



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

Impacts of dementia friendly initiatives

Presenting a global evidence base for
dementia friendly initiatives

Paper 2



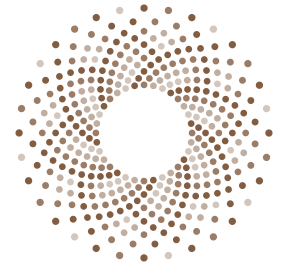
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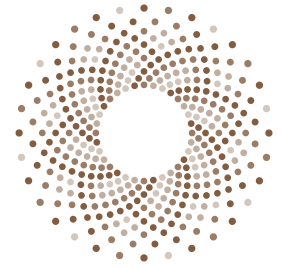
HGPI Health and Global
Policy Institute

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Foreword

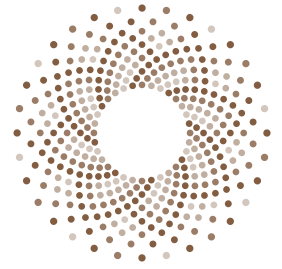


Increasing age is the greatest non-modifiable risk factor for dementia. AARP is the United States' largest non-profit, non-partisan organization dedicated to empowering people 50 and older to choose how they live as they age. With nearly 38 million members, AARP strengthens communities and advocates for what matters most to families: health security, financial stability and personal fulfillment.

AARP seeks to support people living with dementia because in addition to being a major health issue for people as they age, dementia also poses significant harm to people's financial security and threatens their sense of personal fulfillment. AARP's 2018 survey of US adults (aged 18+) found that more than nine in 10 (92 per cent) adults believe that Alzheimer's disease is a serious problem and two-thirds (68 per cent) of adults said they know someone who has had Alzheimer's disease or dementia or another disease causing cognitive decline. It is with great pleasure that together with colleagues from the World Dementia Council, Alzheimer's Disease International, the Alzheimer's Society and HGPI we share information gathered on the impact of initiatives designed to address these serious problems. Each of the different programs described seek to provide solutions to the concerns of people living with dementia by growing awareness, increasing participation in society and providing support for people living with the diseases that cause dementia and their caregivers.

AARP has long advocated for age friendly communities, acting as the US Affiliate for the World Health Organization's (WHO) Global Network of Age-friendly Cities and Communities program. But around 2014, AARP began recognizing the concerns of people living with dementia and their caregivers may be overlooked in communities only focused on normal aging. We worked with ACT on Alzheimer's, a model initiative from the state of Minnesota that later developed into Dementia Friendly America, a national cross-sector effort to help communities better understand, embrace and support residents living with dementia, formally launched in 2015. Addressing the rapid expansion of age friendly communities and the growing incidence of dementia friendly initiatives occurring in the US along with the increasing interest in how the two types of initiatives could work together and complement each other rather than compete, AARP published *Better Together: A Comparative Analysis of Age-friendly and Dementia Friendly Communities* in 2016. The proliferation of efforts demonstrated communities' ability to tailor dementia solutions to their particular needs and available resources, but it also helped us see the need to conduct a more rigorous impact evaluation of the different programs taken in these communities.

When ADI, the Alzheimer's Society, HGPI and AARP joined with the World Dementia Council toward the end of 2018, it was the perfect opportunity to examine the different types of dementia initiatives underway around the world. Scoping out the different programs would allow us to identify the components of meaningful interventions that might work across cultures and what measures we could use



to evaluate their impact. Our joint report was undertaken with the urgency of knowing the problem is immense, the needs are acute, but resources are limited, and in some places, extremely inadequate. We wanted to be able to share lessons about what works to promote inclusion and better serve people living with dementia while saving others from having to reinvent the proverbial wheel or waste time and resources repeating efforts that were not found to be useful or effective.

While we envisioned 2019 as our period to collect the data from across the globe, no one foresaw that the Covid-19 pandemic would arrive delaying the report's release in 2020. But perhaps more importantly, it also has challenged and disrupted many of the dementia friendly initiatives underway in unprecedented ways. Indeed, the pandemic has been particularly "un-friendly" to people living with dementia and their caregivers. For example, in the United States, deaths attributed to Alzheimer's disease and dementia rose to more than 20 per cent above normal over the summer. Increased isolation and stress during lockdown, lapses in nursing home care and missed Covid-19 diagnoses are all likely contributing factors to the unusually high dementia death toll. In the UK, the Alzheimer's Society reports that more than one in four deaths due to Covid have been in people with dementia, and that there has been significant cognitive decline for those who live in the community and care homes. The pandemic revealed the fragility and gaps in existing long term care systems around the world, and the rising mental health burdens being borne by caregivers – paid and unpaid – while creating even greater challenges for people living with dementia and their families.

