The Story of DEEP

[music plays]

Rachael: **So, welcome to the DEEP 10th Anniversary Festival. This is one of 21 events we're running this week to celebrate 10 years of working together to amplify the voices of people with dementia. And when we were thinking about how best to mark this year, we were mindful we couldn't just run one big event, so what we've done is we've celebrated in person across the UK, for the whole year, at 17 events where lots and lots of people with dementia have got together, and you'll get a taste of that, we hope, as the week goes by; there's lots of lovely films and other resources that have emerged. So, we really hope that you can share some of this, some of the resources and the experiences that you have this week; we'd love you to share those as widely as you can and with other people with dementia. We're recording all the events this week, and after a little while we'll tidy them up and they'll go onto the DEEP Anniversary website so we can see everything as a kind of wonderful tapestry that we've had of the year.**

So, as I said, this is our 10-year anniversary event. We're gonna do a little bit of looking backwards, and a little bit of thinking forward, reflecting together. Anybody who's around now may not know that DEEP actually stands for something, and you may hear the origins of the story as we talk about it, but it stands for the Dementia Engagement and Empowerment Project, and it represents a UK-wide network of people with dementia. There's a sense that actually working together, people with dementia feel trust, more trust, in a safe space, their voices can be amplified, they grow in confidence, and together they have the power to influence and change what happens in their world. And whether that be their own home, or street, or town, or country, people with dementia in the DEEP network have been operating at all kinds of different levels. So,

we're going to tell you a little bit about the backstory to that, you know, what happened in 2012, what happened in 2015, what happened in 2019, and what's maybe happening now as we go to the future. And these are all critical funding moments in our DEEP history where we successfully kind of grew and developed and added to the network, reinforced the network, and stand now I guess for a very kind of... an idea that people with dementia are in the driving seat: this network belongs to people with dementia, it's their network. At Innovations in Dementia we say that we host the network, we hope that we provide the scaffolding behind the scenes to keep the network functioning and alive, and you can hear a bit more during the week about what the network is and what groups get up to; loads of things this week.

But our role at the moment is to support more people with dementia to have their voices heard, to have maximum impact for those people by connecting these 80 groups, or so, together, and for people with dementia to be in driving seat of that, to be in control of their groups, to be in control of their interactions with each other to kind of... to drive the direction of the DEEP project.

And before we move into discussion, I must really thank our funders for the last 10 years; they've been tremendous. And at the moment we're supported by The National Lottery Community Fund, until the end of 2023, but we must thank the Joseph Rowntree Foundation, and Emma's here today to talk about the start story. Were joined very quickly by *Comic Relief* in those early days, and then about 2015 we were beneficiaries of funding from Life Changes Trust in Scotland who helped us to develop the DEEP network in Scotland. Innovations in Dementia has hosted the network, building on the shoulders of a piece of work by the Mental Health Foundation, and you'll hear from Toby and David a little bit about some of those stories.

So, much as the network of this tapestry of voices, and people, and experiences, and groups, and differences, I hope that actually the... you know, the behind the scenes work of the DEEP network represents that as well.

[music and film clip starts]

Dory: DEEP stands for Dementia Engagement and Empowerment Project. We, DEEP, are celebrating 10 years of DEEP this year, and there has been 17 face-to-face celebrations throughout the UK.

My name is Dory and I've been involved with DEEP for seven years. For me, DEEP represents unity, kindness, respect, and friendship. And what I hear from my peers all the time is that we meet people from all walks of life who otherwise we never would have met. Because we have dementia, we feel we're in the same boat, and we can share with each other, learn from each other, and support each other – we find somewhere where we belong.

There are many tears along the way, but we must admit they mainly come through laughter. It's extraordinary that people you've never met are like family after a very short time of being together. We breathe confidence in each other. We become more confident to talk about things that matter to us. We know we have a right to have our say. Together we can challenge things that are not right. We value each other and we look after each other, and we've got each other. I am DEEP and we are DEEP.

We have achieved something extraordinary. We went into lockdown in March 2020 and we connected even more widely through different corners of the country, and the world of Zoom. People even learnt from using the Zoomettes guide we had created the year before. DEEPers were creative, kind, and shared so much support through a very dark time. We also lost many friends along the way, and groups, and recovery continues to be a challenge, and there is no one single answer. Covid changed all our lives, but together as a network, there is passion. There

will be a range of expertise, different ideas and support to help us all. The most unlikely friendships are formed in the most unlikely situations – we are stronger together.

The Still Me group in South Wales celebrated 10 years of DEEP. They used trees as a way to represent the DEEP network based on the saying: 'Mighty oaks from small acorns grow'. Tree roots reflect how much goes on beneath the surface and behind the scenes, their roots knit and weave and reach further than we ever know, or see. If there's a tree struggling, the other trees around send out their roots far and wide, healing and supporting that tree. How far-reaching the seeds we scatter grow and are nurtured, nourished and shared. Today we celebrate that network of that magnificent tree, which is DEEP. We are all unique and wonderful, but together as a DEEP network, we are a masterpiece.

