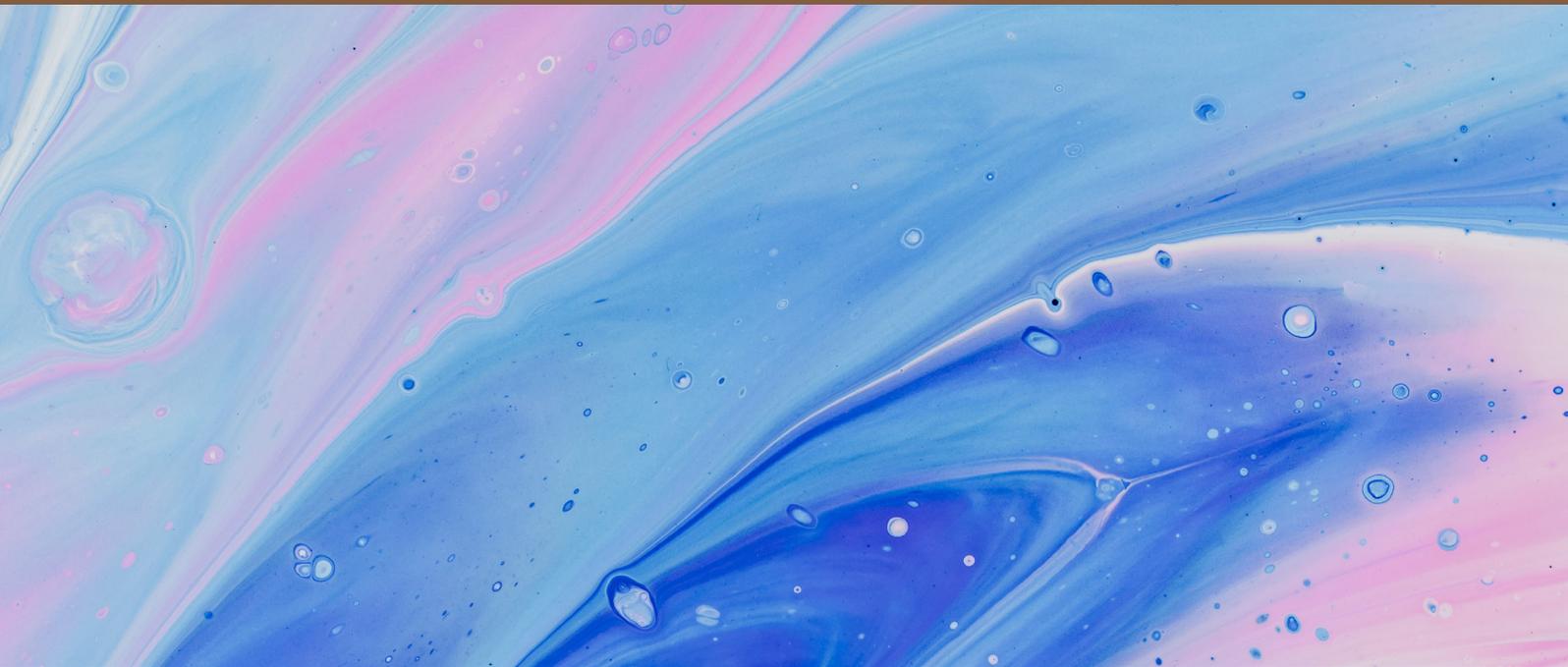


**World Dementia  
Council** Leading the Global Action  
Against Dementia

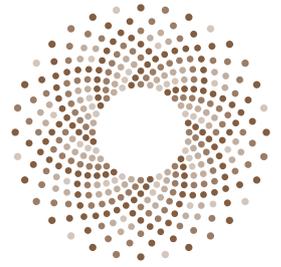
# **Global dialogue on lived experiences of dementia: Transcript**

**The dementia landscape  
project**

**1 November 2021**



# Co-chairs



## Hilary Doxford

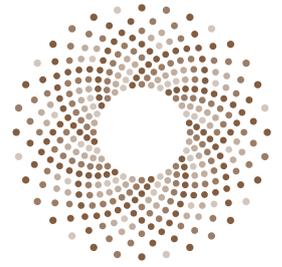
Hilary Doxford is a former Vice Chair European Working Group of People with Dementia, Ambassador Alzheimer's Society speaking nationally and internationally as a person with dementia. She was diagnosed with early onset Alzheimer's disease at the age of 53. Hilary Doxford also volunteers for the Alzheimer's Society in England as part of their research network and user involvement programme; is a champion for "Join Dementia Research;" and is a member of Dementia Alliance International. She is a founder member of the UK Three Nations Dementia Working Group, established in 2017 to advocate for people with dementia and to collaborate with professionals working in the field.



## Maryna Lehmann

Maryna Lehmann was diagnosed with dementia in February 2018 at the age of 58, and lives in George, South Africa. She was born in Johannesburg, South Africa, in 1960. She is the eldest of 5 siblings and matriculated in 1977. She enrolled for a BSc (Agric.) at Pretoria University and completed the Honours Degree in 1981. She married the same year. Her husband, André, retired in February 2019 to take care of her. In January 1982 she was employed as a farm manager of 300 sow piggery, 400 extensive cattle, 3000 head in feedlot. In the next 18 years she reared 4 sons and taught in numerous agriculture schools. On 1 January 2000 she joined Nelson Mandela University, as the Animal Science lecturer and completed a Masters Degree in Animal Science. She received numerous accolades such as upcoming researcher and upcoming teacher in 2006 and also received the "overall" teacher of the year award in 2007.

