

Community Wellbeing Submission informed by the views of people with dementia and family carers in Bray, Greystones, Wicklow, Arklow and Carnew.

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On behalf of Wicklow Dementia Support

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This submission is informed by:

- People with dementia and family carers who attend Wicklow Dementia Support social clubs in Bray and Wicklow town and participated in the 'Our Voice' project funded by Community Foundation of Ireland (November 2017- March 2018).
- People with dementia and family carers in Carnew and Arklow who participated in interviews and a focus group as part of the Alzheimer Society of Ireland, Wicklow Dementia Friendly 2 year project (2014-2016)
- The Wicklow Dementia Action Plan (developed from feedback of stakeholders participating in a forum on services and supports for people with dementia in Co. Wicklow in 2016)

What is dementia?

Dementia is an umbrella term which describes a number of conditions that cause damage to brain cells. This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, the ability to remember, plan, use language, find your way around and regulate mood and behaviour may be affected. The most common causes of dementia are:

- Alzheimer's disease
- Vascular dementia
- Mixed dementia (a combination of Alzheimer's disease and vascular pathology in the brain)
- Lewy Body Dementia.

Dementia is not a normal part of ageing. In fact there are over 4000 people under the age of 65 living with dementia in Ireland. However the risk of developing dementia does increase with age. It is estimated that dementia affects one in 14 people over 65 and one in six over 80. This may be due to factors associated with ageing such as high blood pressure, heart disease, weakening of the bodies natural repair system and changes in the immune system. Our risk of developing dementia is affected by lifestyle choices such as smoking, physical activity, what we eat, so 'What's good for your heart is good for your head'.

There are estimated to be over 1500 people with dementia living in Co. Wicklow¹.

¹ Developing and implementing dementia policy in Ireland (2017) http://cesrd.ie/wp-content/uploads/2017/12/Developing_and_Implementing_Dementia_Policy_in_Ireland.pdf

How dementia affects people.

Dementia affects people in different ways depending on the part of the brain affected and the stage.

Signs and symptoms of dementia can include

- Memory loss, particularly for recent events
- Problems with language, difficulty finding the right word
- Changes in mood and behaviour
- Becoming confused in familiar surroundings or situations
- Difficulty in following conversations, TV programmes or reading
- Difficulty managing money and everyday tasks
- Difficulty solving problems or doing puzzles
- Loss of interest in hobbies and pastimes, lack of initiative.
- Repeating a question or story several times without realising

People with dementia have an equal right to participate and be included in society. However having dementia can make it more difficult to claim your rights as evident in how people with dementia were treated in the past, as a 'non-person', excluded from communities. Legislation and policy now firmly place the rights of people with dementia at the centre of service development and provision. The United Nation Convention on the Rights of People (UNCPRD) outlines how people with disabilities including those with dementia have the right to live independently and be included in the community, right to liberty and security of person, freedom from torture, inhuman or degrading treatment, legal personhood and autonomy. It is imperative therefore for the future wellbeing of people with dementia and family carers that their right to live as well as possible in their community is upheld.

Environment and Sustainability

The natural environment is important to people with dementia. When asked about what was important to them about their town, people with dementia and family carers from Bray, Greystones and Wicklow identified Bray seafront, Bray Head, the Cliff Walk Greystones beach and the Murrough. Being close to nature supports wellbeing, so for people with dementia, now and in the future, we need to ensure that these environments remain in public ownership and are accessible with well maintained footpaths, clear signage, seating and toilets; all incorporated into the natural environment.

To preserve and sustain these natural environments, commercial development should be restrained, with planning laws strictly enforced, e.g. temporary structures, so as not to encroach on these natural amenities.

With the number of people with dementia expected to increase, consideration should be given to developing specially designed reminiscence walking trail in larger towns in the county like that created in Cavan town².

Health (physical and mental)

To enjoy best possible physical and mental health, people with dementia and family carers need access to timely health and social services that meet their expressed needs and preference. Social engagement and occupation are central to maintaining cognitive, mental and physical wellbeing.