[music and film clip ends]

Rachael: **And I'd like to come to the beginning of the story and ask Emma, and Toby, and David, whether you might take your minds back, huh, 10, 11, 12 years as this was kind of in development, to look back on kind of where this came from, and why. And, Emma, we haven't... actually we haven't done introductions, have we? So, let's ask Emma, and Toby, and David, if they might introduce themselves?**

Emma: OK. Shall I kick-off?

Rachael: **Thanks, Emma.**

Emma: So, hi everybody, it's really, really brilliant to be here at this 10-year celebration. And my name's Emma Stone. I work now for an organisation called Good Things Foundation, and we support digital inclusion. But, you know, back when DEEP was starting, I worked at the Joseph Rowntree Foundation in the policy and research department.

Toby: So, hello everyone, and happy birthday to DEEP, I'm not gonna break into song, you'll be glad to hear, but congratulations on going for 10 years

and well done to everybody involved, all the groups, and Innovations in Dementia, and everything else for supporting it.

Yeah, I'm in independent consultant, I work for myself, but I was working at the Mental Health Foundation, a UK research and development charity, back in 2010, 2012, and I was involved in helping to... in partnership to set up the DEEP network.

Rachael: **And I think we can give credit to the name, to you, Toby.**

Toby: I will claim that credit. I think I came up with the acronym, whether people like it or not, but I'm glad it's stuck. Yeah, thank you.—

Rachael: **And I think that, you know, the word 'DEEP' has really stuck, and we can play with the word 'DEEP' so much because it's a great word.**

And, David, we should acknowledge that David is currently at London City Airport, which shows massive commitment to the job. [chuckles]

David: And probably not the best choice of a quiet environment to do a video conference in.

[chuckles]

Rachael: **Would you like to introduce yourself, David?**

David: Yeah, of course. I... it's lovely to be here, and thank you for inviting me. I'm currently Head of Applied Learning at the Mental Health Foundation. I've been at the Mental Health Foundation for a fair old while and certainly for the duration of the time that we've been involved with DEEP. And I guess my... why I was involved and my interest is that I have a... quite a long history of service user involvement from the mental health service user movement side, so I've been involved in a number of independent groups, and as we would describe it: 'for and by mad people,' and I was really, really interested in any kind of project that

encourages people with all sorts of [unclear 12:36] experiences that often makes them... puts them in marginalised positions, to have stronger and more powerful voices and a better chance of those voices being heard.

Rachael: **Thank you, David. And I guess Toby and David particularly: what do you remember in those early days of DEEP? Because what... I should probably say who I am: so, I'm Rachael Litherland. I have been at Innovations in Dementia since its foundation in 2007, and was involved in those very early days of DEEP with Toby and David in the partnership that we had at the time. So, kind of, you know, have seen... have witnessed the growth of the DEEP movement, have witnessed its impact over the last 10 years. I'm really proud that we can still host this amazing kind of thing that has developed. But I just wondered, Toby and David, what you remember of those early years, and particularly that... well, not particularly, but as you've just acknowledged, David, that you were brining your own experiences from the mental health world, you know mental health service user movements had been in progression and development, so we had some opportunities to draw on work that you'd done previously, and I just wondered if you could reflect a bit on your early memories?**

Toby: So, I... prior to working at the Mental Health Foundation, I'd worked in mental health services, and although I hadn't been a mental health service user, I'd always been interested and really supportive of the kind of activism shown and demonstrated by people who had lived experience of mental health problems, typically a diagnosis of schizophrenia, or bipolar disorder, in trying to influence collectively services or research through all manner of different ways, so stemming really from the 1960s of disability activism and other civil rights movements. And when I came to the Mental Health Foundation and became responsible for the programme of work there around mental health in later life and dementia, it was at a time when the national... big

national dementia organisations weren't particularly focused around really supporting the voice of people with lived experience of dementia to be heard, for whatever reason, and really seeing the work that David had done in helping to establish a national service user movement for people with mental health problems, it struck me that well, why... is there someway in which the Mental Health Foundation could support, in collaboration with other organisations, something similar to support people with dementia to have their voice heard, amplified, as you put it, Rachael, to influence both nationally, but also locally. And importantly, for that not to be asking people to speak on behalf of the Mental Health Foundation, but for the Mental Health Foundation to sit underneath that network, which is now DEEP, to enable people to have their voice, to speak about the things that are important to them. And I remember having a very important meeting, over a cup of pints of beer, with Steve Milton from Innovations in Dementia at a Dementia Congress where we discussed this, and on the back of envelope literally thought, 'there's milage in this idea,' and then we met obviously with Rachael, with Philly, and Emma from the Joseph Rowntree Foundation, the Alzheimer's Society were involved at the beginning, and also the Department of Health, and came up with a plan to do what was initially a mapping survey of existing groups led by or actively involving people with dementia around the country, but also to use that as a way of celebrating and promoting a network, and those groups, and to grow it from there. And the report that we produced in 2012, it's still on the Joseph Rowntree Foundation website, and I'm reminded that at that time I identified I think about 20, 21 groups across the country, which has now increased tenfold, so, if that isn't a sign of success of a network, well done again to everyone involved in it – I don't know what is. So, that was my role really in supporting that from the Foundation's point of view, which initially hosted the network and then were very happy to pass their hosting role over to Innovations in Dementia.

