Reflections from the Covid-19 pandemic

[music plays]

Rachael: **Hello, everybody, welcome to our session which is the launch really of a... of a new report from Innovations in Dementia from looking back at the period during which we all lived together through the Covid-19 pandemic, and the various lockdowns, and we wanted collate the stories from the perspective of people with dementia themselves, which is perhaps different than a lot of what was happening at the time, which were... which were researchers kind of coming and asking people what was happening: this comes from the ground up and it's the launch of our report.**

So, just a little bit of housekeeping before we start: our audience, you can't... or you shouldn't be able to do anything with your microphone and your camera, that means that it's easier for us to have the conversation as the presenters, but you're very welcome to pop things in the chat box, and Rachel will keep an eye on that chat box and feed things in, and any questions you might have. But don't feel obliged to use the chat box.

So, just to place where we are and what we're doing today: today is part of DEEP 10th Anniversary Festival. We're midway during our online week's festival. It's one of 21 events that we're running this week to celebrate 10 years of working together to amplify the voices of people living with dementia. And when we were thinking about how best to mark this year, we were mindful we couldn't just have one big event, so we've celebrated in person at 17 DEEP events across the United Kingdom, and we've... we're trying this week to share some of the magic that happened in those sessions, in those live sessions, as much as what is happening this week.

So, we'd really hope that you can share as widely as possible the films and resources that are coming out this week and being launched, especially for people who can't access computers.

And after the event... all these sessions are being recorded, after we've tidied them up a little bit, they'll all go on the DEEP Anniversary website to be watched at your leisure.

Before we start can I ask everybody to introduce themselves [lastly? 02:36] 'cause I'm gonna as Maq first of all to introduce himself.

Maq: Good morning, everybody, and thank you very much. It's nice to see some new faces and some old faces. We've been stroking each other over the last two years anyway on different sessions.

[chuckles]

Maq: But I have to say that I am DEEP otherwise Rachael'll get across... cross with me. Ohh...

[chuckles]

Maq: Yeah, I am probably the longest member of DEEP actually because I was diagnosed in 2010, and I joined the organisation in 2011, and then at 2012 it all became part of DEEP. So, longest serving member, living with the diagnosis of dementia since 2010, and had the honour of meeting both Rachaels on numerous occasions, and thank you very much for... you know, that the support that I've had from both of you has made it so that I'm sitting here talking to you, and I can't thank you enough, thank you once again.—

Rachael: **Thank you, thank you, Maq; thank you. Irene?**

Irene: Yeah, good morning, everybody, it's lovely to be here. Unlike Maq, I'm a newbie, [chuckles] not any younger – just a newbie. So, I'm a member of the STAND peer support group in Fife, and I think as I've mentioned

on previous calls, we are the group [unclear 04:06] and due to the support that we've had from the DEEP network from these particular ladies, Philly, and others in the network, and we'll be forever grateful for the connections that we've made that were particularly important I think during Covid, but have endured and hopefully will continue for a very long time. So, not got the depth or breadth of experience of Maq, but by goodness in short time we've maxed out on the benefits of being part of DEEP.

Rachael: **Oh, thank you, Irene. Ruth?**

Ruth: Morning, everybody. I'm Ruth McCabe and I support the STAND group in Fife. Lovely to see you all.

Rachael: **Thank you, Ruth. And, Rachel?**

Rachel: [dog barks] And the dog's just started to bark.

[chuckles]

Rachel: That's [Megan? 04:58].

Rachael: **[chuckles]**

Rachel: And I'm the... I'm the DEEP coordinator.

Rachael: **Thanks, Rachel. And I'm Rachael from Innovations in Dementia. And one of our privileges is to host the DEEP network, so I've been involved with DEEP since its very beginning.**

So, I think you already know that we're finishing a little earlier than anticipated today: we're finishing at 11.45 because we have to straight into another session; we didn't quite think that through, huh.

