

Policy brief

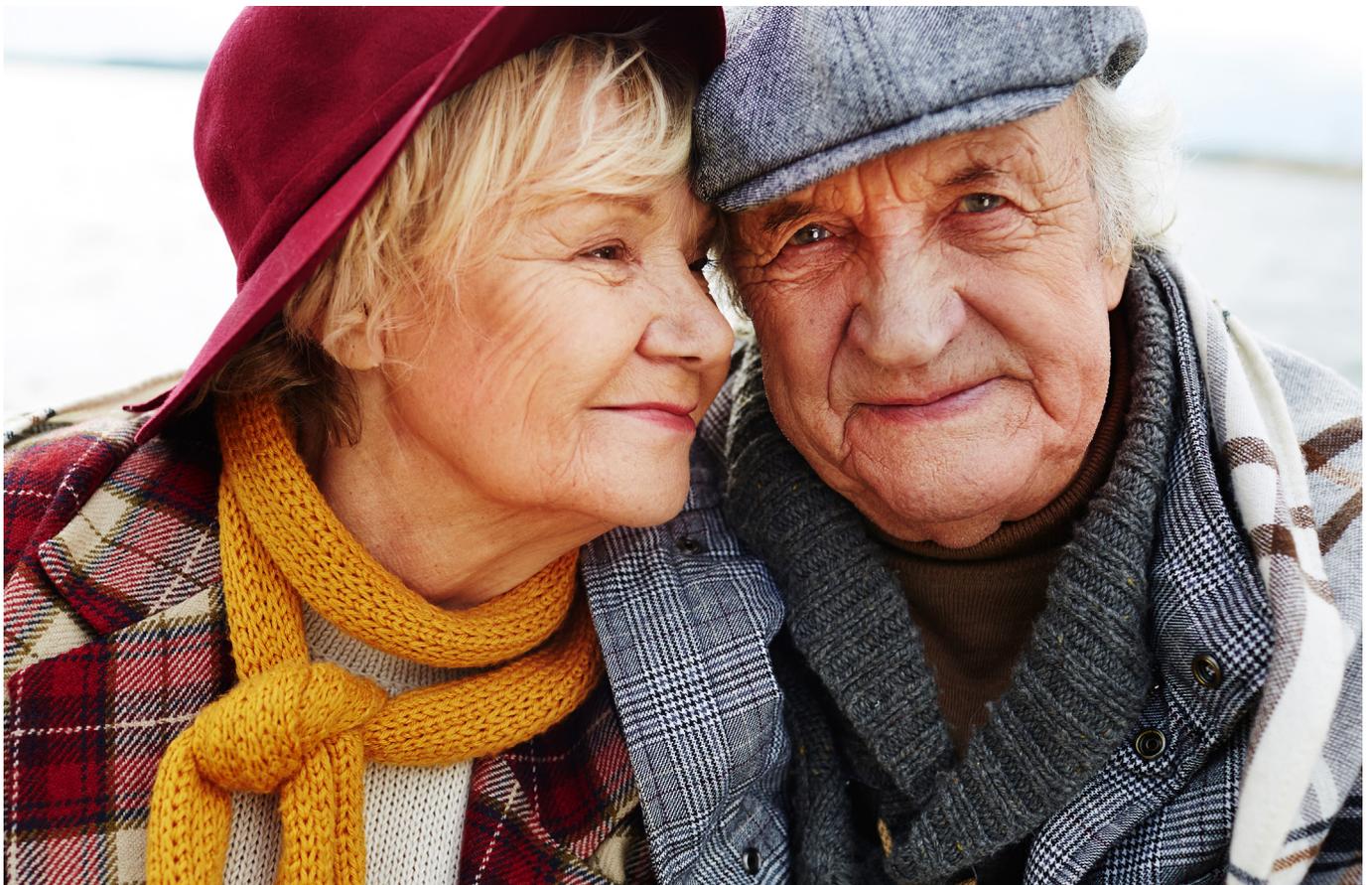


Renewing priority for dementia: Where do we stand?