As the pandemic continues to be terrible for many people, it also provides us an opportunity to pause and reflect on how communities and business can play a role in the development of future, more resilient programs and systems that can better serve people with dementia and their caregivers across the globe. It has also made it crystal clear that sustained social isolation is very harmful to all people, particularly those with dementia. And it has highlighted that dependency on health care providers to resolve all of what we typically think of as health issues is neither desirable or sustainable. Finally, it provides us the chance to receive your feedback on our preliminary read-out of what we learned.

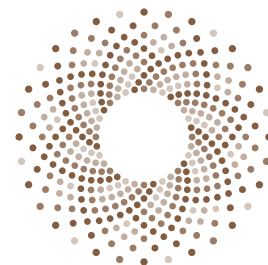
AARP has been very happy to help co-sponsor this evaluation because we are committed to examining the evidence behind interventions designed to improve the lives of people living with dementia and their caregivers. We are very grateful for the many people who took the time and effort to contribute to the global survey and respond to the questions about how their different programs work. We are looking forward to hearing people's reactions and comments to the analysis of the information collected before the final report is produced.

Sarah Lenz Lock

Project advisory committee member and
senior vice president for policy, AARP



Foreword



Dementia Friendly Initiatives (DFIs) have become a priority item on the global agenda. Dementia-focused organizations and dementia-related advocates should welcome the fact that societies are finally striving to become dementia friendly in various ways, such as by creating dementia friendly communities, implementing dementia friendly designs, developing dementia friendly transportation systems, and building dementia friendly supermarkets. Hundreds of initiatives are currently underway around the world and we cannot express the depth of our gratitude for the years of advocacy devoted to this cause by leaders in civil society and government.

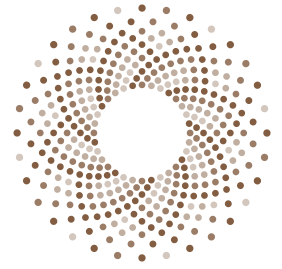
From government initiatives to civil society movements, a broad variety of dementia friendly initiatives are being undertaken in Japan, as well. In 2019, the Government of Japan announced a cross-ministerial dementia policy package called the Framework for Promoting Dementia Care. As the third national strategy for dementia in Japan, this framework will continue adding to the momentum built by the Five-Year Plan for the Promotion of Dementia Measures (the Orange Plan) in 2012 and the Comprehensive Strategy to Accelerate Dementia Measures (the New Orange Plan) in 2015.

This updated framework consists of two policy groups: policies for inclusion and policies for risk reduction. While risk reduction policies are mostly focused on the biological and medical aspects of dementia, such as early detection, inclusion policies generally aim to address the societal side of dementia – in other words, how to improve quality of life for people with dementia in everyday situations. Establishing a dementia friendly society is one of the main targets of the inclusion policy arena.

Our organization, the Health and Global Policy Institute (HGPI), has embraced a unique role within dementia policy advocacy. Based in Tokyo, we are an independent, non-partisan, and non-profit health policy thinktank dedicated to fostering multi-stakeholder health policy debate on a global scale with a strong commitment to the inclusion of civil society. Through conversations with stakeholders, HGPI is working to realize evidence-based health policies that are meaningful in a global context and of real value to the people that need them most.

Located in the most ageing country in the world and chaired by Professor Kiyoshi Kurokawa, a member of the World Dementia Council, HGPI has pursued dementia policy as a key item in its agenda for several years. From our independent and neutral standpoint, we have advocated for a cross-ministerial integrated policy package for dementia since 2014, and the aforementioned Framework for Promoting Dementia Care is precisely what we have been advocating for.

HGPI is committed to multi-stakeholder partnership both in Japan and around the world. In Japan in 2018, we helped establish a research and advocacy platform for dementia called Designing for Dementia together with our partners at Keio



University's Center for Wellbeing Research, Issue Plus Design, and the Dementia Friendship Club. The goal of that platform is to co-create a dementia friendly society with people with dementia. To achieve that, we have collected more than 100 ethnographies of people with dementia to identify the things that matter most to people with dementia.

Globally, we have collaborated with the WDC and other international organizations on various occasions. In March 2018, we helped the WDC hold its 12th meeting. HGPI also participated in the WDC's Tokyo Dementia Summit 2019, which was held alongside the G20 Health Ministers' Meeting in Japan and drew experts, representatives from government, and other parties involved in dementia from around the world. We are highly grateful towards the WDC's efforts for this critically important topic and we are honored to be a collaborator in this report.

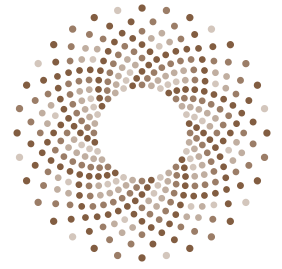
Personally, I think there are two categories of dementia friendliness: process-oriented friendliness and effect-based friendliness. Measuring process-oriented friendliness would involve verifying services claiming to be dementia friendly, such as by checking if they were co-created with people with dementia or if they emphasize ensuring the human rights of people with dementia. In other words, to determine the process-oriented friendliness of services for people with dementia, we would have to examine the foundational concepts under which said services were developed. Effect-based friendliness should provide people with dementia and caregivers technical help in everyday scenes, so measuring it might include assessing designs for providing cognitive assistance to people with dementia or testing digital tools for improving communication between caregivers and people with dementia.

