

Guide to a Dementia Friendly Community

Ideas for cross-sector and cross-generation initiatives



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Global Communication Centre, International University of Japan <http://www.glocom.ac.jp/project/dementia/>

Dementia Friendly Japan Initiative <http://dementia-friendly-japan.jp/>

協力：株式会社 スマートエイジング 株式会社 浜銀総合研究所 株式会社 富士通研究所

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Global Communication Centre, International University of Japan
Dementia Friendly Japan Initiative

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Mr. Mitsutaka Sano and his wife, Mrs. Akemi Sano (dementia patient, Fujinomiya, Shizuoka)

Mr. Sano lives in an area where car is an essential part of daily life. He had no problem with driving until one day, he lost his sense of direction and ended up driving all the way to Tokyo. After this, he decided to turn in his license. “If I drive, my husband would want to drive as well so I decided that we both hand back our driving licenses,” said Ms. Sano.

Now they use the local bus as their mode of transportation. As a regular passenger, they have come to become familiar with some bus drivers. As they are aware of his condition, it reassures Mr. Sano to get around on the bus.

“I’m not looking for a special treatment just because I have dementia. I am grateful if they understand my condition and treat me normally,” said Mr. Sano.

How does our community look like from the eyes of the people with dementia?

What improvement should we make in our community to help resolve some of the problems people with dementia face in their daily life?

And what is a dementia friendly community?

To think about these questions, we conducted a study where we started by asking people with dementia.



Dementia through data

With a progressively aging society, coupled with the advancement in diagnostic technology, the number of people with dementia increases with each estimation. As of 2012, there were 4.62million people with dementia and if we include the 8million+ candidates, we are looking at a sizeable portion of the population who will be affected by dementia.

Most of them are not in hospitals or special facilities but live in their home and communities. Medical service and care are important elements which support their lives but now there is a growing demand for the community organizations and business sector to play a role in creating a more dementia friendly community.

4.62million *as of 2012



Percentage of people with dementia amongst the 65+ in 2025

Preliminary figures issued in “Research on estimation of seniors with dementia in Japan” (Professor Ninomiya, Kyushu University)

According to the latest study, the number of people with dementia will go up to 7million in 2025 which translates to one in every 5 people aged over 65 to be affected. Dementia is not any unique disease and we can say that increase in people with dementia is an unavoidable phenomenon in an aging society.



Percentage of people with dementia living at home

2011 “Distribution of self-sustaining elderly with dementia” (Tokyo) Dementia Elderly Self-Reliance Level I

You may think that people with dementia live in care homes and hospitals but in fact, majority live in their own homes. Given the expected pressure on public finance, we can safely say that this percentage will grow further. This creates a challenge for the communities to think about how its neighborhood could evolve so that people can continue their life living at home.



Social cost of dementia

Estimate for Japan based on a research conducted by Alzheimer’s Association(UK)

This is based on various costs related to dementia starting with public medical care, nursing care, free care by families and converting them to monetary value.

Dementia affects not only the patient and their families but also the society as a whole and there is a growing understanding in Japan and across the world about the urgency of addressing this at a society level.



Number of people who leave their jobs in a single year due to the need to provide care for their parent or other family member.

2012 Occupation Structure Study(MIC)

Each year nearly 100,000 are forced to leave their jobs as they need to care for their parent or spouse. Not everyone is dealing with dementia but many of them are people who are left with no choice but to quit as their parent affected by dementia needs constant care.

Various trouble faced by people with dementia

With increasing number of people with dementia, there are more and more dementia-related accidents and incidents in not just the local community but in the business sectors. However, this should not just be about preventing incidents and accidents. We are at a turning point where we need to rethink about products and services from the perspective of people with dementia.



Keep the utilities (electricity, gas, and water) running



Accidents on railway/ reversing on highway



How the service industry (distribution, restaurants, travel agency, financial institution, etc.) deals with people with dementia



Accidental ingestion of food/beverage



Victims of fraud/defalcation

Column What is a dementia friendly town?



