GOVERNMENT GAZETTE
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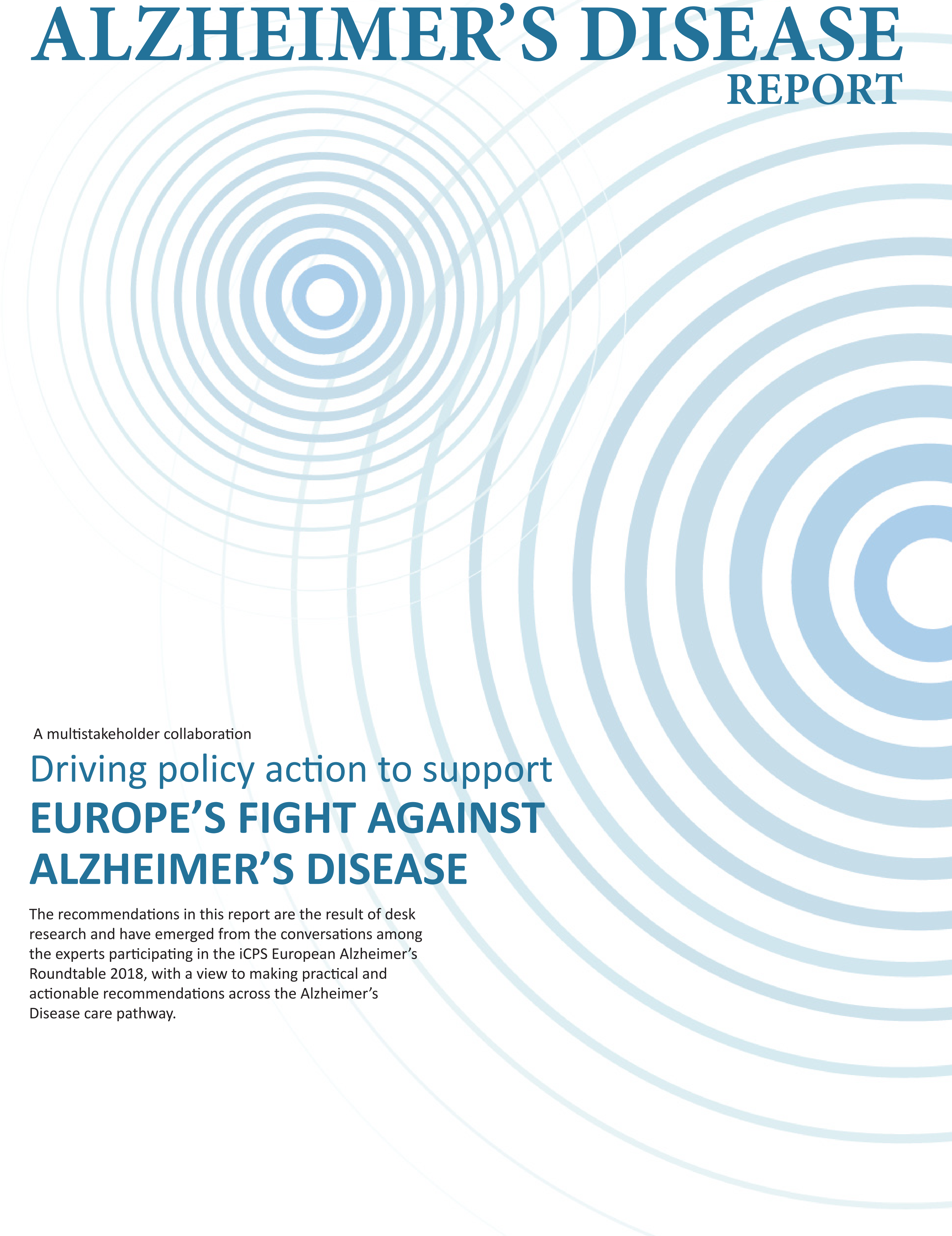
ALZHEIMER’S DISEASE REPORT



A multistakeholder collaboration

Driving policy action to support EUROPE’S FIGHT AGAINST ALZHEIMER’S DISEASE

The recommendations in this report are the result of desk research and have emerged from the conversations among the experts participating in the iCPS European Alzheimer’s Roundtable 2018, with a view to making practical and actionable recommendations across the Alzheimer’s Disease care pathway.

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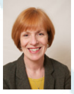

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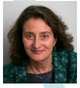

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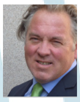

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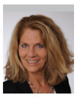

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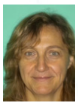

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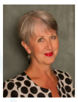

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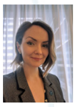

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The state we are in

The global ratio of publications on neurodegenerative disorders versus cancer is an astonishing 1:12. At the same time, not enough people are getting into research on dementia. There are three million papers on cancer as opposed to 250,000 papers on dementia and neurodegeneration.

The total estimated worldwide cost of dementia in 2018 is US$1 trillion. This figure will rise to US$ 2 trillion by 2030.

50 million people worldwide are living with dementia in 2018. This number will more than triple to 152 million by 2050.

There are over 9.9 million new cases of dementia each year worldwide, implying one new case every 3.2 seconds. The number of demented will increase considerably from about 10 million today to about 14 million demented persons in 2030. The total estimated worldwide cost of dementia is US$1 trillion in 2018. By 2030, the global cost of dementia is estimated to rise above a US$ 2 trillion.

The total cost of illness of dementia disorders in EU27 in 2008 was estimated to 160 billion euros, of which 56% were costs of informal care. In September 2018, the International Centre for Parliamentary Studies, representing the voice of Alzheimer's Disease experts and healthcare policymakers in Europe, identified pressing issues to be addressed by the legislators in the new European Parliament and policymakers at member-state level.

This report provides an overview of the policy recommendations tabled during the roundtable and includes independent from policy experts and healthcare stakeholders.

Reformulating the European approach to managing Alzheimer's disease

Alzheimer's Disease (AD) imposes a tremendous burden on individuals, families, communities and societies. It currently affects nearly 6.4 million people within Europe and more than 47 people worldwide, with the numbers potentially expected to rise in the years to come. If this situation is to change, urgent action is required at the policy level and broader collaboration is essential among policy makers, healthcare professionals, patient organisations and industry stakeholders. Calling for a more proactive approach against the neurodegenerative disease, the International Centre for Parliamentary Studies recently brought together key stakeholders to formulate a strategy to better manage AD in Europe

Approximately six million people are affected by Alzheimer's disease (AD) or related diseases in Europe, and the number of new cases diagnosed each year continues to increase. Billions of dollars has been spent on research, yet there is currently no curative treatment for AD. Nevertheless, some drug treatments can help to slow the process and early detection can assist in better supporting patients and their carers.

The European Commission and the Council have recognised AD and related diseases as a public health priority in Europe and have united in their aim to tackle the neurodegenerative disease burden, but while increases in research investment have been welcome, funding is still low in proportion to the scale of the challenge. If we are to head off a global dementia crisis, we must find better treatments and ways to prevent the condition.

The International Centre for Parliamentary Studies recently brought together EU policy makers, medical and clinical professionals, academic experts and key industry stakeholders to examine the ongoing challenges presented by AD and to explore practical solutions in order to build a framework for policy action across the EU.

European Alzheimer's Roundtable housed over 30 experts from across Europe, including representatives from the European Parliament, the European Commission, members of national Alzheimer's associations and key healthcare stakeholders.