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Overview

In recent years...

1 Dementia has stayed high on the policy agenda, but progress in addressing dementia has not kept up with the scale of the challenge.

The number of people living with dementia in OECD countries increased by nearly 2.5 million between 2013 and 2018, while mortality attributable to Alzheimer's and other dementias increased in recent years by more than 50% in some countries.

Across the OECD, more than one in five people aged 85 and over has dementia.

At least 23 OECD countries have developed national dementia plans, up from eight in 2013, though implementation varies considerably.

2 Despite progress in identifying people with dementia, the diagnostic process is still poor and diagnosis rates are too low.

More than half of people with dementia in OECD countries still do not receive a diagnosis, with little progress in most countries since 2013.

In OECD countries, only Denmark and the United Kingdom have set targets to improve diagnosis rates.

26 OECD countries have emphasised the role of primary care in diagnosing and caring for dementia, yet dementia training is not incentivised and the share of general practitioners has also fallen, making up less than a quarter of physicians in the EU.

Linking data across primary care and other health settings, which is important to follow people across the care pathway and provide them with better care, is becoming more frequent. However, two-fifths of OECD countries do not regularly link data across four or more key data sets.

3 Despite progress in increasing awareness and reducing stigma, poor-quality care persists.

More than 90% of OECD countries have developed dementia-friendly initiatives to support the development of dementia-friendly communities, though their reach remains limited.

19 OECD countries have established paid leave for carers.

Despite guidelines suggesting more conservative use, antipsychotic usage for people with dementia has increased in one-third of reporting OECD countries.

Only four OECD countries have developed dementia-friendly design guidelines for health and social care.

Putting dementia higher on the agenda

The priority given to dementia is too low given its impact on society

Across the OECD, 19 million men and women are living with dementia, with far too many experiencing a poor quality of life. Worldwide, someone develops dementia every three seconds. With no clinical breakthroughs, the number of people with dementia is set to grow and OECD countries are under increasing pressure to address the consequences of dementia. The G8¹ Summit on Dementia, held in London, United Kingdom, in December 2013, and a series of follow-up international events drew political attention to the issue and placed dementia squarely on the global agenda. Leaders committed to work towards preventing and treating dementia, improving the quality of life of people living with the condition, and stimulating investment and innovation into dementia research.

Yet five years on, too many of these commitments remain unfulfilled and the political attention has not kept up with the scale of the challenge. In most OECD countries, more than half of people with dementia do not receive a diagnosis, a situation little changed from 2013. Many countries still do not provide high-quality dementia care to those who need it, nor adequately support family and friends of those with dementia. People living with dementia continue to struggle to access important services, and when they do receive care, it is often sub-par. As global leaders return to London on 5 December 2018 to discuss dementia, this brief looks at what progress countries have made over the past five years.

Across the OECD, more than one in five people over 85 lives with dementia. Millions of family members and friends provide care and support to loved ones with dementia. Globally, dementia costs over USD 1 trillion per year.² It is one of the leading causes of disability for elderly adults.

Between 2015 and 2050, the share of the population 65 and over will increase by nearly two-thirds in OECD countries, while the population 80 and over will more than double. Dementia is strongly associated with age, and unless breakthroughs in curing or slowing down dementia occur, these numbers will continue to rise (Figure 1). By 2050, more than 40 million people in OECD countries will have dementia if the situation does not change.

“We, the G8 Health Ministers, met at the G8 Dementia Summit in London on 11 December 2013 to discuss how to shape an effective international response to dementia. We acknowledge the on-going work occurring in our countries and globally to identify dementia as a major disease burden and to address issues related to ageing and mental health.”

