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NATIONAL STRATEGIES TO ADDRESS DEMENTIA

A REPORT BY ALZHEIMER'S AUSTRALIA

PAPER 25

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FOREWORD

The necessity to fight the dementia epidemic has become self evident at the international level and in Australia.

The last decade has seen an explosion of economic and social reports that have documented the current and future numbers of people with dementia and the economic and social cost of dementia to the middle of this century.

Alzheimer's Australia can be proud that it was a leader in commissioning work through Access Economics that documented the economic and social impacts of dementia and positive strategies for the future.

This evidence was crucial to the implementation of the ***Dementia Initiative – making Dementia a National Health Priority*** in the 2005 Federal Budget with additional funding over five years to take action in respect of community care, training and dementia care research.

Other countries have followed and it is important to learn what we can from their actions and experiences.

We live in a region that will have about 53% of the 115 million people living with dementia worldwide in 2050 if medical science does not find ways of better treating and preventing dementia.

The last decade has seen some important developments in addressing dementia. However, it remains true that many plans lack resources for implementation. In particular, dementia research is underfunded. It is critical to increase expenditure on research if we are to better understand the causes of dementia and ways of better treating and preventing dementia.

Our Fight Dementia Campaign is seeking to increase expenditure on dementia medical research to 1% of the current cost of dementia. The total cost per annum of Alzheimer's Australia new 5 year Dementia Action Plan would be $100 million per annum or 2% of current annual total expenditure on dementia. This is modest by any standards but it will tackle vital issues and enable us all to better plan for the future.

Our intention is to review at intervals what is happening around the world to ensure that Australia remains where it should be, and that is at the forefront of policy thinking and action on dementia.

Ita Buttrose

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President
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OVERVIEW

Currently, there are 35 million people worldwide living with dementia, and as the population ages this is predicted to reach over 100 million by 2050.[1] The estimated worldwide costs of dementia in 2010 were US$604 billion, and this cost is expected to increase by 85% by 2030.[2] The economic and social impact of dementia on health care systems and on family carers makes it the major health challenge of this century.

A number of countries have recognised that without a coordinated plan to address dementia individuals with dementia will not have access to the specialised services and supports they require. Some countries have already implemented a plan to address dementia.

This paper provides an overview of a range of approaches that a selection of countries have taken to address dementia. It should be noted that this paper is not a comprehensive review of all national strategies and is only based on readily available information.

Developing a co-ordinated response

Australia was the first country to make dementia a national health priority with a funded five year plan. The policy logic of the need to make dementia a priority with coordinated action has compelled other countries to follow with national plans. These vary greatly from country to country, but all ultimately aim to improve the quality of life of people with dementia and their families by ensuring access to early diagnosis, information, and high quality care and support. Some countries have also focused on reducing the future numbers of people with dementia through investment in research and preventative health.

Action taken at the national level has the capacity to result in effective change, to increase disease awareness across the entire population, to develop consistent services and support and to ensure that there are no barriers between federal and regional programs. Funding can be demarcated for particular programs and regions. There are benefits to allowing regional flexibility in order to respond to the regional context and specific needs, particularly in large diverse countries.

Conclusion

There is no single best approach to addressing dementia as each plan reflects a particular national context. The common themes that have emerged from this review include:

- A need to recognise dementia as a chronic disease that should be addressed through awareness, early diagnosis, good management care, prevention and research
- A coordinated approach that enables coordination and collaboration across all aspects of health, medical, social support and research
- Ongoing evaluation and reassessment of priorities to meet the changing needs of individuals with dementia
- Sustainable funding which promotes both access to needed services and innovation through knowledge translation and dementia care research
- A national commitment to research into the cause and prevention of dementia

SURVEYING THE INTERNATIONAL LANDSCAPE

A number of countries have produced national strategies or plans to address dementia. For the purposes of this paper, the dementia strategies of Australia, England, France, South Korea, Norway, Scotland, Denmark, Japan, Canada and Netherlands will be reviewed.

