

The reality of the lived experience

[music plays]

Rachael: So, I'm Rachael Litherland from Innovations in Dementia. I work on a whole range of projects, but one of my privileges over the last couple of years has to be connected to this film project. We've worked with biggerhouse film, who will introduce themselves in a while, for a long, long, long, long time, and have been working with them to capture some of the stories of DEEP. So, you'll hear a little bit about that. They've ended up in being over 25 films, which we'll put some links into the chat box for you to go and look at all the films.

Martyn, would you like to introduce yourself?

Martyn: Yeah. Hi, good afternoon, everyone. My name's Martyn. I live with dementia. I'm part of the Ashford Phoenix group and I am also a dementia envoy for the NHS, and I've worked on various projects and one of them being with biggerhouse pictures. Thank you very much.

Rachael: Thank you, Martyn. **Dr Michael Andrews, who has to get used to this name, would you like to introduce yourself?**

Michael: Hi, everyone. I'm Michael, and I don't think I'm gonna get used to this.

[chuckles]

Michael: I was diagnosed with a rare form of dementia, PCA dementia, back in 2017. I've been involved, Experts by Experience, for Bradford University and also what... I do work with the other universities, and also done some films with Steve and Tom which was enjoyable.

[chuckles]

Rachael: I think there's all kinds of stories that are gonna come out in this next hour.

Transcribed by gType

gillian@gtypeservices.com | 07753 417725

Michael: [chuckles]

Rachael: Tom?

Tom: Hello. So, I'm Tom Stubbs, I'm one half of biggerhouse films. So, there's a few names that I recognise. Hi Maq, and a Julie, and [Nick's? 02:16] somewhere around, isn't he, on the chat. So, we work with people and collaborate with people to kind of make films and enable to people to try and make sure that their voice comes out somehow through filmmaking, that's our speciality, and it's been a treat to work with Rachael and everybody that we've met on the way through DEEP. So, my colleague is Stephen, he's just here on...

Rachael: Mm, he is actually, he's on mine as well, huh. Stephen? Oh, and you're on mute, Stephen.

Stephen: I thought if I pressed the spacebar it would work, sorry about that. Can you hear me?

Rachael: Yes.

Stephen: Jolly good. I'm Stephen, I'm Tom's friend and colleague. We've been together for a long time making films. I can see lots of people... say hello to Chris there, lots of people we've worked with before, so hello to them; it's really nice to see you again.

DEEP Moments: DEEP Moment is really good title for this project 'cause that's what we found ourselves falling into when we've worked with Martyn, and Michael, and Chris, and Julie, and all these people, we sort of landed in these lovely *DEEP Moments* and we've... especially recently we really tried to slowdown a bit and I hope that you... like the film we did with Michael, 'cause that's the kind of a new way of working is to slow right down and just focus on the moment and not sort of rushing around. So yeah, *DEEP Moment* is a good title.

Rachael: Thanks, everybody. So, yeah, I think we'll... you know, to contextualise what this is about: we had some funding to capture

the stories of DEEP. You know, DEEP is happening in all times and places across the country, in all kinds of different ways, and we wanted somehow to show that variety. So, we went through a really creative process a few years ago, prior to lockdowns, prior to Covid and the pandemic, where DEEP groups were invited to get involved in these filmmaking projects where they would collaborate with filmmakers to make the films that they wanted to make, and we kind of didn't really know what that might look like, so Stephen and Tom set some creative tasks and a number of groups came forward who engaged with that, and almost kind of auditioned I guess through that process to be part of this *DEEP Moment's* project.

So, we are going to show you today some of the earlier films and a couple of quite recent films that are just finishing off this project, and there's... as Stephen has just said, there's a certain slowness as we... as we move through the films today, which we hope you can experience with us. And the final film that we show is Michael's new film, which actually Michael hasn't seen until today, so that'll be interesting. But we're gonna start with Martyn's film. So the idea is that we'll show a film, we hope you'll enjoy watching the film, but you... and we'll put the link in the box where you can go directly to the website to watch all of the films, but we'll show a film, have a short discussion between the filmmakers and the film director, the person to whom the film belongs, and then move onto subsequent films.

So, I'm gonna do a thing that causes the most amount of stress in this whole session, and try and show you a film. So, this is Martyn's film, I hope you can see, indicate... it'll just take a little moment for you to hear the words:

[film clip starts] [06:11]

Stephen: How you doing? It's a funny place to record, isn't it?

?: OK.

Stephen: Are you going to say that: 'how I look at dementia,' or is that just the title?

Martyn: I can't remember.

Stephen: Say it, read it, it's good.

Martyn: How I look at dementia. I think society would learn more if TV wasn't so scripted or clinical, because when it's scripted and you're told what to say, and what to do, it's not real, so the perception is that when people who live with dementia are observed, that nothing is wrong, when actually it's what's going on inside and not on the outside. I am the same person, and I'm also not the same person.

