Dementia Friendly Communities

This publication, originally published in March 2015, has been archived.

We have newer publications on Dementia Friendly Communities, which are available from www.alz.co.uk/DFC

The original publication starts on the next page.
Dementia Friendly Communities (DFCs)
New domains and global examples
Foreword

This document attempts to capture a movement as dynamic as the wind or fireflies, the emergence of a number of lively experiments to create Dementia Friendly Communities (DFCs). This introduction serves as a reminder of certain key strategic considerations;

1. DFC efforts are a response to pervasive and destructive stigma, a key finding in national and subnational Alzheimer plans. Though challenging to measure impact, it is nonetheless vital to understand this desired outcome of DFCs

2. DFCs give full voice to people living with dementia in their design and execution, understanding that at times we have a great challenge to listen to the voices of people living with dementia, especially those who have lost the ability to raise their own concerns. Our growing knowledge of Alzheimer’s and other dementias as lifespan diseases makes this even more complicated.

3. Prior to the earliest experiments in DFCs, for many years the World Health Organization (WHO) and key collaborators have been promoting and designating Age Friendly Cities (now expanded to communities) www.who.int/ageing/age_friendly_cities_network/en/. These two rivers of work are not mutually exclusive and likely seriously intertwined.

4. In the UK, a serious effort to create clear standards for DFCs is underway, using techniques that are common in community development. This will certainly create a baseline that works in a particular culture and resource environment which may have some utility elsewhere in the world, but in no way would mark the end to the ongoing lively experiments in creating and sustaining DFCs.

Lastly, I would like to thank all the ADI member associations who have shared their information with us in order to create this document. We know that this publication will seem out of date as soon as it is published, but we feel it is a good place to start and from which to build on. We would like to extend particular gratitude to Nicole Batsch and Karishma Chandaria for reviewing the document, and to Michelle Seitzer as the lead writer.

Marc Wortmann
Executive Director
Alzheimer’s Disease International
Having dementia is very tough but having a city who excludes dementia — that is really tough.”  
Bart Deltour, Foton Dementia Charity, Bruges

While the world waits for a cure, we need more communities and cities to embrace and engage those living with dementia instead of isolating and excluding them. As more organisations, businesses and individuals become aware of the needs of aging community members, and of those with various physical, developmental and intellectual disabilities, it follows that the unique needs of those with dementia — along with their care partners — must be carefully considered.

These unique needs must also be developed into measurable, strategic, actionable and effective programmes, initiatives and culture change movements: with the ultimate goal of removing stigma and fostering meaningful engagement for persons with dementia of all ages and in all stages.

Dementia Friendly Communities (DFCs) should not only seek to preserve the safety and well-being of those living with dementia, it should also empower all members of the community to celebrate the capabilities of persons with dementia, and view them as valuable and vital members of the towns, cities, villages and countries in which they reside.

Worth noting is the two-tiered approach to making communities dementia-friendly: first, there is the “invisible” network of businesses, healthcare workers, emergency services personnel and other civic employees who are trained and prepared to respond to the needs of persons with dementia within the community. This network requires input from persons with dementia in planning services and strategies, but ultimately, implementation of programmes is “top-down.” Second is the more visible, grassroots, “bottom-up” network comprised by persons with dementia engaging socially in their community. In planning, building and developing DFCs, there is a need to recognise both tiers.

Just as the majority of DFC-building programmes should be driven by those living with dementia, many of the initiatives should also have some fluidity and overlap. Efforts should be streamlined and not duplicative but should feed into one another, all working towards the common goal of a better life for people with dementia and the elimination of stigma.

The existing DFC domains defined by Alzheimer’s Disease International (ADI), within the constructs of WHO’s Age Friendly Cities principles and tactics, are as follows:

- Public awareness and information access
- Planning processes
- The physical environment
- Access and consideration for dementia among local businesses and public services
- Community-based innovation services through local action
- Access to transportation

Based on new trends, literature and innovative programmes of interest around the world, what follows are several updates to the existing DFC domains.
More work can always be done in the sphere of public awareness and information access. While there has been a noticeable increase in regards to dementia-related films, television and movie story lines, news programmes, novels and other mainstream media outlets, there is still a considerable gap when it comes to accessing accurate, reliable information about dementia.

