



ALZHEIMER'S ADVOCATE HELEN ROCHFORD BRENNAN

The importance of being part of a local community

HELEN ROCHFORD-BRENNAN IS FINDING THE COVID-19 RESTRICTIONS DIFFICULT, BUT SHE HAS SEEN TRUE COMMUNITY SPIRIT WHICH HAS HELPED TO LIFT HER MOOD. SHE SPEAKS TO JESSICA FARRY ABOUT HER 70TH BIRTHDAY PARTY, THE CHALLENGES SHE FACES WITH ALZHEIMER'S, AND HOW HER ADVOCACY WORK HAS CHANGED.

It wasn't exactly how Helen Rochford-Brennan planned to celebrate her 70th birthday, but as streams of neighbours, family members, friends and even An Garda Síochána drove by her house last week with balloons to wish her a happy birthday, she realised that community spirit is alive and well, despite these difficult times we live in.

Helen, who was diagnosed with early onset Alzheimer's in 2012, was due to be in Croatia last

week as part of her advocacy work. There, she was going to spend an extra few days as part of her birthday celebrations.

She had also hoped that her son Martin could be with her and her husband Sean for the celebrations.

But, like everyone else, the global Covid-19 pandemic brought an end to all of Helen's plans for the year.

To cheer Helen up, her nieces

made contact with Carmel Geoghegan, who supports Helen to travel abroad to carry out her advocacy work.

Together, they compiled videos of people wishing Helen a happy birthday, and organised the 'drive-by', which ensured that Helen's 70th was a special day.

"They knew I wasn't going to have a birthday, so they got people to do little videos on their iPhone to say happy birthday," she told The Sligo Champion.

"Then they decided to do a drive-by and they got all the neighbours and friends to drive by the house and it was just such a lovely event. The neighbours were saying to me 'it's great to have a bit of excitement on the road'.

"It was great for community spirit. Everyone came out, I just feel that us people with dementia we are lost in a world a lot of the time, we are forgotten. But, we're not forgotten, this is a perfect example of why we need our communities and why we need to live in our communities and know that we are cherished and loved by

our communities. We are the same people we always were.

"I think my 70th proved that community spirit is alive and well in Tubbercurry. I cannot tell you the gratitude I have, and how it lifts your mood. Martin (Helen's son) couldn't be with us and that was hard because we had planned to be together as a family. His cousins and everyone made up for it.

Helen is well known around the continent, as Chairperson of the European Dementia Working

Group and former Chair of the Irish Dementia Working Group, she has travelled the globe.

While on these trips, she promotes Sligo and indeed Tubbercurry, where she lives, to as many people as possible.

"I feel like I try to do my best to show Sligo and Tubbercurry as well as I can. I'm sure everyone knows about it when I go abroad to conferences I'm always talking about Tubbercurry and Sligo. This was the community remembering that and it was a special day to show what our communities mean to us."

A Tubbercurry man, Desmond Bailey, is part of a group of dancers made up of the original cast of Michael Flatley's Lord Of The Dance who have come together to create a video

to raise funds for people living with dementia.

For Helen, being busy and getting out and about

everything helps her massively. She makes sure to keep her brain as active as possible, and her advocacy work helps with that.

But, as soon as Covid-19 hit. All events were cancelled. It took some adjustment for her.

"When everything stopped, advocacy stopped, and it was very hard. The cognition just goes. You keep forgetting. Even now I have to get up in the morning and turn on the phone and see what day it is, I don't know the day or the date. For me to function, everything is writing stuff down. I'm forgetting to write stuff down.

"It really has a major impact, not just on people with Alzheimer's like me, but a lot of older people I've spoken to are saying the same thing, one day is drifting into another. It's hopeless. It's very difficult but in saying that we are very lucky, our community group was set up here locally. If we need anything we just ring them and ask for help.

"Now when you have Alzheimer's you forget to ring. I was talking to one of the guards one day at the door and he said to me 'Helen you know we are here if you need anything' and I had completely forgotten that I can ring them if I want something, even though it's been in the news.

"I have family that live close-by and my nieces do all my shopping, all my family are supportive at this time. The girls have young children. When you have Alzheimer's, you forget to put tea or bread on the list and you find when you need them, they're not there. I had to hop in the car and find the smallest shop I could. Not everyone is as privileged as me that they can hop in the car. You can't keep asking your family, you try but you don't always remember."

The community in Tubbercurry where Helen lives has always been kind to her, and they have really shown her how much she means to them in recent weeks.

She paid tribute to the doctors and pharmacists who have been of assistance to her, now and ever since her diagnosis.

"Going out and getting fresh air is the best thing that I can do, then trying to stay in touch by reading, if you can do a puzzle then do it, if you can take part in a quiz then do it.

"But your neighbourhood is what you depend on. You really depend on your neighbours. In the first weeks I had calls from my neighbours, asking if they could do anything for me, that's what Ireland is all about. It means a huge amount. We are one big community.

"I'm so proud of our frontline staff who are doing a fantastic job in difficult circumstances."

Adjustments have taken a while, and Helen has found ways to keep in touch with everyone, but it's not the same. The first number of weeks were particularly difficult, and now that she can

get out for a walk everyday, it is much easier.