# Global dialogue on lived experiences of dementia



Monday 1 November 2021

08:00 CDT Chicago  
09:00 EDT New York / Toronto  
14:00 BST London / Dublin  
15:00 CEST Central Europe  
16:00 SAST Cape Town



## Discussion transcript

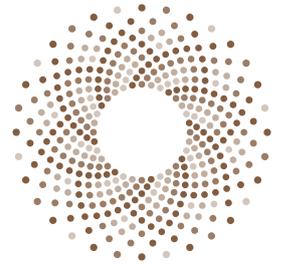


**Lenny Shallcross**  
Executive director, World Dementia Council

Good morning, afternoon, evening even, depending where you are in the world. I'm Lenny Shallcross the Executive Director of the World Dementia Council. I would like to thank you for participating in the dialogue today. I know some of you have been to previous dialogues or other meetings the council has held. But for those of you who have not, the World Dementia Council was established following the London Dementia Summit in 2013 hosted by the UK government as part of their G8 presidency.

The Council is chaired by Professor Philip Scheltens who is Director of the Alzheimer's Center at the University of Amsterdam. There are 24 individuals who are members of the Council, and this includes the co-chairs at the meeting today Maryna and Hilary. Alongside the individual members of the council there are a number of government members and OECD and WHO are also members.

We are holding an in-person summit meeting in London at the start of December as part of the discussion looking at the progress the international community has made since the 2013 Dementia Summit. To help inform that, we want to hear from experts around the world on different aspects of dementia policy. This is the twelfth of thirteen dialogues we have held. Previous conversations have been on biomarkers, clinical trials, technology, dementia in low- and middle-income countries among others. Over 400 global leaders have participated in the dialogues following this conversation as I have said next week, we have the thirteenth dialogue on Early Career Researchers.



We will produce a transcript of the meeting which is why it is being recorded. We don't publish the recording. What we will do is check with you the transcript to make sure you are happy with it before it is published so after the meeting you will have a chance to edit your comments because sometimes things look different when you read them so feel free to say whatever you want in this conversation today and you will have a chance to edit it afterwards.

After all the dialogues we have published essays with reflections from the people who took part in the meeting and essays from governments or international figures. Later this month we will publish a collection of data essays for research with contributions from some of those who participated in the meeting and a closing essay from Bill Gates we will be publishing later this month as well as essays on dementia in low- and middle-income countries and technology and the impact it has both on care and research. All our publications are published on the website.

As I said a moment ago today's conversation will be led by Hilary Doxford who I'm sure most of you if not all of you will know. She is the former Vice Chair of the European Working Group of people with Dementia and has been an Alzheimer's Society Ambassador and a member of the World Dementia Council. In fact, she is standing down from the Council this Autumn to enjoy a well-deserved but I am sure busy as ever retirement – if you can call it that on leaving the Council!

At the end of the meeting Maryna who is a living with dementia and from South Africa and who also sits on the Council will add her thanks at the close of the meeting. We have got about one hour today for the conversation that we will have but obviously if there are things that come to you after the meeting which you want to add to the discussion, please feel free to email me directly. One final thing on housekeeping before I turn over to Hilary which is to say that if you want to say something in the meeting please wave your hand or raise your hand in zoom – we will be watching the screen to see who wants to speak live. With that very short bit of housekeeping, I will hand over to Hilary to take the meeting forward.

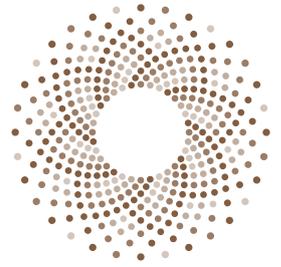


**Hilary  
Doxford**

Thank you, Lenny, and hi everybody. It's great to see you, especially those I haven't seen for so long. It's wonderful. Hopefully we'll meet in person next year, somewhere around the world. And I hope you're all doing as well as you're looking.

So, we've got about 50 minutes and it's all about hearing from you. We've been given an opportunity, I think, to give a pat on the back to those who are trying to help us where it's deserved and also a kick up the backside where we think we want some more action to happen. So, as Lenny said the Council is going to be preparing a paper about what's been happening.

Before we get going, I think we should all introduce ourselves. I will let you introduce yourselves. Perhaps you could just say your name, where you are from and when you



were diagnosed. I will do it alphabetically by surname. So, we will start with Arthena. If you can unmute yourself to say who you are, where you're from, when you were diagnosed, that would be great. Thank you



**Arthena  
Caston**

Good morning. Thank you for letting me go. My name is Arthena Caston. I am coming to you from the USA. I was actually diagnosed March 23rd 2016 at the age of 51.



**Hilary  
Doxford**

Thanks, Arthena. Howard hello.



**Howard  
Gordon**

Hi, I'm Howard from Sheffield in the UK. I was diagnosed in March 2017 at the age of 54.



**Hilary  
Doxford**

Thank you, Howard. Julie.



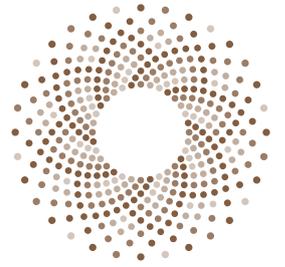
**Julie  
Hayden**

Hello. My name is Julia Hayden and I'm calling in from Halifax in the UK. I was diagnosed four years ago at the age of 54.



**Hilary  
Doxford**

Thank you. Chris Maddocks



**Chris  
Maddocks**

Hi everyone. My name is Chris Maddocks. I'm from Wales in the UK, but I now live in Eastbourne in East Sussex in England. I was diagnosed in July 2016 with vascular dementia at the age of 60. I was diagnosed in 2018 with Parkinson's disease. And last year I was diagnosed with Lewy body dementia.



