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# **A long term care approach to address functional decline in dementia: from prevention to palliative care**

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**Background paper**

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## **1 Introduction**

This paper is meant as background information for those attending the high-level meeting in The Hague, April 25 and 26, 2013, on building systems to address functional decline and dependence in people with dementia.

This paper on dementia is a compilation of literal parts from the following documents:

- WHO & ADI. Dementia: a public health priority. WHO, 2012.
- Pot, AM & Petrea, I. Quality of life and autonomy for Europeans with dementia
- Pathways to implementing national dementia strategies. Trimbos-institute, 2012. (Internal report on request of WHO – Copenhagen, an extended version will be published in collaboration with ADI by Bupa)

The purpose of this paper is to highlight some of the key issues and questions in the field of dementia to stimulate discussion at the meeting in The Hague. It is not meant as an attempt to thoroughly summary all issues and questions that are important in the field worldwide.

## **2 Background and context**

### ***What is dementia?***

Dementia is a significant and increasing public health problem, with a massive impact on patients, family caregivers and society. Dementia is NOT part of normal aging. It is characterized by a combination of symptoms, also called a syndrome, due to disease of the brain. Multiple higher cortical functions are disturbed, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. It is often accompanied by a decline in emotional control or motivation, or a change in social behavior. Consciousness is not clouded. The overall severity of the dementia is best expressed as the level of decline in memory or other cognitive abilities, whichever is the more severe (WHO, 2012). More than 50 diseases can cause a dementia syndrome. The most common disease is Alzheimer's Disease, accounting for 60 to 70% of all cases. Other types of dementia are vascular dementia, fronto-temporal dementia, Lewy body dementia and other types (World Alzheimer Report, 2009).

### ***Increasing numbers worldwide***

According to Alzheimer's Disease International, almost 35.6 million people were affected by dementia worldwide in 2010. This number will nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. Each year, another 7.7 million new cases will be registered, one new case every four seconds. Especially most parts of Asia, Latin America and Africa will have to deal with increasing numbers of people with dementia.

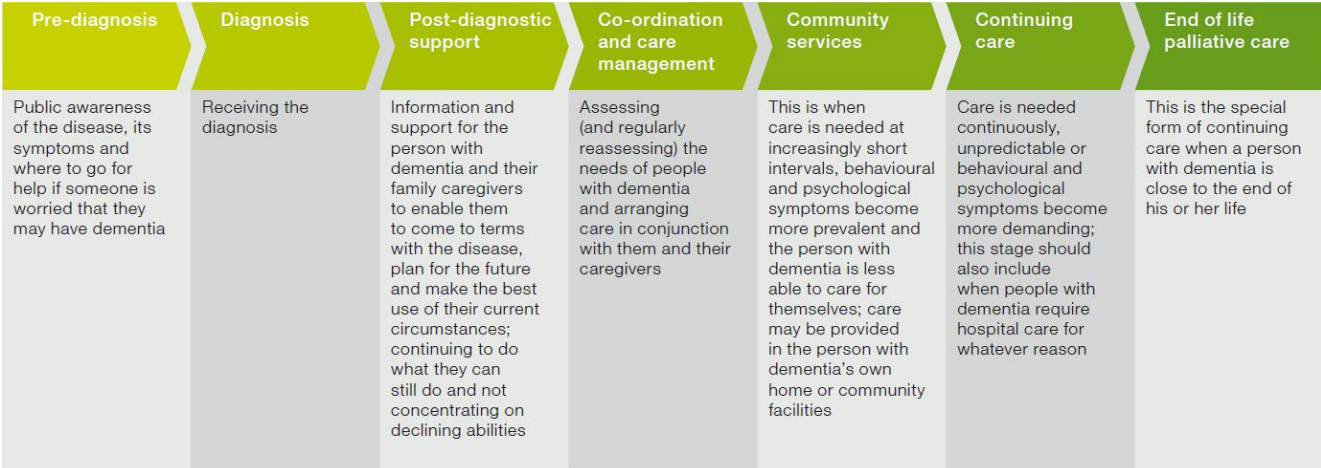
### ***Societal impact***

Dementia is one of the major causes of disability and dependency among older people. It accounts for 11.9% of the years lived with disability due to a non-communicable disease (WHO, 2008). Family caregivers of people with dementia report often high levels of feelings of burden and psychopathology. It is estimated that one in four family caregivers has a depressive disorder, which is much higher than is the case for the general population.

