

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

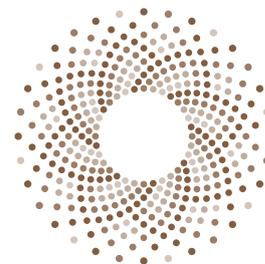
Global dialogue on prevention: Reflections

The dementia landscape
project

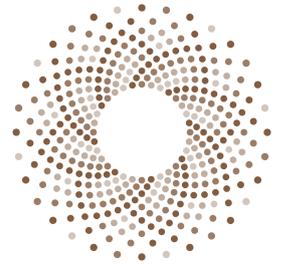
Essays from international leaders in dementia



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1. Introductions



Making progress on brain health promotion

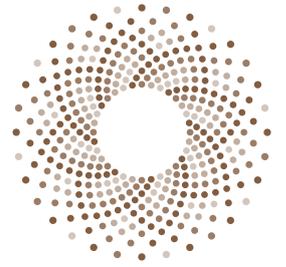
Professor Kaarin Anstey

Professor of Psychology and director, University of New South Wales Ageing Futures Institute



Given population ageing and the projected number of cases of dementia globally, it is critical that dementia risk reduction remains a priority for both public health policy and for research. Over the past decade significant progress has been made in the areas of dementia prevention and brain health promotion. We now have guidelines on interventions to reduce risk of cognitive decline and dementia, and consensus among experts about a range of medical, lifestyle and environmental risk factors. Importantly, recent modelling has established the large impact that modifiable risk factors have on cognitive outcomes in late-life, raising hopes that incident dementia can be reduced through population-wide risk reduction strategies. Another exciting development in this field is the collaboration among researchers, governments and funding bodies to enable the large network of the World Wide Fingers collaboration. Importantly, there is growing recognition of the fact that risk factors for dementia are shared with other chronic disease areas, and that there is economy in joining with other non-communicable diseases initiatives to reduce risk. There are also now several risk dementia scores available to assist with identifying individuals at risk of dementia. The development of mobile and online dementia risk reduction interventions show promise for providing cost effective and accessible dementia risk reduction interventions but it is not yet known whether these modalities are sufficient to bring about lifestyle modification that will be sustained in the long term. Other hybrid models that combine some online intervention with personalised consults from health professionals are also being explored.

As well as increased knowledge and optimism, there remain significant areas where more research is required. We lack understanding about the specificity of many risk and protective factors, and dose. This is often due to risk and protective factors being identified from epidemiological studies which have limited assessments. Detailed clinical trials are needed to further understand mechanisms and links to biomarkers. The evidence base currently is also limited in terms of geographical source of data. For example, whilst there is now good evidence from some western countries that healthy, Mediterranean style diets are associated with reduce risk of Alzheimer's disease, we lack information on dietary patterns from a number of regions of the world, which may

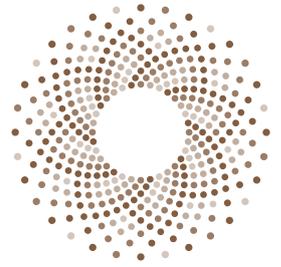


also have protective nutrients, or similar composition to the Mediterranean diet but with different food types. We also lack details on the prescription of physical activity that is required to promote brain health. As more studies are published we learn for example that moderate and vigorous physical activity are associated with benefits, but then questions remain about the efficacy of types of activities such as swimming versus walking. Research is also needed to identify predictors of optimal brain health. For example, while we know that high blood glucose is associated with increased brain atrophy and risk of dementia, we don't know the optimal blood glucose level for brain health.

Another area where there remains uncertainty is both the risk and benefits for brain health of medications that are widely used by older persons. Statins, antihypertensives, antidepressant medication, hormone therapies, opioids, anticholinergics are type of medications that need further investigation and evaluation to provide clinical guidelines for optimal prescribing for brain health.

Alongside individual level risk factors, areas that require further consideration in dementia risk reduction are the social and environmental determinants of health. Low education and social disadvantage both in early life and in adulthood have been linked to faster cognitive decline in late life. Similarly, air pollution and a lack of health promoting built environments impact on brain health and will need to be addressed through better design of transport and cities.

The largest challenges we face in reducing incident dementia are addressing the wider social determinants of health because the levers for these are outside of the health portfolios and impacted by systemic inequalities. We also face challenges in the implementation of risk reduction interventions into health systems as well as keeping dementia prevention on the research agenda. With so many competing health priorities, and a sense that the risk factors are known at a very broad level, we risk not continuing with the rigorous work needed to work out what types of interventions are effective or risky, at which ages, what is needed for specific populations, and why they work. We need to continue programs of research to clarify the parameters of brain health promotion at the individual and societal levels.



Is it worth trying to prevent Alzheimer's disease?



Professor Philippe Amouyel

General director, Fondation Alzheimer (France), professor of epidemiology and public health at the University Hospital of Lille, and chair, European Joint Programming Initiative on Research on Neurodegenerative Diseases (JPND)

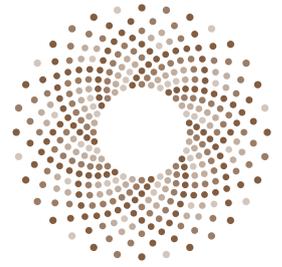
For more than five years, the concept of a possible prevention for Alzheimer's disease has been increasingly documented through observational studies. Of course we would have preferred more experimental prevention studies. But, the complexity, the duration, the number of individuals to be recruited in prevention trials are strong limitations to the large development of such studies. However, presumptions of causation from consistent epidemiological long-term prospective studies from some small-scale intervention trials, and from meta-analyses, have begun to convince more and more researchers and physicians. Convince them that, beside or together with symptomatic and curative treatments to be discovered, prevention could be a major player in the fight against Alzheimer's disease. It is easier and already actionable. Finally, this is not so different from other chronic diseases like cardiovascular diseases – diabetes or cancer – for which active treatments exist but whose impact is far better when daily prevention, mainly based on lifestyle changes, is associated.