As the world is becoming aware of the issues arising with increasing number of people with dementia, more eyes are focusing on the concept of dementia friendly community. In the UK, recognized for their progressive measures, a national survey was conducted amongst people with dementia and their families. The conclusion is that in order for the people with dementia to live an active life, there is a need for not only the adequate medical and nursing care but also social environment and initiatives are underway to address this.

Image of a dementia friendly community
Source: Alzheimer’s Association “Building dementia friendly communities”



The community, businesses, and the society have received many messages from the people of dementia.

How the neighborhood looks from the eyes of people with dementia

When we think about creating a dementia friendly community, we first have to understand what kind of difficulties people with dementia are facing in their daily life. Therefore, we began by conducting a questionnaire with people with dementia on what they think about their communities.

What we discovered is that many of them, since being affected by dementia, have less opportunity to go out and socialize which is caused by certain factors. While it may sound obvious, this was the first time a national study was conducted to understand the initiatives underway as well as how the communities are currently being perceived which helped to provide specific data as well as prioritize the various issues.



"These kinds of services will make my life in the community easier" Services and improvements sought by people with dementia

(percentage of people with dementia who would like to have the service as they live in their community)

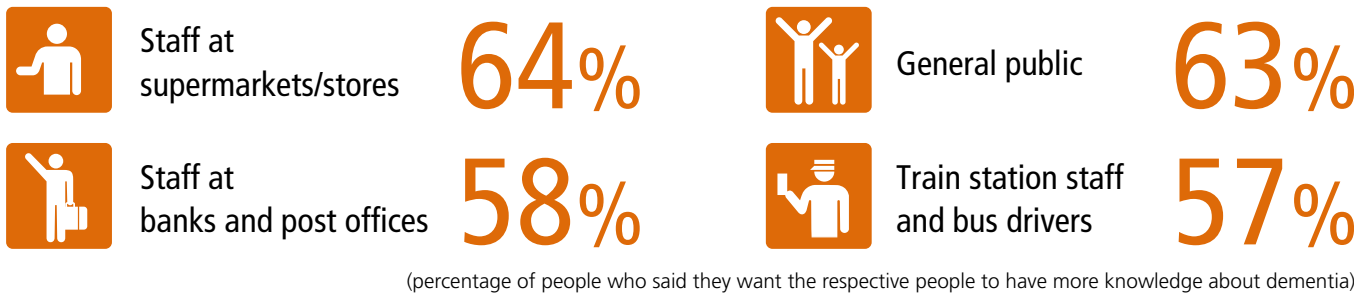


Is your local community easy to live for people with dementia?

39.3% of all respondents said their local community was an easy to place to live for people with dementia. However, when we ask the same question to people who say they 'live a life connected to the local community,' the percentage rises to 63.2%

We want more people to know about us, about dementia.

People with dementia want more people including store managers, bus drivers, and other people who support their daily lives, as well as their neighbors, to know more about dementia.



Research Overview

[Objective]
Understand what difficulties and barriers people with dementia face in their lives in the community and reflect the findings in the efforts to create a dementia friendly society.

[Sample]
People with dementia and their families(can be filled out by a family member or others with the responses from the people with dementia)

[Participation/Collection]
Sent out 1,350 questionnaires to 22 organizations and groups starting with Dementia Friendship Club office and family association. 292 effective response(21.6% of all the questionnaires sent out)

[Period]
October – December, 2014



6 issues in creating a dementia friendly community

While many would agree with the concept of a “dementia friendly community,” there is ambiguity about what constitutes a dementia friendly environment.

Despite the local governments across the nation running courses about dementia supporters, some participants have come back to say that they have yet to translate their learning to action. So how do we know if we have achieved the task? What do we need to do to make progress in the initiatives? To understand this, we have conducted interviews with some of the case studies where groups and communities are successfully driving the process by involving various members of the community.

