



**World Dementia
Council** Leading the Global Action
Against Dementia

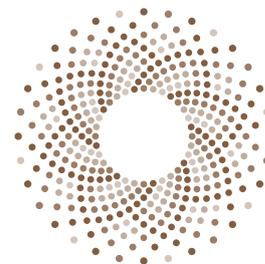
Global dialogue on dementia and an ageing society: Reflections

The dementia landscape project

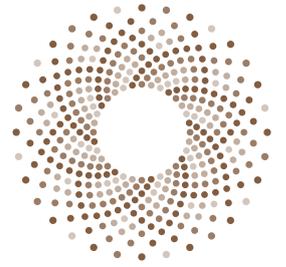
Essays from international leaders in dementia



Contents



1. Introductions	
Dealing with dementia in ageing societies and in the time of Covid	3
Sarah Lenz Lock Senior Vice President, Policy & Brain Health, AARP and Executive Director, Global Council on Brain Health	
Dementia and an ageing society: The need for a synergistic approach	6
Professor Shekhar Saxena Professor of the Practice of Global Mental Health at Harvard T H Chan School of Public Health	
2. Issues in the dementia-ageing nexus	
The decade of healthy ageing: An opportunity to ensure that older people with dementia can also benefit from longer and healthier lives	8
Alana Officer Senior Health Adviser, World Health Organization (WHO)	
Tackling stigma through education and engagement	11
Professor Carrie McAiney Associate Professor in the School of Public Health Sciences, University of Waterloo	
We are preventing some dementias now, but how?	13
Professor Vladimir Hachinski Distinguished Professor, Western University, Canada	
Dementia and an ageing society	15
Professor Jane Rylett Scientific Director, Canadian Institutes of Health Research (CIHR) Institute of Aging	
Dementia, ageism, ableism, and human rights	17
Silvia Perel-Levin Chair of the NGO Committee on Ageing in Geneva and representative to the UN of the International Network for the Prevention of Elder Abuse (INPEA)	
Ageism in an ageing society	19
Professor Myrra Vernooij-Dassen Professor Emeritus, Radboud University Medical Centre	
The need for families and employers to better understand the hidden financial costs of dementia	21
Lorna Sabbia Head of Retirement and Personal Wealth Solutions, Bank of America	
3. Perspectives from the Australian Government	
Investing in better support for people living with dementia	23
Robert Day Assistant Secretary, Dementia, Diversity and Design Branch, Australian Government Department of Health	



1. Introductions



Dealing with dementia in ageing societies and in the time of Covid

Sarah Lenz Lock

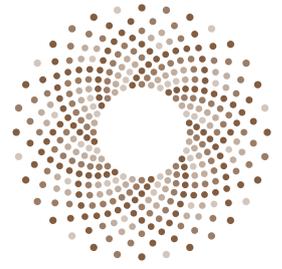
Senior Vice President, Policy & Brain Health, AARP
and Executive Director, Global Council on Brain Health



In order to assess the progress that the G8 countries have made since 2013 towards the ambitious goals of advancing dementia research, care, awareness-raising and prevention by 2025, the World Dementia Council has convened 9 different conversations exploring different aspects of dementia policy. There are four more discussions planned for Autumn 2021. Unfortunately, the prevalence of people living with dementia has increased since 2013. We expect that the number will continue to rise as our global population continues to age. The World Health Organization reports that around 55 million people have dementia across the globe, with over 60% living in low- and middle-income countries. “As the proportion of older people in the population is increasing in nearly every country, this number is expected to rise to 78 million in 2030 and 139 million in 2050.” With increasing age being the greatest single unmodifiable risk factor for dementia, these issues are inextricably intertwined.

In the summer of 2021, 50 people gathered by video conference to discuss how dementia fits within broader aging policies around the world. Professor Shekhar Saxena and I chaired the discussion which opened with Professor Alexandre Kalache and Dr. Adelina Comas-Herrera sharing their perspectives. Much of the conversation of our dialog in June was about the under-resourced way all countries deal with our most vulnerable citizens. Our approach was very matter of fact about it. The grim realities of how few countries are prepared to cope well with aging people in general, whether those countries are relatively economically wealthy or poor, is, frankly, even more grim when it comes to how those countries’ systems deal with those people aging while living with dementia.

We live in the time of Covid. As of Sept. 19, 2021, out of approximately 229 million reported cases worldwide, there have been 4.7 million deaths. We know that Covid-19 disproportionately impacts older people. People over age 65 having a 23 times greater risk of dying from Covid, and 80% of the hospitalizations have been in people over age 65. In the face of this vicious little virus, older people’s immune systems are more likely to fail to clear the pathogen compared to younger people’s. In the United States,



80% of those dying are over the age of 65. While many of those dying from Covid have underlying diseases, of 14 chronic health conditions evaluated for patients receiving health care under our Medicare fee for service insurance program, the most common health care coverage for our older adults, it is those older people with dementia who have the greatest risk of dying. This was true regardless whether they lived at home or in long term care settings. Other research in other countries found those living with dementia in long term care settings had a higher probability of dying.

While theories range from easier transmission of Covid because people with dementia can't take the same precautions to avoid the disease, to more co-morbidities found in people residing in nursing facilities, the fact is that we simply do not know why the human immune system becomes less resilient with age resulting in more cases of dementia. And we don't know why those with dementia seem most vulnerable to Covid either. Is there something more fragile about the brains of people who already have dementia that make them less likely to recover from Covid? It seems to me that we don't have enough people even trying to ask those questions, let alone answer them.

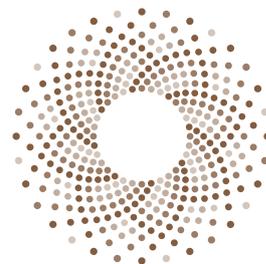
The stark reality of how little societies value older adults and those with dementia in particular along with the fact that we seem unprepared to deal with either issue could not be more clear. In Alberta, Canada as unvaccinated patients now critically ill due to Covid-19 have overwhelmed their hospitals, the Premier announced a public health state of emergency with new restrictions put in place to “maximize our health-care capacity.” Their intensive care units have been so overwhelmed that they are preparing to triage patients with the best chance of survival. Who will Alberta Health Services choose to exclude from the ICU under their 52 pages of guidance? In the first phase, it's those with severe dementia, burns, massive stroke or deep coma. In the second, it's those over age 60 with a poor chance for survival. Triage is such a polite term to describe the protocol health care providers are now told will be followed. That is to give up first on those in most need of their help.

