Dangerous links between dementia and other chronic diseases demand attention.

The links between diseases such as type 2 diabetes and cardiovascular disease with dementia are a growing concern that researchers and health advocates say warrant greater attention. Many people in the community would be unaware of the dangerous links between dementia and other well-known chronic diseases that affect millions of Australians. And yet for scientists, cross-disease research in this area is expanding at a rapid rate, driven in part by ageing populations and soaring rates of chronic disease.

Numerous large, observational studies have demonstrated that cardiovascular and metabolic risk factors such as hypertension, obesity and diabetes are associated with accelerated cognitive ageing, suggesting that treatment of these risk factors could help maintain cognitive health. In addition to chronic medical conditions, several lifestyle behaviours, such as smoking and poor nutrition, have also been identified as risk factors. Studies suggest that there may be multiple pathways linking physical and cognitive activity to better cognitive function.

One of the challenges posed by dementia from a health-management perspective is that it is not a single disease. It is a term given to a collection of diseases that are characterised by cognitive impairment. Two of the more common forms of dementia are Alzheimer’s disease and vascular dementia.

Obtaining a diagnosis of dementia can be a difficult, lengthy and intensive process. Equally, the causes of dementia are complex and influenced by many factors acting in combination. Prevention of dementia and delay of disease onset and progression depend on an understanding of these determinants. New treatments for established dementia are urgently needed.

In line with Baker IDI’s commitment to reduce death and disability from cardiovascular disease, diabetes and related disorders, the Institute’s researchers are working to understand the risk factors and tackle the underlying causes of dementia. This type of broad-based, cross-disease research is indicative of
what is happening in scientific laboratories around the world as scientists move away from disease-specific, or silo-based research, seeking greater understanding of the common mechanisms that link these diseases.

Type 2 diabetes and the most common form of dementia, Alzheimer’s disease, may appear to be very different in their pathologies but scientific evidence is now emerging that links these two diseases.

There is now significant epidemiological data to suggest that type 2 diabetes is a significant risk factor for all cause dementia and that impaired glucose tolerance has an important role as a risk factor. Moreover, growing evidence at the molecular level links these diseases via the development of amyloid beta – a protein that forms a plaque between nerve cells in the brain and is thought to contribute to symptoms of Alzheimer’s disease.

Researchers in the Institute’s Cellular and Molecular Metabolism laboratory have found that cells known as adipocytes principally responsible for storing energy as fat, secrete amyloid beta in obesity. The group has demonstrated that activation of the heat-shock protein HSP72 can prevent the development of obesity-induced insulin resistance and has hypothesised that this is, in part, via the removal of amyloid beta. The laboratory is investigating whether activation of HSP72 could be a common treatment to prevent both metabolic disease and Alzheimer’s disease.

Evidence has also emerged of the supporting link between high blood pressure, particularly in mid-life, and subsequent cognitive decline and dementia development. The evidence shows a lowering of cognitive performance and a more rapid rate of decline in cognition is associated with hypertension. Studies have also shown as much as a fivefold increase in the risk of developing dementia for those who are hypertensive. However, the mechanisms by which hypertension may induce decline in cognitive function remain unclear, and studies at Baker IDI aim to provide greater insight.

Researchers in Baker IDI’s Human Neurotransmitters and Neurovascular Hypertension and Kidney Disease laboratories have investigated the important role of the sympathetic nerves in the kidney as a target for the treatment of resistant hypertension (where conventional treatment has failed). By targeting these nerves to control blood pressure, researchers have noted an improvement in cognitive performance. The researchers are undertaking studies examining the effect of blood pressure reduction on cognitive function. Given that patients with high blood pressure are at increased risk of decline in cognitive function, cognitive impairment and dementia, any treatment that can prevent such detrimental health impacts warrants careful assessment.

The Institute’s researchers are also exploring the role of diet in the prevention of dementia, and specifically, Alzheimer’s disease. Researchers in the Epigenomic Medicine laboratory are interested in dietary interventions using antioxidants that may protect cells from the toxic effects of amyloid beta. It is believed that the accumulation of amyloid beta peptides in the brain form insoluble plaques that are responsible for Alzheimer’s disease. Amyloid beta is highly toxic, inducing progressive atrophy and death of neurons, even in the early stages of disease. Research has shown that activation of a naturally occurring set of genes called Nrf2/ARE can prevent the oxidative toxicity induced by amyloid beta and, in doing so, halt the progression of disease.