Both categories of dementia friendliness I have described above require the standardization of guidelines, the adoption of an evidence-based approach, and diligent scientific verification to ensure that services or initiatives actually contribute to improving quality of life for people with dementia. However, I think we must also keep a mindset of friendliness. While it is critical that we make guidelines and follow them, the bottom line is being considerate, friendly, and inclusive towards people with dementia and all of society. We not only need to standardize dementia friendliness; we must strive to optimize and personalize friendliness in everyday life. Finding the ideal balance between optimization and standardization of dementia friendly initiatives will be an issue we will have to address in the future, and reports that illustrate a worldwide perspective like this one will be essential when doing so. After all, being friendly is an individual, personal effort. As Billy Joel sang, "honesty is such a lonely word". Perhaps it might be true in some cases. But, let's make "dementia friendliness" such a lovely word.

Ryoji Noritake

Project advisory committee member and
chief executive, Health and Global Policy Institute (Japan)





Introduction

This is the second paper published in a series presenting a global evidence base for dementia friendly initiatives. In the first paper you can read more about the project, its advisers and the contributors who helped to conduct the gathering and synthesis of evidence.

The review of evidence highlighted the huge variety of initiatives being delivered. The first paper argued that, despite this undoubted variation, initiatives sought to deliver three broad ambitions: raise awareness, enable participation and provide support.

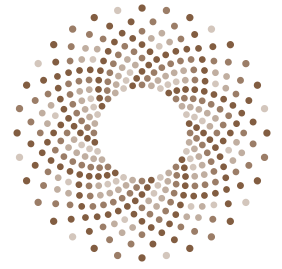
Firstly, initiatives that sought to raise awareness of dementia. The initiatives were almost always not aimed directly at people with dementia or those, such as a caregiver, who had have day-to-day contact with someone who had dementia. Rather they aimed to raise the visibility within the community of dementia among people without a direct connection, knowledge and understanding of dementia. Some of these initiatives encouraged light touch, or more formal, volunteerism.

The second grouping of initiatives were those that focussed on enabling people with dementia and their caregivers to participate in "day-to-day" society. Again, these were not generally aimed at the person with dementia or their caregivers. Rather they encouraged those who provided a "service" within a community (however defined) to think about the specific needs their "customers" who had dementia, and their caregivers. Those "services" could range from the local administration in its approach to housing, or streetspace design through to the local bar.

The final set of initiatives identified were those provided directly to the person with dementia or their caregivers to support them to continue living in, and participating in the community. This included dementia friendly health and care settings. These activities differ from the first two where the direct beneficiary was someone who had limited, or no, connection to someone who had dementia.

Of course all of the initiatives aim ultimately to benefit people with dementia and their caregivers. This paper will reflect on the evidence the review identified for the impact of these initiatives in doing just that: benefiting people with dementia and their caregivers.

We would again like to thank members of the advisory committee that helped shape the project, which included representatives from the Alzheimer's Disease International, Alzheimer's Society (UK), AARP (US), the Health and Global Policy Institute (Japan). We are also grateful for the advice of the World Health Organization.



Awareness

Based on the literature review and the examples of initiatives submitted to this project, the biggest single area that dementia friendly activities have focussed on is raising awareness of dementia. The widely-used term “awareness raising” encompasses a variety of different types of activity aimed at different audiences. As noted in the first paper in this series, this includes activities variously described as raising the 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.

The most cited example of an awareness raising programme was Dementia Friends. Over a fifth of countries around the world have a Dementia Friends programme. The programme began in Japan in 2005 as Nationwide Caravan, to train Ninchisho (dementia) Supporters. The programme involves a 90-minute seminar for the public, delivered by volunteers. The aim of the programme is to educate people about dementia, reduce prejudice and create dementia advocates.

“It is very important to raise public awareness of dementia so that there is less of a barrier when symptoms appear that suggest cognitive impairment. All too frequently people put off visiting a GP because of stigma and misconceptions and this delays diagnosis by a specialist.”

— Person living with dementia

This programme was replicated and modified in the UK, although the core of the model, volunteer-led seminars, remained the same. Dementia Friends are encouraged to take some form of social action which can include staying in touch with someone with dementia through to volunteering. There is also an online route where individuals can watch short films. In the UK different resources are available for the general public and individuals in a range of different work settings. Similar resources have been developed in The Netherlands where 11 specific courses are available for workplace settings.¹

Programmes in Japan, the UK and elsewhere report impressive numbers. Millions of people having gone through programmes in both countries: 11 million in Japan and 3 million in the UK. Many of these programmes have many examples of positive feedback from participants.²

