

speaking out on what matters to us."

Rural isolation is a major concern for people living with dementia, Helen says. Better transport would mean access to meetings, groups and activities across the region, rather than being confined to one place. Nature also plays an important role in her wellbeing.

She says that her house is filled with notes and reminders, a practical response to memory loss that she embraces fully. "I don't care what it looks like," she says. "It's my house, and it works for me."

She believes the government must do more to support people to remain in their own homes. "Governments need to fund people to stay at home - not just people with dementia, but older people in general," she says.

Purpose, she believes, is essential.

Her son, Martin, lives in New York, and they keep in close contact. She recently became a grandmother when Martin welcomed his first child. She spent Christmas with him last year and travels there often. "He stays in touch with me every single day to see how I am," she says. "So I cannot ask for anything more than that."

The days when she does very little worry him, she explains, because they feel like a sign that the illness is taking over. Staying active reassures both of them.

Technology is another essential tool in her life. Alexa, her computer, her diary, pen and paper all help her to manage daily tasks and maintain independence. "My house isn't 'normal', but it's organised in a way that suits me," she says.

Helen's diagnosis journey was long and painful. It took five years, beginning in 2007, when she was considered too young. The uncertainty was deeply stressful for her and her late husband, Sean. When she was eventually diagnosed, there weren't many supports available.

A turning point came when a consultant encouraged her to get out of the house, and a nurse suggested she get involved in research. That led her to the Alzheimer Society of Ireland and the Irish Dementia Working Group, where she later became chair. She said that she was also the first person in Ireland to publicly disclose on television that she had Alzheimer's disease.

She continues to receive messages from people who say her story helped them or their loved ones take their first steps back into the world.

"That's why I do this - to give people hope," she says. "There's no cure, but there is life."

To those newly diagnosed, her advice is simple: live your life. "Keep your brain active. Read, listen to the radio, go out, go to the pub if you want.



Helen at a Dementia Inclusive Community event held in Tubbercurry last year.



Helen Rochford-Brennan presenting a cheque to the Alzheimer Society of Ireland in 2015 following a fundraiser held during the Dublin Women's Mini Marathon.

Don't stop doing what you enjoy."

One practice that still upsets her is when doctors inform families but not patients of a diagnosis. "I believe people deserve the truth," she says. "We are too often spoken about instead of spoken with."

She also wants people to know that palliative care is available from diagnosis, and that it is about quality of life rather than dying.

In Tubbercurry, she says, progress is being made toward becoming a dementia-inclusive community. Monthly gatherings at the Family Resource Centre are particularly important for the rural town.

Helen grew up in the Ox Mountains, the daughter of Patrick and Kate Rochford.

"I wasn't the brightest at school," she reflects, "but I became smart in the ways of the world." She believes hardship and loss shaped her resilience and optimism.

"When you live in rural

Ireland, you depend on your neighbours," she says. "I have the most wonderful neighbours - there's nothing that I could ask them to do and they would say no."

After the interview, Helen followed up to clarify an important point. While she travels and speaks internationally, she does so with support. She receives assistance from Carmel Geoghegan, who cared for her own late mother who had dementia. "It's important people understand I am safeguarded," she said. "I cannot do it alone. Supports are necessary to give me a quality of life and a sense of purpose."

Helen maintains a positive attitude always through adversaries: "I always say, I may not be in control of the length of my days, but I can always shape their depth and meaning - and that's what I try to do every day."

And, she adds, simply: "Nothing carries us through, only hope."



Helen with Mary Robinson at the launch of the Charter of Rights for People with Dementia in 2016.