

# How We Best Respond to the Challenges and Opportunities of an Ageing Population

## Presentation to the Citizens' Assembly 10/6/2017

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I'm Eamon O Fearghail, I'm 47, single and I'm a carer for my mother Cathleen who is 87 and has been diagnosed with Alzheimer's Disease since 2010. I'm here today to put the case for family carers as we attempt to respond to the challenges and opportunities of an ageing population. As a carer for someone with a dementia which has its own specific needs, my perspective will reflect that experience.

Cathleen has been a widow for many years and I am her only child. I was made redundant during the recession and failing to gain employment, I became self employed and availed of any work I could get with the assistance of Social Welfare. When the time came to make a decision about Cathleen's future care it was almost automatic that I would become her carer. My mother had always stated that she didn't want to go into a nursing home and I intended to respect that position. Simply, there was nobody else. My employment situation gave me the flexibility to take on the role of caring and continue to earn a wage. It was not so much a choice but rather a natural decision borne out of necessity.

In hindsight if I knew precisely what I was getting into I might have chosen a different option. I would say that most carers out there are reluctant carers. They have taken on the role out of love and a sense of duty. They certainly don't do it for selfish reasons. Because when you become a carer you throw your life away. Any hopes and dreams you may have had are on hold, indeed they may never be fulfilled. When you become a carer you give up your freedom to come and go as you please, you give up your financial stability, your career prospects and any prospects of a personal life. This in turn can lead to carer ill-health and fatigue.

Carers are on duty 24/7 and even when they are out of the house they are still on alert, looking at their watches and worrying about what might be happening at home while they are out. Cathleen's home is equipped with sensors, cameras and other devices which alert me if she gets out of the bed or if she leaves the house at any time day or night. The camera at the door also serves to ward off anyone who mightn't have a genuine reason to call. Old people are vulnerable and there are those who would exploit that. As well as caring for her medical needs I am Cathleen's protector, her advocate, her financial advisor, her companion among other things. As a sole carer with 100% of the burden of care this has taken its toll on my health and wellbeing. It is not unusual for carers to suffer with anxiety or depression. Let's face it, there is no light at the end of the tunnel. Some day our caring days will abruptly end when our loved one dies or finally goes into nursing home care. I welcome the continuation of Carers Allowance payments for 12 weeks after caring. As a society we need to show compassion to the carer and the state should attempt to assist in the carer

rebuilding their lives. We must find ways of promoting, sustaining and protecting carer health in proactive ways before ill-health sets in and there is a catastrophe.

At one point some years ago, I felt I was on the verge of a mental breakdown. I actually turned up at a psychiatric hospital and asked them if there was anything they could do for me. Unfortunately there was nothing and I was referred back to my GP. My medical insurance would not cover any services they could provide. I had reduced my premium so that I could afford it but obviously there were many services that my insurance would not cover. Many organisations, companies and government departments offer health insurance schemes to their employees at reasonable rates (teachers scheme, nurses scheme etc.). Would it be too much to ask that the state negotiate a scheme for carers so that at least they can feel confident that their health needs are met?

Carers need to feel valuable and valued. They are helping someone to live their life as best they can while sacrificing much of their own lives. The community and local authorities can play their part in inviting carers and their loved ones to public events and facilities to ensure that carers are visible and recognised in the community. Local authorities could do more by making leisure facilities available at reduced rates for carers. Measures like these can raise carers' confidence and self-esteem which unfortunately can be prone to flag.

I welcome new initiatives to extend the Fair Deal scheme to home care services. However, if we are to be realistic, the resources and staff are not there to provide adequately for such care on a broad scale. If we are to effectively meet the challenges that lie ahead, the state must invest heavily in health services in the community, providing timely responses to the health needs of the public and carers in particular. Our local health centres must be adequately resourced and staffed. I should not have to wait two weeks for a visit from the OT or physiotherapist after my mother has had a fall. If additional equipment is required in the home they should be forthcoming without delay particularly if a loved one is dependent on it. Carers should not be caught up in arguments with the health services over funding of such equipment. Responses to crises in the home by the health services should be swift and comprehensive. A carer should not be put at risk of injury due to a lack in resources. In cases of dementia, carers may at times be unsafe in the home with their loved one. Responses by health services and the Gardai, if necessary, must be immediate and sensitive to the situation. The carer's safety has to be protected. Let us not forget, it would cost the state somewhere in the region of €1200 per week to look after someone in a nursing home.

