DEEP voices and human rights

[music plays]

Toby: **Welcome everyone, to this session, it's great to see so many people joining it on a topic that is incredibly important. And the question we're asking today is, 'can a greater focus on human rights make life better for people with dementia, and I guess if so – how?'**

So, my name is Toby Williamson, I'm an independent health and social care consultant, I'll be facilitating the session today, and I do work in the fields of dementia, older people's mental health, mental capacity, research, evaluation, training, education, policy work, a range activities. And for a number of years I worked for a UK charity called the Mental Health Foundation where I led its work on mental health in later life, including dementia, and whilst I was there I had... we had strong connections with the DEEP network and we involved people with lived experience of dementia in a number of projects that I led on. And one in particular in 2015 that Philly and others here were involved with, was looking at human rights issues and how they affect people affected by dementia. And just to say a note here that the late Peter Ashley, who was a person who lived with dementia, was very involved in that, so it's nice in this celebration of 10 years of DEEP, and happy anniversary to DEEP again, that we also remember people who've been involved in the past who are no longer with us, or no longer able to participate, for their contribution as well.

So yeah, I did that work back in 2015 and subsequently became an independent consultant, but I've continued my interest in human rights issues, and dementia, and in 2019 I co-authored a book with Julian Hughes, a consultant psychiatrist, called *The Dementia Manifesto* which had a strong human rights-based approach in the

way it looked at dementia care. So, it remains an issue that I think is incredibly important, it's an issue that's really grown in importance and how people have been talking about it, including people affected by dementia, but services and policymakers quite considerably over the last four or five years, and DEEP can take a big credit for that I think for the way they've raised its profile and helped with those discussions, and so on.

So, I'm gonna now ask panel members to introduce themselves and then we'll go into a series of questions that panel members will be answering. As Philly says, if you have any questions as we go along, please post them in the chat room and we may be able to come to them, perhaps halfway through the session, or at the end of the session, but I really hope there will be time for some questions and answers.

So, I'll now ask the panel members to introduce themselves, and I'll go round as I see them on my screen. And in their introductions I'm going to ask them to say who they are and what their connection is with human rights and dementia issues, and perhaps say one thing in answer to the question about why is it important to talk about the human rights of people with dementia. So, Nigel, you're first on my screen, so can I ask you to introduce yourself?

Nigel: Hi there, thank you Toby. My name's Nigel Hullah, I live in the People's Republic of Townhill, in Swansea. I was diagnosed in 2012. I'm chairing a 3 Nations Dementia Working Group, I'm also a member of the UK Prime Minister's Challenge on Dementia, and I'm a member of the European Working Group [unclear 04:02] as well.

And quite briefly, I mean human rights in the field of dementia is not new, you know, Peter Ashley paved the way really of people like him. It's not new, and it's not extra, it's something which we all should enjoy irrespective our... of our illness or frailty, but unfortunately sometimes it becomes masks... masked by the condition in which we carry where

people with dementia are routinely denied human rights because they're not considered able to understand or practice them, and I... and I... and I get that because it... you know, the Human Rights Act is a very complicated business, but it's just one of the tools of... which should be using, and would run concurrently with things like the Equalities Act and the LPS.

I tend not to talk about schedules anymore, or articles, I tend to talk about dignity, kindness, understanding, fairness, equality, and diversity, and to me it... I'm lucky we live in Wales, which promotes human rights. I'm a member of the Welsh Human Rights [stakeholder's team? 05:13], and I also advise the Welsh Government on all matters of diversity and human rights, and I always say use... look at what you're doing, look at what you're presenting, and say to yourself, 'if this good enough for my mother, or father, or uncle, or brother, or sister?' and if it isn't – then it's not human rights compliant.

I think we have a problem with the way that older people, and people with dementia, certainly are viewed – it's a deficit model. In the early days there's a concentration of what's not... what's not there, not what still is there that built on, and from there I think an ageist rhetoric arises. Human rights gives clarity. Human rights gives integrity to any process regarding services to people, and it's... it must be premised on the inherent indignity of all, no matter where we are, frailty or illness. And I've got quote, and Mandela said, "To deny people of their human rights, is to challenge their very humanity," and I think in some cases, particularly in dementia, we do get that.

Toby: **Great, thank you, Nigel, that was a very powerful introduction, so thank you. I'm gonna go to Howard, Howard Gordon; Howard, would you like to introduce yourself please?**

Howard: I'm Howard Gordon from Sheffield. I was diagnosed in 2017. I've used the Convention locally to get services started, and I've also worked with the UNCRPD committee and the WHO Global Dementia Observatory.

One of the problems with the CRPD is politicians view it as a soft law, but it's not – it's hard law. In the report in 2012 by the Joint Committee on Human Rights called *Implementation, the Rights of Disabled People to Independent Living*, they stated that, "We are concerned that characterising the obligations assumed by the Government under the Disabilities Convention as 'soft law', is indicative of an approach to the treaty which regards the rights it protects as being of less normative force than those contained in other human rights instruments. The UNCRPD is hard law, not soft law. The Government should fulfil their obligations under the Convention on that basis, and must counter the public perception that it is soft law. Like all international human rights treaties, the Disabilities Convention imposes three distinct types of legal obligation on States: obligation to respect, protect and fulfil the rights contained in the Convention." And under 'obligation to fulfil' it "means that States must take appropriate actions including legislative, executive, administrative, budgetary, and judicial actions towards the full realisation of the rights in the Convention".

