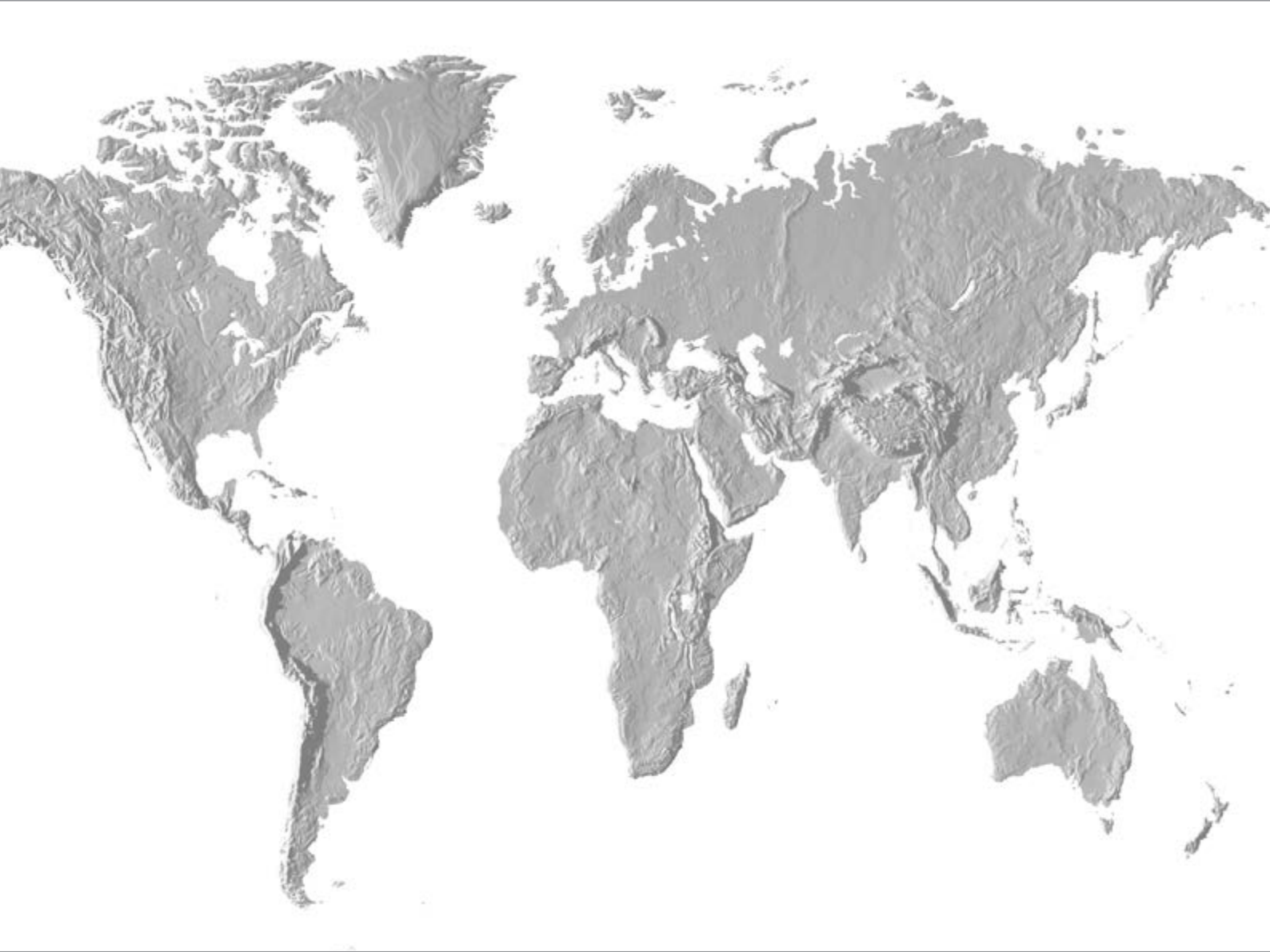


National Dementia Action Plans

Examples For Inspiration





**Alzheimer's Disease
International**

The global voice on dementia

This study has been carried out by Alzheimer's Disease International with the support of the Swiss Federal Office of Public Health. This study does not represent the official views of Switzerland. The opinions expressed and arguments used in this study are those of the authors.



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National Dementia Action Plans

Examples For Inspiration

Introduction

In May 2017 the 70th World Health Assembly adopted a Global action plan on the public health response to dementia 2017-2025. Earlier this year the Swiss Federal Office of Public Health commissioned Alzheimer's Disease International (ADI) to develop this overview of actions taken in the past five years by governments and associations where national dementia action plans or strategies exist. The intention is to highlight successes or best practice which could help governments and associations to embark on the development of a plan or to improve existing ones.

This review is by no means comprehensive but gives a snapshot of the state of play in May 2017. The 9 chapters reflect emergent areas of practice from existing national plans. They do not correlate directly with the 7 action areas identified in the WHO global action plan but the summary table (Appendix 1) provides examples of how existing plans contribute to these action areas.

ADI is now encouraging countries to start the planning process and will continue to advocate for the results expected in the global plan to become a reality. ADI believes a successful plan should address all dimensions. However, any advances are welcome in national strategies, which help people with dementia, their family and carers, whose interest are ADI's primary priority.

There is still a long way to go and ADI will continue to report on progress. From 2018 we will start monitoring the yearly progress working towards 2025 and we will aim to share this with our audiences with the hope that the concerted effort of all those involved will increase our capacity to advocate for the national action plans to become reality.



Paola Barbarino

CEO Alzheimer's Disease International
London, November 2017

Report compiled by Mike Splaine, Marc Wortmann, Michelle Seitzer,
Kate Gordon, Sarah Kerr and Chris Lynch

CHAPTER 1

Inclusion of the voice of people with dementia



Perhaps the most vital component of any dementia plan is the inclusion of people with dementia in both the policy and implementation processes. Ultimately, policies and programming should directly benefit and support these individuals and their carers; not to take their input into account contradicts the goal of such initiatives.

First and foremost, it is a human rights issue. A diagnosis of dementia should not minimise a person's intrinsic worth. While dementia impacts a person's unique memories and cognitive abilities, it does not eliminate personhood. The individual still has rights, and is entitled to express their own opinions, or to have a voice in their respective circles of influence.

Inclusion also contributes to reducing the stigma still surrounding dementia in so many communities. Dementia is not a death sentence. While it is a debilitating disease, the ability to lead a healthy, active, and independent life can be within the reach of a diagnosed individual. Too often, this ability is discounted, and as a result, people with dementia quickly become isolated, lose their voice, and experience an unnecessarily diminished quality of life. If people with dementia are not part of these discussions, how can a strategy's effectiveness be authentically evaluated and its programme's successes truly assessed?

To improve the quality of life for people already living with dementia, their value in the community and in society must be continuously affirmed, their participation readily welcomed. As a matter of principle, care innovations or best practices should not be drafted without participation and engagement of those who will be the direct beneficiaries of such services. Many countries have done so.

Please consider the work of Ireland, Malta and Scotland around this issue. In addition, some analysis about the applicability of the Convention on the Rights of Persons with Disabilities follows.

Ireland

A commitment to develop a Dementia Strategy is included in Ireland's Programme for Government 2011-2016. The Alzheimer Society of Ireland participated in the National Dementia Strategy Working Group to convene workshops for people with dementia, carers, and former carers, as referenced on page 9 (Minister of Health, 2014), to ensure the views of these stakeholders were represented and informed the direction of the strategy.

Also of note, the Minister for Health has decided to establish an Advisory Group to assist in the drafting of a National Dementia Strategy. This Advisory Group is mentioned as shown below (p.36):

Establishment of an Advisory Group

The Minister for Health has decided to establish an Advisory Group to assist in the drafting of a National Dementia Strategy for his consideration.

Meetings of the Advisory Group

Meetings will normally take place in the Department of Health office in Hawkins House. The Advisory Group may invite persons or organisations who are not members of the Advisory Group to present to the Group either in person or in writing or to participate on subgroups along with Advisory Group members to consider specific issues and to make recommendations for consideration by the full Advisory Group.

Malta

In 2014, the Maltese Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing published their *National Dementia Strategy: Malta 2015–2023*. This strategy aims to implement a number of measures in the various areas of dementia management and care with the overarching objective of “*Enhancing the quality of life for individuals with dementia, their caregivers and family members.*” (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015).

Unlike the first Scottish plan and the Northern Irish plan that applied the concept of dementia friendly only to physical environments, the Maltese government took a step further and applied this concept both to physical and social environments (e.g., dementia-friendly attitudes). Moreover, instead of applying the concept to a broad context such as communities, as seen in the UK's *Prime Minister's Challenge on Dementia* (Lin, S.-Y., & Lewis, F. M., 2015) and the second Scottish plan (Scottish Government, 2013), the dementia-friendly terms mentioned in the Maltese national plan were more specific, with narrower contexts such as “dementia-friendly wards” and “dementia-friendly measures” (for monitoring community care homes; Maltese Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014).

Sources: https://activeageing.gov.mt/en/Documents/dementia%20friendly%20english_full%20book.pdf and <https://www.ncbi.nlm.nih.gov/pubmed/26035599>

Scotland

One of the key outcomes of Scotland's National Dementia Strategy reads as follows: “More people with dementia and their families and care partners are being involved as equal partners in care throughout the journey of this illness (Scotland's National Dementia Strategy: 2013-16, 2016).” It also positions the human rights of people with dementia as the first of the three main challenges the plan must address in the coming years: “First, we must offer care and support to people with dementia and their families and care partners in a way which promotes wellbeing and quality of life, protects their rights and respects their humanity. This is a moral imperative and it is unacceptable that too often the experience of people does not meet this standard.” (p.2) http://www.alzscot.org/assets/0001/2697/Guide_to_Standards_of_Care_for_Dementia_in_Scotland.pdf

As such, the plan committed the Scottish government to produce a document, *Standards of Care for Dementia in Scotland*, based on a Charter of Rights which was developed by a Parliamentary Cross Party Group on dementia. Based on these standards the following six value statements emerged (Guide to Standards of Care for Dementia in Scotland, 2012):

- I have the right to a diagnosis
- I have the right to be regarded as a unique individual and to be treated with dignity and respect
- I have the right to access a range of treatment and supports
- I have the right to be as independent as possible and be included in my community
- I have the right to have carers who are well supported and educated about dementia
- I have the right to end of life care that respects my wishes

The Scottish Human Rights Commission (SHRC) produced *Human rights in health and social care – putting it into practice* and *A human rights based approach: an introduction*, which included The Dementia Charter and employed the PANEL principles adopted in Scotland's National Dementia Strategy http://www.scottishhumanrights.com/media/1408/shrc_case_studies_report.pdf. (PANEL: Participation, Accountability, Non-discrimination and equality, Empowerment, Legality)

According to Dementia Alliance International (DAI) report *The Human Rights of People Living with Dementia: from Rhetoric to Reality*, the Scottish government adopted PANEL principles when the UK government ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2009. The report also notes that "Scotland is the first country to have included people with dementia in its implementation of this Convention and to have appointed a Scottish Dementia Working Group in 2002 of people with dementia, which advises the government, with the support of Alzheimer's Scotland." https://www.dementiaallianceinternational.org/wp-content/uploads/2016/10/The-Human-Rights-of-People-Living-with-Dementia-from-Rhetoric-to-Reality_2nd-Edition_July-2016_English.pdf

Consider this practical application of the PANEL principles - and related initiatives and campaigns - for people with dementia and their carers, of the SHRC Case Studies report (Human rights in health and social care – putting it into practice: Case Studies from Scotland, 2016, p. 8).

Participation The project involves a range of stakeholders across communities to raise awareness of the dementia journey and encourages carers to reflect on and share their experiences. To date, an online care partners survey and an analysis of carers letters has captured key messages of the importance of listening to and involving carers at every step of the dementia journey.

Accountability In capturing information from carers and sharing it with Scottish Ministers and other key stakeholders such as the Scottish Public Services Ombudsman and the Care Inspectorate, the project aims to ensure a strong voice for those who use services. The 'You Can Make a Difference' campaign calls upon health and social care professionals to reflect on the lived experience of people affected by dementia, and identify actions that they can take away and apply to their everyday practice to make a difference.

Non-discrimination and Equality The project uses social media, hosts events, delivers workshops and goes around the country to ensure that as many people as possible are aware of the campaign and their views are put forward. The project works with a broad reach of partners across the sector including Alzheimer Scotland and Focus on dementia to ensure views are gathered from a diverse range of people.

Empowerment The project works to empower carers by raising awareness of their rights and the level of services and support to which they are entitled, and provides signposting to organisations which can provide support where these expectations are not met. Through the 'You Can Make a Difference' campaign, and presenting the views of carers, the power of the lived experience of carers is harnessed to influence health and social care policy, culture and practice.

Legality The project follows on from the Charter of Rights for People with Dementia and their carers, which is explicitly based on upholding and promoting the human rights of people with dementia and their carers. It applies universal human rights, strengthened by the rights identified in the United Nations Convention on the Rights of Persons with Disabilities as legally enforceable entitlements underpinning the situation of people affected by dementia.

Also highlighted in the Case Studies report, ALLIANCE (a Scottish third sector intermediary for a range of health and social care organisations) set up and supervised *The Dementia Carer Voices* project in early 2013 “to assist in bridging the gap between the aims of the Dementia Strategy and the experiences of people living with dementia. To ensure that people are aware of their rights and are empowered to know that their views are taken seriously and are at the heart of planning services.”

In engaging with Scottish Ministers and the Scottish Parliament, the project focused on advocacy priorities such as: “advancing the benefits of embedding a human rights based approach in management culture and staff training and highlighting through the care partners perspective issues of staff turnover and time constraints.” (p.6)

UN Convention on the Rights of Persons with Disabilities (CRPD) Member States

The document *Access to CRPD and SDGs by Persons with Dementia* (Alzheimer’s Disease International and Dementia Alliance International) offers a closer look at the UN Convention’s general principles and articles, presenting which Member States have included people with dementia in their implementation. As the text below reveals, much work remains to be done to ensure the compliance of Member States in this area.

CRPD General Principles & Articles

The Convention calls for solutions adapted to age, gender and locality that can be addressed through CRPD General Principles and Articles.

The 38 cross-cutting Articles offer key common elements including: capacity, supported decision-making and the protection of the fundamental human rights first set out in the UN Universal Declaration of Human Rights in 1948.

Articles 8 and 9 are addressed in an increasing number of Member States by Dementia Friendly Communities (DFCs) and organisations which facilitate access to transport, shops and community amenities. It is believed that DFCs can now move to the next step in their development – e.g. by involving people with dementia as equal stakeholders from the outset.

Although persons with dementia are indisputably included in CRPD Article 1, they have been excluded from its implementation by Member States. Although other rights obligations are frequently the basis of dementia policy, CRPD is not reflected explicitly in the dementia strategies and plans of 26 Member States and two regions. The exclusion of persons with dementia could be considered as an example of systemic if unintentional discrimination.

A major obstacle to the continued participation of persons with dementia in society arises from the stigma and fear of dementia in the general population and under-estimation of their capacity by politicians, professionals, researchers and the community, thus creating disability.

As a result of discrimination, persons with dementia are often not diagnosed and/or not told their diagnosis. Even in high income countries (HICs), they often do not have access to support services for themselves and their families or to medical treatment. There is also clear evidence in the social media that isolation begins at the point of diagnosis when friends and family members stop visiting.

An ADI report (Neil Crowther, 2016 <https://www.alz.co.uk/sites/default/files/pdfs/harnessing-crpdc-dementia.pdf>) distils the goals which Alzheimer advocacy organisations should pursue, both on national and international levels, to ensure people with dementia are involved in policy planning and programme implementation from the beginning. Leveraging the CRPD to influence social change could be distinctively valuable in countries where a strong stigma is still attached to a dementia diagnosis, and in all countries as a means for improving access to care and services, as well as reducing the use of restraints and antipsychotics. Its recommendations are (p.4-5):

Involvement of persons with disabilities

The CRPD places particular emphasis on the involvement of persons with disabilities in both implementation and in monitoring whether and how States are meeting their obligations.

At the national level this means:

- Governments should be involving persons with dementia in steps being taken to implement the CRPD, for example in the development of a national action plan
- Persons with dementia should be fully involved in dementia friendly community programmes nationally and locally, including as employees
- Persons with dementia should be involved in the national independent framework tasked with monitoring implementation of the CRPD, for example via forums established by national human rights institutions
- Organisations of persons with dementia should use the CRPD as a framework for advocacy, including actions to influence public policy, especially in relation to strategic litigation and in raising awareness of the situation of persons with dementia.

At the international level this means:

- Persons with dementia and their organisations can contribute to the examinations conducted by the Committee on the Rights of Persons with Disabilities of the States in which they live.
- Contributing to the evolving thinking of the Committee through written evidence and through attending 'General Days of Discussion' which leads to 'General Comments' and Statements to spell out more clearly the precise meaning of the CRPD. The Committee has, to date, issued General Comments and Statements relevant to the rights of persons with dementia in relation to legal capacity and the right to liberty. It is now drafting a General Comment in relation to 'living independently and being included in the community.'

According to *The Human Rights of People Living with Dementia: from Rhetoric to Reality* (Dementia Alliance International, 2016), the UN Convention on the Rights of Persons with Disabilities was adopted in 2006 but is only now beginning to be used by the dementia community. The ratification by the European Union and 163 countries commits governments under international law to implement each of its General Obligations, General Principles and 37 substantive Articles under it.

Amongst the many differences between the CRPD and earlier UN Conventions is that it is the first to include representatives of potential beneficiaries as equal partners with governments in negotiating each of its Principles and Articles. It is also a landmark in the history of the disability movement because international Disabled Persons Organisations representing different constituencies have succeeded in working together as a coalition, despite differences in policies and priorities. People with dementia are included in the definition of CRPD in Article 1.

The all-important General Principles of the CRPD are reflected in each of its main Articles.

