Our Festival launch (with Jane Garvey)

[music plays]

Philly: **Welcome everyone, to the DEEP 10th Anniversary Festival. This is the first 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.**

When we were thinking about how best to mark this year, we were mindful that we couldn't just have one big event, so we've celebrated in person at 17 DEEP events all across the UK. All the events from this year, and this week, will be recorded and available to all; we're recording now. Together these events make up a remarkable and wonderful tapestry to be watched and shared. You won't be visible during this session, but please use the chat box to make any comments, to say hello to each other, and of course to ask questions of Jane Garvey and the 4 Amigos.

Talking of which, a huge welcome to Jane Garvey and the 4 Amigos. As all of you will know, Jane Garvey is a celebrated broadcaster and podcaster. She presented *Woman's Hour* for many years, and also the wonderful and truly hilarious podcast '*Fortunately'*, with Jane *[sic]* Glover; she now presents with Times Radio. It's over three years since Jane came an event that we organised in a London basement, and, Jane, you wrote afterwards, that day turned out to be educational and life-changing in equal measure.

So, I'm now gonna hand straight over to you, Jane, and invite you to ask the 4 Amigos to introduce themselves and get into a conversation with you about DEEP.

Jane: Philly, thank you very much. And it is a real pleasure to be able to talk to you all this morning, I'm very grateful for the opportunity to see some old faces... old fr... old faces – sorry, I got that wrong: old friends, huh, particularly Wendy and Dory who I really enjoyed meeting at that occasion in London that Philly talked about. And when I wrote about it afterwards – I did mean that. I think there's a lot of... as you all know, there's a lot of fear around dementia, and that fear is something that I think grips so many of, if we're honest: we're concerned that we might develop it, we're concerned that somebody we care about might develop it, and we're also very aware often of our own ignorance, and I really found it a really, really interesting and moving day to be a part of that conversation three years ago. So, that's why I'm here today, and delighted to be here as well I should say.

So, I want to introduce the Amigos: Wendy and Dory I've met, as I say; George and Gail are new to me, so if Wendy and Dory don't mind, I'm gonna start with Gail, if that's all right? Gail, just tell us a little bit about yourself.

Gail: Yes, I'm Gail, and I was diagnosed with the dementia at about... well, nearly four years ago now. And I live in Lancashire, I come from a little town called Cleveleys. And I've been with the DEEP now for about two years I think, yeah, and it's just been absolutely brilliant.

Jane: Can you tell us a little bit about your life before your diagnosis? You ran your own business, didn't you?

Gail: I did run my own business. I had my own teddy bear, embroidering business, which we had an online store, and we was very successful, but that there comes a point when you're a sole trader, that when you

have dementia, it's rather difficult to take messages down, answer the phone, and this is when I started to realise that there was something going wrong when people was telling me the orders over the telephone and I was forgetting them and having to ring them back constantly. And figures weren't adding up, and things like that, so that's when we decided that I'd have to take a step back.

Jane: Right, and at the time that you were beginning to have these feelings about yourself and the way you were performing, did you speak to anybody: who did you confide in, or were slightly lonely in all this?

Gail: Very lonely. Didn't want to mention it to my parents, 'cause my parents are still alive, so I didn't want to worry them. I spoke to my hubby about it on several occasions, 'cause obviously he noticed that there was things changing as well, but it was, 'do I go to the doctors?' And we kept putting that off because we put it down to stress, because we'd only just recently moved, so we thought it was just stress with the house move and that's why I was forgetting things and doing things wrong.

Jane: OK, Gail, thank you very much, that's a really useful introduction to you; I appreciate that.

George, I think you are in a different part of the country: where are you, and tell us a bit about yourself?

George: Hi, yeah, I'm George in North Shropshire, in the wonderful North Shropshire Lakelands; we have lots of meres to walk round.

So, I was diagnosed eight years ago, age 63 I think it was, and I had actually just about finished work because I found... I found full-time work... I was a business manager in a school, and I just couldn't cope with it, there was too much going on, and then I got some part-time work, and then I got the diagnosis, yeah. I was expecting the diagnosis, so it wasn't a huge shock for me, I'd sort of done some research and I also

have a couple of family members in the past who've had dementia and really died with it.

Jane: So, would it be fair to say that you were... you were fearful at the time of your diagnosis, or were... was there a level of acceptance from you?

George: There was a level of acceptance. I mean I knew... I knew because of my health history that I was likely to have vascular dementia, but what surprised me, and gave me a little bit of a flutter, was... a bad flutter I hasten to add, was Alzheimer's diagnosis. But after getting the Alzheimer's diagnosis meant that I got donepezil, the wonder drug, which wakes the brain up, and it woke me up almost within 24, 48 hours, so it made a huge difference.

Jane: So, some years on from that diagnosis, you're still... well, I mean you'll present to many people as a very average chap of your age, if you don't mind me saying that: is that how you feel?

George: [chuckles] There's a phrase we all use from time to time, usually several times a day, when we hear people say, "You don't look as if you've dementia," or, "you don't sound like you've got dementia." Yeah, I mean we are all at different levels, we all... we... we... I'll say deteriorate – 'cause it is, but it's... everybody's at different paces. So, I mean I know people in my... in the DEEP group I run in Shrewsbury, who... two of whom have gone downhill very fast in their sort of mid-to-late-60s, and one of whom's now died and another one is really, really struggling, well, dependant 24 hours a day on care, so you know, it's all different.

Jane: Yeah, OK, thank you for making that clear, 'cause you're absolutely right of course.

Lovely to see you again, Dory. Tell us a little about... a bit about yourself. You're in Flintshire in Wales, and how are you doing today?

Dory: I'm fine today. I've got a doctor's appointment tomorrow 'cause I've developed a tremor. But for others who don't know, it says Teresa Davies, which is... that's who I am, but I go by the name 'Dory', in case people are confused, huh.

George: They are now.

Dory: Pardon?

