How to provide the support dementia activists need

[music plays]

Philly: **Welcome everybody. This is second day of our DEEP online 10th Anniversary Festival, and hopefully some of you have already joined some of the wonderful sessions that we had yesterday. We've got loads more later today, and all through the week, ending with the DEEP Symphony on Friday afternoon.**

Tracey: Welcome everyone, and thanks for joining us. I'm Tracey, and I live in Folkestone, and I've been involved in activism for seven years. In this session we're gonna focus on how to provide the support dementia activisisit... activists need. [chuckles]

Philly: **Do you want to say that last bit again? [chuckles]**

Tracey: I can't say that word very well, it's got too many 'Ss' in it for my lisp. In this session we're going to... going to focus on how to provide the support dementia activists need. [chuckles]

Philly: **Yay, [chuckles] thank you, and now you can relax because we're gonna show a short film to kick us off, a very short new film, which highlights some of the activism which happens in DEEP.**

//[music and film clip starts: 01:26]

Philly: **Scottish activists, including Nancy McAdam, James McKillop, and Agnes Houston.**

Most of the work was developed during a short residency in the Lake District. They created textile banners for an exhibition called *No Limits*.

Banners are a classic symbol of activism, protest, and a call for change. About 10 years ago, Dr Ruth Bartlett, a researcher, worked with Scottish activists including Nancy McAdam, James McKillop, and Agnes Houston. Most of the work was developed during a short residency in the Lake District. They created textile banners for an exhibition called '*No Limits. Reimaging life with dementia'*, this explored the individual and collective strength of people with dementia. The exhibition toured Bradford, Glasgow, and Liverpool, and the film, directed by Anne Milne, was screened at the International Documentary Film Festival.

Several years later a number of DEEP groups, mainly in the North of England, worked with photographer – Ian Beesley, poet – Ian McMillan, and cartoonist – Tony Husband, to create a whole series of banners as part of *The Unfurlings* project.

Three Yorkshire DEEP groups from Bradford, Scarborough, and York, came together to campaign for those living with dementia to receive better support and understanding from public transport companies. Here are the two sides of the huge banner that they created as part of the project '*The Right to a Grand Day Out'*. The banner has a negative side, showing everything that is wrong with the transport systems, and a positive side, showing how it should be. The colour red symbolises positivity and revolution. The banner was displayed at York Railway Station.

Here are more banners produced by other DEEP groups: Preston Focus on Dementia. Budding Friends, Exeter. Cottingley Crew. The Raggartmuffins. Hamari Yaadin, from Bradford. Kirklees DEEP. And the six DEEP groups in Kent, all standing together.

[music and film clip ends: 04:44]//

Tracey: So now, can I invite each of you on the panel to introduce yourself and tell us briefly what sort of activisms you have been involved in?

Chris: Yo, morning everybody. Great to see people... well, not see you, 'cause I can't see you, but I can hear you, or hear your messages... oh, I've gone to a blank screen here... ah, that's better... no, it's not.

Philly: Don't worry – keep going. [chuckles]

Chris: All right, OK. Yeah, so I live down in Kent, I live in Ashford in Kent, and I was diagnosed 10 years ago with frontotemporal dementia, and I've been involved in activism for about eight years of those 10 years. So, when you think of the word 'activism', that's a word that can kinda scare people really 'cause when you think of activism, you think of people rising up and in a revolution and kicking people's doors in and yelling and screaming at each other, and activism isn't really like that, it's about influencing and change in society, and just creating a better understanding in society and working towards a better life for people living with dementia, and it can be done in small and big ways.

I would... I facilitated a table at a dementia conference a few years ago and there were different views on how we could be activists, ranging from small ways of changing things, to people demanding that we went and chained ourselves to the Houses of Parliament and we would stay there until there was change, and it... huh, it was a novel idea, but I kinda think if you're starving yourself to death, that's not gonna really help into the future, is it really? So... but we... all ideas were on table, but I feel that gently, gently catchee monkey.