These strategies are summarised below by country. Where information is available, a brief outline of each countries implementation strategy, consultation process and evaluation is presented.

AUSTRALIA

The Dementia Initiative – Making Dementia a National health Priority (2005-2010)

The National Framework for Action on Dementia (2006-2010)

Funding 320 Million AUD.

Focus

- Community care packages
- Training for aged care staff
- Dementia Behaviour Management Advisory Service (services that provide advice to those in the community and residential care staff)
- Support and information for individuals with dementia and families
- Research funding
- Community support grants

Consultation

The Initiative was implemented in the 2005 Federal Budget and the Ministerial Dementia Advisory Group was established in 2008. The Group was established to provide the Minister and the Department with expert advice on the implementation, monitoring and evaluation of the Dementia Initiative. The Group also provides advice on broader aspects of dementia including opportunities to improve prevention, care and treatment and aspects of dementia that are relevant to other areas of health reform. The members of the advisory group include representatives from consumer organisations, the aged care sector, nursing academics in relevant fields and medical professionals.

Evaluation

The Dementia Initiative was evaluated by a consortium and has been found to be cost effective and to have made a substantial contribution to supporting people living with dementia and their carers.[3] The evaluation found that the Initiative did not address a number of key issues including primary care, a communications strategy and risk reduction. In the 2011 Federal Budget the Federal Government terminated the Initiative. However, it is possible many of the programs may continue to receive funding after current contracts expire.

More information

Dementia Initiative National Evaluation
http://www.health.gov.au/internet/main/publishing.nsf/Content/500DD5C951D7E214CA2578170017A8F9/$File/LAMAOverview.pdf

The National Framework for Action on Dementia
http://www.alz.co.uk/sites/default/files/australia_plan.pdf

ENGLAND

Living well with dementia: A National Dementia Strategy[4] (2009 – no end date)

Funding £150 million (approx 231 million AUD)[a]

Focus

The initial focus of the strategy was wide ranging and included awareness, diagnosis, information, quality care, training, community support, end of life care and research.
The implementation of the strategy was revisited in 2010 and four key priority areas were identified:

- Early diagnosis and intervention
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reduced use of antipsychotic medication

The change in focus was partially due to the release of reports which reviewed dementia care in hospitals and the use of antipsychotic medications.

Consultation

The National Dementia Strategy was developed in consultation with key stakeholders. Over 3000 people were involved in the initial consultations which were organised jointly by the Department of Health and the Alzheimer's Society. A second round of consultations was held with over 50 events throughout the country which were attended by 4000 individuals. Approximately 600 responses to the consultation document were received.[5]

Implementation

An implementation plan was published with the strategy setting out how the Department of Health would support delivery of the strategy through its national and regional structure. The plan has been implemented by the National Health Service, local authorities and other key organisations. In 2010 The Department of Health released *Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy* to update the implementation strategy. This included a discussion of measurable indicators against which the strategy could be measured.

Evaluation

In 2011 the Department of Health released the *Good Practice Compendium* which provides examples of successful programs which are linked to the relevant strategy objective. This paper provides an overview of some of the successes of the Strategy.

More information:

Living Well with Dementia a National Strategy:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

Living Well with Dementia: Implementation Plan
http://www.alz.co.uk/sites/default/files/plans/England-implementation-plan.pdf

Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy
http://www.alz.co.uk/sites/default/files/plans/England-quality-outcomes.pdf

Living well with dementia: A National Dementia Strategy Good Practice Compendium - an assets approach
http://www.alz.co.uk/sites/default/files/plans/England-asset-inventory-2011.pdf

SCOTLAND

Scotland's National Dementia Strategy (2010 – 2013)
(A revision of the strategy will occur in 2013)

Funding £150 million (approx 231 million AUD)[b]

Focus

- Standards of care
- Staff skills and knowledge
- Integrated support for local change
- Dementia diagnosis and support
- Access to quality care
- Dementia care in hospitals
- Research

Consultation

The National Dialogue On Dementia - Dementia Strategy Consultation Paper was released for public comment.[6]
The Scottish Government commissioned The Mental Welfare Commission to lead the development of the standards of care, with a multi-representative steering group including people with dementia and carers. Consultation was undertaken on the content of the standards in a series of events held throughout Scotland. The Strategy is overseen by a Dementia Strategy Implementation and Monitoring Group involving all key stakeholders including people with dementia and family carers.