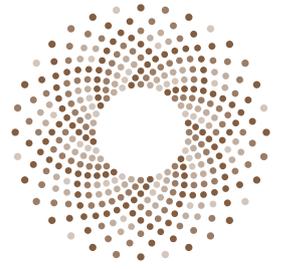
While heart-breaking, it is a deeply gut-wrenching practical expression of not valuing those who are aging or those with dementia as much as other people. Sadly, as of Sept. 16th, Alberta had 268 patients in an intensive care system designed for 173, and so their health care system must choose who they will fight for and who they will not. This is in the lucky, relatively wealthy country of Canada, during a pandemic raging now for more than a year-and-a-half. Many people across the world will never have access to any health care system – period. The vulnerability of those people aging with dementia is even more intensified in countries outside the G8 countries which came together to recognize the problem dementia poses to their societies back in 2013. The fifty people in this dialogue understand this sad truth. The question is what are we going to do about these issues. How do we raise the awareness and urgency of these issues during the pandemic when our best health and economic systems are already fragile and breaking?

In the case of Covid, it's not that older people's immune system fails. It is that Covid appears to make the immune system of older people go into hyper-drive, clotting blood flows and swelling cells, even to the extent that it blocks blood flow to the brain causing neurons to die. Biologically speaking, our bodies' immune functions throw all that we have into trying to fight off the invader. Conversely, politically speaking, many of our societies' health and economic functions simply accept that the combination of age

and dementia are too great an adversary. Our political systems fail to mount a vigorous defense in the face of these intertwined biological vulnerabilities. That is why our systems have failed us all around the world on both these issues.

Let's redouble our efforts to make the goals we set out in 2013 closer to reality. To do so, we have to align our values and our resources, combining our efforts to improve the research and care for both aging and dementia all across the globe. It is up to us to go into hyper-drive to defend older people and those with dementia so that our political systems see it is a fight worth having and one possible of winning. Even if we have to go past 2025 to do so.





Dementia and an ageing society: The need for a synergistic approach

Professor Shekhar Saxena

Professor of the Practice of Global Mental Health at
Harvard T H Chan School of Public Health



We live in world of aging societies and also in one with a high and increasing prevalence of dementia. Though dementia is not exclusively a disease of old age, the vast majority of people living with dementia are older adults. How should global health and development agencies, governments and communities plan to respond to these two distinct but overlapping challenges? I propose that a synergistic approach is necessary, effective and efficient.

Let us begin with the global agencies. World Health Organization has healthy aging as well as dementia as its priorities and the technical teams work very closely together to provide data, evidence and policy advice that is compatible and complementary. Both these areas are covered within the rubric of universal health coverage (UHC)¹ - meaning that all individuals and communities receive the health services they need without suffering financial hardship. UHC should include the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course. In addition, WHO's Global Action Plan on the Public Health Response to Dementia (2017-2025)² links explicitly to WHO's Global Strategy and Action Plan on Aging and Health (2016-2020). WHO's 2021 Global Status Report on Public Health Response to Dementia³ posits this important issue within the larger context of an aging society. World Bank recognizes the economic impact of an aging society and mental neurological disorders and assists countries⁴ in preparing for these in a synergistic way. Global civil society organizations like Helpage International,⁵ Alzheimer's Disease International⁶ and World Dementia Council⁷ too keep both of these challenges clearly in perspective, though their focus and mandate may be on one or the other.

National governments are increasingly becoming aware of the dual and related challenges of their aging populations and a rising prevalence of dementia and are formulating and implementing plans to respond to them. Majority of high and middle income countries have policies on healthy aging and about a quarter of all countries have integrated or specific policies or strategies on dementia.⁸ Some others are in the process of developing these and it will be highly desirable if the policies/plans on healthy aging and dementia are either integrated or synergistic. At the level of health and social care, it is even more necessary to integrate services to achieve efficiencies and cost-savings. Integration of dementia services within services for the elderly also reduces stigmatization. Of course, there are elements of diagnosis and care for persons living with dementia that need to be specifically provided as a part of the services but

1. [https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-\(uhc\)](https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc))

2. <https://www.who.int/ageing/GSAP-Summary-EN.pdf>

3. <https://www.who.int/publications/i/item/9789240033245>

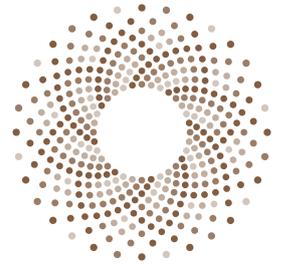
4. <https://documents1.worldbank.org/curated/en/171061542660777579/pdf/132213-PUB-PUBLIC-PUBATE-11-19-18.pdf>

5. <https://www.helpage.org/>

6. <https://www.alzint.org/>

7. <http://www.worlddementiacouncil.org/>

8. <https://www.who.int/publications/i/item/9789240033245>

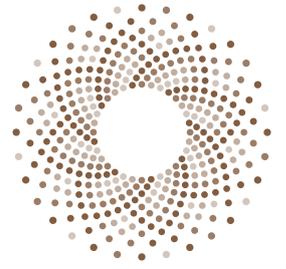


a large proportion of care elements are common based on the extent and type of needs rather than on the exact neurological diagnosis. This is especially true for resource poor settings in low, middle as well as high income countries, that rely on non-specialized and informal workforce to provide the large proportion of its health and social services.

Lastly, from the perspective of persons and families living with age related health issues and dementia, the top priority issues are access to appropriate, adequate and rights-based care. Most people within the elderly age group need or will need health and social care. Very often they have multiple co-morbidities and co-disabilities. These may include neurocognitive elements. As of now, effective risk reduction and preventive interventions⁹ for many of them are the same (what is good for the heart is also good for the brain!). Prevention messages targeted at the general population are likely to be much more effective if they are framed within healthy lifestyle and healthy aging contexts rather than for specific age related diseases. Similarly, general and supportive care especially among the elderly is indicated much more by the disability profile rather than by the diagnosis. A frail elderly person living with multiple physical diseases but without dementia may need care that has many elements that are common to care for a person living with dementia. Health and social care should be needs and rights based rather than demand or affordability based. Unfortunately, most countries and communities are not able to achieve this objective at present even if they are signatories to lofty declarations including as a part of the United Nations Sustainable Development Goals.¹⁰ Synergizing the efforts on care for persons living with dementia within the needs of all people within an aging society can assist in achieving these objectives.

9. <https://www.who.int/publications/i/item/risk-reduction-of-cognitive-decline-and-dementia>

10. <https://sdgs.un.org/goals>



2. Issues in the dementia-ageing nexus



The decade of healthy ageing: An opportunity to ensure that older people with dementia can also benefit from longer and healthier lives



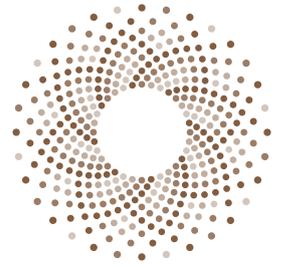
Alana Officer
Senior Health Adviser,
World Health Organization (WHO)

A longer life is an incredibly valuable resource. It provides the opportunity to rethink not just what older age might be, but how our whole lives might unfold. Yet the extent of the opportunities that arise from increasing longevity depend heavily on one key factor: health.