People living with dementia currently face a number of barriers in achieving cognitive, mental and physical wellbeing:

- Negative attitudes, actions and assumptions about dementia can lead to people living with dementia being excluded from activities they enjoy and are a big part of their lives. For example Jean was very involved in her local parish, but now that she has dementia, the group no longer include her or stay in contact with her. Margaret enjoys going to scrabble at her local active retirement group, but can no longer go as she is nervous about getting lost or becoming a bit confused. Margaret just needs someone to accompany her and be there if she needs reassurance and this would enable her to continue playing scrabble. Being enabled to stay doing these activities would benefit Jean and Margaret's cognitive and mental health.
- The focus on deficits associated with dementia restricts the opportunities of people with dementia to use their abilities and talents. Formal supports and services focus on protecting and minding the person, not enabling the person. For example, Lee has dementia. To maintain his mobility, Lee needs to go for a daily walk, but this can be difficult as on the days his family carer works, his home help comes but is not permitted to accompany him for a walk. Mary lives in Wicklow and used to look forward to Thursdays, when her home help would come and bring her to do her weekly shop in the local supermarket, Mary would meet friends, have a chat, whilst doing her shopping. However, home helps are no longer permitted to provide this

² [https://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/Boithrin-na-Smaointe-\(Reminiscence-Walk\)-%E2%80%93-Cavan,.aspx](https://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/Boithrin-na-Smaointe-(Reminiscence-Walk)-%E2%80%93-Cavan,.aspx)

support so Mary's once a week opportunity for engaging with the wider community is gone. Narrowing the definition of home care to just the provision of personal care excludes many people with dementia from receiving the support they want and need to maintain wellbeing.

- Business such as banks and shopping centres give little consideration when introducing technology to the needs of people with dementia. The consequences of such actions as limiting counter services and pushing people to use automatic banking machines is that a person with dementia may lose confidence in managing their money and become dependent on others which leaves them more open to financial abuse. People with dementia in Arklow pointed to how a simple thing like closing the downstairs toilets in the Bridgewater Shopping Centre, Arklow shopping centre impacted on their confidence as they now have to negotiate lifts, stairs and escalators to the top floor to access the toilet, so they are wary about going shopping.
- Poor post-diagnostic supports such as education and rehabilitation programmes for people with dementia in Co. Wicklow limit their opportunity to maintain cognitive functioning and live as well as possible. Few people with dementia have access to cognitive rehabilitation programmes, particularly in South Wicklow.
- Caring for a person with dementia can impact significantly on family carers' mental health. In Co Wicklow there are no professional counselling supports for family carers and opportunities for peer to peer support is limited to a small number of support groups set up in the bigger towns in the county. This carer from Carnew feels her wellbeing would be enhanced with *"a centre to drop into a chat or discuss your situation with others in the same situation as you"*.
- Information is essential to the enjoyment of good health. Currently there are no clear information pathways for people with dementia and family carers. This can have huge negative consequences on their physical and emotional wellbeing. For example, Ann has dementia and lives with her daughter and son-in-law in a two story house in Bray. Ann also has mobility issues, so uses a wheelchair. Each morning Ann's son-in-law carries her downstairs and up again to her bedroom in the evening. The only bathroom in Ann's house is upstairs. Ann uses incontinence wear, which she was buying out of her pension until lately. Ann's family were not aware that they could access incontinence wear from the HSE free of charge or that could have applied for a stair-lift or other home adaptations. Caring for a person with dementia and other disabilities without access to essential resources takes its toll on people's physical, emotional and financial wellbeing.

Work, economy and resources

Co. Wicklow has many resources including its people who have a wide range of talents and abilities and beautiful natural resources – mountains, rivers, sea. People with dementia, as with the rest of the population, have talents and abilities, to contribute to the community. Dementia should not define the person. People living with dementia are artists, poets, knitters, dressmakers, singers, dancers, teachers, listeners, etc. If our communities are to thrive economically, with good jobs and supports for enterprise, business and for people not in work, the talents and abilities of all citizens must be tapped into.

Hence more opportunities should be provided to more marginalised groups such as people with dementia to use their talents and abilities for example through the provision of community exhibition and workshop spaces, where people with dementia can create and share skills. Opportunities need to be provided for people to showcase and sell their crafts, paintings, etc, for example craft markets at weekends in areas with high numbers of visitors such as Bray seafront and Laragh.

People with dementia could be supported to share skills such as dancing and crafts with after school clubs or for other groups including other people with dementia. A demand from Lee, a person with dementia living in Bray, is to work and make money, so a diagnosis of dementia should not automatically be a barrier to employment.

Many family carers find it difficult to juggle work and caring for family member with dementia. For example Ann, a woman who cares for her father in Carnew *explains “I have given up full time employment and just work 4 hours per week. Just to get in the car and go somewhere is not possible unless someone is with dad, even to get to mass, it’s hard at times. having someone else to take over”*. If resources are to be used effectively to sustain enterprises and businesses in the county, workers with responsibility for caring for a person with demnencia must be accommodated and the suport they need to enable them remain part of workforce made available otherwise their talents and experiences are lost to local enterprises.