My name is Martyn. I've been diagnosed with Alzheimer's. I live with it. It was hard, but now it's OK. What's it like for me? At times I look into the distance – I don't see anything, I can't pull my thoughts forward and process like I used to – it can be hard. All I want you to do is talk to me. I want you to pick my brains.

My daughter said to me, "What's it like?" and it's like hard for me to explain: I sit there, but I'm not thinking of anything. I mean, I spent 17 years in the army making split decisions. To go from that, to this, I think, 'what am I doing? I can't remember how to do that.' And if you talk me normally, you'll find a trigger point: if you can hit that trigger point – I'll have a conversation with you.

So, I can climb my ladder into my attic and I can look through my boxes of memories, I want you to help me sort stuff out. I have two different worlds going on: world one – that's my good days, and I'm OK. World two – that's my bad days, I'm at home, I'm stuck.

But yeah, no, I'm out in the fresh air, out in the sun, nice and peaceful and I'm feeling good.

I am ex-military, and we project ourselves. We can get on with things, but we are now vulnerable, so we put a shield up. It's a protective mechanism, but the shield is breaking.

I mean, why have I come out with only glove on?

I've not drawn since I was eight years old, but I was at a conference, I joined into an activity and I just drew something really quickly. Someone said it was amazing. I picked up on that, so I draw things now, and when I'm drawing I'm in another world, it's a third world, one that I'm using my mind, and I like it when I'm there.

[film clip ends] [10:54]

Rachael: Lovely film, Martyn.

Martyn: [emotion: crying]

Rachael: Shall I go to Stephen and Tom? You take your time.

Martyn: [unclear 11:07]. I found it... I found it very emotional to watch, but I mean it's not tears in my eye... it's not tears of sadness, it's tears of joys, and joy, and I think part of it is the wind coming through and it's affecting my eyes. But... I felt very humble and very proud to be a part of something so unique and special for me to be able to express how I felt, and hope to dismiss some of the stereotyping and the stigma that goes along with people who live with dementia.

And it... I didn't want to say much, but what I will say, there's a couple of little things I wrote down, and that was about the whole filming process itself, and I'd really like to... you know, a very special thank you goes to Tom and Steve, [emotion: crying] because what they was able to do was to actually extract exactly how I felt. I'm sorry I can't...

Rachael: No, thank you, Martyn. I don't know if I can ask Tom and Stephen to respond now, but maybe you'll just dip in?

Tom: Well, the humb... the humbling... I was gonna say the humbling goes back, Martyn, 'cause you... but everybody that we worked with on all the projects, each group, we worked with four different groups in different parts of the country, but everybody had a kind of... something they really

wanted to kind of get out and communicate, and Martyn was... wasn't... the exception that he really wanted to communicate the kind of feelings, and like he was saying, Martyn, trying not... trying to chip away at media representation and stereotypes and other stuff like that, and it was just... it was... when people are so up for the challenge of making a film, that it was really, really, for us a very fruitful collaboration as well, it... you know...

Stephen, is there anything you'd like to add? I know you're...

Stephen: Incredibly moved by that. Martyn, I don't think we should be frightened to show our emotions to have some react to a process of working with us like that; [emotional voice] it's quite extraordinary actually. So, thank you for that, yeah.

Tom: So, Martyn, but just on a kind of more... you've... that's now... 'cause I just checked the date, that's now two years old, who... so... and it's been up and about on the net, and who've you shown it to and what comments have people said and...?

Martyn: Erm—

Tom: Only if you're... if you're comfortable talking, that...

Martyn: Yeah, I'm all right now, I've... Yeah, I mean I've posted in on social media and posted it round to many people who I know. I'm trying really, really hard to promote awareness, and I just felt... I've watched every 20-odd films, and every one of them has such a poignant message to me, and... [sighs] and the biggest thanks has to go to you two guys because of... and I will be quick now because I know... and I don't wanna take up everybody's time, but actually it was, with... right all the way from the process from the beginning when you sat down with us and you had the flipcharts and the boards and the crayons, or chalk, I can't remember exactly what it was, and we was all writing down notes, and we came up with a plan, and all the way through the whole process we were talking to you, you were listening to what we were saying. And the one biggest

thing that I really wanted to put across is... and I can't remember if it was... which one of you guys it was, or... we sat in the Eureka and I said to you, "What I won't do is for you to give me a script and say what someone wants me to say. I will tell you how it is from my heart, and how I feel, and how I see things," and you took that on board and you allowed us all the way through the process to say how we wanted to say it. The only time you ever helped is I recall I sat in the car and you can see me looking down at my paperwork, and that's because if I remember you wrote it down for me, typed it out, and you gave it to me the next morning, and so I was able to keep refreshing my memory. But like I say, all the way through the whole process, right up until the end, it was fluent all the way through. And we was allowed to be flexible, you allowed us to be flexible, there was no pushing or shoving, it was very jovial, even to sit down on Sapphire Hill when it was cold, and we was all sat on the table having lunch, and laughing and joking.