In line with this scientific understanding, Baker IDI researchers are investigating the potential of a dietary antioxidant called L-sulforaphane, which is found in vegetables such as cauliflower, cabbage and broccoli and is known to be a potent activator of the Nrf2/ARE antioxidant pathway. Researchers have hypothesised that dietary antioxidants may be helpful for people with a family history of dementia or for those with some of the early signs of producing the amyloid beta peptide.

These are just some of the many basic science studies that are underway at the Institute that are examining the risk factors and tackling the underlying causes of dementia. The good news is that researchers, both in Australia and globally, are making progress when it comes to understanding and development of potential treatments.

International epidemiological studies, such as the well-known Caerphilly Cohort Study in the UK funded by the Medical Research Council, Alzheimer’s Society and British Heart Foundation, also support preventive opportunities. The Caerphilly Cohort Study is one of the largest studies to examine the relationship between healthy lifestyles, chronic disease and cognitive decline over a 35-year period recording the healthy behaviours of 2235 men aged 45 to 59 in South Wales. It found that the people who consistently followed four or five of the healthy habits, which included a healthy diet and regular exercise, experienced a 60 per cent decline in dementia and cognitive decline – with exercise being the strongest mitigating factor – as well as 70 per cent fewer instances of diabetes, heart disease and stroke, compared with people who followed none.

The scientific literature is significant, and increasing. Understanding of the links between dementia and other chronic diseases is growing but there is a lot more work to be done.

References
The Australia I want to live in.

Old is a word most people fear because it is associated with slowing down – even breaking down – of mental fragility, of being tossed on the scrap heap, of failing faculties and ill-health, and of no longer being of value.

ITA BUTTROSE AO, OBE
Former President, Alzheimer’s Australia and dementia advocate

This is an edited version of an address to the National Press Club in April 2013.

I never thought about older old age or dementia until I cared for my father when he was in his 80s. He had vascular dementia and macular degeneration.

We live in exciting yet worrying times. We are on the brink of major social reform in the areas of disabilities and aged care while still experiencing a sense of gloom about the continuing global financial uncertainty and budget deficits. At the same time we see poignant examples of discrimination and violation of basic human rights every day in our aged-care system. I believe our national debate needs to be more about the Australia we want to live in, the kind of society we should be and less about what programs need to be cut or the size of the deficit.

I am proud and very happy to live in a country that has one of the longest life expectancies in the world. We now live almost 25 years longer than Australians who lived 100 years ago. The question we need to ask ourselves is: How do we want to spend those extra years of life? What is our vision for Australia as our population ages?

My vision is simple. I want to live in a society that is inclusive and values the strengths and contributions of all members of our society regardless of their age, disease or disability. I want to belong to a society that values choice over institutionalisation, that promotes wellness and social inclusion over isolation.

Some of Australia’s most socially disadvantaged groups have made the decision to tackle the stigma and social isolation that they have experienced for so long. Beyond Blue has put mental health and depression in the front of people’s minds as something that every Australian should understand better. Similarly, the disabilities movement has argued for many years that people with disabilities should not be defined by their disability.

In spite of the work done over the last few decades, stigma and social isolation remain. Last year, a Beyond Blue survey found that one in four people believe a person with severe depression should just “pull themselves together”. While a survey of people with disabilities found that 94 per cent of people with a disability feel they do not have enough meaningful participation in their community.

Stigma is also alive and well with regards to dementia. Ten per cent of Australians say they would actively avoid spending time with a person who has dementia. Many people admit they avoid seeking help for symptoms of dementia because they are worried about the discrimination they will face if they get a diagnosis. This is just not acceptable. No one should feel ashamed to have dementia. It is not a normal part of ageing, it is a chronic disease.

Greater awareness will help but it is not enough. We need to actively promote social inclusion. Several cities around the world are adopting principles to create “dementia-friendly societies”.

In Bruges, Belgium, businesses display signs indicating their staff is willing and able to help people who have dementia. There are several community initiatives such as memory cafes and dementia choirs to promote social inclusion.

We are doing some of those things in Australia. Many areas have memory cafes or other activities to promote social engagement. The idea of a dementia symbol is not new – it will indicate that a bank, hospital or Centrelink office have staff trained to assist people with cognitive impairment.

Australia needs a commitment like the one made in the UK in 2012 by Prime Minister David Cameron who called for the creation of dementia-friendly cities as part of his dementia challenge. He urged 20 cities and villages to sign up as dementia champions by 2015 and for local businesses to provide support for this concept.

