

The Alzheimer Society of Ireland's Submission in Response to the Draft Design Guide for long term residential care settings for older people

Question 2.1 Do you think that the draft design guide will be helpful when designing, planning, and constructing long-term residential care settings for older people?

Response: Y/N/DK

Question 2.2 Do you think that the proposed design guide will contribute to improving the quality of long-term residential care settings for older people in Ireland?

Response: Y/N/DK

Question 2.3 Are there any sections in the draft design guide that require additional information/further guidance?

Response: Y/N/DK

Para 1.2: Purpose of this Guide

From viewing this guide, many of the elements wherein are for new builds. We believe that the principles of this guide should be reviewed or adapted for existing long-term care facilities. This would seek to significantly improve the lives of people living in long-term care facilities currently in the short term. It is also noted that this guide will be part of the inspection process for HIQA. What will guide the inspection process for existing facilities? (E.g. The 2016 guidelines which are used for self-evaluation and inspection).

Para 2.1.1: Replace "should" with "are required" if these items are to be enforced. It is strongly recommended that the requirements in this document are considered by planning authorities when development plans are being written.

Para 2.3.4: This specifically addresses additional older person's care requirements so is appropriate.

Para 5.1.1: We suggest adding in something to this section on the value and necessity of quiet space to those living with dementia. Many people living with dementia can often experience sensory issues, whether this be visual or auditory. This is particularly important in communal areas. Where possible, separate quiet spaces should be available based on the size of the facility. It is also important that there are sufficient numbers of visiting / communal rooms available, relevant to the size of the facility to allow

family to visit and have a separate space to socialise. Carers have reported dining rooms often being overcrowded / inadequate for the number of residents in place.

We would also welcome advice from HIQA on staff to resident ratio for best practice.

Many family carers also felt that it was incredibly important that when feeding back suggestions to nursing homes that this is acknowledged and actioned in a meaningful way. Carers noted that on many occasions that they did not feel heard by the nursing home about their concerns.

Para 5.2.1: This also relates to the assisted living model of care. Carers believe that differing levels of care should be provided for each resident, based on their needs.

Para 5.6: Communal Areas

Under this section, there is no guidelines on the provision of a reflection room, whether this be for prayer, exercising faith or for contemplation. It is our belief that such a space should be designed and designated to be non-denominational, to support a growing multi-cultural population in Ireland.

Para 5.9.1: This section does not reference laundry of residents' personal items. A part of feeling at home is ensuring personal items can be laundered and returned and that also is a critical component of upholding personhood. The last sentence should include "identity" of residents' personal items.

Question 2.4 Is there anything currently missing from the draft design guide that should be added?

Response: **Y** / N

If yes, please specify below:

Please see reflections of persons living with dementia and family carers/supporters below.

Question 2.5: Is there any additional feedback that you would like to provide on the draft design guide?

Response: **Y**/N

If you selected 'yes' please specify below:

ASI Feedback

The Alzheimer Society of Ireland welcomes the development of this design guide for long-term residential care settings for older people, which seeks to benchmark best practice and is thankful for the opportunity to contribute to this consultation. To do so, we spoke to members of our working groups, the Dementia Carers Campaign Network (DCCN) and The Irish Dementia Working Group (IDWG), which represent informal carers and people living with dementia, respectively.

We are thankful to see that in looking at Universal Design that Dementia Inclusive Design plays a prominent role and is outlined with the understanding that up to 50% of people living in long term residential care are living with dementia, whether that is formally diagnosed or not. We believe that in valuing the key elements related to dementia-inclusive design, this should be the norm. Many of these design elements could and should be made standard. The physical environment in which people who are living with dementia live is extremely important, and we do recognise the work that has gone into this document in both this recognition, and the application of dementia inclusive design principles.

As noted in this document, people living with dementia in a long-term residential care setting should be living in a space that mirrors their home environment as much as possible. We also acknowledge the discussion and practicalities mentioned of the Household Model of Residential care that empowers people to live in small groups, adopting a person-centred approach and promotes dignity, pride, and social engagement.