Evaluation

The Scottish Government released *Scotland's National Dementia Strategy: 1 year on*, a report on the progress of the strategy.[7]
The main areas of success noted were the development of dementia care standards and a skills and knowledge framework to inform dementia training.

More information

Scotland's National Dementia Strategy
http://www.alz.co.uk/sites/default/files/scotland_plan.pdf

Scotland's National Dementia Strategy- One Year On Report.
http://www.scotland.gov.uk/Resource/Doc/350341/0117259.pdf

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[a] Based on exchange rate at 14/9/2011

[b] Based on exchange rate at 14/9/2011

FRANCE

The French National Plan (2008- 2013)[8]

Funding

€1.6 billion (approximately 2.1 billion AUD)[c], Funding is allocated from the health insurance system and the National Fund for the Autonomy of Elderly and Disabled People.

Focus

- Improving quality of life for patients and carers
    - Increasing support for carers
    - Strengthening coordination between all actors involved
    - Enabling patients and their families to choose support at home
    - Improving access to diagnosis and care pathways
    - Improving residential dementia care
    - Dementia training for health professionals
- Knowledge for action
    - Making unprecedented efforts in research
    - Organising epidemiological surveillance and follow up
- Mobilising around a social issue
    - Providing information for general public awareness
    - Promoting ethical considerations and an ethical approach
    - Making Alzheimer's disease a European priority

Consultation

Information not available

Implementation/Evaluation

The French National Plan has defined measures and outcomes to guide the evaluation of the progress. There is a pilot committee which meets every month to check the progress of each measure. An implementation report is produced every 6 months. In June 2011, it was reported that the Plan successfully grew the dementia research capacity of France,[9] established new memory clinics and diagnostic centres, and reduced the use of antipsychotic drugs. It had aimed to increase the number of respite care centres, but has not done so yet. The French Plan has been a coordinated approach that enables interaction across the health, medical, social and research sectors.

This is reportedly the third plan in France that addresses dementia.[8] There is a recognised need to follow this plan up with another plan once it reaches its completion in 2012.

More information

http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/France/Florence-Lustman

SOUTH KOREA

War on Dementia (2008-2013)

Funding

From 1st July 2010 the national health insurance payments in South Korea were increased by 4% to fund long-term care insurance for the elderly. Total funding for this Plan is estimated at 6.46 trillion won[10] (5.7 billion AUD)[d].

Applications for the insurance must be 65 years and above and to have an illness related to ageing such as dementia or stroke. Recipients are those who cannot live independently for more than 6 months.

Focus

2008-2010

- Early diagnosis
- Prevention and treatment
- Infrastructure building
- Public awareness

2011-2013

- Expand outreach service
- Upgrade long-term care insurance
- 'Dementia Service Network'
- 'Managing Dementia Law'

Consultation

Neurologists/psychiatrist associations, nurse's associations, Alzheimer's Association Korea and the Ministry of Health and Welfare were all involved in the development of the Plan.[11]

Evaluation

It has been reported that the Plan has had success in the areas of early diagnosis and prevention, treatment, infrastructure and public awareness. There have been some difficulties in retaining quality of care while increasing the scale of the program to reach more people.[11] In 2010, the long term insurance program had a cap of 180,000 to the number of people who could receive funding. This cap was expected to increase to 300,000 by 2012. There are four additional concerns which have been identified with the plan:

- Focused on the medical/clinical to the detriment of social issues
- Access to insurance depends on physical disability which means a lack of services for individuals early in the disease
- Unprepared for the need for the number of dementia specialists
- Differences between urban and rural areas

More information

Alzheimer's Association South Korea President presentation at the 26th Alzheimer's Disease International Conference, 2011.
www.alz.co.uk/sites/default/files/plans/Korea-war-on-dementia.pdf

NORWAY

Dementia Plan (2007-2015)

Funding

Funding for the Dementia Plan will be allocated in the federal budget annually. In the 2011-12 budget 1.1 billion Kroner (approximately 192 million AUD[e]) in total was committed to the Dementia Plan.[12]

Focus

The Dementia Plan has three main focus areas[13]:

- Day Programmes
- Living facilities designed for dementia
- Increased knowledge and skills (information, education, training, and research)

The Plan also has five strategies to address dementia care:

- Quality development, research and planning
- Capacity growth, and increasing skills and knowledge
- Improving collaboration amongst medical professionals
- Active care
- Partnerships with families and local communities

Consultation

None reported

Evaluation

None reported

More information

Norway Dementia Plan (English version)
http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/DementiaPlan2015.pdf

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[c] Based on exchange rate at 14/9/2011

[d] Based on exchange rate at 14/9/2011

[e] Based on exchange rate at 14/9/2011

SURVEYING THE INTERNATIONAL LANDSCAPE

DENMARK

Dementia Plan[14] (2010-2015)

Funding

€3 million (approximately 4 million AUD[f]), €1.2 million of funding will be for the National Centre for Knowledge of Dementia.

Focus

- Information
    - Exchange of clinical and research information about dementia
    - Creation of a single point of access for information on dementia
- Research
    - Risk factors, diagnosis, treatment and care
- Diagnosis and Treatment
    - Early diagnosis
    - Specialised knowledge about rare forms of dementia
    - Training of health care professionals

Consultation

There is a steering committee and a reference group with trade union representatives of the Health Protection Agency Services Agency, General Practitioners' Association, each of the five regions and municipalities, consumer representatives from Alzheimer's Association and DaneAge and National Association for Huntington Chorea.

Evaluation

None reported

More information

Danish Dementia Plan (Danish version)
http://www.videnscenterfordemens.dk/media/683281/%C3%A5rsberetning.pdf

Alzheimer Europe's overview of the Danish dementia response
http://www.alzheimer-europe.org/EN/Policy-in-Practice2/National-Dementia-Plans/Denmark

NETHERLANDS

Dementia Care Plan (2008- no end date) (Preceded by The National Dementia Programme (LDP)[15,16] 2004 – 2008)

Funding

No additional funds have been budgeted for the implementation of this plan. It will be financed from other programs.
[The National Elderly Care Programme (2008-2011: total budget approximately €80 million), the rules on building and small-scale living (2009-2011: total budget €80 million), the budget for development of indicators for dementia care (2008: €40,000) and the care innovation fund (2009: total budget €15 million)].

Focus

The National Dementia Programme provided guidelines for developing dementia programs at a regional level. Project teams consisting of care providers and consumer representatives worked on improving dementia care in 57 regions of the country. Each team decided on the focus of their work based on regional consultations.

The Dementia Care Plan which followed was informed by the evaluation of the National Dementia Programme. It had three areas of focus:

- Creation of a coordinated range of care options that meet the client's needs and wishes
- Provision of sufficient guidance and support for people with dementia and their carers
- Monitoring of the quality of dementia care annually[17]

Evaluation/Sustainability

Information about the programs developed through the National Dementia Programme have been made available online.
An evaluation was conducted on the National Dementia Programme in 2009 which prompted development of the Dementia Care Plan.

Consultation

Because implementation was at a regional level, consumers, health professionals and care providers were all involved in the development of individual programs.