Chaired by **Prof. Gordon Willcock**, Emeritus Professor of Geratology, University of Oxford, the second edition of the European Alzheimer's Roundtable housed over 30 experts from across Europe, including representatives from the European Parliament, the European Commission, members of national Alzheimer's associations, leading clinicians in the fields of psychology and neurology, and key industry stakeholders to formulate a strategy to better manage the disease in Europe. Key policymakers analysed the current policy framework of Alzheimer's disease in the EU and discussed a wide range of issues including prevention, need for early intervention, sustained research, innovation and the current state of treatment and care.

A central theme to emerge from the roundtable is that research holds the answer, but our scientists must have the patronage and support of governments worldwide if we are to transform the lives of millions of people across the world. Support for areas like cancer, respiratory diseases and circulatory diseases has resulted in lower mortality rates, while support for AD lags behind. We need a recommitment from pharmaceutical companies to continue efforts to fund research into AD. We still require life-changing treatments for dementia and the continuous investment of pharmaceutical companies, which bring resources and expertise in drug discovery and clinical trials. Efforts to restructure the multifarious regulatory process could play an imperative part in delivering new drugs faster, and sustained investment in research is fundamental for ensuring leads for new treatments are taken forward.

Reinforcing what was discussed during the **first edition** of this meeting, participants stressed that we cannot pursue preventative treatments while neglecting our responsibility to improve the quality of life for those living with dementia through investing in care-systems and supporting caregivers.

While the social and economic implications of AD are substantial, treating and caring for people with the neurodegenerative disease costs the EU more than €160 billion per year. These costs are predicted to rise, with an estimated quadrupling of Alzheimer's cases globally by 2050. We have no time to lose. The cost of inaction could be even greater. The importance of early detection and diagnosis in addressing the economic burden of Alzheimer's was highlighted by participants among several other areas.

The iCPS European

Alzheimer's Roundtable 2018 set out a few clear actions to bring about a new management plan to end AD.

1. Different kinds of dementias pose multifaceted challenges which require niche solutions. Facing up to this challenge requires doing things differently. Europe needs a dementia strategy focussing on future generation. A clear priority is to raise quality standards, beginning with diagnosis. Early diagnosis and stratification of the population is needed to prove that the onset of AD can be delayed by pre-symptomatic treatment.

2. National governments must increase funding for dementia research to widen the search for effective treatments and plan for their swift delivery. We must improve early detection and accurate diagnosis, and provide greater support following diagnosis to better the lives of families living with the condition today. And government-led health campaigns should take a crucial role in preparing the society by creating greater awareness and understanding of all stages of AD and the reiterate the importance of timely intervention.

> The European Commission and the Council have recognised AD and related diseases as a public health priority in Europe and have united in their aim to tackle the neurodegenerative disease burden, but while increases in research investment have been welcome, funding is still low in proportion to the scale of the challenge. If we are to head off a global dementia crisis, we must find better treatments and ways to prevent the condition.

3. We must end the inequity people with dementia face by reforming the social care system. We must focus on ways to measure and improve quality of life, access to post-diagnostic support and homecare to create life-altering implications for people with AD. There's a need to create a new accelerated care pathway which involves improving training and development of health and social care workers, analysing cost-effective care initiatives to manage end of life symptoms, and developing advanced care plans.

4. European countries should unite to develop and describe an optimum pathway of care for dementia, from diagnosis to death and beyond in supporting families and carers in their bereavement. We should examine, contrast and compare best practice models across the EU of case management in dementia care and develop a consensus of what elements constitute the optimum pathway of care in dementia.

5. Delegates discussed about the importance of the palliative care approach that provides appropriate control of symptoms, emphasises overall quality of life, takes a holistic approach, involves the patient and the family in decisions, fosters good supportive communication between all concerned and presents an opportunity to honestly acknowledge the terminal nature of the advanced disease.

6. It is important to motivate and educate our GPs to improve diagnosis, care and treatment. For instance, the waiting time for a neurologist in Slovenia, for example, is a year and a half. We either employ more, or make the diagnosis and treatment process more time effective.

7. Although disease-modifying treatments aren't available yet, dementia research is in the most promising position for years. We must promote research to increase the understanding of AD and support the development of improved diagnostics and promising therapies. There is greater need for proactive research on early intervention, more long-term inter-disciplinary studies, wider collaborative projects and increased stringency in evaluating trials. Governments should consider increasing umbrella funding for brain research, which will undoubtedly positively affect Alzheimer's funding.

9. One response to the looming pandemic of AD and related illnesses is the development of biomarkers that can aid in diagnosis, prognosis, selection for clinical trials, and objective assessment of therapeutic response. Advances in biomarkers and neuroimaging have shown that disease pathology begins well

before onset of the symptoms associated with AD. These biomarkers cannot replace clinical diagnosis, but it is important to recognise their clear utility in enhancing treatment.

10. European governments should update national strategies for dementia and neurodegerative diseases to take advantage of new health technologies that will enable earlier and more accurate diagnosis of AD and the appropriate use of new treatments.

11. AD and related disorders often suffer from a wrong or negative image. In order to change the way people think, we encourage any measure promoting the social inclusion of the individuals affected by these diseases. We should launch government-led communication campaigns at a national scale in order to deconstruct the common stereotypes.

12. Half of people who find out they have a cognitive deficit do not seek further advice, especially as people find it difficult to talk about cognitive decline at early stages. The education component is vital. It's high time the society wakes up to this and realise how environmental noise influences early stage of cognitive impairment. We must focus on pathways after diagnosis and create better linkages with social care systems.

13. European governments must continue to amplify its efforts in favour of clinical research and social sciences. We should call for easier access to therapeutic innovation, especially by promoting the patients' participation in scientific research.

14. Efforts must continue to give signals to pharmaceutical industry that we want them to continue efforts in finding a cure or even symptom-modifying treatment for a complex disease that is believed to develop decades before symptoms emerge.

15. The identification and validation of biomarkers in diagnosing AD and other forms of dementia are increasingly important. Advances in biomarkers and neuroimaging have shown that the disease pathology begins before the onset of the symptoms commonly associated with AD. There's a need for developing new biomarkers that can detect abnormal levels of amyloid and support in early diagnosis of AD.

16. Among the actions designed by delegates to diminish the dementia burden is the creation of a new accelerated access pathway for selected breakthrough treatments and medical technologies that fill an unmet need, transform patients' lives or dramatically improve efficiency. We should work with relevant stakeholders to prepare for a new era of treatment and to support health systems to achieve the full benefit of scientific advances in AD.

17. Delegates stated that using assistive technology has a lot of potential benefits, but also has its difficulties. Some pieces of assistive technology have been designed specifically for people with the condition but a lot of potentially helpful technology has not. Providing an overview of a range of assistive technologies helping people with dementia and associated families, delegates agreed that technology can never substitute human contact. It can only assist people in improving their safety and wellbeing, not provide perfect solutions. We shouldn't use tech for tech's sake. We should we use tech to make things easier and advocate changes while making sure citizens notice impact. Insisting on more rigorous trials, delegates agreed that patients should be involved in developing and designing such assistive technology.

18. National governments should ensure policies are in place that will support the needs and rights of people living with dementia. Employers must be prepared to support the people aged under 65 with dementia, many of whom continue to work following diagnosis.

19. Last but not least, delegates emphasised on a crucial need for good data repository systems. We need to liberate data to strengthen our battle against AD. We need more data projects having patients in mind.

