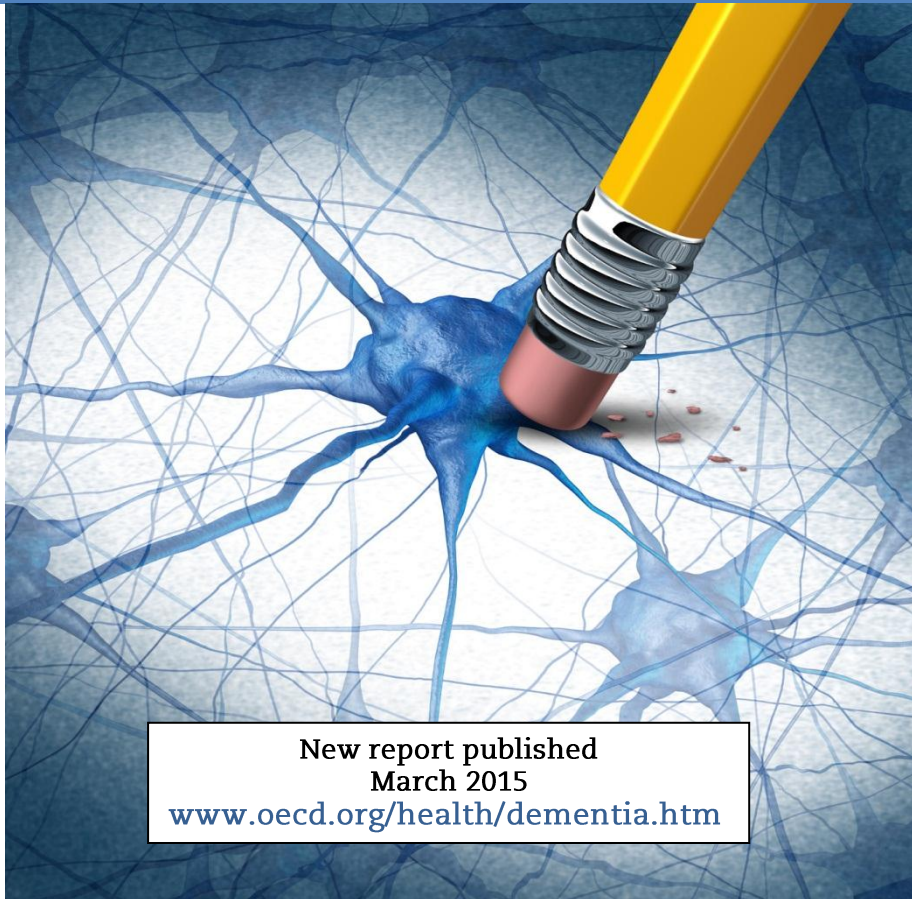


ADDRESSING DEMENTIA

THE OECD RESPONSE

2013



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www.oecd.org/health/dementia.htm

The Organisation for Economic Co-operation and Development

The OECD, which traces its roots to the Marshall Plan, groups 34 member countries committed to democratic government and the market economy. It provides a forum where governments can compare and exchange policy experiences, identify good practices and promote decisions and recommendations. Dialogue, consensus and peer review are at the very heart of the OECD.

Chile, Estonia, Israel and Slovenia became members of the OECD in 2009-2010. Membership talks are taking place with the Russian Federation, Latvia and Colombia. The OECD works closely with the major emerging economies — Brazil, China, India, Indonesia and South Africa.

The OECD is working for a stronger, cleaner and fairer world economy. The principle aim of the Organisation is to promote policies for sustainable economic growth and employment, a rising standard of living and trade liberalisation. By “sustainable economic growth” the OECD means growth that balances economic, social and environmental considerations.