More information

Netherlands' Dementia Plan (Dutch)
http://www.ggzbeleid.nl/pdfouderenzorg/nizw_ldpwerkboek_0412.pdf
Announcement of the Dementia Care Plan
http://www.alzheimer-europe.org/EN/content/download/6977/71008/file/Dutch%20Dementia%20Strategy.doc

JAPAN

Japan does not have a specific dementia plan, but dementia care is funded through a national long-term care insurance system. The Japanese Government has promoted a number of additional strategies to address dementia.

Focus

- Improve the understanding of the realities faced by patients with dementia
- Promote research/development which focuses on dementia
- Implement measures toward early diagnoses of dementia and provision of appropriate medical treatment
- Disseminate accurate information on appropriate care for dementia and support patients/family caregivers
- Develop support measures specifically for patients with early onset dementia[18]

Consultation

None reported

Evaluation

Periodic evaluation has led to an expansion and diversification of strategies since 2000. There is some concern that the long-term care services provided through the insurance scheme are not meeting the needs of individuals with dementia. Access to the insurance program is dependent on a classification on the Government-Certified Disability Index. This index is sensitive to difficulties with activities of daily living but does not accurately assess the impact of the behavioural symptoms of dementia.[19] This has led to the development of further strategies to address dementia beyond the long term care insurance program.

More information

The National Dementia Strategy in Japan
http://onlinelibrary.wiley.com/doi/10.1002/gps.2589/full

CANADA

No national plan, but a number of regional plans:

Ontario's Alzheimer Strategy (1999-2004)

Funding $68 million

Focus

- Staff education and training
- Physician training
- Increase in public Awareness, information and education
- Planning for appropriate, safe and secure environments
- Respite services for caregivers
- Research on caregiver needs
- Advance directives on care choices
- Psychogeriatric consulting resources
- Co-ordinated specialized diagnosis and support
- Intergenerational volunteer initiative

Consultations

Ontario: Broad consultation with key stakeholders across the province. Over 180 submissions were received in response to the government's draft strategy.

More information

http://www.health.gov.on.ca/english/public/pub/ministry_reports/alz/alz_strat.pdf

Quebec Action Plan (submitted 2009, yet to be adopted)

Funding none, not yet adopted

Focus

- Improve quality of life, long term and end of life care
- Support caregivers
- Train providers
- Research

More information

www.rqrv.com/en/display_nouvelle.php?id=26

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[f] Based on exchange rate at 14/9/2011

DEVELOPMENTS TO WATCH

UNITED NATIONS SUMMIT

In September 2011, The United Nations Summit on Non Communicable Diseases (NCD) adopted a Declaration that includes Alzheimer's disease as a major disease area. The final Declaration in paragraph 18 specifically recognises neurological diseases including Alzheimer's disease and other dementias as an important cause of morbidity that contributes to the global NCD burden and that NCD prevention programs and health care interventions should provide equitable access to effective programs for these illnesses. This signifies recognition of Alzheimer's disease and other dementias as a burden on a par with other chronic diseases such as diabetes, cancer and heart disease.

For more information: http://www.alzheimers.org.au/alzheimers-disease-international-statement-on-non-communicable-disease-summit.aspx

THE UNITED STATES PLAN

The National Alzheimer's Project Act was passed by Congress in December 2010 and signed into law by President Obama in January 2011.[20] This Act establishes a coordinating body and sets the stage for establishing 'an integrated national plan to overcome Alzheimer's.

The purpose of the project is:

1. To create and maintain the national plan
2. Provide information and coordination of research and services across all federal agencies
3. Accelerate the development of treatments to prevent, halt or reverse the course of the disease
4. Improve early diagnosis and coordination of care
5. Ensure the inclusion of minority groups in research and service- and reduce health disparities in Alzheimer's Disease
6. Coordinate with international bodies to integrate and inform the fight against Alzheimer's globally

There is an advisory council for the project which consists of two patient advocates, two caregivers, two health care providers, two representatives of state health departments, two researchers and two voluntary health association representatives. Currently the advisory council is conducting widespread consultations in conjunction with American Alzheimer's and dementia organisations. The advisory council will meet quarterly to develop the national plan. The first meeting was scheduled for October 2011.

