

Towards a dementia- inclusive society

WHO toolkit
for dementia-friendly
initiatives (DFIs)



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Foreword

An estimated 50 million people live with dementia worldwide, 60% of whom in low- and middle-income countries. With approximately 10 million people diagnosed with dementia every year, dementia is projected to affect 152 million by 2050. Dementia has a profound impact on every aspect of a person's life and there continues to be much stigma and discrimination against people with dementia. Stigma exacerbates the already significant psychological, social, emotional and financial impacts of the disease - effects that have been amplified in light of the ongoing COVID-19 pandemic. Stigma also increases the likelihood of human rights violations in communities where people with dementia live.

To address dementia as a global challenge, the Seventieth World Health Assembly adopted the Global Action Plan on the Public Health Response to Dementia 2017-2025 (1) in May 2017. The action plan represents an international commitment to improving the lives of people with dementia, their carers, and families. It includes seven action areas: dementia as a public health priority; dementia awareness and friendliness; dementia risk reduction; dementia treatment, care, and support; support for dementia carers; information systems for dementia; and dementia research and innovation. The action area focusing on dementia awareness and friendliness

specifically aims to improve communities' understanding of dementia and create dementia-inclusive societies where people with dementia can live meaningfully, safely and with dignity. Understanding the unique and multifaceted needs of people with dementia and their carers is particularly important within the context of COVID-19.

WHO developed *Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives* to support individuals, communities and countries in empowering people with dementia to remain in, and be a significant part of, their community. The toolkit's person-centered, rights-based approach is grounded in international commitments such as the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs) and Universal Health Coverage (UHC) (2)(3)(4). The toolkit can be easily and effectively implemented by communities worldwide to raise awareness of dementia and improve the lives of those affected by the disease.

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Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities (United Nations)
DFI	dementia-friendly initiative
LMICs	low- and middle-income countries
M&E	monitoring and evaluation
NCDs	noncommunicable diseases
NGO	nongovernmental organization
SDGs	Sustainable Development Goals
UN	United Nations
WHO	World Health Organization

Glossary

Activity: For the purpose of this toolkit, an activity refers to any action that promotes lasting change to the social and/or physical environment to help build dementia-inclusive societies.

Carer/caregiver: A person who provides care and support to a person with dementia. Such support may include:

- Helping with self-care, household tasks, mobility, social participation and meaningful activities.
- Offering information, advice and emotional support, as well as engaging in advocacy, providing support for decision-making and peer support, and helping with advance care planning.
- Offering respite services.
- Engaging in activities to foster intrinsic capacity.

Carers/caregivers may include relatives or extended family members as well as close friends, neighbours and paid lay persons or volunteers.

Civil society: Refers to the wide array of nongovernmental and not-for-profit organizations that have a presence in public life, expressing the interests and values of their members or others, based on ethical, cultural, political, scientific, religious or philanthropic considerations. Civil society is the “third” sector of society, along with government and business (31).

Community: A group of people unified by common interests or characteristics living together within a larger society.

Convention: A formal agreement between country leaders, politicians, and states on common matters, e.g. human rights.

Coordination: Refers to the guidance and direction provided through a governance mechanism, such as a coordinating team, in implementing, integrating, evaluating and/or scaling-up a DFI.

Coordinating team: A team of individuals, organizations and/or partners responsible for the oversight, management and coordination involved in developing a new DFI, integrating dementia into an existing initiative, monitoring and evaluating a DFI and/or scaling-up a DFI.

Dementia: Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain, such as motor neurone diseases, Prion disease, Parkinson’s disease and related disorders, Huntington’s disease, spinocerebellar ataxia, and spinal muscular atrophy. The following International Classification of Diseases (ICD) codes relate to dementia – ICD-9: 290, 330–331; ICD-9 BTO: B222, B210; ICD-10: F01, F02, F03, G30–G31.

Dementia-friendly initiative (DFI): The activities being undertaken to make society more inclusive of people with dementia.

Dementia-inclusive society: A society in which people with dementia and their carers fully participate in society and have a place in it. It is a society where they enjoy respect, freedom, dignity, equality, accessibility and quality of life. It is one where they are empowered to live independently, free from stigma, discrimination, exploitation, violence or abuse.

Disability: The UN CRPD recognizes disability as “an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (2)

Discrimination: Unfair treatment or negative behaviour towards a person or group of people. The UN CRPD defines discrimination on the basis of disability as “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil

Evaluation: The process of tracking key outcomes and impacts related to the different elements of the DFI and its associated activities, and assessing whether the vision and expected outcomes are being achieved. Information gathered through an evaluation can be used to guide future planning, budgeting and scaling activities.

Evaluation indicators: Help determine what information and data to collect so as to answer the evaluation questions (see Evaluation question). Evaluation indicators will vary based on the type of evaluation selected.

Evaluation question: Specifies what will be measured through the evaluation. Evaluation questions vary based on the type of evaluation selected.

Financial resources: see Resources.

Habilitation: Refers to enabling people with disability to attain, keep or improve skills and functioning for daily living; services include physical, occupational and speech-language therapy, pain management treatments, audiology and other services offered in hospital and outpatient settings (RI Global, see: <http://www.riglobal.org/>)

through a variety of activities that intend to improve health.

Health care provider: A professional providing health care to people, including health advice and disease prevention, promotion and treatment; and who implements care, treatment and referral plans. They have completed formal training in medicine, or a related health care discipline, at a recognized, university-level school for a diploma or degree, or have acquired extensive on-the-job training.

Human resources: see Resources.

Human rights of people with dementia: Action related to the following issues to ensure the protection of a person’s human rights: least restrictive care, informed consent to treatment, confidentiality, avoidance of restraint and seclusion when possible, voluntary and involuntary admission and treatment procedures, discharge procedures, complaints and appeals processes, protection from abuse by staff, and protection of user property. In the context of dementia, this means human rights for people with dementia include a comprehensive approach including the full spectrum of civil, political, economic, social and cultural rights.

Human rights violation: When a country fails in its obligations to ensure that the economic, social and cultural rights of people, including people with dementia, are enjoyed without discrimination or in its obligation to respect, protect and fulfil them. Often a violation of one of the rights is linked to a violation of other rights (10).

Impact: The last step in a logic model; in this context, refers to the achievement of, or movement towards, the DFI’s stated vision, following an action or sequence of actions taken as part of the DFI, or associated activities.

Implementation: The process of putting a decision or plan into effect.

Input: The first step in a logic model; refers to activities, sets of interventions and/or resources that produce a series of results (i.e. outputs and outcomes).

Key principles: A set of precepts or values that guide the creation of a dementia-inclusive society, including the development of a new DFI, integration of dementia into an existing initiative, monitoring and evaluating a DFI and/or scaling-up a DFI. For the purpose of this toolkit, there are four key principles: participation, collaboration, coordination and sustainability.

Law/laws: A rule or set of rules, which have been enacted by the governing bodies in a country. For the purpose of this toolkit, laws refer to rules that apply to people with dementia, persons with disabilities, older people and/or the population as a whole and typically focus on issues such as civil and human rights protection.

Leadership: In this context, refers to the action of leading a group of people or organizations through the process of developing a new DFI, integrating dementia into an existing initiative, monitoring and evaluating a DFI and/or scaling-up a DFI and associated activities. In the case of this toolkit, the leadership

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