The OECD is one of the world’s largest and most reliable sources of comparable statistical, economic and social data. It monitors trends, collects data, analyses and forecasts economic development and investigates evolving patterns in a broad range of public policy areas, including agriculture, development co-operation, education, employment, environment, taxation and trade, science, technology, industry and health. The OECD family of organisations also includes the International Energy Agency (IEA), the Nuclear Energy Agency (NEA) and the International Transport Forum (ITF).

www.oecd.org



Yves Leterme
*OECD Deputy
Secretary-General*

Dementia is a devastating condition. Today, no cure is available for the millions of people affected. Caring for a person with dementia imposes a high emotional toll on health professionals, families and friends. As the number of people affected from dementia continues to climb across the world as our populations age, the cost for health systems rises too.

It is time to take decisive steps to deal with the human, social and economic costs of this disease. We must improve the health and social care for people affected by dementia, accelerate innovation and identify effective therapies. Past efforts have shown that this is not a task for governments alone, nor a challenge our societies can successfully address by taking piecemeal actions. Dementia is a global challenge and it requires global solutions. International collaboration is critical to encourage multi-disciplinary, cross-border research and to enhance knowledge transfer of effective solutions on a global scale.

At the OECD, we have been working with countries to address these very important issues. The combination of our global reach and ability to bring together government and non-government perspectives means we are in a unique position to help societies rise to the challenge. For example:

- We explore how to make public-private partnerships work to deliver needed medicines and diagnostics;
- We examine ways to harness the advances in life sciences and information technologies to accelerate innovation in the prevention and treatment of the disease; and
- We develop ways to better support and care for those who are affected by dementia and their families.

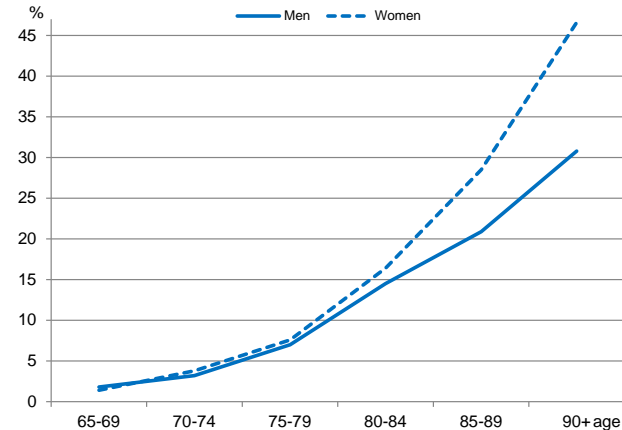
OECD countries account for nearly half the global cases of dementia today and have a particular responsibility in addressing this challenge. Our hope is that international dialogue will help mobilise knowledge that will benefit millions of people globally. We look forward to working with international leaders, the research community and business, so that in the future Alzheimer and other dementias are no longer a disease we need to fear.

Dementia is a major health burden with high social and economic costs

Dementia is the most frequent form of degenerative condition in old people

- Dementia describes brain disorders that progressively lead to brain damage and the deterioration of an individual's functional capacity and social relations. Alzheimer's disease is the most common form, representing about 60% to 80% of cases.
- In 2010, dementia accounted for 4% of all deaths and for 8.5% of all years lived with disability by people aged over 70 years. In France and Canada, it represented the third cause of death among the elderly population.
- About 5.5% of people aged over 60 had dementia across all OECD countries in 2009. Prevalence rates soar to nearly one of every two people aged 90 years and older.
- France, Italy, Switzerland, Norway, Spain and Sweden have the highest prevalence rate, with 6.3% to 6.5% of the over 60 population estimated to live with dementia in 2009.
- Dementia is as common among older people in developing and emerging economies as it is in developed countries.

