Dementia Enquirers: people with dementia in the driving seat

[music plays]

//[music and film clip starts: 00:12]

Wendy: I'm Wendy Mitchell. I live in East Yorkshire, and I was diagnosed with dementia eight years ago.

George: I'm George Rook. I live in Shropshire, and I was diagnosed with dementia eight years ago.

Wendy: I'm an active member of the DEEP network. DEEP connects over one thousand people, just like me, all across the United Kingdom. DEEP helps us to magnify our voices, hopes, and intentions. DEEP is hosted by the not-for-profit organisation – Innovations in Dementia. Our groups are encouraged and supported to identify and speak out about issues that are important to us.

George: In recent years, people like us with dementia, have been more involved in dementia research. We've been offered varying levels of engagement and involvement, but we very rarely set the agenda. Research knowledge processes, and outputs, are inaccessible to most of us, and it's academics and funders who choose what topics to research.

Wendy: More and more of us have said that we want to have ownership and control of the research; the Dementia Enquirers programme has tried to make this happen. Through the DEEP network, people with dementia have been supported to identify our own research priorities; we can plan and carryout our own enquiries with any support we need and want.

George: During the four years of this programme, we have learnt so much, and we have shared a lot of resources openly, for example: the DEEP Ethics Gold Standards which we used in assessing the Enquirers funding applications, these are now being used by universities, such as Stirling, and we produced also an accessible research methods pack. We have

funded and supported around 25 small projects, all led by people with dementia; these are a few of the topics:

?: What's it like for us to give up driving?

Wendy: Can children learn about dementia through interactive games?

?: How has Covid, and the lockdown, made us feel?

Maq: Can people with dementia benefit from technology, like Amazon Alexa?

?: How can DEEP groups and Admiral Nurses work together?

Wendy: So, what do we think the Dementia Enquirers programme has achieved?

?: The Dementia Enquirers programme to me has empowered ourselves; it has given ourselves confidence to move forward.

?: I hope it's changed perceptions about people living with dementia and their involvement in research.

George: A huge impact has been developing relationships with researchers and research communities, actually driving the research, not just being the subjects.

?: I think it's achieved so much in changing perspective, busting through mythologies, prejudices – assumptions.

Irene: And not only give us a voice, it does give us a voice, but it amplifies that voice. Those voices of people living with dementia through their research, can impact all over the world, all over the globe.

George: So, do we think that the Dementia Enquirers programme has changed us and/or others who have been involved?

?: I think being in partner projects has been empowering. We've grown as individuals, and as a group, and it's enabled us to challenge what we don't agree with.

Dory: It's changed my life. I can still be useful.

Maq: It's given me the confidence to be here in front of you and talk about it, because when I was diagnosed – I was scared.

?: It's given me a fire and a passion that I want to move things forward; it's opened my eyes to a whole new world.

Irene: When I got my diagnosis, I initially was positive, and then I allowed the rest of the world, really, to disable me, but through the support of the Pioneers I learnt that I could still really well look at a project, or look at a piece of work, or listen to somebody's take on a project – it's been the thing that has given me my persona back.

Wendy: What do we think is different about research which is led by people with dementia themselves?

?: I believe that it is more authentic, you know, because it comes not only from the head, but from the heart as well.

?: People that have not lived with dementia – it's a whole different story – they think they know, but we can provide that knowledge.

George: When we choose the subject to research, it's gonna be a subject we care about, and that matters to us.

Dory: We know through our experiences what needs to be done.

Wendy?: Research with people with dementia, gives it that reality and suddenly brings the research alive.

George: So, what do we hope and... hope will happen in the next phase?

?: Well, I hope that researchers will look at the project, look at the book, look at the video, and say, 'we can involve people with dementia, they can be partners in research, not participants,' that we can go to them and say, 'what do you want researched, what is important to you?'

Maq: Although I might not see the benefit of this research that we're doing, my grandchildren will.

Wendy: If funders would insist on people living with dementia being involved from the start on equal footing, then what brilliant research would the outcome be?

Tom: I think the Dementia Enquirers programme has shown that people with dementia can be researchers, and, you know, it's often thought that the two must be streets apart, that... but they don't have to be.