I'm definitely not gonna be the next Tom Hanks, but what I'm able to do, and what I feel confident is doing, is actually standing there in front of anyone and telling them how it is, and getting rid of that stereotype, so thank you, everyone.

Stephen: Thank you so much.

Rachael: Thanks, Martyn, you've done that in spades. And I just want to say that your... you may know that your family are here watching and they're rooting for you in this chat box. There's a lot of... and I... it's a powerful message: "You've done exactly what you wanted to do, Dad," so thank you.

**There's a few more films to watch, Martyn – can you cope?
[chuckles]**

We're gonna watch Julie's film. Julie from Pathways, one of the original films. We've got a different Julie's film at the very end, but this is one of the... one of the original films, and Julie isn't here, but

I think for me this is a really special film, and we can ask Tom and Stephen a little bit about what it was like to make that... this film.

[film clip starts] [18:22]

Julie: I've just got to give myself an itch there, there's always one, i'n't it there, just one little bit there, that'll do.

Stephen: Are you ready?

Julie: Yeah.

Stephen: OK, so the first line is, 'I feel embarrassed because I'm getting old.'

Julie: I feel embarrassed... I feel embarrassed—

Stephen: 'I feel embarrassed because I'm getting old.'

Julie: Yes. I feel embarrassed because I'm getting old. I was once a nurse, mm, it was lovely.

Kit?: Who's that?

Julie: Ah, me in Australia.

If you can make somebody healthier by smiling, or whatever, and families going in, mm, you know, I can't... yes, I can't work it... I can't... I can't... I can't... I don't know what I want to say really.

I used to do athletics, then I grew up, and then I met Kit Swann.

Stephen: And how was that?

Julie: Beautiful, because I love him so much.

Kit: Right, OK?

Julie: Yes. Yeah, who's that, Kit?

Kit: Me and you.

Julie: Is it really?

Kit: Uh-huh, can't you tell by the shorts? [chuckles]

Julie: Kit: he'll do anything. He's got six sisters, and we all got together and we all knew each other and it was...

Look at that red hair, I wonder where he got that from?

Who's this, Kit?

Kit: It's Helen, our daughter, Helen.

Julie: Ah.

Stephen: What frustrates you most?

Julie: My memory sometimes, it's running away from you. I go, [clicks fingers] and it goes black, [makes vibration sound with mouth] they'll be... they'll be shutting us out at the bloody place. [makes vibration sound with mouth]

Stephen: And how do you feel today?

Julie: Oh fabulous. It's nice sunshining and, yeah, mm, talking to people and everything and chatting and, 'what did you do, and what do you think,' and it's just chit-chat, chit-chat, so... yeah.

Kit: Are you learning how to do the dance?

Julie: No.

Kit: A bit further out that way again.

Julie: I love to dance. No, no, it's too deep is that, i'n't it?

?: Wow, what a mover.

Julie: I like to dance. I love to dance.

Stephen?: That's beautiful.

Julie: It's almost like running around. Sometimes I'll pick someone and I'll just make them dance, because if they didn't want to do it, they wouldn't do it, would they? Were it you?

Stephen?: Me?

Julie: You?

Stephen?: Yeah.

Julie: Can you dance like that?

Tom?: I don't know, can I?

Stephen?: Is Kit a good dancer?

Julie: Well, that depends on what you think.

[Julie and Kit hum tune]

Julie: That's my foot. I get angry with Kit, poor lad, for no reason, no reason at all.

[humming continues]

Julie: He does all the things that I used to do: the cooking, the baking, the kids, the kids are all grown up now anyway so we don't have a right lot to do. He keeps me going. He does everything. [sings]

Julie: Where's Kit?

Stephen: And then you said something like, 'then I feel bad for shouting at Kit.'

Julie: Yeah.

Stephen: Can you say that?

Julie: Then I'll get bad... [emotion: crying]

?: Are you all right? He looks after you, don't he?

Julie: He does.

?: Huh-huh.

Julie: Thanks.

?: That's all right.

Stephen: This is a good line.

Julie: Go on.

Stephen: 'It's better to be laughing than crying.' Can you say that?

Julie: Yeah. It's better to be laughing than crying.

Stephen: Louder. [whispers]

Julie: It's better to be laughing than crying.

Stephen: Louder. [whispers]

Julie: It's better to be laughing than crying. It's—

Stephen: I believe you, I believe you.

Julie: I can't see a blessed thing now, all water's pour... [chuckles] pouring down here. Oh dear.

Stephen: Really, really... that was brilliant, wasn't it?

Julie: [chuckles]

Stephen: How do you feel now?

Julie: All right.

Stephen: Mm?

Julie: Yeah.

Stephen: You just got sad, didn't you?

Julie: Yeah, thank you.

[film clip ends] [23:23]

Rachael: I feel I should have put a little health warning on today's session. [chuckles] But as you say – it's better out than in.

So, Stephen and Tom, is there anything you'd like to say about the making of that film with Julie?

