Fact Sheet on Dementia

MAGNITUDE

Globally, there are over 55 million people with dementia; 60% of these live in low- and middle-income countries (LMICs).[1]

By 2050, the number of persons with dementia:

- Globally: 139 million;[2]
- Asia-Pacific: 70 million.[3]

Despite the high number, people with dementia and disabilities associated with neurological conditions continue to experience stigma, discrimination and violation of the rights stated in the Convention on the Rights of Persons with Disabilities (CRPD).[4] Most Governments have not yet realized that persons with dementia are persons with disabilities. Many have yet to recognize the significance of dementia as a policy matter of concern. Organizations of persons with disabilities (OPDs) have not yet adapted to the emerging significance of persons with dementia. Thus, most OPDs are yet to advocate for persons with dementia or to welcome them as their members.

This fact sheet addresses the following areas, with recommendations:

- Dementia as a disability;
- Impact of dementia on persons with another disability as they age;
- Impact of dementia on younger persons before the age of 65;
- Impact on care partners.

DEMENTIA AS DISABILITY

Dementia is:

- A major cause of disability and dependence in older persons (those aged 65 and over)[5];
- The third largest contributor of neurological disability-adjusted life years (DALYs);[6]

Dementia is a chronic neurocognitive disorder that results in progressive decline in a person's functioning.[7] Its symptoms can include: memory loss, with changes in speech,

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[1] World Health Organization (2021). Global status report on the public health response to dementia. https://www.who.int/publications/i/item/9789240033245

2 World Health Organization (2021). *Ibid.*

[3] Alzheimer's Disease International (2014). Dementia in the Asia Pacific Region. https://www.alzint.org/resource/dementia-in-the-asia-pacific-region/

[4] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

[5] World Health Organization (2021) *Ibid*

[6] The Lancet Neurology. Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Volume 18, Issue 5, P459-480, May 1, 2019. https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(18)30499-X/fulltext

[7] World Health Organization (2017). Global action plan on the public health response to dementia 2017-2025. World Health Organization, Geneva.

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reasoning, visuospatial abilities,[8] emotional responses, social skills and physical functioning. Abnormal brain changes trigger a decline in thinking skills (cognitive abilities), severe enough to impair daily life, including organizing of activities, and independent functioning. They also affect behavior, feelings and relationships. There are more than 100 possible causes of dementia, and Alzheimer's and vascular dementia make up 90% of dementia cases.[9,10]

The course of dementia varies for each person, depending on multiple factors, such as: subtype of dementia; age at onset; physical health; lifestyle factors; and the availability of a social support system for the person with dementia and the care partner.[11]

Dementia is a terminal condition; currently, there is no cure. It is the seventh leading cause of death in the world.[12]

Age and dementia

Advanced age is the strongest risk factor for dementia, but it is not a normal part of ageing. Young-onset dementia (below the age of 65) accounts for about 7% of cases.[13] Thus, dementia does not only affect older adults.

Meeting the needs of people with dementia requires a person-centred approach, rather than a 'one-size fits all' response.

People with another disability who develop dementia as they age

Persons with learning disabilities are at higher risk of developing dementia.

Persons with Down syndrome, because of the genetic basis of their impairment, have a lifetime risk of Alzheimer's disease of more than 90% by the age of 60+ years.[14] The

[8] Visuospatial ability: a person's capacity to identify visual and spatial relationships among objects; it is measured in terms of the ability to imagine objects, to make global shapes by locating small components, or to understand the differences and similarities between objects. https://library.neura.edu.au/schizophrenia/signs-and-symptoms/cognition/visuospatial-ability/#:~:text=Visuospatial%20ability%20refers%20to%20a,differences%20and%20similarities%20between%20objects.

[9] https://www.alzint.org/about/dementia-facts-figures/types-of-dementia/

[10] Alzheimer's Association series on understanding dementia (2021). Down's syndrome and Alzheimer's Disease. (Updated November 2021). https://www.alz.org/media/documents/alzheimers-dementia-down-syndrome-ts.pdf

[11] The term "care partner," as opposed to "caregiver," is preferred as it underscores the value of the relationship and the dignity of persons with dementia. It shifts the perception of dependence to a relationship in which both parties contribute to the interpersonal dynamic.