But, as someone who is so used to human interaction and meeting people, she has found it somewhat isolating.

It's also vital for Helen to keep her brain active, so she is finding ways to ensure she is doing something.

"It is so difficult. If you're at home all day looking at four walls with nobody to talk to, you're reading papers and there's only so much you can read and only so much you can talk about. My memory and cognition dies, it goes by 'if you don't use it, you lose it'.

"Some of my family had arranged a quiz night, we tried to catch up on the quiz night, it's family and friends. It's great.

"With Alzheimer's groups, we're trying to talk to each other and talk about the future, we've had conferences and everything. That's what keeps me as good as I am, as the doctors keep

reminding me, I'm doing more for myself than they could because I'm keeping my brain as healthy as I can by being active.

"It's hard work, you're an advocate and you're not a paid worker. You try to bring joy to other people's lives and try to give them a chance to say 'look I can get on with it'.

"But you don't have that chance now so just think about it, when you're doing something that makes you feel really good and you're making a contribution to society and then you can't go outside the door. That is difficult.

"I've talked to several people with dementia, we're all feeling the same. Alzheimer's Society of Ireland have meetings online and everybody is learning to use Zoom. I've been using Zoom for many years but it's great to see people learning to use Zoom, it does lift our spirits by keeping in touch with people, we are human and we have

the same needs as everyone else.

"Do I miss the human connection? I miss the human connection so much. In those early days, not having anybody in the house. I think it's 10 weeks since my husband Sean and I had anyone in the house, that's a long time. Our son lives in England.

"He can't come home because he would have to isolate for two weeks here and then isolate for two weeks when he goes back and that's not easy. It was a birthday with a difference."

There are factors that Helen has to take into account that most of us would never even think of. She worries that she will forget about social distancing and all the restrictions that are in place.

"My husband was out walking and was chatting to neighbours and that's a really good boost for people just to be able to get out of the

house and just to chat to each other. People are so respectful of distance.

"I walk everyday and I meet Dads pushing buggies and I meet Mums with children, older, younger people, they are so respectful of social distancing. It's amazing how we have all adjusted to that.

"I could forget easily. I do not go to the supermarket, the reason I don't want to go is that I'm afraid I might go up to somebody. I don't trust my memory because I know well I would. Someone might talk to me and I'd give them a hug because I haven't seen them.

"I just can't do it. For anyone with a memory problem, we have extra issues to deal with."

Helen is also carer for her husband who has a number of chronic illnesses. They get 30 minutes a week of help, and despite making their case for more than that, Helen and Sean have been refused.

She explained: "I have to do everything at home. We don't get the resources. It's ridiculous. Right now is very difficult. We're in a Catch22 situation.

"We haven't been offered any more help for him. I've asked for help in the home to enable me to do things better. People with dementia want to be enabled and not disabled. I don't need someone to come into the house and do everything with me, I need someone to come into the house and help me to continue to do the things I always did."

Going to extra lengths to make sure she does things right at home is not always easy, and sometimes anxiety can take over when Helen realises that she has made a mistake somewhere along the line.

It can be anything as simple as cooking, to cutting herself and not even realising.

Helen said: "If I went about making a cake, sure as hell I will miss something out of that recipe. Or making a casserole or something simple. I don't remember.

"I have to have the iPhone in front of me. That doesn't really work, because I cannot check off everything. If I want to make something I have to print out the recipe so that I can tick off everything and know I have all the ingredients

in the pot. That's a good thing too though for cognition, it makes me work.

"I don't believe that my doctors have to do everything for me, I believe that I have to do a lot of things for my brain health. That's the kind of help I need. I'm constantly burning myself because I forget.

"Or I'm out in the garden pulling out weeds and I look down and see that my glove is filling up with blood because I've forgotten what I'm

doing and I'm taking blood thinner. Then there's panic. I can't remember where I put the sticking plasters. Those small simple things that people take for granted.

"The anxiety that comes with that, there isn't a word for it. You get so stressed out, not meaning to. It's overwhelming. It just happens. You just think 'is this getting worse? Is this where I'm at now?'

Helen feels that she can never thank her community enough for what they have done for her, now and indeed throughout her illness.

"There are challenges. Some days the challenges are immense. Now we still have no end in sight as to when we can go to someone else's house or someone can come visit us. It's the human connection.

"It's the most important thing for us all, because of the type of people we are. I'll be glad when it's all over. I'm eternally grateful to my community because on dark days, and believe me there has been many in my life with this horrendous illness, you're robbed of your ability to write, you're robbed of your ability to remember, remembering names and people.

"In family conversations we're talking about 'when' and I don't remember. And you can't keep saying 'I don't remember' because we're a normal family.

"For me, that's really hard for your children when you don't remember something. Sean and Martin forget I have Alzheimer's and I forget sometimes.

"We want life to be as normal as possible. My pain is their pain. When I don't remember something they've told me that's important, that's hard on them too.

"You can feel the silence."

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”





Helen Rochford Brennan carrying out her advocacy work.



Ciaran brings a bouquet of flowers to Helen from her son, who was unable to come home from London for the occasion.