Like some of these chronic diseases, preventing Alzheimer's is more related to procrastination than to so-called primary prevention. The long-term process that leads to dementia is already engaged when prevention starts, slowing down the process is secondary prevention. So the main goal of the preventive strategy is to postpone the age of onset of the disease for as long as possible and even after death, thanks to competitive mortality occurring massively at this period of the life.

However, developing large scale intervention programs to postpone age-at-onset of Alzheimer's disease needs some very basic questions answering.

1. Does this intervention improve health? Yes, indeed directly but also indirectly on other health targets. The modifiable risk factors concerned postpone the age of onset of Alzheimer's, but also prevent cardiovascular diseases, cancer, diabetes. So life expectancy without diseases could significantly increase.

2. Does it reduce health expenditure? The older you live, the more expensive the health cost is. This is obvious. But clearly, this doesn't consider all the social and care cost reductions, nor the benefits for the quality of life that living with fewer diseases bring about. The only strong argument we can raise against health economists who would



like us to die before we get any diseases is the theory of morbidity compression. The compression of morbidity in public health is a hypothesis put forth by James Fries, professor of medicine at Stanford University School of Medicine, at the end of the last century. Fries's hypothesis is that the burden of lifetime illness may be compressed into a shorter period before the time of death, if the age of onset of the first chronic infirmity can be postponed. This is exactly what we expect for an infirmity that destroys our cognitive functions and our social relationships. To this question we could answer yes too, especially when we know, as physicians, that the increased health expenditure of family and caregivers incurred by their daily burden could be avoided.

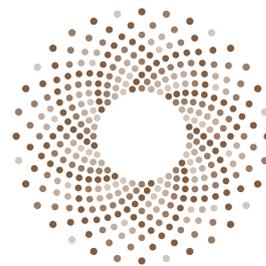
3. Does it improve health inequalities? This is one of the general biases of prevention. The beneficiaries of prevention campaigns are very often the ones who need them less. They are highly educated, they already know a lot about healthy lifestyles and have modified their diet, practice physical activities, don't smoke and are always keen to test the new prevention evidence published on the internet or in their favorite journal. So specific energy should be engaged to target other populations with higher risk that would receive stronger benefits from these preventive measures. To achieve this goal, a specific implementation plan will be needed.

4. Is this a cost effective intervention? Until an implementation plan has been decided, it will be difficult to assess the cost-effectiveness of such measures. However, taking into account the number of cases avoided, one can think that the long-term cost reduction will be proportionally reduced, and that the expected 2,000-3,000 billion euros expected in 2050 will be significantly decreased.

5. When will the desired effect show up? This has been already modelled on a theoretical basis by Ron Brookmeyer in 1998. Assuming the number of US inhabitants affected by Alzheimer's was 2.32 million in 1997, an intervention that could delay the mean onset of Alzheimer's by approximately five years, corresponding to a 50% reduction in risk, would reduce the expected prevalence by 1.15 million after 10 years (2007) and 4.04 million after 50 years (2047), in the US, instead of the 13 million expected.

In conclusion, yes. It is worth trying to prevent Alzheimer's. This prevention can begin at any age – the earlier the better – and should be maintained throughout life. Stimulating our brain, protecting it from traumas and toxins, offering it a sane body and metabolism, and above all maintaining our relationship network for as long as possible while being positive and optimistic will help us to increase our cognitive reserve and resist cognitive decline. This will postpone as late as possible any first symptoms of Alzheimer's allowing us to live better and for longer.

2. Advancing dementia prevention



Population-level dementia prevention: Public health approaches as a way forward



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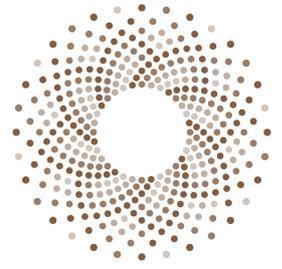
Dr Lindsay Wallace

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Dementia continues to be a global public health crisis. At the World Dementia Council prevention roundtable, experts across multiple disciplines described their understanding of the state of dementia prevention and suggested next steps. In this essay, we suggest public health policy interventions to optimize the impact of research and clinical efforts to reduce dementia globally.

As Kaarin Anstey astutely pointed out, ‘the power of public health has not yet been harnessed for dementia prevention’. Despite increasing awareness, funding, and global collaborative initiatives, we have not yet realized the potential for reducing dementia incidence on a global scale. To date, much focus in the dementia research space, even in prevention has been on biomedical and pharmaceutical interventions that target single protein abnormalities and increasingly target younger and healthier people. Given the epidemiology of dementia, it is unlikely that these single target pharmaceutical

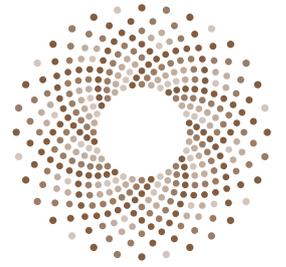


therapeutics will be successful in ameliorating a disorder of higher-order function such as cognition in older frail adults with mixed pathology.

Despite no targeted approaches, it has been established that age-specific dementia prevalence has declined in recent decades in many High-Income Countries which is suspected to be due to post-war investments into societal activities including public health measures on a population-scale, such as better attention to maternal health, early life policies such as vaccinations and early nutrition, as well as increased education. This is reason for optimism and a demonstration that public health policy can be impactful across decades with much greater benefit to be experienced with revival of the long-term policy approach and societal investment. Several reports including the Lancet Commission on Dementia have reported factors across the lifecourse that influence dementia risk. If public health approaches are applied, with policy and practice both brought into play from national fiscal to local environmental approaches the potential impact could be enormous. This requires investment in approaches that are likely to make long-term impacts, but will allow us to prepare for a future that, given the global demographics of increased proportion older adults, will not overburden our health and societal systems.

