



TOOLKIT FOR COMMUNITY WORKERS IN LOW- AND MIDDLE-INCOME COUNTRIES

Guide for community-based management and care of people with dementia

DEMENTIA

TOOLKIT FOR COMMUNITY WORKERS IN LOW- AND MIDDLE-INCOME COUNTRIES:

Guide for community-based management and care of people with dementia

Version 1.0

Mental Health and Substance Abuse Division of NCD and Health through the Life-Course World Health Organization Regional Office for the Western Pacific

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Supervision and Guidance

Dr Susan Mercado

Project Coordination

Dr Hai-Rim Shin, Dr Baifang Xiao Sobel

Technical Contribution

Dr Baifang Xiao Sobel, Dr Heewoo Lee, Dr Jason Ligot, Dr Ma Carmela Mijares-Majini, Mr Kelvin Chuan Heng Khow, Mr Martin Vandendyck

Pilot testing of the dementia toolkit was organized in China by Dr Huali Wang of Peking University and in the Philippines by Dr Shelley de la Vega of University of the Philippines

Technical Guidance and Review

Dr Shelley de la Vega, Professor, College of Medicine; Director, Institute on Aging, National Institutes of Health - University of the Philippines, Manila, Philippines

Dr Hiroto Ito, Director, Department of Social Psychiatry, National Institute of Mental Health, National Center of Neurology and Psychiatry, Japan

Dr Heewoo Lee, Managing Director, Public Health Service Team, Seoul Medical Center, Republic of Korea (research literature review)

Dr Huali Wang, Director, Dementia Care and Research Center, Institute of Mental Health, Peking University Sixth Hospital, China

Additional Technical Support and Review

Dr Tarun Dua, Coordinator, Evidence, Research, Action on Mental and Brain Disorders, Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

Dr Katrin Seeher, Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

Dr Anne Margriet Pot, Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

Dr Neerja Chowdhary, Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

Ms Stéfanie Fréel, Global Dementia Team, Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

Dr Sudhir Kumar, Coordinator, Working Group for Developing National DFC Criteria in India, Cochin, India

Dr Thien Kieu Thi Phung, Senior Researcher, Danish Dementia Research Centre, University of Copenhagen, Denmark

Writing and Editing

Dr Baifang Xiao Sobel, Ms Charlotte Kuo-Benitez

Administrative Support

Mr Jed Cyrus Yparraguirre, Ms Lee Anne Esguerra

Financial Support

Government of Japan

Production

Layout artist: Clarissa Ines

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INTRODUCTION

The number of people living with dementia is growing rapidly. The estimated proportion of the general population aged 60 and over with dementia at any given time is 5–8% (1). Worldwide, 47 million people were estimated to have dementia in 2015 and nearly 60% of them lived in low- and middle-income countries (1). In China and Japan alone, around 12.6 million people were estimated to suffer from the disease in 2015 (2).

Dementia is a major cause of disability and dependency among older people, affecting individuals, families, communities and societies (1). It accounts for 11.9% of the years lived with disability due to a noncommunicable disease (3).

Dementia is not a normal part of ageing. People with dementia often live for many years after their symptoms begin, requiring long-term care and support. Dementia can therefore be overwhelming not only for those who have it, but also for their carers and families. When resources are limited, especially in low- and middle-income countries, delegating dementia-related tasks and responsibilities to community workers can improve the quality of life of people with dementia and that of their carers.

A. Dementia as a public health priority

To address the prevalence and disease burden of dementia, the World Health Assembly endorsed the Global Action Plan on the Public Health Response to Dementia 2017–2025 in May 2017 (4), outlining seven action areas that countries can take to reduce the risk of developing dementia and ensure people with dementia live with respect, dignity and autonomy.

In WHO's Mental Health Gap Action Programme (mhGAP), dementia is identified as one of the priority conditions, particularly in low- and middle-income countries (1,5). Within this programme, evidence-based guidelines have been developed for the management of dementia by non-specialists, with a goal of scaling up treatment and reducing the treatment gap (6). Primary health care workers may receive dementia training through mhGAP.

There are gaps not only in the prevention, detection, treatment and management of dementia, but also in awareness and understanding of dementia (4,7). People with dementia should be treated with compassion and respect. Awareness and advocacy are needed to improve our understanding of dementia across all of society, and to reduce the stigma attached to dementia.

Once individuals with dementia have been identified, it is important to coordinate ongoing health and social care services to ensure that they and their carers can maintain their quality of life. Management should apply throughout the journey of dementia care from diagnosis to palliative (end-of-life) care.

B. Human rights, gender equity and intergenerational bond

Approaches to treatment and care of people with dementia should be anchored in the principles of empathy, compassion and respect.

Human rights:

People with dementia should be treated with respect and dignity (1). In some countries, people with dementia face discrimination, abuse and neglect. Some may not have access to mental health care services, while others may be ignored or locked up in their own homes by family members. In extreme cases, some may be restrained through the use of force or drugs, even when doing so may be against the law and a violation of their rights. People with dementia are entitled to their economic, political and social rights, as well as their freedom (4). All programmes, interventions and access to treatment should be sensitive to the needs, expectations and human rights of people with dementia and that of their carers.

Gender equity:

Gender equity refers to the concept of being fair and impartial to women and men, taking into account the different needs, preferences, experiences and interests of women and men (8). The objective of gender equity is to reduce unjust and avoidable inequality between the two genders and to ensure equal opportunity for both. In general, more women than men develop dementia (7,9–13) and are carers of people with dementia (9). It is important that any treatment and care given to people with dementia take into account gender differences. Carers must be given the support and assistance they need to both take care of people with dementia and take care of their own well-being. All efforts to implement public health responses to dementia must be gender-sensitive.

Intergenerational bond:

Intergenerational bond refers to the relationship between different generations, including grandparents and grandchildren. Positive interactions and joint activities can benefit younger and older people within the same family or community. Older people can impart knowledge, personal and family history, and cultural norms and practices to younger generations, and serve as role models. Younger people can share modern technologies and contemporary art and music so that older people do not feel "left behind". These intergenerational bonds lead to feelings of warmth, affection and mutual respect.

C. What is healthy ageing?

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