So, we are launching our new report today and I... and I just kind of wanted to contextualise really because as we've just been discussing before you all came in, it feels so long ago now in lots

of the ways the pandemic that we lived through, the lockdowns, the emergence from the pandemic, and although I think we probably all know that Covid is still part of our lives, it can be quite hard to look back on; in some ways it feels quite distant. So... but that is what we're doing here today. We'll just take a bit of a kind of breath... breathe to kind of revisit that time.

So, before we go into discussion, I want to share some highlights from a report that we're launching today. So, I've kind of explained I think that this comes from the perspective of the DEEP network, this is... this is our collation of everything that was happening in the DEEP network during the early days of Covid and as we... as we emerge from Covid. It's stories by people with dementia, and all we have done really is to curate those and to... and to bring them together. It was a shock for everybody. There's a little poem here for... from George which he recorded as a dementia diary:

But for now we lie half-awake, half-dreaming
Waiting to see if our clock is about to stop
Waiting for the warming sun to rise on us again
Waiting to pass into a new land
The same, but profoundly different

And I imagine common to all of us, we all were quite surprised and in the same boat as each other to enter this new world that we found ourselves in. At Innovations in Dementia, and consequently in our *DEEP News*, which Rachel pulls together monthly from everybody's stories, we acknowledge that we were in the same place as everybody. You know, we would... the world had lost its familiar landmarks, the mooring... the moorings, we were uncertain, fearful, kind of hopeful that we could support each other to get through this, but we acknowledged also in those very, very early days... and because people were saying this to us, that people with dementia had been living in that condition, that state, that state of being, often, you know, that the experience we all had collectively as the

world was not dissimilar to the experience of living with dementia, and I guess that's what we tried to do together was to share the learning, to share the solutions, to share the tips to support each other in ways through the pandemic.

Things happened, didn't they? We know a lot about the impact of the pandemic on dementia services, that access disappeared, you know, diagnosis rates dropped for the first time for a long, long time; family carers filled the gap. Existing health inequalities were perpetuated. So, people with dementia were finding themselves in a situation where the services and the support and the scaffolding that they had in their local lives and communities was dropping away significantly, and overnight. So, we reacted to that as a... as a small organisation in keeping busy, huh, and maybe most people did. We created quite quickly some videos for the... for the Covid response volunteers who perhaps knew very little about dementia. So, we supported people with dementia themselves to make videos that would help those volunteers to understand a little about how they could best support people in their local communities.

If you have a look on our Dementia Diaries website you will see multiple diary entries from people with dementia about their experiences and their solutions during Covid, so you can either follow this link or pop it in the search box on the website. And we worked really quickly to create some 'how to' videos, and the Zoom videos which kind of were on the back of other videos created by people with dementia about how to use Zoom have been far and wide used. We know that lots of people who didn't have dementia found it really helpful to know how to access a Zoom meeting in this world when we suddenly moved online, so we're really delighted that the impact went beyond our world.

The National Lottery, our funder, the funder of DEEP, the funder of many of our other projects, gave us emergency funding for a... for a... for different... for different projects that might help people with

dementia through the Covid experience, and we were really delighted that we could focus on a few different areas of work. And you might hear a little bit about one of these, *A Good Life with Dementia*, later as we talk to STAND, but we ran a project called *Getting Along*, building on work from our colleague, Damian Murphy, working in relationships and supporting people with dementia and carers together to position dementia in a more positive way in their relationship. *A Good Life with Dementia* are post-diagnostic courses run for, and by, people with dementia, developed in lots of different local areas. We quickly created a new website led by people with dementia called Tip-Share, the link is here, full of solutions and tips, it's in its name, full of solutions and tips by people with dementia. Initially about how to live during Covid and the... and the work arounds and the ideas that people had, but has moved beyond Covid experiences now.

Lots and lots of creative work emerged and if you have a look our report, you'll see huge creativity within the way that people with dementia were spending time during Covid, but not just spending time being creative, but sharing that approach with each other, teaching each other new skills, art, poetry, all kinds of things, so if you visit our website here you'll see loads of examples. We did... made that sequence of 'how to' films and we did some work with libraries, a report which you can read here, knowing that libraries are very safe and trusted places where people with dementia will meet, and were opening again with restrictions quite quickly after the lockdowns ended.