As Michele Cecchini noted, there are extremely complex interactions that underlie lifestyles, risk factors, and diseases that provide risk or protection from dementia. Public health policy approaches that are broadly applicable, cost-efficient, and address multiple risk factors will be the most effective and impactful way to reduce dementia burden in the UK and globally. Successful examples of this type of policy include sugar tax, restricted advertising of tobacco products, and improved walkability of communities. Other crucial advantages of using public health approaches for the primary prevention of dementia include: targeting and reducing inequalities that arise from exposures/risk factors, reducing reliance on individualized interventions that focus on behaviour change rather than environmental changes, and targeting the accumulation of risks using a life-course approach. The Japanese national dementia framework could be useful, presented in the workshop by Yoshiki Niimi as a guide, but another advantage of public health policy approaches to prevention and risk reduction is that awareness and buy-in from individuals is not necessary for them to reap benefits, instead the focus would be putting in place social and environmental changes that will produce impact whether consciously or non-consciously.

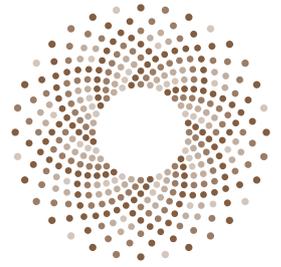
An important question to ask is what does prevention of dementia look like at the population level? It is likely that primary prevention efforts will delay onset of dementia in older adults, and there is evidence this compresses cognitive morbidity into late life, lengthening cognitively healthy lifespan. This will have many positive effects individually but also at a societal level, decreasing inequalities, increasing participation of older adults in the workforce, participation of younger adults in the workforce who will have less caregiving responsibilities, as well as reductions in health care spending for older adults with dementia. Fortunately, the same interventions that target primary prevention, such as increased exercise, improved nutrition, and management of chronic diseases, also improve health for those with early risks and established conditions as well. Even in the presence of strong population approaches to dementia risk reduction, the evidence suggests many of us will experience decline in cognition before death and it is important to also recognise that dementia will still occur. Rather it will occur at later



ages and lower rates. Evaluating and assessing the balance is key to evaluating benefits of interventional programmes and policies.

The research base to support such work must be anchored in population relevance. This includes careful understanding of what dementia is in given populations, not assuming its underlying biology or occurrence. Such population-based approaches can also lend themselves to testing prevention approaches. Studies such as the Cognitive Function and Ageing Studies (CFAS) in the UK provide a platform for such understanding, with further need for national representative studies such as ELSA and focused studies to complement these within particular populations and younger age groups. Targeted and sustainable funding is needed, shifting the focus of investment across the portfolio needed rather than the current all-consuming emphasis on individualized biomedical research.

This goal of global dementia prevention via broad public health measures can be difficult to imagine. Although return on investment from public health measures is excellent, it remains challenging to convince policy-makers to make such decision for many of the reasons that Michele Cecchini brought forth: policy-makers are looking for efforts that create clear impact on a short time scale. Dementia prevention does not fit in this box, but this does not mean that it isn't a worthwhile endeavour. Dementia prevention is a long-term investment that will promote overall population health and reduce risk for many other age-related diseases such as cardiovascular disease, diabetes, and arthritis. Increased investment in this area will be able to produce convincing research to support these initiatives in regionally-specific settings.



Dementia prevention “for all”: Between enthusiasm and prudence

Dr Anja Leist

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Population health studies paint an optimistic picture: Up to 35, if not 40 per cent of all dementia cases could be prevented if a number of modifiable social and behavioural risk factors were eliminated.¹ Preventing risk factors from occurring, such as low education, mid-age hearing loss, smoking or depression, would prevent dementia, or at least delay its onset until very advanced ages. Consequently, public health efforts should be increased to prevent the development of these risk factors. With this strategy of primordial prevention, additionally, cumulative benefits for the prevention of morbidity and mortality at large can be expected, as risk factors for dementia are linked to a number of other adverse health outcomes. This is reason to be enthusiastic, and serious efforts of preventing risk factors to develop will help to reduce dementia burden of future generations.

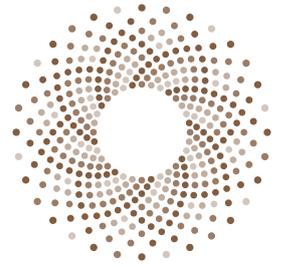
However, practitioners and policymakers usually don't have decades to plan preventative efforts. Dementia prevention in practice often deals with individuals or cohorts with substantial dementia risk due to chronic conditions or less-than-optimal lifestyles. What is the scientific evidence for lifestyle changes to reduce dementia risk in individuals who already accumulated dementia risk factors?

Clinical and epidemiological researchers know the successful trials by heart. There is evidence for cognitive benefits of single-domain interventions focusing on exercise and resistance training, intensive blood pressure control, or cognitive training, which in some trials also decreased the risk of cognitive impairment. Among several multidomain interventions, the FINGER trial showed benefits on cognitive functioning over two years. However, unfortunately, a larger number of dementia risk reduction trials have failed. In all of these trials, issues of sample recruitment and limited power may have contributed to the null findings. Still, we must concede that, at this moment in time, we do not have solid evidence on the actual potential of dementia risk reduction interventions in the presence of risk factors, and we are still quite far from understanding what works best for whom and when in at-risk individuals.

Therefore, some prudence before rolling out mass programs advocating lifestyle changes for older adults with presence of risk factors seems warranted.

Additionally to the need of further studies to increase knowledge on potential for dementia prevention, and similar to other public health interventions, we also need to weigh beneficial effects of dementia prevention programs against the required individual

I. Livingston, G. Huntley, J. Sommerlad, A. Ames, D. Ballard, C., Banerjee, S.,... & Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413-446.



efforts and, not least, considerations of cost effectiveness. Time, economic or cultural constraints may hinder individuals to follow a healthy lifestyle.

