

Dementia today is a devastating condition without a cure. Across the OECD, 19 million people, including one in twelve people 65+, are living with dementia.

Despite growing attention, identifying people with dementia and providing high-quality care remain inadequate, with significant human and financial cost.

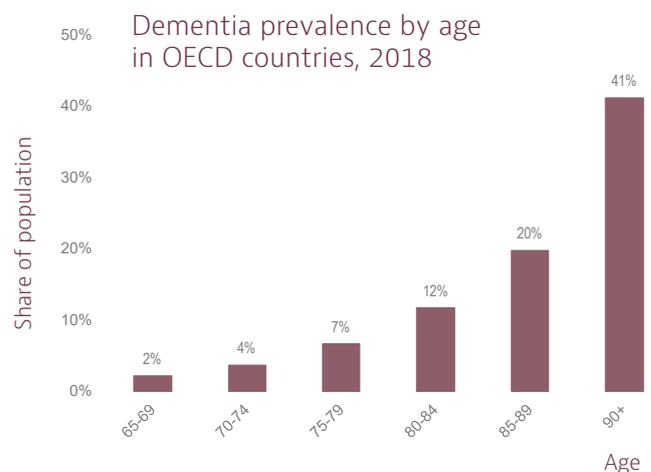
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1 The number of people with dementia and dementia cost will grow

More than 19 million people in the OECD are living with dementia in 2018. Without the development of a cure or disease-modifying treatment, this number will more than double to over 40 million by 2050.

Dementia is strongly linked to age: Nearly one in twelve people in the OECD aged 65 and over, and more than one in five aged 85 and over, have dementia.

The costs associated with dementia are significant: globally, it is estimated that the economic and societal cost of dementia exceeded USD 1 trillion in 2018.



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

2 Too many people with dementia do not receive a diagnosis

Surprisingly little is known about how many people live with dementia. In most of the OECD, more than half are not diagnosed, and identifying dementia remains an uphill battle. A dementia diagnosis is a crucial step in accessing care and support. Yet only eight of 21 countries are able to measure diagnosis rates on a national level.

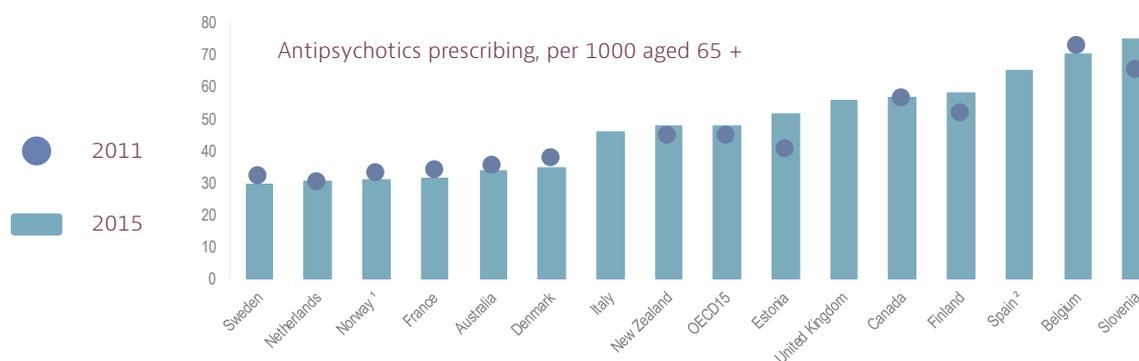
Physicians need to improve their ability to deliver a high-quality diagnosis. Many primary care professionals are still ill-prepared and receive limited dementia

training. Unsurprisingly, primary care physicians identify the condition in only 50-75% of cases in many countries. Incentives to upskill general practitioners and improve diagnosis are limited. Moreover, 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.

3 The quality of care for people with dementia is too poor, too often

Many care workers do not receive the support and training, or have the tools to respond effectively to a person with dementia, particularly when they face difficult behaviours. The use of restraints and antipsychotic medications to control behaviour is widespread.

Despite guidelines suggesting more conservative use, rates of antipsychotic prescribing average nearly 5 in every 100 people aged 65 years and over across the OECD, and vary by a factor of more than two across OECD countries.



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, <https://doi.org/10.1787/9789264085107-en>.

4 Better data and better data governance to improve research and quality of care

Better use of health data is key for improving dementia care and research. Yet there are obstacles to using health data effectively in most countries. In up to 60% of cases where a patient has already been diagnosed with dementia, for example, their diagnosis is not shared when they are admitted to hospital, compromising high quality care. Further, two-fifths of OECD countries do not regularly link data across at least four key health data sets, failing to provide a fuller picture of the care pathways for people with dementia. Information collected in primary and long-term care settings are

rarely linked to other care settings. Better sharing and linking the massive amounts of population-based health and health care data that are routinely collected in health systems with detailed clinical and biological data would create a powerful resource for further improvements in dementia research and care. The OECD Council Recommendation on Health Data Governance, endorsed by OECD Health Ministers in 2017, provides key principles and a framework to facilitate privacy-respectful use of health data.