General Principles

- Respect for dignity, autonomy, freedom to make choices, independence
- Non-discrimination (disability, gender, ethnicity, age)
- Full participation and inclusion in society
- Respect for difference; acceptance of disability as part of human diversity
- Equality of opportunity
- Accessibility

Articles

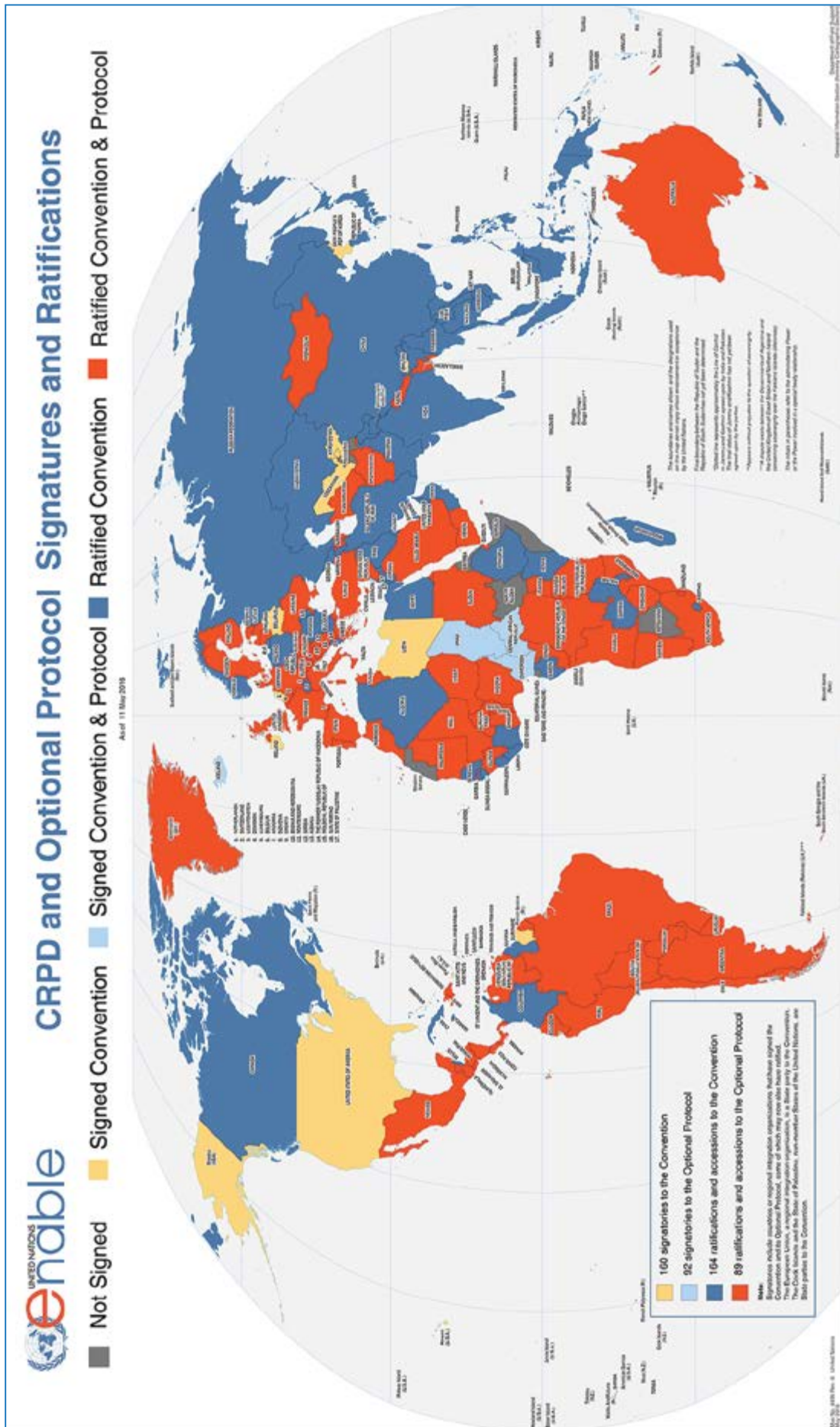
The Articles provide detailed guidance on the relevance of these principles to important areas of everyday life on the same basis as others. These include:

- Right to Life
- Accessibility at all levels
- Equal Recognition Before the Law
- Freedom from torture, cruel, inhuman or degrading treatment, exploitation, violence and abuse
- Living independently and participation in the community
- Respect for home and family
- Health
- Rehabilitation
- Employment
- Adequate standard of living and social protection
- Participation in political and public life, cultural life, recreation, leisure and sport
- Equality between men and women

The UN Convention on the Rights of Persons with Disabilities (CRPD) set the stage for inclusion of people with dementia in policy planning. Building on directives of their national plans, these countries have taken steps to involve people with dementia as key stakeholders at all levels of advocacy, planning, implementation, and evaluation.

According to a UN report (Division for Social Policy and Development Disability: Convention on the Rights of Persons with Disabilities, 2016), 87 countries have ratified the 'Optional Protocol' to the Convention, empowering citizens to bring complaints to the Committee. Once the complaints are brought forth, the Committee can launch investigations and "carry out inquiries regarding 'grave and systemic violations' of human a rights treaty." The figure at the end of this chapter shows the countries which have ratified the 'Optional Protocol.'

Sources: <https://www.alz.co.uk/sites/default/files/pdfs/crpd-brief-alzheimer-associations.pdf>, <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> and <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Figure 1: Source: http://www.un.org/disabilities/documents/2016/Map/DESA-Enable_4496R6_May16.jpg

CHAPTER 2

Awareness campaigns

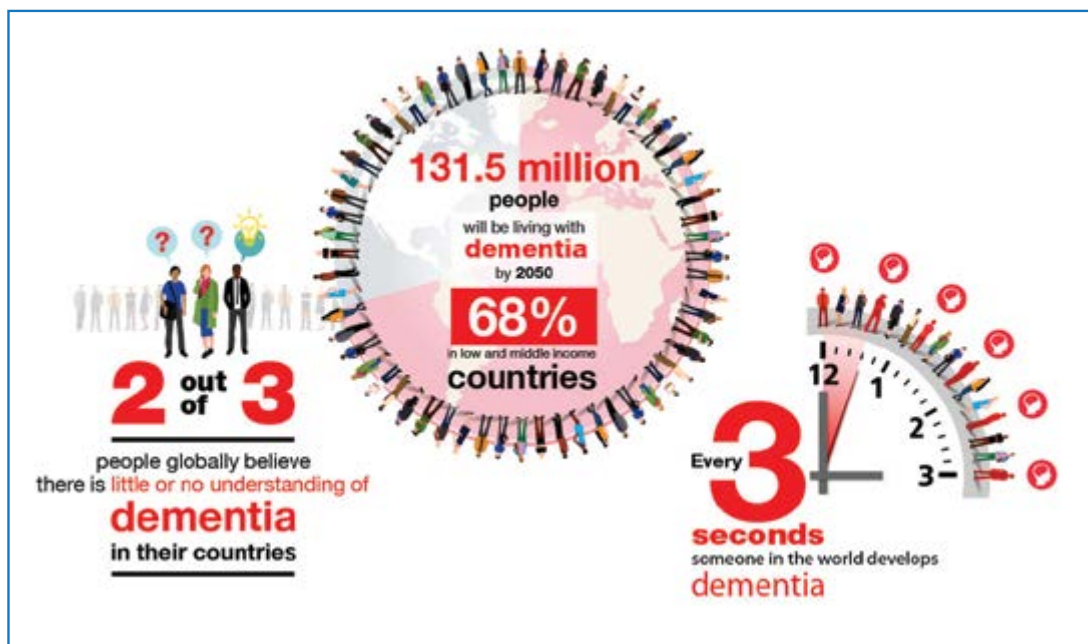


Figure 1: via ADI. <https://www.alz.co.uk/>

Today nearly 50 million people live with dementia worldwide and many more provide formal and informal care. Yet, a tremendous lack of awareness of Alzheimer's disease and related dementias still exists. For many - health care professionals included - a basic understanding of the disease and its far-reaching impact is sorely missing. Much of the education about dementia begins from the moment a diagnosis is received or a caregiving experience starts, not before. Also, that education is often piecemeal and acquired from a variety of sources, which are not always relevant.

As a result, the stigma associated with dementia is still strong in many cultures and communities. Despite the growing numbers of early-onset cases and the science stating cognitive impairment is not a normal part of ageing, it is often considered an "old person's disease." Not only is that readily accepted myth false, it further contributes to age discrimination and an unfairly diminished quality of life as a result. While it can be an entirely debilitating disease in its later stages (regardless of one's age at diagnosis), many people living with dementia remain physically active and able to maintain some level of cognitive function for years - even decades.

The lack of awareness and basic education about the disease also has consequences in terms of early detection and diagnosis: without a general knowledge of the warning signs, individuals living with the disease may lose years of helpful interventions and a longer period of independence.

All national plans mention the issues of awareness and stigma. This includes identifying possible actions to reduce the gap between what the public knows, believes, and understands about the disease versus what a person living with the disease (or caring for someone with it) knows from first-hand experience. The awareness actions that have been taken as well as their outcomes are less documented.

Backdrop: ADI Survey on Stigma

ADI conducted an anonymous online survey on stigma in June 2012. The majority of respondents recommended education and awareness raising as a solution for reducing and overcoming stigma. Over 2,500 individuals representing 54 countries responded with their personal experiences of stigma - people with dementia, family members, and informal carers included.

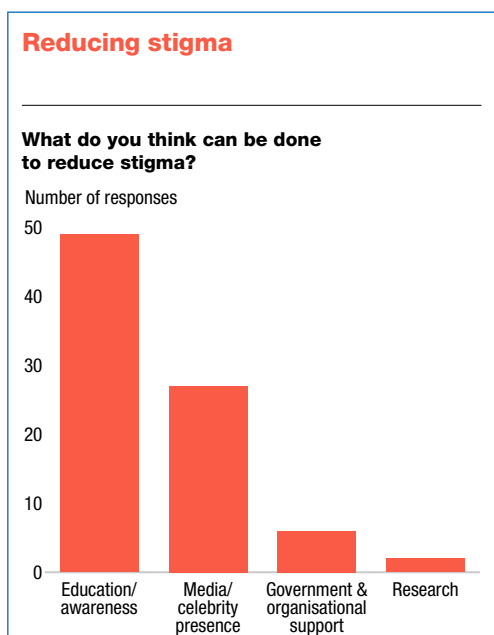
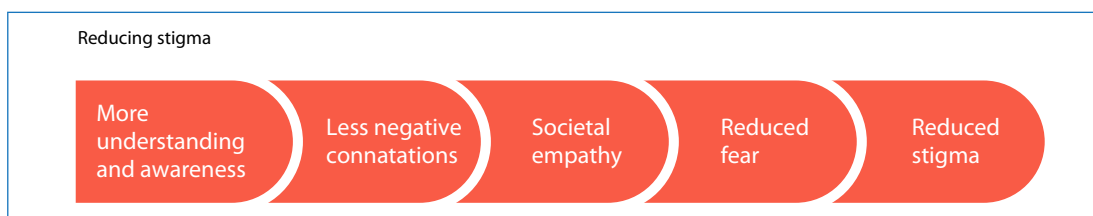
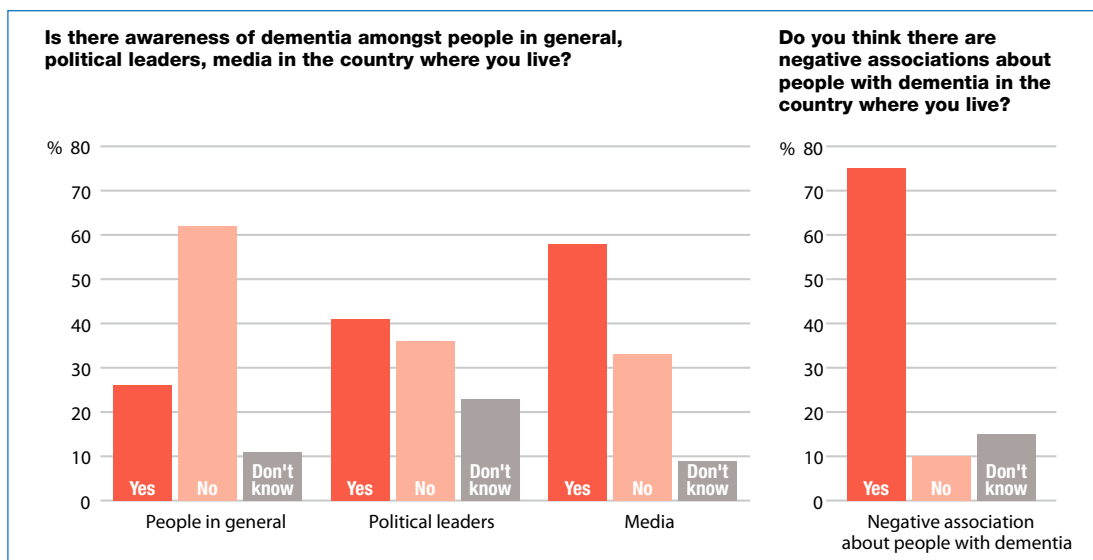


Figure 2:

Source: www.alz.co.uk/worldreport2012

Examples below illustrate governments (Australia, England, Indonesia, Japan, Netherlands, Scotland, Switzerland, Slovenia, South Korea, USA and Wales) which are implementing their National Plans with awareness and education efforts to ensure all citizens are more informed about the realities, not just the myths, of Alzheimer's and related dementias.

Australia

Dementia is the 2nd leading cause of death in Australia, but according to Australia's National Framework for Action on Dementia 2015-2019, only an estimated one in five Australians understand the disease to be terminal, and nearly one-third of the country's population reports feeling "uncomfortable spending time with people with dementia." A study on dementia literacy [http://www.alzheimersanddementia.com/article/S1552-5260\(08\)00090-3/references](http://www.alzheimersanddementia.com/article/S1552-5260(08)00090-3/references) in Australia revealed similar gaps in knowledge and negative perceptions. A cross-sectional telephone survey of 2,000 randomly selected community-dwelling adults

(23.4% response rate), produced the following results:

- 82% of the sample correctly identified "dementia" or "Alzheimer's" from a short vignette. There were no differences in recognition rates between vignettes describing mild or moderate dementia symptoms.
- Almost 50% incorrectly thought that at least partial recovery would occur, given appropriate treatment.
- More than 80% of the sample knew that genetics, old age, brain disease, and stroke or mini-stroke contributed to a person getting dementia.
- 72% percent knew that the risk of dementia could be reduced.

- The most frequently suggested methods for risk reduction were mental exercise (38.8%), eating healthily (31.0%), physical exercise (30.2%), and socialising (13.9%), aligning with evidence.
- Sociodemographic characteristics were also associated with dementia knowledge and beliefs.

The Framework identifies that negative perceptions can lead to marginalisation for people with dementia and their carers and thus Australia has identified *Increasing awareness and reducing risk* as a Priority Area for Action.

Alzheimer's Australia Campaigns

Sources: <https://www.fightdementia.org.au/about-us/campaigns>

From a 2016 Election campaign to the promotion of Dementia Awareness Month (September), Alzheimer's Australia has sponsored several public awareness efforts with the goals of reducing stigma, alleviating loneliness and isolation, and fostering better public education about Alzheimer's and related dementias. They also conducted the *Dementia and Loneliness* report, which revealed people with dementia and their carers as "significantly lonelier than the general population."

In 2016, on World Alzheimer's Day, 21 September, Alzheimer's Australia promoted a "Selfie Challenge" via social media, encouraging participants to take and share a photo to "let people know that they are not alone if they are managing the impact of dementia." For further awareness, support, and education, the campaign instructed participants accordingly:

- Use the campaign hashtag #Dementia2016
- Take the photo quite close up so the writing on the poster can be easily read by your followers.
- Feel free to dedicate your social media post to a loved one living with dementia, someone who has died with dementia or someone caring for someone living with dementia.
- Please don't joke about memory loss or dementia in your post. For people who do experience this symptom of dementia, forgetting things can be devastating.
- Remind your followers that they are not alone if they are impacted by dementia and encourage them to seek information or support by calling the National Dementia Helpline on **1800 100 500** or by visiting **www.fightdementia.org.au**

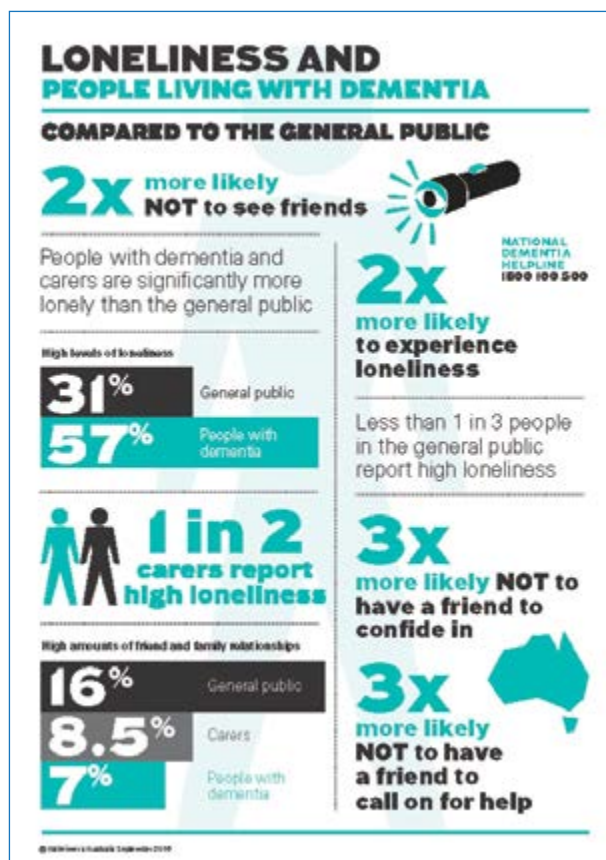


Figure 3: Via Fight Dementia: <https://www.fightdementia.org.au/dementia-and-loneliness>



Figure 4: Via Fight Dementia: <https://www.fightdementia.org.au/dementia-awareness-month/selfie-challenge>

The Caring for Cognitive Impairment Campaign

This campaign, a collaborative effort between a number of supporting organisations <http://cognitivecare.gov.au/about/caring-for-cognitive-impairment-campaign/> and the Australian Commission on Safety and Quality in Health Care, was focused on “improving our knowledge and care practices, providing better outcomes for patients, hospitals, staff and loved ones, and reducing the risk of harm in hospitals.”

Launched on January 28, 2016, the campaign is set to run until the end of 2018. By then, says the campaign home page, it is “expected that Version 2 of the National Safety and Quality Health Service (NSQHS) Standards will be implemented, [and] the campaign will assist hospitals to be prepared for the inclusion of cognitive impairment in the National Safety and Quality Health Service Standards.”

Campaign actions and strategies were developed based on “A better way to care” resources <https://www.safetyandquality.gov.au/our-work/clinical-care-standards/delirium-clinical-care-standard/> which according to the campaign site, “collate current evidence and best practice for delirium and dementia recognition and care.” A vital component of the campaign is a resource app called *Actions for Clinicians* that provides education and tactics specific to clinicians. Additionally, the site reports the Commission is working on the following objectives:

1. **A Clinical Care Standard to outline the key components of clinical care for patients with suspected delirium and patients at risk of developing delirium in hospital.** This will guide clinical practice and facilitate the provision of appropriate clinical care. The Delirium Clinical Care Standard was released in early 2017 and was accompanied by a set of indicators to support clinical teams and health services to identify and address areas that require improvement at a local level. <https://www.dementiatrainingaustralia.com.au/delirium-clinical-care-standard/>
2. **Incorporating cognitive impairment into Version 2 of the National Safety and Quality Health Service (NSQHS) Standards.** The NSQHS Standards are designed to protect the public from harm and to improve the quality of health service provision. All hospitals and day procedure services and the majority of public dental services across Australia need to be accredited to the NSQHS Standards. Version 2 of the NSQHS Standards will be introduced in 2017.
3. **A Cognitive Impairment Advisory Group** has been established to provide advice, expertise and support to the Commission’s Cognitive Impairment Program, specifically to provide leadership and advice on the implementation of the Caring for Cognitive Impairment campaign.

The Australian Multicultural Foundation’s National Dementia Campaigns

In recent years, two national campaigns have been sponsored by the Australian Multicultural Foundation. For more information please visit these summaries from the Foundation’s website <http://amf.net.au/entry/national-dementia-campaigns>

Memory loss: Disrupting daily life. A national dementia campaign <http://amf.net.au/entry/memory-loss-disrupting-daily-life-a-national-dementia-campaign> is a project of the Australian Multicultural Foundation (AMF) and was a Dementia Community Support Grant Program funded through the Australian Government, Department of Health and Ageing under the Dementia Initiative in 2009. The AMF in collaboration with SBS radio developed the health campaign to promote awareness of dementia in the following community language groups: African, (English), Amharic, Dari, Persian-Farsi, Somali, Sudanese (Arabic) and Burmese. The campaign involved delivering a series of dementia awareness announcements broadcast through SBS in-language radio programmes over two to three month periods.

