

Dementia

Report by the Secretariat

EPIDEMIOLOGY AND BURDEN OF DEMENTIA

1. Dementia is an umbrella term for several progressive diseases affecting memory, cognitive abilities and behaviour that interfere significantly with a person's ability to maintain the activities of daily living. The most common types of dementia are Alzheimer's disease and vascular dementia. Crucially, although dementia primarily affects older adults, it is not a normal or inevitable consequence of ageing.¹
2. Dementia is a major cause of disability and dependency among older people worldwide, imposing a tremendous burden on individuals, families, communities and societies. It accounts for 11.9% of the years lived with disability due to a noncommunicable disease.
3. Recent reviews estimate that globally nearly 8 million people develop dementia each year, which translates to one new case every four seconds. In 2015, dementia affected more than 47 million people worldwide, a figure that is estimated to increase to 76 million in 2030 and 145 million by 2050.
4. Dementia leads to increased long-term care costs for governments, communities, families and individuals, and to losses in productivity for economies. In 2010, the global cost of dementia care was estimated to be US\$ 604 000 million, constituting 1% of global gross domestic product.² By 2030, the cost of caring for people living with dementia worldwide has been estimated at US\$ 1 200 000 million or more, a total that could undermine social and economic development globally.
5. Nearly 60% of people with dementia currently live in low- and middle-income countries and most new cases (71%) are expected to occur in those countries.³ This may contribute to increasing inequalities between countries and populations.

¹ Alzheimer's Disease International and World Health Organization. Dementia: a public health priority. Geneva: World Health Organization; 2012 (http://www.who.int/mental_health/publications/dementia_report_2012/en/, accessed 14 April 2016).

² Wimo A, Prince M. World Alzheimer Report 2010: the global economic impact of dementia. Alzheimer's Disease International; 2010 (http://www.alz.org/documents/national/world_alzheimer_report_2010.pdf, accessed 2 March 2016).

³ The epidemiology and impact of dementia: current state and future trends. Geneva: World Health Organization; 2015 (document WHO/MSD/MER/15.3; http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf, accessed 8 April 2016).

6. The gap between the need for treatment and care for dementia and their provision is wide. Dementia is underdiagnosed worldwide, and, when a diagnosis is made, it is typically at a relatively late stage in the disease process. In high-income countries only between 20% and 50% of cases of dementia are routinely recognized and documented in primary care. Data from low- and middle-income countries are scarce; in one study, 90% of people with dementia had not received any diagnosis, treatment or care.¹

7. The social and economic impact of dementia is diverse and far-reaching.

- There is a lack of awareness about dementia and the disease is highly stigmatized. For both the person with dementia and his or her carer, this stigmatization can contribute to social isolation and delays in seeking diagnosis and care, and encourage reluctance to ask for help.
- Behavioural and psychological symptoms linked to dementia profoundly affect the quality of life of people living with dementia and their carers. Providing informal care to people living with dementia incurs a substantial emotional burden, including a detrimental impact on carers' mental and physical health. One in four people who care for people living with dementia become clinically depressed.
- The indirect costs of care incurred by informal carers and family members trap millions of people in chronic poverty. In high-income countries, the costs related to dementia are shared between informal care (45%) and social care (40%). In contrast, in low- and middle-income countries, social care costs (15%) pale in comparison to informal care costs which predominate.²

8. The fact that dementia is not yet a national priority in most countries has led to a lack of systematic monitoring and evaluation of dementia efforts in Member States, and to fragmented social and health services for dementia care. For example, only 22 of 194 Member States have a national plan to address dementia.³

INTERNATIONAL CONTEXT

9. The Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases acknowledged that “the global burden and threat of non-communicable diseases constitutes one of the major challenges for development in the twenty-first century” and recognized that “mental and neurological disorders, including Alzheimer’s disease, are an important cause of morbidity and contribute to the global non-communicable disease burden.”⁴

¹ Alzheimer’s Disease International and World Health Organization. Dementia: a public health priority. Geneva: World Health Organization; 2012. (http://www.who.int/mental_health/publications/dementia_report_2012/en/, accessed 8 April 2016).

² Wimo A, Prince M. World Alzheimer Report 2010: The global economic impact of dementia. Alzheimer’s Disease International. 2010 (http://www.alz.org/documents/national/world_alzheimer_report_2010.pdf, accessed 8 April 2016).

³ Global Dementia Framework. Leadership [website]. (<https://globaldementiaframework.wordpress.com/leadership/>, accessed 8 April 2016).

⁴ United Nations General Assembly resolution 66/2 (http://www.who.int/nmh/events/un_ncd_summit2011/political_declaration_en.pdf, accessed 8 April 2016).