But, I mean, David, you probably want to say a bit more about those sort of principles of a service user movement, or an activist movement.

David: Yeah, and I guess I think what attracted me... I mean there are a number of things that attracted me to the idea, Toby, I mean obviously the excuse to go and do planning meetings in pubs over pints, and as Steve said: it wasn't all over beer, we had gin and tonic as well, was very attractive, but it was really about trying to get those... we love a challenge, and we... in the [unclear 17:30] movement we'd experienced a lot of excuses and reasons why things can't be done, and a lot of kind of divisive and avoidance tactics by people who have and hold the power, but don't want to pass it onto others. And I guess part of what I wanted to do was help this new and emerging network learn from our mistakes and really started to think about what it was that was really important to people living with dementia, and do it. And I think, yeah, I have lots of memories that involve rickety flipcharts, brainstorms of strange ideas. I know Rachael and I, we still haven't actually worked out how to measure the [unclear 18:09], but we've graphed it several times, we just don't think there are enough dimensions in conventional maths to do it properly, but it's just that really exciting and really challenging stuff. And then as it started to evolve and started to... or the groups that we found that did exist, started to coalesce, it was just exciting, interesting, lovely people doing... you know, who [we? 18:35] really, really value forever. And I think it was that sense of being able to offer some support on... you know, and learning from what we'd done, to people who were really... and pioneers is the word that sticks with me, and I still think of all of you as pioneers, and you're doing phenomenal stuff.

Rachael: Thank you, David. Emma, with all our funders over the years, they've really been phenomenal actually in terms of their positive, kind of, really open outlook, but I think JRF, you know, at the very beginning they were our... they took a real interest and commitment to this idea of people with dementia having voices, having a network, having a space in which to influence the world around them: could you just say a little bit about the Joseph Rowntree Foundation's perspective at that time and how this fitted?

Emma: Yeah. And I am really, really honoured and so delighted to be on this call, but I just do want to give a shoutout because such a key person, Philly Hare, who I know is somewhere on this call, and actually was just really instrumental in terms of just all the work that Philly did in championing the issues, championing the evolution of DEEP, and just doing a lot of the heavy lifting, so I just wanted to really pay a tribute to Philly.

I think... so similarly to what Toby was saying, I think from the Joseph Rowntree Foundation's perspective what was new around this was it being in relation to the voices of people with dementia. Where it kind of built and fitted in, was actually part of a context for at least 10, if not 15 years, there had been different programmes around supporting, you know, whether it was a service user involvement, where it was the combination of, like, activism and academia in terms of thinking about the social model of disability, thinking about choice and control in a number of different areas, thinking about an aging society from a perspective that is challenging a concept of aging, and also concepts of social care and care. And also this kind of real key point about voice, but voice in a way that has power and influences, so it's not only let's share voices in quite a passive receiving way, it's kind of, how do you enable people to make their own voices heard, as opposed to sharing voices that are then kind of packaged and taken by others.

I think one of the other things that we've not talked about yet, but really struck me, was I remember feeling really inspired by what was happening in Scotland. So, this for me is an example of a UK network where actually the Scottish Dementia Working Group was already doing a lot of pioneering work within Scotland in terms of influencing government, in terms of gaining traction. And I mention that because I think that was also really important in terms of a funder being able to see the potential here for real power and influence coming from a grassroots-led organisation, then stepping up to influence at a national level. And that's always important in terms of paving the way with them getting... you

know, getting the board on board with making a decision. And so that was the bit also that the... and kind of the mapping work really helped... I suppose helped consolidate that view that actually groups are existing, you know, it... and so how can they be better supported to operate at different levels, locally to nationally, and also for that to be coordinated.

And I think just the last thing I'll say that also felt really positive, was being able then to develop that partnership with *Comic Relief*. So, I think when you can get funders working together and almost like... you know, it... that there was just... it was just one of those coming together where actually *Comic Relief*, they were having conversations about this as well. The same with Life Changes Trust, you know, and it doesn't always happen that funders really playball and work well together, but I think there was just such a sense of the fit with the different strategic priorities of those different funders, and the recognition of the... just the importance and power of what was happening through those different grassroots groups, and through already that sense of a nascent network, that meant it was like the stars were aligned, so... yeah. And it is absolutely phenomenal to see how DEEP has just continued to grow, and thrive, and strengthen, and just... yeah, it's just brilliant, so just huge congratulations to everyone on this call and everyone who's been involved in the DEEP story over the last 10 years – really amazing work.