A National Radio Dementia Awareness Program – in Community Languages <http://amf.net.au/entry/a-national-radio-dementia-awareness-program-in-community-languages> is a project of the Australian Multicultural Foundation (AMF) and a Dementia Community Support Grant Program funded through the Australian Government, Department of Health and Ageing under the Dementia Initiative in 2011. The AMF in collaboration with SBS radio developed the campaign to address some of the key issues and barriers to increasing the level of dementia literacy in culturally and linguistically diverse communities. The campaign delivered segments over three weeks on SBS national radio

programmes with a final segment, a talkback session, with a bilingual general practitioner. The segments were broadcast on four SBS national radio language programmes including Hindi, Turkish, Arabic and Amharic.

The ‘Remember’ missing persons and dementia awareness campaign

The National Missing Persons Coordination Centre annually spotlights awareness messaging efforts around “one of the key groups in the community most at risk of going missing.” The 2014 campaign was devoted to “raising awareness within the community of the links between dementia and missing persons.”

<https://missingpersons.gov.au/about/national-events/national-missing-persons-week>



Figure 5: Via Missing Persons Campaign Site: <https://missingpersons.gov.au/about/national-events/national-missing-persons-week>

ExxonMobil Australia’s Holiday Awareness Campaign

This national campaign took a seasonal approach: “ExxonMobil Australia is pleased to support Alzheimer’s Australia Victoria efforts to raise awareness about dementia this festive season, including the changes we notice in our family, friends or colleagues and the steps we can take to limit our risk of developing dementia,” said Dr. Marcus Hirschfield, Occupational Health Manager, ExxonMobil Australia.

Beyond its awareness-raising messages, the campaign promoted Alzheimer’s Australia Victoria’s newly developed resource, *The Dementia Guide*, described as an “essential tool for anyone impacted by dementia, including people living with the condition, families, friends and carers” and offering readers “information on support services, tips on how to live well with dementia and making plans for the future.”

The series addressed some of the most common and most pervasive myths about Alzheimer’s and related dementias, and included contact information for immediate support and access to available resources.

Also, the ExxonMobil campaign press release offered the following noteworthy media guidelines (in this Australian context, ‘consumers’ refers to people with dementia):

- Please avoid the use of the word ‘sufferers’ or ‘suffering’. Consumers prefer to be referred to as people/a person living with dementia.



Figure 6: Via ExxonMobil Australia’s Holiday Awareness Campaign: <https://vic.fightdementia.org.au/vic/about-us/news-and-media-releases/exxonmobil-helps-create-urgency-around-dementia-in-new-awareness-campaign-for-the-festive-season>



Figure 7: Via <https://vic.fightdementia.org.au/vic/about-us/campaigns/alzheimer's-australia-vic-public-education-and-awareness-campaign#Introduction>



Figure 8: Via <https://vic.fightdementia.org.au/vic/about-us/campaigns/alzheimer's-australia-vic-public-education-and-awareness-campaign#Introduction>

- When writing or talking about dementia, please provide your audience with the number for our free National Dementia Helpline 1800 100 500 - telephone information and support service available across Australia.
- The words used to talk about dementia can have a significant impact on how people with dementia are viewed and treated in our community. Please read our Dementia Language Guidelines (<https://www.fightdementia.org.au/resources/dementia-language-guidelines>) that have been developed by people living with dementia and carers.

England

England's National Dementia Strategy, under Objective 1, aims at 'improving public and professional awareness and understanding of dementia', and calls for the development and delivery of a general public informational campaign. The key messages of England's national campaign are to promote preventative decision making about healthy lifestyle choices, to stress the benefits of timely diagnosis, reduce social exclusion and discrimination, reduce anxiety while promoting understanding and to stress that dementia is a disease not a normative process of ageing. Further, 'what's good for your heart is good for your head', would be utilised as a strong prevention slogan throughout the campaign. <https://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf>

The EDUCATE Programme

One of England's efforts to reduce stigma is *The Early Dementia Users' Co-operative Aiming to Educate* (EDUCATE) project (www.educatestockport.org.uk). This was developed as a community outreach programme for those in the early stages of dementia in a community in Manchester, UK.

The project aims to improve the confidence of those who have recently received a diagnosis by providing them with opportunities for communication about their experience with a variety of groups including school children and social care professionals. An 18-month pilot project began in 2009 and by April 2012 had 20 volunteers. Group meetings take place monthly. The project is currently funded by the European Union through their Senior European Network Support programme.

Indonesia

The National Plan for Indonesia includes "seven action steps to manage Alzheimer and other dementia diseases: towards healthy and productive older persons". First on the list of 7 steps is a *Campaign on Public Awareness and Promotion of Healthy Lifestyle* (p.12):

Campaign on Public Awareness and Promotion of Healthy Lifestyle

To increase community awareness that dementia ("senile") is not a part of normal ageing process, various efforts and brain healthy lifestyle for life are needed. These include physical, mental, and social activities as well as balanced nutrition. These efforts should be applied consistently and continuously.

Netherlands

In 2008, the Ministry of Health, Welfare and Sport, Zorgverzekeraars Nederland (the Health Insurers' Association), Alzheimer Nederland (the Dutch Alzheimer Association) and ActiZ (the Employers' Association for Care Providers) joined to initiate the Programme on Integrated Dementia Care: <https://www.alz.co.uk/sites/default/files/plans/netherlands.pdf>

"Deltaplan Dementia: creating a dam against dementia" created a multi stakeholder platform with public and private stakeholders: health insurers, care providers, patient organisations, business, science, government.

They established an eight-year ground-breaking national action programme (2013-2021) with three aims:

1. Prevention and cure of dementia
2. Improving healthcare for people with dementia
3. Creating a more dementia friendly society

Within the Deltaplan a TV campaign was launched and evaluated as follows.

TV Campaign & Results

In addition, during the Netherlands EU Presidency in 2016 a website a campaign was launched to create a *more dementia-friendly society* in Holland.

The campaign – for which 10 million euros has been made available over the next five years – was launched at the EU conference ‘Living Well With(out) Dementia’. It will be run by Alzheimer Nederland and pension administrators PGGM as part of the ‘Dementia Delta Plan’. Supermarket chain Albert Heijn, Connexxion Taxi Services and Amsterdam city council will all join the effort to make the Netherlands more dementia-friendly. They were all represented at the launch.

A short online training course is now available.

Source: <https://www.government.nl/documents/speeches/2016/05/09/speech-by-martin-van-rijn-deputy-minister-for-health-welfare-and-sport-at-the-eu-conference-living-with-out-dementia>

Campaign

Based on the experiences of the circle of friends we produced four animated commercials (for tv and social media) about:

1. A lady with dementia, who **cannot find her way home**, being helped by someone on the street;
2. Someone **keeping an eye on her neighbour** with dementia;
3. A man in a swimming pool **being assisted to open a door**;
4. A supermarket employee **helping a customer** with dementia to find the right kind of bread.

The first commercial was aired on World Alzheimer's Day



Our results after 5 weeks:

- Main goal 2016 en 2017: raising **awareness**
- Reach of **TV commercial: 4.593.420 views** has seen the commercial approximately 2.2 times.
- **LinkedIn:** 137.362 views
- **Facebook:** 443.755 views (10+ seconds 44.979)
- **Twitter:** 123.296 views (10+ seconds 36.088)
- Interested companies: 14
- Participating companies: 12
- Participating local authorities: 70
- **Online registrations: 7.500**
- Conversion to online training: 36%



Scotland

Scotland's national initiative made distinctive recommendations to conquer negative stigma associated with dementia through research and publications. In 2008, the Scottish Government established the Dementia Clinical Research Network, with over €1 million in funding. One objective of the research network is educating the general public to help negate the stigma associated with dementia. An example is the establishment of a research volunteer registry that now has significant numbers of unaffected people enrolled.

In addition to research initiatives, the Scottish Parliament's Cross-Party Group on Alzheimer's Disease published a *Charter of Rights for People with Dementia and their Carers in Scotland*. The document was based on the recognition that a great stigma existed about individuals with dementia and that people with dementia and carers often experience discrimination and isolation. The document stated that individuals with dementia and their care providers have the right to participate in the decision-making process, are eligible for human rights and freedoms, can be free from discrimination, should consider themselves empowered to access all levels of care and have the full range of legal human rights regardless of diagnosis. https://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf

The central messages of the publication were similar to the other national campaigns. However, Scotland's creation of a 'framework' document could be a strong template for disseminating information in other national plans. <https://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf>

South Korea

South Korea's first National Dementia Plan was developed in 2008 and revised in 2012. The Dementia Management Act (DeMA) passed the National Assembly in 2011. Article 5 addresses Dementia Awareness Day, and its accompanying objectives are reflected in the figures shown below.

In the *World Alzheimer Report 2012: Overcoming the Stigma of Dementia* (<https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>), Korea's continued commitment to raising awareness was evident in the launch of support groups for carers, particularly their 'Loving our wife' group, which "enabled the exchange of experiences and creation of new friendships."

"War on Dementia"

In a presentation at the 26th ADI Conference in Toronto in 2011 (<https://www.alz.co.uk/sites/default/files/plans/Korea-war-on-dementia.pdf>), Sunghee Lee, President of the Alzheimer's Association Korea, shared updates on the Republic of Korea's *War on Dementia* campaign, launched in September 2010:

As part of this campaign, the national Alzheimer association coordinated training programmes in an effort to raise awareness and reduce stigma. A range of measures have been taken, including the training of large numbers of people as 'dementia supporters'. The programmes were attended by a variety of groups, from young school children to those working in public places who are likely to come into contact with people with dementia. Nursery school children also spent time playing with residents of nursing homes and a number of schools offer community service credit to those who work with people with dementia. Funding for the new activities and improved services for people with dementia was generated by a 4% increase in the national health insurance payments of all of those living in the Republic of Korea. The association trained 5,000 individuals as well as a number of other institutions before the responsibility for implementing the programme was returned to the government.

Switzerland

Partners in Switzerland, including the Alzheimer Association and Pro Senectute have launched an ongoing awareness campaign. The campaign is based on different elements. It focuses mainly on this website (<https://www.memo-info.ch/fr/>) which provides essential information on the disease and its warning signs, prevention possibilities and different therapies. A mass media campaign includes TV advertising, posters and online advertising.

The primary objective is to encourage people to go to the website for more information, where there is also an online observational test.



USA

The USA's *National Plan to Address Alzheimer's Disease* includes an investment of \$8.2 million over two years to support public awareness and to improve public knowledge and understanding of Alzheimer's disease (Goal 4) (<https://www.alz.co.uk/plans/usa>). Since the general public still views Alzheimer's as primarily a disease affecting older adults, the National Early-Stage Advisory Group offers the needed perspectives of those impacted by early onset dementia.

Wales

In their national plan, the Welsh Assembly Government aimed to raise awareness through inclusion of dementia in health campaigns, communication of dementia issues through professional, paraprofessional, lay networks and bulletins to health colleagues as well by updating voluntary organisations funded by government. (<https://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf>)

The Welsh Government's Consultation Document, *Together for a Dementia Friendly Wales: 2017-22* lists these ongoing community initiatives: (https://consultations.gov.wales/sites/default/files/consultation_doc_files/170109dementia-consultationen.pdf)

1. Building public awareness and support through the Dementia Friends/Dementia Supportive Communities campaigns (examples below).
 - **Brecon and Hay Dementia Supportive Community:** In October 2014, the community in Brecon (<http://www.dementiafriendlybrecon.org.uk>) became the first town in Wales to be recognised as dementia friendly under the Alzheimer's Society programme. A pilot project carried out in the town saw a number of local service providers join the campaign, including a pharmacist, police, fire and rescue staff, a medical centre, theatre and the Brecon Beacons National Park Authority. A training exercise was also undertaken by the Brecon Mountain Rescue Team who are often called to help in searches for missing people with dementia. The exercise was carried out in partnership with members of Brecon and Hay Dementia Supportive Community Group. More recent activities carried out in the area include a dementia friendly Christmas concert, the introduction of multi-sensory hands-on music activities, a supportive communities information event, and a coffee morning.
 - **Dementia Friends:** The Alzheimer's Society's *Dementia Friends* campaign (<https://www.dementiafriends.org.uk>) was launched in Wales in February 2014 and has been widely promoted. One year after its launch, the National Assembly for Wales announced its intention to become dementia friendly.
2. Publishing *Dementia: reduce your risk* guidance, which sets out the lifestyle choices people can take which could lower the risk of developing some types of dementia. Supported by The Welsh Government and Public Health Wales, the campaign encourages the public to take the following 6 steps to reducing dementia risk:
 - Active (physically and socially)
 - Check your health regularly
 - Try new things
 - No to smoke
 - Only drink alcohol within the guidelines, if at all
 - Watch your weight.

The Minister for Social Services and Public Health, Rebecca Evans explains:

"The risk of dementia increases with age and as more people are living longer, the number of people developing dementia will grow. These are simple steps that people can take not only to reduce the dementia risk, but other conditions including cancer, heart disease and stroke. The message is clear – don't wait; act now to reduce your risk." <http://gov.wales/newsroom/health-and-social-services/2017/dementia-risk/?lang=en>

Japan, Indonesia and Slovenia

Japan, Indonesia and Slovenia are three examples of countries where government support of World Alzheimer's Month 2016 was marked through the lighting up of national landmarks in a colour reflective of dementia support. Japan's Kyoto tower was illuminated orange, Indonesia's national monument purple, and Slovenia's Ljubljana Castle turned blue for World Alzheimer's Month.

CHAPTER 3

Improving detection of cognitive impairment and diagnosis



The *World Alzheimer Report 2011* (<https://www.alz.co.uk/worldreport2011>) notes that in high income countries only 20-50% of dementia cases are diagnosed, and that in low and middle income countries as many as 90% remain unidentified. This means a large segment population who have dementia is likely not receiving care.

More successful inclusion of people with dementia in policy planning, paired with public awareness campaigns aimed to reduce stigma, should shift the focus on improving early detection of cognitive impairment and diagnosis. As a society, the more we know and the less we fear about dementia - particularly what we learn from people living the experience - the better we become at paying closer attention to the warning signs and the changes in an individual which may be signalling cognitive impairment.

Though a cure has not yet been discovered, the bulk of dementia research points to the value of early diagnosis for proactively accessing available treatments, to better cope and live with the disease. And while some people may prefer not to know if they will develop dementia in the future, in most cases, early detection and diagnosis ultimately serves to improve the quality of life of the person living with dementia.

Besides the potential cost savings impact, early detection and diagnosis also benefits carers: the sooner an individual is diagnosed, the sooner the family can come to terms with the diagnosis, mentally, emotionally, physically, legally, and financially.

As Alzheimer's and related dementias can present in many ways, and many individuals also have co-morbid conditions, diagnosis becomes accordingly complicated, regardless of timing. After receiving an accurate diagnosis the next challenge is to get in touch with appropriate services for support and treatment.

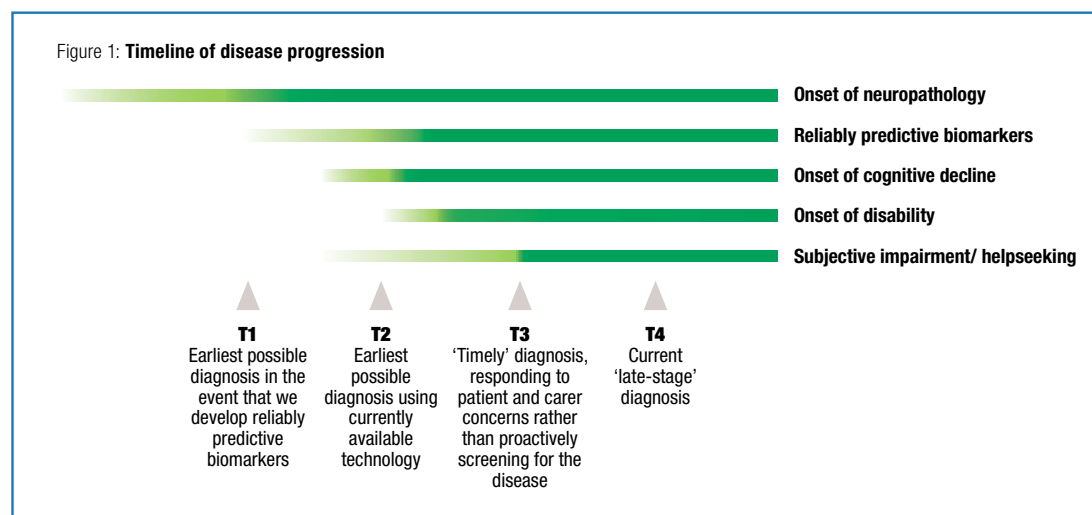


Figure 1: Via *World Alzheimer Report 2011*: <https://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf> p. 11

Currently 17 national plans have established early detection and diagnosis as a priority issue. These countries are committed to actively improving early detection and diagnosis in the following areas:

- Awareness and education of society
- Awareness, education, and training of professionals
- Role of General Practitioners
- Primary healthcare
- Hospital and acute care settings
- Specialist assessment and services
- Chain, network, or pathway of care
- Home, care home, and adult day settings
- Support of multi-disciplinary teams
- Tools to support the diagnostic process
- Research and data

Source: Early Detection and Diagnosis paper, available soon at <https://www.alz.co.uk/dementia-plans/small-papers-on-national-and-sub-national-dementia-plans> and <https://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>

In the following pages we review the early detection and diagnosis activities in Australia, Cuba, England, France, Greece, Italy, the Netherlands and Norway.

Australia

Australia has three action areas that specifically address early detection and diagnosis. These action areas include: the need for timely diagnosis; accessing care and support during and after hospital care; and promoting and supporting research. Australia addresses the need for timely diagnosis through awareness and education of society, awareness and education of professionals, ongoing education of General Practitioners (GPs), the use of multi-disciplinary teams (MDTs), and guidelines.

Australia states that increasing awareness among the general population and professionals is important because people have difficulty distinguishing the early signs of dementia from their perception of “normal” ageing. Stigma is also an issue. Increased knowledge and awareness can be achieved through national public awareness activities such as circulating communications and resources to help people recognise the early signs of dementia. Additionally, Australia describes how increased awareness among health professionals may help detect the early signs of memory loss, monitor changes, and decide on the need for further investigation.

Furthermore, Australia specifically mentions the need for ongoing professional education for GPs to inform their practice on recognising, assessing, diagnosing, and providing support. Ongoing support and education needs to be provided in such areas as: the impact, prevalence, and manifestation of dementia; the use of evidence-based diagnostic tools; awareness of services for people with dementia and their carers; and clinical decision-making tools, such as referral systems and pathways. Moreover, because dementia is a multifaceted condition and diagnosis requires the expertise of multiple stakeholders, Australia says that the support of MDTs is also important in providing assessment for people living alone without carers or family nearby. Finally, in response to the need for timely diagnosis, Australia describes how diagnostic instruments exist, but additional consideration is needed where separate guidelines and assessment methods are required for people with Culturally and Linguistically Diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander people.

Another action area that addresses early detection and diagnosis is accessing care and support during and after hospital care. Engaging the person with dementia, their carers, and family in the planning of care while in an acute care setting may facilitate more accurate assessment, diagnosis, and support. To do this, better education programmes are required for the healthcare workforce, as well as implementing dementia training in all undergraduate and postgraduate health professional programmes. Finally, Australia's action area promoting and supporting research discusses how research in technology and neuroimaging will provide more timely diagnoses. The development of blood tests will also enable a more accurate and earlier diagnosis.