So, I have a quote here from Agnes about what it was like, you know, we... it was... it was hard to know one day to the next sometimes in lots of way, and she concluded by saying: "I'm trying to become not a human-doing," which we're perhaps all used to being, "but a human-being," about being in the moment.

So, Zoom happened. People surprised themselves in how these ways of connecting online suddenly became available. We had the 'how to' guidance, but also people found that with support that they could still be in contact which... with each other, which I think fulfilled a huge social need. You'll see, and if you read the report, Roy and his waving bench, his way of staying connected in his community. Across the network there were blanket squares being created which helped to connect DEEP groups to each other, which I guess is that... is a strong purpose of the DEEP network is that we had these connections. And again for us, our work that... the ways we had been working with groups in the DEEP network had to... had to change overnight. So, there were sunflower competitions, loads of crafts and learning and teachings between people with dementia. We launched 24 films by people with dementia that had been created prior to Covid, but the whole launch took place during Covid, and the whole editing process with the groups in charge of their films took place in quite creative ways. So, we had a lovely launch of those films.

As we were emerging from lockdowns and groups were reconnecting to each other, there were lots of opportunities to start to have that influence again, which is one of the kind of goals of a lot of DEEP groups. So, here we have a report generated by the DEEP groups about what they wanted [their? 15:38] Government to include in future dementia strategies, and we were able to work with the Chinese Wellbeing group up in Liverpool to have that translated and for them to contribute their views in their own language.

So, you can have a look at the full report, it's full of beautiful photographs, on our website at Innovations in Dementia. And here is the STAND group.

Irene and Ruth, what's it like looking back on that period and perhaps thinking about what you did as a group in that period?

Irene: Well, we did... we did lots. I think Agnes' comment about 'being' and not 'doing' was something that we all struggled with, and I think that's when the work was [deep? 16:35] where the engagement and empowerment part really took hold because we were all rendered quite useless for quite a bit of time, I think.

STAND had met on six occasions before the Covid pandemic hit, and when the first lockdown came, STAND as a group was lost. Like everybody else, we were lockdown, had to stay inside, and the connections which were still quite young and new and fresh [sighs] were very important, but were... but looked like they could very readily and very easily become lost. And as... as a community we are quite diverse, we don't live entirely close to each other, and as a group we're quite far spread out geographically, and we don't have... all drive, and we don't have the most marvellous network, transport network either, so potentially our group became very vulnerable as the... each individual within the group, and so the support and help we got from DEEP, and from Rachel Niblock in particular, really shored us up and kept us going. And it wasn't... it wasn't just because of distance, or whatever, I mean, we've benefited greatly from Zoom, but many of our group members were unable to access Zoom, do you know, just because of dementia, not because of financial hardship or lack of resources, but because of, you know, just that skill or dementia difficulties that dementia brings with it. And so whilst Zoom was really important to us and we were grateful to Rachel for enabling us to become connected through Zoom, a technique that was entirely new and strange to all of us, but that engagement and empowerment through the teaching and the learning of how to do Zoom, was an entire lifesaver to us. But for those members who couldn't benefit from Zoom, for the difficulties I've just explained, Rachel and DEEP helped us to get a gazebo, so even in the most inclement weather, and we did have an occasion where two members stood and held the gazebo in place in howling wind and rain, but it meant that other people in the group, who couldn't access Zoom, could still meet, we could still be together, and those was very young, new

connections we'd made as a group, could continue to thrive. So, despite the real adversity that came, DEEP was a proper lifebelt, it was a proper lifesaver for us as a group.

So, we did the Zoom, we met with Rachel on a Zoom, those of us who could, on a weekly basis, and through that, lots, and lots, and lots of opportunities came. We had a myriad of really expressive positive experiences that shaped us as individuals and therefore has shaped us as a group and how we influence ourselves, each other, and taken that influence across our community on a much wider basis.