The UK’s Health & Social Care Partnership sponsored Dementia for Schools: Creating a Dementia Friendly Generation. Students and teachers developed a toolkit called the Dementia Resource Suite, which launched in 22 pioneer schools across England in 2012-2013 as a means for teachers to promote dementia awareness and “create a dementia friendly generation.” The curriculum integrates the concepts across all disciplines and is used in all grade levels. Students visit local care homes and are “trained story telling facilitators” to encourage creativity and rediscover/preserve the social role of people with dementia.

In June 2014, Alzheimer Scotland launched a Dementia Friends programme based on the scheme and success of England’s programme. Participants can attend free information sessions and learn more about dementia, and what it means to be a dementia friend, via the website, DementiaFriendsScotland.org.

The San Francisco Strategy for Excellence in Dementia Care includes an important recommendation around acquiring better diagnosis information for those living with dementia. While a variety of screening tools currently exist in a number of health care settings around the world, further development of a universal, standardised screening tool that considers cognitive function, mood, input from family members and care partners, and activities of daily living should be used in any health care/care services setting where staff are evaluating adults with memory loss concerns.

Japan has launched a campaign called the Heart Ring Movement to raise awareness, encourage compassion, thoughtfulness, kindness and cooperation between individuals, organizations, and the community, and to change the negative image of dementia to a positive one. Based in Tokyo, the campaign is spearheaded by three directors of medical organizations in Japan. As per a campaign document, the movement is focused on telling society the “positive truth that people with dementia can spend satisfying days.”

Throughout Germany, a multi-faceted public awareness campaign sponsored by Deutsche Alzheimer Gesellschaft/Selbsthilfe Demenz includes resources for caregivers, such as e-learning courses and other educational opportunities, TV spots, posters in public places, empowerment for persons with dementia and their carers via meetings and support groups, and a special programme focused on the younger generation called “Alzheimer’s & You,” comprised of materials for educators and an interactive website for children and teens to learn more about Alzheimer’s.
Innovations around dementia-friendliness must be developed with input from persons with dementia, as many countries have already done successfully. As DFCs continue to grow, this hierarchy should guide planning processes: input from people with dementia must come first, then the carers, then the professionals and experts.

Throughout the UK, the DEEP Project (Dementia Engagement and Empowerment Project) is committed to bringing together groups of people with dementia to change services and policies affecting the lives of those who have dementia.

Trevor Jarvis, who has lived with vascular dementia for 10 years, represents the needs of people with dementia as an ambassador for the Alzheimer's Society and a member of the Dementia Friendly Champion Group, a response to the Prime Minister's challenge on dementia. For Jarvis, a key piece of building a Dementia Friendly Community is recognising that dementia is not often a visible disability but is nonetheless one that requires compassion and consideration. He also believes one of the biggest challenges in creating Dementia Friendly Communities is getting the public talking about dementia.

The Alzheimer's Society (UK) recently partnered with the British Standards Institution (BSI) to develop a Publicly Available Specification (PAS) for DFCs. Recommendations for communities working towards a dementia-friendly designation include the following: who must be involved in
the process of becoming dementia-friendly, what goals must be central to all DFCs, what areas of focus and processes are necessary for a successful operation of a DFC, and what positive changes persons with dementia would expect to see in a DFC. The code of practice is slated for release in March 2015.

One of the biggest challenges in creating Dementia Friendly Communities is getting the public talking about dementia

In the US, the state of Minnesota offers an extensive hub of Action Resources for Dementia-Friendly Communities through a collaboration with the Alzheimer’s Association and several state agencies. Among these resources (many of which are also age-friendly) are such unique programmes as a Public Health Initiative delivered via the barber shop, which focuses on outreach to the African-American community; a guide on dental considerations and oral health for older adults and persons with dementia; a dementia-enabling environment project with practical tips for enhancing independence and quality of life; toolkits and checklists for building and developing DFCs; and information on offering meaningful engagement through the development of Memory Cafes, a model which originated in the Netherlands.