And we face an assumption of incapability when we're diagnosed. I mean I worked in health care for 20 years and I often heard consultants say it wasn't appropriate to refer someone with dementia to OTs, physios, whatever, but we have a right to those things, and we're denied those rights because the... a professional will assume that we can't deal with that service, that we can't communicate, and it's up to those people to learn how to communicate with us.

Toby: **Thanks, Howard, yeah, I mean that's a question we're gonna come onto about how professionals could become... and practitioners, become more aware of human rights. I'm just conscious that when we start talking about the law and human rights, there's a... it's easy to start using terms that some people are familiar with, but not everyone's familiar with: so, the CRPD, just for everyone's benefit, is the United Nations Convention on the Rights of Persons with Disabilities that the UK signed up to, so that was what Howard was**

referring to. And I think Nigel mentioned LPS which are the new... it stands for Liberty Protection Safeguards, which are the new yet to be implemented safeguards for people living in... well, living anywhere actually, who may be deprived of their liberty. So, if we can just remember to try and, yeah, to... that not all people... all members of the audience will know what all the acronyms stand for. Thank you, Howard.

I'll now go to Lucy. Hello, Lucy, nice to see you.

Lucy: Hi everyone. Happy birthday, [chuckles] it's lovely to be with you all. So, I'm an academic at Bristol University and my research looks at human rights in relation particularly to social care and mental capacity law, and I'm particularly interested in how that relates to the lives of people with long-term cognitive impairments, like dementia. And I think they're really important, and I think they are hugely important for shifting cultures, cultural attitudes, and as an expression of ethics and values. So, put as simply as I can: just recognising that people with dementia, and other people with long-term cognitive disabilities, are persons first and foremost, and treating them accordingly.

I think... I do a lot of work at the moment teaching social work students human rights, and I think... I think human rights are a good tool for getting people to sink themselves into the shoes of the person and recognise their equal worth and dignity, but we've got a hugely long way to go on that front in terms of education and culture reform.

And I'm also interested in human rights as a remedy, so that means when something goes wrong, can you use the law to solve the problems, and there are lots of problems there; I'm happy to talk about that, further... later. But again, we've got along way to go, and I'm interested in working with people living with dementia on how we can fix some of those issues.

Toby: Great, thank you, Lucy. And you've... are you still doing your blog, the *Small Places* blog you—

Lucy: Oh, only when my children and students allow, Toby; I'll try and do it more.—

Toby: OK, I would recommend Lucy's blog called... it is *Small Places*, isn't it, about...

Lucy: That's right, yeah.

Toby: —issues to do with rights?

Lucy: Yeah.

Toby: Tom, Tom Shakespeare, can you introduce yourself please?

Tom: Certainly. So, mine is Tom Shakespeare. I'm at the London School of Hygiene and Tropical Medicine, which is a university in London, and I come at this from a disability rights point of view; I've written a lot about disability. And for me, dementia is another variety of the range of many, many impairments that people have, and therefore for me, if disability theory is to get it right, it has to be open to people with dementia. And that means several things: it means, as everybody has said, talking about human rights, it means listening to people with dementia first and foremost because their experiences... they should... 'nothing about us without us' is a principle from the disability rights movement; the importance of language.

But also what I've tried to do in my disability work is to look at illness and impairment, because everybody with a disability has an illness or impairment. I have a spinal cord injury, and achondroplasia, and ADHD: other people have different impairments, and therefore I don't wanna ignore that and I wanna have that there too; I'm not gonna say that that's not important. So, that's the contribution I've made to disability theory I think, and I think it's relevant to people with dementia also.

So, back in day, in about 2001, I worked with Julian Hughes, and he's a psychiatrist who... really pioneering in understanding disability, and he talked about the situated embodied view of the person, which I think is

what Lucy was talking about: people with dementia are people, and it's... you know, people are people, not... it's not about what you can do, it's about who you are, and why you're important, and Julian has been very important in that. And then I was very lucky in 2017 to work with Peter Mittler, who many of you know, and with Peter Mittler and my friend Hannah Zeilig, we did a paper which was called *Rights in Mind: Thinking Differently About Dementia and Disability*, and people like Neil and Toby, and others around this call, don't need to read that because it's what you think anyway, but others do, and so we try to contribute to that. And I was very, very happy to be an advisor to the Dementia enquiry... Dementia Enquirers and to work with, and get to know, people like Howard and many people in this call, through that wonderful programme as part of Dementia Voices. And I was really lucky, with Hannah Zeilig, to be called to help evaluate the Dementia Voices programme, and that's what we're doing at the moment, and we're gonna report back next year, and we've talked to so many people with dementia, and so many people who support or work with people with dementia, all of whom say how important this work is – of course it's important, and it's valid, it's important, and long may it continue. Happy birthday.

Toby: **Great, thanks, Tom. And it's just really important and exciting in a way that sort of we're building these relationships across the disability movements that it isn't just about a specific disease or impairment, that actually these alliances are forming and we're learning from each other, so it's... I was so excited when you became involved, Tom, 'cause obviously I knew your work in dis... the disability field, so to have you involved is [unclear 15:02]—**

Tom: Well, it's like what Howard said, you know, let's not have a deficit model. And in disability rights since the eight... the 70s, people have been saying that: 'let's not rely on the deficit model, let's look at the way that problems or barriers have created,' and I think that's very relevant to people with dementia, pe... barriers have created in society.

Toby: **Yeah, yeah, yes, definitely, so thanks, Tom. And last, but by no mean least, Neil, would you like to introduce yourself please?**

Neil: Then what a group to follow. First of all, happy birthday DEEP. I have watched with great excitement DEEP evolve over the last decade and it's really lovely to be able to be invited to be part of this today.