There is no doubt that the Carers' Allowance of €209 per week and annual Carers Support grant of €1700 are inadequate and place many carers in financial difficulty. The Carers Allowance is means tested but allows the carer to work for 15 hours outside the home. The criteria are quite restrictive and we need to find more imaginative ways of allowing carers to be financially confident, able to meet their expenses and be able to save for the day when their caring ends. In my own case, I left my own home to care for my mother in hers. I still have a mortgage to pay on that home. I also have a property tax to pay on it as well as service charges associated with apartment living. For many years my apartment lay empty. To rent it out commercially would have given me an income that would put me outside of the means for Carers Allowance. Should I be paying myself for the work that I do in saving

the state so much money? How would I pay my stamps so that I might have a pension on retirement? To this day I still don't know what kind of pension entitlement I might have when the time comes. When I queried this with Social Welfare I got a letter that only a civil servant could understand. I have been caring for 5 years now. I could be doing it another 5. That's a significant chunk out of my life. I want my contribution to society to count and that I may have the confidence of a reasonably comfortable old age myself. I don't have that confidence right now. I believe the state should endeavour at all times not to penalise its citizens unnecessarily.

While it is generally considered at this time that we need to provide more flexible care options for our citizens and that home care is the way forward instead of building more nursing homes, we need to provide more respite facilities. Carers need a break. That may not necessarily mean a holiday for them but simply time off when they can indulge in their own needs, confident in the fact that their loved one is in fully supervised care and that they can turn their minds to other things for a change. Although the state may not be able to provide as many respite beds as required, there are many charitable organisations that can provide respite facilities. The state must support these facilities by providing enough funding to ensure adequate staffing levels and comparable pay and conditions to the public system. These facilities need to stay open and until such time as the state may provide its own facilities it needs to support them.

Although much of what I have said to you focuses on the challenges there are certainly some opportunities. With old age comes a wealth of knowledge and experience which we need to keep in the community, not locked up in nursing homes. Cathleen, my mother, has been living well with dementia under my care for 5 years. There has thankfully been a very slow progress in her condition and she still has a lot of independence. However, she cannot live alone although she herself would argue otherwise. She is very happy and content in herself. She has no real worries as I take care of everything. When I compare today with 5 years ago there is no comparison. I genuinely think that my mother's condition was worse at that time. My intervention has made a huge difference to her life and I attribute her relative good health to my caring. Cathleen is living in her community where neighbours and friends can easily drop by. She can, with my assistance, collect her pension at the post office if she wishes. She can attend mass with her neighbours and take part in local parish events with the help of neighbours. As someone with a dementia it is vital that she retains her familiar environment and those close to her to allow her to live as long as possible with such a debilitating disease. I

am proud of the work I have done in facilitating Cathleen's wish to stay at home however, it comes at a price to me and I speak for all carers. For dementia alone the state pays €1.8 billion per annum. 48% of this cost is attributable to family carers. How will the state reward and protect the contribution of family carers going into the future? Home care is by far the cheaper option for the state. Undoubtedly we will pay for this in our taxes but I would rather have effective and efficient services in my community than an extra bit of money in my pocket.

I would like to thank you, the Citizens' Assembly for the opportunity you have given me to address you on the issue of the challenges and opportunities we face with an ageing population. You have heard from the experts this morning and now you have heard the human stories. I hope both perspectives have been informative to you and have opened your eyes as to what goes on behind closed doors in our communities and which can feel very much unrecognised and undervalued. I sincerely hope it informs you of a better vision for our futures as we grow older.