

## Interview

# 'I'm not invisible - I'm living with Alzheimer's'

**Cara McHugh spoke to Helen Rochford-Brennan about her passion in life - advocating for the visibility of and right to live life well for people with dementia and why the barriers of stigma need to be broken down to stop it defining those who still lead fulfilling, independent lives**



**HELEN** Rochford-Brennan describes herself simply as a global dementia advocate, though "busy woman" might be the phrase that first comes to mind. Speaking from her home on the Ballymote Road in Tubbercurry, she is thoughtful, direct and clear about what matters most to her: visibility and the right to live well with dementia.

When Helen meets new people and tells them she has Alzheimer's disease, the reaction is often the same. "People say, 'Oh God, you look well,' and then they say, 'I'm so sorry,'" she explains. "I always have to tell them, don't be sorry for me. I live well. I live alone. And I think people don't really understand yet how we can or should live."

That misunderstanding, she says, is exactly why she continues to speak out. Even now, Helen believes many people still struggle to understand what living with dementia can look like. "Nothing much has happened locally for a long time, and we need to get the message across that you can live with this illness and not be afraid - including not being afraid

to live alone," she says.

The default reaction, she feels, is pity. "The general reaction is pity, and that's because dementia is still stigmatised. And that's the pity, it shouldn't be like that. I'm not a tragedy. I'm not just coping. I'm still living, growing, and part of the world."

Helen lives by herself and shares her home with her dog, Lexi, whom she

describes as her companion. Her son Martin lives in New York, and she speaks warmly about the friends and neighbours who form part of her daily life. Technology also plays a vital role, she says, as does her voice.

"This shouldn't mean I'm left behind," she says of her diagnosis. "It should mean I'm supported to live how I choose, with dignity, joy and connection."

Support, Helen is keen to stress, is not a sign of weakness. Around the world, she says, more people are living alone and thriving with dementia when the right supports are in place.

Her daily life is rooted firmly in her community. She walks her dog, meets people and stays engaged with what is happening around her. She has always had a strong interest in politics and world affairs, and that has not disappeared. "I have short-term memory loss, and that's okay," she says.

She still goes to the shop, though not as often as she would like. Cooking is no longer possible because she sometimes forgets to turn off the stove, but going out is not about errands, it is about connection. "When I go out, it's about meeting people and connecting," she says. For Helen, stigma

remains one of the greatest barriers facing people with dementia. Asked how it can be tackled, her answer is immediate: "We remedy it by being visible and being heard. We need to humanise dementia."

She believes stigma strips people of their agency. "It tells us that once we're diagnosed, we no longer contribute to society, that we're defined only by decline. But that's not true," she says. "Dementia doesn't erase my humanity, and it doesn't negate my work."

In Ireland, she feels dementia is too often treated like a curse rather than a medical condition. The consequences are serious: social isolation, delayed diagnosis and fear of seeking help. The solution, she believes, lies in education, visibility and storytelling.

"People like me telling our stories openly chip away at outdated fears," she says. "That's why I speak. Lived experience is at the forefront of my advocacy. No one understands dementia better than those of us living with it."

Schools are particularly important in understanding the disease, she says. Speaking to children is one of the great joys of her life.

"They learn that granny or grandad might forget names, and that's okay,"

she explains. "Sitting on the floor and talking to them makes a real difference."

While she acknowledges progress through campaigns such as Understand Together, Helen says more needs to be done.

"That work shows people we can still function, still do things, and that there's no need to be afraid," she says. "I always say I'm the same Helen today as I was before my diagnosis, except I have short-term memory loss."

Assumptions about contribution particularly frustrate her. She has always cared deeply about her community, region and country, and that has not changed. She remains actively involved in campaigning for the opening of the Western Rail Corridor, a cause close to her heart.

"That's my passion — the freedom to travel, to get to Galway, to access services," she says. As a founder member of this, she has long highlighted the importance of transport for rural communities. Having Alzheimer's, she says, should not disqualify her from involvement.

"Because I have Alzheimer's, some people think I shouldn't be involved - and that's wrong," she says. "We shouldn't be afraid to



Helen at European Parliament in 2024.