Therefore, possible drawbacks from dementia prevention programs are to overplay individuals' capacity to substantially modify their individual risk of dementia. This could result in overemphasizing individual responsibility to maintain cognitive health, and increase guilt, blame, and stigma for those affected by dementia. These issues are problematic per se; however, in the light of limited knowledge of what works, we need to be even more cautious that large-scale dementia prevention programs would not result in largely negative unintended consequences on older-age quality of life – additionally to not being able to reduce dementia prevalence.

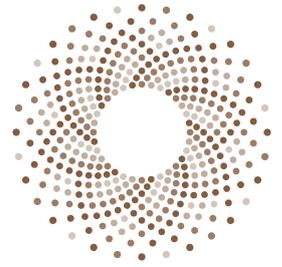
There are several ways to address this dilemma. First, larger and longer trials could provide more solid evidence on the dementia risk reduction potential of lifestyle interventions, and improve our understanding of what works in which subgroups. The worldwide FINGERS Network² is an important step towards that goal. Another way forward is to estimate dementia risk reduction potential in observational data. The necessary time window for trials to fully understand the potential of lifestyle changes is often beyond the limits of both funding and researcher careers. Here, aging surveys such as the family of Health and Retirement Studies have assessed (changes in) risk factors in large samples and followed respondents in some cases over decades. Quasi-experiments, instrumental-variable analysis, and the possibility to 'emulate' clinical trials in observational data³ can improve data analysis, methods which have potential to substantially improve our understanding of dementia risk reduction. Our CRISP Cognitive Ageing project funded by the European Research Council (grant agreement no. 803239) explores these and other ideas to accelerate research in dementia prevention.

Finally, we ought to adopt pragmatic solutions such as the WHO guidelines for dementia risk reduction.⁴ Physical activity is among the few established protective factors of dementia. However, even in the light of scarce high-quality evidence for dementia risk reduction specifically, we know that some lifestyle behaviours such as smoking or hazardous drinking come with unnecessary morbidity burden on individuals. We should offer interventions for these lifestyle behaviours because of their proven health benefits, and may offer other interventions such as cognitive trainings to those who are interested. Still, before advocating lifestyle interventions for all, we should strive to back up claims on individual potential for dementia risk reduction with high-quality evidence.

2. Kivipelto, M., Mangialasche, F., Snyder, H. M., Algeir, R., Andrieu, S., Ara, H., ... & Carrillo, M. C. (2020). World Wide FINGERS Network: A global approach to risk reduction and prevention of dementia. *Alzheimer's & Dementia*, 16(7), 1078-1094.

3. Hernán, M. A., & Robins, J. M. (2016). Using big data to emulate a target trial when a randomized trial is not available. *American Journal of Epidemiology*, 183(8), 758-764.

4. World Health Organization. (2019). Risk reduction of cognitive decline and dementia: WHO guidelines. Retrieved 15 June 2021 from <https://apps.who.int/iris/bitstream/handle/10665/312180/9789241550543-eng.pdf>



The scientific base for prevention of dementia: Progress made and challenges ahead



Professor Gill Livingston

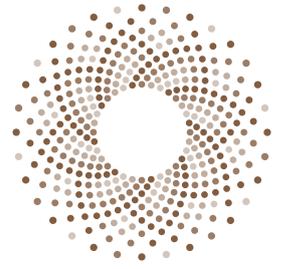
Professor of Psychiatry of Older People,
University College London

Dementia is the most feared illness of older people, with numbers of people living with dementia is increasing as the population ages. However, in some but not all countries there has been a 25% decrease in the age-related incidence of dementia over two decades. This gives hope that some dementias are potentially but not inevitably preventable.

The scientific basis of analysing risk for dementia is informed by longitudinal studies, including randomised controlled trials. Analysing populations for risk factors for dementia is complicated. Studies showing that people with a problem are more or less likely to get dementia can be misleading, as is often said correlation is not causation. People change as they are developing dementia, and correlation may be because a behaviour is caused by rather than causes dementia, although the relationship may be bidirectional. Some scientists suggest a putative risk may have to occur over ten years before to be a true risk factor. However, traumatic brain injury, may lead to someone developing early dementia in their thirties to fifties only a few years after injury. Very few could have had dementia at the time of the brain injury, so some risks lead to dementia more quickly.

Life-course is also important. Obesity and hypertension are mid-life risk factors but in dementia, blood pressure falls and people lose weight. People in their 70s and 80s with hypertension and obesity are probably those not developing dementia. Lack of social contact in mid-life is a risk factor for dementia but in late life people developing and with dementia see more of their relatives as they need care and less of their friends. People are complex and risk factors cluster individually and in populations. So for individuals obesity, hypertension, diabetes, and inactivity occur together more often than by chance. Those with less socio-economic resources often have little choice about living in environments which are more be obesogenic, dangerous to walk in and with higher air pollution. Risk factors also cluster and their importance change within or between populations. We found a higher prevalence of risk factors in Latin America, than in India, and China, and all had a higher prevalence than globally. Within a country, we found that the prevalence of risk factors for dementia was higher in New Zealanders of Maori than in those of Asian origin.