Now, I'm part of two groups down in Kent: I'm part of the Phoenix group which is in Ashford, and part of the East Kent Forget-Me-Nots, and sometimes when you're involved in activism, or change, sometimes you win and sometimes you lose. And a good example of that was in Canterbury, and we've got the Marlowe Theatre, and we were invited in to have a look at... after they'd changed everything, and reshaped it all, they invited us in, and Philly came along, and she helped us, and so we went in there and we get... put forward our suggestions on how it would be much more dementia friendly – the things that they did. The trouble

was that they'd already done it, and so therefore there was very little change that they could, and in fact, have done to the... to the building. I mean particularly the toilets: it was like going into a dark cave, you know, and then... and there was no signs on the door to be able to get out, and it was... it was horrendous. Conversely, the Phoenix group were invited to go into the borough council offices to do... the public reception area, and put forward some ideas, which we did, and quite a lot of things that we suggested – they did change, like the surface outside was very uneven. And there were some things they couldn't change – like the lift: when the doors opened you had a black rubber floor and you had mirrored walls and it was really quite horrendous, and we suggested they might change that, but they weren't able to because that... you know, that was already part of the building and it was gonna cost them too much apparently to change that. So, sometimes you can get change and sometimes you can't.

But... and a good example of that is one of the chaps that's actually on the screen today, Martyn Gardener, who's a member of the Phoenix group alongside me, he felt that we should be able to record the meetings that we have on Zoom so that we could then go back and look at them again, and it's all right to have minutes of a meeting, but they don't actually cover everything that you've discussed, and he felt that we should be able to do that, particularly as it's challenging to try and remember things after the event, and so we were straightaway up against: 'can't do that, data protection,' but that didn't deter us, and it didn't deter Martyn as well, and so we pushed on and pushed on. And at the beginning of every one of the meetings we always say, "Well, this is gonna be recorded," like this one was recorded, and so everybody knows, and through the actions that Phoenix took, they... KMPT, which is the local health authority, changed their approach, and they agreed – yes, we could record the meetings, and now not only do we have the minutes from our Phoenix meeting, but we also have the recording of the session as well. So, it is possible to get change.

But you can get change... and another way we got change was the dementia envoys, in Kent.

Wayne: Hi, I'm Wayne, like Chris, in Kent, but I'm in the Medway part of Kent. I'll try and be a bit briefer than... huh, briefer than Chris, and just say that I think my activism probably started about the same time as my dementia, back in 2004, where I was laid up with a major heart attack, was in hospital, and that sort of thing for about six months, and I was so disgusted by what was going on in the hospitals around heart attacks and the wards and that sort of thing, that started my activism 'cause I think I'd kind of been given a second lease of life having survived this major heart attack, and I thought, 'well, I really don't care.' What I didn't realise at the time is that dementia had taken away my 'caring about consequences' and now I just say what needs to be said whenever I feel like it needs to be said. And I think that's a major part... for me the definition of activism is doing whatever is necessary to change the details of a day to make it doable, and I hope that having a voice, and through DEEP, that makes a lot of change for a lot of people. Thank you.

Danielle: Yeah, I'm [Dannie? 11:00], I support the SUNshiners down in Kent. So, we've got involved in many different projects, supporting activist work, so... but yeah, I mainly support them – they direct me. [chuckles]

Tricia: Oh, hi everyone. My name's Tricia, and I'm an assistant psychologist. I work with the Forget-Me-Nots and I also have been with the SUNshiners for the last couple of months, and like Dannie – I support as and how I'm needed, and I guess the most recent thing I've done with the SUNshiners is they created some really amazing leaflets for children of different ages to explain dementia, and we've managed to get those onto national teaching websites, and international websites, so educators around Britain and the world can access these wonderful information leaflets that also have some puzzles and things for the children, so, well done.

