

How to facilitate a DEEP group

[music plays]

Rachel: So, this is the event number 11 out of 21... ouu, and we've got a very cold Cambridge saying hello to everyone, and it's very cold in Wales as well. I've invited along four people who are facilitators for groups within the DEEP network and are all very, very different, and we are hoping to kinda capture of the sort of top tips for facilitating groups. One of the most frequent questions I get is about how to start a group and how to support a DEEP group as well. We have 17... ouu, good morning from a cold Outer Hebrides too. [dog starts barking] We had 17 in-person events across the UK over the last year, celebrated 10 years of DEEP, and we very much wanted to make sure that as many people as possible within the network can access and **[some of the joys? 01:12]** and celebrations, but also the whole ethos of sharing, learning, and supporting as well. And all of the films will be available to watch, the recordings will be available to watch... competing with the dog in the background. So, I'm gonna handover for introductions and do a bit of muting, and I'm hoping that it's all a quick that it's all the Christmas cards are being delivered in several postbags. So, first of all can I handover to Ruth?

Ruth: Oh, good afternoon everybody. I'm Ruth, and I work up in Fife in Scotland, and it's pretty chilly here too, and I support the peer support group called STAND.

George: Hello, hi, I'm George from North Shropshire and I facilitate a DEEP group based in Shrewsbury, although we have people coming from Telford and further afield, even Stafford occasionally, and we also do weekly Zooms. So, we do face-to-face once a month, and weekly Zoom meetings, and

I've been doing that for... well, I set it up about two or three years before Covid, so five or six years now. And that's me.

Rachel: Thank you, George. And if you don't me saying so, George is one of the several facilitators within the DEEP network who also live with dementia as well, so thank you for being with us today George. **[Dannie? 02:39]?**

Danielle: Hi, I'm Dannie, and I support the SUNshiners group in Kent, yeah, I've been doing so and now for four years, and it's just come up to the anniversary for me, so... yeah.

Rachel: Brilliant, thank you, Dannie. And Dannie was one of the facilitators who hosted a bit event down in Kent at the beginning of September, and I forgot to mention that Ruth, and STAND, hosted a big event too as well. Damian?

Damian: Hi, I'm Damian Murphy, I am here in York, and I help facilitate York Minds and Voices and also the East Riders group in the East of Yorkshire.

Rachel: Thank you very much indeed. You'll be all pleased to know that the postman has now gone. We will be using these... ouu, so it might... the blurry 'I want to speak please' cards, to take sort of turns, which always works really well on Zoom, and in person **[unclear 03:37]** as well.

So, we had... after the first lockdown in September 2021, we had a Facilitators' Gathering in Woodbrooke, which is how we... we framed it as a bit of a kinda of recover and regenerate and recouperation kinda session, but it also create... brought about this fantastic resource of top tips for facilitators, which is available to download on the DEEP website. So, we're kinda picking up on some of the themes from this resource, and I highly recommend that you go to that resource and have a read of it, but some of the discussion points that we want to discuss today were, you know, the sort of what makes the DEEP groups unique, what is a... what

is the... what's u... what's different about the DEEP groups and, you know, thinking about the values base and the fundamental essence of the DEEP groups. Who would like to start with that? George?

George: Yeah. Used... I'm usually happy to put my foot in first.

Rachel: I'm sure.

George: So... yeah, what makes DEEP groups different from any other groups: the DEEP values probably define it best of all, but basically a DEEP group is a group of people meeting together socially – basically, and they are for people with dementia – primarily, and they're... they are... what they do is decided by the people there – not by some facilitator. I mean, you know, speaking for myself as a facilitator, I'll go along with suggestions, but they are a very democratic lot and they will do things that they want to do, and they will often raise things as well. So, it's about... yeah, I'll come back to the values: it's about being a safe environment to belong. It's about encompassing safety, belonging, and unity, and it's about DEEP members treating each other with kindness and respect, and listening. So, for me – that sums up what a DEEP group is: a great social engagement and opportunity to support each other.

Rachel: Thank you very much, George. Ruth?

Ruth: I think for me the uniqueness of the DEEP groups is that there's a kinda... they're based on people's, you know, desire to get involved and be connected, you know, that's the kind of underpinning thing. So... and that they're kinda based on the assumption that people can, people will, people want to, and it's a very active form of engagement; it's not the kind of passive sitting there being entertained. I mean the kinda stuff that we've done in my experience of being involved in health and social care for the best part of 40 years, is actually that... like for example the work that we're doing with the musician: I've never experienced a piece of work like that before. You know, the work that we did with Damian and STAND to create the *Good Life* course: I've never experienced that

before, despite all these years, so there's something about that hugely assuming that people can, people will, and people will backoff if you don't want to, and it's that kinda sense of, you know, just getting that kinda... and putting the opportunities in front of people and seeing who picks it up and runs with it. And it's based on courage and, you know, that kinda sense of trying something different, you know, putting yourself out there, you know, being exposed to new experiences and thinking, 'well actually, that wasn't so bad,' or, 'that was absolutely hugely powerful.'