10. The comprehensive mental health action plan 2013–2020¹ adopted by the Health Assembly in resolution WHA66.8 (2013) included references to dementia care. Other resolutions and global programmatic documents pertinent to coordinated and comprehensive public health response to dementia are WHO's global action plan for the prevention and control of noncommunicable diseases 2013–2020, the World report on ageing and health,² and the draft global strategy and plan of action on ageing and health.³ In discussing the draft global strategy at its 138th meeting in January 2016, members of the Executive Board urged that particular attention be paid to dementia and the Secretariat undertook to enhance the inclusion of mental health, dementia and disability considerations in the draft strategy and plan of action.⁴

11. The G8 Dementia Summit (London, 11 December 2013), which included many stakeholders, including WHO, as participants, culminated in a communiqué and signed declaration of commitment.⁵ WHO provided technical assistance to the Summit. Following the Summit, the World Dementia Council was created⁶ and three global dementia events were organized. These events explored in more detail specific topics, including funding models, partnerships between academe and industry, and technology; all helped to place dementia high on the international policy agenda.

12. WHO organized the first Ministerial Conference on Global Action against Dementia (Geneva, 16 and 17 March 2015). The Conference aimed to raise awareness of the fact that the global burden of dementia can be reduced, but only if there is a shared commitment among countries and stakeholders to put in place the necessary policies and resources for care of people with dementia and finding disease-modifying treatments or cure, and to place action against dementia higher on national and global political agendas. A call for action was endorsed by the participants of the Ministerial Conference.⁷

13. Other actions include the formation of the Global Alzheimer's and Dementia Action Alliance by a group of global nongovernmental organizations to raise awareness about dementia, to increase the understanding of dementia as a disease and to reduce the stigma surrounding it.

¹ http://apps.who.int/gb/ebwha/pdf_files/WHA66_REC1/A66-REC1-en.pdf#page=106, accessed 8 April 2016.

² World report on ageing and health. Geneva: World Health Organization; 2015. (http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf, accessed 2 March 2016).

³ For the text of the draft global strategy and plan of action on ageing and health considered by the Executive Board at its 138th session in January 2016, see <http://www.who.int/ageing/ageing-global-strategy-revised-draft-for-who-eb.pdf?ua=1>, and also document A69/17 "Multisectoral action for a life course approach to healthy ageing: draft global strategy and plan of action on ageing and health" submitted to the Sixty-ninth World Health Assembly.

⁴ See summary record of the sixth meeting of the Executive Board at its 138th session (document EB138/2016/REC/2).

⁵ Policy paper RDD/10495: G8 Dementia Summit Communiqué. London: Department of Health, Government of the United Kingdom; 2013 (<https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-communique>, accessed 8 April 2016).

⁶ World Dementia Council. Available at <https://dementiachallenge.dh.gov.uk/category/wdc>, accessed 28 April 2016.

⁷ Call for action by the participants in the First WHO Ministerial Conference on Global Action Against Dementia. Geneva: World Health Organization; 2015 (http://www.who.int/mental_health/neurology/dementia/call_for_action/en/, accessed 8 April 2016).

14. In 2015 OECD released a report with its response to the large and growing cost of dementia.¹ The report provides an imperative for policy action on improving dementia care and also includes recommendations for sharing data in dementia research.

15. The European Commission has initiated numerous partnerships and funding initiatives for dementia. The European Council of Ministers in December 2015 adopted the conclusions of the Council of the European Union on “Supporting people living with dementia: improving care policies and practices”.²

16. The World Innovation Summit for Health, an initiative of the Qatar Foundation, published a call for action through innovation in policies.³

17. The first WHO regional strategy and plan of action on dementia was developed and released by PAHO in 2015.⁴ The strategic lines of action in this strategy are promoting plans, policies, and programs on dementias; establishing, in health systems and health services networks, interventions for prevention and quality care; implementing a quality long-term care system that addresses the needs of people with dementia and their families; developing or strengthening the necessary human resources; and improve research and surveillance capacity to generate and collect quality information to address the social and health needs of persons with dementias.

EFFECTIVE STRATEGIES WITHIN HEALTH AND SOCIAL SECTORS FOR PUBLIC HEALTH ACTION

18. The response to dementia requires a concerted and coordinated response to maximize global impact and research. WHO thus recommends the following strategies:

- (a) strengthening global leadership and a call for action by:
 - raising the priority accorded to global efforts to tackle dementia and strengthening international efforts to support plans and policies at all levels for people living with dementia, particularly in low- and middle-income countries. For example:
 - mainstreaming dementia into policies on noncommunicable diseases, given that they share similar points for risk reduction, and healthy lifestyle promotion has positive implications for cognitive health

¹ OECD Health. Addressing dementia: The OECD response. Paris: OECD Publishing; 2015. (http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/addressing-dementia_9789264231726-en#page1, accessed 8 April 2016).

² Council of the European Union. Supporting people living with dementia: improve care policies and practice – council conclusions. Brussels; 2015 (http://ec.europa.eu/health/major_chronic_diseases/docs/councilconclusions_1505515_en.pdf, accessed 8 April 2016).

³ Rubinstein E, Duggan C, Landingham B Van, Thompson D, Warburton W. A call to action: The global response to dementia through policy innovation. Report of the WISH Dementia Forum 2015. (http://mhinnovation.net/sites/default/files/downloads/resource/WISH_Dementia_Forum_Report_08.01.15_WEB.pdf).