Rachael: **Thank you so much, Emma. And I think it's really nice to look back on kind of the... yeah, where the roots of the DEEP network began. And just a very, very short potted history, if you want to kind of look in those kind of funding periods, I think for all of... you know, you're absolutely right to draw attention to the work of the Scottish Dementia Working Group, and I guess that's been the beauty of the DEEP network the whole way through as it's grown to 80 groups, is that all... the groups that come along are building on the learning and the activity and the feelings within all the other DEEP groups who have gone before, and taking away a lot of the hard work that was needed in those really, really early days to... that the Scottish**

Dementia Working Group for example went through to build their groups.

So, as Toby pointed out, there were about 20 examples at the end of the Mental Health Foundation's scoping project. With the first round of funding it grew to 50 groups, by having that energy, by having that commitment to wanting to connect groups together to become more powerful. We've heard a lot of those words so far about power and control, and I think they're really striking in the DEEP network. And then we employed Rachel Niblock and Paul Thomas for work up in Scotland and the North, and they grew it again, huh, and we're now at the point where we're sustaining and kind of honing and making... putting the values... and making sure the values are really explicit, so we will probably touch on some of that as we... as we go through.

But I'd really like now to bring in Irene, and Keith, and Paul, and Tommy: could I ask you each just to give a little introduction? Irene, just say who you are and where you are, maybe?

Irene: Hi ya, hello, yes, I'm Irene. I do apologise, I have to start with an apology for the state of my hair, but I literally had the dog out for a walk with a hat on, put the hat on and sat down at the table, so I do apologise, it's not the best look. Anyway, I'm Irene, and I'm very cold, but very beautiful, in Fife, in Scotland today.

Rachael: Hi, Irene, thank you. Keith?

Keith: Morning, everyone, or good afternoon as is it now. I'm Keith, and I live in Canterbury, and I'm a member of the East Kent Forget-Me-Nots, which is part of the DEEP network.

Rachael: Thank you, Keith. Tommy?

Tommy: Hi, I'm Tommy, and I live up in Liverpool, and I'm a member of the THRED, DEEP group.

Rachael: **Thanks, Tommy. And, Paul?**

Paul: Ditto, [chuckles] well I'll never... my name's... my name's Paul and I'm a member of the THRED group affiliated to DEEP, up in Liverpool, yeah.

Rachael: **Thanks, to everybody. Sarah and Rachel, and you haven't yet had your chance to introduce yourself, but I will come to you, 'cause I don't want you to feel like you're just not gonna have your chance; we've got a lot to say, we've got a lot of ground... 10 years to cover. So, Keith, Tommy, Paul, Irene: you have been involved with DEEP for different amounts of time. You're all involved in DEEP groups, and some of you I have known for a long time, and some are my new friends, so I just wondered if you wanted to say any memories, or any memories of DEEP, and what DEEP gives to you, or what your group gives to you especially. But, Keith...—**

Tommy: Shall I go?

Rachael: **—oh, so Keith and then Tommy.**

Keith: Yeah OK, thanks, Rachael. So, I've prepared a few reflections this morning in advance of being able to speak with you all, and three key words come to my mind: the first one is 'collaboration', the second one is 'opportunities', and the third one is 'impact'. So, what I'm gonna say in the next couple of minutes I hope you'll be able to cling onto those three words, because that's where I'm gonna cover.

And also, I mentioned being a part of the East Kent Forget-Me-Nots: we are an unidentical twin of DEEP because we were born in the same year, so we also were started in 2012 and have a very close, long association with DEEP. And I guess 10 years brings 10 top memories for me. The first one is around those people who I got to know as friends when DEEP was set up, some of them are still around and some of them sadly are not. So, three names just to drop into the mix: first of all Peter Ashley, who was one of the very first people with dementia who was part of the DEEP network, and was a driving force to be reckoned with. Secondly

was Nada, who is still a really good friend of mine and was a really fabulous part of the DEEP set up. And thirdly Gaynor Smith, who often is forgotten but trod a very lonely path for the Alzheimer's Society when DEEP was established and really brought the Alzheimer's Society into the mix in a very brave way.

Next, moving onto that, I saw a DEEP launch film soon after we established the Forget-Me-Nots, and that inspired us. It was an event I think up in Stockport, or Manchester, that was on video, or DVD, at the time, and that really inspired our group to think, 'well, we can... we can do what these people up north are doing,' so that was an opportunity and it had an impact upon us all.

The next thing was around the Mental Capacity Act where we were invited as a group to speak about a review of the Mental Capacity Act, which desperately needed reviewing, and they hadn't thought to speak to anyone with dementia, so DEEP knocked on the Forget-Me-Not door, and we answered.

Next we... I was invited with Nada to speak at Westminster Hall at a National DAA annual conference where we launched the DEEP guides, and they were really, really ground-breaking pieces of work, which at the time, back in 2013, really set the scene for what DEEP was setting out to do, and I was proud to be alongside Nada, and others, vocalising what DEEP was about at that stage.

The DEEP diaries, many of us are part of, and they... wow, what a project that is; what a project that is. It's the go-to source of inspired information which everyone should access and get as many people involved in as possible.

