



**World Dementia
Council** Leading the Global Action
Against Dementia

Defining dementia friendly initiatives

Presenting a global evidence base for
dementia friendly initiatives

Paper 1



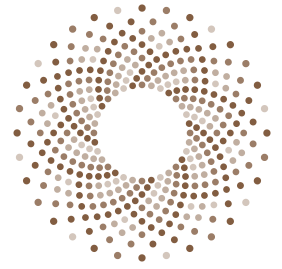
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HGPI Health and Global
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The Council would like to thank the contributors who helped to conduct the gathering, comparison and synthesis of evidence for this project:

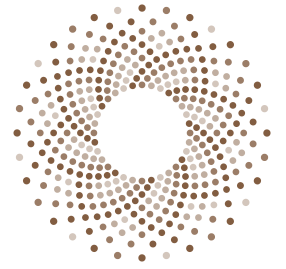
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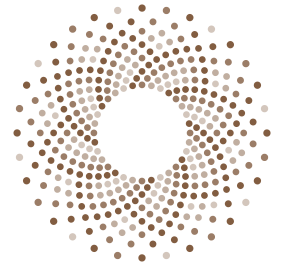
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We are also grateful for the advice of Tarun Dua, programme manager for dementia (and WDC associate member), and Katrin Seeher, technical officer for dementia, both from the World Health Organization.

This paper should not be read as representing the views of any one individual on the World Dementia Council, nor the individuals and organizations listed above or on the previous page that have contributed to or advised the project.



About this project

The World Dementia Council hosted a summit in London in December 2018 bringing together global experts from different disciplines in dementia to reach consensus on some of the challenges the world faces in reaching the 2025 goals (set by the G8 in 2013). One of the priorities identified at the meeting was a better understanding of the evidence base for dementia friendly initiatives.

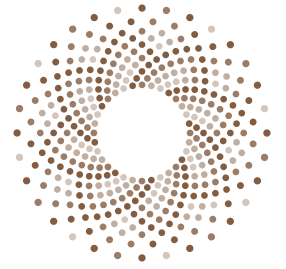
In 2019, the Council launched a year-long consultation to gather international evidence on the design and delivery of dementia friendly initiatives. An evidence framework was designed to compare and synthesise a global evidence base, attempting to consider the variety of initiatives designed to have impact, the breadth of evidence likely to be submitted from countries around the world, and the range of voices who would contribute. A literature review, field survey and a number of consultation events informed the project.

The Council postponed the publication of a report planned for Summer 2020 due to Covid-19. We are now publishing a series of papers over the autumn that reflects on the evidence gathered. The Council welcomes views and feedback on the papers – [get in touch here](#).



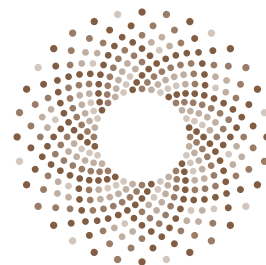
A consultation roundtable organized with AARP, gathering participants from across the globe in Los Angeles, US, in July 2019. A similar international event was held in Sydney, Australia, in September 2019.

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Introduction



This project began in Spring 2019 in a very different world. After six months of evidence gathering through surveys, a literature review and holding roundtables, the Council's intention had been to publish a report in Spring 2020 that looked at the evidence underpinning dementia friendly initiatives. Covid-19 changed that.

A planned conference was cancelled. A global pandemic, where health officials were urging people to stay home, was the wrong time to launch a report about engaging in the community. The Council would not want the report to be read as encouraging participation in day-to-day life when health systems were grappling with containing a pandemic, and a pandemic which has tragically killed significant numbers of people with dementia.

To many, the pandemic illuminated how much we value social connectivity and the freedom to participate in the community. That was lost during numerous national lockdowns. Furthermore during this period, many countries have seen indications of an increasing incidence of mental (and physical) health problems, including among people with no pre-existing medical condition.

The belief that people with dementia should be able to participate in the community, and a recognition that social isolation is bad for an individual's health, has helped drive the momentum of the dementia friendly movement. As set out in the first part of this paper, at the 2013 G8 dementia summit the international community recognized the importance of people with dementia living well in the community.