George: We are confused now.

Philly: Carry on, Dory.

George: I slipped into 4 Amigo speak then.

[chuckles]

Dory: You've interrupted me now. [chuckles]

Jane: No, I... and, Dory—

Dory: I was... I was diagnosed when I was 59.

Jane: Right.

Dory: I was a landscape gardener, but I'd already finished that career before my diagnosis, after a car accident. It came as a shock to me because I didn't... I'd never heard... I'd heard of dementia, but when they were doing all the tests and they didn't... nobody mentioned the word 'dementia', you know that they could... it could be dementia, they were doing this test to rule it out or... so when they gave me that diagnosis, it was like I hit a brick wall really 'cause I didn't know anybody else who had dementia either. And they said my life expectancy would be five to eight years, so it was horrible really. And everybody started talking over me or patronisingly sort of, so I did feel, 'yes, I've got a death sentence,' and it wasn't till I got involved with DEEP, which I think was a couple of

years later, that I realised, now, I know it's progressive, you know, but we're all gonna die sometime, aren't we?

Jane?: Hmm.

Dory: And made loads of friends, they built my confidence up and showed me how to smile again really.

Jane: You mentioned the word 'patronising' there, and I think that's so important, Dory. The great thing about DEEP, I imagine, is that it's a place where you don't get patronised, and that's important to you, isn't it?

Dory: Very, yes. Yeah, nobody... we all understand, you know, the challenges, and we can just be ourselves and relax. And the 4 Amigos: we're really great friends, and through the DEEP network, and I don't worry about the later stages now 'cause we sort of educate, or hopefully, educate the professionals not to be patronising, to see us as a person, and I so I think when I come to later stages, if and when, as long as I'm treated with respect and dignity and empathy, which the 4 Amigos, and other DEEP groups, is what we do, try and educate the future people who are coming into that career.

Jane: Brilliantly expressed, Dory, thank you very much.

And that brings us onto Wendy Mitchell. Now Wendy, I've got to be absolutely honest with you, I interviewed you on *Woman's Hour* some years ago now, I can't actually remember how many years ago it was, when your first book came out, and I remember us having a meeting, at Broadcasting House, before your interview, during which I asked, "Well, am I... is this woman... is she gonna able to come on the programme? Is this... is it sensible to have her on live radio? Will it be difficult for her, or embarrassing, or even humiliating?" and I was assured that – no, you would be absolutely brilliant, and you were absolutely brilliant in talking about dementia, in talking about your life, but are you aware, Wendy,

that people do have misconceptions about dementia and about what it does to people?

Wendy: Oh my goodness, I... even now, eight years later, you think you've taken steps forward, and in fact there are certain occasions when you think you've gone 10 steps back: I broke my wrist over Christmas, and I did it good and proper, and the consultant called me and my daughter in to discuss what we thought was the operation, but the first thing he said when we sat down, before hearing anything from me, was, "Well, on paper, you don't need an operation – you've got dementia, why do you need a left hand?" and at that moment you can imagine I was just stunned into silence through the shock of it all; I felt like I'd gone back the eight years ago. And luckily he had the grace to backdown, because my daughter found her voice very quickly and told him, and then I found my voice fairly quickly and told him that I needed a left hand just as much as he did. And he'd made that dreadful assumption that because I had dementia, I'm not worthy of anything, I'm not worthy of the discussion, but as I said, he had the grace to backdown and now I have a fully-working left wrist which I wouldn't have had, it would have been totally useless 'cause I'd broken it in several places, and dislocated it, and he didn't see any need to mend it.

So, the assumptions are still being made in some areas, which shows how much work we still have to do. But unless we keep doing it, and it's that that keeps me going, it's the... it's the bad experiences that keep me going. The good experiences are wonderful, and I think, 'yes, we've got... people are getting it,' but then the bad experiences and you think you... 'OK, let's start again, let's repeat, and repeat, and repeat what I've been saying for eight years.' And it's not just me, it's... you know, eight years before me, people were saying the same things. So, we're continually nibbling away and sewing seeds of... mm, sewing seeds of new concepts, new images that people can take away with them.

Jane: Wendy, I think that's such a powerful answer to my question, and not a... an answer I was expecting, I've got to honest. I'm just...—

Wendy: [chuckles]

Jane: —I'm looking in the chat here and a lot of people are really shocked by what that—

Wendy: Right.

Jane: —doctor said to you – as I am actually. I mean this... presumably this man didn't know that you're a bestselling author—

George: [chuckles]

Jane: —and that your—

Wendy: He did before we left the room.

Jane: Yeah, I bet he did, yes, OK; I mean that is genuinely shocking. Can we talk then about... if you don't mind, Wendy, starting this section off, about what DEEP means to you and what it's done for you?

Wendy: Oh goodness: DEEP means to me friendship of a kind that I've never had before. It means that one word, 'dementia', that people fear so much, has brought together so many good friends. And I call them my second family, because that's what it feels like. It's that instant connection you feel with someone when you hear they have dementia, because suddenly you're not alone, and it's that bond of a cruel disease that brings about a closeness that I've never felt like before.

When I... be... when I was diagnosed, like Dory, I thought it was the end, and I learnt that it wasn't by hearing another playmate speak – the wonderful Agnes. I saw her speak on stage and she'd been diagnosed for 10 years, now suddenly I thought, 'well, she's been diagnosed for 10 years and is speaking so eloquently, why can't I?' and it was at that meeting I found out about a DEEP group in York. But the strength it took

to walk through that door, not knowing what I would find, was so immense, I can't tell you how frightened I was to walk through that door, but once I did – well, all I found were people laughing, people having their cup of tea, people chatting, and people welcoming me, and it was that instant feeling of being accepted that I'm so glad I walked through that door, 'cause I've never come back out again.

Jane: That's fantastic.

Gail, if you don't mind, can we talk about the first time you encountered DEEP: how did you find about out it and what has it done for you?