Mike Oliver, an academic living with a disability who is credited with starting the disability rights movement in the early 1990s, developed the concept “not about me without me,” which is the goal of the National Dementia Initiative from the US-based non-profit, CCAL, focused on person-centered care for those with dementia. This philosophy must guide every planning process, steering committee, foundation or government organisation taking action to become dementia-friendly.

In Port Macquarie, Australia, the DFC Steering Committee reflected their opinion of the correct order of importance for its members: people living with dementia, family carers and representatives from the Local Council, service clubs, the Education Department, emergency services, aged care providers, the Local Health District, church groups, Alzheimer’s Australia NSW, and other interested community representatives.

A symposium titled “Dementia Friendly Communities: Opportunities and Challenges” held in New Delhi during the Asia Pacific Regional Conference of Alzheimer’s Disease International 2014, highlighted DFC work occurring in India. Among the topics discussed: defining and implementing DFCs, the challenges to adapting the DFCs concept in lower-resource settings, and deliberating certain methodological considerations. Presenters shared details of a national recognition system for DFCs, along with the possible challenges such a programme faces, particularly regarding outcome measures. Work around DFCs already being done, particularly the success of the Kerala Dementia Friendly Initiative, was also covered, with an emphasis on the importance of collaborative efforts between government, non-governmental and voluntary sectors. Key components and goals of the Kerala Dementia Friendly Initiative are comprehensive dementia awareness in the community, equipping social and health care personnel in dementia care, memory clinics in medical colleges for early diagnosis and intervention, a telephone-based Helpline service for information and support, standard operating procedures for care homes, the development of protocols for diagnosis, treatment and care.

The Dementia Friendly Japan Initiative, in cooperation with the Iba Laboratory at Keio University, published a book “Words for a Journey: The Art of Being with Dementia” to serve as guide for living well with dementia. The book is a collection of 40 words that provide “hints” for living well with dementia, categorized in 3 groups: Words for the Cared, Words for the Caring, and Words for Everyone.
A checklist of characteristics of dementia-friendly neighbourhoods is outlined in the UK-based Housing Learning and Improvement Network’s (LIN) white paper “Neighborhoods for Life: Designing Dementia-Friendly Outdoor Environments.” A dementia-friendly neighborhood includes “places that are familiar, legible, distinctive, accessible, comfortable and safe,” per the report.

In a 2012 project from the Joseph Rowntree Foundation, several recommendations were made to push the city of York to becoming dementia-friendly. The Foundation consulted experts to examine nearly every aspect of everyday life in the city and called upon people with dementia to determine how these daily activities could be made easier for people living with it. Among the suggestions: leisure centres should offer new sport sessions that allow easier participation from people with dementia, simplified bus timetables, “safe haven” shops, restaurants and banks based on the DFC model in Bruges, Belgium, a streamlining/clear-out of...
the number of street signs, and designated “slow routes” for those walking through the city centre.

SITRA, a UK-based membership organization that provides expertise, training and consultancy in housing with health, care and support, has launched an innovative training programme in collaboration with the Housing LIN and the University of Worcester’s Association of Dementia Studies (ADS). Titled “Dementia Leaders Programme for the Housing Sector,” the training consists of two courses to equip delegates in housing and dementia support best practices and a better understanding of dementia and person-centered care.

### Though Cygnet is a tiny village, it provides a rich example of how the ideal dementia-friendly community is built around the people with dementia

Access and consideration for dementia among local businesses and public services

A Naturally Occurring DFC in Tasmania: Gordon Nutt and his wife and carer, Ginger, moved to Cygnet, Tasmania, Australia, after Gordon was diagnosed. During their years in Cygnet, a naturally occurring Dementia Friendly Community was born. The town embraced Gordon; they looked out for him, included him and protected him. Teachers welcomed him into their classrooms when he would walk by and peer in the window. Shopkeepers allowed him to straighten up and tidy their counters and shelves when he would visit. Gordon could walk safely through the town and always end up in a place where people accepted him. Though Cygnet is a tiny village, it provides a rich example of how the ideal dementia-friendly community is built around the people with dementia.

The San Francisco strategy maps out recommendations for a health care and social services workforce that is effectively trained to meet the challenges of dementia care, particularly around issues related to medication prescriptions, diagnosis, end of life care, crisis care, and managing difficult behaviours.