Tom: Well, Martyn and others that took part would... will recognise lots of similar elements. We always recorded... we kind of worked and chatted... Martyn mentioned it a bit about flipcharts and notes and writing down and hearing stories without really at that point getting much of the camera out, and from those notes bits of ideas of a script would come about, and depending on the person, if they felt comfortable talking out of script, they would talk out of script. Or with Julie, Stephen was recording the voiceover and was prompting her with lines that we'd already... she'd said and we just copied down.

But I guess what we always try and do is be spontaneous and improvise, and... but when we... with Martyn's film we decided that we needed to get out of the building that we're in and that we went to that place on the coastline and it was just... it seemed the perfect place, the weather was lovely. And when we were up in Bradford we had access to the City Hall there and the total run of the place, that would... there was hardly anyone else there, we... and we were able to suddenly go into these big rooms, and it seemed... and we just used it, and that both Kit and Julie came, I think they were relatively new to the group, and then it just... we'd always thought, 'well, we should just make the film with the person who's got dementia and is part of the group,' but with... but then we just tore up the rule with that and Kit... Julie always seemed to always want to refer to Kit and he kind of came into the film and supported the film and that they wanted to do this dance, so we were like, 'yeah,' and then where do we go dance, and we found a lovely kind of... there's a mod... it's a bit like... it became a bit like a fairy tale almost that there was a picture of the

building outside and then there was a model of the building and then they were dancing past the... you know, I... from a filmmaker's point of view the... Julie's one... lots of things just suddenly happened that were just like, 'yes, brilliant, this is... this is really great,' and they also... Kit had bought... and I think he had got it, a series of photos that he's been... he had been doing some kind of work with Julie, just keeping her memory of all her family, so that's where those... the photo montage sort of came from.

Anything else, Stephen, about... but it was very spontaneous to work with everybody, so hopefully you got a bit of that... a sense of that with Julie and a sense of that with Martyn's film, so... Stephen, anything to add?

Stephen: I just love... it's the same with Martyn's as well, I just love the lovely connections that we make the relationships that we make when we're working with people when we're making films is what's striking me at the moment; I'm not really thinking about how we do it. I have noticed though that I really like the playful nature of a lot of the work we've done with you all. I like it when people want to play and take a risk, you know, even if it's just doing something we haven't done before.

I remember with Martyn's group actually, I know there was quite a lot of reticence at the beginning, 'cause people hadn't done it before, so I love the fact that people take a risk with us, and I love the fact that Julie was up for playing, and I do like the playful nature of the work, and I think that really comes through. Yeah, thank you.

Rachael: **I'm just wondering from Martyn's perspective and Michael's perspective, actually it can be... to take a risk you perhaps need to feel safe, huh, so... and I think you perhaps touched on this, Martyn, but you know the kind of... you know, making films that you're quite... it's exposing, isn't it? And that's kind of what I'm just thinking, and yeah, you're saying like, you know, you're really pleased that people did want to play with the ideas and take a risk,**

but I suspect you created very... well I know you created very safe spaces in which that could happen.

Martyn: I think both Stephen and Tom, and I'm assuming that they read the DEEP literature on... I can't remember what it's called, about the filming if you... if you're doing a film, these are things which you should take into consideration, and when you read through it, it's like Stephen and Tom had read it, chewed it, and remembered it, because everything we went through, there was so much empathy there, and listening. And going back to what Stephen said about being jovial – we was, and there was scenarios where [Mick? 28:15], Mick who was... one of... part of the group, was quite funny, and [Brian? 28:20], but Stephen and Tom had that ability to... because they were listening, able to draw that part out of us, and that's what came across. So, everyone in the group, including Chris, who was part of it, Tom and Steve had that ability just to draw it out from us, and that's what made it so good as well.

Rachael: Martyn, you'd said about Stephen and Tom having read all the DEEP guides, and that's great, you know, we've got loads of ideas there about how to communicate well with people with dementia, and to create films, but actually we worked with biggerhouse a long time ago before DEEP came into fruition and Tom made four, not dissimilar, films with individuals with dementia in 2008 or nine maybe, and a group of... a group that became a DEEP group, the Forget-Me-Nots in Swindon, and I guess we... so we were encouraged from our funders to find a professional filmmaker to make these films, we thought we could have a go ourselves, I don't know why we thought that, and we were encouraged to find professional filmmakers, and biggerhouse were recommended to us as having that particular approach and ethos that would fit really nicely with kind of where we were and what we needed, so I think we had just one of those ongoing partnerships that, yeah, we trust... I guess we trust that if we send out this film company to work with DEEP groups, that they share the same values that we do.

So, I'm a bit worried now about premiering Michael's film, huh, given that we're in quite an emotional place altogether, but I think it's a lovely film and it's [low? 30:18], so we've got 10 minutes now to just sit and enjoy this film at the seaside.

[film clip starts] [30:28]

Michael: He's gonna drag this.

Stephen: OK, second camera. The main camera.