**Hilary  
Doxford**

You're going for it Chris aren't you? James, hello.



**James  
McKillop**

Good day, everybody. I'm James McKillop from Glasgow, Scotland. I'm the dinosaur of any group I am in now as I was diagnosed last century. Still going, but very slowly now.



**Hilary  
Doxford**

Jim, I apologise. I talked you out of sequence.



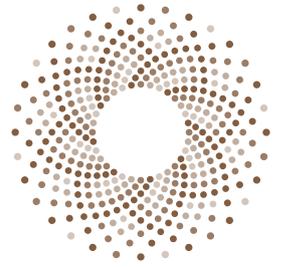
**Jim  
Mann**

I'm Jim Mann and I live in Canada, Vancouver, on the west coast, and I was diagnosed when I was 58 in 2007.



**Hilary  
Doxford**

Thank you, Jim. Emily, hello.



**Emily  
Ong**

I am Emily Ong I am from Singapore, and I was diagnosed in 2017 at the age of 50 years old.



**Hilary  
Doxford**

Thank you, Emily. Chris Roberts.



**Chris  
Roberts**

Good afternoon, everyone. Proud Welshman, living in north Wales. I was diagnosed, firstly with Alzheimer's and then, with vascular as well, so it was mixed dementia my final diagnosis. I'm also living with emphysema and arthritis.



**Hilary  
Doxford**

Thank you, Chris, Helen, hello.



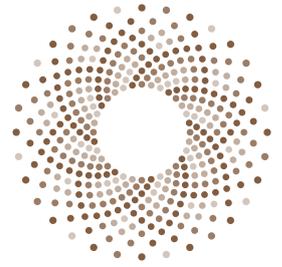
**Helen  
Rochford-Brennan**

Hello everybody. Nice to see you all. My name is Helen Rochford-Brennan. I am from Sligo on the Northwest coast of Ireland. I'm delighted to be with you I was diagnosed with Alzheimer's at the age of 57, in 2007.



**Hilary  
Doxford**

Thank you for that, everybody. So, we've got three parts to this meeting. We are going to share the good things, in particular I would like you to keep it focused on your country. So, your experiences and your knowledge about what happens in your country. So, we start off with the good, then we'll move on to the bad. And then finally I'd like everybody



to come up with one thing that they'd like to tell their government is their top priority to improve the lives of people affected by dementia. Before we start, I'm just going to hand over briefly to Maryna so she can say hello to you. Maryna Lehmann, my co-partner on the World Dementia Council.



**Maryna  
Lehmann**

Thank you very much, Hilary. I am Maryna Lehmann and I live in South Africa and have dementia. I was diagnosed in 2018 on the age of 57. I am a member of the World Dementia Council and wanted to add my welcome to all and thank you for joining this meeting.



**Hilary  
Doxford**

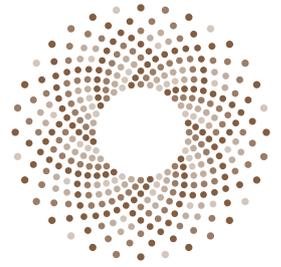
Thanks Maryna. Okay, so I'm going to stop waffling on and get down to business. So, our first question then is: thinking about your own country, what do you think has improved since the World Dementia Council was formed back in 2013? Anybody got anything they would like to share? If we just think about, mentioned awareness, stigmatism, getting a diagnosis, care and research opportunities. If anybody's got any comments around any of those themes. I'll go to Chris Maddocks first, then James. Thank you. Chris.



**Chris  
Maddocks**

Hi Hilary and thank you. I don't think that there are many improvements around dementia, but I would say that people like everybody on this call, who I would describe as dementia activists, raising awareness of dementia, I think that helps so much. Because there's still so much ignorance and misunderstanding around dementia. So many people think that dementia is all about memory, and it's not just memory, as we all know. It's the cognitive issues and problems that we have as well.

The other positive thing I've noticed since lockdown is that we've been able to meet via Zoom and other medias with people from all over the world and maybe opportunities that we would not have had, you know, had we been just still traveling to meetings. And I did cut short a few of my Zooms because I found I was doing up to five Zoom calls a day whereas ordinarily if you're going places you maybe go to one meeting. So, I think that we've been able to reach more people, because of lockdown and zoom and that dementia activists are the ones that really are making a difference.



**Hilary  
Doxford**

Thanks, Chris. That's great. I see, I think this this Karen that's just joined us? Karen, hello and welcome. We will just carry on for now. Perhaps let's catch up with you in a minute, but we're talking about our countries, what has changed for the better. So, I think next was James and then after James, Chris Roberts. So James over to you please, thank you.



**James  
McKillop**

At the time I was diagnosed the post diagnosis support was: "you have up to six years to live, go home and put your affairs in order". I fought against that for a year and in 2013, the Scottish Government gave everybody newly diagnosed new post diagnosis support for after a dementia diagnosis.



**Hilary  
Doxford**

Great. Thanks James. Chris Roberts.

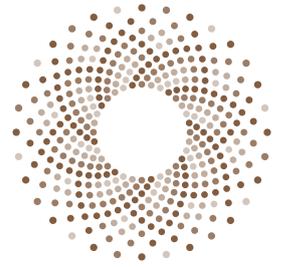


**Chris  
Roberts**

Yeah. I'm going on your agenda, Hilary. So much has improved since I was diagnosed, which is a good thing to say, but sometimes I think everything's changed, but nothing's changed.