More banks across the UK are also integrating suggestions from persons with dementia to make banking easier and more secure; among them, creating a photo ID bank card and a chip to store information to indicate to the cashier, discretely, that the individual may need extra support or a side room to prevent embarrassment. The Alzheimer’s Society’s report, “Shortchanged: Protecting people with dementia from financial abuse,” contains data and analysis focused on money management challenges for persons with dementia, scam prevention tips for care partners and persons with dementia, and a number of actionable recommendations for awareness raising around this issue. This includes the appointment of dementia champions in banks and other local organisations who will be trained to spot the signs of financial abuse, and specialised money management services for care partners, and for individuals with dementia who may not have the active support of a care partner.

In dementia-friendly Bruges, local police are building a database that identifies residents prone to wandering, for a more rapid response to missing persons and for immediate assistance should an individual need redirection.

In Motherwell, North Lanarkshire, one of three ‘Dementia Demonstrator Sites’ in Scotland, most of the community’s firefighters have attended awareness/training sessions around working with persons with dementia.

There are currently 11 persons with dementia who have formed the Japan Dementia Working Group to advocate for themselves and for others impacted by the disease.
A variety of participatory arts programmes for people with dementia and their caregivers are gaining traction around the world, from storytelling programmes to museum tours to expressive arts, music therapy sessions and more.

In Australia, per the spring issue of Australian Mosaic (a publication of the Federation of Ethnic Communities’ Councils of Australia) a number of DFCs are sponsoring memory cafes, educational programmes for carers who are culturally and linguistically diverse (CALD) and therefore require specialised outreach efforts, dementia choirs (also popular in Bruges), walking groups, and collaborations with the Men’s Shed organisation, which provides support to men with mental illness or other illnesses such as dementia.

Alzheimer Scotland’s Action on Dementia Football Memories programme focuses on engaging men...
with dementia through their close connection to football. The Scottish Football Museum recruits and trains volunteers to bring reminiscence sessions to men with dementia in care homes and adult day service settings.

The US-based TimeSlips Creative Storytelling programme seeks to transform dementia care through creative engagement. Individuals and organisations can be certified in the programme, specifically in the area of engaging people with memory loss. Through improvisation and poetry, TimeSlips gives everyone the opportunity to express themselves and connect with others, regardless of dementia, by “replacing the pressure to remember with the freedom to imagine.”

Japan’s Fujinomiya Project, “Bridging Communities; Sharing Our Memories” is an ongoing collaborative effort to create interactive spaces in the community (a recent event was held in a shopping district) for intergenerational exchanges between high school students and older adults with dementia.

Access to transportation

Though it is an unconventional example of access to transportation, fake bus stops are an initiative currently taking root throughout Germany and other parts of Europe; public transportation departments partner with local care associations to construct exact replicas of standard bus stops outside of care homes. The International Association of Chiefs of Police highlights this initiative, the goal of which is to diffuse the panic and anxiety that many people with dementia experience when they feel they need to be elsewhere (a trend observed in many care homes). The system has been successful; many individuals will sit and wait, believing their bus will arrive, and can eventually be redirected by a carer.

In the UK, input from the County-established Northumberland Dementia Forums launched the development of a dementia awareness training package for local bus drivers, as part of their Certificate of Professional Competency. As many older adults with dementia utilise public transportation in rural and urban areas throughout the UK, having a well-trained and sensitive point of contact in their bus drivers is certainly a positive step towards dementia friendliness in all aspects of daily life.

The Florida Alzheimer’s Disease Initiative has been committed to resolving transportation challenges for people with dementia since the early 1990s, and in 2010, the Florida Alzheimer’s Disease Initiative submitted the Florida Dementia Friendly Transportation Research Project. The report defined dementia friendly transportation as “Going beyond senior friendliness, a transportation service that considers the special needs of passengers with all stages of memory loss.” Tip sheets, a training curriculum for transit providers, transportation profiles for several counties, and information about dementia passengers and drivers were among the outcomes of the Florida Alzheimer’s Disease Initiative’s research. They also explored several service delivery models that could better accommodate passengers with dementia.