What we discovered was that there are generally 4 objectives – “Change the

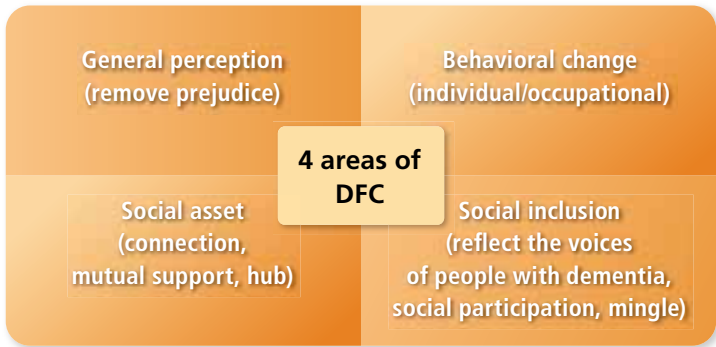
prejudice that ‘people with dementia loses all understanding’ and the general perception towards dementia” ; “Individuals and businesses to act to help the people with dementia and their families” ; “Go beyond the differences and interests and try to relate to each other” ; and “Participate in the creation of the products and services.” While one community is addressing just one of these four objectives, another has a balanced approach to all four objectives where all their initiatives are organically connected.

Though we talk about community-building as a single concept, it’ s important that each community identify their objectives and think about what they are addressing now and what areas they need to challenge.



4 Objectives in Community Building

When we gather all the information from Japan and abroad, we can identify 4 areas to address in creating a dementia friendly community.



DFC: Dementia friendly Community

Why doesn't community building work?

All the efforts being made to create a dementia friendly community can be categorized into 3 areas. The first is to build knowledge as seen with the dementia supporter training courses. The second is the bottom-up approach which is an extension of the support provided to individuals with dementia. The third is the top-down approach to realize a set vision.

What we uncovered through our national interview is that there are structural issues in Japan in creating a dementia friendly community which can be categorized into 6 topics.

In the knowledge-building efforts, while organizers are successfully relaying information and knowledge yet this is not leading to any action or behavioral change. In the bottom-up efforts, because the initiative begins from individual cases, it may produce results in the local area or in that branch of a company but