Gail: I was lucky enough to find DEEP during the lockdown and it was only by chance by searching social media that I'd seen... it was actually a talk by Wendy Mitchell, and I joined... I signed up to join, and I think it was *Tea with Wendy*, or something like that, and that was the first-ever encounter with the DEEP, and then very quickly I got invited to join other things. And we had a group which was like a funster group, and that was absolutely wonderful, and the togetherness that you feel when you come into these groups, because you're with like-minded people, and you don't get treated any differently, and you can say what you want, and you can do what you want, and nobody judges you, and it's just absolutely brilliant. And I'm so glad that I found it because I can laugh with people now, and I can cry with people now, and we've built some wonderful friendships over the years, and people believe in you, and I think this has... the biggest thing for me: people believe in you, they listen to you and they don't ignore you, and that's what DEEP is all about – they're so caring, they really are, it's absolutely brilliant.

Jane: Well, that's a fantastic endorsement. Can you remember, Gail, the first time that you spoke to somebody at DEEP, or maybe some bit of information that somebody at DEEP gave you, or something personal that somebody told you that just made a connection with you?

Gail: I think there's been many people. Because of the groups, there's always been about eight people within those groups and everybody gives you different advice. Whether you take the advice is up to you,—

Jane: Yeah.

Gail: —but it's very good advice because everybody's in the same boat: we're all going on... and a very similar journey, it's not the same, but it's very similar. And some people have been living with dementia a lot longer than what I have, so... yeah. I think Wendy once give me some advice of just do what you want to do, do what you... makes you happy, and I think that's been one of the best pieces of advice because it's what I want to do, so...

Jane: Yes.

Gail: Yeah.

Jane: OK, no, that makes absolute sense.

And I've got to put it to you, George, that you are the only male member of the 4 Amigos: now, what is that like?

[chuckles]

George: Well, perhaps you wanna ask them. It's...—

[chuckles]

George: —honestly, I am... I am an honorary woman anyway, so...—

Jane: Oh good, OK.

George: —and it's absolutely fine. I don't particularly like football and I don't conform to the male stereotype – sorry; that's gone national now, so I'll probably live to regret that.

Jane: Oh, don't worry.

George: But I... we just... we just... we have become such good friends and we know each other so well. We just say things, as will probably become clear, we just pick each other up, you know, like Dory hasn't yet told us what her favourite plant is from her... the time when she was landscape gardening – but that will come.

Dory: [chuckles]

George: I mean Gail is the most remarkable crafter:—

Jane: Yeah.

George: —she can learn, and do, and excel at anything you put in front of her, and she... and by time we've sort of half-mastered it, she's onto the next thing, and it's just incredible. And I'll tell you what: one of the things that I think has come out very clearly to me in the last three years, is about the fact that we may have dementia, our brains may be a bit porous in places, but we can still learn stuff, and no one out there believes we can. They think, you know, what was I told when I was diagnosed: "Don't take any risks, don't get tired, prepare for the future," in other words – plan your death.

Jane: Yeah.

George: I mean, you know, that's a pretty depressing thing to be told. So, we ignore that advice as much as we possibly can, hence Wendy's broken wrist and, oh, I don't know whatever else we ever get up to. And being the only man in the group doesn't fuss me at all. I mean there are lots of men in other groups,—

Jane: Right, OK.

George: —it just happens that this has just been a happy confluence of tributaries.

Jane: Right.

George: Thank you.—

Jane: And what about in lockdown, George, how significant was it?

Participant?: Yeah.

George: Oh God, it... huh, do you know we didn't used to use Zoom, 'cause we didn't have to, and all of a sudden we found that we could meet each other every week, and sometimes even more than once a week, and we just... and we just could natter. And I mean as Gail said, we had a Monday funday group where we just used to do silly things and jokes and dress up and whatever else – just for the sake of it, and nothing else at all. And we got to know each other so much better than... and than when we were just meeting every, you know, four or five months in person, having sort of traipsed around the country to a conference. And I think Wendy pretty much said this earlier, but... I have made the best friends of my life in the last three years. I mean I started going to DEEP stuff about six or seven years ago. By happy coincidence I just met someone who said, "Come to this conference in Llandudno," and I thought, 'oh, I'm not that old yet, but I'll go anyway,' and it... and it just worked, and from then on I engaged with stuff that DEEP, and DEEP groups, were doing. But... where was I going with that...—

Jane: Don't worry.

George: —yeah, I've made the best friends I've ever had.

Jane: Yeah, yes, well and that's not insignificant, is it?

George: Oh God, it's huge, it's huge,—

Jane: Yeah.

George: —'cause, you know, it... we... over... [sighs] the thing is, I can just sort of tumble out of bed, like I did this morning, late, and I'm thinking, 'oh God, how'm I gonna wake up in time?' and I just trundle onto this and we just come alive when we...—

Jane: Yes, yes.

George: —when we push that magic button.

Jane: Yeah. No, it's noticeable, the connection between the four of you is... I can... I can sense it and it's brilliant.

Dory, you'd better tell us now about your... is it your favourite plant? I'm—

Dory: [chuckles]

Jane: —desperate to know. What is it?

Dory: It's not my favourite plant, George. [chuckles]

Wendy: Oh, what?

Dory: There's a plant that I came across when I was landscaping, and it's called... and this is true, George didn't believe me: 'cockburnianus'. [chuckles]

Jane: Right, well I don't believe that either, so we'll move on.

Dory: But it's a raspberry.

George: It's true.

Dory: It's true, it's a raspberry, a type of raspberry cane, or is it a raspberry cane...?

George: I don't know.

Jane: Right.

Wendy: I just knew it was funny, Gail... Dory.

Dory: Yes. [chuckles]

Jane: OK well—

Dory: But George did Google it and it is true;—

Jane: Right.

Dory: —and that's what it's called.

George: And I think that's an example of where Jane would be pulling her hair out if we were on Radio 4.

