World Health Organization
Western Pacific Region

DEMENTIA

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

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

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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

© World Health Organization 2018

ISBN 978 92 9061 844 7

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Suggested citation. Dementia toolkit for community workers in low-and middle-income countries: guide for community-based management and care of people with dementia. Manila, Philippines. World Health Organization Regional Office for the Western Pacific. 2018. Licence: CC BY-NC-SA 3.0 IGO.

Cataloguing-in-Publication (CIP) data. 1. Dementia. 2. Primary health care. 3. Teaching materials. I. World Health Organization Regional Office for the Western Pacific. (NLM Classification: WM220)

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I

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?

Signs and symptoms of dementia are often misunderstood as a normal part of ageing. However, while age is the strongest known risk factor for developing dementia, dementia is not a normal part of ageing (*1*).

The term *healthy ageing* refers to the functional ability that enables well-being in older age (*14*). As individuals age, they may undergo physical, mental or psychological changes that affect their abilities and capacities; however, it is possible for older people to continue to experience the aspects of life that are valuable to them, and to enjoy happiness, satisfaction and fulfilment.

Some things that older people identify as being important to them include:

- independence and autonomy;
- sense of identity and role in their community;
- sense of belonging;
- feeling safe;
- being respected; and
- having potential for personal growth.

As people age, they may experience loss of autonomy or feel that they are no longer able to contribute positively in their communities, or that they are no longer respected. These feelings may become even more acute for people with dementia and increase as their disease progresses. Their families, carers and other social supports should be sensitive to these issues.

D. WHO principal goals for dementia care

Although there is currently no treatment available to cure dementia or alter its progressive course (*1,15*), much can be offered to support and improve the lives of people with dementia, their carers and families, through improving dementia care, management and support. The principal goals for dementia care are:

- early diagnosis in order to promote early and optimal management;
- optimizing physical health, cognition, activity and well-being;
- identifying and treating accompanying physical illness;
- detecting and treating changes in mood and behaviour; and
- providing information and long-term support to carers.

II

ABOUT THE TOOLKIT

A. Who is the toolkit for?

This toolkit is intended for anyone who works in the community and has at least a secondary level of education. It complements the mhGAP intervention guide for primary health care professionals.

B. What is the purpose of this toolkit?

This toolkit aims to help community workers gain skills and build capacity in: (a) identifying people at risk for dementia and making referrals when necessary; (b) providing support to people with dementia, their families and carers; and (c) engaging local communities in dementia-related activities and contributing to the development of dementia-friendly communities in low- and middle-income countries.

Community workers are people who provide services to or for the benefit of community members, ranging from community health workers, social workers, community rehabilitation workers and volunteers to anyone working at community centres and facilities.

C. What are the components of the dementia toolkit?

This dementia toolkit includes the following:

- community resource checklist
- screening and detection tools
- tools for dementia management and care
- list of dementia prevention and promotion activities
- monitoring and evaluation tools
- pocket guide for carers.

D. How do I use this toolkit?

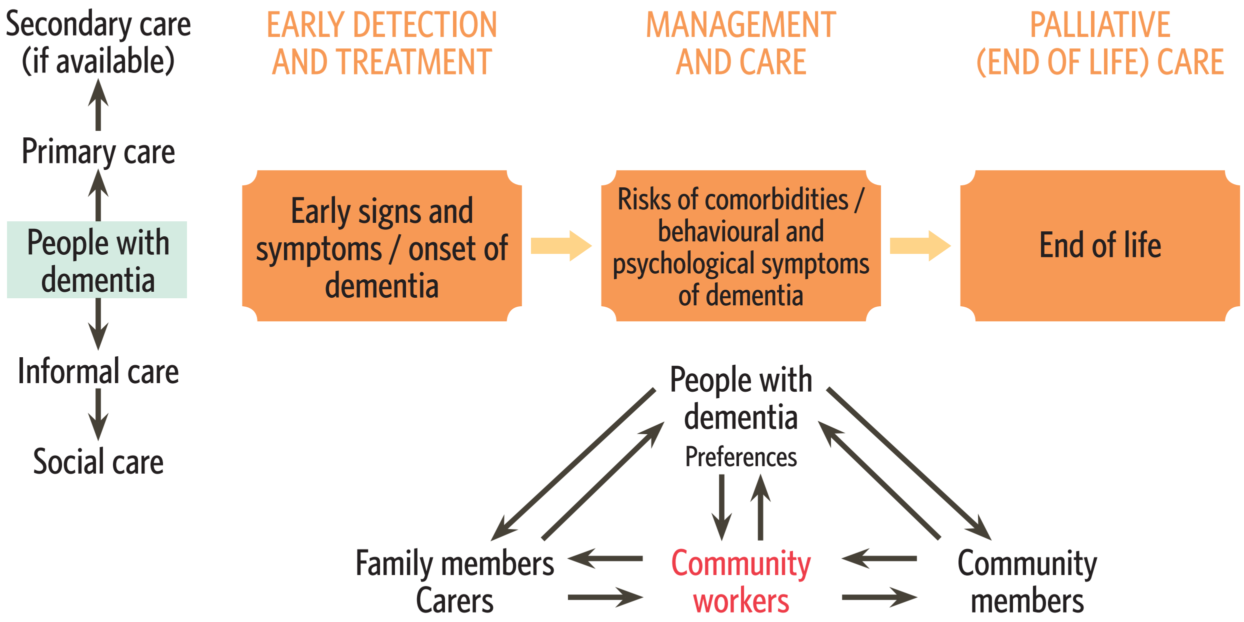
First, realize that as a community worker, you may be the first person a family seeks out for help when they have concerns about an elderly relative. You may therefore be in a position to observe and assess dementia symptoms in somebody in your community. This toolkit will tell you how to:

- detect the signs and symptoms that indicate dementia;
- provide care and make referrals for a person with dementia;
- give support to carers and family members of people with dementia; and
- engage others in the community in achieving a dementia-friendly community.

Dementia management and care diagram for community workers:
The following diagram, provided through expert consultation, shows the role of community workers in the journey of dementia management and care from early detection, through treatment, to the end of life. Care of people with dementia can be provided by primary and secondary health care professionals and by non-professionals at the community level (i.e. social and informal care). After training in the use of this toolkit, community workers will be able to mobilize community resources, engage members of their community, provide early detection and management, and support people with dementia, their families and carers.