The Australian Institute of Health and Welfare released a report in 2013 that found that more than 90 per cent of older Australians want to
continue to live in their own homes rather than enter residential aged care. But this is not reflected in our aged-care system.

Only about 54 per cent of Australians requiring long-term care receive such care in their homes. Countries such as Japan, Norway and Switzerland put us to shame. They provide more than 70 per cent of long-term care in the community to their citizens. The change in culture that is required to bring the element of choice into the lives of those people who require assistance is huge – but it is the challenge we have to face in the Australia I want to live in.

Reform is key. The reforms in DisabilityCare Australia go further than those in aged care. They promise to transform a heavily rationed system into a market in which funding is allocated to the person with the disability and their families, enabling them to exercise choice over the services they receive. The aged-care reforms aim to create a system with greater choice and flexibility but they stop short of the entitlement approach recommended by the productivity commission. Aged-care places will continue to be rationed.

We need to focus on implementing more high-care community packages for people who otherwise would have no option but to move into residential care. We need to expand flexible dementia respite services, to give carers a needed break and the person with dementia social engagement and activities that interest them. And we urgently need to address longstanding disquiet about quality in residential care, particularly for those with the severe behavioural and psychological symptoms of dementia.

In 2012, during consultations Alzheimer’s Australia held on the aged-care reforms, we heard that within weeks of entering residential care, many carers find that family members and friends they have spent years caring for have become unrecognisable in terms of their physical, mental and emotional welfare. Nearly one-quarter of residents are chemically restrained with antipsychotic medications, often without their consent or the consent that is legally required from their family. It is unacceptable that such practices are taking place today in Australia. These medications provide a clinical benefit to only one in five, and are associated with an increased risk of serious side effects.

In addition to an inclusive society, my vision also includes a health system that is accessible and works for all Australians regardless of age, disability or disease that focuses on prevention and wellness as well as treatment.

We could prevent around one-third of chronic disease in Australia by reducing tobacco smoking, blood cholesterol and obesity, and by controlling blood pressure and increasing physical activity. However, only 50 per cent of Australians know that there are ways to reduce their risk of developing dementia, and very few are aware of the link between diabetes and dementia.

We also need to promote mental health. A recent study commissioned by Beyond Blue suggests between 10 and 15 per cent of older people living in the community experience depression. Another Australian study shows 35 per cent of aged-care residents experience depression.

There needs to be a focus on wellness and capitalising on strengths once a person does develop a disability or chronic disease. There are strategies that can be put in place to help people with dementia make the best use of their remaining cognitive abilities.

A focus on wellness is impossible, however, in a system where people with dementia have to wait an average of three years between the first symptoms of dementia and a confirmed diagnosis, and where hospitals often do not even record a diagnosis of dementia. The aged-care reforms contain proposals to tackle issues that have been neglected in Australia for too long. There is the commitment to funding initiatives that will promote timely diagnosis, make hospitals safer places for people with dementia and encourage dementia risk reduction. But these reforms are just a start.

We might also set the objective of embracing dementia risk reduction within the preventative health campaigns for heart disease, obesity, alcohol and smoking. We know if we can delay the onset of dementia by just five years we would be able to reduce the numbers of people with dementia by one third.

An important part of addressing health and wellness is investing in research. I am pleased that the Australian government has committed $200 million, announced as part of the May 2014 budget measures, to boost dementia research. This is a good start.

We need action to achieve this vision … I have issued a challenge to politicians on both sides of politics. Firstly, to support the full implementation of DisabilityCare Australia and the 2012 Aged Care Reforms. Secondly, to explain to Australians how they will work to achieve a more inclusive society that values people regardless of their age, disease or disability. And thirdly, to announce plans for increased investment in health and medical research to mitigate the increasing economic and social cost of chronic disease.

In the next few years, we have a unique opportunity to implement major social reforms in Australia, to become a world leader in a system of care and support that enables people to achieve the highest quality of life, and makes them want to contribute and be a part of a society that values them.
Postponing your retirement is a great investment in your cognitive health.

There are few things that people fear more as they age than losing their cognitive capacity. The current view in the wider community is that if you start to have real trouble with your memory in your later years, you may well be facing an inevitable downward spiral into dementia, nursing-home care and loss of independence and dignity.

