend that he has got dementia and he just won't go out, and this is all wrong: we've got to find people like that and get them out and about.

We do a lot of things trying to make things easier for people with dementia, like Barnitts in town – it's like a maze, and we've suggested you put signs up saying where different places are, otherwise people with dementia and they get lost, and things like that.

Damian: **Do you need to tell somebody when you're out and about in the shops, that sort of stuff? 'cause that was a really debate that people had, and some people said – no, some people said – yes, some people said, "Well, it should be customer service; they should welcome you and speak to you anyway."**

Participant?: Mm, yes.

Wendy: We don't want any special treatment,—

Participant?: No, no.

Wendy: —we want customer service just to be kind to everybody, and then we wouldn't need a dementia-friendly—

Participant?: [unclear 12:32].

Wendy: —service. Oh, yes, Damian.

[laughter]

Eddy: When I... when I go and get the pension and all that, I just say to the lady, “Look, I’ve got dementia, I’m a bit slow,” and she just understands it. If you tell them that you’ve got dementia and you’re a bit slow – no problem.

Pat: But she has yours already worked out and ready for you, doesn’t she?

Eddy: Oh yes...

[laughter]

Damian: And they’re the sort of discussions we had, didn’t we, on our *Good Life* course, about what’s accessible out in the community, what helps at home, you know, all those messages: if you’ve got it – flaunt it,—

Participant?: Yeah, yeah, [unclear 13:08], yeah.

Damian: —as some would often say, you know it’s...

Barbara: I’m Barbara...—

Colin: [Wileman? 13:12].

Barbara: —Wileman, and we’ve been coming... oh gosh, Colin. Sorry, Colin has to...

Colin: Colin Wileman... over three years.

Barbara: In as... I mean when we first came, when Colin said, you know, “We’re going to go,” and I said, “Oh, I don’t think I wa..” he said, “We’re going to try it, and we’ll just see what happens,” and I’m pleased that he did because it’s been absolutely a really good thing for me and I’m sure all the other ladies and gentlemen that come in.

[laughter]

Damian: And we created our strategy, didn’t we?

[collective voices] Ohh, mm.

Damian: **That was two years ago now,—**

Participant?: Yes, gosh.

Damian: **—and actually – it was actually very easy to create—**

Eddy: Yeah.

Damian: **—because it was the conversation you'd all been having for like five or six years by that time, about accessibility, about 'hang on a minute, why is it... why don't... why don't we get a say in what services are out there?'**

Wendy: They believe it has to be complicated otherwise it's not posh enough, or whatever the word is, I can't think of the word, so if it's not like 50 pages long – it can't possibly be a council strategy,—

Eddy: That's right, yeah.

Wendy: —whereas ours was something like four or five pages of simplicity.

Participant?: Yeah.

Damian: **Yeah.**

Monica: Some people like more company, or permanent company.

Participant?: Mm.

Participant?: Yes.

Damian: **But you're happy on your own?**

Monica: Well, that's the way it's worked out at the moment.

Damian: **Yeah.**

Monica: Yeah.

Damian: **Good.**

Monica: Is that so bad?

[collective voices] No, no.

Participant?: No, it isn't, no.

Paul: You live life as you want it yourself,—

Monica: Well, that's the way it's worked out.

Paul: —and if there's anybody here says that they don't agree with it – hard luck, isn't it?

Monica: Yeah, I find it's quite agreeable.

Paul: Yeah.

Monica: And then you can always... I mean there's always things you can join if you want company, and that's a matter of choice, isn't it?

Participant?: Yes.

Monica: And if we're all the same – life wouldn't have much variety, would it?

[collective voices] No.

Pat: And he's always saying to me, "Just go, I shall be perfectly all right," and I say, "Oh yes," and the first night I'm away, you fall over, hit your head on the bed, and where are we? We aren't there at all. "Oh, don't be daft, I won't do anything so stupid," and then he goes and does it, but [unclear 15:38]—

[laughter]

Pat: —but he's constantly telling me to go.

Damian: The weighing up of risks,—

Participant?: Yeah.

Damian: **—you know, and the risk to be independent against the risks of the worry and the... all that, these are conversations we have all the time, aren't we? And why are the... they're really important conversations to be listened to—**

Participant?: Oh, they are.