Dory: Yeah.

Jane: Yeah, I was just thinking actually what a profound relief, in any number of ways, it is that I'm not still doing *Woman's Hour*; anyway, there you go.

[chuckles]

Jane: What about lockdown and the pandemic and your approach to it, Dory, I mean what would it have been like for you if you hadn't had these connections with the people you've met through DEEP?

Dory: It would be... I would have been very isolated because I live by myself, and in the lock... you know, before, I was travelling ev... quite a lot of places, and that all came to an end, so I think dementia would have took over me a bit more without the Zooms and meeting friends, you know the Zoomettes? We had the Zoomettes, and...—

Jane: Yes, yeah, and...

Dory: —the 4 Amigos, and...

George: I'll tell you what... can I just interrupt? I think what we all find so brilliant about meeting together, is the smiles, the laughter and the smiles, and that... if you get... if you... if you meet a really genuine good smiley laughter, once a day, you'll have a happy life because it just regenerates all that stuff that's going inside you,—

Jane: Yes.

George: —and without that, you can become very down, and if you've got dementia, you can get even further down, so it's as much about just smiling and seeing smiles as anything else – regularly.

Jane: Can I ask you, Dory, you met... thank you, George.

Dory, you mentioned living alone: I wonder whether... or you'll have to just answer this, I can't answer for you: is it easier to live alone with dementia, or is it tougher if you're in a partnership, or the other way round? Sorry, my question didn't make much sense, but what is it like—

Dory: No it...

Jane: —as a person living alone with it?

Dory: I find it's better because you haven't got somebody else coming and moving stuff. You know where things are,—

Jane: Yeah.

Dory: —and I can... if I want to go out, I'll go out. Where I think... well, I know people with partners who... and they disable them, they stop them doing things, only because they care, but they're actually disabling the person. So, even if I burn some dinners, it doesn't matter, 'cause it's only my dinner, it wouldn't be a hubby's dinner or... [chuckles] so...

Jane: Right, OK, thank you.

Wendy, I know that you also live... I think you do live alone and I think your daughter is close, isn't she, but not in the same place?

Wendy: Yep, absolutely. I... in the words of one of my playmates from Minds and Voices: "It's sheer luxury living alone," simply because for me, I have to find a way to overcome the challenges that dementia throws at me because there's no one else to do it for me, so it forces me into that

situation where I'm trying to outwit dementia. And as Dory said, for the kindest of reasons, people start doing things for you, it's an instant automatic reaction from people, you know it's nothing unusual, but for people with dementia, that kindness can be the worst thing you can do. Because my daughters, when I first moved into this house, they started putting my coat on, and I began to realise when I was at home alone – I was getting confused putting my arms in my own coat, and I said to them, "If you continue to put on my coat, you're gonna have to come to my house every single time I want to go out for a walk," and they stopped immediately because they were disabling me for... through kindness.

Jane: Yeah.

Wendy: And I... it doesn't matter if I take an hour, it doesn't matter if I take two hours to do anything – I'm doing it myself,—

Jane: Yeah.

Wendy: —and dementia strips away so much from you, but just having that little bit of self-respect to be able to do some things yourself, is huge with dementia – anything small.

Jane: Thank you, Wendy.

Can I ask you, Gail: you live with your partner, don't you? So, what is that like; how does that work for you both?

Gail: Yeah, obviously it was a big shock when I got my diagnosis, I was only 54, and we'd moved here to retire and do lots of things, so it was a big shock to the system. Hubby, I might add, is absolutely brilliant: he let's me get on with it, and he doesn't interfere with what I'm doing, until I need him, and I'm normally at screaming point by then, so he knows anyway if I can't do something. But it's also, I have a terrible feeling of guilt and that comes and goes quite often, because when you're with a partner and you was retiring together and you'd all these things that you wanted

to do, and there's certain things that we can't do now – we try and do what we can – we've just had to adapt and change things slightly. But I still feel that as I start to deteriorate and progress, will I hold my hubby back from doing what he... what I think should be doing, and so I do have that guilt of our retirement is not what it was going to be. But now I try to look at things positively that we are still doing things together,—

Jane: Yeah.

Gail: —and we can still do things. Yeah, so it's just accepting – it's acceptance.

Jane: I was really interested in what Wendy said about her daughters helping her on with her coat, and the fact that in the end she said to them, "Stop doing this," and now she does it herself in her own time: do you recognise that; is that something that has happened in your life that you've had to stop somebody helping you?

Gail: No, not really. I'm quite a strong person that I've always been [chuckles] quite independent, and people that know me anyway, know that I'm very independent, so I think people wait for me to ask them, but I'm not very good at asking for help, that is my other downfall: I don't like to ask for help – I muddle along.

Jane: And a lot of people... well, George certainly said he'd made the best friends of his life as part of the... his association with DEEP: can I ask you about your friends from the rest of your life – how are they around your diagnosis and how are they with you now?

Gail: I only have one friend now. It's funny when you get that diagnosis: the majority of friends slowly deteriorate and stop contacting you, and stop calling round, and stop phoning you. It did bother me and it did upset me, but then when I found the DEEP, I got lots of new friends, and it's a different kind of friendship: it's a deeper friendship because they're people that you can trust, yeah, they... you can share anything with

anybody from the DEEP and you know that you can trust them, and that means an awful lot to have a friendship like that is just wonderful, so the fact that I've lost friends – to me, it's their loss because I've gained lots of new friends.

Jane: Thank you. That's... it's sad though that other people do seem to have let you down, but as you say – their loss.

George, what about your friendship group, how have they reacted?

George: [chuckles] I've got to be candid here and say I didn't have a... very much of a friendship group: I'm a little bit of a loner in life I suppose, and I... my friends are probably basically my garden and my dog. So, I mean in terms of neighbours though, the few neighbours that are... live near me, yeah, they've tended to be frightened of ever mentioning anything, and keep away more than they used to. No, I mean I... [sighs] maybe I... God, I don't know what I'm gonna say here... no, I don't know, sorry.