Tom: What am I doing?

?: [unclear 30:48], yeah, lean against the...

Tom?: I might want to wait for this canoeist.

Michael: There's gonna be a lot of noise now because he's gonna drag this.

Stephen: Well, let's just enjoy it then. Have you ever fancied that, Michael?

Michael: I have done it.

Stephen: Well, I beg your pardon.

Michael: Yeah.

Stephen: Tell us about it.

Michael: A bit younger days with the army.

Stephen: Do you miss the army?

Michael: I do yeah, yeah.

Stephen: Tell me why you miss the army.

Michael: 'cause I... you're fit and you can do everything. Now, you can't, you can barely walk.

Stephen: We had you running down the beach to get to the seat though, didn't we?

Michael: Well, I wouldn't say running.

Stephen: Are we all right, Tom?

Tom: Yeah.

Stephen: Look at that lovely boat.

Tom: It's gonna come through the shot, [unclear 31:46].

Stephen: Just watch that, Michael, that's pure gold that is.

Tom: And it's coming back out and [unclear 31:55], perfect.

Stephen: Michael, how's your life right now?

Michael: I think I'm a bit content, I'm happy. Yeah, I could be happier, but I'm... yeah, I'm happy.

Stephen: What are you happy about?

Michael: At the minute being on this holiday and having fun and joy. A break from the usual rigmaroles of Bradford.

Stephen: What do you miss about Bradford?

Michael: [unclear 33:00], there's not really a lot you can miss about Bradford. [chuckles]

Stephen: So, I'm just leaving lots of spaces 'cause it's just really nice to see you thinking and looking at my question, and thinking about my questions. I just wanted to more into inside the real Michael. What's inside the real Michael?

Michael: I would be honest that just... I'd be a lot happier if there was no dementia; get your true self back.

Stephen: How does dementia stop you from being your true self?

Michael: There's too many barriers – it holds you back. The biggest thing I have is... now, they always say to me it doesn't really... you shouldn't worry about it, it was reading, writing and arithmetic, and when you've done that all your life and then all of a sudden you can't do it, and they keep saying they know... "Don't worry about it because there is people that can't read and write," but when you've done it all your life and then all of a sudden you can't.

[dog barks]

Stephen: [unclear 34:27], and cue irritating dogs. [chuckles] Sorry about this, Michael, I did say to them earlier, but you know... I slightly lost my thread then. That was about the frustration, wasn't it, of dementia. So, you can... you were aware... 'cause you must be aware of those things that you can't do, which might make it even more frustrating?

Michael: It does, but they keep saying to you, you know, "Life goes on, you can still do things," but there's a lot of things you can't do, and the things you can't do is the things you always miss. I mean I used to love reading Stephen King books and I used to love reading true life stories, and then all of a sudden you can't read them. If I do pick a book up, I can read a paragraph and then the words just... they seem to jump off the page, and then you've got to put it down and then leave it for so long, come back and just hope that your memory... you can still remember what it was you've read, otherwise you've got to start from scratch again. It sounds daft but if you give me a big... a big book, where somebody could maybe read the whole book in a couple of weeks, and maybe, you know, a couple of months, it would take me years to read it.

Stephen: Is the mic OK, Tom?

Tom: Uh-huh.

Stephen: There's something so good about sitting here actually 'cause we... this is a good place to sit and talk, isn't it, 'cause when we were on the pier, it wasn't so good, was it?

Michael: No.

Stephen: What's good about where we are... I mean I chose this spot, but you saw it as well, didn't you?

Michael: Yeah.

Stephen: Because you're a photographer, you can tell what it looks like. What's good about this spot that we're in now?

Michael: It's just nice and relaxing and the sound of the sea, and there's something about the sea, it just relaxes you. I've done the same... the room I'm in, because it's right at the front, I sleep with the window open and through the night that's all I can hear is the waves, and it's... oh, it just puts you to sleep, and I think last year I recorded it so I can listen to it at home.

Stephen: You don't play videos of us when you're trying to get to sleep, or at home?

Michael: No. [chuckles]

Stephen: You could film me and Tom just sort of looking into the lens with some waves in the background, to help you.

Michael: [chuckles]

Stephen: Sorry about that. Even I'm find... 'cause I find it very difficult to relax, so I'm just finding sitting here, next to the sea, in this spot, we're slightly... we've the people watching us, Elaine with the microphone, but it's still kind of enclosed, isn't it?—

Michael: Yeah.

Stephen: It feels really nice and safe, yeah. Lovely. Tell me about the music in your life.

Michael: I actually love music. But that's another problem with dementia – it affects the music. I've always been able... well, I was able to read music,

and now I can't. It's the same as reading the book, that you've got the stuff with the notes on it, and the notes just keep jumping all over the place, so you just can't read it.

Stephen: But you do still play 'cause we forced you to play in one of the videos.

Michael: Well, it's all by ear now I do it, but then you get... well, you're doing it you're put the spot and then your mind goes blank, and I can't remember what the tune was or...