Rachel: Mm, thank you, Ruth. So, Dannie, I know that when we've talked previously you talked about that sense of a leap of faith, and obviously as a... as a clinical psychologist, you are in... you're sort of in two camps in a way, so you spoke about this leap of faith?

Danielle: Yeah, I guess for me the DEEP group is about empowering our service users to have a voice, to... and I guess I'm gonna kind of seep into the next part really which is a facilitator is someone who turns up the volume of that voice and doesn't really do an awful lot else to be fair, we're just there to support; they tell us what we need. And for me it is sometimes difficult being that I work in the NHS, and so I do kind of have the dual role, shall we say, but then they do compliment one another because it means that whatever they bring to us, means that we can then help support that change. And vice versa, it means that when we change our services, we can involve them to ask what their opinions are and to get them involved in helping us to modify and get that right. So yeah, a dual role, [chuckles] it's time-limited at times, but I think in general it creates for a better service for both them and for us.

Rachel: Thank you, Dannie. It's interesting that the groups in Kent, of which you're a part on, or are supported by the health trust, and I just... and the funding comes from this whole kind of service user movement, and so you describe the people as service users, whereas I know a lot of people in other groups, kind of really bulk away from being described as service users. And I wondered how

people within the group, do you feel that they treat you differently 'cause they also know that you're their psychologist?

Danielle: So, we do try to... shall we... [communication breakdown]—

Rachel: Ouu, can't hear you, Dannie.

Danielle: —they keep those things separate. It doesn't always work that way... ouu, am I back?

Rachel: Yeah, you're back now.

Danielle: Can you hear us now?

Rachel: Yeah.

Danielle: [unclear 10:13]. I was just saying I think some... we do our best to try and make sure that the two are separate, because I don't feel that... I wouldn't want one of my SUNshiners coming in and feeling awkward because they know that I know something in their personal life and they're worried about me, I don't know, spilling the beans or whatever it is, although you are bound to confidentiality of course. That said, it has sometimes spilt over, but it does enable our SUNshiners to also come up with difficulties that they might have and get that clinical advice in quite a nice environment. And I guess when we talk about services, and coming through sort of the memory clinic, or getting a diagnosis of dementia, quite often there are frustrations, right, that things weren't done quick enough, or that there was too much information given and it wasn't relevant, but I guess working in both fields means that we're able to explain why that is, and they're able to say, 'OK, well what about if we...?' and then we kind of compromise and meet in the middle and find something that works for everyone, which I think's really beneficial. And they have, they've massively recreated some of our memory clinic pathways and we've found gaps in terms of, you know, 'how do we explain this to children?' And so our SUNshiners have recently developed some storybooks for different age ranges for children, and it's

not always nan or granddad who's got dementia, sometimes it's just an aunt, or an uncle, or a sister, or whoever it might be, to show that that isn't... you know, it's not... it doesn't just happen for older people, it happens no matter what your age is. So yeah, I think... yeah, it's a challenge and... at times, in terms of sort of you wanna give more time than sometimes you can, so it does sometimes mean that it can... it can spill over, but generally the two do compliment one another.

Rachel: Thank you, and I guess it sounds like you're in a position to be able to carry a lot of the things through, which is quite a unique position I think for many groups, for some... to have someone with that power, if you like. But also I was thinking about a lady who was a dementia support worker... who is a dementia support worker to the people who are within the group, and she said that after the group she always comes away with a... kind of a long list of things to do, and I... and so my sort of feedback for her was that in a way she needs to leave that role at the door because a lot of the groups are about finding solutions together, and amongst ourselves, so kinda... so I guess it's quite difficult to remove that identity of who you are from the group so the group can flourish within its own right. I don't know if you've got any thoughts about that, Damian?

Damian: Interesting you use the word 'flourish' there, Rachel, I was gonna say that. And it is, it's a... and also picking up on what George said about those values, and you mentioned belonging two or three times, and welcome: when we showed the video of the Minds and Voices group, I think the word 'welcome' came up three or four times in the first minute or so, and yeah, those values: belonging, welcome, and that safe space I think that you mentioned, George, that seem to be, I wouldn't say unique to DEEP, but, you know, that they're certainly universal across the network, you know, whichever groups you go to, you feel at home, and people with dementia have grown in confidence because of that and said yes to things, and said... you know, and been open to take part, as Ruth said, in all sorts of things. And I think, you know, one of the biggest

challenges as a facilitator I suppose, you know, and Danielle's talked about that as well, is the... you know, the idea of letting go and saying, 'OK, yeah,' and almost stopping that inner gatekeeper I think that we've all got, you know, and I know I certainly sort of thought and said, 'ouu, is this person able to do that' or 'shall we invite this person' or 'can they...?' and actually just let it go, you know, and you get used to that handing over, and when you do – it's quite liberating and then you see people flourish be... and people then say yes to so many things in the group.

We had the artist, Alun, on our group session the other day talking about a project he did, and he'd gone round other groups across York, but he had no takers for his art project, yet he came to Minds and Voices and everyone was up for it straightaway, and there was that self-confidence, and I think that that's... it's great, and when you sort of ferment that sense of belonging in that safe space, you know, all those DEEP values – people do flourish, and people do wonderful things, and yeah, and I think... you know, I'm very conscious of me as a facilitator, not being a barrier, you know, and I think there's a difference between running a group and facilitating a group, and I always try to use the word 'facilitator' rather than 'run', yeah.