Source: Early Detection and Diagnosis paper, available soon at <https://www.alz.co.uk/dementia-plans/small-papers-on-national-and-sub-national-dementia-plans>

Cuba

Cuba's national plan presents several objectives that relate to improving diagnosis and detection. One objective is to increase promotion, information and education of professionals and families. A national prevention and risk reduction campaign, with societal participation, should have a positive impact on many areas, including supporting earlier diagnosis. Stigma is another issue that a national campaign should tackle and emphasis placed on institutions and media launching campaigns, television spots and health promotion activities, with the approach that all sectors should adapt to the ageing population.

Cuba's Strategy for Alzheimer Disease and Dementia Syndromes

Dementia is a great challenge to public health in Cuba due to its impact on society and families. Cuba's National Intervention Strategy for Alzheimer Disease and Dementia Syndromes is designed to address this challenge. The Strategy includes working guidelines for primary and secondary care, education about rights of people with cognitive impairment, professional development, research, and health promotion and dementia prevention. An associated action plan, focused on primary care, includes proposals for creation of memory clinics, day centers and comprehensive rehabilitation services for cognitive stimulation. Short-term measures proposed include increasing early detection; creating a dementia morbidity and mortality registry; promoting professional training; providing support for families; and promoting basic and clinical research on dementia. Mid-term proposals aim to reduce dementia incidence and mortality by controlling risk factors and promoting healthy lifestyles, offering new treatment options and optimizing early detection. A set of indicators has been developed to evaluate strategy implementation. With this strategy, Cuba joins the small number of developing countries that have responded to WHO's call to improve care for patients with dementia and alleviate its impact on society and families.

Source: http://www.scielo.org/scielo.php?script=sci_abstract&pid=S1555-79602016000300009

Cuba's plan also discusses diagnostic tools and research. It states the need to increase research to improve diagnostic tools, neuroimaging and biomarkers for early diagnosis, as evidenced in the project Multimodal Quantitative Neuroimaging Databases and Methods: the Cuban Human Brain Mapping Project by Hernandez-Gonzalez et al (<http://journals.sagepub.com/doi/abs/10.1177/155005941104200303>)

The study also describes the creation of Cuban normative databases, starting with the Cuban EEG database obtained in the early 90s, and more recently, the Cuban Human Brain Mapping Project (CHBMP). This project has created a 240-subject database of the normal Cuban population, obtained from a population-based random sample, comprising clinical, neuropsychological, EEG, MRI and SPECT data for the same subjects. This database allows the comparison between imaging techniques on a medium scale.

Lastly, Cuba presents an action to implement guidelines for good clinical practice in the prevention, diagnosis, and management of chronic diseases. This does not refer specifically to dementia, but rather the importance of guidelines for good clinical practice for all chronic non-communicable diseases.

Source: Early Detection and Diagnosis paper, available soon at <https://www.alz.co.uk/dementia-plans/small-papers-on-national-and-sub-national-dementia-plans>

England

Increased diagnosis rates are one of the promising outcomes stemming from The Prime Minister's Challenge on Dementia, launched in May 2012 (Challenge report, page 8):

Better diagnosis

Currently only 42% of people with dementia in England have a formal diagnosis. The diagnosis rate varies – from 27% in the worst-performing areas to 59% in the best. Too often, diagnosis comes too late – during a crisis or beyond the point where people can plan for the future and make informed choices about how they would like to be cared for. This is not good enough.

Surveys show us that people with dementia would like early diagnosis. We know that with early intervention, and access to the right services and support, people with dementia can continue to live well for many years.

The people most at risk of developing dementia (the over-75s) see their GP at least once, if not several times, a year. Around 97% of people aged over 75 go to their GP surgery at least once a year, and around 87% at least once every six months.

Key commitment 1

Increased diagnosis rates through regular checks for over-65s We will ensure GPs and other health professionals make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.

Clinical commissioning groups and local health and wellbeing boards will be encouraged to work with wider local partners to improve diagnosis rates. We will incentivise improved diagnosis rates by including a new indicator in the NHS Outcomes Framework 2013/14.

Source: <http://media.dh.gov.uk/network/353/files/2012/11/The-Prime-Ministers-Challenge-on-Dementia-Delivering-major-improvements-in-dementia-care-and-research-by-2015-A-report-of-progress.pdf>

France

The French Alzheimer's Disease Plan aims to develop research, promote optimal diagnosis and take better care of patients.

In the area of diagnosis, and in order to evaluate the clinical interest and use of cerebrospinal fluid (CSF) biomarkers, a data-sharing project, the PLM (Paris-North, Lille and Montpellier) study has emerged through collaboration between the memory centres already involved in this field. Altogether we could demonstrate in both mono-centric and multi-centric cohorts from memory clinics the capacity of CSF biomarkers to discriminate AD from non-AD patients in clinical routine with a high sensitivity and specificity.

Source: Impact of the 2008–2012 French Alzheimer plan on the use of cerebrospinal fluid biomarkers in research memory center: the PLM study. J Alzheimers Dis. 2013;34(1):297-305. doi: 10.3233/JAD-121549 (<https://www.ncbi.nlm.nih.gov/pubmed/23186986>)

Greece

Greece's national dementia plan contains several action areas that relate to early detection and diagnosis. One action is a national information campaign to foster early detection of the disease and to manage it in the early stages. Information campaigns for the general population address the benefits of early diagnosis, prevention of dementia and reducing stigma. Another action is integrating dementia in primary care and, as a result, ensuring equal and easy access for people with dementia and their families in early diagnosis and treatment. Further action includes the establishment of memory and mental function clinics in hospitals. Each clinic will provide diagnosis, treatment, and monitoring of people with dementia by region in collaboration with their primary care physician. Lastly, the Greek plan includes action to strengthen valid and reliable data in order to improve the quality of diagnosis. For example, the Shaw National Archive Registry (a dementia registry), is a systematic and standardised recording of cases of dementia. This would help improve the quality of diagnosis, treatment, and care.

Source: Early Detection and Diagnosis paper, available soon at <https://www.alz.co.uk/dementia-plans/small-papers-on-national-and-sub-national-dementia-plans>

Italy

Italy's national dementia plan has four objectives, two of which specifically talk about early detection and diagnosis. Their plan discusses the need to increase the knowledge of the general population for timely diagnosis, which requires both increased awareness and reduction of stigma. Another objective is to create an integrated diagnosis, describing how the creation, reorganisation and expansion of an integrated network will help to ensure timely diagnosis. While this is not an objective, Italy also mentions how they were one of the first countries to focus on creating specialised centres for diagnosis and coordination of a therapeutic phase.

Also of interest is this research by Veneziani et al (Int Psychogeriatr. 2016 Jul;28(7):1111-24. doi: 10.1017/S1041610216000041. Epub 2016 Jan 28. about the levels of knowledge and training on dementia diagnosis for Italy's General Practitioners <https://doi.org/10.1017/S1041610216000041>):

Examination of level of knowledge in Italian general practitioners (GP) attending an education session on diagnosis and management of the early stage of Alzheimer's disease (AD): pass or fail?

Results: Specific screening tests or protocols to diagnose and manage dementia were not used by 53% of our GPs. The training on the recognition of early AD signs and symptoms was considered inadequate by 55% of the participants.

Conclusion: In our survey on GP clinical practice, several problems in properly recognizing early AD symptoms and subsequently screening patients to be referred to secondary/tertiary care centres for diagnosis confirmation have emerged. In the future, specific training programs and educational projects for GPs should be also implemented in Italy to improve detection rates and management of dementia in primary care.

The Treviso Dementia Registry is another promising practice in Italy aimed at earlier diagnosis and prevention.

The Treviso Dementia Registry (TREDEM)

Materials and Methods: The TREDEM Registry is an observational data collection on cognitive decline conducted at the Cognitive Impairment Center at the Local Health Authority no. 9 of Treviso (LHA9) and consists of data from 1364 subjects in the TREDEM study collected between 2000 and 2010 plus those collected later using the same methods. There are more than 2500 subjects up to now.

An action plan: *Camminando e leggendo... ricordo* (CLR) (Translation: *Walking and reading... I remember*) is a practical initiative of secondary prevention built by the Cognitive Impairment Center and the Department of Prevention of LHA9 in Treviso. It is aimed at no-frail, pre-frail and frail mild cognitive disorder (MCI) subjects. The CLR physical exercise program is composed of a two-phase group training with 30 min of walking at moderate intensity on a dirt path and 30 min. of exercises for balance, flexibility and joint mobilization; resistance training with small equipment and weights; gait training with rapid changes of direction and speed variation. Each session ends with 7 minutes

of stretching.

Additionally, the Dementia Study Group of the Italian Neurological Society has published guidelines for the diagnosis of dementia, including a section on early diagnosis.

It highlights: “Although there is evidence that the initial phases of dementia often go unrecognised in clinical practice, an early diagnosis would allow:

- timely intervention against the causes of reversible dementias;
- the start of therapies that can slow disease progression;
- the start of therapies that can potentiate the cognitive performance of patients by exploiting the non-complete impairment of their neuronal circuits;
- the implementation of measures that reduce the effects of the comorbidity associated with dementia;
- the timely implementation by patients and their families of the measures necessary to solve the problems related to the progression of the disease.”

Sources: International Psychogeriatric Association 2016 doi:10.1017/S1041610216000041; <http://www.pagepressjournals.org/index.php/gc/article/view/6056/5926>; <https://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf> and Early Detection and Diagnosis paper, available soon at <https://www.alz.co.uk/dementia-plans/small-papers-on-national-and-sub-national-dementia-plans>; *International Psychogeriatrics*: page 1 of 14

Netherlands

The national plan for the Netherlands was informally structured and written in a letter format by Dr. J. Bussemaker, The State Secretary of Health, Welfare and Sports. The plan was developed from the National Dementia Programme (LDP), which ran from 2004 to 2008, in conjunction with the Dementia Delta Plan. The LDP was launched in 57 regions. Each region searched for solutions to the problems that were most prevalent in their particular region. The national plan outlined by Dr Bussemaker focused on three key aims:

1. creating a coordinated range of care options that meet client’s needs and wishes
2. delivering sufficient guidance and support for people with dementia and their carers
3. measuring the quality of dementia care annually

In the prior system, detection of dementia usually surfaced after years of struggle and accumulation of symptoms by an individual. Therefore, the national dementia plan for the Netherlands called for targeted, easily available information to help individuals with dementia onset, as well as family, identify symptoms of dementia. Special emphasis was placed on differences in normal ageing symptoms compared to dementia symptoms. Alzheimer Nederland and the municipalities under the Social Support Act would play a crucial role in policy development for early-detection. To achieve earlier diagnosis, general practitioners (GPs) were to be knowledgeable about dementia-like symptoms so early detection could be made at general visits. Additionally, the GPs should know when and where to send patients symptomatic of dementia for secondary care, using professional standards (NHG Dementia Standard) and the Regional Support Structure.

To improve access to dementia diagnosis, the Netherlands’ national plan looked towards a multidisciplinary approach. GPs have often viewed a dementia diagnosis as “there is nothing you can do about it.” This reflects the limited pharmacological interventions for dementia and the lack of specialised training among practitioners. Interagency collaborations were to use opportunities created by the outlined programme for research and experiments in the area of dementia. By gaining new knowledge, the aim is a more efficient diagnosis process across healthcare professions.

Source: <https://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf> and Early Detection and Diagnosis paper, available soon at <https://www.alz.co.uk/dementia-plans/small-papers-on-national-and-sub-national-dementia-plans>

Norway

Norway's dementia plan discusses five strategies and actions. Within the improved coordination and medical follow up strategy, they state that they will continue their initiative of training and implementing the diagnostic tool among the country's primary care doctors and local authorities. Additionally, their plan states that the government shall prepare a national strategy for enhancing specialised health services for the elderly. Specialised health services have a key mission to evaluate and diagnose people with dementia. Another strategy related to development, research and planning, discusses continuing the development of evaluation tools for diagnosing people with developmental disabilities who develop dementia. Furthermore, a new initiative under this strategy focuses on those with minority language backgrounds who develop dementia. The strategy emphasises that this should be a key topic and include issues related to diagnosis.

Of note is the research by Kada et al which looked at the quality and appropriateness of referrals for people with dementia. It found disagreement between geriatricians and GPs regarding the appropriateness of referrals. They found that time-consuming tests were infrequently performed or reported and key information was missing from referral letters.

Source: <http://primarycare.imedpub.com/quality-and-appropriateness-of-referrals-for-dementia-patients.php?aid=1417> and Early Detection and Diagnosis paper, available soon at <https://www.alz.co.uk/sites/default/files/national-alzheimer-and-dementia-plans.pdf>

CHAPTER 4

Dementia capable supports at all stages

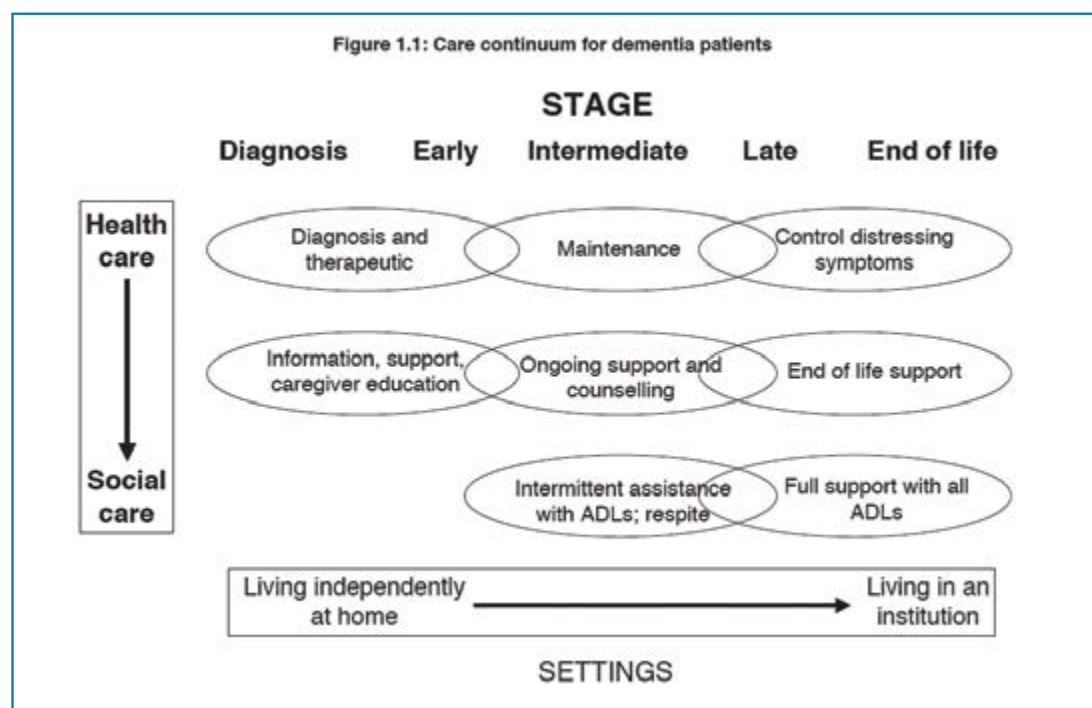


Figure 1: Courtesy of *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers: <https://www.oecd.org/els/health-systems/33661491.pdf> p. 10

Following diagnosis, individuals and family carers should have access to a continuum of dementia friendly services in the community and in health care settings. These dementia capable supports should saturate every aspect of care, from post diagnostic support to care at the end of life.

Most health care systems around the world are complex, and for people with dementia (especially those without a carer advocate), there is a critical need for easily accessible services tailored to their cognitive challenges. Community-based services can also be hard to find, even for those without a cognitive impairment, as well as for carers who are overwhelmed with the daily duties of dementia caregiving.

As research shows the great majority of older adults wish to receive care, support, and services in their homes for as long as possible. Therefore, there is a growth in demand for dementia capable supports at all stages - from diagnosis to death. These supports and services should also keep the carers in mind, meeting their needs too as they provide the backbone of the long-term care system in most countries.

“At all stages” is a key consideration as well: as dementia advances, while personhood remains, the individual’s ability to perform and manage the activities of daily living decline. If support around the post-diagnostic period is strong, end of life care is not. The person with dementia is not being supported through the lifespan—and the focus falls on the informal caregiving system. For the many dementia carers who have provided support on their own for years and are feeling the effects of compassion fatigue or carer burnout, the need for assistance at the end of life intensifies.

In the following pages we will present some activities taking place in Finland, France, Japan, Scotland and Switzerland - tasked with ensuring and expanding the availability of dementia capable supports at all stages.

Finland

Finland's *National Memory Programme: 2012-2020: Creating a "Memory-Friendly" Finland* https://www.julkari.fi/bitstream/handle/10024/126202/Reports_2013_9_Memory_verkko.pdf, seeks to "build solidarity to create a 'memory-friendly' Finland on the basis of [these] four pillars:

- Promoting brain health
- Fostering a more open attitude towards brain health, treatment of dementing disease and rehabilitation
- Ensuring a good quality of life for people with dementia and their families through timely support, treatment, rehabilitation and services
- Increasing research and education"

A look at current and past projects around dementia supports in Finland (in cooperation with the Alzheimer Society of Finland) shows these promising practices:

Expert and Support Centres Network – The Memory Pilot project

The network of local expert and support centres aims to strengthen volunteer work and cooperation in the dementia work and to improve and expand the services for people with dementia.

Customer-orientated service system for people with dementia

The aim is to strengthen the service system and especially rehabilitation services for people with dementia and their families. The project has made a vast study about life with dementia in the first year after the diagnosis.

Finnish Social Security System

157 professionals who work with people with dementia (e.g. memory nurses, dementia coordinators, social workers) were interviewed using a questionnaire. Eight people with dementia and some of their family members were interviewed individually. The primary aim of the study was to clarify how and if equality is achieved in the availability of public social security when people with dementia and people with other challenges are compared.

The results of this study showed that certain social security services are not equally available for every diagnostic group. Especially rehabilitation and transportation services which are easier to get for people with other diagnosis than for people with dementia. Both professionals and people with dementia experienced the accessibility in the same way.

Source: <http://www.muistiliitto.fi/en/home/development>

Memory Advice

A new service in Finland, has been in its pilot phase for about a year, and provides personalised support by phone:

"The service is targeted for people with memory-related diseases, their carers and professionals in the field. The service is available three days a week. Calls are cheap; only 8 cents / minute + local network charge.

On the basis of the one-year pilot phase, the Alzheimer Society of Finland (Muistiliitto) says that the service is needed. In the past year the phone line received 349 calls, and many calls were left unanswered because of the congestion of the phone line.

The most common questions received by the Memory Advice phone service related to specific issues having to do with nursing, symptoms of memory-related diseases, studies on memory-related diseases, as well as legal advice. The most common questions on legal advice were about continuing power of attorney and advance directives.

The vast majority of callers were women and people with memory related diseases. Most of the callers were between 41 and 65 years of age, though the age range was large, ranging up to more than 80.

The Memory Advice phone service calls are answered by professionals working in the Memory Pilot centers. Memory Pilots are expert and support centres maintained by the member associations of the Alzheimer Society of Finland.

The Society is pleased to note that people are aware of and have been using the Memory Advice phone service. Phone calls have been received from all the regions of Finland.

The Memory Advice phone service will now be expanded for calls to be answered in each region of Finland. There will thus be 18 professionals on duty in total.”