Health is central to our experience of older age and the opportunities that ageing brings. If people are experiencing these extra years of life in good health, their ability to do the things they value will be little different from that of a younger person. If these added years are dominated by declines in physical and mental capacity, the implications for older people and for society are much worse. As with many other chronic conditions, dementia is more common with increasing age (see figure 1) but it is not a normal part of ageing.

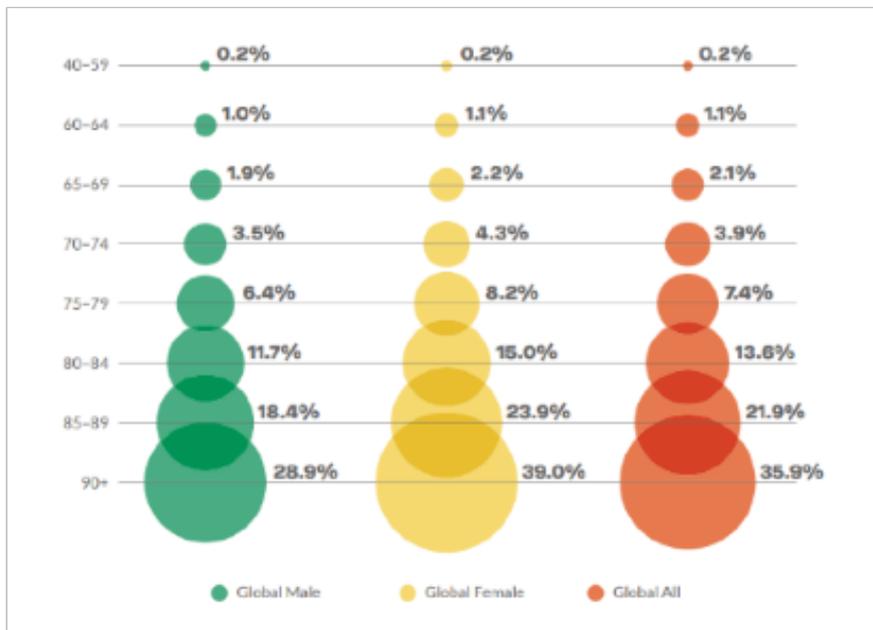
It is often assumed that increasing longevity is being accompanied by an extended period of good health. Evidence is mixed and there are huge and unacceptable variations within and across all countries (for example, if you were a 65-year-old female in Slovakia today you could only expect to live 4 years in good health, whereas if you lived in Norway you could expect 16 years).

The United Nations General Assembly, recognizing that the world is far from prepared for ageing populations - declared 2021 – 2030 the Decade of Healthy Ageing. The plan for the Decade of Healthy Ageing is aligned to the last ten years of the 2030 Agenda for Sustainable Development and was developed through a broad consultative process led by Member States and engaging UN Agencies and international organizations, along with non-State actors (civil society organizations, representatives of older people's associations, professionals, academics and the private sector). The Decade is intended as a global collaboration that will bring together the diverse sectors and stakeholders that



developed the Decade – to take concrete and concerted action improve the lives of older people their families and communities and ensure that no one - including older people with dementia - is left behind.

Figure 1 Global dementia prevalence rates by sex and age



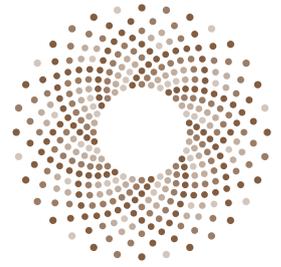
(source [Global status report on the public health response to dementia \(who.int\)](https://www.who.int/publications/m/item/global-status-report-on-the-public-health-response-to-dementia))

The UN Decade prioritizes four actions:

- Change how we think, feel and act towards age and ageing
- Ensure that communities foster the abilities of older people
- Deliver integrated care and primary health services responsive to older people
- Provide access to long-term care for older people who need it

These four action areas are all relevant to improving the lives of people with dementia, their families, caregivers and the communities in which they all live. Globally one in every two people are ageist against older people. Ageism is associated both with the onset of dementia and its effects on older people’s health, wellbeing and social participation. For example, research by Dr Becca Levy from the Yale School of Public Health has shown, with negative stereotypes, older people have a higher risk of dementia. They have greater accumulations of plaques and tangles in the brain, the biomarkers of Alzheimer’s disease, and a reduced size of the hippocampus, the part of the brain associated with memory. The New UN Global report on Ageism¹ also highlights that how ableism and ageism intersect and are mutually reinforcing. By tackling ageism, we can improve understanding on ageing and help reduce stigma and discrimination towards people with dementia. The Global report sets out the evidence on the three strategies that work including intergenerational contact, education and policies and laws.

1. <https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/combating-ageism>



By making communities more Age-friendly - they can become better places to age with and without dementia. However, this will require that local actions take into consideration the lived experience of people with dementia and include dementia friendly initiatives in their response. Opportunities already exist to make this happen that can be scaled. The WHO supports a Global network for Age-friendly cities and communities that currently includes over 1300 communities from 51 countries covering more than 260 million people. New Guidance entitled Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives outlines initiatives² that can be used by these communities and others to make their places more inclusive of persons with dementia.

By providing integrated care and primary health services responsive to older people we can ensure that people receive comprehensive assessments and a single care plan that address all their health care needs including those related to dementia. By improving access to and the quality of long-term care over the next ten years more people with dementia will have the opportunity to live lives with respect and dignity. A range of guidance and tools are available Ageing and Health unit (who.int)³ to support countries to develop and implement integrated services and pathways for older people with complex health and social care needs, shifting the delivery of care away from acute hospitals towards community based, planned and coordinated care.

As WHO Director-General Dr Tedros Adhanom Ghebreyesus said in a recent paper in Nature Ageing⁴ it takes knowledge to transform the world to be a better place to grow older. To realize the potential of the UN Decade for healthy ageing we have built a multilingual knowledge exchange Platform that:

- can mobilize diverse stakeholders across multiple sectors;
- offers news ways to connect and engage with each other;
- provides access to diverse types of knowledge

The UN Decade Platform links to other knowledge from across the world including the WHO Global Dementia Observatory Knowledge Exchange Platform.⁵ In this way, Decade Stakeholders will be able to find specific knowledge on dementia and people working on dementia can access and co-produce knowledge on healthy ageing.