Jacqui: Hi, I'm Jacqui. I live in Stockport, which is a couple of miles from Manchester. When I was diagnosed with young-onset [Alzheimer's?

12:19] in 2017, I was given the contact for Dementia Diaries, and that was a lifeline for me to be able to say exactly how I felt, and as Chris Norris says, “You get the nitty-gritty and the raw feelings from us,” so I can recommend Dementia Diaries.

Philly: **That’s great, thank you, Jacqui, and we can put that link in the chat as well. And in fact Wayne, and Chris, and Jacqui, and Tracey are all Dementia Diarists, it’s a fantastic resource and really recommend it.**

So, I do apologise about a few of the technical problems we’re having, guys, but stick with us.

I think now, what I’d like to do is ask each of you what you think others can do to support people with dementia in their activism, and I’m gonna go back to you, Chris, ’cause I’m feeling really guilty for interrupting you in mid-flow, so this is my penance. [chuckles]

Chris: No you shouldn’t... you shouldn’t feel guilty, you’ll have to shut me up ’cause I... that’s what I’m like; I saw the shepherd’s crook come on and drag me off.

Philly: **[chuckles]**

Chris: So, yeah, you can... you can help support people in their activism through small steps: so an idea is put forward, or a ch... a person’s having a challenge, and then you can all sit down and work out a way forward. And it’s my belief that you can... change comes in small amounts, and it’s a drip-drip on the rock that splits it: it's not going in... certainly not going in kicking down doors, ’cause all you do is you put people’s backs up, so you have to... it’s gently, gently catchee monkey, and you have to... and so you can support other people to put their voice forward – it’s much more powerful if you’re doing it as a group, rather than individually on your own, because then, you know, there’s a... there’s a weight behind it. But encourage people to be... get their voice out, because so many you us, it’s very easy to just think, ‘oh no, I really... I haven’t got

the courage to say that,' but in numbers – you have got the courage to say it, and you're not specifically identified as being... as being this revolutionist that's gonna... you know... And in truth, if you... if you speak to people in the right way, you have to get them on the right lines to be with you in the first place, and so it really is like Winston Churchill said, "George, you're not [war, war? 15:03]," I think that creates... that creates the change that we're looking for.

Philly: **Thanks, Chris. And I think that's a really important point to pull out, the importance of just encouraging people to feel that their views and the things they're not happy with, perhaps, are worth talking about and worth making a fuss about that; thank you for that.**

Who else would like to come in with thoughts on what support can help activists? Jacqui, and then Wayne I think.

Jacqui: As I go to quite a few events up in Bradford, and hopefully soon – other places, people assume that every day – I'm OK, even if I'm in my powered wheelchair, and I can go fast on a mobility scooter, they think that I'm OK. What would help is if people would say, 'do you need any help today when you're going to your event?' or to say, 'Jacqui, do you know how to get back to the station?' If we don't look after people every day, people are gonna feel vulnerable and not volunteer again to do things.

Philly: **And do you find that these... those sort of practicalities are still often overlooked, Jacqui?**

Jacqui: Yes, definitely, [except? 16:32] when you're with people from Innovations in Dementia: they never assume you're OK, they always ask you, "Is there anything you can do... I can do for you, you know, is there anything you need?" but other people just always assume you're OK because I can go fast on a wheelchair.

Philly: **Mm, OK, but that's a great point. Wayne, did you want to come in?**

Wayne: Yeah, before answering your question and just to be a bit of a... [chuckles] a pain rather than a activist, on most of the sessions so far, there's always been a mention about the Dementia Diaries, which is wonderful 'cause as a Dementia Diarist obviously I'm bias, but one of the greatest and unsung resources from DEEP is the hints and tips site with thousands of ideas from people with dementia, for people with dementia, of how to get through their day better, and seen as that's what's kind of come out of all the activism over the 10 years, I think that should get the highlight mentioned. So, there you go, I'll shut up on that one now.