Stephen: It's like thinking about the sea and what it feels to be by the sea and chat... how does it feel when you're playing music and you're not worrying so much about the notes?

Michael: It's just total relaxing. I actually find if I'm sitting at home and I'm having a really bad day, I pick an instrument up and start playing it, you forget about everything else, so your dementia sort of goes then because you forgot about dementia, and then just sort of play away, and then after you just feel chilled out, you just feel relaxed.

Stephen: And let's just relax here for a little bit and then stop. It's very peaceful, isn't it? You all right, Elaine? You all right, Julie? All right, [Lawrence? 39:03]?

Lawrence: Yeah.

Stephen: [Handy? 39:05]. It's good here, isn't it?

Michael: Yeah. The only... the only trouble I have of music now is I can't remember the name of tunes. It'll be in my head what I'm playing, you know, 'oh yeah, I like this, I'll play this,' but I can't remember what it's called. You know, so if somebody was to say to me, 'well, do you know such and a tune?' and I'm thinking, 'yeah, I know it, but I can't remember how it goes then,' 'cause you lose track of the names.

Stephen: There must be some harm when people say, 'yeah, but don't worry about it, it doesn't matter,' because...?

Michael: That's... and they all say that, but it's not them what's got it.

Stephen: How do people help then?

Michael: Just leaving me to my own devices, and sometimes and peoples trying to help and they're more a hinderance than anything. They think they're doing good, but they're not, they're making the situation worse.

Stephen: Strike a chord, anyone? People try and help and they make it worse? Yeah, Julie? 'cause everyone's nodding [chuckles] Elaine? People try and help and they make it worse. OK, let's stop. That was really great. Cut, everybody. There's gonna be a loud noise, Elaine.

[loud bleep] [film clip ends] [40:33]

Rachael: Fantastic. So, Michael, Stephen, Tom, the premier of that film, different pace; different pace. Michael?

Michael: I would be honest, and if I go back to what Martyn said about Stephen and Tom have a way of drawing out something from you. I mean they sort of drew out of... what was going through my head just by the way they say something and it triggers something inside you and then you try to answer it. So, I actually... hats off to Stephen and Tom and the way they work. They've just got this way of drawing things out of you.

Rachael: It's all very implicit though isn't it? I don't know that you said a lot actually, Stephen, in that... in that film.

Stephen: Yeah, I think it was all about the space that we found. And I would like to say that moving on from Martyn's... moving from Martyn's film, and Julie's film, and the fact that we learn a lot to making this work, and this is what I really... well, 'cause Tom and I had an experiment on the last project, just going to Llandudno with Pathways, we didn't really have a plan, so we just sort of let ourselves be open to see what would happen, and it changed the way we worked, and I really... the film with Michael, it was like a conversation, it's a different way of making a film, and I think Louise has said how different they all are, in the chat, it's a very different

way of filmmaking, and it's something that's new for us, and new for me, is to allow that space, and I really like the audience seeing us together and making the film. So, you've got Lawrence and his wife, and then Julie's doing the other camera, you get a sense of this group of people making the film, not just the person in front of it. So, in Michael's film you get a lovely sense of him and us taking the space to make it, and you also see everyone making it. And that's changed the way Tom and I make films, working with you lot has changed, and I've certainly personally been encouraged to slowdown.

Rachael: Tom, is there anything you want to add?

Tom: Just that it's the... the hardest thing about filmmaking is being in... being in a... is getting to the space to work, but kind of when you're... with Martyn's film we went to the seaside, huh, Michael's... and this... we... with this film, going to Llandudno, we needed to and wanted to work again, 'cause we made such a nice connection with everybody and we just thought, 'let's see what the people at [Bradford? 43:33] are up to,' and they were going to Llandudno, so we just said, "Can we come along too?" Being in that... so being in that... being in the space, and I guess we're just trying to... we're so used to sometimes overthinking filmmaking and that's what's just... so for this particular experiment with Martyn, we did do some other little bits of filmmaking, but this was just a lit... of all the thing, and we've obviously... there a few people like Lawrence who was there that we made a film with, and Julie, and that was our first time, but because Michael was our sort of person that we'd worked with, you know, we'd met him... met him a couple of years before and obviously been chatting to him on Zoom since the pandemic and stuff, it was nice to just do this other thing and then suddenly realise later when you get back, when you look at the footage, that an experiment... it's just worth just showing it as this is – a conversation...—

Michael: Yeah.

Tom: —a 10-minute... literally, and that's the same... you know, there's not... there's editing in that we jump to different perspectives, but there's no editing in terms of—

Stephen: But nothing's cut out, it's really important when people have watched our films and then nothing has been taken... and usually we chop, chop, chop, chop, chop, chop, and nothing's been deleted, we just let the whole thing go, so thank you for going with it, thank you, Michael, very much for letting us do that.