What can community workers do?

Overview



Components

Needs assessment
1. Situational analyses; include awareness on dementia
2. Be aware of common physical and mental disorders in older people
3. Determine population of older people in the community
4. Resource mapping

Community engagement
1. Organize community support for healthy ageing and dementia

Early detection and management
1. Detect signs and symptoms that require referral to a primary health care physician/nurse/midwife with special attention on dementia
2. Manage and care for people with dementia
3. What to do with comorbidities

Support people with dementia/family members
1. Support self-care for healthy ageing
2. Be able to talk to people with dementia and their families and make referral
3. Support family and carers
4. Self-care

III

ABOUT MY COMMUNITY

A. What is the role of communities?

A person's quality of life is influenced by a sense of their self-worth, which includes feeling connected to their community. However, because of the stigma attached to dementia, people with dementia may feel they are a burden to their communities. They may choose to isolate themselves, causing their quality of life to suffer and health issues to worsen.

The cost of caring for people with dementia is high. Besides the medical costs, there are other costs in terms of lost productivity of the individual and their carers. In low- and middle-income countries, carers are often family members who may have stopped working or attending school to care for a relative with dementia.

The community can support people with dementia, their families and their carers by ensuring that a range of health and social care services is available, and that their physical and social environments enable them to participate in community life for as long as possible. Having community support in place for people with dementia can be therapeutic in and of itself. People with dementia will feel welcomed, listened to and respected, which can improve their overall health. This in turn can reduce the risk of developing other health issues or even delay the need for institutional care. Enhancing quality of life for the increasing numbers of adults with dementia can thus lower overall costs for people with dementia, their families and carers, and the community as a whole.

B. What resources are available in my community?

Local community resources, programmes and services for dementia may be available in or near your area. These could include professional associations, organizations from different sectors, local partnerships and support groups. Valuable resources may span all aspects of dementia care, such as clinics with health practitioners who can manage dementia, adult day care centres, home care services, hospice care, volunteer groups, charitable foundations, and legal and transportation services.

Prepare a directory or list of resources and services and share this with people with dementia and their carers. You can use the **Checklist for Community Information and Resources (Appendix I)** as a guide to help you identify all the available and relevant resources in your area.

C. What are common physical and mental conditions among older people?

Besides dementia, it is common for older people to also suffer from a number of physical and other mental conditions that may affect their overall health. Some common conditions are listed below (see **Glossary of Terms** for details).

- Anxiety disorder
- Chronic obstructive pulmonary disease
- Depression
- Diabetes
- Dyslipidaemia
- Heart disease
- Hypertension
- Musculoskeletal disorders
- Obesity
- Stroke
- Visual impairment/hearing loss.

D. What are the common beliefs and misconceptions about dementia?

Common beliefs influence people's decisions about whether and when to seek help, treatment and care. Some common misconceptions are (*16*):

- Everyone develops dementia when they get older.
- Dementia is curable.
- There is nothing people can do to prevent dementia.
- People with dementia cannot continue to live with their families.
- People with dementia should be treated like children.
- Because people with dementia do not have the ability to judge, they do not have to be given explanations about decisions made for them.

IV

UNDERSTANDING DEMENTIA

A. What is dementia?

Dementia is a chronic and progressively debilitating syndrome. People with dementia show deterioration in cognitive functions beyond what might be expected from normal ageing. Dementia affects memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. It is caused by a variety of diseases and injuries that primarily or secondarily affect the brain. Alzheimer's disease is the most common form of dementia, accounting for 60–70% cases of dementia (*1*). Vascular dementia is the second most common form, accounting for 10% of dementia cases (*17*). Please see the **Glossary of Terms** for a detailed description.

Signs and symptoms of dementia can be subtle, especially in the early stages. Individuals with dementia may experience one or more of these signs to different degrees. **Table 1** lists some examples of the behaviours one might notice in people with dementia.

Three stages of dementia

Dementia affects each person in a different way, depending on the impact of the disease and the person's personality before becoming ill. Dementia progresses in three stages.

Early Stage

It is often overlooked because the onset is gradual. Common symptoms are:

- mild forgetfulness
- losing track of time
- becoming lost in familiar places.

Middle Stage

Signs and symptoms become more obvious and more restricting. Common symptoms are:

- becoming forgetful of recent events and people's names
- becoming lost at home
- having increasing difficulty with communication
- needing help with personal care
- experiencing behavioural changes, including wandering and repeated questioning.

Late Stage

The person is nearly totally dependent and inactive. Memory disturbance is severe and physical signs and symptoms are obvious. Common symptoms include:

- becoming unaware of the time and place
- having difficulty recognizing relatives and friends
- having an increasing need for assisted self-care
- having difficulty walking
- experiencing behavioural changes that may escalate and lead to aggression.

Source: Dementia fact sheet. WHO 2017. http://www.who.int/mediacentre/factsheets/fs362/en/

Table 1. Signs and symptoms of dementia

Memory loss

- forgetting important dates or events
- forgetting something that has already happened
- forgetting information they recently learnt
- repeating the same information
- doing the same tasks over and over again
- forgetting familiar names and places.

Trouble with visual images and spatial orientation

- unable to judge distances
- difficulty telling apart colour and contrast.

Confusion with time and place

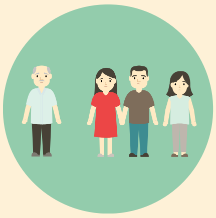
- losing track of dates and the passage of time
- confused about where they are or how they got there.

Decreased or poor judgement

- giving money away to questionable people or causes
- paying less attention to appearance.

Difficulty completing familiar tasks

- driving to a familiar location
- writing a check
- playing a favourite game
- taking medications
- taking care of personal hygiene.



Apathy or loss of interest

- no interest in hobbies, activities and social events they once enjoyed
- withdrawing from other people
- isolating themselves.

Difficulty speaking or writing

- trouble following a conversation
- stopping in the middle of a conversation and being unable to continue
- struggling to find the right words
- calling or labelling things by the wrong name.

Changes in mood, behaviour and personality

- depression
- suspicion
- fear
- anxiety
- upset when taken out of familiar surroundings
- sometimes aggressive or violent behaviour.

