



Kinections Community Bulletin Series

Bulletin 1: Dementia-Friendly Communities and Care Homes

Welcome to Kinections First Community Bulletin

This Community Bulletin is the first in a series of bulletins that will be shared over the coming months as part of the Kinections, strengthening community in care homes, research project.

What is Kinections?

Kinections is a 3 year project (2017-2020), which is working with care homes across East Ayrshire, to explore what a dementia-friendly community in the context of care homes, looks and feels like for people who live, visit and work in care homes. The project is led by a team of researchers in the University of the West of Scotland, with funding from Life Changes Trust. More information about this project can be found by visiting the [Kinections webpage](#).

What is the focus of this Bulletin?

This bulletin will share insights the Project Team gained from reading literature, from around the world, on what others have written on the topic of dementia-friendly communities and care homes. Kinections is a project that has been funded through the Dementia-Friendly Communities funding stream of Life Changes Trust www.lifechangestrust.org.uk. A key aim within Kinections has been to explore what helps a sense of community in care homes to grow and flourish, with a particular attention to people living with dementia and those who support them.

As Kinections was one of the first projects within Life Changes Trust Dementia-Friendly Communities funding stream to involve care homes, we (the Project Team) wondered if anything had been written that described care homes as being 'dementia-friendly communities'. We carried out an extensive search of what has been written about dementia-friendly communities in academic journals, and in publications by dementia-focused organisations. We didn't find any record of the term 'care home dementia-friendly community' being used as a way of talking about how care homes care for and support people with dementia.

We looked at a number of documents which talked about dementia-friendly community initiatives, in the wider community setting, to explore if/how care homes were referred to in these documents. This bulletin will offer reflections on what we found.

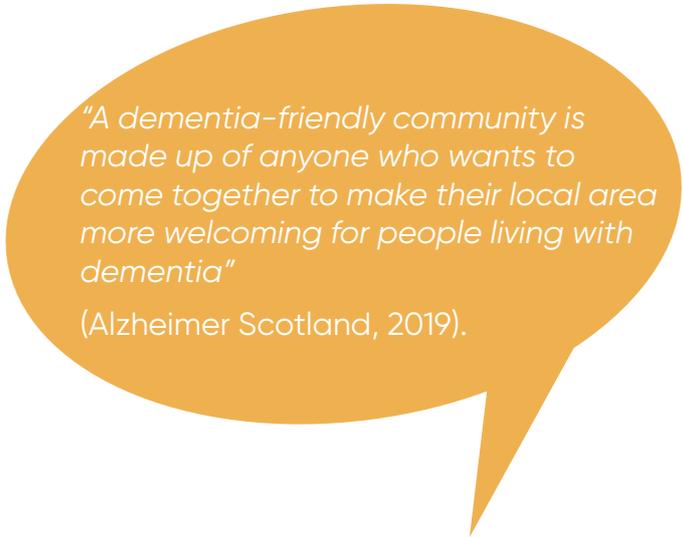
What is a Dementia-Friendly Community?

While there is no one agreed definition of what a dementia-friendly community is, it is broadly understood to be a collective of people/groups/organisations who seek to view the person beyond their diagnosis of dementia, with a focus on their strengths. The dementia-friendly community concept has emerged as an effort by society to enable people living with dementia to feel included in their communities, whereby there are the supports and resources available to people with dementia and their carers to enable this inclusion to happen.

Some ways of describing a dementia-friendly community found in the literature include:



"A dementia-friendly community can be defined as a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential".
(Alzheimer's Disease International, 2019).



"A dementia-friendly community is made up of anyone who wants to come together to make their local area more welcoming for people living with dementia"
(Alzheimer Scotland, 2019).

We found that across the world there are a number of alternative terms used for this concept of creating welcoming spaces for people with dementia; other terms include dementia-friendly initiatives, dementia-enabled and dementia-positive. Discussion within the literature about the term 'community' highlights how multi-faceted it can be, as it can be a geographical space, a community of interest or be based on particular attributes such as race, ethnicity or social situation^{1,2,3}.

What we Discovered in what Others had Written

A fundamental discovery from looking at the literature was the considerable similarities between the thinking, values and goals which lie at the heart of dementia-friendly community initiatives and those which lie at the heart of care and support offered to people with dementia living in care homes.

Key underpinning frameworks which inform dementia-friendly community initiatives include: Personhood, Human Rights and Citizenship⁴.

These three frameworks are also central to aspirations for how care and support is structured within care homes, as laid out in the five Principles of Scotland's National Care Standards framework. These principles are: Dignity and Respect, Compassion, Be Included, Responsive Care and Support and Well-Being⁵.

This would ring true to the experience in the Kinnections project of seeing care homes operate from a value-base which seeks to develop understanding and knowledge of the unique and particular needs of their residents, in order that they can then develop the structures and supports required when striving to meet these needs.