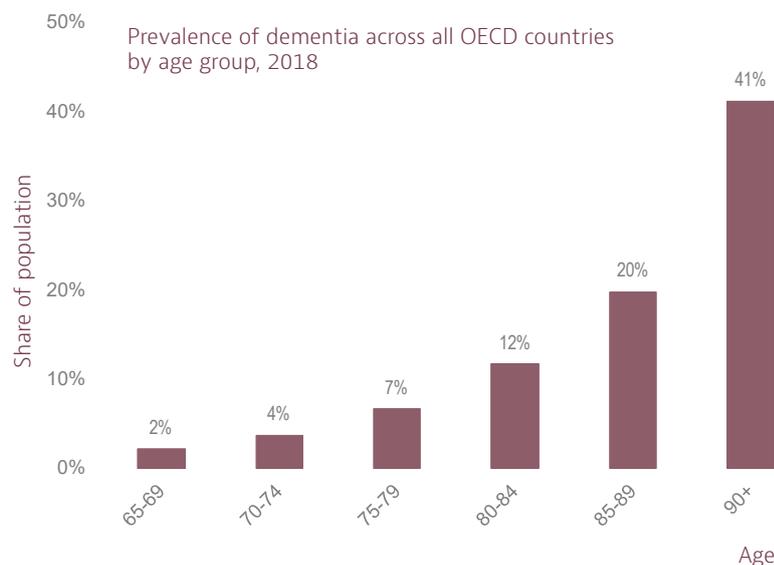
- 2013 G8 Dementia Summit Communiqué

¹ Since 2014, the G8 forum has been replaced by the G7.

² Alzheimer's Disease International (2015), *World Alzheimer Report 2015: The Global Impact of Dementia*, Alzheimer's Disease International (ADI), London.



Figure 1. Dementia prevalence is strongly linked to age



Source: OECD 2018. Analysis based on data from the *World Alzheimer Report 2015* and the United Nations World Population Prospects 2017.

More countries have developed dementia plans, but still not enough

In the past five years, strong efforts have been made to put dementia on the national agenda through the development of national dementia plans and strategies. In 2013, only four G7 countries – France, Japan, the United Kingdom and the United States – had developed national plans or strategies for dementia and other neurodegenerative diseases. By 2018, 32 countries globally, including at least 23 OECD member states, had developed national plans. However, more progress could be made. Only one additional G7 country, Italy, has developed a national plan or strategy for dementia since 2013. Canada and Germany have committed to developing national strategies in the near future but do not yet have them in place. Crucially, more than 80% of countries globally still do not have a national plan.³

Developing a national strategy or plan is not the endpoint for countries. Governments must ensure that what is laid out in national plans is carried out. Initiatives must be sufficiently funded and progress towards objectives regularly measured.

³ Alzheimer's Disease International (2018), *Dementia plans* [website], <https://www.alz.co.uk/dementia-plans>.

Diagnosing and identifying dementia

Dementia diagnosis has not adequately improved

A timely dementia diagnosis is a crucial step for accessing care and support for a person with dementia. Further, without a proper diagnosis, family members and carers will not be connected with training and support programmes to help cope with caring.

Just nine of 21 OECD countries can measure diagnosis rates on a national level, and no G7 country other than the United Kingdom has set a target to improve diagnosis rates since the 2013 Summit. More than half of people with dementia are not diagnosed in the OECD.

"Priorities for investment include... making timely diagnosis and early intervention feasible, affordable and cost effective"