Overall, considerable strides have been made with good scientific evidence for causality, considering not only consistency of results, biological mechanisms, dose relationship and whether the risk factor occurs before the dementia, but also accounting for timing, controlling for other risks and the population in which the risk is derived. Our Lancet



commission on dementia in 2020 concluded that there were 12 factors -less education, hearing loss, head injury, high blood pressure, excessive alcohol, obesity, smoking, depression, social isolation, physical inactivity, air pollution and diabetes -which fulfil these criteria. In total their population attributable fraction account for 40% of the risk for dementias worldwide, adjusting for individuals often having multiple risk factors. Hypothetically, if these risks were removed, 40% of dementia would be prevented or delayed. Three of them (in order of magnitude of effect) account for 20%. These are mid-life hearing loss, lack of education in early life and smoking in late life. We considered other risk factors which did not yet fulfil all these criteria such as sleep and diet. In 2021, papers have reported that reduction in sleep time in mid-life more than 10 years before dementia develops is a risk factor; that early life education is important but cognitively stimulating occupation in midlife is independently protective; that while high alcohol consumption is a risk (>21 UK units), binge drinking is a greater risk.

The mechanisms for these risks have broadly been considered as through lack of cognitive reserve or by causing neuropathological damage. For example, cognitively stimulating environments from more education, social interaction and being able to hear, leads to higher cognitive reserve, so that a brain can withstand neuropathology which would cause dementia in those without reserve without developing dementia. Similarly, exercise is thought to deliver more oxygen to the brain and to stimulate neurogenesis, while air pollution, hypertension, head injury, smoking, diabetes are thought to increase neuropathological damage. More recent work has found circulating proteins detected a decade or more before dementia onset are related to increasing cognitive decline and may lead to blood brain barrier dysfunction vascular pathology, inflammation, inhibition of axono- and synaptogenesis and central insulin resistance.

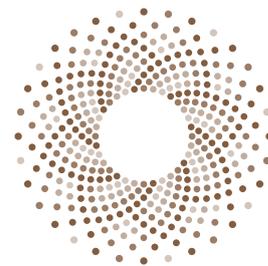
The reduction in dementias in populations is very impressive. Interestingly hearing aid use removes excess dementia risk of hearing impairment. However, traditionally the randomised controlled trial (RCT) is the gold standard for testing causal relationships and interventions in medicine as randomisation reduces biases. Nonetheless, RCTs are often impossible and many effective interventions, such as reducing cigarette smoking to reduce cancer and cardiovascular disease have not been tested in RCTs.

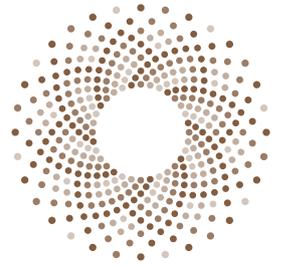
RCTs to prevent dementia are difficult because of the long period between exposure and developing dementia and therefore cognition tend to be used as a surrogate outcome. Trials of treating hypertension more energetically are usually stopped as the control group does badly. Nonetheless for example, SPRINT MIND five-year follow-up of a discontinued hypertension trial, found a reduction in cognitive decline in the intervention group. RCTs of multicomponent trials include FINGER targeting diet, exercise, vascular risk, and cognitive training with a small cognitive benefit at two years (Cohen's $d=0.13$). HATICE an e-Health with coaching intervention targeting cardiovascular risk resulted in risk reductions, larger in those with less education, but not cognitive benefit. PreDIVA, a nurse-led intervention to reduce cardio-vascular risk, improved blood pressure, but dementia incidence decreased only in those with untreated hypertension.

Reasons for these studies being less effective than hoped may include only cardiovascular risk and education being targeted. Additionally, RCTs tend to recruit those who are more educated and motivated and have less cognitive risk. In FINGER, the

control group did much better than expected. Those with more to gain, who have more risk factors may also be digitally excluded from some trials. It is of course possible that these interventions do not work well and are too little or too late.

The way ahead are to implement three types of prevention. The first are public health interventions to make it easier to, for example, protect hearing and from traumatic brain injury, smoking and pollution. The second are RCTs of multicomponent interventions which need to be scaleable, engaging to increase adherence, include behaviour change techniques, be individualised, and be inclusive for those most at risk, who are socioeconomically disadvantaged, from minority groups, live remotely and more digitally excluded. This requires skills including experts in human computer interactions, health psychology, hearing and social contact. Finally, as we learn more about mechanisms of potentially reversible risk factors including changes in proteins, we may be able to consider and test drugability of some risk factors. There has never been a time of such hope for dementia prevention. The time for action is now and we can all be part of it.





Brain health awareness

Sarah Lock

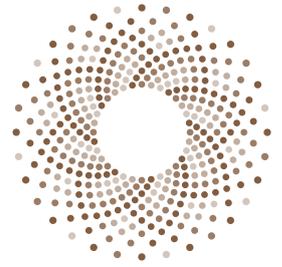
Senior Vice President for Policy, AARP and Executive Director, Global Council on Brain Health



Since the G8 Dementia summit in London in 2013, we have made great strides in terms of the policy and research communities having a greater understanding of brain health awareness. The excellent dialogue event on prevention and brain health co-chaired by Professors Kaarin Anstey and Phillippe Amouyel demonstrates how much work has been accomplished particularly within the last half decade. But we still have far to go in terms of public health, and miles before we reach the point that health care providers, individuals and their governments realize that by acting to promote brain health we are not only reducing risks for cognitive decline and dementia, but we will also be enabling healthy aging across generations thereby reducing future health and social care expenditures for all kinds of chronic diseases while fostering stronger economies. The enormous policy challenge facing the international community is to change public norms and expectations from the commonly held views that cognitive decline is inevitable for an aging population and that the only solution worth pursuing is to develop a pharmaceutical cure for the diseases that cause dementia.

I am the Executive Director of the Global Council on Brain Health, an independent collaborative of scientists, health professionals scholars and policy experts from around the world working in areas of brain health. Convened by AARP with support from AgeUK, we have spent almost six years examining the evidence behind what works and what doesn't to support the brain health of adults 50 and older as they age. With our 10 reports on different modifiable lifestyle factors along with a special report on COVID-19 and brain health, we have aimed to drive awareness about brain health and communicate the consensus on the state of the science with respect to what can be done to maintain or improve older adults' brain health. The developing science is exciting but the confusion to the general public as it plays out with sometime conflicting messages belies just how much progress on the overall subject is being made. As our experts have concluded and the World Dementia Council's Dialogue on Prevention shows, there is quite a bit that can be done to reduce risks for cognitive decline, much to be done to improve care and quality of life for those who are living with dementia, and growing evidence that cases of dementia can be prevented or delayed at the population level. But unfortunately, that is not yet widely understood by policymakers. We have yet to convincingly demonstrate that the benefits of implementing policies to promote brain health society-wide will be worth the necessary investments.