[12] World Health Organization (2019). Risk Reduction of Cognitive Decline and Dementia: WHO Guidelines https://www.who.int/publications/i/item/9789241550543

[13] Stevie Hendriks, et al (2021) Global Prevalence of Young-Onset Dementia: A Systematic Review and Meta-analysis. JAMA Neurol. 2021 Sep 1;78(9):1080-1090. Pubmed

[14] Juan Fortea, Vilaplena, E, Carmona-Iragui, M, et at. Clinical and biomarker changes of Alzheimer's disease in adults with Down syndrome: a cross-sectional study. The *Lancet*, Volume 395, Issue 10242, P1988-1997, June 27, 2020. DOI: https//doi.org/10.1016/S0140-6736(20)30689-9

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disease causes up to 80% of deaths in this population. [15,16] The lifespan of persons with Down syndrome will not increase further until treatments for Alzheimer's disease are available.

"Acting now on dementia prevention, intervention, and care will vastly improve living and dying for individuals with dementia and their families, and thus society…."

Lancet Commission, 2020 Report:
Dementia prevention, intervention, and care

Potentially modifiable Dementia risk factors

Around 40% of cases of dementia are associated with 12 modifiable risk factors, which could be prevented or delayed.[17]

Early life (<45 years): less education;

Midlife (45-65 years): hearing loss, traumatic brain injury, alcohol misuse, hypertension, obesity;

Later life (> 65 years): air pollution, smoking, physical inactivity, depression, social isolation, and diabetes.

Midlife hearing loss may be the largest modifiable risk factor for dementia, while hearing aid use is protective against cognitive decline.[18] High blood pressure throughout midlife increases dementia risk, even without stroke.

Type 2 diabetes is consistently linked with an increased risk of dementia, including Alzheimer's disease and vascular dementia; mild cognitive impairment, which is a condition preceding dementia; and cognitive decline, which is the progressive clinical hallmark of dementia.[19]

Less education is an early-life (younger than 45 years) risk that affects cognitive reserve.[20] Taking this into consideration, the COVID-19-related education crisis[21] that is impacting today's children could contribute decades later to an increase in dementia.

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[15] Maria Florencia Iulita, Garzón Chavez D, Klitgaard Christensen M, et al. Association of Alzheimer Disease with Life Expectancy in People With Down Syndrome. *JAMA Netw Open.* 2022;5(5):e2212910. doi:10.1001/jamanetworkopen.2022.12910

[16] Rosalyn Hithersay, Startin, CM, Hamburg, S, et al. Association of dementia with mortality among adults with Down syndrome older than 35 years. *JAMA Neurol*. 2019;76(2):152-160. doi:10.1001/jamaneurol.2018.3616

[17] Gill Livingstone, *et al* (2020). Dementia prevention, intervention, and care: 2020 report of the *Lancet* Commission. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30367-6/fulltext

[18] Gill Livingstone, *et al* (2020). *Ibid.*.

[19] Michal Schnaider Beeri and Bendlin, B.B (2020). The link between type 2 diabetes and dementia: from biomarkers to treatment. https://www.thelancet.com/journals/landia/article/PIIS2213-8587(20)30267-9/fulltext; Xue M *et al* (2019). Diabetes mellitus and risks of cognitive impairment and dementia: a systematic review and meta-analysis of 144 prospective studies.

[20] Gill Livingston, *et al* (2020). *Ibid.*.

[21] Amar-Singh HSS, Ong Puay-Hoon, Gill Raja, Srividhya Ganapathy, Ng Lai-Thin, Yuenwah San (2022). A National Emergency - Our Children's Learning Loss: Keys to Post-COVID-19 School Recovery in Malaysia. Situation Report and Recommendations. Malaysia. 27th April 2022.