Philly: **[unclear 17:52], we'll put the link up – dementia TipShare, yeah.**

Wayne: [chuckles]

Philly: **OK.**

Wayne: Second point: before talking about what... I've got six points that I wanna make on how DEEP support us, or what is needed to support for activism, which I'll deal with quickly, but before that, can I just sort of say some of the things that MemoryBilia have done as activism that'll support why I think those six things are important? We've had our local council change the process for re... for people with dementia to reapply for their Blue Badges and bus passes, cutting out the paperwork and that sort of thing. Local GPs are now starting to do home dementia reviews instead of you having to get to the surgery, which leaves you in a bad mental state and therefore clouds the issue of the dementia. We do lots of mystery shops in... yeah, mystery shops in the local shops, companies, museums, around the hospitals and all those sorts of things to change things on a daily basis. We got the local cinema to change their lighting systems before the film starts so that people could get to their seats without falling over going up and down the... going down the... up and down the steps. McDonald's now are changing their black mats and putting a big red 'M' on them so that people can see it's not a hole in front of the door. And doing lots of dementia training for the bus and the

railway staff, which... all of which I think make a difference to people's daily lives, so that they're the sorts of things—

Philly: **Amazing, that's amazing, and really practical achievements, yeah.**

Wayne: Well, that is over eight years, so it's not like we've been beavering away for the last month, but, you know, all those things, I think have made a difference for hundreds if not thousands of people throughout Kent, so we're rather chuffed with that. And the answer to your question, Philly, about what DEEP can do, I think [unclear 19:55]—

Philly: **Not what DEEP can do, but what can anybody do to support you.**

Wayne: [unclear 19:58], right, well first of all, as... once they've found out that we are activists, and a group, which as Chris says – gives the power, I think giving us access to the people that have the issues, 'cause we don't necessarily have the issues that we can make changes to. And then help us to understand the priorities, because if they're not our issues we might not realise how big a priority something is. A lot of help, 'cause we do have dementia after all, in understanding the technical and legal elements of what it is we're about to undertake. Helping in acquiring... and I suppose this is where Danielle and Tricia come into the groups that they work with, in accessing the resources needed to carry out the activism, and then support in dealing with the consequences of the actions that we've taken, which quite often is a biggy. [chuckles] I do... I do have a reputation for, as I said, if it needs to be said I'm gonna say it, and quite often it's without filters, so there can be consequences to that, that others have to deal with for me.

But then a specific DEEP bit, which I feel is important, is the DEEP information sheets that come out of all of this, where people can be pointed and examples of the information sheets about how to talk to people with dementia, how to include people with dementia. And specifically one that I'm not sure whether [Rachel ? 21:38] actually did it, or just directed us to it, but how to put people onto this sheet that tells them how to arrange the travel and transport for people to go to an event.

All these things are vital and have come out presumably of all the activism, so thank you very much to DEEP and everybody for doing those things.

Philly: **Brilliant, loads of stuff to ponder on there, and we'll get the links up to some of those resources that you mentioned as well; thanks, Wayne.**

I'll come to Dannie and Tricia in a moment 'cause it'd be really nice to hear about the ways that you have learnt to support people in their activism.

But, Tracey, I know that you can't see us perhaps, or... but hopefully you can hear us, you're nodding: I wondered if you'd like to talk a little bit about what sort of support you feel people can give people like you to be activists?

Tracey: Yeah, I think... I think people just forget that even though we act independent, and we are independent to the point... to our best... our best, sometimes it'd be nice if people just say, 'oh, do you... what help do you need, what help do you need?' I mean I've done loads of... like I'll help businesses in our local towns looking at how to collate things more better for... not just people for dementia, but everybody really. If you can do it right for one person... for a person with dementia, you should be... get it right for everybody with all sorts of conditions, because why should... why should people be: 'oh, you've got dementia so we have to be nice to you'? you should be nice to everybody. And I've had that told... said to me before, and it's just... and it's how... and it's not... sometimes in the past I've wanted help to get to London, or if there's lots of complicated changes, and people just don't... or meet you from the station, meet me from the station so we can get take... get to the venue without me having to figure out what taxis to get, or how to get to... 'cause people don't... sometimes... even around Kent, people don't think about that, we just have to get... if you're supposed to be doing a talk and you have to make your own way, and they... they just forget, and I don't

think... it's just 'cause they just don't think about it; does that make sense?