In terms of me: my background's also in the field of disability rights, and human rights more generally, both professionally and in activism. So, for example I was the advisor on the Joint Committee on Human Rights Report on Independent Living that was... they mentioned earlier, and that was my work. And... but then in 2014 my dad was diagnosed with Alzheimer's, and what immediately occurred to me, even though I know DEEP was underway and things there, and some of the discussions that we heard were underway, but it still felt to me like dementia had been absolutely peripheral to the thinking around disability rights and the work that I'd been doing, but by absolute chance, the same year, Peter Mittler got in touch with me and introduced me to Kate Swaffer, and then I heard about the work DEEP was doing, and Philly was doing, and I got involved in some work around the UN Convention and the Rights of Persons with Disabilities as Innovations in Dementia and DEEP were trying to influence that, that process, and those connections were made I guess in the same way they were made for kind of Tom and for other people, and that was a really... it's been a really powerful... really powerful thing.

Two reasons why I think human rights are really important: one very practically, because I think people who are living with dementia are far more likely to find themselves in situations of risk concerning human rights, whether that's from discrimination or the right to take... decisions being away taken away from people, or people's liberty being deprived, or facing institutionalisation, and so on. So, I think dementia and the lives of people with dementia should be the focus of the wider human rights community and human rights defenders generally, not only advocates of people living with dementia, and I think that's still not the case and that's still work we've been... and need to do.

But I wanna really echo what everybody else has said, that I think there's this cultural dimension, and this political dimension, which is about human rights being a reaffirmation of the humanness of people living with dementia, and I think that's no more important than right now.

I wrote a blog last week after the announcement about the latest medical... drugs breakthrough, of how that overall debate, potentially, just screamed out the idea that the lives of people with dementia right now were important, and these social barriers were important, and that's not to diminish the value of that medical breakthrough, but the overall narrative seems one that doesn't actually point to improving the lives of people living with dementia. And I was reading an article last week in *The New Yorker*, it was actually about an idea in France that I imagine will be deemed controversial: it was alternative to nursing care, it was village in which people with dementia lived, but there's a quote in it that really caught my attention, which was that this place had this insistence that a person with Alzheimer's is not just diminishing in the sum of her symptoms, but are flourishing and evolving as a human being until the end. And I sort of feel that's what the DEEP network represents, a bit like People First movements, or the Independent Living Movement, or the psychiatric survivors movement, or for that matter – things like Pride, or Black Lives Matter, or me too, it's about reclaiming and reasserting equal dignity and worth, and it's about making hope possible rather than despair convincing.

And I think to those ends, as Tom has just outlined, I think disability rights focus, as well as reaffirming the rights of people living with dementia to be in our world, has put... is much a part of human diversity as everyone, it has that added ingredient of widening our lens to think about these external socially constructed barriers that just don't permit people living with dementia to live the lives they could do – were they removed. Whether that's social attitudes, the way we design our built environment, communications, transport, our health and social support systems, so it allows us to analyse and see where those barriers are, and actually to

begin tracing a world which is inclusive and can improve people's health and wellbeing in different ways, thank you.

Toby: **Great, thank you, Neil. And I don't want to add... I don't think there's much that I can add to what... everything's that been said so far. I suppose one thing that springs to mind is, no, for all of... all the audience and of us who live in England, obviously where we live under a government who aren't that, let's say, keen on the notion of human rights, and changing the dialogue around dementia to understand it as being both a disease and a disability, it has been an uphill struggle in some respects, but that the numbers of people on this... in this session reflects, I think, the growing interest and relevance of human rights in both policy and practice. But it's worth reminding ourselves that, as Nigel has already said, that in Wales, and in Scotland, and I think in Northern Ireland as well, they have explicit human rights-based approaches at the heart of their policymaking around dementia. Now, what that issue looks like in practice – I'm not sure, but the fact that they explicitly say we want to take a human rights-based approach, is significant, so it's not something that's just this slightly odd thing that sort of possibly gets in the way of policy and practice in the eyes of some people, who have a negative view about human rights, but actually some parts of the UK have very much embedded it at the heart of what they do.**

So, I'll stop there, and I'm gonna now ask the panel to ask... answer some... two or three questions we've got. And the first one is really, 'how can we make sure that more people with dementias, and their families, know about their rights?' And I just suggest to panel members you just wave your hand and I'll spot you when you... and ask you to answer. So, who would like to have a crack at answering that question? Nigel, you've got your hand up first, off you go, you're on mute at the moment, yeah.

Nigel: Yeah, what... first off, let's demystify the Human Rights Act altogether, let's talk about what it really is: it's a charter of fair play, it's a charter of representation, it's a legal document, but it's also a philosophical document, and people's eyes roll in the back of their head when you start quoting articles from the Human Rights Act because they don't understand it, but do they understand terms like fairness, equality, and human... and dementia after all though is wholly a matter of human rights and social justice, so nothing else, but that's to my view what it is. So, when we are presenting human rights to... or human rights issues to people either with a diagnosis, or their carers, that we present it in a way which says, 'well, you know, you shouldn't be treated like this, there's laws and legislations protecting you and here's where they are, here's what they mean, here's what that say.'

We're producing a booklet in Wales called *Knowledge is Power*, along with DEEP, the Caban group – DEEP, the DEEP group – Caban, I should say, and there it sort of simplifies what the legislation means, and it weaves it in then with all the other legislation like the [Good Work Act? 22:29], like the Health and Social Care Act that goes in it.