AARP recently completed two research surveys on the perceptions of dementia in the United States in June 2021. The first survey is a representative sample of more than 3,000



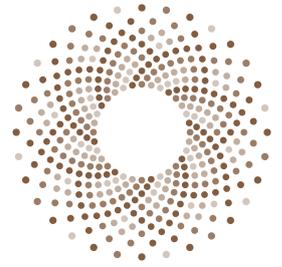
adults in the general population age 40 and older, and the second was of health care providers (500 providers) with experience diagnosing dementia among their patients. The results confirmed that adults and health care providers consider dementia to be highly stigmatizing and that many people dread the diseases that cause dementia but do not understand the condition well. Only three health conditions rated a higher level of stigma than dementia in our survey: addiction, obesity and mental illness. Common diseases, such as heart disease and diabetes, and even lung cancer, holds far less stigma.

Underscoring the challenge we have in driving greater awareness of the facts around brain health, the survey shows people hold many misperceptions about the likelihood of them maintaining good cognitive function as they grow older. The general population considerably overestimates their risks for developing cognitive decline and dementia as they age. More than six in 10 (66%) of adults in the U.S. age 40 and older believe it is likely that they will experience cognitive decline in their future, and 30% are already concerned that their mental sharpness has declined. Significantly more Hispanic and Asian Americans, along with those in the 40 to 49 age group, are worried that their mental sharpness has declined than the general population.

Almost half of adults (48%) believe they will likely get dementia — far more than will actually develop it. While estimates vary, according to a 2007 NIA-funded epidemiological estimate, the prevalence of dementia among individuals age 71 and older in the U.S. was 13.9%. The World Health Organization estimates the global prevalence of dementia to be 5 to 8% of people 60 or older at a given time. According to the Alzheimer's Association, the overall prevalence of Alzheimer's disease is 11 percent among adults age 65-plus, rising to 35 percent for those 85 and older. We created an index to identify how many respondents felt high levels of concern about their cognitive function and found that 12% of adults 40 and older in the U.S. showed significant concerns across eight self-reported responses, which is much closer to the epidemiological estimates of actual risk.

Perhaps most striking was the significant disconnects between the providers' perceptions and those of their patients. The vast majority of health care providers surveyed believe that healthy lifestyle choices can improve the symptoms of dementia. An overwhelming majority of adults (91%) said they would want to be informed of a dementia diagnosis, but a smaller percentage of health professionals (78%) said they always reveal the truth to their patients. Even more tellingly, one in five adults (19%) said they would feel ashamed of a dementia diagnosis, but seven out of 10 healthcare providers (69%) thought their patients would feel that way. This shows a significant opportunity for better communication and understanding between providers and their patients. Our survey showed there is also enormous opportunity for providers to educate people on the power of modifying their habits to improve their brain health. Many adults unfortunately have not yet learned about the practical steps that can be taken to support brain health.

The good news? Our research shows that people are willing to take actions to sustain good brain health once they learn that healthy behaviors can help them maintain their thinking skills.



Adults would engage in selected activities to maintain thinking skills and HCPs believe these activities help dementia symptoms

A majority of adults age 40 and older said they would be extremely or very likely to add brain-healthy activities into their daily lives if they knew that the activity may help them maintain their mental functioning. A large majority of healthcare providers think each activity helps with the symptoms of dementia. Notably, six in 10 adults age 40 and older would engage in exercise and 92% of HCPs feel exercise helps dementia symptoms, a 32-point difference.

Percent of adults age 40 and older who are extremely/very likely to engage in selected brain-healthy behaviors if they knew the activity may help them maintain mental functioning and percent of HCPs who feel each activity is helpful for dementia symptoms



Q47a-f If you knew the following may help you maintain your mental functioning/thinking skills, how likely would you be to incorporate more of these activities into your daily life? (Q47, % extremely or very likely, among adults age 40+, n=3,022)
Q37 In your opinion, which of the following help with the symptoms of dementia? (among healthcare providers, n=500)

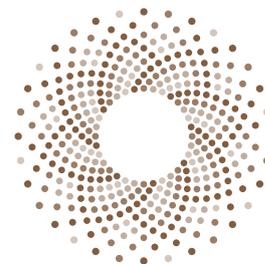
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Overall, 81 percent of adults surveyed said they would be motivated to have a healthier lifestyle if it could slow the onset of dementia. A majority of those surveyed said they exercise only occasionally or not at all. Yet of this group, more than four in 10 (44 percent) said they would exercise more often if they knew it would help them stay sharp. Better still, 85 percent of those who exercise frequently said they would work out even more often if they were aware of the benefits to brain health.

The top reasons AARP members age 50 plus say they are interested in brain health as of April 2021 is that they want to remain independent as long as possible (74%), they want to be “with it” till the they die (65%), they don’t want to burden others (54%) and they want to be mentally sharp to work at their best. (51%). These are all reasons to drive individual awareness to make a difference in these people lives. But it is also all the more encouragement for us working in the field to make sure that policy makers understand the benefits to themselves and the broader benefits to society as a whole. Because it is only through policy change that we will be able to reach those less aware and those less resourced who may face numerous socio-economic barriers to implementing the actions that we know can reduce their risks to their brains across their life spans.