Delegates at iCPS European Alzheimer's Roundtable 2018:

AbbVie; Geriatrician, Dementia Centre, Association Amnesia; Chairman of the Board, Alzheimer Finland; Research and Communication Officer, Alzheimer's Society; Head of Policy, Alzheimer's Research UK; Dementia Workstream Lead, British Psychological Society; EU-Project Manager, Catholic University of Applied Sciences; Consultant, Cognitive Medicine; Head of Research & Publications, Dementia UK; Head of Sector: Neuroscience, DG R&I, European Commission; MEP, European Parliament; Alzheimer's Alliance; Advisor on Civil Liberties, Justice and Home Affairs, European Parliament; Secretary General, European Federation of Nurses; Founder and Medical Director, Fundació ACE ICNA; Deputy Director, Fundació ACE ICNA; Researcher, London School of Economics; Principal Clinical Scientist, Medtronic; Psychiatrist/ Neurologist, Masstricht Unviersity Medical Centre; Secretary General, Norwegian Health Association; Early Stage Researcher, Maastricht University; National Observatory for Dementia - Athens; Neurologist-Psychiatrist, Alzheimer Association; Otsuka Pharmaceutical Europe; Medical Doctor, Sorbonne University; Director, Saarland University; Emeritus Professor of Geratology, University of Oxford; Director of the Department of Psychiatry, University Hospital of Cologne; Professor of Mental Health and Social Care. University of Nottingham Lecturer and Honorary Consultant, University of Cambridge; Speaker and Senior Research Group Leader at the DZNE/Witten, German Center for Neurodegenerative Diseases; PhD researcher at the Faculty of Social Sciences, University of Leuven; Head, Translational Medicine Neuroscience, UCB Biopharma Sprl

Investigating the contribution of arts-based interventions

Dementia affects not only the individual and family circle, but the wider community and society at large. We need to know more about the psychosocial methods that bring most benefit to individuals with a diagnosis of dementia and to their carers, while taking account of their societal impact as well as costs. A priority here is social inclusion, to avoid the harmful isolation and neglect that can arise when communities fail to address the needs of people with dementia and their close supporters.

Most people with dementia live in their own homes with family carers, and therefore research is needed into the best approaches to improve their quality of life. This should be multi-disciplinary because of the need to adapt interventions to individual needs and circumstances in a wide range of social contexts.

While neurology, psychiatry and clinical psychology have much to offer efforts to improve post-diagnosis care, a contribution can also be made through the insights of social psychology, social work, sociology and social policy. For example, the reliance on family carers to support people with dementia is largely unquestioned by policy-makers. Do carers have a choice? Is everyone willing and able to take up this role? What are the consequences for carers' health and employment of assuming caring responsibilities?

Most people with dementia at some point experience distressing symptoms, such as depression, agitation and repetitive vocalisations that appear to have little communicative function. Whether carers are family members or paid professionals, knowing how to deal with such symptoms is vital.

In care homes, agitation can be addressed through communication skills training, person-centred care, music therapy and other approaches (Livingston et al., 2014). Research is now needed into how these skills can be taught most effectively and implemented more widely by people with sufficient training and preparation.

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In relation to the quality of life of individuals with a diagnosis of dementia, the evidence base for cognitive stimulation therapy (Woods et al., 2012) and reminiscence therapy (Woods et al., 2018) is reliable and positive. Knowledge about the benefits of music is growing (Sihvonen et al., 2017) and there are promising results from a range of arts-based activities although studies are not o the highest quality overall, or not focussed on dementia. Specifically, research using more robust methodsis needed into the potential benefits to people with dementia of arts-based interventions such as singing (Särkämöet al., 2016) , dance movement therapy (Machakova et al., 2017), visual art appreciation and object handling(Beard, 2012; Young et al., 2015).

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Most people with dementia live in their own homes with family carers, and therefore research is needed into the best approaches to improve their quality of life. This should be multi-disciplinary because of the need to adapt interventions to individual needs and circumstances.

These interventions are relatively low-cost to develop and may be easy to deliver because they are already embedded in many cultures. Moreover, harnessing the power of the arts in the care of people with dementia and their supporters taps into a new source of skills, talent and labour that is likely to be a boon to the effort to improve the lives of people with dementia, while benefitting society through their cultural inclusion.

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The genetic side of Alzheimer's Disease

Teresa Griffin MEP reviews European Parliament's action against AD

Alzheimer's is a growing concern and a recurrent topic amongst policy and research circles. There are currently 6.4 million people living with some form of dementia in the European Union and more than 50 million worldwide. Estimates suggest that this number will almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050. However, despite the amount of money, research and time spent studying the disease, we are still far from a proper understanding of what causes it.

This notwithstanding, researchers have identified several different factors that can increase the risk of developing Alzheimer's. Indeed, there are genetic factors and environmental factors, and it is not an 'either-or' situation, but rather a mix of factors that can make a person more or less at risk of developing Alzheimer's. We cannot change the most important risk factors, such as age, family history and heredity, but more and more, we hear studies indicating other influences, confirming the need for a multi-disciplined approach to tackling the disease.

For instance, a family history of Alzheimer's is not necessarily an indication that an individual will in fact develop the disease. However, the research shows that those who have a parent or sibling with Alzheimer's are more likely to develop the disease than those who do not. Those who have more than one first-degree relative with the disease are at an even higher risk. Either genetics, environmental factors – or both – may play a role when diseases tend to run in families.

In the case of genetics, unless it is early-onset Alzheimer's, there is a smaller chance that it is hereditary but the risk is still higher. In this case, the immediate family members still do not know for sure whether they will develop the disease, thereby leaving them in a state of limbo. Meanwhile, caring for relatives with the disease can significantly affect their own mental health, thus further increasing their chance of developing the disease themselves. This is because mental health problems and depression, in particular, are seen as contributors to Alzheimer's, as some evidence suggests that people who are depressed produce high levels of the hormone cortisol, which in turn has an adverse effect on the hippocampus — a part of the brain responsible for new learning and short-term memory.

Furthermore, there are not many options available for those family members who would like to know their chances of developing the disease. Neurologists do not recommend DNA tests to identify whether genetic markers are present because 1) even if biomarkers are present, it does not mean that the disease will manifest itself and 2) without a known cure, there is no real benefit of knowing. This is the position held by some neurologists at least. The contrary argument is that the earlier the diagnosis, the earlier people can make lifestyle changes, such as changing their diet and environment or reducing stress levels, that may help slow down disease progression, as well as being better able to make better informed decisions for the future.

We need, therefore, a holistic approach to Alzheimer's. Here at the European Parliament, we have the privilege of being a part of the decision-making process. That means we are able to listen to the latest researchers and healthcare professionals dealing with these issues, but those views have been both disparate and sometimes pessimistic. More optimistic voices claim that we will have a cure in 10-15 years, while others regret that there will never be a cure and that we need to start looking at prevention rather than cure. Yet there appears to be no real means of prevention given the disparity of the causes. As things stand, being diagnosed with Alzheimer's means people with it are merely surviving, coping with whatever means are available to them. This is incredibly dispiriting for those who are afflicted with the disease or have seen their loved ones suffer through it.

Europe has been - and must continue to be - a trailblazer in scientific breakthroughs. Concerning Brexit, being a member of the EU has enabled huge amounts of collaboration in dementia research. Once the UK leaves the EU, it is vital that infrastructure is put in place to continue the important work happening in cross-border research programmes across Europe and the government must secure maximum co-operation and alignment with EU regulations.