But in Wales itself, (I can't speak for England, because I know there's lots of you here that are going to speak about England), things have changed for the better absolutely. We have now adopted the English hospital charter and tweaked it to make it better of course! We've just launched that. We've also got the dementia pathway and standards now. No one's going to get left behind. There is a hundred percent diagnostic rates and attendance by dementia services now across Wales and, especially in north Wales, there's new services being launched. We've just had the next five years of the dementia support workers again. And we've also had the Dementia Charter, that has cleared up a lot of things.

Our government is more approachable, I think, than the English government. It's a lot smaller. We can knock on the door and speak to people. There's less security and they



listen. And to be fair, they weren't getting it right in the beginning at all. But then when we sat around a table and actually had a conversation together as equals, carers, professionals and all the services they said, what can we do? And they did it!

So, things are changing immensely, it's a massive difference from when I was diagnosed and if someone is diagnosed now, the dementia services get in touch with them within a few days, if they don't want to visit, then it's fine. They ask you if you want to speak on the phone. They are told what services are available because we don't know what we don't know. And I think that's another fantastic resource. They actually get told what is available for them. They might not need it all on diagnosis, but you know, that's great. And also, the disability sector now is recognizing dementia and they want us to join them, which is also a massive resource. Anyway I could carry on. I'll stop there. It's not all doom and gloom.



**Hilary  
Doxford**

Thanks, Chris. I'm not commenting on what people are saying, because I want to hear what you've got to say. I don't want you to have to sit and listen to me. So, we've got lots of hands up, so I'll give you the order: Jim, Helen, Emily, Julie, Howard. So Jim, would you like to go next thank you.



**Jim  
Mann**

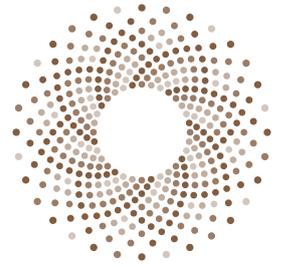
I do think that there has been some progress and certainly the idea of co-research or patient oriented research is being emphasized a lot more, at least in Canada. And, in fact, I'm co-investigator of a project and co lead of another. I don't think that would have happened, even a few years ago.

The Alzheimer Society of Canada has an advisory group of people with dementia and the Alzheimer Society of British Columbia, which is my province, has a leadership group of people with dementia. And the societies look to them for advice and direction. The advisory group for the national Society developed a few years ago, a Charter of Rights for People with Dementia. So, I think while there's been progress, it's been limited, but nevertheless, we have taken some positive steps forward.



**Hilary  
Doxford**

Great. Thank you, Jim. Helen.



**Helen  
Rochford-Brennan**

Thank you. Yeah, lots have happened since we met Hilary in 2013. I think that here in Ireland, if I think back to early 2013, it wasn't really spoken about it in the media, by anybody from Ireland. That has all changed. We have a National Dementia Strategy. We have a national dementia office within our health service. We have a charter of rights for people with dementia. I sit on the monthly committee off the national dementia strategy, which certainly, is terrific because we can keep an eye on things from the Irish dementia working group point of view.

We also have another Stand Together Campaign, and that campaign is about raising awareness of people with dementia and this a national campaign provided through our health service. We are also lucky that now we have memory clinics, we have dementia advisers. We have all those things that we didn't have all those years ago. So, I think there's a lot of work done. There's a lot more work of course, to be done, but it has been positive. And, as an Irish dementia worker and as a member of the Irish dementia work group we continually do our work with researchers, which is something we weren't doing back then. So, a lot has been happening in our tiny little island.



**Hilary  
Doxford**

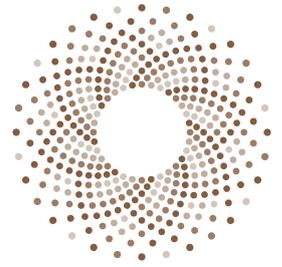
Thanks Helen that's great. Emily.



**Emily  
Ong**

Well, for this part of the world we are very far behind. I was diagnosed in 2017 and only referred to a support group by Dementia Singapore after 2 years. The support referral has not improved much even though it has been a few years after I was diagnosed. People are still not getting the needed support upon diagnosis. In September 2020 Singapore has its first Post Diagnostic Support (PDS) and only referrals from selected hospitals would be accepted into the programme for a period of one year upon diagnosis. The recipients are predominantly older people diagnosed with dementia.

So, for the young-onset dementia, we don't have the appropriate support system put in place. Hence, I started a peer-to-peer (P2P) support group last year under the Dementia Alliance International (DAI) for people with dementia. I take this opportunity to let the World Dementia Council knows that in this part of the world, especially the Southeast Asia countries, we are having a lot of problems, and people living with dementia still don't have a voice. Every day I'm fighting and advocating for the voice of people living with dementia to be heard. This morning I attended the first civil society on dementia



that included people with dementia to address this issue. I know it's a long way to go but I'm not giving up.

The issue is that people living with dementia, especially those with the young onset, are diagnosed late. By the time they are diagnosed, they are no longer high functioning enough to become an advocate. We only have a few who are living with dementia and capable enough to represent themselves without their care partners to speak for them.



**Hilary  
Doxford**

Thanks Emily that's an interesting perspective. Julie, over to you.



**Julie  
Hayden**

Hi there, here in the UK, we've certainly had a great increase in the number of dementia voices and advocates are being included. There has been an increase over the years in the number of researchers who were actually working in co-production with people who are living with dementia, which is a great hope for the future.

