



Building a dementia friendly world

Showcasing
innovative
dementia-friendly
programmes



Building a dementia-friendly world

This booklet was compiled in preparation for the 'Building a Dementia-Friendly World' symposium co-hosted by Alzheimer's Society (UK) and WHO Kobe Centre at the 32nd Alzheimer's Disease International (ADI) Conference in April 2017. The pre-conference event showcased dementia-friendly initiatives from around the world and was an opportunity to inform the development of a WHO dementia-friendly toolkit. Thank you to the dementia-friendly programmes featured in this booklet for sharing their initiatives at the symposium, helping to inspire the growing global dementia-friendly movement.

The concept of 'dementia-friendly' is starting to capture the imagination of consumers, policy makers and researchers around the world and is recognised in national dementia policies and the Global Action Plan on Dementia under development. At one level the concept of dementia-friendly is simple – to work for the common goal of a better life for people with dementia and their families. But it is much more than this. The framework of dementia-friendly has the power to change the way we think about living with dementia.

Alzheimer's Society's dementia-friendly programmes in England and Wales

The rationale for our dementia-friendly initiatives comes from the voices and experiences of people living with and affected by dementia.

Alzheimer's Society's 2013 report 'Building dementia-friendly communities: A priority for everyone' revealed that 47% of people living with dementia in the UK did not feel a part of the community.

We believe people with dementia must have a new deal.

In 2012 Alzheimer's Society began the UK's first Dementia Friendly Communities programme and launched our national Dementia Friends programme.

We recognise a Dementia Friendly Community as being a city, town or village where people with dementia are understood, respected, and supported to contribute to community life. Everyone, from governments and doctors, to the local shop and hairdresser, all share part of the responsibility for ensuring that people with dementia feel understood and valued.

Every community which wishes to be 'working to become dementia-friendly' must go through a recognition process. They must meet a foundation criteria (which was established in line with direct feedback from people with dementia), focus on the areas for action outlined by the British Standards Institute (BSI) Code of practice for dementia-friendly communities, and submit an annual self-assessment. This ensures that all communities are working towards truly changing the things that matter to people living with dementia and their carers.

As of March 2017 there are over 225 Dementia Friendly Communities in England and Wales, and nearly 2 million Dementia Friends.

Life doesn't end when dementia begins, and together we can enable people living with dementia and their carers to carry on doing the things they enjoy and to have the same human rights as we all expect.

[Find out more at alzheimers.org.uk](http://alzheimers.org.uk)

'Communities can make a real difference to the lives of people like me, both now and in the future'

Lorraine Brown, person living with dementia.



Community action in Curridabat

Dementia is a public health priority in Costa Rica. The prevalence of dementia in the country is forecast to increase by 430% by 2050. Facing this dramatic increase, the national Alzheimer Plan of Costa Rica was launched in 2014. The plan was the first of its kind in Latin America and the very first of any low or middle income country in the world. Since the plan's launch, the Costa Rican Alzheimer's Association (ASCADA) has developed a series of actions to achieve the plan's aims on dementia, including building dementia-friendly communities.

To implement the ambitious goals of the national Alzheimer's Plan, ASCADA prioritised community action to inform and educate the population on dementia-friendliness. A highlight of their work is the ASCADA partnership with the city of Curridabat, population 80,000. Since June, 2015 ASCADA has worked closely with the city council to develop a range of high-profile activities to sensitise the community to dementia. Themed awareness-raising events, such as 'Run for your memories' marathons have brought together the city's inhabitants to understand the realities of living with or caring for someone with dementia.

In parallel, ASCADA trains all of the city's general practice doctors on early detection of dementia symptoms. This training includes being aware of the distinct needs of dementia care partners, ensuring that carers' requirements are met. To provide care partners with additional support, ASCADA is also building a Carer's Centre for peer-to-peer support and learning exchange to help build a dementia care partners network.