¹Delanty, G. (2003). *Community*. London, Routledge.

² Life Changes Trust (2019) *Dementia-Friendly Communities Toolkit*. [Online] Available at: <https://www.lifechangestrust.org.uk/sites/default/files/publication/files/DFCs%20Toolkit%20WEB%20VERSION.pdf>.

³ Alzheimer's Disease International (n.d.) *Dementia-Friendly Communities*. [Online] Available at: <https://www.alz.co.uk/dementia-friendly-communities>

⁴ Hebert CA, Scales K. Dementia friendly initiatives: A state of the science review. *Dementia (London)*. 2019;18(5):1858-1895.

⁵ Scottish Government, 2017. *Health and Social Care Standards: My Support, My Life*. Edinburgh.

What might you notice about a community that is Dementia-Friendly?

A report by Alzheimer's Disease International⁶ report suggests that the following outcomes should be aimed for in a dementia-friendly community.

Dementia-friendly Community Outcomes

Increased awareness and understanding of dementia

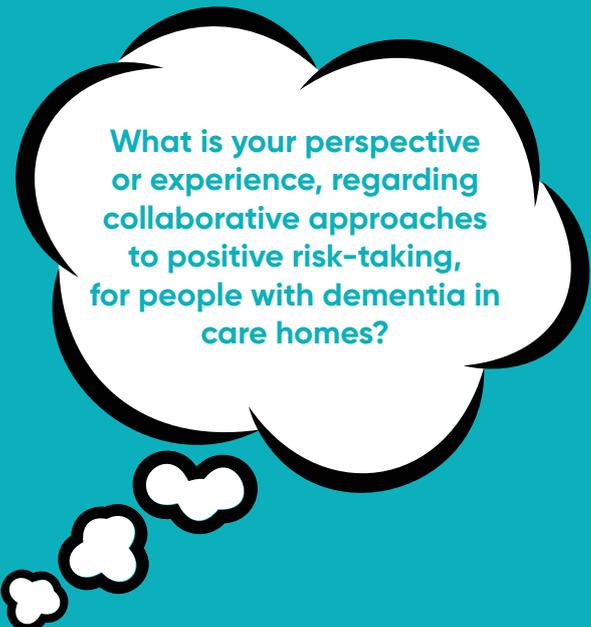
Increased social and cultural engagement for the person with dementia

Legal and other measures in place to empower people with dementia to protect their rights

Increased capability of health and care services to develop services that respond to the needs of people with dementia

Actions to improve the physical environment whether in the home, residential care, hospitals or public places

Other writers⁷ have honed in on the necessity for positive risk-taking to be embedded within the practices and outcomes of dementia-friendly communities, whereby in a dementia-friendly community there is a collaborative approach to the care and support of the person with dementia. This can then lead to responsibility for positive risk-taking being shared among the person with dementia, family, friends, healthcare professionals and local emergency services, rather than the weight of responsibility lying on one persons' shoulders.



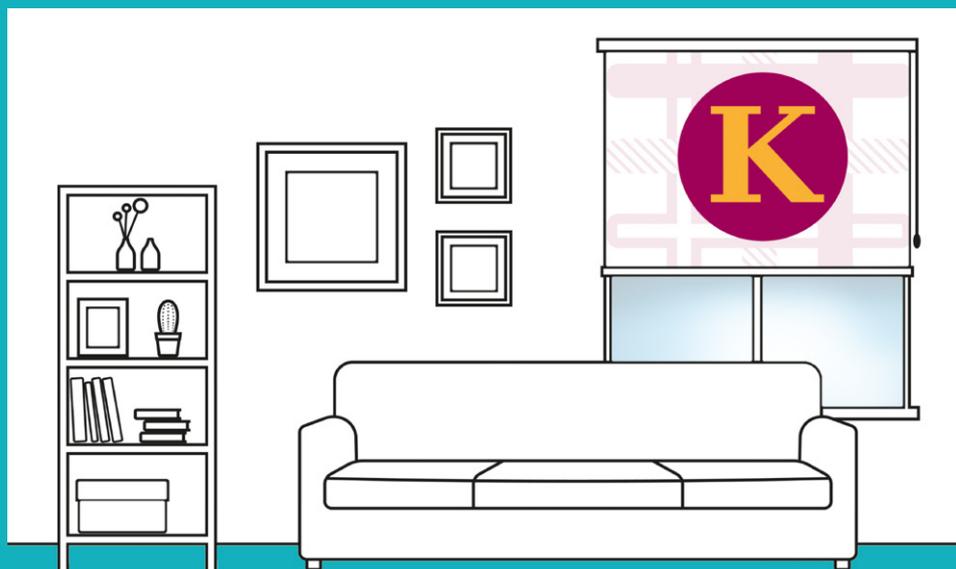
What is your perspective or experience, regarding collaborative approaches to positive risk-taking, for people with dementia in care homes?