However, the impact of dementia is not only for patients and caregivers but also for society as a whole. "The total estimated worldwide costs of dementia were US\$ 604 billion in 2010. In high-income countries, informal care (45%) and formal social care (40%) account for the majority of costs, while the proportionate contribution of direct medical costs (15%) is much lower. In low-income and lower-middle-income countries direct social care costs are small, and informal care costs (i.e. unpaid care provided by the family) predominate. Changing population demographics in many LMIC may lead to a decline in the ready availability of extended family members in the coming decades.

**A long term care approach**

Dementia is a chronic disease for which there is still no cure. During a process of several years, people with dementia become increasingly functionally impaired and dependent on their environment, including family members and professional care staff for help. A long term care approach is needed to address functional decline related to dementia, from pre-diagnosis to the end of life stage, to ensure that services specific for each stage of the disease process are taken into account, but also to put attention to the importance of the mutual integration of services related to these stages and the integration into regular health and social care services.



The co-ordination and care management stage should apply throughout the journey of dementia care from diagnosis to palliative care.

FIG 4.2 Seven-stage model for planning dementia services (3)

### **3. Ideal situation: A long term care approach to dementia**

In the last decade, dementia care has received increasingly attention due to the intensive lobbies of Alzheimer Disease International (ADI), Alzheimer Europe (AE), and national Alzheimer Associations. In 2004, the Kyoto declaration initiated by ADI was agreed upon, that put forward ten overall recommendations, such as to educate the public, to make appropriate treatment available and to support more research. The Kyoto declaration was followed in 2006 by the Paris declaration, initiated by Alzheimer Europe. This declaration went further and defined priorities in four areas: public health, research, medical care and social support and legal and ethical approaches.

Building on these declarations, ADI formulated six principles that should be adopted for making Alzheimer's disease and other dementias global priorities:

- Promote awareness and understanding of the disease;
- Respect the human rights of people with the disease;
- Recognize the key role of families and carers;
- Provide access to health and social care;
- Stress the importance of optimal treatment after diagnosis;
- Take action to prevent the disease, through improvements in public health.

In the recent report on Dementia of the WHO (2012), seven priority areas of action to address worldwide have been formulated, partly overlapping with the principles defined by ADI:

- Raising awareness
- Timely diagnosis
- commitment to good quality continuing care and services
- caregiver support
- workforce training
- prevention
- research

These priority areas will be described in more detail in the next paragraph.

#### 4. Lessons learned worldwide

Some of the key lessons learned are described in this paragraph. They are related to different stages of the long-term care process from prevention to end of life palliative care (see figure 1), or to overarching issues, including training the workforce, committing resources, and national leadership and long-term policies. The following lessons learned will be described:

- Public health approach: Raising awareness and education
- (Timely) diagnosis and treatment
- Post-diagnostic support and patient engagement
- Integrated pathways of care and care coordination
- Community services for people with dementia and their family caregivers
- Training of workforce
- Committing funding
- National leadership and long-term policies

##### a. **Public health approach: Raising awareness and education**

To keep the population as healthy as possible, it is important to tackle risk factors that can lead to significant decreases in prevalence rates of dementia. Research showed that several preventable risk factors for Alzheimer's Disease are the same as for other diseases, such as diabetes, midlife hypertension, midlife obesity, smoking, depression, cognitive inactivity or low educational attainment, and physical inactivity. Projections on the effect of risk factor reduction on the prevalence of dementia were made based on data for Alzheimer's Disease, since most cases of dementia are caused by Alzheimer's Disease and the risk factors will be generally the same. Results showed that half of the dementia cases worldwide (17.2 million) are potentially attributable to a combination of these factors: "A 10-25% reduction in all seven risk factors could potentially prevent as many as 1.1-3.0 million AD cases worldwide and 184,000-492,000 cases in the USA" (Barnes & Jaffe, 2011). Nowadays, early changes in the brain can be shown even before clinical symptoms fully appear (Berti et al., 2010; Twamley et al., 2006). These new insights open avenues for raising the attention of the general public to dementia as a serious non-communicable disease.