Source: <http://www.alzheimer-europe.org/News/Members-news/Friday-24-March-2017-Finland-provides-personalised-advice-on-memory-related-issues-over-the-phone>

France

Objective Four in France's National Plan is focused on “improving access to diagnosis and care pathways.” It includes the following measures, indicative of its commitment to dementia capable supports:

- Preparing and implementing a system for giving the diagnosis and providing counselling
- Experimenting new payment terms for health professionals
- Creating an Alzheimer's disease information card for each patient
- Creating memory units in areas that are not covered
- Creating “memory resource and research centres” in areas that are not covered

The national Alzheimer information system, as described below, encompassed several of these measures.

The 2008–2012 French Alzheimer Plan: description of the national Alzheimer information system.

In France, one of the aims of the current national Alzheimer's disease plan is to collect data from all memory centres (memory units, memory resource and research centres, independent neurologists) throughout the country. Here we describe the French Alzheimer Information System and present a ‘snapshot’ of the data collected throughout the country during the first year of operation. In 2010, the French National Alzheimer Databank (BNA, Banque Nationale Alzheimer) received data from 320 memory centres relating to 199,113 consultations involving 118,776 patients. The BNA will provide longitudinal data that can be used to assess the needs of individual local health areas and size specialized care provision in each regional health scheme. By contributing to the BNA, the memory centres enhance their clinical activity and help to advance knowledge in epidemiology and medical research in the important field of Alzheimer's disease and related dementias.

Source: Le Duff, F., Develay, A. E., Quétel, J., Lafay, P., Schück, S., Pradier, C., & Robert, P. (2012). The 2008–2012 French Alzheimer Plan: description of the national Alzheimer information system. *Journal of Alzheimer's Disease*, 29(4), 891-902. <https://www.ncbi.nlm.nih.gov/pubmed/22366771>

This report from Alzheimer Europe suggests that progress has been made towards the patient care pathways goal, which is part of the 3rd French Alzheimer plan:

On 26 June 2013, Marisol Touraine, Health and Social Affairs Minister, Geneviève Fioraso, High Education and Research Minister, and Michèle Delaunay, Minister for Older Persons and Autonomy, received the evaluation report of the third French Alzheimer Plan.

The evaluation was made by Prof Joël Ankri and Prof Christine Van from Broeckhoven. It highlights the major achievements of the plan in research, diagnosis, support of people with dementia and support to their families. The report also lists 56 recommendations for future action. The authors noted the significant progress in patient care pathways.

Source: <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies/France?#fragment1>

Japan

Japan's National Plan, revised in 2015 is entitled *The Orange Plan*. It establishes 7 priority areas: raising social awareness; appropriate and timely medical and social care; improvement of care for early onset dementia; carers support; elderly and dementia friendly communities; research and establishment of prevention, diagnosis, treatment, rehabilitation, care; and placing importance of the view of people with dementia and their carers. Japan is setting a global example particularly in the areas of end of life and palliative care, as illustrated in the following research.

An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper

This study aimed to evaluate the contents of national dementia strategies with a focus on palliative care content, and concluded that some strategies covered palliative care in dementia, although they did not frequently label it as such.

'Japanese Care Location and Medical Procedures for People with Dementia in the Last Month of Life' by Nakanishi M, et al, illustrates the 2015 revision to Japan's dementia plan which introduced objectives around end of life care and support. It concludes that education and policy efforts are required to provide palliative care to people with dementia at home.

Source: Japanese Care Location and Medical Procedures for People with Dementia in the Last Month of Life DOI: 10.3233/JAD-150898 <https://www.ncbi.nlm.nih.gov/pubmed/26890762>

Another promising area around dementia capable supports at all stages is evidenced by training for professional and informal caregivers, as mentioned in the 2014 ADI *Dementia in the Asia Pacific Region* report.

AAJ [Alzheimer's Association Japan] provides training courses with various organisations involved in dementia care. Currently the number of training sessions is increasing. AAJ's members serve in the role of lecturers as experienced caregivers and spokespeople for people with dementia and their actual caregivers.

For professional caregivers: three regular courses (4 times per year)

1. Understanding of dementia and care
2. Medical care for people with dementia
3. Palliative and end of life care for people with dementia

For informal caregivers: Training workshops

1. Dementia supporter session for adults/children
2. Workshop for the telephone counsellor (monthly)
3. Workshop for the facilitators of monthly meetings (1 to 2 times per year)

Source: <https://www.alz.co.uk/adi/pdf/Dementia-Asia-Pacific-2014.pdf>

Scotland

Improving Post-diagnostic Support (PDS) was one of the two key improvement areas in Scotland's first National Dementia Strategy (June 2010). The Scottish Government announced its intention to introduce a post-diagnostic support target to ensure people with dementia receive the help they need following diagnosis. A Local Delivery Plan (LDP) target 'To deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a link worker, including the building of a person-centred support plan' came into effect in April 2013. The target applied:

- To all ages
- To all settings
- The first year of the target focused on community settings

Source: <http://www.gov.scot/Resource/Doc/324377/0104420.pdf> and <http://www.isdscotland.org/Health-Topics/Mental-Health/Dementia-Post-diagnostic-Support-Target/>

The Local Delivery Plan target specific to dementia was one of 3 new targets out of the 15 proposed:

“For 2013/14 there are 15 targets which set out the ‘performance contract’ between Scottish Government and NHS Boards - these include:

- Dementia - a minimum of one year’s post diagnostic support, through a link worker, for people newly diagnosed with dementia including person-centred support plan. This target will be due for delivery by 2015/16. This supports sustained independence within context of strong family and community support and promotes early decision making on future care options as part of person-centred care.”

Source: <http://www.gov.scot/Publications/2012/12/8405/4>

Being Dementia Smart (BDS): A Dementia Nurse Education Journey in Scotland

Management and care of an individual with dementia requires a multidisciplinary approach with expertise and a competent skill base. Nurses are central to dementia care delivery in hospitals, community and residential care settings. Thus this pre-registration integrated dementia curriculum was developed to build capacity and capability with dementia expertise among the future nursing workforce in Scotland in line with the National Dementia Strategy.

Source: Macaden, L. (2016). Being Dementia Smart (BDS): A Dementia Nurse Education Journey in Scotland. International Journal of Nursing Education Scholarship, Volume 13, Issue 1, ISSN (Online) 1548-923X, ISSN (Print) 2194-5772, DOI: 10.1515/ijnes-2015-0019 http://dspace.stir.ac.uk/bitstream/1893/23919/1/Published%20Version%20-%20Being%20Dementia%20Smart_LM_IJNS2016.pdf

Health and Social Care Integration

An excerpt from this article on the Scottish government’s website details recent advancements in linking health and social care, which could greatly benefit people with dementia:

“Positive changes are already happening. Scotland is leading the way in integrating health & social care in the UK. We are acknowledged for our vision and commitment and we should be justifiably proud of that.

The Scottish Government has provided an additional investment of almost £500 million in transitioning to this new approach to date, including:

- £100 million per year since 2015 on an Integrated Care Fund to shift the balance of care towards prevention and support services to deliver improved outcomes for local communities.
- £30 million per year to support Integration Authorities to reduce delayed discharges, including the development of a range of community based services like Intermediate Care Beds, reablement at home and other preventative services.
- £250 million transfer in the 2016/17 budget to support payment of the living wage and health and social care integration
- £107 million of additional investment to be directed to Health and Social Care Partnerships, which will deliver Scottish Government’s commitment on the Living Wage and support sustainability in social care.”

Source: <http://www.gov.scot/Topics/Health/Policy/Health-Social-Care-Integration>

Switzerland

Switzerland has a national dementia strategy, which has been prolonged until 2019. Two action areas are highlighted below:

Action Area 3 - "Quality and Specific Skills"

The new law of protection of adults, came into force in January 2013 and strengthens the patient's right to self-determination. It has implications for the process of medical decision regarding patients who are no longer capable of discernment. To guarantee safety and quality of care, enhanced and specialized training may be required for professionals for each stage of dementia – early, mid and late.

From an ethical point of view, every human being has the right to make decisions independently and thus also the right to refuse medical interventions. Advance directives are a way to assert that right. With regard to the new adult protection law: The National Ethics Commission in the area of human medicine, (CNE) concluded that advance directives contribute to respecting the autonomy of people with dementia.

The new adult protection law allows people to have self-determination mode with regard to their future medical situations. Yet, in the case of dementia, the defence of these rights and their implementation requires early diagnosis so that patients can express their wishes clearly.

It is also necessary to aim for the highest possible quality in treatment, support and care. Experience showed that the systematic application of ethical guidelines can significantly contribute. The treatment and care of people with dementia may be particularly demanding, for example with aggressiveness behaviour or resistance to therapeutic interventions, and in these situations people with dementia may face a higher risk of abuse.

Source: From Switzerland's Dementia Strategy -

<https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/nationale-demenzstrategie.html>

Action Area 2 of the Swiss National Dementia Strategy 2014-2017 also offers some promising priorities as it pertains to dementia-capable supports:

Action Area 2 – "Appropriate services"

Goal 3 Dementia patients and the people closest to them can call on flexible, high-quality and appropriate care services at every point in the care chain.

- 3.1 Establishment and expansion of regional, networked centres of competence for diagnostics
- 3.2 Promotion of coordinated services to meet individual care needs
- 3.3 Establishment and expansion of flexible regional respite (relief) services for day and night care
- 3.4 Promotion of dementia-appropriate care in acute care hospitals
- 3.5 Promotion of dementia-appropriate care in long term in-patient nursing and care

Goal 4 Appropriate compensation and the financial viability of appropriate services for people with dementia are guaranteed.

- 4.1 Reflection and appropriate compensation of services

CHAPTER 5

Improving health care: Long term care supports and services

According to the *World Alzheimer Report 2013: Journey of Caring: An Analysis of Long-Term Care for Dementia*, around half of all people with dementia need personal care. The others will develop such needs over time. In addition, nearly half of all older people who need personal care have dementia, while four-fifths of older people in nursing homes are people with dementia (Prince, Prina, & Guerchet, 2013) <https://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>.

Because dementia often leads to some level of dependence on others - and in the later stages, total dependence - people with dementia are among the highest users of long term care services and supports. Any long term care system must therefore consider the unique care needs of the full spectrum of dementia, from the early stages to the final ones. In the earlier stages, such support may be reflected in meal time and medication reminders, or assistance with certain activities of daily living (ADLs), like bathing and dressing, and instrumental activities of daily living (IADLs), like bill-paying or setting doctor's appointments.

As the disease advances and other difficult symptoms emerge - such as gait and balance issues which affect an individual's mobility, or behavioural challenges like sun downing, aggression or hallucinations - the care must increase. Meal times can be especially harrowing for people with dementia as they lose basic hand-eye coordination or the physiological ability to chew or swallow food safely. Accordingly, dementia-friendly long term care systems should include considerations such as: activity programming that offers dignified, meaningful engagement opportunities; dementia-specific training for professional carers; dementia-capable physical environment with accommodations for vision/mobility issues (many people with dementia experience discrepancies in depth perception) to minimise aggressive behaviours or elopement attempts, and cues and prompts built in to foster independence.

Relating to the increasing level of care and dependency is the rising cost of long term care for people with dementia. Quality long term care services and support for people with dementia does not have to be expensive, but often is. Financing this costly care stretches community and government organisation's budgets alike because of its long term implications.

Some examples follow from Australia, England, France, Norway and the USA and in providing innovative long term care services and supports for persons with dementia.

Australia

One of the Australian National Plan 2009-2014 objectives is tied to the Behavioural and Psychological Symptoms of Dementia (BPSD). It is encouraging relevant training, education and assessment to better identify and address the triggers of BPSD without using antipsychotic drugs as a treatment or care practice.

The Halting Antipsychotic use in Long Term care (HALT) Project and its success in non-pharmacological, person-centred approaches to BPSD instead of antipsychotics is referenced in the following articles:

"In 2009, a study from King's College London and funded by Alzheimer's Research UK, highlighted the long-term dangers associated with the use of antipsychotic drugs to treat symptoms such as severe anxiety and agitation in people with dementia. The Australian project, called 'Halting Antipsychotic use in Long Term care' (HALT), used nurse training and non-drug, person-centred approaches to help reduce the use of antipsychotics in over 100 long-term dementia care residents who were regularly prescribed the drugs. Of those participants who started the study, around 86% had their antipsychotic treatment stopped and three-quarters of those remained off the drugs six months later. Using available data, the team found that over 60% of the participants were prescribed antipsychotics after being admitted to long-term care (Alzheimer's Research UK, 2016)."

"The HALT study proposes a model for deprescribing antipsychotics in residential care through person-centred approaches to managing challenging behaviours. A targeted, evidence-based training package has been developed to up-skill general practitioners and nursing home staff in this area, as well as in the quality use of medicines.

HALT is a collaboration between consumers, residential aged care providers, staff, general practitioners, pharmacists, the Dementia Behaviour Management Advisory Service (DBMAS), the National Prescribing Service (NPS) and specialists to reduce inappropriate antipsychotic use in nursing home residents and respectively reduce adverse events associated with these medications such as cognitive decline, falls, parkinsonism, hospitalisations, stroke and death. The results of this project will be used to support the development of a nationally applicable and sustainable approach to the care of people with challenging behaviours in long-term care facilities. The HALT project is funded by the Australian Department of Social Services through the Aged Care Service Improvement and Healthy Ageing Grants Fund" (Brodaty, Shell, Jessop, Harrison, & al.).

More information on the HALT Project's success can be found at http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&view=dcrc&layout=project&Itemid=202&pid=249

Also of note is this research on implementation of a tool to measure depression among persons with dementia in aged care homes:

An evaluation of a national program to implement the Cornell Scale for Depression in Dementia into routine practice in aged care facilities

Background: Screening tools have been recommended for use in aged care to improve the detection and treatment of depression. This study aimed to evaluate the impact of a program for the routine implementation of the Cornell Scale for Depression in Dementia in Australian facilities, to determine whether use of the instrument by nurses led to further monitoring of depressive symptoms, medical referral, and changes in treatments prescribed for depression.

Methods: A file review was completed for 412 participants out of a total of 867 older people (47.5%) who resided in ten aged care facilities. The review examined Cornell Scale assessment data, medication charts, medical history, nursing progress notes and resident care plans. Nursing staff who administered the Cornell Scale to each participant were also interviewed, and ten facility managers took part in an interview to determine barriers to the effective implementation of the instrument.

Results: The researchers found that the Cornell Scale had been administered to 46.8% of the 867 person sample in the previous 12 months and recorded in their medical records. A score of 12 or greater indicates probable depression. 25% of those with a record of the test being done scored 9–13 and 27% scoring 14 and above, yet, less than one third of the residents with high scores were monitored by the staff following the assessment and only 18% of residents with high scores were referred for further assessment of depression, while 10% received a treatment change.

Conclusions: The absence of a protocol for responding to high Cornell Scale scores limited the potential of this program to result in widespread improved treatment of depressed older people. The use of the Cornell Scale by aged care nurses with limited training raised concern (Davison, et al.).

Source: Davison, T., Snowdon, J., Castle, N., McCabe, M., Mellor, D., Karantzas, G., & Allan, J 2010 DOI: 10.1111/j.1741-6612.2010.00450.x <https://doi.org/10.1017/S1041610211002146>

England

In regards to decreasing the use of antipsychotics among people with dementia, please refer to this study and trends:

Trends in diagnosis and treatment for people with dementia in the UK from 2005 to 2015: a longitudinal retrospective cohort study

Summary

Background: The objectives of this study were to describe changes in the proportion of people diagnosed with dementia and the pharmacological treatments prescribed to them over a 10 year

period from 2005 to 2015 at a time of UK policy strategies and prioritisation of dementia. We aimed to explore the potential impact of policy on dementia care.

Methods: In this longitudinal retrospective cohort study, we included all patients registered at a Clinical Practice Research Datalink (CPRD) practice between July 1, 2005, and June 30, 2015, with a diagnosis of dementia defined using Read codes. The main outcomes were the number and proportion of acceptable patients, who met the CPRD threshold for data quality, in a GP practice defined by the CPRD as contributing up-to-standard data with a diagnosis of dementia and the number and proportion of these with a prescription for an antidementia or antipsychotic medication. We examined the prevalence of dementia diagnosis and prescribing by calendar quarter, and stratified by age, sex, and UK country (England, Scotland, Wales, or Northern Ireland). We investigated the use of antidementia drugs, alone and in combination, antipsychotics, antidepressants, anxiolytics, and hypnotics. The trend in the proportion of patients with a diagnosis of dementia, before and after the introduction of the UK National Dementia Strategy, was estimated using an interrupted time-series analysis.

Findings: 8 966 224 patients were identified in the CPRD whose most recent registration period overlapped the study period. Of these, 128 249 (1.4%) had a diagnosis of dementia before the end of the study period. The proportion of people diagnosed with dementia in the UK doubled from 0.42% (19 635 of 4 640 290 participants) in 2005 to 0.82% (25 925 of 31 597 54 participants) in 2015. The proportion of those who received antidementia medication increased from 15.0% (2942 of 19 635) to 36.3% (9406 of 25 925). The interrupted time-series analysis showed a significant acceleration in the rate of diagnosis of dementia after the introduction of the UK National Dementia Strategy ($p < 0.0001$). There was a large reduction in antipsychotic drug prescription in dementia from 22.1% (4347 of 19 635) in 2005 to 11.4% (2943 of 25 925) by 2015.

Over the 10 years studied, there is evidence of a sustained positive change in diagnosis rates of dementia and in the quality of drug treatment provided to those diagnosed. The prescription of antidementia drugs more than doubled and the prescription of potentially hazardous antipsychotics halved after the introduction of national dementia strategies. These data support the formulation and delivery of national policy to improve the quality of care for people with dementia (Donegan, et al., 2017).

France

“Improving residential care for better quality of life for Alzheimer’s disease sufferers” is Objective 5 in France’s National Plan, followed by Objective 6, “Recognising skills and developing training for health professionals”. The following measures under these objectives are germane to long term care services and support (an EHPAD, établissement d’hébergement pour personnes âgées dépendantes, is a nursing home):

- Creating or identifying specific units for patients suffering from behavioural problems within EHPADs
- Creating specialized units within health care rehabilitation and follow-up (SSR) departments for Alzheimer’s patients
- Accommodation for young patients
- Identifying a national reference centre for young Alzheimer’s patients
- A specific career and skills development plan for Alzheimer’s disease

Per the report:

Currently, on the basis of a survey of registered institutions, 6,100 receive Alzheimer’s patients, and 1,135 declare that they have a specialist units (representing a capacity of more than 18,000), although many impose restrictions on accepting people with behavioural problems. In order to deal with the length of waiting times for EHPAD places, and the lack of capacity in these establishments to offer differentiated, evolving care according to the seriousness of the patient’s condition, two challenges must be faced: continuing to create places, reducing disparities between regions, and the need to adapt the ways in which EHPADs is organised to deal with the specific needs of Alzheimer’s sufferers, as this is the only way to avoid repeated hospitalisation.

The Plan indicates an incentive for creating these Alzheimer-friendly EHPADs (nursing homes), through:

An “Alzheimer’s architecture prize” to reward the most innovative EHPADs. The prize will emphasise the advantages of thinking about architectural quality in caring for Alzheimer’s patients.”

Training for dementia care personnel, including a new dementia-specific position/qualification, was noted in this Alzheimer Europe update of the French plan:

In 2011, 86% of the structures that accepted people with dementia at entry point provided their staff with some specific training to help them care for these people (Fontaine et al., 2012).