Curridabat's community action has raised dementia awareness in the city's population, particularly among health sector professionals and key political actors. The number of people attending awareness-raising activities such as the marathons has increased, as has the number of doctors specially trained on dementia detection and treatment. These dementia awareness activities, have led to more people than ever before being screened in the Curridabat community, resulting in higher rates of dementia diagnosis. For people with dementia this translates

as having more control over their own health and lives. Alongside the introduction of dementia-friendly initiatives, people with a dementia diagnosis in the city now also have more therapeutic options, such as cognitive stimulation, and a better choice of medical treatments.

Local political support matters

The community's focus on dementia has also clearly influenced the local authorities' decision-making process when it comes to implementing local projects. Many new construction schemes have started as a result of the city's dementia-friendly commitment, such as the Carer's Centre and a new specialist accommodation facility for those living with dementia. These successful developments demonstrate the far-reaching impact of building up a dementia-friendly community.

Lessons learned

Reflecting on Curridabat's dementia-friendly achievements, ASCADA notes the necessity of having a well-established and knowledgeable national Alzheimer Association to test dementia-friendly programmes over time. The team at ASCADA found that partnering with local government representatives was key to the Curridabat programme's success. They also learnt that maintaining close ties with official representatives after the project's implementation would have resulted in better follow up for dementia-friendly actions. Overall, ASCADA recommend that civil society organisations approach local officials with ready-made dementia-friendly solutions, rather than asking government or council members to provide answers.

With thanks to Dr Norbel Roman Garita, President, Costa Rican Alzheimer Association. For more information on this programme please visit ascadacr.wordpress.com



Case Study:
Costa Rica

Together Dementia Friendly

Like many countries, the Netherlands has an aging population. Out of 17 million people, 260,000 currently live with dementia. This number will double by 2040. However, as in other countries, dementia awareness needs to improve. 70% of people with dementia currently live in their own homes and the Dutch government aims to ensure they can continue to do so for as long as possible.

To make sure people with dementia and their care partners feel supported by society, in May 2016 the Dutch Ministry of Health, Welfare and Sports implemented a five-year programme 'Together Dementia Friendly'. The programme encourages dementia-friendly communities across the country and aims to raise awareness of dementia with at least one million people.

The programme does this by offering free online training courses for the general public and a range of tailor-made online courses for organisations. Course modules increase participants' knowledge and skills in recognising and supporting those living with dementia. By the end of 2017, 200 voluntary trainers will give training courses to companies and community groups. Alzheimer Nederland has produced media adverts to promote the programme and encourage the general public to take up dementia-friendly courses.

'Together Dementia Friendly' has increased awareness among the general public that everyone at some point will meet someone living with dementia. The television adverts and publicity in national and local media is significantly increasing public awareness and interest in dementia. Alzheimer Nederland assesses that due to their training courses many individuals and organisations are now more capable of understanding and supporting people with dementia appropriately.

Big companies have a big impact

Since the programme's launch there has also been a growing interest among large companies to join the dementia-friendly movement for their customers living with dementia. Big companies are having a big impact. The Netherlands' largest bus operator and biggest supermarket chain have trained their staff to recognise and help customers with dementia in a friendly and appropriate way. People living with dementia are supported to maintain their daily routine for longer, through dementia-friendly grocery shopping and accessible public transport. Care partners of people with dementia also feel more supported in their daily lives because of the growing awareness and help from the society they live in. The result is that care partners now talk more openly about their experiences of dementia, and social stigma is being eroded.

Lessons learned

Alzheimer Nederland strongly believes that creating awareness around dementia alone is not enough. Providing people with the tools and skills on how best to interact with someone living with dementia is also an important element of building dementia-friendly communities. By offering people this basic knowledge and skills everyone can actually make a difference in the lives of individuals living with dementia and their care partners. The dementia-friendly programme managers continuously adjust and optimise their working methods to ensure they are flexible enough to change their focus if a part of the project does not work out as planned.

With thanks to Iris Spanjers, Campaign Manager, Alzheimer Nederland. For more information on this project please visit samendementievriendelijk.nl



Case Study:
The Netherlands

Sahabat Demensia (Dementia Friends) programme

In 2015 the estimated number of people living with dementia in Indonesia was approximately 1.2 million. This number is expected to increase to 4 million by 2050. The economic cost of dementia for Indonesia is estimated to reach US\$ 2.2 billion per year by 2050.