Social and community development

Social inclusion is where all groups of people within a society feel valued and have the resources to participate in activities which are considered the norm in a society. These resources include income, housing, health, education.

For people with dementia, devaluation, discrimination and stereotyping are an everyday reality. Stigma associated with dementia represents a significant obstacle to the wellbeing and quality of life of people with dementia and their families. Research undertaken for the HSE Understand Together campaign shows that stigma and fear leads to unnecessary loneliness and isolation for people living with dementia and for their families³. There is often reluctance on the part of friends and colleagues to engage with people who have been diagnosed with dementia, resulting in family carers and the person with dementia experiencing hurt, contracting social networks and negative social encounters. It is evident from the feedback received from people with dementia and family carers living in Co. Wicklow that this too is their experience:

- In Arklow, a carer spoke of how his wife's friends never called to the house to see her and neither did her nieces or nephews. This loss of contact had a big emotional impact on him.
- In Bray, family carers spoke of how they were no longer included as a couple; how friends and neighbours "*crossed to the other side of the road*", to avoid having to make conversation with family carer and her spouse who has dementia. Another spouse spoke of his "*disappointment and upset at how friends no longer include his wife who has dementia*". The experience of members of the Bray social group, is that word "dementia" has negative connotations, with friends, and society in general immediately withdrawing from the person.

To participate in society, people with dementia, like any other citizens, have the right to social security and an adequate standard of living. However, anomalies in the administration of some social welfare payments fail to take account of the particular needs people with dementia may have. Joan, a person with dementia living outside Wicklow, related how she lost her household benefit package when she moved into an extension she added to her cottage when her husband died and her niece and husband moved into the main house to be there for support at night. Joan now must pay her TV licence, electricity, property tax and other bills out of her basic contributory pension of €243.30 per week.

³ <https://www.hse.ie/eng/about/our-health-service/making-it-better/campaign-to-tackle-dementia-stigma.html>

For people with dementia, having a permanent home is hugely important, as familiar surroundings maintain confidence in their ability to manage and remain independent. However, like the rest of citizens, people with dementia living in private rented accommodation are experiencing insecurity of tenure. For example Lee had to move from the home he lived in for many years and an area he was familiar with due to the sale of the property he rented. After many months of searching, Lee and his wife managed to find a property they could afford in another town. The property is very small and not suited to the needs of a person with dementia, who spends long hours in his home, Lee wants: *“more security in having a home and space to work in my own home”*. By work, Lee is referring to his painting, playing musical instruments, all of these things are important to his wellbeing.

For people with dementia transport is critical for social inclusion as many people have to give up driving as dementia can affect spatial surveillance. Lack of access to transport is associated with a two-fold increase in the odds of being lonely⁴. For a person living in a rural area, this has huge consequences. Without family or neighbours to drive them shopping, mass etc, early admission to residential care could be there only option.

Whilst there are bus services in the urban areas of Bray and Greystones, these buses do not service many of the housing estates in the towns. Many people with dementia can also have mobility issues, so getting to the bus stop on the main road is an issue. Mary, a person living with dementia in Bray, thinks a town mini bus service that goes into housing estates would enable her go to the shops and Active Retirement.

The viability of public services in local communities should be evaluated not solely on economics but also on social inclusion indicators, such as does the service contribute to personal independence, provide an opportunity for social engagement and access to information. Many local public services such as post offices and libraries perform a dual role, providing a service but also social connection and human interaction. As people age, their social networks contract, this is particularly the case for people with dementia. Face to face encounters that arise organically in the context of everyday activities strengthens the person’s links with their community and should be facilitated rather than impeded. These are important functions for social inclusion and in promoting independence of a person with dementia and in the long term economically benefit the

⁴ Kneale, D (2012) Is Social Inclusion still important for Older People?. London: AgeUK

state as loneliness and isolation are associated with a range of negative health outcomes and increased risk of hospital and long-term care admissions⁵⁶.

Participation, democracy and good governance

For local authorities to support the wellbeing of people with dementia and family carers in our community, they must learn the facts about dementia, listen to and link up with people with dementia. It is only in this way, will inappropriate negative public images and stereotypes such as people with dementia do not have views or can't give their opinions, be debunked.

It is important therefore that local authorities review their processes for inputting into public discussions and information gathering on public issues to ensure that they are dementia inclusive to give people with dementia and family carers a voice.