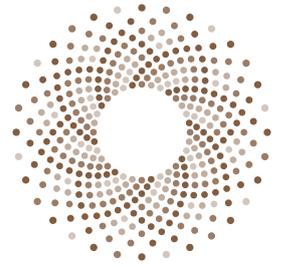
We will all benefit from reduced ageism, improved health and long-term care and more age-friendly communities – the outcomes prioritized in the plan for the UN Decade of healthy ageing. The greatest costs to society are not the expenditures made to foster healthy ageing or to care for people with conditions like dementia. The greatest costs are the benefits that might be missed if we fail to make the appropriate adaptations and investments. These benefits include longer AND healthier lives, enhanced skills and knowledge, greater financial security and ensuring all people live lives with dignity.

2. <https://www.who.int/publications-detail-redirect/9789240031531>

3. <https://who.cloudflareaccess.com/cdn-cgi/access/login/cm.who>

4. <https://www.decadeofhealthyageing.org/find-knowledge/resources/publications/nature-ageing-it-takes-knowledge-to-transform-the-world-to-be-a-better-place-to-grow-older>

5. <https://www.decadeofhealthyageing.org/find-knowledge/resources/databases-repositories/detail/who-global-dementia-observatory-knowledge-exchange-platform>



Tackling stigma through education and engagement

Professor Carrie McAiney

Associate Professor in the School of Public Health Sciences, University of Waterloo



Alzheimer's disease and other dementias are amongst the most stigmatized conditions in the world. Stigma involves having negative thoughts and beliefs about a group of people because of a characteristic that members of the group share – such as living with dementia. These negative thoughts can create prejudice and lead to discrimination.

For people living with dementia, stigma can seem to exist everywhere.

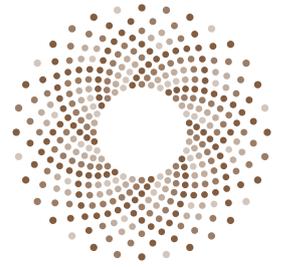
It often starts at the time of diagnosis, where there can be an immediate assumption that because a person now has dementia they are no longer capable to make decisions or contribute to society. This can undermine an individual's confidence, leading to self-stigma, where negative attitudes are internalized, and the individual begins to doubt their abilities and self-worth.

Stigmatizing experiences may continue. Family, friends, and neighbours may not understand dementia and may make false assumptions about the person. Some may be afraid or embarrassed to be around the person with dementia and may reduce or even eliminate their connections with them. Health and social care providers may assume persons with dementia cannot, or are not interested, in participating in decisions about their care, and may direct their conversations to others instead of speaking to the person with dementia directly.

These experiences can be further compounded by the lack of understanding of dementia among the public. As a result of this limited understanding, persons living with dementia may not be provided with opportunities to participate in social, wellness, and spiritual activities. Some may also be subject to negative comments and insensitive 'jokes' about dementia.

There is often a limited understanding and appreciation that dementia progresses in stages, and that the rate of progression as well as the specific changes a person experiences varies across individuals. Particularly in the media, there tends to be a focus on negative aspects of dementia including personal expressions (behaviours), often implicitly suggesting that this is the typical if not universal experience for persons living with dementia.

Importantly, there is a lack of attention and understanding regarding the capabilities of persons living with dementia and the important contributions they can – and do – make.

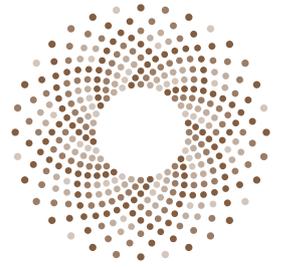


This includes persons living with dementia being involved in decisions about their care and their future, and the activities they engage in to support their well-being. For some people living with dementia, their contributions extend to other areas as well including the development of services and supports, participation in research, and advocacy for the rights of persons living with dementia.

Combating stigma requires a multi-pronged approach. Education for all individuals – including the public, health and social care providers, employees in service industries (such as banks, the post office and grocery stores), as well as children and youth – is essential. These educational activities should include learning about what dementia is, the individualized nature of dementia, and how stigma impacts persons living with dementia.

In addition to education, there is a need for opportunities to engage with persons living with dementia. Research has shown the value of providing opportunities to spend time with persons living with dementia and to see the contributions they make. Engaging with persons with dementia pushes all of us to question our stigmatizing beliefs and to see the uniqueness and value of each person living with dementia. For persons with dementia, having the opportunity to see other individuals with dementia who are active and engaged in many aspects of life may help combat self-stigma and inspire action.

Stigma is a global challenge. We need to work together with persons living with dementia to identify effective interventions and strategies and share them broadly to help tackle stigma and its negative impacts, and to increase opportunities for persons living with dementia to live in ways that bring them meaning, purpose, and joy.



We are preventing some dementias now, but how?



Professor Vladimir Hachinski

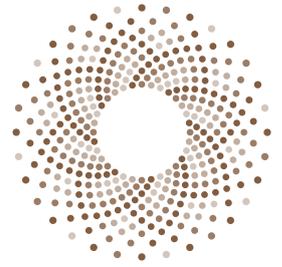
Distinguished Professor,
Western University, Canada

“What is the hardest thing to see” asked Johan Wolfgang Goethe, the German poet and polymath. “That what is in front of our eyes” he answered himself.

Prevention of dementia has become near synonymous with finding a drug that will slow it or stop it. However, no drug has yet slowed the progression of dementia with the dubious exception of aducanumab. What has been before our eyes, but we have not seen, is that we have been preventing some dementias in some high-income countries, including Canada. In its largest province, Ontario, with a population of 14 million we showed a decline incidence (cases/1000) of 7% over 12 years. That meant that, in the last year of the study, 4000 individuals, families and the health care system were spared the personal tragedy of dementia and the associated family, social and economic costs.

However, we do not yet know what we are doing right or what else accounts for the decline. A partial answer might be that we are preventing strokes that, of themselves, double the chances of developing dementia. We showed that over the same 12-year period stroke incidence fell by 32%. However, the answer probably comprises other factors. We know that environment, socioeconomic factors and individual risk and protective factors all matter. As far as the literature attests, no study has looked at all relevant factors together at once. Fortunately, we have just been funded by the Weston Brain Institute to undertake such a study for Canada. It is to the Weston's great credit that, although their focus is neurodegeneration, they are enabling a much broader approach. This multimodal pragmatic paradigm is in a David and Goliath competition with the single minded, attractive and elusive idea of finding a silver bullet drug that will slow or stop dementia backed by the ample resources of pharmaceutical companies.

Luckily, the availability of new databases, new analytic techniques and new researchers with more open minds and belief in open science, will allow for a more comprehensive approach. Prevention needs to take into account all relevant factors: Environmental, socioeconomic and individual. On the other hand, prevention has to be customized. The factors vary from one area to another and from one individual to the next. Hence, targeting the most important and/or tractable factors for a particular location or person would prove the most affordable and hence cost effective. Cost can be considered in terms of money, time or effort. For maximal effectiveness, stroke, heart disease and dementia (The Triple Threat) should be prevented together. They share the same risk factors, pose risks for each other and together account for the greatest number of deaths and disability adjusted life years (DALY's) in the world.



