

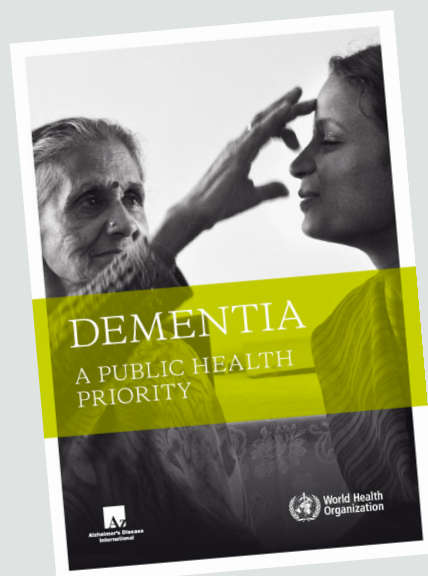
DEMENTIA

A PUBLIC HEALTH PRIORITY



KEY MESSAGES

- Dementia is not part of ageing.
- In 2015, 47.5 million people are estimated to be living with dementia (1). There are 7.7 million new cases of dementia each year, implying that there is a new case of dementia somewhere in the world every four seconds. The accelerating rates of dementia are cause for immediate action, especially in low- and middle-income countries (LAMIC) where resources are few.
- The huge cost of the disease will challenge health systems to deal with the predicted future increase of prevalence as long as there is no cure. The costs are estimated at US\$ 604 billion per year at present and are set to increase even more quickly than the prevalence.
- People live for many years after the onset of symptoms of dementia. With appropriate support, many can and should be enabled to continue to engage and contribute within society and have a good quality of life.
- Dementia is overwhelming for the family and other caregivers and adequate support is required for them, from the health, social, financial and legal systems.
- Countries must include dementia on their public health agendas. Sustained action and coordination is required across multiple levels and with all stakeholders at international, national, regional and local levels.
- People living with dementia and their caregivers often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them.
- The time to act is now by:
 - promoting a dementia friendly society globally;
 - making dementia a national public health and social care priority worldwide;
 - improving public and professional attitudes to, and understanding of, dementia;
 - investing in health and social systems to improve care and services for people living with dementia and their caregivers;
 - increasing the priority given to dementia in the public health research agenda.



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INTRODUCTION

Dementia is overwhelming not only for the people who have it, but also for their caregivers and families. It is one of the major causes of disability and dependency among older people worldwide. There is lack of awareness and understanding of dementia, at some level, in most countries, resulting in stigmatization, barriers to diagnosis and care, and impacting caregivers, families and societies physically, psychologically and economically. Dementia can no longer be neglected but should be considered a part of the public health agenda in all countries.

Awareness must be raised to reinforce that dementia is a public health priority, that needs a public health approach and to advocate for action at international and national levels based on the principles of inclusion, integration, equity and evidence.

BURDEN OF DEMENTIA

We have a growing body of evidence on the global prevalence and incidence of dementia, the associated mortality and the global economic cost. Most of the information is from high-income countries with some data becoming increasingly available from LAMIC.

Prevalence and incidence projections indicate that the number of people living with dementia will continue to grow, particularly among the oldest old, and countries in demographic transition will experience the greatest growth. The total number of people living with dementia worldwide (in 2015) is estimated at 47.5 million and is projected to be 75.6 million in 2030 and 135.5 million in 2050 (1). The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds.

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 LAMIC may lead to a decline in the ready availability of extended family members in the coming decades.

There is a growing body of evidence on modifiable risk factors for dementia. Prevention efforts should include countering risk factors for vascular disease, including diabetes, midlife hypertension, midlife obesity, smoking, and physical inactivity, and to enable access to appropriate education for all.

COUNTRY PREPAREDNESS FOR DEMENTIA

The challenges to governments to respond to the growing numbers of people living with dementia are substantial. A broad public health approach is needed to improve the care and quality of life of people living with dementia and family caregivers. The aims and objectives of the approach should either be articulated in a stand-alone dementia policy or plan or be integrated into existing health, mental health or old-age policies and plans. There are currently at least 19 countries with a national dementia policy or plan: Australia, Belgium, Costa Rica, Cuba, Denmark, Finland, France, Ireland, Israel, Italy, Japan, Luxembourg, Mexico, Netherlands, Norway, Republic of Korea, Switzerland, United Kingdom of Great Britain and Northern Ireland (separate plans for England, Northern Ireland, Scotland and Wales), and the United States of America.

There are several key issues that are common to many national dementia policies and plans, and these may be necessary to ensure that needs are addressed in an effective and sustainable manner. These include: scoping the problem, involving all the relevant stakeholders, including civil society groups, identifying priority areas for action, implementing the policy and plan, committing resources, having intersectoral collaboration, developing a time frame, and monitoring and evaluation.

The priority areas of action that need to be addressed within the policy and plan include raising awareness, timely diagnosis, commitment to good quality continuing care and services, caregiver support, workforce training, prevention and research.

People living with dementia and their families face significant financial impact from the cost of providing health and social care and from reduction or loss of income. Universal social support through pensions and insurance schemes could provide protection to this vulnerable group.

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Formal recognition of the rights of people living with dementia and their caregivers through legislation and regulatory processes will help reduce discriminatory practices. Fundamental to upholding a person's rights is the recognition of capacity in persons with dementia.