Jane: What... no, not at all. What about... I'm really interested in the point of partners and people who love and care for you,—

George: Yeah.

Jane: —trying to help, perhaps though sometimes doing too much, is that...—

George: [Well... 38:23]

Jane: —is that something that you've come against, George?

George: Oh yeah, yeah. I mean my wife is very... huh, you know, I'll say the usual things about her being very understanding and so on, and so forth, and she is, but nevertheless, she does things the way she's used to doing them: so she clears things away, puts them in places that I don't... I can't find them, and I keep saying, "Well please, just always return things to the same place," but she doesn't seem to quite click, [chuckles] so yeah, I... and then when I ask she says, "Well, have you looked?" and

[chuckles] I say, “Yes.” Sometimes I have to admit, the things were in the right place and I just didn’t see them.

Jane: Yeah.

George: One of the... one of the symptoms, classic symptoms, is when you look at something and don’t see it, and then you turn round, come back two minutes later, you do see it, so that can be quite stressful for both sides. I mean I... in terms of whether I prefer to live on my own with this disease or not, there are... I’d have to say I wouldn’t prefer to live on my own, just because I’m not that sort of person – I like to have someone around,—

Jane: Mm.

George: —but it is a sort of stress for both sides, without doubt.

Jane: Well, thank you all very much for talking so honestly, and also with... well, just frankly about everything you’ve been going through. And if anybody was offended by Dory’s plant reference by the way, I’m sure there’s a complaint line that you can ring up—

Dory: [chuckles]

Jane: —and we’ll sort that out.

George: [chuckles]

Jane: I’ve certainly learnt a thing or two, again, this morning. So, I’m just gonna bring Philly back in, if that’s all right? But lovely to talk to all of you: Dory, and George, and Gail, and Wendy – you’re all absolutely brilliant, thank you so much for taking part this morning.

George: Thank you.

Dory: Thank you.

Wendy: Thank you.

Philly: **So powerful, thank you all so much, and we can't see all the people who are with us but we can see some of the comments in the chat coming in, absolutely wonderful, this is really striking so many chords. And as with everything connected with DEEP, it's always, always a wonderful mixture of the moving, the sad, the shocking, and the wonderful, and the joyful, and the loving, all those things coming through and that is what DEEP is about.**

So, we're gonna turn the tables a little bit now, and I know each of the 4 Amigos has got a question that they'd like to ask Jane. And Wendy, I hope I've just put in there.—

Wendy: You have.

Philly: **And my...**

Wendy: Don't panic, George, Philly'll send you a message 'cause she's just done that to me.

[chuckles]

Philly: **So—**

Wendy: So, Jane...

Philly: **—would you like to ask your question?**

Wendy: Jane...

Jane: Yes.

Wendy: What has most surprised you since you first met people living with dementia, since your first meetings, what has surprised you most?

Jane: Well, I think it's probably important that if I sort of make it clear who I am and where I'm from: so I'm 58, and my parents are still alive, they are 88, and 89, and neither of them have dementia, although inevitably they

are... they are getting frailer, and I, as a small child, was aware of an elderly aunt of mine who had dementia, but it wasn't really talked about. This was the 1970s and it was something that we all just gently pretended wasn't actually happening to the... to the poor woman. And I think the conversation around all sorts of things have changed so much during my lifetime, particularly during my working life, that it does feel that the conversation around dementia is getting more honest, and it's getting franker, but it's still something, as I said at the beginning, that people are very fearful of. And all of you this morning have been very clear that when you first got your diagnosis, it was frankly a very frightening set of circumstances.

But I mentioned to a friend of mine this morning that I was doing this session today and she.. and she lit... she's a lovely woman, but her first reaction was just to say, "Oh, poor you, that's gonna be terrible," and I said, "No, no actually, no you don't understand, it isn't, because these people are astonishingly articulate and they know so much stuff," and she sort of looked at me as though I'd just gone completely crackers. And I think... that's the thing I'm so passionate about, I think people outside this conversation would be amazed... to be really honest with you, they would be amazed by how articulate and funny and clever you all are, and I think that is the thing that really I wish more people were taking part so they could see and hear what you are all capable of, but I—

Wendy: I think I... sorry,—

Jane: Go on.

Wendy: —sorry, Jane, go on.

Jane: No, you go on.

Wendy: I was just gonna say I think people when they think... when they hear the word 'dementia', they believe it all happens at once,—

Jane: Yes, yeah.

Wendy: —and in fact, you know, there is still a beginning, a middle, and an end. There still is life to be lived, and that's the one thing I want people to hear that when you're diagnosed – it doesn't all happen at once, and that's what I think your friends with images in their head. Yeah, yeah, wonderful,—

Jane: Yes.

Wendy: —thank you so much.

Jane: No, I mean honestly, I think... I mean I think it's also worth saying that you would acknowledge this too, Wendy, that I remember you telling me that you were, before your diagnosis, quite a self-effacing rather quiet person,—

Wendy: Yeah.

Jane: —who probably kept... did that classic cliche, kept herself to herself,—

Wendy: I did.

Jane: —and now you're... you know, you're a bestselling author, a public speaker, and George called you, I think, 'the Queen of dementia' earlier.

Wendy: [chuckles]

Jane: This is... this is an extraordinary journey that you've been on, to use that expression.

Wendy: My daughters call me a gregarious alien 'cause they obviously knew the past me, and that...—

Jane: Yes.

Wendy: —but I quite like this new me.

[chuckles]

Jane: I think a lot of people do, thank you, Wendy.

Gail: My question, Jane, was in the world of presenting, do you think the perception stigma around the 'D' word, 'dementia', is changing; are people becoming more aware that dementia can affect any age?