Therefore, we need to be more ambitious in finding a cure (or cures) for Alzheimer's disease, as well as incorporating the needs of patients, their immediate family members and caregivers. We cannot leave people in limbo; they need to believe that there will be a cure, that they will have access to the best care possible and that they will keep their dignity in the face of such an overwhelming and devastating disease.

Living with Alzheimer's Disease

In Europe, there are over 11 million people estimated to be living with dementia, of which 60-80% have Alzheimer's Disease (AD) as the underlying cause. Expectations are that this number will rise to over 18 million by 2050 .Alzheimer's Disease is a chronic, debilitating, complex and challenging illness that places a significant strain on the quality of life for those affected, patients and caregivers alike. In addition the growing number of people living with the AD places a burden on already stretched healthcare resources with the societal and economic cost of AD in Europe estimated to increase by 43% from 2008 to 2030 to in excess of €250bn.

It is clear that providing good quality, patient centred, co-ordinated care for individual patients and caregivers is a priority for governments and health systems. According to the Alzheimer's Europe Dementia Monitor 2017, 21 European countries had published strategies and put in place guidelines. In addition there areinitiatives investing in research, raising awareness of AD and working to build dementia friendly communities within the European community.

Whilst the details of country strategies vary there are common themes that aim to improve the quality of life for those living with AD. The strategies and policies acknowledge the essential need to provide good quality, accessible care and treatment care throughout the life course of the disease.

> ▶ People living with AD and their caregivers are central to developing and implementing services, treatment options and care. The ultimate goal is to ensure that people with AD and their families have a good quality of life and are able to live well at every stage of the illness. For all involved in the research and development of treatment and care; the way in which services are structured and funded, we must take account of the whole of the life course of the illness.

Alison LAWRENCE is Director Public Affairs at ***Otsuka Pharma Europe***

Perceived opinion being that if we are able to support people to live well it will ease the economic pressures for governments and health systems.

Not surprisingly there is considerable interest, publically and among experts, in finding a pharmaceutical intervention that will stop or slow the progression of AD (a disease modifying treatment or DMT). The setbacks in recent years have been well documented and whilst much is learned at each stage a breakthrough has yet to be realised. DMTs and the associated requirement for advancement in early detection and diagnosis remain an essential goal. Yet focussing on this end point runs the risk of losing sight of the not insignificant unmet care and treatment needs for people living with AD and for those not eligible potentially for a DMT in the future.

Until such time people with AD and their families require high quality care, support and information to manage the complex challenges they face living with AD. It is essential that we continue to research new treatments and therapeutic strategies for all symptoms, cognitive and behavioural alike, and at all stages of the disease.

Cummings et al noted that "there is a paucity of clinical trials for new treatments targeting the moderate to severe symptoms of AD". In addition his report shows that whilst there is an increase in total number of agents in research (2017 vs 2018) of the 112 agents in the pipeline as shown on clinicaltrials.gov 34% are symptomatic cognitive enhancers andsymptomatic agents addressing neuropsychiatric and behavioural changes – just 8 of which are in phase III specifically for neuropsychiatric and behavioural changes.

Memory difficulties, problems with other aspects of thinking, perception and communication are well recognised and document symptoms of Alzheimer's Disease . Asking a family member if their loved one knows who they are over simplifies the complexity of symptoms.

Whilst these memory challenges for patients and carers are not without their impact on peoples' quality of life, the behavioural and psychological symptoms of dementia (BPSD), often present the greatest challenge for the person with AD and their carers .BPSD can occur at any stage of AD and are not necessarily a reflection of how a family member may recall a person's character before the onset of AD.

When pausing to contemplate the range of symptoms, such as agitation, anxiety, apathy, depression, wandering, hallucinations, insomnia, incontinence,disinhibition, it is possible to comprehend how distressing it must be for the person with AD and their caregiver.

Studies show that 90% of people living with AD will experience at least one BPSD during their illness and caregivers report these symptoms cause them more stress and distress than cognitive decline. Furthermore, evidence suggests that, if untreated, BPSD can accelerate the decline in quality of life and be the leading factor for people living with AD moving into residential care.

Moving into residential care is not only costly it can be stressful as often the move is triggered by a crisis of some kind. Caregivers often have little choice as to where they would like their loved one to live, be cared for and spend the remaining time of their life.

People living with AD and their caregivers are central to developing and implementing services, treatment options and care. The ultimate goal is to ensure that people with AD and their families have a good quality of life and are able to live well at every stage of the illness. For all involved in the research and development of treatment and care; the way in which services are structured and funded, we must take account of the whole of the life course of the illness.

Guidelines and policies must be aligned to a clear patient pathway that enables accessible, patient centred, integrated services at all stages of the disease. Patients and caregivers will live with AD for many years and until there is a means to prevent or stop the progression patients and caregivers have the right to as good a quality of life as possible.

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ADI's recommendations to reduce the global burden of Alzheimer's Disease

Fifty million people are currently living with dementia, with someone developing dementia every 3 seconds. Figures are forecast to increase to 152 million by 2050, with the majority of increase in low- and middle-income countries. (1)

It is ADI's role to advocate for and to raise the profile of dementia globally. After 10 years of advocacy, we saw concrete policy action when the WHO implemented its Global action plan on the public health response to dementia 2017-2025, with targets for the advancement of dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners and research. (2)

National dementia plans are an essential tool for responding strategically to the global dementia epidemic and for measuring health and care preparedness. However, less than 15% of WHO Member States currently have a national plan. Much more progress is needed to meet the WHO's target of 75% by 2025. It is my belief that a series of simple policy measures could drastically improve the lives of people living with dementia. There are many that we support but the few listed below should resonate easily in Europe.

▶ National dementia plans are an essential tool for responding strategically to the global dementia epidemic and for measuring health and care preparedness. However, only less than 15% of WHO Member States currently have a national plan.

1. Countries should share experiences and best practices

There are currently only 30 national plans globally; over half of those are in Europe.

However, the existence of a plan doesn't mean it is funded and fully implemented –take Italy as an example. Our report on progress -one year into plan implementation - revealed that certain areas, such as data sharing, risk reduction and research, are being overlooked in national plans (3). We also really need more plans in low- and middle- income countries as we know that the majority of people with dementia are living in those.

More sharing of best practice from high income and better resourced countries is needed. I recently visited South Korea, where they are on their third version of the national dementia plan. They are innovating on many levels and they are funding and resourcing their effort adequately. There are 256 large dementia care centres across the country catering for all stages of dementia. I saw classes for at-risk and early stages, where cognitive training helps reduce the risk of getting dementia or slows down progression. They are pioneering a mobile application called the "Dementia-Free Index" which gives individuals a score based on limiting their lifestyle behaviours that increase their risk of dementia. There is also a widespread dementia awareness education programme. Their database of people with dementia in the country 'K-DREAMS' has a dashboard that shows progression for each person at-a-glance, encourage people to access services they have not yet used,pinpointshotspot areas andmay eventually become an instrument for fine tuning their research priorities. I encouraged the Korean government to become an advocate, and an example for other countries developing dementia policies. This can only be done by sharing. It seems like a simple policy prescription, but it is essential if we are to achieve progress towards global goals.

