

Need for action on dementia recalled

SUMMARY

Dementia is one of Europe's biggest challenges in the context of demographic change. It has wide-ranging social and economic consequences for those living with the condition, their families and carers, and society as a whole. The Council's conclusions of December 2015 acknowledge the importance of this challenge.

Dementia is not one specific disease, but an overall term for a syndrome that affects memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. There are many different causes and forms of dementia.

The condition remains little understood, and there is currently no cure. Action to tackle dementia is centred on its prevention, early detection and timely diagnosis, and on improving the quality of life of those living with it through care and support. Research focuses on the causes and possible treatments, on better care and prevention, as well as on developing assistive technologies.

The European Commission has published a communication on dementia, undertaken various activities and funded research. A European Parliament resolution from 2011 called for dementia to be made a health priority. Major global dementia initiatives include a G8 declaration, the creation of the World Dementia Council, and the first Ministerial Conference on 'Global Action Against Dementia', hosted by the World Health Organization. Civil society is also actively involved.



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Context: Council conclusions

Dementia is one of the biggest challenges facing Europe in the context of demographic change. It has wide-ranging social and economic consequences for those living with the condition, their families and carers, and society as a whole.¹ The recent Council [conclusions](#) on 'supporting people living with dementia: improving care policies and practices', adopted at the Employment, Social Policy, Health and Consumer Affairs Council meeting of 7 December 2015, acknowledged the importance of this challenge. The Council noted 'with concern' that an estimated [6.4 million](#)² people in the European Union (EU) are living with dementia, which has a serious impact on the financial sustainability of national health and social systems. It called for appropriate treatment and assistance to those affected, and invited Member States to address dementia as a priority.

What is dementia?

Dementia is not a specific disease, but an overall term for a wide range of symptoms. The World Health Organization (WHO) [defines](#) dementia as a 'syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. The impairment in cognitive function is usually accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation'.

Although dementia mainly affects older people, it is not a natural part of ageing, but occurs when the brain is damaged by disease. There are many different causes and forms of dementia. Alzheimer's disease is the most common, accounting for an estimated 60 to 70% of cases. Other forms include vascular dementia, which may occur after a stroke; dementia with Lewy bodies (abnormal protein aggregates that develop inside nerve cells); and fronto-temporal dementia (degeneration of the frontal lobe of the brain), considered a [common cause](#) of dementia in people under the age of 65. Multiple overlapping forms often co-exist (mixed dementia). The signs and symptoms³ of dementia gradually evolve over the course of the disease, to reach a stage of near total inactivity and dependence, at which point the person needs full-time assistance.

While the understanding of the different forms of dementia is still limited, many of them are thought to have at least two [shared characteristics](#): long periods⁴ in which the disease is active but not detectable; and complex patterns of transmission (that is, how a particular genetic trait or disorder is passed from one generation to the next) in which both genetic and environmental factors play a role.

Addressing dementia: prevention, care, research

The pathophysiology of dementia is still not fully understood,⁵ and there is currently no cure. The medicines available today mainly [help modify](#) some of the symptoms for a period of time. Essentially, no new medicines have been approved for dementia [in over a decade](#). This has been [linked](#) to the fact that research into dementia drugs has experienced a high failure rate, mainly in the early stages of development, and that, because of huge investment costs and no or little return on the investment, dementia has become 'uncompetitive compared to other diseases', a driver for 'disinvestment'.

In the absence of a cure, action to tackle dementia is centred on prevention, early detection and [timely diagnosis](#), and on improving the quality of life of those living with

dementia through care and support. [Definitive evidence](#) on what can prevent dementia is still lacking. However, research is increasingly looking to identify [modifiable risk factors](#), and a 2014 [analysis](#) found that the likelihood of certain types of dementia may be lowered by reducing the main risk factors for vascular disease – high cholesterol, raised blood pressure, diabetes, smoking and overweight/obesity (according to the motto 'what is good for your heart is good for your brain'). It is assumed that the adoption of a lifestyle that includes a healthy and balanced diet,⁶ physically and mentally stimulating activities and lifelong social engagement may help protect against age-related brain-function decline. [Epidemiological evidence](#) seems to suggest that optimum health early in life might benefit cognitive health late in life, whereby primary prevention (aimed at lowering risk and increasing [cognitive reserve](#)) is thought to have the largest effect on reducing the occurrence of dementia in the later course of life.