There's also a greater range of organizations to choose from for support and information. Whereas previously, we really only had the one. And this includes a number of specialist groups, which are formed particularly for example either young onset or for the rare dementias.



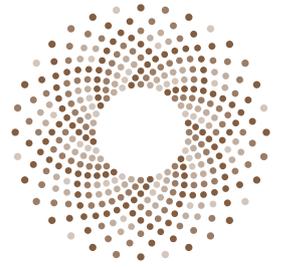
**Hilary  
Doxford**

Thanks, Julie. Howard,



**Howard  
Gordon**

Well according to Chris everything's changed but nothing's changed. I mean, Wales has shown fabulous work and it puts England to shame. In England it's very much a postcode lottery. Places like Sheffield, Bradford, Liverpool are doing lots of good work. But 10 miles up the road in Barnsley it's a completely different story. You know, we've got Dementia Friends, the hospital charter, John's campaign, but quite often they're seen as a badge of honour and the organizations don't follow through with it. So, it's very hard to say that anything has really changed.



**Hilary  
Doxford**

Thank you, Howard. Okay has anybody else got anything they want to add? I'm just conscious of the time. Karen, would you like to say something, or would you like to listen a bit longer?



**Karen  
Borochowitz**

Well, I just firstly want to say thank you so much for the invitation to join this group. It certainly is a great privilege. I see there is Maryna from South Africa. I haven't met Maryna yet but I certainly would like to. I have met James at a conference many years ago. We sat next to each other. And certainly, if I look at what's happening in South Africa, and I speak on behalf of Dementia SA, some of the discussion that I've had with Petra at Alzheimer's SA we're far, far behind all of you.

We can certainly take a leaf out of your book and how you've actually got people with dementia to speak up. Because in South Africa it's still very highly stigmatized. There's a lot of tribal and indigenous challenges with people with dementia. And I think that the services that are available for people with dementia and Alzheimer's, and rarer dementias, is few and far between. So, I'm hoping to learn a lot from all of you to help us in terms of being able to get voices of people living with dementia more heard. I wish you all well on your journeys with getting the advocacy out there and voices heard. Organizations like ours and Alzheimer's SA are trying to increase awareness and make the disease far more accessible and not as highly stigmatized as it is now. So, thank you for the invitation. Thank you.



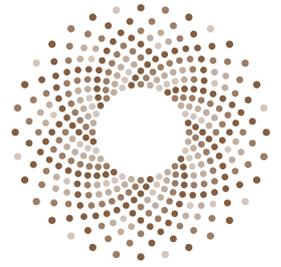
**Hilary  
Doxford**

Thank you Karen. Okay, James, if you could keep it brief, that would be great. Thank you.



**James  
McKillop**

When we spoke earlier, I thought you were just looking for one item. So, I told you about the post diagnostic support, but there's also a charter of rights. The fact that, after years knocking on the door, we got to meet the Minister for Health. And we got to meet the First Minister. We had regular meetings and whenever they were bringing out anything new about dementia they always came to the group for somebody on that to represent



them. And even now with Alzheimer's Scotland they altered their constitution allowing person with dementia to go on that board as a full voting member.



**Hilary  
Doxford**

Thanks, James. Chris, did you put your hand up again?



**Chris  
Maddocks**

This is just a quick one. I think the biggest change that I've seen is having rights and we've all been involved in that. And that has made such a difference because that's touching on lawful rights.



**Hilary  
Doxford**

Yes. I think we should all be proud of ourselves. You know, you all deserve a huge pat on the back for what's been achieved over the last few years. There is still a lot to be done as you've seen and said, but I think we've done pretty well all in all. And it's great just hearing it summarized like that. So going from the positive we'd better move to the negative. So Helga, I rudely interrupted you when you spoke before, I apologize for that. So would you like to kick off with the negative.

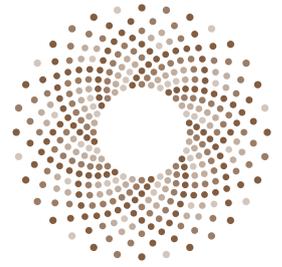


**Jim  
Mann**

Thanks, Hilary. I think as much as we talk about so many of the improvements, there is still, at least in my estimation, a lack of awareness of dementia within the community at large. The Alzheimer Society of Canada did a survey a few years ago that reported that half of those that were polled said 50% of all Canadians don't believe that they could live well with dementia, and 46% of Canadians would feel ashamed or embarrassed that they had dementia. So, that impedes progress.

I was a member of the Ministerial Advisory Board for the creation of the National Dementia Strategy in Canada. It was a three-year term and my term, actually all members' terms, have ended.

We have a strategy, but I think what it was developed the Agency really wasn't sure what to do next because it was such a big issue, with so many areas to deal with. And,



as far as just letting people understand what dementia is, at this juncture where we are faced within society not only the whole issue of Covid-19 but the opioid issue, at least in Canada that is certainly the case, those are big issues that have, I think, deflected attention from dementia.



**Hilary  
Doxford**

Yeah. So I think you're quite correct. Okay. Thank you, Jim. We've got Chris Maddocks and Chris Roberts then Arthena.

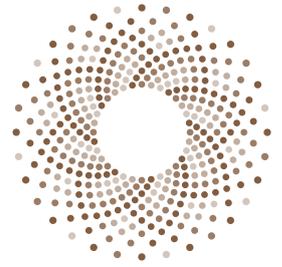


**Chris  
Maddocks**

Thank you. I have quite a few little bullet points, but I'll, I'll keep them brief. I think that the majority of people that I've spoken to in the UK are not followed up after diagnosis, and the only reason I got my Lewy body dementia diagnosis last year was I kept asking when I moved from Wales to England to see a consultant, I was only under my Parkinson's nurse. And the main, well one of the main reasons for that was I thought, well, things are changing and nobody's monitoring me, but I have to apply for my driving license every year in the UK, because I have dementia and the Department of work and Pensions and the Driver and Vehicle Licensing Authority no longer accept reports from specialist nurses it has to be from consultants, but if you're not under the consultant, how can you get these reports?