Jane: Well, I really hope they are, I'm sure that there was a lot of interest from DEEP last week in the new drug for Alzheimer's, which got an enormous amount of publicity, and which I did do a relatively brief interview about on Times Radio, and the... it does sound like this might be a breakthrough, this new drug, which is obviously in development, not yet available in the UK, it may be many, many years away, but I was interested, 'cause I now with colleagues, most of whom are in their early 20s, at the Times Radio station, and they're all great, enthusiastic young people, but they thought dementia really was only something that the over 80s would have to be worried about, they were really surprised when I told them that people of my age, and younger, can be diagnosed with it, and I do think there's an enormous amount of education still to be done, I'm afraid.

I think there was a film a couple of years ago, *Still Alice*, with Julianne Moore, which I think did... which is... she's a great... she's a great actress, and it was a brilliant film and an outstanding performance, and I think that may have altered a few minds, but people... you know, films come and go and the conversation moves on, so I still think there's a great deal of education to be done, I'm afraid. Things have got better, and groups like DEEP are doing everything they can to get rid of the stigma and to be more open and transparent about dementia, but there's still a lot of people who either don't know which questions to ask, or they're too frightened to ask any at all actually, is the truth. And I do think, Gail, that the diagnosis in your 50s is something that most people know absolutely nothing about, which I imagine, if I could be... go back

to you, if you don't mind, is possibly why some of your friends, who presumably were around the same age as you, you know, they weren't able to cope,—

Gail: Yes.

Jane: —they didn't know what... they didn't know what to say or do.

Gail: That's just it, they don't know what to say to you and they don't know what to do, but the thing is we just want to be treated as... we've always been [unclear 47:45], we just want to be [unclear 47:46] the same, the same as anybody else.

Jane: Yeah, yes, no I appreciate that, and I think it's the rest of us who've got to... who've just got to man and woman up actually and get over our... get over our fear – 'cause that's what it is.

Gail: Yeah.

Jane: Thank you.

Philly: I'll just mention and I don't know whether Rachael is able to find this and put in the... in the chat, but Wendy wrote a really powerful blog just a couple of days ago about the way that the new drug is being hailed, so I don't know if you can find that, Rachel, and put that in the chat, that's... and you were making the point, Wendy, that everybody's very excited about a new drug, but actually there's a million people who already have dementia in the UK,—

Wendy: Oh yeah, yeah.

Philly: —and the drug will mean nothing for them and we need to be putting resources into support and peer support and all the... all the other things which can help to make life still be meaningful.

Wendy: That's right, I think... I think I was actually on the Times Radio with some of your colleagues, Jane,—

Jane: Yes, and yes you were, yeah.

Wendy: —and they... you know, I was saying how I've become optimistically pessimistic when I hear these breakthrough headlines, simply because I've been hearing them for so long, and the actual drug will only treat those with purely Alzheimer's,—

Jane: Yes, yeah.

Wendy: —and that excludes a huge number of people, so although it's wonderful, you know, that they haven't forgotten us, it's... you know, we still need the social and technological research to help us living with the condition.

Jane: Yeah.

George: Can I... can I just come in and say I think... and this is another issue with this drug, and that is that it's only available... it will only work with people diagnosed very, very early,—

Wendy: Yes.

George: —and most people are not diagnosed early enough for it.

Jane: Yeah.

George: That there is... it's a great start, and may be the gateway to a lot of other things.

Philly: Did you want to put your question to Jane, George?

George: Well, I think...—

Philly: One question. [chuckles]

George: —I think the question was about what surprised you most, and I think Jane's probably answered it already, so: what surprised you most, Jane, about...?

[chuckles]

Jane: So, it is worth saying that I am genuinely surprised by...—

George: Ahh.

Jane: —by... I have to say, the thing that I remember when I came to the meeting a couple of years ago in London, I seem to remember that day was very hot, which is quite hard to imagine now, but it was a very hot afternoon, and the first thing I heard, as I walked into the room, was the sound of laughter, and that hadn't been what I was expecting.

George: Yes.

Jane: I was actually a bit nervous, I was a bit cross at myself for having agreed to come – if I'm honest, and I think we often in our lives say, 'oh yes, I'll do that,' and then you... the day actually dawns and you think, 'oh God, you know, why did I say I'd do that?' and if I'm really honest, and everybody's been so honest today, I know I can be, I did feel that way that day, but as soon as I heard the laughter, I thought, 'oh actually, this is probably gonna be all right, and I think we'll have a... I think we'll have a good time today,' and we did. And the idea that a diagnosis of dementia means that you sit... you simply sit in silence awaiting your fate, that's the hurdle that we all... and we need to get over, it isn't like that, they'll be some very tough and challenging times, but with the help of good friends and partner, if you're in that situation, and organisations like DEEP, you know, they... it's not all doom and gloom, they'll be some good times and some good days as well.

George: Yeah, and I think... I mean to take that on a bit further: that what we tend to find in the DEEP groups around the country, is that we learn most from the other people in the group. So... 'cause all of... all of us know some stuff about... oh, it might be about benefits, or it might be about council tax, it might be about new symptoms, whatever, and I keep finding that I find out from someone else about something I didn't know and didn't

realise, and they find out from me. So, we are our best support and best... probably for most of us, the only real support that we get, and for that matter, need, in the first, I don't know, two-thirds of our journey, which could be... I say 'two-thirds' 'cause it could be two years, it could be 20 years.

Jane: And, George, is there anything you'd be afraid to say when you meet up with your other Amigos; are there topics you wouldn't discuss in... or is nothing off limits?

George: I think there's probably one topic that we don't go anywhere near, but other than that everything is... everything and anything. I mean obviously me being a bloke and them being women, means that they're not gonna mention certain things, and I'm not mention certain things, but we just don't go there, so it doesn't matter.

Jane: Yeah, no.

George: I mean my... the group I have in Shrewsbury, we are I think it's seven-eights men and one-eighth a woman, and so when the woman doesn't turn up, we do sometimes stray a little bit into maley stuff, but you've got to know each other very, very well before you start instigating sort of ideas about sex and stuff at our age, so I... it is... it is the great untalked of,—

Jane: Yeah.