Rachel: **Thank you. George?**

George: I just wanted to add that I mean there are one or two groups that have folded over the years, for all sorts of reasons, but basically I think members of DEEP groups come back for more, all the time, the successful ones, and that's most of them, because it's the best form of support that we can find, and that is, in a sense, it's proof, they just go on and on because people need them, and want them, and enjoy them, yeah. I mean I think... I think it's very hard for some facilitators, especially if they're coming from organisations who have been running groups in a what I'll call 'a different way', I think it's very hard for them to step back at times. Oh dear, I've just got a phone call. I'll be back in a moment, sorry.

Rachel: OK. Ruth, I wanted to... I wanted to ask you about... 'cause you've been... you were employed by your local council as a dementia-friendly kind of coordinator, was it? Yeah, and I know that when you have been in the situation and position of asking people who are part of the STAND group to take part in anything, you've been very mindful about not overloading people, but not... but not being a gate... a gatekeeper as well.

Ruth: I mean it is hugely interesting, Rachel, 'cause there is quite a element of risk in the whole thing. I mean, you know, you are conscious... I mean when I first started out with the... you know, the person I met first in STAND was Gerry, and he was one individual that I knew and it was him who wanted to set up the group, so the nurse who supports him, and myself, we supported that process. And to be perfectly honest, I was being quite selfish because I kinda recognised that I was wearing Gerry out: you know, he was carrying my bags, he was being the satnav all of the Kingdom, and I'm thinking, 'God, this guy's going to be exhausted here,' so setting up the group was really helpful for me because it meant I could draw on other people. But I suppose what I've really recognised out of it, is how much they get out of doing the presentations.

I mean we've recently been involved in schools, and it's mostly Gerry and Irene who help with that, sometimes Audrey, but mostly Gerry and Irene. And, you know, they get a real buzz of it. I mean we sometimes have to be at the school at nine o'clock in the morning, I mean that's a huge ask, you know, there's a bit of travel involved and yet they absolutely thrive on it. So, I think that's what I mean about assuming that people can, that people want to, and not, you know, stopping yourself from, you know, allowing them to do things. But, you know, it's kinda really quite inspiring. I mean they would say that they're still alive and doing really well living with dementia because of all the experiences that they've had, whether it's doing dementia [friends? 18:35] with me, or the kinda stuff that we've had in the group. You know, so from that point of view there is... you know, that kinda... the word is flourishing – it's a really

useful word, 'cause that's... I mean they're blooming, you know, in that sort of sense. And, you know, all the kinda memories that they're creating are so positive around the years that they're living, really, really matter because what a difference they're making. And, you know, that kinda sense of, you know, the activism came sort of second-hand really for us, it was more about kinda peer support and doing the kinda activities to, you know, promote wellbeing, and the activist came sort of at the back of that, so... But, you know, the people themselves get so much out of it, it's worth every bit of energy that you put into it.

And sometimes, as Danielle says, you know, it can be really quite complicated. I mean you've got maybe a group where you've got a range of different needs in the group, so you're almost having kinda groups within groups, but actually that's where the peer support comes in, and people naturally kinda matchup, and I think it... you know, it's really worth it, it is really worth doing it, because at the end of the day you know that people are just getting such a lot out of it, so it really matters. And peer support I believe, you know, now as I say after all these years in health and social care, that actually peer support's the way forward. You know, no offence Dannie, but [unclear 19:52] the workers, [chuckles] you know, just let them be... and, you know, with a wee bit gentle, you know, facilitation or whatever. You know, I was astonished to find out that people never paid any attention to what I said as a worker, but, you know, they'd listen to each other and they get that information and they do it, do you know it's quite upsetting really after all these years, but if that's the reality then let's embrace it, you know, let's get on with it, huh.

Rachel: Is there an element of having to leave your ego at the door as well as leaving your profession at the door as well?

Ruth: Oh dear, well I never really had much of ego, Rachel, but, you know, I think there's certainly something about... you know, there's a kinda real mutuality about it, there's a real kinda levelling about it, if you really open yourself up to the whole experience, it is about truly getting alongside people and going at their pace, you know, not driving it from your agenda.

I mean I was very, very lucky to meet STAND, 'cause it's really helped me with my work, you know, my main job, but actually I've got... you know, hopefully I've given as much back as they've given to me, you know, hopefully that's the case.

Damian: Hi, yeah, I just wanted to reiterate really what Ruth said about that sort of... groups becoming activists: it sort of flows very, very naturally from that sense of belonging, from that confidence, from those conversations that people have and then pe... in those conversations there might be a question, [unclear 21:15] 'is that fair, has that happened to you, shall we ask about that?' and suddenly you're challenging people, or people are coming to you to find out more about your point of view because, you know, over the time you've gained a reputation for being able to have a say, you know? And it's just, yeah, I think... I suppose our role as facilitators is... as Dannie said, is giving a little bit of volume to those voices, you know, so that's very much the way I think to go.