3. National perspectives



Risk reduction and inclusion: A lesson from Japan

Ryoji Noritake

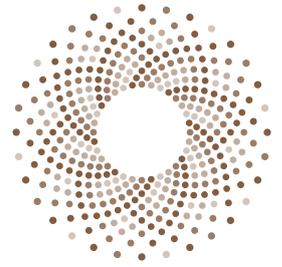
CEO and Board Member, Health and Global Policy Institute (HGPI)



2019 was an epoch-making year for national dementia policy in Japan. On June 18, 2019, the Government of Japan's Ministerial Council on the Promotion of Policies for Dementia Care unveiled the National Framework for Promotion of Dementia Policies. This Framework is Japan's third national strategy for dementia after the Five-Year Plan for the Promotion of Dementia Measures (the Orange Plan) in 2012 and the Comprehensive Strategy to Accelerate Dementia Measures (the New Orange Plan) in 2015.

The fundamental philosophy of the National Framework is to promote policies that will advance inclusion and risk reduction. This philosophy will be pursued in five pillars, which are (1) promoting public awareness and supporting efforts made by people with dementia to disseminate their stories and opinions among the public; (2) risk reduction; (3) providing support for healthcare, caretaking, and nursing services and caretakers; (4) promoting the creation of barrier-free spaces and services for people with dementia and providing support to people with early-onset dementia; and (5) promoting research and development conducted by industry and disseminating their results internationally. The central theme linking all of these elements is that the perspectives of people living with dementia and their families are to be emphasized.

The Orange Plan and New Orange Plan were created by the Ministry of Health, Labour and Welfare (MHLW) and related ministries, but the National Framework for Promotion of Dementia Policies was formulated through joint efforts involving the entire Government. Established in December 2018, the Ministerial Council on the Promotion of Policies for Dementia Care brought together every Government branch and worked to include and unite a broad range of concerned parties in fields related to everyday life outside of healthcare and long-term care. To create the National Framework, this Council scaled up dementia policies outlined during discussions at the MHLW focused on healthcare, long-term care, and welfare. The position of the Ministerial Advisory Board on Dementia (Provisional Name) and Expert Meeting was declared in December 2014 by HGPI Chairman Dr. Kiyoshi Kurokawa acting as the Special Advisor to the Health and Medical Policy Office Cabinet Secretariat, and Health and Global Policy Institute (HGPI) has considered this an important direction since then.



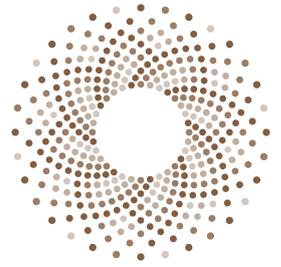
When the Government first shared its proposal for the National Framework in May 2019, its basic concept mentioned “risk reduction and inclusion.” This drew criticism from advocacy organizations and similar parties. Just as in many other developed countries, Japan has made progress on policies for building a dementia-friendly society with active involvement from dementia-related organizations. However, to the representatives of those organizations, the words “risk reduction” sounded cold and indifferent, and using these words as the leading element made them feel that dementia was being treated as a risk and a target for hate. Therefore, the basic concept of the National Framework was revised to say “inclusion and risk reduction,” and its content was revised to place greater emphasis on inclusion. At first glance, it may seem that nothing was changed but the word order, and the fact remains that both elements are central themes that must be pursued in parallel. However, to the organizations representing people with dementia that took part in creating the National Framework, the order of these words was very important.

Those of us involved in dementia policy must take another look at this event and ask ourselves if this type of discourse is occurring regularly in Japan. Has past clinical research and dementia policy really been co-created with people living with dementia and their loved ones? It is not wrong to discuss risk factors for dementia and dementia prevention. When doing so, we must also make sure we are not placing dementia within a context that also amplifies stigma and leads to the segregation of people with dementia.

The Government’s current version of the National Framework has no intent to intensify stigma whatsoever and carefully emphasizes the need for integrated, cross-ministerial collaboration on dementia policy. We think that it provides a good guideline for policy that reflects many of the real-world circumstances facing people living with dementia, and that it deserves global recognition. Despite these strengths, the National Framework still caused a great amount of debate over the sequence of words in its basic concept.

There is only one thing we can do, whether we are working on policy, clinical research, daily life care, or in any other area: we must always co-create with people with dementia. If people living with dementia are not actively involved in clinical research, that research will not advance. Their understanding and cooperation is essential. “Inclusion or risk reduction” is not what we need. What we require is “inclusion and risk reduction.” Inclusion must be kept in mind at all times.

The wonderful thing about the World Dementia Council (WDC) is that it brings together parties from around the world and places everyone on an equal playing field for discussions and advocacy, whether they are from an organization representing people with dementia, a leading advocate for people with dementia, a clinical researcher, or a governmental officer. The WDC’s prevention workshop brought together multi-stakeholders for a global discussion in the truest sense and provided an opportunity to highlight the importance of co-creation. I would like to once again express my gratitude for the WDC’s leadership.



Aspiring to prevent dementia: An approach from Canada



Dr Theresa Tam
Chief Public Health Officer, Canada

The global impact of dementia is expected to grow as many countries, including Canada, are experiencing aging populations. With the rate of dementia much higher after the age of 80, sharing information about reducing its risk is increasingly important.

As researchers continue to seek promising treatments for dementia, research on prevention is providing valuable direction on risk reduction. Rates of new dementia cases are decreasing in some countries and the understanding of factors linked with reduced risk is growing. This evidence suggests that focusing on certain modifiable risk factors can contribute to delaying or preventing dementia.

As noted in the Lancet Commission's 2020 recommendations and the WHO guidelines for risk reduction, along with other research studies, it is clear that promoting a healthy life course approach plays a role in reducing new cases of dementia and delaying symptoms. We have learned that there are tangible actions people can take to reduce the risk of developing dementia. While every country has a different context that needs to be considered, acting on these evidence-based findings to support healthy aging is not only important, but necessary.