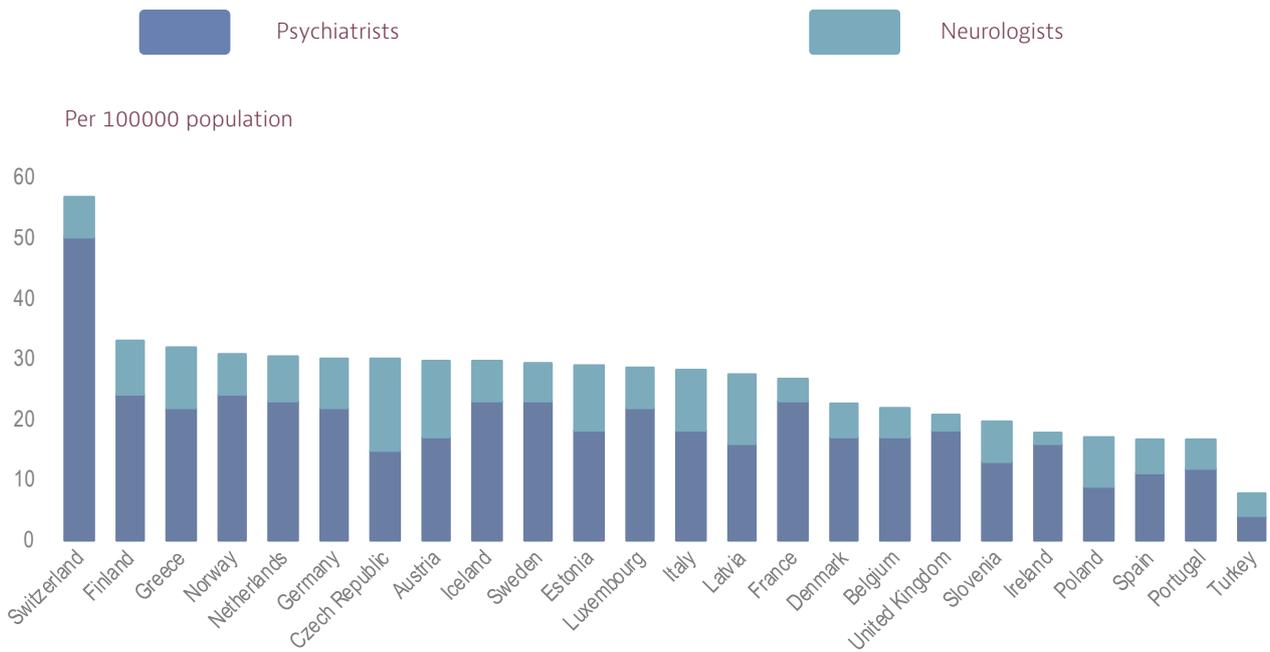
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Primary care serves as the first point of contact for people concerned about memory problems in 26 OECD countries. More than half of the countries with national dementia plans and strategies have emphasised the role of primary care to increase dementia diagnoses and ensure a continuum of care. But primary care professionals and services are ill-prepared to take on this role. Medical school training on dementia care averages just twelve hours, and primary care physicians correctly identify the condition in only 50–75% of cases. Physicians often have little incentive to strengthen their dementia

skills, even where programmes are available. No G7 country provides financial or other incentives for upskilling primary care physicians or improving diagnostic testing for dementia.

Receiving a good dementia diagnosis often requires access to specialists, including neurologists, psychiatrists, and geriatricians. But the density of these specialists varies more than three-fold across the OECD, meaning patients can experience inconsistent access to specialist care depending on where they live.

Figure 2: Specialist density per 100 000 population (2015 or nearest year)



Source: OECD (2018), Care Needed: Improving the Lives of People with Dementia, OECD Publishing, Paris.

Memory clinics, which are specialist clinics devoted to diagnosing and sometimes caring for people with dementia, are used in at least 25 OECD countries. However, a lack of guidelines and regulation of clinics

means that the quality and availability of services, such as follow-up care, varies significantly.



Better measurement of dementia care is a must

There is enormous potential to improve the delivery and quality of dementia care by harnessing the data that countries already collect. This includes linking together, at the level of the individual, data collected across different parts of the health system.

However, poor measurement has hampered efforts to better identify and care for people with dementia. Since the 2013 Summit, many countries have improved their health data infrastructure and are better able to link data at an individual level across different health settings. But there has been little progress in linking data in the parts of the health and social care system most important to people with

dementia, with areas such as primary and long-term care rarely linked to data from hospitals and other care settings. Dementia registries, which have been set up in the G7 in Italy, France, and the United States, can help to fill the information gap by building a comprehensive data infrastructure for dementia which can include patient information from across clinical settings. There has also been slow progress in recording dementia in electronic health (clinical) records, and the extraction and use of such data to support research, statistics and clinical improvement.