And yeah, it flowed quite naturally and people have gained that confidence, and are banging the table. And yesterday with a couple of members of the East Riders group, I was at the County Hall in Beverley, we were reporting to the... what... it's a very fancy name, 'Overview and Scrutiny Committee': councillors who are basically saying, 'well, what are you doing with our money' to all the sort of... the commissioners, and they presented a very long report with lots of jargon and words like 'coproduction' repeated about 82 times I believe, but two members of Minds and V... of East Riders came along and just said how it was, their experience of being part of the group and going on a... on a *Good Life* course in fact, and they just blew everybody away, the whole council were just blown away, and they said, "Well, you've brought this really incomprehensible report to life, you know, and we want more of this, and we want this to continue," and the guys, you know, and I texted to say thank you, you know, and one chap replied, you know, oh, it's just... you know, it's great to feel important and have that role again because

obviously that's been compromised with the dementia and it shouldn't necessarily so... be so, yeah.

Rachel: **Mm, mm, thank you, Damian. George?**

George: I just wanna pick up on something that Damian said, and if this has already be... if anything I say now has already been said while I was on the phone, sorry, stop me...

Rachel: **Wouldn't dare.**

George: Oh God, what was I gonna say? Oh yeah, jargon: I... and what... DEEP groups are very good at busting jargon, and those who use it, and it's interesting that we do tend to have a... have a way of reducing those in hierarchical positions, down to our level, which is not down at all, but it's... it is away from obfuscation and irritating jargon, and just do it please – do it, you know, and I think that's one of the great things about it. We don't have... huh, we don't tend to have pretensions 'cause we've left them behind when we come to the DEEP group, we just... we're just ourselves and we trust each other.

Rachel: **Uh-huh. Ouu, Dannie?**

Danielle: I was just gonna say I think that's definitely one of the challenges of having a dual role and being in the NHS and working with a DEEP group, just because [chuckles] the NHS is full of jargon, absolutely full of it; we break everything down into totally new words. And I mean I'm dyslexic so for me starting in the NHS it was the most confusing thing ever, so I try to be very aware of it, but it does become quite a normal sort of language to use.

So, I remember speaking to Rachel after our... huh, our SUNshiners day that we had had as one of the DEEP Anniversary days, and she had given me a jargon jar, which is supposed to sit and help to remind us really. I mean our SUNshiners are brilliant at picking it apart, but yeah, definitely one of the challenges.

Rachel: And I suppose as well that... I think Dannie's frozen, but one of the... one of the challenges is that... is about feeling comfortable within your group to challenge the facilitator to say, 'actually go back and, you know, put a... put a pound in jargon jar because actually we don't understand a word you're saying,' and I think it... I think one of the beauties of the... of the jargon jar challenge is that it slows... it slows your processing down as a professional, to the level that actually you need to slow down for that to be able to be, you know, understood and followed by everyone within the group as well. And we mentioned earlier... George?

George: And using these cards in ordinary meetings, if you're a member of a DEEP group and you get invited to a council or a... and a health authority or something group – take some cards along if you've got them, and say, 'could you use these please because it helps me to...' 'cause it slows everybody down, it's great.

Rachel: Mm, yes, yeah. And I was thinking about picking up on the trust that I'm gonna talk about within the group, and I think that, you know, with any group of people in life, there are gonna be people who don't necessarily like each other, don't get on: I guess what would you say as facilitators, have you had any kind of challenges in the groups where you've needed kind of intervene and step in or to... or what... or what strategies [unclear 26:55] that you have in place which kinda can reduce that stress?

George: So, I think... I think the one that I would suggest... no – offer, is... I mean I said earlier on that primarily DEEP groups were [for? 27:12] people with dementia, but inevitably some do include carers, and then maybe what we do is we will split after a few minutes and they'll have their meeting somewhere else and we'll have ours, and I made a mistake recently, and I just wasn't feeling particularly well, and I just let it run, and the carers stayed with us, and one carer, I hope he's not watching this, but if he is, huh, you know who you are, ha-ha, did dominate a bit, and... well, you do have to watchout for that, and that's the beauty of splitting because,

you know, carers get used to talking for their loved one, or their friend, or whoever it is, and they dis... they disable people, without meaning to, with the best of intentions, but they do sometimes, so it's good to separate away. And I'll tell you what – you soon see people who have been slightly disabled, become enabled again, when they're away, and they'll... And, you know, we had a lady... I often quote this, an old... a elderly lady with dementia, quite far on, and after one meeting where her husband stayed, he... I persuaded him not to come the next time, because he didn't need to, and he was happy, and she immediately started to order coffees that she wanted, which were not the ones that he always ordered, and to have... put loads and loads of brown sugar in her coffee which she... he wouldn't let her do, and she just... you know, she blossomed, she flourished.

Rachel: **Thank you, it's interesting, George, that you went immediately and saw the kind of the source of tension in a group maybe being a carer, and I think that, you know, there are some groups where carers are, you know, incredibly integral and an important part of the group—**

George: Oh, sure.