Over the past decade, there has been growing international discussion around whether there is a gap between the activity of 'dementia friendly initiatives', and the evidence underpinning their impact. The second part of this paper considers what these initiatives are seeking to achieve, and suggests that increasing awareness (overwhelmingly the main focus of activities, especially volunteer-led ones), enabling participation in the community, and providing support, are primary aims. A second companion paper will review the evidence of the impact initiatives are having in these areas.

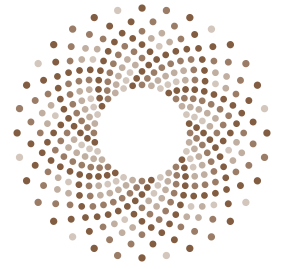
We are grateful to all the organizations and individuals who contributed to this project. We recognize and acknowledge the commitment and drive of all those involved in this work, and their determination to improve the lives of people with dementia and their caregivers.

Lenny Shallcross

Executive Director, World Dementia Council



The development of dementia friendliness



Context

The term dementia describes a number of different diseases, the most common of which is Alzheimer's. It predominately occurs in older people, although it does occur in younger people (defined as under 65).¹ Dementia is characterized by a progressive loss of cognitive function (frequently amnesic, but there can also be language, visuospatial, and executive disorder).

The last decade has seen a significant increase in the funding for research, from governments, not-for-profits, philanthropy, and others. This funding, alongside important technological development, is helping to accelerate research.² There are pharmacological and non-pharmacological treatments to manage symptoms but, to date, no interventions that can stop or slow the progression of the disease. There is growing evidence that, at a population level, the prevalence of dementia over time can be lowered, through public health measures.³

Globally, more than 50 million people are living with Alzheimer's or other forms of dementia. That number will triple by 2050.⁴ Dementia is a progressive disease, and research suggests biological changes can proceed by many years the clinical expression of the disease, and subtly cognitive changes proceed the clinical manifestation. After clinical expression the rapidity of the progression is variable, but individuals have increasing health and social care needs as the disease develops. In the earlier stages of the disease, people with dementia can continue to live in the community, independently or with the support of a caregiver.

The proportion of people living with dementia in the community varies depending on a country's health system, but around two thirds of people with dementia live in the community in most high-income countries. As the disease progresses, increasing care and support is needed. Depending on a country's health economy, and an individual's need, that may be met through the provision of informal or formal care provided in the community, in specialist residential or nursing settings, or in a hospital environment.

Policy focus

National governments, advocates and international organizations have increasingly drawn attention to the challenge of supporting people with dementia to live in the community. The 2013 G8 dementia summit called for governments to "disseminate successful approaches to supporting people with dementia and their caregivers including ... community-based programmes fostering inclusion and improved quality of life".⁵ The World Health Organization (WHO) states that "increasing

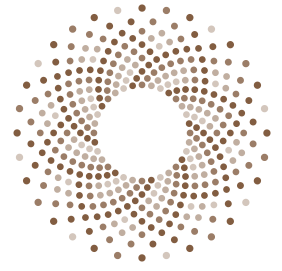
1. By way of example it is estimated around 200,000 people under 65 live with dementia in the US compared to 5.6 million people over 65
<https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>

2. <https://worlddementiacouncil.org/sites/default/files/2018-12/Defeating%20Dementia%20Report.pdf>

3. https://www.who.int/mental-health/neurology/dementia/guidelines_risk_reduction/en/

4. <https://www.alz.co.uk/research/statistics>

5. <https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-communique>



public awareness, acceptance and understanding of dementia and making the societal environment friendly will enable people with dementia to participate in the community and maximise their autonomy through improved social participation”.⁶ The G20 summit in June 2019 restated governments' commitment to “a comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and caregivers”.⁷

Alongside this international focus there has been increasing national, regional and local activity. A 2015 report by Alzheimer Europe noted that “the concept of dementia friendly communities has developed rapidly in some parts of Europe, and there are now examples of towns, cities, countries and organizations that are working towards becoming dementia friendly.” In the same year, the Dementia Friendly America⁸ network began, following the White House Conference on Aging. A 2017 Alzheimer's Disease International (ADI) report showcasing examples of various efforts reported that dementia friendly initiatives were taking place across the world and in all continents, including in low- and middle-income countries.⁹

To speak of international communiqués and policy reports risks doing an injustice to the diversity, commitment, and energy of the dementia friendly movement. The Council has received submissions from around the world that show¹⁰ example after example of individuals and organizations striving to improve the quality of life for people with dementia. It has been described as a global movement.¹¹ Initiatives like Dementia Friends¹² and memory cafes¹³ have been replicated from country to country. From the submissions received, there is a sense some individuals and organizations feel part of a 'global movement' and are drawing inspiration from that.