An integrated growing campaign to prevent all three would result in huge savings of lives, misery and money. However, the campaign would need to shift the emphasis from fear: “If you do not do this, you will have a stroke, a heart attack or dementia” to: “Brain health: By doing this you will have a healthy brain to enjoy life to the fullest and decrease your chances of falling victim to one of the Triple Threats to your brain and your life.”

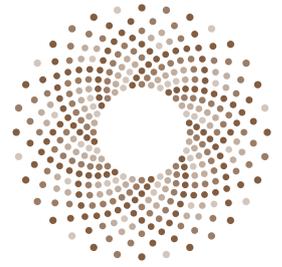
The pandemic has helped us to see more of what is in front of our eyes. The close relationship of brain, mental and social health and the realization that if we are to curb the Triple Threat, it will need to be done in a comprehensive, customizable and cost-effective approach unified by the overarching goal of brain health. Governments, funding agents and doctors know that prevention by multiple known and yet to be discovered, measures does not have the glamour or profit of a drug, but it is yielding results and we need to multiply and amplify the approach immensely with their help.

We have been preventing vascular (blood vessel) diseases very successfully. Coronary heart disease, stroke and without knowing it, some dementias. One of the reasons why we have not noticed the dementia decline is that we equate it with “Alzheimer disease”. This pathology only exists in the pure form in the dominantly inherited type, which only accounts for 1-3% of cases of “Alzheimer disease”. In the elderly dementia results from up to 8 diverse pathologies in cases diagnosed as “Alzheimer disease” and even these do not account fully for the dementia.

Can we find a way forward through all of this confusion? Alexander the Great, confronted with a nigh impossible task to untie the Gordian knot, unsheathed his sword and cut right through it. Can we cut through the complexity with a pragmatic sword? What matters is whether any of the multiple pathologies contributing to dementia are treatable and preventable. At the moment only one has been proven to be treatable, the vascular component. It is present in all major dementias, ranging from 61% in frontotemporal dementias and 80% in “Alzheimer disease”, moreover, the presence of a vascular component in tandem with Alzheimer pathology doubles the chances that the individual will develop dementia. But how does one identify the vascular component? One simple way is to apply the ischemic score. It is no different in predicting progression to dementia than APO E4, the strongest risk factor for developing late stage Alzheimer disease. The difference is that we cannot change our genes, but most of the items making up the ischemic score are treatable and preventable conditions.

This is the vascular cognitive impairment approach: Any cognitive impairment associated with or caused by vascular risk factors or disease. It covers the range of symptomless brain infarcts (death of tissue due to a blocked blood vessel) and hemorrhages to full blown dementia. The reasons for the decline in incidence of coronary heart disease, stroke and some dementias almost certainly goes beyond treating vascular disease. But it is a start and we know how to treat and prevent vascular disease now. It is in front of our eyes.

Dementia is being prevented in several countries, but we do not know yet how. Let’s find out how and apply the lesson worldwide.



Dementia and an ageing society

Professor Jane Rylett

Scientific Director, Canadian Institutes of Health Research (CIHR) Institute of Aging

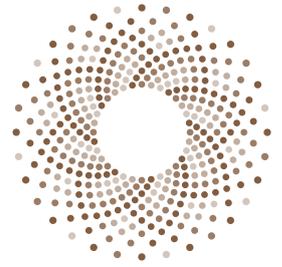


Population demographics are shifting around the world, with the proportion of older adults increasing rapidly in many countries. For example, in Canada, this is the first time in history where the proportion of older adults is greater than that of children under the age of 14 years.¹ While population ageing began in high-income countries and is often related to an increase in life expectancy, this change is now being seen in many low- and middle-income countries as well. This signals a shift in the roles that older adults may play in societies and identifies a need for change in the approaches to and provision of care, health services and housing for older persons.

The age at which someone is thought of as an older adult or as elderly can be subjective, hard to define and can differ between cultures. This can be marked by certain life events, but it is commonly considered that individuals enter older adulthood in the range of the seventh decade of life and beyond. However, when reflecting on the health and wellbeing of older adults and the complex challenges of ageing, it is important to consider biological or physiological ageing and not only chronological age or the number of years that a person has lived. Ageing is often considered to be synonymous with the chronological age of an individual, but this is generally not a good indicator of how well a person may be ageing. Individuals of the same chronological age can have very different risks for developing age-related health disorders because they are in fact ageing at different rates.

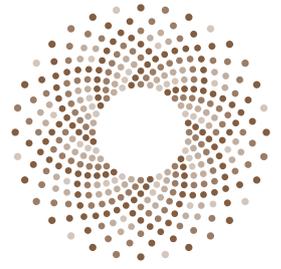
Several inter-related factors play a critical role in determining biological age, including accumulated life course factors, demographics, physical activity and epigenetics (how behaviours and environment can cause changes in the way genes are expressed). An individual's health and activities across the life course can profoundly alter health in ageing. These factors can impact overall health status leading to a gradual decrease in physical and mental capacity, and can provide insight into both life-span and health-span as well as the risk for age-associated diseases, including dementia. It is important to consider the physical and mental functional abilities of an individual relative to their age and not just consider their chronological age. Selective changes in functional abilities can be associated with more rapid ageing in some individuals and this underscores the potential need for increased support and care at an earlier point in time than would be predicted based on chronological age alone. This selective loss of function also emphasizes the need for greater understanding of those factors that can sustain functional abilities.

1. <https://www150.statcan.gc.ca/n1/pub/11-402-x/2011000/chap/seniors-aines/seniors-aines-eng.htm>



Brain ageing also progresses at varying rates in different individuals, with structural and functional changes appearing at an earlier age in those undergoing more rapid biological ageing. Moreover, evidence is emerging that some brain areas can age more rapidly than others, with potential impact on the development of age-related neurodegenerative changes. A faster-running epigenetic clock – or older epigenetic age – has been associated with poorer health and function as well as decreased cognitive ability. Faster biological ageing can intersect with genetic factors such as expressing the Apolipoprotein E4 (Apo E4) genotype which is associated with increased brain ageing and an increased risk for dementia. More research is needed to identify the relationship between biological ageing and increased disease risk and rate of progression. Are there risk reduction strategies and interventions that can delay the rate of biological aging or even attenuate age-related decline in cognitive function and the development of dementia?