Living well with dementia

Despite good progress, there is insufficient community support for people with dementia

Stigma remains one of the biggest impediments to living well with dementia. Insufficient and fragmented support can prevent people with dementia from living independently and being included in their local communities. Cohesive care and support following a diagnosis can be particularly important for people who have complex needs, such as those who develop early-onset dementia.

"Dementia is our collective social responsibility. We affirm our commitment to improving the lives of people affected by dementia, regardless of nationality, identity, background, culture, socioeconomic status, language or religion."

"We commit to improving the understanding of community attitudes towards people with dementia across generations."

- 2013 G8 Dementia Summit Communiqué

A growing number of countries have developed 'dementia friends' initiatives that engage businesses, services, and the general public in becoming more dementia-aware. More than 90% of OECD countries, including five G7 countries, have developed at least some local dementia-friendly community initiatives.

Yet services remain ad-hoc and availability varies substantially even within countries. Dementia-friendly initiatives remain largely driven by local input, and the availability of such services depends largely on the resources and level of organisation of local communities. As a result, the population who benefits from these initiatives remains small.

Better services for family carers are needed

Carers of people with dementia often lack available training and counselling services. While informal care represents the backbone of dementia care, the availability of respite care, training, and support for working carers remains weak, and available services are often unfamiliar to carers or difficult to navigate.

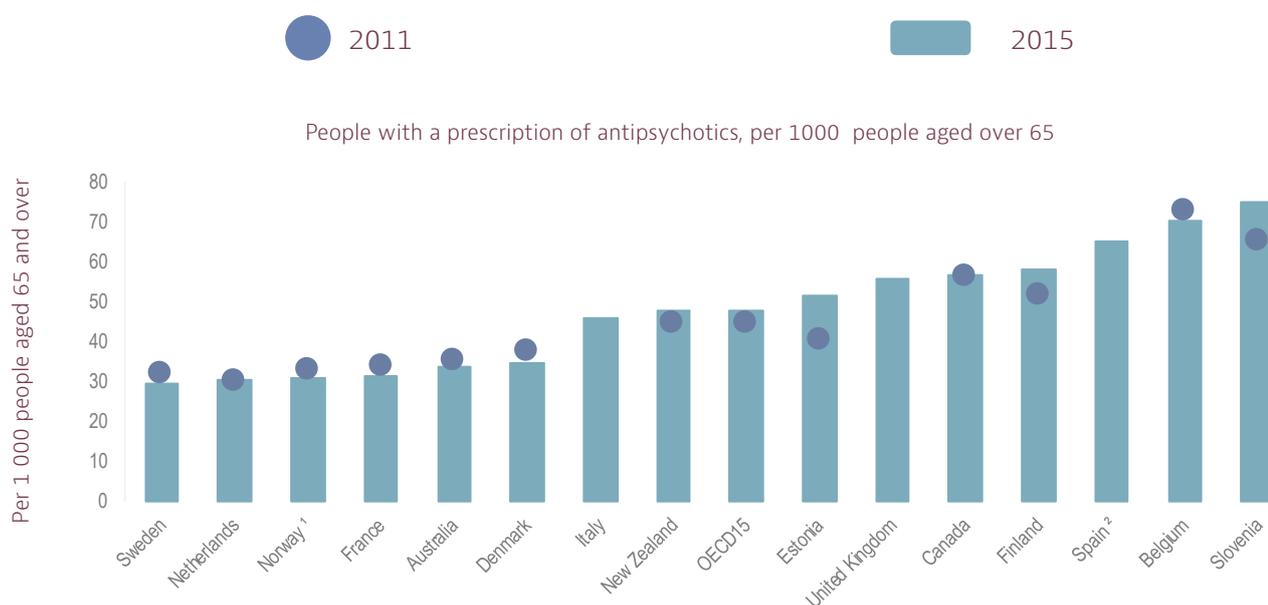
Balancing the dual responsibilities of working and caring is difficult without good external support. Informal carers in the OECD have a 20% higher prevalence of mental health problems than those who do not provide care. Providing informal care can also reduce an individual's ability to undertake paid work, as well as the number of hours they are able to work. Across the OECD, 19 countries offer some form of paid leave for caring, with four having introduced paid care leave in the past decade.