Dementia friendly society

This project has received submissions from all six continents of the world. We have received examples of government-led initiatives, of programmes led by civil society, of initiatives by businesses both big and small, and of volunteers in schools, hospitals and local communities. The range of activities described as dementia friendly is vast: improving a care home; providing a support service in the community; developing insurance products; through to signage at airports. Nor are the beneficiaries just individuals with dementia. The progressive nature of dementia means an individual increasingly needs the support of a caregiver, and it has been argued that the nature of the disease means support for caregivers is an important part of any initiative.¹⁴

Alongside the range of activities, there is also a bigger societal ambition. Much of the activity reviewed describes individual initiatives that aim to improve the lives of people with dementia within a geographical area. But the cumulative ambitions of these individual activities go beyond that, to delivering societal change. The ambition of programmes is described in sweeping terms such as “an inclusive society”, “a dementia friendly society” or “building a dementia friendly world”.¹⁵ The scale of the ambition, and how it is described, is similar to many other national and international movements, including but not limited to age (child-friendly and baby-

6. https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

7. <http://www.g20.utoronto.ca/2019/2019-g20-health.html>

8. <https://www.dfamerica.org/>

9. <https://www.alz.co.uk/adi/pdf/dfc-developments.pdf>

10. The methodology annex to this paper can be found here: <https://worlddementiacouncil.org/DFCS/evidence>

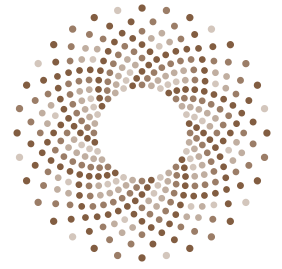
11. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/global-dementia-friends-network>

12. https://www.alzheimers.org.uk/sites/default/files/2018-11/Global%20Dementia%20Friends%20Network_0.pdf#:~:text=Under%20the%20Global%20Dementia%20Friends,and%20we%20have%20more%20purpose

13. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5527402/>

14. Dementia-friendly community initiatives: an integrative review (Shannon and others)

15. www.alzheimers.org.uk/sites/default/files/migrate/downloads/building_a_dementia_friendly_world.pdf



friendly just as much as senior citizen-friendly), disability, gender and sexuality.

Different models have been developed articulating ‘principles’, guiding participants through practical measures such as in ‘toolkits’ to deliver dementia friendly initiatives, and proposing measures to evaluate the cumulative societal change of individual initiatives.¹⁶ These models are sometimes set out in some form of ‘theory of change’, with intermediate and long-term measures of change.

Some advocates have described a process of ‘working towards dementia friendly’, recognizing that no organization, community or society could be universally acclaimed as dementia friendly.¹⁷ It is not the Council’s intention to define what a dementia friendly initiative (or community or society) is, for similar reasons. This project has considered the initiatives being delivered, the intent behind them and the impact that they are having.

Age friendliness

This trajectory of development (and many of the concepts of dementia friendly) is similar to, and preceded by, the age friendly movement. The 2002 UN Madrid International Plan of Action on Ageing¹⁸ recognized that governments must “seek the full inclusion and participation of older persons in societies; to enable older persons to contribute more effectively to their communities and to the development of their societies; and to steadily improve care and support for older persons as they need it”. In 2006, the WHO brought together city leaders from 22 countries for a project to help determine key elements of the urban environment that support active and healthy ageing. In 2010, the WHO Global Network for Age-friendly Cities and Communities¹⁹ was established, which includes domestic networks, but also individual cities.

No one participates in society solely as someone living with dementia. Most people living in the community with dementia are senior citizens. Around 95 per cent of people living in the United States²⁰ and the United Kingdom²¹ with dementia are over 65. Dementia is most prevalent not among recent retirees, but older seniors. Four in five of those living with dementia in the United States are over 75. Unsurprisingly, examples submitted to this project have shown on-the-ground programmes being delivered by the same organizations and individuals who have identified as being part of an age friendly movement as well.

16. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6840971/>

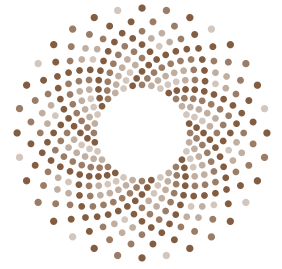
17. <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/how-to-become-dementia-friendly-community?text=Our%20recognition%20process%20enables%20communities,friendly%20communities%20across%20the%20country>

18. <https://www.un.org/development/desa/ageing/madrid-plan-of-action-and-its-implementation.html>

19. https://www.who.int/ageing/projects/age_friendly_cities_network/en/

20. <https://www.alz.org/media/documents/facts-and-figures-2018-r.pdf> p18

21. <https://www.dementiastatistics.org/statistics/prevalence-by-age-in-the-uk/>



Dementia friendly initiatives

In reviewing all the submissions received, as well as the literature review, we consider three main areas where dementia friendly initiatives aim to have impact:

1. Raising awareness – and consequentially decreasing stigma;
2. Enabling participation;
3. Providing support – including in health and care settings.

Awareness

Much of the activity reviewed has the ambition to address societal awareness of dementia. One currently unpublished review of dementia friendly community programmes across England concluded “the main emphasis in the provision of services and activities by the reviewed dementia friendly communities was on awareness raising”.²² A European-wide study drew similar conclusions.²³ A compilation of examples of global activity from 48 countries by ADI²⁴ included 161 examples of activities. Seventy per cent of those had exclusive, or at least some, focus on raising awareness. Much of this awareness activity has been focused on raising general societal awareness, either within a local community or part of it (such as a faith group) or, less frequently, through nationally-driven initiatives such as Dementia Friends or other public awareness campaigns.

The term ‘awareness’ is a broad one and in different contexts is used to describe activities with different ambitions. Examples include (but are not limited to): raising public awareness about dementia and the symptoms; the fact people with dementia live in the community; challenging stigma; or seeking to empower individuals to engage with people who have the condition. Despite this variability, in general these initiatives aim to share knowledge about dementia with people who, while they may have some connection with the condition, are not themselves living with the disease.

Participation

A second frequently cited, and related ambition, is enabling participation in the community. To participate in the community as one chooses means “the conceptualization of people with dementia as ordinary citizens and members of the community”.²⁵ This would mean, for example, “individuals are consumers prior to the onset of dementia and remain as consumers of businesses and services after diagnosis”.²⁶

Examples of activities include dementia friendly banks, shops, tourist attractions and restaurants. Other aspects of the social realm have been a focus of activity such as dementia friendly transport,²⁷ or dementia friendly public spaces²⁸, or more

22. Currently unpublished paper (reference will be provided upon publication)

23. “The importance of raising awareness... was a consistently important theme” EFID p28

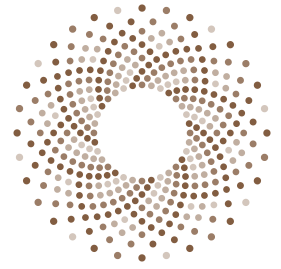
24. Dementia Friendly Communities: Global Developments

25. EFID p15

26. An exploratory study of creating dementia friendly businesses

27. Example from survey respondent – dementia friendly airport in Australia

28. There is an example here such as dementia friendly parks/or some of the design evidence



suitable housing. Addressing barriers to participation goes beyond mere awareness. For example, to navigate an airport, someone with dementia may require well designed signage, special assistance at check-in, and quiet spaces.

Although these activities are varied, in general they have a shared ambition: to enable people to participate in day-to-day social activities. The onus rests on providers in the public realm (from local government to local shops) to ‘take action’, the result of which is enabling someone with dementia (and their caregiver) to participate.

Support

Many of the submissions received concerned the provision of community services for people with dementia or their caregivers. Most often this is a memory cafe (a meeting place for people with dementia and/or their caregiver which usually has some combined elements of information service, socialization, structured activity, or respite). Some of the evidence reviewed extends the concept from support services into the health and social care system. Some have argued for the exclusion of health and social care provision from dementia friendly activity “since how people use those services was defined by their dementia, not by being a member of a community”.²⁹

Others have not. For example, a report³⁰ on making Bradford and York (two cities in the UK) dementia friendly communities included dementia awareness of healthcare reception staff, and highlighted dementia friendly environments in hospital wards and in-patient services. In the UK, where the idea of dementia friendliness was championed as part of the Prime Minister’s Challenge on Dementia,³¹ the recognition process as part of that initiative includes health and social care as one of eight areas for action.³² The UK Alzheimer’s Society also has resources for health and social care services,³³ and the British Standards Institute recognition process on dementia friendliness (PAS 1365:2015)³⁴ includes a timely diagnosis, after-diagnosis advice, through to good end-of-life care.³⁵

At times there has also been a focus on supporting people to stay healthy in the community, including lifestyle changes. There is more evidence around the impact of cardiovascular risk factors on the development of dementia, and some dementia friendly initiatives have focused on promoting risk reduction. This is less common, however. In general, these activities aim to provide support to someone living with the condition (or their caregiver).