The Sahabat Dementia (Dementia Friends) programme in Indonesia consists of educational sessions about dementia for multi-disciplinary professionals, family care partners and communities. The programme has so far been attended by a total of 11,566 participants. An adapted version of the Sahabat Demensia sessions are also given to social workers, health care specialists, nurses, psychologists and general practitioners as part of the 'Purple Troops' programme. 'Purple troops' are a volunteer team formed of a variety of health and social professionals who serve as first responders in cases of missing people who may be living with dementia.

New technology connecting families

The Jakarta local government also supports this initiative through its app (Qlue) which can be used to report missing people. Trained social workers identify if a located person may be living with dementia, and take the individual to the nearest primary care centre. Once at the care centre, a health check and dementia screening is arranged. Meanwhile, the Purple Troops work with the Provincial Social Welfare Office to connect the lost person to their family, using Qlue.

Many people and organisations in Indonesia are now requesting the Sahabat Demensia sessions. These sessions spread awareness of dementia, leading to behavioural change in local communities. Alzheimer's Indonesia reports that the quality of life is improving for people living with dementia, as the educational and informational sessions target everyone in society. Sahabat Demensia sessions are also resulting in a significant increase of people requesting dementia screenings, improving early detection rates.

This programme has had a deep impact on many of its participants. One Dementia Friend who participated in a session was inspired to use her knowledge of the traditional Indonesian dance, *poco poco* to become a dementia risk reduction specialist. The *poco poco* dance is the subject of a research study by an Indonesian psychiatrist, which found that the dance improves the quality of life for people with mild cognitive impairments. The Sahabat Demensia programme also played a significant role in work to establish Jakarta as the world's first dementia-friendly capital.

Lessons learned

Alzheimer's Indonesia believes that visibility and trust are key to building a dementia-friendly community. Evidence of this trust being built is shown by those living with dementia themselves starting to attend support groups, despite the existing social stigma around dementia in Indonesia.

Running the programme has taught its coordinators the importance of linking up all partners, including government, private sector, institutions, community leaders and school principals. The programme manager also recommends setting up an integrated system for data collection involving innovative technology and making full use of social media.

With thanks to Amalia Fonk Utomo, Alzheimer's Indonesia Country Manager. For more information on this project please visit alzi.or.id



Case Study:
Indonesia

Kyoto Bunkyo University project

Japan is an aging society and a fifth of the population (7 million people) are predicted to live with dementia by 2025. Japanese society is learning to live well with dementia and many communities around the country are already dementia-friendly.

In March 2016, the Uji Dementia Action Alliance (Lemon-aid) was formed in Uji, Kyoto. The Alliance coordinate dementia-friendly activities including tea picking, tennis and dementia cafés. Among these initiatives is the collaboration between Kyoto Bunkyo University (KBU) and people living with dementia. The KBU project focuses on intergenerational education, practice, and research into dementia.

The project is directed by working groups, consisting of individuals living with dementia, their care partners, students and supporters. These groups collaboratively design and implement dementia-friendly ideas, such as shopping support services. KBU also holds lectures by people living with dementia and their partners. The project hosts its own dementia café which is both run and enjoyed by those living with dementia and students.

A new generation of supporters

Feedback from participants living with dementia reveals that the KBU project improves and develops the social lives of people living with dementia and their families. Participants report feeling motivated by working with young people and are proud to have transmitted their knowledge to the younger generation. Importantly, the project increases

interaction and collaboration between people living with dementia and their supporters to jointly realise a dementia-friendly community.

The participating students' perceptions of dementia have been transformed by taking part in the project. Students have gone from having negative stereotypes of the condition to understanding the individualised nature of dementia. Students and supporters now have a much better, first hand, awareness of dementia, reducing negative labels around the condition.

In addition, KBU is forming a new generation of dementia supporters and advocates. For instance, two ex-university lecturers gave talks on their experiences of living with dementia as part of the project. Participating students were so moved by their stories that they themselves went on to address conferences about their experiences of collaborating with those living with dementia.