Day centres serve as the most widely available form of respite for carers, but high demand and uneven availability means quality programmes are often oversubscribed. Dementia-specific respite, which offers an option for carers to relax with the assurances that their loved ones receive high-quality care, is still rare. Compelling examples of dementia-specific respite, such as in Austria, should serve as models for other countries looking to strengthen their support for carers. Better integrating training for carers into standard dementia care is key.

Poor care for people with advanced dementia persists

Too many people with dementia continue to receive sub-par care. Yet very few OECD countries offer financial or other incentives for staff to undertake dementia training to improve quality of care. Poor training makes it particularly difficult for paid care workers to respond effectively to difficult behaviours, including behavioural and psychological symptoms of dementia. Antipsychotic medications, for example, are still widely used, even though they can increase health risks, restrict autonomy and do not reflect a person-centred care approach. Rates of antipsychotic prescribing average nearly 5 in every 100 people aged 65 and over across the OECD, and vary by a factor of more than two across OECD countries (Figure 3). Worryingly, antipsychotics prescriptions among people 65 and older increased in one-third of reporting OECD countries between 2011 and 2015.

Figure 3. High rates of antipsychotics reflect poor quality of care for people with dementia



Note: 1. Data for Norway do not include people in institutional care, so underestimate the use of antipsychotics.
2. Data for Spain refer to 2014.

Source: OECD (2018), *Care Needed: Improving the Lives of People with Dementia*, OECD Publishing, Paris.

In acute hospitals, those with dementia comprise up to a quarter of all patients. Yet in up to 60% of cases where a patient has already been diagnosed with dementia, the hospital is not informed of their condition. This can further compromise the ability to deliver high-quality, appropriate care.

Nearly six million people over the age of 65 live in care facilities in the OECD, and close to 70% are estimated to have some form of cognitive impairment. Yet the vast majority of long-term care

facilities remain poorly designed for people with dementia. Beds in innovative care facilities, such as small-scale living communities and dementia villages, remain severely limited. Only four OECD countries – Denmark, Ireland, Norway, and the United Kingdom – have developed guidelines for developing dementia-friendly buildings and living environments.



What should policymakers do next?

Since the 2013 Summit, the OECD has worked with countries, the World Dementia Council, the World Health Organization and other global stakeholders to address the challenges of dementia.

But more needs to be done to live up to the 2013 commitments, notably:

- 1 Strengthen the transparency and monitoring of the effectiveness, safety and patient-centredness of dementia care.** Step up efforts to better identify and diagnose patients with dementia, and raise standards of care through better measuring of quality of care metrics for dementia.

- 2 Harness the power of data available across health care settings to improve research and the quality of life for people with dementia.** Promote efforts to link data to ensure information about patients is shared across parts of the health system frequently used by people with dementia, including primary care, long-term care, and hospitals.

- 3 Strengthen collaboration between stakeholders and increase public investment in dementia research.** Maintain the commitment of countries and the global community to encourage clinical breakthroughs that can help improve the lives of people living with dementia both today and in the years to come.



Contact, Further reading, Acknowledgements

For further information

Please visit our website
<http://www.oecd.org/health/dementia.htm>

or contact Elina Suzuki
Health Policy Analyst
Health Division, OECD

elina.suzuki@oecd.org
+33.1.85.55.68.83

Further reading

[Care Needed: Improving the Lives of People with Dementia](#)

[Addressing Dementia: The OECD Response](#)

[Dementia Research and Care – Can Big Data Help?](#)

[OECD Council Recommendation on Health Data Governance](#)

Disclaimers

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