New domains

Field research reveals two emerging domains in DFCs: support for caregivers and care partners, and the empowerment and equipping of faith-based communities to carry out the important work of nurturing the spiritual health of, and supporting the caregivers to, persons with dementia.

In breaking down these emerging domains, more specific themes surface, such as end of life care for persons with dementia; special initiatives focused on those with early onset dementia; relationship-building for care partners; removing stigmas and distinctions between levels of care in continuing care retirement communities/other senior care facilities; creation of opportunities for intergenerational relationships and interaction; and establishing connections to/outlets for creativity and the arts.

Access to and support from faith-based communities and the exploration of spirituality

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exception. There seems to be a positive move towards making religious buildings dementia-friendly and in the crucial role that these places can and should play towards supporting and nurturing the spiritual health of persons with dementia and their care partners, and more effectively welcoming and engaging persons with dementia in their communities.

This emerging domain references again the two-tiered approach: there is a need for faith-based communities to become dementia-friendly, and a need for persons with dementia to have better access to spiritual connections and opportunities within their community.

In this online resource from The Church of England in Devon, The Diocese of Exeter’s Dementia-friendly church, a number of programmes and resources are outlined, including Guidelines for Pastoral Visitors, information on becoming a dementia champion or dementia friend, and an Methodist Homes Association’s (MHA) Dementia Resources Package that includes information on worship and people with dementia, and spirituality care for people with dementia.

The Dementia Friendly Gurudwaras Project based in Bradford is an Alzheimer’s Society Dementia Friendly Award finalist. A local initiative centered around the Gurudwara (Sikh temple), which is a hub for both social and spiritual activities among the Sikh community, is led by a group of dedicated Sikh healthcare professionals who were driven to make a positive difference. Lack of knowledge about and the stigma surrounding dementia are the catalysts for this project. Specially designed courses, workshops, lectures and information, available in both English and Punjabi, are among the project’s actionable outcomes.

Livability, a UK-based Christian disability charity, has an active campaign: “How Dementia Friendly Is Your Church?” And informal poll taken during the Christian Resources Exhibition in Esher, Surrey, found that “while 95% of the people they spoke to during the week knew someone affected by dementia, less than a third attended churches with activities engaging with people with dementia.”

In Minnesota, the Twin Cities Jewish Community is working to help rabbis recognise the symptoms of dementia and referring them for support and help in acquiring a diagnosis.

John McFadden, Chaplain of the Appleton Health Care Center (part of the Fox Valley Memory Project in Appleton, Wisconsin, USA) explores spirituality in his report, Aging, Dementia, and the Faith Community: Continuing the Journey of Friendship.

Dementia care is mentioned in the January 2013 issue of Insights: Evidence Summaries to Support Social Services in Scotland. The issue, entitled Spirituality and Ageing: Implications for the Care and Support of Older People, highlights best practices and an evidence base supporting connections to spirituality for encouragement along the journey through ageing.

There is a need for faith-based communities to become dementia-friendly, and a need for persons with dementia to have better access to spiritual connections and opportunities within their community.

The Dementia Voice, issued by the Dementia Services Development Centre for the South West, is a Bristol-based publication that released a report, The Spiritual Care of People with Dementia, with recommendations from local ministers.

John Swinton, Scottish-American theologian and journalist has written extensively on the subject of spirituality and dementia, of note is his book, Dementia: Living in the Memories of God, which offers a practical theology of dementia for caregivers, persons with dementia, hospital chaplains, ministers, and medical practitioners.

The Catholic Medical Quarterly’s November 2011 issue included an article entitled The Spiritual and Religious Needs of People with Dementia, which suggests the potential of an increased sense of well-being for people with dementia who are given sufficient opportunities to maintain a link or reconnect with their religion as part of their provision of care.
In Bruges, dementia choirs are open to persons with dementia and their carers as well, and a carer in the community who attends the choral group with her husband believes that Bruges stands out in this recognition and inclusion of the care partner (other DFCs overlook the carer, she believes, in their focus on the person with dementia). Some support groups in Bruges offer therapy for the caregiver alongside of practical help and support for the person with dementia.

Alzak House is an intergenerational community day centre in southern Italy’s Lamezia Terme. Here, people of all ages and the families of those with dementia are invited to participate and narrow the generation gap. The Alzak House was a 2012 winner of the European Foundations’ Initiative on Dementia (EFID) awards.