My view, and it is my view, is that all legislation for all people should be based on the Human Rights Act, because it's in danger, you know, you hear yest... the other day, we... Cameron would say the way to stem the tide of illegal immigration was to... was to come out the Convention on Human Rights: well, that's just nonsense, you know, that's just nonsense, that's just because they're uncomfortable with the notion of having to treat people fairly I think, that's basically what it is. And I... and I... if presented that way, people pick up on it a lot quicker than just being given, you know... We did DEEP document, I can't remember what it was called now, Philly, was it Human Rights, Your Rights, the booklet we—?

Toby: Yeah.

Nigel: Yeah.

Toby: **And, yes, you involved that, that Philly led on, and that DEEP guide to human rights for people with dementia, and if we could put that up in the chat room, a link to that possibly, then people can have a look at it.**

Philly: It's called *Our Dementia, Our Rights*,—

Nigel: Great.

Philly: —and I'll have to look for that, yeah.

Toby: **OK, thanks, Nigel. Would anybody else... other panel members, yeah, Lucy?**

Lucy: Thank you. Nigel, I really love that, as... "the Human Rights Act is a charter of fair play", I'm gonna be borrowing that in future lectures and conversations with human rights sceptics.

So, I think... I do... I teach social workers human rights law currently, and I think getting it embedded in education is important, but it really is just the start, because if they go into workplaces where there isn't a culture of valuing and talking about human rights, it will swiftly get forgotten and left behind. So, I think it... there need to be ways to get people to, not just talk about human rights as just an additional layer of legislation they've got to think through, but as something that they value, that they see the value in, in their own practice.

I think as Nigel pointed out, 'knowledge is power,' is absolutely essential, but I would worry about an approach which requires people living with dementia, and their supporters, to have a fully-fledged knowledge of the Human Rights Act right at the moment when their rights are being violated, because I think ultimately human rights law is also about making sure that people have got the resources they need to redress that imbalance. So, if you take for example the right to liberty, if somebody is deprived of their liberty, there's actually a legal duty, on the people who are depriving them of their liberty, to tell them about their rights and

tell them what they can do about it, tell them that they have rights to advocacy and to go to court and what's happening. So, I think there probably needs to be more of an emphasis on professionals signposting to information about human rights for people where it's important. And I was just thinking that you could create... you could create a really accessible guide actually to... a human rights guide to living with dementia, which instead of breaking it down in the way that lawyers love to do, you know, 'article 8 means this, article 3 means this,' starts with the problems that people living with dementia commonly encounter and then talking about that in human rights and... terms, and what people can people could do to solve that. So, starting with the problem, and then human rights as the solution, rather than expecting people to learn about, you know, the different bits of Human Rights Act and the ECHR. I think there's a lot we can do, but I think that that 'knowledge is power' point is vital because if you don't know you've got rights, there's not a lot you can do about them.

And access to justice is another massive problem. I think if you look at what happened to people living with dementia during the Covid pandemic, particularly in care homes, we... we're talking really about mass illegality on an unprecedented scale in human rights terms, in terms of unlawful detention, unlawful violations of rights to family life, really, really devastating stuff, not even to mention the violations of the right to life for people who weren't able access treatments that could have benefited them. And the fact that there has been next to no litigation around that, tells us how weak the Human Rights Act is if people can't actually get to lawyers, can't afford to go to court, and don't know that they can do that. So, I think it... we need to, as a start, keep it on the statute books, but we need to be thinking, well, how can people actually make this useful, that they're evidently not able to use it right at the point where they need to.

Toby: **Yeah, thanks, Lucy. And yeah, you mentioning Covid: Steve, this might be a bit of a tricky link to find, there was a really excellent**

report produced by the University College London, I think International Care Network, which looked at how the rights of people with dementia had been violated during Covid, it's an international study, so it covers a whole range of countries, so if you find the link perhaps you could put it up, but not to worry if you can't. Yeah, Neil, you've got your hand up.

Neil: Yeah, I just want to put a slightly different take on it I guess, and that this is odd because I've spent my kind of working and activist life sort of promoting human rights, but increasingly... and still inspired by them, inspired by the ideas they contain, but increasingly sceptical about what they actually offer directly, immediately, to secure change, and I think it's... in a conversation like this, it's interesting when we begin to talk about practically using human rights, we immediately then talk about violations or preventing or addressing kind of violations of rather than there being a kinda programme in terms of how we create the world that we actually want to bring about, and I think that's where I would... I would think the focus needs to be, and I think it's what the work that DEEP does, but we were talking about kind of individuals and families. I think one of the really deep things is about people's imagination and expectations, and that that is being repeatedly shaped, the idea that dementia is a kind of life-ending event, rather than life-changing event, that there isn't possibility beyond the diagnosis of dementia, that we're not imagining living with dementia in the same way perhaps we're imagining the lives of other disabled people. So, I think there's a massive job to do about addressing stigma and attitudes and raising our sights, and our expectations, before people will ever begin to think about using rights or that they're necessarily relevant to them in their own lives, so I think that that for me is the kind of... they're both important, not one or the other, but I think that's equally part of the challenge. If our interest is in building a kinda more inclusive world, then we probably have to start there; equally at the same time though, the points that Lucy and Nigel have made, are crucial too.