Source: Alzheimer's Disease Association of the Philippines, Recommendations on the diagnosis, prevention and management of Alzheimer's disease, Second Edition, 2014; WHO, Dementia fact sheet (1).

B. What are the risk factors for dementia?

Some people may have a higher risk for developing dementia. Some of these risk factors are modifiable, meaning you may change the level of risk through behaviours or interventions such as taking medications (**Table 2**). Other risk factors are non-modifiable, meaning there is nothing you can do to change them (e.g. age) (**Table 3**). Although there is no cure for dementia, there is evidence that the risk of developing dementia may be reduced by managing some modifiable risk factors (*1,9,18–20*). WHO is developing guidelines and recommendations based on best-available scientific evidence to prevent cognitive decline and dementia.

Table 2. Modifiable risk factors in dementia*

RISK FACTOR	EXPLANATION
Tobacco use	Smoking or exposure to tobacco smoke has been linked to an increased risk of developing many noncommunicable diseases, including dementia (*18–27*).
Harmful use of alcohol	Drinking too much alcohol can increase risk for noncommunicable diseases (*28-31*).
Unbalanced diet	Healthy diets with more vegetables, fruits and fish help reduce vascular risk and thus may reduce the risk for dementia (*9,32-35*).
Hypertension, diabetes and obesity	These medical conditions may increase dementia risk (*3,9,18-20,36-40*).
Physical inactivity	People with lower levels of physical activity may have a greater risk of dementia than those with higher physical activity levels (*41–44*).
Social isolation	People with less social participation, less frequent social contact, and more feelings of loneliness have an increased risk of developing dementia (*45–49*).
Low education attainment	People with more years of formal education may be at a lower risk of dementia than those with fewer years of formal education (*3,50-54*).
Cognitive inactivity	People who challenge their brains may be at a lower risk for developing dementia (*55-59*).

**Modifiable means there are things you can do to reduce or eliminate these factors (9,18–20).*

Table 3. Non-modifiable risk factors in dementia*

RISK FACTOR	EXPLANATION
Age	Most people develop dementia when they are over the age of 65.
Genes	Having certain genes might slightly increase the risk of developing dementia.

**Non-modifiable means there is nothing you can do to reduce or eliminate these factors. However, knowing about these factors can help in early detection (1,9).*

C. What other conditions could be mistaken for dementia?

Sometimes older people with certain conditions exhibit similar behaviours or symptoms as people with dementia. A correct diagnosis will ensure that proper treatment and care are given. Before a diagnosis of dementia can be made, it is important to rule out other conditions with symptoms that may be mistaken for dementia. These conditions are listed in Table 4.

Table 4. Medical and mental conditions that may be mistaken for dementia

MEDICAL CONDITIONS	MENTAL CONDITIONS
• Thyroid disease • Head injuries that cause internal bleeding in the head • Chronic liver or kidney disease • Brain cancer • Vitamin B12 deficiency • AIDS (in young people).	• Depression – withdrawing from life, losing interest in daily activities, losing appetite and sleep • Confusion/delirium – becoming agitated, confused or delirious • Psychosis – experiencing hallucinations, becoming suspicious.

Source: Patel V. Where there is no psychiatrist: a mental health care manual; HealthCentral. 10 conditions that can mimic dementia

V

COMMUNITY-BASED MANAGEMENT AND CARE OF PEOPLE WITH DEMENTIA

One major barrier to appropriate dementia treatment and care in low-resource countries is the lack of specialists, so primary care physicians and non-specialists such as community health workers play a much bigger role in identification, management and care of people with dementia. This section covers what you can do as a community worker to manage and care for people with dementia.

A. How do I communicate with people with dementia and their families?

General rules for talking to people with dementia:

- Do not use too many words.
- Use culturally appropriate body language to convey affection (e.g. smiles, hugs, touching hands).
- Reassure them that everything is going to be okay.

Talking to the family member(s) or carer(s):

- Balance involvement of the family with the privacy of the person with dementia.
- Speak to family members alone at least once.
- Find out about family relationships and dynamics.

How to listen to stories and narratives told by the person with dementia and their family members:

- Listen attentively by facing the person who is talking.
- Show proper respect that is appropriate for your culture.
- Do not show any impatience even if the person is repetitive or you have heard these stories before.

B. How do I screen and identify someone who is at risk of dementia?

Early detection of dementia can lead to earlier access to treatment, care and prevention support that in turn can help better manage the disease and enhance the quality of life for people with dementia and their carers (*4,60*). It also gives the individuals, their families and their communities time to set up support networks to help in the ongoing care of the patient.

The earliest sign of dementia is memory problems. As people grow older, it is normal to occasionally forget names and appointments but remember them later. However, people with dementia may forget more often or not remember at all. The kind of memory loss in dementia is much more severe than it is in normal ageing. People with dementia may have difficulty remembering what they have recently done, the names of their family members and relatives, and where they live, as well as keeping track of valuables like a wallet or keys.

1. Screening for people who are at risk of dementia

There are screening questions that will help you identify an elderly person who is at risk for dementia. You can ask the person the following basic screening question (Table 5):

> **"Have you noticed a change in memory, behaviour or function in the last year?"**

A more elaborate dementia screening test is the AD8 Dementia Screening Interview developed by Washington University. This is an eight-item informant interview with carers or family members to differentiate between normal ageing and dementia (see Appendix II).

2. Identifying people who are at risk for dementia

After the initial screening, you can ask more questions about the person's abilities and daily activities. Symptoms of dementia may vary greatly; however, to be considered as having dementia, at least two of the following five core mental functions must be significantly impaired: memory, communication and language, attention and concentration, reasoning and judgement, and visual perception and spatial ability (see Checklist in Appendix III). You can direct the questions to the individual or his/her family members or carers.

Table 5. Screening of people at risk for dementia

Please check the answer that applies:		**Have you noticed a change in:**
YES	**NO**	
☐	☐	memory
☐	☐	behaviour
☐	☐	function (daily activities, mental functions)?

If answer is YES to any of the three, further assessment is needed.

If answer is NO to all three, the person is unlikely to be suffering from dementia.