Regarding the impacts of ageing on human health, it is necessary to increase our understanding of conditions and processes that promote healthy ageing. There should also be a move to balance the development of programs that sustain wellbeing and growth with those that evaluate adaptations to age-related change. Older adult populations are increasingly diverse in terms of capabilities and challenges, with increased risk for chronic diseases that negatively influence brain health. In terms of biological ageing, it is important to establish metrics for increased vulnerability to age-related health problems and to monitor the effects of interventions, including modifiable risk factors, on the ageing brain. This knowledge will facilitate clinical trials with cohorts that may be enrolled by biological age and increased risk of cognitive decline rather than by chronological age. This would be useful, for example, to test strategies for slowing biological ageing, promoting brain health and reducing dementia. One outcome of these initiatives will be to better inform the development of public health and health service approaches to support the ageing population and promote resilience and the maintenance of intrinsic capacity and functional abilities.



Dementia, ageism, ableism, and human rights

Silvia Perel-Levin

Chair of the NGO Committee on Ageing in Geneva and representative to the UN of the International Network for the Prevention of Elder Abuse (INPEA)



While dementia is not an inevitable part of ageing, the risk of getting dementia increases with age placing dementia at the intersection of ageism and ableism. People living with dementia experience age discrimination in addition to the stigma and discrimination associated with dementia and other disabilities. Age and dementia take over as the main descriptors of a person cancelling their personhood with specific personality, abilities, or history.

Older persons represent the most heterogenous group in the population. And yet, we are all considered in the same way, with numerous assumptions and stereotypes. People living with dementia may be at different stages of a sometimes long and slow process of cognitive decline. And yet all persons with dementia are put in the same basket and are denied their fundamental right of exercising their legal capacity, choosing where to live and with whom and in many cases losing their freedom of movement or participation in social, economic and political life. Assuming we are all the same simply because we are at certain age or because we have acquired a disability or have been diagnosed with dementia, is not only against the Convention on the Rights of Persons with Disabilities (CRPD), but is also immoral and unethical.

According to the CRPD all persons have the right to live independently and to be included in the community, in dignity wherever they want to live and with whom. However, deprivation of their autonomy and independence, their liberty, and involuntary institutionalisation are only too common.^{1,2} Their rights are routinely violated and many fail to see the injustice.

Growing old, in any condition, does not mean that we should stop doing what we like doing or indeed what we may be able to do. We are forced to retire and to give up life as we knew it, simply because we reached a certain age or/and because we may experience physical or mental decline and we may have been diagnosed with dementia. If we wish to work, we should be able to do so and train throughout our lives.³ On the other hand, some people are forced to work as they cannot afford to retire. We are looked at through a lens of the impediments with stereotypes, assumptions, and prejudice.⁴

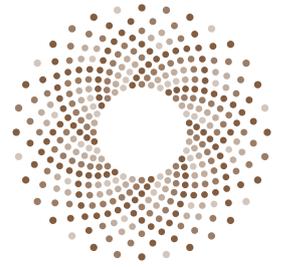
Assumptions about older persons can lead to wrongly perceive a functional impairment as a natural part of ageing, therefore older persons themselves may not self-identify as having a disability. The age at which a disability is first experienced often affects an individual's sense of identity. But persons who acquire a disability at younger age and

1. CRPD

2. <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>

3. <https://www.lse.ac.uk/cpec/assets/documents/CPEC-Covid-Desinstitutionalisation.pdf>
International Labour Organization: ILO declaration on fundamental principles and rights at work and its follow-up, International Labour Organization, 1998. <https://www.ilo.org/declaration/lang-en/index.htm>

4. Ayalon, Liat et al. Participation of Older Persons With Mental Health Conditions and Psychosocial Disabilities in the Labor Market, *The American Journal of Geriatric Psychiatry*, Vol. 29, Issue 10, 1033 - 1037



persons who acquire impairments in old age, face both common and distinct challenges.⁵ The disability movement rejects the medicalized model and focuses on the societal barriers that impede persons with disabilities from fully exercising their rights. Persons living with dementia seem to be excluded from that paradigm because of old age. We need a rights lens and focus on the barriers and on what we are being denied - to be considered as individual human beings with human rights.

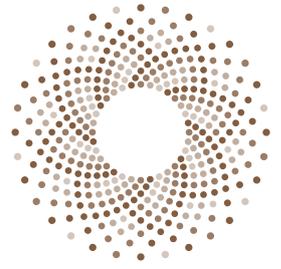
Older persons are rarely consulted in decisions that are relevant to their own lives meaning that their specific situation remains largely unknown and unaddressed. Covid-19 amplified ageism in multiple ways. Examples abound including in the way the media and public service announcements portray older persons, in social media demonization, in discriminatory practices such as enforced confinement for older persons, non-acceptance to hospitals and age-based triage, in the cancellation of health care treatments, rehabilitation and essential services, in the lack of access to information and information tools and above all in the absence of the voice of older persons.⁶

Even though most international human rights treaties apply in principle to people of all ages, specific reference to older persons is rare, including in CRPD resulting in the lack of adequate protection of the rights of older persons, including those living with dementia. According to an analytical report by the Office of the High Commissioner for Human Rights (OHCHR), the assumption that existing United Nations human rights mechanisms, in particular the human rights treaty bodies, can give significantly greater time and attention to the human rights of older persons is unrealistic and impractical. The silence, neglect and relative invisibility of the rights of older persons are so widespread and systemic in the international human rights system that fundamental change is required.⁷ A UN Convention on the rights of older persons can assist governments to respect, protect and fulfill our rights. It will raise awareness that we all have the same rights and that we should all age free of discrimination. We need a solid, legal foundation to end systemic ageism. An international convention will provide a definitive, universal position that age discrimination is morally and legally unacceptable. It will make more visible the rights of people living with dementia and will also strengthen the application of CRPD and other treaties, as all rights are interrelated and interdependent.

5. https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/11/CRPD_CSP_2020_3.pdf

6. Report by the Independent Expert on the enjoyment of all human rights by older persons to the UN General Assembly A/75/205 Impact of the coronavirus disease (COVID-19) on the enjoyment of all human rights by older persons <https://www.ohchr.org/EN/Issues/OlderPersons/IE/Pages/Reports.aspx>

7. <https://social.un.org/ageing-working-group/documents/eleventh/OHCHR%20HROP%20working%20paper%2022%20Mar%202021.pdf>



Ageism in an ageing society

Professor Myrra Vernooij-Dassen

Professor Emeritus, Radboud University
Medical Centre



In June 2021 during the pandemic WDC organised a Global Dialogue on Dementia and Ageing Society in the context of ageing societies all over the world. Becoming old is desirable, but being old comes with ambivalence. In many places in the world older adults are confronted with declining esteem and ageism. I want to raise the point of ageism and its dangers for healthy ageing and cognitive functioning.