A public health approach is not only important for keeping the general population as healthy as possible, but also for timely diagnosis and treatment to maintain and improve the quality of life of people with dementia and their caregivers and to delay or prevent institutional placement.

##### b. **(Timely) diagnosis and treatment**

Dementia is under-diagnosed worldwide, and when a diagnosis is made it is typically at a relatively late stage in the disease process. Even in high-income countries only one fifth to one half of cases of dementia are routinely recognized and documented in primary care case note records. There is only one such study conducted in a LMIC country (India) and, in this study, 90% of people with dementia had not received any diagnosis, treatment or care. Both demand- and supply-side factors interact, highlighting the importance of understanding the links between health seeking behaviour, health and social service availability and a preparedness to understand the diagnostic and treatment gap.

In the absence of (timely) diagnosis, treatment and care cannot be provided, and functional decline and dependence not addressed. The training of specialists to provide a rapid assessment and accurate diagnosis.

It is widely accepted that the initial identification of likely cases of dementia is an important function of primary care. Many suggest that formal diagnosis should be done by specialists. Therefore, in several high income countries actions are focused on f.i. creating memory clinics or units in areas that are not covered, or the creation of a specific, new service for early diagnosis. However, primary care has an important role to play, it would be challenging to decrease the treatment gap even in well-resourced high-income countries without effective coordination between primary care and specialist services. In LMIC, primary care and non-specialists have a much bigger role to play in diagnosing and managing dementia because of insufficient numbers of specialists. Furthermore, outreach in the community and regular home visits are important for identifying older persons with early-stage dementia.

Regarding treatment, there is specific attention needed for reducing anti-psychotic drug use and the improvement of correct anti-dementia drug use.

### **c. Post-diagnostic support and patient engagement**

In the field of dementia, it is particularly important to pay attention to and to ensure patients' engagement in the improvement of the national health system. Due to their cognitive problems, people with dementia are easily overlooked and unjustly patronized. From the beginning of the eighties, awareness arose that behaviour of people with dementia is only partly due to changes in the brain (a.o. Kitwood & Bredin, 1992; Kitwood, 1997). Personal characteristics, experiences based on the life they have led, and the way in which they cope with the disease determine who they are. Since then, attention for the preferences and experience of people with dementia has increased. However, the prejudice that people with dementia can no longer articulate their problems and preferences, is still widespread.

#### Example from England

Contrary to the English belief that it might be better not to tell people with dementia about the nature of their illness, a clear message from people with dementia themselves was their wish to be informed on their own health needs. Another important message from the people with dementia and their caregivers was that they needed support and advice on how to engage with services and how to identify and access appropriate care, based on their specific needs and circumstances.

#### Example from The Netherlands

The active involvement of people with dementia, family caregivers and national and regional representatives of the advocacy group Alzheimer Nederland, is seen as one of the success-factors for the improvement of the dementia care in this country. Through regional consultations carried out by volunteers of Alzheimer Netherlands, people with dementia and their carers identified 14 problem areas, out of which they priorities three: 'What is going on, and what can help'; 'It is too much for me', and; 'Miscommunication with health care providers'.

### **d. Integrated pathways of care and care coordination**

Like in management of other chronic conditions, care coordination with a single point of contact is a key factor improving dementia care. Ensuring coordination between different components and services along the care pathway is crucial for the success of dementia care to address functional decline and dependency in people with dementia. Due to the cognitive impairment in dementia, the need for a case-manager or adviser is felt particularly strong among the target group.

#### Example from The Netherlands

One of the important pillars of coordinated care in The Netherlands is setting up a case management system, whereby case managers are assigned to people with dementia to

provide support with problems they may encounter, to address their care needs, and information and guidance on possibilities for care and counselling. Care coordinators tackle uncertainties about the course of the disease, feelings of overload and miscommunication between caregivers workers and between workers and clients (Peeters et al, 2012). Case management is often seen as a means to greater coherence, coordination and continuity in dementia care, the case manager is the crucial link in the chain of care (Guideline integrated care Dementia, 2009). Currently, case managers are available throughout the country, and vocational training courses for case managers have been developed, although long-term funding has still to be organized.