Section 1.2: Quality long-term care considerations

In their consideration of what they felt quality, long-term care encapsulated, people living with dementia thought that care facilities should be secure, where family members felt that the person with dementia could live. This would be somewhere that would not look clinical in design, but a space that could be viewed as home. As one member of our IDWG stated,

“Home sweet home.”

Quality long term care would also be somewhere where those living with dementia would not have to anticipate a lack of respect or a loss of autonomy. Improved inspections and regulations did offer some comfort in this regard. One family carer mentioned,

“Years ago, I would have been scared but not now, respite was amazing, it has come on so much.”

In addition, carers from our DCCN felt that quality long-term care similarly would offer comfort to a family carer / spouse who may have to move a loved one into residential care.

Carers felt that the physical layout of the facility could also support quality care for their loved ones; this was inclusive of ensuring that the space was well lit, open planning with additional dining and recreational areas where groups and individuals could socialise together. Where possible, individuals should be given their own rooms with a window, inclusive of double beds and wet room style bathrooms. Carers also felt that the environment should mimic or mirror the person's home and should be designed in a way that could be personalised. Items that could cause confusion for a person with dementia should be limited, this includes patterned flooring, mirrors. It would be best to adopt plain colours / designs to as not to cause confusion. This may include ensuring the colours of handrails / grabrails are appropriate, with respect to the colours of the walls to ensure the person with dementia can discern them.

Where possible, the most appropriate beds should be in place to accommodate the person living with dementia and associate grab rails installed. Many carers also felt that CCTV should be installed to ensure that staff are able to monitor people who may wander through the day. In designing spaces for people living with dementia, we also feel that these spaces should be adaptable as needs change, so initial design elements and features should be cognizant of such.

Worries when considering long-term care facilities

The main worries for people living with dementia and considering long-term care include a) ensuring their voice is heard and respected by staff (this is inclusive of them as a whole person, including their likes/dislikes, not just what is seen on a medical chart), b) having staff appropriately trained in dementia care and awareness of how best to support a person with dementia, c) restriction of visiting hours, d) lack of rapport with staff and e) not being able to continue their hobbies that they used to do or have suitable activities available to them to stay well.

Similarly the main worries felt by family carers and issues with long term care facilities include a) feeling that they are "abandoning a loved one" or feeling like they are "locked up", b) location of the nursing home inhibiting visits (poorly linked with local transport/local communities), c) fear their loved one's privacy might not be respected, d) their loved one feeling 'locked up' with a reduced world / limited world, d) staff with insufficient training or dementia awareness, e) person with dementia not having access to activities to participate in and f) fear that their loved one isn't treated with dignity and respect.

As reflected by IDWG members, it is important for the person with dementia to have the choice of decision of which care facility (if this is their wish) to attend. It is important that families have this discussion as early as possible with the person living with dementia.

Section 4: Importance of retaining connection with the local community

The physical location of long-term residential care settings was discussed, with both IDWG and DCCN members feeling that it should be a space that is not incredibly remote (devoid of public transportation links/difficulty to get to). This would reduce feelings of isolation and loneliness among residents. An IDWG

member stated that they had experience in people stepping back from them once they shared their diagnosis,

“I don’t tell people because it would change things. If you say you have a disease, you are a disease.”

To combat this stigmatisation, it is important that wider society and nursing home staff are trained in dementia awareness and care. Ideally, nursing home facilities would be developed close to local communities so that residents could access the local church, day centres, community events, etc. and continue to conduct their lives as they have previously done.

It is essential that residents of long-term care settings can be supported to remain linked in with their local community. They should also be supported to continue hobbies and interests for as long as possible. For those living with dementia, many noted that they would still like to keep up their hobbies such as attending a local GAA match but acknowledge that this might change as their dementia progresses. In the earlier stages, the nursing home could support this with transport / staff support but setting up a communal area for people to watch matches could also be an option. This should be on ongoing commitment and not a once-off event. Residential care facilities should ensure there is sufficient communal space available so that all residents can engage in social activities, whether that is in-house activities such as music, bingo, physical activity, or bringing in local volunteers or community leaders to offer their services. Where residents can no longer reach out and engage with the local community, it is important for the residential care setting to ensure these ties remain. For people who may be non-verbal, the use of reminiscence therapy with local sporting heroes or photos could be beneficial.