Damian: **—by the people who provide services, so...**

Roland?: Yeah, I wear a watch and it's a [bracelet? 16:02] you wear constantly for five or six days, and some sleep patterns.

Wendy: I was down in Birmingham one day: my daughter was doing this study with me, and she text me to say, "Why are you in China?"

[laughter]

Wendy: So, that watch didn't work.

[laughter]

Damian: **Well, shall we sort of stand up and hold the banner up completely—**

[collective voices] Yes.

Damian: **—so it can be all...**

Eddy: The chap called Alun, he decided he wanted to make a banner, and on the banner he's put all what people have said about dementia, and then he asked us to do our hands, and so we all [unclear 16:44] our hands out, he took them all away, and the cut all the hands out, and a lot of us said, "How do you want this?" and I said, "Well, I'd like mine with Spitfires on," and as you saw on there, and so he did and it's unbelievable, it... and we've shown it off... well, it's been all over... it was on the news at one time about the banner.

//[Monica plays piano: 17:10]

Damian: **[Elaine? 17:20] always used to say... who died last year, Elaine always used to say it changed her life, and get... you know, gave her back her life. You know, you see people become so much more eloquent, and so much relaxed because we spoke about today how horrible it is being new anywhere, and so we really work on the welcome, so, you know, when you see people relax and be amongst friends and be chatting amongst themselves over lunch, you know, that's just fantastic really, so yeah, it's a place for growth for individuals, it's a safe space, or a space for growth as well.**

[piano playing and film clip ends: 18:16]//

Damian: **What do you think of that?**

Eddy: Oh, I mean it's great, it's... I think it's good 'cause everybody sees what each of the groups do to get the feeling that we're all one family, and I think it's really good.

Damian: **Great, that's nice, yeah, that family feel, Eddy, absolutely,—**

Eddy: It is, yeah.

Damian: **—and a lot of people mention that, don't they, in the group? OK.**

Eddy: Yeah, I'd have been lost without... my biggest fear was when we got lockdown, everything started shutting down and I started panicking, until Zoom came out, and then I was all right after that.

Damian: **And we'd have a... we'd have a quick Zoom, only half an hour on a Monday morning, wouldn't we?**

Eddy: Yeah, yeah, yeah it was good.

Damian: **Yeah, great.**

Eddy: But, huh, everybody's so friendly. My... I mean I go to three groups and it... so everything's so friendly, it's unbelievable, 'cause we're all in the same boat, so why worry about it – just live your life to the full.

Damian: **Sounds like a decent philosophy, Eddy.**

Eddy: It certainly is.

Damian: **Thanks.**

Eddy: I always say I've got two people looking after me: my good wife, and the good Lord, and at 86 – what more do I want?

Damian: **What more do you want indeed – a little bit of DEEP.**

Eddy: Yeah.

Damian: **That's fantastic; thanks, Eddy.**

Alun, I think the sun must be shining in Porto there, you're wiping something out your eyes, I think it's... [chuckles]

Alun: Yeah, absolutely.

Damian: **I saw you quickly pop something in the chat box: what did you wanna share?**

Alun: In... well, yeah, and I miss the meetings now that I've moved, and I think the film really did capture some of that sprit that... that's there in Minds and Voices. Everybody seems to feel comfortable speaking their mind and saying what's... what concerns they've got, what good things have happened, bad things have happened. It's a really open, honest place and just so genuine, I think... yeah, so yeah, it's made me miss it a bit.

Damian: **Ah, thanks, Alun.**

Eddy: We missed you as well, Alun.

Alun: Thanks, Eddy.

Damian: **Yeah, people are always asking after you. Alun, I just... I remember when you did the first art project with us, which was the small art project, and we had a little display in the local library, didn't we, or**

you put it up there, and I just remember you'd been searching for people to take part in your project for quite awhile and going to various groups: do you wanna tell us a little bit about that?