Going to impact as well: Rachel Niblock and I... well, really Rachel to start with, were... we sort of got wind of the Royal Horticultural Society having a conference on people with disabilities accessing gardening, so they didn't think to include dementia to start with until Rachel got on the case, and then Rachel, Rosemary and myself attended Hampton Court

Flower Show and I spoke about my passion for gardening, which had an enormous impact upon the Royal Horticultural Society, to the point where they made me an honorary member of the Society in recognition of what I was saying, and Abbeyfield who were, and are, a large care home, were really keen to involve themselves in making gardens for people with dementia, living in care homes, much more dementia accessible, and alongside that the charity, Thrive, were in audience, and I've done certain amounts of work with them since, because again at that point they had no recognition of people with dementia in gardening.

The rights of people with dementia have always been part of the DEEP set up, and Steve Milton, and Philly, and Rachael, were really drivers in setting up a thinktank which I was proud to be a part of a few years ago, which resulted in the rights of people with dementia being platformed at a place where they'd never been before, and that in-turn led to Philly, Rosemary and I going to the United Nations in Geneva and addressing the UN about its provision for people with dementia: none of this would have happened without DEEP, none of it, and the outcome was that the UK Government was inspected by the UN and certain changes were contributed to from our time with the UN, and a private meeting that Philly, Rosemary and myself had with a senior civil servant, which significantly improved the PIP arrangement for people with dementia, because that's what we spoke to the UN about, and the Blue Badge, which the Government saw as an easy fix.

Next, DEEP have been important to our group in supporting us with projects such as photography; the DEEP Enquirers, which again many DEEP members have been part of; a Canterbury conference; and books, including the publication of this book, the *Forget-Me-Nots, The First Ten Years*, which as you'll see on the back has the DEEP logo proudly printed on the back of the book, so we as twins are proud to associate ourself with DEEP.

And then we had Covid, and Covid caused lots of angst, lots of heartbreak, lots of problems, but also a few opportunities, again that was

one of the words I began with, and one was a DEEP art group, and the outcome of that is that I've learnt to paint. Frances has taught me to paint, George Rook encourages me, and we each encourage each other, and the outcome of that is, the impact of that is, for the first time ever in the world, a book series is being published about dementia, and each of those books will have a front cover painted by someone with dementia – that would never happen without DEEP.

And lastly, Congress last week: what a fabulous opportunity to come together again as friends.

Rachael: **Thank you so much, Keith. What a wonderful potted history, thank you. And if you look on the DEEP website you'll see links to all the DEEP groups, and the DEEP network, and they'll be a link up there to Keith's group in Canterbury. And as you say, non-identical twins, on the same... on the same journey, thank you.**

And, Tommy, you wanted to say something.

Tommy: Yeah. My memories of DEEP are meeting people who have become friends. The fantastic times we... we've had a way, but most of all the laughter. Yes, we've all cried hearing each others' sad stories, which always inevitably ended up with us all laughing.

I loved doing the Stockport theatre with Rachel Niblock, and singing along with Paul and Dory [live? 35:26] there. Interviewing Dory about her flying haggis, dressing up as ABBA, and years later Dory telling Joyce how she had to rip my clothes off in dressing room 'cause I couldn't get out my ABBA thing: I remember the divorce lawyer laughed about that story. The days we had in Birmingham at the Quaker retreats. Being in the same room as Philly when she helped create the infamous [Ladettes? 35:52]. Meeting, [Amy? 35:54], a woman that could play rugby better than me. Being in York and Rachel and Philly helped us create our DEEP, THRED group, and later the project we did. Being in Edinburgh and having a sing-song with a glass of grog. Doing Zooms and learning how talented my peers are. Our dear group meets in

Manchester, hearing the stories and working together to develop research questions. Learning from a fantastic book that Keith just showed that I was at the same Nottingham Forest versus Everton FA Cup game in April 1967 as [Keith, Willy, and Stanley Moore? 36:28] scored three goals and Jimmy Robertson scored two. Have... having a Q&A session to... giving a Q&A session to psychologists in Southport with Rachel and Paul. And recently having a pint with Steve Milton and Paul the other week and talking about real music, and talking about a... and Steve taking a real interest in our stories about when we were diagnosed, and how can someone understand that it was like when I told them the story of how I had been misdiagnosed with bipolar and was put on lithium.

But what does DEEP give to me? It gives me a safe haven where I don't have to be anyone, or anything, other than myself. The fact that we are celebrating 10 years from its start and all still want to be here, it gives me self-belief and confidence, that's the biggest word I could spell there, Keith, [chuckles] it gives me love, empathy, and most of all it gives me a family whom I would pick.

I want to finish with: the Bee Gees wrote the right words for DEEP, [unclear 37:38] with DEEP and us in mind, these words are from the second verse and chorus of *How Deep is Your Love*, and it goes:

I believe in you. You know the door to my very soul. You're the light in my darkest... deepest, darkest hour. You are my saviour when I fall. And you may not think I care for you, when you know deep-down inside that I really do, and it's me you... and it's me you need to show. How deep is your love? How deep is your love? How deep is your love? I really mean to learn because we're livin' in a world of fools. Breakin' us down, when they all should be letting us be. We belong to you, and me.