29. Mapping dementia friendly communities across Europe

30. How can we make our cities dementia friendly

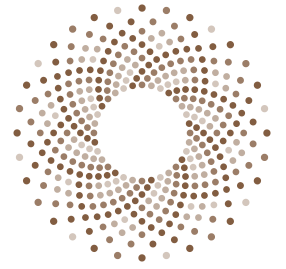
31. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf

32. <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/how-to-become-dementia-friendly-community>

33. <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/resources-organisations>

34. The British Standards Institution (BSI) is the national standards body of the United Kingdom. BSI produces technical standards on a wide range of products and services and also supplies certification and standards-related services to businesses <https://shop.bsigroup.com/forms/PASs/PAS-1365-2015/>

35. <https://shop.bsigroup.com/upload/PASs/Free-Download/PAS-1365.pdf>

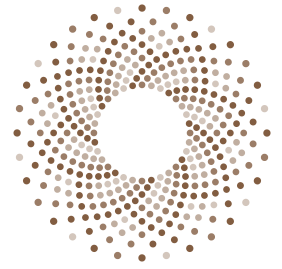


Is 'friendly' the right expression?

It would be hard to find many people who argue against a society where stigma is reduced, where knowledge, awareness and visibility about dementia is increased, or where people are able to participate as they choose.

There are champions and detractors of the terms 'dementia friendly', 'dementia capable' and 'dementia inclusive'. Similarly, there are those who argue for a 'rights-based' approach, for 'disability rights', or other intellectual frameworks.

Debates over language are inevitable. While tactically they might suggest different ways of achieving an outcome (for example through legal or regulatory change), the destination appears broadly similar. For consistency, this project uses 'dementia friendly' terminology. Individuals, organizations and others will need to identify language which resonates for them.



Conclusion

There is a huge diversity of initiatives being delivered around the world. There is also much commonality. In reviewing the evidence on the impact of dementia friendly initiatives, we suggest it is possible to consider different categories of activities: ‘awareness’, ‘participation’ and ‘support’.

- The biggest focus is awareness, whether that be raising visibility of dementia in the public narrative, reducing stigma, empowering individuals to interact with people with dementia, or workplace training. The audience could be national, a community, a workplace, or indeed a home, but the activity generally involves transferring knowledge about the condition to someone without dementia.
- Participation involves activities that aim to enable individuals to continue to engage in activities in their community. The range of activity is considerable, from the provision of housing and the design of the public realm through to local convenience stores. But in general, it is focused on organizations, that have a footprint in the community, taking action.
- Support involves providing a service to someone who has dementia. Often this is in the form of community services such as memory clinics, but it has also been applied more broadly to the provision of health and social care.

Does any initiative that raises awareness, enables participation or provides support count as ‘dementia friendly’? While recognizing the ambition and energy of a global movement, it is easy to find activity in one or another of these categories that is being delivered, but that is not described as dementia friendly. This paper has already noted the different approaches taken to describing healthcare (see page 9), but a similar case can be made for other areas of activity. The ambition to deliver activities that raise awareness, enable participation or provide support predates the term ‘dementia friendly’. This is a challenge that will be returned to in subsequent papers.

The Council is not suggesting that what makes a dementia friendly community is initiatives to raise awareness, enable participation or provide support. We have not set out to come up with (another) definition of what is a dementia friendly community. Rather the initiatives that the Council reviewed – either as part of the literature review, or in examples submitted by survey respondents or roundtable participants – fit broadly into the categories of awareness, participation and support.

These initiatives are not an end in themselves. By way of example, raising awareness of dementia in the community may not impact on the lived experience of people within that community. An underlying presumption is that these initiatives have impact because they affect lived experience in some way. Whether that is so, the matter of what evidence of impact exists, and how it can be measured, will be explored in the next paper.

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

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