David: I think it's challenged my prejudices about dementia. It's made me realise that actually living with dementia is something that is gonna face a lot of us, and we can do it a lot better. This group has influenced everything from the questions we ask in research, through how we ask those questions. What data we collect. How we consolidate feelings and emotions into knowledge.

Tom: My message for other academics is really – listen, and consider where could they fit within your programme? If you're thinking that this is important to people with dementia – why don't you check, why don't you ask?

David: Academic researchers tend to have a formula about how they generate research questions: people with dementia aren't bound by that, so what they actually ask, is the questions that matter to them.

Tom: I also hope that researchers who look into dementia, realise that it's very, very important to hear from people diagnosed with dementia themselves, and indeed they can play a part in their projects and their teams – and should.

David: What I'd love to see is the whole academic world become much more open and accessible to people living with dementia, as members of that research community, so that we can all start to generate knowledge together.

Tom: My message to funders is you should expect involvement of people with dementia in projects to do with dementia.

Wendy: We'd like to thank The National Lottery Community Fund for giving us this amazing and ground-breaking opportunity – we hope we've done them proud. And also the many academics, and others, who have supported us with huge enthusiasm, and a lot of practical guidance. They have helped us to navigate the labyrinthine world of research.

George: Finally, we invite you to help us carry forward the legacy of Dementia Enquirers, whether you're an academic, a research funder, whether you provide or commission services, or sit on an ethics committee, what ever your role – we need you to be our allies and our champions.

Wendy: At last, we are where we want to be – in the driving seat.

[music and film clip ends: 09:47]//

Chris: The premise that we put forward was that the music is always deemed to be beneficial for people, and their involvement in music is a known fact of the success that helps them. So, what we wanted to do is develop our own research and development around what it's like to instead of just be invited along to sing in a choir, or that sort of thing, to actually learn a brand new musical instrument which... and see how that felt, see whether it made us feel better, made us feel worse, and what the process of that was, and so that was... that was the idea. The idea was put forward by Martyn who's just to my right there, on the screen, and we kicked off. And it was very much led by us, but Jack... Jack Fakley over there, he really supported it, I mean he was diamond, and we ended up with a 42-page report about how we benefited from... there it is, lovely, how we benefited from it, and how it made us feel, and we've also got a 25-minute video, which is available as well, which shows the whole process from being brand-new raw, to lovely, soft tender fingers to blistered fingers, as it were, and along the way, and so that was the idea of it. And it went... we're very proud of it, and I... we intend to share that with as many people as we can.

Martyn, I'm gonna handover to you because I don't wanna talk too much.

Martyn: Oh cheers for that, Chris. I think the only thing I would like to say is the first thing is that... the process, the process that we went through: it was quite hard at times and this is written down in black and white, but it was also very interesting. We had some very good times all the way through the process; some very funny times. Hard learning, very sore fingers, but we had a lot of laughs. But the main [part? 12:06] about it was the research, and when we went through the research, the good part about the research was actually the support that we did get from Jack and [Abigail? 12:18] through our research. But not only did we learn how to play the ukulele, we learnt a bit about music, or that those of you... us that didn't have a musical background, so we learnt quite a bit about music. And Phil Self, our tutor, along with us, we produced this piece of music, and so we produced it, we couldn't get anyone to sing it, 'cause no one was willing to volunteer to sing, although I did offer after a couple of gin and tonics, but that didn't come about, so... But apart from that, yeah, it was really enjoyable, and the research itself, there was so much came out of it, and the bottom line was, for me, is at the end it was a great piece of music that we had created and performed, and we actually achieved our aim. And what we proved is that even with a diagnosis of dementia, and I've heard this all week, killing this stigma about what if you have a diagnosis of dementia you can't do this, you can't do that, but we actually proved that we can because four of the members had no background at all about music, and we picked up that ukelele, and we were taught how to use it, we used it, we had a keyboard rocking away, a cello rocking away, Chris on his... I'd better get this right – horn, and Chris is playing his horn, and we produced a piece of music, and so it just goes to show that we can learn new things, and we can still carry on.

Philly: **Thank you, Martyn, thank you so much, thank you. And, Jack, did you want to add anything about the process of doing the research together?**

Jack: I think firstly Chris and Martyn, you... I think you've absolutely nailed the entire process of the project and the outcomes that we gained from it. You know, we... not only do we have a wonderful music piece, but we have a fantastic report with some really solid findings, but also a really good insight into how it is for people living with dementia to lead their own research projects, and I think that's a really powerful piece of evidence that we now have, you know, this is what it's like for people with dementia to lead on these kinds of projects.