So, that was the main reason I asked to see a neurologist. And when I went along there, I wasn't expecting to get a new diagnosis. I was just expecting to be told about changes in my brain or whatever. Once again, when I had the Lewy body dementia diagnosis, there was no follow up. I was not given any information. It was just like, well, you know, this is your diagnosis. You may have Lewy body dementia, but it cannot be confirmed until autopsy. The main thing I thought was, well, I'm not ready for that yet. So, I've heard people saying "I've been to a doctor and said I've got Lewy body dementia". And they said, "what's that?" And if you went to a doctor and you said, I have breast cancer, you wouldn't be faced with a question "what's that?"

So there's so many forms of dementia. And yet most of the medical health professionals I have found, and speaking to others, are not aware of the basics of dementia, let alone maybe 200 different forms of dementia. Then there's research and co-production. I think that's really good. And, I'm involved in quite a few research things where we are co-producing and I like to say, well, don't do anything about us without us, because I think that if we're involved in research, we should be involved right from the word go. And also lack of peer support, everything you have to find out, you have to find out for yourself, and you may not get help at all until you reach crisis point. None of us want to reach crisis point before, getting any help.



The last point I'm going to make is that I think that in the UK, you have to apply for benefits, social benefits. I lost my job within three months of getting my diagnosis and I was turned down for all the benefits that I applied for. I ended up having to go to a tribunal and I went from scoring zero points to 30 points. That enabled me to have benefits. I really feel if you get a diagnosis of dementia, you should automatically get the benefits that you're entitled to.



**Hilary  
Doxford**

Thank you, Chris. Other Chris.

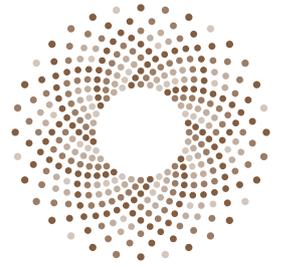


**Chris  
Roberts**

Yeah. The biggest space to my experience, the biggest challenge for me is, progression. You know, that's my biggest challenge, and having this pressure of being expected to live well, with a life-changing illness, means it's not possible. We all have bad days. We all have good days and that's without a life changing illness. It's such a pressure, this label. And the biggest challenge also, as Christine was saying, is lumping in all these different illnesses and brain conditions and neurological conditions into having symptoms of dementia. Let's get rid of the word dementia, let's call each different illness as it is. "You've got Lewy bodies". People would understand better then. It's very hard for people to get their head round what dementia is because of all this messing about, and we need to get rid of it, it just causes confusion. That causes all the stigma.

I think one of the biggest problems is social care, the care homes and not having stage-appropriate care. It's not about age. It's not about old or young. It's about having stage-appropriate care. You know, when I get to the later stages, I want proper care, but the moment I'm in the middle stages I want proper care for that. And I want to be with other people so we can learn off each other. Like Chris was saying again, peer support is where I think a lot of the emphasis is. If there's not a resource out there that you think is missing, push for it to become there. I've worked for universities and we wrote books on what people should need to know. And then the services can also use them. Then we are able to be proactive.

But the biggest problem is everyone thinking that we are disabled. Because everyone wants disability payments on the diagnosis. Well, do you know, eventually we will become disabled, but we're not all disabled on diagnosis. So that's another legal stigma, the challenge for me is progression.



**Hilary  
Doxford**

Thanks, Chris. That's very helpful. We've got Arthena, Julie, Howard then Emily. I'm conscious of the time. I don't want to rush anybody So just try and be, what's the word, I want never mind you know what I'm saying? Carry on Arthena.



**Arthena  
Caston**

It's always amazing to me. I'm listening from across country. How we sound so much alike, as far as United States. I'm looking at all the women on the screen! I just had menopause just to deal with the fact that I had dementia at such an early age. In the United States, we have good things, and we have bad things. I listened so much to Emily, and who is saying that they almost have no care and it's almost the same. But, in the United States, we have advanced quite a bit since my diagnosis and we're moving on.

But the biggest thing is, again for early onset, because it's not recognized as a disease, I've always said is we look at the person from when they are at the last stages and that's when you start looking for the care. What about the person who was diagnosed at 40 or 45? We need that same care. We need that same help. I don't need you to push me in a wheelchair or that, but I need you to help me and talk to me. It helped me with my speech and my vocabulary.

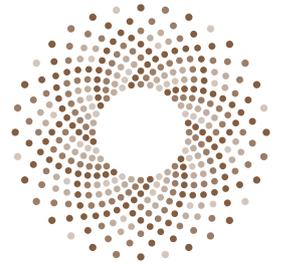
The United States is working very hard in some places but the biggest thing that we have here is that the stigma is very high and the worst thing about it is that it's always set in certain places. If you're in a bigger city such as Chicago or New York or somewhere like that, your chance of getting good care is much better than if you live in a small town such as me.

So, between the care and the stigma is where we have the problem in United States. As with everything it's all about if you have money to get to the doctors, you get the care. If you don't, you have that stigma placed on you, such as in my country. We as black women have the hardest time. We have the highest numbers, but we have the lowest, and I'll say it again, the lowest diagnosis in the African-American community. Even though we carry the highest numbers. So that's something that me as an African-American woman is working hard in the United States for. And I thank you.