Paola BARBARINO is Chief Executive Officer at ***Alzheimer's Disease International***

2. Involve people living with dementia and caregivers in the discussion

The voices of people living with dementia and their carers need to be included in the development and assessment of strategic plans. This is so important as we know the diagnostic experience of people with dementia can be extremely difficult, leading to depression in many cases. We need strong post-diagnostic care, rehabilitation and support, which many people do not get. Involving people with dementia in the drafting of national plans, for instance, can uncover where institutional stigma needs to be addressed and enable person-centred care.

We encourage the inclusion of a rights-based approach to the development of national plans, ensuring that they are embedded with human rights and Conventions on the Rights of Persons with Disabilities (CRPD) Articles. The ultimate goal of any policy on dementia (until we have a cure) should be to support people to live positively with dementia, and this can only be achieved by listening to people's lived experiences.

3. Develop a dementia friendly society

Dementia awareness and friendliness are a prerequisite for any meaningful dementia policy – especially at the global level. The Dementia Friends programme was pioneered in Japan and successfully exported to many countries (4). Effective dementia friendly initiatives such as this help to alleviate pressure on health systems. We do need to ask ourselves, however, what a dementia friendly society looks like because only by having a society, not just a community, that homogeneously includes people with dementia will we make any real progress. And I would like to emphasise that dementia friendly initiatives should be locally acceptable and cannot simply be transplanted from one cultural setting to another.

One of the cornerstones of dementia friendliness is access to appropriate healthcare,and we need to ensure that healthcare systems themselves are dementia friendly. A recent report revealed a lack of awareness and specific training in dementia among primary health workers in OECD countries, where primary care doctors correctly identify only around 50-75% of dementia cases (5). By adequately training primary doctors and not relying too heavily on specialist services, governments can also enhance efficiency and help achieve the goals of universal health coverage (UHC).

4. Make care accessible

It is a fact that ageing societies will demand advances in care. It is also a fact that people living with dementia have a right to access adequate healthcare and social protection. (6) Governments need to improve mainstream health and specialist services for dementia. Post diagnosis support needs to be addressed, using examples such as Scotland (where people are given at least 1 year of post-diagnostic support) as the basis for inspiration. We must give consumers confidence aspeople need a guarantee and coordinated services. We also need to build on integrated care given that financial costs associated with dementia are so burdensome on individuals, often intensified by lengthy duration of illness and co-morbidities. The example of Slovenia's government-run care homes - recent recipients of a European award - is one of the best in Europe.

In line with SDG target 3.8, governments must pursue sustainable solutions for financing and implementation of dementia services, spanning the continuum of care; risk reduction, early diagnosis, treatment, rehabilitation and palliative care.

In response to the scale of the global challenge, and the increasing pressure on health and care systems, innovative approaches to care in the community and community responses are also needed.

5. Develop flexiblee mployment laws

The economic costs associated with dementia are huge: US$1 trillion per year and set to double by 2030. 40% of this cost is attributable to informal or unpaid care, which amounts to the equivalent of 40 million full time jobs; a number that is forecast to reach 65 million by 2030. I urge governments to be innovative in drafting employment laws around flexible working for carers, to reduce the burdens of loss of income and career interruption. Such policy should acknowledge that women are disproportionately affected by dementia; as well as more women developing dementia, 71% of informal carersare female (7). Singapore is a country that is making steady progress on this front.

6. Education

Education at primary level can have a lasting impact on children, for example by increasing dementia awareness and influencing healthy lifestylebehaviours from an early age. Many resources are already available for children – we have seen examples from Argentina to Israel. There are, however, fewer examples of dementia education among older cohorts. One example is a pilot project at the Universidad Latina de Costa Rica to provide standardised dementia education. South Korea are really leading the way with a dementia awareness education programme which extends to students, parents, and teachers by including courses in elementary and middle school curriculums.

Conclusions

Dementia is a global epidemic requiring global policy responses. The ones outlined above are easily adaptable to multiple country contexts – especially, I would argue, in Europe. Sharing of best practices among countries at different levels of Global plan implementation is essential. High-income countries must take a leading role in this. Developing a dementia friendly society which is appropriate to the country's cultural context is the first step towards effective dementia policy. Governments should also make care accessible; make labour laws flexible to support informal carers and people with dementia as far as possible; and develop strong educational programmes. All of thiswillhelp relieve the pressure on health and social systems later in life. Importantly, any policy must directly involve people living with dementia and caregivers; whilst remembering that one size does not fit all, people centred care is what we all should aspire to.

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Nurses leading change in Europe's fight against AD

Paul De RAEVE is Secretary General at ***European Federation of Nurses (EFN)***

> Alzheimer's Disease (AD) imposes a tremendous burden on individuals, families, communities and societies. It currently affects nearly 6.4 million people within Europe and more than 47 people worldwide, with the numbers potentially expected to rise in the years to come. The six million nurses in Europe are in a unique and privileged position of having direct access to the daily care needs of people with AD and having a key role to play both in managing and preventing this condition.

The EFN led the European stakeholders consortium in the European Public Health Forum calling for the coordination and collaboration between policy actors, greater recognition and involvement of all relevant players and changes in the management and governance of the health and social care ecosystem in order to accommodate quality care for people with AD.

The European Commission and member states are ready for upscaling existing best practices that have shown their excellence, impact and sustainability: community nurses delivering home nursing and involving patients and their caregivers in all procedures in order to get over the barriers of their disabilities and enhance their independence; nurse-led clinics to educate and engage people in their care; and community nursing for older adults involving counselling and guidance to promote independence and greater quality of life, while at the same time reducing healthcare costs.

Sweden was one of the first European countries to create nurse-led clinics for patients with long-term conditions such as AD, but these clinics are now becoming integrated in many countries: they are present in Denmark, England, Estonia, Finland, France, Sweden and two regions of Spain (Andalucía and Catalonia). In Iceland, nurse-led clinics have been developing where there is a special emphasis on assisting patients and their families towards greater self-care management, particularly in relation to the treatment of chronic illnesses.

The six million nurses in Europe are in a unique and privileged position of having direct access to the daily care needs of people with AD and having a key role to play both in managing and preventing this condition.

Nurses' unique insight into the patient conditions and familiarity with people's social and family contexts enables them to form a comprehensive assessment and to develop a more holistic picture of needs that form the input for 'personalised care'. Policy-makers, researchers and politicians should recognise this.

Nurses have unparalleled access in the co-design of people's care plan and treatment profiles and, through regular reviews, they can ensure their medications are fit for purpose (medication reconciliation) and respond to the complexities of co-morbidities. Nurse-prescribing has a key function in supporting people with AD to cope with their (at times) overloaded medication regimes bysafeguarding the appropriateness and accuracy of prescriptions; providing education on medication safety and its proper administration to people with AD, their families and carers; and by reviewing medications regularly so that the needs of the individual are met and that referral is timely when relevant investigations are needed to ensure the safety of prescriptions. Nurses as health coaches and as care co-ordinators have proven to be effective in leading change in the health and social care ecosystems.

To make personalised 'medicine' more inclusive, deployable and accessible, continuity of care becomes a key enabler supported by 'fit for practice' ICT solutions which operate within the big data approach, which are with the support of technology supporting the motivated and highly qualified nursing workforce with the appropriate skills mix to deliver high quality and safe care.

The EFN ENS4Care project, with a consortium of a mix of professional associations in nursing and social care, nursing regulators and unions, informal carers, patients, researchers and research communities, civil society representatives and industry, delivered five EU evidence-based guidelines for nurses and social workers on the use of eHealth services, building on existing 175 best practices across the European regions, in prevention, clinical practice, integrated care, advanced roles and e-Prescribing.