George: —no, there are two great untalked of: sex and death, and we really need to talk about them both more.

Jane: Yeah.

George: I just don't wanna be the first person to do it.

Jane: No, I don't... but I get that, George, believe me, don't worry. But it's... I'm glad you have mentioned it because it's not like these issues aren't important,—

George: Yeah.

Jane: —because, you know, they clearly are.

Philly: Yeah.

George: Yeah.

Philly: Dory, you wanted to... oh, can we just let Wendy come in first? I can see you waving now.

Jane: Yeah, sorry, sorry, I should have noticed, Wendy.

Wendy: So, on the subject of death: [chuckles] my third and final book is coming out in June.—

George: Oh God, I knew she'd do this.

[chuckles]

Wendy: It's called *One Last Time*.—

Jane: Sorry, Wendy, I talked over you there. When is your book coming out?

Wendy: And I do go through... June, [chuckles] but if we do... and I interviewed the 4 Amigos about the subject as well, you know the future planning, so I... I'm so passionate about DEEP destigmatising the world of death as well.

George: Yeah, yeah.

Philly: Dory, your question to Jane?

Dory: Yeah, I don't know whether Jane's answered this already, but before... did your... has your perception of dementia before meeting... the meeting in London, has it altered since meeting?

Jane: I would say it definitely had... has altered, and I would say it's altered for the better, but it's made me realise what a complicated set of circumstances it is, and how very varied, experiences of dementia are. And... you know, I mean you are... the four of you are a fairly extraordinary bunch of people regardless of your dementia diagnosis: you've all had interesting working lives, stuff has happened to you, you've done things, you've been to places. You're not four ordinary people by any stretch of the imagination, and now you have dementia, but that isn't what defines you, it's what you are currently living with. And frankly, who knows what lies ahead for me or for the people I care for, but I would now, having met some of you, and spoken to all of you, I would not be anywhere near as fearful of a diagnosis of dementia if I were to get one; I really wouldn't be. And I think you should all pat yourselves on the back for that because that's... I'm not talking about the impact just on me, but if more people like me could see and hear from you, I think you'd spread that reassurance because—

George: And that's exactly why we do the 4 Amigo films because we want people just to sit back, relax, and learn a bit, but also just to have a bit of... listen to a bit fun, banter, whatever.—

Jane: Yes, yeah, yeah. I mean I think there's—

Wendy: [unclear 57:35].

Jane: Go on, Wendy.

Wendy: So Dory had the card up, sorry.

Dory: Oh, yeah, locally to me, I'd met other DEEP groups round different parts of the country, but there wasn't any DEEP groups locally to me, so... and

I just thought that was a real shame because people were missing out on this friendship and peer support. There was memory cafés, but they all seem to concentrate on the older generation, [unclear 58:23].

George: Yeah.

Dory: And the people that go – enjoy them, but there was nothing for the younger-onset, and so I set up my own group, I'm called 'LikeMinded', and it's growing, and the people that come say they're so pleased they came along, and we talk about everything: incontinence, all sorts, and we're a mixed group, but incontinence affects men, you know, as well, so we have these discussions and we have a [natter and a chat? 59:03]—

Wendy: And tell them how long... Dory, tell Jane how long it took you and how many visits to the pub you had to make.—

George: [chuckles] Yeah.

Dory: Well, before lockdown, I sat... set it up in a pub,—

Jane: Yeah.

Dory: —early evening, and for nine months I sat there every Thursday night on my own, with a glass of wine, just waiting for somebody to come, and I started to get a bit of reputation...

[chuckles]

Dory: But then one night a lady come through the door and she... and at the end... she lived alone with dementia, and she said, "Ouu, I'm so glad I came, I didn't know to expect, but it's been like a proper night out, hasn't it?" And then it grew and grew, and it was good for everyone because she was saying that things were happening to her, and I was able to share, "Oh, that... yes, that happens to me," and she said she was so pleased because she thought she was the only one that this was

happening to. And we all have different things, but a lot are very common,—

Jane: Yes, yeah.

Dory: —and so I'm so... then lockdown came and the pub shut and people sort of went off the radar, but I've started another one now, at the Mold Rugby Club, called 'LikeMinded' and I think we're gonna need a bigger boat soon.

Wendy: Yeah.

George: Why didn't you call it Moldy Oldies—?

Dory: But I've [unclear 61:10].

[chuckles]

George: I just wanted to mention the DEEP values which I think are really essential to the way we all, well, work together, and meet together, whatever. 'cause Dory mentioned those things that are called Dementia Cafés and they... well, they're very varied, but the thing about these DEEP groups is that we decide what we wanna do, and we pretty much organise what we do. We have some help periodically from others, but that is just purely facilitation, and what I spend some of my time doing is trying to persuade organisations to run groups that are like DEEP groups, instead of putting on activities for us, which we probably don't want, and which only... you know, you name an activity which applies to all 10 people in a group of 10, which they wanna do – you won't get them. So, we just meet socially and if we want to do other things – we'll say it. Like my group want to go indoor bowling, so we'll probably go indoor bowling, just... it's not 'cause we'd enjoy bowling, because it's just an opportunity to have a bit more fun and throw balls around.

Philly: **And we've got a few questions coming in. Oh, just to mention that Rachel's put up the link to the DEEP values, so do have a look at those. Those are...—**

George: Oh good.

Philly: **—those are the things that underpin all the groups across the country. There's about 80 groups now, is that right, Rachel? Yeah, so if there isn't one in your area, just go and sit in a pub [unclear 63:06]**

[chuckles]

Philly: **—like Dory did, and there will be one – eventually.**

[chuckles]

Philly: **So, questions: these are actually for the 4 Amigos, not for you, Jane, but...**

Jane: That's all right, but that's all right.