On the Zoom calls Rachel introduced us to a whole host of amazing people, many, and most who lived with a diagnosis of dementia, and many who were supporters, far too many to even begin to try and detail today. But a couple of really influencing ones were activists like Keith Oliver and Wendy Mitchell, and they were both people who had written books and we were completely in awe of them, I mean they were... they had superhero status, and to be on Zoom call with them, it was... you know, it was like meeting the people who we hold in the highest esteem, it was a completely mind-blowing experience, and it really buoyed us up, it raised our confidences and it gave us confidence and courage to become more activist in our approach, and that was really pretty much the approach that we then adopted, hugely shaped by meeting these people.

I personally was invited to participate in a poetry project, along with Keith and a group of other people living with dementia, supported by literature experts and also by students, so the whole intergenerational thing that would never have been possible for me, became a reality, and it resulted in us publishing a book called *Time and Place*. I mean, so from meeting people with published titles, I became part of a published title, what a mind-blowing experience – all down to DEEP.

Rachel linked us up with many other groups across the network and we had the most marvellous social occasions, this included the four nations

group called Voices Across the Land, the Gaelic groups, which still meets today, and these are fun and enjoyable, and you just forget all your hassles and all your hardships and you just blither to people likeminded, and through... being able to do that through the pandemic, through Zoom, or in a gazebo, the pandemic wasn't as harsh, or as hard, or as limiting, or as devastating as it could of, and probably should have been, had we been left unsupported, so DEEP really made that happen. And we had lots of fun, we had amazing times, but also through the link with the DEEP, through being on Zoom, STAND as a group became quite well-known throughout the country and we ended up being consulted by the Scottish Government and we became the kind of go-to group, do you know, if they were wanting information about what was happening, especially about the pandemic, but on a much wider basis, they came and they consulted with us, and I say 'they came': they came into our living rooms, or our bedroom, or our kitchen, or wherever our Zoom calls were taking place, and we were just delighted and totally privileged to have a conversation with people in power and influence that was meaningful and valuable and could make a difference to the way the pandemic was being handled. But bigger than that, that relationship continues and we're on the lived experience panel looking at the Scottish strategy now for dementia and trying to make an influence there. So, it started socially, it got bigger and it continues, it continues to grow.

Rachel prompted us to write our story in the hope that we could inspire other people to embrace life and peer support in the way that we were doing because STAND changed our lives. The result of this was the creation of *The Recipe for Life* booklet, and this has been distributed far and wide across the UK and across the wider world, and copies have gone to Australia, New Zealand and the United States. The group was also involved in developing the *Knowledge is Power* booklet, the first publish... publication of its kind in English and in Gaelic, and we have copies of these and you can get them from STAND; I think we have electronic copies as well as paper copies – STAND can provide those.

Rachel also introduced us to Damian from ID, Innovations in Dementia, and he supported STAND to write a self-management course aimed at people who were newly diagnosed with dementia, and again this was all done over Zoom. So, through Zoom, four of us in STAND lived what a course could look like, and through living that, with Damian, we created our own course, and this is an offer unique in Fife that the course has been designed by people who are living with a diagnosis of dementia, and facilitated by them. STAND received funds from the alliance and has run two courses... oh, I think we've actually run more than that now, I think we're on our fourth or fifth course actually and we have more in planning, and again the influence hasn't just stayed there within STAND and... but DEEP helped us to develop a relationship with the NHS, and the NHS have seen the value of *Living with a Good Life* course and they have granted us some funds to continue its provision. So, again the support DEEP has proved, STAND has branches that are just going further and further and growing and growing.

Through DEEP we met [unclear 25:36] and further online poetry stuff and, you know, the projects... I said earlier, they're too far to mention, and I'm not gonna stop because I could go on, and on, and on. But in... and just in final: DEEP and Rachel were and are our very best friends and they have to take a huge amount of credit to what we have achieved and who we are and where we are today. And I do believe that the pandemic was one of the worst things that happened to us, but as a group it was one of the best things that happened to us because those relationships, and friendships, and links were founded that might not have happened without that adversity.