So, there you are – what more could I want?

Rachael: **Tommy, you've made Rachel cry. [chuckles]**

Tommy: [chuckles]

Rachael: **Thank you. I'm just laughing about kind of... well, you know if we'd put this in the Joseph Rowntree objectives in the year one report that we were gonna do an ABBA tribute band and do all these lovely things, lots of beer, huh; thank you, Tommy.**

Irene or Paul, is there anything you'd like to say about your memories of DEEP or what DEEP means to you? Irene, and... so I'll do Irene and then Paul.

Irene: Yeah. So, I'm a member of STAND peer support group in Fife, affiliated to DEEP, and we're newbies, we're kind of newbies to the DEEP scene, but I think it would be fair to say that in a very short time we have completely maxed out; [chuckles] we've made the very most. And, do you know, I wrote [scrids and scrids? 39:22] when I was trying to think what it meant to me, but I've [not bored you yet? 39:24], so here's a kind of summary: I love the engagement and empowerment part because I feel that DEEP... and my engagement through DEEP has given me the empowerment that has enabled our group to grow, individually my empowerment. But DEEP has enabled STAND to survive. We were a very young group when Covid hit and had it not been for DEEP and Rachel Niblock in particular, I don't think our group would have continued to grow, because Covid, like it did with everybody else, stuck everybody indoors with no way of meeting up. Through Rachel's help, DEEP support, we were able to do Zoom meetings, and Rachel and DEEP helped us to get... oh, I forget the word, anyway, a shelter that we could go to, and even in all sorts of weather we could be outdoors and be together, and without that support, advice, love, encouragement, I very much doubt that we would have continued, certainly not to be as strong a group of individuals as we... as we now are. So, I think... I really believe we owe a lot of survival to that.

And the group is just such a significant impact on our council where we live, the community we live in, because we feel much more confident,

we're much more empowered, much more able to hear and have our voices heard. We're setting up meeting centres across the council and things, and do you know while we take credit for it, the support and love of DEEP has most definitely contributed hugely to all of that.

So, for me DEEP gave me back some control. When I got a dementia diagnosis, I lost all control, I seemed to lose all control of everything and everybody in my world, and through the involvement of DEEP and the opportunities that I got, I got a lot of that back, and I feel like I'm in control again of my life, and helping others to regain the control that they too feel they have lost.

So, it has given me opportunities, too many to mention, but include poetry writing, ah, just too many, too many to mention. And skills, the most wonderful skills, some are new, that I never even knew I had before, but some that I had completely lost, some that had been taken from me, and through the Pioneers project in particular, those skills all were given back to me and I was able to use them again, and I remember a little bit more about the person I used to be that I had forgotten about. It has offered opportunities for friendship, the Voices Across the Land group being a particular favourite of mine, but through all of the other opportunities and groups that I've been in, and you just make friends for life. There is a kindness, an openness, a generosity, and nobody cares about your diagnosis, in the sense that it makes a difference to you as a person – they care very much about how it impacts on you, but they don't care that it's there.

It has made connections for individuals, and for us as a group we now have huge connections across the UK and beyond, and those would not have been available without the DEEP support and network. We have purpose, but most of all we have joy. We laugh, we rejoice, and we'll... you know, things like the panto that we had last year, and the Christmas show, and there was really frivolous moments where laughter has almost abandoned you, and you guys have helped us to bring it back, not just within our local, and community, but across the whole piece, that people

that would never ever have met and never have come in connection with. And most importantly it brings us hope because we're involved in opportunities and we're involved with people who see our value, who help us to retain our sense of purpose and our individuality, and as an individual, and as a member of the STAND group, we will always be thankful and in your debt.

Rachael: **Thank you so much, Irene. So, many important words that you've just brought out there for us, and people are picking up... I can see in the chat box, people are picking up on that word 'control' again, so thank you so much.**

Paul: Good afternoon everyone. I think I'd like to be known as the Alan Whiker of DEEP, you know, been all over the UK sometimes with Tommy, Scotland, Wales, and you name it, we've been there doing stuff. And it's funny because, you know, getting back to diagnosis, all these... all these things are washed away, they're not... they're not... you're not conscious of them anymore because you think you can't do them, and so... and we did a lot of work with Sarah, Sarah Butchard, which was very encouraging when she was at Mossley Hill, and then I think which led us onto DEEP and then... and since that moment it's been... you know, it... life has become a bit more pleasurable because how can they say we've been almost normal, if I can put it that way, and, you know, the fears and trepidations of life just seem to slip away when you're involved in projects, and we've been involved in tons of projects with DEEP, and also been funded by them, and we've done things that we'd never ever think we would do. You know, it's too many to go into right now but, you know, hundreds of different things what we've done, and I must say it's been a pleasure. And the camaraderie and friendship of the people we've met has just been tremendous, so it's been... everything we've done with DEEP has been so enjoyable, and it really is a tonic came to our lives I think.