Alun: Yeah, so there's quite a few groups around York that offer opportunities for people with dementia to go and meet other people. Lots of them are things like Dementia Cafés, and I went to there a couple of times and helped out and I did some origami classes for people, and I tried to get people interested in joining this project that I wanted to do, and I was really struggling, and I came to Minds and Voices and it was just a different attitude and a different kind of... a different way of approaching things really, and it was very proactive, and everybody there wanted to be involved and they wanted to tell others about dementia and what life with dementia was like, and I wasn't getting that from the other groups. And Minds and Voices really were the people who... they didn't want to sit still and be quiet, and it's just... it's all in the title, i'n't it, it's Minds and Voices, you really wanted to tell people what is was like, and it just grabbed me and I really wanted to use whatever I could with art, to help get those voices out there. So, right from that first project, none of the words, or even the pictures really, have been made by me: they're all words and pictures that have come from the people in Minds and Voices. 'cause I think, 'I can't say anything,' I have no experience, so all I want to do is try and put your words, put Minds and Voices out there to help people who've not been to Minds and Voices realise what living with dementia is like, and that it shouldn't be hidden and there shouldn't be the social exclusion that Eddy's spoken about already, and that we heard mentioned in the film, and if I can do that, then I feel like it's a good thing, and plus it's utterly enjoyable for me, and I must say, being involved.

Damian: That's great, Alun, thanks. And all the words on the... on the banner behind us, they're stuff you wrote in your little book, little gems that—

Alun: Yeah.

Damian: **—you just picked up, weren't they, over the years, visiting us?**

Alun: Yeah, so I kept coming... and I kept going to the meetings every month and we're... and really enjoyed the Zooms during lockdown, and I'd write down the phrases that really stuck with me that people said, and I made sure I wrote down who said them, and then eventually I had enough to do the banner, so we've got all the sayings. And then I was inspired by the little yellow cards that you have at the Minds and Voices meetings, so the title of the banner is *I want to Speak Please*, and that's kind of... it's almost a motto of Minds and Voices really. I feel... I feel like you've got things to say, and you want people to listen, and you want to be listened to, so that was the inspiration behind banner really. So, I took... I went to everybody at Minds and Voices and we made paper cut outs of everybody's hand, and I asked them what fabric they'd like to represent their hand, which is why all the hands are in different colours, 'cause it was like... it's supposed to represent putting their hand up and saying, 'I want to speak please,' and then all of... all the... all the words, yeah, and all the... and the wise words and the phrases that people like Eddy and the others that we saw in the film have bestowed upon me over the last few years.

Damian: **Brilliant, Alun, thanks so much, and you did provide a little sort of summary of who chose which fabric and what it meant and what the significance behind all that, so that was absolutely fabulous,—**

Alun: Yeah.

Damian: **—so that's definitely something that... that's definitely something that we can share and we'll get that up in the final sort of push out.**

//[music and film clip starts: 25:01]

Frances: And is it through this peer support that you gain strength and knowledge about how you can live your best possible life as you go through this, and I think without it I would have floundered very early on and been a really miserable sort of soul. And it's taken me to places I'd never been,

and I've met people from all sorts of walks of life, and it's been a huge eye-opener, and we just share things and help each other along, and it's absolutely heart-warming, and it's made all the difference to my life. It's been probably one of the best times of my life, you know, I wouldn't really want to change anything now.

[music and film clip ends: 26:17]//

Damian: **So there. We're really open now to the chat room, so people posing questions, fire them away, please do, keep then in. We've got Rachel... 'Nibbers', our fav... our great coordinator, Rachel, looking at the chat box, any questions coming up – feel free to sort of flag them up and, you know, we'll hopefully answer them.**

Some reflections really on re-watching the Minds and Voices video: I think the word 'welcome' appeared, I don't know, five or six times, very frequently, in the first, you know, opening few moments of that, and what the filmmaker's picked up and I think that's so important. We mentioned how horrible it is being new and coming to somewhere for the first time, and, you know, that really struck me coming across. When you're going to Minds and Voices regularly, we've been doing it eight years now, you know, maybe you get sort of... whether it's immune to it, or you don't see it as much, or it becomes second nature, but it's great to have that objective view of Jasper and his film crew, you know, because what they've captured, you know, was some of the stuff that we hadn't maybe realised, you know, really... you really focused on that warmth and welcome, so we're really delighted with that.

Yes, the DEEP—

Rachel: Oh, I've got... I've got a question for you.

Damian: **There's a question for me, Rachel?**

Rachel: Yeah, yeah. So,—

Damian: **Go on.**

Rachel: —there's a question about how do you recruit new members?