There is a growing sense of urgency regarding the importance of discussions about end of life care between persons with dementia and their carers, particularly those who will be entrusted with making health care decisions when their decision-making capacity is diminished or gone completely.

Alzheimer or Memory Cafes continue to be a great source of support for the individuals with dementia and their carers; an entry point/hub of
professional and personal support, resources and information for carers and persons with dementia; and a place rich with opportunities for relationship-building and interaction with other carers and people living with dementia.

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Compare and contrast

The WHO defines an Age-Friendly City (AFC) as an “inclusive and accessible urban environment that promotes active ageing.” In November 2014, the WHO Centre for Health Development in Kobe, Japan, released a draft, which will be piloted in 12 countries prior to its final version and release, slated for 2015. Within the document, “Measuring the Age-friendliness of Cities: A Guide to Using Core Indicators” is the framework for defining a local AFC that includes input, output, outcome, impact and equity indicators in the physical and social environment, along with core and supplementary indicators for measuring age-friendliness.

Case studies/bibliography

What follows is a list of case studies and articles featuring DFC programmes and initiatives for further exploration and consideration:

The 2012 Winners of the EFID (European Foundations’ Initiative on Dementia) Awards

- The Bistrots Mémoire, first set up in Rennes in 2004, and now existing in 41 communities across France, which provide ‘normal’, pleasant locations where those with dementia, their carers, professionals and volunteers can meet to exchange feelings and experience
- The Enger Alzheimer’s Counselling Centre in Germany is successfully involving many actors from the local community in providing opportunities for those with dementia to meet other inhabitants of all ages in a wide range of activities
- Alzak House, in Lamezia Terme, southern Italy, is an intergenerational community day centre for those with dementia and their families, which encourages participation of people in all age groups and the natural networks in society so as to improve integration in the community whilst also narrowing the generation gap
- Together for a dementia-friendly Bruges! is a long-term awareness-building programme aimed at fighting the stigmatisation associated with dementia, by involving the whole community and encouraging respect and tolerance for those with the condition
- Better together than alone! in Lübbecke, Germany, has demonstrated an innovative approach in providing support explicitly for early-stage dementia through bi-weekly support groups, sports and other activities through specially-trained volunteers
- Campaign Dementia, in Vorarlberg, Austria, is succeeding with limited resources, in mobilising communities to fight the stigmatisation related to dementia by involving all actors of civil society to develop original and effective programmes
- The Twinning Programme of Alzheimer’s Disease International, in Bulgaria, has facilitated the transfer of expertise between Bulgaria and elsewhere, to fight prejudice and exclusion experienced by those with dementia via a robust awareness-building programme among the general public
- The Missing Persons project in HEKLA, 5 local authority areas in Belgium, was the result of collaboration between the local police and others in the community to rapidly locate and return home missing persons with dementia, a network-based approach that has been so successful it has already been adopted by 8 other local police forces
- Oficinas Terapêuticas, in Lisbon, Portugal, aims to help those with dementia regain their self-esteem through the development of old and new capacities and through changing the image of dementia through collaboration with community institutions such as museums.
• The Joseph Rowntree Foundation’s Dementia Without Walls Resource Hub: a range of external links about developing Dementia Friendly Communities.

• The Fox Valley Memory Project offers Memory Assessments, Memory Cafes, community education, workplace enrichment and a host of other resources and services in their DFC in Appleton, Wisconsin.

• Dementia Aware Donegal’s DFC programme is comprised of 5 project components, each of which fall into several of the key DFC domains, both existing and emerging: “Be a Sport for Dementia,” which encourages persons with dementia to continue their involvement in local sports clubs, “Ordinary Man, Extraordinary Memories,” a play designed to grow awareness and understanding of dementia, “You’ve Got a Friend in Me,” an effort to establish Dementia Champions to recruit and train new Dementia Friends, “Hearth and Home,” an effort aimed at providing support for those living with dementia in the community, and finally, “Faith, Hope and Charity,” a development of best practices for clergy to better support members of the congregation living with dementia and their families.