Values, Culture and Meaning

For people with dementia to be included and valued as citizens, the eight guiding principles that underlie the Convention on the Rights of People with Disabilities must be implemented fully and adhered to by all. The hope for the future is that there will be a cultural change from the current deficit based approach which focuses on what the person can not do and the risks associated with this to a strengths-based approach, where abilities are nurtured and the person with dementia is supported to be an active member of their community.

The Future Wellbeing of People with Dementia and Family Carers

The Co. Wicklow Dementia Stakeholders' vision for the future is that:

People with dementia and their carers will be enabled to live life to the full, at the heart of their community, through making the supports, services, and information they need accessible and available in Co. Wicklow.

If this vision is to be realised, the following actions are required:

⁵ Walsh, K., O'Shea, E., and Scharf, T. (2012) 'Social Exclusion and Ageing in Diverse Rural Communities'. Galway, NUIG

⁶ Gabriel, Z., Bowling, A., (2004) An integrational model of quality of life in older age. Results from ESCR. London. Social Indicators Research 2004, 69:1-36

1. Dementia inclusiveness becomes the norm

For future wellbeing, this person with dementia in Bray hopes *“for the world to be more understanding’*. To achieve this, public bodies, service providers, businesses, clubs and the general public throughout the county would need to be educated about dementia to become dementia aware. With this awareness comes understanding and people are no longer fearful, but confident that they can support a person with dementia in their day to day lives as they would a person with arthritis or heart disease. As observed by this person with dementia in Carnew – *“people become so frustrated and make me frustrated tooso meeting people, helping the person in a patient and understanding way is what is needed for the future”*.

For future wellbeing, friends would call for a friend with dementia on the way to an activity like scrabble. Services provided by public bodies and businesses in Co. Wicklow would be dementia friendly enabling people with dementia to keep using essential every day services that maintain their independence and social inclusion.

2. Formal services and supports developed are informed by person with dementia and family carers and meet their needs and preferences.

For future wellbeing, people with dementia can access the services and supports they need to stay included in their communities: such as a chaperone service, people with dementia in Arklow identified as important in supporting them go about their daily activities such as shopping, going for a walk, to Active Retirement, to GP visits, to hospital visits; centres in every town and village where people with dementia and family carers can meet and participate in activities, education programmes, therapy and support.

Family carers are supported to stay involved in activities they enjoy contributing to their wellbeing, such as being able to go out one night a week with their spouse or friend, and not to feel like *“a prisoner”* as observed by one carer, *“being tied down can be hard, having to be there 24/7”*.

3. Local governments listen to the voice of people with dementia and family and design and provide public services that meet their needs

For future wellbeing, Wicklow County Council engage with people with dementia to find out about the particular services and public amenities that are important to their social inclusion. In particular different housing options to support people with dementia to remain in their communities with as much independence as possible should be examined. There are a number of housing models that could be explored as ways of supporting people with dementia to live as part of their communities for example supported housing model such as Respond, St. John's Waterford⁷; housing with care models such as that provided by FOLD⁸; community village such as Carnew Community Care Day Care Centre and Community Village⁹ ; group living homes, group villages for people with dementia¹⁰, care villages within towns¹¹ as in the Netherlands.

Wicklow County Council should explore opportunities for create innovative ways of developing housing for people with dementia through partnering with other European countries, such as through the Interreg programme, on projects like Community Areas of Sustainable Care And Dementia Excellence in Europe (CASCADE)¹².

It is evident from the experiences of people with dementia and family carers, that information on home adaptation and mobility aids is not accessible to people with dementia and family carers. For future wellbeing of people with dementia and family carers, Wicklow County Council need to adopt a more proactive approach in providing people with information on stairlifts and mobility aids to ensure people with dementia maintain their independence and dignity by not having to depend on family to carry them up and down stairs. In designing and building homes in the future, dementia friendly elements should be incorporated.

Addressing all of these issues will enhance the wellbeing of people with dementia and family carers in the future.

⁷ <http://www.respond.ie/estate/johns-college-house-and-college-mews/>

⁸ <https://www.foldireland.ie/pages/32/cherry-fields-housing-with-care>

⁹ http://www.carnewlocalinformation.ie/comm&vol/index_files/Page441.htm

¹⁰ <https://hogeweyk.dementiavillage.com/>

¹¹ <http://www.evidentlycochrane.net/social-living-models-dementia/>

¹² <https://www.interreg2seas.eu/en/cascade>