Damian: **That's a really good question because when we first started, I happened to know one of the old-age psychiatrist consultants, having met her in the playground, all the best things happen in playgrounds, the school playgrounds, and when we first started we knew two or three people between us, myself and Emily – my colleague, and then we invited people to come along. The consultant referred new people, newly diagnosed to us, which was fantastic, and then she moved away, she emigrated to Canada – how dare she, and things seemed to dry up, so it was quite slow progress at the start. But just being there... and when you get people together, and this is what I wanted to say, is when you get people together – they start talking, and when they start talking sometimes they ask questions, so then we said, "Well, let's investigate these questions, let's bang the drum, let's knock on the door of the local council to ask why is this, that or the other happening," or not happening, and so we got ourselves quite well-known locally and got... and then more and more people would come very, very gradually. And so it sort of happened I think when you get a reputation and people come, and it is a good place, and people say, "Yes, I'm coming back again:" Barbara who you saw in the video there, you know, she was very reluctant to come, she hated coming the first time, her husband said, "Well, come along and see what it's like," "OK, I'll see what it's like," and at the end of that session she says, "Well, I'm not leaving, I'm coming back here, when's the next one?" and, you know, and so for Barbara, it's just a real highlight of her week, you know, or of her month, and, you know, she really sort of... she's the first one there and the last one to go, and she's just smiling and giggling, you know. And her needs have changed over time, but she continues to smile and giggle and participate, and see how great she is, and she's just so**

happy, and she engages in conversation with those around, and it's just absolutely fantastic, and really relaxing for her, and I think when other people see that, they say, 'yeah, this is a safe space, I'll come back.'

And then now we're a lot more... we're getting more and more referrals through social prescribing. Now social prescribing is a lot more established, we're known in York and people say, 'right... you know, we've got... we're... you know, there's this group, this is Minds and Voices,' so we're getting regular enquires now: you know, maybe one a month or so, but then that builds up the group and some will stay, some will come and not stay – that's absolutely fine as well, it's not everyone's cup of tea, but, you know, it is, it just gradually builds over time really. So, I'd say have faith in what you're doing, you know, those DEEP values, I think we've spoken about this morning, you know, that's what makes people come and stay and want to come, and that's what gains, I think, the reputation of the group. So, becoming more established, people come, being more known to the social services, to the mental health teams, the memory services, and social prescribers, is really good and we've got our own reputation. We've done stuff, we've got engaged, as Alun said, you know, it's a group of doers who want to shout and put their hand up because there's that confidence that's there, that the people can sort of feel that they can sort of speak up and shout and have a say. For, as Elaine said, who named our group, Eddy, didn't she? She said, "Well, we've all got a mind and we've all got a voice, so that's our name," and we always remember Elaine who died earlier this year, but she left deep tracks. Eddy?

Rachel: So, [Di McCarthy? 31:14] was [unclear 31:15] saying, "How to do you publicise the group?" But then I think you were saying, you know: word-of-mouth is incredibly powerful.

There's another question here from... about having care partners in the group as well, and how... I know that you've very recently sort of had a population explosion shall we say in your group.

Eddy: [chuckles] We certainly did.

Damian: [chuckles] Yeah, we have a lot of care partners as the group grew, you know. And I remember one meeting early last year and there was probably the biggest number of people we'd ever had, and a lot of people coming for the first time and brought care partners along with them as well, so people were spread out around the room. And yes, it's church hall, somebody mentioned that, so the acoustics aren't the best, and people with dementia are faraway from other people with dementia, so we sort of said let's get this... 'cause people were missing out, or not hearing stuff, or there was cross-conversation, and so we split the groups and we had them in another side room there and we filled it full of cakes and biscuits and lured the care partners into there. And they would share the same sort of discussions we were having, but it meant then the people with dementia were around the table together. And, you know, like we'll be seeing across all DEEP groups, you know, when people with dementia have that space themselves amongst peers, they become more eloquent and they're freer to say things and not have people speaking for them, and, you know, it's a great balance to have, you know, it's always an ongoing thing, but it's a fantastic, you know, mix, and it's all very enriching, you know, with everybody being there. But we always say, you know, the group is primarily a group for people living with dementia, but care partners are welcome. And care partners, and Roland on the video, saying, you know, he benefits from meeting the care partners and just seeing other people with dementia express themselves.

Rachel: Thank you...