Ageism has been defined by the WHO as the stereotypes, prejudice and discrimination directed towards others or oneself based on age.¹ Ageism has a negative impact on health, leading, for instance, to preventable death and serious physical and mental health problems. It accelerates cognitive impairment.¹

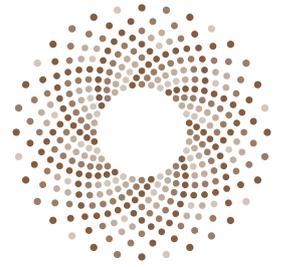
The media play an important role in spreading ageism. Ageist stereotypes in the media can have a negative impact on older people's self-esteem, health status, physical well-being and cognitive performance. Ageism also undermines social health.¹ Social health is the social domain of health, that refers to the influence of relationships on well-being.² Ageism has a negative impact on social relationships and contributes to older people being socially isolated and lonely. Ageism increases social isolation and loneliness when it results in feelings of being undesired and when ageist stereotypes are internalized – e.g. that old age is a time of social isolation and low social participation. – and then act accordingly by social withdrawal from society. On a societal level, ageist society-wide laws, norms and practices, such as mandatory retirement or design features of the living environment (e.g. inaccessible transport), can act as barriers to older adults' participation in social activities, leading to social isolation and loneliness.¹

Covid-19 fuelled ageism in the media. While in the beginning of the pandemic there was a huge intergenerational solidarity, this turned in later phases into blaming older adults to prevent younger persons to have a normal life. Older adults should shield to allow normal life to return. With the argument that they already have "a life behind" they were excluded and marginalised. While discrimination based on race or homosexuality raises great aversion, ageism was nearly fashionable by ageist statements being presented in the media without being counterbalanced.

By ageism, the societal value of harmoniously living together between generations is undermined. It's completely ridiculous to have a battle between generations. The forced societal withdrawal of people because of their age and its negative consequences on well-being and cognitive functioning even brings along additional burden for younger generations having more older adults that function below their capacities.

1. World Health Organisation. *Global report on ageism*, 18 maart 2021

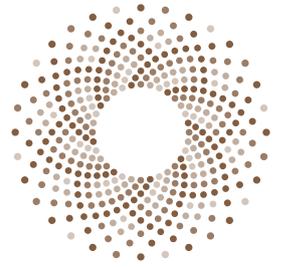
2. Vernooij-Dassen M, Moniz-Cook E, Jeon YH. *Social health in dementia care: harnessing an applied research agenda*. *International psychogeriatrics*. 2018;30(6):775-8.



Fortunately there are counterforces. Many older adults decline societal withdrawal and continue to live their societal life, often finding new opportunities to contribute, such as grand-parenting, which allows their children to work and their grandchildren and themselves to have a kind of extended family life. On the level of public health, the WHO guide for age friendly societies provides valuable recommendations such as the recognition of capacities and resources among older people, respecting decisions and life style preferences and promoting their inclusion in and contribution to all areas of community life.³

The consequences of research on ageism and cognitive functioning should be taken very seriously and considered in public health policy. This is really a point on which public health policy can make a difference.

3. World Health Organisation.
Guide age friendly societies: [https://
extranet.who.int/agefriendlyworld/
age-friendly-cities-framework/](https://extranet.who.int/agefriendlyworld/age-friendly-cities-framework/)



The need for families and employers to better understand the hidden financial costs of dementia

Lorna Sabbia

Head of Retirement and Personal Wealth Solutions,
Bank of America



As we go deeper into the 21st Century, our health and wealth depends on adapting for the era of longevity. Today's longer lives mean more time for the people and pursuits we love, but also present complex new challenges at the intersection of healthcare and financial security. To protect both, we must bring greater focus to the immense, but often hidden, financial burden of Alzheimer's disease and dementia – one of the greatest threats in our aging world. Researchers estimate the annual costs of medical and long-term care, including lost wages for those with dementia and their caregivers, will double every decade from \$1.3 trillion in 2020 to \$9.1 trillion – each year – by 2050.¹

How can we uncover and manage these costs?

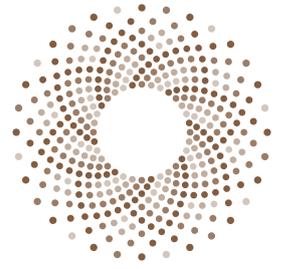
While these staggering figures highlight the need for action, we must consider the perspective of the individual to find meaningful answers. Ultimately, this is the level where costs are felt most acutely – and where we must propose new solutions. For several years, I watched my mother care for my father as his health declined. I was struck by the toll of the experience on both my parents, but particularly my Mother. She was consumed by her responsibilities.

In building a roadmap for their life and older adulthood, people rely on assumptions. How old were my parents, siblings, other relatives when they died? What diseases have been common in older members of my family? What decisions would I make if I had a condition needing expensive care that is not covered by public medical coverage options?

Currently, many people underestimate the risk of dementia and long-term care in this calculation, for a number of reasons. On the average, people are living much longer than their parents and grandparents. Chronic diseases other than Alzheimer's are better controlled, but also produce a need to compensate for compromised functionality. In addition, numerous societal trends and pandemic-driven transformations in the long-term care industry could affect the quality and quantity of care – both paid and unpaid – available to help older adults when dementia and other chronic diseases necessitate institutional care.

It is essential to help people update their assumptions to reflect these new realities. That's why, at Bank of America, we have made a long-term commitment to helping people and employers understand and address the costs of dementia, cognitive decline, and caregiving.

1. Addressing Alzheimer's disease and related dementias to realize the promise of the UN's 'Decade of Healthy Ageing', VOX CEPR, March 2021



Our research shows that employers could play a key role in solutions. Nearly half of employees serve as caregivers to children or adult family members, and they report missing an average of 12 hours per month of work due to these responsibilities. Yet, because of stigma and other factors, a much smaller number identify as caregivers. We also found that the average annual cost of caregiving is ~\$7,000 per year in the U.S. However, for someone with cognitive decline those costs are 2.5 times higher – presenting an enormous financial burden for people, caregivers, and families.²

Employers can take action to help employees understand this burden and related risks, manage potential career impacts, and plan for the costs of their own care or the care of a family member:

- Develop a company-wide understanding of cognitive decline and caregiving – including pathways, policies and actions to make this more visible as we help to take it out of the shadows.
- Train managers on the effects of cognitive decline and caregiving, which has major financial, healthcare and societal impacts.
- Encourage managers to dispel incorrect assumptions about working caregivers, so that we disrupt the stigma around it.
- Create support groups in the workplace, which can also include making available toolkits and resources for employees.
- Offer benefits and services to support working caregivers - to attend to the needs of elder family members, which is a powerful growing trend.