#### Example from France

In the French plan, a separate objective is dedicated to the strengthening of the coordination between all stakeholders involved. Single entry points called *Maison pour l'autonomie et l'intégration des maladies Alzheimer* ( MAIA), available in all locations throughout the country, take up the coordination of care as soon as diagnosis is established. A care coordinator is appointed to the person with dementia and the family. The coordinator is responsible for implementing the recommendations from the memory clinic and can be consulted during the whole care process. Health status and needs of people with dementia are assessed annually under the care coordination system.

#### **e. Community services for people with dementia and their family caregivers**

Community services for people with dementia need to be improved, for example for engagement and stimulation of people with dementia, to enlarge the availability of leisure activities and support them in living a meaningful daily existence. This type of care may also relieve family caregivers for some parts of the day. Other examples are specialized teams, consisting of gerontology assistants, psychomotor therapists and occupational therapists to provide patient education, assessment of housing adjustments, rehabilitation and cognitive stimulation and where appropriate, in crisis situations, help with behavioural problems, because behaviour problems are an important reason for psychological distress in family caregivers and institutionalization of people with dementia.

Effective family caregiver support needs to be scaled up and strengthened. The key role of family caregivers for the quality of life of the people with dementia and their chances to stay at home as long as possible is widely acknowledged. An example of an action to improve caregiver support is the setting up of dedicated support groups or schools for family caregivers, reinforcing and improving support at home and creating several types of respite care.

Innovative technology may play an important role in reaching caregivers, also those in rural areas and those not being able or wanting to visit health care institutes because they see themselves not as the ones in need of care. Internet interventions can also provide a maximum of flexible help. Innovative technology also offers new perspectives for people with dementia themselves. It may be used for adjusting the physical environment with regard to the cognitive impairment of people with dementia apart from telecare for the support of people with dementia and their caregivers.

Research on the effectiveness of these types of care is of the utmost importance due to the fact that although in several guidelines it is stated that psychosocial interventions are the primary interventions for mood and behavioural problems in dementia, research on these interventions is methodologically still weak and needs a push forward.

#### **f. Training of work force**

Five core competencies have been identified for people requiring long-term care: person-centred care, partnering, quality improvement, information and communication technology, and a public health perspective. The challenge is to translate these core competencies into practice through the institutions that produce and deploy the health workforce. Changes in the curriculum, new teaching methods, including continuous education, and innovative training models are necessary.



There is a need for training in the basic medical, psychological, nursing and therapy curricula regarding diagnostic and needs-based assessments, and to move beyond the current preoccupation with simple curative interventions to encompass long-term support and chronic disease management. Given the frailty of many older people with chronic health conditions, there is also a need for training in outreach care, and in assessing and managing patients in their own homes. But there is also a need of training the health care force in nursing home care, hospital care and end of life care.

Inherent in the new paradigm of care is a strong emphasis on collaboration and teamwork between different categories of health care provider and people with dementia and their families. Creating a relationship that values the role of the person with dementia and of the family as a partner in care has been frequently shown to improve health outcomes. The multidisciplinary team includes psychiatrists, neurologists, psychologists, nurses, general practitioners, occupational therapists and community / social workers who can share their expertise and collaborate with each other.

#### Example in LMIC

The scarcity of the health workforce in LMIC presents a special challenge. An innovative strategy to overcome this scarcity is task shifting. The 10/66 dementia research group has tested the effectiveness of training community health care workers to deliver a brief intervention involving training of caregivers and this has been found to decrease caregivers' psychological morbidity and strain.

#### **g. Committing funding**

Adequate dementia care to address functional decline and dependence implies funding allocation from different sources (e.g. health, social welfare) covering different services. The question is if more money needs to be put into the system to improve the quality of care to address functional decline. Some argue that funding would be necessary for the development of flexible, innovative respite solutions for family caregivers or to develop more memory clinics for people with dementia throughout the country or to provide extra staffing in residential care. At the same time, others stress the need to focus on improving the effectiveness of current resources, while acknowledging the limits of resources available. They noted that stakeholders need to be empowered to seek solutions to improving care also when resources allocated to dementia care in particular are limited. One solution is for example to tap into resources of the general health care system, and to ensure that available resources are used effectively. Moreover, they noted that in resource-poor settings, where expanding the existing services would not be feasible, reorganizing the care system, for example by changing the place where services are provided or by whom they are provided could help.