Damian: Eddy's got his finger up, there.

Eddy: No, let the lady talk.

Rachel: No, no, no, actually I was gonna ask Pat what she thought about it.

Pat: About which part, the separation or the...?

Rachel: Yeah, yeah.

Pat: The first time I went, I wasn't very happy: it just meant that whatever was discussed in the group – I really never found out from Eddy what was said, which was probably a good thing, or a bad thing, which ever you like to look at.

Rachel: [chuckles]

Pat: But then it settled down a bit, but I found we were consciously looking at the clock all the time,—

Participant?: [What? 33:49]

Pat: —saying, "Is it 12 o'clock yet to go back for our cup of tea?" [chuckles]

Rachel: [unclear 33:53].

Pat: So, I had mixed feelings about it. I think at the time Damian was right, that we did have an explosion, and people were saying they couldn't hear other people, and I think we tried it once with us being in the room, but we were too noisy, so [chuckles] we were sent out to the other room, [chuckles] so I think it's just a case... I'm not really one for a change anyway, and it takes me awhile to get used to having a different go, but everyone to their own, I mean you do what you have to do.

Rachel: Yeah, absolutely, and I think that as... you know, as we always say, all of the DEEP groups are very unique and very different, and it's the... it's about what works for you in your own group really.

So, there's another question: "Do you... do you ever have to turn anyone away and do you have a maximum amount of people—?"

Eddy: Oh, no, no, no, no, no. No, no: the last thing you wanna do is turn anybody away. But I mean we tried ['cause look? 34:58] with people that had been newly diagnosed, and we invite them in and we have a talk with them and, "Do you like it, if you don't like it then... if you like it, come again,"—

Pat: And that's the courses.

Eddy: —and that's the course we... courses we do, we invite people that's [being? 35:12] diagnosed, and we have certain of our members: we talk to them and ask them questions, and they seem to like it and they come back again.

Rachel: Mm.

Eddy: [They? 35:21] need to go out and look for them.

Rachel: So, bearing in mind... my dog is about to bark 'cause there's [unclear 35:28]...

Eddy: [laughs]

Rachel: So, bearing in my that you'd never turn anyone away: there's a question about are there any kind of legal requirements like ratio of volunteers to members?

Damian: Well, I would say no because everyone comes freely of their own will; we're all equal. It's not a case of caring for people, it's everyone being together, so no, and we haven't overrun the church yet, there's plenty of space, you know. There's always a couple of us at least in terms of getting in to do the teas, and, you know, Dawn who's our helper and Anna, Eddy's mentioned before, would help us and so there was all... and there was myself and Emily when we... so there's always been two of us. I'm like Doctor Who with this changing assistants every couple of years, but... yeah, no, it's just a meeting amongst equals and we're free to come and go, so... absolutely, yeah.

Rachel: I think there is a... there's a question here from [Clare? 36:33] saying that she works in voluntary services and they have as many volunteers as are needed by the group. But I guess that, again, all groups are different, and, you know, a lot of groups which are run by organisations maybe do have to satisfy a legal requirement in order to run a group, but your group is very... has a flexibility 'cause everyone kind of just comes along and takes responsibility for themselves really, don't they?

Damian: Well that... yeah, that's very much how the group is run, that's... they're the values of the group, you know, so everyone's welcome, and everyone looks after each other, you know, if that's... it's a peer group, it's peers, so there's no sort of doing to as it... as it were, you know,—

Rachel: Mm.

Damian: —yeah, it's very much just a meeting of peers. Eddy?

Eddy: Yeah. I go to a group at Clements Hall and there's about 50 people there at different stages of dementia, and we all do different things, it's... huh, I think the more you get – the more merrier, quite honest, and it... huh, it's just a new life altogether.

Rachel: Well, there's a point about the church hall which I'm... pick up on because as you were talking about the kind of the echoey environment and everything, and I know that there's a... there's a couple of people with dementia who say, "Never meet in a church hall," huh, but actually it's... the place that you meet, is very important in terms of claiming your own identity and your own place, isn't it?

Damian: Yeah, yeah, I mean it was an available space when we first started; it had different size rooms. When we were small we met in a much smaller room and we've just only last year or so gone into the church hall because of the space, because of the expansion of the group, which is great, but, you know, we can breakoff 'cause there's space there for the care partners, so there's... it's a really good

community facility actually and it's a really welcoming venue. So, yeah, we've never had a real hangup about meeting in a church hall for our group, basically, yeah.