Toby: **And yeah, that's a good point, Neil, and I suppose sometimes people think of human rights as very much sort of protecting people from things that shouldn't be done to them, but when if you look at the CRPD, the United Nations Convention on the Rights of Persons with Disabilities, there's a number of articles in there which talk about access to services, so it's about how do you promote people's... the opportunity for people with disabilities to participate in society and to receive support, and gain education, and employment opportunities, so it's not just about [unclear 29:36], it's about empowerment in a general sense.**

If it's OK, I'm gonna move onto the next question. I hope that Howard and Tom will come in, but I'm just conscious of time. And we've talked a little bit there about making sure that people with dementia can know about their rights, but what about practitioners, and professionals, and services: 'how can we make sure that more professionals know about human rights in relation to dementia?' Tom?

Tom: I think it's very important to start with training: so we train social workers, we train doctors, nurses, all the other professions that people with dementia come into contact with, and I think we need to say that people are not... you know, primarily, it's not [about sickness? 30:22], it's about difference, and diversity, and disability. And right, you know, you ought to be able to speak to people, and you ought to be able to hear from people, and have dialogue with people, not merely see them as invalid or, as Howard says, you know, suffering from a deficit. So, if we train people, both at the start and during their train... during their practice, then we can help educate them. I think also what Innovations in Dementia and Dementia Voices have done, which is very much to say, 'look, there is this network, we're publishing papers, we're publishing research, we are, you know, here, we're real, we are proper,' helps when academics and others are thinking about dementia; it changes the conversation.

Toby: **Yeah, yeah, and I totally agree that the education, education, education is crucial. Yeah, Howard, you wanna come in here?**

Howard: Yeah, I agree, I mean there's a lot of work in a lot of universities now where they're involving people with dementia in their courses, either helping to set up the units or actually speaking at lectures. The problem is, as Lucy said, when they get into the workplace, you know, the attitudes of dementia in the workplace, I know from working in health care, are so engrained that the people at the top cascade those ignorances, or whatever you want to call it, down to different levels, and it's very hard to change those perceptions for those that are at the top, it's finding a way to change their perceptions and their attitudes that's gonna be the biggest challenge,—

Toby: **Yeah.**

Howard: —but, you know, people going though university now will be the consultants and the professors of the future, so hopefully when they get to those positions, they'll remember what they learnt at university, and in their training, and put that into practice, but unfortunately for people like Nigel and me, it'll be too late, you know, we're talking 20 years or so into the future.

Toby: **Yeah, no, that's a good point, Howard. Yeah, I'll bring you in in a sec, Tom. I just wanted to say, I mean, Philly, you may recall this, but actually health and social care services are sometimes the slowest to pick up on human rights, and when you were involved with the Government's initiative around dementia-friendly communities, I think you were on a panel, or on a group, that involved people like British Telecom and Lloyds Bank, and when human rights was put in the context of the Equality Act, they got it immediately because they want to be compliant to the Equality Act and they say, 'well, what do we have to do to make sure we're compliant?' And actually services that have been working with the Equality Act on a regular basis – get human rights, because human**

rights isn't just about the Human Rights Act, it's about all the legislation like mental capacity, and the Equality Act, the Care Act which sits underneath it, which if services aren't compliant with that, they're ignoring people's human rights, so making that link is important. Yeah, sorry, Tom, come in there, please.

Tom: I just want... sorry, yeah, I'm going... speaking, yeah. I just wanted to say very briefly: I really enjoy hearing from Nigel, Howard, and all of my friends and colleagues with dementia, because one of the things that's really important about the Dementia Voices network, about all the work that's happening around this week, is that we are working with, empowering and listening to people with dementia, and I don't think that was previously possible. And so the work through DEEP to empower, not just the folk on this call, but hundreds of people, and say, 'you have rights and we will help you claim your rights,' and that can't be ignored as part of the conversation.

Toby: **Yeah, thanks, Tom. Philly, if you could just keep an eye on the questions and see if there are any good questions coming up, maybe when we've looked at the third question, then we'll pick those up, so thanks for that.**

Does anybody else on the panel want to come in about this issue about making sure that practitioners know about human rights in relation to dementia? Yeah, Nigel?

Nigel: Well, we all accept I guess that dementia services should be value-based, should they, so, we all accept that. And to do that we need better... we need better informance on... inform people on human rights and the Equality Acts and all the legislation that goes to making everybody's life one of value and quality. Better literacy in human rights can inform better care, planning as time goes on, turning decision making on its head really where everything becomes a right base... right space [unclear 35:04] space and we're not actually looking at people as something [unclear 35:10] being done to for people who need to be

engaged to do things together. And a human rights approach... and the human rights approach has revolutionised dementia care... and dementia care, in Wales and the way it's planned, and nothing happens in Wales unless it's coproduced. And one of the Children, and Human Rights, and Equality Act has is coproduction because you've got people in the room talking which they should be which is the basis, then human rights decisions become rights based, not risk based, and it's almost like a light-bulb moment. And going back to my... one of my original thing, and it should be premised that everybody has a right to have a say in the way they're treated, and this is why we need the integrity of the Human Rights Act to ensure that Act, and the Equality Act, and any other tool that supports us.

Toby: **Thanks, Nigel. Yeah, Neil?**

Neil: Yeah, I agree with those and particularly the importance on the central voice of people living with dementia in these debates, and of people... [unclear 36:19] people, the people who draw on the social care and other things, I think can be utterly transformative in the outcome. And if you look at the new House of Lords report today, which took that approach, the kind of focus of it is just radically different as a... as a consequence.