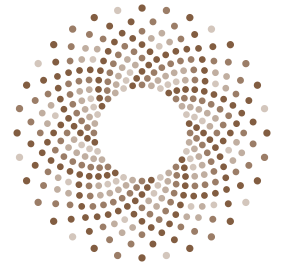
Many other examples were submitted of how local communities have sought to raise awareness of dementia. Initiatives are incredibly diverse. From university students in Brunei raising community awareness by running information stands,³ to raising awareness in schools among children⁴ including classroom lessons and community

1. Evidence submission from The Netherlands

2. Evidence submission from Australia and <https://pubmed.ncbi.nlm.nih.gov/26979582/>

3. Evidence submission from Demensia Brunei

4. Evidence submission from UK



visits. Another approach has been intergenerational work, such as choirs bringing together people living with dementia and younger citizens.⁵

Aimed at mass audiences, organizations have run advertising campaigns including national television advertising with significant spend.⁶ The UK has run a national television advertising campaign with the key message “I have dementia I also have a life” and has used market polling to track perceptions of people with dementia.

These are diverse activities but with a common audience. Although the ultimate beneficiary of activity is the person with dementia, in general, the activity is aimed as individuals who have some or no connection with dementia.



Much of the evaluation reports the impact on the individuals who have been participants in the programme. For example, participants in Dementia Friends programmes or similar information sessions, when information has been collected, are positive about the personal impact. Although this information tends to be collected immediately after rather than collected over time, where there has been follow up, participants remain positive. A review of a project in Australia⁷ found increased knowledge from community-based activity, and over time a follow up survey of Dementia Partners in Germany found participants rated their experience as positive.⁸

In some countries, Dementia Friends has been widely used in the workplace. The London Fire Brigade reported anecdotal evidence of the employee benefit of Dementia Friends both in their professional and personal lives.⁹

National media and advocacy campaigns have had evaluation included. A national advertising campaign in The Netherlands achieved a high level of target audience recognition.¹⁰

In these examples, which reflects the evidence reviewed, the person with dementia is one step removed. The assumption made is that this activity does bring benefit

5. Brady Harris, Phyllis and Caporella, Cynthia Anne. Making a university community more dementia friendly through participation in an intergenerational choir. <https://doi.org/10.1177/1471301217752209>

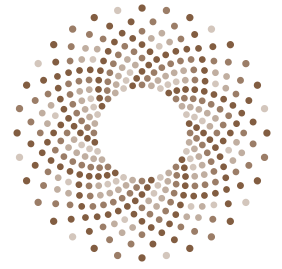
6. Evidence submission from The Netherlands

7. <https://journals.sagepub.com/doi/abs/10.1177/1471301218754455?journalCode=dema>

8. https://www.demenz-partner.de/fileadmin/user_upload/doc/zum-ansehen/DP-Ergebnisse_Wissenschaftliche_Begleitung-2018.pdf

9. Evidence submission from the London Fire Brigade, UK

10. Evidence submission from The Netherlands



“There is much more to be done. Many places have very little understanding of the needs of people living with dementia, particularly younger people. My husband has early onset dementia and most places we visit (even if they are dementia friendly) don't recognise that he is someone with the condition. This can be distressing when he is challenged when using a disabled toilet or a priority seat on a bus.”

— Caregiver

to someone living with dementia and their caregivers, but what is measured, in general, is the impact the activity has on the "participant" from the person receiving training to the television viewer at home.

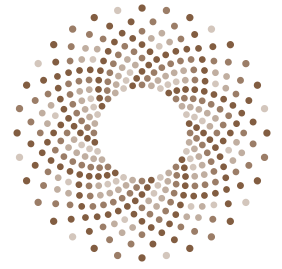
All the initiatives reviewed involve relatively short and time-limited interactions.

Awareness of dementia (or any other disease) will all be significantly influenced by a whole range of factors, not least by proximity.¹¹

As more people live with dementia globally, more people have direct experience. It is difficult to construct an argument that an initiative would have a negative effect. But measured over a period of time, it would be difficult to disaggregate the impact of a programme from the many factors that raise awareness.

This is not though a path untrodden. Many conditions and causes set out to raise awareness and have done so in broadly similar ways: awareness sessions, information, advertising and campaigning. They do so with the not unreasonable assumption that good things may flow from it. Through increasing awareness, you ultimately bring benefit to the people you are trying to help. A history of feminism, racial equality or gay rights campaigns suggests this faith is not misplaced.

¹¹ <https://journals.sagepub.com/doi/10.1177/1471301220965552>



Stigma

One of the ambitions cited for many of the initiatives that submitted evidence to this review is reducing the stigma faced by people with dementia and their caregivers. It has been argued that stigma is a particular issue for people with dementia “due to [the conditions] progressive nature and that it is incurable, dementia might be expected to attract worse stigma than an episodic mental illness with periods of remission”.ⁱ Many national and international surveys have highlighted stigma as a significant challenge. A recent ADI study gave examples of people with dementia experiencing terrible discrimination. But the study also highlighted, beyond extreme examples, how pervasive stigma was.ⁱⁱ

Although widely cited as a challenge for people with dementia and their caregivers, a systematic review highlighted the limited research evidence both on the extent of stigma and the evidence for interventions that address it.ⁱⁱⁱ Most research has focused on the North America and Europe, with limited focus even in those areas on minority populations and has mostly “described the subjective experience of stigma”.^{iv} As such, it is difficult to generalise on a regional, national or international level about the biggest challenges individuals face.