Dementia care focuses, among other things, on optimising the health, cognition, activity and well-being of people with dementia, as well as on treating the physical illnesses and psychological symptoms that may accompany the disease. [Psychosocial interventions](#) may include talking therapies such as [cognitive-behavioural therapy](#); [life story work](#), where a person with dementia records their life experiences in a photo album or scrapbook; and [cognitive stimulation](#), which might involve doing word puzzles or discussing current affairs. [Assistive technologies](#) and [eHealth](#) solutions, such as wearable devices linked to appropriate platforms or to computer-based disease modelling, are also thought to have potential in helping to face the challenges linked to dementia.

Support for those living with dementia and their carers aims at recognising and respecting the [human rights](#) of people with dementia⁷ and their carers, together with ensuring that they live in dignity and free of stigma and discrimination. A further goal is to provide informal carers with the appropriate health, social, financial and legal support to face the burdens, challenges and high stress levels associated with their role.

Dementia research focuses on investigating the underlying physiological processes of the disease, finding effective diagnostics and treatments, improving care and looking at ways to reduce the risk. It also aims at developing technologies to support people with dementia-related disability (see also under 'EU action').

EU action

Council of the EU

On 14 November 2014, the Italian Presidency of the Council organised a [conference](#) on dementia to discuss strategies adopted in the field for the purpose of developing prevention and treatment initiatives. In the conference conclusions, Member States were invited to 'continue addressing dementia as a core issue in their policies, to share information about their activities and to identify priorities for further dementia initiatives at EU-level'.

Preserved emotional life

'I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.'

This quote by American author Maya Angelou intuitively mirrors the findings of a 2014 [study](#), namely that people with Alzheimer's disease can experience long-lasting states of emotion that persist beyond the patients' memory for the events that caused it. Referring to this kind of '[emotional memory](#)', the British Alzheimer's Society recently emphasised how important it is for people with dementia to feel connected, and that 'spending time with loved ones and taking part in meaningful activities can have a powerful and positive impact' on them, even if they do not remember the event itself.

One of the health priorities of the Luxembourg Presidency included addressing dementia as part of a multi-sectoral approach. The discussions at the [informal meeting](#) of Health Ministers on 24-25 September 2015 fed into the December 2015 Council conclusions that invited Member States and the Commission to take forward an EU-level discussion on the following issues: advancing the role of prevention and health promotion; placing stronger emphasis on risk reduction, early detection and post-diagnostic support; exchanging best practices to ensure quality of care for patients and support for carers; promoting the empowerment and rights of people with dementia to ensure healthy ageing in dignity; using eHealth and assistive technologies for improved support and care; and fostering the continuing education of health professionals. The conclusions further called upon Member States to intensify research on dementia and to emphasise the work of non-governmental organisations as a contribution to national strategies, action plans or programmes.

European Commission and Member States

In a [communication](#) of July 2009, the Commission set out actions – a European initiative – to support Member States in ensuring 'effective and efficient recognition, prevention, diagnosis, treatment, care and research for Alzheimer's disease and other dementias in Europe'. The [four strategic objectives](#) of the European initiative concerned prevention and early diagnosis of the disease; improving epidemiological knowledge and coordinating research; exchanging best practices for care; and respecting the rights and dignity of people with dementia.

According to the Commission's 2014 [implementation report](#) on the European initiative, one of its key achievements has been the [ALCOVE](#) Joint Action, carried out between 2011 and 2013 under the leadership of France, and with support from the second EU Health Programme.⁸ Addressing all four objectives of the initiative, the Joint Action has delivered findings and recommendations and has led, inter alia, to the creation of the [European Dementia Ethics Network](#) on the rights and dignity of people with dementia (see also under 'civil society involvement', below). The initiative has inspired action on dementia in other policy areas too: the European Innovation Partnership on Active and Healthy Ageing (2012-2015) ([EIP AHA](#)),⁹ for instance, developed [activities](#) targeting prevention of cognitive decline and the creation of age-friendly environments. The initiative seems also to have had an influence on the Member States, since the majority of them have either adopted or are working on national plans or strategies on dementia.

Under the Seventh Framework Programme for Research and Technological Development (FP7), research into dementia and neurodegenerative diseases received over €584 million in [funding](#). Building on this, the 2014-2015 calls for proposals made by Horizon 2020 (the current Framework Programme) have already allocated around €103 million to projects addressing the pathophysiology, treatment and diagnostics of dementia, as well as the development of technologies for assisted living. Examples include two ongoing projects: [MIAMI-MD](#), on assistive technology for mild dementia sufferers, and [MARIO](#), on the use of care robots.