Rachel: **—and it works very successfully. But if we are to continue on the carers being part of groups, and come to Ruth.**

Ruth: I mean what's happened in our situation, Rachel, we're a bit like George: so sometimes we're altogether, sometimes we split, and I think it is really important that people with dementia get that chance to find their own voice. We find that absolutely crucial, 'cause like George, you'll often find that people are talked over or whatever. We haven't had a lot of problems about group dynamics. We did have one situation where there were one couple and it was unfortunately particularly the carer who was quite destructive in her dialogue with other group members, and she... they actually, you know, disappeared from the group quite naturally. We didn't a... we were at the stage where we thought we're gonna have to

intervene here, but actually they just disappeared. And I think what happened there was, the group themselves kinda almost eased them out, because people wouldn't listen, you know, people weren't responding to the sort of stuff that she was talking about, so from that point of view they sort of disconnected with us, and thankfully they found another group where they felt much more able to be connected there. So, we haven't had a lot of problems.

I think the diversity of the group and, you know, you get like wee, you know, sections that are maybe more comfortable with each other, or whatever, but again, because of the different activities and stuff that we support people to do, then there's a kinda collective. So, it's almost like you've got a big group, and you've got small groups within groups, and then that opportunity to split really works quite well with people. And now we've got some paid carers coming into the groups with people as they get more unwell and are needing driven to places and stuff like that, and actually that's been hugely helpful 'cause they're learning a huge amount from us, you know, in relation to what their person with dementia can actually do and stuff, you know, so they're seeing a hugely different side of people, so, you know, that there's swing and roundabouts. But I say, we haven't had a huge amount of problems with it, thankfully, and hopefully that will continue. But I think that's about the sort of scene that you set; it's about the conditions that you create. You know, as Damian says, you know, George has said as well, you know, you're creating a safe place, so if people don't feel safe, because of some of the dialogue that's going on, then actually that dialogue, they just stop it, you know, because they maintain their own level of safety and connection with the group, so they don't want it poisoned, do you know for want of a better word?

George: Yeah, yeah.

Ruth: Which was really a little bit about what was happening, so...

Rachel: At risk of going into a bit of jargon land: are we talking about, you know, setting some terms of reference and ground rules for the group, so... to enable people to feel safe? And that could be in a... in a more formal or an informal way, you know, having a kind of a contract, if you like, agreeing amongst the group about, you know, what you need within the group to feel safe?

George: I think that's... that's... that's a good idea in principle, but if anybody's thinking of setting up a group, I wouldn't advise that that's the first thing you do.

Rachel: Mm.

George: I think, you know, they should be informal social groups, for my money anyway, and if something begins to rustle a bit, under the bedcovers, so to speak... sorry, that was an awful... awful... right...—

Rachel: [chuckles]

George: —if something happens to be... seem to be going slightly wrong, then I think that's the time to start introducing things like, you know, 'respect, oh man – 'respect', and all that.

Rachel: Thank you. Dannie, do you have... do you have terms of reference or ground rules in your groups?

Danielle: Yeah. So, we're a little bit more formal than perhaps George's group. So, we are set out like a business meeting: each time that we meet, we have an agenda of what we want to discuss – don't get me wrong, it's not your typical formal business meeting, we have lots of giggles in between, but it does keep us on track for talking about all the different projects that they're involved in. Also we only meet once a month, in terms of the actual SUNshiners meeting, and then we have lots of spinoff meetings depending on what projects they're involved in at the time. So, recently they've had a grant for the research project, the Dementia Enquirers project, so we've had plenty of side-line meetings looking at

data and developing questionnaires and things like that. So, ours are a little bit different. We do have terms of reference, and we do have a like a little sort of contracty thing that people sign, but that said, we don't... you know, it's not a matter of, 'come along to our group, but you need to sign this before you can enter.' We enable people to come along for their first session with a carer or a family member or whoever they want to come with, if they wish to; they don't have to do that of course. They're not... we don't accept any carers after that point, so we are just for people with dementia. That said, it's actually created a really nice community – without meaning to.

So, all of the carers and now have one another on WhatsApp, and they're... yeah, all the wives and husbands sort of text one another. You'll find that quite often lots of members arrive together, because there's quite a few of our members that in similar areas. So, you know, it'll be, I don't know, John's wife who does the run this week, and somebody else's husband might do the run next week, so it kinda gives people a bit of a break, so that's been quite nice. And actually the feedback from our SUNshiners themselves, have been that they feel that they're able to talk about things that they wouldn't necessarily be able to talk about at home, because they're worried that these things that they want to talk about, or have noticed – would upset people.

And we find that by not having carers, or family members, one thing that really does come from it: you notice that if somebody comes along, they'll... they might be telling a story, but they'll correct them, "No, that didn't happen on Wednesday, that happened on Thursday." "No, it wasn't the 2nd, it was the 1st." well actually, that's completely irrelevant to what this person is trying to say, so it stops that from happening and it just lets the person feel empowered to talk about whatever they... and they can tell us that it happened 16 years ago or they can tell us it happened yesterday – it doesn't matter – for them it happened, and that's all we're interested in really. But yeah, so yeah, we are run a little bit differently. Go on, George.