To date, the United States has no funding attached to this plan.

For the text of the legislation: http://www.opencongress.org/bill/111-s3036/text

DEMENTIA PLANS IN DEVELOPING COUNTRIES

Sixty-six percent of people with dementia live in low or middle income countries.[21] As developing countries are facing a large increase in the number of older individuals there is a need to respond to the demand for dementia services.

These nations have a unique set of obstacles to overcome when developing an effective dementia plan in respect, for example, of issues around awareness and stigma, health infrastructure and funding. An important start has been made to better understanding these issues though the work of the 10/66 Dementia Research Group and Alzheimer's Disease International. The 10/66 Dementia Research Group is a collective of researchers carrying out population-based research into dementia, non-communicable diseases and ageing in low and middle income countries. This Group aims to provide a detailed evidence-base to inform the development and implementation of policies for improving the health and social welfare of older people in low and middle income countries, particularly the 14 million people with dementia, their relatives and carers.

More information about the work of the 10/66 Dementia Research Group can be found at: http://www.alz.co.uk/1066/

Another positive development was the release in 2010 of *The Dementia India Report 2010*, by Alzheimer's and Related Disorders Society of India. This report provided evidence on the number of people affected by dementia and the social and economic impact of the disease. It also provided a review of the current state of care and identified gaps and areas for further development. The report was a call to Government for dementia to be made a national health priority. The report emphasized the need to invest in strategies to improve awareness, care, and community support for people living with dementia. It also recommended that dementia be included in the national legislation for disabilities and for older persons.[22]

As a result of this document and other advocacy work, The Alzheimer's and Related Disorders Society of India was invited to be part of a subgroup which was developing a response to a review of the National Policy for Older Persons. This subgroup recommended that the Government set up a national centre on dementia. Further proposals have been submitted to Government on strategies to address dementia care in India. A comprehensive plan to address dementia has yet to be developed.[23]

The Dementia India Report can be found at:
http://www.alzheimer.org.in/assets/dementia.pdf

COMPARISON OF NATIONAL PLANS

It is clear that there is a broad range of approaches to addressing the dementia epidemic. Each country has developed plans within their own social, political and health care contexts.

POLICY CONTEXT

Both the international policy context and the specific country context must be taken into account when understanding the development of dementia plans.

On an international level, Japan hosted the 20th International Conference of Alzheimer's Disease International (ADI) in 2004 in Kyoto. At the conference, the ADI members developed the Kyoto Declaration, which is a call to action to address the priorities for combating dementia. [24] In broad terms, national dementia plans tend to reflect the recommendations of the Kyoto Declaration.[25] The ten recommendations were:

- Provide treatment in primary care
- Make appropriate treatments available
- Give care in the community
- Educate the public
- Involve communities, families and consumers
- Establish national policies, programs and legislation
- Develop human resources
- Link with other sectors
- Monitor community health
- Support more research

In 2006, Alzheimer's Europe and its member organisations released the Paris Declaration which called upon the European Union, The World Health Organisation and the Council of Europe and national governments to recognise Alzheimer's disease as a major public health challenge and to develop European, International and national action programs.[26]

In response to the calls for action and the increasing evidence base of the social and economic impact of dementia there has been an increase in the number of countries which have developed plans to address dementia over the last ten years. Most plans include strategies to address awareness, diagnosis, access to care and support for families. The focus of each plan is specific to the policy context of that country. For instance, South Korea has recognised a need to address the stigma associated with dementia. Although stigma is also a concern in Australia, it has not been directly addressed through the national action plan.

DEVELOPING THE EVIDENCE

Quantifying the social and economic impact of dementia has been an important first step in the development of national plans. The impacts on both the family carer and on the wider community, including the workforce and the economy, must be recognized and well understood. If dementia is considered just an unfortunate consequence of ageing, there is little drive for action to improve quality care.