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Asia-Pacific accounted for 63% of the global non-communicable disease (NCD) mortality burden in 2016.[22] Cardiovascular diseases, cancers, diabetes and chronic respiratory diseases are the most prevalent non-communicable diseases (NCDs). In most countries, there has been a minimal NCD mortality reduction during 2000–2016. Dementia risk for populations can be modified through:[23,24]

- Reduction in tobacco use;
- Better control and detection for hypertension, diabetes and cardiovascular risk factors.

For preventing dementia or delaying its onset, it is efficient and cost-effective to strengthen NCD prevention.

Mental and neurological disorders, including Alzheimer's disease, are recognized[25,26] as important contributors to the global NCD burden, sharing common risk factors, including tobacco use, harmful use of alcohol, an unhealthy diet, and lack of physical activity. They can benefit from common prevention responses targeting priority NCDs (cancer, diabetes, cardiovascular disease and chronic respiratory diseases).

Persons with dementia in low- and middle-income countries (LMICs)

Globally, 75% of people with dementia are undiagnosed. In some LMICS, 90% of persons with dementia are undiagnosed.[27]

Furthermore, the impact of Long COVID on the brain, causing cognitive impairment,[28, 29] a precondition for dementia, might in the foreseeable future be linked with an increase in dementia that could be traced back to Long COVID.

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[22] Chalapati Rao and Kelly, M. (2020). Empiricism in non-communicable disease mortality measurement for the Asia-Pacific: lost in translation. https://gh.bmj.com/content/5/11/e003626

[23] Gill Livingston, *et al* (2020). *Ibid.*.

[24] World Alzheimer Report 2014. https://www.alzint.org/u/WorldAlzheimerReport2014.pdf

[25] Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases, 16 September 2011. https://documents-dds-ny.un.org/doc/UNDOC/LTD/N11/497/77/PDF/N1149777.pdf?OpenElement

[26] World Health Organization (2022). Intersectoral Global Action Plan on epilepsy and other neurological disorders 2022-2031. https://www.who.int/publications/m/item/intersectoral-global-action-plan-on-eepilepsy-and-other-neurological-disorders-2022-2031

[27] Serge Gauthier, Rosa-Neto P, Morais JA, and Webster C. 2021 (2021). World Alzheimer Report 2021. Journey through the diagnosis of dementia. September 2021. London: Alzheimer's Disease International, available at: https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf

[28] Hampshire, et al (2022). Multivariate profile and acute-phase correlates of cognitive deficits in a COVID-19 hospitalised cohort. *Lancet*, Volume 47, May 2022. <https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(22)00147-X/fulltext>.

[29] Yu-Hui Liu, et al (2022). One-Year Trajectory of Cognitive Changes in Older Survivors of COVID-19 in Wuhan, China: A Longitudinal Cohort Study. *JAMA Neurol*. 2022;79(5):509-517. <https://jamanetwork.com/journals/jamaneurology/fullarticle/2789919#:~:text=Findings%20In%20this%20cohort%20study,a%201%2Dyear%20follow%2Dup>

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Access to information, services, support and care is deeply uneven. It is especially uneven for persons with dementia in LMICs. This unevenness exists, despite this group constituting nearly two-thirds of all persons with dementia worldwide.[30]

Advocacy and engagement of people living with dementia in decision-making at all levels have resulted in significant progress -– with resources and efforts focused mainly on high-income countries.

In view of the 12 modifiable risk factors for dementia, the potential for prevention is high, especially in LMICs where more dementias occur. Culture, poverty and inequality are key drivers of the need for change. Individuals who are most deprived need these changes the most and will derive the highest benefit.[31]

Against the WHO target of 146 plans by 2025, only 40 countries and territories[32] have developed national/territory policy, strategy or plans for supporting people with dementia and their families. Of these, seven are in Asia and the Pacific.[33,34,35] Only in two cases do plans reflect dementia as a disability.[36]

Gender dimension

Regarding women, the DALYs score due to dementia: about 60% higher in women than in men.[37]

Dementia impacts women more than men. More women live with dementia (female-to-male ratio of 1:69) [38,39] as women:

- Live longer than men;
- Comprise the majority of older adults at advanced ages.