⁶ Alzheimer's Disease International (2015). *Dementia-Friendly Communities: Key Principles*. London.

⁷ Morgan, S. and Williamson, T. (2014) *How can 'positive risk-taking' help to build dementia-friendly communities*. Joseph Rowntree Foundation: York.

What does Dementia-Friendly look like in the context of Care Homes?

The review of the literature carried out by the Kinctions team did not find any specific piece of research which explored the concept of dementia-friendly communities within care homes. The majority of references to care homes made up a small part of reports about dementia-friendly



communities in the wider community. The references to care homes tended to focus on issues around the physical environment and staff training & competency in providing person-centred care. The following paragraphs will highlight three specific pieces of writing which focused on dementia-friendly themes in the context of care homes. These three documents are My Life, My Home, National Dementia Strategy 2017-2020 and Kings Fund Dementia-Friendly Environment Assessment.

My Life, My Care Home

The Care Inspectorate (Scottish regulatory agency for care homes) carried out dementia-themed inspections in 145 care homes in 2016-2017. The 'My Life, My Care Home' report was published to share the findings of these inspections and outlines the extent to which the Standards of Care for Dementia are being met in care homes. Explicit references to being 'dementia-friendly' in the report pertained to the physical environment and mealtime experience. The full report, with the findings from the dementia-themed inspections, is accessible at [Care Inspectorate My Life, My Care Home](#).

National Dementia Strategy 2019-2020

The most recent Scottish National Dementia Strategy 2017-2020 (Scottish Government, 2017) refers to a commitment to the work of the National Group on

Dementia in Care Homes in their work of ensuring that the ongoing modernisation of the care home sector is reflective of the needs of people with dementia. Commitment 8 of the Strategy also refers to the consideration of the findings of dementia-themed inspections as discussed above.

Kings Fund Dementia-Friendly Environment Assessment

The King's Fund has developed an assessment tool specific to care homes about assessing the extent to which the environment of care homes is dementia-friendly. The Kings Fund Tool, Is Your Care Home Dementia-Friendly, Enhancing the Healing Environment Assessment Tool, can be used to assess how well the care home design supports a range of areas including meaningful interactions and purposeful activity, mobility,

eating and drinking⁸. The importance of focusing on the person's experience rather than condition when thinking about dementia-friendly environments in care homes has been highlighted⁹. It has been suggested that attention be paid to cultivating a culture in care homes whereby the physical environment is centred on people's experiences, and the social environment is underpinned by person-centred care (Davis et al. 2006).

⁸ King's Fund (2014). Is your care home dementia-friendly? EHE Environmental Assessment Tool. London.

⁹ Davis, S., Byers, S., Nay, R., & Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia*, 8(2), 185-203.

Our Key Messages

Different Words- Same Heart

Our reading of the literature on dementia-friendly communities has led us to see how principles and values such as personhood, human rights, citizenship, inclusion and assets-based approaches inspire and inform both care homes, and dementia-friendly community initiatives. Care homes perhaps align more closely with the language of the healthcare sector when using terms such as 'person-centred care' and 'quality of dementia care'; so while different terminology may be used by dementia-friendly communities and care homes, at the heart of both lies the desire to create spaces where people with dementia and their carers feel welcome and can flourish.



Connections between Care Homes and Dementia-Friendly Community Initiatives

It has been interesting to note how, up to now, much of the literature on dementia-friendly communities has made limited references to care homes. Dementia-friendly communities are often positioned in the literature as being a community response to the needs of people living with dementia, with the focus therefore within the literature on how dementia-friendly communities have developed initiatives at community-level to support people with dementia.

Owing to care homes central role in supporting people with dementia, we believe that there is scope for the connections between care homes and dementia-friendly community initiatives to be further celebrated. Anecdotally, we know that there are many excellent examples of where dementia-friendly community initiatives and care homes have collaborated, and so are hopeful that future publications will reflect these partnerships and innovations.

Questions to Consider

In Kinnections, we have a particular interest in how questions can shape the types of conversations we have. The questions below are an invitation to move the conversation from this page into everyday life, and so you might like to talk about them with family, friends and colleagues.

In a time when there is now enhanced awareness of complexities in the care home sector owing to COVID-19:

What types of questions and conversations among us all do you think would benefit people living with dementia in care homes?

What would you like to see in the future with regard to how people with dementia in care homes are seen as citizens of the wider community? What small steps might enable this to happen?

If you are interested in continuing this conversation about community, dementia-friendly communities and care homes we would be delighted to hear from you. Please contact: edel.rodgy@uws.ac.uk