A review into strategies to combat mental illness divided initiatives into three categories: protest, education and contact.^v Within this conceptual framework, dementia friendly initiatives can be fitted. There are examples of initiatives that involve knowledge sharing, visibility and contact. The aims of awareness campaigns are “manifold, among them disease prevention, improving access to and uptake of treatments, tackling stigma and discrimination, and promoting research”.^{vi} But there is “a general lack of research into the effectiveness of anti stigma programs”.^{vii}

i. Mukadam, Naaheed and Livingston, Gill. Reducing the stigma associated with dementia: approaches and goals. <https://doi.org/10.2217/ahc.12.42>

ii. Alzheimer's Disease International. World Alzheimer Report 2019: Attitudes to dementia. <https://www.alzint.org/u/WorldAlzheimerReport2019.pdf>

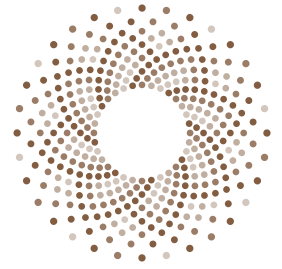
iii. Herrmann, Lynn et al. A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial? <https://doi.org/10.1016/j.jagp.2017.09.006>

iv. Ibid.

v. Corrigan, PW and Watson, AC. Cited in Mukadam, Naaheed and Livingston, Gill. Reducing the stigma associated with dementia: approaches and goals. <https://doi.org/10.2217/ahc.12.42>

vi. Editorial. Increasing the power of public awareness campaigns. [https://doi.org/10.1016/S1474-4422\(15\)00105-2](https://doi.org/10.1016/S1474-4422(15)00105-2)

vii. Mukadam, Naaheed and Livingston, Gill. Reducing the stigma associated with dementia: approaches and goals. <https://doi.org/10.2217/ahc.12.42>



Participation

The still all too frequent perception of someone with dementia being dependent on care and residing in a nursing home is wrong. Dementia is a progressive condition and increasingly, someone with dementia will need the support of a caregivers. But, overwhelmingly, most people today living with dementia live in the community and can participate in the community.

Someone with dementia is still a consumer, a tourist, an explorer and a risk taker. People with dementia “are free to make their own choices... with the same rights as everyone else to belong to society”.¹²

Participation in initiatives is focussed on enabling people with dementia and their caregivers to participate in "day-to-day" society. People with dementia “can contribute to community life... and have choice and control over their day-to-day existence”.¹³

The variation in activity is considerable. Different rationales are given for delivering such activities. For example, it may be practical (“we have customers who have dementia”) or ethical (“people with dementia have a right to participate independently, for as long as they are able, like any other citizen”). However, the activities have a broadly similar ambition: an organization, big or small, public or private, for profit or not, makes adjustments to be inclusive.

They are initiatives that enable someone to participate despite the fact they have dementia. In some cases these are activities specifically put on for people with dementia and their caregivers, for example “dementia friendly” cinema screenings. But the intent of these activities is to enable participation in day-to-day society. The “adjustments” are not made by the person with dementia but the individuals or organizations serving the community.

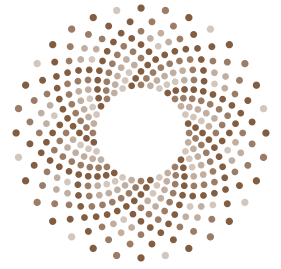
These initiatives encompass the physical and social environment. In theory there is no aspect of a local society this does not touch. One framework for communities to use as a guide gives “the physical environment, planning process, access and consideration for dementia among local businesses and public services and access

“I have become increasingly concerned about public toilets on several counts. They are being closed down. There are so many different ways of flushing a toilet/turning on a tap/drying hands. New toilet compartments are often very cramped, there is such a variety of segregation. I was very amused to come across a dementia friendly toilet (designated as such on the door) which was distinguished by a red toilet seat. I do understand that contrast is helpful for some people affected by dementia but it looked odd to me and I suspect would feel equally alien to many people affected by dementia. Surely a black seat would serve as well and be more 'normal.’”

— Person living with dementia

12. <https://worlddementiacouncil.org/sites/default/files/2019-10/DFP%20EXECUTIVE%20%20SUMMARY-1015501910-03b.pdf>

13. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/building_dementia_friendly_communities_a_priority_for_everyone.pdf



to transportation” as areas of focus.¹⁴ Another cites being “able to access ordinary community activities... (shops, theatres, cinemas...)”.¹⁵

The review has identified dementia friendly initiatives to address all these areas. How police forces understand the need of someone with dementia¹⁶ and search for and look after someone missing¹⁷ (in a number of countries, including Japan and the US, community networks have been established to help locate missing people).¹⁸ The fear of something going wrong is widely cited as a barrier to participation: “managing risk and focusing on personal safety have become primary elements in information and formal care for people with dementia”.¹⁹



“Transport to and from venues, because most people with dementia can no longer drive, and maybe partners (as in my case) don't drive.”