Rachael: **Thank you so much, Paul. So, you've beautifully brought in Sarah there. Sarah, you've been, as you say, involved with the DEEP**

network since the beginning, but also you have been a fantastic link to some of that influencing work into the psychology field, so I just wondered if you could say a little bit about what you've been up to?

Sarah: Yeah, thanks, Rachael. So, my name's Sarah Butchard, and I'm a psychologist who works up in Liverpool. And like Rachael said, I've been involved with DEEP for a long time actually, and similar to what Keith was saying, I first really started trying to think about how I could support people with dementia to come together to have a voice, in around 2012, when we were involved in a project called *Innovate Dementia*, so not Innovations, but *Innovate*, so I remember at the time thinking, 'someone's got a very similar name to us,' and I did not know you at the time, and within that we were really thinking about how we could... or how I, as a clinician, and working with loads of people with dementia, such as Tommy and Paul, could bring people together. 'cause what we were seeing was that there'd be one person with dementia, so it might be Tommy, and everybody in Liverpool wanted to go to Tommy to kind of ask him questions, and we thought, you know, 'this is great,' and it's great, isn't it, and there was this kind of real enthusiasm there, but at the same time it felt like that was quite overwhelming maybe for you, Tommy, and also, you know, there was lots of other people out there where we're like, 'let's bring people together.' And we knew that actually, there was support in numbers and that there was power in that, and, you know, from kind of working in psychology I also was very aware of the kind of stuff around self-identify of coming together with other people that are in a similar position to yourself, and really wanting to kind of facilitate that for people. So, we set up a group called SURF, which Tommy was one the first chairs of, together with our friend, Gina, who isn't here, but is still with us, but isn't here today, and really, kind of, I was blown away by how successful that was, and I think myself and my colleague, [Jill? 47:37], who was involved in this, we just loved it, it was our favourite part of the kind of... the month that we'd go to, we really enjoyed this, and I think just that work.

And I think one of the things I wanted to reflect on in relation to how that linked in with DEEP, is then I came across DEEP through various networks, I think probably through Keith from the Forget-Me-Nots, and with Reinhard who is a fellow psychologist who I work with, and the work I did for The British Psychological Society, I suddenly came across that we weren't the only people doing this, there's this wonderful network out there of people, and all of a sudden it kind of meant that it wasn't just Liverpool, we could go a lot wider than that as well. But it also, over years has given me, personally, as someone who helps to facilitate the groups, a really great source of support.

Because I think we've talked today about all the positives, and there are so many positives coming together, but... well, what maybe you haven't talked about is some of the tricky things that happen and the support DEEP can give in relation to that. And I think groups by their nature are just funny beasts, aren't they, and they can take on a life of their own. And I think, you know, over the years I probably have learnt a lot about what I would do differently, if I was setting up groups again, if I was facilitating them and helping people come together. And I think, [Rachael? 48:50], you and I have learnt together around that, both [Rachaels? 48:53] actually, about what we would do. And we talked a little bit about power and control before, and where the power sits in a group makes such a difference, and I think from a psychological perspective I've been really interested in how we kind of do that and how we make sure that the power remains with the people living with dementia and that their voice is always central to this. But I think, for me, DEEP has just been that massive source of support as well in terms of a sounding board when things are going a little bit wrong as well, and how we do that. So, you know, eternally grateful for that actually, yeah.

Rachael: **Thank you, Sarah. I just wonder, Rachel Niblock, huh, if there's anything you want to reflect on? So, you joined... 2015?**

Rachel: Yeah, 2015, yeah, seven years. [chuckles] And I just want to say that I'm, you know, constantly completely overwhelmed and humbled by, you

know, what people say, and I think that... and, you know, and I think us at Innovations we feel like we're kind of stage managers in just, you know, making these things happen. I think what DEEP is about is about those relationships that form, and we've had 17 in-person events across the country this year, and it's been such a joy to see people coming together who maybe have never met before, or if they have met before, they haven't seen each other for ages, and that connection about being... you know, finding your tribe, being in the same boat as somebody. And we've talked a lot over, you know, the last few years about how it's all about sharing and learning from each other, and supporting each other with all those different, you know, obstacles and joys that we face in life. But I think that a lot of people have spoken today about hope, and I think very early on we adopted hope as our kind of... one of our mantra words in our... in our Facebook image, and I think it's that everyone has to hang onto hope. You know, and again, going back to what Rachael was saying about the little changes, whether it be in your own home, or whether it be on the platform at a national conference, I think what is... and what's really important is when groups come together, and I know that Happy go Luckies, a big shoutout to them in Plymouth, they're watching, is that you wrote a wonderful poem about how that joy of coming together and just sharing a cuppa and a piece of cake, how I think that social derivation of that peer support coming together. You know, who knows what comes from that? And it might be one word you say in your own home, and it might be one word you say in your street, or in your community, that can make a real, real difference, so I think that's what drives us all is to feel that we... you know, we don't want anyone to be alone in that diagnosis process, after that post-diagnosis, because no one needs to be alone because there's such a wealth of friendship, support, and knowledge, expertise out there for people to share. And I think that... I remember a story from the Dementia Diaries where there was a lady from the group in Stoke who said to somebody who had just been diagnosed, "I'm not gonna say anything to you, but except, go and listen to some Dementia Diaries and then come back," and they met up again several weeks later and this woman went up to