E-health services constitute an effective vehicle for managing the current challenges and realising the benefits from a shift towards personalised care as people who suffer from AD experience the full spectrum of healthcare services due to the nature of their condition. Blockchain is therefore

an excellent tool to foster patient empowerment and boost integrated care along the care continuum to ensure optimal health and social outcomes being achieved for all people living in the EU, and especially those burdened with chronic disease and complex care needs who require attention from a range of professionals from primary and secondary health and social care sectors. Integrated care through blockchain can improve the continuity of care for individuals by breaking down any barriers between primary and secondary care settings, in this way ensuring a smooth patient trajectory through the simulation of nursing care pathways and its expected outcomes. Integrated working of acute, community, primary and social care services is critical to reduce the fragmentation within the health and social care systems and deliver improved patient/health outcomes. A renewed focus on delivering health and social care in the community therefore implies an appropriately designed frontline community nursing workforce composition at the interface of health and social care services and the use of blockchain to empower people/patients.

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Integrated care should increase direct patient care with blockchain potentially to decrease the burden of data collection pending on nurses, allowing them to spend more time at the bedside, in the community.

How is Alzheimer's Disease and architecture related?

The body changes with age and populations around the world are getting older. Increased age is accompanied by physical, sensory and mental changes as well aspotential cognitive impairments due to dementia. If the senses can no longer "read" the environment and the memory can no longer retain previously known patterns, the result is uncertainty and fear.

For example, when a person suffering from Alzheimer'sis unable to find the toilet or thinks it is occupied because the mirror has beenmounteddirectly opposite the entry door, this is case of architecture meeting Alzheimer's. If the toilet space were designed in a different way, it could result in three major benefits:

1. The Alzheimer's patient would not feel uncertain orconfused, avoiding a humiliating experience

2. The Alzheimer's patient would not need assistance, maintaining a degree of independence

3. The caregiverwould not be required to help the patient, giving them more time for other tasks

This brief example illustrates the link between Alzheimer's and architecture. The more the physical, sensual and mental capabilities decrease with age and/or dementia, the more architecture and design are called upon to compensate those deficits.

The perception of the environment in a healthy adult is acquired up to 85% through sight, this being the foremost human sense in determining spatial orientation. Age-related alterations result in a decrease in sharpness of vision, decreased color vision, poor contrast sensitivity, glare sensitivity and a reduction of the visual field.

In addition, a steady decrease in the size of the pupil necessitates an increased amount of light, while the depth of focus becomes more difficult to adjust. Protein deposits may also restrict the flow of short-wave blue color spectrums to the eye. Warm colors, such as red, orange, yellow or brown, remain distinguishable longer (think of the red traffic light!) and are also preferred. The degenerative process brought on by aging often affects the retina. The macula, the area responsible for sharpness of vision, becomes cloudy under the effects of macula degeneration (AMD) in the elderly. The surroundings then appear more clearly, rendering them easier to recognize than the objects or faces that are being focused upon. Consequently, everything must be easy to understand: if the floor is a little darker than the wall it provides more orientation and security,clearly defining the edges of the room. Blue floors are repeatedly associated with water and are thus best avoided. Doors that can be usedare emphasized by color, the others, painted in a similar color to the wall, remain "hidden" as though part of the wallpaper and present no further interest. Light switches should be outlined in a strong color, rendering them easier to see than a white light switch on a white wall. There are a wide variety of such modifications that can be made.

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Distinct contours with a high luminance contrast can be very helpful. Darker color fields used on floors or dark shadows may appear lower than the rest of the floor and can be seen as barriers, potentially leading to falls.

Building for the elderly means thinking about acoustics, colors, orientation aid, lighting and additional details. As we age, we all have to adjust to the increasing functional limitations of our bodies, of our senses and those of our mind. Individuals can compensate for as long as they are still able to understand what is happening around them.

However, when the normal ageing process is accompanied by dementia, we must strive to offset all limitations of our surroundings with the help of our design solutions. A decline in abilities should trigger our efforts to make our surroundings safe and understandable. Our goal is to maintain as much balance for as long as possible. If this does not occur, a loss of competence becomes evident. Such a loss of competence leads to a feeling of fear, which in turn may result in actions like running away or hiding and eventually social isolation.

We can minimise the feelings of incompetence and uncertainty by adopting a sensory architecture for the elderly and/or cognitively impaired.

Let us go back to the toilet example. We now highlight the importantareas to support the independent use of the bathroom.

While this action is simple, itcould save 58700 of valuable working hours in an800-bed hospital. This isbased onan assumed 560 patients, 20% of whom require nursing support, each using the toilet six times a day.For each toilet visit, around 16 minutes of care timeis required.

Should the case for the improvements in safety, orientation, well-being and independence for elderly and cognitively impaired patients not be convincing enough, there are also strong financial arguments for a supportive architecture for the elderly and/or cognitively impaired.

Consequently, there is currently an immediate need for interdisciplinary and international research and exchange in this field.

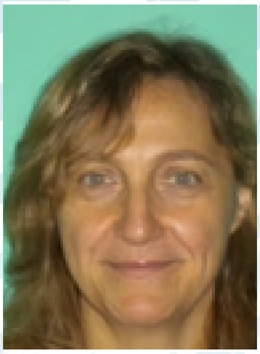
Postgraduate courses in this area combining the relevant research fields in both architecture and medicine would make a significant contribution to meeting this need, resulting inwell-trained professionalswith an in-depth understanding of the key issues at hand.

Europe should invest more in care-oriented training

AD elapses completely unnoticed in its earliest and intermediate stages and it's called to the attention of medical professionals only when it is already in its advanced stage and all the therapeutic possibilities are further reduced.

Alzheimer's Disease should be a priority in diseases field since it is affecting the population worldwide, both due to the increase in cases and to its long duration which can sometimes be several decades.

The lack of scientific knowledge on the onset and development of the disease and the heterogeneous clinical manifestations, are limiting the study of new drugs, resulting in reduced interest from pharmaceutical companies.



Moreover, the impossibility of having diagnostic tools that help the formulation of a firm diagnosis, creates confusion and underestimation of the problem also by the health professionals themselves involved in this work, and then also by other professional figures involved in various ways in the process.

AD elapses completely unnoticed in its earliest and intermediate stages and it's called to the attention of medical professionals only when it is already in its advanced stage and all the therapeutic possibilities are further reduced.

All these reasons create a delayed diagnosis, which occurs when the disease is at its most severe phase, when the clinical symptoms leave no diagnostic doubt, when the behavioral changes appear and other symptoms that make management difficult for the family and at home. At that point everything is more difficult for the doctor, for the family members/caregivers and for the PWD too.

The negative spiral in which all are projected is no way out, very often requires the misuse of drugs for both the PWD and the family in burn out, and occurs the use of dedicated facilities. This causes an uprooting of the person from his living environment and entrusts their care to professionals who often don't have the proper competences.

In the initial stages of the disease, when it is possible to identify it, people are reticent, with enormous difficulty talking about it and they are not available to perform psycho-social interventions.

Only after a long educational process a small percentage of these people decide to carry out non-pharmacological interventions.

Our experience in setting up a Meeting Center was proposing to a group of people with mild dementia, a comfortable and welcoming environment where they could meet, even with their spouses and families, and discuss the process of awareness of AD with experienced professionals, share and analyze needs emerged and work to give voice to their own needs.