The Innovative Medicines Initiative (IMI), a public-private partnership between the EU and the European pharmaceutical industry, offers additional funding for dementia research. One such example is the ongoing [EPAD](#) project, which has a budget of almost €64 million and focuses on a more flexible ('adaptive') approach to clinical trials of medicines designed to prevent Alzheimer's disease.

The Joint Programming Initiative on Neurodegenerative Disease Research ([JPND](#)), a Member State-led international research initiative co-funded by FP7, aims to better coordinate research into neurodegenerative diseases, including Alzheimer's and other dementias. Its priorities are to find the causes of diseases, develop cures, and identify appropriate ways to care for those affected.

Furthermore, to facilitate the coordination and exchange of views on dementia policies among Member States, in early 2014 the Commission set up a [Group of Governmental Experts on Dementias](#), which is also involved in international activities aimed at enhancing global action against dementia (see also under 'global initiatives').

European Parliament

In its [resolution](#) of 19 January 2011 on the European initiative, Parliament called for dementia to be made an EU health priority, urging Member States to develop specific national plans and strategies and to facilitate access to research funding. It underlined the importance of preventing Alzheimer's disease through encouraging healthy lifestyles, and recognised the relevance of telemedicine services in patient support. It stressed the need to preserve the dignity of people with the disease and to eliminate stigma and discrimination. Moreover, it asked for medico-social research and health, employment and social policies to take into account the specific needs of women, given that they are twice as likely to be a dementia patient and that they form the majority of carers.

European Alzheimer's Alliance

The [European Alzheimer's Alliance](#) (EEA), created in 2007, is a cross-party group of, currently, [126](#) Members of the European Parliament 'committed to support Alzheimer Europe and its members to make dementia a public health priority'. The alliance meets regularly and organises various discussion events, the most recent among them being a lunch debate on ['Dementia, a priority of two EU Presidencies'](#) in December 2015.

Global initiatives

G8

On 11 December 2013, the United Kingdom (UK) Presidency of the Council of the EU and the G8¹⁰ organised a summit on dementia. In the resulting [declaration](#), the G8 Ministers of Health committed themselves, among other things, to call for greater innovation to improve the lives of people with dementia and their carers, while reducing their burden; to strive to identify a cure or a disease-modifying therapy¹¹ for dementia by 2025; to increase collectively the funding for dementia research to reach the afore-mentioned goal; to share information about the research being funded; to identify priority research areas; and to develop a coordinated international research action plan. One of the main outcomes of the summit was the creation of the [World Dementia Council](#), tasked with encouraging innovation and the development of medicines, treatments and care for people with dementia by providing independent, non-governmental advocacy.

WHO

The WHO considers dementia a public health priority. Its 2012 [report](#), elaborated jointly with Alzheimer's Disease International (ADI), aimed to overcome the lack of awareness about dementia and to advocate action. Moreover, the first [WHO Ministerial Conference](#) on 'Global Action against Dementia',¹² held on 16-17 March 2015, brought together political, research, clinical and advocacy stakeholders. It emphasised, among other things, the need for coordinated efforts to advance prevention, diagnosis and treatment of dementia, notably by fostering innovation and research, and to facilitate the delivery of care, including carer support and workforce training. The conference

launched a ['call for action'](#) against dementia, and resulted in the WHO's pledge to establish a global dementia observatory that would monitor action on dementia and track the establishment of national dementia policies and plans.¹³

OECD

In addition to participating in the 'Global Action against Dementia', the Organisation for Economic Co-operation and Development (OECD) has produced a number of [publications](#) on dementia. In a [2013](#) report on long-term care, co-financed by the European Commission, the OECD focused on the quality of long-term care services, and notably on the aspects of effectiveness and care safety, patient-centredness and care coordination. In a 2015 [report](#), the OECD presented its 'response' to dementia, detailing its vision and giving recommendations. In view of the high human and financial cost of dementia, it made a case for policy action: while the long-term goal had to consist of finding a cure and preventive treatment, the short-term focus should be on improving the lives of people living with dementia now. The report stressed the importance for healthcare systems to better support patients and their families, and the need to reform regulatory frameworks so as to advance progress in dementia research and care. In particular, it pleaded for harnessing the potential of 'big data' (defined as the collection, storage, processing and effective use of massive amounts of research, clinical and transactional information) to improve understanding of the disease.