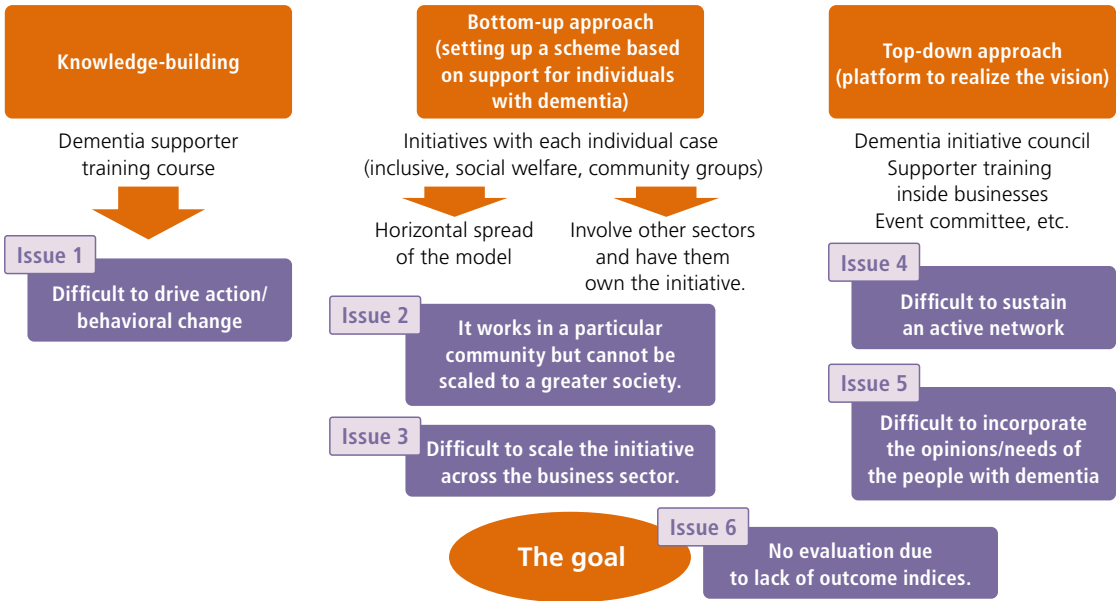


scaling to a larger community or an entire company remains an issue. Also, many of the top-down initiatives are implemented without the involvement of the people with a dementia, thus a lack of clear vision. This leaves any effort to be notional which fails to make any impact and leaves whatever network and platform produced in the process to have no substance.

What is consistent across all approach is that there are no clear measurement to find out how much contribution the effort has made(outcome index) nor assessment to identify whether investments are being made in the necessary areas, leaving any so-called improvements and changes to be merely speculative.

This research has given us tips on how we can resolve these issues. From the next page, we will start to look at new ideas and insight which are a clear departure from the traditional approaches.

3 Approaches and Issues in the Community building





Tips for
DFC

1

Getting people with dementia involved is the driver for the initiatives



What is consistent across all communities passionately engaged in creating a dementia friendly environment is an active participation by the people with dementia. In places where they play a specific role in the efforts, we can sense this sense of excitement and spirit across the community, including the people with dementia.

In Fujinomiya, they place importance on people with dementia to participate in the dementia supporter courses and local events. In a course for high school students, they are the lecturers sharing their personal experiences which helps the students to not only understand about dementia but to be able to imagine

what it's like for people with dementia to live in the community. This has led to various cross-generational social events. In the "Softball Tournament for People with Dementia," organized by the city, people with dementia sit on the committee, playing an active role from the planning stage. Initially, there were concerns about whether people with dementia will be able to play a game but it was the strong will and the desire of people with dementia which convinced not only the people in local government to nursing care business but also local high street and community FM station who play an active role in the Tournament.

What's consistent across many of the communities

struggling to sustain their dementia-related initiatives is the absence of people with dementia in the effort. While the residents may feel that it is important to make a contribution in this social issue in the beginning, it soon becomes a strain to maintain their motivation. When people involved cannot see what their contribution has achieved or feel a sense of satisfaction, it's no wonder the effort fails to continue.

Softball Tournament for People with Dementia (Fujinomiya, Shizuoka)

People with dementia always participate in the monthly committee meeting. Their presence in the room makes the purpose clear for all members, leading to a productive exchange and discussion.



Dementia Café (Uj, Kyotoi)

Uji city has set up dementia cafes in various locations where they have an informal group of regulars which includes people with dementia, making it possible for the organizers to hear what they have to say. "I-message," an evaluation index developed by Kyoto for their dementia care program stems from these voices of the people with dementia.



Community Development Workshop (Machida, Tokyo)

It all started from personal stories shared by people with dementia on how they had lost all contact with society since suffering dementia. The project aims to personalize the issue for various members of the society to think about what they can do.



Column How do we get people with dementia to get involved?

"There is no one with dementia in our community who can and is willing to speak at meetings""We do invite them but no one with dementia shows any willingness to participate"These are comments heard from some of the communities. But when we talk to communities who are successfully engaging people with dementia, we started to see that this is a step-by-step process.

STEP 1 There are individuals and groups people with dementia and their families feel safe to talk to or to consult with (trusting relationship, place to feel safe)

STEP 2 There are individuals and groups who not only listen to the problems but is actually working to solve the problems. (don't stop at just listening)

STEP 3 Form an informal network of people with dementia, their families, and supporters to create a place where people with and without dementia can easily participate in.



Yokamon Shotengai(Omuta, Fukuoka)
Representative:
Mr. Masahiro Matsunaga(optician)

I've never had any contact with welfare people but as I got to talking, I felt that they are partners with whom I can work together to solve our common issues in the community. Starting with the problems faced by the people with dementia, I'd like to think about how we can further energize our local community.