Rachel: Philly makes a point about having visited the group, and actually, and I completely agree with this: you're never sure who is a volunteer, and who is a group member, and who's the chair, and who's doing the chair monitoring, and that kind of thing, because it... everybody comes across as an equal.

Damian: Absolutely, yes.

Eddy: Yeah, we all just... we all just muck in.

Damian: Yeah, yeah.

Rachel: So, who gets told off when you forget the Liquorice Allsorts?

Eddy [laughs]

Damian: Oh, there's trouble... there's trouble if you don't bring the Liquorice Allsorts.—

Eddy: Oh, they know all about you, Damian; they know all about you.

Monica: Can I play a carol; would anybody like to join in?

Damian: I think we'll do that in a couple of minutes,—

Monica: [Sorry? 39:16].

Damian: —and that would be fantastic. Monica's just offered to play us out shortly, so that'd be brilliant.

Rachel: Oh, I [unclear 39:20]. "Do you allow services to visit to see first-hand what happens at local groups?"

Damian: Yeah, we get contacted by a whole range of people, whether it's adult social care, nurses, students, clinical psy... we've got a really

good relationship with some of the local universities, and clinical psychology students come and ask to do projects. You know, they'll... I'm the contact point but, you know, before they come it's... I'll say to group, 'so and so's been in touch, they'd like to come and ask about this,' so you know, everything goes through the group before anyone's then invited to the group, and I don't say, 'right, well so and so's coming next week, like it or lump it,' you know, it's very much a case of being invited and... Yeah, absolutely open and... 'cause... you know, and the group thrive... I mean Alun will tell me, thrive on any opportunity to, huh, show off I suppose in terms of: 'look, you know, people with dementia can... people with dementia can contribute, people with dementia can have a say,' you know, and we've been having these conversations for years, you know, and every time... as Eddy says, any time someone new comes along, you know, you find out yet another different version of somebody's diagnostic journey that... you know, and the inconsistency of the services out there, and how we still need to campaign, or where we need to go, and, you know, the questions that people with dementia themselves are left with, swirling around unanswered, you know, after a diagnosis.

And... you know, and Eddy mentioned the course: we've got the *Good Life with Dementia* course which York Minds and Voices pioneered, you know, and... you know, it was that question, 'what's the message you wanna give to someone with dementia?' which you saw on the video, and that was the question I asked when we started to say "let's do a course", and we didn't say 'what should we put on a course?' we asked that question instead, and everyone... within five minutes we had the course content because it was the sort of conversation we'd been having. Eddy?

Eddy: Yes, we... what happens sometimes when visitors come, in the end they ask us to go and do a talk at their premises. I mean like a doctor invited

me to talk to his students about dementia, and this is how things have spread and with our Minds and Voices.

Damian: **Yeah, so you get greater links. Healthwatch did a big project with us, didn't they, Eddy, for a year—?**

Eddy: Yeah, they certainly did.

Damian: **And we... so we heavily contributed to the sort of... it's a document called *'What's Out There for People with Dementia and Their Care Partners'*, or something, in York, and it's a really comprehensive sort of one-stop shop of what's available and all the groups and all the sessions and, you know, that was borne was from the Minds and Voices consultation and then updated between lots of stakeholders recently, including ourselves and... you know, so... and that means, you know, people can get ev... you know, Minds and Voices contact is in there, so that's another way people get in touch with us. But yeah, the groups contributed to what is out there, you know, because people come to visit and because people come and ask, "What's it all about?" Social prescribers come along finding out, you know, 'cause they're all making local connections, and local area coordinators, and all that sort of stuff. So yeah, there's huge amounts of... yeah, and there's always a... yeah, there's always interest, and there's always something happening.**

Often people say, "Well, you know, what do you talk about in a group, if you're gonna get a group together, how do you start it, what do you...?" and I think it's just that conversation, and once you get the conversation going, and you've got stuff to tap into with the DEEP network, with the *DEEP News*, the national sort of what's going on across all the groups, and big-up for Rachel here because Rachel's been producing that Deep newsletter every month for God knows how long – it's absolutely fantastic. There's loads of taking part opportunities we always share, there's stuff that people can

read, you know, so there's all that sort of stuff, so there's loads of stuff we get up to.