her and gave her a big hug and say, “That was the best piece of advice you could have given me,” is just connecting with those other voices of people living with dementia, and some of those voices are... you know, are able to be confident and be here today, but we know... often know there are so many people who are just gaining comfort in a very small way, or in a massive way, about what the whole of the DEEP network can give to each other living with dementia. So, and... yeah, it’s a constantly emotional rollercoaster experience just being in my privileged role, and it’s all Tommy’s fault.

Rachael: **[chuckles] Thanks, Rachel.**

Rachel: Because Tommy interviewed me and employed me. [chuckles]

Rachael: **Thank you, Rachel. So, we’ve just got a few minutes left. Any other comments from anybody about this last 10 years, about maybe a little nod to the future; has anybody got anything they would like to add to what you’ve said already?**

Sarah: Well, I guess for me, Rachael, there’s something about future about legacy, isn’t there? About it be really lovely to see, you know, Irene and other people who are kind of joining the DEEP network, and it keeps growing, and it keeps going, because it’s great that we... you know, Tommy, Paul, Keith, you, we talk about having been around for 10 years with this, but actually kind of new people coming in, and that’s what it’s all about, isn’t it? I know that whenever we kind of look at this, people talk about paying it forward, so you’re doing kind of stuff now so that other people don’t have the same experience maybe that you had that was negative, and the positivity of that, so that feels so important.

Rachael: **Thanks, Sarah. David?**

David: Yeah. I just wanted to say really how welcoming and enjoyable I found my involvement with DEEP as an ally and as a supporter, and not every movement is as good at welcoming allies and being friendly and supportive, and very few groups have as much fun. So, you know I... it’s

been a genuine joy and I've learnt every bit as much as everyone else involved, and I'm glad to have been part of it and able to offer a little bit of support along the way.

Rachael: **Thank you, David. I haven't been keeping an eye on the chat box, has any... Philly, is there anything that you might want to bring from the chat box?**

Philly: There's loads of wonderful comments. There's also just a quick question from [Tristan? 55:07], and I'm not sure if we've got time to go into it in detail, but he's asking to learn about what things people have done to enable them to stay independent and living in their own homes, and I was just gonna suggest maybe looking at people's blogs, or reading Wendy Mitchell's books, or listening to Dementia Diaries actually, but I don't know if anyone else wants a quick answer to that; it's rather a long... [chuckles] it's a long discussion that one, isn't it?

Sarah: Join a group, kind of get involved; it seems to do lots of people lots of good. [chuckles]

Rachael: **Yeah, I think a lot of the solutions are there, aren't they, in the groups? And I guess, you know, if we're just coming to the end, I would reflect that in my involvement with this kind of work, and with the DEEP network, then it is just... you know, that idea of what has changed? In the session earlier people were... some people were saying that actually sometimes things don't change, it feels like you're still nibbling away, trying to influence the world around you, and on the other hand, lots of things have changed. But I think the thing that has changed from what I've witnessed has been this... the peer support, the connections between people with dementia, and that what started out 10 years ago as disparate small groups of people who didn't know of each other, huh, who were learning this each time, and not... and it being hard work each time, but now that there is a strength in number, the strength in connection, but**

actually some of the... that giving of hope and power and control, and possibilities, perhaps becomes a little more accessible.

Rachel, did you have your card?

Rachel: Yeah, just really quickly: you know, we always talk about, you know, asking people with dementia in your communities what they want, but I would also say that I often hear from people saying, “Well, we tried doing that,” and I think you need to build confidence in your communities, people living with dementia, to trust that you’re the right place to go to and you’re the right person to... for them to confide in, because it’s too easy to forget that people have been through a very traumatic experience where their confidence has just been taken away, and any opinion that you’ve held for so many years, might have suddenly been told, ‘oh no, you’ve said that before,’ or, ‘that doesn’t count anymore,’ or... so it’s really important if you’re looking at setting something up, that you recognise that you need to really win that confidence of people, and it’s not gonna happen overnight – you need to take it slowly.

Rachael: **Thank you, Rachel. I’m conscious we’ve reached the end of our session. You’ve heard a lot about the last 10 years, I feel like this is a moment in time; they’ll be more years to come, more stories to share. We hope that you can join us for other sessions as the week progresses. There’s lots of other bits of the jigsaw that pull this together, but it’s been fantastic for me to look back on those 10 years with all of you here today, so thank you very much and, you know, what a pleasure it’s been to have known you for so long and to be meeting you along this progress of this movement, so thank you very much.**

[music plays]

[End of Film]