But just on this question, I think, so to bang on about it, I think again it's affected by narratives of dementia and public expectations, and the public story of dementia I think weighs very heavily on how public services are organised, how professionals behave. So, some of it's about an understanding of the law, but some of it is just deeply cultural. And I think one of the challenges, I felt this... I worked for the Equality and Human Rights Commission for several years and then after that trying to do work to shift public thinking around human rights, but if you imagine kind of where people's human rights might be violated in a kind of relationship with a frontline worker in a residential care home, we're not gonna expect those frontline workers to really understand chapter and verse of the Human Rights Act, somebody needs to do the job to translate that into the practice and the behaviours and the cultures that

you would expect to see. And I still think that's a bit of a deficit; I still don't think that work is being done. I think there was real energy when the Human Rights Act came into being, around this stuff, but over time it's dissipated, but fundamentally that's where it makes a difference, and not necessary at the level of strategy and policy, so it's how it then flows down through this system into people's lived experience, and I think that's the work that's left to be done.

Toby: **Thanks, Neil. I'm gonna move us onto the last question in order that we have time for Q&A. But I'm conscious that Lucy did mention about training social workers, so if you can segue an answer you have for this final question to talk about obviously that work as well, do feel free.**

So, the last question I'd like to ask the panel is... it's quite a big one: 'what would the world look like if the human rights of people with dementia were fully realised?' So, a nice straightforward question there. Anybody want to have a crack at that?

Nigel: Well, it certainly would be different, wouldn't it?

Toby: **Yeah.**

Nigel: And it certainly would be fairer, it would have more equity in health, social justice, and all the things that we talked about. I think we've come a long way in terms of groups like this, you know, folk talking about... and sometimes it's a bit like talking in an echo chamber. But I'm finding more and more that I'm involved with... in fairly high-level discussions where the issues of human rights does come up. But Neil is quite right, that there's a kind of... you know, and if you can... if you can skim... when you talk about it in a group of managers for instance, or commissioners, it's like... it's like giving a load of children a jam jar with the top on it and saying, 'don't open that because you might not like what's inside it,' yet they play with the top, they play with the top, and they shake the... they shake the jam jar, but they never actually open it. And it's getting them to... getting people to understand that there's nothing mystical about this,

there's difficult about it, it's just being fair, and just, and proper. And a world... I kind of think that there's a world just governed by human rights would be... would be a dream for everybody, but I think the difficultly would be to get people to interpret them in the correct manner, as Neil eluded to.

Toby: **Thanks, Nigel. Anybody else want to have a go at future thinking of...? Yeah, Lucy, go on.**

Lucy: So, I think... OK, this is gonna sound like a bit of downer, but I promise it's gonna lift up in the end: I think the reality is – humans being humans, there will always be individuals who don't really get that the person in front of them is fully human, like them, and they don't treat them with the kindness and dignity and empathy that they deserve, because that is just how humans are towards each other. But... and what I have learnt in my working in social care and the people I work with in research and teaching, is that there are also some really, really, really good humans out there who don't even need a lesson in human rights to get that. And actually, what human rights can really do, if they're set up right, is empower those people to work arm in arm with people living with dementia, and their allies, to challenge and call out bad practice where it's happening, and tackle it. And I think for me that was the real revolution for me about discovering human rights, is that actually it wasn't just that what I was seeing in care was unpleasant, or nasty, or unkind, it's that actually there was a legally enforceable language for saying 'something's going wrong here'.

Now, as a frontline care worker, it gave me no tools to fix that, so that's how I ended up in academia, though I think what we really need to do is create human rights frameworks that properly resource the people who want to do the right thing, to do it, and give them the means to call out the bad things where it's happening, and I think that that requires a radical transformation that goes far beyond the law books. It includes completely reconfiguring how we set up care and support, and health care, to make sure the right people are given the right resources. I think

it requires reshaping how the general public view older age, view care, view dementia, and disability of other kinds, because I think we need to give everybody faith that actually there's a good life possible for everyone if we resource it well, and it's only once we've got to that position, that the people who want to do good – will really be able to do that.

Toby: **Great, thank you, Lucy. And, Howard, you wanna come in? Oh...**

Howard: So, about 40 years ago they did it with cancer, they changed perceptions of cancer, but they changed the understanding of cancer and they realised that putting the services in – people would live a better life, you know, and somehow we've got to get politicians, and the NHS, and everybody else, to think like they did 40 years ago, instead of about cancer, but think about dementia and other disabilities in the same way and realise that in the long run it's cheaper to provide these services, than it is not to,—

Toby: **Yeah.**

Howard: —because you... with dementia, you have a situation where the... that my wife might put her health at risk to give me the best life possible, but at some point she'll end up in hospital, and because there's no social care available, I'll be in hospital as well, and that costs the NHS £3,000 a night for the two beds, you know, we need to change perceptions and understanding around dementia.

Toby: **Yeah, thanks, Howard, that's really important. And, Tom, you wanted to say something.**

Tom: Thank you, yeah. I mean for me, from a disability perspective, seeing dementia within disability rights and human rights, is about looking at our world and how it disables people, and therefore you might not like WHO's work on age-friendly cities, and some of it... you know, some of this language can appear patronising, but if we see people with dementia like other people with disabilities, as citizens, entitled to equal right, then we might pay attention to the ways in which we design public spaces, we

design technologies, we design interactions, we design services, and really put humans, including people with dementia, right in the centre of those and ensure that people are treated fairly, it's exactly what Howard, and Nigel, and Lucy have said, and Neil, it's about treating people as equals, and we can do that, and therefore we can lessen the difficultly, or the burden, of having an illness or impairment like dementia.