George: Well I just wanted to follow up a bit, because I mean I'm very aware that every group is different, and each group depend... what... the way groups work together, I suppose, is always dependent upon who's in the group. So yeah, you... and also of course, as you said... just said, Dannie, you... there are a lot of projects going on down there, so you need to have a little bit more structure to make sure that they are, let's say 'coordinated'; whereas, you know, we've done a couple of Enquirers projects, but it's been, you know, quite ad hoc, and they've worked because one or two people have done them and it hasn't needed a business-like approach. But I mean I would be... I would hate a business approach. I would hate, you know, a chair and a secretary and terms of reference, it's just that's what I don't like, so I wouldn't go to that group, but I would go to another group – I'd go to my own group. So... you know, horses for courses, I guess.

Rachel: Absolutely, and I think that's the beauty of the network, isn't it, the kind of how all the groups are completely individual?

George: Yeah.

Rachel: The only... the only thing that connects you are the... kind of that... those DEEP core values, and you can do what you want in your group. Damian?

Damian: I suppose York Minds and Voices, we're probably somewhere in between the two, you know, so there is that real blend of, you know, formalities. And we did write a constitution a couple of years ago, which was just a really nice exercise be... you know, we're still on the journey to becoming, you know, some sort of recognised sort of formal group as such, so to have some sort of statutory relevance I suppose. But yeah, the... you know, it's... there's that general understanding, and I think George hinted at that, that general understanding of this is a group of people with dementia, this is a safe space for you to air your views, and so the... we don't sort of stand there and here's all the terms of reference and here's the sort of behavioural contract, or anything like that, and I

don't think anyone does really, but, you know, it's just generally understood, and maybe as Ruth hinted, that the like-minded people will stay connected and will stay coming to the group because they like it, because this is a place I can flourish, because I feel I can belong here, because there's a welcome. And that's probably one of the reasons why, yeah, we've not had really any sort of big... any beefs really. I remember a family brought a chap in and we were welcoming him and everyone was interested in him, and his family around him were speaking over him, and one of the... there was a friend of the family said to... "Ah yes, but you lot, you don't look like you've got dementia," the classics. [chuckles]

George: Ou, ou.

Damian: So, as a facilitator I... "Would anyone like to, huh, respond to that?" and, yeah, they didn't really come back again after that,—

George: [chuckles]

Damian: —or... which was a pity because we said, "Look, go away and have a cup of tea, and, you know, your... the chap you brought, you know, he's very, very welcome to come along," but, you know, it was... it was a pity, we didn't get to see him again, but... So sometimes there's missed opportunities, but yeah, those shared values, if there's a disparity there, as Ruth said, then people will move away I think. Ruth?

Ruth: Yeah, I'm just... I've picked up something in the chat there that's probably quite helpful just to kind of touch on. I mean one of the problems that we have in Fife is that some of our groups have very small numbers, and, you know, people with dementia, in my experience, it's not the first thing that they look to do to come to a group, it can be really... I mean Irene would tell you herself that it wasn't... she didn't really want to do it, she came along because family were insisting and she thought, 'well, I'll just go and get over with and I'll never go back,' so there is a real hurdle about getting people to come to groups. Now, I don't know what the answer is. I mean we know that if people come and get something out of it, and feel that they fit — they will stay. But for some people it just

doesn't work, and I don't know how you provide them with peer support. I mean you can maybe do it on a one-to-one, and we've tried some of that, but I just... I despair sometimes of the fact that people won't even try it. I mean if somebody tries something and it's not quite right, then that's absolutely fine, and sometimes it's just the dynamics of the group on the day. But, you know, it is really hard to get people with dementia to come out to things, really hard. And if anybody's got a magic pill that would make that happen, then, hah, you know, I'd be happy to disperse it, huh.

Rachel: Yeah, that kinda ties into the whole thing of starting up a group, and I very often hear from people saying, "Well, where do you find these people with dementia who want to become part of these groups?" George, and then Damian.

George: Damian was first, go on.

Rachel: Are you sure?

George: Yeah.

Rachel: Ouu, [oh, you are? 41:39] Lord Damian.

Damian: It was just in relation to the chat there that Di [sic] pointed out, she felt a bit uncomfortable about, you know, maybe badmouthing the care partners: I would say not at all, I think certainly in the reality, you know, that there are... many care partners come to our group and there are many people with dementia, as I think Di [sic] mentioned, you just couldn't even imagine without their care partner coming along, they were very much a twosome, I'm thinking very much of [Eric and Elaine? 42:06] in our group, and Elaine sadly died last year, but Eric still comes to group, so he's very much a member of the group as a... as a former care partner, but he's still welcome to the group.

And I think, yeah, there is a whole mix and, you know, there are certainly people... you know, and care partners who are there, and I think that's

the message we give as well is, you know, your role is very much to support the person you care for, you know, in their participation in the group and... you know, and that... and that does work well, you know, it... I would hate to give the impression there's a constant battle between care partners and people with dementia.