Philly: **It does indeed; people are nodding.**

Tracey: Yeah, yeah, [unclear 24:05].

Philly: **I think often people just don't realise what a huge effort it is for all of you guys just to get to where you're going, whilst you're also thinking about the reason you're going and what you're gonna say, and all these things as well, so yeah, thanks for raising those point.**

Tracey: As my dementia's got worse, or has... is worsening, I find I probably need more help; whereas, and like seven years ago, I ha... I didn't hardly do anything, I use to make my own way, just sort myself out, because I was able to, but now I find it very complicated, very hard, and I... and it... for me, I have... I have a problem in asking for help 'cause I think people should... huh, and it... the expectation is that I think people should understand and they should offer, but now I... now I've learnt that actually people just don't think about offering, so if say... if they don't know, how are they supposed to understand that we are—?

Philly: **Yes, we're all guilty of that, yeah, absolutely. OK, so who'd like to go now, Dannie or Tricia? Stick your hand up one of you. [chuckles]**

Tricia: I was just gonna say actually picking up on the transport issue that Tracey... that's something I learnt very quickly that personally I hadn't thought about when I started working with dementia service user groups. 'cause I started, I think it was like a week before the Forget-Me-Not's 10th anniversary and they were celebrating in Grove Ferry, and I'm not from that part of Kent, so I had no idea where it was, and I was ringing people to remind them, and one of the service users said to me, "Well, yes I am coming with my friend, but I don't have transport, I don't know how I'm going to get there," and I thought, 'ouu.' So, I actually ended up going to pick, huh, this lov... lovely lady and her friend up, but I... it hadn't

even occurred to me that, you know, people with dementia would struggle, and it... you know, it was quite a steep learning curve 'cause I realised how naïve and ignorant I was. But that really helped because when it came to the DEEP event in Folkestone, in September, I knew that beforehand I would have to sort out transport if it meant that our service user members could get there, so I was able to kind of think ahead and try and book taxis so that they could attend the event, and I was lucky that I did find some good firms that were... that were flexible. But I think you're right, and to be honest with you, I think it's something that the rest of us take for granted and we don't appreciate how difficult it is just getting somewhere, because not everyone... I know Chris drives himself normally, but not everyone is able to do that.

Philly: **Great, thanks, Tricia. And, Dannie, how have you learnt to support people in their activism?**

Danielle: I think echoing sort of the transport issue, I think one thing that I have noticed is that it's a fine line. It's a fine line between sort of supporting and taking over, by giving the lift, but also empowering the person to stay independent. So, quite often I'll find that, you know, people with dementia will struggle to get to our group or will struggle to get wherever we've planned to go, 'cause we're not always in the same location, and so we try to sometimes reach a compromise: "Where can you get to; where does feel easier?" and then I'll pick them up from that point. So, it might be that they need to travel into the centre of Folkestone, and then I'll take you the rest of the way to Hythe, just to try and keep that independence so that they're aware that they are still able to do it as well, rather than taking over. Because I know that something that's been echoed in our group quite a lot, is, "Please don't take over because, you know, we will lose our independence quicker." So, to be honest with you, I guess my learning of support has been to listen, hah, more than anything else, you know, 'what do these people need from me, what do they want?' and then finding out what their experiences are and how it might be frustrating at home when 'my husband always makes the cup

of tea, but I'm more than capable', so then taking that and transferring it into another environment I guess.