I think personally, something I took away with, you know, I don't live with dementia, but I work every day with people that do, and as much as our trust down here in Ashford, in the Garden of England, we try to be as collaborative as we can for people living with dementia. Too often I think people are recipients, you know, they're recipients of our diagnosis, recipients of our care, recipients of the therapy I might give to someone, and there just aren't enough opportunities for people living with dementia to be collaborative, you know, to work alongside me, for me to kinda take on board their ideas and their views of things that are really important to them, and that's most certainly something I'd like to do way more in the future through loads more Dementia Enquirers reports or however it may look in my working role.

Chris: Another benefit that came out of it was the actual Phoenix group, those that took part felt so much more together afterwards. We kind of got to know each others... because the way the Phoenix is, it's quite formal, but... so we were chatting and we were laughing, we were joking, and we really got to know each other and got under the skin of each other, not in an annoying way, but just... and that... and that was the... one of the best results that came out of it I think was that interaction – smashing it was, yeah.

Philly: That's wonderful, that's a wonderful extra thing to hear about, thank you. OK, so last but not least we've got the York project, and we've got Damian and Eddy here, and if you could just tell us briefly about what you did and what you got out of it?

Damian: Yeah, our project was in one of the first rounds of funded projects, so it was a while ago now, Eddy, and it was sort of... it was before the pandemic, but we... so it was a very long process, and obviously got halted, but we managed to get it done in the end. And it stemmed from a conversation that was often had within Minds and Voices, and I think that that... you know, that point was made in the chat there that the questions arrive... arise from people with dementia getting together themselves and, you know, in Minds and Voices we get together, and questions arise, and this was one of the questions that we had, it was a conversation about being on your own, or being with a care partner. Eddy, what did you used to say about people living—?

Eddy: Well, I used to get problems hearing about people living on their own, people that have a carer, well they're all right, but people on their own – we were getting concerned about, and so we found out that quite a few people were on their own – they were quite happy, nobody moved anything, that they didn't know where it is, and so they were quite happy about it.

Damian: Yeah, absolutely, it was, it was a frequent bit of banter within our group really, you'd say, "I pity those poor people and my wife, and she's marvellous," and then... and then... and obviously Wendy would say, "Well, I'm happy living on my own because no one moves things," as you said. So, we had a group of people, we split and we decided what we'd do and, Eddy, you were an interviewer, weren't you; you interviewed quite a few people?

Eddy: Yes, I did, and it was interesting that when you'd talk to them, then they weren't sure about whether they'd come back, but the next thing [unclear 18:38], they all came back to our Minds and Voices. And it's people like that that's... they get diagnosed with dementia and they're just frightened about it, that they don't want to be seen, they don't want to go out, and I've always said, "Everybody that has dementia, should get people who's [unclear 18:55]... newly diagnosed, out and about 'cause it's nothing to be ashamed about."

Damian: I think what was... the beauty of it was the simplicity that's been mentioned before. You know, we did a literature view because [Brian? 19:07] said, "You've got to find out what's on t'internet."

Eddy: [laughs] Yes, yeah.

Damian: And... you know, and so I went round to Brian's, and we even had to translate these abstracts that were out there, supposedly a summary of things, 'cause they were full of jargon and academic language, and... but once we sort of simplified them, Brian was able to comment on those, and that was the feedback, and it was a brilliant piece of work that Brian did. You know, [Stuart? 19:32], when we made the questionnaire, he was a stickler for the punctuation, if you remember, Eddy, and—

Eddy: Oh yes.

Damian: —yeah, and he... you know, so he really sort of... the wording and the information sheet was absolutely spot on. And Barbara did a group facilitation, she... and we had some of Minds... some of the Up and Go group for our group session on Zoom, and Barbara did a fantastic job on that, and... so everyone was involved really, it was... it was just lovely to see. And yeah, so we reput... we produced a report with some recommendations about not what's better living alone, or apart, but what are the particular needs. So, you know, it's advice you can give to GPs if they're diagnosing someone living on their own and they need to say, 'OK, well let's look out for supporting people with appointments,' etc. And if they're diagnosing someone in a partnership, 'let's look out for the arguments at home,' or whatever. And we've also been able to... I mean that report also contributed to the... a piece of research that Sheffield Hallam are now carrying out, on the needs of people living on their own without informal support, people living on their own without even a family member down the road or anything like that, and that's a fascinating piece of research that we've just started, but they've drawn very much on the Minds and Voices report, which was great. I think we'll stop there.