In the Australian context, the economic problem of dementia was quantified through reports by Access Economics, commissioned by Alzheimer's Australia. By building an economic argument based upon independent data, Alzheimer's Australia had the evidence base to lobby the federal government to take action, which led to the *Dementia Initiative*. ADI has taken a similar strategy through the World Alzheimer's Disease prevalence report.

Developing an evidence base can have an ongoing influence on the focus and sustainability of dementia plans. In the UK, the release of a report by the National Audit Office on dementia care in hospitals provided an economic argument for government action to improve the quality of dementia care. Similarly, a release of an independent audit in the UK on the use of antipsychotic medications in people who have dementia, resulted in media attention and political pressure for action to address this concern. The UK Dementia Action Plan was reviewed in 2010 and the four focus areas included action on dementia care in hospitals and action to reduce the use of antipsychotics.

FOCUS OF PLANS

In Australia, the Dementia Initiative has focused on improving the quality of dementia care through the aged care system. As a result there has been little action on issues such as diagnosis, safety in acute care or dementia risk reduction. Similarly, in Scotland dementia is delegated to the mental health framework. In contrast, the French Plan facilitates interaction between various different areas of health and aged care in a comprehensive approach to dementia. This approach recognises that dementia is not simply a segment of aged care or mental health, but recognises the broader health impacts of the disease.

Dementia plans also differ in whether the focus is solely on improving quality care and support or whether they include a longer term approach to address the number of people with dementia through investment in research and preventative health activities.

In Australia, dementia research was included as a part of the *Dementia Initiative*. Three Dementia Collaborative Research Centres were established and funded through the Initiative. These centres are focused on the assessment, care and prevention of dementia. These centres provide seed funding for small projects which can then lead to larger grant applications through funding bodies such as the National Health and Medical Research Council.

Despite this investment, funding for dementia research in Australia is small in compared to the total cost of care. In Australia annual expenditure on dementia research is currently 0.5% of the total direct cost of dementia. In comparison with other major diseases, this is about 50% of research funding for cancer, relative to current disease burden or 5% relative to predicted direct cost of care in 2023.[27]

Many of the other plans reviewed have included an investment in dementia research. Despite a focus on research, in many developed countries dementia is underfunded compared to the cost of care and burden of disease.[28] Perhaps an exception is the French Plan which has made research a high priority, investing €50 million (approximately 66 million AUD[9]) into research over 5 years, including developing new research institutions dedicated to dementia.

The evidence for the link between physical health and risk for dementia is growing, with recent research suggesting that a reduction of 25% of some of the risk factors for dementia could prevent as many as a million cases of Alzheimer's disease worldwide.[29] Yet, with the exception of Korea, none of the plans reviewed have had an explicit focus on reducing the numbers of people with dementia through preventative health strategies. In Australia, the Dementia Initiative did not have an explicit focus on prevention but a small amount of funding through the Initiative supported the development of a program to increase community awareness of ways to reduce the risk of developing dementia.

FUNDING

One of the key differences between countries is in the financial commitment to their plans. Progress is likely to occur when dementia plans are accompanied by a solid financial commitment across many years with sufficient funding to achieve the overall aims and flexibility to trial new approaches. Unfortunately, many of the strategies outline what must be done and how, without committing the government budget to implementing the strategy.

The French National Plan has committed €1.6 billion (approximately 2.1 billion AUD) across the priority areas and objectives of their Dementia Plan. This is accompanied by clear outcomes by which the success of each program can be measured. In contrast, the United States has set up a program to develop a National Plan for dementia but has not allocated any funding for the implementation of this plan.