Civil society involvement

The European Foundations' Initiative on Dementia ([EFID](#)) aims to improve the lives of people with dementia by enabling a dementia-friendly and inclusive environment. It launches calls for proposals to support projects encouraging a community approach.

Two non-governmental organisations are among the major players in the field: Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations and has official relations with the WHO. It publishes a yearly [world report](#), holds an annual international [conference](#) and organises the World Alzheimer's Month in September, with World Alzheimer's Day falling on 21 September. ADI, Alzheimer's Society (England, Wales and Northern Ireland) and the UK Department of Health jointly [launched](#) the [Global Alzheimer's and Dementia Alliance](#) at the WHO World Assembly in May 2014, with the objective of raising more awareness globally and changing attitudes to dementia.

Patient organisation Alzheimer Europe carries out [research projects](#) and produces dedicated [publications](#). It established the [European Dementia Ethics Network](#) in 2009 and launched the [Glasgow Declaration](#) in 2015, calling for the creation of a European dementia strategy and national strategies in every EU Member State.

Future trends in dementia: Could the 'tsunami' be levelling off?

Dementia is [strongly associated](#) with old age, and many argue that, with population ageing, the number of people with this disease is set to increase. In the words of WHO Director-General, Margaret Chan: 'There is a [tidal wave](#) of dementia coming our way'. Yet, a recent [paper](#) that examined studies done in different western European countries found that the overall level of dementia occurrence could be stabilising, mainly due to improvements in prevention, healthcare, education and living conditions. Commentators have observed that, while the evidence [may not be indicative](#) of a continuing trend, it [seems to be pointing](#) to a more optimistic picture.

Further reading

[Addressing Dementia – The OECD Response](#), OECD, March 2015.

[Ageing – Debate the Issues](#), OECD, January 2016.

[Dementia: a public health priority](#), WHO and ADI, 2012.

[Dementia Research and Care – Can Big Data Help?](#), OECD, February 2015.

[World Alzheimer Report 2015 – The Global Impact of Dementia](#), ADI, 2015.

Endnotes

- ¹ According to the Organisation for Economic Co-operation and Development (OECD), the [financial cost](#) of dementia is large and growing, but hard to quantify, especially with regard to informal care.
- ² According to other [estimates](#), 8.4 million people aged 60 years and over were suffering from dementia in the EU in 2012, accounting for 7.0% of the population in that age group.
- ³ Symptoms depend on the cause and the individual. The WHO describes three stages: early-stage (forgetfulness; losing track of time), middle-stage (getting lost in familiar places; communication problems; behaviour changes such as repeated questioning), and late-stage symptoms (becoming unaware of time and place; difficulties recognising relatives and friends; behaviour changes that may include agitation and aggression).
- ⁴ Estimates vary. The European Medicines Agency (EMA) considers Alzheimer's as a [disease continuum](#) with a pre-symptomatic phase of 10 to 20 years.
- ⁵ Tentative explanations for the pathogenesis of, for instance, Alzheimer's disease include the [cholinergic hypothesis](#), the (leading, though not [uncontested](#)) hypotheses implicating [amyloid-beta](#) and [tau](#) peptides, and the [inverse-Warburg hypothesis](#).
- ⁶ An example is the [research](#)-based [MIND](#) diet that has been associated with slowing down cognitive decline in elderly adults and potentially lowering the risk of Alzheimer's disease.
- ⁷ See also Alzheimer Scotland's [Charter of rights](#) for people with dementia and their carers in Scotland.
- ⁸ A second Joint Action is [planned](#) under the third EU Health Programme (2014-2020), to focus notably on diagnostic and post-diagnostic support, crisis and care pathways, improving the quality of residential care, and dementia-friendly communities.
- ⁹ The [Partnership](#) was launched in 2011 with the overarching goal of increasing the average healthy life-years of EU citizens by two years by 2020. It brings together stakeholders in the innovation cycle.
- ¹⁰ G8 was composed of the heads of state or government of Canada, France, Germany, Italy, Japan, Russia, the United States and the United Kingdom, plus EU leaders. Following Russia's suspension in March 2014, it has returned to the G7 format.
- ¹¹ In contrast to symptomatic therapies, [disease-modifying therapies](#) are those that can change the course of a disease, that is, slow or reverse its progression.
- ¹² The conference was supported by the UK Department of Health and the OECD.
- ¹³ According to the WHO, [priority actions](#) in such plans should include: raising awareness of the disease; building capacity for timely diagnosis; commitment to good quality care; carer support; workforce training; and research.

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