George: No, I mean I agree entirely – there isn't. That... and we found that our carer halves tend to... they now form a wonderfully supportive group of their own, and they're in touch with each other, like Damian's mentioned about some others, you know, they're in touch with each other at different times, and they don't mind at all when I say during a meeting, "So, let's have half an hour apart now," you know, and it works fine.

What I was gonna say though about getting people to go and try groups is, firstly: we've agreed that groups are different, depending on who goes, and for me that makes the argument that we should have a lot more groups, because then you're more likely to get a group to suit you, if you keep trying. Secondly: I think it's really important that someone accompanies the person the first time, I mean it might be a member of the group goes and picks them up and collects them, or it might be a... I mean this social prescribing, I think is a fantastic approach, but I do wish the social prescribers had the time to actually take people the first time. 'cause people with dementia, when they're first going to a group, I mean, you know, you run a... you run a big risk because... I... the first one I went to, it wasn't a DEEP group, it was run by the local memory service and it had sort of 70- to 80-year-olds who were being fed fish and chips, and could not have a conversation, and I had to... you know, I virtually ran out of the place, and there is that danger, you have to try and fit the person to the group. But... yeah, I think... yeah, take people the first time, yeah.

Rachel: **As Damian said, it's horrible being new anyway. And I always harp back to a blog that Wendy Mitchell, who's part of York Minds and Voices, where she writes about meeting someone who was new coming into... and we talk about this in the facilitators' top tips**

booklet as well is about ensuring that someone is always made to feel welcome, and if another... but if it's a group member that is doing that welcoming, how important and powerful that is: 'oh, you've got dementia as well, have you?' 'Oh yes, I've got thing too,' kinda thing. Dannie?

Danielle: Yeah, sorry, I wanted to go back and just touch again on the comment that was put in the group. I guess one thing that I wanted to acknowledge about being quite unique to DEEP groups, is how it builds people's confidence. We've had a few people who have been in similar scenarios, where after diagnosis, didn't want to go anywhere without a partner, and of course, you know, we do have partners to come along to the first session, maybe two if someone's really uncomfortable, but more often than not, you find that after a session or two, they're not talking to their partner anymore, they're kind of so immersed with everybody else that they become a bit more comfortable, which is really nice to see. Yeah, just wanted to kind of acknowledge that that, I think, is something that is quite unique to DEEP is how it does build people's confidence and makes them realise that they can do these things on their own sometimes.

Rachel: **And I think that I might sound like a stuck record when I say we must never forget the experiences that people have had up to... leading up to a diagnosis and being given this label of dementia being, you know, on a very kind of... a destructive pathway, you know, often and, you know, people have talked a lot about hope this week and about how your hope is taken away, but if hope was given at the point of diagnosis in terms of being... had the education for both the person with dementia and the family members as well, how valuable that would be. And the *Good Life with Dementia* course that Damian is involved with, and STAND have delivered as well, is so important in giving people a kind of... a pathway where they can choose to become, you know, involved and continue to come to a group, or choose to opt out of it as well.**

And there's a question that I've noticed about the value of meeting online as well as in person, and I guess it harps back as well to, you know, how it's possible as a coordinator to support a UK-wide network in that we have... I wondered if anybody wanted to talk about the facilitators' peer support that happens, which kind of mirrors, you know, what we want to see happening in groups really? How've you benefited from coming along to the facilitators' Zooms for support, anybody want to talk...? Ruth?

Ruth: I mean I've not been at the group for a long time now because one... as soon as we started to be able to meet face-to-face, my schedule just became too difficult to manage it. But certainly over the pandemic I found it absolutely invaluable, just that kinda sense of finding out from other people. Particularly people like George who are living with dementia, who are facilitating a group, there was a huge amount that I could learn from their conversation and the kinda things that they were trying, and stuff like that, so it really made me see it from the perspective of the person with dementia, which I think I was probably doing, but just to have that kinda safe dialogue on screen, you know, was really, really helpful. But the kinda... just that kinda sense though... 'cause I think that one of the things that, you know, it says in the booklet is, you know, to make sure that you get support for yourself; it can be quite a lonely job. I mean I'm very lucky that, you know, [Maggie? 48:54] and the nurse who supports people like Gerry and Irene, you know, she's around in Fife and we've got other projects that we work with, so I've got a bunch of people quite easily to kinda link with. But I probably get as much care and concern from Irene and Gerry, as I do from them, so you can use the group well to get that kinda sense of, you know, support and that you're not alone in things.

But I certainly found these conversations invaluable 'cause we were really just starting. I mean we'd only started the STAND group in the September 2019, you know, the pandemic hit in March 2020, we were really new, and were kinda making up as we went along really to be

perfectly honest, so, you know, from that point of view that huge learning curve that came through the pandemic and these kind of conversations, were really exceptionally helpful, and we are where we are today because of all that kind of input and support that was available.

Rachel: **Thank you. George?**

George: Yeah, thanks. We [riverside? 49:56] of the group did meet once a week and still are [meeting? 50:01] once a week on Zoom, and it's been good, it's been useful. There are weeks when people don't have much to say, and weeks when people have a lot to say, and I must say as facilitator I find it quite challenging when it... when people don't have much to say, I find I have to... well, I probably shouldn't, but I do try to keep filling the empty space... well, that's the story of my life, anyway...