Rachael: **Thank you so much, Irene; thank you. Ruth, is there anything you'd like to add? Huh.**

Ruth: Nothing at all, Rachael, Irene has said it beautifully, so there's nothing at all that I can add to that, apart from my thanks personally to Rachel: we would have folded if it hadn't been for these Zoom calls in the early days, and I'm a complete and utter Luddite with technology, still probably am,

but I'm better with Zoom now because of all that Rachel taught us. So, the confidence to meet online was something that was use... and quite unique to me, and I think it's just been marvellous. As I said, we would have died if it hadn't been for Rachel and that Zoom call – inspired us completely.

Rachael: **But I think I was also taken by what you were saying, Irene, about how you... you know, Zoom was a lifeline, wasn't it, online... these online meetings became lifelines, but actually as a... as a new group you worked very hard to stay connected to people who could not be part of that. And, yeah, I mean I think that's what's really interesting ab... to look back on, on the growth of the STAND group, you know, as you say you were new and you'd only met a few times and then the pandemic came, and to perhaps to look back on all that you have achieved is quite remarkable.**

We'll come back. But, Maq, can I ask you if you can think back on the lockdown experiences and the Covid-19 pandemic and how you faced it?

Maq: Yeah, thank you very much. The bulk of that has already been said, I don't know what to say in all honesty.

Rachael: **[chuckles]**

Maq: Zoom has actually been part of our life, hasn't it, let's be honest? And one thing I can safely say here is that if it wasn't for Zoom, I wouldn't have met all of you; that's one thing. And the other thing is the beauty of Zoom is that you're at home, you're in your own private place, you can talk, you feel that you're safe and then you can open up. To me it's been a virtual holiday because I've travelled the world. I've seen people from Hong Kong, from Australia, from America, from Canada, and I've got friends for life because of Zoom. And not only Zoom, I think social media in general has played a big part in it: Twitter, Facebook, has given me the confidence, and Zoom gave me the confidence to be able to sit here and talk and open up and come out and talk about the disease, and it's

educated me, and from the feedback that I've had on the Zoom sessions, some people have said that they've been educated by me. So, it was a learning curve for both of us, people learnt and I learnt from them.

And the other thing is that we've adapted to it. You know, we've got a condition that's... let's not get away from that, we can't pretend that we haven't. We are diagnosed with dementia and it does affect us day-to-day, every day, every minute, every hour, and we've adapted, and we've adapted to technology. We have actually been able to access [unclear 29:48] in the manner that I have ended up in sharing some of the non-diagnosed people how to work it, so, you know, we've actually managed to do it. And there are people obviously who were a bit down... further down the line than myself and they were struggling to join us with Zoom sessions, so, what we did was we started supporting them on the phone, and we went a bit further with Beth Johnson's Foundation, the group that I belong to in Stoke-on-Trent, we actually wrote letters to people, and do you know, a letter is so personal and it's handwritten, and it's that person at heart and it means so much to them, the response we had is unbelievable, and, you know, on some of the responses that I've had from letters, bought tears to my eyes, and it also opened up a new avenue, as it were, and highlighted the fact that how much support is needed out there, how much of this connection is needed. And I started a trend there when the... when this Covid came out, and said that I don't agree with the term 'social distancing' because I think that we are at a distance now, but socially we are connected, so I think that term of 'social distancing' should be changed to 'physical distancing' because that is what actually spreads the disease – the physical closeness. Socially: I mean, we're all over the place, and we're still connected, and that connection in Covid was more important than ever.

You know, we talked about... like Irene was saying, when you're first diagnosed, you go into a lockdown anyway, you know, you stay away from your friends, and there are times when you don't want to talk about this, 'cause it's not easy to talk about the condition of this nature, and I

think the thought of having a disease that's not curable has a bigger impact on you than the condition itself – that's what it's done to me anyway. And I remember when Rachel met me for the second time, that's Rachel Nibbles, and she said to me, "I couldn't believe that you were the same person," because I had changed, and the reason why I had... I had changed was because Rachel provided a platform where I could be me and I could... wasn't judged, I was taken as a person, not with a condition, just somebody who was part of the team and who was acknowledged, appreciated and listened to, and, you know, provided a place where I could waste my whatever it is that I wanted to say, and that place was provided by Rachel and that's what really lifted me up from being down there.