**Hilary  
Doxford**

Thank you Arthena. Julie.



**Julie  
Hayden**

Yeah, there's a huge lack of professional awareness and knowledge as Chris Maddocks, touched on. Very poor, post diagnostic support, and no rehab. There is the only access that most people tend to have to dementia services is through older people services across health and social care, and you only then get that access to help through dementia services once you get to the point of being quite far advanced to not being able to wash and dress yourself. Prior to that there just isn't the help there.

Back when I was a nurse and when I was a social worker, if I came across someone in my care that had a condition that I didn't know much about, then I will go away and do my homework, to make sure that I was providing the best care possible for that person. And when I go along to my doctors, and even when I've been along to see my consultant neurologist, I get back from them and I don't know much about dementia. You're supposed to be in charge of my care. There's very little person-centered care. After all I am a person, I'm not a disease. I'm a person and so that needs to change.



**Hilary  
Doxford**

Thank you, Julie. Howard, Emily and then Helen. Howard.



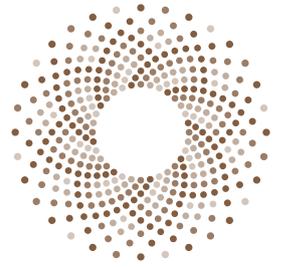
**Howard  
Gordon**

I think there's still too many barriers put up and not enough service. I mean, in Sheffield, if you're under 65, there's nothing provided. If you're over 65, you get a year at memory services and then you're left to wait for the crisis team when it's too late, you know, there's no continuity of care, no continuity support to enable us to to live as well as we can. I'm not saying that we can live well, but to live as well as we can. Yes that's about it I think.



**Hilary  
Doxford**

Thanks Howard, yeah totally agree. Emily



**Emily  
Ong**

Singapore has its first national survey on dementia in 2019 and the result showed that nearly three in four people living with dementia feel very ashamed to come out, rejected, lonely and less competent. Being a multicultural society, cultural stigma is a thing and dementia can be seen as a punishment from God or possessed by spirit for those who hallucinate. It is very hard to get these people to go and seek medical help and diagnosis. In terms of dementia awareness, I would say that in general, people in Singapore have heard the word dementia but they don't know what it is. Hence, people tend to stay away from people with dementia including their care partners.



**Hilary  
Doxford**

Thank you. That's very interesting. Helen.

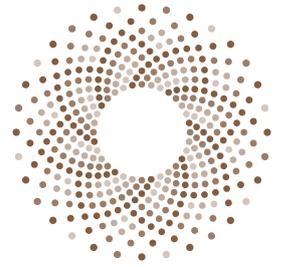


**Helen  
Rochford-Brennan**

For me it's about the lack of support, of person-centred support, to stay at home. All of the time we hear stay at home as long as you can, and we all want to stay at home, but there are no real supports for our psychosocial interventions, which is really difficult because we are doing so well. And yet, as many of you know, Sean, my husband passed away at the end of last year. I am now alone, but I'm alone without support. So, yes, I was able to get cognitive bereavement counselling through cancer support. But I mean we need to have cognitive, rehabilitative therapy, which, you know, I've experienced at the beginning of my research, which is fantastic. We all need that. If we need stimulation, then it should be available to us. So, I think there's a lot of work to be done in having person-centred home care support.

Not just talking about it, but implementing it, and ensuring that we are well and happy and living in our own homes. There's no point in government telling us we want to keep you at home as long as you can. And we as advocates go out every day, looking forward to staying at home as long as we can. My other big gripe of course and has already been mentioned is, which infuriates me may I add, is doctors diagnosing dementia. You know, what the hell is dementia? There are 200 types.

Let's try as advocates in our own countries to get rid of that once and for all it is not appropriate. I noticed the easy thing for doctors is to tell somebody of dementia. And as Chris rightly said, I always go back to the lack of meaning of that word dementia. We're not all demented. I think it's time that we stood up and abolished it around the world, the word dementia. We have a brain disease, a brain disorder, and that's all we have



at the end of the day. I don't have anything other than a brain disorder and that brain disorder should help me to know I should have all the supports to live at home, not just me, but everybody to live in our own homes for as long as we can. And may I add that for as long as we can.



**Hilary  
Doxford**

Thank you. Lots of claps there. James I saw that you had your hands up. If you could be brief it would be appreciated, thank you.



**James  
McKillop**

Since 1906 the powers that be have had all those years to do something for us. They didn't, and it was only in this century when they started to be active, that things happened.



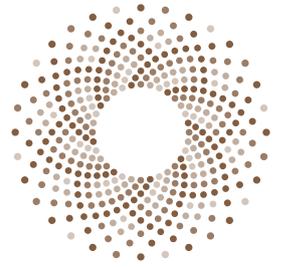
**Hilary  
Doxford**

Thanks, James. Okay. I think Lenny's got a wealth of information there that's going to be useful. So I think we've covered pretty much. Well, I think we've done really well. I'm very conscious of the time. So the last question is what is your top priority for your government to tackle? Because of the time, if you could just actually say what it is, but don't justify it. I'm going to start with Helen because I know she's got to disappear.



**Helen  
Rochford-Brennan**

I just want to say for the last thing, our human rights are human rights. From diagnosis to pathway of care, to end of life. But the UN convention on the rights of people with disabilities is fully implemented. And I talk about Ireland, of course, and that language matters to us. You know, I am a person with a brain disease, I suppose under the UN convention is considered a disability, but I want to continue to live in the same community that I lived in before my diagnosis, my community shouldn't change. It should embrace me the same as it did before I had my diagnosis. And that it fully embraces all walks of life, not just people with dementia, that we have a very, I go back and go back that I never left my diverse community. It embraces all and I suppose for me, as you all know, human rights are really important and I believe inclusivity, not labels.