And for me personally, and working with Dementia Enquirers, you know, all of the work I've done in this area, has been really liberatory. 'cause like many people like me, and like others, relatives of mine have had dementia and it's been a frightening diagnosis, I'll be candid with you, but in the interactions that I've been able to have with a lot of people, it's taken away that fear, and it's like, OK, that exists, that might be part of life, but it's not something to be frightened of, it's something that is part of life and therefore the sooner we respect and include people, regardless of their impairment – the better.

Toby: **Great, thank you, Tom. And finally Neil, and then we'll move to Q&A.**

Neil: Yeah, well I absolutely echo all of that. There's some... there's a story I've told a few times recently and it's in a... in a paper I wrote earlier in this year about my dad's experience of Alzheimer's and how, you know, as Tom has just sort of explained, and would explain, you know, without doubt the illness, if you like, was progressing and it was affecting his functioning, his ability to do various things, but he managed to maintain a pretty high-level of wellbeing, and that wellbeing was derived from the fact that he was living in the place he called home, he was living with my mum, he was seeing his friends, he was still going to watch the rugby matches that he loved, he was still doing lots of... lots of things that kinda held his wellbeing together. And actually his health and his wellbeing came apart in the first lockdown, and not really because of the dementia, but because he was suddenly unable to do all those things that held his life together. And for me, if we take that fact, and I think everyone on this call probably recognises it, that dementia isn't simply predicted by

the trajectory of the disease, but by the social and, you know, the circumstances in which we're able to live our lives. And that points so clearly to the thinking that's evolved through disability rights in sort of ways that we can actually change the world, not just some political ends, but to the ends of people's health and wellbeing, and potentially, given the big claims that were made last week about a kinda new drug that might kinda modestly delay the progress of dementia, actually I think these social external factors can have that effect too.

So, in the future I want, I don't think the work is ever really done, as Lucy has said, but I think the focus has to be on people living their best lives, and I think we'd relentlessly innovate to open up the world to everyone to improve people's experience of living with dementia, and what I'd love to see is that some non-pharmaceutical innovation could get the kind of news coverage that the drug that was announced last week saw, because it could improve people's cognitive and wider health and wellbeing, and I'd like to see that across every TV news bulletin, and social media, just as we see breakthroughs in biotech, you know, from physical ramps to cognitive ramps, occupational therapy, investing in these things that hold our personhood and wellbeing together, and new technologies. And I'd love to see thinking around human rights and disability rights evolve to really take account of the experience of people living with dementia, for people living with dementia to be sat around those tables, shaping that thinking into the future.

Toby: **Great, thank you, Neil, and I certainly agree with that. And just... before we move into Q&A, I'm just gonna throw a swerve-ball in, and this isn't about me trying to plug a publication, but I've recently written a chapter in a book about critical studies of dementia, and was challenged by someone who comes from what's called the 'post-humanist group' who challenge the notion of human rights because it's seen as exceptionalist and speciesist, ie we put humans at the top of the tree, as it were, and because of that, we're ignoring other... the rights of other sentient beings and the planet**

itself, and therefore that's, you know, part of the reason why we're having problems with climate change, as it were. It's was a... it's a very... so I ended up writing a chapter and trying to think how can disability activism and people with dementia find alliances with climate change activists so we recognise the rights of the planet, as well as everything that lives on it, without necessarily only focusing on one species, as it were, and so... Yeah, the book's not yet been published, but just to throw that as a swerve-ball, not as a question.

I'm gonna go to questions now, so I think Steve and Philly have been kinda monitoring the questions and I... if you could just kinda come up with one or two questions, and if you know who they're from, please do say so if people were asking with lived experience and you know they don't mind you saying that, perhaps you could say that, but if you could just read out one or two questions and throw them open to the panel whilst we've got a few minutes left?

Steve: Oh...

Philly: OK.

Steve: Do you want to go first, Philly?

Philly: Shall I? Yes. OK, so we've got one from Di, "So, I have an elderly relative who's living independently and has just received a dementia diagnosis: what's the first thing I do to protect their human rights?"

Toby: Good question.—

Philly: Do you want another one? Do you want another one to ponder on, or shall we go one at a time?

Toby: Yeah, one more to ponder on whilst people are thinking about protecting...

Philly: George says, “Most of us find it hard...” George is living with dementia, “most of us find it hard, or impossible, to stand up for our own rights, especially when ill – any advice?”

Toby: So, two very practical focus questions there, anybody wanna come in with responses to Di or George; how do we... how do we actually put this into practise on a day-to-day basis when living with dementia or supporting someone living with dementia?

Tom: I think what we were challenged to do earlier: ‘imagine this is your mother, your grandfather’ – would change a lot of the way we treat people. And we know from those terrible exposures of Winterbourne View that people with intellectual disabilities can be treated like animals, that older people can be treated like animals, that lots of people can be treated really, really badly, and so we need to model better care, train people to get it better, and it all starts with run... understanding that everybody’s equal, that we are all human beings.

Toby: Yeah, and I was... I was going to sort of pick up your point, Tom, about education, I suppose it’s looking at that DEEP guide, looking at accessible sources of information about what human rights means in practice for you and someone living with dementia or supporting someone living with dementia and, you know, informing yourself and remembering it’s about everyday legislation and not just the Human Rights Act. And Lucy put her hand up and then I’ll come to Nigel.