And the other thing with Covid was that because this was a lockdown for me, and this lockdown was imposed on me: when I was diagnosed I chose to go into a lockdown, but this lockdown was I was forced to go into it, and there is a difference. When you decide in something yourself, you're... for instance, I'll give an example: there are people that I've met on Zoom sessions who were told that they couldn't drive anymore, I was one of them as well, as soon as I was diagnosed they said you couldn't drive, and I disputed that and I appealed against it and eventually they allowed me to drive. Because although I've got a condition, I still know what my capabilities are, and I have always concentrated on the abilities that I've retained, not the disabilities or the abilities that I've lost, and I think that's what's kept me going. So, this second lockdown we were told to do it and it's difficult to actually adapt to, and that is... that applies to everybody, not just people with the disease. You know, I felt that people with hidden disabilities adhered to the law and listened, it was people that were normal that misused the system, and because of that the [unclear 34:50] the disease went... anyway, I mean I can tell you have somebody on the Zoom session said to me that he went to the shop and there were six youngsters out at that shop and they were sharing the same mask: one was going in and then he was coming back and giving the mask to the other, and he was going in, so on and so forth, and if

somebody's got a hidden disability, that type of action does not do them any good, and that's where Zoom played a big part because we learnt all that from there and we adapted and we tried to come to terms with things and not let it bother us as much as it might have done had we not had Zoom.

Thank you very much for listening.

Rachael: **Thank you, Maq. There's loads of... in there from what you've said, but I'm thinking about the connections that you all managed to create, or maintain, and it feels like that is actually at the heart of how DEEP groups, STAND, the Beth Johnson Foundation was responded to this situation was the kind of... you know, the question of how are we going to maintain our connections to each other, and then I guess what we perhaps had was an opportunity to grow those connections by moving a lot of things online. But I also recall how groups were waiting for that moment that they could physically get back together again. So, you sustained yourselves and your groups, and built and learnt and adapted and shared solutions and ideas as we all had to, but kind of... yeah, then kind of waiting for those moments when safely you could... you could reconnect.**

I wanted to ask a question to all of you including... is she now called 'Nibbles'? including Rachel Niblock, about what... you know, it is strange, isn't it, looking back on that particular period and certainly that first year when we were living under lockdowns that were imposed on us, but I wondered from the perspective of your group, or from the DEEP network as the whole, what are we... you know, what are the things that we might take from that experience, even though we're not kinda thinking about it in the same way that we were when we were living in it, just in discussion now, do you think there are things that you're taking as a group into your... into your work now, or, Rachel, your observations from what the DEEP network as a whole has taken?

Irene: I think we've just learnt... well, I think we've learnt never to underestimate ourselves or each other. Because in 2020, none of us would ever have dreamed we could have done what we've done, and I genuinely believe that adversity always brings really amazing things. And for me it's the real... do you know, the real belief in ourselves and the ability to look within groups and across groups at the talents that are there, and draw on each other. So, you know, the belief in ourselves, but also that willingness and openness to accept help and seek help and ask, 'is there anybody out there that can do this, or can help us with this, or who's done this already?' and so that connect... it's that word 'connection' again, but that connectivity and self-belief I think really were two things for me that were huge in the pandemic that I hope I can take on,—

Rachael: Thank you.

Irene: —much longer, and much further.

Rachel: And it's hard to come up with anything really corny to say in response, but I automatically think of Terry Wogan in order to say: "There's no... there's no 'I' in team," 'cause I think it is about a team, and that's what the DEEP network is, and also what they say when they leave *Strictly Come Dancing* is that you are... we've made friends for life, and I... it doesn't... it feels like we've overcome a lot of this stuff about, you know, personal and professional boundaries in many ways, 'cause I think we all come from a place of recognising what it feel like to be isolated, or to be different, and I'm thinking about our confidence with using Zoom how that all sprang from a couple of ladies being isolated who were living with dementia and then... and the Zoomettes started, and then the Zoomettes created an accessible guide and a film with Aimee and Fanny about how to use Zoom, which was used widely, and then, you know, it's all about that kinda sharing of that knowledge, so that whole ethos of sharing, learning and supporting each other.