Activities that engage the local community and families should be supported, including local choirs, pianos for music, the use of video games to allow intergenerational fun, and bringing in coffee /ice cream/food trucks to residents and visiting family members. Family carers also supported staying connected by day trips to the local cinema, local parks, and cookery classes in community settings. The importance of having the community come into the residential space is incredibly important, across many different activities and domains. Not only would those living with dementia not feel isolated, but they could remain an active member of the local community, which is empowering. They can feel valued, respected, and retain a source of purpose. As a family carer stated,

“Every day is important”

Section 5.10 Outdoor space (s) within a long-term care facility

Both people living with dementia and family carers felt strongly that appropriate, safe, and accessible outdoor space should be available to all people living in nursing homes. This would include flat, even, non-sloped space, set up so that residents can walk safely if they wish and accessible to wheelchair users. Physical exercise is incredibly important not just for people with dementia, but for all older persons. Additional safety features to support this could include having paving that is lightly coloured and smooth to reduce confusion amongst residents, and railings to support those with mobility problems.

Communal and private areas should be included, allowing residents to socialise, and space inclusive for family members when they come to visit. Fresh air and Vitamin D can have a positive impact on people living with dementia, with an IDWG member stating,

“If there’s no outdoor space it could feel like a prison.”

Private space should also facilitate intimate relationships.

Another carer felt it was important that residents have the freedom to come and go as they please in outdoor spaces. It is imperative that all residents have access to outdoor space if they wish, and not just those on ground floor level. Additional communal areas should be made available for residents to socialise/watch sports.

When designing outdoor spaces, location of the outdoor space should be acknowledged; whether it is set up in a sunspot or not, and how awnings /covered in areas should be retained for use in the summer / wintertime. Where there are flowers / shrubbery planted, it is essential that these are maintained to uphold the general look and feel of the place. Both family carers and people with dementia reiterated the importance of having benches / tables and chairs available outside. Where possible, many felt that if there was a designated smoking / vaping area outdoors this could be beneficial. Designated zones, such as quiet zones or family friendly zones could also be adopted.

To allow for mental stimulation, many felt that outdoor space should have areas for horticultural hobbies to take place; the use of raised plant boxes for example would allow people to engage in gardening safely or vegetable patches. Outdoor areas could also encompass space for hobbies and other activities such as adaptative physical exercise machines and boules. Carers also felt that having small bird tables / bird boxes could also offer residents some mental stimulation and enjoyment. Where appropriate, many also felt the retention of small animals such as rabbits / cats could be therapeutic to residents.

Additional Comments

In 2022, The Alzheimer Society of Ireland has published a briefing paper in collaboration with Dr Sarah Donnelly on the issue of adult safeguarding and people with dementia in nursing homes. This co-created paper brought together people affected by the care available who have a vision for a rights-based future, and academic expertise. We reiterate what has been outlined in this consultation guide in many ways; the physical environment is essential for the well-being of nursing home residents, and regardless of disability, cognition, or dementia, they have a right to good quality and safe services.

We believe there should be a strong commitment by all nursing home providers to support and fully implement recommendations found within this guide if they have not already done so. We know that most nursing homes support and promote the human rights of people living with dementia and strive for the highest standards in ensuring the safety and protection of all residents. This briefing report can be found on our website: <https://alzheimer.ie/wp-content/uploads/2023/09/Adult-Safeguarding-and-People-with-Dementia-in-Nursing-Homes-Final-Report-2.pdf>.

We suggest that when this design guide is completed and published, that a plain language summary be made available to the wider public. This would allow accessibility and ease of understanding, particularly for those living with dementia and their families.