Long term sustainable funding is a significant challenge for most countries. One approach to establish sustainable funding that has been used in both South Korea and Japan is long term care insurance. In South Korea an increase in health insurance premiums for everyone over the age of 20, is used to generate funds for services for people over the age of 65 with an ageing-related illness such as dementia. Funding through a long term care insurance program can also have limitations including whether it is affordable. For example, an evaluation of the South Korean model suggests that there has not been a focus on support for those in the early stages of the disease. The model has been suggested as being overly medical and not addressing the social supports required for individuals with dementia and their families.[30] Similarly, in Japan eligibility for funding through long term care insurance does not take into account the impact of behavioural and psychological symptoms of dementia.

Without sustainable funding it is difficult to plan for future services. For example, funding in the Netherlands was not ongoing, and subsequently in the evaluation it was noted that many high performing programs were unable to continue. Australia is facing a similar situation, where the Dementia Initiative has been terminated. The programs funded through the Initiative no longer form part of a cohesive dementia plan and there is no guarantee of funding once existing contracts expire.

CONSULTATIONS

Developing a dementia plan that addresses the diverse needs of the dementia community requires consultation with individuals with dementia and their families. The outcomes of these consultations must be used to shape the strategies to address dementia.

Most strategies have been developed in consultation with professional stakeholders and community members. South Korea emphasized consultation with key professional stakeholders, although they did not mention community consultations in their development process. England also extensively consulted stakeholders including community members. In a number of countries including Australia and Scotland, individuals with dementia or family carers have been included in a steering or oversight committee. Adopting this approach helps to ensure that the strategies are appropriate and therefore more likely to lead to real changes for people with dementia.

Development of a dementia plan can also be assisted by close working relationships between Alzheimer's organisations and the government. The Alzheimer's Association of Korea had a close working relationship with the government for 15 years before the Plan was developed and implemented. Similarly, Alzheimer's Australia worked closely with the Government in the development of the Dementia Initiative.

[9] Based on exchange rate at 14/9/2011

CONCLUSIONS

Ten years ago, few countries had a plan to address the growing number of people with dementia. Now, several countries have plans, and others are in development. This paper presents the publicly available evidence on national government plans with a particular focus on those that have been funded.

There is some consistency between countries on the issues that need to be addressed in national dementia plans. The Kyoto Declaration, prepared by Alzheimer's Disease International (ADI), has set out the range of areas of focus in framing a dementia plan. The Paris Declaration from Alzheimer Europe went further, stating the shared political, public health, research, medical, care, social support, legal and ethical priorities of responding to dementia.[31]

Broadly, the suggested areas of focus would be found in any public health framework for a chronic disease – awareness, early diagnosis, effective management and care, prevention and research. From this review the focus of most dementia plans thus far, however, have been mostly on awareness, diagnosis, and care. Most of the plans have had not led to significant work on prevention and research. Investment in research and risk reduction will be key to reducing the future numbers of people with dementia.

In many cases dementia is still considered within an aged care or mental health framework. To fully address dementia it must be recognised in the broader health systems. The quality of life of people with dementia is unlikely to improve unless there is a higher profile in health policy for issues such early diagnosis, safer hospitals and reduced reliance on medical restraint.

The success or failures of a formulated dementia plan should be measurable. Both the Australian and the French Plans developed frameworks with measures to evaluate progress that allow straightforward assessment of each plan. Evaluation should be conducted periodically, allowing reassessment and structuring if the implementation process requires adjustment.

Finally, sustainable funding must be a priority. Many countries faced challenges in the implementation of their plans when provided with inadequate funding or funding that focused on assisting those with the greatest disability instead of care for individuals from the point of diagnosis.

There is no single best approach to addressing dementia. The common themes that have emerged from this review include:

- A need to recognise dementia as a chronic disease that should be addressed through awareness, early diagnosis, good management care, prevention and research
- A coordinated approach that enables coordination and collaboration across all aspects of health, medical, social support and research
- Ongoing evaluation and reassessment of priorities to meet the changing needs of individuals with dementia
- Sustainable funding which promotes both access to needed services and innovation through knowledge translation and dementia care research
- A national commitment to research into the cause and prevention of dementia

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