Philly I think has just flagged up the piece of research we did which was the Dementia Enquirers project that our group got a little grant for, and that was borne of a conversation, wasn't it, Eddy, between you and Wendy?

Eddy: Yes.

Damian: Yeah, and you would say, what is it... "I pity those poor people on their own, 'cause our patch is marvellous," you'd say.

Eddy: Well, yes, it... I was... I just couldn't understand how people get on, on their own. Does anybody go and see if they're coping all right? It's all right somebody that's got a wife there that's a carer as well that look after you, don't you darling?

Pat: Yes.

Eddy: And as long as we keep in contact with people that's on their own and with partners.

Damian: Mm, absolutely. And then Wendy answered that: "Ah yes," she says, "but at least nobody moves things when I'm at home."

Eddy: Yeah. [laughs]

Damian: And that was our... that was our research, not to say which was better, but what are the specific needs so we could flag up to local GPs? So, if somebody on their own comes for a diagnosis, then you need to make sure that they're gonna get access to their medication and their appointments and all that. If somebody in a couple comes, and they need to say, 'right, well we know you two are gonna be fighting like cat and dog possibly, and [unclear 44:15],—

Eddy: [chuckles]

Damian: **—you know, 'cause dementia sets all these traps,' so it's about equipping people to brace themselves for, you know, possible changes in the future as well. One of the big findings of that research in the group, from our conversations, was that people were afraid... and we'll probably talk about this on Wednesday, but people were afraid of... you know, of the future, and when we asked, "Well, what happens if, you know, let's say your partner died or had to go into hospital?" and we found that the people on their own, who were on their own, were coping all right: the people who were in couples, had sort of been relying on each other, and had not created those external links and stuff.**

Monica, you live on your own, don't you?

Monica: Yes, I do.

Damian: **Yes, I remember you describing—**

Monica: It's just the way it worked out.

Damian: **Yeah, that's fair enough. And I remember you saying you were an inveterate picker-upper of leaflets.**

Monica: Oh yes, I can't resist.

[chuckles]

Damian: **So, you pick up... you obviously picked up a Minds and Voices leaflet and rang it, 'cause you're here. I... it's always a mystery how Monica appeared, but there you go – you did, which is a blessing.**

Rachel: I've got a final point from [Wayne? 45:20] in Kent, where he talks about the three different types of groups that he's familiar with in Kent, which are the local groups which are kind of like... a bit like our understanding of memory cafés, and meeting cafés, and then there are peer support groups, but then there are also actions groups, so they don't quite work together in the way that you seem to at Minds and Voices.

Damian: **And the question is?**

Rachel: Well, the question is... I think he's just making a point really about the fact that there are different models—

Damian: **Yeah.**

Rachel: —of doing this.

Damian: **Absolutely, Wayne, yeah, I mean obviously... yeah, I know you, Wayne, and yeah, there are different models, and people go at different paces, people wanna do other things and different things, and, you know, there's certainly that flexibility in the group, there's a lot of people, you know, want... didn't want to go into the research project that we did: others were keen to participate, [dog barks] others will go and give a talk, two or three will give a talk: other people won't – that's absolutely fine, you know, but there's... you know, there's... I suppose we've got that element, there's a lot of work, there's a lot of play and a lot of mingling, and it all sort of moulds into one, and yeah, it's probably a bit chaotic. We call it 'faffing about', but we have plenty of faffing time, but I think faffing time is important. You've got to witness of the faffing time before with the... with the video and the knock on the door and the barking dog, but... yeah, that's all right I think.**

I'm conscious of time, and Monica's invited us to... would you like to play us a little piece on the piano? There's a—

Monica: Yes, what would you like?

Damian: **Well, there's a bit of music on there, if you fancy? And I'll bring Monica over to the piano, I'll bring the piano over to Monica... no, I won't bring the piano over to Monica, that's too heavy.**

[chuckles]

[Monica plays piano: 47:02–48:41]

[applause]

Eddy: Well done.

Damian: Marvellous, Monica.

Monica: OK.

Damian: Marvellous.

Monica: Thank you.

Damian: Thank you very much, Monica.

[music plays]

[End of Film]