Then we could decide together which activities perform in order to exercise the main physical functions and giving them an active part in their life and not only passively receive our external interventions.

At the same time the spouses were informed and supported by professionals.

Working with PWDs and their closest relatives multiplies the scientifically proven benefits, improves the knowledge of the disease that is necessary for the development of compensatory strategies to reduce the criticality in their disease process and provide the tools to overcome the functional limitations due to the aggravation of the clinical condition.

In this general framework, there are several desirable interventions:

1. Activating improvement processes of the diagnosis through the promotion of specific studies both with the improvement of instrumental technologies, and through observational studies of the population that involve significant population samples;

2. Implementing the financing of national policies to increase awareness of AD, launching prevention campaigns, promoting a healthy lifestyle through specific actions, including group actions also to overcome loneliness and isolation within the communities;

3. Starting and constantly monitoring the training of all the professionals, in order to improve the healthcare itself.

Developing a care pathway: the place for case management in dementia

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European success bases on the excellent education, stable and predictable regulatory and legal frameworks, and transparent market structures.

Dementia is a growing global challenge. As the population ages, dementia is one of the most important health and care issues facing the world. The number of people living with dementia worldwide is estimated at approximately 44.3 million people and predicted to reach over 75.6 million by 2030 and 135.46 million in 2050 (ADI 2013). The needs of people with dementia affect global functioning and are often long term, cumulative, and also have a significant impact upon the health and well-being of family carers, and as such require support from a complex matrix of health and social care networks and services (Koch et al. 2012). However, whilst there has been a strong thrust to identify the needs of people with dementia against a background of person centred care they actually live within relational contexts, whether that be with family members or with professional carers but often, both. There are an estimated 670,000 family and friends acting as their primary carers in the UK alone (Newbronneret al.2013)and any intervention is required to support their family carers also. Such family centred interventionsare best delivered through a relationship centred approach and one that delivers this is case management (Harrison Dening et al. 2017). Case management has a long and successful history in supporting people with long term conditions and people with a diagnosis of severe mental illness.

Case management

For many families,concern arises very early on when it is detected that 'something is not right', often before a diagnosis is established. Once a diagnosis has been made, interventions structured around a family-centred approach can help to untangle and clarify issues, and provide a structure to help unite families, whilst still recognising individual values. Case management in dementia care can provide longitudinal structure in supporting families affected by dementia. Case management was developed to provide specialist services or to support narrowly defined population groups with severe and/or intractable illnesses to improve outcomes through coordination of care, reducing fragmentation of service delivery and supporting the receipt of the right level of care at the right time for an individual. Case management has since been applied in the UK for the coordination of other long term conditions and for those experiencing multiple conditions and more recently in dementia (Ross et al. 2011).

In a Cochrane Review Reilly et al. (2015) assessed 13 studies and found that how case management was organised and implemented varied widely across European Union (EU) countries in respect of access, national policy drivers and funding arrangements. They found clear benefits to adopting a case management approach in dementia; such as, reducing admission to hospital, delaying admission to residential or nursing homes; reducing length of stay in hospital and reduction in behaviour disturbance. They also found evidence to suggest that whilst a case management approach may increase the use of community services initially, cost savings were demonstrated within the first year and indeed research since has shown significant health economic value to case management (Vroomen et al. 2012).

Case management for families affected by dementia in many EUcountries is a relatively new concept with early research being inconclusive (Koch et al., 2012), however, it is proving to be a successful model in Holland (Vroomen et al. 2012; Van Mierlo et al. 2014). The Dutch approach offers support to the family unit from the point of diagnosis throughout the period of time the person with dementia resides in their own home; indeed its emphasis is on supporting the person to live in their own home for as long as possible. Discharge from the case manager's caseload only comes about upon the death of the person with dementia or upon their admission to a care home (Vroomen et al. 2012). However, care home provision in Holland is very different to that in other EUcountries; the Dutch provide specialist units of care with the support of a dedicated multidisciplinary team led by a 'care home physician'.

Thus the Dutch case manager would hand over care to this skilled and professional workforce. In the UK the prevailing models are care homes, staffed by unqualified care workers, and nursing homes where the care staff are led by a qualified nurse. Pathways of care for families affected by dementia in the UK, and in many other EU countries is patchy with few consistent approaches.

Recommendations for research

1. EU countries unite to develop and describe an optimum pathway of care for dementia, from diagnosis to death and beyond in supporting families carers in their bereavement.

2. Examine, contrast and compare best practice models across the EU of case management in dementia care.

3. Develop a consensus of what elements constitute the optimum pathway of care in dementia.

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Why early detection of AD needs to be a priority

Dr Alison EVANS is Head of Policy and Impact, **Alzheimer's Research UK**

Today, there are over 8.7 million people living with dementiaacross Europe. With an ageing population and no effective treatments, this number is set to rise to 152 million globally by 2050, highlighting the huge unmet need of this condition. In the UK, the health and social care costs of dementia aremore than cancer and coronary heart disease combined. The sheer number of people living with dementia and the cost of providing make dementia is one of the greatest medical challenges of our time.

Dementia is the only leading cause of death with no treatments to prevent, delay progression or cure the diseases that cause it. Investment in research has helped to change the outlook in other diseases like cancer and HIV, with people now surviving cancer or living with HIV to a normal life expectancy. We know that investing in research will make similar breakthroughs possible in treating Alzheimer's disease.

Most people living with Alzheimer's disease,the most common cause of dementia,are diagnosed when either they or a loved one started to notice changes in their memory, orientation or behaviour, allcommon symptoms associated with dementia. Because dementia is a progressive condition, these diseases slowly, and unforgivingly, attack people's ability to think, move and communicate over time. But current scientific evidence suggests that changes in the brain can occur 10-15 years before these symptoms develop. While this sounds scary, this may be the hidden saving grace in this devastating condition. At Alzheimer's Research UK we believe that if we could identify the diseases that cause dementia at this early stage, we could treat and delay progression, even before the symptoms arise.

Until recently, researchers focused on treating the symptoms of Alzheimer's disease.But for newer treatments aimed at slowing the progression of the underlying disease, scientific evidence suggests that the onset of symptoms may be too late for such treatments to be effective. It is now widely believed that detecting the diseases that cause dementia before symptoms occur willnot only provide the best chance of developing treatments to slow progression of these diseases but will be vital in ensuring these treatments can be effectively administered. Furthermore, earlier detection of Alzheimer's disease would enable people to start making lifestyle changes, such as a healthy diet and exercise, that could help to maintain their brain health as well as giving them the opportunity to participate in clinical trials, an opportunity which is too often already closed to those diagnosed at a later stage of the disease.

This turning point in our understanding demonstrates why early detection of Alzheimer's disease must be a European priority.

We need to see increased investment in research into understanding the early changes in the brain associated with Alzheimer's disease and identifying effective ways of detecting these changes at an early stage.

This effort is likely to be enhanced by advances in big data and technology such as artificial intelligencethat were not previously available, which are opening the door to new ways to shed lightin these areas. Through this research we can work toensure

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that people will be able to benefit from the right treatments at the right time.

Alongside investment in research, we need to facilitate data sharing from research cohorts and clinical trials among the research community so that we can glean additional insight and make further progress through this data. The complexity of the disease and sensitivity needed to detect it at an early stage means that datafrom clinical trials and longitudinal cohortsmay help unlock new insights into early detection. While protection of this data and appropriate consent must be upheld, the benefits of using this wealth of information to make progress in dementia research cannot be understated. People living with dementia who have taken part in these research studies have been generous with their time to help advance research, and we owe it to them to ensure that we learn as much as we can from this data to improve the lives of people affected by this condition.