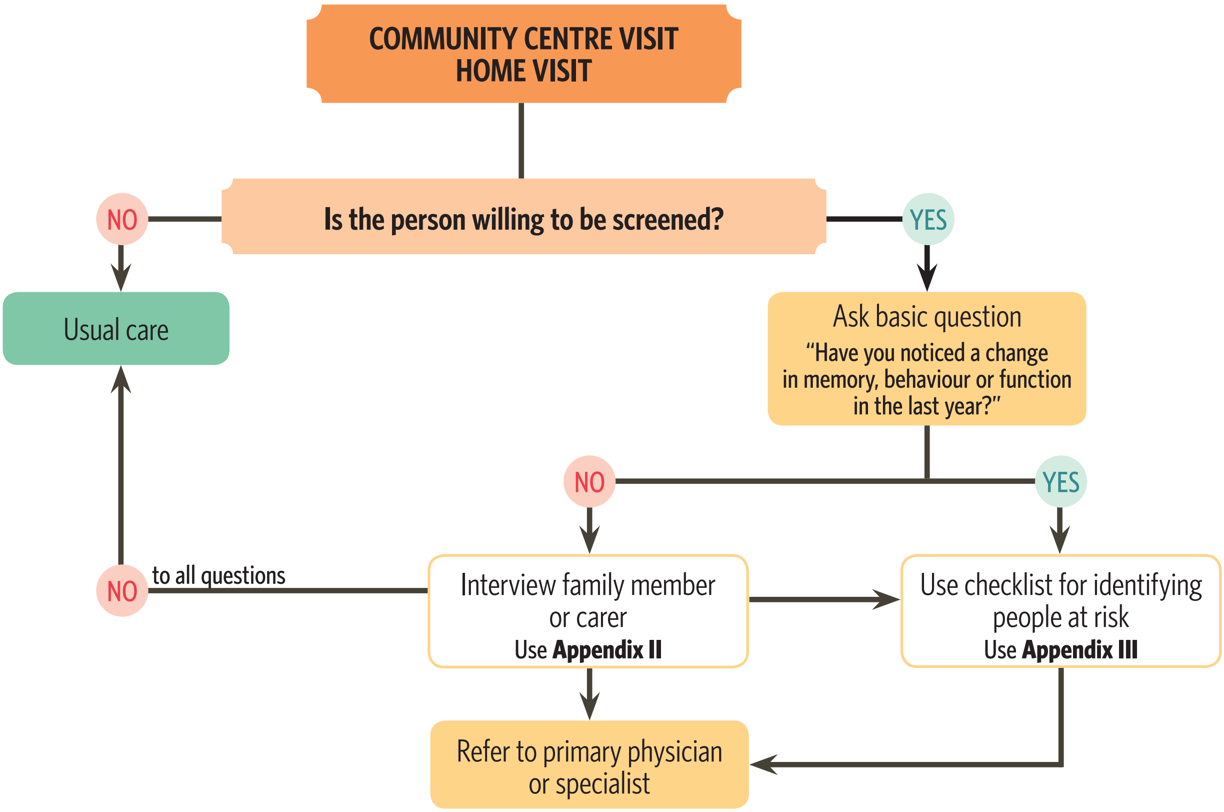
10 early warning signs of Alzheimer's disease*

1. Memory problems that interrupt daily life
2. Difficulty completing familiar tasks at home, work or play
3. Difficulty with planning or solving problems
4. Confusion with time or place
5. Language problems either in speaking and/or writing
6. Poor or impaired judgement
7. Difficulty with visual images and spatial relationships
8. Misplacing things and losing the ability to retrace their steps
9. Changes in mood and personality
10. Withdrawal from work or social activities

** Alzheimer's Association. http://www.alz.org/10-signs-symptoms-alzheimers-dementia.asp; Alzheimer's Disease Association of the Philippines, Caregiving guide for persons with Alzheimer's disease*

Screening flowchart:
The following screening flowchart shows how people who are at risk for dementia can be screened and detected in the community. Community workers can interview people who are at risk for dementia at the community centre or do a home visit at the request of the families. If the person is willing to be screened, then the community worker can ask the basic question: have you noticed a significant change in memory, behaviour or function in the last year? If the answer is "yes", please conduct a further assessment using the Checklist for Screening People at Risk for Dementia (see Appendix III). If the answer is "no", please interview family members or carers for a further assessment using the AD8 Dementia Screening Interview (see Appendix II). If the answer is "yes" to either of the two further assessments, please refer people to a primary care physician or specialist if available. If the answer is "no", please follow routine care.

Screening flowchart



C. When should I refer the person to another professional?

1. Conditions under which you should refer:

- If you are not sure of the cause of dementia.
- When the carer is unable to manage the older person.
- When physical problems become serious.
- When the Early Detection Tools (**Appendices II and III**) indicate it.

2. To whom should I make the referral?

To receive a diagnosis of dementia, people need to see a specialist (e.g., psychiatrist, neurologist or geriatrician) or a trained general/family practice doctor and undergo physical, neurological and cognitive examinations.

In communities with limited resources, you may make a referral for the person to see a primary care physician or nurse with mental health training who can further assess the person.

D. How do I prepare a referral note?

There are different ways to prepare a referral note. However, the important information to be included are:

- name of the individual
- date the referral is being prepared
- professionals and institutions receiving your referral note (e.g. doctor, nurse, specialist)
- reason for referral
- a brief description of symptoms and behaviours
- a suggested follow-up date
- names, affiliations and contact information of all people who are involved in management and care of people with dementia (e.g. community workers, social care workers, carers, family members)
- care preference and wish list of people with dementia (if available).

Documenting the referral is important so you can keep track of the person's records and receive feedback from the referred doctors, nurses or specialists (see an example of a referral note in **Appendix IV**).

E. How and when should I follow up after a referral?

After the person who is referred to a primary care physician or specialist returns to the community, please follow up within one month.

Please ask the person to bring back the doctor's notes. If the physician delivers poor service or does not send back a note, consider not referring to that doctor again.

If possible, form a small community support team with doctors, nurses, social care workers, family members and carers who will work together to support and plan activities for people with dementia.

F. How do I manage and care for people with dementia?

At present, there is no cure for dementia. Although there are some drugs that can help reduce severe symptoms of dementia (see **Appendix V**), efforts should go into supporting and improving management and care of people with dementia (see **Appendix VI**).

