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‘The stigma of Alzheimers *creates terrible loneliness*’

DUBLINER **Jacinta Dixon** has learned to cope with her dementia diagnosis and is determined to remain as independent as possible. But, she writes, misconceptions about the condition can lead to isolation

I NITIAALLY I used to joke about it in work, “I am definitely getting Alzheimer’s” and my colleagues would say: “Sure, we all have a bit of that.”
I’m 68 now. But looking back, that is where my journey with dementia began.

A few years ago, as working in the disability sector in Ireland when the early signs and symptoms started to become apparent. I was slowing down and I found reading and writing reports were becoming more difficult. I knew something was wrong.

I went to Beaumont Hospital in Dublin and, after about a year, I was given my diagnosis in 2017. In some ways getting a diagnosis was a relief; because I knew myself that something wasn’t right.

I grew up in Dublin, in East Essex Street, which is now Temple Bar, and when I got married we moved to East Africa. Originally the plan was to go for three years, but we ended up staying 25 years, and raised three children in Kenya and Tanzania before returning to Dublin.

After my diagnosis my family were a fantastic support to me; I still love having them close. My granddaughter Ruby, who is nine years old, does my make-up and helps me to find things in the house and her brother Ollie helps me to find things in the house. They are both great helpers.

I have recently joined the Irish Dementia Working Group (IDWG), which is an advocacy group for people living with dementia. It gives me an opportunity to be productive and active. After my diagnosis people kept offering me tea, and while I like tea I can do a lot more than sit down with a cup of tea!

Becoming an advocate has been life-changing. It gives me a chance to do radio interviews, public speaking and be involved in consultations on policies that affect people with dementia. Now, I am almost too busy for those cups of tea.

But to be honest, I was really struggling

before being involved in this working group.

You see, there is a big stigma around having dementia. People think that you are not really a person anymore and that your life is over. This horrible stigma creates a lot of unnecessary loneliness for people with dementia around the country.

Often people overcompensate and treat you too nicely – sometimes this is even worse than being ignored. I like people to be patient, but I would like them to remember that I am an adult and I can make decisions.

Before getting involved in the group, I was lonely. My family are so caring and they are wonderfully supportive; they take me out and call to my house, but when I close the door I am alone.

It can be hard for people to understand that I still want to be independent, and even though I have a wonderful family, I want to live my own life. Who wants to simply be an accessory to someone else’s life?

I have experienced isolation. My neighbours and people in the community are great – but a lot of people still don’t really know what dementia is, how it affects people. And they definitely don’t understand that it can affect people at a relatively young age.

It’s not just something that happens to

so-called ‘old people’ or is a normal part of ageing. These misconceptions need to be challenged.

It can be hard to be independent, but I try. I enjoy collecting my grandchildren Isabella and Rachel from school, I go supermar-

ket-shopping locally and take regular walks. I enjoy hiking, gardening and the outdoors.

All these things just take a bit more planning now. I am just back from visiting my new grandson Benjamin and his brother Sam in Aberdeen. I travelled alone and although it was challenging I’m glad I did it.

I call myself ‘selectively stubborn’, in that I won’t give in if something is important to me. Maintaining my independence is very impor-



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tant and I hope to have many more visits to Aberdeen.

My particular type of dementia has made me dyslexic and I can no longer read. I have accepted it, but it has been a huge loss and has compounded the social isolation I experience on occasion.

Even little things like listening to the radio and choosing the right radio station can be a challenge. These things are my lifeline to the community, my county and the world.

I struggle with using my phone, which means I am quite dependent on family and I am constantly losing things in my own house and, when this happens, it is frustrating and upsetting.

I am constantly checking and rechecking and if I lose my keys or phone it does make

me feel down and, sometimes, the tears come.

But I lift myself back up. There are things that I can do that are very helpful, such as my course in mindfulness, which I did after my diagnosis.

I want to be as independent as possible and I like things being clearly explained to me. When I am not listened to, or professionals make assumptions about me or my health, I find it very frustrating.

I am glad that The Alzheimer Society of Ireland the HSE's "*Dementia: Understand Together*" campaign has gotten people talking about dementia — that conversation is powerful in improving understanding about the condition.

I know that my dementia will progress and that many people in Ireland live with more severe symptoms than I do. That is my motivation for advocacy work — we are all people, and even though we forget and lose words, we still matter.

● **The Alzheimer Society of Ireland helpline is open six days a week on freephone 1800 341 341. For further information about the "*Dementia: Understand Together*" campaign, visit understandtogether.ie**



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