- The staff members that provide home care, nurses in EHPAD and psychologists can access short training courses (2-5 days) or longer courses (10-15 days)
- In order to offer a professional qualification to the auxiliary nurses and the psycho-medico staff who are already employed in a structure dealing with people with dementia, a new qualification has been created within the Alzheimer Plan 2008-2012; gerontology care assistant (Assistant de Soins en Gériatrie). This 140-hour training does not deliver any diploma, but a EUR 90 bonus each month.
- Any employee working with people with dementia can also train as an auxiliary medico-psychologist and get a state diploma. France Alzheimer provides this training which includes some 500 hours of theory including 140 hours specific to the care of a person with dementia.
- Finally, the Alzheimer Plan 2008-2012 has included the training of an additional 2,000 occupational therapists and psychomotor therapists. An information document directed to these professionals spells out the evaluation and the modalities of re-adaptation and care likely to be carried out in the home of a person with dementia (Haute Autorité de Santé/French Health Authority, 2010) (France 2013: National policies covering the care and support of people with dementia and their carers, 2014).

Another measure of France’s *National plan for Alzheimer and related diseases 2008-2012*, focuses on “improving correct use of drugs” and ties in well to long term care supports:

Improving correct use of drugs

Patients suffering from Alzheimer’s disease are particularly sensitive to drugs, and particularly psychotropic drugs. They are frequently prescribed psychotropic medication, due in particular to the behavioural problems that arise in certain phases of the disease and associated pathologies. The risks of addiction and drug-related accidents are thus considerable. To deal with behavioural problems, sedative medication, although raising many questions, can nevertheless prove indispensable in certain specific cases. However, there are no data in the literature that would enable a particular class of medication to be recommended for these patients. The risk of iatrogenic accidents and of accelerating the disease’s development with certain psychotropic drugs makes the use of such medication highly complex.

The objective is to improve the quality of practice and the use of psychotropic drugs in dealing with this disease by:

Drafting clinical practice recommendations about sedation for dealing with behavioural problems in difficult situations and how to handle behavioural problems. Drafting and circulating programmes to evaluate and improve professional practice in the effective use of medication, including psychotropic drugs, in elderly patients including those suffering from Alzheimer’s disease. Implementation details setting up a working group responsible for drafting recommendations.

The evaluation will depend on the degree of participation by professionals in training and improvement in their practice, as well as the reduction in consumption of psychotropic drugs (regular monitoring of indicators)

Antipsychotic prescribing for Alzheimer’s disease and related disorders in specialized settings from 2010 to 2014 in France: a repeated cross-sectional study (Tifratene, Manera, Fabre, Gros, & al., 2017)

This study investigated prevalence, correlations and trends of antipsychotic prescribing among people with dementia between 2010 and 2014 in France. An increase in antipsychotic prescribing

among individuals with dementia in French specialized settings over the last five years has occurred despite safety warnings, suggesting that alternative solutions for the management of behavioural and psychiatric symptoms in these populations are urgently needed.

Source: <https://www.alz.co.uk/sites/default/files/plans/Alzheimer-Plan-2008-2012-France-ENG.pdf>

Norway

Norway's National Dementia Plan (a part of Care Plan 2015) includes an objective (1.2) for creating living facilities better adapted to people with dementia. Professor Knut Engedal, in his book *Aldring og hjernesykdomer* (Ageing and brain disorders), describes the need this way:

"We need different living arrangements for patients with dementia. In many ways the principle for residential facilities of this type is the same as the one found in sheltered units in nursing homes – 'small is beautiful'. That is, residential units are set up to accommodate six to eight residents, and patients with dementia are offered the chance to participate in ordinary everyday activities.

Institutionalisation can easily lead to passivity precisely because passivity, forgetfulness and a lack of ability to plan are part of the dementia disorder. It is our experience from studies as well as practice that getting the patient with dementia active pays off. Stimulation through everyday activities can have a very beneficial effect on behaviour, and we recommend that all institutional units that provide care to dementia patients emphasise a programme based on just those activities that daily life presents. The degree of difficulty needs to be tailored to the remaining resources the patient possesses."

As this plan objective continues:

"At the same time, everything that is built or modernised with financing through the Norwegian State Housing Bank's grant scheme for nursing homes and assisted living facilities should be adapted to persons with dementia. This means that small-scale communal living arrangements and wards with programmed activities and direct access to adapted outdoor areas are better than old-fashioned multi-storey institutions with large wards and long corridors.

A dementia disorder means impairments in memory, attention, orientation in time and place and understanding of space and direction. The optimal framework for such patients is small living groups in an easily navigated physical environment with only a few residents (four to eight persons) and a stable staff with the necessary knowledge and skills. There are not many studies in Norway and the Nordic region that have evaluated such adapted living environments.

In professional circles, however, there is agreement that new institutions and assisted living facilities should in principle be constructed as small living groups with stable staffing. Shared social activities and direct access to adapted outdoor areas should also be provided for. Persons with dementia who have behavioural problems specially need adapted services in small and reinforced units. In this area skills development and collaboration between professions and municipalities are necessary."

Under the four-year action programme heading in *Norway's Care Plan 2020*, a commitment to capacity growth follows in the form of investment grants for modernised care facilities:

"There is an exciting development taking place in the municipalities in which the rooms in nursing homes are beginning to resemble actual homes and today's residential care homes are being built together and used both as a supplement and as an alternative to nursing homes. Soon it will not be possible to see the difference between small, modern nursing home units with a high living standard and local living and service centres with separate residences. There are now nursing homes with a private housing standard and residential care homes with nursing home services. When seeking answers to future challenges, there are good reasons to continue and reinforce this trend, rather than returning to the cumbersome institutional solutions of the 1980s. The Government wishes to take the best from the two different traditions."

Meld. St. 29 (2012–2013) Future Care, white paper from the Ministry of Health and Care Services <https://www.regjeringen.no/contentassets/34c8183cc5cd43e2bd341e34e326dbd8/en-gb/pdfs/stm201220130029000engpdfs.pdf>

USA

In the USA's 2016 National Alzheimer Project Act 2016 Update, a relevant objective/practice worthy is that of the National Partnership to Improve Dementia Care in Nursing Homes.

"The focus of the National Partnership to Improve Dementia Care in Nursing Homes remains on the improvement of comprehensive dementia care in nursing homes across the country. In September 2014, the National Partnership, a public-private coalition, established a new national goal of reducing the use of antipsychotic medications in long-stay nursing home residents by 25% by the end of 2015, and 30% by the end of 2016. The partnership continues to report progress quarterly, both nationally and regionally. The Partnership's larger mission is to enhance the use of non-pharmacological approaches and person-centred dementia care practices. The Centers for Medicare and Medicaid Services (a government health financing agency) (CMS) is monitoring the reduction of antipsychotics, and the possible consequences, reviewing residents whose antipsychotics are withdrawn to make sure they do not suffer an unnecessary decline, monitoring antipsychotic measures for the calculations that CMS makes for each nursing home's rating on Nursing Home Compare; the agency's public reporting website."

The updated report from the *Centers for Medicare & Medicaid Services (CMS) National Partnership to Improve Dementia Care in Nursing Homes: 2014 Quarter 2 – 2015 Quarter 3*, released in June 2016, offers more insight into current promising practices:

- Each State has a coalition that serves as a clearinghouse for activities, tools and resources around dementia care in nursing homes for their State. These groups, many of which continue to be led or co-led by the State's Quality Innovation Network-Quality Improvement Organization (QIN-QIO), coordinate educational programs, develop tools and resources, and conduct outreach to facilities that continue to have high rates of antipsychotic medication use. CMS continues to support the efforts of each State Coalition.
- CMS continues to conduct national provider calls through MLN Connects®. These quarterly calls help to broaden discussions related to quality of life, quality of care and safety issues. They target consumer and advocacy groups, nursing home providers, the surveyor community, prescribers, professional associations, and other interested stakeholders. Beginning in 2015, the Quality Assurance and Performance Improvement (QAPI) program teamed up with the National Partnership to co-facilitate these calls. QAPI standards expand the level and scope of quality activities to ensure that nursing homes continuously identify, correct quality deficiencies and sustain performance improvement.
- In 2014, CMS launched a call for proposals to utilize Federal CMP [Civil Money Penalty] Funds for the support and further expansion of the National Partnership to Improve Dementia Care in Nursing Homes. Proposed projects were expected to directly benefit nursing home residents, build on the existing work of the National Partnership, and provide innovative and unique strategies for the safe reduction of antipsychotic medications for individuals with dementia. The Eden Alternative, Inc. was awarded a grant for their project entitled "Creating a Culture of Person-Directed Dementia Care." Their project consists of a multi-state, interdisciplinary initiative combining in-person and online group education, self-directed learning and application, implementation resources, and the opportunity to engage with other US nursing homes in the pursuit of best practices. The goal is to support the continued reduction of antipsychotic medications through person-directed care practices that redefine perceptions of and approaches to dementia care (Centers for Medicare and Medicaid Services, 2016).

Per *The National Partnership to Improve Dementia Care in Nursing Homes: Antipsychotic Medication Use Trend Update*, "CMS is tracking the progress of the Partnership by reviewing publicly reported measures. The official measure of the Partnership is the percentage of long-stay nursing home residents who are receiving an antipsychotic medication, excluding those residents diagnosed with schizophrenia, Huntington's Disease or Tourette's Syndrome. At the end of 2011, 23.9 percent of long-stay nursing home residents were receiving an antipsychotic medication; since then there has been a decrease of 28.8 percent, to a national prevalence of 17.0 percent at the end of 2015. Success has varied by State and CMS region, with some having seen a reduction of greater than 25 percent (National Health Quality Campaign, 2016)."

Source: <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html> and https://www.nhqualitycampaign.org/files/AP_package_20160505.pdf

CHAPTER 6

Improving health care: Hospital care initiatives

Whether an individual with dementia is living at home or in a residential care setting, there may come a time when hospitalisation is necessary. Unfortunately, people with dementia frequently experience too many hospitalisations. In fact, a recent USA cohort study mentioned in the *World Alzheimer Report 2016: Improving Health Care for People Living with Dementia* suggested hospital admission rates were 419 per 1000 person years for people with dementia, compared to 200 per 1000 person years for similarly aged controls.

Source: <https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf>, p.59

Unnecessary hospitalisations - and repeated admissions - have unfortunately become a recurring theme in the dementia population. Both can be prevented, and every effort to do so should be made. The delirium, agitation, and dysregulation that so often occurs during and after a hospital stay typically translates to setbacks instead of progress forward.

Another critical component of improving hospital-based care and services for people with dementia is accessing community-based supports and follow-up care upon discharge. When the person is released from the hospital and returns to the community, the days following discharge are crucial for both the individual and carer. If the necessary support is not in place and care is not thoughtfully coordinated, readmission is more likely to occur.

Effective, streamlined communication and care coordination between the hospital, care providers and community-based providers leads to greater success post-discharge. Unfortunately, this is not yet the norm.

Physicians and other hospital care providers must recognise the primary carer and gather as much information for making informed decisions. Advocacy for individuals with dementia in hospital settings is vital, but providers must be open to listening - and taking action.

The following pages will show some promising hospital care initiatives in Australia, England, France, Scotland and Wales.

Australia

Australia's National 2006-2010 Framework for Action on Dementia recognises that a diagnosis of dementia in the hospital setting is critical to providing adequate care and minimising adverse outcomes. Despite the importance of a diagnosis, a study of 20,748 people with dementia commissioned by the Australian Institute of Health and Welfare found that 47% of participants were not given a principle or additional diagnosis of dementia by hospital staff. Without a diagnosis of dementia, hospital staff may not know how to care effectively for the patient and cannot develop care pathways aimed at minimising complications and improving outcomes. In order to promote the inclusion of dementia in a patient's hospital record, the Victoria government implemented a bed-based cognitive impairment identifier graphic initiative. The initiative was intended to alert the staff of a patient's cognitive impairment and an evaluation of the programme found that 80% of staff felt the identifier improved the quality of care offered to the patient and 40% found it improved their response to carers. While the cognitive impairment identifier graphic initiative only benefits patients with a standing diagnosis of dementia, the initiative's evaluation clearly demonstrates how a diagnosis of dementia in the hospital setting can improve care dramatically (Baker, Hospital Care for Persons with Dementia: An Evaluation of National Dementia Strategies, 2013).

England

England's National Dementia Strategy recognises that diagnostic improvements are important while simultaneously presenting a clear plan for improving the quality of care for people with dementia in general hospitals. Through demanding defined leadership roles, care pathways for patients with dementia, and commissioning specialist liaisons for older people's mental health, England has created a system of accountability and progress. Since the release of the *National Dementia Strategy* in 2009, the Department of Health has partnered with the Royal College of Nursing Foundation to help bring about tangible change in hospitals. One of many notable achievements of this partnership

comes from the Elsing Ward of Norfolk and Norwich University Hospital. Elsing Ward is a 37-bedded hospital ward that caters specifically to elderly patients and is where most people with dementia in the hospital are placed. In an effort to improve staff knowledge of dementia as well as to provide personalised care for patients, the ward appointed a registered mental health nurse and all staff underwent dementia awareness training and learned how to prevent and manage aggression. Elsing Ward is now recognised by the Royal College of Nursing Foundation as a best practice example. It is a clear demonstration of how creating systems of accountability can help provide for improved care of people with dementia in the hospital setting (Baker, Hospital Care for Persons with Dementia: An Evaluation of National Dementia Strategies, 2013).

France

The French government's *2008-2012 National Alzheimer's plan* is person-centred. In the context of hospital care it focuses on improving emergency care. Emergency situations place additional strains on people with dementia, family carers and health care professionals. It can also adversely affect the quality and continuity of care. An innovative component of the plan is the development of Alzheimer's patient information cards that are designed to streamline care and minimise negative outcomes. The card is an informational tool that can provide critical information, care techniques and details of care for people with dementia in emergency situations to health professionals, carers and patients. Since 2008, the French government has allocated over €280,000 for the development of the cards and now more than 17,300 cards are in use. The Alzheimer's patient information card is an example of an innovative yet simple measure that can be developed to improve hospital care for people with dementia (Baker, 2013).

Scotland

Scotland's first *National Dementia Strategy* in 2010 prioritised finding alternatives to hospital admission. The current economic climate in Scotland demands that resources for patients with dementia are effectively and efficiently utilised. As such, the development of programmes that minimise costly hospital admissions is crucial. The Enhanced Assessment and Support Team in North East Fife is an example of an initiative that effectively provides care and assessment for people with dementia while minimising hospital admissions and improving outcomes. The team operates out of a local health centre and is comprised of qualified practitioners who work to keep people with dementia living in their local communities. Initial studies suggest that outcomes for people with dementia and their carers have improved, patients with dementia have used fewer inpatient beds, and the length of stay at hospitals has been reduced since the development of the team. Through providing assessment and care management services to people with dementia in the local community, the team demonstrates that the objectives of the National Dementia Strategy are feasible and that tangible change is possible.

Improving care in hospitals was the second of two key improvement areas in the first Dementia Strategy. The challenge remains to ensure that, when admission to acute general hospitals is unavoidable for people with dementia, they experience, on every occasion, safe, effective, dignified and person-centred care (Scottish Government, 2013).

In 2008/9 a demonstration site in Midlothian showed that people with dementia accounted for 20.4% of the occupied bed days used by people aged over 65, even though they only accounted for 5.4% of the total population over 65. As the number of people with dementia increases, the Midlothian site recognised the need to do more work to understand why people with dementia are admitted to hospital and take more action on key areas such as unscheduled care, patient flow and delayed discharge. Their objective is twofold: (1) to make the current system of care in hospital work better for people with dementia in ensuring better quality of care and (2) to begin to look at how to remodel the wider system of care, including care in hospital to best provide acute health care for people with dementia in a way which keeps them at home wherever possible and which ensures they are discharged from hospital safely and timeously. The wider context for this work is, of course, the integration of health and social care.

In recent years there has been a significant investment in the capacity and capability of staff in hospitals, including the training of over 600 Dementia Champions in line with the skills framework set out in Promoting Excellence and the Scottish Government's support of the appointment to each NHS Board of an Alzheimer Scotland Dementia Nurse Consultant. In addition, some Boards have also appointed an Alzheimer Scotland Allied Health Professional. These dementia specialists

are making good progress and they support the prioritisation given by the Scottish Government to older people's care since 2011. This prioritisation has led to a number of actions, including: work on implementing the Standards of Care for Dementia in Scotland; the programme of inspections into older people's care in acute hospitals by Healthcare Improvement Scotland and resultant Board Action Plans; and the associated national "Improving Care for Older People in Acute Care Programme" led by the Chief Nursing Officer. The Dementia Dialogue process included discussions about acute care and also a national event specifically on care in these settings. The findings of these meetings reinforced the need to retain hospital care as a key change area and to consolidate and build upon the work taken forward since 2010, but also to identify areas where additional support and leverage is needed.

In January 2012, an expert Dementia Standards in Hospitals Implementation and Monitoring Group (IMG) was set up. Chaired by the Chief Nursing Officer it included representation from key partners such as Alzheimer Scotland, Healthcare Improvement Scotland, the Mental Welfare Commission, clinicians and healthcare services. A major part of this group's work is to scrutinise all the evidence in relation to dementia care in hospitals in order to provide information on progress at national level, to highlight and learn from examples of best practice and, where areas for improvement were identified, to provide expert support and guidance (Scottish Government 2013).

Source: <http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/Implementation-Monitoring-Group>

Wales

The Welsh government's *National Dementia Vision 2011* aims to create dementia friendly communities where dementia leadership exists in all sectors of society and local communities work actively to develop alternatives to hospital admittance. A key factor in developing dementia friendly communities is raising awareness and improving training within hospitals.

The Wrexham Maelor hospital in Wales has recognised the importance of improving care for people in the hospital's wards and has utilised local initiatives like the *1000+ lives programme* to become one of the nation's leaders in hospital care. The *1000+ lives programme* is dedicated to improving the quality of life and care for people with dementia. A key target area is improving the value of general hospital care for people with dementia and reducing length of stay.

To help facilitate this goal, the programme has developed a "how to" guide for improving dementia care in hospitals. It has determined that identification of dementia upon admission, improved care planning and implementation of care plans are essential for improvement. The Wrexham Maelor hospital has adopted these principles and has stated that adequate training, support and teamwork as well as maintaining the interest of staff is critical in ensuring programme sustainability. The partnership between the Wrexham Maelor hospital and *1000+ lives programme* demonstrates the importance of multi-sector collaboration in developing dementia friendly communities and that improvement is possible (Baker, Hospital Care for Persons with Dementia: An Evaluation of National Dementia Strategies, 2013).

CHAPTER 7

Brain health promotion

Infographic Source: Alzheimer's Disease International <https://visual.ly/community/infographic/can-we-reduce-risk-dementia>

Alongside research aimed at finding a cure it is increasingly important to increase awareness of brain health, risk reduction and prevention.

Awareness campaigns are tasked primarily with educating the general public about dementia, teaching citizens to know the warning signs, how to acquire an accurate diagnosis and access community supports and health services. Brain health promotion activities are centred on prevention and what each individual can do to maintain brain health for as long as possible.

By inspiring individuals to reduce their risk, the aim is risk reduction for the population at large. According to the *World Alzheimer Report 2014: Dementia and Risk Reduction*, brain health promotion messages should be integrated in public health promotion campaigns (such as anti-tobacco or non-communicable disease awareness), reminding citizens it is never too late to make changes and that “what’s good for your heart is good for your brain” (Prince, Albanese, Guerchet, & Prina, 2014).

Dementia prevention and risk reduction must therefore be included in national non-communicable disease (NCD) planning and within the WHO Global Action Plan on Dementia. The ADI report suggests modifiable risk factors in these four key domains: developmental, psychological and psychosocial, lifestyle, and cardiovascular.