Basic everyday care of people with dementia involves the same activities as general care of older people, such as eating and drinking, getting around, grooming (dressing, bathing), and sometimes toileting and continence care. However, because dementia symptoms cause declines in memory and functional abilities, people with dementia may exhibit changes in mood, behaviour and personality, such as agitation, aggression, repetitive actions, wandering or getting lost, and poor judgement. It is necessary to be vigilant and patient and to focus on the positive.

There are some drugs available for people with dementia in some countries. These drugs are not a cure but may help people manage some of the symptoms of dementia. If you are interested, you can contact physicians for more information.

1. Engaging the family

Some issues specific to care and support of dementia patients should be discussed with family members, including:

- *Keeping track of medications* – People with dementia may forget to take their medications or not remember whether they have already taken their medications. The health consequences of forgetting some medications (such as pills for hypertension) or taking too many of other medications (such as sleeping pills or painkillers) can be life-threatening.

- *Making financial arrangements* – Dementia may progress to a stage where the person is unable to manage their finances. These arrangements should be made while the individual is still able to think clearly about these matters.

- *Discussing advance directives* – It is extremely important to talk about advance directives and end-of-life/palliative care issues while the person still has the capacity to make such decisions. These decisions should be well-documented and shared with the person's primary care physician.

- *Self-care for carers* – It is important for carers to be supported so they do not suffer "burnout". Carers who are well-rested and in good physical and mental health will be able to provide better care and show more patience towards the care recipient.

2. *Encouraging independence and self-care*

Management and care plans should aim at promoting and maintaining the independence of people with dementia, enhancing their function and abilities, and minimizing the need for support. It is important to promote self-care of people with dementia; these include eating, bathing, taking care of personal hygiene and toileting.

3. *Promoting home safety*

People with dementia are at risk for falls and injuries. Check each room for potential hazards and put in place safety measures to prevent falls and injuries. These include keeping walkways well lit, placing a shower chair or non-skid mat in the shower, monitoring hot water temperature, installing a monitor device in the bedroom, using appliances with an auto shut-off feature, installing a hidden gas valve or circuit breaker on the stove, locking away sharp and dangerous objects like knives and guns, removing plastic fruits, and securing door knobs.

Guide for carers and family members: how to work with people with dementia at home

- Be patient and understanding.
- Show compassion and respect.
- Establish a daily routine.
- Speak clearly and slowly.
- Do not speak negatively.
- Keep tasks simple.
- Avoid confrontation and arguments.
- Laugh together.
- Use memory aids such as labelling doors.
- Avoid unnecessary medication.
- Encourage daily physical activities and mental exercises.
- Encourage independence and self-care.
- Provide a safe home environment.
- Use assisted technologies to minimize falls and injuries.

4. *Accessing and using available resources*

Encourage people with dementia, their family members and carers to take advantage of the resources around them to learn more about dementia and elder care, and to find a support network. These could be activities at senior centres in their neighbourhood or seminars on elder care. Arrange a meeting with people and representatives from the organizations on your resource list in the Checklist for Community Information and Resources (Appendix I). You can liaise with them and form a network, co-organizing or participating in dementia-related activities. When referrals are needed, you will know to whom and where to refer.

5. *Managing changes in mood, behaviour and personality of people with dementia*

People with dementia may exhibit some noticeable changes in mood, behaviour and personality, which should be managed properly. These should be discussed with the family members and carers:

- *General safety* – Because judgement can be impaired in people with dementia, their safety can sometimes be compromised. For example, they may not take the necessary precautions when crossing the street or they may forget to turn off the stove. Carers and family members should be vigilant.

- *Wandering* – Wandering behaviour is a very serious risk for people with dementia. Carers should be vigilant at all times. It is a good idea to make sure the person has some form of identification on their body so that their family can be contacted if they are lost. In China, people with dementia wear a yellow wristband containing the person's name, home address and phone number of immediate family members or relatives. (Also see **Section VII. Community Engagement, (D) Promotion of Safe Environments**.)

- *Agitation or aggression* – Feelings of helplessness, confusion or fear may lead some people with dementia to become verbally or physically abusive, especially towards their carers. To cope with this problem behaviour, find out the cause of their aggression so you can address it, and use methods such as distraction or redirection to shift their attention to another task or matter. Do not argue with them; do not forcibly restrain the person unless absolutely necessary for their safety or the safety of others around them.

- *Withdrawal* – People with dementia may become sad and withdrawn, isolating themselves from other people. This may be due to feelings of shame or embarrassment, or because they no longer enjoy activities they once did because of their diminished capacities. Be sensitive to their feelings. Encourage them to participate in low-key activities with fewer social requirements (e.g. one-on-one interactions), and offer to stay with them to give them extra confidence.

In extreme cases where people with dementia are harmful to themselves or others and all methods of calming them down have not been effective, a health professional may prescribe certain medications to help manage acute behavioural symptoms of dementia (see **Appendix V**).

G. How do I support carers?

Carers of people with dementia experience a lot of stress on a daily basis. Caring for older people can be physically and mentally draining, and caring for someone with dementia may cause extra stress. For instance, people with dementia may become physically or verbally abusive to their carers and may be uncooperative or uncommunicative. If the carer is the person's spouse, child, close relative or friend, there is also the added emotional pain of seeing the decline of a loved one.

As a community worker, you can encourage carers to provide proper care and practise self-care. Give them educational materials, such as the Pocket Guide in this Toolkit (see **Appendix VII**) or inform them about WHO's iSupport for dementia (see **Appendix VIII**) so they can learn how to take care of others and themselves. If it is possible to organize seminars or training workshops on a variety of relevant issues such as coping skills, encourage carers to find time to attend these. They may also be able to find support in their community.

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Caregiver support group, Beijing, China

H. How do I care for myself?

Being a community worker can be a stressful job. Caring for other people can be exhausting, so it is important to take time out to take care of yourself (see **Appendix VII** and **Appendix VIII**).

Things you can do to reduce your stress are:

- Lead a healthy lifestyle.
- Make time for hobbies and activities that you enjoy.
- Go to a movie or a show.
- Do physical activities and exercise.
- Spend time with your family and friends.
- Take a break or a vacation.
- Join a social or interest group.
- Go to religious services.
- Join a professional support group.