AEON(Tokai region)
Working with District Support Center

AEON(Tokai) and the District Support Center have joined hands to work together to solve their mutual issues. When AEON runs the dementia supporter course for its staff, they ask a member of the Center to be their lecturer. By forming a relationship with a member of the Center, when the employees need professional support in dealing with a customer with dementia in the stores, it becomes easier for them to reach out for advice. For the Center, the relationship they build with retailers and financial institutions allows them to take preemptive measures to support people beginning to face difficulties due to their dementia based on the situations and episodes the organizations provide in their request for help and advice. Seen with the comment by a staff from the District Support Center, "Having a relationship with local businesses like this is a tremendous help for our work," this relationship is proving to benefit their work mutually.



Mobile stores organized by Omuta city and a care facility. It benefits not only the care facility users but local seniors who have difficulty in travelling far.

Tips for
DFC

2

The key to success is a win-win structure across sectors



To scale the dementia initiatives across the entire community, all members must play a role, from welfare to businesses, schools, and community organizations. If the initiative is solely driven by the welfare organization where they ask for the help from other sectors, they may get some help initially but it will become difficult to sustain and will lack substance.

The city of Omuta(Fukuoka) has successfully scaled their efforts with a system which local businesses, schools, and welfare all gain from their contributions (ties in to their primary business).

So that they can provide a friendly shopping experience to people with dementia, the group of

local businesses, "Yokamon Shotengai," enrolled in the dementia supporter course. Through this course, they were able to build a relationship with the welfare organizations, leading to a regular and active exchange of information. One result of this exchange is a 'mobile store' where they take the store to the communities and care homes. They were able to respond to the needs of the shopping-disadvantaged while increasing their sales. This program has scaled since then, spurring on new projects and initiatives.

A local junior high school has made the subject of local studies as not a mere one-off but a 3-year curriculum which includes the theme of dementia.

The students participate in the mock wander training, pair up with local seniors and visit the high street and present their findings to the local government, etc. This direct interaction with the local people is providing the students with a valuable learning experience.

Column How do you develop a win-win relationship?

What we found with many communities who are successfully building a win-win relationship is that in addition to having a long-term perspective and conceptual vision, they have a more specific, individual-based approach.

It's about sharing their respective situations and discussing what would make their efforts easier or engage others to get on board. It is important to structure the initiative so that the motivating factor is based on their behavioral pattern and interests. In the case with the high street retailers, it's about how much sales the initiative would generate. For a large business, it's about the facts or evidence that will help the entire organization to understand and embrace the specific behaviors demanded of the staff in that situation.

When they can build a proper win-win relationship, it's likely that the initiative will continue and automatically gain depth. If this is not happening, the members need to question whether it really was a win-win relationship.



Wander SOS Network Mock Training(Omuta, Fukuoka)

This mock training was designed so people can reassuringly lend a hand when they encounter someone with dementia who've lost their way. Today, this has become a model for a national initiative where the purpose is not just about gaining practical knowledge but for people with dementia, local residents, and care staff to get acquainted and start to build personal relationships. Again, the key to this initiative is not the knowledge but the experience of actually interacting with people with dementia.



Kamakura Migaki(Kamakura, Kanagawa)

A local organization committed to keeping the city clean and people with dementia came together to work on the task of keeping the city of Kamakura clean(migaki). It all started with a group of people with dementia wanting to give back to the community but has now successfully engaged teens and citizens, helping to naturally build a cross-generational interaction.

The Dementia Café project in Kamakura which is now underway is expected to become a place for realization and action through the interaction with local residents and local people with dementia.