— Caregiver

Dementia friendly swimming pools²⁰ and cinemas²¹ have put on special sessions or showings for people with dementia and their caregivers. Financial services (many countries have developed guidelines for financial institutions such as Singapore where the Monetary Authority of Singapore together with the Association of Banks developed Guidelines for Handling Customers who Lack Mental Capacity)²² and energy companies²³ have changed their procedures around identification

of vulnerable customers. A guide produced by a tourism organization²⁴ includes a range of activities such as awareness, providing information and addressing the physical environment. Efforts to make airports dementia friendly have included a similar wide scope of activity.²⁵ Many organizations specifically develop products targeted at a segment of their customer base.²⁶

Being able to participate does not just mean being able to remain in employment, perhaps with additional support from the employer, or find new employment, including voluntary work.

14. <https://www.alzint.org/u/dfc-principles.pdf>

15. https://efid.info/wp-content/uploads/2016/05/Mapping_DFCs_across_Europe_final_v2.pdf

16. <https://journals.sagepub.com/doi/abs/10.1177/1471501216688605>

17. <https://northyorkshire.police.uk/staying-safe/personal-safety/the-herbert-protocol/>

18. https://www.oecd-ilibrary.org/social-issues-migration-health/care-needed_9789264085107-en?itemId=/content/publication/9789264085107-en&csp=11a1bdeb68a5ca69e5f95b616404c3f7&itemIGO=oe&itemContent=book

19. Bailey and Clark both cited in <https://journals.sagepub.com/doi/abs/10.1177/1471501217699677>

20. Evidence submission from UK

21. <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/dementia-friendly-screenings-cinemas>

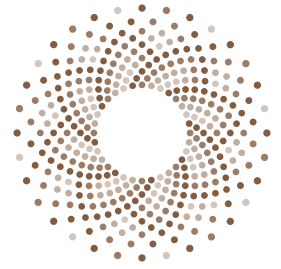
22. Evidence submission from Lien Foundation, Singapore

23. <https://www.eonenergy.com/content/dam/eon-energy-com/Files/about-eon/reporting/Switch%20on%20to%20Dementia%20Report.pdf>

24. https://www.visitbritain.org/sites/default/files/vb-corporate/business-hub/resources/dementia_friendly_guide_for_tourism_businesses.pdf

25. Evidence submission from Australia

26. The Dementia Services Development Centre at the University of Stirling, UK, runs a Product Accreditation service, and have showcased examples of products in the paper Products for Dementia. <https://stir.app.box.com/s/bmsy6tk04ohqaiX5xa4yb53cn0i4f2nk>



Design is cited as important in ensuring inclusion, not just of venues but the public realm in general.²⁷ There are plentiful suggestions for activities²⁸ in the various resources and guides that have been produced. Suitable housing²⁹ is integral to someone's ability to remain in the community and planning policy has made attempts to reflected that.

This can seem a bewildering array of activity that touches every aspect of society. Although almost all the examples received in evidence included some element of workplace awareness raising/training to help support employees in their interactions with customers who had dementia.³⁰ Some of this training is explicitly marketed as dementia friendly while others are marketed as workplace training. In the US, the University of Massachusetts Medical School conducted an evaluation of training programmes for the Massachusetts Executive Office of Elder Affairs and reported that participants found that the training was effective.³¹

Some organizations track customer perception, the number of complaints or serious incidents as a way of measuring the impact of initiatives to support customers who have dementia. There have been examples of "mystery shopping" as a way to evaluate venues. Organizers point to attendance, at cinema showings, as examples of how initiatives have enabled participations. There are anecdotal examples of how people have been able to keep going to the local pub or bowling club.

What these individual examples do not evidence is that the cumulative impact of these initiatives enable more people with dementia to participate. Of course being able to participate is dependent on many factors other than the receptiveness or inclusiveness of an organization. The dementia friendly leisure facility is dependent on people being able to travel there. A paper examining the perception of people with dementia and their caregivers to accessible tourism identified a large range of barriers beyond the institution itself.

Nor has this review seen evidence that enabling participation leads to a better "quality of life" or better health outcomes. Although there is significant body of evidence on the negative health – both physical and mental – of isolation and loneliness. It has been argued that it is not necessary to so demonstrate: as set out earlier, some have built a case for participation around human rights, or equality.

This is again a path well trodden. Age, gender, sexuality movements have prompted organizations to consider whether they are inclusive. Does main street retailers and bankers marketing their Pride inclusiveness help enable more LGBT people participate? The very least that can be said it is does not do the inverse.