Where capacity is impaired due to dementia, legal provisions should recognize and protect the right to appropriate autonomy and self-determination including substitute or supported decision-making and procedures for implementing advance directives. Education and support relating to ethical decision-making and human rights should be an essential part of capacity-building for all involved in providing dementia care, including policy-makers, professionals and families.

RESEARCH PRIORITIZATION

Given the urgency of addressing the growing burden of dementia in countries around the world, and the existing limitations of resources, there is a growing need for governments, funding agencies, and the private sector to prioritize dementia research investments in a systematic way. The development of a sound methodology for conducting a global, inclusive, and rigorous review of research priorities for dementia is vital for informing and promoting a coordinated international action plan. The goal of research prioritization is primarily to maximize disease burden reduction in the most realistic, equitable and cost-effective way. Other goals include improved health system efficiency, intervention delivery, discovery and development of new interventions, and education regarding controllable risks. To reach these goals, highly collaborative enabling activities are required: Increasing investment, developing infrastructure for coordinated implementation, building capacity, facilitating international partnerships on a global basis, shared learning, and monitoring and evaluating progress.

HEALTH AND SOCIAL SYSTEMS DEVELOPMENT

The health and social care needs of the large and rapidly growing numbers of frail dependent older persons should be a matter of great concern for policy-makers in all countries. This is particularly so for LAMIC which will experience the greatest increase in ageing in the coming decades.

This challenges governments to develop and improve services for people living with dementia, focusing on earlier diagnosis, provision of support in the community, and a responsive health and social care sector. Integrated and coordinated health and social pathways and services will be needed to cater for the changing needs of people living with dementia and their caregivers. Such pathways should ensure that the needs of specific or minority population groups are taken into account.

Improved community support will assist families to provide care for longer and to delay or reduce reliance on high-cost residential care. Where resources are finite, especially in LAMIC, a focus on community outreach could be an efficient use of scarce resources to improve the quality of life of people living with dementia and their caregivers. The effectiveness of task shifting (with appropriate guidelines and training) in LAMIC should be further evaluated as a solution to the under-supply of a professional workforce.

Capacity-building of the workforce is essential to improve knowledge and awareness of the benefits of a coordinated response to care. Dementia care, long-term care and chronic disease management incorporating a multidisciplinary team should form part of professional education and should be supported by the development of appropriate practice guidelines. In a world with an increasingly mobile population, the migrant workforce brings its own set of challenges that need to be understood and addressed.

SUPPORT FOR INFORMAL CARE AND CAREGIVERS

Dementia has an immense impact on the lives of the family, and particularly the person who takes the primary role in providing care. Most care is provided by family and other informal support systems in the community and most caregivers are women. However, changing population demographics may reduce the availability of informal caregivers in the future.

The provision of care to a person with dementia can result in significant strain for those who provide most of that care. The stressors are physical, emotional and economic. A range of programmes and services have been developed in high-income countries to assist family caregivers and to reduce strain. The beneficial effects of caregiver interventions in decreasing the institutionalization of the care recipient have been clearly demonstrated.

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Evidence from LAMIC also suggests that home-based support for caregivers of people with dementia, emphasizing the use of locally-available low-cost human resources, is feasible, acceptable and leads to significant improvements in caregiver mental health and in the burden of caring. Despite evidence of effectiveness, there have been no successful examples of scale-up in any of the health systems in which the evaluative research has been conducted. Further research should focus on implementation in order to inform the process of scale-up.

Despite the availability of services in some countries or parts of countries, there are barriers to uptake. Lack of awareness of services, lack of understanding or stigma attached to the syndrome, previous poor experience with services, and cultural, language and financial barriers create obstacles to service utilization. Information and education campaigns for the public – including people living with dementia, their caregivers and families – can improve service utilization by raising awareness, improving understanding and decreasing stigmatizing attitudes.

Support is needed to enable informal caregivers to be able to continue in their role for as long as possible. Support includes information to aid understanding, skills to assist in caring, respite to enable engagement in other activities, and financial support.

AWARENESS-RAISING AND ADVOCACY

Despite the growing impact globally, a lack of understanding of dementia contributes to fears and to stigmatization. For those who are living with dementia (both the person and their family), the stigma contributes to social isolation and to delays in seeking diagnosis and help.

There is an urgent need to improve the awareness and understanding of dementia across all levels of society as a step towards improving the quality of life of people living with dementia and their caregivers. Governments have a role to play in resourcing public awareness campaigns and in ensuring that key stakeholders are involved in such campaigns.

Awareness-raising campaigns should be relevant to the context and audience. They should be accurate, effective and informative and should be developed in consultation with people living with dementia, their families and other stakeholders, including civil society.

THE WAY FORWARD

Dementia is a global public health challenge. A range of actions is required to improve care and services for people living with dementia and their caregivers. These actions include advocacy and awareness-raising, developing and implementing dementia policies and plans, health system strengthening, capacity-building, supporting caregivers and research. The actions need to be context-specific and culturally relevant.

References

1. Alzheimer's Disease International. Policy Brief for G8 Heads of Government. The Global Impact of Dementia 2013-2050. London, UK: Alzheimer's Disease International; 2013.

Acknowledgements

This thematic briefing was prepared for the First WHO Ministerial Conference on the Global Action Against Dementia and is an updated version of the executive summary of Dementia: A public health priority by the World Health Organization and Alzheimer Disease International (2012). The updates concern new numbers on the prevalence of dementia, the research prioritization and the countries with a national dementia strategy or plan.

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