Tips for
DFC

3

Breakthrough in idea — from knowledge to experience



Many of the initiatives to create a dementia friendly community begins with gaining a medical knowledge about dementia. This has helped to remove the common prejudice such as “They have lost all of their awareness” or “People with dementia are scary” to some extent. However, having knowledge does not necessary translate to action or behavioral change or it may lead to inaction, “I don’t know enough about dementia so there is nothing I can do.”

In communities where there is active interaction between people with and without dementia, the focus is shifting to starting the initiative, not from knowledge, but through the experience of interacting

with people with dementia.

With the National Softball Tournament for Dementia People organized by Fujinomiya city(D Series), in addition to the teams of people with dementia and supporters, many citizens take part in the operation, cheering squad, and various social events. Some were asked by their friends while others simply decided to take part as this is softball but many of them didn’t necessarily have a prior knowledge about dementia.

However, many who saw and interacted with people with dementia through the tournament said it “changed their image of dementia” or “felt that there is something I can do for dementia which is now a

familiar issue.” Quite a few of them have decided to take the dementia supporter course as a result of this experience.

Given how the community is made up of all kinds of people, it is worth recognizing that in addition to building knowledge, there are alternative entry point such as the experience of meeting and engaging with people with dementia which can help them to learn and act.



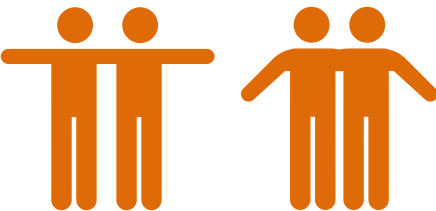
Building a structure that accelerates the efforts to build a dementia friendly community

Dementia Action Alliance — Civil platform to promote Dementia friendly Community —

The launch of the “National Dementia Strategy for England: Living well with dementia” in 2009 has accelerated the initiatives to build a dementia friendly community. As of January 2015, 80 local governments across England has declared to build a dementia friendly community.


The platform to drive this collective effort is Dementia Action Alliance. Organizations and groups who are engaged in dementia initiatives sign up to the alliance to share objectives and engage in joint projects to collectively promote the effort. What is unique about DAA is its diverse range of members starting with people with dementia and their families, government, and welfare to businesses, retailers, universities,

community-building NPOs to public facilities. While the initial intent to create platforms under DAA varies, majority is driven by an individual passionate about creating a dementia friendly community who are supported by coordinators from the Alzheimer’ s Association(UK) to call out to organizations and groups to come together. As individuals and groups join DAA voluntarily, the level of participation across sectors will vary by regions.




What is DAA? (in the case for Plymouth)


Organizations who are members of Plymouth DAA




Alzheimer’s Association(UK)




Groups for seniors




Plymouth city office (multiple departments including social welfare)




City bus




Schools




Hospitals




Library




Marine base



Fire department



Church



University

, etc

Plymouth — Library

The city of Plymouth, recognized for its leading efforts in dementia within the UK, is working to set up an environment for people with dementia and their families to learn about the disease and a life with dementia by setting up a section in the local library specifically for dementia-related literatures. The library is actively thinking about what they can do and one action they are taking is a book reading session which welcome people with dementia.

Plymouth Citybus — Help Me Card

The Plymouth Citybus has taken an idea from one of its employees to introduce a Help Me Card for passengers with dementia. The passenger can write their destination stop on the foldable card and show this to the driver when they board. If they get confused, the driver can help the passenger get off at the right stop.

York — British Trasnport Police

The British Transport Police is taking an active role to support passengers with dementia in the York train stations.

They organized a monitored travel program participated by people with dementia and their families to identify places and signage which is difficult to see or confusing which has led to numerous improvements across the stations.

Dementia Friendly Charter

Along with regional efforts, the business sector is now also engaged in the dementia friendly initiatives with some industry-wide efforts. The Alzheimer’ s Association(UK) has released the Dementia Friendly Charter, a report which compiles their study into what is necessary in working towards a dementia friendly community by industries – finance, distribution, transport, etc. The first issue released in 2013 was the Dementia Friendly Financial Service Charter which outlines the areas the financial industries must address.