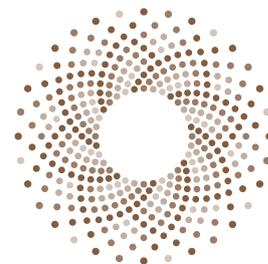
As the average life span continues to increase in the 21st century, it is important to understand how cognitive decline impacts individuals and families as their loved ones age. This includes the science of cognitive function and what happens when mental abilities decline. Based on that understanding, individuals, families, employers, financial advisors, institutions, communities and society can plan for the hidden financial impacts of an increasing prevalence of dementia and cognitive decline.

The scale of these trends underscores the urgent need for both new healthcare solutions and new financial solutions. The impacts on families and across society are prevalent across economic, fiscal, social and health disciplines. While scientific progress will fight and ultimately end dementia, people need comprehensive information, benefits and policies to understand and manage its potentially catastrophic costs right now. Given the size of our populations now reaching older adulthood globally, these financial solutions are essential to a healthy, prosperous future in a world defined by longevity.

This material should be regarded as general information on health care considerations and is not intended to provide specific health care advice. If you have questions regarding your particular situation, please contact your legal or tax advisor.

2. The Journey of Caregiving, Merrill Lynch

3. Perspectives from the Australian Government



Investing in better support for people living with dementia

Robert Day

Assistant Secretary, Dementia, Diversity and Design Branch, Australian Government Department of Health



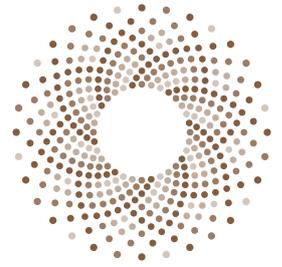
In its May 2021 Budget, the Australian Government announced a significant \$229 million package of support for people living with dementia and their carers. The context of this investment is that, like many countries, Australia is facing an increasing impact from dementia as our population ages. Dementia is now the third leading cause of disease burden in Australia, and as our population ages, the number of Australians with dementia is projected to more than double by 2058.

In 2021 it is estimated that up to 472,000 Australians are living with dementia. We also know up to 337,200 Australians are providing care for a person with dementia, and that 1 in 3 of those carers feels worried or depressed due to that role.

There are two other factors which particularly influenced the Australian Government's dementia support package.

Firstly, the investment is part of a bigger package of reforms which was announced following a Royal Commission into Aged Care Quality and Safety. A Royal Commission is our most strenuous form of public inquiry and it was difficult to hear the ways in which our aged care system was falling short in the support delivered to our senior citizens. More than half of the people living in residential aged care homes have dementia and many more people living with dementia in the community will access home care packages which are also offered by our aged care system to support people to remain living in their own homes.

Secondly, the investment follows a multi-year project of listening to people living with dementia, their family carers and the health professionals who look after them to better understand their experience with the disease. This process combined in-depth discussions with people living with dementia and their carers with policy co-design workshops across Australia with a diverse range of stakeholders. The groups worked



together to design new policy opportunities that spanned community supports, dementia literacy, access to health services and new models of both health and aged care practice. Many of these policy concepts formed the basis of the dementia initiatives announced in the recent Budget.

The dementia reform package is explicitly designed to support people living with dementia and their carers at each of the stages they identified in our listening process: from diagnosis through to palliative care.

The package is aimed to ensure that people living with dementia are connected with the support they need post-diagnosis, able to remain in their home for as long as possible and – when they need it - to access high quality, dementia informed aged care services. A major focus of the Government’s investment is trying to better support people living with dementia in getting more timely diagnosis and assisting them to access support which will help them and their carers to maintain health, wellbeing and independence. Specifically, this includes:

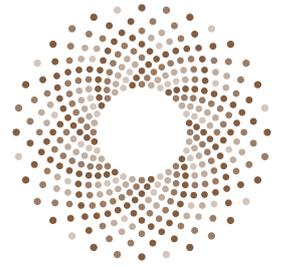
- New dementia specific health pathways for primary care physicians. This is an information technology tool which puts locally tailored information about dementia diagnosis and post-diagnostic services on the desktop of primary care physicians. It gives them the information they need to support a person with dementia at the point in time that they need it.
- A major increase in early intervention supports through our National Dementia Support Program, including counselling, education sessions and peer mentoring.
- Additional outreach capability for our National Dementia Helpline (NDH) so that people don’t fall through the cracks and so that supports can be adjusted in a timely way as a person’s condition progresses.

Other elements of the wider aged care reform package that are intended to support people living with dementia and their carers include:

- A significant increase in the number of home care packages available
- Improvements to the aged care assessment process, including a specific focus on dementia
- Better coordination between our aged care, dementia and carer support systems.

Taken together, the aim of these measures is to support people living with dementia and their carers to remain living in their own homes for as long as possible. This reflects the frequently expressed desire of people living with dementia and senior citizens generally and avoids or delays the significant cost associated with residential aged care.

We also know that respite care services are not always well suited for people living with dementia and that changes in environment and routines can be distressing. As a result,



there is some new investment in dementia-specific respite models.

- One measure is about building the capacity of all residential respite services by teaching them to develop specific dementia care plans in consultation with family carers.
- We will also be expanding on innovative models of respite care that cater for both the person living with dementia and their carer: combining an opportunity for the pair to focus on their personal relationship as well as providing support for both members of the pair.

There are also significant investments in making our aged care system work better for people living with dementia.

- Increased training for aged care staff in dementia
- A major boost in funding for our advisory services which assist aged care providers to manage changed behaviours resulting from dementia without the need to use restrictive practices
- Development of new design standards for residential aged care facilities which will put dementia friendly design principles at their centre.

There will undoubtedly be more for us to do in order to provide the best possible support for people living with dementia and their carers: both as we learn from the experience of this latest investment and as new knowledge brings with it the possibility of new treatments and earlier diagnosis.

As a key enabler for this process of continuous improvement, the Government is also funding the Australian Institute of Health and Welfare to establish the National Centre for Monitoring Dementia, to routinely monitor dementia care in Australia. To date there have been significant data gaps in dementia in Australia. Having accurate and reliable statistics for dementia is vital for policy developers, service planners and researchers. Without these statistics it is not possible to truly understand the magnitude of the condition, its impact over time, or the burden it has on health and aged care systems. A dementia monitoring program will provide Australia with the data resource to underpin national dementia policy development, service provision and research.

The Australian Government also continues to invest in dementia research including through the \$185 million Dementia, Ageing and Aged Care Mission funded through our Medical Research Future Fund.

The challenge of dementia in the context of an ageing society is one that many countries are working to address and there is much which we can learn from each other. I hope that this summary of the Australian Government's latest investments adds to the global discussion about what is possible. In Australia we look forward to sharing our experiences as we implement these measures and learning from the efforts which other countries are making in this field.

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

worlddementiacouncil.org

© 2021 World Dementia Council
UK charity registration number: 1170743

Cover image editorial credit: Shutterstock.com