A wider perspective, often reinforced by government and medical expert commentary, is that the Western world faces a tsunami of older people incapacitated by Alzheimer’s disease and other dementias, and that there is currently no preventive action possible nor any effective treatment. Such views have galvanised Western countries, including Australia, into proactive investments in brain and dementia-related research.

The substantive questions, therefore, for those actively engaged in health and medical research for older persons are whether these perceptions and predictions are really justified and to what extent we are able to engage in a much more productive population-health-based approach now to reduce the societal burden associated with those brain disorders that become more common as we age.

The big conceptual issues to resolve are that: all cognitive decline in older persons is not due to classical Alzheimer’s disease; we already know a large number of potentially modifiable risk factors for cognitive decline, particularly for vascular-type and other similar dementias; and for many people the goal of current strategies is not simple primary prevention or curative treatment but rather earlier identification and then significant modification of illness course. That is, it may well be already within our reach to detect many cases early and then so significantly delay the progress of illness that older persons are able to continue to live independently for the larger part of their remaining years.

At the population level and for those in very early stages of illness, therefore, we need to focus on risk-factor modification. Three types of risk-factor profiles really stand out. The first are those most closely linked to vascular risk (smoking, hypertension, lipid profiles and diabetes). The second relate to cognitive activity, being most closely linked to factors such as lower levels of education or employment histories and loss of active cognitive lifestyles. The third relate to other factors that interact with both physical and mental health, including late-life depression, loss of physical activity and alcohol misuse. Even for those with more typical Alzheimer’s disease of late-onset, it has become increasingly clear that some of those same risk factors are shared and worthy of specific population-based approaches.

Fortunately, vascular risk modification is alive and well in our community due to the extensive public health and clinical activity that has already had a major impact on rates of cardiovascular and cerebrovascular deaths in younger populations. The risks associated with other modifiable factors such as alcohol-related harm are the subject of active debate in our community and appear to also be headed towards continuous improvement. While the societal factors related to increasing obesity and lower levels of physical activity are recognised and are the subject of much debate, there is clearly more to be done in this area. Similarly, the increased recognition of issues related to depression and other mood disorders and the need to foster active treatment – particularly in older persons – is an active area of medical and public-health development.

Perhaps the most controversial topic for Australians as they get older is the notion of enforced or voluntary ‘retirement’ by age. It is a cherished national ideal that at some point we can all give away our normal ‘stressful’ daily work life and then enjoy the rewards. Visions of an older life spent lying on a beach, strolling around a golf course or roaming around the vast Australian continent are a prized part of the national psyche.

The first error here is the failure to appreciate how much a productive or organised work life plays in maintaining our cognitive, social, mental and
Real brain challenges are not easily replaced by crosswords, Sudoku or computer games. Human faces, social groups and intergenerational interactions are all much more challenging.
Awareness of dementia risk could influence lifestyle changes.

Convincing people to substantially change their lifestyle or adhere to taking their medications in order to reduce their risk of cardiovascular disease or further cardiovascular complications is often challenging.

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Professor Jennings and Dr Ellims are both cardiologists and cardiovascular disease researchers

With definitive evidence of a link between cardiovascular risk factors and dementia accumulating, the authors of an editorial in *Nature Reviews Cardiology* (2010)1 opined that capitalising on patients’ concerns about future dementia might be necessary to overcome reduced compliance to prescribed preventative medications and lifestyle changes for those at risk of heart disease. They stated that loss of memory is a far worse prospect for most people than traditional cardiovascular diseases, which can often be treated with a combination of therapies and interventions. “We can now appeal to patients’ heads and hearts when discussing the importance of reducing cardiovascular risk factors,” they espoused. For health professionals, this presents an opportunity for action, with education through patient empowerment having the potential to improve both heart and cognitive health.

There are, of course, many barriers to medication adherence including issues regarding access to health services, lack of understanding about treatment regimens, and miscommunication between health professionals and patients. It would be too simplistic to suggest patient motivation is the sole reason for non-adherence. Regardless, the literature is littered with examples that highlight the major challenges that cardiologists, health professionals and patients alike face when it comes to non-adherence to treatment. For example, one study demonstrated that after people were hospitalised for a heart attack, almost 25 per cent did not fill their cardiac medication prescription by day seven post-discharge.2 Another study showed that about half of all patients prescribed anti-hypertensive medications stopped taking them within one year of the initial prescription.3 These findings are of no surprise to health professionals. We tend to blame the patients, even if our own communication with them is sub-optimal. There is much room for improvement. With clear evidence of a link between cardiovascular risk factors and dementia, cognitive decline is another risk of which patients should be aware. The reality is that many people are unaware of this link or that they have any control over their risk of cognitive decline. With the high prevalence of heart, stroke and vascular disease in the Western world today and dementia already affecting more than 35 million people globally, it is important that health professionals raise this issue with their patients.