The new European framework, Horizon Europe, offers the opportunity to consider mission-oriented areas for research investment. With the large and growing unmet need associated with dementia and with one in three people born today likely to develop the condition, it is critical that we increase research investment now to change this trajectory.

The current investment in dementia research pales in comparison to the cost of dementia to the economy. In the UK, we currently only spend 0.3% of the £26bn cost of dementia on research in the UK. Across Europe, this is just 0.18%. Increasing investmentin research to the equivalent of just 1% of the cost of dementiawould enable progress to detect the disease early when treatments are likely to have the biggest impact,improve our understanding of the underlying diseases, andhelp to develop better treatments for people living with Alzheimer's disease.

Alzheimer's Society UK is tackling dementia from all sides

Dr Aoife KIELY is Research & Communications Officer, at ***Alzheimer's Society***

There are an estimated 46.8 million people living with dementia and the numbers affected will double every 20 years, rising to 115.4 million in 2050. There is no cure for Alzheimer's disease or any other type of dementia. Delaying the onset of dementia by five years would halve the number of deaths from the condition, saving 30,000 lives a year.

Dementia research is desperately underfunded. For every person living with dementia, the annual cost to the UK economy is over £30,000 and yet only £90 is spent on dementia research each year.

There are not enough researchers and clinicians joining the fight against dementia. Five times fewer researchers choose to work on dementia than on cancer.

Alzheimer's Society is committed to ensuring the rights of people affected by dementia are recognised and until the day we find a cure, we will continue to support anyone affected by dementia.

The UK health minister Matt Hancock recently stated that the British healthcare system can become the most advanced in the world by embracing the best innovations in new technology and artificial intelligence. With over 850,000 people in the UK currently living with dementia and that number being set to rise to one million in the next three years Alzheimer's Society is working to ensure that dementia is at the forefront of the care technology revolution.

Alzheimer's Society is investing in, and accelerating dementia research. We're committed to spending at least £150m in the next decade on dementia research. As part of this we have pledged £50m to fund the UK Dementia Research Institute (UK DRI), a highly collaborative, multicentre research initiative of over 700 world class researchers. Research at the UK DRI is split into two work streams – biomedical and care and technology.

The latter will launch in the New Year and is set to investigate care technologies that can benefit the quality of life of people living with dementia by increasing their independence and reducing hospital admissions.

In 2014 Alzheimer's Society launched the 'Dementia Friendly Technologies Charter' – to help every person with dementia to have the opportunity to benefit from technology appropriate to their needs. The charter also provides detailed information to inform commissioners of services for people with dementia on implementation and best practice for technology in dementia care.

We also funded and are still funding research into the application of technologies for the care of people affected by dementia. For example, one of our researchers looked into the acceptability and use of GPS tracking devices and concluded that they can be of use to people affected by dementia if introduced at the right stage and with full consent. GPS trackers are an example of technology that can help people with dementia remain independent for longer.

Alzheimer's Society is also using technology to drive advancements in diagnostic tools and assistive care. This year Game Changer was launched – a smart phone app research project led by University of Oxford and supported by Alzheimer's Society.

Since the launch thousands of healthy volunteers have signed up to play simple games on their smart phones for five minutes a day. These games assess how the brain works and this data will be used to build a baseline against which researchers hope to be able to spot the very earliest changes in the brains of people with dementia in the future, and use this information to develop new treatments.

Improving diagnosis, understanding the underlying causes and developing new treatments for dementia is a priority for Alzheimer's Society, as is improving the quality of life of those living with the condition today. Improving standards and access to dementia care is a key part of this. To help to tackle this issue Alzheimer's Society has launched a campaign urging the British government to 'Fix Dementia Care'.

We know that the social care crisis is a dementia crisis – three fifths of people using homecare and 70% of people in care homes have dementia. Decades of squeezed Government funding have left people with dementia and their families enduring inadequate care and crippling costs. From the man forced to choose between a hot meal and being washed during a homecare visit, to the husband spending over £370,000 on his wife's care – decades of starved funding is causing neglect, suffering and forcing people with dementia and their loved ones to foot the bill.

We are calling on the Government to put in extra funding to fix the social care system once and for all.To increase the evidence base, we have also funded a care Centre of Excellence at University College London with the focus of developing new solutions to help people with dementia maintain independence at home

We are working to make community as a whole more understanding and supportive of people affected by dementia. Alzheimer's Society's Dementia Friends programmes is the biggest ever initiative to change people's perceptions of dementia. It aims to transform the way communities, businesses and nations act and speak about the condition.

Mayor of London Sadiq Khan has committed to making London the world's first dementia-friendly capitol city by 2022. Talking to people affect by dementia in every borough of London, we have identified five key areas for improvement: transport, housing, health, care and emergency services, business and retail and social inclusion.

Through our research, campaigns and innovative care and technology strategies Alzheimer's Society is making an impact to further research and to improve the lives of people in the UK affected by the condition. We hope that you will unite with us in our vision for a world without dementia.

The future of Alzheimer's disease therapy is early intervention

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Well established routine diagnostic procedures easily identify the presence of the Alzheimer's Disease years before the patients function in every-day life notably declines. This opens a window of opportunity for prevention.

Past research provides us with a wealth of information on lifestyle, medical, environmental and genetic risk factors. Extensive and more-often-than-not controversial epidemiological data highlight many potential interventions for primary and secondary prevention.

However, we currently don't understand how to implement this knowledge. Hardly any of those risk factors have even been tested yet in high-quality clinical trial settings designed to answer the question whether modifiable risk factor management would be of benefit in dementia treatment? In the rare instances when this had been done in a highly reliable setting the answer had always been that it can't. E. g., epidemiological data point to a correlation of physical activity with a lower Alzheimer's risk, yet a well conducted randomized controlled clinical trial failed to observe any clinical benefit for dementia patients undergoing a physical exercise intervention program. Even worse,if anything, exercise patients experienced acceleratedcognitive decline

At the moderate and severe dementia stage therapy development failed, without exception, to provide evidence that treatment can change the disease process beyond marginal and short-term symptomatic-only relief.

Instead the evidence points in the direction that risk reduction or slowing, stopping or reversing the disease processhappens between mid-life and the hypothetical point-of-no-return. The latter point arguably being somewhere at the interface between prodromal AD/MCI-AD and mild dementia. This describes the very time span when Alzheimer pathology has already kicked in, but neurodegeneration is still sufficiently subtle so that affected persons feel no or only small cognitive impairment.

Most recently, randomized controlled clinical trials in that population provided us with the first evidence that patients with genuine AD pathology can responded to treatment by beneficial alterations in pathophysiology, evidenced by biomarkers, and cognition and function, e.g. clinical dementia rating, the cornerstone of any AD disease modifying treatment.

Now is time to harvest those first achievements and to move future research in the direction to improve the clinical benefit over what pioneering studies already accomplished.

The need is to move forward and to evaluate the treatment approaches in this most relevant population, early stage Alzheimer's disease. Many of those approaches will be risk-factor modifying non-pharmacological therapies. Because such approaches don't promise a commercial return on investment the political challenge to fund that research is even higher.

If action is taken now, first such therapies may be ready for implementation rather swiftly as development time for non-pharmacological intervention is short.