*Japanese translation is available to download from the GLOCOM website.
<http://www.glocom.ac.jp/project/dementia/>

In 2015, similar charters will be released for the transport and distribution industries.

Dementia Action Alliance which propels the regional efforts and the Dementia Friendly Charter which accelerates the industry efforts – So that we don’ t have to rely on the passion of the few and coincidences, in Japan, we need these two approaches so that the small efforts can be scaled to a large movement.

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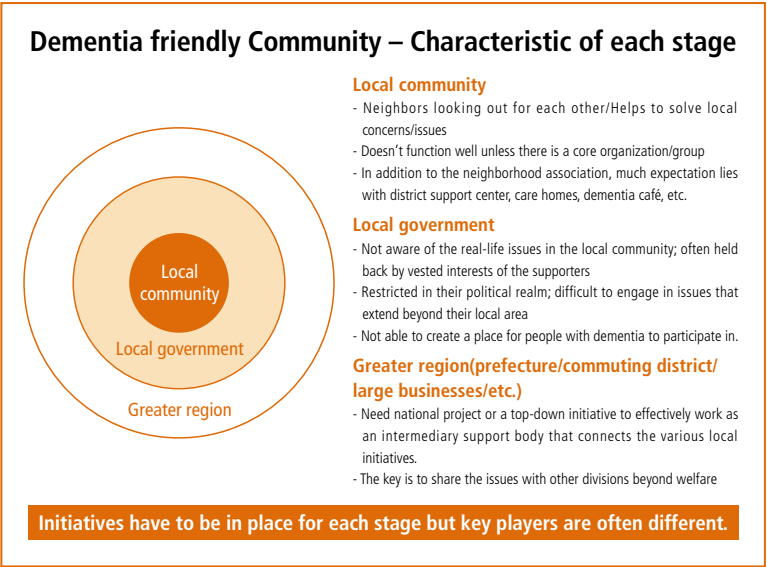
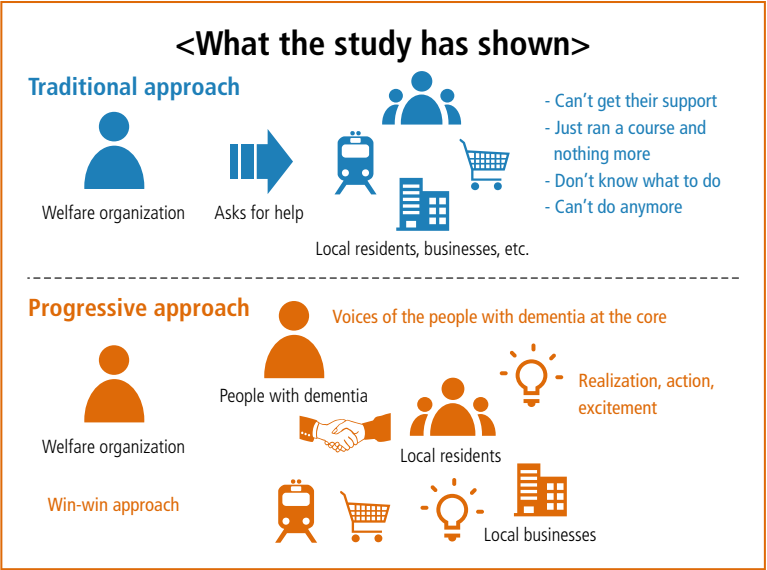
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6 tips to overcome issues in creating a dementia friendly community