And then how the beauty of it, the analogy of a tree, how supporting other trees along the way through the roots that spread and grow, and that

how the roots will support other trees that are struggling to thrive. And so I think it's... it is all about that... you know, that system of, you know, supporting people who then go on to support other people, and I'm thinking about... I just wanted to pay one of my strong personal memories of the... of joining STAND, you know, over Zoom was, you know, people like Fiona who is, you know, no longer with us, but Fiona who lacked that verbal communication skills, yet we were still able to have conversations about the crime thriller that she was reading through the support of her friends. And so I think that whilst Zoom can create many obstacles for the majority of people with dementia, I think it's what comes from the Zooms where people who can take part, how they then go on to cascade that strength and that positivity and that self-belief and those connections, is the most important thing that happens out of the connections that we make, and we made through Covid as well.

And, you know, STAND, you know, it is definitely not about me, it's about you, and about how you are, and the way that you have embraced people who want to talk to you and the kindness that you have shown and sharing of yourselves, so it... I think, you know, Covid has for me, lockdown feels like it created more positives than negatives in so many ways, and that that's... you know, that sounds like a very naive comment to make when so many people's lives were lost, but I mean in terms of in this context I think we've opened up the doors and the opportunities to far more people and those connections. And, you know, I live in Wales so I was on a Wales Zoom meeting and Maq suddenly appeared, and I go, "Maq, have you moved?" [chuckles] So yeah, so... so thank you, thank you for your support as well 'cause, you know, it worked both ways throughout lockdown.

Rachael: **Thanks, Rachel. Any other final comments?**

Ruth: I suppose I would just like to say, Rachael, that it doesn't work at all unless the people with dementia, you know, have the courage to come forward. I mean Gerry and Irene particularly in the STAND group support

me extensively in all sorts of different ways, but none of it would be possible unless they had the courage to come forward.

And I suppose my parting thought would be it's so inspirational that I just wish other people with dementia would feel able to come and be part of a group, because one of the things that we struggle with most is getting people to come forward and be part of a group who says, you know, just take the risk, you know, have that wee element of courage, you don't have to lock yourself down the way that Maq describes, most people do, but there is a way to emerge if you just find other people. You know, peer support is just hugely important and we know it makes a huge difference, so come forward, if you're living with dementia and you're shutting yourself down, come out and find somebody, because there's an absolutely beautiful world out here. Look at the flourishing that these people have done, and all our folk in STAND, do you know, come and find other people, don't sit on your own, you don't have to lock yourself down. It's a... as Maq says, it's an act of choice, you make that choice, you don't have to make that choice, so come and find other folk – please, and there's hundreds of them on the DEEP site, there's a few of us in Fife, but there's... all over the world, there's people there, find somebody, you know, they'll be inspiring – I promise.

Rachael: **Thank you, Ruth. That's a perfect call to action. Maq, I think you had...?**

Maq: Yeah, I just wanted to say that knowing what I know about dementia today, had I known that at the diagnosis, I would have been a different person altogether. I wouldn't have stopped work, I would have carried on, and I don't think I would have gone into a lockdown, and I might have been a better activist than I am now for the cause, and all that – thank you, DEEP.

Rachael: **Ahh.**

Maq: That is where bulk of my education has come from.

Rachael: **I think there's something really tremendous that you've all done today which is to think about the lockdowns that people experience in diagnosis and relate it to something that we all went through, so I think there's a lot... a huge message that I need to process in there.**

So, we've reached our limit. Thank you so much to our audience for being here with us. Thank you so much, Irene, and Maq, and Ruth, and Rachel. Please go and have a look at our lovely report, it's full of joy, you know, and I think... well, it tells the adversity stories, but it's full of the joy and the... and the solutions that you've heard here today, so thank you so much. Goodbye.

[music plays]

[End of Film]