Advancements in medical science alone will not solve the problem in the short term. It is true that the second half of the 20th century has seen a rise in the effective treatment of most forms of cardiovascular disease ranging from medications to effectively manage hypertension and cholesterol levels, to improvements in cardiovascular intervention and surgery. Likewise, improvements in diagnostic techniques have also occurred. Baker IDI scientists, for example, have developed a test that can predict the size of a heart attack from a single blood sample at the time of hospital admission, leading to quicker diagnosis and treatment. These advancements have also coincided with effective public-health campaigns, most notably those targeting cigarette smoking. Overall, the combination of better preventative strategies and improved therapies has contributed to a decline in cardiovascular disease mortality in developed countries. However, there are currently no interventions to halt the progression of dementia that are either licensed or recommended for clinical use.4

With increasing life expectancies and people wanting to participate in both their professional work and community life for longer than ever before, the importance of cognitive health...
is receiving greater focus. While the rates of dementia increase with age, it is important that people understand that it is not a normal part of ageing. The various forms of dementia are chronic, or long-lasting, diseases, and can be managed, but not cured, like cardiovascular disease and diabetes. However, awareness of this appears to be low globally. The results of a survey of more than 2000 people in the US in 2008, commissioned by the Alzheimer’s Association and the American Heart Association, showed that most people did not know about the connection between cardiovascular disease and the risk for dementia. The World Health Organization also acknowledges there is a lack of awareness and understanding of dementia in most countries. Health professionals, including cardiologists, can play a role in addressing this.

Controlling risk factors for cardiovascular disease and diabetes remains challenging but most people are aware that diet and lifestyle can play an important part. There is far less clarity and understanding around the prevention of dementia. An array of studies have shown that reductions in death rates from heart disease are a result of a decline in people suffering heart disease in the first place, as well as improvements in treatments. Studies have shown that improved mortality rates in wealthier countries are a direct result of risk-factor changes. The Nordic countries, for example, have shown the importance of reducing risk factors through the implementation of effective policies. Conversely, these same factors are driving the increases in cardiovascular mortality rates in middle and low-income countries. In China, mortality increased rapidly from 1984, reflecting a Westernisation of their diet compounded by an ageing population. Health professionals can help raise awareness of the links between cardiovascular disease and dementia when discussing ways to reduce cardiovascular risk factors with their patients, for example. This alone may not bring about significant change but it will be a step in the right direction and may motivate some people to take greater control of their health.

References
Social action needed to create a
dementia-friendly Australia.

The everyday stories of people living with dementia suggest that social action is necessary to achieve an improved quality of life and to reduce the stigma that is still attached to a diagnosis of dementia. This is despite some remarkable developments since 2000 sparked by an increasing recognition in policy to serve the needs of people with dementia and their family carers.

GLENN REES AM
Former CEO of Alzheimer’s Australia and Chair-elect of Alzheimer’s Disease International

After years of institutionalisation and silence, people with dementia have been given the opportunity to self-advocate. The first time that people with dementia had a voice at the biennial National Conference of Alzheimer’s Australia to tell their stories was in 2001, 20 years after the organisation was first founded. In 2014, it is hard to imagine holding a conference without people with dementia being front and centre. We now have a national advisory group made up of people with dementia and have recently employed a person with dementia in a paid consultancy role.

Government policy has also progressed a long way since 2000. The Dementia Initiative: Making Dementia a National Health Priority in the 2005 Federal budget was a world first in recognising the social and economic significance of dementia. Not only was it a building block for planning for the future, but it also came with a $320 million investment over five years for dementia-care research, training and expanded community-care services for people with dementia.

The 2012 Aged Care Reforms included an important commitment to tackling dementia with $273 million over five years to achieve timely diagnosis, better dementia care in hospitals and dementia key workers for younger people with dementia. It also included for the first time a recognition of dementia as an official National Health Priority Area.

Translating these important initiatives into improvements in the quality of life of people with dementia and their family carers is, however, painfully slow.