Philly: **That's a really great point, Dannie, thank you. Got a comment from [Cathy? 28:49], who says, "I love this, a literal version of meet us where we are," and a comment from Chris as well, who's nodding away, and so's Jacqui there.**

We've got a question from Martyn, but I just wonder, Rachel, whether we could have a little look at the other film that we've made, it's only just over a minute long, give us all a little break and then we'll come to Martyn's question.

//[music and film clip starts: 29:14]

Melvyn?: We all stand together. Here we are, all standing together.

Alan?: We all stand together. Here we are all standing together in the teeth of this rough world's gale, working as one to fight against whatever threatens to make us fail. Here we are, we're all standing as one, as history's slow pit wheel turns, and we'll stand together till the work is done and everyone lives and learns. Here we are, all shapes and sizes. The sunshine shines and the paths are found, and the seaside's new and the phoenix rises from this ancient Kentish ground. Here we are, please forget us not. We're a memorabilia of the powerful kind, we stand together where the struggles hot in the endless battle of the mind.

Melvyn & Alan: We all stand together; here we are all standing together.

[music and film clip ends: 30:44]//

Philly: **Lovely. I think that poem was written by all the Kent groups together, is that right? And spoken by Melvyn and Alan from the SUNshiners. Lovely; sums it all up. And of course our very own [unclear 30:59] on the trumpet.**

So, and we were gonna go to Melvyn... to Martyn's question, weren't we? Martyn Gardener asks, "If you're not a member of a group and feel something needs change, who do you turn to?" Good question. Anybody got any thoughts? Wayne.

Wayne: That's really why the groups all started in the first place because so many people individually were having issues and there is nobody to turn to that listens, so people started coming together, and that's what the groups are for, so, you know, if you... if you have an issue but don't wanna become part of the group, there's still ways through all the Dementia Cafés, etc, etc, that word can get back to your local group, and then your local group can take it on and hopefully you'll benefit from it.

Philly: Mm. Any other thoughts?

Chris: I would agree, it is very difficult if you... if you put yourself out there in isolation and stay in the wilderness and wander for 40 days, you're not gonna... you're not gonna be able to get the support, so it's really just encouraging people, or making them aware that these various groups exist. And certainly down here in Kent, we've now started having dementia coordinators who are there to guide people in the various directions that they can go, whether it's to a café, whether it's to come along to an activist group like Phoenix, and having somebody there to guide you. I mean at the end of the day you can lead a horse to water, but you can't make it drink, and Martyn and I were talking about this yesterday that, you know, we do an awful lot to try and encourage people, but if they feel it isn't for them, then I think they're just... they're gonna carry on with their frustration. Well... but we all... we... there are groups out there that can help, and DEEP is evidence of that, the bringing together of all the... all of those various groups so that we're stronger and more powerful and we have a solidarity if we're putting a message across. So, that's the only thing I can do, you can just talk to people, but if they feel it's not for them – well, then it's for them. But it can be frustrating 'cause you think, 'it's there, all you need to do is just grab it, we're offering you... come on in, you know, welcome all, you

know, it's a wonderful place to be, come in and join us,' that's really all I can say really.

Philly: **Wayne?**

Wayne: Yeah, on that, people that are feeling alone, I... and fighting something, I think that's where the diaries really come into their own because once you're given access to the diaries, I'm not... I'm not trying to minimise anybody's individual issue, but once you get access to the diaries you'll find that you're not alone. It's probable that whatever it is you're going through on an individual basis – others have been there before over the... over the time, and have found local or national solutions, so the diaries really offer a step in the right direction of not being alone. [chuckles]

Philly: **Mm, that's a good point. And also I guess even if there isn't a physical DEEP group in your area at the moment, there have been... you know, there has been a development of quite a few online groups, hasn't there? I mean the Dementia Diarists meet every week online, so that's a good way for individuals I guess to get that feeling of solidarity and group support.**