Tom: Yeah, and it's... as Stephen said, it's like... for us we're thinking, 'next time, how can we find space?' That was... it was... like it was... it was the sound of the sea, it was your back was against the wall, how can sometimes being... and we were doing it in the recording with Martyn, how can we be next to Martyn rather than across interviewing him like that, we would... Stephen was sat in a car, 'cause we only had a... sometimes it's like necessity: a car is actually a really good space to do a voiceover 'cause it's got a padded ceiling and it's soft and as long as they're not... like there, as long as it's not too noisy, it sounds really good, but also you're next to somebody, and I think that's why some... that's why people in... when they drive you often have more interesting conversations 'cause you're not looking at each others' faces, you're engaged in something else. So, we... it's inspired us to sort of think about, you know, if we're ever in situations again, how can we nudge the situation to be more open and more kind of conversational, like Stephen was saying, and kind of give space so people could just talk.

Rachael: **Yeah, that sitting alongside people is perhaps, yeah, not what we think of as film... as a different approach to filmmaking. And I guess that's what all of these films were about, you know, that kind of collaboration with all these people with dementia and all these groups who were involved in that project, and you can see that in some films, it's more explicit in some of the films, isn't it? So, I think we saw that very much, as you just said in Michael's film, that you had members of the group holding cameras, holding**

microphones. And I think in Pathways original film... so each of the original groups had individual films for people who wanted to get involved, like Martyn and Michael, and then a little group film as well, and I think in the Pathways film, their group film, you see that editing process, you see that collaboration in terms of actually making the film together, and that... yeah, that is very different often than the way a filmmaker approaches a situation. I... having watched Michael's film last week, I was absolutely lulled into that seaside place. I really felt like I was sitting with you in that end of the pier kind of space and listening to the waves and it was incredibly relaxing.

We've got a few comments in the chat box: "The slow pace is very appreciated." Somebody said that they really like this... all the difference in these films and what an insight it gives to dementia, and I think that's... you know, if you watch all the films collectively, there's such a lot of insight that comes from everybody's different experiences. And, [chuckles] "I think it's a real skill when something that is so professionally done just looks like mates having a chat." [chuckles]

Tom: Well, it was... the thing is – it was.

[chuckles]

Tom: It was... you know, it's... you know, we... it felt... you know, it was lovely to see Michael again and spend that time, and around... on that particular holiday, around that we were sharing meals, we were all in the same hotel, so it... we were on holiday with the Bradford Pathfinders, in Llandudno, with some equipment.

Rachael: [chuckles] So, we've got about five minutes left. I just... I mean I think you've touched on this already, but has it changed the way you make films, Tom and Stephen, this particular work?

Stephen: Definitely; definitely. This whole idea of the third... the second camera that sees everything that's happened. The whole idea of showing the process of making the film while we're making it, that's... and that's... and that's new and that's come from the *DEEP Moment's* project, and I really, really like that. We've done more of that in this recent batch of films. We've shown a lot more of the making of, and other people... well, what's actually going on, 'cause that's the reality of it. We're not doing... they're not... they're not on their own these people, we're making these together, and I want the audience to know that, so that's changed. And also as I said before, this just making space, slowing down, letting the things that go wrong stay in the film, you know the dog going past, or one of us forgetting what to say, or slightly losing track at one moment and then just stopping. I really love the audience seeing that, and usually in filmmaking you hide that,—

Rachael: Mm.

Stephen: —it's all cutaway.

Rachael: Martyn and Michael, I... again you've both touched on this, but what... you know, why's it important for other people to watch these films?

Michael: I think...

Martyn: Yeah, go on, Michael, all right.

Michael: I was just gonna say the films actually show that we're still a person. Yes, we have good days, we have bad days, but it actually shows we can... we could still do things. You know, we've still got feelings, we've still got emotions; these films actually show this.

Rachael: Thank you, Michael. Martyn?

Martyn: Yeah, I'd like to echo what Michael said actually: it is, it's... you know, people have to understand that we're still us, and there are changes, and changes will come... will come on in the future, and it's just making sure

that, you know, you need to keep up with what's going on to understand, and keep talking and... 'cause we still need help. You'll certainly be told if we don't need help because we tell you, "We don't need any help." But sometimes we don't ask for help 'cause we forget, you know, and I think you have to be aware as well with people with dementias – they do need help, but sometimes they're not afraid to ask for help, but they don't realise they need the help, so it's under... it's having that understanding as well.

And I think my last point is, Michael, I thought your film was great, the only thing that let you down actually was talking about Stephen King,—

Rachael: [chuckles]

Martyn: —and I have to draw the line at Stephen King,—

[chuckles]

Martyn: —otherwise I was...

Tom: That's all about taste though, isn't it?

[chuckles]

Tom: [unclear 51:33].

Rachael: But I think that's what's the wonderful thing about the films in their totality is that they are the films that people wanted to make about the things that were important to them. They're so different. They're so full of humour and insight and individual life experiences and hopes and, huh, wishes, and that's the beauty of them. And I guess that's what we try to capture, or that one of the purposes of the project was to show that vast array that Michael's film is gonna be different than Martyn's film, it's been different than Julie's film, and that's the nature of dementia.