VI

DOs AND DON'Ts OF HEALTHY AGEING

Community-based care and support actively promote prevention activities so that the prevalence of dementia can be reduced. Some of these activities or habits also contribute to general health, well-being and quality of life.

Table 6. Dos and don'ts of healthy ageing

DO...	DON'T...
...exercise regularly and stay physically active.	... smoke or be around smokers too much.
...work on mental exercises often, such as “brain teasers” or puzzles.	...drink too much alcohol.
...eat a balanced and healthy diet that includes adequate amounts of omega-3 fatty acids, fruits and vegetables, whole grains, and vitamins and minerals.	...eat too much unhealthy food.
...see your health care provider regularly.	...avoid seeing your health care provider.
...stay in touch with family, friends and neighbours.	...withdraw or isolate yourself.
...talk to someone if you feel depressed, anxious or confused.	...try to solve big problems without seeking help from other people.

VII COMMUNITY ENGAGEMENT

As a community worker, you are concerned with the well-being of the whole community. It is a good idea for you to personally visit homes, schools, workplaces and gathering places so you can understand and learn about people's concerns, worries and health conditions. You can also share with them good habits and practices that promote physical and mental health. Before you start any programme or activity, please make sure that you identify the following:

1. What are their most important health issues?
2. What do they plan to do about it?
3. Are they ready to make changes?
4. What are the resources needed for the activity or programme?

What kind of activity or activities you plan to do will depend partly on what resources you have in your community. Map out the local resources in your community (you can use the **Checklist for Community Information and Resources** in **Appendix I**) and consider how each resource can help you or play a role in the care of a person with dementia. The sections below describe some of the steps you can take to engage your local community.

A. Memory/Dementia café

In some countries, memory cafés or dementia cafés are situated within a community to provide a safe and caring space for older people and their carers. Activities organized by such a place could be exercise classes, social activities and educational talks. It is also a place where carers may meet and find support among other carers, allowing them opportunities for social interaction as well.

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Memory café, Beijing, China

© Institute of Mental Health, Peking University

Memory café, Beijing, China

Some communities organize dementia support groups for people with dementia and their carers. The groups may meet regularly at a physical location, but some are available as groups that meet online. Some online groups host a "bulletin board" or forum on which visitors or members of the group can post their questions and receive answers from others in the community. An example of a carer support group is one on the Alzheimer's Association website: http://www.alz.org/care/alzheimers-dementia-support-groups.asp. There may be other groups located in your community or country.

B. Organizing and scaling up dementia support groups and partners

Social interaction and support enhance the mental well-being of older people. Various groups in the community can engage older people and foster positive relationships by creating elderly-friendly initiatives, programmes and opportunities. For example, a theatre company in Japan specializes in staging shows with the theme of ageing (see bottom-right photo below).

© Kasaoka City, Japan

A community workshop on dementia, Japan

© OiBokkeShi Troupe, Japan

A scene in a theatre on ageing, Japan

C. Public awareness campaigns

Raising public awareness promotes a deeper understanding of dementia, the needs of people afflicted with the disease and how the community can offer support. In addition, government agencies, non-profit organizations, charities, volunteer groups and other stakeholders can be mobilized to raise funds for dementia-related campaigns and activities.

© Alzheimer's Disease Association Philippines

Dementia awareness campaign, Baguio City, Philippines

© Institute of Mental Health, Peking University

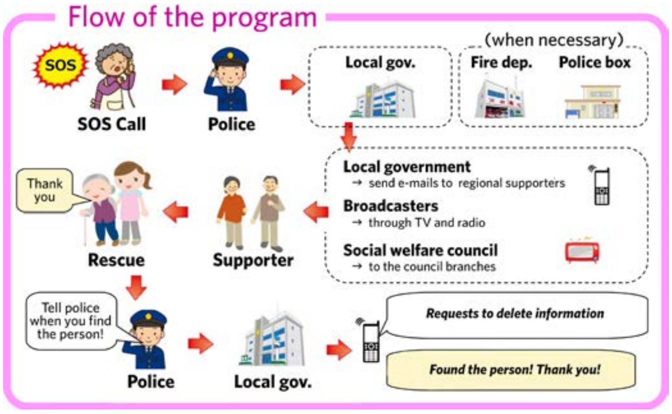
Dementia awareness campaign, Beijing, China

There are many different strategies to raise awareness, but any communication campaign begins with understanding the target audience through research, and determining the communication outcome. Once you have determined your audience and outcome, select the appropriate channel (e.g. interpersonal or face-to-face, community media, mass media, or online and social media) and proceed to develop materials and key messages. Public awareness campaigns need not be expensive to be effective.

When developing materials and messages, remember to: (a) keep it simple; (b) focus on the audience and the outcome; (c) use a combination of channels, as much as resources permit; (d) pre-test before finalizing; and (e) engage with networks and partners (you are not alone!). When done regularly and methodically, public awareness campaigns can also influence norms and attitudes and help build communities of care.

D. Promotion of safe environments

Individuals with dementia may not always remember where they live or where they are going. This leads to situations in which older persons may be found lost and wandering, unable to tell people who they are or how to contact their loved ones. Some communities have programmes in place to help older people when they are found to be disoriented. For example, Kasaoka City in Japan has an "SOS" network programme in which community members receive special training on how to respond to wandering people with dementia.



© Kasaoka City, Japan

"SOS" network, Japan

© Kasaoka City, Japan

Training programme of the "SOS" network, Japan

VIII MONITORING AND EVALUATION

Monitoring progress and evaluating outcomes allow you to see how you have been doing, what you have achieved and what you can improve on.

There are a number of ways we can monitor the progress made by community workers and the community as a whole, including:

- outcomes from training community workers in detecting people at risk for dementia and managing people with dementia;
- level of awareness of dementia and stigma reduction;
- level of community engagement, including the number of programmes developed; and
- involvement of policy-makers (funding, policies, level of involvement).

A. How can I monitor my progress?

It is important to periodically reflect on and document the progress you have made in providing dementia care and service. The number of people you refer is a good outcome measure (see Appendix IX).