Wayne: And activism isn't... you know, you don't have to be afraid of it, it doesn't have to be about big things, it might just be a simple thing like, 'well, how do I do this?' and it might be something very, very... 'how do I... how do I phone a Sky engineer and get them to understand my language rather than their language?' you know, and it... so it can be little things, but those little things bubble away when you're on your own and become overwhelming. [chuckles]

Philly: **I'm gonna ask Rachel if you want to come in, if you want to put your camera on, Rachel, and help us with this?**

Rachel: So, there I am, rocking in a corner, stressing over technology and you'll suddenly be on the spot. [chuckles]

Philly: **You're doing great; I knew you could cope.**

[chuckles]

Rachel: Sorry, what was the question?

[chuckles]

Philly: We're still on Martyn's question really: if there isn't... if you haven't got a local group, where can you get support as an activist?

Rachel: Yeah, you know, I have increasingly... I guess since Covid and lockdown, have increasingly received emails from individual people who are saying "I've been diagnosed" or my... you know, "a friend of mine" or "my parents have been diagnosed and where can I go and what can I do?" and of course, you know, it's a postcode lottery of where there is good and bad support really, and... but increasingly there are more and more people who are coming up and saying, "Well, can I set up my own group?" it doesn't need to be very complicated in terms of having a bank account and everything like that, it can be that, you know, there are some people, like Wayne for example, has got... they've gone out independently, and I know that there have been lots of issues around setting up a bank account and things like that, but if you're looking to just get peer support and not necessarily have to generate an income, or receive money, then actually you can do that. And there's a really good recording from the Leamington Spa, the Buddies event, where Ken Howard talks about his motivation for wanting to get a group started, and he talks about how he just wanted to get people together in a kind of a non-clinical environment. So, they found a pub, which was quite quiet on a certain in the week and a certain afternoon, and they just started meeting as a group, and this group has grown, and grown, and grown, and... but it's a really... it's a really powerful audio to listen to with Ken talking about it, and then Roy talks as well about the importance of the group. But a lot of people sort of say, "Well, where do you find other people with dementia?" and funnily enough it's often professionals who ask that question as well, but I mean social media is always a really good starting point, and I know not everybody's on social media, but it's just about making those first

connections. And I think that very often, you know, signposting people towards the diaries have been important. And... you know, and we've got Lorraine Dunn up in the North East who is setting groups up in the North East now; she's a lady living with dementia. We've got a lady in Leicestershire who's only been diagnosed a few weeks who's talking about setting up her own group, and kind of really working with kind of local community resources like library [setting? 38:48] to say, you know, 'can I have a group meet here?' or, you know, there are some groups that use... and some supermarkets have community rooms where they'll give you free tea and coffee to go and be in that space as well. So, I'd say, you know, speak to other people with dementia, and through the DEEP resource. If there isn't a group in your area, you can connect someway with other people living with dementia around the UK through Zoom, and yeah, just don't be alone with it and come up with inspiration and ideas by talking to other people.

Philly: **Brilliant, thanks, Rachel. Jacqui?**

Jacqui: I think that we all need that comfort and that feeling that what we are going through, other people are listening to us, and that's what happens on the diaries – we know that the coordinator is listening to us. And sometimes we are able to be connected to other people who have been through the same thing, or are going through the same thing. In addition to that, it's nice to know that in Dementia Diaries, people become friends, and if you are not having a good day – they notice that, and if they are concerned about you, they are able to just make a gentle contact and say, you know, 'we're here for you,' because sometimes it can be very lonely and you go on all these Zoom meetings and you're putting on a nice face, but it's nice to be with people that know you well, that you are putting on that face, and they can offer support.

Rachel: I agree, Jacqui, and I think that... this is something I mentioned yesterday in one of the Zooms as well, that we can't underestimate how much effort it takes to reach out. You know, if you've been... when you... when you reach the point of receiving a diagnosis, you may have been struggling

for a few years and your confidence will be lower, and lower, and lower, and so your sense of being a worthwhile individual to do anything, or to reach out to anybody, that [unclear 41:25] and might be interesting, which is why I think we... you know, all of us need to invest so much energy in supporting people and being that friend before anybody is in a position to... you know, to stand up on a bigger stage and do bigger things.