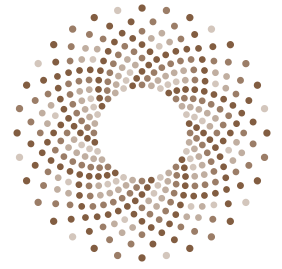
27. Evidence submission from DDS Architects, UK

28. <https://onlinelibrary.wiley.com/doi/10.1111/ajag.12287> and <https://www.jrf.org.uk/report/creating-dementia-friendly-york>

29. https://www.alzheimers.org.uk/sites/default/files/2020-06/Dementia%20Friendly%20Housing_Guide.pdf

30. HSBC UK chief executive Ian Stuart delivered a speech to the Dementia Forum X meeting in Stockholm in 2019, which included examples of how the bank does this

31. Evidence submitted from the United States. Evaluation of the Massachusetts Alzheimer's Disease Supportive Services Program 2015-2019; Alzheimer's Association Train-the-Trainer and Advanced Training; Savvy Caregiver Training; and INTERACT Stop and Watch Tool. Submitted to Massachusetts Executive Office of Elder Affairs April 11 2019

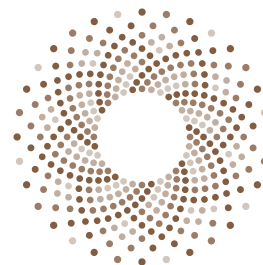


Meaningful involvement of people with dementia

Without exception, people delivering dementia friendly activity spoke about the importance of including people with dementia. Much of the activity described in this paper reflects an ambition to plan, deliver, improve and evaluate service provision and local communities. This review has seen examples of involvement ranging from information sharing, through to consultation and into co-design. People with dementia said in the survey response that they had been meaningfully involved (65 per cent said yes and provided examples of positive change). However, there were also responses that showed involvement could be perceived as tokenistic “although my presence on the committee was accepted, there was no real attempt to involve people living with dementia in the process of developing the initiative. Some people are listening to me, but it is a constant battle trying to keep the whole team focused on the inclusive approach of “Nothing About Us Without Us”.

This varied perspective on involvement is unremarkable. It is beyond the scope of this review to say what is “meaningful” involvement. But system design generally involves “expert” and “user” involvement, a combination of knowledge, experience and data. What is right in one context may be inappropriate in another. Given that it seems unlikely that there is any correct approach. But it is noticeable in reviewing evidence that (understandably perhaps – it is a challenge beyond dementia) gathering representative views particularly reflecting gender, socioeconomic status, ethnicity, sexuality and other characteristics is challenging. There is also, particularly in policy design and again understandably, a tendency to place significant weight on consultation and, often because it is absent, not utilise data, particularly on lived experience. The data is often simply not available.

Support



The first paper in this series drew a distinction between initiatives intended to provide support to someone because they have dementia and those that enable someone to participate despite the fact they have dementia. As noted in the first paper, it is here where some commentators have drawn a line between “dementia friendly” initiatives and other initiatives.³²

Over a quarter of the submissions received concerned the provision of community services for people with dementia. Most often these took the form of a memory cafe – an easily replicable model that does not require a significant administrative infrastructure. Reports into community activity included “signing for the brain groups, the secret garden... social events for the over 50s... wellbeing cafes”.³³ The range of support services includes art and music therapy to support people living with dementia in Nigeria,³⁴ a theatre company in England³⁵ and memory cafes in Russia.³⁶ Broadly, these activities are social meeting places. Many are described as providing support to the person with dementia and their caregivers, to reduce things such as social isolation and loneliness.

Not all services provided to support people with dementia and their caregivers are regularly described as dementia friendly. These include services that come into the home (such as assisted living services), the provision of information services, services that help individuals get out and about (“befriending services”), respite services including day care, and fiscal measures that support caregivers.

Sometimes the concept of dementia friendliness is extended into the healthcare system. Hospitals, care homes, primary care practices and community facilities such as pharmacists have all been described as dementia friendly. Sometimes these initiatives sit more comfortably with those outlined in the previous chapter, for example awareness training for the GP receptionist. A resource for primary care practitioners becoming dementia friendly includes resources to help promote diagnosis.³⁷

One attempt to define what is dementia friendly in the context of hospital care is: “at the patient level, dementia friendly healthcare is the practice and organisation of care that is aware of the impact dementia has on a person’s ability to engage with

“The dementia nursing team are excellent and very supportive within the hospital and provide a dementia cafe for inpatients and non-inpatients and family once a month. The only reason that I haven't given the initiative an excellent is that not all members of staff within the hospital are on board with the project or seem to have read or fully understand what is required when caring for a patient with Alzheimer's, which ever type it is.”