The following are examples of what Australia, England, Finland and the USA are doing in the practice area of brain health promotion.

Australia

Per *Australia's National Framework 2009-2014 Objective 1.2 Tailored Evidence-Based Approaches*, “Risk reduction and awareness strategies should be evidence-based and seek to improve and build on the current body



of evidence. Messages about risk reduction and dementia awareness must be easy to read and encourage the public to seek further information and help if needed.”

The *Your Brain Matters* national campaign includes a brain health checklist, brain busters quizzes, a 21-day healthy brain pledge; 5 steps guide to maximising brain health, a “brainy app,” and more downloadable resources (Your Brain Matters: The Power of Prevention , n.d.).



Source: <https://www.yourbrainmatters.org.au>

England

In England's *National Dementia Strategy: Living Well with Dementia*, the following objective corresponds to the push for brain health promotion:

Objective 1: Improving public and professional awareness and understanding of dementia.

Public and professional awareness and understanding of dementia have to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

While a national campaign has not yet launched, the *Blackfriars Consensus Statement*, issued in May 2014, called for a new policy to focus on risk reduction:

Fifty-nine organisations and experts from across the dementia and public health community, including practitioners and researchers, have signed the consensus statement which is accompanied by a correspondence in The Lancet. The agreement, known as the Blackfriars Consensus Statement, highlights the need for a new national focus on dementia risk reduction. It was drawn up following a meeting held earlier this year by the UK Health Forum and Public Health England (PHE) in Blackfriars, London. <https://www.gov.uk/government/news/call-for-new-policy-focus-on-brain-health-to-reduce-the-risk-of-dementia>

The Blackfriars Consensus Statement says that the scientific evidence on dementia risk reduction is evolving rapidly and is now sufficient to justify action to incorporate dementia risk reduction into health policies and to raise wider awareness about which factors can reduce the risk of developing dementia. The Statement is launched during Dementia Awareness Week (19 to 24 May 2014) and is intended to help raise awareness among policy makers and the wider health and care workforce as well as the public that dementia is amenable to risk reduction in similar ways to other non-communicable diseases (Public Health England, 2014).

Finland

The Finnish National Plan encourages “TARGET 2020” which focuses on brain health promotion:

“Brain health promotion has been factored into all sectors of society. Health promotion, including the promotion of brain health, is an integral part of the strategies of local authorities and joint authorities and consequently reflected in local and joint authority action plans and budgets. The effectiveness of the strategies is measured systematically. Public awareness about brain health has increased, and people are supported in their efforts to keep their brain healthy. Social welfare and health care professionals are more knowledgeable about brain health and better able to promote their customers’ mental well-being. Problems resulting from work-related stress are identified earlier and proactive intervention is provided (Ministry of Social Affairs and Health, 2013).”

The *Life is Cool with Fit Brains* project aims to promote teenagers’ knowledge about the issues that affect their learning capability and the good condition of brain and memory. Five associations with the Alzheimer Society of Finland participated in the campaign in 2014-2015.

“Life is Cool with Fit Brains” Campaign Goals and Target Audiences:

- Add a brain health promotion perspective to school health education programs
- Campaigns emphasize importance of cooperation between people with different occupations, in school world and NGOs
- 6 lower secondary schools in five different municipalities
- More than 600 hundred pupils participated
- Six different campaigns

• THE LECTURES • How does your brain work • How does your memory work • How do you learn and study more effectively • How does your lifestyle and the choices you make influence your brain health and well-being	• THE GROUP WORKS • Memory strategies • Nutrition • Alcohol, cigarettes and drugs • Depression and stress • Sleep • Physical exercise • Social relationships
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IMAGE SOURCE SLIDE 6: http://www.muistiliitto.fi/files/8313/7645/8763/Life_is_Cool_with_Fit_Brains.pdf

The methods of the campaign

- Questionnaires held out before and after the campaign
- A lecture on brain health, memory and learning strategies
- Group works
- Website: www.timmitaivot.fi
- Post cards and post it notes

Results from the campaign showed a small increase in the students’ knowledge about brain health after the lectures and workshops. The research showed that teenagers are interested in the well-being of their brains but they did not pay much attention to the questions. A key conclusion was how important it is to pay attention to both the message and how it is delivered.

USA

The *National Alzheimer's Plan Act* (NAPA), of the USA puts risk reduction under "Goal 1: Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025." To that end, the following initiatives demonstrate the federal government's commitment to brain health promotion for the purpose of prevention and risk modification.

The Centers for Disease Control, in collaboration with the National Institutes of Health, released the baseline data for the *Healthy People 2020* topic areas, *Dementias Including Alzheimer's Disease*. Additionally, the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Administration for Community Living (ACL), and Centers for Medicare and Medicaid (CMS) participated in the *Healthy People 2020 Progress Review on Older Adults and Dementias, Including Alzheimer's Disease* (Healthy People 2020).

The CDC *Healthy Brain Initiative* is now testing messaging on brain health for specific sub audiences, and in several states implementing public health campaigns on dementia risk reduction with validated messages. An example is a pledge based campaign in South Carolina (South Carolina Department of Health and Environmental Control (SDHEC)) - <http://www.scdhec.gov/Health/DiseasesandConditions/Alzheimers/TakeBrainHealthToHeart/TakeThePledge/>.

As mentioned in the NAPA update, the USA has also devoted some basic research funding to disease prevention, such as the following study:

Lifestyle Alzheimer's Disease Prevention

NIH is studying whether lifestyle interventions, such as diet, exercise, and cognitive enrichment, may be preventive interventions for cognitive decline and AD/ABD. Currently, five NIH-funded clinical trials are underway to test whether exercise can influence Alzheimer's onset and progression. For example, one active study is currently recruiting participants and using brain imaging and cognitive measures to investigate the effects of cycling on cognition and hippocampal volume. Being obese or overweight in middle age has been linked to increased risk of dementia. The findings suggest that maintaining a healthy BMI at midlife might be considered as one way to delay the onset of Alzheimer's. National Institute on Ageing has recently funded a Phase III randomized controlled trial designed to test the effects of a 3-year intervention of a hybrid of the Mediterranean and dietary approaches to stop hypertension (DASH) diets, called MIND, on cognitive decline. This intervention will be tested among 600 individuals 65+ years of age without cognitive impairment who are overweight and have suboptimal diets that may place them at risk for developing dementia.

For more information, visit <https://clinicaltrials.gov/ct2/show/NCT01954550>

CHAPTER 8

Attention to people in particular settings and with special needs



Although Alzheimer's disease and related dementias do not discriminate, the impact of the disease on particular populations presents distinctive challenges requiring specific solutions. For these populations, accessing healthcare services, community supports, diagnosis, treatment or education is more complicated.

The World Health Organization's report, *Dementia: A Public Health Priority 2012*, called for the consideration of distinct populations within national plans, such as adults with intellectual and developmental disabilities (IDD) and Down syndrome. However, per an ADI report, *Intellectual and Developmental Disabilities and Dementia in National and Sub-National Dementia Plans*, 28 plans (out of 79), mention dementia and IDD. Many of those plans are based in the USA. Additional countries with language around IDD and dementia are Australia, England, Germany, Ireland, Northern Ireland, Norway, Scotland, Switzerland and Wales.

Beyond those dually diagnosed with dementia and IDD, other populations include those with young onset Alzheimer's, those with Alzheimer's and Down Syndrome, ethnic minorities and refugee groups and indigenous population, often remotely located. National plans have considered the challenges of these unique individuals and their carers. While several have implemented actions for one or more of these populations, there was no country that has covered all of them.

The following pages show examples from Australia, England, France, Norway, and the USA.

Australia

In the *Australian National Plan* (National Framework for Action on Dementia 2015-2019, 2015), there is reference to people with dementia and intellectual disabilities and those from indigenous or other special populations, as per the below:

- "People with physical and intellectual disabilities are increasingly surviving to older age and therefore are vulnerable to age-associated disorders such as dementia. It is reported that one in five people, with an intellectual disability, aged 65 and older, have dementia."

- “There are challenges associated with achieving an accurate diagnosis in some population groups, including but not limited to people with an intellectual disability, people from CALD (Culturally and Linguistically Diverse) backgrounds, and Aboriginal and Torres Strait Islander people.”
- “Planning for diversity: meets the expectation that department-funded programs should provide a flexible response for individual and diverse needs and preferences, including those of people of diverse backgrounds, such as Aboriginal and CALD communities; people with intellectual disabilities; people who identify as gay, lesbian, bisexual, transgender or intersex; and younger people with dementia” (p. 41).
- “Older people are not a homogenous group. Needs and preferences for support and services may vary among people from diverse backgrounds, for example, Aboriginal and CALD communities; people with intellectual disabilities; people who identify as gay, lesbian, bisexual, transgender or intersex (GLBTI); and younger people with dementia” (p. 41).

Source: https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/09_2015/national-framework-for-action-on-dementia-2015-2019.pdf

Aboriginal Disability Justice Campaign (ADJC)

The ADJC is made up of agencies and individuals who are concerned about the incarceration of Aboriginal people with cognitive impairments, such as intellectual disability, acquired brain injury and psychosocial disability, who commit crimes or are considered a risk of harm to others.

A wide range of organisations are involved, including: Australian Lawyers for Human Rights Northern Territory, Blake Dawson Legal Firm of Sydney, Brain Injury Australia, and the Central Australian Aboriginal Legal Aid Service.

The example which has the most impact on the human rights of people with cognitive impairments, and the current focus of the Aboriginal Disability Justice Campaign (ADJC) is the Northern Territory. In the Northern Territory, Aboriginal people with a cognitive impairment who are found mentally impaired (under part IIA of the NT Criminal Code) are incarcerated in maximum-security jails in both Darwin and Alice Springs.

In summary, here are several statements (not an exhaustive list) from the Aboriginal Disability Justice Campaign:

- Aboriginal people with a cognitive impairment are being unfairly incarcerated in maximum-security jails
- That the Northern Territory is not providing a range of custodial and non-custodial options for Aboriginal people with a cognitive impairment who have offending histories
- There is no treatment of significant benefit for Aboriginal people with a cognitive impairment who are being incarcerated in maximum-security jails

The Campaign seeks to implement many principles; a few are listed here:

- You cannot imprison people with an Intellectual Disability/Acquired Brain Injury in a maximum-security prison when they have not been found guilty of a crime
- Specific amendments to Disability Act and the Mental Health Act outlining the principles and mechanisms by which people with a cognitive impairment who commit crimes or are assessed as a risk to the community are detained
- Custodial or non-custodial options that restrict the freedoms of people with a cognitive impairment with offending histories have at their core treatment that is of significant benefit
- An ‘independent of government’ guardianship service that is better funded
- Joint Management Committee between Department of Health and Department of Justice overseeing the development and implementation of a response (What We Do: Aboriginal Disability Justice Campaign).

England

The following update on England's approach to supporting special populations with dementia is from the ADI report, *Intellectual and Developmental Disabilities and Dementia in National and Sub-National Dementia Plans*:

"The draft strategy was very well received by the public and professionals alike, and the recommendations it set out were seen as being the right ones if dementia services are to fully meet the needs of people with dementia and their carers. Areas where changes have been made are: provision for people with learning disabilities; the need for better peer support networks; improved end of life care; housing for people with dementia; and the particular needs of people with early-onset dementia (people under 65 years of age) (p. 11).

In the second phase, between June and September 2008, the Department undertook a formal public consultation exercise on the draft proposals for the Strategy. This ensured that the views of diverse populations were taken into account in the development of the Strategy, including: younger people with dementia; people with learning disabilities; people from minority ethnic groups; people from rural and island communities; and older people in prisons (p. 18).

Services need to be able to work for the diverse groups of people who may be affected by dementia (p. 48).

Training should enable an understanding of the diversity in dementia, including younger people with dementia, those who have dementia and a learning disability, and those with particular needs from minority backgrounds (p. 66).

Effective commissioning for dementia involves a wide range of partners at strategic and operational levels. At all levels, commissioners need to take account of and appropriately prioritise [...] wider risk factors – targeting support for vulnerable groups who often suffer disproportionately poorer health outcomes, such as people with learning disabilities and dementia (p. 80) (Alzheimer's Disease International, 2016)"

Black, Minority Ethnic, and Refugee Populations (Truswell, 2011). This article examines the role of black, minority ethnic and refugee (BMER) communities in the implementation of the National Dementia Strategy in London. It highlights the work undertaken by the London Region Dementia Implementation Task Group to support commissioner engagement with BMER communities in planning dementia services and to help these communities to have more influence on the implementation of the National Dementia Strategy in London.

Source: https://www.researchgate.net/publication/254255643_Black_minority_ethnic_and_refugee_BMER_communities_and_the_National_Dementia_Strategy_the_London_experienceLink_Diversity_in_Health_and_Care_Volume_8_Number_2_June_2011_pp_113-1197

Understanding dementia: Effective information access from the Deaf community's perspective (Young, 2014). Concerns older deaf sign language users in the UK. The discussion demonstrates how these specific features of effective information access and awareness building have universal implications relevant to public engagement and the promotion of general knowledge consistent with the National Dementia Strategy of England.

Source: https://www.researchgate.net/publication/269172333_Understanding_dementia_Effective_information_access_from_the_Deaf_community%27s_perspective

France

France's National Plan includes two objectives and measures relevant to people with younger onset dementia.

Measure 18 Objective 2, Accommodation for Young Patients, reads as follows:

The first necessity is to take advantage of the study organised as part of the launch of the national centre for young Alzheimer's patients to find out the numbers and accommodation needs of these young patients. The second necessity is then to design better facilities and accommodation for young patients.

According to the results of the survey, units dedicated specifically to young patients will be created

within reference institutions.

To that end, the following partners launched a study in 2008 and adapted institutional plans to include these accommodations in 2009: Direction Générale de l'Action Sociale (DGAS) and Directorate of Hospitalization and Organization of Care (DHOS), in partnership with the national centre for young Alzheimer's patients (Centre national pour les malades Alzheimer jeunes).

Measure 19 of the National Plan also outlined the need for a national reference centre for young onset people with dementia. Portions of the objective and measure are shown below, supervised by DHOS and DGS, and launched in 2008:

To improve access to the diagnosis, the quality and the co-ordination of treatment for young patients by putting in place a care strategy that takes account of all the health problems affecting patients and aims to:

- Develop knowledge, particularly in epidemiology and the social sciences,
- Reinforce research, as the disease in young subjects constitutes an observation and analysis model enabling its genetic and physiopathological mechanisms to be better identified and innovative therapeutic methods to be imagined,
- Produce and distribute standards for good practice and shared tools to guarantee quality of care and to coordinate treatment across the whole territory.

Measure 19: Identifying a national reference centre for young Alzheimer's patients

a - Description of the measure

Identifying one or two national reference centres for young Alzheimer's patients among the newly funded network of diagnostic centres created in the French plan: Its mission will be to develop knowledge and organise care in the field of early-onset Alzheimer's disease, and—to name a few goals in particular—to:

- Optimise the diagnosis and provision of care for patients in the territory, in relation with existing care and treatment structures (memory centres, hospitals, EHPADs, independent medical professionals, occupational doctors etc.),
- Define standards for good practice and tools for organising the diagnosis and the provision of care at national level,
- Set up epidemiological monitoring by creating patient cohorts that can also serve as a basis for research projects,
- Develop information for patients, their families and health and social professionals,
- Train the health professionals and social partners involved,
- Ensure immediate voluntary access to any new therapy that might act on the evolution of a patient's disease and level of comfort.

b - Implementation details

- Specifications for the missions of the national centre to be drafted by a working group supervised by the DGS and the DHOS and bringing together representatives of health professionals, researchers, learned societies, patients' associations and the institutions concerned (HAS, the National Health and Medical Research Institute (Institut National de la Santé et de la Recherche Médicale, INSERM), CNRS),
- Launch of a DGS/DHOS call for bids procedure based on a set of specifications,
- Applications examined by a jury including independent national and international experts giving a consultative opinion to the Ministry of Health,
- Nomination of the centre by ministerial order for a period of five years, renewable according to the results of the evaluation (National plan for "Alzheimer and related diseases" 2008-2012, 2008).

Norway

In Norway's *Dementia Plan 2020* (Ministry of Health and Care Services, 2016), the following updates regarding people with dementia and ID, per the ADI report, *Intellectual and Developmental Disabilities and Dementia in National and Sub-National Dementia Plans* are as follows:

"Life expectancy for people with developmental disabilities has risen since the mid-1900s, which has resulted in a strong growth in the number of older people with developmental disabilities (Westergaard and Larsen 2004). Research has shown that people with these disabilities have a higher risk of developing dementia (Strydom et al. 2013). This will make additional demands on municipal services. The rehabilitation service, which is part of the specialist health services, plays an important role in the evaluation and diagnosis of people with developmental disabilities who develop symptoms of dementia. Evaluation in these cases is time-consuming, complex and requires special expertise.

It also requires close cooperation between those who know the person, the specialist undertaking the evaluation and the municipal health and care services (p. 22).

Older people with developmental disabilities in addition to dementia are particularly vulnerable; other people with special needs are individuals with a Sami or minority language background and younger people with dementia" (p. 29) (Alzheimer's Disease International, 2016).

USA

One source of information, or a resource for the inclusion of intellectual disability within a national plan, is drawing upon other plans. Some national plans include the issues of persons with intellectual disability with dementia. One example is the *My Thinker's Not Working* document created by the National Task Group on Intellectual Disabilities and Dementia Practices in the United States (National Task Group on Intellectual Disabilities and Dementia Practices, 2012). This document provides a wide-ranging analysis of the needs of adults with ID affected by dementia and includes a 20-goal plan for the development of services and addressing of needs. Other such documents exist elsewhere and can be used as a formulary for issue inclusion in general dementia plans.

The *International Summit Consensus Statement: Intellectual Disability Inclusion in National Dementia Plans* was released following the 2016 International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland on 13-14 October 2016. As per the document:

The Summit proposes that inclusive thoughtful planning on dementia must include this important subpopulation. In addition to the topics noted above, plans also should designate a policy home for persons dually affected, accurate census/surveillance of the numbers of persons affected and possible policy changes to empower the caregivers and services staff in becoming advocates and address barriers to health care. To make this happen, it is incumbent on disability organisations to prepare background matter and rationales for inclusion, as well as working with legislators and other elected officials to sensitise them to the disability constituency and promote inclusion of their concerns and needs in national dementia service delivery efforts at national and regional levels. (Watchman, et al., 2016).

The Indian Health Service (IHS) is taking steps to support carers from Tribal communities in the USA. Per a Department of Health and Human Services Statement (DHSS) from a Senate Special Committee on Aging Field Hearing:

"Care for persons with dementia and support for their families requires care coordination and care management often beyond the capacity of many IHS, Tribal, and Urban Indian health programs. These caregiving challenges are amplified by the relative lack of formal long-term services and supports in Indian Country. Prior to 2010, Tribes took the lead in using their own resources or grants, contracts or reimbursements from other federal and non-federal entities to provide long term services and support. The IHCA reauthorization in 2010 provided new authorities for long-term services and support to the IHS and to Tribes. The capacity of the local tribal and federal care systems to expand access to services remains a significant challenge to implementing these new authorities.

Our work on these goals builds on Indian Country strengths: strong families and a tradition of family caregiving, community-oriented primary care, committed and active public health nursing and community health representatives, and the Tribally operated aging network. The challenges in

rural and frontier settings require significant coordination and service integration efforts to improve the lives of those with dementia across the usual boundaries of clinical and community-based services.