Female and male dementia prevalence rises with age



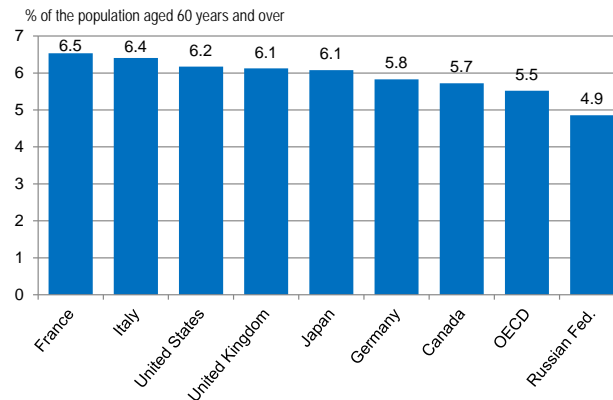
Source: Alzheimer Europe (2009), "Prevalence of Dementia in Europe", available at www.alzheimer-europe.org/EN/Research/European-Collaboration-on-Dementia/Prevalence-of-dementia2/Prevalence-of-dementia-in-Europe

- An estimated 36 million people lived with dementia in 2010 worldwide, of which 42% lived in high-income countries. This could rise to as many as 115 million worldwide in 2050.

Dementia represents a major cost for economies and for families

- The worldwide cost of dementia was estimated at USD 604 billion in 2010; 70% of this cost occurred in Western Europe and North America.
- In Germany and the Netherlands, dementia accounted for 3.7% and 6% of total health expenditure – greater than the costs of depression or schizophrenia. These expenditures are well below the total economic cost of dementia.
- Over 15% of people aged 50 and over provided care for a dependent relative or friend, including people with dementia, in 2010. More than 60% of these informal carers are women. Two-thirds of them provide care on a daily basis.
- Family carers providing more than 20 hours of caring per week to frail, dependent elderly persons have a 20% higher prevalence of incurring mental health problems (such as depression), a higher risk of reducing hours of paid work, and are at greater risk of becoming poor.

Prevalence of dementia among population over 60, 2009



Source: Wimo et al. (2010), "The Worldwide Societal Costs of Dementia: Estimates for 2009", *Alzheimer's & Dementia*, Vol. 6, pp. 98-103.

DID YOU KNOW...

Chronic diseases such as dementia account for 80% of the burden of disease in most OECD countries.

Health systems are still unprepared to deal with dementia... this must change

Addressing unmet needs in dementia

- Several OECD countries – such as France, the United Kingdom, Germany, Australia – have designed dementia strategy plans or created special benefits for dementia. However, there is still evidence of gaps in services across the OECD.
- A large number of people – according to some estimates half of those living with dementia in the UK– live without proper diagnosis and support.
- Even when people are diagnosed with dementia, evidence suggests that they may still not receive the most appropriate services. This can and must change.

Giving prevention a high profile

- Prevention policies addressing risk factors for several chronic conditions are also good for dementia. However, today, health systems across the OECD spend less than 3% on prevention.
- Diabetes is a risk factor for dementia. Good management of cardiovascular risk factors improves cognition and may delay dementia onset. Physical and cognitive training can improve cognitive capacities in early diagnosed cases.



Encouraging a diagnosis without stigma

- A diagnosis of dementia is too often associated with shame. Policy makers, the medical profession and society must fight this stigma.
- People living with dementia should get support and be encouraged to participate in clinical research. General Practitioners (GPs) have an important role to play in assessing and guiding people with signs of dementia.
- Screening for pre-dementia is a policy priority in some OECD countries. Early detection might help individuals and their families make arrangements for their future. However, so little is known about the disease that there is much uncertainty about whether people with preclinical signs of dementia will develop the condition. There is a lack of robust evidence that early detection will improve outcomes.

Better support and quality of dementia care

- Access to dementia care services – memory clinics, drug treatment, community care services, GP and specialist support – varies greatly across and within OECD countries, leading to disparities in the quality of life for people with dementia.
- Hospitals are not the right place for people with dementia and represent a costly solution. The average duration of hospitalisation for dementia is still 45 days across the OECD, though it has dropped by one sixth since 2000. Hospitalisations represent the largest health cost for people with dementia.
- An integrated approach to the provision of services to people with dementia, spanning social and health care, is essential to high-quality dementia care.
- Quality standards for dementia care help deliver good quality care. The UK standards set by the National Institute for Clinical Excellence cover different areas of the dementia pathway, such as staff training, choice, living arrangements, personalised care plans and end-of-life care.
- Up to 90% of patients with Alzheimer’s disease have one or more behavioural and psychological symptoms of dementia (BPSD) (e.g. agitation, verbal and physical aggression, wandering). Drug treatment remains widespread, though its efficacy and safety have been challenged.

