

Opening Alzheimer Europe Oct 2019

Dr. Helen Rochford Brennan

Good evening

Goedenavond (KHOO dun AH font)

For those of you who haven't met me, my name is Helen Rochford Brennan and I am from Tubercurry, Co Sligo in Ireland. I was diagnosed over 8 years ago with early onset Alzheimers disease. My diagnosis took me into dark depression because there were no services for me.

I was always a warrior but after my diagnosis I was a WORRIER. There was no cure for my illness. But with courage, bravery and strength I sought help. Most importantly it took a major change in attitude. I thought my life was over but with support I found a new way to live.

This is for the people in the audience who are not part of the European Working Groups , you can find that courage too. Seek out support and find what makes you hopeful.

I have now returned to being a warrior with the support of The Alzheimer Society of Ireland and Alzheimer Europe and I now longer worry!

I am honoured to speak representing the European Working Group of People with Dementia and the voice of the person living with dementia throughout Europe and beyond. Thank you to our Dutch colleagues for hosting the Conference, thank you to Alzheimer Europe for supporting us throughout the year and thank you to

the Alzheimer Society of Ireland for supporting my preparation for today and all my advocacy work. And I want to thank Carmel Geoghegan who travels as a volunteer to support me and cannot be here this evening.

The European Working Group was founded by Alzheimer Europe in 2012, members are nominated by their National Association and as the Groups Chair I sit on the Board of Alzheimer Europe.

We aim to increase awareness of dementia, challenge stigma, take part in research and speak about what it is like to live with the condition. I believe we have made a major change to how dementia is viewed in Europe and throughout the world. And as we begin this Conference I am heartened to see people living with dementia as active participants in the event and indeed many in the room this evening.

I am proud of the work of my colleagues on the European Working Group, in particular our robust engagement in research. This year we have continued our work with several EU projects ; PARADIGM on patient engagement in medicines development, PACE on palliative care, SPAN+ on empowerment, INDUCT and DISTINCT with PhD students on technology and dementia.

We are also involved in two new projects which are very relevant for people with dementia and where the group is highly involved ;**RADAR-AD** (about technology to assess functioning in people with Alzheimer's. And **Alzheimer Disease Detect and Prevent**: were we we provide feedback about issues linked to the use of risk reduction programmes.

I am honoured to have a number of internal groups embrace me as an expert by experience, I am delighted to work with the Global Brain Health Institute and ensure the voice of people living with dementia is influencing their research work.

As I was preparing today I thought about why we come to Conferences. I know for most of you in the room it is an opportunity to share your work, speak about innovation and new initiatives and interact with other researchers from around the world. And that is important.

But if I may (now that I am an official older person and veteran conference attendee) I would like to give you some advice!

Firstly please do not get complacent; let's not go home thinking the job is done. There are many innovations happening but there are also people living with dementia getting poor care. As a dementia researcher or policy maker you must also be a dementia advocate. I urge you to fight for funding and make those innovations the norm not the exception.

I also ask you to consider the theme of this Conference – *making valuable connections*. Please make those connections so you do not have to reinvent the wheel. Share your work, think about scale and learn from others. We must all work together.

Next I hope all of you think about how you can involve more stakeholders in your work, to hear voices not just of institutions, organisations and policy makers but of real people. Those real and authentic voices are critical to your success.

I receive many invitations to participate in research and I am glad to have my voice heard. But I challenge all of you here to ask yourselves – is Helen the easy option?

There are millions of people living with dementia throughout Europe; people living in rural areas with no transport, people living alone with no support to prepare and travel; people who do not use email, or whose sight is poor and need support with documents; people who live in a country where they do not speak the language. And they have lost their voice.

I am going to say that again, they have lost their voice. *(Pause)*

You have the power to support them to find it again. You need to reach out to those people and take practical steps to support diverse voices in research. Find the Helen in your own country and don't take the easy option. Person Public Involvement is about many people not consulting with one person with dementia to tick a box.

The day will come when I cannot participate at this level. In fact the day is coming; already my son is beginning to worry about what mum is going to do when I stop down from my role as Chair of the European Working Group.

If you are looking at me thinking I would love Helen for my research project – stop it! Go home and find people living with dementia in your country. I hope when I

can no longer travel that there will be researchers and policy makers at home in Ireland who will continue to consult me and offer appropriate support.

I would also advise you to **look at the whole person and in particular our social health**. It is a theme that comes up again and again when I speak to other people living with dementia.

We want to be viewed as people with hopes and dreams and autonomy. Even as our dementia progresses we can still make choices and we can maintain hobbies and interests. We want to be connected in our communities. I am more than a set of symptoms I am a person. No matter what the project or healthcare situation my personhood must be honoured.

We speak a lot about Dementia Friendly but I want to move to Dementia inclusive communities. I and others living with dementia have a right to be included. Friends come and go but inclusion is my right.

I want to see an all-inclusive community with no disability left behind. I believe we have a major amount of work to do on Education from infant school onwards, we need to educate people we come in contact with and give them the skills to understand our needs and difficulties we may be experiencing. I want to find solutions to a better quality of life for all and end the loneliness and isolation many people experience.

This is the world that I want to live in, to participate in and to feel that I am a part of.

Finally I want to remember the people who are not here; the people living with dementia and their families throughout Europe.

The people who are in Nursing homes or fighting for home care; who struggle to walk, to communicate; the families who struggle to care. They must be in our thoughts for the next three days.

It's not easy, but as Martin Luther King said;

'If you can't fly then run, if you can't run then walk

If you can't walk then crawl

But whatever you do you have to keep moving forward because only in the darkness can you see the stars'

I have ran, walked, crawled, gone through the dark place and now I can see the stars. I can feel the change coming. That has been the power of research for me. But I want to share that feeling.

When you go back to your home country make connections with the marginalised people with dementia, support them to rise up and find their voice.

Despite all the sadness living with dementia we also have to have enjoyment and hope. I hope all the people here with dementia find joy and connection in the next days and I wish everyone in the room a productive and enjoyable two days ahead.