Lessons learned

Reflecting on the KBU project, coordinators believe that it could be improved by people living with dementia participating earlier in the planning stages. They are refining the style and process of group meetings including more face-to-face participation in the working groups.

The KBU project highlights that to realise a dementia-friendly community, people from different fields and generations need to collaborate, while always focusing on those living with dementia. KBU members see individualised, grass-roots programmes, rooted in each community as the most effective way to achieve dementia-friendly success. They also note the importance of exchanging international knowledge and learnings to build up a dementia-friendly world.

With thanks to Kazuyuki Hirao, Professor/Psychiatrist/Clinical Psychologist, Kyoto Bunkyo University; Alzheimer's Association Japan. For more information on this project please visit ujilemonaid.com



Case Study:
Japan

Dementia Friendly Kiama project

Dementia is the second most common cause of death in Australia, yet it is poorly understood and largely ignored by most of the population. In response, many communities are interested in becoming 'dementia-friendly'. The Dementia Friendly Kiama project in New South Wales is the first Australian dementia-friendly programme to actively involve people living with dementia in all aspects of the process.

The Kiama project raises awareness of the impact of dementia on individuals and addresses the environmental factors that pose challenges to people living with dementia. People with a diagnosis of dementia and their care partners lead the Kiama project, alongside local council representatives, members of the University of Wollongong and interested stakeholders. The composition of Kiama membership ensures that the voices, opinions and needs of people living with dementia are central to the project. Kiama's unique structure empowers those living with dementia and their supporters to proactively steer dementia-friendly actions, rather than professionals representing the wishes of those directly affected by the condition.

Through Kiama's work traditional stigmas are being challenged and overturned. There is now increased awareness and acceptance of dementia in the local community. A University of Wollongong study reveals that approximately 10% of the total local population has attended an awareness training session or project presentation. The study also demonstrated that since taking part in the Kiama project, members of the local community are now more positive towards people living with dementia.

Valued contributors, not tokens

Most importantly, those with dementia report experiencing 'better social acceptance' and find it easier to maintain community connections. Some care partners report that their role has become easier as both those they support and they themselves are better understood by the community. 'Third party' supporters now are proud to stand up and advocate for people living with dementia, and the Kiama model is even inspiring other initiatives to actively involve people with dementia as valued contributors and partners in the programmes, 'not just tokens'.

After his diagnosis at 59, Dennis began to retreat from interaction with his wider community, partly because of the changes in his own life but mainly because of the silent stigmas and invisible hurdles that society put up around him. After being involved in the Dementia Friendly Kiama project he found interactions within the community far easier and more rewarding. He now feels much more part of the local community than ever before, after thirty years of living in the area. Today, he knows that he has the support he needs to confront stigma about dementia and overturn many of the invisible barriers. Dennis is chair of the Dementia Advisory Group that is central to the project.

Lessons learned

The Kiama project's success highlights that sustained positive change on dementia needs to come from the community itself. Awareness, education and exposure to people living with dementia are the best tools to create a dementia-friendly programme. Ensuring meaningful involvement of people with dementia in all aspects of any programme from inception, through execution, to ongoing roles in the everyday fabric of a community is the simplest and most credible way to achieve a dementia-friendly community.

Project members advise those creating their own dementia-friendly initiatives to 'not be afraid to make mistakes, they will learn more from what didn't work than what did work. Indeed, these diversions strengthen dementia-friendly projects.'