Rachel: **[chuckles]**

George: I was going to say that one guy in our group cannot use Zoom, he cannot... he just cannot u... it's not because he can't handle the actual technology: he cannot follow what's being said, so he can't use Teams, Zoom, or anything like that, so he can't do it online, so for him it's been quite a lonely experience, and he's very thankful that we are now meeting in... once a month face-to-face again.

Rachel: **Before I come to Dannie I just wanted to ask you, George, as someone living with dementia, and about what... you know, how important the support is for you with some of the things that happen within the group: how do you get your support for you in your role as facilitator?**

George: Well luckily... luckily I don't actually have to do very much, I mean I just send out emails basically. I could be more... well, [sighs] Shropshire is just so far-flung that people who don't live reasonably close to Shrewsbury, or who cannot dr... or... yeah, or if they cannot drive, then I'm afraid they're not gonna get there, and I can't do much about that, but hopefully very soon, and I'm hinting at [Jackie? 51:52] here, then

hopefully soon that will be addressed because we'll have groups around the county. What did you say?

Rachel: I think I was thinking about kind of emotional support and [psychological, I suppose? 52:06]—

George: Oh right, OK, I think I prob... if I get any it's from meeting the DEEP people, like yourselves, online, as long as that goes on then I'm... you know, I feel rejuvenated. It... it's... I don't find it extremely hard to do, that's all, and I do have... I would call him my deputy, but... or co-chair, whatever – Clive, he will always do things if I can't make it for some reason, and he and his wife are great at contacting people, and I mean they actually contact people who... one or two people who have left the group 'cause they went downhill very fast, and they keep in touch with them, which is more than I do, so I am not... [sighs] I do what I'm good at doing, let's put it that way, and I leave the other things to other people who are good at it.

Rachel: Thank you, George. Dannie?

Danielle: Yeah, I was just gonna touch on some of the facilitator sessions that were run on Zoom, and I personally found them a bit of a lifesaver, huh. I think because we were in the middle of Covid and our groups weren't allowed to meet, obviously being NHS, we also had to follow the guidance that the NHS were creating, so it meant that our group couldn't meet for longer than some other DEEP groups as well. But we were... I'm quite pleased to say we were first group in Kent to make it online, and that in itself came with several challenges because a lot of people hadn't had a computer throughout their life, and never needed one, so actually this was completely new technology to some, other people had really good... you know, were really good at it and knew what they were doing, but it took quite a long time to sort of have one-to-ones with people and to try and support them on the telephone with how to access it and [whatnot else? 54:18], but I think once we got to Zoom, I just expected it all to run smoothly, hah, and it really didn't. And so things like 'I want to

...speak' cards were kind of talked about in the facilitators' groups, and it kind of just enabled our meetings to run smoothly. Like, George said, a lot of our members reported that they didn't like to be on Zoom: they struggled with how long the meetings were, so we had to shorten our meetings because they were on Zoom, but again it was also difficult for them to follow conversations... [communication breakdown]—

Rachel: **Ouu...**

Danielle: —or change settings perhaps, unmute them, remute... are you with me, yeah?

Rachel: **We are now, yeah, you're back.**

Danielle: [chuckles] Yeah, I was just saying, it can be difficult for people to sort of know how to use the technology as well, and mute and unmute, so yeah, for me the facilitator sessions really helped to find out what other groups do and how we might be able to adapt.

Rachel: **Thank you very much indeed. We've got some people who are heading off, and we're down to our last couple of minutes, but Martyn Gardener says, "Flexibility is absolutely the key, and also being free to sort of digress and go off a bit on different directions, it always seems to happen in these meetings." George?**

George: Can I also say one thing? When you're starting the group, I think it's important not to panic when very few people turn up for a while. Word does get round, I mean, you know, you do the obvious things like putting it in the local libraries and, you know, possibly even a doctor's surgery might even take a note, mine doesn't, but some would, but I think it's important just to wait, and Dory of course is the shining of example of just waiting for nine months in a pub until someone turns up, yeah.

Rachel: **Yeah, and—**

George: Oh, ah, good point actually: now, we should mention where we meet as well.

Rachel: **Yes, and...**

George: Find a nice social engagement place if you possibly can,—

Rachel: **And of course...**

Participant: —which isn't too noisy.

Rachel: **And of course that is in facilitators' top tip booklet as well. So, we... we're coming to the New Year, we will be having regular facilitators' meetings on Zoom which brings facilitators across from all of the United Kingdom together to chew the cud and have discussions like this, so that is always available to facilitators or people who want to be facilitators, because of course anybody can set up a DEEP group that are based on the DEEP values, the most important thing.**

Thank you everybody who has been listening to us, is behind in the background, and... but a particular thank you so much to Ruth, and Damian, Dannie, and George, very much for your... sharing your words of wisdom, and it's all about sharing, learning, and supporting and... you know, and everyone who... 'cause part of the DEEP network it feels like everybody's very happy to share.

[music plays]

[End of Film]