More women die from dementia: women make up 65% of total dementia-related deaths.[40]

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[30] Alzheimer's Disease International (2022). "From Plan to Impact V: WHO Global action plan: The time to act is now," presentation at the 35th Global Conference of Alzheimer's Disease International, London, 9-11 June 2022.

[31] Gill Livingston, *et al* (2020). *Ibid.*.

[32] Austria; Bonaire; Canada; Chile; **China;** Costa Rica; Cuba; Denmark; Dominican Republic; Finland; Germany; Gibraltar; Greece; Iceland; **Indonesia;** Ireland; Israel; Italy; **Japan;** Luxembourg; **Macau, China;** Malta; Mexico; Netherlands; Norway; Puerto Rico; Qatar; **Republic of Korea**; **Russian Federation**; Scotland (UK); **Singapore**; Slovenia; Spain; Sweden; Switzerland; **Taiwan, province of China**; England (UK), Northern Ireland (UK), Wales (UK), United States of America.

[33] World Health Organization (2021). *Ibid.*.

[34] Alzheimer's Disease International (2022). *Ibid.*.

[35] Another seven countries in Asia-Pacific are developing their national dementia plans.

[36] Australia and New Zealand.

[37] World Health Organization, (2020) *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia.

[38] GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. The *Lancet*. Volume 7, Issue 2, E105-125, February 1, 2022.

[39] World Health Organization, (2020) *Ibid.*

[40] World Health Organization, (2020) *Ibid.*.

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Older women are more likely to develop dementia than men of the same age, probably partly because, on average, older women have had less education than older men.[41] This is the case until now. When more girls are educated and have better education than boys, the numbers may be reversed.

Women and dementia care

Women contribute about 70% of care hours globally.

In LMICs, these are primarily daughters and daughters-in-law giving care at home; in high-income countries, these tend to be spouses. Informal care constitutes 133 billion unpaid hours each year globally (about eight hours a day per care partner), equivalent to the work of 66 million full-time workers. [42,43] The care that women provide is critical to the quality of life and outcomes for the persons with dementia in their care.

Care required for people with dementia includes primary health care, specialist care, community-based services, rehabilitation, long-term care, and palliative care.

The Global status report on the public health response to dementia[44] highlighted the following:

- The cost of dementia (medical[45], social[46] and informal[47] care costs), estimated at more than $1.3 trillion globally in 2019, is expected to rise to $2.8 trillion in 2050.
- Informal care accounts for about half the global cost of dementia, while social care costs make up over a third.
- In LMICs, most dementia care costs are attributable to informal care (66%). In high-income countries, informal and social care costs each amount to approximately 40%.

Women's increased likelihood of dementia

Informal dementia care partners are at increased risk of physical, mental, psychological, social, and financial impact leading to higher levels of stress, depression, anxiety

[41] Gill Livingston, *et al* (2020). *Ibid*..
[42] World Health Organization (2021) *Ibid*..
[43] Alzheimer's Disease International, (2022) Plan to Impact V. Available at https://www.alzint.org/u/From-Plan-to-Impact-V.pdf
[44] World Health Organization (2021). *Ibid*..
[45] Medical care: direct health costs incurred by the medical care system including hospital care, medicines, diagnostic tests and visits to clinics.
[46] Social care: care services provided outside of the medical care system, such as community-based services to assist in activities of daily living, and also including long-term institutional care. Source:
[47] Informal care: support and assistance with basic and instrumental activities of daily living and supervision.

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disorder, and social isolation. These, in turn, expose them to increased risk of developing dementia[48,49,50] --- up to six times more likely to do so.[51]

Generally, female care partners report overall higher levels of burden, stress and depressive symptoms than male care partners.[52] Support services, such as training and education on dementia management, psychosocial support, respite services and information for care partners, are mostly available in high-income countries, but less so in LMICs. Where dementia information exists in LMICs, it is mostly confined to urban settings for better educated groups, despite the needs of people in slums and in rural and remote areas for information in languages and formats that they can easily comprehend.