Philly: **What are the things you wish you were told, or wish you had input from services when you were first assessed and diagnosed? I think we'll just let it go from one thing each in the interests of time. Can I go to Wendy and then Dory?**

Wendy: Well, I would just say I wish I'd been told that no there's nothing that they can do for me, but concentrate on what you can do, there's still much... still much life out there still to be lived – go and live it.

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

Dory: The same as Wendy really, that it's not what we can't do, it's what we can still do, and just handout some hope—

Wendy: Yeah.

Dory: —instead of giving you this death sentence, which is what they give.

Philly: And Gail?

Gail: Yeah, I think if the medical professional made it more of a positive experience, rather than a negative experience, let's focus on the things that we still can do. Don't tell us that we can't do – because we can.

George: Yeah.

Philly: George, did you have one?

George; So, I'd add, the thing I tend to say to people is you're still the same person you were yesterday. Just 'cause you've got a diagnosis, that's just a snapshot of your journey which I mean remember: dementia is in your head, the disease for 20 to 30 years very often before you actually have the symptoms sufficient to actually trigger you to go to a doctor, so it's a very, very long slow process for most of us. So, just remember, you're exactly the same, continue to do what you enjoy, do new things you enjoy, and just go on living.

Dory: Could I just say as well, that we can learn new things, because I couldn't draw even matchstick men before, and then a lady, Frances Isaacs, who lives with dementia, who's a very good artist, during lockdown did videos teaching us how to use watercolours, and I mean I don't think mine are brilliant, but I'm very proud of them really, but—

George: Yeah, me too, there's a few of us who did—

Dory: Yeah, I'm glad that we found Frances.

George: Yeah.

Dory: Yeah.

Philly: Do you want to reflect back on any of that, Jane?

Jane: Well, I just think it's fantastically... it's so interesting, and, you know, to go back to what I said after my first trip to your meeting, it is, it's life-enhancing to hear about... I mean I am absol... I haven't got an artistic bone in my body, and I love the idea that Dory was able to do something new at such a challenging time for all of us during the lockdown; that must have been amazing. But also listening to George talk about how gifted Gail is as a crafter as well, you know, the fact that not only is Gail really skilled, but that George is able to say how much he values her skillset. It's just a... I've just got a real sense of your very genuine and important friendship this morning, and I...—

Wendy: Yeah.

Jane: —I hope everybody else has a well, I think it's... honestly, I think it's brilliant – I really do.

Dory: And Gail did some videos as well and taught us how to do cardmaking and other things.

Jane: Right, fantastic.

George: Oh yeah, we've done a lot of stuff called... we call it 'Craftivism', and we've done all sorts of things in order to in a sense, well, primarily to enjoy them, but also to demonstrate to people that actually we can still learn things, and we can still do them, we are still quite capable, it's just a small bit of our brain has stopped to work... has stopped working.

Philly: And you've got something to show us there, Rachel, that Gail made.

George: It's one of Gail's children.

[chuckles]

Wendy: Amazing.

Philly: Has anybody else got anything they made that they want to hold up?

Jane: Very sweet.

Philly: George, have you got any of your beautiful woodwork around the place?

George: Not the woodwork; I've got a painting.

Philly: Oh God, we're gonna lose them all now.

[chuckles]

George: There you are, there's a painting.

Jane: Oh, that's lovely.

Wendy: Yay, wonderful.

George: And like you, Jane, I... well, I was told all my life that I hadn't got an ounce of artistic ability, and I've now found it.

Jane: Right, there you go, fantastic.

Gail: Yeah, I think... I think so many of us was told whether... when we were at school, that we couldn't do things, or that we wasn't good enough, and as we've got older, and obviously we've got dementia, we have more time on our hands, so what's not better to do but to find something that we want to learn.

George: Yeah.

Gail: And the thing is people should give us the chance to learn. It might take us longer, they might have to repeat their self quite a few times, but we do get it in the end.

George: Yeah.

Philly: Dory?

Dory: Yeah, I'd like to say a big thank you, I know we are DEEP, the people with dementia, but I'd like to thank the DEEP organisa... network,—

George: Yeah, yeah.

[applause]

Dory: —you – Philly, Rachael Litherland, Rachel Niblock, Damian, Steve, who give us the opportunities to do all these things, and give us the confidence and support us to do them.

George: Innovations in Dementia is a) that—

Wendy: And [unclear 69:33]...

George: After you, Wendy.

Wendy: They're the only people that I will do [anything? 69:43] for, but that's how much trust I have in them, because they go that just extra mile to make things happen for you,—

George: Yeah.

Wendy: —and without that, we can't... you know, without their leadership, if you like, they're enabler-ship, we would flounder on our own with a lot of things, so they enable us to do so much more than we ever, ever could.

George: And I... and I find the contrast between the way Innovations in Dementia people run meetings and help us to find new things, the contrast between that and working with other groups, who don't really get it, and who can't run meetings to... for us, they run them for them – it's remarkable, you guys are fantastic, you just have the right values and empathy and emotional intelligence and all that sort of stuff.

Wendy: Yeah.

Philly: **Oh well, thank you very much, everyone. This has been a wonderful [unclear 70:59]—**

Dory: And we'll expect the cheque in the post.

Participant?: Yes, sounds like it.

Philly: **Jane, I'm gonna leave you to wind up for a minute or two and, yeah, just finish us off please.**

Jane: Right, thank you, Philly, and thanks to everybody who's taken part today. Once again, I'm gonna leave a session involving DEEP, feeling... and much more positive than when I started it. It's a horrible grey cold day here in London, and like a lot of people, I've got quite a few things on my mind – who hasn't at the moment, but honestly, you have all really, really made a difference to my day in a positive way. It's been really lovely to see Dory, and to see Wendy again, and to chat to George, and to Gail. I'm hugely impressed by everything you're doing, and I just hope you all keep smiling, and keep talking to each other, and just keep making a difference. Thank you all so much for taking part today.

[music plays]

[End of Film]