Social action is needed for several reasons: to address issues in respect of the quality of dementia care; to recognise the rights of people with dementia; to better support family carers; and to increase awareness of what can be done to reduce an individual’s risk of dementia.

Social action is needed because dementia is as much a social issue as it is a medical issue. Too often I hear stories of people with dementia being encouraged to give up their hobbies and other activities they enjoy as soon as they get a diagnosis. We have been slow in Australia to recognise the need for greater recognition of the rights of people with dementia to ensure that they have access to the services we all enjoy including those provided by banks, retail, emergency services and Centrelink.

A high priority in Alzheimer’s Fight Dementia Campaign, Creating a Dementia-Friendly Australia, is to create communities that enable people with dementia and their family carers to participate fully in society through being able to engage in activities of lifelong interest, continuing studies and opportunities for paid and voluntary work. Interestingly, the concept of a dementia-friendly community is taking off across the world, and it is an important strategy to counteract the stigma and social isolation that still result from a diagnosis of dementia.

The stories that I have been told by people with dementia and family carers over the years about the quality of dementia care and lack of access to dementia services are perhaps the most upsetting of all.

Over the past three years, Alzheimer’s Australia has focused much of its advocacy on the need for zero tolerance in respect of poor-quality care, especially in residential-care services. The evidence shows that physical and medical restraints are widely used in residential care. This is despite clear evidence of their risks – which can include falls, stroke and even death – and best-practice guidelines that recommend antipsychotic medications be used for treatment of behavioural and psychological symptoms of dementia as a last resort, only after other non-medical approaches have been tried.
Yet they are too often used as a frontline response, and mostly without the consent of the person with dementia or their carer that is legally required.

The belief of Alzheimer’s Australia is that this is not just an issue of funding, but lack of leadership in many services and a disregard for the rights of people with dementia. There are examples of services that have been able to reduce their use of these medications dramatically through implementing person-centred approaches to care focused on providing access to meaningful activities and engagement. It is unfortunate that these examples are the exception. Too often, there is not a partnership that respects the individual in terms of person-centred care or partnership with the family carer who knows the individual best.

The bipartisan political commitment to consumer-directed models of care, where the individual has a say in the decisions taken about the services to be provided, may lead to greater responsiveness in services to individual need. But if people are to make choices about the care they need, clearer information is needed. This includes quality indicators that help consumers understand the nature of the care being provided by individual services on the basis of surveys of residents’ experiences in particular services.

The political rhetoric in support of family carers has always been strong but arguably not consistent with the actions of government or the wider community in providing the support that people providing 24-hour care for people with dementia require.

The community service most valued by people with dementia and their carers is respite. Well-designed respite not only gives the carer a break but also provides opportunities for social engagement for the person with dementia.

Respite dazzles the bureaucrat because it can take so many forms and be provided in so many different locations at different times. If flexible respite is to respond to the needs of the individual, Australia should trial individualised funding that puts cash in the hands of the family carer. This will allow the person with dementia and their family carer to have the option of purchasing services and support that best meet their needs, when and where they need it, including from their own family and friends.

Such an approach needs to be properly evaluated so as to provide a basis for decision-making in the longer term on the benefits of individualised funding approaches in aged care.

In respect of dementia risk reduction, we know that less than 50 per cent of Australians are aware of the steps they can take to possibly reduce their risk of dementia. This includes not only adopting lifestyles that embrace physical, mental and social activity, but also enhanced management of chronic diseases that are linked to dementia including stroke, vascular disease, diabetes and obesity.

In this area, Australia has been a world leader in developing a publicly funded national educational program, Your Brain Matters, delivered through Alzheimer’s Australia. But a sustained approach is needed that makes better links to other chronic diseases that share modifiable risk and protective factors with dementia.

This agenda to make Australia dementia-friendly has to be combined with a commitment of governments around the world (including Australia) to invest more in dementia research to give hope that in the longer term we will be better able to identify those at risk of dementia and develop the interventions necessary to delay the progression of the disease. To this end, the Australian Government has committed an additional $200 million to dementia research in the 2014 Federal budget.

The G7 Dementia Summit in London in December 2013 established a World Dementia Council and endorsed the ambition of finding a cure or a disease-modifying therapy for dementia by 2025. Global leaders committed to collaborating on research, increasing funding and facilitating research participation and data sharing. The World Dementia Envoy, Dr Dennis Gillings, is leading the work of the Council, and significant international collaborations are already underway.