**Hilary  
Doxford**

Thank you, Helen. Okay. Right. I'll go down the list in the order that we started the introduction. So Arthena what would you like your government to do? One thing, please keep it brief. Thank you.



**Arthena  
Caston**

I just want my government to understand that again, like I said, we have a brain disease. We need help. We need to have healthcare overall. I want everybody to be able to say we have a problem. Not just some people, but I want everybody to be able to share the wealth and get help for the disease of dementia or Alzheimer's or Lewy body, or whatever's going on. That's what I want as a person.



**Hilary  
Doxford**

Brilliant. Thank you. Howard.



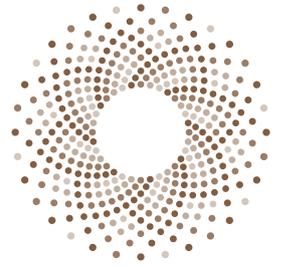
**Howard  
Gordon**

Thank you, for politicians to know, and understand and recognize we have rights and put those rights at the basis of everything they do, because over the last few years, those rights are being eroded.



**Hilary  
Doxford**

Yeah. Thanks Howard. Julie.



**Julie  
Hayden**

I would like our governments commit to a national dementia care pathway to raise quality standards and to end the postcode lottery and to make that person centered.



**Hilary  
Doxford**

Thank you. Chris Maddocks.



**Chris  
Maddocks**

I agree with everybody else. But I think that, we should be given an automatic, and appropriate benefits and that we are living with a life limiting disease and that we should come under health care and not under social care. Because you get nothing if you're in social care, if you come into health care, you get a lot of support. Also in recognition for the caregivers out there who do so much and get nothing and allow us access to things like neuro-physiotherapists and things like that, things that would benefit us. If we had the appropriate treatment, we would save money from our National Health Service because we would get the care that we need, and we wouldn't be ill and admitted to hospital.



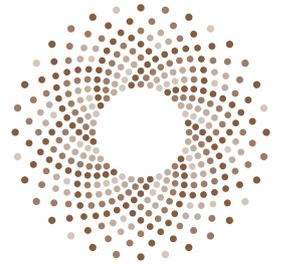
**Hilary  
Doxford**

Thanks, Chris, Jim Mann.



**Jim  
Mann**

I would like to see more education in the medical and health care areas. To educate the doctors, those in acute care and the home care workers around dementia, patient-centred care. Expanding that to the community at large might also address the whole stigma of dementia that's in the community.



**Hilary  
Doxford**

Thanks Jim James,



**James  
McKillop**

Even in this day and age, there are people in Scotland do not understand or know about dementia. I have long advocated information about dementia should start at school appropriate to their age group, because that way someday in the future everybody in Scotland will know something about dementia.



**Hilary  
Doxford**

Thank you, James. That's great, Emily.



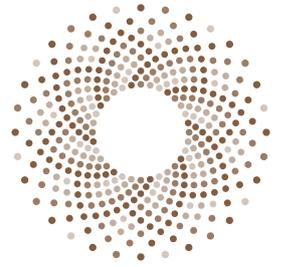
**Emily  
Ong**

Well, I want my government to start to hear the voice of people with dementia. And don't say that because we have cognitive impairment, we have no capacity to represent ourselves.



**Hilary  
Doxford**

Thank you. Chris Roberts.



**Chris  
Roberts**

Yeah, totally agree with everyone. I think we're all coming from the same thing there. But to make this happen, we need to stop being the poor relative don't we. Dementia needs to stop being the poor relative of illnesses. So, to make all this happen, we need more funding, I would like to ask my government to give us the money and ask us what we want. Speak to us.



**Hilary  
Doxford**

Karen?



**Karen  
Borochowitz**

I think in South Africa, for dementia and dementia care to become a healthcare priority. It isn't at the moment.



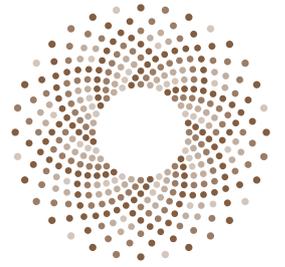
**Hilary  
Doxford**

Thank you. Thanks everybody. I hope I haven't been too bossy. I'm just going to hand over to Maryna. And now if she can hear me for a few words.



**Maryna  
Lehmann**

Thank you very much, Hilary. And thank you to all of you for taking part in today's conversation. I am grateful to all for taking the time off to be sharing your perspectives. I found the conversations very interesting. The meeting is about to close. I won't take up any more time, but I will hand to Lenny. Thank you.



**Lenny Shallcross**  
Executive director, World Dementia Council

Just to say, thanks very much to both the co-chairs and thank you to all of you for participating today. As I said at the top, we will produce a transcript of this meeting, which we'll send to you in the next couple of weeks to check that you are happy with the content. And then, for the next month when we will be publishing a discussion paper and then a final version of report will come out in the middle of next year. So Josh will come back to you with a transcript shortly, but just let me once again say thanks very much. And whatever time of day it is, where you are, have a great rest of the day, however long that is. So take care. Thank you.

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

[worlddementiacouncil.org](http://worlddementiacouncil.org)

© 2022 World Dementia Council  
UK charity registration number: 1170743

Cover image editorial credit: Shutterstock.com

