

Impact of the Diagnosis on Care/Support Partners

Carmel Geoghegan*

Dementia Ireland Empowering Communities, Ireland

Introduction

As a former primary carer for my mother who received a very late diagnosis for Vascular/ Frontotemporal Dementia I can give the lived experience of the wider impact the diagnosis has on not just the person but the care partner/supporter and the wider community. The late diagnosis robbed my beautiful mother of many years of a productive, meaningful life, where she could have made decisions as to what her preferences were around her care when her dementia advanced [1-4]. Unfortunately for my Mum once the diagnosis was received her wishes were ignored and she was basically a non-identity in her community, some of her family and the clinicians in general dismissed it as the ageing process. Instead of having more control over her life, she and I lived in a glass bowl for over 3 years with constant fears, anger, confusion, feeling isolated and ignored.

The difficulties began with the question 'What was wrong with my mother?' over a number of years there had definitely been a change in her personality, she became withdrawn from the world around her. After the death of my father it was possible to intervene and finally a Gerontologist referred her to a Neurologist, who finally diagnosed the mixed dementia [5]. We left his office with the diagnosis but no explanations, referrals or signposting to any supports that were available.

We were happy we now had a name for what was happening but no idea of what it meant or what would manifest each day going forward. In Ireland, in 2011 there were no dedicated clinics where it was possible to go for a diagnosis. If you were living outside the main urban areas you were completely isolated and left to work out for oneself how life would progress. Homecare was impossible to secure, it was not person centred and had no dementia specific care plan. It was a person care plan not a social care plan which is what is required. Care/support has to give the person with dementia the opportunity to maintain dignity and autonomy not reduce their self-worth and confidence [6-8]. Life changes very dramatically when dementia comes to visit, so if you are not prepared or have no means of accessing information, supports or medical advice life becomes a vicious circle of staying upright on the hamster wheel. In our case I was lucky to have been involved in various community projects so self education was not new to me. I began my own journey of exploring life with dementia and how best to deal with the day to day challenges.

Life would have been so much easier if at the point of diagnosis we were given some information and support to help us understand the meaning of the diagnosis. What we need to do to support our loved ones live the best life possible. The sensory challenges were something we struggled with, but now thanks to Agnes Houston these have been highlighted. The sensory issues can affect all of the senses or just a few depending on the individual, touch – taste – smell – hearing - sight. Other issues that can manifest such as delirium are very disturbing both for the person with dementia and the carer/supporter but if they have prior knowledge of the possibility of this occurring and how it is manageable will lessen anxiety.

The importance of a good balanced nutritional diet for the brain to nourish is vital as documented in the report by ADI in 2014. This

applies to both the person living with the diagnosis and the carer. There was a stigma around the diagnosis of dementia in Ireland [9] for many years and still is to some extent. Even after the awareness building campaign that has been in place since the National Dementia Strategy 2014 for some there has been little to no change. For others it has to be stated that they are experiencing more fulfilled lives, the awareness programme is taking the mystery out of dementia and the public in general have a more educated understanding of the diagnosis. They also see that getting a diagnosis as early as possible leads to a better quality of life.

Becoming an advocate for those less vocal is something that is a powerful way of getting involved and now putting the person with the diagnosis at the centre of Public Patient Involvement and their voice has become so strong that they are now deciding on the research projects. Building awareness is being achieved and has become very evident in recent years, but following on from the success of the awareness campaign there has been an increase in the demand for services that are not available. This is where we have to put the resources on the ground by support those who wish to remain independent, remain in their place of work, their home and their community. For those who need some extra support and may need full time care they have to be given the choice of remaining in their own homes or if they wish to go to residential care facility. A value based health care model is the most effective and one where the patient is centre stage. For the supporter/ care giver involvement in awareness campaigns can be a very powerful way of connecting with the outside world, meeting your counterparts and exchanging vital information. Sometimes it is as simple as having human contact with someone who understands where you are at in your life journey.

During the Covid 19 pandemic, while social and rural isolation were extreme for many it also brought the virtual world to those of us with access to internet and technology. [10] We connected on a global scale on a daily basis, it was a very positive experience, and one project that was a privilege to be involved in was My Support Study. End of life is a conversation that is not always broached but it is inevitable and has to be prioritized. There are a number of elements entangled in end of life care including physical comfort, mental and emotional needs, spiritual needs, and practical tasks. While the whole experience of living with a loved one who had very little knowledge of what had actually happened to her over a number of years, we both got through the experience on a completely different course of life. Mum went her

*Corresponding author: Carmel Geoghegan, Dementia Ireland Empowering Communities, Ireland, E-mail: carmelg@dementiaireland.com

Received: 1-Nov-2022, Manuscript No: dementia-22-80850, **Editor assigned:** 3-Nov-2022, Pre QC No: dementia-22-80850 (PQ), **Reviewed:** 17-Nov-2022, QC No: dementia-22-80850, **Revised:** 22-Nov-2022, Manuscript No: dementia-22-80850 (R), **Published:** 28-Nov-2022, DOI: 10.4172/dementia.1000142

Citation: Geoghegan C (2022) Impact of the Diagnosis on Care/Support Partners. J Dement 6: 142.

Copyright: © 2022 Geoghegan C. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

way – experiencing a beautiful pain free, at peace death. I continue to advocate for her voice and my own so that in time in the near future no one will experience the isolation, loneliness, fear and abandonment we felt.

References

1. Kitwood T, Bredin K (1992) Towards a theory of dementia care: personhood and well-being. *Ageing and Society* 12: 269–287.
2. NIH (2021) What Is Dementia? Symptoms, Types, and Diagnosis .
3. Life Changes Trust (2015) Dementia and Sensory Challenges. UK
4. Alzheimer's society (2017) Delirium Alzheimer's Society .UK
5. Nutrition and dementia: A review of available research.
6. Irish Dementia Strategy (2014) irish-dementia-strategy-1.
7. Gove D, Diaz-Ponce A, Georges J, Moniz-Cook E, Mountain G, et al.(2018) Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging Ment Health* 22: 723-729.
8. Russell J, Fudge N, Greenhalgh T (2020) The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? *Res Involv Engagem* 6: 63.
9. Yolima Cossio-Gil, Maisa Omara (2021) The Roadmap for Implementing Value-Based Healthcare in European University Hospitals—Consensus Report and Recommendations. *Value Health* 25: 1148-1156.
10. Harris, Dylan (2007) "Forget me not: palliative care for people with dementia." *Postgraduate medical journal* 83: 362-366.