Philly: **Thank you so much guys, both Damian and Eddy, that's been a brilliant summary of what you've done, and I think what comes out from your report, and from everybody's, is how actually everybody in the groups has been able to be involved using their particular skills, their life experiences, the things that they enjoy, and you've all come together as teams and contributing individually into a wonderful team project, so thank you so much. Looking back on the whole programme that you've both been involved in for four years, I'd love to just very briefly hear you; maybe start with Rosie.**

Rosie: Yeah, it's great to hear the work that's been going on, and I think the bit that really resonated for me is that thing of once you start doing this type of research – you can't... you can't go back, you just... you see the value of having user-led involvement, having that lived experience. And I think something that's very important in my line of work is making sure things like those cures in clinical trial research things, become accessible and become spoken about in a way that people can engage with, and I think that's something that, you know, Dementia Enquirers have really put a flag in the sand of saying, 'this is your starting point now, and now you need to be better, you need to keep building on this,' and I think it's so exciting to see people come together and want to learn about this, because actually co-production, and this type of work, has just snowballed, it's... you know, you can see it growing and growing, and everything about Dementia Enquirers is at the core of that, it really is what's... has certainly given me that kind of motivation to do things differently and to work so closely with you all. So, I've been incredibly lucky to be an advisor for the Pioneers, they have made my life so much better, and it's been so great to work with [Rachael? 22:40] and Philly, and just to see even on this... on this chat, just see people enthusiastic about changing the way we approach things, whether that be a researcher in care, I think it's about being open to change.

Philly: **And I just want to take this opportunity to thank you, Rosie, for sticking with us for four years and contributing so wonderfully in so many ways – you've been absolutely great.**

Rosie: Oh, thank you, Philly, [unclear 23:03], I mean I don't want it to stop, so if anyone wants to just keep on going – we'll do that. [chuckles]

Philly: **That would be great. And I'll leave you, Rachael to have the last word.**

Rachael: Amazing, I never get the last word. [chuckles] I think somebody mentioned Covid, Damian and Eddy, it was your [experience? 23:21], so I just thinking that this... having run a Covid session this morning, this programme started just before Covid, and was really affected by Covid, but actually we had huge opportunities because of Covid as well, and a lot groups continued with their projects and provided the foundation for the next couple of cohorts who came along, and we had a special cohort in the middle who actually researched the experiences of people with dementia during Covid, so I think it should be placed in the context of some kind of, you know, massive life-changing event that we all went through. But for me, Dementia Enquirers, it's been an inspiration, it's been... it's watching the growth I think of this togetherness, then... and multiplying all of your projects. You know, we've got 25 projects and we know that groups have been through similar processes to you. They've identified the research question that they wanted to investigate because it was something important to them, not given to them by academic researchers or other people wanting to dig around and find out their perspective, that these were generated by people with dementia themselves, who then learnt new skills: you know, we heard about Brian and his literature review, we don't have the SUNshiners here today, but they've done a... you know, learnt a lot about how to analyse quite a bit amount of data that they were surprised to get, so lots of new skills along the way – research skills.

And I guess I'm always struck by asking early groups, "Do you feel like a researcher?" and everybody went, "Oh, no, no, I'm not feeling very... you know, I don't even really know what the word 'research' means," and I think what we've managed to create is a network, a Dementia Enquirers network, of more confident people with dementia who've had a lot of fun and enjoyment, and done a lot of hard work, and are part of this kind of movement towards leading research, really being in the driving seat of research, not just on the end of other people's research, and it's been phenomenal to kinda witness. And also I think... well, do you all feel like researchers? Eddy? Martyn? Chris? [Warren? 25:49]? I can't see Warren. – I reckon Warren feels like a researcher, [chuckles] and that's been the best outcome.

And I guess, you know, just to reiterate what Rosie's saying: this was an exploratory project, so we really hope that we can take the learning, the huge learning that we've had together and continue to do more with that.

[music plays]

[End of Film]