#### **h. National leadership and long-term policies**

In general, the mandate of the national government is viewed as key for the successful implementation of actions to improve the health of people with dementia. This might include the involvement of the Ministry of Health at the level of full ministers or deputy-ministers, but also the involvement of higher level officials, such as the Prime-Minister or President. Such top-level leadership mobilizes forces, not only for setting the strategic direction in the field of dementia and committing resources, but also to facilitate the implementation of actions for improvement, and to ensure all stakeholders keep their promises and deliver.

Strong governmental leadership can act as a protective factor against several barriers to the planning for an improvement in dementia care, such as ageism and a lack of awareness, but also fear of costs and competing health priorities. Governmental leadership can facilitate a cross-sectoral approach to dementia. Dementia prevention and care requires involvement of and collaboration between several governmental sectors, such as mental health care, old age care, social care and prevention of NCD. In addition, regularly reporting to the top-level leaders, will also stimulate the involvement and commitment of the other parties involved.

In addition to strong leadership: The improvement of the quality of life and autonomy of people with dementia and their caregivers is very much a co-production in our network society. Implementation should be discussed and decided in partnership. If a key partner is not involved, serious problems may rise.

#### Example from France

In France, the intensive personal involvement of former President Sarkozy was seen as crucial to generating political pressure for the implementation of the French dementia plan. Every six months there was a briefing with Sarkozy on the progress implementation of the Plan, which stimulated all stakeholders to deliver on their commitments.

Long-term attention is needed for the improvement of care to address functional decline and dependency of people with dementia. National plans may stimulate the temporary nation-wide improvement in all stages of dementia care, but for the improvement in the long run one national plan will not be enough.

## **5. The way forward: A long term care approach**

Dementia is a global public health challenge raising several questions related to different stages of the disease and care process and to training the workforce, resources, research and national support as overarching subjects. These questions are for example:

Pre-diagnosis:

How to teach and raise awareness of the general public to reduce cardio vascular risk factors in order to reduce the risk of getting dementia?

Timely diagnosis:

How to improve global awareness and understanding of dementia, taking fears and stigmatization, isolation and delays of seeking help into account?

Post-diagnostic support:

How to create a supportive, person-centered environment and improve their quality of life at home (f.i. dementia friendly communities) as well as in care settings (f.i. small scale person-centered care)?

Coordination and care-management:

How might health and social systems and pathways to care in LMIC countries be developed and strengthened, also taking the needs of specific and minority population groups into account, and create single points of contact?

Community services and continuing care:

How to scale up successful long-term home-based support for family caregivers worldwide?

In what way might a reduction or loss of income of both the person with dementia and the family caregiver be protected by for example pensions and insurance schemes?

In what way might the rights of people with dementia and their caregivers through legislation and regulatory processes be recognized, to reduce discriminatory practices?

Training the workforce:

In what way can we stimulate the capacity-building of the workforce involved in all stages of the disease (prevention, health and social care, hospital care and palliative care)? (Hospital care: Many are admitted for health problems, whereas dementia is often not recognized and due to the dementia wrong decisions with long-lasting adverse consequences for their well-being are taken.)

Resources:

How to involve a broader range of stakeholders from private sector, that could contribute to the development and (co-) funding of innovative treatment, products, technologies, or environmental designs to support people with dementia and their caregivers?

How to trace inefficient health care for people with dementia and their caregivers that might be closed down, to enable fruitful new initiatives?

How to reallocate funding for services to improve dementia care?

Research:

How to stimulate research to a) find a cure for dementia, and b) to generate knowledge on the best ways to support people with dementia and their caregivers?

National leadership and dementia policies:

In what way might the development and implementation of national dementia policies and plans especially in LMIC countries be stimulated?

How to develop a long-term approach to guarantee the improvement in dementia care over time?

## **6. References**

As stated in the introduction, this paper is a compilation of literal parts from the following documents:

1. WHO & ADI. Dementia: a public health priority. WHO, 2012.
2. Pot, AM & Petrea, I. Quality of life and autonomy for Europeans with dementia - Pathways to implementing national dementia strategies. Trimbos-institute, 2012 (to be published in 2013).

For all references, we refer to these two documents.