B. How can I tell if awareness of and attitudes about dementia have improved?

Questionnaires that measure people's awareness, knowledge and attitudes towards dementia can be administered before and after the dementia media advocacy campaigns, which will allow you to find out if they have become more aware and if the stigma towards dementia has been reduced. In addition, the level of community engagement in dementia promotion, education and prevention can serve as an indicator for the level of awareness campaign, which in turn is linked to improving the attitude towards and understanding of dementia (see Appendix IX).

C. How do I assess the degree of involvement by community leaders?

Community leaders play a pivotal role in community-based dementia education, prevention and management. They can mobilize stakeholders, help secure funding, liaise with various organizations, and coordinate activities across different sectors in the community.

Community work progress can be monitored and evaluated at pre-training and at 3, 6, 9 and 12 months after the training (see Appendix IX).

Dementia prevention and promotion, diagnosis and treatment, and care and support are a continuous process involving people with dementia, their family members and carers, primary health care workers, specialists and local communities. (See Appendix X for a list of dementia prevention and promotion activities throughout the continuum of care for people with dementia.) In resource-poor settings, trained community workers can provide much-needed support and services to people with dementia and improve their quality of life and that of their family and carers.

GLOSSARY OF TERMS

Alzheimer's disease
A progressive, degenerative disorder that attacks the brain's nerve cells, or neurons, resulting in loss of memory, worsening of thinking and language skills, and behavioural changes.

Anxiety disorder
A common mental disorder characterized by excessive worry and feelings of fear, dread and uneasiness that lasts six months or longer.

Chronic obstructive pulmonary disease
A lung disease characterized by chronic obstruction of lung airflow that interferes with normal breathing and is not fully reversible.

Depression
A common mental disorder characterized by persistent sadness and a loss of interest in activities once enjoyed, accompanied by an inability to carry out daily activities, for at least two weeks.

Diabetes
A chronic disease that occurs either when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces. Insulin is a hormone that regulates blood sugar.

Dyslipidaemia
A disorder of lipoprotein metabolism being either overproductive or deficient. There is an increase in the total cholesterol, the "bad" low-density lipoprotein (LDL) cholesterol and the triglyceride concentrations, and a decrease in the "good" high-density lipoprotein (HDL) cholesterol concentration in the blood.

Hypertension
A medical condition also called high blood pressure. It happens when blood flows through the blood vessels with a force greater than normal.

Musculoskeletal disorders
Injuries or pain in the human musculoskeletal system, including the joints, ligaments, muscles, nerves, tendons and structures that support limbs, neck and back.

Obesity
A medical condition in which abnormal or excessive body fat has accumulated to the extent that it may impair health.

Stroke
A serious medical condition that occurs when the blood supply to part of the brain is cut off. When this happens, the brain does not get enough oxygen or nutrients, which causes brain cells to die.

Traumatic brain injury
The disruption of normal brain function caused by a bump, blow, or jolt to the head, or penetrating head injury.

Vascular dementia
A disorder in cognitive functions and thinking skills caused by blockage of the blood supply to the brain, depriving brain cells of vital oxygen and nutrients.

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COMMUNITY RESOURCES

Alzheimer's Association: https://www.alz.org

Alzheimer's Australia: https://www.fightdementia.org.au

Alzheimer's Society: https://www.alzheimers.org.uk

NHS Choice (UK): http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-choices.aspx

APPENDICES

Appendix I – Resources available in my community

Checklist for community information and resources

Important information for my community		
How many older people (60 years or older) are in my community?		
Who are the people in leadership roles? (e.g., policy-makers, champions, stakeholders)		
Type of resource	**Name of resource**	
Individual	**Name of individual**	**Contact details**
General physician		
Psychiatrist		
Nurse		
Nurse practitioner		
Dentist		
Midwife		
Counsellor/Therapist		
Community worker		
Social workers/social care workers		
Other		
Organization	**Name of organization**	**Contact details**
Faith-based group		
NGO		
Charity		
Foundation		
University		
Other		
Dementia-friendly places	**Name of place**	**Contact details**
Dementia/Memory cafe		
Senior centre		
Community centre		
Recreational facility		
Other		
Dementia support groups	**Name of support group**	**Contact details**
Social support group		
Online support group		
Other		
Other local community resources	**Name of resource**	**Contact details**

Appendix II – Early detection tool 1

AD8: The Washington University dementia screening test (8-Item informant interview to differentiate ageing and dementia)

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	**YES, A change**	**NO, No change**	**N/A, Don't know**
1. Problems with judgement (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., computer, microwave, remote control, mobile phone)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. Daily problems with thinking and/or memory			
TOTAL AD8 SCORE			

Source: Adapted from Galvin JE et al, The AD8: a brief informant interview to detect dementia, Neurology, 2005, 65:559-564. The AD8 is a copyrighted instrument of Washington University, St. Louis.

Appendix III – Early detection tool 2

Checklist for identifying people at risk for dementia

Core mental function	Examples to ask about (check all that apply)
Memory	☐ Forgetting events that happened recently ☐ Forgetting the names of people who have just been introduced ☐ Forgetting the names of family members or friends ☐ Forgetting how to get home ☐ Forgetting where they have put important things like house keys, cell phone, or wallet/purse
Communication and language	☐ Have difficulty finding the right words or calling things by the wrong name ☐ Have trouble reading or writing a passage ☐ Have a hard time following a conversation ☐ Stopping in the middle of a conversation and unable to recall what they were talking about ☐ Repeating themselves a lot
Attention and concentration	☐ Have difficulty completing familiar tasks, such as making a meal or keeping track of monthly bills ☐ Have difficulty managing finances, particularly working with numbers ☐ Taking a much longer time to do things than before
Reasoning and judgement (problem solving)	☐ Have difficulty making simple decisions, such as what to wear on a cold day ☐ Giving away a large amount of money to someone they just met ☐ Losing track of the time, dates and season
Visual perception and spatial ability	☐ Have more difficulty judging distances accurately than before ☐ Find it more difficult than before to judge directions accurately ☐ Have difficulty determining color or contrast
If at least 2 of these functions have items checked on the right, then further assessment by a primary physician or specialist is necessary. Please refer the person.	