— Person living with dementia

32. Williamson, Toby. *Mapping dementia-friendly communities across Europe: A Study Commissioned by the European Foundations' Initiative on Dementia (EFID)*
https://efid.info/wp-content/uploads/2016/05/Mapping_DFCS_across_Europe_final_v2.pdf

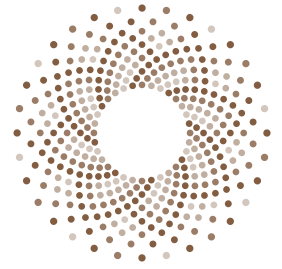
33. <https://www.jrf.org.uk/report/how-can-we-make-our-cities-dementia-friendly>

34. Evidence submission from Gabi Williams Alzheimer's Foundation, Nigeria

35. Evidence submission from Leeds Playhouse, UK

36. Evidence submission from Russia

37. Evidence submission from Alzheimer's Western Australia



services and manage their health. It promotes the inclusion of people living with dementia and their caregivers in treatments, care decisions and discussions, with the aim of improving outcomes for the patient and caregiver.”³⁸ Evidence reviews have looked at the benefits of staff training and design.³⁹ The UK-based Kings Fund has designed toolkits for the environmental evaluation of health centres, hospitals and wards.⁴⁰ Some studies have applied the concept of dementia friendly more broadly, highlighting the disparity of outcomes for people with dementia in hospital settings.⁴¹



Many of the community-based services either did not collect evidence of impact (and resource constraint and the scale of the initiative were often cited as challenges) but some collected positive user feedback. Researchers have looked at the impact of some generic service models (such as memory cafes). It reflects the nature of

the dementia friendly movement that the initiatives that have proliferated in support (such as memory cafes)⁴² and awareness (such as Dementia Friends) tend to be low-cost, easily replicable and can be led by volunteers.

“I, and other friends who are/ have been carers of family members with dementia have not always felt that our town is as dementia friendly as it would like to think it is. We have all struggled to access the right help for our loved ones and our own stress levels have been huge. Carers often do not realise that there is help out there as we are not told about it from any of the GPs or other health professionals until a lot further down the line, if at all.”

— Caregiver

Successive studies have highlighted how health and social care systems are not meeting the needs of people with dementia. To give one example, someone with dementia is much more likely to spend longer in hospital for the same medical admission as someone without dementia.⁴³ Good design has been shown to be important, but isolating any particular factor is challenging. The UK National Institute for Health and Care Excellence guideline (published in 2010 and updated in 2019) on delirium

38. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5541590/>

39. <https://bmjopen.bmj.com/content/7/7/e015257>

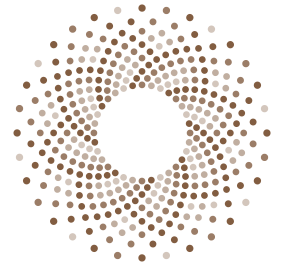
40. https://www.kingsfund.org.uk/sites/default/files/field/field_pdf/is-your-care-home-dementia-friendly-ehe-tool-kingsfund-mar15.pdf

41. <https://doi.org/10.1097/yc0.000000000000304> and <https://doi.org/10.7748/nop.2018.e982>

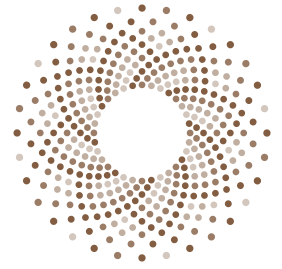
42. https://www.dementia.org.au/sites/default/files/NATIONAL_documents/Community-Cafe-Toolkit.pdf

43. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_hospitals.pdf

management in hospitals and long-term care settings suggests the risk of someone with cognitive challenges developing delirium can be managed through managing the environment. But design was only one element in the best practice guidelines to minimise and, when necessary, manage delirium.



As the disease develops, someone with dementia increasingly relies on good quality health and social care. It is fundamental to quality of life. The initiatives highlighted as “dementia friendly” as part of a review have only a small impact on that and predominately are targeted at people in early stage dementia.



Next paper

While it is difficult to do justice to the diversity of dementia friendly initiatives, that can mask the similarities. The reason why Dementia Friends, memory cafes, or even the concept of dementia friendliness has potency is perhaps the ease it can be delivered by volunteers who want to do something to make a difference. Advocates, campaigners and volunteers can take comfort from the fact their approach does not differ widely from other conditions and causes. Raising awareness, enabling participation and providing support is a path well trodden. While acknowledging the lack of systematic evidence, which this review has highlighted, champions have argued the limited evidence there is strengthened by the belief this is a trajectory others have traveled.

We recognise and pay tribute to the effort of all those involved to improve the lives of people with dementia and their caregivers. These efforts are particularly admirable in nations and communities where dementia is little understood and receives little policy attention.

Many countries and communities do not collect data on the number of people living with a dementia diagnosis, let alone track their health and social care outcomes or quality of life. For some dementia even remains a taboo subject. From the perspective of the volunteer or advocate trying to do something asking for evidence that engages such metrics may seem unreasonable. While theories of change can explain how activities might impact on such outcomes that is, evidently, not the same as evidencing it.

The last paper in this series will draw out conclusions and recommendations from this review.

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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