

Towards a dementia- inclusive society:

a WHO toolkit for
dementia-friendly initiatives

EXECUTIVE SUMMARY





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Dementia affects every aspect of a person's life. In the early stages a patient may experience loss of memory that causes them to forget how to perform even simple day-to-day tasks, such as taking a shower, cooking or cleaning. As the illness progresses, the person living with it may become more dependent on others.

Yet, as challenging as it may be to live with dementia, stigma and discrimination make it worse. Stigma heightens the already significant psychological, social, emotional and financial impacts that dementia has on individuals, their carers, families and communities. It also exposes people with dementia to increased threats of human rights violations in their own communities. It is not uncommon for people with dementia to experience physical and emotional abuse, social isolation or loss of dignity.

There is a need to raise public awareness and improve understanding of dementia by engaging communities and helping them assume ownership of this endeavor. This is the first step in combating stigma. Dementia awareness and friendliness feature prominently in the Global Action Plan on the Public Health Response to Dementia 2017-2025¹, adopted in May 2017 by the Seventieth World Health Assembly. WHO is committed to helping individuals and communities empower people with dementia to remain in, and be a significant part of, society. It is for this reason that WHO developed *Towards a dementia-inclusive society: a WHO toolkit for dementia-friendly initiatives*.

¹ For additional information, see: https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/



A look inside the toolkit

About this toolkit

The toolkit provides individuals working in communities with a practical guide and tools that can support efforts, including planning and implementation activities, to create dementia-inclusive societies. The toolkit is tailored towards the needs of non-expert programme planners, managers, implementers and/or evaluators. It is designed as a facilitation tool for team members, partners and stakeholders working in group settings.

The toolkit is divided into two parts:

- Part I contains introductory information on dementia and on the toolkit, and includes a conceptual framework.
- Part II is an implementation manual comprising four modules that are directly linked to the conceptual framework. Each module features a series of practical steps and exercises. The modules can be used together or separately and they offer guidance, which can be adapted to suit local needs and settings.

What is dementia inclusiveness and friendliness?

Around the world, local communities are coming together to fight stigma and discrimination and meaningfully include people with dementia and their families in society. Different terms have been used to refer to these efforts, including dementia-capable communities, memory-friendly communities, living well with dementia in the community, sustainable environments for people living with dementia, dementia-sensitive living environment, and a society conscientious of and friendly toward neurocognitive disease.

For ease of communication in this document we use the term, “dementia-inclusive society” to refer to the kind of society to strive for, where everyone, including people with dementia, has a place. By “dementia-friendly initiatives” (DFIs) we mean the activities being undertaken to make society more inclusive of people with dementia. Examples of DFIs include, but are by no means limited to, showing 45-second films about dementia at supermarket queues, establishing mechanisms to enable people with dementia to vote in elections and educating children about dementia.

The framework

The DFI framework draws on a Theory of Change model. It provides a step-by-step template for carrying out, integrating, evaluating and scaling initiatives that are adaptable to local contexts, cultural norms, community practices and population needs. More specifically, the framework provides a structured process that guides users to start their own initiatives by identifying a vision and subsequently leads to translate it into actionable steps. Among other things, users learn to choose primary focus areas for their vision. In other words, they learn to decide whether they require changes to their social environment, built environment, or both to achieve their vision. Once they have selected their focus areas, users rely on the framework to help them determine which activities to implement for each group targeted by the initiative in order to achieve the stated vision. Target groups are the individuals, or groups of individuals, who stand to benefit from the DFI and its activities.

The framework is presented on the right.



Vision

IMPACT

MONITORING & EVALUATION

Implementation & scaling

Key principles

Target groups

Activities/ actions

Primary Focus

Examples of target groups may include:

Examples of activities and actions include:

A dementia inclusive society

is one where people with dementia and their carers experience no stigma and discrimination and fully enjoy participation, inclusion, empowerment, respect, dignity, equality, freedom, accessibility, independent living, and quality of life.