Appendix IV – Preparing a referral note

Example referral note

Referral note

Date:

Refer to: [name of professional]
[name of professional's institution]

Patient: [name of patient]	**Date of birth:** [patient's birthday] ☐ M ☐ F
Reason for referrral: [suspected dementia]	
History and observations: [list symptoms and behaviours]	
Referred by: [your name and institution]	**Contact number:** [your contact number]
Suggested follow-up visit: [within a month after the diagnosis]	

Appendix V – Dementia interventions

List of non-pharmacological vs pharmacological interventions

Non-pharmacological interventions	Pharmacological interventions
• Psychoeducation - Provide basic information or explanation. • Psychosocial interventions to manage behavioural and psychological symptoms: - Identify physical health problems that may affect behaviours. - Identify events or factors that may precede or trigger problem behaviours. - Create a safe environment such as a wandering area. - Use soothing, calming and distracting strategies to shift attention to other activities. • Interventions to promote functioning in activities of daily living (ADLs) and community life: - Enhance independence and self-care skills. - Keep home environment safe to prevent falls and injuries. - Engage in physical activity and exercise and other recreational activities. - Use assisted aids such as magnifying glass or hearing aid. - Occupational therapy if needed. • Interventions to improve cognitive functioning: - Provide regular orientation information (e.g., name, place, date and time). - Stimulate memory and cognition. - Keep things simple; avoid changes to routine. - Use simple language to communicate and listen carefully to what the person has to say. • Interventions to support carers: - Assess carer's needs. - Acknowledge difficulties of their job; encourage carers to be respectful of people with dementia and to avoid neglect of and hostility towards them. - Encourage carers to seek help if necessary. - Provide information on dementia. - Provide training and support in specific skills.	• Do not consider cholinesterase inhibitors (e.g., donepezil, galantamine, rivastigmine) or memantine routinely for all cases of dementia. • Consider medications only in the settings where specific diagnosis of Alzheimer's disease can be made AND where adequate **support and supervision** by specialists and close monitoring of side effects and response by carers is available. - For dementia associated with suspected Alzheimer's disease and with close monitoring, consider donepezil, galantamine, rivastigmine or memantine. - For dementia with associated vascular disease, consider memantine. • Psychotic symptoms: - Provide psychosocial interventions first. - If there is imminent risk to person or carers, consider antipsychotic medication. Start with a low dose and slowly increase the dosage; use the lowest effective dose. - Avoid i.v. haloperidol. - Avoid diazepam. • Behavioural disturbances or agitation: - Evaluate the underlying causes. - Try to calm the person, remove the trigger and find solutions. - If all possibilities have been exhausted and the person is still aggressive, medication to sedate the person may be necessary to prevent injury. This is can be done under the care of a health professional.

Source: mhGAP-IG Version 2.0, http://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_02/en/

Appendix VI – Management and care of people with dementia

Checklist for management of people with dementia

Engaging the family	☐ Keeping track of medications ☐ Making financial arrangements ☐ Discussing advance directives ☐ Seeking legal protection ☐ Self-care for carers ☐ Use of resources
Patient's independence	☐ Self-care ☐ Safety
Changes in mood, behaviour and personality	☐ Wandering ☐ Irritation or aggression ☐ Withdrawal

Appendix VII – Resource: Pocket guide for dementia caregivers (caregiving and self-care)

Caring for someone with dementia can be stressful, and physically and emotionally draining at times. Caregivers can easily be overwhelmed and neglect to take care of their own needs, health and well-being. There are strategies that can help make caregiving more manageable, reduce stress and prevent burn out for caregivers. This pocket guide covers basic information on dementia and practical tips on how to care for a person with dementia and how to self-care.

Appendix VIII – Resource: iSupport for dementia

WHO developed iSupport, an online training programme to support caregivers of people living with dementia. iSupport helps caregivers to understand the impact of dementia; deal with changes in mood, behaviour and personality; provide good care; and take care of themselves. Caregivers can tailor the programme to their personal needs and select as many lessons as they want. All lessons consist of several exercises and caregivers receive immediate feedback as they work through them. At the end of each lesson there is a relaxation exercise. (https://www.isupportfordementia.org/en)

Appendix IX: Community worker progress on dementia (first year)

Checklist for community worker progress (first year)

Outcome indicators for community workers	**Pre-training**	**Months after toolkit training**			
	Last 3 months	**3**	**6**	**9**	**12**
1. How many elderly people have I seen?					
2. How many people have I referred for further assessment?					
3. Of these people I have referred, how many are diagnosed to have dementia by a primary care provider or specialist?					
4. How many referred people have I followed up on?					
Outcomes for awareness campaign- Level of community engagement	**Pre-campaign**	**Months after dementia campaign**			
	Last 3 months	**3**	**6**	**9**	**12**
1. How many dementia prevention activities are there in the community? • physical exercise (running, hiking, dancing) • cognitive training					
2. How many dementia support groups do you have in your community? • face-to-face • online					
3. How many educational seminars on dementia are there?					
4. How many training workshops are there for carers?					
Involvement of community leaders					
1. How many dementia prevention and education activities are supported financially by community leaders?					
2. How many activities have community leaders participated in?					

Appendix X: Continuum of care for dementia

Dementia prevention and promotion activities

Promotion and prevention (national campaign)	Dementia physical exercises Mental exercises • Memory training • Cognitive stimulation Reducing risk factors • Tobacco use • Unhealthy diets • Harmful use of alcohol • Physical inactivity
Self-care	Promote independence • Eating • Bathing and hygiene • Toileting Manage changes in mood, behaviour and personality • Suspiciousness and anger • Withdrawal • Wandering away from home
Family and household	• Establish a daily routine • Do not talk negatively • Keep tasks simple • Avoid confrontation and arguments • Laugh with the elderly person • Speak clearly and slowly • Use memory aids such as labelling doors • Avoid unnecessary medicine
Community care (for mild and early-stage dementia)	• Screen for possible signs of dementia • Prevention and promotion activities mentioned above
Primary care (for mild to severe or middle-stage dementia)	• Detection and diagnosis of dementia • Medical treatment for co-existing medical conditions • Medicines for severe symptoms of dementia • Psychosocial support
First-referral level (for severe or late-stage dementia)	• Diagnosis and treatment of dementia • Medical treatment for co-existing medical conditions • Medicines for severe symptoms of dementia • Cognitive rehabilitation • Psychosocial support

World Health Organization
Western Pacific Region

WHO Western Pacific Region
PUBLICATION

ISBN-13 978 92 9061 844 7