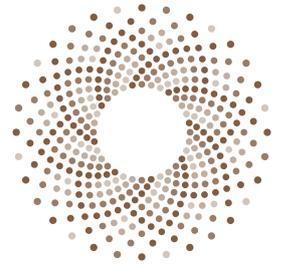
With the identification of modifiable dementia risk factors, Canada has prioritized awareness raising on prevention in our implementation of the national dementia strategy. As of 2016-17, more than 432,000 Canadians aged 65 years and older were living with diagnosed dementia.¹ While it is expected that the number of Canadians diagnosed with dementia will continue to increase given our aging population, it is encouraging that the incidence of dementia has decreased over the past 8 years; from 1,576 newly diagnosed cases per 100,000 Canadians in 2008-2009, to 1,440 new cases in 2016-2017.² Public opinion research in 2020 found that approximately 9 in 10 Canadians are aware of at least one risk factor linked to developing dementia, although knowledge is less widespread about some risk factors such as smoking, hypertension and diabetes.³ I am hopeful that through our collective efforts to encourage and expand the adoption of healthy behaviours, we will continue to see a decline in new cases of dementia in Canada and around the world.

Over the past year, Covid-19 has had an impact on the ability to maintain healthy behaviours. For example, due to the closure of many activity spaces and other public health protection measures, dementia risk factors such as physical inactivity and social isolation have been more difficult to address. As a result, over 40% of Canadians who

1. Canadian Chronic Disease Surveillance System, 2019 - <https://health-infobase.canada.ca/ccdss/data-tool/>

2. Canadian Chronic Disease Surveillance System, 2019 - <https://health-infobase.canada.ca/ccdss/data-tool/>

3. Data from EKOS' Dementia Survey 2020 for the Public Health Agency of Canada - https://epe.lac-bac.gc.ca/100/200/301/pwgsc-tpsgc/por-ef/public_health_agency_canada/2020/076-19-e/index.html



reported being inactive prior to the public health measures taking effect, reported being even less active after they were imposed, and just over 20% of active respondents reported becoming less active.⁴ Rates of social isolation have also increased, while some Canadians reported increasing their use of alcohol (14%).⁵

The growing understanding of factors linked to the risk of developing dementia is the reason preventing dementia is one of the three national objectives of A Dementia Strategy for Canada: Together We Aspire. The strategy outlines the need to advance our understanding and build the evidence base about which actions are most effective in reducing risk, and to broaden awareness about actions Canadians can take.

Supporting health equity is a top priority for Canada and efforts are made to systematically integrate sex and gender considerations into all research, policies, programs and services, including the national dementia strategy. Canada's national dementia strategy places an emphasis on groups who have been identified to be at a higher risk of dementia, as well as those who face barriers to equitable care. These groups, which include but are not limited to Indigenous peoples, individuals with existing health conditions, older adults, women, ethnic and cultural minority communities, and LGBTQ2 individuals, are prioritized in our work to develop dementia risk reduction interventions.

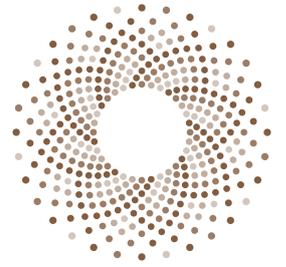
Canada is investing in building awareness by supporting initiatives focused on dementia prevention, reducing stigma, encouraging dementia-inclusive communities, supporting community-based projects to optimize the wellbeing of people living with dementia and family/friend caregivers, and increasing knowledge of dementia and its risk and protective factors. Awareness raising activities include developing, testing, disseminating and scaling up initiatives, knowledge, and tools. A knowledge hub is also disseminating program findings, lessons learned, and best practices to dementia policy and program stakeholders across Canada.

Research is one of the many ways Canada is contributing to the global effort to prevent dementia. At the centre of research investments is the Canadian Consortium on Neurodegeneration in Aging (CCNA), a pan-Canadian research network that brings together over 350 Canadian researchers and clinicians to accelerate progress in research on age-related neurodegenerative diseases that affect cognition in aging, including dementia. The CCNA's research is focused around three main themes, one of which is risk reduction and prevention. The flagship program of this theme is the CanThumbsUp initiative that is linked to the international FINGERS initiative, established to support and convene global multidomain dementia prevention trials, share experiences and data, and harmonize methods. Recommendations from the 5th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia were also recently published to share this group's latest guidelines on dementia risk reduction.

In Canada's annual reports to Parliament on dementia, examples of the work undertaken every day by many organizations and dedicated individuals across the country that support our national dementia strategy are highlighted. Prevention related data points are also included.

4. Lesser, J. A. & Nienhuis, C. P. The Impact of COVID-19 on Physical Activity Behavior and Well-Being of Canadians. *International Journal of Environmental Research and Public Health* 17, 3899 (2020)

5. Rotermann, M. Canadians who report lower self-perceived mental health during the COVID-19 pandemic more likely to report increased use of cannabis, alcohol and tobacco. *Statistics Canada* (2020)



Initiatives related to dementia prevention move us closer to one of our national strategy's aspirations, to work towards preventing dementia through risk reduction. As our understanding of dementia prevention grows, it is increasingly important to create effective ways of sharing this knowledge in a way that persuades and enables Canadians to take action. Increasing individual awareness of risk reduction actions and promoting the development of supportive social and built environments are some of the ways we can help support changes in behaviour.

The World Dementia Council has furthered the global conversation on dementia and its recent workshop on dementia prevention was a welcome discussion, reaffirming the importance of advancing our collective knowledge about risk reduction. We are seeing a declining incidence of dementia in some countries, a trend that provides hope for the future. To make this more widespread and accelerated in other countries, dementia prevention should be a priority.

Our vision for Canada is one that we wish for the world; a nation and world in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood and effectively treated.

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.

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