- Countries should explore the potential of using broad and big data to improve dementia care quality, for example by linking clinical data and biological data with transactional data on hospitals, diagnostics and medical services.

Helping family carers

- Supporting family carers effectively is a win-win-win solution. It is beneficial for carers, for the person with dementia, and for the sustainability of public systems.
- Family carers can be supported in three ways. First, by promoting a better work-life balance through more choice and flexibility for example about care leave. Second, by introducing support services, such as respite care, training and counselling. Third, by providing carefully designed cash benefits.

OECD WORK ON HEALTH

- We address what dementia means for health systems and careers.
- We examine how OECD countries finance and deliver services for dementia and other long-term conditions.
- We work on innovative data strategies to better understand, prevent and provide care for people with dementia.
- We develop methodologies for collecting comparable data on the cost of dementia services and other mental illness.

Finding reliable diagnostic and effective treatment remains difficult

Alzheimer's disease is a complex multifactorial and multigenic neurodegenerative disease

- While significant progress has been made in the past decades to characterise Alzheimer's and other dementias and understand their complex biology, diagnosis remains difficult and no solutions have been found to efficiently diminish its symptoms, slow its progression or cure the disease.
- So far drugs for Alzheimer's and other dementias do not offer a sufficient benefit relative to their potential risk. In addition, when the diagnosis of the disease is made, the patient's condition is often already at an advanced, currently untreatable and irreversible stage.
- Addressing the biological complexity of dementia will require an environment that stimulates innovation, particularly in emerging fields of science and technology, from which breakthrough innovations could come. Indeed, many of the innovative solutions to address dementia will depend on rapid advances in emerging fields of biomedicine such as genomic technologies, nanosciences, and regenerative medicine.



Integrating emerging technologies for breakthrough innovation in dementia research

- Emerging technologies, in particular 'omics' technologies, are supporting the discovery and development of new solutions for the prevention, diagnosis, monitoring and treatment of dementia, notably through the discovery of new biomarkers.
- All stages of research are important – from basic research to more applied research – covering the great need both to understand the mechanisms of the disease at the molecular level and to rapidly find clinically applicable ways of managing the disease.
- However, an improved environment for innovation and for the integration of 'omics' technologies into medical research is needed, in particular for facilitating the transfer of technology-associated discoveries from the laboratory to the point of care.

Governance challenges to dementia research and translational research

Reinforcing models for stakeholder collaboration at national and global levels

- Stronger stakeholder collaboration is needed to overcome the complex development and validation of new interventions for dementia.
- Collaboration will facilitate medical discoveries; the transfer of innovation from the laboratory to the patient; and most specifically, the processes used to determine the suitability of the diagnostics and therapeutics for dementia.

OECD WORK ON BIOMEDICAL AND HEALTH INNOVATION

- We enable the exchange of good practices to strengthen effective co-operation at a global level for the governance of biomedical innovation for dementia.
- We examine the mechanisms to support responsible innovation in science and technology that could lead to breakthrough innovation in research for dementia.
- We review regulatory frameworks, on a global scale, and their impact on the speed at which new technology-driven solutions reach the patient; we look at innovative mechanisms to support public/private collaborations in research for dementia.

- Innovative partnerships between governments, public entities, and the private sector can bring together the resources needed for efficient research and for risk sharing among the different actors. Patients are central to these collaborations.

Modernising the regulatory pathway for translational research

- Improved pathways are needed for regulators to navigate through an uncertain environment vis-à-vis emerging technological solutions for ageing, in particular regarding the conditions for developing innovative therapies going from bench to point of care.