Care partners face stigma, discrimination, challenges and disadvantages that are similar to that experienced by persons with dementia.[53,54] There is, as yet, little policy recognition and few legislative measures that specifically protect the human rights, and respect the preferences of persons with dementia and care partners.[55]

Key messages for ESCAP secretariat policy advocacy:

1. Dementia is a disability.
2. Dementia disproportionately impacts women as persons living with dementia and as informal care partners.
3. As Asia-Pacific is home to two thirds of the global population, it is in this region that leadership on policy changes will benefit the largest number of persons with dementia.

Recommendations for ESCAP secretariat action:

1. Underscore to Governments of the ESCAP membership the importance of early responses on the following:
    1.1. Recognize explicitly in disability policies and programmes that dementia is a disability.

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[48] World Health Organization (2021). *Ibid*

[49] Alzheimer's Disease International, (2019). World Alzheimer's Report 2019: Attitudes to Dementia. Available at https://www.alzint.org/u/WorldAlzheimerReport2019.pdf

[50] Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*,*11*(2), 217–228. https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/

[51] Norton, M. C., Smith, K. R., Østbye, T., Tschanz, J. T., Corcoran, C., Schwartz, S., Piercy, K. W., Rabins, P. V., Steffens, D. C., Skoog, I., Breitner, J. C., Welsh-Bohmer, K. A., & Cache County Investigators (2010). Greater risk of dementia when spouse has dementia? The Cache County study. *Journal of the American Geriatrics Society*, *58*(5), 895–900. https://doi.org/10.1111/j.1532-5415.2010.02806.x

[52] Alzheimer's Disease International (2015). Women and Dementia: A global research review. Available at https://www.alzint.org/resource/women-and-dementia-a-global-research-review/

[53] World Health Organization (2021). *Ibid.*.

[54] Alzheimer's Disease International (2019). *Ibid.*.

[55] World Health Organization (2021). *Ibid.*.

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1.2. Acknowledge the critical role of, and contributions by, informal care partners in supporting persons with dementia and national/local dementia responses.

1.3. Establish channels for informal care partners to share their lived experiences of dementia care and how they and persons with dementia are impacted by stigma, discrimination, and challenges.

1.4. Generate, in collaboration with civil society dementia and care partner advocates, country-level data for evidence-based dementia-related policymaking, programming and budgeting.

1.5. Review/develop/strengthen dementia-related policies and plans and allocate resources, using pro-poor and gender-sensitive lenses, as well as legislative measures to protect the human rights of persons with dementia, their families and care partners in line with the Convention on the Rights of Persons with Disabilities.

1.6. Encourage cooperation between dementia advocates for empowering environmental design and multisectoral partners working on accessibility of the built environment and ICT ecosystems.

2. Partner with entities in the ESCAP region that are committed to working on dementia, in activities to generate knowledge products for consideration by the Governments of the ESCAP membership. The activities could include but are not limited to, for example, the following:

2.1. Convene webinars on dementia issues, in relation to poverty, gender and other parameters, to explore in depth the subregional dimensions of this issue, with a view to identifying elements for developing model national action plans, related good practices, and potential for partnerships to strengthen responses at all levels and across sectors for ESCAP subregional reference.

2.2. Develop model dementia plans, including care partner coverage for action at national, State/ region/ province/ prefecture/ county/ municipality/ city/ village levels that could be adapted to contain features that would be better suited to each ESCAP subregion, member State and partners at all levels.

3. Develop (with multi-stakeholder engagement) for Asia-Pacific the world's first regional advocacy response focusing on encouraging support for persons with dementia living in low- and middle-income circumstances.

4. Highlight Asia-Pacific dementia issues in the agendas of legislative meetings proposed for consideration by Governments and in ESCAP secretariat knowledge products circulated and uploaded for the attention of Governments, civil society and private sector entities.

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