If we can build on the progress made in recent years through social action and greater investment in dementia research it may be yet that the stories I have heard daily as CEO of Alzheimer’s Australia over the past 15 years will become history.
In danger of over-diagnosis.

The pattern of over-diagnosis is the same for many diseases: we screen healthy people and those with minimal symptoms; we use sophisticated technologies that detect early or minor abnormalities that may not progress; and we treat people with these abnormalities on the assumption that this will prevent significant illness and death.

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The downside of all this medical intervention is that we are exposing healthy people to the potential harms of diagnosis, investigation and treatment without any certainty about long-term benefits. Indeed, there is a growing unease that this trend is being driven by the financial benefits of creating a larger market for drugs rather than genuine health gains.

I work in geriatric medicine and over the past few years, I have seen how the changing definitions of dementia and Alzheimer’s disease has insidiously been leading to over-diagnosis.

Screening the healthy

Let us start with the schema of over-diagnosis: are we screening healthy people and those with minimal symptoms? Yes. In the past, we diagnosed older people complaining of minor memory impairment with “benign senescent forgetfulness” and told them that it did not require any further action. It was, after all, benign.

But this terminology progressed to “mild cognitive impairment (MCI)” and now (more ominously) to pre-dementia and pre-clinical Alzheimer’s disease. We are also being encouraged to screen older people for any memory impairment because this has now been defined as a pre-disease or early disease.

The screening tools are usually simple questionnaires, such as the mini-mental state examination. There is variability in how well the assessments are performed and forgetting the date or stumbling on a repetition task can lead to a diagnosis of mild cognitive impairment. But how many of these people actually progress to dementia?

Most studies show that only one in 10 cases of mild cognitive impairment progress to dementia each year and many improve. One study that followed outcomes for 10 years concluded: “The majority of subjects with MCI do not progress to dementia at the long term.”

Yet all of these people will potentially be faced with the stigma of a dementia diagnosis and its consequences – paternalism, incapacity and loss of autonomy. And then there is the fear of impending dementia, which can generate stress and despair.

Better technology

Are we using sophisticated technologies to detect early or minor abnormalities? Yes. In attempting to improve the diagnosis of early dementia, we now have a range of investigations to detect the earliest cases before symptoms have developed. These include brain scans and measurement of biomarkers in the fluid that surrounds the brain.

The gold standard for such diagnoses is post-mortem brain pathology. Alzheimer’s disease is characterised by deposits of a protein called amyloid in plaques between brain cells and another protein called tau in tangles within the cells. But the relationship between amyloid plaques and the clinical features of dementia lessens as people age.

Many older people with the characteristic pathology of Alzheimer’s disease did not have any features of dementia post-mortem or memory problems when they were alive. On the other hand, the majority of older people with dementia have multiple changes in their brains including those related to ageing and vascular disease. So the characteristic pathology of Alzheimer’s disease is not very useful in diagnosing dementia in the largest group of people with dementia – the elderly.

Early treatment

Are we treating these early abnormalities on the assumption that this will prevent the development of dementia? Yes, in some cases.
There are two groups of medicines available for the symptomatic treatment of Alzheimer’s disease (cholinesterase inhibitors and memantine). Although these drugs have not been proven to have any effect on influencing the progress of dementia, review articles in some medical journals promote the possibility of their “disease-modifying activity” and the need for early treatment with these medicines.

It is important to add that a trial of one of these medicines attempting to show a reduction in the conversion from mild cognitive impairment to dementia found that it actually increased the death rate.

The medicines are only funded by the Pharmaceutical Benefits Scheme for moderately severe Alzheimer’s disease but undoubtedly some people will be using them (and probably a variety of alternative therapies as well) in the hope that they will delay dementia.

There are other industries aiming to profit from the diagnosis of mild cognitive impairment (or early and preclinical dementia) by selling various brain-fitness technologies ranging from video games to smartphone apps.

Dementia is a tragic illness that places enormous burden and demands on patients, families and society. There is no question of the value of increasing recognition of the care needs of people living with dementia, and for more research funding. These are essential because effective treatment and prevention of dementia will have a dramatic impact on the human race. But the growing emphasis on early diagnosis of dementia, mild cognitive impairment and pre-clinical dementia in everyday practice (with the subsequent risk of over-diagnosis and its consequences), seems to be giving the disease, not the patient, greater priority and importance.

Most studies show that only one in 10 cases of mild cognitive impairment progress to dementia each year, and many improve.