Our study has uncovered some key concepts which are consistent across all community-building initiatives which are thriving across sector and generation. First, they fundamentally revolve around the voices of the people with dementia. When a social welfare group calls out for help, conflicting interests of the sectors and unchanging dynamic in the relationship which prohibits the initiative to continue or scale. But if the subject with the problem are thrown into the mix, suddenly the objective becomes clear and the sectors become more willing to go beyond their vested interest to from a constructive relationship. Secondly, it's the importance of building a win-win relationship. Majority of the issues with dementia requires cross-sector approach, including professionals and other stakeholders. They key to a successful and progressive initiative is to start by identifying the area where they can create a win-win relationship. With businesses, the key to a continued effort is to tie into the issues identified not by the CSR but the business divisions. Thirdly, it's realization, action, and excitement. The approach based on a correct medical understanding will lead to a hierarchy based on the knowledge level which may prevent behavioral change

and system improvement. Many of the initiatives which successfully engaged a wide range of stakeholders have built in some kind of interaction point with the people with dementia to allow action to kick off the process. Another extremely important aspect is that sense of excitement where people don't feel that it's an obligation but look forward to as it looks fun. Actually meeting people with dementia helps people to have a deeper understanding or realization and this is likely to lead to action.



Hints for the 6 Issues



Here are some of the important hints we've uncovered while studying the various initiatives across Japan.

If communities begin to learn from each other and resolve one issue at a time, it would surely accelerate the process to build a dementia friendly community across Japan.

- Issue 1** Difficult to drive action/ behavioral change

1. From knowledge to experience

 - Currently skewed towards classroom delivery of knowledge (medical knowledge to build correct understanding of the disease)
 - Importance of designing a structure to drive behavioral change from realization from the experience of doing something with people with dementia such as events, training or opportunity to meet and interact with people with dementia

► **Mock training(Omuta), cleaning program(Kamakura), Softball Tournament (Fujinomiya)**
- Issue 2** It works in a particular community but cannot be scaled to a greater society.

2. Civilian Platform

 - Need a platform that brings people running an initiative for a specific community with people who work in a larger region together to share their issues and collaborate.
 - Difficult for local government to take on this role due to their obligation towards equality and representation.

► **Fujinomiya Event Committee, Machida workshop, DAA(UK), etc.**
- Issue 3** Difficult to scale the initiative across the business sector.

3. Initiative by the Business Sector

 - Excluding small retailers, companies need top-down initiative
 - Manuals and program to drive behavioral change through work seminars

► **AEON company-wide policy, Dementia friendly Financial Service Charter(UK)**
- Issue 4** Difficult to sustain an active network

4. Start with people who can

 - Collaboration and platform developed as a formality will remain as just that due to the vested interests of the industries and divisions
 - Start with people, groups, division who can
 - Make the voice of the people with dementia the basis(as a way to resolve conflicting interests)

► **Fujinomiya Event Committee, Kyoto "I" Message, Omuta High Street**
- Issue 5** Difficult to incorporate the opinions/ needs of the people with dementia

5. Multiple Entry Points

 - Excluding small retailers, companies need top-down initiative
 - Manuals and program to drive behavioral change through work seminars

► **AEON company-wide policy, Dementia friendly Financial Service Charter(UK)**
- Issue 6** No evaluation due to lack of outcome indices.

6. Set outcome indices

 - Try to set at least one outcome index such as the kind of change did the initiative bring to the lives of people with dementia; not output index such as the number of dementia supporters.
 - No standardized method yet but mindset change can be expected by setting an outcome index.

► **Kyoto verification process**

Column The first step the sector can start with is...?

When you hear about some of the progressive initiatives, about the various stakeholders and friends they have engaged, the ideas, and the structures in place, some may feel overwhelmed and think this is not possible in my community.



But when you listen to the episodes about how it all began, it tends to be an individual with a sense of mission who encounters another similar individual from a different sector and gradually the story evolves. It's no wonder that people's reaction and intentions will vary given their position in the society whether you are in government, business, welfare, people with dementia and their families. The first step is to meet somebody to share your feelings and aspirations. What is your first step to create a dementia friendly community?

Dementia friendly Japan Summit 2014 - July 2014

200 people from various sectors took part in sharing their own ideas about how to solve the identified issues. Moving forward, we need a similar platform where people across sectors can come together to share the issues and drive action.