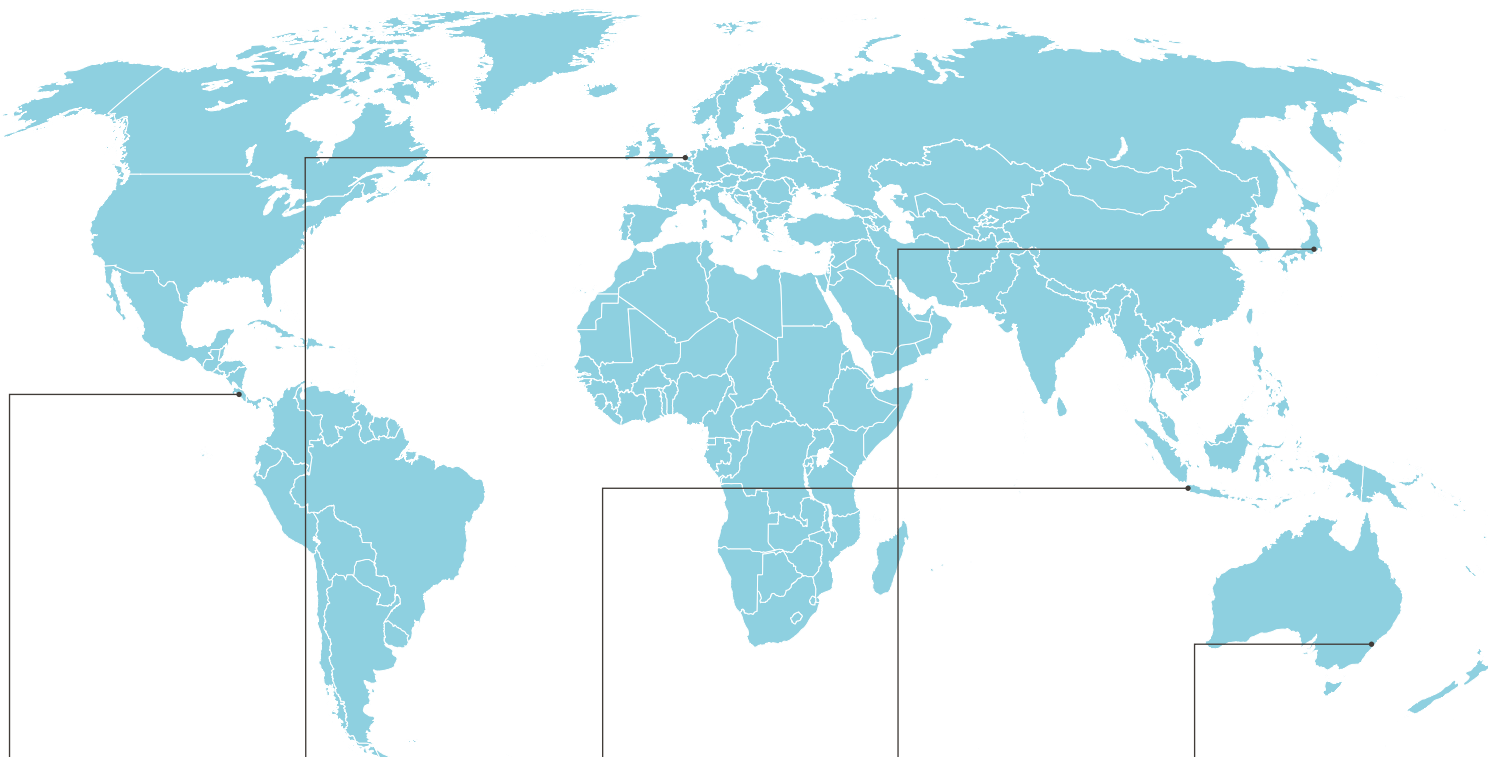
With thanks to Dennis Frost, Chairman, Dementia Advisory Group, Dementia Friendly Kiama Project. For more information on this project please visit kiama.nsw.gov.au



Case Study:
Australia

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Showcasing innovative dementia-friendly programmes



**Community action
in Curridabat**
Costa Rica



**Together
Dementia Friendly**
The Netherlands



**Sahabat Demensia
(Dementia Friends)
programme**
Indonesia



**Kyoto Bunkyo
University project**
Japan



**Dementia Friendly
Kiama project**
Australia

This booklet showcases the five innovative dementia-friendly programmes featured in the April 2017 Building a Dementia-Friendly World Symposium, part of ADI 2017 in Kyoto, Japan

About Alzheimer's Society

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website and more than 2000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

At Alzheimer's Society we're committed to supporting countries to develop dementia-friendly initiatives by sharing our experience, as well as collaborating with other international partners on research and campaigning to help tackle the global dementia challenge.

For more information about dementia and the support available, visit alzheimers.org.uk

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