Assuring the effective regulation of emerging technologies and technology-enabled products requires careful consideration of their possible benefits, risks, associated ethical and social concerns and the need for “blue sky” research and innovation.

- Regulatory systems must be dynamic and forward-looking.

Re-examining the conceptual models of the disease

- Alzheimer’s and other dementias are complex human diseases that have proven very difficult to replicate in animal models. Governance mechanisms could help to facilitate the development of novel approaches to drug development based, for example, on emerging fields such as in silico modelling (e.g. using stem cells as a predictive model for brain diseases).

Taking advantage of the informatics revolution and computational power to advance research and care

The use of the Internet and Information and Communication Technologies (ICTs) is transforming economies and societies

- Over the last two decades, access to and radical improvements in information and communication technologies have unleashed new opportunities. It is essential to take stock of global capacity to undertake multidisciplinary, cross-border research and enhance knowledge transfer.
- Advances in our ability to generate, capture, store and process information on all aspects of the onset and progression of the disease have the potential to accelerate innovation on Alzheimer's disease and dementia at an unprecedented scale.

Big Data can create a tremendously powerful new resource for research and evaluation

- The rapid growth of the range of data collected (behavioural, genetic, environmental, epigenetic, clinical data, administrative, etc.) and the development of large databases and their linkage can create a tremendously powerful new resource for research and evaluation.

- This resource could serve a range of different research initiatives and has the potential to be a “game changer” in global efforts to accelerate innovation in neurodegenerative disease research.
- Creating and using this resource will require careful planning and collaboration of researchers, governments and industry.



OECD encourages multi-stakeholder co-operation in policy development for data governance on five key areas:

- **Sustainability.** Identify the framework conditions for the development and long-term sustainability of large data sets for research on Alzheimer's.
- **Exchange and access to data.** Identify the framework conditions and incentives to facilitate exchange and access to data.
- **Linkage.** Identify policies and good practices that foster co-ordination and complementarity of existing datasets sets at national, regional and international levels.

OECD WORK ON THE DIGITAL ECONOMY

We examine key questions on the information economy:

- **Connectivity and openness** – to promote and protect the free flow of information and interconnected nature of the Internet
- **Creativity** – to enable inclusive economic growth, social activity and innovation.
- **Confidence, privacy and security** – to promote trust and confidence and best address security risks.



- **Quality and efficiency.** Identify practices for enhanced effectiveness of existing data sets.
- **Capacity building.** Identify incentives to promote education and training.

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OECD Health Update

www.oecd.org/health/update

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<http://oe.cd/sti-working-papers>

Selected publications



A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care

<http://dx.doi.org/10.1787/9789264194564-en>

As ageing societies push a growing number of frail old people into needing care, delivering quality long-term care services – care that is safe, effective, and responsive to needs – has become a priority for governments. Yet much still remains to be done to enhance evidence-based measurement and improve the quality of long-term care services across EU and OECD countries. This book offers evidence and examples of useful experiences to help policy makers, providers and experts measure and improve the quality of long-term care services.



ICTs and the Health Sector: Towards Smarter Health and Wellness Models

<http://dx.doi.org/10.1787/9789264202863-en>

The future sustainability of health systems will depend on how well governments are able to anticipate and respond to efficiency and quality of care challenges. Bold action is required, as well as willingness to test innovative care delivery approaches. This book examines the whole new world of possibilities in using mobiles and the Internet to address healthcare challenges.



Emerging Trends in Biomedicine and Health Technology Innovation: Addressing the Global Challenge of Alzheimer's

<http://dx.doi.org/10.1787/5k44zcpt65vc-en>

The economic and social impact of chronic brain disorders (CBD) such as Alzheimer's disease (AD) and other neurodegenerative diseases will become the number one public-health problem worldwide, directly affecting 100 million people by 2050. Healthcare systems worldwide soon will confront a serious crisis as a result of unprecedented demand in a climate of shrinking resources.

Find out more about OECD's work on dementia

Online

www.oecd.org/sti/biotechnology

www.oecd.org/sti/nano

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