So, I want to bring this session to an end. Thank you so much to our audience, I hope everybody's OK, huh. We've had a chance to

support each other, and I know you're all sitting away from each other, so I hope everybody's OK. I will pop my email into this chat box here in case anybody wants to drop me a message. But thank you so much for being with us today. So, I want to end by showing an extract from the other Julie's film. Now, you... I know Julie's in our audience and I had her permission to show this. It's an extract from a film similar to Michael's film that she made at the same time, and I just think it's a perfect moment to leave you with.

[film clip starts] [53:13]

Julie: Oh, I do like to be beside the seaside. North Wales is the best place to be. Having great laughs with the Pathways gang, and Dory on the drum going bang, bang, bang.

Michael on his flute, begins to tootle. [Sue Brandish's? 53:52] furry mic. Jacqui takes a roll along the prom, prom, prom, while Lawrence tries to control his hair from being blown. And biggerhouse captures every moment. Steve and Tom really earn their dosh, and when the days end, we will see, we'll be filled with lots of glee, beside the seaside, beside the sea.

[film clip ends] [54:32]

Rachael: **And I think we can see Julie on our screen now, so thank you so much, Julie, for allowing us to show that. And thank you, everybody, for being here with us today, it's been a really special session, so we will say goodbye.**

Speakers: if you'd like to stay on just as we say goodbye to everybody else, that would be great. Thank you.

Stephen: I hope you liked it, Julie, [chuckles] see you again.

Julie: Thank you. And thank you for all the patience with me getting used to my new chair and being a bit nervous, and everything, and being a bit hard for me to take direction, so very... thank you very, very much.

Stephen: You're welcome.—

Rachael: Oh, thanks, Julie. A new career awaits you.

Julie: Huh.

Rachael: [chuckles]

Julie: See you folks, bye.

Stephen: Are you going? I just wanted to say before you go that actually, you know, Julie was part instrumental in getting us to slowdown, because I realised we were, like, bossing everyone around and getting people to do things fast to try and get things done, and I noted that Julie needed everything to be more directed and clearer, and actually we took a pause after that moment and then we did slowdown with everybody, so you contributed to this idea of taking time to do things.

Julie: Thank you.

Rachael: Julie, that's amazing, you've developed a new genre of filmmaking.

[chuckles]

Julie: Just great to have you there.

Stephen: Yeah, and the rest of your film's lovely, and you will see that soon when there's a launch, 'cause obviously... 'cause that's just the ending of your film, yeah.

Julie: Yeah, OK.

Stephen: Thank you.

Tom: Thanks, Julie, thank you.

Julie: See you, folks. Bye.

Stephen: Bye, bye.

Tom: Bye.

Julie: And congratulations again, Michael.

Michael: Oh, thank you.

Rachael: [chuckles] Erm...

Michael: Oh, Martyn, thank you, thank you, thank you, my goodness gracious me.

Martyn: No, thank you guys, and—

Michael: Wow. Amazing.

Rachael: Yeah, are you OK, Martyn? Huh.

Martyn: Yeah, I'm fine, yeah, honestly it was... it was... I think it was seeing the film again – it was just very emotional.

Rachael: Yeah.

Stephen: Mm, mm.

Rachael: Rachel?

Martyn: No, no, and thank you to DEEP as well. I mean, it's just amazing. I mean, as you know I've been on every one so far, apart from one because—

Rachael: I know, you've been such a trooper, huh.

Martyn: —I [didn't? 57:03] get my invite and I was annoyed about it, but anyway...

Rachael: [chuckles]

Martyn: All the stories, they're just so amazing, you know, they're such strong people. No, it's just great.

Rachael: Thank you so much, everybody, that was a really powerful session.

Stephen: Yeah, thank you, Rachael, very much indeed.

Tom: And, yeah, it's so... all of them, it's lovely to leave... 'cause it's been about a year or so since I saw your film, Michael, as well, so it... they don't... they don't age at all, they're still absolutely relevant and all your... all the thoughts that you kind of got out into the film, it... you know, all of that's... it's so lovely to hear, so... yeah.

Rachel: I just wanted to say that at the in-person events that we had down in... with the SUNshiners, and in Bradford, and we showed a couple of the films at those events, and the SUNshiners in particular, the film included somebody who had... who had died, and it was incredibly powerful for them and there was not a dry eye in the house, 'cause they're marking [unclear 58:19] was there at that time too. But reflecting on a film that was made two years ago and to look at that and to, you know, really sort of appreciate that whole legacy that you're creating incredibly powerful... and of course in Bradford we had [Claire's? 58:40] dad who had died recently as well, and again that was incredibly powerful to hear him singing, so it's capturing so, so much that is going... means so much to so many people, and it was also an incredibly powerful session and thank you very much, Martyn, and Dr Michael in particular – you're amazing.

[End of Film]