Philly: **Thank you. And, Tracey?**

Tracey: Yeah, I was just thinking back to when I first got diagnosed, and I was quite young when I got diagnosed: I was 45, and I got... and I had trouble when I was 44, so it was like a year before I got diagnosed, and it... I felt like I... I remember feeling like I [unclear 42:06], because one) there was nobody in my age in my area with dementia, and I didn't know... quite know where... what to do because nobody... talking to my friends, they didn't really understand because they didn't have any problems, and I remember being signposted to a memory café, which is all very well, and to... hands on heart, you know, there are... but they were... [sighs] they were full of 80- and 90-year-olds unfortunately, and I just felt like... although they were very kind, I just felt like I didn't really belong because the age group was so wide – [it was vast? 42:51]. And I remember somebody saying about the SUNshiners, who I belong to, and... who I belong to now, but then it's still very scary when you first get a diagnosis, you're overwhelmed from the diagnosis, and then you go into a group that you're not sure about, when you've only been to memory cafés for the older generation.

So, I met somebody called [Diane? 43:23] who... and who belonged to the group, and we met on one-to-one basis, we went for coffee, and it was just like coming home. Coming home, just because one person out there in the whole vast of what... of anything, and it can... even though we had different dementias, it was... and that helped, and I always say to people, "You can find a group..." it might not be a... I'm not... I'm not... I wouldn't say I was a groupie person, but I love my group that I belong

to because we do so much good, we do a lot of activist work within the group. We do a... and we get involved in projects, we help people understand, you know, it's about... you know... I prefer to be a doer, so the group we... like SUNshiners is a doer group, so we go out and try and change the world, [chuckles] but they are... if those... but it's nice to have a group for even if you wanna support... a group for support, it's trying to find the right group that suits you in that way, rather... you know, in a... and unfortunately we've had people in our group that haven't... it hasn't... they didn't like it because it wasn't either supportive for them, but I just think if people... if people can find the right group for them that would [nitch? 44:47], that helps them, and then that should help them with their dementia because actually – it really helped me.

Philly: **Thank you, Tracey, that was really powerful, I think your phrase '"coming home" sums up what many people find and feel about just meeting someone else who's in the same boat, or a small group, and then starting from there. And I know peer support and activism are kind of two different things, they seem so closely intertwined that you can't really have one without the other.**

So, we're coming up to finishing point, and we've just got a couple of minutes. Could you just hold up your hand if you've got a final point that you'd like to make and then we'll see... or if there's anybody who's got a final point that they'd like to make? Have we got any more questions? I'll just... right, OK, right, we've only got one person who wants to make a final point and that is Wayne, so take it away, Wayne.

Wayne: This would be my final point: I think this is the greatest thing for dementia meetings ever. [chuckles]

Philly: **Thank you so much, Wayne, and I think you can actually print those off, can't you, from the DEEP website, Rachel? Or if somebody wanted a whole batch of them we can sometimes send them out.**

Rachel: Yeah, and actually what very few people know is that you can actually download a Word version of it and bespoke it, so you could download a card version saying, 'Wayne wants to shout', or something like that, you know, [unclear 46:30]—

Philly: And we've got them in different languages?

Rachel: And they're available... they're available in Scots, and Gaelic, and Welsh, but they are... the reason it's got an [unclear 46:42] version is so that anybody in any language can create their own language on the card.

Philly: Well, on that note, I'd like to thank all of our panel, you've been brilliant, you've given us loads of food for thought, and I'd encourage all of the other participants to register for any more sessions you'd like to come to this week, the more the merrier, and have a lovely rest of the day. Bye everybody.

[music plays]

[End of Film]