The IHS works with multiple partners to improve care for those with dementia. The IHS and ACL are working with the Department of Veterans Affairs (VA) to adapt and implement the evidence-based REACH (Resources for Enhancing Alzheimer's Caregiver Health) VA program of caregiver support in Tribal communities through both public health nursing and the Tribal aging network. REACH VA is an evidence-based translation of the REACH II behavioural intervention that uses structured interventions to provide caregivers of individuals with dementia with the tools and skills to manage ongoing problems that arise in the course of caregiving. The IHS is building on VA work to test strategies for early recognition among family members as well as clinical and aging services staff. Participation in the VA Dementia Steering Committee links the IHS to the approaches and tools in use at the VA to improve dementia care. The VA is also a source of clinical expertise in diagnosis and management of dementia for the many Native Veterans who receive primary care in IHS and Tribal sites (Finke, 2014)."

Sources: https://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf and https://www.ihs.gov/newsroom/includes/themes/newihstheme/display_objects/documents/testimony/113/113th-August-13-2014.pdf

CHAPTER 9

Research funding and agendas

The ultimate goal of any dementia national plan is to become outdated and unnecessary, and in that regard, this final practice area is fitting. Indeed, a world without dementia is what every country wants, but until a cure is found, research funding fuels each nation's future hopes.

The worldwide cost of dementia was estimated at US \$818 billion per year, according to the World Alzheimer Report 2015. As the number of people with dementia increases, the costs will continue to rise. In addition, nearly 60% of the 47.5 million people living with dementia are in low- and middle-income countries.

These numbers only tell part of the story. The out-of-pocket financial costs - as well as the immense and non-quantitative emotional costs - are crushing informal caregiving systems around the world, in high, low, and middle-income countries alike. Some also experience loss of employment, debilitating depression and diminished health from the strain and intensity of dementia caregiving.

Investment in and prioritising of research is key in any dementia plan or strategy. This report offers examples from England, Netherlands, Norway, Scotland and the USA.

While not driven by national plans, we acknowledge that there are EU bilateral activities underway to address and advance the mission we all support: finding the cure for Alzheimer's and related dementias.

England

In February 2015, the UK Prime Minister published the successor to the 2012 challenge on dementia. *The Prime Minister's Challenge on Dementia 2020* focused on boosting research, improving care and raising public awareness about the condition in England.

The Prime Minister set two key objectives for the *Challenge on Dementia 2020*:

"By 2020 I want England to be:

- The best country in the world for dementia care and support for people with dementia, their carers and families to live; and
- The best place in the world to undertake research into dementia and other neurodegenerative diseases (Prime Minister's Challenge on dementia 2020, 2015)."

The Government committed to invest over £300 million into research and medical innovation, in order to back the country's science and medical sectors to lead the way in dementia research and medical trials (Baker & Parkin, 2016).

Prime Minister's Challenge on Dementia 2020: Implementation Plan (Research)

A great deal had been achieved during the first Prime Minister's Challenge and this has created a strong foundation to build on up to 2020. Government research funding doubled between 2012 and 2015, to over £60million a year. This money, alongside increased investment from charities and the private sector, was used to develop key infrastructure and research activity that has placed the UK at the forefront of dementia research.

The 2020 Challenge sets the ambition to see total research funding from all sources on track to double by 2025. We are delivering new research infrastructure to support and catalyse research, and so attract investment. We are supporting more people than ever before to be available to take part in research studies. Importantly, we are training new researchers and developing capacity across the spectrum of disciplines that need to be engaged. This strategy is transforming and expanding the field, to deliver better care and treatments.

Since March 2015 the Government has committed to a further £300million for funding for dementia research by 2020, and announced up to £150million for a Dementia Research Institute (DRI). The Government has also spearheaded the launch of the Dementia Discovery Fund a global investment fund that aims to invest over £130million on the early-stage development of potential treatments.

Engaging with the research community and people with dementia

Five key priority themes emerged during the engagement exercise:

- providing more opportunities for people with dementia and their carers to get involved in research.
- improving collaboration across the sector by creating new opportunities and improving communication.
- developing capacity in the field – ensuring a diverse, engaged researcher workforce to deliver the aspirations.
- providing coordination and alignment of current and future research initiatives.
- encouraging inter-disciplinary working and innovation in research.

There is significant activity in place or in the pipeline to deliver against these themes. This Implementation Plan ensures there is a coherent and sustainable strategy, to deliver benefits for people with dementia, their carers and the wider community. Initiatives across the research spectrum from basic research, through to translational and applied research have been funded such as the Medical Research Council, Dementias Platform UK (DPUK), NIHR Dementia Translational Research Collaboration, NIHR-ESRC investments in Living Well with Dementia, the Dementia Consortium, Alzheimer's Research UK Drug Discovery Institutes and the Alzheimer's Society Doctoral Training Centres (Department of Health, 2016).

Source: <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN07007>

Netherlands

Everybody in the Netherlands knows the 'Deltaplan', a series of dykes and waterworks that were built after the devastating North Sea flood in 1953. This was a 30-year, multibillion euro investment that led to a lot of engineer knowledge that is still useful in many parts of the world. The dementia epidemic being a 'flood' as well, the name *Deltaplan Dementie* was chosen for a national campaign to underline the urgency (Deltaplan Dementie) <https://deltaplاندementie.nl/en>

Deltaplan Dementie

The main elements of the plan are research funding, dementia care and support improvement and a campaign to make the society more dementia friendly:

- Research funding has increased significantly and in 2016 an amount of €32 million was made available. The research programme is linked to the EU Joint Programme – Neurodegenerative Disease Research (JPND).
- Implementation model is a public private partnership with the creation of a social enterprise with members, including Ministry of Health, payers (health insurers), corporate members (pharma, banks) and non-profit organizations. The enterprise gets funding from its members and has a budget itself of around €370,000 per year.

The ambition to lower the cost of dementia care in 2020 with 20% compared to estimated increase while increasing the research funding and the quality of care.

Three pillars have been created:

- National registry
- E-health portal
- A research programme MEMORABEL

Investment of €200 million over 8 years. For the first round of projects in 2016 €32 million was spent by the government with additional €5 million private funding. 79 projects were funded including 27 under JPND

A platform with all partners, public and private was created to discuss the work and this is at arms-length of the government with its own board.

Norway

Norway has a national dementia strategy. Page 16 of the national plan sets out the country's commitment to research funding:

Research efforts into dementia will be increased by NOK 5 million in 2008, which will primarily be channelled through the Research Council of Norway's programme for health and care services. The amount is part of the Government's overall increase of funding for care research totalling NOK 15 million in 2008 (Norwegian Ministry of Health and Care Services, 2015).

Researchers involved in the Norwegian Health Association's dementia research programme met in March 2017, to discuss processes and results midway. The programme, launched after the Norwegian Broadcasting Corporation's telethon in 2013, has received approximately €10 million. Themes covered in the programme are: research into the causes, prevention, diagnosis and treatment of dementia (Alzheimer Europe, 2017).

Sources: <https://www.ceafa.es/files/2017/05/NORUEGA.pdf> and <http://alzheimer-europe.org>

Scotland

As explained in Scotland's National Plan, the Scottish Government established the Dementia Clinical Research Network for Scotland from August 2008, with over £1 million of funding. This funding was extended to 2014.

The Scottish Dementia Clinical Research Network, together with Alzheimer Scotland, seek to enable people with dementia and their carers to become partners in research, including the opportunity to participate in early studies of potential treatments.

People living with dementia have a major role to play in bringing about change in dementia prevention, treatment and care by becoming partners in research. The Scottish Government will:

- strengthen research by continuing to support the Scottish Dementia Clinical Research Network to develop clinical dementia research capability and capacity.
- broaden support across a wide range of world class research teams from basic science through to social studies to integrate dementia research by working with the new Scottish Dementia Research Consortium to maximise the impact of and funding opportunities for research in Scotland.
- promote the use of world class Scottish Health Informatics, including record linkage, in dementia research.
- ensure that every person who is newly diagnosed with dementia is given the opportunity to be a partner in research.

The Scottish Dementia Research Consortium (SDRC) is a membership based organisation which aims to support the development and expansion of high quality, co-ordinated, collaborative dementia research throughout Scotland.

Membership of the SDRC is open to anyone with an interest in dementia research, planning to start a research project or currently involved in the dementia research community. People with dementia, their carers, partners and relatives who are interested in research, or who are already registered with the Scottish Dementia Clinical Research Network, can also join

Source: Alzheimer Scotland, 2016 http://www.alzscot.org/news_and_community/news/3548_be_part_of_a_driving_force_behind_dementia_research_across_scotland

USA

The first goal in the USA National Plan is focused on preventing and effectively treating dementia by 2025, these objectives are:

- Identify Research Priorities and Milestones
- Expand Research Aimed at Preventing and Treating Alzheimer's Disease
- Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease
- Coordinate Research with International Public and Private Entities
- Facilitate Translation of Findings into Medical Practice and Public Health Programs

The National Institute on Aging (NIA) at the National Institute of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Administration for Community Living (ACL) are collaborating on the Recruiting Older Adults into Research (ROAR) project (NIH/NIA, 2015) to encourage older adults and their family cares, including underrepresented populations, to participate in research. They are focussing on Alzheimer's and dementia research. For other organisations wishing to join the project they have created a toolkit (available in English, Spanish and Chinese) of easy-to-use, customisable materials that features information on:

- Why research is important to healthy ageing
- What volunteers need to know about research studies
- How older adults can make a difference by participating
- Easy steps to take

This 2017 press release from the Alzheimer's Association announced the \$400 million increase for the Alzheimer's budget at National Institutes of Health, bringing the total up to \$1.4 billion:

"Today, the Alzheimer's Association and the Alzheimer's Impact Movement (AIM) are celebrating the announcement that Congress will pass a \$400 million increase for Alzheimer's research funding at the National Institutes of Health (NIH) in the FY2017 budget. This marks the second consecutive year that Congress has approved a historic funding increase for Alzheimer's (Alzheimer's Association/Alzheimer's Impact Movement, 2017)."

Sources: <https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit> and http://www.alz.org/documents_custom/historic-funding-2017.pdf.

Concluding Remarks

The examples contained in this report are meant to be a source of insight for governments and associations in developing their own strategies, action plans and activities. The WHO Global action plan on dementia provides a framework for activities. Ongoing compilation and sharing of best practice can provide further inspiration.

This overview of some national Alzheimer's and dementia plans and related activities provides a range of lessons regarding the process of generating plans, as well as on the content of these plans and delivery of key actions:

- National dementia plans are a relatively new development and multiple agencies may be engaged in the development, implementation and outcomes of plans. Overall, there is not yet much information about the implementation of national plans. This might be related to a lack of resources to monitor implementation or the relatively short period of time over which actions have been deployed.
- Some plans are comprehensive; others focus on a few key areas. This is the case when they are following up on previous plans, for example in Japan, Netherlands and UK.
- Plans may be more successful in implementation when they have clear targets and reporting structures, for example the 2008-2012 plan by France. Further consideration should be given to measurement, reporting and fine tuning.
- Ideally, national dementia plans should be developed through an inclusive process, involving multiple stakeholders, including people with dementia and carers, Alzheimer associations, researchers, medical and care professionals and policy makers from health, social affairs and finance departments. This has been done, for example, by Australia, England, France, Indonesia, Scotland, Switzerland and the USA. Doing this also contributes to more awareness about dementia, for instance in England, where consultations were organised during a road show.
- A national action plan creates a framework for action. Yet a framework in itself is not enough – it may be a trigger but there is “no progress without action”, as the NCD Alliance highlighted.
- There is a certain overlap in prioritised topics as most plans pay mixed attention to awareness; diagnosis, treatment and care; and caregiver support. Countries approach these topics in very different ways.
- Awareness campaigns are one of the most frequently implemented actions. Many countries conducted such campaigns, often in partnership with the national Alzheimer association.
- There is growing evidence that risk reduction for Alzheimer's disease and other dementias is possible. However, brain health promotion has not often been included in general health promotion nor in national dementia plans. Australia and Finland are exceptions.
- Collecting public health data on dementia to determine prevalence, incidence and mortality rates is not often addressed in the plans. The WHO Global Dementia Observatory will have an important role and add value in this area.
- Promoting research is a prominent topic in some of the national plans. The USA, UK and Netherlands are increasing public funding for research. However, in many other national plans this is not a focus.
- Scottish plans were the first to emphasize a human rights approach towards improving the quality of life for people with dementia and their carers. This approach is now reflected in the WHO Global Action Plan. It is also mirrored in some of the most recent plans.

As we work towards the global plan target date of 2025 it is important to recognise and acknowledge the time and involvement of the many people who contribute to the generation of national plans. These are notably governments, civil society including dementia associations, the health and care sectors and the many people whose lives are affected by dementia, as well as their families and carers, who share their insights and experiences.

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WHO Strategic Action Areas

These 7 priority action areas are reflective of those detailed in the Global action plan on the public health response to dementia 2017-2025, WHO May 2017. Because of the great variation among countries in relation to which department is tasked with dementia policy and implementation, we are positing that by having a national dementia plan, the country demonstrates a commitment to making dementia a public health priority. This table shows some examples, it is not exhaustive. ADI is committed to ongoing reporting of national dementia plan progress.

	Argentina	Australia	Costa Rica	Cuba	Denmark
** Dementia as public health priority					
Dementia awareness and friendliness		A number of public/private awareness campaigns; dementia literacy study			
Dementia risk reduction	BRAIN HEALTH PROMOTION with social security offices	“Your Brain Matters” campaign		National TV/multimedia campaign about prevention strategy and modifying risk factors	
Dementia diagnosis		Education of General Practitioners (GPs); use of Multidisciplinary Teams (MDTs); develop/validate cognitive screening/ assessment tools in a variety of settings (including a bed-based option for hospitals); improving access to diagnosis		Improving diagnostic tools, biomarkers, and neuroimaging for early diagnosis; Human Brain Mapping Project	
Support for dementia carers		HALT Project, a multidisciplinary collaboration to reduce use of antipsychotics; implementation of a tool to measure depression among persons with dementia (Cornells Scale); attention to Culturally and Linguistically Diverse (CALD) populations: Aboriginal Disability Justice Campaign			Better care and rehabilitation, support and counselling for caregivers (incl toolbox and improving day-care and respite care), and a dementia friendly society and homes (Incl national and local partnerships, involving all municipalities; dem. friendly hospitals, nursing homes and apartments).
Information systems for dementia					
Dementia research and innovation					

England	Finland	France	Greece	Indonesia	Ireland
				National campaigns on public awareness and brain healthy lifestyles; dementia friendly billboards; national monument turned purple	Establishment of an Advisory Group via the Minister of Health; Northern Ireland: collaborative National Dementia Strategy Working Group
Blackfriars Consensus Statement calling for new policy focus on risk reduction	Brain Health for Teenagers campaign; national campaign targeting general public on responsibility for risk reduction				
Increased diagnosis rates through regular checks for 65+ age cohort; improving formal diagnosis process		PLM Study on CSF biomarkers for AD diagnostic accuracy	Shaw National Registry to standardize collection of info to improve diagnosis; national information campaign to foster early detection and address benefits of early diagnosis; Cognitive Signal Processing Lab project/EEGs for better diagnosis and prognosis		
EDUCATE Programme for early stage dementia outreach; study on diagnosis trends and treatment and reduced use of antipsychotics; HELP Programme for prevention of delirium in hospitals; RN Mental Health Training Registry; attention to special populations (young onset, IDD, BMER, deaf community)	Customer-oriented service system for PWD; expert and support service centres; Memory Advice phone service;	Data collection from memory centers; creating memory units, research and resource centres in “uncovered” areas; Alz disease info cards for patients; system for diagnosis and counseling; patient pathways; special Alz friendly units; innovation in Alz friendly architecture; training for dementia care personnel; reducing use of antipsychotics; accommodations for young onset PWD	Dementia registry; rating system to measure the burden to families; 7-8 new day care centres; 5 memory clinics; 2 palliative care centres, one in the North and one in the South of Greece; specialised centres for dementia palliative care		
		Alzheimer’s patient information card for emergency care			
Prime Minister’s Challenge: doubling government funding for research; engaging with research community and PWD to improve collaboration, develop capacity, provide coordination, encourage interdisciplinary work/ innovation in research, etc.					

WHO Strategic Action Areas

	Israel	Italy	Japan	Malta	Netherlands	Norway
** Dementia as public health priority						
Dementia awareness and friendliness			Kyoto Tower lighted orange for World Alzheimer Month 2016	Applying concept of dementia-friendliness to physical AND social environments (e.g. dementia-friendly attitudes); dementia-friendly terms used in national plan language	TV/social media campaigns for World Alzheimer Day; Netherlands EU Presidency speech/conference, "Living Well With(out) Dementia"	
Dementia risk reduction						
Dementia diagnosis		training for General Practitioners; Treviso Dementia Registry; Dementia Study Group/Italian Neurological Society published guidelines for diagnosis, with early diagnosis section			General Practitioner formal diagnosis training and awareness of secondary services; increased public access to information following diagnosis, interagency collaborations	More effective evaluation tools; ICT-based eval/diagnostic tool; interdisciplinary approach to diagnosis; quality and appropriateness of referrals for those with AD
Support for dementia carers	RFP to issue health funds to address continuum of care from community-hospital-community with emphasis on primary caregiver; caregiver support and in-service training of professionals; Dementia Care Pathways program to improve/streamline hospital discharge process		appropriate and timely medical and social care (including palliative care); improvement of care for early onset dementia; carers support; elderly and dementia friendly communities; treatment, rehabilitation, care; importance of the view of people with dementia and their carers.			"Small is Beautiful" initiative for better design of facilities/better adapted to unique needs of persons with dementia; modernization of facilities; funding committed to renovations; focus on PWD and IDD
Information systems for dementia		Treviso Dementia Registry			National Registry and E-Health Portal	
Dementia research and innovation					Increase in research funding linked to European JPNB (Joint Programme Neurodegenerative Diseases); MEMORABEL program;	Increase in funding for research; Norwegian Health Association dementia research programme covering themes like diagnosis, prevention, causes, treatments; TV action campaign for dementia funding (4 year programme)

Scotland	Slovenia	South Korea	Switzerland	USA	Wales
Scottish Dementia Working Group; European Working Group (initial meeting launched in Scotland); Dementia Charter/PANEL Principles; Scottish Human Rights Commission for inclusion of PWD	Ljubana Castle turned blue for World Alzheimer Month 2016	Dementia Awareness Day; web-based national information portal; raise supports from students, clubs, etc.; honorary ambassadors; War on Dementia campaign			Raising awareness in hospitals
				Lifestyle AD Prevention/NIH; CDC and NIH Healthy People 2020 includes dementia as topic area	
"Being Dementia Smart" Nurse Education Program; post-diagnostic support and HEAT Target strategy (LINK worker); alternatives to hospital admission; improving care in hospitals; better care and assessment for persons with dementia (Enhanced Assessment and Support Team in North East Fife); Implementing of Standards of Care in hospitals			Patient's right to self-determination, quality and special skills for dementia care workers, needs-appropriate care and services	National Early Stage Advisory Group; National Partnership to Improve Dementia Care in Nursing Homes; decreased use of antipsychotics; VA REACH program for Indian Health Services; inclusion of PWD/IDD	dementia supportive communities (Brecon and Hay); Dementia Friends; publication of risk reduction guidance doc; improving training in hospitals
establishment of Scottish Dementia Research Consortium (SDRC), individuals engaged in/ planning to engage in research; research funding support via Scottish Dementia Clinical Research Network				ROAR Toolkit (Recruiting Older Adults into Research) via NIA/NIH; NIH Research Funding Increase	