⁴ PAHO. Strategy and plan of action on dementias in older persons. 54th Directing Council of PAHO, 67th Session of the WHO Regional Committee for the Americas; 28 Sep-2 Oct 2015; Washington, DC: Pan American Health Organization; 2015 (Resolution CD54.R8).

- policies, plans and programmes on dementia should be framed within a public health approach to stress the importance of reducing the number of people who develop dementia
- plans should emphasize the importance of timely diagnosis at the primary care level, training, and monitoring mechanisms to measure progress of implementation of dementia plans at national, regional and local levels
- plans should balance care and treatment, pay attention to raising the profile of dementia and awareness of the disease, include input from people living with dementia and their carers, and ensure both of them are involved in the planning process at every stage
- strengthening capacity, leadership, governance, multisectoral action and partnerships to accelerate responses to tackling dementia
- developing strategic approaches to dementia research, including the need for more timely diagnosis, more rapid and less costly clinical trials, and diversification of therapeutic approaches including non-pharmacological as well as pharmacological agents;

(b) improving awareness of dementia, reducing stigmatization and sharpening the focus on risk reduction by:

- promoting a better understanding of dementia by the general public by raising public awareness and engagement, including respect for the human rights of people living with dementia
- empowering and building the capacity of people living with dementia, their families and community members to be able to disseminate knowledge about dementia – for example, through the development of training courses for carers and support groups in their communities
- advancing prevention, risk reduction, diagnosis and treatment of dementia in ways that are consistent with current and emerging evidence;

(c) supporting individuals to live well with dementia by:

- facilitating the coordinated delivery of health and social care services for people living with dementia, including capacity-building for health care and social workers involved, support for mutual care-taking across generations at individual, family and societal levels, and strengthening of support and services for carers and families
- supporting a gender-sensitive approach in the elaboration of plans, policies and interventions aimed at improving the lives of people living with dementia
- promoting further work to identify and remove barriers to care for people with dementia, particularly in low-resource settings

- facilitating technological and social innovations to meet the needs of people living with dementia and their carers.

SECRETARIAT ACTIVITIES

19. The most salient activities of the Secretariat in the area of dementia are summarized below.

Advocacy

20. In May 2012, in collaboration with Alzheimer's Disease International, WHO launched a global report on dementia as a public health priority to raise awareness and to advocate action at international and national levels to improve services for people with dementia and their carers.

21. WHO's First Ministerial Conference (see paragraph 12) convened government ministries and policy experts, international, regional and national nongovernmental organizations, academics and national research organizations, and carers and people living with dementia from all countries to raise awareness and understanding of dementia worldwide.

Information and surveillance

22. During the First Ministerial Conference against Dementia in March 2015, WHO announced the plan to develop a global dementia observatory, with the aim of facilitating the sharing of best practices and providing technical support to Member States through an online platform currently under development. The functions of the observatory include:

- providing information on disease prevalence and aspects of the dementia care system in the countries such as governance and financing, human resources, service availability and delivery, and prevention and risk reduction efforts
- monitoring the implementation of policies relating to dementia, and advocating the development of plans and strategies on dementia
- understanding the range and scope of policies, plans and laws related to dementia (e.g. disability and human rights), especially as dementia care and services cut cross health and social sectors (namely, employment and labour, education, housing and social security)
- promoting investment in and coordination of global research into dementia
- disseminating information on policy, programmatic and research developments and promoting best practice.

Service development

23. The Secretariat works with Member States to develop services and care for people living with dementia. Specifically, it supports countries to integrate dementia diagnosis, treatment and management of dementia into general health care and to develop community-based services. In 2008, WHO launched the Mental Health Gap Action Programme, which included dementia as a priority condition. The Programme's objective is to expand services for mental, neurological and substance use disorders in countries, especially those at lower income levels.

24. The Secretariat has issued an Intervention Guide for the Mental Health Gap Action Programme,¹ which contains evidence-based interventions for prevention and management of dementia. Training, based on that guide, is provided to health care providers working in non-specialized health-care settings in low- and middle-income countries, with the aim of shifting away from stand-alone mental health programmes to an integrated approach, thereby promoting mental health at all levels of care.

25. WHO's iSupport is an e-health programme providing evidence-based education, skill training and social support for carers of people living with dementia that will be integrated into, and implemented through, a country's existing health system.

26. WHO's activities on dementia are conducted in close coordination with those undertaken through the Comprehensive Mental Health Action Plan 2013–2020, the global action plan for the prevention and control of noncommunicable diseases 2013–2020 and the World report on ageing and health.

ACTION BY THE EXECUTIVE BOARD

27. The Board is invited to take note of the report and provide further strategic guidance, including on the specific recommendations in paragraph 18.

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¹ mhGAP-IG Intervention Guide for mental, neurological and substance use disorders in non-specialized health settings, 2011 (http://www.who.int/mental_health/publications/mhGAP_intervention_guide/en/, accessed 8 April 2016).