General population

Volunteers

School children

Participation

Awareness raising campaigns

Training/ capacity building

Civic/socio-cultural participation

Social Environment



Physical Environment



Remove barriers/ improve accessibility

Enhance transportation system

Improve affordable & enabling housing

Improve safety

City planners

Bus & taxi drivers

Community workers

Sustainability

Traditional healers

First responders, police force

Leadership

Use of enabling technology

Dementia-friendly businesses and services

Shop owners

Bank employees

Hospitality staff

Pharmacists

Public civil servants

Collaboration

Religious leaders



Module A: **developing a new DFI**

Module A offers practical guidance and tools to start a new DFI. Firstly, Module A uses a series of guided steps and exercises to help users identify stakeholders and partners, as well a coordination team that will oversee and manage the initiative. Secondly, it helps users gather the information necessary to identify the most pressing issues that the DFI will address and to define a vision for the initiative. Thirdly, module A provides exercises on how to set goals and outcomes, to help users identify focus areas. Lastly, it guides users in translating goals and expected outcomes into specific activities and developing a risk- and resource-management plan.

Module B: **integrating dementia into an existing initiative**

Module B offers practical guidance and tools to integrate dementia into an existing, initiative. Working with a series of guided steps and exercises, Module B firstly helps users identify stakeholders and partners, as well as a coordination team to oversee and manage the integration. Secondly, it helps users gather the information necessary to make an inventory of relevant existing initiatives. It also enables users to pick the most pressing issues that they will address by integrating dementia into an existing initiative. Users together with partners and stakeholders can then draw up their vision for the integration. Thirdly, Module B prepares users to jointly define their goals and expected outcomes – in other words their focus areas. Fourthly, users receive guidance to translate their goals and expected outcomes into specific activities so as to achieve the joint vision. Lastly, users learn how to develop a risk- and resource-management plan.



Module C: monitoring and evaluation (M&E)

Monitoring and evaluation (M&E) ensures that every step in the theory of change model has been achieved. Module C offers a series of exercises and tools that enable users to decide what type of evaluation best suits their initiatives and then develop a logic model. A logic model is based on the theory of change model, which is the cornerstone of the DFI framework. The logic model illustrates how resources (inputs) make it possible to carry out DFI activities, which in turn produce results (outputs and outcomes) and move the DFI towards achieving its stated vision (impact). Module C also guides users in formulating evaluation questions and indicators. Evaluation questions specify what the evaluation will measure. Evaluation indicators on the other hand specify what information and data to collect so as to answer the evaluation questions.

Module D: scaling up DFIs

Scaling up an existing DFI is an effective way of spreading good practices and lessons learned from one geographical location or target group to another. With the help of practical tips, checklists and exercises, Module D assists users in selecting a DFI for scale-up, ensuring that it fulfils the four key principles (participation, collaboration, coordination and sustainability) included in the DFI framework. The module also helps users identify the appropriate type of scale-up and develop a vision, focus areas and goals. Finally, Module D helps users plan and implement activities, including expanding DFIs to new locations, to achieve the vision, as well as develop a risk- and resource-management plan.



CONCLUSION

With its solid theoretical basis, practical guidance and exercises, the toolkit is a valuable resource that will enhance the skills and knowledge of individuals working within communities to build dementia-inclusive societies. By providing M&E guidelines, the toolkit fills a big gap and helps build capacity as well as generate new evidence to support the implementation of DFIs. The toolkit is person-centred, rights-based and focused on raising public awareness of dementia. It will support communities in their efforts to achieve the vision of the Global Action Plan on the Public Health Response to Dementia 2017–2025. The specific goal of DFIs is to help bring about lasting changes to the social and/or physical environment. DFIs, therefore, need to work towards a society that includes and empowers people with dementia, as well as older people in general and people with other disabilities, rather than one that segregates them. For this reason, DFIs draw on the strengths of people with dementia, their carers and families, provided that appropriate support is in place to enable them to participate fully in society and the economy.

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