Lucy: I think... I’m just thinking about recognising... I think one of the human rights and disability rights principles that’s really calling to me there is actually recognising the knowledge and wisdom that’s held by people already living with dementia, so reaching out to local self-advocacy groups and actually saying to them, ‘what would you suggest for me and my relative here right now?’ how... what would have been useful to you seeing if my relative or if it was me if I wanted to go along to that group and join it. And then with my mental capacity law hat on, and also the

work I've done lately around thinking about the significance of home, starting to really think about what's a good life, what's important to that person and really starting to get to know better what their... what their values are, and what's important to them, so that I can stand by their side in advocating for that.

Toby: **Mm, yeah, I agree, Lucy, and I think bringing mental capacity is really important because our ability to make decisions is so fundamental to how we live our lives, and it's now enshrined in law that if we're not being allowed to make decisions, or not supporting people to make decisions themselves, or not following something like the Mental Capacity Act, then that's clearly not supporting someone's human rights, so, you know, the mental capacity is often a good place to start. Nigel, then Neil.**

Nigel: Well, the wind has been taken out of my sails by Lucy, and by you actually, but—

Toby: **Sorry.**

Nigel: —[unclear 52:30] of what I was gonna say, but I mean it's a very difficult decision to make where... and nearest and dearest. When I was diagnosed, the only living relative I had was a stepbrother in Chicago, and what I didn't want to happen was him to give up his life to come to me, so we had a very difficult conversation over that, but the sooner you talk to people right after diagnosis – the better, then you can capture their likes, their dislikes, their preferences, and not wait until the crisis happens, you know, when services are not available or where the situation at home becomes unmanageable.

There's a lot of talk about advanced directives, it doesn't necessarily mean... you know, or how you want to be treated when you're seriously ill [unclear 53:19] this could be how you wanna be treated on the rest of your dementia journey. Put that into place, get a... give... don't rush to power of attorney, wait and see, but when you do go for power of attorney, somebody you trust implicitly, and somebody who understands

the responsibilities of power of attorney as well, 'cause more often that not relations breakdown because one family member is given a power of attorney, and the other isn't, and then when the wills are read and all the rest of it, you know, there's all that cuffuffle about where do... where did all... where did all the money go. And—

Toby: **Nigel, I'm gonna... I'm gonna sort of thank you there 'cause I'm really conscious of time, and Neil wanted to come in, so, sorry to cut you off, but I just wanna see if Howard wants to say something very briefly. But, Neil, can you very briefly respond to those questions and then we can see if Howard's got something to say before we finish? Over to you, Neil.**

Neil: It's gonna echo very much what Howard just said: I think that the key mistake I think my family made, and happens, is that we didn't talk about it enough; we found it really hard to talk about it. The psychology of talking about the future is really, really difficult, and I think that's something we need to focus a lot of energy on, because I think too many people end up spinning into a crisis and only talking about it a late stage, when that could be avoided. What we were fortunate to have was a woman working with us called Helen Sanderson, and what we were using, it's a bit of jargon, it's this methodology called the 'strength-based conversation', we're trying to focus much more on the life that my dad and my mum wanted to lead, and how we could bring that about, and we developed a community circle and it wasn't about statutory services and signing forms and things like that, at that stage, it was about having a life, so I think if we could start there, I think that'd be my key tip, if you're able to.

Toby: **Yeah, thank you, Neil. Howard, do you just wanna come in with a final comment?**

Howard: Well, we need to be seen as the primary decision maker because it's all very well making advanced directives and living wills, but I've known them be overrided *[sic]* by a... two consultants in the person's best

interests, this is the horrible thing, the best interest meetings, which often aren't in the individual's best interest, they're in the best interests of the service, if you like; I've seen that happen during my time in health care. We should be able to document our choices, not our wishes, our choices and that should direct decision making in the future, you know, because at the end of the day, it's our life, you know, and strangers are making decisions about people's lives every day, and that shouldn't be happening.

Toby: **Yeah. So, information and awareness, but also information that's produced by the person about their lives to inform how decisions get made and how their rights can be upheld that take into account them as individuals, I think is perhaps a... and some summary that I've attempted from what people have said.**

I'm really conscious of time and I'm sure people have got other meetings to go to, so I'm... I could talk about this with all of you and the audience for hours, to be honest with you, but we're gonna have to call it to halt there, so I'm sorry if you asked a question and didn't manage to get it answered, but I'm conscious a lot of activity's going on in the chat room, so perhaps answers are coming up there. The session has been recorded so you can watch it again, or contact DEEP, or contact Innovations in Dementia if you want to follow things up, I'm sure they'd be happy to hear from you.

So, it just remains for me to say, at one minute to one, to thank Howard, and Nigel, Neil, Tom, and Lucy, for all their contributions and for sharing their expertise today. For Phil... to Philly and Steve for excellent backroom facilitation and making sure the technology ran. Thank you everybody who's come along today for your questions and your contributions, and listening; I hope you got something from this. I always find I learn something and think about things in different ways as a result of this, so I think it's been a great session.

The panel members, and I think Steve and Philly, are just going to stay on for a couple more minutes, but it just remains me... for me to say happy anniversary to DEEP again, and there are more sessions as part of the festival later today, and tomorrow I think, so please do join them. The ones I've been to have been absolutely fantastic, and if nothing else, look forward to another festival in 20 years' time, or 10 years' time, the 20th anniversary. So, thanks everyone and we're all gonna say goodbye now, but we're staying on the panel, just staying on the call for a short period of time. Thank you and goodbye; enjoy the rest of your day.

[music plays]

[End of Film]