• The Azure project and The Abbey Theatre are two arts-based programmes in Ireland. Focused on “exploring the greater inclusion of people with dementia in an Irish cultural context,” the Azure Project includes efforts to make art accessible to persons with dementia through based on the popular US model (NYC), “Meet me at MoMA.” Workshops designed to bring “high quality drama to people living with dementia and their carers” is the focus of the Abbey Theatre project.

• The Japanese Nursing Association has implemented an advanced education and training programme to prepare managerial staff, practitioners, and dementia care specialists among nursing staff in a number of health and long term care settings. Through this programme, nurses can receive dementia-specific qualifications and credentials after completing the established continuing education requirements.

After the change, the government launched a nationwide campaign, “Ten years to understand dementia and to build community networks, to raise public awareness and understanding of dementia.” At the heart of this campaign is the Nationwide Caravan to train Ninchisho (Dementia) Supporters programme. This programme provides specialised seminars for the public held at schools and offices and for community groups across the country. The purpose of the seminar is to encourage individuals not to devote their whole life to caring for a person with dementia as this is believed to be unrealistic.

By the end of the seminar attendees are expected to have a good understanding of dementia, freeing themselves from any prejudice they may have, and to become supporters and advocates for those living with dementia in their everyday lives. Those who attend the seminars become Ninchisho (Dementia) Supporters.

Lecturers of the seminar must complete a six-hour training workshop to develop their knowledge enough to be able to deliver the seminar’s content.

During the 90-minute Ninchisho Supporter seminar, attendees learn about the disease itself, how it affects the lives of those living with dementia and what they should know in order to effectively support people with dementia. Standard text and video materials are used nationwide for the seminars, with variations according to the attendee groups (for example, schoolchildren).

The seminar covers seven key areas including recognition of the symptoms of dementia, diagnosis and treatment, the role of each health care professional, prevention, attitudes towards people with dementia, and understanding of the caregiver experience. Over 3.3 million people in Japan had attended this seminar as of March 2012.

• Dementia Elevator is another innovative DFC initiative in Ireland; their training programmes include Dementia Champions, Dementia Awareness, Memory Assessment, Everyday Ethical Care Decision Making, and more.

• A report issued September 2014 from Alzheimer’s Australia NSW: A Guide to Becoming a Dementia-Friendly Community. The report is built on a Kotter’s 8-step change model (steps are outlined below) and includes a section with other examples of DFCs within Australia and overseas.

  • Step 1: Create a sense of urgency
  • Step 2: Form a powerful coalition
  • Step 3: Create a vision for change
  • Step 4: Communicate the vision
  • Step 5: Remove obstacles and empower action
  • Step 6: Create short-term wins
  • Step 7: Build on the change
  • Step 8: Anchor the changes in community culture
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fforts to create DFCs are happening in a variety of social and cultural contexts, driven by a desire to reduce stigma and promote the inclusion of people living with dementia into a fuller life in their communities. The success of DFC programs relies on the attentiveness to the needs of people living with dementia and the processes that can put them control.

There are variety of lively experiments with the outcomes not yet known and it may be that a singular model may emerge that can be replicated in some fashion. What is replicable is person centeredness in the spirit of collaboration across sectors that are so evident in the rich examples in this document.

There are important parallels between the age friendly communities’ efforts fostered by the World Health Organization (WHO) and DFCs and these ties need to stay strong and continue, in the spirit of mutual learning as a community of practice develops for both.

It is possible, if not a surety, that this document has not included DFCs from everywhere in the world. Should you be interested in contributing to the next version please do get in touch. We expect this booklet will be a living document, and look forward to adding more and more contributions in future editions.
About Alzheimer’s Disease International

Alzheimer’s Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 84 members is a non-profit Alzheimer association supporting people with dementia and their families.

ADI was founded in 1984 and registered as a non-profit organization in the USA. Based in London, ADI is in official relations with the WHO since 1996 and has consultative status with the UN since 2012.

ADI’s vision is an improved quality of life for people with dementia and their families throughout the world. ADI aims to make dementia a global health priority, to build and strengthen Alzheimer associations, and to raise awareness about dementia worldwide. Stronger Alzheimer associations are better able to meet the needs of people with dementia and their carers, and to be the global voice on dementia.